

**GUJARATI HINDU CARERS**  
**THEIR EXPERIENCES WITH PRIMARY HEALTH CARE NURSING SERVICES**

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## ABSTRACT

This thesis explores Gujarati Hindu carers' experiences with primary health care nursing services. It focuses primarily on carers' experiences of support from primary health care nursing services and the extent to which they felt supported by them. A pragmatic qualitative approach located within the research tradition of retrospective accounts was adopted and the perspectives of different types of carers, caring at home were obtained. The views of primary health care nurses were sought to examine their perspectives of caring for minority ethnic carers and the views of health service managers sought to examine their views about how primary health care nurses provide support for carers. A total of 43 in-depth interviews were conducted. A fieldwork diary was kept throughout the study and the data were analysed using a framework approach.

The findings identified that despite policy intentions that health services should meet carers' needs and emphasis on the need for partnership, there was little evidence of this. Rather, Gujarati Hindu carers were not supported because primary health care nurses adopted a restricted model of the 'patient-centred' approach to caring and failed to fully involve carers in holistic assessment. This subsequently affected their ability to access information, overcome communication difficulties and their need for emotional support. The interviews with primary health care nurses confirmed carers' claims of being unsupported. Primary health care nurses focused their attention on patients and viewed carers' needs as secondary. Health service managers also endorsed this view.

An explanatory model is developed. It shows that socio-economic factors, carers' general material disadvantage, lack of awareness about service provision, coupled with primary health care nurses' lack of recognition of the need for support, compounded further by institutional racism and structural issues in the health services all served to disadvantage carers.

Recommendations for policy, research and practice are made throughout.

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## INTRODUCTION

This principal aim of this thesis is to examine Gujarati Hindu carers' experiences<sup>1</sup> of using primary health care (PHC) nursing services to ascertain whether they felt supported by these services. This is done by exploring three differing perspectives those of Gujarati Hindu carers, PHC nurses and management adding to the complexity and originality of the thesis.

The thesis aims to address the following questions:

- What are the experiences of Gujarati Hindu carers in terms of using PHC nursing services and do carers feel supported by them?
- What are the experiences of PHC nurses in terms of caring for Gujarati Hindu carers and do they encounter any difficulties in supporting carers?
- What are the views of managers in terms of how PHC nurses support informal carers and what strategies or services are in place to enable PHC nurses to meet needs?

A pragmatic qualitative approach located within the research tradition of retrospective accounts consisting of in-depth interviews was adopted primarily as this was an under-researched area and due to the sensitivity of some of the research questions to be addressed. As advocated by Bulmer (1986) and as successfully applied by other researchers (Gerrish, 1998), as opposed to limiting the literature review by focusing on a single discipline, the literature review for this thesis draws on several disciplines to address the research questions. For this study, literature relating to health policy, social policy, sociology, nursing, informal care, and more specifically to race, ethnicity and different forms of racism has been incorporated.

## THE NEED FOR RESEARCH

The needs of carers in general have only come to the forefront in the last fifteen years or so. A number of factors have influenced this. Firstly, there have been marked changes in the demographic profile of the population with the number of elderly people rising. Secondly, social policy has witnessed a shift in care for elderly and disabled people away from institutional settings towards community based care, with government fully endorsing its support for this view. Policy now makes explicit that the needs of carers are to be recognised and met (Department of Health, 2001a). However, community care policy has to date focused

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<sup>1</sup> From here on, the term 'experiences' refers to Gujarati Hindu carers', PHC nurses' and managers' retrospective accounts.

on meeting the needs of the majority white population. The needs of minority ethnic carers have received little attention, with only one large-scale study to date (Katbamna and Bhakta, 1998). Further, health services have largely neglected carers' issues (Twigg and Atkin, 1994).

Further, social, economic and health factors can all affect carers' ability to care and continue caring. Specific issues for South Asian communities include increased rates of divorce, more mixed marriages both within and between communities, children moving away from home for improved job prospects or education, and changes in attitudes among younger generation South Asians towards caring for elderly people. These factors have economic implications for the country as a whole, as well as impact on the needs and demands of health and social service provision.

Nurses have been identified as being the next best person to the general practitioner to support carers (Audit Commission, 1999). Yet there is limited information which looks at minority ethnic carers' experiences of using PHC nursing services, and none to date that explores the perspectives of PHC nurses of the support they provide for Gujarati Hindu carers. With policy now endorsing that PHC nurses be involved in identifying carers' needs and assessments, the study came at an important time and aimed to fill the evident gaps in literature and knowledge.

## **BACKGROUND TO THE RESEARCH STUDY**

It is only recently that a strategy aimed at supporting carers has emerged within policy (Department of Health, 1999a). However, whilst a substantial amount of literature exists concerning the needs and experiences of white carers, there is little research concerning the needs of minority ethnic carers.

In 1995, the Nuffield Community Care Studies Unit was commissioned to explore the caring experiences of minority ethnic carers and their experiences with PHC services (The South Asian carers study - Katbamna and Bhakta, 1998). I, along with another researcher carried out the study. The South Asian carers study had two main aims:

1. To establish the nature of caring responsibilities and the impact of caring
2. To develop practice guidelines for members of PHC teams.

I was involved only with the first part of the aims of the study. The methodology used for the study is summarised here.

The South Asian carers study was undertaken by setting up focus groups in Leicester and Bradford with different types of male and female carers from four main language/religious groups - Gujarati Hindu, Pakistani Muslim, Punjabi Sikh and Bangladeshi Muslim. Each focus group met three times. In-depth interviews were subsequently carried out with selected male and female carers. Focus groups and in-depth interviews were conducted in the carers' own language and tape recorded. The tapes were translated back into English and transcripts were professionally developed. Transcripts were read and indexing guides formulated for coding. Transcripts were then coded and data transferred into large A3 sheets for analysis. A framework approach was used for analysis (Ritchie and Spencer, 1994).

However, although one of the stated aims of the South Asian carers study was to explore minority ethnic carers' experiences of using PHC services, a major limitation of the study was that it reported, largely, carers' experiences with general practitioner services. Little was reported about carers' experiences with PHC nursing services. Despite an extensive recruitment campaign to identify carers, recruitment was problematic (see Katbamna and Bhakta, 1998 for a full discussion). One reason for this was that the study sought to recruit carers who had experience of using PHC services as well as those that did not have contact with PHC services. A consequence of this was that very few carers were recruited who had experiences of using PHC nursing services. The basis of my thesis thus emerged from my involvement in the South Asian carers study, knowing that Gujarati Hindu carers' experiences with PHC nursing services was still an area that needed to be researched.

Policy research is defined as:

The process of conducting research on, or analysis of, a fundamental social problem in order to provide policy makers with pragmatic, action-orientated recommendations for alleviating the problem. (Majchrzak, 1984, p12)

The literature review identified that much policy related research has been largely quantitative as opposed to qualitative (Walker, 1985; Bulmer, 1986; Finch, 1986). Indeed, Wildavsky, (1979 in Majchrzak, 1984, p11) argued that 'there can no more be only one approved mode of policy research than there can be only one way of learning'. Given that the aim of policy research is to provide policy makers with the options and information they need to solve the problems we face today (Majchrzak, 1984) and this study aimed to ascertain what impact if any, policy such as the Carers Act had on the lives of carers, it was decided that a qualitative approach was the best means to research the area.

In addition, there were a number of underlying factors that led to my interest in the subject. Firstly, I was a registered general nurse and although I no longer practised, I retained my interest in the nursing field. I was aware that both health policy and nursing policy directives were placing the onus on nurses to deliver care that was responsive to the needs of minority ethnic clients and carers (Department of Health, 1993; Department of Health 1999a). The nurses' code of professional conduct (Nursing and Midwifery Council, 2002, p8) also clearly states that for nurses to practice competently, they must possess the knowledge, skills and abilities required for lawful, safe and effective practice. Secondly, based on previous experiences of working on a busy acute medical ward, I was also aware that some nurses held very negative views about minority ethnic patients. Yet, at the same time I knew that at times nurses worked within limited resources and experienced other pressures in meeting the needs of patients. I therefore wanted to explore whether the same would be true within a primary health care setting.

Finally, my interest in the subject of informal caring also emanated from personal experiences of having a daughter with cerebral palsy. The care and attitudes of nurses and midwives on the maternity unit were the worst I had ever experienced. After two months in hospital our daughter came home. She was very 'floppy' and I was told that she would be dependent on us in every way from then onwards. The reality of taking a home a baby that was 'not healthy' soon dawned on me. My life changed overnight. I was ill prepared for what was to follow. I was unable to accept the situation that I had suddenly found myself in and did little but cry for the first few years. Accepting her disability and coming to terms with the situation was made more difficult due to widespread negative attitudes about disability and its causes among family, relatives, friends and the wider community, with a number of people placing the cause of her disability firmly with me. There was little emotional support and I found myself alone despite knowing and having contacts with many people. This was largely because there was no one else in my own community or among friends that had a child like mine. Moreover, there was no one in my large circle of contacts that I felt I could trust enough to really talk about how I was feeling without them adding to my problems by portraying a different account to people 'in the community'.

Over the months, long established friendships also collapsed, partly as result of not fulfilling social obligations and also as a result of friends feeling that we were not paying enough attention to their child who was born just a few days before my daughter. However, the initial years were very difficult and I felt that no one else knew what it was like or could possibly understand what we were going through. It was extremely difficult to listen to and share in

the joys of their child's development when my own daughter was hardly able even to hold her head up. Consequently, at a time when I needed the support of friends and relatives the most, they were not there for me, and I found myself becoming more religious-minded for a while.

Over the years, caring touched many areas of my life. Initially it felt as though I was always 'struggling': struggling to find basic information in the first instance about cerebral palsy; struggling to find a nursery placement and a school that was willing to 'take her'. Yet, when I found placements for her, I then found myself 'battling' to have her needs met from all service sectors. Things were further complicated by trying to live up to the expectations of the many professional and therapy staff and other well meaning people all of whom had different expectations of me as to what I needed to do and which 'new therapy' I needed to try out to 'help' my daughter.

I would describe myself as being of Indian ethnicity as my parents originated from India. I was also fluent in both the English language and Gujarati and technically speaking, I was also a carer. Yet, if, as a professional nurse, I found it difficult to get through 'the system,' what hope did those unable to speak English have of getting the services they needed? Indeed, if care in the community is supposed to mean care *by* the community (Department of Health, 1981) then the realities of those caring and their circumstances need to be highlighted and brought to the attention of PHC nurses, managers and policy makers alike.

## **OTHER FACTORS INFLUENCING THE RESEARCH**

The work reported here took place between October 1996 to August 1997 and during a period when the internal market was still operational. The internal market was seen as a means of overcoming the financial pressures and difficulties the NHS was experiencing. The idea was to promote competition in the NHS for greater cost-efficiency and responsiveness to the consumer. In theory, the most efficient providers attracted greatest revenue because they gave 'value for money', but in practice, the reverse was true, as patients followed contracts negotiated between purchasers and providers, often at great inconvenience to the patients (Baggott, 1994). Since the Labour government's victory in the 1997 election, Britain has witnessed marked changes in the delivery of health and social care. The internal market has since dissolved, in a bid to develop a modern system of integrated care combining efficiency, quality, fairness and partnership (Department of Health, 1997). The purchaser/provider split, however, still remains in theory. Primary care groups have now developed, led by general practitioners who are now the commissioners. Further, the Labour government's election saw the development of policy aimed at supporting carers (Department of Health, 1999a).

Whilst conducting this study, Stephen Lawrence, a young black teenager was murdered. His parents campaigned for many years to no avail to bring to justice those responsible. An official inquiry was then launched which looked at the handling of the case by the police. Institutional racism was found to be rampant throughout the police force (Macpherson, 1999). Despite institutional racism being written about and known about for many years prior to the Stephen Lawrence inquiry, it was the Stephen Lawrence inquiry which really heightened awareness again and made providers of services from all service sectors more conscious of their duty to promote equality.

## **STUCTURE OF THE THESIS**

The thesis is divided into ten chapters. Chapters one to four look at the related literature to help contextualise the research study. Chapter one provides 'background' information about the Gujarati Hindu community in Britain and also provides an overview of the demographic and socio-economic circumstances of minority ethnic carers. Chapter two reviews the literature on race, ethnicity and different forms of racism and the approaches used to manage ethnic diversity within a health service context. Chapter three looks at the literature relating to informal carers and policy and the impact of policy in practice. This is followed by a discussion on patient-centred care and holistic assessments. The chapter also reviews the literature which looks at the issue of informal carers from a PHC nursing perspective. Chapter four provides a comparison (where possible) of the needs and experiences of white and minority ethnic carers. Chapter five provides an in-depth account of the methodology adopted for this study. It is divided into three parts. Part A provides an account of why a pragmatic qualitative approach was deemed most appropriate for this study. The limitations and benefits of using in-depth interviews are also discussed as are issues concerning validity and reliability within qualitative research. Part B provides a comprehensive account of how the study was carried out and how issues concerning addressing sensitive topics and the concept of power were dealt with in practice. Part C provides an account of some of the dilemmas encountered whilst conducting the research study. Chapters six to nine report the core findings emanating from the study. Chapter six provides a comprehensive account of Gujarati Hindu carers' experiences of caring and provides an analysis of support from informal and formal structures. This chapter contextualises what caring was like for them and helps put the remainder of the results chapters into perspective. Chapter seven provides a detailed analysis of Gujarati Hindu carers' experiences with PHC nursing services and addresses the issue of support from PHC nursing services. Chapter eight provides the PHC nurses perspective of caring for minority ethnic carers and looks at the issue of patient-centred care and holistic

assessment. Structural difficulties which impeded PHC nurses ability to meet needs are also addressed. Chapter nine provides a management perspective of meeting the needs of minority ethnic carers. An analysis of structural issues which affected their ability to meet carers' needs is also given. Chapter ten reports on areas of originality in this thesis and provides a synthesis of the main issues to arise from the separate results chapters to conclude the thesis. An explanatory model is presented and recommendations for future research are provided.

## CLARIFICATION OF TERMS

**Table1: List of terms and their associated meanings in the context of this thesis.**

### **Definition of carer**

Someone whose life is affected in some way by the need to provide physical, emotional or personal care for a friend or relative who cannot manage at home without help (National Federation of Women's Institutes, 1993).

### **Carer**

In the context of this thesis, the term carer denotes Gujarati Hindu carer/s . However, where there was a need for distinctions to be drawn, the term GH (Gujarati Hindu) carer is used.

### **'All care'**

Providing care that involves practical/personal/emotional caring tasks. This includes for instance, feeding, dressing, washing and toileting the cared-for person and 'keeping an eye on them'. The cared-for person is very restricted in their ability to help the carer.

### **'Hands on' care**

Referring to practical caring tasks as opposed to emotional support.

### **Colonisation**

Assertion of ownership and control over other areas of the world by a particular country.

### **Imperialism**

The imposition of another country's cultural values and behaviours upon colonised areas.

### **Black**

In referring to the work of other scholars, their existing terms have been used. Hence, the term Black is occasionally used in referring to both South Asian (including African Indians) as well as Black Caribbean and Black African people.

### **South Asian**

Refers to people who originated from the Indian sub-continent. This includes India, Pakistan and Bangladesh and those that originated from Africa.

### **Gujarati Hindu**

Refers to people of Indian descent, born in India, Africa or the United Kingdom. They may or may not speak Gujarati. Hindu is a means of categorising people by religion.

### **Extended family**

Consists of three generations living in one household. This includes elderly parent/s, married son/s and their wife/s, unmarried sons and daughters and grand children.

### **Nuclear family**

Consists of a married couple and their children.

## **CHAPTER ONE**

### **BACKGROUND**

#### **INTRODUCTION**

The intention of this chapter is to provide a brief overview of related background literature.

The following areas will be looked at:

- The background of Gujarati Hindu people in Britain
- Demographic, economic, social and health related factors affecting minority ethnic carers.

It is only by looking historically at migration and settlement patterns that an awareness and understanding of the circumstances of minority ethnic carers be developed. Equally important, however, is the need to look at the literature relating to race, ethnicity and different forms of racism if services are to be responsive to the needs of minority ethnic carers. These issues are addressed in chapter two.

#### **THE INDIAN COMMUNITY IN BRITAIN**

In order to gain a fuller understanding of Gujarati Hindu carers' experiences of caring in Britain, issues concerning cultural heritage and historical influence are explored briefly. It is important to address these issues as 'it is only by searching the roots, one would be able to identify and appreciate the differences which exist within the South Asian community' (Baxi, 1993, p20).

Gujarat is on the West coast peninsula of the subcontinent. It is bounded by the Arabian Sea to the South and West, Pakistan to the North West and by the Indian States of Rajasthan to the North and Madhya Pradesh to the East ([www.travelinfo.com](http://www.travelinfo.com)). Gujarat gets its name from "Gujjar Rashtra", the land of the Gujjars, a migrant tribe who came to Gujarat in the 5<sup>th</sup> Century. The history of Gujarat dates back to 2000 BC. Gujarat has had many Kingdoms ([www.gujaratplus.com](http://www.gujaratplus.com)) and has been subjected to a number of foreign invasions. Its capital, Gandhinagar, was named after Mahatma Gandhi, the political and spiritual leader who campaigned for the end of British control over India by peaceful methods (Simkin, 1987).

#### **British rule**

In 1600 AD, the British East India Company set up with the aim of selling Indian products such as cotton, sugar and silk to the world market. It proved successful and strong enough to

raise an army. However, tensions soon mounted when the British army tried to force Hindu and Muslim soldiers to adopt Christian values and customs. As soldiers rebelled, it gave the British government the opportunity to take over control of the country from the East India Company (Simkin, 1987). As part of the government's expansion policy, the company began to conquer many parts of India in light of declining Mughal powers. 'So with judicious self-interest, combined with military force – and all in the name of peaceful trade – the East India Company began the policy of playing off one prince against the other, interfering in the internal affairs of the states, or lending 'help' to a 'friendly' state against its enemies' (Visram, 1986, p5). Many parts of India were soon conquered. By 1818 AD, British rule was established in Gujarat ([www.travelinfor.com](http://www.travelinfor.com)) and by the 1850s Britain ruled India (Visram, 1986). It was not until 15<sup>th</sup> August 1947, that India became a self-governing independent state. In 1960, Mumbai was split and the State of Gujarat created ([www.travelinfo.com](http://www.travelinfo.com)).

### **Gujarat and its diversity**

Gujarat is one of thirty-five states in India ([www.mapsofindia.com](http://www.mapsofindia.com)). States are diverse, each having their own history, language, dialect, foods, customs and beliefs. India has eighteen official languages and over 200 different mother tongues consisting of a host of dialects and variations. Many of the states in India were created based on the language boundaries, for instance, Punjab for Punjabi speakers, and Gujarat for the Gujarati speaking community ([www.tripod.com](http://www.tripod.com)). However, the dialect spoken varies within regions and between States. It is not uncommon for people who originate from India to speak more than one language, usually Hindi and Gujarati.

India is a country which not only encompasses but founded many of the world's religions. Many Gujarati Hindu people are religious minded and a number are influenced by spiritual leaders and saints such as Sri Morari Bapu<sup>1</sup>. Gujarati Hindu people are usually vegetarian and regard the cow as sacred. A place of worship is usually set aside within the home. In addition, they worship at the *Mandir* (temple). This enables them to discuss their beliefs further as well as fulfilling a social function.

Fasting is a common practice among Gujarati Hindus, not only by adults but also among children, with the reasons for fasting varying between each individual. For instance, it has

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<sup>1</sup> Hindu Priest, whose talks are based on scriptures from the Ramayana.

been known for girls to fast during the month of Shravan<sup>2</sup> (July/August) for up to five days in the hope of finding a 'good' husband in the future (Baxi, 1993). Fasting can include total abstinence for the whole day or can be carried out for several days or even a month, whereby a person would be allowed certain foods and have one main meal, having said prayers.

There are many traditional beliefs and customs dating back hundreds of years that are still practised today. The Gujarati Hindu community is well known for its folk dances in honour of Lord Krishna, known as *ras garba*<sup>3</sup> and for their devotional holy songs dating back to the 14<sup>th</sup> Century – *bhajans*, usually one for any occasion such as birth, marriage and death (www.travelinfo.com; Baxi, 1993). Gujarat is famous for its festivals, many of which are still practiced in Britain today, although each festival may have a different meaning depending on which part of India one is from. The most distinguished of these is Diwali<sup>4</sup>

### Migration

The presence of South Asians in Britain is not a new phenomenon and has been recorded to date back to the seventeenth century (Visram, 1986). The Gujaratis from Gujarat constitute the largest group of South Asians in Britain. The majority migrated from the region of Kutch and South Gujarat (McAvoy and Donaldson, 1990).

Several factors influenced migration to Britain from the subcontinent during the early 1950s and 1960s. The rebuilding of the war-shattered economy led to a demand for labour that could not be satisfied by the British population, particularly within the National Health Service (NHS), public transport, manufacturing industries and manual labour (Modood et al, 1997).

A second 'wave' of migration occurred in the early seventies from East Africa, particularly from Tanzania, Uganda and Kenya. Political tension and 'Africanization' resulted in East African South Asians being expelled from Uganda in 1972 within a period of three months. Many had to leave behind flourishing businesses, property and considerable wealth. There are noticeable differences between the Indian communities that came from Africa and those that came from India. Many of those that arrived from India had little formal education, came from remote villages and had little money upon arrival. Younger men tended to migrate first, resulting in them leaving behind their families altogether or having to wait several years

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<sup>2</sup> Fasting in the month of Shravana dates back to a belief that Lord Shiva was pleased with Parvati's devotion that he decided to marry her. It is believed that if girls do the same, they too will be blessed with a husband like Shiva (Baxi, 1993)

<sup>3</sup> A dance usually done in a circular motion during the nine nights of dancing to honour the Mother Goddess

<sup>4</sup> Festival of lights to celebrate the return of Lord Rama to his home after defeating Ravana

before they were able to raise enough capital to enable other members of their family to join them. Many arrived with the intention of returning (Norman, 1985, McAvoy and Donaldson, 1990). Indian people from East Africa, on the other hand, migrated largely as a result of political tension and were slightly older but literate and often arrived as whole family units with 'no myth of return'. A number were skilled businessmen. This enabled them to use the skills they already possessed to set up businesses in Britain (Andrews, 1995).

## **THE CIRCUMSTANCES OF MINORITY ETHNIC CARERS**

### **Demographic, social, economic and health factors**

It is important to contextualise the circumstances of minority ethnic carers in order to understand how this might affect their ability to care and continue caring. An overview of demographic, social, economic and health factors is given below.

#### **Demographics**

Evidence from the 2001 Census (Office for National Statistics, 2002), shows that, overall, Britain's minority ethnic population is very much in the minority, making up approximately 4.6 million (7.9%) of the total population. The two largest South Asian groups are the Indian group comprising of 1,053,411 people, followed by the Pakistani group at 747,285 (Office for National Statistics, 2002). The 2001 census illustrated that all minority ethnic groups (including Black Caribbean) are younger than the white population as a whole.

However, within the South Asian community, the Indian community display the most elderly age structure of all groups (Office for National Statistics, 2002).

#### **Settlement patterns**

Although many migrants saw themselves as 'temporary' residents, 'chain migration' based on kin-networks, kin support and sponsored passages partly influenced settlement patterns in Britain as it 'ensured that new arrivals entered existing areas of settlement near kin and friends' (Robinson, 1981, in Andrews, 1995, p69). Modood et al (1997) however identified that in women in particular were disadvantaged because they lived in a community where the mother tongue would be used over English and were therefore less likely to be exposed to the English language resulting in communication difficulties despite living in Britain for many years.

The South Asian community is unevenly distributed throughout England. The highest concentrations can be found in the large urban areas. The Indian group have the highest concentration in the London boroughs and in the Midlands (Office for National Statistics, 2002).

Settlement patterns have implications for community care policy. In some wards or districts, minority groups form the majority. For those settled in large urban areas in the inner city, needs may be defined as 'inner city problems' and seen as irrelevant to the majority (Blakemore, 1998). Wales on the other hand, is virtually an all white country. Minority ethnic people residing in areas where the white community forms the majority may find it even more difficult to have their needs met (Blakemore, 1998). Pharoah's (1995) study, for instance, showed that where service development had occurred, it was clearly related to the size of the minority ethnic population.

### **Structure of the family and household composition**

Households comprising more than one generation are highest among the South Asian population, with 15 per cent living in such households compared to 2 per cent overall (Murphy, 1996). Although multi-generational households are reported as being a feature of South Asian communities, one should be wary about the strength of South Asian family structures and of the family support available to them (Warnes, 1996; Katbamna and Bhakta, 1998). It is no longer unusual for minority ethnic elderly people to live alone and the number appears to be rising (Cameron et al, 1989a; Modood et al, 1997).

### **Literacy and educational attainment**

A survey by the Policy Studies Institute (Modood et al, 1997) reported that three quarters of men in all three South Asian groups could speak English fluently or fairly well. In contrast, overall women from all three South Asian groups were reported as being less fluent in English. When looking at age and sex, women over fifty years are less likely to speak English despite living in England for a considerable length of time (Rudat, 1994; Modood et al, 1997). Literacy in mother tongue, (Gujarati) was reported as being as low as 34 per cent within the Indian group, compared to the Bangladeshi community where it was reported that seventy nine per cent were literate in their own language (Rudat, 1994). Overall, South Asian women from all three groups had fewer formal qualifications in comparison to men (Rudat, 1994; Modood et al, 1997). South Asian carers' knowledge and use of services is directly related to their length of stay in Britain and whether they can communicate in, as well as read and write English (Modood et al, 1997).

### **Employment and unemployment**

Evidence suggests that Indian men and women are better qualified than white people yet this is not reflected in employment statistics. Higher rates of unemployment within minority

ethnic groups have been reported when compared to the white population (Mason, 1995, Modood et al, 1997); further, periods of unemployment within these groups are reported as being longer (Jones, 1996). Modood et al (1997) reported that, generally women were less likely to be in paid employment compared to men. There is also significantly lower representation of minority ethnic people within higher occupational positions such as management or supervisory roles.

### **Household income**

Minority ethnic groups have lower levels of household income than the white population (Office for National Statistics, 2002). Modood et al (1997) report that men from East Africa have higher weekly earnings than any other group and now seem to have caught up with the white group. However, among manual workers, South Asians were the poorest paid, irrespective of whether they worked shifts or not. Women from all ethnic groups had weekly earnings that were considerably lower than men.

Evidence suggests that minority ethnic groups' claims for income support heavily outnumbered those for national insurance payments (39% Indian, 50% Pakistani and Bangladeshi compared to 24 % for the white group), illustrating that those that did not work within the minority ethnic group did not have adequate national insurance benefits and were therefore more dependent upon means-tested benefits (Modood et al, 1997). Previous small-scale studies have made similar arguments (Farrah, 1986).

### **Housing**

Studies have shown that home ownership remains high among the Indian and Pakistani groups and lower within the Bangladeshi group (Jones, 1996; Modood et al, 1997). Although the number of owner occupiers is high among minority ethnic groups, there is ample evidence which illustrates that accommodation is usually poor quality terraced housing, located within the inner city, over crowded, lacking in facilities such as central heating and often in need of repair (Jones, 1996; Ahmad, 1996a Modood et al, 1997).

There is little research among minority ethnic communities, which has actually looked at the suitability of houses to meet the needs of a person with a disability (Chamba et al, 1999). In Chamba et al's (1999) survey, six out of ten parents reported that their home was unsuitable for their disabled child. This figure is higher than that reported in studies with white parents (Beresford, 1995). Appropriate accommodation can not only improve the

quality of life for the cared-for person, but also make performing caring tasks easier (Morris, 1989 in Parker, 1993; Harrison and Davis, 2001).

## **Health**

There has been growing interest in the health of the minority ethnic population of Britain over the past few decades (see for instance, Modood et al, 1997). However, much of the earlier work on the health of minority ethnic communities focused on diseases usually termed as 'port medicine' or exotic diseases (Ahmad, 1993a). Tuberculosis was one such disease, also referred to as a 'disease of immigrants'. In order to prevent the spread of disease, one measure that was put in place was for all immigrants entering Britain to undergo an x-ray. Ahmad (1993a) argues that such practice merely legitimises racist immigration policies. In the search to legitimise the disease as one that 'belonged' to immigrants, authors failed to highlight the high rates of mortality associated with the disease during the early nineteenth century and that it was only when factors such as sanitation and housing were improved that the mortality figures for the disease were actually reduced (McKeown, 1976 in Ahmad, 1993b). At the time, it was believed that once the new migrants had fully integrated to the British way of life, differences in health needs would not be evident.

The 1980s saw a shift towards multi-culturalism. This approach however placed too much emphasis on culture at the neglect of life threatening diseases and illnesses such as coronary heart disease, cerebrovascular disease and non-insulin dependant diabetes, all of which have a very high prevalence rate among all minority ethnic groups in comparison to the white population (Smaje, 1995). As a consequence, the multi-culturalist approach resulted in fierce criticism from minority ethnic people, whom these strategies were designed to help in the first instance (see related chapter two).

Premature aging and self-reported ill health are reported to be high within minority ethnic communities in comparison to white groups (Smaje, 1995; Office for National Statistics, 2002). However, there is very little literature, which looks at the nature of long-term illness and disability among minority ethnic communities (Shah, 1992; Begum, 1992; Chamba et al, 1999). Earlier work by Donaldson (1986) reported that elderly South Asians, like their indigenous counterparts, become frailer as they grow older. Over half were not fully independent in relation to mobility indoors or outdoors, climbing stairs, bathing or dressing and a number were often or occasionally incontinent of urine. Ebrahim et al (1991) looked specifically at the elderly Gujarati community. Based on controlled comparison, they

examined health service use and the prevalence and severity of chronic illness. The South Asian subjects, when compared to the indigenous population, had a higher prevalence of illnesses such as diabetes, myocardial infarction, peptic ulcers and asthma. Although South Asian women were more likely to have seen their family doctor, South Asians in general were less likely to have seen a community nurse, a chiropodist or a dentist but were also reported as having higher lifestyle satisfaction and low prevalence of depressed moods.

Moreover, as opposed to biological, genetic and cultural factors, other factors such as socio-economic status, the effects of migration, racism and class are likely to contribute to the ill health experienced by minority ethnic communities and may play a significantly larger role in explaining health variations (Modood et al, 1997).

## **CONCLUSION**

The Indian community is the earliest of the South Asian communities to arrive in Britain. Many migrated from India or Africa although the reasons to migrant varied between the migrants of the two countries. Overall, the minority ethnic population is still small in comparison to the majority white community of Britain. Extended families continue to be a feature of minority ethnic households although many elderly South Asians now live alone. Overall, South Asian women are less fluent in English and have few qualifications in comparison to men. Literacy in the Gujarati language is low among the Indian community. Although better qualified than white people this is not reflected in the employment statistics and hence, household income is low. Household ownership is high but of poor quality. The minority ethnic community has a higher prevalence of certain diseases and illnesses such as diabetes.

## **CHAPTER TWO**

### **THEORIES OF 'RACE' AND ETHNICITY AND DIFFERENT FORMS OF RACISM**

#### **INTRODUCTION**

The aim of the study is to explore Gujarati Hindu carers' experiences of using primary health care nursing services to ascertain whether they felt supported by these services. Chapter one provides an overview of the demographic profile of minority ethnic communities, which help facilitate an understanding of their circumstances, and needs. Previous research has identified that health professionals have been slow to incorporate an analysis of 'race' and ethnicity into theory or practice (Gerrish et al, 1996). Further, 'social and health policy as a whole needs to consider how the concepts have shaped Britain's response to ethnic diversity' (Gerrish, 1998, p21) and, thereby, the subsequent impact this may have on the experiences of Gujarati Hindu carers. Gerrish (1998) provides a comprehensive account on the subject of race and ethnicity, hence this chapter draws upon her work to provide a structure for this chapter.

The first part of this chapter briefly reviews the concepts and terms ethnicity, 'race' and different forms of racism, to which reference will be made in this thesis. It is essential to have this background knowledge in order effectively to address Gujarati Hindu carers' experiences with primary health care nursing services. The second part of the chapter reviews three main approaches to managing ethnic diversity that have been taken within the health service.

#### **'RACE': A HISTORICAL OVERVIEW**

A multitude of definitions and terms have been put forward to explain human diversity. With increased exploration by Europeans to America, Africa and Asia in the fifteenth and sixteenth centuries, Europeans became aware that people overseas appeared different from themselves, hence 'race' was a concept developed first within Europe to help interpret new social relations (Gerrish, 1998; Banton, 1977). Interest in the subject of 'race' continued to develop, partly due to the growth in scientific enquiry and need for explanation (Gerrish, 1998; Mason, 2000).

Early accounts in the Bible represented all humanity as descendants of Adam and Eve, and Biblical chronologies suggested that the earth was about six thousand years old. However, the discoveries of geologists that suggested that man had been in existence for much longer (Banton, 1977) challenged the Biblical timescales and differing theories rapidly emerged and replaced those which linked human diversity to religion. During the late eighteenth and early

nineteenth century the term 'race' came into more frequent use and the first early attempts at classifying people according to 'race' were reported (Solomos and Back, 1996). The German physician Franz Joseph Gall, for instance, employed cranial measurement to classify 'races' according to intelligence, morality and beauty. The French anatomist Georges Cuvier on the other hand, argued that man could be categorised into three racial types: Caucasian (white), Mongolian (yellow) and Ethiopian (Black) with an ordering of superior to inferior in the typology (Gerrish, 1998; Banton, 1977). It was largely on the basis of these ideas that the concept of 'race' emerged. Four distinct features of the concept can be noted:

- The physical appearance and behaviour of individuals was an expression of a discrete biological type which was permanent
- Cultural variation was determined by differences in biological type
- Biological variation was the origin of conflict between both individuals and nations
- 'Races' were differentially endowed such that some were inherently superior to others (Gerrish, 1998, pp23; Solomos and Back, 1996; pp. 42-43).

Variables used to define 'race' included being culturally, psychologically and physically distinct. Colour (phenotype) for instance, became the means of 'distinguishing groups of people and of identifying the behaviour expected of them' whilst 'race' provided the theory which accounted for the consistency between sign of category membership, colour; and the characteristic behaviour of members of the category' (Husband, 1982, p13). Obsession with measurement and statistics generated a conception of 'race' founded upon the idea of difference and inequality. This worldview generated the notion that there was a hierarchy of life on earth based on the concept of the *Great Chain of Being* (Solomos and Back, 1996). 'Each 'race' represented a rung in the vertical construction with Black people somewhere near the bottom and whites somewhere near the top.... Just as various forms of creation had their places in the Chain of Being, so society was properly ordered according to rank and status' (Solomos and Back, 1996, p43). However, the idea of categorising 'race' neatly into pure types was dismissed with the emergence Charles Darwin's work (*Origin of Species*, 1859). In relation to zoology, Darwin argued that changes could take place both within and between 'races' (Gerrish, 1998; Husband, 1982) because species were not permanent entities but were subject to evolution by adaptation and selection (Banton, 1977). However, Darwin's work was later simplified and arguments about 'natural selection' and 'survival of the fittest' were adopted as part of racist thinking (Solomos and Back, 1996).

Racial thinking along these lines grew in popularity and became widely known as Social Darwinism, and is also associated with the Eugenics movement and anti-Semitism (Gerrish,

1998). It was believed that superior pure 'races' may be contaminated through contact with inferior 'races' resulting in racial degeneration. As a result, it was the responsibility of the superior 'race' to resist such degeneration. It was suggested that a pure 'race' could be produced through deliberate human intervention and control (Husband, 1982).

By the end of the nineteenth and into the early twentieth centuries Social Darwinism was flourishing and played a significant part in British imperial expansion, occupation and control of a number of countries and sub-continent (Gerrish, 1998). Subordination of inferior people was seen as a necessity (Mason, 2000). Further, 'race' was often used to explain health differences without any basis in reality. For example, Hitler and his Nazi followers chose to distinguish Jewish people as a separate 'race' from the Germans. The Jewish 'race', according to Nazi physicians, suffered from a higher incidence of metabolic and mental disorders. Further, it was argued that 'there is a resemblance between Jews and tubercle bacilli: nearly everyone harbours tubercle bacilli and nearly every people of the earth harbour Jews, furthermore, an infection can only be cured with difficulty' (Peltret, 1935 in Loue, 1999, p50). Ideologies such as this paved the way to legitimise the elimination of inferior 'races' (Smith, 1986). It was not until the lives of millions of Jews, Slavs, Poles and Gypsies were lost on racial grounds that the international academic community took a stand and challenged the scientific basis of 'race' and racial difference (Gerrish, 1998; Husband, 1982).

After the Second World War, the United Nations and its agencies were particularly influential in looking at the problem of 'race' relations and turned first to biologists to contribute to the debate, since racial oppression had been justified on biological grounds in the first instance. It was assumed that correction of these ideas would lead to improvements (Gerrish, 1998; Rex, 1986a). The work of Gerrish, (1998) and Rex (1986b) is drawn upon here to address both a biological and sociological perspective. Biologists reported that the human species had a single origin and that the different 'races' were statistically distinguishable groups only. Therefore, although it was possible to classify groups of people according to skin colour, for instance, it was essential to recognise that there was much overlap between one group and another. It was concluded that racial differences had no relevance to political differences or conflict among men, thus the notion that 'race' could be used to justify unequal treatment was rejected (Gerrish, 1998).

Sociologists were subsequently approached to look at the structural contexts in which racist ideas flourished. They responded in three ways (Gerrish, 1998): Firstly, it was suggested that all racial problems should be grouped under the heading of ethnic problems. However, this

overlooked cases where, for instance, two ethnic groups were simply culturally different or where one group oppressed another (Gerrish, 1998).

A second suggestion was to recognise 'that physical differences did exist and that they could act as markers for the assignment of rights to individuals' (Gerrish, 1998, p25; Rex, 1986b, p19). Two situations in which this could have been possible were those in which 'racial groups' could be distinguished by phenotype and secondly, in situations where the only differences were of culture. However, this did not account for the way in which phenotypical differences were treated in different situations (Gerrish, 1998, p25; Rex, 1986b).

The third response was to group situations which were marked by severe conflict, exploitation, oppression and discrimination, irrespective of whether it was a result of phenotypical differences, and to accept all those situations which were marked by racist justifications as race relations situations (Gerrish, 1998, p25; Rex, 1986b).

However, race relations based on such theories gave no recognition to the differences between situations in which phenotype was the marker of role-obligations and those in which such markers were cultural. Rex (1986b) argues that 'phenotypical differences, which are physical and visible, do provide a basis for making invidious distinctions that are much difficult to challenge than cultural differences' (Rex, 1986b, pp20-21).

In recent years, much has been written about the concept of 'race' within sociology (Gerrish, 1998). Despite the discrediting of the biological concept, sociologists have argued that it is legitimate to continue to use the concept because people treat it as real and organise their lives and exclusionary practices by reference to it (van den Berghe, 1967 in Mason, 2000).

Marxists such as Robert Miles, on the other hand, argue against using the concept at all. He argues that use of such a construct only 'serves to legitimise it, giving comfort to those who wish to still maintain that there are indeed real biological differences between groups of human beings' (Miles, 1982a in Mason, 2000, p8). He argues that there are no 'races', biological or social, only social processes through which social relationships become racialised, that is, represented ideologically as entailing 'race' (Miles, 1982a in Mason 2000). Miles (1982b) further argues that the focus of research should be racism and not race relations as suggested by sociologists such as Rex (1970). Miles (1982b) argues that 'such relations are phenomenally 'different' from other social relations *only* in that people *believe* that biological differences (real or imagined) are of significance, despite the fact that such a belief has no foundation in scientific fact' (p280). For Miles (1982b) it is 'preferable to use

Marxist theory which has the capacity to distinguish between phenomenal appearance of the world and the essential relations which in turn, can be used to explain why the social world appears as it does' (p282, original emphasis).

Sociologically, 'race' does not divide people into categories, 'rather 'race' is a social relationship in which structural positions and social actions are ordered, justified, and explained by reference to systems of symbols and beliefs which emphasize the social and cultural relevance of biologically rooted characteristics. In other words, the social relationship 'race' presumes the existence of racism' (Mason, 2000, p8).

However, racial discrimination or racial inequality are not static and unchanging phenomena. Numerous complex social, economic and political processes are at work. 'Patterns of direct and indirect racial discrimination are only part of the story and it is essential to recognise that class, gender and spatial processes also shape the ways in which racialised inequalities are formed and reproduced over time' (Williams, 1995 in Solomos, 2003, p228). We now turn to look at 'race' and class and 'race' and gender in turn.

#### **'Race' and class**

Evidence firmly illustrates that minority ethnic groups experience low socioeconomic status and poor health (Black et al, 1982; Modood et al, 1997). It is therefore imperative to have an understanding of minority ethnic carers' overall class position and the likely impact this may have if their needs are to be adequately met. There exists a large body of work addressing the race and class debate, the main themes of which are summarised here.

In relation to class and race, much of the sociological literature in this field has been addressed from Marxist or non-Marxist viewpoints. The non-Marxists have argued for an independent causal role for 'race' whilst the Marxists have insisted that 'race' is merely one manifestation of more fundamental class struggles (Mason, 1986). Early Marxists' work tended to concentrate on race and class as modes of exploitation. Oliver Cox (1948 in Solomos, 2003) for instance, argued that racial inequality was an outcome of the interest of the capitalist class in heavily exploiting sections of the working class (Solomos, 2003).

Mulholland and Dyson (2001) writing about the work of Cox claim:

Racism served a function for the capitalist system as a whole. It served to divide the working class and in so doing fragment its economic and political power. As a result capitalists could exploit the Black working class to an even greater extent than the white working class (p22).

More recent radical and neo-Marxist researchers argue that race is a political construct and that the politics of race is narrowly confined to the struggles against racism, as it is not race but racism which is 'the modality in which class is lived and fought through' (Miles, 1988 in Solomos and Back, 1996, p9).

The major themes to have emerged in the field of race and class have been summarised by Gerrish, (1998, p27) by drawing the work of Solomos, 2003:

- The autonomy of racism from class relations
- The role of the state and political institutions in respect of racial and ethnic issues
- The impact of racism on the structure of the working class and the dynamics of class struggle and political organisation
- The processes through which racist ideologies are produced and reproduced

Sociologists such as Rex (1970; 1986a; 1986b) adopt a Weberian perspective and argue that minority ethnic communities have an underclass position within the class system. For Rex, class is a position related to the market, such as through employment. In discussing the position of minority ethnic communities who arrived in the 1950s and 1960s, Rex questioned 'how far the new dark-skinned minorities enjoyed the rights which the working class had won in the welfare state' (1986a, p75). He identified class competition for scarce resources and concluded that minority ethnic communities were being denied access to housing, that they were confined to the least acceptable jobs and that there was increasing segregation in inferior schools. He goes on to suggest that the colonial heritage of minority ethnic groups provides the basis upon which they become stigmatised by white working class people. Minority ethnic people were treated with hostility by white working class people who perceived them as a threat, resulting in them acting against and in competition with them. Minority ethnic communities thus became a 'class for themselves' 'because instead of identifying with working class culture, community and politics, they formed their own organisations and became effectively a separate underprivileged class' (Rex and Tomlinson, 1979 in Solomos and Back, 1996, p7).

Phizacklea and Miles (1980 in Anthias, 1990) on the other hand, relate colonialism, migrant labour and class by arguing that Black migrants form a 'class fraction' of the working class, of which racial or ethnic divisions are only two forms.

### **'Race' and gender**

It is only recently that the sociological literature has begun to address 'race' and gender as a joint issue. Indeed, it has been argued that research has remained gender blind (Carby, 1982 in Solomos and Back, 1996) or that race and ethnic relations are by and large theorised as genderless (Allen, 1987). This is because work on 'race' has failed to address gender and gender studies have failed to address 'race' (Gerrish, 1998). Gerrish (1998) in writing about the work of Allen (1987) argues that if the two issues are discussed separately, this marginalises black women further.

Feminist texts which emerged during the 1960s and 1970s showed little or no awareness of the historical background of minority ethnic women and their experiences of racial inequality (Solomos and Back, 1996). Feminist writers have been criticised for over concentration on the subject of patriarchy and neglecting 'race' and ethnicity as sources of women's oppression (Solomos and Back, 1996). By contrast, feminists such as Allen (1987) argue that 'The divisions created by British imperialism cannot be ignored or dismissed as of no consequence within contemporary Britain' (p174).

Black feminists have been particularly influential in highlighting some of the shortcomings of white feminist work (Gerrish, 1998). They argue that:

- The ethnocentric nature of white feminist work failed to take account of the experiences of Black women, and the assumption of a unity of women's interest was based on white experience.
- White feminism is regarded as racist since it fails to take as central the anti-racist struggle, and the ways in which Black women have been oppressed.
- Black women have been oppressed not only by men but also by institutional sexism.
- White feminism has ignored Black women's experiences of institutional racism (Anthias and Yuval-Davis, 1992).

Studies by white feminists from the 1980s have also been criticised for failing or neglecting the experiences of Black women, overlooking their common interests with Black men, or constructing the 'ethnic' family as the major source of women's oppression (Amos and Parmer, 1984 in Allen 1987). Examples include the construction of South Asian women as passive and submissive and the fixation of studies on the subject of the arranged marriage (Anthias and Yuval-Davis, 1992). Anthias and Yuval-Davis (1992) argue that the problem with some of these studies is that 'Black' is seen as a unifying category, and posits the experience of racism as the defining difference with white women. However, contemporary

feminist literature is now beginning to address questions about 'race' and racism (Solomos and Back, 1996).

## ETHNICITY

As noted earlier, Charles Darwin argued that species were not fixed, but subject to change (Gerrish, 1998). It was not until many years later, with advances in genetics, that it became clear that groups of people who were called 'races' would be better designated 'ethnic groups' (Gerrish, 1998; Banton, 1997). Hence, the term 'race' is often used alongside ethnicity (Ahmad, 1993a). However, 'Ethnicity is notoriously difficult to define and record' (Gillam, 1990, p989), and to date there remains no single universally accepted definition (Banton, 1997). As a result a number of different theories have been put forward to define the concept (see for instance, Wallman, 1986; Yinger, 1986).

Ethnicity is derived from the Greek word *ethnos*, meaning nation (Gerrish, 1998). Ethnicity is therefore used as a form of identity by people as a means to differentiate themselves from others and has largely replaced the controversial term 'race', whereby differentiation was based on physical appearance (Smaje, 1995).

Smaje (1995) argues that phenotype differences are just one of the sets of characteristics that people use to differentiate themselves from others; people could however choose any of a number of markers to differentiate themselves (Gerrish, 1998).

From an anthropological perspective, Wallman (1986), argues that the two terms ethnicity and 'race' are alike because in both cases:

Once it is clear that ethnic relations follow on the social construction of difference, phenotype falls into place as one element in the repertoire of ethnic boundary markers. Further, ... it is the classifier's *perception* of choice or immutability which is decisive; the differences observed and the way they are interpreted say as much about the classifier as about the classified.... (p229).

Smaje (1995) argues that factors such as language demarcate social differences which are of importance only to the individual concerned and, therefore, there is no logical reason why they should become ethnic markers with strong exclusionary implications. For this reason, the notion of 'race' should be subsumed into the concept of ethnicity. However, concerns have been raised about discussing ethnicity in this way. Commentators such as Bhopal (1997) argue that although 'ethnicity' is preferred to 'race', ethnicity has become a euphemism for 'race' which at times is not clearly defined (see also, Gerrish, 1998). Further, it has to be remembered that explanations for ethnic differences are still routinely sought in

genetic terms (Gerrish, 1998; Smaje, 1995). It has been suggested that if ethnicity is defined according to arbitrary ethnic markers, this would overlook the political and historical significance by which these markers were originally given concrete social meaning (Smaje, 1995). 'To be ethnic is to be different, foreign and marginal: not one of us' (Smaje, 1995, p13). As a result, some argue that ethnicity should be perceived as different from race and not as a synonym for it and therefore clear distinctions still need to be retained (Rex, 1986b).

It is not uncommon for people to stress some sort of cultural distinctiveness as the mark of an ethnic grouping. Smith (1986) defines an ethnic unit as: 'a population whose members believe that in some sense they share common descent and a common cultural heritage or tradition, and who are so regarded by others' (p192). Ethnicity means a group that people belong to because of shared characteristics, including ancestral and geographical origins, cultural traditions and languages (Bhopal, 1997). Members of an ethnic group are therefore conscious of belonging to the group (Banton, 1997). Banton (1997) divides ethnicity into two types:

*Primary ethnicity* – when ethnic alignment coincides with national alignment (for instance, the Poles in Europe)

*Secondary ethnicity* – when ethnic groups compare themselves with one another within a framework of shared citizenship. 'African-Americans and Black Britons can then be presented as ethnic groups which define themselves by their shared experience and attitudes towards their social environment' (p38). People may therefore identify themselves as members of one group or different groups, according to context.

During the early 1960s, Geertz (1963 in Rex, 1986b) used the term *primordial* ethnicity in discussing ethnicity as a group identity (Gerrish, 1998). In his view ethnicity:

stems from the 'givens' ...the givenness that stems from being born into a particular religious community, speaking a particular language, or even a dialect of a language, and following particular social practices...One is bound to one's kinsman, one's neighbour, one's fellow believer, *ipso facto*, as the result not merely of personal attraction, practical necessity, common interest or incurred moral obligation but at least in great part by virtue of some unaccountable absolute import attributed to the very tie itself (p27).

This element to ethnicity explains the fervour of commitment to cultural identities (Banton, 1997), which also cuts across class systems (Rex, 1986b). Within this context ethnic identity is not shed when individuals move within the social class system (Gordon, 1978 in Rex, 1986b). However, recent evidence (Modood et al, 1997) suggests that 'minority identities are

continually changing and reinventing themselves through fusing with elements of majority cultures...the ways in which minorities conceive themselves and the cultural syntheses that are taking place are various, changing and generating new mixed forms of ethnicity' (p338).

Situational ethnicity was a concept developed by anthropologists (Gerrish, 1998). According to this view, ethnicity functions primarily as a resource which can be used when needed or remain latent and ignored (Rex, 1986b). However, situational ethnicity may also be used as a basis for denying rights, hence becoming a stigma or liability which actually stands in the way of people achieving their goals (Rex, 1986b).

Mason (2000) advocates the use of ethnic boundaries to assess the way people define themselves and their relationship to others. In line with this thinking, Wallman (1979 in Mason 2000) draws upon the work of Fredrick Barth (1969) and argues that ethnicity is more a matter of the processes by which boundaries are created and maintained between ethnic groups than of the internal content of the ethnic categories (Gerrish, 1998):

She argues that:

two sets of people with common origins placed in similar minority positions [will not] necessarily use the same elements of their traditional culture to mark themselves off from non-member 'others'. What they do use will depend on the resources they have, on what they hope to achieve (whether consciously or not) and on the range of options available to them at the time (p13).

Ethnicity is then situational because people have different ethnic identities in different situations (Gerrish, 1998). For example, a person may describe themselves as Gujarati, Hindu, Indian, South Asian, Black or British depending on the situation. Evidence also suggests that people's identifications are made in the context of their recognition of the ways that others categorize them. Modood et al (1997) for instance, found that a number of South Asian people identified themselves as 'black' when in contact with white people because they believed that this is how they would have been defined by white people.

Usage of the term 'ethnicity' can also vary over time and location. Wallman (1986) suggests that 'in Britain it signifies allegiance to the culture of origin and implies a degree of choice and a possibility for change' (p229). However, the emphasis on choice and change could easily lead to a naïve view that the 'absorption' or 'assimilation' of newcomers or migrants is only a matter of time. A consequence of this is that those who refuse to change or adopt their ways will be held responsible for any continued disadvantage they may experience. Secondly, the term 'ethnic' is usually used as a synonym for those thought of as culturally different; people are thus apt to see ethnicity only as an attribute of others, something that distinguishes

'them' from 'us', (Gerrish, 1998) but it is a term that is equally applicable to white people (Mason, 2000).

Ideas of race are thus beliefs about the involuntary effects of genetic inheritance and the supposed innate or inborn traits of different 'racial' groups. Ideas about ethnicity concern beliefs about the customs people choose to follow, their way of life or culture (Banton, 1997; Blakemore, 1998).

## **RACISM**

The term 'racism', like 'race', has been used in a variety of differing ways and is almost as contentious as 'race'. The term racism is closely associated with the period when attempts to identify people according to racial types were made, the rise of Nazism in Germany and anti-Semitism (Banton, 1997). When the Nazis came into power the term was used to refer to the defining of some racial or ethnic groups as inherently superior and others as inferior (Gerrish, 1998; Solomos, 2003). As discussed earlier, biological theories of 'race' and racism were subsequently discredited.

Racism it is argued is socially constructed (Dominelli, 1997). Yet people still continue to believe and behave as if biological differences between races exist (Gerrish, 1998; van-den Berghe, 1967 in Mason, 2000). During the late 1960s, its meaning was extended to include the use of beliefs and attitudes to subordinate and control a category of people defined in racial terms. Racism then became a means to express a moral judgement, and therefore anything which could be classified as racist was by definition bad (Banton, 1997). However, the term has continued to evolve and had different meanings attached to it.

Bromley and Longino (1972 in Dominelli, 1997) identify three main forms of racisms: 'new racism' or cultural racism; individual racism or personal racism and institutional racism (Gerrish, 1998). Each is discussed in turn below.

It is argued that biological racism was soon replaced by 'new racism' (Gerrish, 1998; Barker, 1981) or what is sometimes termed cultural racism (Modood et al, 1997). However, there are different versions of the concept of 'new racism'. Barker (1981) for instance, stresses the alleged naturalness of group exclusiveness. One of his arguments concerns immigration and the concept of genuine fears expressed by the majority community that Britain would be 'swamped' by minority populations (Margaret Thatcher in the Daily Mail, 31 January 1978 in Barker, 1981, p15). Many of these views started to emerge during post-war Britain when

workers were imported from former British colonies in response to the acute labour shortage (Williams, 1989). Barker's (1981) argument is that minority ethnic groups and their cultures are viewed as a threat to the British nation and its way of life, hence feelings of resentment or hostility are natural instincts which come into play in a bid to preserve national identity and defend one's territory. The nation's 'way of life' is constituted of feelings of belonging, of sharing traditions, customs, beliefs, language or, in a word, culture: 'therefore the very existence of fears about damage to the unity of the nation is proof that the unity of the nation is threatened' (Barker, 1981).

Hence, it is argued that minority ethnic communities are 'different' and do not try to 'fit in' (Modood et al, 1997). 'Such racism uses cultural difference to vilify, marginalise or demand cultural assimilation from groups who also suffer colour racism' (Modood, 1996 in Modood et al, 1997, p9). It is a means to exclude or segregate members of different groups by arguing that different groups are culturally incompatible and that assimilation would lead to disruptive and negative consequences by forcing cultures to mix (Balibar, 1991 in Mason, 2000).

Many of these views were particularly influential during the time that the Conservative party was in power (1979-1997) (Gerrish, 1998). It was a period when attempts were made to define the characteristics of the dominant national culture and the ways in which it differed from those of racial and ethnic minorities, and formed a key element of new right thinking. Husband (1987) states that 'the concept of nation is crucial in providing a linkage between the political and economic concerns of the new right and the racist discourse of new racism' (p320). Minority ethnic communities were increasingly presented as 'enemies within' who were undermining the moral and social fabric of society (Solomos, 2003). These views continue to prevail among right wing extremists (Gerrish, 1998; Dominelli, 1997)

However, some have argued that there has been a conceptual inflation of the word, which at times has been applied to an ever greater range of things in order to stigmatise them (Miles 1989 in Banton, 1997) with the consequence that there has been an increasing tendency to use the term more widely to apply to any expression of intergroup hostility or ethnocentrism<sup>5</sup> (Mason, 2000). Matters are made worse by racism being produced and reproduced through political discourse, the media, the education system and other institutions (Solomos, 2003).

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<sup>5</sup> Ethnocentrism refers to the practice of evaluating other groups, and their cultures and practices, from the perspective of one's own. Such judgements may, in principle, be positive or negative but will frequently entail misunderstanding. When judgements are negative ethnocentrism may, in practice, easily shade over into xenophobia (literally fear of foreigners) or racism (Mason, 2000, p10).

With conflicting theories being proposed, some have argued that the term racism no longer serves any place in the emerging theoretical language of social science (Banton, 1997).

The second form of racism identified concerns individual or personal racism (Gerrish, 1998). It concerns attitudes and behaviours depicting a negative prejudgement of racial groups. Hence, racist attitudes constitute racial prejudice (Dominelli, 1997). In service delivery terms, this can be when a health worker treats a person less favourably simply by virtue of their ethnicity. This is then a form of direct discrimination (Smaje, 1995). Gerrish (1998) identified that one means of dealing with personal racism was through the introduction of 'race awareness training' and equal opportunities training by local authorities during the 1980s. This included the move away from seeing minority ethnic people as victims and the promotion of anti-racism awareness training geared to raise consciousness of racism in all its manifestations. It attempted to 'deconstruct racism by demonstrating how personal change, affected through increased consciousness of what one does, as an individual, fits into changing organisational and societal policies and practices (Dominelli, 1997, p74).

This training had two main aims:

- Challenge individual prejudices and values
- Inform decision makers and employers, for instance, about the problems faced by black and ethnic minorities (Solomos, 2003).

It was argued that the root cause of racism was the inherent prejudice of white people and institutional practice which discriminated against black and ethnic minority people. However, this approach was heavily criticised because:

- It assumed that changes in attitude would lead to changes in practice
- It was based on the assumption that all white people are inherently racist (Solomos, 2003)
- The initiative was counterproductive as it ignored socioeconomic, cultural and historical factors and the material and political conditions that helped reproduce discrimination and racist ideas (Sivanandan, 1985 in Solomos, 2003).

The third form of racism considered here is institutional racism or what is sometimes known as indirect racism (Gerrish, 1998; Smaje, 1995) or camouflaged racism. The concept emerged in the United States during the 1960s in a bid to challenge the view that racial inequality was merely the result of the behaviour of a few pathologically prejudiced white people (Mason, 2000).

In Britain, institutional racism came to the forefront around the 1970s, and has been the subject of intense debate since the Macpherson (1999) inquiry which looked at the case of Stephen Lawrence. Institutional racism is defined as:

The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviours which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people (Macpherson, 1999, para. 6.34).

Following the inquiry, the Government placed statutory duties on health and social care providers to promote race equality. This was enforced by making amendments to the existing Race Relations' Act (Race Relations Amendment Act, 2000). Health care providers now had a legal responsibility to not only promote equal opportunities for employees but also identify and tackle institutional racism.

Institutional racism moves away from individual prejudice and discrimination to racism of the state. Analytically, it combines two specific themes, that of ignoring difference and diversity and secondly, misrepresenting needs (Atkin, 2003). It is argued that state racism provides the context for racist policing, discriminatory practices in employment and education, for media calumny and the creation of popular racism which in turn reinforces prejudiced attitudes (Sivanandan, 1976a in Bourne, 2001). Within a health context, it is when policies and procedures are put into place with little thought for the needs of minority ethnic people and which lead to discriminatory outcomes for them (Mason, 2000). Another important statement made by Macpherson (1999) was that prejudice alone is of no great concern unless a person is allowed to act out their prejudice in discriminatory ways. Hence, 'it is the acting out of that (individual) prejudice that makes for (social) discrimination. And when such discrimination becomes ingrained in the institution of society, it becomes institutional racism' (Bourne, 2001, p19).

## **APPROACHES TO MANAGING ETHNIC DIVERSITY AND ITS RELATIONSHIP TO THE PROVISION OF HEALTH SERVICES**

### **Assimilation and integration**

As reported in chapter one, in response to the acute labour shortages following the war, many people migrated to Britain from India, Pakistan and parts of Africa to help fill positions in service sectors such as the National Health Service. For the government, importing workers from the Black Commonwealth was viewed as a cheaper option compared with other foreign workers (Williams, 1989).

However on arrival, minority ethnic people were treated with hostility by white working class people and trade unions who viewed them as a threat, as it was felt that the new migrants were taking away their jobs (Gerrish, 1998; Rex, 1986a). Further, the arrival of large numbers of migrants supplied ready-made scapegoats on whom the acute housing shortage could also be blamed (Rex and Moore, 1976 in Mason, 2000). The tide of white hostility eventually resulted in the Notting Hill riots of 1958 (Gerrish, 1998), a series of attacks on white youths. Yet, although 'immigrant' populations were essentially the 'victims' as opposed to aggressors, politicians and the media sought to excuse the actions of convicted whites (Ramdin, 1987 in Gillborn, 1990). Following the riots, pressures to end immigration reached new levels. With mounting pressure, the government passed The New Commonwealth Immigrants Act (1962) which established tighter controls on entry to Britain from Commonwealth citizens (Mason, 2000).

Migrants were seen as a 'problem' (Gerrish, 1998) and the government adopted a *laissez-faire* attitude: a system in which there would be no state intervention to provide housing and welfare support and the treatment of immigrants only as units of labour (Sivanandan, 1976 in Williams, 1989). Assimilation and integration strategies were adopted, aimed at helping immigrants adapt to their circumstances and at the same time control immigration. It was, however, made clear that any problems or difficulties experienced would be the responsibility of migrants to sort out, and that they would have 'to adapt, make out or go home' (Williams, 1989, p89). It was believed that once the migrants had assimilated to a British way of life, by mastering the English language, traditions and values, problems would be resolved. Importantly, this approach reflected a 'belief in the cultural and racial superiority of the 'host' metropolitan society' (Mullard, 1982 in Gillborn, 1990, p146).

Integration and assimilation strategies were also adopted within a health context (Gerrish, 1998) where it was argued that that existing services were adequate and that people should use what was available. Further, there was a push towards encouraging minority ethnic people to abandon their cultural values and beliefs and make the necessary adjustments in order to 'fit in'. These strategies required little action on the part of service providers (Roys, 1988) as minority ethnic people's culture was viewed as the problem.

Work from the Institute of Race Relations, however, identified that the 'real' problems of the adjustment process were 'discrimination' in the form of irrational prejudices and intolerance by employers, for instance, and policies which focused on cultural practice (Williams, 1989).

It was the aim of the Race Relations Acts of 1965 and 1968 specifically to address discrimination against black immigrants through two main routes, that of setting up special bodies to deal with the problems experienced by immigrants such as discrimination and welfare and by educating the public about race relations (Solomos, 2003).

### **Multi-culturalism**

There was then a move away from integration and assimilation to a strategy known as multi-culturalism which was aimed at encouraging tolerance and respect and the promotion of understanding and celebration of different lifestyles (Gerrish, 1998; Williams, 1989) which in turn would result in more sensitive and responsive services. However, within this framework, 'white' culture is still presented as the norm (Ahmad and Atkin, 1996).

Such approaches are argued to have been a response to the presence of 'too many' black immigrants and anxieties that cultural differences might result in racial conflict (Solomos, 2003). Yet government departments did not tackle these issues, as would normally be the case. For instance, the responsibility of dealing with immigration controls relating to the 1965 and 1968 Acts was passed onto the judicial system instead of the Home Office. Secondly, issues concerning discrimination were to be dealt with by bodies such as the Race Relations Board, yet government provided no direction or support to them (Solomos, 2003). This approach therefore failed to recognise how the existing hierarchy of cultures had a long history, particularly through imperialism and, without reference to racism, only served to reinforce stereotypes rather than remove them (Williams, 1989).

Since the 1970s immigration has continued to be tightened, (Gerrish, 1998) for instance, the 1971 Immigration Act allowed only those whom had a parent or grandparent born in the United Kingdom or who had been resident in the United Kingdom for five years by 1973 to enter and stay in Britain. This immediately created a distinction between white and black potential immigrants (Williams, 1989).

The implications of multiculturalism within health resulted in a fascination with exotic diseases or unusual aspects of black people's illnesses (Gerrish, 1998; Williams, 1989). Campaigns such as the 'Stop Rickets Campaign' attempted to define South Asian people's health problems in terms of their 'pathological' culture, arguing that 'if the cause lies in their culture, so must the solution' (Ahmad, 1993a, p20). The Stop Rickets Campaign was aimed at dealing with the perceived needs of minority ethnic communities and factors that were associated with specific aspects of South Asian lifestyles were targeted and linked to

prevalence rates. The cause of 'South Asian Rickets' was put down to inadequate sunshine and unhealthy diet (Gerrish, 1998; Donovan, 1986; Ahmad, 1993a). Variables such as poor housing and low income, which can lead to unhealthy diets, were largely ignored in the analysis (Ahmad, 1989). This victim blaming approach led some authors to suggest that the long term answer to rickets lay in health education and a change towards the Western diet and lifestyle (Goel et al, 1981 in Ahmad, 1989). Rickets was therefore racialised, despite its being prevalent in British working class communities before the Second World War (Mason, 1995).

The concept of 'special needs' or 'special treatment' within healthcare is often associated with minority ethnic communities and their culture, and this also serves to reinforce racism and lack of opportunities (Cross, 1982 in Williams, 1989). It is no wonder that 'the majority of these 'special' health initiatives have met with fierce criticism from some of the communities which they purport to help...Moreover, the research agendas have been defined by professionals and their perceived priorities of health problems, which are not necessarily those of black people using the Health Service' (Pearson, 1986, p102). Fascination with 'port medicine' and exotic diseases resulted in a neglect of conditions which were more life threatening to minority ethnic communities such as heart disease (also see chapter one). This approach placed too much emphasis on personal racism and ignored structural inequality (Dominelli, 1997) and failed to recognise that white and minority culture do not meet on equal terms (Ahmad and Atkins, 1996). The multi-cultural approach to delivering health care and managing ethnic diversity thus had limited effect (Gerrish, 1998).

### **Anti-racism**

With a lack of conceptual clarity about what was meant by multi-culturalism or multi-cultural society and the failure of previous strategies, anti-racism was thought to be the way forward for tackling inequalities and discrimination. Together with black-led self-help initiatives this approach played an important role in policy development during the 1980s and 1990s (Gerrish, 1998; Solomos and Back, 1996; Stubbs, 1993;).

Racial inequality was now to be addressed within a wider context where the focus would be upon institutions and organisations (Gerrish, 1998) and the eradication of institutional racism was now a central concern. Within health, this could include the failure of health services to adequately publicise their services to minority ethnic communities thus reducing opportunities for making use of them (Commission for Racial Equality, 1992 in Smaje, 1995).

Multiculturalism has been criticised for being 'too soft' on racism. It is argued that it ignored social, political and economic power relations which have resulted in the exploitation of minority ethnic groups (Gillborn, 1990). For anti-racists, then, the focus of concern is that of addressing racism and not culture, unlike the multi-cultural approach that attempts to incorporate 'ethnic sensitivity' into the process. Thereby, the dominant racist construction of minority ethnic communities as 'undeserving' is addressed (Stubbs, 1993; Ahmad, 1993).

However, this approach has been widely criticised and was seized upon by the new right, the media and academia, where anti-racism was portrayed as an 'intrusion into individual freedom and a threat to the interests of the white majority' (Solomon, 2003, p188)<sup>6</sup>. Further, it was argued that it was minority ethnic communities who had failed to respect the way of life and customs of the white majority. Indeed, those local authorities that tried to tackle the issue of racism fell into the category of supporting the 'loony left' (Solomos, 2003).

In writing about this approach, Stubbs (1993) suggests that there is a danger that 'racism' may be used as a catchall category without demonstrating the processes through which racism operates. The meaning of racism continues to change, as it is not a fixed entity. It interconnects, operates and is reproduced at different levels, by the state, professional ideologies and practice (Ahmad, 1993a; Stubbs, 1993). Racism cannot be treated as an autonomous social process; the connection between other forms of oppression such as gender and class has to be made in order to address health inequalities (Gerrish, 1998). Secondly, this approach assumes that black and minority ethnic people have the same-shared experience of oppression and racism (Stubbs, 1993).

This approach was also criticised by minority ethnic communities who argued that it ignored cultural differences between minority ethnic groups and failed to bring about any definitive changes (Gerrish, 1998; Gilroy, 1990 in Solomos and Back, 1996). However, lack of political will to address the issue contributed significantly to this failure. The Conservative government did little to tackle the issue of racism and New Labour has also distanced itself from this unpopular issue (Gerrish, 1998).

This lack of conceptual clarity of the political and social objectives of the anti-racist movements had thus made tackling the issue difficult and it is argued that it has had little

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<sup>6</sup> The level of understanding and prejudice among both the public and professionals is illustrated in the Macdonald panel's report (Macdonald et al, 1989 in Gillborn, 1990) to a Manchester school where a South Asian pupil was stabbed to death by a white peer. Although the murder was racially motivated, the news media somehow managed to twist the facts so that they seemed to condemn the whole thrust of anti-racism (Klein, 1988 in Gillborn, 1990, p154). The school added to confusion by refusing to publish the report.

effect (Smaje, 1995). Mechanisms are clearly still needed for treating as equal all citizens in societies that are increasingly multi-cultural, (Gutmann, 1992 in Solomos and Back, 1996).

## **CONCLUSION**

This review has attempted to provide some clarification of the concepts 'race', ethnicity and the different forms of racism. It illustrates that the terms 'race' and ethnicity often have different meanings attached to them and that they are notoriously difficult to define. The review illustrates the different types of racisms that are prevalent in society. In addition, the review illustrates the different policy responses used over the years to manage the diverse minority ethnic population in the context of health services provision and why some of the strategies failed to meet the health care needs of minority ethnic populations. Further, although other reports (for instance, Macdonald et al, 1989) also clearly identified racism as the 'cause' of problems, it was not until the publication of the Macpherson Inquiry report (1999) that changes in all service sectors have been promised.

## **CHAPTER THREE**

### **POLICY AND PRACTICE: COMMUNITY CARE, INFORMAL CARERS AND MINORITY ETHNIC COMMUNITIES**

#### **INTRODUCTION**

Informal carers play a vital role in providing care in the community. The most recent census evidence (Office for National Statistics, 2002) suggests that there are 5.2 million carers in England and Wales, with women more likely to be carers than men. The value of informal carers to the economy is estimated in the region of £34 billion a year (Hirst, 1998). It is estimated that over 225,000 people provide 50 hours or more hours of unpaid care per week (Office for National Statistics, 2002). Carers can be divided into a number of different types, for instance, spouse carers, parental carers, filial carers, sibling carers and non-kin carers (Parker and Lawton, 1994). As reported in the subsequent chapter, the costs of caring for both white and minority ethnic carers are considerable, having an impact on many facets of carers' lives. For instance, caring is known to cause ill health, social restrictedness, financial costs and to disrupt family life. Carers therefore need to be supported, not only from a social care perspective but from a health one too.

The first part of this chapter examines the policy literature concerning community care and traces the emergence of informal carers within that. It then explores what policy expects of services, including the health service, in providing support for carers. Detailed accounts of community care policy and its implications for service users already exist (see for instance, Means and Smith, 1998), and these are not repeated here.

The second part of the chapter explores what general health and community care policy has to say about how the needs of people from minority ethnic communities should be met.

In the third part, these two elements are brought together by examining what is known about how services do support carers and those they care for, moving finally to a particular emphasis on nurses and carers from minority ethnic communities. This part also includes a discussion of patient-centred care and holistic assessment and their relevance to carers, an essential background to understanding why carers' needs may not always be paramount for PHC nurses.

The review thus looks critically at aspects of policy concerned primarily with carers' issues and the ways in which both policy and practice have tried or failed to meet their needs.

## **INFORMAL CARERS – THE EMERGENCE OF POLICY**

### **Community care**

The term community care appears to have originated at the turn of the century (Parker, 1990), and various phrases and meanings have been attached to it ever since. Originally, the notion was linked to people with mental handicap. The Royal Commission on the Care of the Feeble Minded (1904-1908), for example, advocated guardianship and supervision in the community and a move away from large institutions (Jones, 1960, in Parker, 1990). A subsequent Royal Commission on Lunacy and Mental Disorder (1924-1926) advocated the need for medical social workers to help keep families together and assist patients and their families (Lonsdale et al, 1980 in Walker, 1982). Successive policy documents and legislation (e.g. 1927 Mental Health Act) continued to endorse this view, and from the perspective of different groups of people who were also in need of care and support. For instance, within mental health, there was a definite shift away from hospital-based care to community care. The 1954-1957 Royal Commission on the Law Relating to Mental Illness and Mental Deficiency recognised that 'the sense of belonging to a family may be of great importance to the patient. It is not always in his best interests to remove him from a not entirely satisfactory home to even the best run foster home or public institution' (cited in Parker, 1990, p9). Policy statements thus started focusing on statutory domiciliary and social care provision required by individuals in need of care and support to enable them to live in the community and remain independent. The move towards deinstitutionalization took precedence following the publication of a number of official and unofficial reports which explicitly described the appalling conditions and circumstances of residents in institutional care in a variety of settings (see for instance, *Institutional Neurosis* (Barton, 1959); *The Last Refuge* (Townsend, 1962); *Sans Everything* (Robb, 1967); *Asylums* (Goffman, 1968) and *Put Away* (Morris, 1969).

Following public outcries, the need for community-based care began to gain strength. Clear messages were sent signalling that people with mental handicap should live with their families if it did not pose any undue burden on them or the person needing care.

The rising costs to the National Health Service (NHS) added to the shift towards community based care.

### **Community care policy since the 1980s**

The aim of community care is to provide services and support for people affected by ageing or disability, for instance, to enable them to live as independently as possible in their own homes or in homely settings in the community (Department of Health, 1989a). In 1981 the White Paper, *Growing Older*, argued that:

Providing adequate support and care for elderly people in all their varying circumstances is a matter which concerns and should involve – the whole community...Public authorities simply will not command the resources to deal with it alone (Department of Health and Social Security, 1981, para. 1.11).

The role of informal carers was thus made explicit:

The primary sources of support and care for elderly people are informal and voluntary. These spring from the personal ties of kinship, friendship and neighbourhood...it is the role of public authorities to sustain and, where necessary, develop – but never to displace – such support and care. Care *in* the community must increasingly mean care *by* the community.

(Department of Health and Social Security, 1981, para: 1.9 original emphasis).

Community care continued to be promoted and policy documents continued to emphasise that the state could no longer bear the costs of institutional care; neither could it shoulder the costs of providing comprehensive packages of health and social welfare services to enable services to support people to live in the community. 'This combination of financial considerations with the avowed aims of promoting care in the community has led to an inevitable shift in emphasis from statutory provision (which is seen as expensive) to informal and voluntary provision (which is seen as inexpensive or even free)' (Parker, 1993, p23). Policy made clear that its main purpose was to support carers to sustain their role, not to replace them (Department of Health, 1989a, para. 2.3). However, it was argued that this left those who provide care, in informal settings (i.e. unpaid), 'in a strange Alice-in-Wonderland place where they are the main providers of community care but never the subjects of policy that deals with the provision of care' (Baldwin and Parker, 1989, in Parker, 1990, p11).

Sir Roy Griffiths, in his 'Agenda for Action' stated that families, friends and other local people would continue to be the primary means by which people were enabled to live normal lives in community settings (Department of Health, 1989a). A key objective of policy thus became to '[e]nsure that service providers make practical support for carers a high priority' by integrating services from different service providers (Department of Health, 1989a para.1.11, p5).

The subsequent NHS and Community Care Act (1990) appeared to offer unprecedented opportunities for both users and carers. It had the potential to involve both users and carers, not only in care management and the planning and organisation of community care services but also in 'needs-led' assessment:

The assessment will need to take account of the support that is available from such carers. They should feel that the overall provision of care is a shared responsibility between them and one of mutual support. The preferences of carers should be taken into account and their willingness to continue caring should not be assumed. Both service users and carers should therefore be consulted – separately, if either of them wishes – since their views may not coincide. The care plan should be the result of a constructive dialogue between service user, carer, social services staff and those of any other agency involved. (Department of Health, 1991: 28)

However, the stream of policy and practice guidance that followed always referred to users and carers together, rarely carers individually. Some policy guidance documents went as far as to state that, although consensus should be reached about user needs, by involving carers, ultimately, 'the user views should carry the most weight' (Social Services Inspectorate 1991, in Parker, 1999, p53). Policy continued to stipulate that carers should be supported by means of access to information and carer support groups without the need for separate carer assessments (Nolan et al, 1996).

Policy also appeared to suggest an orientation towards negotiation and partnership rather than professional dominance (Fisher, 1994 in Nolan et al, 1996). However, the definition of need within policy documents was left rather fluid and it was left to the enabling authorities to determine what constituted need as opposed to need being defined by users and carers themselves (Nolan et al, 1996).

These weaknesses in the guidance soon became evident. Ellis's (1993) observational study of user and carer involvement in the social care assessment process showed that professionals continued to focus needs assessments on physical functioning and dependency of the cared-for person as the main eligibility criteria for services, thus overlooking carer needs. The extent to which services were deemed appropriate was also based on preconceived ideas, professional training and background. Moreover, in terms of allocating services for carers, professionals' own value judgements about 'deserving cases' strongly influenced decisions. Similar observations were made by Twigg and Atkin (1994) in relation to district nursing services and carers.

Other studies (Manthorpe and Twigg, 1995) have reported that conducting separate carer assessments is problematic in practice. Professionals were not used to incorporating carers in the equation, largely because this had never been part and parcel of professional practice.

More recent evidence indicates that many carers do not have their needs met and some do not even manage to gain access to an assessment and thereby the services that might follow (Rummery et al, 1999).

Further, although there was an abundance of policy and practice guidance after the 1990 Act aimed at social services staff (e.g. Social Service Inspectorate, 1991), clearly spelling out the roles of both managers and practitioners in terms of assessing and arranging care underpinning the elements of community care, little was directed to health services (Department of Health, 1989b). It is no surprise, then, that health care providers and commissioners did not regard informal caring as 'their issue' (Twigg and Atkin, 1994).

### **Policy for carers**

The development of the carers lobby, exemplified by the organisation now known as Carers UK, was crucial in ensuring that the work of carers was formally recognised. Pressure group politics led to the successful acknowledgement of the work of different types of carers, and helped push carers' concerns on to the political agenda by campaigning for separate carer assessment. This was eventually recognised and translated into policy with the Carers (Recognition and Services) Act 1995.

The Carers (Recognition and Services) Act 1995 was built on existing community care legislation and was designed to address the needs of informal carers, in terms of being recognised for their caring role, addressing support needs and to discourage exploitation of their work. The Act gave carers the right to request an assessment of their own needs at the same time the cared-for person was being assessed or reassessed. Any decisions concerning the allocation of services had to take the carers' assessment into account. The Act covers three distinct groups of carers:

- adults (18 years and over) providing care for other adults
- parents of ill or disabled children
- children and young people

There are, however, limitations to the Act. For instance, only carers who provide or intend to provide *regular* or *substantial* help are eligible for an assessment. However, it is left to local authorities to interpret what is meant by the terms *regular* or *substantial* help. This suggests that there is bound to be national variation in its interpretation which could indirectly influence the services carers are able to access on a geographical basis.

How carers' assessments are carried out is also left to the discretion of the local authorities. There are no set rules as to whether carers' assessment should be carried out in the presence of the cared-for person or whether carers would have a separate carer assessment of their own. This is left to individual practitioners to determine. This begs the question of whether carers' would have the ability to request a separate assessment for their needs. Indeed, evidence suggests that carers' assertiveness is crucial in determining whether or not their own needs are fully addressed (Henwood et al, 1996 in Parker, 1999).

Although carers have a right to an assessment, this is on the basis that the cared-for person would be eligible for community care services in the first instance (Department of Health, 1996; Department of Health, 2001a). Decisions about services to support carers would thus be dependent on the needs of the cared-for person with an emphasis on carers sustaining their caring role. Guidance suggests that professionals should:

Encourage an approach which considers support already available from family, friends and neighbours, the type of assistance needed by the person being assessed and how and whether the current arrangement for care can sustain the user in the community. (Department of Health, 1996, para. 9)

It appears, then, that the message is clear:

as long as carers are managing, then their presence per se, will not influence how needs are prioritised...Only when they become vulnerable do they become a legitimate focus of intervention. (Parker, 1999, p53)

Further, as with the NHS and Community Care Act (1990), the Carers Recognition and Services Act (1995) had no *additional* financial commitment from government for implementation. There was, however, greater emphasis on multi-agency working, partnership and collaborative working between sectors in order to overcome fragmentation (Department of Health, 1997; Department of Health, 1998; Department of Health, 1999b).

The election of the Labour Government in 1997 overlapped with the implementation of the Carers Recognition and Services Act (1995). The early years of the new administration saw much activity around carers' needs. For example, a National Strategy for Carers (Department of Health, 1999a) was launched in 1999. This stated that those carrying out assessments should 'listen first to what carers have to say' (Department of Health, 1999a, p37). And for perhaps the first time, the duty of health services to meet carers' needs was emphasised. It was made explicit that health staff would have a key role not only as providers of care but in helping carers access the support they need by providing information which was accessible, relevant and comprehensible. General practitioners and members of the primary health care

staff were seen as the first point of contact for carers (Department of Health, 1999a), therefore, referring carers to other organisations, reviewing carer health needs, and assessing the ability of carers to continue caring were viewed as important roles for these professionals (Department of Health, 1999a).

It was also made clear that carers needed proper training provided by the health service to learn the necessary skills to care without the risk of injury to themselves (Department of Health, 1999a).

### **Collaborative working within health and social care**

Prior to the National Strategy for Carers, the role of health services in supporting informal care had been implicit and largely assumed to be part of 'joint' or collaborative working between health and social care. However, such joint working has been problematic for many years. For example, an early report by the UK independent watchdog on value for money within public services (Audit Commission, 1986) was highly critical of the way in which health and social care providers functioned. It was reported that progress in implementing community care policy was slow due to inadequate staffing levels, mismatched budgets, and multiple assessments which were not truly 'needs led'. Rather there was a fixation among service providers to tailor needs to existing services and fragmentation between the two services.

The two key white papers (Department of Health, 1989a and Department of Health, 1989b) that preceded the NHS and Community Care Act (1990) played a significant part in trying to reform health and social care, in an attempt to develop a properly needs-led service. Key elements of the Act included:

- Development of the internal market to create competition between providers from the two different sectors
- Delegation of power to local management structures
- Separation of the commissioner and provider function.

Social services were to take the lead role in conducting assessment of individual needs, to design care packages working in collaboration with health service providers, and purchase appropriate packages of care from the different sectors (i.e., voluntary, private, public). In addition, social services had the responsibility of developing community care plans consistent with the plans of health authorities.

Within health, the commissioning authority was responsible for assessing the health needs of the local population. Relevant services were then to be purchased to address those needs from appropriate providers.

Although specific roles were divided between the two sectors, the overall aim was to develop a seamless service; the reforms assumed that collaborative working would not be problematic. However, evidence suggests that the reforms largely failed in this objective (see for instance, Lewis and Glennerster, 1996). Other commentators criticised the government for its optimistic view of the challenges of collaborative working. Hudson (1987) for instance states:

From an agency's point of view, collaborative activity raises two main difficulties. First, it loses some of its freedom to act independently when it would prefer to maintain control over its domain and affairs. Second, it must invest scarce resources and energy in developing and maintaining relationships with other organisations when the potential returns on this investment are often unclear and intangible. (Hudson, 1987, in Means and Smith, 1998, p141).

The 1997 Labour government also tried to tackle these long-standing problems and proposed a move towards improved inter-agency working between health and social care (Department of Health, 1997; Department of Health, 1998; Department of Health, 1999b). Further, provided that arrangements had been made between the local council and health agency, it was stated that health professionals could also carry out assessments (Department of Health, 2001b). Policy also stipulated that health and social providers should work together to provide carers with the right information. In order to do this, health staff also had to be knowledgeable about carers' issues and the services available locally to support carers (Department of Health, 1999a). As with earlier policy documents, there was again emphasis on supporting carers by seeing them as partners in the provision of help to the person needing care but also on seeing them as individuals in their own right (Department of Health, 1999a).

## **HEALTH AND COMMUNITY CARE POLICY AND MINORITY ETHNIC COMMUNITIES**

We turn now to the more general issue of health and community care policy and minority ethnic communities.

Health and community care policy has largely ignored the needs of minority ethnic communities. If mentioned, there has been a tendency to make passing reference to addressing needs as opposed to concrete policy direction. For instance, the Government's White Paper, *Caring for People* (Department of Health, 1989a, para 2.9, p11) addressed 'people from ethnic minorities' in one paragraph, committing itself to taking account of the circumstances of minority communities and advocating that good community care should be

planned in consultation with them. Such bland statements failed to take account of the many different kinds of communities that exist in Britain. Instead, it has been argued, Britain was portrayed as a country devoid of cultural diversity and the rich ethnic mix that actually exists (Blakemore, 1998).

However, recent policy (for instance, Department of Health, 2001d) documents are now beginning to address the needs of minority ethnic communities. Moreover, general policy documents do suggest that providers and commissioners play a vital role in ensuring equity in service provision, delivering a more seamless service, take steps to reduce inequalities as well as ensure that carers needs are addressed (HMSO, 2000; Department of Health, 2003). 'Equity means in essence that those in equal need should have equal access to a service, and that those whose needs are greater should be targeted for more resources' (Tudor Hart, 1971 in Pearson et al, 1992).

A host of checklists, good practice guides and reports now exist, providing guidance to managers to enable them to provide services that are appropriate, accessible and equitable to all (Gunaratnam, 1993; Yee, 1995; Silvera et al, 1996; Royal College of Nursing, 2000; Mir et al, 2001).

Both policy expectation and practical guidance, therefore, suggest that good health service provision will include a framework encompassing ethnic monitoring, health needs assessments, links with local communities, as well as identifying and establishing links with carers.

### **A suitable workforce?**

A key issue in delivering an equitable health service capable of meeting diverse needs is an equitable and diverse workforce. It is essential, therefore, that equal opportunities policies are in place which also address staff needs.

In response to the shortage of workers in the early 1960s and 1970s, an active recruitment campaign to encourage nurses from the former British colonies took place. These nurses however, many of whom were well qualified, were only able to access jobs in the least popular areas such as mental health and care of the elderly (Thomas and Morton-Williams, 1972). Many nurses, despite having qualifications or the ability to pursue the State Registered Nurse qualification, found themselves channelled into the less prestigious State Enrolled Nursing course or working as unqualified auxiliary nurses (Baxter, 1988a). Some have argued

that the position of minority ethnic professionals has changed little over the decades (McNaught, 1994), especially in relation to senior management positions. Ellis (1990) for example, has argued that:

Racial inequality in the nursing profession is wide ranging and deep seated. It has been entrenched for a long time and will be difficult to remedy. (p38)

The first national survey of minority ethnic nurses (Beishon et al, 1995) reported a slight improvement in terms of career development for minority ethnic nurses. At the same time however, it provided evidence of an increase in the reporting of racial harassment by both clients and colleagues and fewer applications by younger generation South Asians. A later study of the recruitment of minority ethnic nurses (English National Board for Nursing, Midwifery and Health Visiting, 1998) reported that although equal opportunity policies had widespread acceptance, there was in general only patchy understanding of the rationales for more focused and proactive recruitment strategies.

Health service managers have a duty not only to assess the health needs of the local population in order to purchase appropriate health services (see above), but also to support nurses to enable them effectively to meet patient and carer needs. If nurses are to provide holistic care which underpins the philosophy of nursing and be involved in participating in providing holistic assessments as prescribed within policy (Department of Health, 2001c) then their training and education need to ensure that they are adequately prepared to meet the needs of clients and carers they come in contact with. However, 'there is evidence to indicate that nurses frequently fall short of providing sensitive and appropriate care to minority ethnic communities' (Gerrish and Papadopoulos, 1999, p1457). Evidence suggests that basic training does not adequately prepare nurses to meet the needs of minority ethnic clients, (Gerrish et al, 1996, Boi 2000). Managers thus have a responsibility to ensure that staff are able to access post-qualification training to provide non-discriminatory practice (Commission for Racial Equality, 2000). Recently, the Audit Commission (2001) made a number of recommendations for health service managers to support the development of an organisation-wide culture that values training and learning. Managers were recommended to identify and develop training needs, as well as improve access and appropriateness of training available to staff.

## **POLICY INTO PRACTICE**

### **MINORITY ETHNIC COMMUNITIES AND SERVICE USE**

There is now ample evidence that health and social care services are not fully utilised by minority ethnic communities (Askham et al, 1995; Butt and Mirza, 1996; Katbamna and Bhakta, 1998). Askham et al, (1995) for instance, in a study which looked at social and

health authority services for elderly people from black and minority ethnic communities, found low uptake associated with lack of knowledge of services, fear of discrimination, services being inappropriate and lack of referral. A number of common factors affect utilisation but the extent to which individual attitudes, perceptions, knowledge and health beliefs interact to influence use remains unclear.

Further, there are some contrasts in the evidence. For example, although some minority ethnic communities are known for their use of traditional folk medicine, overall the western medical health care system appears to be favoured (Bowes and Domokos, 1993). Indeed, historically there have been much higher levels of registration and consultation with general practitioners among some minority ethnic groups compared with, say, African Caribbean and white groups (Johnson, 1986).

Some evidence in this area is also open to different interpretations. Early and smaller studies, for example, have reported low levels of minority ethnic clients featured on district nursing caseloads (Cameron et al, 1989b; Hek, 1990). A larger-scale survey looking at the health needs of minority ethnic communities (Nazroo, 1997) appeared to confirm these findings. However, the picture from this survey is not entirely clear. Respondents were asked if they had used either health visiting or district nursing services, but the data were combined into one group without separating out differences in utilisation patterns between the two professions. Although health visiting is often referred to as a profession which caters for a person's needs from 'cradle to grave,' in practice, health visitors tend to work with families and young children and district nurses with older people. Minority ethnic groups have a younger age structure than the white population, reflecting past immigration and fertility patterns (Warnes, 1996; Office for National Statistics, 2002). Had Nazroo's (1997) findings been analysed separately, they may have illustrated differences in utilisation patterns between the professions. For instance, health visitors may have been found to have more contact with minority ethnic groups (especially with the Bangladeshi population) than district nurses as there are more young children within these groups.

A number of studies similarly report that social care services are not utilised as expected by minority ethnic communities (Atkin et al, 1989; Nazroo, 1997), despite evidence of need. For example, Farrah's (1986) local study of the needs of Black elders showed the need for home help was greater than usage of the service.

### **Lack of knowledge about services**

Information such as clear explanations about diagnosis and prognosis, being aware of what to do in emergency situations, where to turn to for advice and support, and how to provide care, enable carers to cope, manage, organise and perform caring tasks more effectively (Baxter, 1989; Katbamna and Bhakta, 1998, Atkin and Ahmad, 1999). Information that enables carers to make informed choices is thus crucial for effective delivery and utilisation of services.

However, almost 20 years of research evidence show that not knowing where to turn for information, what services are available or how to access them have been, and remain, substantial barriers to minority ethnic communities using services (Opie, 1992; Cameron et al, 1988; Askham et al, 1995; Katbamna and Bhakta, 1998; Atkin and Ahmad, 1999; Chamba et al, 1999; Jewson et al, 2000; Vernon, 2002). This is irrespective of age or disability (Butt and Mirza, 1996, Nazroo, 1997) and includes carers as much as those they help.

Katbamna and Bhakta (1998), for example, reported carers as having poor knowledge about the role of different professionals within primary health care and how they could be supported by them. However, although lack of knowledge and awareness was a theme that was evident across all language groups, differences between the groups as to the type of information or services they were able to access were also reported, illustrating the complexity involved in accessing information and services. Gujarati Hindu carers, for instance, were more successful in obtaining information on benefit entitlements, services and equipment and the least successful in obtaining information on how to care. This may be because the Indian population (especially, East African Indians) is more fluent in the English language than any other South Asian minority ethnic community (Modood et al, 1997).

Cash benefits, as well as services, can also provide support for carers. Although benefits such as the invalid care allowance are available, there are often stringent criteria for eligibility and they often involve filling in complex application forms. Again, the literature reports that there is also a general lack of awareness about benefit entitlements. For example, a study by Cocking and Athwal, (1990) illustrates how carers missed benefits to which they were entitled. Other studies have identified that minority ethnic people have been fearful of applying for benefits to which they are fully entitled (Walker and Ahmad, 1994). Cultural and religious beliefs are also reported as contributing to low benefits take up, where there is a sense of stigma attached to claiming benefits (Law et al, 1993 in Craig and Rai, 1996). Further, a major study provided extensive evidence that racism was common in the social

security system (National Association of Citizens Advice Bureaux, 1991 in Craig and Rai, 1996).

Yet once people from minority ethnic communities are made aware of services, they are willing to use them, if important provisos are met. These include meeting religious and cultural needs and improving communication and language barriers via interpreting facilities (Cameron et al, 1988; Atkin et al, 1989; Askham et al, 1995; Butt and Mirza; 1996; Jewson et al, 2000).

### **Language and communication**

As reported in chapter one, a high proportion of South Asian communities do not consider English as their main language (Rudat, 1994; Modood et al, 1997). Knowledge about services or conditions is thus often hampered by limited, inappropriate or complete lack of translated information, often further compounded by communication barriers. Some have suggested that, as a result 'services are currently being taken up by those who can communicate effectively and not necessarily by those most in need' (Hatton et al, 1998 in Mir et al, 2001, p40). Minority ethnic carers who are unable to speak or understand English are at a disadvantage from the onset and carers from these communities continue to experience difficulties in accessing information and services (Opie, 1992; Katbamna and Bhakta, 1998; Atkin and Ahmad, 1999).

Even when services are known about and used, language and communication issues can still cause problems. A crucial and important element of effective nurse-client and carer relationships is that of effective communication. However, studies of acute sector nurses' experiences with minority ethnic clients found that language and communication barriers led to difficulties in developing therapeutic relationships (Murphy and Macleod Clark, 1993), leading to feelings of frustration and stress. And a study by Bowler (1993) showed how midwives regarded the inability to speak English as associated with lack of intelligence and rudeness. There is limited evidence of nurses' experiences of caring for minority ethnic clients or carers.

Ineffective communication can lead to the needs of minority ethnic clients being misunderstood and minority ethnic clients being labelled as non-compliant when they continue to practice 'what makes sense to them' (Narayan and Rea, 1997, p462). In order to avoid the risk of misleading assessments and inappropriate care, practitioners need to be able to recognise and deal with cross-cultural communication issues (Pedersen, 1988 in

Papadopoulos and Alleyne, 1998), especially when evidence suggests that minority ethnic clients have been treated differently and less favourably at times (Alibai, 1986; Donovan, 1986; Anionwu, 1993). Nurses may thus need to be creative in order to overcome language and communication barriers. This could be as simple as developing a list of useful phrases written on a card (Papadopoulos and Alleyne, 1998).

Community-based studies (Askham et al, 1995; Pharoah, 1995; Katbamna and Bhakta, 1998) have also reported difficulties in communication due to language barriers. As a result, nurses have been found to be heavily reliant upon family members and children to interpret (Pharoah, 1995; Gerrish, 1998). In some cases, nurses have tried to overcome difficulties by miming for instance (Pharoah, 1995); although useful this practice is clearly not adequate.

It is now over twenty years since it was reported that untrained interpreters cannot overcome communication difficulties (Richter et al, 1979). A study in Leicester looked specifically at the bilingual consultation, by videotaping consultations in outpatient departments with Gujarati speaking clients, the interpreter (usually a family member) and the doctor. It was reported that 'the basic structure of the dialogue was that a question from the doctor to elicit information was translated, or mistranslated, into Gujarati, sometimes with editing... in each case, the quality of information given in the history would have made it difficult to form a correct initial diagnosis' (Ebden et al, 1988, p347). More recent evidence suggests that things have not changed a great deal and that professionals continue to rely heavily on using family members to interpret, rather than using professional interpreters (Pharoah, 1995; Gerrish, 1998). The use of informal interpreters can cause embarrassment for both interpreter and patient. Further, reliance on relatives to translate as opposed to trained interpreters can result in information being lost, changed or filtered as well as compromising patient confidentiality (Ebden et al, 1988, Askham et al, 1995).

### **Stereotyping and cultural issues**

Misrepresentation of the needs of minority ethnic communities also influences use of services. Services providers can be preoccupied with cultural differences and practices, while both individual and institutional racism exacerbate the difficulties for minority ethnic groups and deprive them of equal rights to services (Ahmad, 1993). A preoccupation with difference may lead to clients being blamed for not making appropriate use of services, whilst service providers fail to examine the appropriateness of those services (Ahmad, 1993). Whether services are considered to meet needs will thus have a bearing on utilisation patterns.

Early studies, for example, reported that nurses spent significantly more time with patients of the same cultural background (Stockwell, 1972; Jones and Van Amelsvoort-Jones, 1986, in Lea, 1994). Even when language was not a barrier to communication, poor communication was observed with minority ethnic patients owing to cultural differences. Studies in the acute sector looking at nurses' experiences of caring for minority ethnic clients (e.g. Murphy and Clark, 1993; Bowler, 1993; Boi, 2000) suggest that nurses hold negative attitudes towards minority ethnic clients, (Bonaparte, 1979; Ruiz, 1981 in Murphy and Clark, 1993) that are often stereotypical in nature (Hek, 1991; Bowler, 1993).

Similarly, in community settings, stereotyping and lack of cultural awareness are apparently common. Cameron et al's, (1988) study based on interviews with service providers (nurses and social workers) reported that district nurses held stereotypical views about black people and their situations. These affected nurses' views of the health needs of people from ethnic minority groups in relation to other client groups, in terms of priority and appropriateness of intervention. It was reported that this was largely due to myths of the strength of minority ethnic communities 'caring for their own'. District nurses often assumed that there was extensive family support for black elders and disabled relatives from their families. In addition, low uptake of services was attributed to lack of need due to family support, as opposed to inadequate referral procedures or the failure of the health service to meet needs.

Cameron et al also reported that nurses knew little about the biographical backgrounds of black people on their caseloads in relation to their migration history, lifestyle or need relative to other communities. Yet their data showed that disabled and old black people were a very heterogeneous group.

Bowler's 1993 study showed how midwives believed that women from minority ethnic communities were uncompliant, rude, attention seeking, over fussy and lacking normal maternal instincts, with communication barriers leading to a poorer quality of care.

Pharoah's (1995) study looked at the extent to which primary healthcare addressed the needs, preferences and difficulties of elderly people from black and minority ethnic groups. As part of the study, semi-structured interviews were also conducted with nine community nurses and six practice nurses; stereotypical attitudes concerning carers' needs were evident. Like Cameron et al's (1988) findings, nurses were generally of the opinion that elderly people were supported because minority ethnic families care for their own. Further, nurses felt that carers

from minority ethnic groups did not have the same level of need for facilities because of the support available from the family and, if they did have needs, they did not make them known.

These and other studies (Butt and Mirza, 1996; Department of Health, 1998b) have thus identified that assumptions such as 'they care for their own' among services providers leads to lack of referral. Yet, as shown in chapter one, household structures are changing and many older people from minority ethnic groups live on their own (Modood et al, 1997; Office of National Statistics, 2002). Further, where extended families do exist they may do so out of economic necessity as opposed to desire (Butt and Mirza, 1996). Moreover, despite living within an extended household, carers often have little support from other members of the family (Katbamna and Bhakta, 1998).

However, there is also a need to strike a balance in service provision. Askham et al, (1995) for instance, reported that minority ethnic elders in their study had a preference to be treated in a 'special way' because of their religious and cultural beliefs and language and communication issues. Further, evidence from Gerrish's (1998) observational study reported that while nurses held stereotypical views these did not translate into practice and did not disadvantage minority ethnic patients and carers in terms of the care they received from district nurses. District nurses were also said to have accumulated considerable knowledge about the make up of their caseload over time.

Although Gerrish's (1998) study suggests that there are signs of some improvement in service delivery to minority ethnic patients and their carers, like others, it is a study which only obtained the views of one party (the nurses). Also the use of participant observation may have influenced how nurses behaved, knowing that their actions were being monitored.

These issues are discussed more in the final part of this section, as we examine in some detail the few existing studies specifically about carers and PHC nursing services. Next, however, we examine the development of the influential nursing theory of person-or patient-centred care, to set the context for later analysis of why carers seem to find it difficult to get support from PHC nursing services.

## **THE DEVELOPMENT OF PATIENT-CENTRED CARE**

A patient-centred or a person-centred approach to working is increasingly regarded as crucial for the delivery of high quality care by professionals. Four reasons for this shift in the way in

which health care is delivered are identified in the literature. They are now discussed in turn (adapted from Gillespie et al, 2002).

- **Social change**

Social change has had a major impact on the way in which the public views health professionals. An increasingly critical media, improvements in education and technology have led people to question as well as challenge health professionals. Moreover, several high profile cases<sup>7</sup> have highlighted the failure of health professionals to live up to the standards expected by the general public. For instance, recent concerns over the MMR vaccine highlighted how failures in partnership between professionals and patients can have repercussions in the policy arena.

- **Policy**

Coupled with escalating costs within health care, the 1980 and 1990s witnessed a move towards an increasingly consumerist approach to delivering health services. Initiatives such as the Patient's Charter (1991), the named nurse initiative and policy aimed directly at health authorities outlining the need to include the views of local people in planning services (Department of Health, 1992) emerged, with the specific aim of making health services more responsive to needs as well as setting out the rights of patients. With the Labour government's victory in the 1997 election, a commitment to providing a more open, accountable and patient-centred service gained momentum. Initiatives aimed at improving access to information and greater transparency over performance and quality of local services were rolled out (Department of Health, 1997, Department of Health, 2001a).

- **Organisational change**

Although organisational change has been a feature of the National Health Service since its inception in 1948, the focus in the past has been to change organisations and their structures as opposed to face-to-face relationships. The advent of Primary Care Groups (PCGs), Primary Care Trusts (PCTs), reconfiguration of trusts, and partnership working between health and social care services offer opportunities for increased partnership.

- **Professional development**

In the past, professional practice was tightly controlling, using closed questioning techniques with a focus on defining problems in a biomedical style. A patient-centred model of care requires a shift from the traditional notion of the health professional being the dominant participant, and the patient a passive recipient, to one in which power and control are shared.

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<sup>7</sup> Other examples include, the Bristol Royal Infirmary Inquiry 1984 -1995 concerning children's cardiac surgical services and the removal, retention and disposal of organs at the Liver Adler Hey Hospital in 1999.

Further, patient-centredness involves taking account of patients' (and carers') desire for more information and responding appropriately to them in a holistic manner.

However, like the terms 'race' and ethnicity (see chapter two) there remains considerable ambiguity concerning the meaning of patient-centred care. Indeed, PHC nurses in this study used terms such as individualised care, patient centred care, and holistic care interchangeably, apparently meaning the same thing.

Hildegard Peplau (1952) and Ida Jean Orlando (1961) were the front-runners in conceptualising patient-centred care. Both nurse theorists emphasised the potential of nurse-patient interactions in improving health and illness outcomes as well as making nurses accountable for their actions. The 'nursing process' was developed (Yura and Walsh, 1967) aimed at documenting patients' expressed and unexpressed needs. Integral to the successful implementation of a care plan, was 'the involvement of the patient in mutual goal setting and decision making' (Cox, 2000, p184). However, it has been argued that these and other nurse theorists still focused on meeting patient needs by way of supporting the authority of the social institution of medicine, with a provider-defined, disease-centred approach to defining and meeting patients' needs (Lutz and Bowers, 2000). 'The prevailing assumption is that provider assessment of need and provider determination of strategies to meet those needs is accurate, prudent, and effective without fail' (Cox, 2000, p184).

These debates are not, of course, new. Florence Nightingale (1859/1992) was a firm advocate of separating nursing from medicine because the discipline of nursing focused on the patient rather than on disease. Similarly, more recent nursing models such as Orem's model (1995) propose that patients' needs should be defined by nurses; this, however, still places someone (this time, the nurse) in a dominant position over the patient.

There has since been a move towards encouraging patients to take more of an active part in the decision making process concerning their needs, wants, and aspirations for nursing care (Ford and McCormack, 2000). Mallett (1996), for example, suggests that patient-centred care should place the patient at the centre of the system of care and develop good services that revolve around them, whilst others (Grin, 1994 in Lutz and Bowers, 2000) advocate a collaborative effort consisting of patients, families, friends and professionals to meet needs. However, overall, meeting the needs of patients is still paramount within these models.

Some nursing academics, by contrast, are now spelling out the need also to incorporate the needs of carers into the equation. Nolan et al (1995) suggest that there should be a change in emphasis from 'nursing care' towards 'family care'. They argue both that 'it is no longer acceptable that a professional perspective should be allowed to dominate and [that] it is time to redefine the fundamental relationship between family carers and professional workers so that a genuine partnership develops and flourishes and interventions are facilitative, rather than obstructive' (p13).

In the current study, the ideal of 'patient-centred' care refers to Kitwood's (1997) definition of 'person-centredness'.

...a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust (Kitwood, 1997 in McCormack, 2004, p33)

By this definition, relationship, context, place and self are key components of the concept. So, for example, using Kitwood's definition in the context of gerontological nursing, McCormack (2004) suggests that 'being person-centred relies on knowing the older person in their social context and care plans include others significant to the older person and the needs of the community of formal or informal carers' (p33). Knowing the person (cared-for person) in their social context/environment thus strongly suggests that the needs of informal carers should also be considered.

### **Holistic assessment**

In developing a person-centred care plan, however, it is first necessary to conduct an holistic assessment of need. Holism is defined as 'identifying the inter-relationships of the bio-psycho-social-spiritual dimensions of the person, recognising that the whole is greater than the sum of its parts; and understanding the individual as a unitary whole in mutual process with the environment' (Dossey, 2001, p1). An important part of planning care should, therefore, be utilising carers' knowledge and expertise (Davies et al, 1997 in Walker and Dewar, 2001).

The American Holistic Nurses Association (AHNA) in one of its core standards of practice, describes the holistic caring process as being based on an assessment during which each person is assessed holistically, using appropriate traditional and holistic methods, while the uniqueness of the person is honoured (AHNA, 2000). Actual and potential patterns, problems, and needs and life processes related to health, wellness, disease, or illness that may facilitate well-being are identified and prioritised and outcomes specified. A care plan focusing on

health promotion, recovery, restoration or peaceful dying, so that the person is as independent as possible, is mutually created. This plan of care is prioritised, and holistic nursing interventions are implemented accordingly. Responses to holistic care are regularly and systematically evaluated and the continuing holistic nature of the healing process is reorganised and honoured (AHNA Standards of Holistic Nursing Practice, 2000 in Dossey 2001).

Like patient-centred care, it is advocated that the holistic assessment should also incorporate the needs of informal carers (Department of Health, 1991, Ham-Ying, 1993; Nolan et al, 1995). Nolan et al (1995) suggest that nurses working with carers must ensure that a holistic assessment, which includes attention to carers' needs, is one of the touchstones of minimal good practice (p13). Bowers (1987 in Nolan et al, 1995) similarly argues that:

...the efficacy of nursing interventions depends on the nurses' ability to assess family involvement in the care of older parents. Distinctions among the various categories of care giving activity must be included in this assessment...A carefully performed assessment of the caregiver's perceptions and priorities can prevent the nurse from being perceived as an adversary rather than an advocate for the patient and his or her family (p11).

A good holistic assessment, then, would take into consideration the needs and wishes of the cared-for person as well their carers. Further, as Department of Health guidance suggests, identifying need should not be determined by pre-existing services or the roles of individual professionals (Department of Health, 1999a; Watson et al, 2002).

## **INFORMAL CARERS AND PRIMARY HEALTH CARE NURSING SERVICES**

Finally in this chapter we turn to the existing literature about informal care and the role of PHC nursing services, particularly in relation to minority ethnic communities.

In their review of the literature on carers and services, Twigg et al (1990) argued that although 'the community nursing service plays a potentially important role in the support of carers, there is an almost total lack of evaluative work in the area' (p.40). Almost 15 years later there are still only a small number of studies that have addressed the issue of informal carers within PHC nursing (e.g. Luker and Perkins, 1988; Cameron et al, 1989 a&b; Buckledee, 1990; Atkinson, 1992; Katbamna and Bhakta, 1998; Gerrish, 1998; Pickard et al, 2000). Further, there are some limitations with these studies in relation to the work reported here.

First, most have looked at carers' views of specific nursing services, such as district nursing, while other community nursing services such as learning disability nurses or health visitors

have not been explored. Secondly, most studies focus purely on needs of carers to the neglect of obtaining a perspective of what it is like for nurses to provide support for informal carers. The exceptions are Cameron et al (1989a) who report carers and 'service provider' views and Gerrish (1998) who provides a district nursing perspective and, based on data gathered through participant observation, reports the interactions that occurred between nurses and minority ethnic clients and carers. Thirdly, only three of these studies have addressed issues concerning minority ethnic carers (Cameron, et al 1989; Katbamna and Bhakta, 1998; Gerrish, 1998). Finally, all provide only the views of one party, the nurses or the carers but not both. Thus none have looked exclusively at minority ethnic carers as well as the nurses' perspective. With limited evidence in this field, it is worthwhile taking a closer look at the three studies that have tried to incorporate minority ethnic carers' perspectives (Cameron, 1989a; Katbamna and Bhakta, 1998; Gerrish, 1998).

As part of a larger community care project based in Birmingham, Cameron et al (1988) looked at the needs of older disabled black women and black women who were carers of disabled family members. Service providers from district nursing, health visiting, community psychiatric nursing, social work, occupational therapy and home help teams were interviewed from a random sample, using a structured schedule, about their knowledge of, and their work with, clients and patients on their caseload. However, the study fails to clarify its random sampling procedures. Further, it is reported that only in a few selected cases were interviews with carers carried out, yet they give no indication as to how many interviews were conducted. It is also reported that referral networks into and between services did not allow for effective service delivery, but it is not clear between which services (for instance, between nursing and social work) problems of referral existed.

Cameron et al (1988) also reported that general practitioners did not refer black patients to district nursing services despite having a high concentration of minority ethnic people residing in the area. General practitioners working on stereotypical assumptions about minority ethnic people 'caring for their own' was one of the reasons identified for lack of referral. However, the study does not provide data to substantiate these claims neither were the views of general practitioners obtained.

In a different paper, Cameron et al (1989b) report that, generally, nurses knew little about patients' sources of income and when asked whether they thought the patient's household had enough money coming in to manage, no black patients were thought to be hard up or very hard up compared to eleven per cent of white patients. It is also reported that nurses perceived

patients' income and financial status as falling outside their area of concern. Inadequacy of interpreter services were also identified in terms of their unavailability or inflexibility (Atkin et al, 1989).

The study does, however, provide valuable insight into South Asian elders' knowledge and use of services, as well as obtaining the views of nursing and social care providers about their experiences of caring for minority ethnic clients and carers. Evidence of services being inaccessible or inappropriate to meet need is documented. In addition, as reported later, there were widespread myths of extensive family support within minority ethnic communities among service providers that, in their view, 'explained' low uptake of services. The study is valuable in the light it sheds on the inadequacies of service provision to meet the needs of minority ethnic people, compounded further by the disadvantaged position of black old people in society.

The second study is Katbamna and Bhakta's (1998). It is the only large-scale study to look at the needs of minority ethnic carers to date. It had two main aims. The first was to establish the nature of caring responsibilities, the impact of caring and to examine carers' experiences of using primary health care services. The second was to develop practice guidelines for members of the primary health care team. Katbamna and Bhakta's study was undertaken by setting up focus groups in Leicester and Bradford with male and female carers from the four main language/religious groups - Gujarati Hindu, Pakistani Muslim, Punjabi Sikh and Bangladeshi Muslim. Each focus group met three times. In-depth interviews were subsequently carried out with male and female carers. Focus groups and interviews were conducted in the carers' own language and tape recorded. The tapes were translated back into English, indexing guides developed, transcripts coded and a framework approach used for the analysis (Ritchie and Spencer, 1994)

Although one of the aims of Katbamna and Bhakta's (1998) study was to report carers' experiences of using primary health care services, a major limitation was that it reported primarily on carers' experiences with general practitioner services. Little was reported about primary health nursing services. The study enlisted the support of carers through a variety of means; one approach was that of establishing links and contacts with community organisations in order to capture the views of those carers who did not have contact with formal services. However, this approach inevitably led to the sample being biased towards carers who could talk only about their experiences with general practitioner services.

However, the study provides valuable insight into the care giving experiences of minority ethnic carers from different groups. It was reported that carers' experiences of caring were made worse due to difficulties in accessing services and negative consultations with general practitioners. Further, concerns were not taken seriously and carers were rarely given advice or information to support them in their caring role.

Gerrish (1998; 1999; 2000; 2001) in her ethnographic study examined how policy directives concerning the provision of individualised care were modified in practice and the implications of this when caring for minority ethnic patients and carers. However, the views of minority ethnic patients or carers were not sought, although interactions between them and nursing staff were observed.

The study was conducted in the north of England and involved two distinct stages. First, an organisation profile was developed and in-depth interviews conducted with eight senior managers to ascertain the local policy context. Secondly, participant observation was used as a method of data collection. Six district nursing teams were studied, four of which had a high concentration of minority ethnic patients on their caseloads. Two teams with white patients provided a comparative sample.

Twenty two nurses were observed in total. A total of 291 nurse/patient interactions were observed spanning three separate stages over a period of one year. The use of participant observation meant that the study is reported in terms of the number of interactions or visits. For instance, it is reported that 75 visits were made to South Asian patients who spoke limited or no English. Some of these patients were visited on several occasions, and it was observed that on occasion's nurses put the needs of carers over those of the patient and therefore made time to ensure that the needs of carers were not overlooked.

Gerrish (1998) uses the term Asian to refer to patients on nurses' caseload who were of Pakistani, Bangladeshi or Indian origin (including descendents of East African Asians and those born in Britain). As all South Asian patients have been grouped together into one category it is not possible to distinguish what percentage of the sample made up the individual groups and whether there were any differences *between* the South Asian groups. This is important as Katbamna and Bhakta (1998) illustrated that access to information and services was complicated and varied between minority ethnic groups.

Gerrish (1998) also reported that in-depth interviews were carried out with 'G' grade nurses which took place two weeks after the first period of observation. However, there is no indication of how many in-depth interviews took place. She states that there were six teams headed by a 'G' grade nurse. However, it cannot be assumed that all six 'G' grade nurses participated in the interview. Even if all six 'G' grade nurses did take part in the in-depth interviews, the sample size for the in-depth interviews remains small. In subsequent published work, it is reported that in-depth interviews were undertaken with *the nurses* or *some* of the nurses following an episode of fieldwork. The broad use of the term 'nurses' gives the impression that other nurses who formed part of teams may have been interviewed in-depth as opposed to senior G grade nursing staff alone. Moreover, if in-depth interviews were carried out only with 'G' grade nurses, they would be relatively senior in comparison to other grades of staff. Thus it is likely that they were more skilled in terms of meeting patient and carer needs, knowledgeable about aspects of policy and its relevance to practice and worked under different types of pressures from other grades of staff who were more likely to be involved in the practical and clinical aspects of nursing. Had the views of junior nurses been obtained using a similar approach, the reality of working 'on the ground' may have portrayed a different picture from that gained during observational visits, particularly as participant observation aims to 'observe events as they occur naturally. How far this aim can be fulfilled remains doubtful, because the act of observation influences the observed in any case' (Flick, 1998, p141).

There is reference to the make up each team (Gerrish 1998; 1999; 2000; 2001) - for instance, that each team comprised of a G grade nurse, an RGN and qualified health care assistants or comprised of 2-4 other nurses. Discussions which took place over time with other nurses from the team were written up as detailed field notes. However, one wonders whether sequencing of visits over a period of time influenced nurses' views and behaviour in terms of how they ought to behave or speak. Time lapses between repeated visits would have been sufficient to allow nurses the opportunity to discuss with each other their own views and experiences about being 'observed' and perhaps have even influenced their views as to what they should be saying or doing.

In-depth interviews were also conducted with eight senior managers in Gerrish's work. Again, the sample size is small and interviews were conducted only with senior managers. Obtaining the views of some junior managers may have provided a differing perspective.

As discussed earlier, Gerrish (1998) used an ethnographic approach for her study, hence, different methods for data collection were employed, namely, participant observation, in-depth interviews and documentary evidence. Here, a critique of participant observation is reported, as this was the main form of data collection used for her study. This discussion is strengthened and elaborated further in chapter five where a comparison of participant observation and the interview method can be found along with a discussion on why a survey approach was not adopted and why in-depth interviews were deemed to be the most appropriate method of data collection for this study.

### **A critique of participant observation**

The method originates from the Chicago School of social research when during the 1920s and 1930s students were encouraged to study by observation the constantly changing social phenomena of Chicago (May, 2001). Over the years, the approach has gone from strength to strength, so much so, that it is often regarded as the 'gold standard' for naturalistic research.

One of the distinct features of participant observation is that it enables the researcher to obtain an insider perspective of human meaning and interaction (Jorgensen, 1989). However, 'the insider's conception of reality is not directly accessible to aliens, outsiders, or non-members, all of whom necessarily experience it initially as a stranger' (Schutz, 1967 in Jorgensen, 1989). Hence, it is not possible to acquire more than a very crude notion of the insider's world (Hall, 1959 in Jorgensen, 1989). The idea that the method enables meanings of those being researched to be uncovered is also criticised on the grounds that there is no foolproof method of ascribing meaning to observations: 'how can we be certain that such and such reality did mean what I say it meant?' (Strong, 1979 in Murphy et al, 1998, p102)

Gold (1969) identified four types of roles for field research involving participant observation: complete participant<sup>8</sup>, participant as observer<sup>9</sup>, observer as participant<sup>10</sup> and complete observer<sup>11</sup>. It has been argued that the type of role adopted by the researcher will inevitably affect the data produced (May, 2001). Gerrish (1998) in her study switched between roles of participant as observer and observer as participant. This is problematic in that she attempts to combine remaining distant as well as being part of the group, depending on her observations and personal judgement of the situation at the time. May (2001) suggests that the role of

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<sup>8</sup> Here the researcher adopts a covert role and engages fully in the activities of the group or organisation being studied.

<sup>9</sup> Here the researcher adopts an overt role and is up front about their presence and intentions.

<sup>10</sup> Here the researcher observes and participates in the activities of the group

<sup>11</sup> Here the researcher is a non participant and simply observes the activities of the group being studied

observer as participant cannot strictly speaking be classed as participant observation. This view is also endorsed by Gold (1969) who suggests that:

The observer-as-participant role is used in studies involving one-visit interviews. It calls for relatively formal observation than either informal observation or participation of any kind. (p36)

Further, as contact is so brief, it is suggested there is the risk that the researcher misunderstands what is actually happening (Gold, 1969).

It is time which often tells us how deeply people feel about certain subjects. It is time that tells us how long it takes an outside influence to become a meaningful part of the lives of people in a culture. Those social meanings which really count in people's lives cannot be calculated by reference to the temporally limited, stimulus – response framework of the experimentalist. Cultural influences have an incubation period which takes time and close association to the study. (Bruyn, 1966, p207 in May, 2001, p161)

May (2001) argues that it is highly questionable that facts can simply be gathered on the social world. This is largely because it is assumed that 'data are collected and somehow 'naturally occurring' – without being mediated by the theoretical concerns and biography of the researcher – while theory is derived from observations' (May, 2001 p 152). Moreover, it is also argued that the presence of the researcher contaminates the social scene and that human beings will behave differently when they know they are being studied (see for instance, Roethlisberger and Dickinson, 1939 in Jorgensen, 1989; Douglas, 1976 in Jorgensen, 1989; Flick, 1998; May, 2001). Similarly, the character of field relations heavily influences the researcher's ability to collect accurate and truthful information (Jorgensen, 1989).

Another problem is that the method is heavily dependent upon the researcher's powers of observation and selection. Hence, it is possible that researchers could omit a whole range of data in order to confirm their own pre-established beliefs, leaving the method open to the charge of bias (May 2001). Further, separation of fact and the value that is found in versions of naturalism is argued as being highly problematic. Realists have criticised the idea that we can observe events or relationships free from theories or concepts, as observations are mediated through concepts acquired in everyday life (May, 2001)

Although Gerrish's (198) study was conducted with only one National Health Service (NHS) Trust, it is unlikely that an NHS trust would be classed as a small scale organisation. This is important as the method has been reported to be poor at dealing with large-scale cases such as big organisations (Hammersley and Atkinson, 1983 p237). Further, the method relies on

material that observers have solicited or provoked from participants. Hence, there need to be clear distinctions between what is overheard or witnessed and what is generated by direct observation (Murphy and Dingwall, 2003).

Gerrish (1998) provides an account of how her personal history, biography and professional biography may have shaped the research. She acknowledges that the nurses related to her as 'one of them' as she and the nurses shared the same ethnicity (white) and that had she been from a visible ethnic minority group, the nurses would have responded differently. The notion of white people studying minority ethnic groups has been challenged (see for instance, Andersen, 1993; Gunaratnam, 2003). It is argued, for instance, that 'research occurs in the context of power relationships, both between the researcher and research subjects and in society at large' (Stanfield, 1993, p40).

Scientific research does not occur in a vacuum...The control, exploitation, and privilege that are generic components of social oppression exist in the relation of researchers to researched, even though their manifestations may be subtle and masked by professional ideologies. (Blauner and Wellman, 1973, in Andersen, 1993, p40)

Andersen (1993) in her influential article on 'studying across difference', raises these questions:

The problem of doing research within minority ethnic communities are compounded by the social distance imposed by class and race relations ... How can white scholars elicit an understanding of race relations as experienced by racial minorities? How can white scholars study those who have been historically subordinated without further producing, sociological accounts distorted by the political economy of race, class and gender? (p41)

Hence, it is argued that certain aspects of racial phenomena are particularly difficult if not impossible for a member of the oppressive group (white over South Asian in this case) to grasp empirically and formulate conceptually (Blauner and Wellman, 1973).

White people don't understand what it is like to be black and therefore can't understand the complex structures and behaviours of the black community (Parekh, 1981 in Connolly, 1993, p 1)

Similarly, Edwards (1990 in Gunaratnam, 2003) in paper on interracial interviews in feminist research, reports that black women were less trusting of her as a white women. However, acknowledging differences in 'race' and racialized experiences encouraged the development of rapport and talk with the women. Gerrish's (1998) study did not involve any interviews with minority ethnic patients or carers as only the interactions between them and the nurses were observed. This does lead to the question of how far observed

interactions alone adequately portray or reflect the views of minority ethnic patients and carers. Hence, some advocate that minority ethnic scholars themselves should engage in research studies involving minority ethnic people as they are better able to understand the nuances of oppression (Blauner and Wellman, 1973 in Andersen, 1993) or 'when ever possible' ethnic matching between researcher and research participants should be considered to produce 'ethnic sensitivity' in the research (Papadopoulos and Lees, 2002). However, not all are in favour of ethnic matching. Edwards, (1990 in Gunaratnam, 2003) for instance, suggests that research needs to take account of racialized meaning, of the research topic and how these meanings might change across the social spaces such as in talk about the 'public' and 'private' spheres of life. Similarly, Bhavnani, 1993 in Gunaratnam, 2003) suggests that 'matching strategies often fail to take account of power relations between the researcher and research participants, because the rationale of matching can imply that forms of 'unevenness' within the research interaction have been dealt with' (p83).

## CONCLUSION

The review in this chapter illustrates how the meaning of community care has changed over time. What is evident, however, is that the publication of several high profile reports concerning the conditions in large institutions was the start of the deinstitutionalization process and a shift in attitudes. By the 1980s the government made clear that people were now to be cared for at home, but with the support of family, friends and neighbours. Hence, care in the community was effectively care by the community.

It was after the Labour government's victory in the 1997 election, however, that meant that the duties of health services to meet carers' needs were spelled out for the first time. Hence, meeting the needs of carers was no longer just a social services responsibility. However, policy to address the needs of minority ethnic carers is still limited. Available evidence about minority ethnic people's experiences of using health and social care services highlights a number of shortfalls in service provision, as well as explanations as to why services may not be used.

In the context of this thesis, the development of patient-centred care and the use of holistic assessments signals that this could be one means of meeting carers' needs. This is important, as there are few studies that have addressed the carers' perspective of using PHC nursing services.

## **CHAPTER FOUR**

### **INFORMAL CARE AMONG WHITE AND MINORITY ETHNIC COMMUNITIES**

#### **INTRODUCTION**

As outlined in the introductory chapter the aim of this thesis is to explore Gujarati Hindu carers' experiences with primary health care nursing services in order to establish whether they felt supported. Bearing in mind the sensitivity of some of the issues to be addressed, it was felt that the study warranted an overview of carers' experiences of caring. First, from a methodological perspective it was imperative to discuss with carers what their experiences of caring actually were. Secondly, if PHC nurses and managers are to be committed to providing support for informal carers, then it is necessary for them to appreciate and understand carers' perspectives, to enable them to acknowledge and recognise the contribution of informal carers and the costs at which they continue to care.

The aim of this chapter is, therefore, to provide background about carers' experiences of caring among both white and minority ethnic carers. It principally draws upon key studies, comparing and contrasting (where possible) the literature and thus establishing a context for the main aims of the research study.

This overview will focus only on issues relating to carers' experiences of caring, divided into two broad subject areas: carers' experiences of caring, including a discussion of 'why' they care and the costs of caring and, secondly, the role of support in caring. Relatively few studies address the needs of minority ethnic carers (Katbamna and Bhakta, 1998; Chamba et al, 1999), and none to date look specifically at the caring experiences of Gujarati Hindu carers as well as depicting their experiences with primary health care nursing services. Much of the material in the chapter is thus drawn from studies relating to white carers. Selected studies are touched upon in the introduction and discussed more fully where appropriate later in the chapter or used to provide a dialogue with the results chapters.

#### **SCOPE OF THE LITERATURE**

As we saw in chapter three, until the mid 1970s informal carers were effectively invisible and their needs largely unrecognised. There was limited information about numbers, experiences or needs concerning white or minority ethnic carers. The seminal text by Townsend (1957) is a notable exception. Although not directly about informal care, it has contributed significantly to the debate. Townsend's (1957) study of the family life of old people living in

the London Borough of Bethnal Green, illustrated how family life was shaped by the support of relatives. In his work he suggested that the families had an extensive network of family support and friends whereby they looked after one another, as opposed to a single person (a carer) taking on the responsibility. He also argued that the responsibility of caring was happily carried out by the women as it enhanced their prestige and power within the wider community and, hence, the women felt rewarded for their efforts.

However his findings contrast notably with later studies. Bayley (1973), for instance, studied the lives of parents caring for 'mentally subnormal' adult children. His study supports Townsend's view that the majority of caring is carried out by women. However, unlike Townsend, Bayley (1973) graphically describes caring as demanding, draining, hardly reciprocal and very rarely rewarding. Routine tasks were seen as onerous, often involving considerable labour such as carrying adult children up and down the stairs. These labour intensive tasks were frequently carried out by mothers, with fathers having more of a peripheral role. In addition, tasks that had to be carried out routinely as part of caring on a daily basis were described as 'the daily grind' (a phrase commonly reported in the carers literature ever since).

Since Bayley's (1973) study, there has been a considerable growth in the volume of literature on informal care among the white community. Some researchers have concentrated on particular illnesses or conditions such as dementia (Opie, 1992) or learning disabilities and mental health problems (Twigg and Atkin, 1994). Others have addressed the needs of different types of carers such as elderly people, (Hicks, 1988), or parents caring for severely disabled children (Beresford, 1994) and spouse carers (Parker, 1993). All these studies and others like them have ultimately raised the profile of white carers. In addition, they have provided useful insight into care giving experiences, while larger scale, national surveys have given an indication of the incidence and pattern of care giving (Green, 1988; Parker and Lawton, 1994; Rowlands, 1998).

In contrast, although the British population consists of nearly five million people from minority ethnic communities, there is little research on informal care within these communities. Modood et al (1997) provide evidence on the diversity of minority ethnic groups and their circumstances. An attempt to address the lack of statistical evidence on informal care among minority ethnic groups was made by looking specifically at the care of elderly parents. Comparisons between white and South Asian people aged 40 to 59 years who cared for a parent identified that the vast majority of parents from the white community did

not live within the same household as their children. In contrast, half of the minority care relationships were within the same household, placing them in a good position to receive family care (Modood et al, 1997). However, the aim of Modood et al's (1997) study was providing statistical evidence of who provided support for one particular group (namely elderly parents). The study did not set out to provide an account of the caring experiences of those providing support. Thus the needs and caring experiences of minority ethnic carers have continued to be a neglected area of research. Until recently, we have been dependent on a sprinkling of small-scale studies from the late 1980s and 1990s (see for instance, Lee, 1987; Bould, 1990; Cocking and Athwal, 1990; McCalman, 1990). Baxter (1988) aptly described the plight of minority ethnic carers as 'the invisible carers'. Further, none of these studies addressed the nursing and management perspective of providing support for minority ethnic carers.

Some studies have tried to identify the needs of both minority ethnic people and their carers (Cole, 1990; Sage and Sanghavi, 1992; Chakrabarti and Cadman, 1994). These studies have, however, been instigated in order to satisfy the needs of social service departments to identify and meet local needs. Although a useful starting point, it cannot be assumed that issues identified within social service reports would be equally applicable within a health context. In addition, there are methodological weaknesses with some of these reports. Cole (1990) in her study of the needs of elderly black people and their carers, for instance, used a questionnaire but it is not clear how many people the questionnaire was distributed to or whether the questions were asked in person to the carer. Sage and Sanghavi's (1992) study is based on the views of female carers only, and a survey of elderly people and their carers (Chakrabarti and Cadman, 1994) resulted in only nine carers responding. Chamba et al (1999) provide statistical evidence concerning the socio-economic circumstances of minority ethnic carers caring for a severely disabled child. However, the focus of their study was addressing social care needs as opposed to carers' experiences with primary health nursing services. With limited evidence concerning carers' experiences with health services in general, then, these studies and others like them have had limited impact on policy and practice in terms of meeting the needs of minority ethnic carers within healthcare.

To date, as reported in chapter three, there has been only one large-scale study that has tried to close the gap in the literature (Katbamna and Bhakta, 1998), yet the findings of this study relate predominantly to general practitioners. Little is reported about carers' experiences with primary health care nursing services.

Given that there is very little literature addressing minority ethnic carers' experiences with primary health care nursing services, the study on which this thesis is based fills an important gap.

## **EXPERIENCES OF CARING**

### **Carers' experiences of caring**

Tasks that involve physical tending are often the defining feature of informal care (Twigg and Atkin, 1994). Physical tending activities have been described as those activities where the person needing care requires help with, for instance, bathing, dressing, feeding, getting in and out of bed, toileting, lifting and taking medication. In addition, carers frequently combine their caring activities with their household chores such as cooking and cleaning as well as seeing to the needs of the family. These types of activities can be another source of stress and have been well documented in the white carers' literature (Lewis and Meredith, 1988; Opie, 1992; Parker, 1993; Twigg and Atkin, 1994) and more recently, in the minority ethnic carer's literature (Katbamna and Bhakta, 1998 Chamba et al, 1999). One of the most striking features of all these studies is that caring tasks, whether physically demanding or not, are most frequently carried out by women.

Personal care activities frequently include bathing, toileting and managing incontinence, and these may involve touching, nakedness and contact with excreta. Although it could be argued that meeting the needs of children is equally taxing at times, when it comes to providing personal care, seeing to the personal needs of an adult is reported to be more problematic. Both the mainstream and available literature on minority ethnic carers reports that one of the most difficult and stressful aspects of personal care-giving concerning adults is dealing with incontinence and that it is problematic for both male and female carers (Wright, 1986; Lewis and Meredith, 1988; Parker, 1993; Katbamna and Bhakta, 1998). Incontinence is often underplayed or hidden as carers want to protect the person being cared for or because of embarrassment (Twigg and Atkin, 1994). Along with meeting incontinence needs, comes the practical difficulties of managing the extra laundry (Baldwin, 1985) combined with meeting the needs of the rest of the family. Consequently, tasks that have to be carried out routinely on a daily basis have been described as arduous, very much 'the daily grind', mixed up with feelings of sacrifice and embattlement (Bayley, 1973; Opie, 1992; Katbamna and Bhakta, 1998).

In most cultures there is an unwritten code of behaviour regarding the violation of personal privacy, particularly when intimate contact is involved (Katbamna and Bhakta, 1998). Men are more confined by unwritten rules and regulations as to the kinds of tasks they should or should not do and for whom. As a result, it appears that cross-gender caring seems to be more problematic for men (Twigg and Atkin, 1994). With the exception of Katbamna and Bhakta's (1998) study, there is little other evidence about cross-gender caring activities among minority ethnic carers. Katbamna and Bhakta (1998) reported that both male and female carers were involved in carrying out intimate caring tasks. Male carers experienced considerable shame if involved in cross-gender caring activities. Females were involved in carrying out intimate tasks not only for children and spouse, but other relatives as well. On occasions, this meant having to see to the needs of their elderly father-in-law in the absence of a male relative. However, given that the views of society overall suggest that it is inappropriate for male carers to be involved in cross-gender caring activities involving intimate personal care, there is, perhaps, a legitimate 'excuse' for male carers not to be involved in such tasks (Ungerson, 1987; Twigg and Atkin, 1994; Katbamna and Bhakta, 1998).

Although not all caring activities require physical endurance, having to lend practical support, by cutting up food and giving medication for instance, is another source of stress for carers (Twigg and Atkin, 1994; Katbamna and Bhakta, 1998). Even more taxing and stressful are situations which involve little practical support but considerable effort in 'keeping a watchful eye' over the person needing care. Studies have reported how carers have found it hard to relax because of fear that something would happen to the person needing care in their absence, fear that the person needing care would get themselves into dangerous situations and, in some instances, fear for the carer's own safety (Opie, 1992; Katbamna and Bhakta, 1998).

Carers experience a range of emotions throughout their care-giving careers. Overall, the majority of studies have highlighted the difficulties experienced and the negative aspects of care giving and its impact on other family members. The idea that caring could be satisfying has received relatively little attention. It has been suggested that those carers who do find caring satisfying are more likely to have positive relationships as well as improved emotional well-being (Hirschfield, 1983). Parker (1993) in her study of spouse carers reports that 'despite the fact that all couples described some negative impact on their lives together many also said that the experience had brought them closer together or strengthened their relationship' (p91).

More recently, some studies have tried to explore satisfaction with caring more fully and called for more understanding of the benefits of providing care (Beresford, 1994; Nolan et al, 1996). This approach shifts away from seeing families involved in caring in a negative light and does not reduce the role of the disabled person to that of a 'constant burden' (Vosey, 1975).

Beresford (1994) used a qualitative approach to assess how parents managed the stresses associated with caring for a severely disabled child. It is reported that parents managed to achieve some sort of equilibrium, by balancing how they managed the stresses in their lives. Much was dependent upon the type of relationship they had with the child and the satisfaction and reward gained by the successes they experienced as they brought up the child. However, the sample consisted largely (16 out of 20) of children who were seven years of age or under, with the eldest being ten years of age. Even the smallest of achievements by children when they are so young would be satisfying and rewarding for any parent and more so, perhaps, for those with a disabled child.

By using data from several studies, Nolan et al (1996) provide a multidimensional view of family care giving. Caring has been reported as being satisfying because carers feel they have gained something from their role, such as feeling a better person (Nolan et al, 1996). However, there was no representation of minority ethnic carers within these studies, which would have added an interesting dimension. Katbamna and Bhakta (1998) in their large-scale study of carers from different minority ethnic groups also failed to address carers' coping mechanisms.

Importantly, however, an over-emphasis on carers' ability to cope may inevitably draw attention away from the demands placed on them in reality, resulting in lack of support from formal and informal sources. The implications of this could be considerable for minority ethnic carers, when they have limited awareness of services available in the first instance (McCalman, 1990; Katbamna and Bhakta, 1998; Chamba et al, 1999). These issues are discussed more fully later.

### **Why care?**

The aim here is to examine the literature which looks specifically at why the responsibility of caring is taken on by either male or female carers.

Evidence demonstrates that while caring is gendered, with women being the main providers of care for sick and disabled relatives and friends (Lewis and Meredith, 1988; Katbamna and Bhakta, 1998), several factors influence decisions to take on the responsibility of caring and to continue to care.

Lewis and Meredith (1988) in their study of daughters caring for mothers reported that a significant number of daughters 'drifted' into the role, with only ten out of forty-one making a conscious decision to care. Opie (1992) on the other hand, reports that daughters in her study knew that their mothers would inevitably need to be cared for at some point and made a conscious decision to care once they had realised their mother's deterioration. The difference, however, was that many had not foreseen the amount of work that would be required of them. In addition, for many, there was no alternative person to take on the responsibility

Ungerson (1987) in her study which looked at gender and informal care identified that women's sense of duty was often a motivating factor to care, whereas for men it was more a matter of love and affection. Katbamna and Bhakta (1998) on the other hand, report that, although duty to care was frequently reported among different types of carers in their study, this was often inter-linked with cultural beliefs and values and often ranked higher than love, emotions and wanting to care, issues usually reported in the white carers literature (Hicks, 1988; Opie, 1992; Parker, 1993). Hicks (1988) however, reports that, although women's sense of duty led them to care, 'emotional traps' and feelings of guilt made it difficult to refuse. Similar findings have been identified in the minority ethnic carers' literature (Katbamna and Bhakta, 1998). Consequently, it is a decision that is frequently regretted by many women (Ungerson, 1987). Parker's (1993) study of spouse carers supports these findings and reports that, although many couples stayed together after the onset of disability, the reasons for doing so were varied. Some felt a sense of duty, whilst others remained together because of feelings of guilt when they clearly would have parted long ago. Ungerson (1987) also argues that 'the call of duty' was not a concept applicable only to women themselves, and that expectations of society at large of sex role expectations are also a significant factor. Nissel and Bonnerjea (1982) in their study of carers of elderly handicapped people, found that, once the person needing care had settled in with one of his/her children, other children in the family contributed very little.

Kinship ties are such that people differentiate between those who have stronger or weaker claims to being looked after by a relative. The duty to care for immediate relatives is stronger than for distant relatives whom people would feel less obliged to care for (Finch, 1989). The white carers literature suggests that wives, daughters and daughters-in-laws are far more likely to be 'expected' to care than, say, nieces. In the absence of a spouse, daughters remain the firm first choice as to who should provide care (Finch, 1989). Within South Asian communities, however, the eldest son (or more accurately, his wife) would be the first firm choice. Katbamna and Bhakta's (1998) work showed that although traditional patterns of obligation remain strong, there is, nonetheless, great diversity in terms of how these work out in reality. Many parents do not necessarily live with their eldest son. Caring relationships of South Asian female carers appear to be more problematic as they constantly try to juggle between meeting the needs of their in-laws as well as their own family. Ties of family obligations and 'policing' of actions by the wider community added to their problems, making it difficult for carers to simply give up their role.

Studies on dementia by Hirshfield (1983) and Gilhooly (1986) both report that the quality of the relationship with the cared-for person was an important factor when considering the need for institutionalisation. There are no studies to date looking specifically at the quality of relationships and the need for institutionalisation in the minority ethnic carers' literature. What is clear, however, is that cultural factors, upbringing and the influence of wider society mean that for some carers, refusing to do what is expected of them [i.e provide care] is simply not an option (Katbamna and Bhakta, 1998).

### **Costs of caring**

A sizable literature describes in detail carers' experiences, workload and the sacrifices made in order to continue caring. The negative impact of caring has thus often been associated with the concept of burden (see for instance, Poulshock et al, 1984, Zarit et al, 1986). However, burden is frequently defined and measured in diverse ways; for instance, the confining nature of care giving or its impact on health (Zarit et al, 1980). Burden can be objective, relating to the extent that it has had an impact on carers' leisure time for instance, or subjective, relating to the extent to which carers feel that they are carrying a burden (Hoenig and Hamilton, 1969 in Huckle, 1994). Specific tasks are met with differing degrees of ease by different people; as a result, what may be problematic for one person may be inconsequential for another (Braithwaite, 1990).

The aim here is not to provide a critique of the concept of burden, as it is not the focus of this study, but rather to acknowledge awareness of this field. In the context of this thesis, it was felt important to identify carers' subjective experiences of the costs of caring rather than comparing whether someone else in a similar situation coped better. This section will discuss the literature on three main groups of costs: health related costs, social and family costs, and employment and financial costs.

### Health related costs

There has been considerable debate about the effects of caring on health over the past two decades. This is particularly noticeable within psychiatry (Gilleard et al, 1984; Herrman et al, 1993) and studies on childhood disability (Truesdale and McConkey, 2001). Numerous studies have identified care giving as having an impact on carers' physical or emotional health in the mainstream literature (Quine and Pahl, 1985; Braithwaite, 1990; Parker, 1993; Truesdale and McConkey, 2001). For example, it is well recognised that families of children with disabilities are under greater stress than other families (Baxter et al, 2000). Studies that have compared groups of children in different diagnostic categories have confirmed that caring for a child with, for example, Down's syndrome is no less stressful, even though the child may be able to communicate and be mobile in comparison to a child with cerebral palsy (Quine and Pahl, 1985). However, similar studies with adult carers of stroke patients (physical disability) and dementia sufferers concluded that although both groups of carers experienced similar levels of burden and high psychiatric morbidity, psychiatric aspects of chronic disability were more stressful for carers (Draper et al, 1992).

There are no longitudinal, large-scale, specific diagnostic groups or group comparison studies to date which have addressed the health impact of care giving among minority ethnic carers. Smaller scale studies have, however, identified that care giving does affect carers' emotional and physical well-being, and report similar findings, particularly in relation to carers feeling fatigued, stressed and suffering from generalised aches and pains (McCalman, 1990; Katbamna and Bhakta, 1998). As with Parker's (1993) study on spouse carers, Katbamna and Bhakta (1998) reported that carers in their study felt that their caring role had affected their mental well being, making them angrier, resentful and fearful compared to how they used to be. Some health problems can partly be explained by lifting and handling and some by existing health problems (Bould, 1990).

As with white carers, minority ethnic carers often associated their ill health directly with their caring responsibilities or felt that their ill health had been aggravated by caring (Braithwaite, 1990; Katbamna and Bhakta, 1998). Whether or not there is a causal relationship between caring and ill health has, however, been debated (Parker, 1990). Recent evidence from the British Household Panel Survey on the health needs of informal carers is the most extensive and convincing to date (Hirst 1998). Hirst's (1998) analysis confirms that the reduced health status of carers could be attributed to their caring role. It is reported, for instance, that:

- many of the detrimental changes in carers' health are probably over and above those that would have happened and could be attributed to taking on a caring role
- caring has greatest impact on carers' emotional health, especially among carers who are more 'heavily' involved in caring
- the health of carers is more likely to deteriorate than improve over time compared with health changes in non-carers

These are important findings, and can have a significant bearing when anticipating the need for informal care to be provided, trying to sustain existing care-giving relationships, or enabling carers to limit or relinquish their care-giving roles.

#### Social and family costs

Evidence from both mainstream and minority ethnic carers literature (Lewis and Meredith, 1988; Katbamna and Bhakta, 1998) has illustrated that the responsibility of caring imposes restrictions on carers' social and family life, resulting in considerable isolation. Twigg and Atkin (1994) describe restrictedness as falling into three categories:

- carers feeling unable to leave the person needing care because of the need to do things for them, such as toileting or keeping an eye on them to maintain their safety
- restrictedness associated with carers' anxiety about what might happen to the person needing care in their absence, although there may be no objective reason for concern
- shared restrictedness, whereby carers feel guilty because the person needing care is unable to go out and socialise.

It has been suggested that younger adult carers are more adversely affected by restrictions on their social life and leisure activities (Wright, 1986; Lewis and Meredith, 1988). However, evidence to the contrary is reported in the minority ethnic carers' literature. For instance, Cameron et al (1989), in a study which looked at community care issues and black older women, reported that cultural taboos and fear of an alien outside world where their own norms, values and social skills might be in danger of misrepresentation or regarded as inappropriate, contributed to the isolation of black older women in their study. Katbamna and Bhakta (1998) identified elderly female carers as the most socially isolated group.

Caring disrupts 'normal life' in many ways, with mothers, for instance, feeling that their other children have been neglected as a result of their caring responsibilities (Beresford, 1994; Katbamna and Bhakta, 1998). Caring is also argued to have an impact on marital relationships. In some instances, having a disabled child may lead to a breakdown of the marriage (Quine and Pahl, 1986), in other cases, it may bring people closer together (Parker, 1990). Evidence of increased bad temper, feelings of 'living on top of one another', and problematic sexual relationships have also been reported in both parental and spousal caring relationships (Parker, 1993; Katbamna and Bhakta, 1998).

#### Employment and financial related costs

Both white carers and minority ethnic carers are known to experience financial hardship as a result of their caring responsibilities (Baldwin, 1985; Katbamna and Bhakta, 1998). One factor relates to employment. Carers may, for instance, leave employment, reduce their hours considerably to continue caring, take a lower paid job, or lose pay between hospital appointments. Caring can thus have a detrimental effect on carers' working lives. For long-term carers, caring activities may have a substantial effect on employment, which in turn affects pension rights (Hancock and Jarvis, 1994).

Other aspects of financial impact relate to recurrent household expenditure on items needed to provide care (such as extra warmth, special foods or buying extra clothing) or on labour saving or time-saving items (such as a dish washer) (Glendinning, 1992; Katbamna and Bhakta, 1998). For South Asian carers, the financial implications appear to be greater, in that many may be wholly dependent upon benefits and allowances (Cocking and Athwal, 1990). Not having enough contributions and resultant poor benefit and pension rights only add to their problems (Ahmad, 1996). A recent study (Chamba et al, 1999) reports that many minority ethnic lone or two parent families had incomes of less than £200 per week. A number of carers had given up work altogether to care and a number were not receiving

disability living allowance care and mobility components, or invalid care allowance. This is in contrast to the Family Budget Unit calculations that a modest but adequate budget for a family with two children and a car was around £450 at that time (McClusky and Abrahams, 1998 in Fazil et al, 2002).

## **SUPPORT AND CARING**

This second area in relation to carers' experiences will address issues concerned with support. As discussed in the earlier policy chapter three, there has been a strong emphasis within policy on encouraging the support of frail, elderly and disabled people via informal and voluntary networks. In this section, the focus is on informal support for carers from relatives, friends and neighbours and formal support from care agencies.

### **Informal support**

Support can include practical support, emotional support or simply keeping an eye on the person needing care whilst the carer gets on with other chores. Although such tasks may not appear to amount to much, for carers, they can be significant acts and can prevent situations seeming intolerable (Wright, 1986). Support from informal networks can enable carers to achieve a more balanced perspective on life, where fears and anxieties may be filtered and re-conceptualised, leading to a more positive and optimistic outlook (Mutch, 1997). Further, the role of support from family and friends in assisting carers to meet care giving demands has also been documented as having a positive impact on carers' health (Chappell and Blandford, 1991 in Neufeld and Harrison, 2003).

Bayley's (1973) study of a sample of families living with a mentally handicapped son or daughter at home concluded that neighbours were just as helpful as relatives in terms of the care and support provided for families. However, other studies have drawn somewhat different conclusions, consistently showing that carers receive very little, if any, support from friends and neighbours (Wright, 1986; Parker, 1993; Katbamna and Bhakta, 1998). Abrams, in summarising existing community care studies, described kinship as the most reliable basis of care:

Moral communities' (those associated with churches, races, friendships and certain occupations) were the second most significant source of care, whilst 'neighbours, or more broadly local communities, came a very poor third and the relationships within them provide at best a means of mediating larger processes of social care – they are the means of contact and communication rather than care as such. (Abrams, 1978 in Wright, 1986, p.109).

On the whole, then, support from informal networks consists of support from relatives (usually spouses or siblings). Further, once a carer has been singled out as a carer other relatives, friends and neighbours rarely contribute (Parker, 1990). Where they do contribute they may do the shopping, mow the lawn or keep an eye on the person for a short time, but are less likely to get involved in 'hands on' caring tasks requiring personal or physical care (Parker, 1993).

Among minority ethnic carers, cultural attitudes towards seeking and receiving support, attitudes of the cared-for person in accepting support and attitudes of relatives towards disability further reduce the support available (Katbamna and Bhakta, 1998). Although extended families continue to be prevalent among minority ethnic communities in Britain (Modood et al, 1997), available evidence suggests that often there is limited help and support from the extended family. Chamba et al (1999) in their study of parents caring for severely disabled children reported that a quarter of Pakistani and Bangladeshi parents reported that members of the extended family 'helped a lot'. However, Indian and Black African/Caribbean parents received less support from the extended family. If the extended family is involved in providing support, it tends to be incidental, occasional or due to there being no other alternative but to leave the cared-for person with a family member (Bould, 1990; Cameron et al, 1989; Katbamna and Bhakta, 1998).

It is vital that the diversity of minority ethnic groups is recognised and differences in cultural and religious beliefs taken into account. Substantial class differences between minority ethnic communities, combined with changes in attitudes concerning family obligations and views about living in extended and nuclear families, also need recognition (Ahmad, 1996). For example, recent evidence suggests that young South Asian disabled people and their families viewed extended families as, 'sometimes oppressive, like a moral police force but providing very little support' (Hussain et al, 2002, p12).

There are thus inherent dangers in assuming that the extended family will provide support. Service providers' stereotypes that minority ethnic families are self sufficient may lead to reluctance on the part of professionals to provide support and may obscure the need to support carers and their families, creating a potential barrier to accessing services (Shah, 1992; Yee, 1995). Moreover, the traditional pattern of sharing the responsibility of caring through a network of family support is not so readily achievable in Britain (Butt and Mirza, 1996). This is because migration has divided families (Ahmad and Atkin 1996) and because demographic changes as discussed in chapter one have, if anything, resulted in fragmentation and isolation

of families (Ahmad and Atkin, 1996). Further, living in large families does not mean that service support is not required because other 'potential' avenues of support are already in place. Rather, it may be in these very situations that carers have to meet competing demands with little or no support. Moreover, as we now move on to explore, services may not be used because carers simply do not know what is available.

### **Formal support**

The review now focuses on support via formal services. Meeting the needs of carers is not only a social service priority but a health one too, and this policy issue was explored in chapter three. Chapter three also reviewed the more general messages about the ways in which services address (or not) the needs of minority ethnic carers and those they help. The aim here is give a broad overview of the range and types of services available to carers, and show how they might support carers in practice. Support groups may also fall within a definition of informal support when the group is wholly organised and run by parents, for instance. Here, however, reference is to formally organised support groups only.

Twigg et al (1990) identified a number of ways in which services could support carers. They include:

- *Services aimed at the carer*: such as emotional support for the carer
- *Relief from caring*: through day centre provision, respite or even holiday
- *Getting more from the care system and from his or her own abilities*: such as advice on welfare rights and information

### **Services aimed at carers**

One means of support for carers is through contact with support groups. It is one of the few services aimed directly at supporting the carer as opposed to the cared-for person. Although there are few evaluations of the effectiveness of support groups, evidence suggests that those who use them value groups and report high levels of satisfaction, and that they are an important coping resource (Milne et al, 1993). Further, carers who have links with a support group may be better able to provide care (Department of Health, 1999a). Sharing experiences and feelings, either in a support group setting or with other carers in a similar situation, can be a valuable source of emotional and moral strength for carers. Groups can provide a safe environment where they can be confident of acceptance and understanding, where there is a reduced risk of embarrassment and rejection, and where carers can be relieved of potential isolation (Parker, 1990; Mutch, 1997). They can be effective channels of advice and communication providing mutual support and the sharing of information (Parker, 1990). If

professionals are involved, they can play a key role in directing carers to other avenues of service support, such as respite.

However, despite their usefulness, support groups do not appeal to everyone. Not all carers want to hear about other people's problems and the difficulties encountered as a result of caring. Further, carer's caring circumstances are not static and needs change. Some carers may value the chance to talk initially but then, having gained some experience, want other types of support such as recreation or advocacy (Twigg et al, 1990; Twigg, 1992). Support thus has to be tailored to individual need. And carers' perceived views about support services may also have a bearing on whether they are used (Beresford, 1994).

The evidence addressing the effectiveness of support groups for minority ethnic carers is limited. What there is suggests that often minority ethnic carers lack awareness not only about support groups but also health and social care provision in general (Butt and Mirza, 1996; Katbamna and Bhakta, 1998; Chamba et al, 1998; Vernon, 2002).

#### Relief from caring

A range of support services is in place aimed at supporting the cared-for person such as: day care, respite care, short stay residential care, sitting services and financial support. Although primarily aimed at meeting the needs of the cared-for person, services can, by implication, support carers.

There is ample evidence around the issue of service support for white carers (Parker, 1990; Twigg, 1992; Beresford, 1994; Twigg and Atkin, 1994). These studies provide valuable insight into the different types of service support available, why carers value them or not, the impact of service support on carers, and how service providers view carers in the service system.

The 'daily grind' (Bayley, 1973) of care giving and the impact of caring was explored earlier in the review. 'It is not simply the extent and repetitiveness of the care giving tasks that can cause distress, but the limitations it places on life as a whole' (Twigg et al, 1990, p35), in particular, the restrictedness (Twigg and Atkin, 1994) that is attributed to caring. It is not surprising then that carers value day care support. It not only provides relief from the 'daily grind' of care giving but also provides carers the opportunity to have some time for themselves, get on with other chores such as shopping, and it provides a much needed break

(Wright, 1986; Twigg and Atkin, 1994). Several descriptive studies have reported day care provision as being beneficial to carers (see for example, Wright, 1986).

Evidence about the experiences of minority ethnic carers in terms of specific service support is limited. Although some attempts have been made to address the issue from a social care perspective, (Patel, 1990; Askham et al, 1995), studies have largely focused on the cared-for person's needs. Available evidence on minority ethnic people's experiences with social care provision indicate that day centres provide not only a social function but can also provide intellectual stimulation and fulfil a recreational function for minority ethnic elders (Patel, 1990). Although extended families continue to prevail (Modood et al, 1997), social isolation among minority ethnic older people and their carers is reported to be high, especially among women (Butt and Mirza, 1996; Katbamna and Bhakta, 1998). Often, older people are left at home during the day whilst other family members are at work (Gadher, 1991). Further, as indicated in the earlier chapter one not all minority ethnic families consist of extended families. The structural make up of families is changing with many old people now living on their own (Modood et al, 1997). Day centres can thus be useful in eliminating the social isolation experienced by minority ethnic older people and, in some instances, their carers.

Another form of support is short-term respite care for the cared-for person which is available in different type of organisational settings from hospitals, hostels and other residential establishments. Most forms of respite care tend to be provided on an infrequent basis (yearly) which essentially allows carers to go away on holiday. Others may be provided on a rotating basis and, occasionally, on demand (Parker, 1990). Evidence suggests that respite is valued by those that have used the service (Levin et al, 1989; Twigg and Atkin, 1994), 'although respite presents more sharply than any other service the potential conflict of interest between the carer and the cared-for person' (Twigg, 1992, p85). Studies have shown that if the cared-for person shows lack of interest, female carers especially are less likely to pursue the matter (Parker, 1993). Dynamics of relationships and whose interest has priority are also reported to affect take up (Lewis and Meredith, 1988). Other barriers to take up, however, include fears of the cared-for person deteriorating (Wright, 1986); fears of care being sub-standard when compared to that provided by the carer, and carers being unable to relinquish their caring role until they reach a crisis point (Twigg and Atkin, 1994).

Studies of minority ethnic carers' views about respite are very limited. Netto's (1998) study of carers of older people suggests that carers would be open to using respite services as it would allow them to have a much needed break, especially as there was limited support from

other members of the family (Netto, 1998). Low uptake was attributed to lack of awareness of availability and services not being able to cater for linguistic needs, dietary needs, gender sensitivity and religious and cultural needs (Netto, 1998).

## **CONCLUSION**

The review in this chapter illustrates that there has been little research which has addressed Gujarati Hindu carers' perspective and their experiences with PHC nursing services. What is evident from the review, however, is that the experiences of white and minority ethnic carers are very similar in many respects. This includes, for instance, the decision to care, their experiences of providing care and the associated costs of caring. Moreover, caring is often carried out with little support from family, friends and neighbours.

There are however some noticeable difference within the literature. Firstly, minority ethnic female carers appear to be particularly disadvantaged as they often have to meet not only the demands of their own family but also the extended family. Further, they are more restricted in their ability to give up caring due to pressures from the wider community which acts like a 'moral police force'. There has been little work done on the issue of coping and caring. The literature which also looks at specific service support for minority ethnic carers is limited but indicates that carers do find some services such as day care beneficial.

## **CHAPTER FIVE**

### **METHODOLOGY: PART A**

#### **INTRODUCTION**

This chapter provides a rigorous account of the methodology used in this study. It is divided into three parts.

Part A, provides insight into some of the key features of qualitative methodology and the rationale for using in-depth interviews for this study.

Part B, provides a comprehensive account of how the study was carried out combined with a discussion of the main influences on the research process.

Part C, provides an account of my experiences of the research process and some of the dilemmas encountered whilst conducting the study.

A qualitative approach was adopted as it was best suited for studying the empirical world through the perspective of those being researched as opposed to the researcher (Duffy, 1986). The data is gathered and analysed from the subject's frame of reference as a whole, allowing carers, PHC nurses and managers to give first hand accounts rich in meaning, value, belief, thought, feelings and views (Leininger, 1985 in Duffy, 1986, p356). The approach enables description and understanding of behaviour and situations as well as enabling the exploration of complex and sensitive issues. Unlike other methods, it does not reduce people to measurable objects independent of their historical, cultural and social contexts. A quantitative approach would inevitably have constrained the extent to which this complexity and richness could be drawn out, might have imposed a structure which did not tally with carers' own experiences and views, and thus could have led to a loss in the variety of information that could be obtained (Parker, 1989, p30).

#### **A PRAGMATIC QUALITATIVE APPROACH**

Those that are in favour of one method over another - that is purely quantitative research or purely qualitative research, argue that their method is best and that the other is basically flawed (Bogdan and Biklen, 2003). Bogdan and Biklen (2003) argue that there is no best method, 'it all depends what you are studying and what you want to find out' (p38). I strongly agreed with this view, further, I also felt that some of practices attached with quantitative research were not suited to research the questions I wanted to address. For instance, the use of random sampling techniques.

I decided that a pragmatic qualitative approach using in-depth interviews was best suited to address the aims of this study. There were a number of reasons for this rationale. Firstly, the subject area that I was researching was 'under-researched' sensitive topics and issues needed to be addressed. Any other design would not have been able to capture the depth of information attainable through the use of interviews. Secondly, I was interested in the views and experiences of small groups of participants to better understand the meanings they attached to these experiences or views to obtain a deeper understanding. Moreover, I was interested in the 'participants perspectives' (Erickson, 1986 in Bogdan and Biklen, 2003). An important part of the study was to obtain the data in the participants 'natural' settings, hence, the context in which views were obtained was also important. The use of interviews enabled me to obtain data rich in description in the form of words as opposed to numbers which allowed the why, what and how types of questions to be addressed, this is important given that the study did not set out to prove or test out a hypothesis or theory (Silverman, 2001).

This method was also chosen because of prior knowledge about limitations of methods used in previous research. Cameron et al (1988) for instance, used a structured schedule to obtain the views of different 'service providers'. The main drawback of this method is that although attitudes, motivations and opinions can be sought, they are not designed to explore issues in-depth, nor do they allow you to learn about the participant's perspectives and what matters to them. Structured schedules enable simple descriptive information to be obtained quickly and nuances and tone of voice in response to questions can not be detected (Arksey and Knight, 1999). Further, structured interviews aim to capture precise data of a codeable nature in order to explain behaviour, whilst unstructured interviews attempt to understand the complex behaviour of members of society without imposing any prior categorisation that may limit the field of inquiry (Fontana and Frey, 1998).

Katbamna and Bhakta's (1998) study includes very few carers who actually had experience of using PHC nursing services even though the study set out to obtain carers views about PHC services. The study aimed to be inclusive as possible of different types of carers and the methodology adopted aimed to capture those carers who did not have contact with services without actually approaching health and social care service providers that would have 'ready' access to those carers in touch with services. The drawback of this approach was that very few carers who had PHC nursing input were recruited. Although a similar strategy was initially adopted for this study for the same reasons, the design was altered slightly in light of continued difficulties in recruitment of carers and PHC nurses were approached and asked if they could help in the identification of carers. Recruitment of carers for this study is discussed

further in Parts B and C of this chapter. Issues concerning changes to the original design are discussed in Part C.

As discussed, Gerrish (1998) used an ethnographic approach to examine how far district nurses were able to provide individualised care to patients from different ethnic backgrounds and to what means individualised care was provided relative to policy intentions. Hence, observation and participation were interwoven with other procedures. A further limitation of the method was that:

They are interested in answering the question of how likely it is that an activity or an attitude that is found is valid for the group studied in general or only for individual members or specific situations. They start from the notion that attitudes deduced from activities in the group are most likely shared by the group...

The most important thing again is to answer the question of how likely the observed activities and statements are to occur independently of the researcher's observation and participation. (Flick, 1998, p147).

Lastly, in comparison to Katbamna and Bhakta's (1998) work, this study was small-scale and was carried out in addition to working full-time on other projects. Restrictions on time and resources did not permit a large-scale study to be conducted. Inevitably, this study does have its limitations. Firstly, behaviour of PHC nurses was not observed and the views of patients have not been reported and sought for a variety of methodological difficulties as reported in Part C. Lastly, this study focuses on one minority ethnic community only – the Gujarati Hindu Indian community.

As discussed in detail later in this chapter, a combination of factors led to the development of this study. This included for instance, knowledge gained from both the methodological literature and previous work in this field as well as my own personal experiences. Hence, the need to conduct the study had been identified together with the areas that needed exploration. With this in mind, it was imperative that right method was chosen to address the research questions, as the method would have clearly had an impact throughout. A decision was taken that a pragmatic qualitative approach would be best suited. As located within the research tradition of retrospective accounts, in-depth interviews were chosen as the main method of data collection to report retrospective accounts of Gujarati Hindu carers, PHC nurses and managers. The purpose of the in-depth interview was to understand the experiences and perspectives of those that participated not to control or predict their responses. Moreover, the aim of the study was not to make the findings generalisable to a much wider population, but to present the experience of those that were interviewed in sufficient depth and detail so that those who read the study could connect to that experience, learn how it was constituted, and

deepen their understanding of the issues it reflected (Seidman, 1991). In acknowledging the limitations of in-depth interviews a critique is reported at the end of this section. In choosing a qualitative approach, I was mindful that my own personal biography, ethnicity and language skills could have a bearing on the research study and consideration to these factors is also discussed later in this section.

Qualitative research is a highly contested field. There is little consensus or agreement as to what exactly qualitative research is, its purpose, status and the practice of its methods (Murphy and Dingwall, 2003; Murphy et al, 1998; Cresswell, 1998; Mason, 1996; Denzin and Lincoln, 1994). Denzin and Lincoln (1994) for instance, describe qualitative research as:

Multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical material – case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts to describe routine and problematic moments and meanings in individual's lives. (p2)

Cresswell (1998) on the other hand, relies less on the sources of information but expresses similar ideas:

Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explores a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in natural a setting. (p15)

Much of the controversy surrounding qualitative research stems from the lack of representation of a unified set of techniques or philosophies (Mason, 1996). Qualitative research is a field of inquiry which cross cuts disciplines, field, and subject matter (Denzin and Lincoln, 1994). It has no theory, paradigm or set of methods that is distinctly its own (Denzin and Lincoln, 1994). Hence, the approach has been developed from a wide range of intellectual schools of thought and disciplinary traditions, for instance, ethnomethodology; symbolic interactionism; phenomenology and post modernism (Mason, 1996; Kvale, 1996; Denzin and Lincoln, 1994). Some have therefore argued that we should avoid insisting that there is only one legitimate way of doing qualitative research based on only one philosophical tradition (Mason, 1996).

The practical aspects of conducting the study are reported in-depth later in this chapter. Here, the focus is to provide a comprehensive account of the principles underpinning qualitative research. The following areas are discussed:

- Key features of qualitative research

- Methodological issues in qualitative research
- Soundness of qualitative research

## KEY FEATURES OF QUALITATIVE RESEARCH

Despite the controversy surrounding qualitative research, Bryman (1988) identified six key features of qualitative research. Each is discussed in turn here.

### 1. Seeing through the eyes of those being studied

Bryman (1988) described this as a commitment to viewing events, actions, norms and values from the perspective of those being studied. According to Bryman (1988) the central feature of qualitative research is the ability to empathize with those being studied and penetrate the frame of reference of meaning within which they operate. Agar (1980 in Murphy et al, 1988) in writing about ethnography advocates the importance of seeing the world through the eyes of the participants. It is argued that 'people are not automata who simply respond to stimuli. They are able to reflect upon and interpret both their actions and the actions of people around them' (Murphy and Dingwall, 2003, p30). Qualitative research will therefore enable us to identify ideas relating not only to individuals but also groups and also enables interpretations that would have otherwise remained obscure to be identified (Murphy and Dingwall, 2003; Murphy et al, 1998). Jensen (1989 in Murphy et al, 1998, p74) suggests that 'the practical implications of recognising what people believe to be true may be more important than any so-called objective reality, given that people can be expected to act on the basis of what they believe to be the case'. Thomas and Thomas, (1928 in Hammersley, 1989, p68), in their much quoted maxim, similarly argued that 'if men define situations as real, they are real in their consequences'.

In conducting qualitative research, the idea of 'grasping the actors definition of a situation for: *Verstehen*' is often suggested in the literature (Schwandt, 1994, p118). *Verstehen* was formulated by the sociologist Max Weber. The term means 'to understand' in German (Bryman, 1988, p57). The process of *Verstehen*, has however been conceptualised in different ways<sup>12</sup>, from that of 'the pure seeing of things' to constructive processes drawing on the whole person of the interpreter (Hammersley, 1989). Dilthey (1894 in Hammersley, 1989, p27) for instance, argued that:

Human social life is more complex than the physical world, but that whereas natural science must rely on observation of the external features and behaviour of phenomena, in studying human life we have access to the thoughts, feelings, and desires that motivate action. This is achieved by the process of *Verstehen*, in which we draw out our

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<sup>12</sup> See Schwandt, (1994) for a detailed discussion of the different philosophical traditions surrounding *Verstehen*.

experience the ideas and beliefs from the expressions and behaviour we are studying arose.

The process of 'taking the role of the other' was conceived by the philosopher G.H. Mead. The process is conceived as a mental act in which the researcher, if placed in the same situation as the other would ask himself, how would I react? what would motivate me? (Murphy and Dingwall, 2003).

## **2. Emphasis upon description**

A central aim of qualitative research is to provide description of the social setting being investigated (Bryman, 1988). Some have gone as far as to say that description alone is explanatory. LeCompte and Preissle (1993 in Murphy et al, 1998) for instance, argued ethnography is primarily descriptive as it involves studying the interplay among naturally occurring empirical variables rather than measuring the outcome of experimental manipulation. Secondly, the need of description is advocated on the grounds that the perspectives and subjective meanings of those being researched can be discovered (Emerson and Pollner, 1981 in Murphy et al, 1998). It is based on the premise that 'knowledge about humans is not possible without describing human experience as it is lived and as it is defined by the actors themselves' (Polit and Hungler, 1987, p349). Moreover, 'qualitative research is particularly useful in providing rigorous descriptions of practice and the organisational contexts in which they occur' (Murphy and Dingwall, 2003, p35). Importantly however, it has to be remembered that a researchers descriptions are a 'representation' rather than a 'reproduction' of what was observed (Murphy and Dingwall, 2003).

Hammersley (1998) reports that 'descriptions are one of the most important sorts of arguments to be found in ethnographic (and other kinds of) research reports, since explanations depend on them, and so do theories and evaluations (p47). Bryman (1988) suggests that descriptions should at least be consistent with the perspectives of the participants in the social setting and also focus on 'the apparently superficial trivia and minutiae of everyday life' (p63), as it these descriptions that enable us to better understand what is actually happening in a particular context. Similarly, Hammersley (1992 in Murphy et al, 1998) in reporting about settings suggests that descriptions can subtly or dramatically change our understanding of settings even those considered as being familiar to us. However, despite thick description being advocated, Hammersley (1998) suggests that there is still a need to be selective when writing. Descriptions need to represent phenomena from particular points of view and attention needs to be paid to the function they are intended to serve as well as relevance on which they are based.

### **3. Contextualism**

It is argued that context and holism cannot be divorced from each other. Bryman (1988) in defining contextualism suggests that it entails 'understanding events, behaviour etc in their context (p64) and that holism 'entails an understanding to examine social entities – schools, tribes, firms, slums, delinquent groups, communities or whatever – as wholes to be explicated and understood in their entirety' (p64). 'Whatever the sphere in which data are being collected, we can understand events only when they are situated in the wider social and historical context' (Bryman, 1988, p65). Qualitative researchers therefore attempt to understand the phenomena being studied in the context of its culture, sub-culture, group, organisation or setting (Murphy et al, 1998). Hence, they confront the constraints of the everyday social world. 'They see this world in action and embed their findings in it' (Denzin and Lincoln, 1994, p5). Contrary to the approach often used by quantitative researchers, qualitative researchers do not attempt to isolate variables from their personal and social context. A process often referred to as context stripping (Mishler, 1979 in Murphy et al, 1998). Indeed, some have argued that to 'treat them as such, as quantitative research does, is to reduce them to machine-like figures that are only a sum of their parts (Duffy, 1987 in Murphy et al, 1998, p82).

### **4. Process**

Bryman (1988) also identified process as a key feature of qualitative research as it is able to view social life as it happens rather than in static terms. Hence, this approach is particularly well suited to policy research (Finch, 1986 in Bryman, 1988) as 'a qualitative approach would emphasize the various responses of both those who implement and those who are affected, how they respond to each other's views, how perspectives change and so on' (Bryman, 1988, p66). Hence, qualitative research not only enables description, it also enables explanations to be drawn out. Wiener (2000 in Murphy and Dingwall, 2003) for instance, reported why service redesign had not worked in health care delivery in United States hospitals. In her study, she not only described what happened but also presents data on how it happened. Observational studies are particularly suited to 'uncovering the social processes that intervene between input and output variables and identifying the reasons why the general relationship does not hold in particular cases', for instance, it is possible to establish a link between A and B, and explain the process by which A was transformed into B (Murphy et al, 1998, p83).

### **5. Flexibility**

Another distinct feature of qualitative research is the flexibility of its research design because the research process is iterative (Murphy and Dingwall, 2003). In contrast, with quantitative

research, it is not decided in advance precisely what ought to be investigated and how it should be done (Bryman, 1988). Lincoln and Guba (1985) coined the term 'emergent design' to describe the flexibility of qualitative inquiry as it enables the research design to flow, cascade, unfold rather than the research designed being fixed from the outset. It is argued that 'it is inconceivable that enough could be known ahead of time about the many multiple realities to the design adequately; because what emerges as a function of the interaction between the inquirer and phenomenon is largely unpredictable' (Lincoln and Guba, 1985, p41). Progressive focussing (Atkinson, 1979 in Murphy et al, 1998) is closely associated with the emergent design. It is suggested that the ethnographers for instance, collect any data that may have some relevance. Sharpening of their problems into specific research hypothesis is avoided until considerable exploratory investigation has taken place before hand.

## **6. Theory and concepts**

Lastly, Bryman (1998) identified that qualitative researchers avoid imposing a prior theoretical framework from the outset. With the emphasis on discovery within qualitative research, the flexibility of the design enables researchers to respond to unanticipated opportunities as they arise, to pursue significant leads and ideas as they emerge and uncover issues or situations that may have been discrepant because of prior assumptions (Murphy and Dingwall, 2003). Hence, it is particularly useful for hypothesis generation (Kirk and Miller, 1986) as the formulation of theories and concepts in advance of beginning the fieldwork is rejected (Bryman, 1988).

## **METHODOLOGICAL ISSUES IN QUALITATIVE RESEARCH**

It is not possible to study intensively and in-depth all instances, events or persons. It is necessary to sample. Choosing the setting, population or phenomenon to study is fundamental to the design of the study (Marshall and Rossman, 1995). Patton, (1987 in Lee, 1993) suggests that the aim of sampling is to select elements for the study in a way, which adequately represents the population of interest. The aim was therefore to identify, choose and gain access to the relevant areas and people to be studied (Mason, 1996). This section reports some of the considerations that influenced the sampling decisions and strategy. The practicalities of sampling are reported in Part B.

## **SAMPLING STRATEGY AND SELECTION**

As discussed in detail in Part B, a variety of strategies were used to identify, sample and recruit Gujarati Hindu carers. This included, sampling from a list; using snowballing techniques, personal contacts, through district nursing caseloads and from contacts established

through the support of community organisations. 'The breadth versus depth trade-off is applicable not only in comparing quantitative and qualitative methods; the same trade-off applies within qualitative methods' (Patton, 1990, p98). Given the nature of the questions to be addressed combined with the limitations in time and resources, it seemed appropriate to identify and include a wide range of experiences from a smaller group of carers as opposed to trying to cover a narrow range of experiences with a large sample (Patton, 1990).

For this study, purposeful sampling was one of strategies used to sample Gujarati Hindu carers. Their respective PHC nurses were all included. Sampling and interviewing elites however, is reported to be problematic (Morton-Williams, 1993; Lee, 1993) and indeed, proved to be the case as discussed in Part C of this chapter, hence, a combination of purposeful, maximum variation and opportunistic sampling was used with them.

### **Purposeful sampling**

Purposeful sampling suited the needs of the study and was used to identify and recruit Gujarati Hindu carers. Patton (1990) suggests several ways in which purposeful sampling techniques can be applied. These include: maximum variation, snowballing, criterion sampling, extreme case, confirming or disconfirming case, theory based or operational construct sampling and typical case sampling. Although different strategies may be combined, depending on the topic or information wanted and resources available. Purposeful sampling is also known as judgemental sampling and is similar to theoretical sampling (Murphy et al, 1998, see Glaser and Strauss, 1967). In the context of this study however, maximum variation and snowballing techniques were used as part of the purposeful sampling strategy along with the other strategies mentioned earlier.

The main reason for using this strategy was that it enable information-rich cases for in-depth interview to be selected strategically, as the strategies are well suited for studies involving 'hard-to reach' sample groups or for researching sensitive subjects. It was known from the outset that the sample group would be limited, but exactly how many carers would be included was not known until for instance, saturation had taken place (Glaser and Struass, 1967). The sample group was not by any means representative of the whole population as the aim was to sample purposefully carefully selected cases which would provide optimum insight into issues concerning caring and support for instance, without the need to generalise to all such cases (Patton, 1990). An important point to remember however is that purposeful sampling is not a haphazard procedure. Careful selection rules were developed and applied so that I did not sample according to preference (Patton, 1990). Hence, I had to be mindful that I did not simply pick those Gujarati Hindu carers, which supported my argument and disregarded those that did not, but rather, selected Gujarati Hindu carers which enabled me to

make a meaningful comparison of their experiences (Mason, 1996). For instance, it was decided from the outset that both male and female carers would be included and that the study would not restrict to just female or male carers. This meant that Gujarati Hindu carers who met the following criteria were put into the pool of potential carers from which I would draw upon. Carers had:

- to be of Indian ethnicity
- to be Gujarati Hindu
- to be caring for someone at home\*
- to having input from PHC nursing services
- to be over the age of 18years

\*Gujarati Hindu carers who cared for someone outside the home, for instance, someone whose relative was in a residential home or if the service user lived by themselves were excluded as it was felt that their needs, experiences and issues would be somewhat different from those Gujarati Hindu carers who were still caring in their own home.

### **Maximum variation**

Maximum variation refers to both sites and people (Tagg, 1985). It involves purposefully picking the widest possible ranges of experiences or views. It is suggested that there must be enough variation to enable description. By increasing the diversity and ranges represented in the study, 'the evaluator will have more confidence in those patterns that emerge as common among sites, while at the same time being able to describe some of the variations that has emerged' (Patton, 1990, p102). The literature identified that there are many different types of carers and likewise, PHC nurses cared for patients and carers with a range of condition/s. With this in mind, a decision was taken to be as inclusive as possible in terms of recruitment of different types of Gujarati Hindu carers and not focus on single category for instance, Gujarati Hindu carers of older people. It was decided that Gujarati Hindu carers who cared for either a child or an adult with either a physical or mental health condition and was caring for that person at home would be included into the pool. To include only one single type of Gujarati Hindu carer would have constrained the study and resulted in severe recruitment problems because factors such as ethnicity, language and geographical location also had to be considered. Moreover, the area that I was researching also fell into the category of 'sensitive research' where sampling is reported to be particularly problematic (Lee, 1993) and in reality proved to be the case, see Part C of this chapter.

Seidman (1991) argues that maximum variation is the most effective strategy for selecting participants for interview studies. However, it was equally important to sample those that were 'outside the range' (Lincoln and Guba, 1985). Hence, Gujarati Hindu carers who did not have PHC nursing input were also included as well as PHC nurses and managers who were supposedly more knowledgeable about ethnic minority needs as opposed to 'just' managers. Similarly, commissioners were included because it was felt they would provide a different dimension. Indeed, as evidence from chapter eight, illustrates, this strategy proved useful in that it highlighted that issues concerning access to information during assessments affected both minority ethnic PHC nurses and white PHC nurses. This is important in that it illustrates that shared ethnicity does not make accessing information any easier. Secondly, as evidence from chapter eight shows, having a wide range PHC nurses in the study identified that the patient was the priority across the different PHC nursing services.

One of the benefits of purposeful sampling is that it enables the sampling strategy to be tweaked depending on new information gained. In the context of case studies, Stake (1994) argued that the case from which we can learn the most should be selected because the 'potential for learning is a different and sometimes overriding criterion to representativeness. Often it is better to learn a lot from an atypical case than to learn little from a magnificently typical case'(p243).

### **Snowballing techniques**

Snowballing was another strategy adopted in the study. The technique is particularly useful if trying to reach hard to reach groups. It involves asking participants to identify others who might be helpful. It is sometimes referred to as chain sampling or network sampling (Lee, 1993). However, despite its name, it must not be assumed that it will automatically lead to lots of contacts of rare populations (Lee, 1993). In instances where very few contacts have been established it is suggested that the criteria should be less specific (Coleman, 1958 in Lee, 1993). The advantages however are that where participants have already agreed to take part, 'security features are built into the method because the intermediaries who form the links of the referral chain are known to potential respondents and trusted by them. They are thus able to vouch for the researchers *bono fides*' (Lee, 1993, p67). A drawback however, is that instead of identifying a group with differing characteristics; it may result in a group with homogenous attributes (Granovetter, 1973 in Lee, 1993). Although this was not the case in this study as the only homogenous characteristic was that they were all carers. Moreover, as mentioned earlier, the criterion had been set to have a mixed group of Gujarati Hindu carers, from different age groups that were either male or female.

### **List sampling**

List sampling is on occasions used to sample rare population, although access to it may be closed to the researcher or the researcher may lack knowledge as to whether a list exists (Lee, 1993). List sampling is useful as a start to snowball sampling (Lee, 1993). In this instance, I turned first to original South Asian carers study as I had been involved in the study and had compiled the lists. Two lists had been created, one that consisted of those that declined to take part in the South Asian carers study and another, which listed all those that did take part.

### **Key individuals: community organisations**

Becker (1970 in Lee, 1993) suggests that researchers where possible should use indirect data sources such as people whose work brings them in to contact with the group in question because they will have available to them 'prototypical portrayals and knowledge of operative social structures' (Sudnow, 1965 in Lee, 1993, p73). For this study, key individuals from community organisations who worked with carers or had some indirect contact with carers were identified and approached. The key individuals were not interviewed but rather they were asked to help identify carers for the study. My involvement with community organisations is discussed further in Part B.

### **Opportunistic sampling**

Honigmann (1982 in Murphy et al, 1998) defined opportunistic sampling as following no strict logical plan. Yet, it is not unusual to use opportunistic sampling in qualitative research Hammersley and Atkinson (1995). In the context of this study however, opportunistic sampling was embedded within the maximum variation strategy. Therefore, criteria were still applied and abided to as to whether a person would be included or not in order to obtain maximum variation, as the aim was to obtain the views of management throughout the hierarchy as opposed to interviewing only junior staff.

Criteria for sampling PHC nurses and managers was also used. For PHC nurses, the main criteria was that they were involved with the patient and carer concerned. It was decided that both male and female PHC nurses would be included and that a range of PHC nurses views would be sought.

The main criteria were that the manager would be the PHC nurse's immediate manager and then the identified managers manager would be contacted and so on. As with carers, it was decided from the outset that a sample of managers would be inclusive of a range of managers throughout the management hierarchy. The sampling was not restricted in terms of gender or

ethnicity, rather the aim was to be as inclusive as possible so long as I was able to sample a wide range of managers as possible.

At the same time, there was a need to draw the line somewhere in terms of how many participants were 'added', especially as approaches such as snowballing had been used to recruit carers. Two strategies were used. This included sufficiency of numbers and saturation. This involved looking at the sample group that I had and deciding whether the carers that I had in my group reflected the range of carers 'out there' in the wider community of carers. Secondly, saturation of information (Glaser and Struass, 1967; Lincoln and Guba, 1985) was also used. Once no new information was being gleaned from the interviews, I stopped recruiting more participants to the study. In this study, fifteen Gujarati Hindu carers; fourteen PHC nurses and fourteen managers (including two commissioners) formed the sample groups. Some sample characteristics of the different groups of participants are reported below. A summarized version of carers' characteristics can be found in appendix 5.

## **RESEARCHERS BIOGRAPHY**

One of principles of qualitative research is that the researcher enters the field without imposing prior theoretical frameworks or having too many preconceived ideas. Yet, at the same time it is necessary to have an awareness of ones own personal biography and how that could affect the research process as:

'The researcher is the 'instrument': Her presences in the lives of the participants invited to be part of the study is fundamental to the paradigm. Whether the presence is sustained and intensive, as in long-term ethnographies, or whether relatively brief but personal, as in in-depth interview studies, the research enters into the lives of the participants. This brings a range of strategic, ethical and personal issues that do not attend quantitative approaches (Locke, Spirduso & Silverman, 1993 in Marshall & Rossman, 1995, p59).

Indeed, in terms of my own personal biography then, this had implications and it inevitably exerted some influence on the research process. This was because; I was of Indian ethnicity and a Gujarati Hindu female. Although I no longer practiced, my background was in nursing and at the same time I researching the views and experiences and views of PHC who were still practising. I also fell into the category of being as 'carer' as I had a disabled daughter of my own. Lastly, I had previously worked on the closely associated South Asian carers project and therefore had already acquired some knowledge in the subject. Although steps were taken to try and minimise the effect by thinking through how my biography could influence the research as well as being alert and conscious throughout the research study to these consideration, it is argued that 'if the researcher is sufficiently reflexive about her project, she

can evoke these as guides to data gathering or creating and for understanding her own interpretations and behaviour in the research' (Olesen, 1994, p165). This is important because the participants equally would bring with them a 'history or biography' of their own to the interview.

## **ETHICS**

In using in-depth interviews to obtain retrospective accounts, ethical issues need to be considered as in-depth interviewing commonly elicits highly personal information about specific individuals. This may include for instance, participants feelings and reflections as well as their perceptions of others or knowledge about a setting that goes against that settings public front (Johnson, 2001).

### **Informed consent**

This implies that the participant has agreed to participate in the study having been carefully and truthfully informed about the research (Fontana and Frey, 1994)

### **How deep?**

One ethical issue concerns that of how far an interviewer should go to probe for answers (Johnson, 2001). In-depth interviewing is a procedure, which allows further probing and following up on leads or information gleaned through the interview. The interviewer therefore needs to put some thought into how these issues would be addressed beforehand. However, it is argued that the real consequences of such probing can never truly be anticipated. For instance, Rubin and Rubin (1995 in Johnson, 2001) reported that a respondent committed suicide shortly after a revealing interview.

### **Protecting subjects: confidentiality**

It is usually advocated that 'the researcher must do whatever is necessary to protect research subjects' (Johnson, 2001, p115). Protection from harm includes, physical, emotional and any other kind (Fontana and Frey, 1994).

### **Protecting communities**

Another consideration needs to be whether the researchers should feel any obligation to avoid causing harm to the reputation, social standing, or social prestige of their informants (Johnson, 2001). Here, the researcher needs to try and assess as best as possible the possible risks and consequences for those that agree to participate.

## **Truth**

The most important ethical consideration is that of telling the truth (Johnson, 2001). Where multiple perspectives or interpretations arise, the researcher needs to consider whose criteria or standards of truth prevail in the final report? (Johnson, 2001).

## **SOUNDNESS OF QUALITATIVE RESEARCH**

There are different opinions as to whether or how qualitative research should be assessed. Some argue that strict criteria cannot be applied to qualitative research and totally reject the notion of applying criteria because of its commitment to relativism and anti-realism (Smith, 1984 in Murphy et al, 1998). Hence, people construct their realities in their own ways, time and places (Smith, 1984 in Murphy et al, 1998).

Others however, argue that 'social science is in every sense of the word fully as 'scientific' as physics, and has fully as much need for reliability and validity as any other science' (Kirk and Miller, p14). Kirk and Miller (1986) therefore advocate that the same criteria as applied to quantitative research needs to be applied to qualitative studies.

Marshall (1985 in Murphy et al, 1998) however, argues that by imposing strict validity and reliability criteria, it constrains the work of discovery and hypothesis generation.

Lincoln and Guba (1985) however, reject the application of quantitative criteria on qualitative research as the two research approaches are from differing paradigms. It is argued that 'criteria defined for one perspective may not be appropriate for judging actions taken from another perspective' (Lincoln and Guba, 1985, p293). They argue that different criteria are needed to establish trustworthiness. They describe trustworthiness as:

How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of? What arguments can be mounted, what criteria invoked, what questioned asked, that would be persuasive on this issue? (p290)

Lincoln and Guba, (1985) suggest that the following four criteria<sup>1</sup> be adopted for assessing qualitative research:

## **Credibility**

Lincoln and Guba (1985) propose five techniques to enhance credibility:

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<sup>1</sup> Lincoln and Guba (1985) have renamed the terms usually used for quantitative approaches and propose alternate criterion as follows: validity = credibility; generalisability or external validity = transferability; reliability = dependability and neutrality = confirmability.

- Activities that make it more likely that credible findings will be produced (such as prolonged engagement)
- An activity that provides an external check on the inquiry process (for example, peer debriefing)
- An activity that is aimed at refining working hypotheses as more information becomes available (for example, negative case analysis)
- An activity that makes possible checking preliminary findings and interpretations against archived 'raw data' (referential adequacy)
- An activity providing for the direct test of findings and interpretations with the human sources from which they come (for example, member checking)

(adapted from Lincoln and Guba, 1985, p301).

However, the idea that the researchers conclusions can only be deemed credible if those who participated confirm that what is reported is their particular version of reality is highly contested (Murphy et al, 1998). It is argued for instance, that 'direct comparison between researcher and member accounts is not feasible' (Emerson and Pollner, 1988 in Murphy et al, 1998, p180) because for instance, 'the accounts produced by researchers and informants will each be formulated in the light of different purposes at hand and can be expected to differ from one another in ways which have no bearing on their validity or otherwise' (Pollner, 1988 in Murphy et al, 1988, p180) (see Murphy et al, 1998 for a detailed discussion on respondent validation and member checking).

### **Transferability**

Generalisability or external validity is also rejected on the grounds that it impossible to apply such criteria to qualitative naturalistic studies. 'Within quantitative research, the demands of external validity require research to be carried out in such a way that time and situational variables are irrelevant to the findings and truth statements are context free' (Murphy et al, 1998, p170). In contrast, 'the naturalist can only set out working hypotheses together with a description of the time and context in which they were found' (Lincoln and Guba, 1985, p316). The qualitative researcher cannot specify the external validity of an inquiry, she can only provide thick description (Lincoln and Guba, 1985).

### **Dependability**

The notion of reliability as used in quantitative research was also rejected by Lincoln and Guba (1985). Within quantitative research it is assumed that reality is unchanging (Murphy et al, 1998). In contrast, the qualitative researcher should accept that the entity being studied

will change because of new insights or discoveries for instance and that the changes are indeed real and secondly, consideration also needs to be given to the way in which the research design may have induced change (Guba and Lincoln, 1989 in Murphy et al, 1998).

### **Confirmability**

Lastly, Lincoln and Guba (1985) suggest that a confirmability audit trail would enable the findings of research to be judged as confirmable. The process would enable other researchers to examine the process which the researcher arrived at the conclusions for their study (Murphy et al, 1998).

However, much of this early work by Lincoln and Guba (1985) was heavily criticised on the grounds that they tried 'to identify parallel criteria for assessing research within the constructivist paradigm' (Guba and Lincoln, 1989 in Murphy et al, 1998, p172). In light of these criticisms, they proposed five alternative criteria for assessing evaluation research (Guba and Lincoln, 1989 in Murphy et al, 1998). They propose that researchers must be able to demonstrate:

**Fairness:** representation of the range of different realities in a balanced way.

**Ontological authenticity:** that in the course of the evaluation, they have developed a more sophisticated understanding of the phenomena than they possessed at the outset.

**Educative authenticity:** that in the course of the evaluation, they have developed a greater understanding of and appreciation for the understanding of other members or groups

**Catalytic authenticity:** that the evaluation process has stimulated action.

**Tactical authenticity:** members have been empowered to act.

(from: Murphy et al, 1998, p172).

### **VALIDITY**

Validity in qualitative research seeks to address whether the study actually measures, explicates or illuminates what it claims to do (Mason, 1996) as well as demonstrate the reliability of its instrument (Denzin, 1970 in Murphy et al, 1998). Denzin (1970 in Murphy et al, 1998) identified several issues concerning invalidity of interviews. These included for instance, that the information could be distorted and the possibility that interviewees may fabricate the discussion. In order to enhance validity, strategies such as methodological triangulation or respondent validation are recommended (Lincoln and Guba, 1985). Hammersley (1990 in Murphy et al, 1998) attempted to draw together a comprehensive list of criteria based on key works. He identified the following:

1. The degree to which substantive or formal theory is produced or developed

2. The novelty of the claims made
3. The consistency of the claims with empirical observation
4. The credibility of the account to readers and those studied
5. The extent to which cultural description produced provides a basis for competent performance in the culture studied.
6. The extent to which findings are transferable to other settings
7. The reflexivity of the account

However, he argued that points 3, 4, 5, and 7 are means of assessment as opposed to standards against which assessments should be made. He also rejected point 1, that all research should be concerned with producing theory and argued that the criteria were applicable to all research not just qualitative research (Hammersley, 1990 in Murphy et al, 1998, p173).

The following principles are suggested by Murphy et al (1998, p185-192) to evaluate research studies:

- **Clear exposition of data collection** - is the data collection method clear?, for instance, is the process by which the data on which the analysis is based clearly described?; are wide ranges of events, interviews, kinds of experience included? How was access gained?
- **Clear expositions of process of data analysis** – has the researcher described the process by which the findings were derived?, are concepts clarified and definitions provided to make clear why the phenomena has been labelled in such a way? Are the conclusions justified on the basis of data collected?
- **Reflexivity** – has the researcher considered that their presence in the research setting has contributed to the data collection and that their own prior assumptions have shaped the data analysis?
- **Attention to negative cases** – Has consideration been paid to negative or deviant cases?

As evident from the divergent views reported, there are no universal set criteria for assessing validity in qualitative research studies. Phillips (1987 in Murphy et al, 1998) argued that no methods that can reveal sound data or true conclusions regularly. Although the use of checklists is often advocated, they only serve to 'become rigid constraints which become an end in themselves rather than serving to enhance validity of the study' (Marshall, 1985 in Murphy et al, 1998 p178).

Validity in research is concerned with whether you are actually investigating what you claim to be investigating (Arksey and Knight, 1999, p51). That is:

An account is valid or true if it represents accurately those features of the phenomena that it is intended to describe, explain or theorise. (Hammersley, 1998, p69)

There exist a number of approaches to assess the validity of research studies. One such method is that of procedural validity as advocated by Wolcott, 1990 in Flick, 1998, p228.

Some points relating to this approach are summarised below:

1. The researcher should talk less and listen as much as possible
2. Produce notes that are exact as possible
3. Begin to write early
4. Notes should be in a form that allows readers of his or her notes to make their own inferences and follow those of the researcher
5. The report should be candid as possible (free from prejudice and impartial)
6. The researcher should seek feed back from colleagues

Arksey and Knight (1990) suggest that validity can also be enhanced by:

1. Interviewing techniques that build rapport, trust and openness
2. Schedules that contain questions drawn from the literature
3. A set of questions that fully addresses the research questions
4. Prompts that encourage informants to clarify, expand or illustrate
5. A sample fit for the purpose of research
6. Giving consideration to interview settings

However, it is important to bear in mind that no matter how diligently we work to that effect, the interviewer is part of the interviewing picture (Seidman, 1991) and therefore interviewer effect can not be totally eradicated. Secondly, researchers own values can also have a bearing on the research (Silverman, 2001). Validity is in many respects similar to reliability.

## **RELIABILITY**

Reliability involves the accuracy of the research methods and techniques used for the study (Mason, 1996). As with validity, there are again several camps as to whether conventional reliability criteria should be applied to qualitative research. With some rejecting the notion altogether, some in favour of it and others who propose different sets of criteria are needed suited to qualitative research see for instance, Lincoln and Guba, (1985); Mason, (1996); and Murphy et al, 1998 for a detailed discussion. Conventional approaches include standardisation

of research instruments or tools, and cross checking the data, for instance, reliability could be measured 'by observing the consistency with which the same method of data collection produce the same results (Mason, 1996, p145). In qualitative research, it means for instance, thinking through the implications of using data from several sources and making a judgement about how accurate, reliable or authentic a set of data can be generated from the chosen sample (Mason, 1996).

Rigour in qualitative research can be ensured through the research design, data collection and interpretation and analysis. The aim is to provide a detailed and thorough account of the methodology, to enable another trained researcher essentially to come to similar conclusions, as well as producing a coherent and plausible explanation for the area being studied (Mays and Pope, 1995). It has been argued that the assumptions that underpin qualitative research mean that the classic concepts of reliability do not sit very well with this approach:

Qualitative research is not looking for the principles that are true all the time and in all conditions, like laws of physics; rather the goal is understanding of specific circumstances, how and why things actually happen in a complex world. Knowledge in qualitative interviewing is situational and conditional. (Rubin and Rubin, 1995 in Arksey and Knight, 1999, p54)

Although 'complete reliability is not attainable' (Arksey and Knight, 1999, p53). It is important not to corrupt the findings during the research process (Arksey and Knight, 1999). In writing about ethnography as a method, Altheide and Johnson, (1994) write:

The ethnographer is not committed to 'any old story', but wants to provide an account that communicates with the reader the truth about the setting and the situation, as the ethnographer has come to understand it. (p496)

Reliability can be enhanced using a number of strategies. Procedural reliability is one such means to assess the reliability of data and its interpretations (Kirk and Miller, 1986). Reliability can be increased through interviewer training and by checking of the analytical codes against the actual texts and passages. Indeed, as discussed in Part B, I not only attended a training course which taught me how to conduct in-depth interviews and use the framework approach for data analysis but the analytical categories and the data to which they were applied were also checked by my supervisor.

Mays and Pope (1995) advocate that reliability can also be ensured by maintaining meticulous records of interviews and observations and by documenting the process involved in the analysis. The analysis should report both negative and positive cases, with an explanation of

why this might be so, arguing that one of the advantages of taped interviews is that they are available for subsequent analysis by independent observers. The use of a framework approach for analysis, as used in this study, ensures that independent observers can access the charts used for the analysis and confirm or verify reported statements.

This also includes giving consideration to the adequacy of the sampling strategy, the appropriateness and power of the interview questions, flexibility of the design and transcript quality, and ensuring that consideration has been given to concepts of power and ethical issues addressed (Arksey and Knight, 1999).

How some of these limitations were addressed in practice is discussed in Part B of this section.

In context of this study, the use of strict conventional validity or reliability criteria was not adhered to.

#### **IN-DEPTH INTERVIEWS AS A METHOD FOR THIS STUDY**

‘Many kinds of social science enquiry now use interviews as a method of serious data collection’ (Brenner et al, 1985, p1). Similarly, I also felt that despite some of the limitations as described later in relation to interviews, in-depth interviews were deemed the most appropriate means to address the aims of this study. In-depth interviewing allowed me to:

... find out what is in and on a person’s mind..., to access the perspective of the person being interviewed ...to find out from them things that we cannot directly observe. (Patton, 1990, p278)

Further, it was a method which:

...allows *both* parties to explore the meaning of the questions and answers involved. There is an implicit, or explicit sharing and/or negotiation of understanding in the interview situation which is not so central, and often not present, in other research procedures. Any misunderstandings on the part of the interviewer or the interviewee can be checked immediately in a way which is just not possible when questionnaires are being completed, or tests are being performed (Brenner et al, 1985, p3, original emphasis)

In-depth interviewing allowed access to the context of people’s behaviour and thereby enable me to understand the meaning attached to behaviour. This is important because ‘a basic assumption in in-depth interviewing research is that the meaning people make of their experience affects the way they carry out that experience’ (Siedman, 1991, p4). Importantly, interviewing allowed people to symbolise their experience through language.

‘To understand human behaviour means to understand language’ (Heron, 1981 in Seidman, 1991, p2).

The use of language, itself...contains within it the paradigm of cooperative inquiry; and since language is the primary tool whose use enables human construing and intending to occur, it is difficult to see how there can be any more fundamental mode of inquiry for human beings into the human condition (Heron, 1981 in Seidman, 1991, p2).

The biggest advantage is that more sensitive and complex issues can be probed and answers clarified; they are conversations with a purpose (Rose, 1994; Bowling, 1997), with the discussion being as frank as possible. ‘No questionnaire could provide the information in sufficient depth’ (Fielding, 1994, p7).

As reported in chapter four, very little work has been done in this area before. In-depth interviewing is an approach that is particularly recommended if the area being researched is ‘on new ground’ and little is known about the phenomena to be studied (Fielding, 1993). The approach proved used in understanding the perspectives of carers, PHC nurses and managers and the meaning they attached to their experiences and a powerful means of helping participants make explicit things that were hitherto implicit – to articulate their tacit perceptions, feelings and understandings (Arksey and Knight, 1999).

Most importantly however, the use of in-depth interviews with Gujarati Hindu carers enabled those carers that did could not speak English to be involved and tell their side of the story. In-depth interviewing allowed the flexibility needed in the phrasing of questions or topics. Issues could be probed, re-phrased or repeated, with the option of switching between languages if issues needed to be developed further to ensure carers understood what was being asked.

It is however, acknowledged that it is never possible to fully understand someone perfectly ‘because to do so would mean that we had entered into the other’s stream of consciousness...If we could do that, we would *be* the other person’ (Schutz, 1967 in Seidman, 1991, p3, original emphasis). Some of these issues are explored further below in the discussion, which looks at some of the benefits of qualitative in-depth interviewing.

## **BENEFITS OF QUALITATIVE IN-DEPTH INTERVIEWING**

Murphy et al (1998) in their comprehensive review of qualitative research methods in health technology assessment, identify three distinct benefits of qualitative interviews:

### **Accessing the respondent's definitions and interpretations**

One of the main benefits of using qualitative interviews is that it enables the researcher to understand 'the experience of other people and the meanings they make of that experience' (Seidman, 1998, p3). It gives the participant an opportunity to define the problem in their own terms and to challenge the researcher's preconception about what is important or significant (Murphy et al, 1998, p115). McCracken, (1988) argues that:

The method can take us into the mental world of the individual, to glimpse the categories and logic by which he or she sees the world. It can take us into a lifetime of the individual, to see the content and pattern of daily experience. The long interview gives us the opportunity to step inside into the mind of another person, to see and experience the world as they do themselves. (p9)

Hence, in-depth interviewing enables us to find out things, which we are not able to observe directly (Patton, 1980 in Murphy et al, 1998):

We cannot observe feelings, thoughts and intentions. We cannot observe behaviour that took place at some previous point in time...We cannot observe how people have organised the world and the meanings they attach to what goes on in the world (p116)

In gaining these insights, 'there is a commitment not simply to describing the way in which insiders understand the world, but also to treating any differences between the subject's understandings and those of the researcher as legitimate cultural differences (Silverman, 1993 in Murphy et al, 1998, p116). Hence, the method allows the participants' view to unfold, not the researchers' (Marshall and Rossman, 1989, in Murphy et al, 1998, p116).

A quantitative approach on the other hand, would have been too rigid and restrictive and would not have been able to gain the depth of information sought as topics and questions are predefined.

### **Penetrating the respondents' public accounts**

The other distinct advantage of using qualitative in-depth interviews is that the researcher is more likely to obtain an accurate and honest account than if a structured interview had been carried out because the researcher is able to develop a closer relationship with the participant (Denzin, 1970 in Murphy et al, 1998). However, the notion that interviewing enables authentic accounts to be produced is still contested (see for instance, Silverman, 1993 in Murphy et al, 1998).

### **The flexibility of qualitative interviews**

Qualitative in-depth interviews are particularly useful for exploratory research as the researcher is able to follow up new dimensions or leads which the participant would not have

anticipated (Burgess, 1982), they are also useful for the generation of theories and ideas (Miller and Kirk, 1986; Glaser and Strauss, 1967) and for exploring lay logic into why they may behave in the way they do (Morgan and Watkins, 1988 in Murphy et al, 1998).

## **JUSTIFICATION OF THE CHOSEN METHODOLOGY**

The aim of this section is to provide a rationale as to why in-depth interviews were chosen as the method of data collection for this study. This is done by comparing and contrasting the use of interviews with participant observation and discussing the limitations of both surveys and participant observation to address the research questions for this study.

## **SURVEYS AND STRUCTURED QUESTIONNAIRES**

There are several different types of survey research methods, these include for instance, self-administered surveys, interview surveys, telephone surveys and with advances in technology, web based internet surveys. Survey interviewing is frequently referred to as a structured or standardised interview. The interview usually involves the use of: a standard schedule interview (in which the wording and order of all the questions is exactly the same for every respondent), a non-schedule standardised interview (in which the interviewer works with a list of the information required), or a non-standardised interview (in which no specific set of questions is employed and questions are not asked in any particular order) (Murphy et al, 1998). The type of questionnaires used for the survey may be highly structured or have a combination of structured and open-ended questions which enable the respondent to use their own words (Lewins, 1992).

Although the aim of this section is to illustrate why in-depth interviews were chosen over survey research, this is not to say that survey research does not have its uses, rather the most appropriate method needs to be chosen depending on the nature of the question. Indeed, there are many inherent benefits of conducting surveys, they include for instance, the ability to access information on public opinion, population distribution, demographic data, attitudes, behaviour, beliefs, values, memories and future plans (Fowler, 2002; Peil, 1982). This section will, however, focus on why a standard schedule interview (using a structured questionnaire) was not used for this study.

### **Positivism and surveys**

A notable critic of survey research was Herbert Blumer. Blumer criticized the idea that if social science was to be successful, 'it must develop devices which secure objective data suitable for quantitative treatment by the techniques of statistics' (Blumer, 1930 in

Hammersley, 1989, p113). He agreed with Znaniecki, (1934, in Hammersley,1989), that 'scientific laws are universal not probabilistic' (p114) and argued that 'case-study, interviews and life history may be valuable because they reveal generalizations which are not statistical; to force them to yield such generalizations may be to destroy their value' (Blumer, 1930 in Hammersley, 1989, p114).

Blumer (1930 in Hammersley, 1989) argued that statistical methods are of little value as they can only deal with static situations, not processes developing over time. It is also difficult to infer knowledge about an individual from knowledge about an aggregate. It is argued that statistical methods only enable correlations not causal relations to be identified and therefore it is important to show the relationship of one basic attribute of social life to another (Blumer, 1954 in Marsh, 1982).

Blumer argued that like mathematical or quantitative expressions, ordinary language also has the capacity to make precise discriminations. He argued that survey variables would never be able to capture the 'intimate and inner-moving complex of meanings' (Blumer, 1954 in Marsh, 1982, p55). It is suggested that surveys are incapable of getting at the meaningful aspects of social actions because people make choices, have memories, wills, goals and values, which motivate their behaviour (de Vaus, 1993).

In criticising the use of variable<sup>13</sup> analysis as often used in survey research, he argues that it neglects the crucial role that interpretative processes play in the formation of human behaviour. Its use leads to an 'inevitable tendency to work with truncated factors and as a result, to conceal or misrepresent the actual operations in human group life' (Blumer, 1930 in Hammersley, 1989, p116).

Another difficulty concerns the use of statistical techniques to define and operationalize sociological concepts<sup>14</sup>. He argues that 'concepts are defined in terms of the results produced by procedures designed to yield stable and definitive findings in repeated applications' (Blumer, 1954 in Hammersley, 1989, p119), and that 'the stable content that is isolated does nothing more than indicate that there is something stable' (Blumer, 1940 in Hammersley, 1989, p119). He argues that the operational definitions used often do not capture everyday usage of the concept that they are supposed to be defining, that meaning is often fragmented

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<sup>13</sup> A variable is a trait or characteristic, which changes from one situation to another. Research is focused on the relationship between variables (Peil, 1982)

<sup>14</sup> A concept is an abstract idea, which can be used to describe situations, events and individuals. Concepts are studied empirically as variables (Peil, 1982).

and that quantitative measurement would be appropriate 'if the problems out of which the concepts arose and the items to which they refer were themselves essentially quantitative' (Blumer, 1940 in Hammersley, 1989, p122).

Blumer is a firm advocate of the use of naturalistic research as it respects the nature of the social world. At the level of method, this involves the investigation of 'a given area of happening in terms of its natural or actual character, as opposed to the observation of a surrogate or substitute form' (Blumer, 1979 in Hammersley, 1989, p155). Blumer (1979 in Hammersley, 1989, p156) contrasts naturalistic methods with survey research, which aim to provide an idea of how people *might* act as opposed to how they have acted or are acting or which seek to measure attitudes or personality traits. He criticises survey research for being dehumanising and for producing a distorted picture of the world (Hammersley, 1989, p3). Others have also criticised survey research along similar lines. Mills, 1959 (in de Vaus, 1993, p8) for instance, states that survey research is basically empiricist in that it collects a mass of facts and statistics and adds nothing of theoretical value. Phillips (1971) likewise argues that measurement is a particular problem when using data from survey interviews as the data collection process has an unrecognised influence on the results.

#### **Issues concerning the use of structured /standardised survey methods**

The criticisms of survey research fall into two main categories: philosophical and technique based (de Vaus, 1993). It has been argued that 'standardised interviews do not and cannot achieve the degree of control they aspire to and therefore, cannot be treated as the gold standard against which qualitative interviews can be measured and found wanting' (Murphy et al, 1998, p113). It is assumed that if survey interviews are standardised, the 'interviewer can be sure that any differences between respondents which are uncovered are attributable to real differences rather than to differences in the instrument or research procedures' (Denzin, 1970 in Murphy et al, 1998, p113). Critics like Cicourel (1964 in Marsh, 1982) however, argue that standardised interviews are unrealistic. Although questions could be standardised (through the use of a structured questionnaire) there is no means of standardising the actual interview, which ensures that the interviewer asks exactly the same questions in exactly the same way. Moreover, it has to be remembered that the interview itself is a social interaction and thus the interview has to operate within the framework of socially accepted norms (Morton-Williams, 1993). Hence, the meaning of behaviour could be misunderstood because surveys only look at particular aspects of people's beliefs and actions without looking at the context (de Vaus, 1993). As the interviewer is expected to develop a degree of rapport with all respondents, this can be problematic given that the interviewer has to follow the same

procedure whilst at the same time adapt to respondent (Murphy et al, 1998). The relationships developed between the interviewer and the respondent will therefore either inhibit or facilitate the flow of certain types of information (Gorden, 1975 in Morton-Williams, 1993).

### **Main problems concerning structured questionnaires**

It is suggested that structured questionnaires are often used too readily, with insufficient thought, many are inadequately designed, and are often not an appropriate way of collecting the information that was required (Marsh, 1982). Hence, surveys are criticised for their technique in that they are too restrictive because they rely on highly structured questionnaires, which are limiting and allow little room for creative thinking. When using structured questionnaires, the answers are pre-determined. Although respondents can often select from a range of options to answer a question, respondents are restricted in that they have 'forced-choice' answers from which to select an answer (Fink and Kosecoff (1998). Hence, the deeper issues that can only be uncovered during the process of analysis are effectively missed.

Other difficulties concerning the use of standardised structured questionnaires concern wording effect, which is sensitive to minor changes when questions are asked, and the sensitivity and type of information sought in a questionnaire (Lewins, 1992; Marsh, 1982). Another criticism of structured questionnaires relates to how respondents interpret the questions. Although the same questionnaire may be administered, there is no guarantee that all the respondents would have interpreted the questions in the same light and as having the same meaning, hence it is argued that the 'statistical analysis of survey data depends crucially upon the assumption that the meaning of both question and responses can be treated as identical for all respondents and that this fails to recognise the possibility of variation in meaning across the sub-groups of the population' (Mishler, 1979, in Murphy et al, 1998, p114).

In order to conduct my research, a self-administered survey using a structured questionnaire or an interviewer-administered survey could have been carried out. Both approaches and why they were inappropriate are looked at briefly here.

### *Self-administered survey*

For this approach, questionnaires are usually mailed to the respondent and the method is often cheaper than interviewer-administered surveys. Whether all respondents receive their questionnaire is one cause for concern. A major limitation of this method, however, is that, it is skewed towards the more literate population and only simple one-stage questions can be

asked (Morton-Williams, 1993). Given that many of the carers in this study were not able to speak or read and write in English, and further probing was required in order to elicit answers, this method would have been clearly inappropriate to adequately capture carers' views.

#### *Interviewer administered survey*

Here, the interviewer questions samples of people and fills in the questionnaire at the respondents home, on the doorstep or in the street, for instance. Phillips (1971) suggests that the attributes of an interviewer can have an effect on the responses given to the interviewer. It is suggested that an interviewer's role requires a synthesis of discipline and initiative as persuasion may be necessary for those reluctant to take part, probing may be required if the answers do not conveniently 'fit' the pre-coded categories in the questionnaire, or the interviewer may need to deal with situations when respondents do not behave as expected by the interviewer (Morton-Williams, 1993). Likewise, the attributes of the interviewee can also be problematic as the interviewee may try to please the interviewer, be apprehensive or need approval for the views they hold (Phillips, 1971). Morton-Williams (1993) reports that people in industrialized countries are familiar enough with the concept of a survey in broad terms i.e. that they will have to answer questions. This is not necessarily the case with the South Asian population as respondents expect the interviewer to follow the usual rules of mutual disclosure used in polite conversation. For the majority of carers in this study, it was the first time they had ever participated in a research study. Given the sensitivity of some of the questions addressed in the study, carers may have found it difficult to provide truthful answers when their interaction with me would have been limited to a very short duration. A survey simply could not have captured this sensitivity or adequately captured the full range of carers' experiences if they were expected to provide responses that fitted predefined categories.

Lastly, feminists such as Oakley have argued that structured/standardised approaches are based on hierarchical, exploitative relationships between the researcher and the researched (Oakley, 1981). Given that the study was concerned with the experiences of Gujarati Hindu women and the sensitivity of the subject area, it seemed inappropriate to unnecessarily unbalance the relationship further.

#### **PARTICIPANT OBSERVATION AND INTERVIEWS COMPARED**

Participant observation is often regarded as the 'gold standard' for naturalistic inquiry (Murphy and Dingwall, 2003). The influential articles by Becker and Geer (1957/1969a & b) advocating the use of participant observation over interviews, and Trow's (1957/1969)

counter argument in defence of interviews are drawn upon here to make clear why in-depth interviews were deemed to be the most appropriate method of data collection for this study.

In defence of participant observation, Becker and Geer (1957/1969a) argue that participant observation is:

The most complete form of the sociological datum, after all, is the form in which the participant observer gathers it: an observation of some social event, the events which precede and follow it, and explanations of its meanings by participants and spectators, before, during and after its occurrence. Such a datum gives us more information about the event under study than data gathered by any other sociological method. Participant observation can thus provide us with a yardstick against which to measure the completeness of data gathered in other ways, a model which can serve to let us know what modes of information escape us when we use other methods. (p322)

Although Becker and Geer (1957/1969a) claim participant observation to be a superior method of sociological data collection over other interviews, it has been argued and reiterated many times by other scholars that the choice of research method should be dictated by the research problem (see for instance, Murphy et al,1998).

Different kinds of information about man and society are gathered most fully and economically in different ways, and ... the problem under investigation properly dictates the methods of investigation (Trow, 1957/1969, p332).

Moreover, 'political change, both globally and within the academic world, has meant that the ethnographer's authority to provide the only, or most legitimate, account is no longer accepted' (Ahmed and Shore, 1995 in Savage 2000, p1400).

In using interviews to measure against the yardstick of participant observation, Becker and Geer (1957/1969a) assume that people are looking for equivalent types of data. However, this is not the case, because 'interviewing and participant observation would rarely produce equivalent types of data, and should not be asked to, but rather produce rather different kinds of data designed to answer quite different kinds of questions about the same general phenomenon' (Trow,1957/1969 p333).

Trow (1957/1969) also argues that Becker and Geer's (1957/1969a) claim that participant observation 'gives us more information about the event under study than...any other sociological method, is to assume that all events are directly apprehensible by participant observers'. Yet, 'most of our problems require for their investigation data of kinds that can not be supplied by the participant observer alone' (p333).

Becker and Geer (1957/1969a) also claim that participant observation enables to 'learn the native language'. They argue that although we speak one language and share in many ways one culture, we cannot assume that we understand precisely what another person means by any particular word. Unlike interviews, participant observation enables the observer to learn the meaning of words with great precision. As the observer spends much time with the people being studied, it is argued that the observer sees things, which might not be reported during an interview (Becker and Geer, 1957/1969a).

In response, Trow (1957/1969) argues that 'ordinary social life may well inhibit the casual expression of sentiments which are actually or potentially important elements in the explanation of the social phenomena under study' (p334). Further, 'participant observation is a relatively weak instrument for gathering data on sentiments, behaviours, relationships which are normatively proscribed by the group under observation' (p334).

Participant observation makes it possible to check description against fact as the observer can note discrepancies and distortions. When interviews are used as a source of information about situations and events, these distortions are less likely to be discovered (Becker and Geer, 1957/1969a). In response, Trow (1957/1969) argues that certain important facts for instance, about a man's early life experiences and what his father did for a living, can be reported quite accurately to an interviewer or on a questionnaire and give the analyst invaluable data. Moreover, 'the amount of information people can tell us, quite simply and reliably, about their past experience is very great; and it is only in light of that information, I would maintain, that we can frequently understand their behaviour in the "here and now" that the participant observer is close to' (p335).

Participant observation enables changes in behaviour over time to be observed and the events that proceed and follow them can also be noted. Becker and Geer, 1957/1969a) argue that interviews do not provide an accurate account of events concerning change and process, only inferences, that is, an educated guess can be made concerning the problem (Becker and Geer, 1957/1969a). Trow (1957/1969) argues that all interpretation of data, however they are collected, involve inferences regarding meaning and significance, likewise the data an observer collects are not a substitute for the interpretive inference. Progress in social science will not come about by 'getting closer' to the source of the data, but rather, by developing 'systems of theoretically related propositions – propositions which are 'checked' at more and more points against the data that are collect...the inferences that we make from data, and the theory from which they derive and to which they contribute, may indeed be nothing more than "educated guesses" – but that is the

nature of scientific theory. Our aim is to make them increasingly highly educated guesses. We cannot evade the fate, which is the fate of science, through reliance on a wrongly conceived participant observation, which apprehends social reality' (p337).

Many of these criticisms have also been reiterated in a more recent analysis of Becker and Geer's (1957/1969) work (see, Atkinson and Coffey, 2001).

### **LIMITATIONS AND CRITIQUE OF QUALITATIVE IN-DEPTH INTERVIEWING**

One of the main criticisms of the use of in-depth interviews is that it gets at what people say rather than what they do. Hence, it is argued that what actually happened and the story provided might not match up and more so if the event occurred a long time ago (Arksey and Knight, 1999).

It is also suggested that as 'the interviewee works with a memory that remembers some aspects and not others; which orders memory in the light of what happened subsequently and in the light of the interview situation; which tends to neaten things up; and which tends to put the interviewee in a socially acceptable light' (Arksey and Knight, 1999, p16). Concerns about the concept of power in the interviewing relationship have also been noted. For instance, it has been suggested that interviewing as a process turns participants into subjects so that their words can be appropriated for the benefit of the researcher (Seidman, 1991).

Other limitations could arise from the interview itself. These include for instance:

- People may withhold true accounts, offering instead a rational approach to their actions
- Some people may not be able to express themselves clearly
- Respondents may fear being 'shown up'
- Respondents may be over-shy or anxious – distorting the response (Fielding, 1993)

Hence, it is suggested that interviewers need to have certain qualities that are the hallmark of a good interviewer (Arksey and Knight, 1999, pp40-41). These include:

- Understanding the topic
- Understanding people - being interested in what is being said
- Body language - dressing appropriately for instance
- Affect

In writing about affect, Rubin and Rubin, (1995 in Arksey and Knight, 1999, p41) write:

The researcher's empathy, sensitivity, humour and sincerity are important tools for the research...How the researcher asks questions depends on how he or she feels about the topic or the interviewee. And what the researcher hears from the answer may depend on his or her mood and prior experience.

In addition, in-depth interviewing is time consuming, labour intensive and can also be costly if tapes are to be transcribed professionally for instance.

Here, a brief critique of qualitative in-depth interviews is reported. It draws on the work of Murphy et al, (1998) who provide a critique of both structured and qualitative interviews.

Whilst quantitative researchers try to control the context of interviews rigidly; qualitative researchers on the other hand argue that this 'inhibits the expression of what the respondent really thinks' (Murphy et al, 1998, p120). As discussed earlier, interviews are contextually situated social interactions (Murphy et al, 1998), as a result it is argued that interviews are opportunities for 'impression management' (Goffman, 1959 in Murphy et al, 1998) 'to support personal goals and structured by the expectations of others' (Dingwall, 1997). As such, it is argued that if the interview is a social encounter, then it needs to be analysed in the same light as:

The products of an interview are the outcome of a socially situated activity where the responses are passed through the role-playing and impression management of both the interviewer and the respondent...as such, its relationship to any 'real' experience is not merely unknown but in some sense unknowable. (Cicourel, 1964 in Dingwall, 1997, p56).

The research interview thereby enables the production of *accounts* (Dingwall, 1997). However, the notion that each party will be aware of how to behave and have knowledge of the expectations of each other during an interview has been contested. Scott and Lyman (1968 in Dingwall, 1997) for instance, classified accounts as being either excuses or justifications for one's untoward behaviour, whilst Drew and Heritage (1992 in Murphy et al, 1998) argue that accounts represent 'any occasion on which the fabric of social order is put under stress' (p121). However, Bowler (1997) reports interviewing Pakistani women for her study which looked at their experiences of maternity services as being particularly problematic as the women were not used to being interviewed, did not understand what it entailed and therefore did not share the same shared notion of the research process. As a consequence, Bowler (1997) had to abandon the idea of obtaining the perspectives of the women for her study and had to focus on obtaining the views of midwives only. Similarly, Curren (1983 in Bowler, 1997) found that permission to visit and permission to research were two different things. 'This means that what is said in interview situations must be treated as an account, which represents the respondent's attempt to present self as a competent member of the community, rather than as literal descriptions of the respondent's reality' (Murphy et al, 1998, p121). However, it is suggested that by analysing what people do during an interview, 'we can

identify what the respondent takes to be self-evident about the world of which they are speaking' (Murphy et al, 1998, p122). Although interview data is particularly useful for informing health service provision and policy, they are 'simply representations of the world, they are part of the world they describe and are thus shaped by the context in which they occur' (Hammersley and Atkinson, 1995 in Murphy et al, 1998, p122).

However, despite the limitations reported above, there are still distinct advantages of using the method when appropriate:

If we can collect data with which to tell a plausible story...if the upshot [of phenomenological and postmodernist challenges] is methodological paralysis it might be better to take a more anarchic, or at least pragmatic approach...with all that in mind, going off to interview people and coming back to tell Strong's 'plausible story' probably is, as he said, 'the best we can hope for' (Melia, 1997 in Murphy et al, 1998, p123).

## **PART B**

### **FIELDWORK**

In the previous section of this methodology chapter, reasons for adopting a pragmatic qualitative approach were reported. Here, in part B, the steps followed to carry out the study and how the general principles of qualitative research were applied to address the aims of the research study are reported.

The principle aim of this study was to examine Gujarati Hindu carers' experiences with PHC nursing services to ascertain whether they felt supported by them. In exploring Gujarati Hindu carers' experiences with PHC nursing services it was deemed appropriate to also explore the views of PHC nurses. The views of managers<sup>15</sup> were also sought once it became apparent that some of the reasons identified by PHC nurses for not meeting carers needs concerned management issues. Hence, this thesis aims to address three specific questions:

1. What are the experiences of Gujarati Hindu carers of using PHC nursing services and did they feel supported?
2. What are the experiences of PHC nurses of supporting Gujarati Hindu carers and did they encounter any difficulties?
3. What are the views of managers in terms of how PHC nurses should support carers and what strategies, resources or services are in place to enable PHC nurses to support carers?

### **SETTING**

Given that this study aimed to address a particular minority ethnic group, it was essential that the chosen geographical area in which to undertake the study adequately reflected the Indian population within it. Evidence from published demographic data identified one geographical location in the Midlands as adequately reflecting this population. The prevalence of limiting long-illness was also reported to be high in this particular geographical area especially in relation to the Indian community. Table 2, provides information on the population makeup of the area in which the study was conducted using 1991 census figures.

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<sup>15</sup> The generic term 'manager' is used in this chapter when referring to both providers of learning disability, health visiting, district nursing and mental health services and commissioners from the health authority.

All	White	Black Caribbean	Black African	Black other	Indian	Pakistani	Bangladeshi	Chinese	Other Asian	Other	Irish
<b>Ethnicity by age 0-4</b>											
21833	13446	303	79	417	6097	370	167	42	275	637	22
<b>Ethnicity by age 5-15</b>											
40686	24102	569	152	673	12634	646	297	109	512	992	148
<b>Ethnicity by age 16-29</b>											
62368	43949	1103	226	447	14011	673	270	313	676	700	463
<b>Ethnicity by age 30-pensionable</b>											
97042	67953	1750	275	187	23784	883	302	271	994	643	2193
<b>Ethnicity by age pensionable age+</b>											
48564	44052	387	13	32	3771	72	17	35	113	72	1308
<b>Ethnicity total residents</b>											
270493	193502	4112	745	1756	60297	2644	1053	770	2570	3044	4134
<b>Ethnicity and limiting long-term illness</b>											
36769	28919	478	242	102	6253	215	88	38	225	209	872

Source: OPCS county monitor 1992: CEN 91 CM 26

**Table 2: information on the population makeup and limiting long-term illness**

Hence, it was anticipated that by conducting the study in this particular geographical location, this would increase the probability of identifying sufficient numbers of Gujarati Hindu carers to take part in the study.

Combined with knowledge from the literature and personal awareness about the area, I knew that the vast majority of Gujarati Hindu people resided within the inner city. It was acknowledged however, that minority ethnic communities are now dispersing into the county areas (Jewson, 1995). Hence, given the nature of the sample sought, to 'stick' only to the inner city would have constrained the sample recruitment and a decision was made to recruit carers from within a five-mile radius of the city because on one particular side of the city, this was where the boundary for the county begun and where the most notable movement and concentration of minority ethnic communities from city to county had taken place.

Hence, careful consideration and selection of the geographical area resulted in this study being carried out in an area not only having a large ethnic minority population but also one in which a large number of people of Indian ethnicity resided.

## PLANNING THE RESEARCH STUDY

To address these questions a systematic approach to identify the sample groups and make arrangements to conduct in-depth interviews was required. The steps taken are summarised below.

- Identify and negotiate access a small group of Gujarati Hindu carers as a starting point.
- Recruitment of Gujarati Hindu carers to take part in in-depth interviews with identification of other potential Gujarati Hindu carers being done simultaneously.
- Arrangements to conduct in-depth interviews with those Gujarati Hindu carers that agreed to participate in the study.
- Using a system of 'tracking' for identification of PHC nurses and managers.
- Conducting in-depth interviews with those managers that agreed to participate.

Gujarati Hindu carers were always interviewed first. Followed with interviews with PHC nurses and managers taking which took place simultaneously. Due to the workload commitments of professionals, interviews could not deliberately be sequenced in blocks. For instance, it was not possible to carry out interviews with carers in say the first four months of the data collection phase, then follow this up with interviews with PHC nurses for the next four months and subsequently with managers. Moreover, it was important to interview PHC nurses soon after the interviews with carers because it would have made it difficult for PHC nurses to recollect events pertaining to particular cases or patients may have been discharged from PHC nurses books if there were prolonged gaps.

Having obtained ethical approval the field work commenced. Data collection took place between October 1996 and August 1997. Initial analysis began soon after. This approach enabled modifications to the topic guide to be made as well as enabling new issues identified to be incorporated in subsequent in-depth interviews. Data gathering and analysis therefore took place concurrently. Here, a detailed account of the steps taken to carry out the study with a discussion on how issues such as the sensitivity of the research topic can affect research is reported.

Carrying out the study was not as straight forward as often reported in research reports. Yet, the dilemmas encountered as part of the research process are an important of the research process and can contribute to the methodological area of research. Hence, an account of some of the difficulties encountered together with a discussion on changes to the original design and experiences pertinent to some issues addressed in this chapter can be found in Part C of this methods chapter.

### **Access to carers**

The first task was to establish access to carers. A variety of approaches were used to identify the sample of Gujarati Hindu carers. This complicated matters slightly because it meant having to use different approaches to negotiate access depending on how or whom I was trying to access carers from. The benefits however, was that together with purposeful

sampling techniques, I was able to draw a wide range of Gujarati Hindu carers into the study, all of whom who had a unique and individual contribution to make.

As a starting point, to aid identification of Gujarati Hindu carers I went back to the original lists of carers from the South Asian carers study. The list contained names and contact details of carers from four different language and religious groups. A total of nine Gujarati Hindu carer's names with PHC nursing input pertinent to the geographical area that was to be researched were identified and contacted. List one contained contact details of those carers that had been identified and approached but **declined** the offer to take part in the South Asian carers study. It was important to start building the interviewer relationship as soon as possible. Once potential carers had been identified, contact was established with me writing to them asking if they would be interested in taking part in this new study which was to address carers' experiences with PHC nursing services (appendix 1). Each letter had had a reply slip attached and a pre-paid envelop was enclosed. A copy of the same letter in Gujarati created on the home computer was also attached (appendix 2). This procedure was followed with all potential new 'recruits' of Gujarati Hindu carers to the study. All carers were also provided with information about how they could verify my position at the University along with my contact details. It was reiterated in the information that carers could contact me directly if they had any anxieties, questions or concerns. I dealt with telephone calls from carers personally. Although one district nurse helped identify potential carers as reported later, she was not used beyond this point.

Three female Gujarati Hindu carers from list one agreed to take part that had previously refused to take part in the South Asian carers study (Radha Nayan; Alisha Ram and Madhuri Krishen). One reason for this may have been that one year had elapsed since they had been approached about the South Asian carers study and carers' circumstances or views about participation may have also changed in this light.

One Gujarati Hindu male carer was identified from list two (Vikesh Anand). This list contained contact details of all carers that **had** participated in the South Asian carers study. Vikesh Anand was approached again and asked to participate. He agreed and was included as he formed part of an unusual sub-group. This issue is discussed in more detail later. Although a total of four carers were identified from list one and two of the South Asian carers study, only the male carer had previously taken part in the South Asian carers study. The three female Gujarati Hindu carers were therefore effectively, 'brand new' and had not taken part in research prior.

The remaining five carers did not take part (although two carers from the remaining five did originally agree to take part but 'dropped out').

Gujarati Hindu carers were also accessed using a combination of other approaches. This included identification of carers by: using snowballing techniques; personal contacts; through district nursing caseloads and visiting local community organisations and day centres.

Once a small group of Gujarati Hindu carers had been identified that were willing to take part, they were asked if they knew of any other Gujarati Hindu carers with PHC nursing input that may like to participate in the study. If these carers were able to suggest someone, I obtained contact details from them. Consent was also obtained from these carers to use their name in a letter which I then sent to their friend asking if they would like to participate. Snowballing as a recruitment technique helped to identify a total of four Gujarati Hindu carers (Shivam Ranchord, Pritesh Krishen, Prabha Laxman and Madhu Gokhani).

In one instance, I used my own personal contacts to include one particular carer into the study (Shanta Hari). Whilst nursing, I cared for a gentleman who owned the local dry cleaners. I knew of his home circumstances and he knew of mine as my daughter had accompanied me several times to the dry cleaners in a very large 'buggy'. It was by chance that I was visiting the dry cleaners at the time of the study. We started talking and he asked how things were on the ward. I explained that I no longer worked at the hospital and that I had taken up new research post. The project was explained and I used this opportunity to ask if he would be interested in taking part. Due to his work commitments, he was unable to take part but suggested that I contacted his wife, who was at home during the day and was more involved in their son's care. He said he would speak to his wife about the study and let her know that I would be in touch. I took down his home address and telephone number and contacted his wife. She agreed and a date was arranged for me to conduct the in-depth interview.

One Gujarati Hindu carer (Gopal Mithun) was identified with the support of one district nurse who had been identified as the named nurse for another carer already involved in the study. She had also agreed to be interviewed for the study. After the interview had finished, I discussed issues concerning recruitment of carers with her and asked if she would be prepared to help me identify potential carers. She agreed. She passed on information about the study to this potential pool of Gujarati Hindu carers after I had selected relevant carers. This was done by the district nurse going through her books to first identify potential carers. I explained that I was looking for Gujarati Hindu carers and gave examples of the types of names which

would fall into this category and ones which would not. I did not look at the district nurses books. Instead, she gave me some background information about the type of caring responsibilities these potential carers were involved in. I then selected different types of carers if they were Gujarati Hindu Carers. On occasions the district nurse identified 'South Asian' sounding names of patients but they were not Gujarati Hindu patients, hence, they were not included.

As purposeful sampling was used, I had to remain aware of the character of carers that had already agreed to participate. Hence, other potential carers were excluded and not approached on the grounds that I already had carers that were caring for people with similar health problems such as carers of people who had a stroke.

Ultimately, decisions concerning whom to include or not were taken by me and not the district nurse. In one instance, a carer of a daughter with mental health problems contacted me but was not included as I already had sufficient numbers of carers with 'no PHC nursing' input.

The remaining five Gujarati Hindu carers were identified by establishing links in the local community with local community organisations, day centres and groups. These included Mencap, a local mental health organisation and three day centres. A key individual was identified within the organisation. I then contacted them and made appointments to discuss the study and ask for assistance to help identify potential carers. The same literature was left with these key individuals and they were asked to pass the information onto carers they had contact with. This was followed up with telephone calls and another set of visits to the day centres and mental health organisation to explain the study once again and to ask if they had identified any carers. By this time, these key individuals had identified some carers for me. Letters were subsequently sent to these carers having obtained permission to use the names of the key individual in letters to carers. The process was labour intensive and time consuming but it did lead to five carers agreeing to take part (Priya Thakrar, Anant Laxman, Sameer Gokhani, Sheetal Soni and Mital Popat). Mital Popat had previously taken part in the South Asian carers study but on this occasion he had been identified through the support of the local day centre. As it happened, he had called in at the day centre the day that I had arranged to revisit. I was introduced to him and we discussed this new study. He was included as he had no involvement with PHC nursing services in the past and formed part of the unusual sub-group of carers.

#### **Access to PHC nurses**

PHC nurses were accessed using a system of 'tracking'. The names of PHC nurses and their contact details were obtained from carers after they had been interviewed. Letters were then sent to PHC nurses outlining the study with a request to participate in the study. Photocopies of signed consent forms from patients and carers stating that they had already taken part in the study and given permission for me to contact them together with a reply slip and pre-paid envelope were also enclosed (appendix 3). In addition, copies of letters from senior management giving permission to carry out the study as well as a letter from me, stating that ethical committee had been granted were also sent to PHC nurses prior to interviews taking place. Interviews with PHC nurses took place concurrently with managers' interviews, largely because it was a case of scheduling interviews with managers whenever they could spare the time.

### **Access to managers**

Managers in this study provided services for the learning disability trust, mental health trust, district nursing services and health visiting services. Two purchasers or commissioners as they are now known that served the health authority were also included as initial analysis from the interviews with provider managers suggested that the role of commissioners appeared to affect their ability to meet carers' needs.

Managers were also identified by using the same system of 'tracking'. PHC nurses were asked for details of their immediate nurse manager at the end of the interview. This manager was then asked for details concerning the next level of management.

A few managers responded quickly to my initial letter requesting them to participate in the study and suggested that I contact their secretary to arrange a date to conduct the interview. With the majority however, although I was able to arrange dates, I had to wait several months to see them as their diaries were much fuller. Some however, would not respond to letters, phone calls or messages. Interviews were conducted throughout the management hierarchy from team leaders through to directors.

Once the interviews with managers had started, initial analysis suggested that managers experienced difficulties in meeting the needs of carers because of lack of resources. Including the purchasers perspective was therefore deemed appropriate as it would have added a different perspective. Two commissioners from the health authority were therefore included.

### **Consent**

Verbal and written consent was obtained from all Gujarati Hindu carers, PHC nurses and managers at various stages of the research process. Permission was first sought requesting participation to the study, followed by permission to use their names to contact other relevant

persons. Once interviews had been arranged, permission was sought to tape the interviews (appendix 4). It was reiterated that names would be changed to preserve anonymity and that confidentiality and utmost care would be taken to ensure that they are not recognised or identified in any subsequent reports or publications. For Gujarati Hindu carers, this was done by using a combination of traditional and modern Gujarati names. On occasions I used two first names to make up one 'whole' name (first name and surname). Other times, I used traditional names for younger carers and modern names for older carers and other times I just used names which I felt suited the carer. For PHC nurses and managers, I used a slightly different approach. Names were selected by looking down the reference list of an atlas. I then picked out names that stood out or I liked the sound of. Precautions to preserve anonymity and confidentiality were also taken when handling tapes, transcripts and charts for analysis. This is discussed further later.

As the research study involved a qualitative in-depth interview and sensitive issues needed to be addressed, for instance, carers' feelings about caring, those taking part in the study were given full insight into the study they were being asked to participate in and what their involvement would mean for them. All those that participated received information about the study first through the letters that were initially sent to them and then verbally on the day of the interview. Further clarification was also provided over the telephone any time before the interviews if necessary. The following information was provided to all participants to enable them to make an informed decision concerning their involvement:

- The aims and nature of the study, including methodology to be used, duration of the study and what their role would involve.
- The proposed benefits of the research, both for them and service provision in future.
- My contact details.
- The type of questions that I was likely to ask in the interview and how long the interview was likely to take.
- Maintaining anonymity and confidentiality.
- How the findings were likely to be disseminated – through production of a thesis and publication in journals.

It was made clear that they were free to refuse to answer any questions they did not want to share with me because for instance, they felt that the answer was considered private or embarrassing and that they had the right to withdraw from the study anytime they wanted to. Indeed, one female carer withdrew from the study on the day of the interview and informed me after I had reached her home. This approach was taken to enable those taking part to make a decision by letting them weigh up the proposed benefits against any possible drawbacks or

reservations they may have had. Discussing sensitive issues is discussed in more detail later; however, when discussing issues such as benefit entitlements, consent was again renegotiated verbally.

## **CARERS**

In relation to this thesis, the sample of Gujarati Hindu carers consists of people who are visibly distinctive from the majority white population. The sample consisted of seven male and eight were female Gujarati Hindu carers who together formed a sample of different types of carers. Carers were aged from 21 years to 80 years of age. Three lived in extended households; others lived in nuclear families. Most carers had migrated to England from Africa and India. A few were born in Britain.

Some carers were recruited because they formed an 'unusual' sub-group:

- sister and brother caring for both parents
- male carer who cared for his mother who did not have nursing support and subsequently married after one year
- spouse carer who cared for his wife and was not able to have nursing support because his wife insisted only he provided care
- ex-parental carers whose son had died
- male carer who gave up working. He cared for his son jointly with his wife.

Here I introduce carers from this study using their own words. All cared-for persons lived with the carers. Carers are described individually except in the case of joint carers.

**Prabha Laxman** and **Anant Laxman** cared for their 21 year old son who was 'mentally and physically disabled' as a result of encephalitis. They lived in a terraced house which they owned in the inner city with one other son who was studying at a local university. They were in receipt of attendance allowance and neither of them worked. Their son was alive when I interviewed them but has since died.

**Sheetal Soni** cared for her 17-year-old daughter with cerebral palsy who was 'mentally and physically handicapped'. She lived with her husband and two other children in a semi-detached house in the city which they owned. She worked part time on 'transport' and received disability living allowance.

**Madhu Gokhani** and **Sameer Gokhani** were both ex-parental carers of their 18 month old baby boy who died. He had congenital heart disease and cerebral palsy and was quadriplegic. The three of them lived in a terraced house in the inner city which they owned. Madhu Gokhani worked part-time as a clerical officer and Sameer Gokhani worked full-time as a personnel officer. They were in receipt of attendance allowance and disability living allowance.

**Radha Nayan** cared for her daughter (aged 3) with no diagnosis. She lived in a semi-detached house which they owned in the city with her husband and other daughter. She worked part-time as a nurse.

**Shanta Hari** She cared for her twenty-seven year old 'physically and mentally handicapped' son. She was a full-time carer. She lived in the inner city in a terraced house which they owned with her husband and one other daughter who was studying at University away from home. She had another daughter who was married. They had part owned a launderette. They were in receipt of mobility allowance, income support and severe disability allowance.

**Gopal Mithun** cared for his wife who had 'shaking problems' and a stroke. They lived with their son and his family in his semi-detached house in the inner city. He was a full-time carer. They were in receipt of disability allowance.

**Priya Thakrar** cared for her husband who 'heard voices'. She lived in a terraced house which they owned in the inner city with her son. She was a full-time carer. She had another daughter who was married. They received disability benefit.

**Alisha Ram** cared for her mother-in-law who had a stroke, her daughter (aged 6) with leukaemia and her elderly father-in-law. She lived in a detached house in the county which they owned with her other two children. She worked part-time as a check-out operator. She was in receipt of carer's allowance.

**Shivam Ranchord** cared for his daughter (aged 15) with cerebral palsy and epilepsy. He lived in a terraced house which he owned in the inner city with his wife and two other daughters. He worked full-time as a bus driver. His wife was the main carer but she did not want to be take part. They received disability living allowance and invalidity benefit.

**Madhuri Krishen** and **Pritesh Krishen** cared for their parents: mother had a stroke/epilepsy and diabetes; father had mental health problems and possible learning disabilities. They all lived together in council semi-detached property in the inner city. She worked part-time as a nursing auxiliary and he worked full-time as a crisp packer. They received disability living allowance and carer's allowance.

**Vikesh Anand** cared for his wife who had had a stroke and epilepsy. He lived in a town house which they owned in the inner city with two daughters. He was a full-time carer. He received disability living allowance. He injured his back whilst caring and had to leave work, he was therefore also in receipt of invalidity benefit.

**Mital Popat** cared for his mother with depression and arthritis. He lived with his wife and their four children in a terraced house in the inner city which they owned. He was training to be a driving instructor. They received invalid care allowance and income support.

#### **PRIMARY HEALTH CARE NURSES**

As different types of carers participated in the study, the sample of PHC nurses was equally diverse. The following types of PHC nurses participated: one auxiliary nurse (general nursing); one auxiliary nurse (learning disability); two district nurses; three health visitors; three community psychiatric nurses and four learning disability nurses. The table 3 provides details of the characteristics of the primary health care nurses who participated.

**TABLE 3**  
**Characteristics of the primary health care nurses who participated**

<b>Name *</b>	<b>Occupation ***</b>	<b>Discipline</b>	<b>Grade</b>	<b>Gender</b>	<b>Ethnicity ***</b>
Abberton	Nursing auxiliary	Learning disability	B	Female	Asian
Badby	Nursing auxiliary	General	B	Female	Polish
Carie	District nurse	General	ns**	Female	British
Dobcross	District nurse	General	G	Female	British
Elgin	Health visitor	General	ns	Female	British
Faygate	Health visitor	General	ns	Female	Irish
Golant	Health visitor	General	G	Female	White British
Hakin	Community psychiatric nurse	Psychiatry	F	Female	Asian
Innis	Community psychiatric nurse	Psychiatry	E	Female	Asian
Jaywick	Clinical supervisor	Learning disability	ns	Male	English
Kindle	Clinical supervisor	Learning disability	G	Male	White English
Likisto	Clinical supervisor	Learning disability	G	Female	White European
Startley	Community nurse	Learning disability	D	Female	British
Mathern	Community psychiatric nurse	Psychiatry	F	Female	Asian

\* All names are fictitious

\*\*ns = not specified

\*\*\* As described by participants

## **MANAGERS**

Fourteen managers also took part in the study. This consisted of five team leaders from the general nursing discipline; one team leader from the learning disability discipline; three community general managers; one locality manager; one assistant director; one director. This includes two purchasing 'managers': one locality commissioning manager and one chief nursing advisor. Table 4 lists some characteristics of managers who participated.

**TABLE 4**  
**Some characteristics of managers that took part in the study**

<b>Name*</b>	<b>Gender</b>	<b>Ethnicity**</b>
Niddrie	Female	British
Oldpark	Male	British
Peplow	Female	White British
Quatt	Female	British
Risley	Female	Asian
Tugby	Female	White British
Ullock	Female	British
Veness	Female	British
Westwell	Female	Asian
Zennor	Male	British
Woolwich	Male	African
Ticknall	Female	British
Sontley	Female	British White
Rochester	Male	White British

\* All names are fictitious

\*\* As described by participants

## **DATA COLLECTION**

Data were collected by use of in-depth interviews. In the case of carers, observations of their home circumstances were also made. Some documentary evidence was also collected. A field work diary was kept. However, before any interviews could take place, a topic guide was developed.

### **Topic guides**

Before the in-depth interviews could take place, individually tailored topic guides were produced for Gujarati Hindu carers, PHC nurses and managers (see appendix 6 for carers, appendix 7 for PHC nurses and appendix 8 for provider managers and appendix 9 for commissioner managers). It took several attempts to develop a succinct enough guide to cover the range of issues that I wanted to address. Although the process was time consuming, it was important to spend time developing the guides as I was not trying to test a hypothesis but was asking participants to reconstruct their experiences in order to explore meaning (Seidman, 1991). Although having insight into the literature helped in the development of the guide, 'new' dimensions were added to the guides as the interviews progressed. 'New' areas that were added concerned issues that puzzled me in some way about the topic under discussion. These issues were then followed up in subsequent interviews. Each guide had several broad topic areas to be addressed which were then arranged in order so that the more general issues could be addressed first. When interviewing carers for instance, I obtained some background information about them and their family and then went onto explore about their caring experiences. By this time I had built up enough trust with carers which enabled them to part with quite personal information. This was followed with a more specific line of inquiring around their experiences with PHC nursing services. The last section went back to a more general line of questioning again, this time, by exploring with carers how they felt services could be improved. With all three groups of participants, the topic guide was divided into several broad areas with probes in between.

However, during the interviews, it was essential to keep some flexibility in terms of the order in which issues were discussed. Hence, at times, it made sense to let participants continue talking even if the issues were not in the 'correct' order. The guides themselves were pretty minimal covering distinct topic areas, yet, at the same time they were detailed in that probes were added to the guides. These probes were fine tuned during the interview depending on my estimation of comprehension and to allow ease of response. A view endorsed by Gilbert (1993). The probes were used to elicit more information about the topic area and enabled me to mentally keep a check on the areas that I had covered and the ones that I had not.

### **Observation of home circumstances**

A structured survey was not carried out for the reasons outlined in this chapter. However, in recognising that opening questions are particularly important and should consist of those that can be answered easily (Peil, 1982), 'Background' information was collected from all participants prior to the interviews commencing (see appendix 10 for carers) prior to leading into more informal discussion. This consisted of set questions covering areas such, as language spoken, age, education and occupation for carers and grading, ethnicity, gender, occupation for all other participants.

In the case of Gujarati Hindu carers, this also included information on the type of housing and number of people living in the accommodation for instance, eleven carers owned their homes. However, accommodation was usually lacking in space. Six carers lived in household comprising of 2 other adults. In all of these cases, the cared-for person was also an adult. Thus there were 4 adults per household (excluding younger children). This excludes Alisha Ram who was the only carer to live outside of the city in a five bedroom linked detached property. However, she also lived in a household comprising of 4 adults and 3 children (including the cared-for person).

Additional mental notes of their home circumstances were also taken and added to the summary of profiles that had been created which provided an overview of carers caring circumstances and background. These profiles were kept separate from the fieldwork diary and deliberately placed in the respective transcript files as it was easier to go straight to relevant files when I needed to 'jog' my memory as opposed to filter through pages of field notes in the fieldwork diary. The profiles acted as a 'quick reference' guide (see appendix 11). Data were however filtered, collated and drawn together for the purpose of analysis.

The following are examples of the types of mental notes recorded in carers' profiles:

- Whether the house was in need of repair (such as, the state of plastering; paintwork; wallpaper and external doors)
- Whether household furniture was in a good state of repair
- Whether the windows were in good repair from the outside
- Whether the house was cold or lacking in central heating
- Whether the house had doors wide enough for a wheelchair to go through (in cases where this was felt to be a necessity)
- Whether the house had any adaptations, disabled equipment, aides or ramps

### **Documentary evidence**

It was not the intention of the study to gather documentary evidence as the study was more concerned with trying to elicit participants' experiences and views. However, a few pieces of documentary evidence were collected as they were 'readily available' to members of the public. These included: a leaflet on how to make complaints; summary of 1996/1997 business plans for the mental health trust; Dialogue 1997 – a magazine of mental health services and a Trust annual report for community services (1996).

### **Fieldwork diary**

A fieldwork diary was kept throughout and constantly updated. Different types of field notes were recorded, such as descriptions of observations, settings, events and initial thoughts about what had been discussed and whether other avenues needed to be explored at subsequent interviews as well as reflections of the research process overall. On occasions, I also listened to 'bits' of interviews on the tapes to confirm or verify issues which were then recorded in the diary.

A number of difficulties were encountered whilst conducting this study both in terms of the design and in terms of setting up and conducting interviews with some participants. These issues were also recorded in the fieldwork diary. Field notes were always written up in the diary soon after the interview. On occasions I sat in the car to make notes, other times, I wrote up field notes as soon as I reached the office or reached home. Below are a few examples of the types of notes recorded. The aim was not to record 'everything and anything' but issues which I thought would be pertinent to the research in some way. The information recorded provided a basis for the initial analysis. Data collection and analysis was therefore an ongoing process.

Detailed records of the *dilemmas* encountered during the fieldwork pertinent to groups as a whole or specific participants and an account of 'what happened' on the day of the interview was recorded.

Got to the house and husband opened the door. Wife waiting in the front room. Husband explained that wife had changed her mind about the interview. She asked me to take her name off of the list. She did not want to take part any more. I agreed. But it will be a real loss. She fills in all the forms for benefits, makes visits to hospitals, has all contact with nursing services. Shivam Ranchord does not know the nurses name and could not even tell me how they got contact with her. Good interview with Shivam Ranchord about his experiences and his role in caring for daughter though. Mother looked very stressed and tearful throughout. She kept getting up and walking out of the room. Goes to work for one hour a day at the local school as a dinner lady. When asked if her daughter was at school that day she replied "yes" as cheerfully as possible but you could just see how upset she was. She just answered that question. They haven't had a holiday together for ten years. Both have been to India separately for 2-3 weeks. Asked

me if I knew of holidays abroad that catered for disabled people. Send information from DIAL, (1.2.1997: Shivam Ranchord: FWD)

Notes on *methodology* used and the steps taken to overcome the difficulties that I experienced.

Left another message for his secretary to contact me this time to ask whether I will get an appointment with him or not. She hasn't rang back. (13.2.1997:FWD)

He never rings back. (20.2.1997)

Left several messages for him or his secretary to contact me. Left my home number in case I was not at work. They never return my call. (21.2.1997:FWD)

Tried to catch him at work. Asked the receptionist to check whether he was in. Asked her to call his secretary and get an answer off him, whether he will or will not be able to take part. He has given me an appointment for 10<sup>th</sup> March.1997. (26.2.1997:FWD)

Accounts of *how I felt each interview 'went'* were also recorded. This included information on for instance, the behaviour of participants before, during and after the interviews, and comments made after the tape recorder was turned off. Body language, emotions and expressions, verbal comments and reactions as well as my own personal feelings and thoughts at the time.

His wife was present. He sometimes had to think through the answers. He looked emotional and wiped his eyes. He said that caring had not affected their personal life. Yet, when he was with the other men in similar situation [in the South Asian carers focus group where I was also present] he mentioned that his sex life had deteriorated. He found it difficult to talk about it this time. I think the fact that I am pregnant might have put him off. (27.2.1997: Vikesh Anand:FWD)

My experiences of *establishing relationships* and building rapport with particular participants were also noted together with any ethical dilemmas encountered. For example:

Met Madhuri Krishen at the Dr's surgery. She was really tearful. Said the marriage didn't last. They are "splitting up". They saw each for eight and half years but it only last seven months after they got married. Main problem was his mother and he never said anything in her defence. There was resentment about her visiting and keeping an eye on her parents. Brother involved in accident. Madhuri had to go home for 3 weeks to take over. When she went back, everything had changed. Mother in law said: "they'll be ten others like her, let her go." No sympathy from mother in law about her brother's accident. Said she will take part in another interview. (29.4.1998: Madhuri Krishen)

Managed to speak to Madhuri Krishen. Very upset about marriage break up. Does not want to get involved anymore. Wants to see me only as a friend but does not want me to tape and not as part of research project. (22.9.1998:FWD)

I was keen to interview Madhuri Krishen for a second time. A second interview would have provided valuable insight in to how the caring tasks were divided, how she juggled things between her new married life and her ties with her family, how her brother coped in her absence and what type of support he received from PHC nurses in her absence. However, she did not want to take part in an interview for research purposes. I respected her wishes and she was not interviewed. The moral responsibility I had towards her had to take precedence over the study and my desire to gather additional information.

*Reflections of my own assumptions.*

I was under the impression that the nurses wouldn't take part. Nurses on the wards were always totally against research. I thought nurses would refuse. In actual fact only one has refused because she works part time. Another nurse has asked me to call her in 3 weeks time because she is busy now. I was proved wrong. (1.2.97:FWD)

Description of *physical setting* - the image some settings portrayed in my mind as I reached my destination.

Lives on the main road in XX [name of area]. I recognised the name of the road but I couldn't remember where it was until I got closer. It was really dirty inside and freezing. Clothes and papers everywhere. No where to sit even. Great big dog [Alsatian] sat right in front of me all through the interview. (7.11.96: Priya Thakrar:FWD).

*Reconstruction of conversations.* This included discussions that were recorded and those said in private. The notes contained sentences or summaries of particular accounts. I used quotation marks around sentences or phrases for instance where participants own words had been used and noted.

Spoke to Anant Laxman on the phone. Tried to get an appointment to interview his wife separately. I specifically wrote a letter addressed to her. When I asked if I could see her he kept saying "they" would be happy to talk to me again. He wouldn't agree to me seeing just her. They have started work again as son has died. They work as home care workers, helping other families with caring tasks like washing and dressing. Had a lot of problems with finance. "They only give invalid care allowance for four weeks then it is stopped. It is difficult to get a job in four weeks". (13.7.1998: Anant Laxman:FWD)

**Off tape:** "providers don't have time to meet carers' needs as much as they would like to because they are so busy" (24.6. 1997: Commissioner Sontley: FWD).

As demonstrated in chapter nine 'on tape', this same commissioner spoke positively about negotiations taking place with providers to address needs. However, one does wonder to what extent carers' needs were taken on board given that it was recognised and 'accepted' from the outset that carers' needs could not realistically be addressed anyway.

## THE INTERVIEWS

Forty three in-depth interviews were conducted in total between the different groups of carers, PHC nurses and managers. This includes 15 in-depth interviews with carers - two of which were joint interviews and 13 were single interviews. The interviews with 'professionals' were all single interviews, of which I conducted 14 in-depth interviews with PHC nurses and 14 in-depth interviews with managers. All interviews were tape recorded. This generated a total of 56 tapes. On average each in-depth interview lasted about 90 minutes. A few lasted several hours. I tried to limit the number of interviews I carried out to one per day; however, difficulties in arranging appointments with PHC nurses and managers meant that on occasions I conducted two per day as I wanted to fit the interviews in around their schedule.

As reported earlier, much of the fieldwork was carried out largely when the Conservative government was still in office. However, in May 1997, the labour government had a landslide victory. Twelve out of the total 43 in-depth interviews, took place following the labour government's victory. These included:

2 in-depth interviews with carers: Joint interview with Madhuri Krishen and Pritesh Krishen

4 in-depth interviews with PHC nurses: DN Carie, NA Badby, Clinical supervisor Jaywick, and CPN Mathern.

6 in-depth interviews with managers: Manager Zennor, Manager Woolwich, Manager Veness, Manager Westwell, Manager Tugby and Commissioner Rochester.

### Carers

Those carers that agreed to take part returned a reply slip consenting to participate in the study. They were also asked to note down a contact number, which I then used to arrange an appointment, convenient to them. Interviews with carers were conducted at their convenience, at their homes. Although preferences for timing of the interviews varied, the majority were conducted during the day. A few were also conducted during the evening. Some carers had a preference for me to call on the day when they knew they would be alone. One interview was conducted four days before the carer was due to get married. Having realised that Madhuri Krishen was getting married, I offered her the chance to withdraw or postpone the interview until much later if need be. However, she felt that should we go ahead with the interview as planned.

The majority of carers were interviewed on their own. On a few occasions the cared-for person was at home but in a different room. Joint interviews were conducted with:

- Prabha Laxman and Anant Laxman

- Madhuri Krishen and Pritesh Krishen.

Once a suitable time and date had been agreed over the telephone, letters were written to carers to confirm the date and time once again. The day before the interview, carers were telephoned again to make sure that they were still happy for me to interview them.

#### *Language preference of interview*

Carers were also asked their preference of language for the interview. Seven were conducted in Gujarati; six were conducted in English and two were a combination of English and Gujarati. I was fortunate that I did not have to rely on interpreters, which might have resulted in having to address an added layer of meanings and biases.

#### PHC nurses and managers

Arranging appointments with PHC nurses was not too problematic once I had identified which PHC nurses were involved with the family. Issues' concerning identification of PHC nurses is discussed further in Part C. However, as also reported in Part C, accessing managers and arranging appointment suitable to them was far more problematic.

### **RESEARCHING SENSITIVE TOPICS**

Some of the issues to be addressed within this study fell into the area of research often regarded as being 'sensitive.' Lee and Renzetti (1993) suggest that a sensitive topic is

One that potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and /or the researched the collection, holding, and/or dissemination of research data (p5).

Hence, it is suggested that research should be directed at studying powerful groups as opposed to the powerless (Hammersley and Atkinson (1995). Yet, just because research is sensitive, does not imply that such topics should not be studied.

Sensitive research addressed some of society's most pressing social issues and policy questions. Although ignoring the ethical issues in sensitive research is not a responsible approach to science, shying away from controversial topics, simply because they are controversial, is also an avoidance of responsibility. (Sieber and Stanley, 1988 in Lee and Renzetti, p11).

The research literature that addresses the issue of providing guidance in researching sensitive topics is limited. Sensitive research is reported to affect every stage of the research process (Lee, 1993). This section draws heavily on the work of Raymond Lee to highlight some of the issues concerning researching sensitive topics.

Sieber and Stanley (1988 in Lee, 1993) define socially sensitive research as:

Studies in which there are potential consequences or implications, either directly for the participants in the research or for the class of individuals represented by the research. For example, a study that examines the relative merits of day care for infants against full-time care by the mother can have broad social implications and thus can be considered socially sensitive (p3).

Sieber and Stanley definition focuses on the consequences of research. Farberow (1963) on the other hand equates sensitive research with areas that are often regarded as taboo, such as sex or death.

In other words, they are subjects which are laden with emotion or inspire feelings of awe or dread (Lee, 1993), usually, topics which people feel uncomfortable discussing or do not wish to discuss. However research can also be sensitive for situational reasons (Brewer, 1993) or because of its socio-political context (Rostocki, 1986 in Lee, 1993).

It is important therefore to remember that research into sensitive areas poses threats, which go beyond the 'incidental or the merely onerous' (Lee, 1993) and can affect the personal life and security of both the researched and the researcher (Plummer, 1983). Sensitive research can involve three different types of threat.

### **Intrusive threat**

This includes research, which deals with areas that are seen as private, stressful or sacred. Evidence from survey research suggests that interviewees may become embarrassed and not answer a question because of the over-personal nature of the question or because the question is viewed as a threat to their self-esteem (Morton-Williams, 1993). People are also less likely to report behaviour, which would not meet with social approval (Morton-Williams, 1993). To make the definition clear, research which addresses bereavement, for instance, is emotionally charged but is not necessarily private and therefore not necessarily intrusive. A particular difficulty with this type of threat concerns remaining composed when in a face-to-face situation. This applies to both the researched and the researcher (Lee, 1993)

### **Sanctioning threat**

This includes research, which relates to deviance and social control. The information given by the person being researched may be viewed as being stigmatising or incriminating. Hence, the presence of a researcher may be feared as it is assumed that deviant activities may be revealed (Lee, 1993). Within an organisational context, fear of scrutiny is common as it is assumed that

the researcher has deliberately set out to look for discreditable information (Payne et al, 1980 in Lee, 1993). Researching particular groups can be problematic for fear of exploitation or derogation.

### **Political threat**

This includes research that impinges on political alignment, powerful people or organisations (Lee, 1993). Brewer (1993), for instance, looked at policing in Northern Ireland. In his study, the research setting posed risks, for both the participants and the researcher because the research was being carried out in an area where there was a lot of conflict - Northern Ireland was a divided society. However, even if the environment does not pose any risks, if the research is viewed as threatening to the interests of those being studied, it is still sensitive. 'As a result, there has been a tendency for social scientists to study 'down' rather than 'up'; directing their attention to the relatively powerless rather than the elites or powerful organisations' (Lee, 1993, p8).

Some studies may encompass all three aspects of sensitivity (Lee, 1993). Importantly, however, it has to be remembered that research which addresses sensitive topics is not only a threat to the participants but can also have an impact on others, for instance, family members, the wider community and society at large (Sieber and Stanley, 1988 in Lee, 1993).

Addressing sensitive topics spanned all three sample groups of participants. The types of sensitive topics addressed across the three groups is summarised below.

### **Carers**

Some of the issues that I explored for this study were essentially private and delved deep into personal experience. For instance, discussing benefit entitlement and financial circumstances with carers is a subject which would not be discussed openly with strangers. At the same time, issues such as attitudes to disability or caring for instance are not so much private, but emotionally charged subject areas. Finding out that a child will be disabled and need 'all care' in future, can be a traumatic and devastating experience for parents, yet I wanted to explore how carers felt and coped with their caring responsibilities. Carers in this study were therefore essentially being asked to 'relive' and reconstruct their experiences and reopen old wounds that had perhaps been hidden for some time. Hence, there was a chance that carers could have experienced heightened anxiety and emotional distress. I also wanted to explore what impact caring had on their lives. This included the impact it had on their marital and personal relationship. Again, the sexual relationship of a married couple has been

traditionally constructed as a private one not to be discussed with outsiders (Kinsey et al, 1948 in Bergen, 1993, p199).

The primary aim of the thesis was to explore carers' experiences with PHC nursing services to ascertain whether they felt supported. The sensitive aspect to this stage of the interview was that I was essentially asking carers to speak frankly about the PHC nursing services they were still receiving services from and having regular contact with. I was conscious of my own personal experiences of feeling very unhappy with the way I was treated by staff on the maternity ward. Yet nothing was said for fear that 'the word would get round' that we were 'difficult parents' and that this might somehow influence the care my daughter received. I wanted to explore with carers in what ways they felt supported or not and reconstruct their experiences of occasions when they felt they needed support from PHC nurses.

### **Nurses**

With PHC nurses I wanted to explore for instance, their views about supporting carers and the strategies they used to provide this support. This subject was 'sensitive' in that I was asking them to focus on a particular minority ethnic group coupled with issues surrounding providing support to carers as opposed to patients. PHC nurses were therefore being asked how they support carers when their role essentially involved meeting the needs of the patient.

### **Managers**

The areas that I wanted to explore with managers concerned their views about how carers were supported by PHC nurses and the means they provided PHC nurses to enable them to support carers. This included managers' views about meeting minority ethnic carers' needs. Although these topics are not personal, they are controversial in that I was to explore a subject which has often been defined as 'not belonging to health', and secondly, the research was taking place at a time of heightened awareness of the subject of ethnicity and race due to the Stephen Lawrence inquiry which in itself made it difficult to recruit managers to the study.

Brewer (1993) suggests that sensitivity of the research can affect almost every stage of the research from formation to design, implementation, dissemination and application. It was therefore paramount that I paid special attention to the way in which the research was conducted. Specific measures were taken to ensure that sensitive issues could be addressed without causing deliberate harm to participants. These are reported below.

### **Confidentiality and anonymity**

First and foremost it was vital to obtain informed consent. This issue was discussed at length earlier. Importantly however, where informed consent was concerned, was the need to renegotiate consent where necessary. Hence, consent was obtained from all participants to tape the interviews before the interviews started. I also offered to take notes if they had a preference for the interview not to be taped. None refused to have the interview taped although managers needed repeated reassurance of confidentiality and anonymity.

Secondly, it was stressed to all participants that the information they provided would remain confidential, in that I would not discuss what they had told me by making comments to other people in a manner in which they would become recognisable, and that, when it came to writing up my findings, real names, organisations and locations would not be disclosed. It was also explained that I would preserve their anonymity by not publicising the data in a manner by which they could be identified and that I would not misuse the data.

A number of steps were taken to safeguard confidentiality of those that participated. Firstly, all participants were assigned fictitious names. The strategies used to develop names were reported earlier. These names were then used throughout the research study, for instance, on all tapes, transcripts and charts. As well as protecting data by disguising names, steps were taken to ensure that 'other' people could not access the files and information relating to personal details. All material was kept in a locked filing cabinet.

### **Rapport in interviewing**

Interviewing required the ability to develop some degree of rapport with the participants. 'Rapport refers to the degree of understanding, trust and respect that develops between the interviewer and interviewee' (Arksey and Knight, 1999, p101). Hence, it was vital that I created a 'good first impression' as well as being mindful that my own personal experiences of caring and nursing should not influence how I behaved or reacted to respondents' answers. Hammersley and Atkinson (1995) however, suggest that 'minimising the effect of the researcher is not the only, or always even a prime consideration. Assuming we understand how the presence of the researcher may have shaped the data, we can interpret the latter accordingly and it can provide important insights, allowing us to develop or test elements of emerging analysis (p131). I therefore remained friendly and courteous and combined this by behaving like a professional researcher maintaining some degree of distance. At the same time, it was hard to react as if nothing of significance had been said, especially when interviewing carers, in which I tried to be as sensitive and sympathetic to the situation as possible. Feminists such as Oakley (1981) are critical of interviews which merely pose questions and treat the person as an 'object', arguing that it puts the researcher in an unnatural

position with those being interviewed. It was equally important to end the interview on a positive note as well as thanking participants for taking part.

### **Interviewing**

Although I was conducting in-depth interviews they were still meant to be guided conversations (Arksey and Knight, 1999). Hence, whilst interviewing I let participants use their own words to describe events. More importantly however, was the need for me to listen and be attentive to what participants were saying. This meant having to concentrate on what was being said as well as understanding it and making sure that I had 'logged' this information in my mind to pick up on other issues later on in the interview if necessary. At the same time, I had to remain conscious of the time and the purpose of the interview. This involved listening yet at the same time, moving the interview forward.

The topic guide proved useful in this instance in that some structure could be retained albeit loosely at times. The process involved quashing the normal instinct to talk but being able to respond to emotional outbursts, and handling pauses and silences (Seidman, 1991). I did this by listening and generally being supportive. Indeed, there were a number of occasions when carers started crying uncontrollably. In these situations, I maintained eye contact and tried to be sympathetic. The interview was stopped, carers asked if they wanted to continue at an appropriate time and restarted once carer's had recomposed themselves. Of those carers that started to cry during interviews, all agreed to continue with the interview.

The process of interviewing was mentally exhausting, it involved asking questions or seeking clarification based on what the participants had said, yet at the same time, I had to be mindful not to ask leading questions to avoid influencing the response of questions. Likewise, it meant picking up on both verbal and non verbal clues. Although, probes were added to the topic guide, they were there to act as a means to explore further particular areas. Open ended questions were largely used. For instance, PHC nurses were asked to reconstruct what they did on an average day. Some open-ended questions were not as detailed, instead they limited to particular experiences or events. For instance, carers were asked how they felt when they were told the diagnosis. Carers provided emotional and moving accounts in this study. Hence, there were occasions when I had to resist the temptation to interrupt when they were talking. Instead, I jotted down issues that I wanted to follow up on the topic guide and went back to them at a convenient point during the interview.

It is often suggested that researching sensitive topics can be 'intrusive' as it researchers private and sensitive areas of life (Clark and Haldane, 1990 in Edwards, 1993). Yet, those carers that had spoken for the first time about their experiences mentioned that they felt 'better' because they had the opportunity discuss with me, a stranger with no ties or

connections with them, the difficulties they were experiencing and listen to their side of the story. This method therefore allowed me to explore their perspective.

### **Interviewing relationships and the concept of power**

It is often suggested that some researchers investigate those typically less powerful than themselves putting the researcher in an advantageous position over those being researched Hammersley and Atkinson (1995). Secondly, it is argued that those being researched feel exploited because research fails to make any improvements. Katbamna and Bhakta (1998) for instance, found that there was a sense of resentment towards research 'on ethnic minorities' when they tried to enlist support from community organisations for their study because of this very view.

It was certainly the case that carers in this study could be classed as falling into a social group of those who are 'powerless' not only because the sample consisted of a number of women but also because I was researching a specific minority ethnic population. At the same time, however, I would not class the two remaining sample groups of PHC nurses and managers as being in a position where I could exercise power over them. Whilst the interviews with PHC nurses were definitely on a more of an equal footing, where managers were concerned, they had a slight edge over me in that they ultimately decided what information they were prepared to release to me or not. Further, managers were also in essence not only senior to me in terms of their position but also in terms of their age.

The concept of power in interviewing was therefore particularly pertinent to this study as three very different kinds of groups of participants formed the sample groups. Seidman (1991, p76) suggests that issues of equity in an interviewing relationship are affected by the social identities that participants and interviewers bring to the interview. I was conscious that participants might be influenced by factors such as my age, race, gender and social class and that these might influence how they reacted to me (Burgess, 1984). This is important because, social identities can control the direction of interviews (Seidman, 1991).

Feminists have argued that researchers should attempt to establish a non-hierarchical relationship thus eliminating power inequalities and that researchers should give something back in return (Hammersley and Atkinson (1995). In this study, I attempted to do this by taking interest in what participants were saying to me. All carers were given extra gratis payments of £10 to cover their expenses. I felt a little guilty, as I could not promise anything in else in return other than stating that their experiences would help in the development of

recommendations, which I hoped would improve services in future. Some carers asked me for advice or information; in a few instances, I did not have full answers, only general awareness. For instance, Shanta Hari asked me about residential placements in the area, in these situations, I identified the relevant information they needed and posted it them. All participants received a letter of thanks for taking part in the interview. Feminists such as (Oakley, 1981) suggest that this also involves self-disclosure, trust and reciprocity, i.e. sharing own experiences with the respondent leading to richer and detailed accounts. Hence, those participants that asked about my background or reasons for interest in the subject were told. However, others such as Ribbens (1989 in Webb, 1993) disagree with such sentiments arguing that, ultimately, power lies with the researcher as they have taken away the words of the respondents to be objectified as an interview transcript. Similarly, Hammersley (1992) suggests that researchers may be said to exercise power over participants in that they are more able to publish, and thereby gain wider readership for their accounts.

Siedman (1991) writes that in our society, with its history of racism, researchers and participants of different racial backgrounds face difficulties in establishing an effective interviewing relationship (p76). It has been argued for instance, that ethnicity can influence the type of information elicited and obtained during interviews. Anderson, (1993) for instance, reports that 'minority group members have insights about and interpretations of their experiences that are likely to be different from those generated by white scholars' (p42). In this study, I was fortunate when interviewing carers that I shared the same ethnicity as them and spoke the same language. However, although shared characteristics made establishing rapport easier, the aim of the study was to explore and ask questions, not share assumptions (Seidman, 1991).

Many of the steps needed to facilitate equity in an interviewing relationship were reported earlier, for instance, being explicit about the purpose and processes of the research, arranging interviews convenient to participants, obtaining written consent, and using appropriate interviewing techniques. The advantage of this was that I was able to gain access to information in an under researched subject area.

In this study, some of the PHC nurses were older than me and white and a few managers were male and white. When interviewing PHC nurses and managers, it was crucial that I remained respectful to all participants and addressed issues with sensitivity as well as taking a genuine interest in what was being said to me.

My ethnicity no doubt had some bearing on the interviews as discussing race and ethnicity issues with some PHC nurses and managers proved problematic. Interestingly however, where

PHC nurses were concerned, my professional background as a nurse had more of an impact in the initial stages of data collection as opposed to my ethnicity, gender, age or social class. On the whole, PHC nurses saw me as a professional researcher and openly discussed their method of working and the issues affecting them.

In direct contrast, I also believe that it was my background as a researcher that made accessing and interviewing a few managers problematic. Again, like PHC nurses, discussing race and ethnicity issues proved difficult with a few managers who used a variety of strategies not to answer certain questions. Although I was able to maintain control of the interviews by 'bringing' managers back to my line of questioning, conducting interviews with these few managers proved to be difficult in that they ultimately chose what they would or would not disclose to me. At the same time, it is important to reiterate that I did not feel that my gender, age, social class had a bearing on the interviews with managers overall.

Research has also identified that gender can also affect the results obtained during interviewing. Finch (1984) argues that women are more likely to disclose things to other women because they 'share a subordinate structural position by virtue of their gender' (p184), hence, other women would be better able to 'understand' another women's perspective. Certainly, when interviewing female carers, they showed more emotions than the male carers in the study and provided very in-depth accounts of their caring experiences. However, I believe the accounts of male carers were equally rich. Although I encountered difficulties in accessing information from male carers this only concerned two male carers and was only in relation to specific issues. For instance, it was difficult discussing the impact of caring on marital relationships with one male carer. Yet, as noted earlier, this is an issue that is regarded as private. Indeed, evidence suggests that women also see matters relating to ones personal life as being a private matter (Bergen, 1993).

Another male carer appeared to give a public account of his experiences of caring repeatedly stated that he did not find caring difficult. One reason for this may have been that he wanted to be perceived as 'coping'.

Richardson et al (1965 in Seidman, 1991) wrote that participants of "low intelligence, low socio-economic status, or low status in an organised hierarchy may find it difficult to tolerate a preponderance of open questions" (p79). This study contained a variety of carers, some of whom could be classed as falling into the lower social strata in the occupational hierarchy, yet, carers in this study responded very well to the interview and gave telling accounts because they were allowed to discuss issues from their perspective.

Briggs, 1986 in Siedman, 1991) identified that older participants may feel uncomfortable being interviewed by younger interviewers. I was conscious of age differences between me and the managers, some PHC nurses and carers. It was therefore imperative that I remained sensitive and did not use patronising language and that I was able to connect to people on an equal level as possible.

It is important to reiterate once more, that this chapter provides an account of the research process. My experiences of conducting the research study together with a discussion of some of the issues addressed in this section are explored further in Part C.

### **Leaving the field**

As well as generally being satisfied that I had recruited the mix of people in the sample whom I thought would provide useful insight into the study, a decision had to be made to leave the field and stop interviewing. Based on some of the preliminary analysis, notes from the fieldwork diary and issues discussed at the interviews, I decided to leave the field and stopped interviewing when I felt that the area that I was researching was saturated and no other new themes were emerging. The final stage of the research involved analysis of the data collected.

### **DATA ANALYSIS**

Data analysis was an on-going process and emerging theoretical themes (although tentative), helped structure subsequent data collection. On occasions the process of analysis was rather informal with me making notes of issues which I thought were of significance based on ideas or quite simply what my 'gut instinct' told me as the interviews progressed.

A framework approach was used to analyse the data. It is a systematic approach to data analysis, well suited for applied social policy-orientated research (Ritchie and Spencer, 1994). The reasons for adopting this approach and an account of how the analysis was conducted are reported below.

As a qualitative approach was used for this study, much of the material collected was invariably unstructured and consisting of lengthy verbatim transcripts of interviews and field notes. Moreover, much of the data collected contained opinions, sentiments and thoughts (Arksey and Knight, 1999) and feelings for instance, PHC nurses feelings about meeting the needs of minority ethnic families. Hence, there was a need to provide some coherence and structure to the accounts from which they were derived and turn the pages of transcripts and notes into a succinct account that offered an answer to the research questions (Arksey and Knight, 1999).

‘Qualitative data analysis is essentially about detection, and the tasks of defining, categorizing, theorizing, explaining, exploring and mapping are fundamental to the analyst’s role’ (Ritchie and Spencer, 1994, p309). The framework approach was therefore chosen to aid analysis as it is well suited in research in which one or more of the following functions need to be addressed:

- For defining concepts: understanding internal structures
- Mapping the range, nature and dynamics of phenomena
- Findings associations: for instance, between experiences and attitudes
- Seeking explanations: explicit or implicit
- Developing new ideas, theories or strategies
- Creating typologies: categorizing different types of attitudes, behaviour or motivations (Ritchie and Spencer, p309).

The key features of the framework approach are described below in table 5.

**From: Ritchie and Spencer, 1994, p310**

- *Grounded or generative*: it is heavily based in, and driven by, the original accounts and observations of the people it is about.
- *Dynamic*: it is open to change, addition and amendment throughout the analytic process.
- *Systematic*: it allows methodical treatment of all similar units of analysis.
- *Comprehensive*: it allows a full, and not partial or selective, review of the material collected.
- *Enables easy retrieval*: it allows access to, and retrieval of, the original textual material.
- *Allows between and within case analysis*: it enables comparisons between, and associations within cases, cases to be made.
- *Accessible to others*: the analytic process, and the interpretations derived from it, can be viewed and judged by people other than the primary analyst.

**Table 5: Key features of the framework approach**

Framework is an analytic process which although systematic and disciplined, relies on the creative and conceptual ability of the analyst to determine meaning, salience and connections (Ritchie and Spencer, 1994). Hence, I felt comfortable using this approach as I had acquired the relevant skills and knowledge through training at the Social and Community Planning Research (SCPR) centre in London, where the approach originated. In addition, this approach was adopted for the South Asian carers’ project and I had by now become familiar with it. Moreover, I decided not to use a computer assisted package such as NUD.ist, because as a

novice researcher, I wanted to gain insight into the more intuitive aspects of data analysis using traditional methods, a view supported by Webb (1999).

An advantage of the framework approach is that by following a systematic approach, it is possible to jump ahead or return to earlier ideas to rework them because the analytical process is documented and therefore accessible. The approach involved systematically sifting, charting and sorting the material according to key issues and themes.

The process of analysing the data using the framework approach involved five distinct stages:

- Familiarisation with the data
- Identifying a thematic framework
- Indexing
- Charting
- Mapping and interpretation.

Before I worked through the five distinct stages, the tapes generated from the interviews had to be transcribed. The issue of anonymity and confidentiality was discussed earlier. However, these issues were equally paramount when handling tapes and transcripts. All tapes and transcripts had the ‘new’ names that I had given the participants recorded on them to preserve anonymity.

Table 6 illustrates the language in which the in-depth interviews were conducted.

<b>Language of in-depth interviews</b>	<b>Carer</b>	<b>Professional</b>
Gujarati	*7	0
Bilingual (Gujarati +English)	2	0
English	*6	28
<b>Total in the sample</b>	<b>15</b>	<b>28</b>

**Table 6: Language of interview** \* = one joint interview

Table 7 illustrates the number of tapes generated for the different groups of participants. The table also gives an indication of the number of tapes generated in Gujarati which were then interpreted and translated before being transcribed.

**Table 7: tapes generated**

<b>Tapes</b>	<b>Tapes generated</b>	<b>English only</b>	<b>Gujarati and English</b>	<b>Gujarati only</b>
Carer	19	8	2	9
PHC nurses	22	22	0	0
Managers	15	15	0	0
<b>Total tapes</b>	<b>56</b>	<b>45</b>	<b>2</b>	<b>9</b>

### **Interpretation, translation of Gujarati tapes**

As illustrated in the table earlier, some of the interviews with carers were conducted in Gujarati, or a combination of Gujarati and English, hence, these tapes had to be translated and interpreted back into English. Translation and interpretation of tapes from Gujarati into English began soon after interviews. This involved listening to Gujarati tapes on one tape recorder, interpretation into English, and then recording the English interpretation onto another tape on a second recorder. It was a lengthy and complicated process as it involved more than literal translation. Instead, complex sentences had to be thought through carefully and reworded in English without losing the context, meaning or emphasis of what had been said originally. On average, it took about eight hours to interpret one tape with 60 minutes of recording. The process required substantial thought because, for instance, commonly used phrases could not be interpreted from Gujarati into English and vice a versa.

To avoid losing the meaning of what had been said different phrases or sentences had to be reconstructed and restructured.

The process was also very labour intensive and I found that I could only interpret and translate from Gujarati onto another tape in English for a few consecutive days at a time and then revisited the tapes to restart the process of interpretation and translation and recording of tapes. Carers also used English words at times, these were kept as they were and the sentence restructured around them. A number of the interviews were very long and intensive. It was paramount then, to keep myself focused to avoid losing or misinterpreting what had been said.

### **Transcribing of Gujarati and English tapes**

Once the translation and interpretation of Gujarati tapes was completed, tapes were then transcribed. A transcribing machine was used to listen to the tapes and facilitate the process of transcribing. This involved listening to tapes with headphones and stop/starting the transcribing machine with a foot pedal as necessary and typing the dialogue into a document in the computer in WORD format. Initially, the first few tapes were transcribed fully; as I

became more familiar with the issues, I then moved on to a process of transcribing only information which I felt to be relevant. Whilst transcribing, pauses, expressions of emotions such as laughter or crying and other background noise for instance, were also recorded because it was felt that the richness of the data would be lost if these types of expressions were not documented. Table 8 provides a key to the transcripts.

<i>Italicized text</i>	<i>Gujarati words have been used and typed as pronounced</i>
...	Material has been edited
[ ]	Background information
FWD	Material taken from fieldwork diary
“ ”	Speech

**Table 8: key to transcripts**

The counter number was recorded on the transcripts at specific intervals and topics to allow me to go back to the tape if need be. As the process of interpretation, translation of Gujarati tapes and re-recording of tapes into English took a substantial amount of time, some tapes were sent to professional transcribers and transcribed fully to relieve me of some of the pressures of working full-time on another project where I was employed. The length of the transcripts varied, with some having up to 55 pages.

### **Familiarisation**

The process of familiarisation was complex and time consuming. It involved not only sifting and sorting the data in order to become familiar with the range and diversity of the material generated, but the ability to try and make sense of the data in order to gain an initial broad overview.

In order to familiarise myself with the data, I first listened to the tapes twice, I then read through my fieldwork diary, material recorded in the summarised profiles and then read the transcripts. In total the transcripts were read four times over:

- When the tapes had been transcribed and transcripts printed
- When I started to think about the initial analysis
- When I began to identify core themes and categories
- When the transcripts were coded numerically

Throughout the analysis, parts of transcripts were frequently read and re-read to verify or check things. The process involved immersion with the data, taking stock and getting a feel for the material as a whole (Ritchie and Spencer, 1994, p312). The adaptability of the framework approach allows material to be selected to aid the familiarisation process, however, for this study, I chose not to select sections of transcripts, and rather I chose to read the transcripts as a whole. I made notes of ideas and recurrent themes and refereed back to my fieldwork diary if necessary to help make sense of events or issues.

### **Identifying a thematic framework**

The process of familiarisation marked the beginning of the process of abstraction and conceptualisation of key issues, concepts and themes. Whilst reading the transcripts, I made notes for the different groups of interviews and listed what I thought were the main issues or themes. I also made notes of on the different types of responses to specific questions and reoccurring themes. As I became more familiar with the data, and was able to recognise key issues more easily, I began a process of making notes or brief comments at the side of the transcripts. By using the information generated from notes, notes on the transcripts, together with information from the fieldwork diary and prior knowledge of the literature, the material was used to aide the development of indexes. Individual indexes were developed for the different groups of participants (see appendix 12 for carers; appendix 13 for PHC nurses; appendix 14 for provider managers and appendix 15 for commissioner managers). This enabled the data to be labelled and coded into manageable chunks for subsequent retrieval and exploration. The process involved identifying major themes, each containing several sub-categories within them. The generation of theory was therefore based around these core themes. The process involved sifting and sorting through the material (Ritchie and Spencer, 1994, p313) by looking back at the original aims of the research and looking at the issues covered in the topic guides. Some of the key concepts and themes emerged from the data and some by the reoccurrence or patterning of particular views or experiences. It took several attempts to develop the indexes as the initial attempts were largely descriptive and tended to gloss over issues that I had some general awareness of. However, once applied to several transcripts, additional themes and issues soon became apparent. Hence, the indexes had new themes and categories added to enable the many experiences and views to be conceptualised and captured. The process was not as straight forward as it appears in that it involved being logical in my thinking and at the same time being intuitive. The number of main themes and categories to emerge varied between the different participant groups, however, the carers indexing guide for example, had 12 main themes and a total of 63 categories (for instance, 1.1; 1.2, 1.3; 1.4;1.5, etc).

## **Indexing**

The next stage in the data analysis involved indexing whereby the transcripts were referenced and numerically coding using the indexes (appendix 16 provides an illustration of a coded transcript). This code could then be linked back to the index. On occasions several different reference numbers were applied to particular sections, (for example, 1.4, 3.2, and 6.3). This is because several major topics were interconnected and interwoven. Although the indexes were developed by me, the flexibility of the approach allowed my supervisor to check the indexes and the data to which the indexes were applied because the system of annotating the data allowed the process to be made visible and accessible to others. Hence, the process allowed 'others' to see for themselves how the data were sifted and organised, as well as enabling them to check out the basis of their assumptions (Ritchie and Spencer, 1994, p316).

The process of indexing involved having to make judgements about which themes or categories to include or discard as well as having the ability to make connections between ideas not only relating to that passage but the interview as a whole. For instance, when the index for PHC nurses was initially developed, issues concerning difficulties experienced by PHC nurses on return from maternity leave were discarded even though originally I had placed the category under the core theme which addressed inequalities in PHC nursing.

The process of indexing allowed patterns and connections and the context in which they arise to be seen visibly.

## **Charting**

The next stage involved charting the data. The process enabled me to build up a picture of the data as a whole by giving consideration to the differing perspectives and experiences of each theme or category. In order to chart the data, the data were lifted from their original context and rearranged according to the appropriate thematic concept and transferred onto A3 size charts, (appendix 17 provides an example of charting).

The sub-categories of major themes were listed along the top of the chart. Names of carers, PHC nurses or managers ran down the left hand side. The ordering of the participants always remained the same throughout the different subject charts, so that the whole data set for each participant could be reviewed. The process of maintaining the same order also enabled comparisons to be made between cases. The charts contained a mixture of distilled texts and summaries as well as full quotes and involved a considerable amount of abstraction and synthesis. Hence, on occasions 'new' sub-headings were also included or deleted. The transcript page numbers were also noted onto the charts so that I could refer back to the transcripts if necessary. Using this approach meant that other outside observers could have access to the data and check for validity with my reported findings.

## **Mapping and interpretation**

The final stage of analysis involved mapping and interpretation of the data from the charts. The process was guided by some of my original research aims whilst some emerged from the data. I tried to find associations, links, patterns and explanations for my findings by looking through my notes and reviewing the charts. This involved for instance, looking for similarities as well as contrasting cases and searching for patterns and connections and trying to find explanations from within the data. This was 'not simply of a question of aggregating patterns, but of weighing up the salience and dynamics of issues, and searching for a structure rather than a multiple of evidence' (Ritchie and Spencer, 1994 p321).

Once the key themes and concepts were identified, I tried to pull these issues together and draw out why for instance; carers said the things they did; whether other factors contributed; whether there were any associations or patterns between different types of carers; whether there were differences between cases. I took account of issues, patterns, and statements by examining why for instance, carers, PHC nurses and managers said, did, or behaved as they did. In addition, I continued with my reading throughout.

The analysis covered issues such as, mapping the range and nature of phenomena, finding associations, providing explanations and the development of strategies. However, all of these issues were not necessarily addressed with each participant group as the aim was to address only those pertinent to the particular participant group. Below are some examples of the type of issues covered in the analysis. Appendix 18 illustrates the main issues identified in the analysis concerning support for carers.

### Mapping the range and nature of phenomena

#### *Carers and coming to terms with disability*

- Comparable to bereavement
- Husbands had more difficulty accepting that their son was disabled
- Adjustment was episodic
- Turned to alternative forms of treatment alongside conventional treatment to find a cure or improvement in condition

### Finding associations

#### *PHC nurses and holistic assessments*

- Issues for white nurses and lack for information on the referral forms
- Issues for minority ethnic nurses and conducting bilingual assessments
- Issues for both white and minority ethnic nurses and access to information

### Providing explanations

*Carers reluctant to ask for help from relatives and those they had contact with because of:*

- Widespread negative attitudes to disability in the wider community
- Repeatedly being tuned down when carers requested support
- Having to be 'eternally' grateful to those that helped them
- Having to 'listen' to how terrible an ordeal it was for them in return.

### Development of strategies

*Putting carers on the 'Health' agenda*

- Strategies and in-house policies needed which illustrate both recognition of carers needs and a demonstration of how needs will be met
- Carers need to be involved at committee meetings and consulted
- PHC nurses training needs to place greater emphasis on recognition of carers needs

Using a qualitative approach meant that I gathered a lot of data. However, as part of the analysis and writing up of the results, some things had to be discarded altogether. Instead, I focused on the issues that helped to build the theory and was pertinent to the area that I was researching. For instance, some managers talked about 'general management issues' in a much wider context these issues were subsequently dropped. Hence, the process of analysis involved inductive and interpretative thinking.

## **PART C**

### **DILEMMAS IN THE RESEARCH PROCESS**

In this final part of the methodology section, experiences of the research process and some of the dilemmas encountered are reported. The material focuses upon distinct areas: why it was necessary to make changes to the original design; access to carers, identifying PHC nurses and the recruitment of managers and the concept of power in interviewer relationships.

#### **CHANGES TO THE ORIGINAL DESIGN**

Although in principle, this thesis was a continuation of the South Asian Carers study, I was only involved in the first part of the South Asian Carers study. However, despite my involvement with the South Asian carers study, I still encountered a number of methodological problems which meant that I had to adapt the design for the work reported here.

My initial plans were to adopt a case study approach. I planned to interview twelve Gujarati Hindu carers, the cared-for person and their respective PHC nurses to gain insight from three perspectives. However, I was unsuccessful in adopting this approach.

Firstly, there were few carers in the South Asian carers' study who had PHC nursing input that I could draw upon to interview for this study.

Secondly, whilst recruiting carers for the study, I realised that although I had managed to recruit a number of 'new' carers on to study, some were, in fact, sharing the same nurse. This made interviewing difficult as only one case could be discussed at any one interview due to time constraints.

Thirdly, PHC nurses were protective of their caseloads. Names and contact details of PHC nurses were given to me by the carers and the cared-for person. PHC nurses were sent copies of signed consent forms from carers and patients where applicable, in which it was stated that they had already taken part in an interview with me and gave permission for me to contact their PHC nurse and interview them. In addition, copies of letters from senior management giving permission to carry out the study as well as a letter from me, stating that ethical committee had been granted were also sent to the PHC nurses prior to the interviews. Yet, having contacted the PHC nurses, and arranged the interviews, PHC nurses stated that they were not happy speaking about particular cases because of issues concerning confidentiality and identified that they were bound by their professional code of conduct not to discuss their patients and their families. Instead they had a preference to speak broadly about their experiences of caring for minority ethnic carers and patients. Their wishes were respected and

I decided instead to interview PHC nurses about their experiences of supporting minority ethnic carers in general.

Lastly, although the original intention was to also obtain the views of the cared-for person, this also proved difficult in practice and the idea was eventually dropped. A total of five interviews with adult cared-for persons were conducted. However, the material was not analysed and it is not reported in this thesis. There were a number of reasons as to why the decision not to include the cared-for person's perspective was taken. The cared-for person was identified through carers for instance. The process enabled me to recruit different types of carers for the study but I could not 'control' the type of person they were caring for so, by including 'only' those that were fully conversant for instance. In a number of cases, the cared-for person was simply unable to participate due to severe speech and language difficulties as well as difficulties in comprehension. Some cared for person's had severe learning disabilities or they were children or the person they were caring for had died.

In one case for instance, I was informed by the carer (Vikesh Anand) that his wife would be willing to take part and that they were both happy for me to call. However, once I reached their home, it soon became apparent that the carer's wife could only say a few words. Secondly, these same words were continuously repeated for the different questions asked, such as the number twenty two. In this case, I persevered for a while in the hope that I could obtain her views through gestures such as nodding, but even this was difficult. What was supposed to be an interview with the cared-for person became an interview with the carer. He answered all the questions based on his view of what he felt she would have said. With this particular case however, I felt that the fact that I had offered £10 as extra gratis payment was taken up by the carer because they were experiencing considerable financial hardship, and although £10 may seem like an insignificant amount, it is 'a lot' when you have to live each day wondering how you will get through the next day.

Secondly, the number of people that could not be or I was unable to interview outweighed those that could be interviewed. Hence, there were not only insufficient 'numbers' but the material collected was also limited making it difficult to develop case studies. Coupled with the overlap between carers and PHC nurses and the inability to interview PHC nurses about specific cases as mentioned earlier, the idea of developing case studies was consequently abandoned. In writing about research methodology, Arksey and Knight, (1999) write:

Altering the research design is not a sign of failure. It shows that you have critically evaluated the work accomplished so far and initiated a change of direction in order to turn a potential failure into a success. (p71)

Once the interviews with the PHC nurses had begun, it emerged that other external factors impinged on their ability to provide care and meet the needs of minority ethnic carers, some of which were directed at management. In order to verify and explore further PHC nurses' concerns, I felt it was important to get a management (provider) perspective on their claims. Managers were therefore approached and interviewed. Again, it appeared that managers put some of their difficulties down to the purchaser/provider split. Consequently, although there are fewer commissioners overall, they were also approached. The thesis therefore provides an account of issues concerning informal caring from four distinct angles: carers, PHC nurses, provider managers and purchasing managers.

This approach proved to be fruitful. For instance, although PHC nurses were at first reluctant to discuss individual cases, once immersed in the interview, they provided a wealth of information by using different cases to illustrate their point. There are also new dimensions to this study not reported previously in the South Asian carers study.

## **ACCESS TO CARERS AND GATEKEEPERS**

### **Formal gatekeepers**

Access to carers is not as straightforward as it often appears in research accounts (Burgess, 1984). In this study, other PHC nurses that were taking part in the study were also asked if they would be able to support me in terms of identifying Gujarati Hindu carers. It was made clear to PHC nurses that I understood that for reasons of confidentiality they would not be able to release contact details of patients and their families. Hence, PHC nurses were asked if they were prepared to distribute letters explaining the aims of study to Gujarati Hindu families they were in contact with. Thereby, carers could contact me if they wanted to take part in the study. However, many PHC nurses still had reservations and expressed that the ties of confidentiality meant that they were unable to support me. One nurse approached her senior manager to ask if she could help me by giving out my letters, but again she stressed that her manager has told her that confidentiality had to be maintained and they could not support me. Yet, the reality was that confidentiality was not being broken because no information concerning patients and their families was going to be released to me. The decision to take part would have rested solely with carers, with carers contacting me having read the information letters. Moreover, these difficulties were still encountered despite having letters of support for the study from higher levels of management which were shown to PHC nurses. It appears then that the decision to support the research had more to do with concerns about 'getting involved in research' especially given the heightened awareness about issues concerning race and ethnicity following the Stephen Lawrence Inquiry.

### **'Other' gatekeepers**

In another instance, it appeared that access to a carer may have been blocked by the carer's daughter. Initially, the carer's daughter asked me to phone at different times on several occasions. Each time however, she gave a different reason as to why she had not managed to ask her mother if she would like to participate. Despite attempts to speak to her mother, I was always turned down. I was eventually told that her mother did not want to be involved in the study although I never did manage to talk to her mother.

### **Other factors affecting recruitment of carers**

A few carers said they were generally not interested in taking part. Hence, their wishes were respected. All carers in this study were informed that they were not under any pressure to participate and could 'drop out' at any time. Indeed, on one occasion, having arranged a joint interview with a husband and wife couple, his wife, who was the main carer, requested not to take part. She was extremely emotional whilst making her request. Her daughter required all care, and was at the time fifteen years old. She said she could not bring herself to talk about her caring role. Although she did not speak, she sat in for short periods, whilst her husband took part in the interview but even whilst he spoke of their caring experiences, she found it difficult to control her emotions and cried. She drifted in and out of the room but eventually left and the interview was finished with her husband.

Another couple (grandparents) had also initially agreed to take part but telephoned to cancel the interview. They cared for their adult daughter who had mental health problems as well as their grand daughter. His wife suggested that I contact them again, a few months later. I telephoned as suggested, but they felt unable to spare the time as most of their time went on looking after their granddaughter and they were also not in good health.

I lost contact with one carer who had moved house, and another appeared to have left home. When I telephoned the carers' home, her father answered the telephone and said that she had left home and he did not know where she lived anymore.

### **IDENTIFYING PHC NURSES**

I was apprehensive as to whether PHC nurses would participate based on my experiences of acute nurses attitudes towards research from working on the wards. To my surprise only one district nurse declined as she worked part-time and there was no one to take over her caseload. Although recruiting PHC nurses was not as problematic as I had envisaged, trying to trace them was very difficult. This was largely because carers often did not have contact details or

did not know the full names of the PHC nurses that called. Hence, the relevant PHC nurse had to be identified first. The matter was further complicated by telephone lines to the health centres being busy. This made it difficult to 'catch' PHC nurses before they left base to do their calls. However, once the relevant PHC nurses had been identified, and the study had been explained, they were happy to rearrange their schedules to fit me in. All the interviews with PHC nursing staff took place after I had interviewed the carers. I preferred to do it in this order as it gave me the opportunity to clarify or raise issues mentioned by carers that related to specific nurses.

## **RECRUITMENT OF MANAGERS**

However, accessing managers and arranging interviews with them proved to be extremely difficult. Although managers were supportive of the work, the higher up the management hierarchy I climbed, the more difficult it became to encourage participation. Senior manager had a tendency to pass the task of onto those junior to themselves. In addition, a few managers felt they were not sufficiently informed on the subject of ethnicity and informal care, and that they were not the 'right' people, and therefore passed me on to people whom they felt would be 'up' on these issues, they were included as I felt that they might be able to add a different dimension (a nurse and a senior manager). One manager said that I could interview her provided that other senior members from the hospital board could be present. As the aim of the study was to obtain the perspective of different strands within the management hierarchy, the offer was declined, and the study was explained again. This time, the trust arranged for me to see a team leader but I was never able to interview a member of senior management.

## **INTERVIEWER RELATIONSHIPS AND THE CONCEPT OF POWER**

Each group of interviews was different from the others, with the intensity and difficulty increasing as I moved from carers to PHC nurses to managers. Carers wanted to tell me as much as possible, providing both emotional and expressive accounts, for instance, by using their hands, standing up and raising or lowering their voice to illustrate their point. The majority of carers were not overly concerned about the tape recorder being present and spoke openly and freely. A few PHC nurses on the other hand were a little apprehensive about being taped. Yet, once the interviews started they did provide honest accounts and frank accounts. In contrast, interviews with managers were shorter in duration and more factual, with managers doing their best 'not to let their guard down'.

### **Interviews with carers**

For the majority of carers, this was their first opportunity to tell 'their side of the story'. The length of the interviews therefore varied because some gave more detailed accounts than others. The majority were very open and provided detailed accounts of how caring had impacted on their lives, their experiences of caring and using nursing services. Most carers spoke in a chronological order, starting with when they first suspected things were 'not right' or with the birth of their baby, before going into discussion about their experiences of caring. Some carers were more emotional than others.

Interviews with carers took much longer than anticipated. Firstly, traditions of hospitality meant that carers offered drinks and snacks before the interview. I chatted with carers informally for quite some time before setting up and starting the interviews. This involved giving a lot of background information about me. Consequently, although the interviews took on average about an hour and a half, I was frequently at the carer's home for much longer. This initial interaction helped develop trust and rapport more easily with carers.

In one case, I tried to arrange separate interviews with a set of parental carers, but Anant Laxman preferred a joint interview with his wife as "they had nothing to hide." However, I found conducting the joint interview with Anant Laxman and Prabha Laxman difficult. They provided care jointly for their adult son who required all care. However, at times, Anant Laxman had a tendency to take-over and would not allow his wife to answer. On the occasions that she did speak, she tended to look across to him, as if to confirm and have acknowledgement that she was saying the right thing. Prabha Laxman sat a little distance away, and cried at various stages. Anant Laxman on the other hand, was very composed and appeared to provide a 'public' account in relation to their caring experiences. He repeatedly stressed that they did not find caring difficult. At one point, Prabha Laxman started crying and left the room. When the interview had finished Anant Laxman went to his car to get something. I used the opportunity to return my teacup to the kitchen. At this point, Prabha Laxman turned and looked straight at me and with her eyes filled with tears and said "it's very hard". Her emotions, tone of voice and body language throughout the interview, told a different story from that of her husband. Indeed, difficulties in conducting joint interviews have been reported by other researchers (Seymour et al, 1995) as have issues concerning public and private accounts (West, 1990).

Anant Laxman had, however, taken part in the South Asian Carers study. This may have had some effect because he was potentially more aware of my line of questioning.

In contrast, the joint interview with Madhuri Krishen and Pritesh Krishen went very smoothly, with both sharing and discussing their experiences equally.

### **Interviews with PHC nurses**

Although I could not be certain, it appeared that a few PHC nurses may have discussed the study with other colleagues. In one case, for instance, one health visitor explained that she had spoken to her manager prior to coming to see me. Although, on the whole, the interview went well and she spoke freely, this may have had an impact on what she would have readily disclosed on tape, because occasionally it felt as if she had rehearsed some of her answers based on her discussion with the manager. In contrast, I suspected that two other PHC nurses may have also spoken to each other, yet it did not appear as if they had 'compared notes'. These interviews were, I feel, genuine and individual. Alternatively, if they had 'compared notes' they certainly were not 'put off' by the presence of a tape recorder.

One of the difficulties I experienced when interviewing PHC nurses concerned disclosing my identity. Those that asked before the interview started if I was a nurse were told that I used to be, but that I no longer practised. However, I found that this made interviewing problematic at times, as some nurses started using phrases such as 'you know what I mean'. On these occasions I had to ask nurses to be more specific and describe things in their own words. Having been in this situation a few times, I tried to avoid telling PHC nurses that I used to be a nurse; instead I focused on what I was currently doing, and that I was a researcher at the university.

Secondly, discussing ethnicity and race issues also proved to be problematic with some PHC nurses. Some PHC nurses clearly stated that they found it difficult to discuss the subject with me. One PHC nurse even asked me if she was saying the right thing during the interviews, whilst another said that she did not want to offend me. I reassured the PHC nurses that there were no right or wrong answers and that I was only trying to obtain their perspective, as in a PHC nursing perspective.

The majority of PHC nurses however, viewed me as a professional researcher. When it came to discussing issues concerning ethnicity, race and informal caring, some PHC nurses openly made remarks or comments about minority ethnic carers and patients, which at times, were derogatory. It appeared then, that my ethnicity had less of an impact with PHC nurses based on the type of information they were willing to share with me. It is also probable that because some PHC nurses were aware I had a nursing background saw me 'as one of them' and therefore felt 'safe' in speaking their mind.

## **Interviews with managers**

As with a few of the PHC nurses, a few managers may have also discussed the study with each other. This may have been because the approval letter sent to me had been copied and sent to other divisional managers by the trust. Managers were generally more unnerved by the presence of the tape recorder than any of the other participant groups. At times, it felt as if a few of them were 'on their guard' and were careful about what they said. Again, as with PHC nurses, a few managers found it difficult to 'open up' when discussing ethnicity and race issues, and set about using a variety of strategies to avoid answering the questions. For instance, a few ignored the question totally, even if I rephrased the question or went back to it later. Some of them gave an answer, but it did not necessarily link to what I had asked them; some used phrases such as "I'll have to think about that one" and then did not answer, others tried to diverge from the issue, or gave inappropriate answers. However, the manner in which managers responded to my line of questioning, their tone of voice, posture and their eyes and facial expressions in particular suggested that they had a different opinion or view on certain issues. One of the frustrating things was that, on occasions, they used phrases or said things, which clearly implied that they had a different view, but would not make any further comments.

A few managers provided richer accounts when the tape recorder was turned off. These issues were then written up in the fieldwork diary. For instance, off tape, one manager clearly stated that nothing had been done to meet carers' needs for years (Manager Quatt, FWD).

Although interviewing managers was problematic, overall I do not feel that it invalidates the data. Firstly, the difficulties encountered relate to a few, not the majority, of managers. In addition, managers like the other groups, also provided rich accounts, the difference being with managers was that they needed much more thorough and detailed explanations about the project, repeated guarantees of confidentiality and reassurance that data would not be mishandled and was reported in the context that it was said.

Although the project had been outlined in the letter that I had written to them, a few managers appeared to think I was there to 'test' them. For instance, one manager was ready and waiting for me on the day of the interview, and sat armed with policy documents. When trying to discuss the type of things that had been done for carers, bits of these documents were read out to me. The manager commented that if it was written in the documents then, that was what was being done. In another instance, the manager kept rushing to the filing cabinet to get documents or strategies to show them to me. Consequently, each time I moved on to a

different area, the manager quickly got up and went to the filing cabinet, stating that she had something about that. Another said that she kept a little resource file and wanted to look things up before I interviewed her but did not have time to do it. As mentioned earlier, some were reluctant to take part because they felt they were not sufficiently up to date on the subject.

In one case, the manager seemed reluctant to take part and appeared to be doing so out of obligation because the task had been handed down to him. Having arrived for my appointment, the manager made a point of stressing that he did not have very much time. As usual, I introduced the project and spoke of the type of issues that I hoped to address. Issues concerning confidentiality were also stressed. The manager asked for more detail about the project. I gave a very thorough explanation of how the project started, my aims, the types of issues that I wanted to discuss, future expectations and so forth. Before starting the interview, I asked the manager to sign a consent form which gave permission to tape the interview. He declined and said he did not have time. I also asked for a brief 'general' background information form to be filled in, again, he partially filled it in and did not declare that he was a member of management; in addition, the ethnicity section was not filled in. I had, by now, spent more than twenty minutes introducing the project. He also insisted on seeing the topic guide beforehand. I was able to tape about fifteen minutes of the interview. I was conscious that the manager had said he did not have long and therefore stopped recording as soon as my allocated time was coming to an end. I explained that there were many issues that I had not managed to cover, and asked if I could arrange another appointment. It was agreed that I see him again the following week.

The following week, I asked for the consent form, but he said he did not have it with him. I had another with me, but he refused to sign it but gave verbal permission to tape the interview. Before leaving, the manager made a point of telling me that 'he had friends at the university'. The manner in which I was spoken to, I found a little unnerving. I asked who his friends were and explained that I also knew them. At this point he appeared to relax and started to talk more informally, and also gave me literature produced by the trust to take away with me.

## **CONCLUSION FOR METHODS: PARTS A, B AND C**

A comprehensive account of the methodology was reported in this chapter. Part A of this chapter outlined the need for a pragmatic qualitative approach and reports why in-depth interviews because of their flexibility and ability to delve deep into participants experiences were the deemed the most appropriate means to address the research questions in this study.

Part B provides a thorough account of the how the research study was carried out and reports how limitations and influences on the research process such as sensitivity and the concept of power were addressed in practice. Part C reports on the dilemmas experienced in attempting to conduct the study. A dimension often neglected within research reports. Issues such as why changes to the original design were necessary and factors affecting recruitment and interviewing are discussed. It is equally important to report the difficulties experienced in conducting research as it is to report the results, as research in general is not without its problems and researching minority ethnic communities is far more difficult than often envisaged or reported.

## CHAPTER SIX

### GUJARATI HINDU CARERS' EXPERIENCES OF CARING AND SUPPORT

In addressing the core aims of the study, it was important to explore first, what the caring experiences of Gujarati Hindu carers were before examining their experiences with primary health nursing services and whether they felt supported by them. The analytical findings reported here and throughout the thesis are drawn from the data obtained via interviews during the fieldwork and analysed using the framework approach. Here, Gujarati Hindu carers' retrospective accounts based on their subjective caring experiences are reported. The analysis illustrates how little influence policy had on carers' day to day lived experience of caring. Literature from the earlier review is used to dialogue with the analysis and, where appropriate, it builds upon it. In doing so, it provides the context to understand the analysis presented in subsequent chapters relating specifically to the aims of the study.

This chapter is divided into two broad sections: carers' experiences of caring and support in caring. The first section starts by looking at carers' initial reactions to disability. This then leads into the section which explores their caring experiences. Main analytical themes are presented in bold capital lettering and second-level themes in bold lower case lettering. In some places third-level themes are identified in italics.

#### **REACTIONS TO DISABILITY**

The reactions of carers in this study towards disability were similar to those reported in the white carers' literature (Hicks, 1988). However, beliefs about the causes of disability were linked to religious and cultural values not usually reported in the other carers' literature.

##### **Being told**

All carers were shocked when told that there was cause for concern about the cared-for person's health or upon being told the diagnosis. Parental carers found it much more difficult to comprehend or accept the news than other carers in the study. The news caused "instant worry" and anxiety among both male and female carers. Some carers, although having doubts about their child's development for some time, did not feel prepared for what they were about to be told. In some cases, this was after months of frustrating attempts trying to persuade health professionals that they suspected that their child's development was not, in their

opinion, within 'normal' milestone parameters. This issue is discussed in detail in chapter seven.

When disability occurred suddenly, carers found themselves experiencing a 'partial loss of the taken-for-granted' (Schutz, 1964 in Vosey, 1975, p198). Although people are generally aware that things may not go according to plan, it is generally assumed that life will have a typically predictable course:

Knowing the traditional normality that is, should be, where you have two children, you're married and you have a perfect home, you have a perfect job and every thing is OK, hunky dory...I felt cheated with life...you feel cheated that it's not gone according to how you planned in your mind. (Sameer Gokhani, p16)

The onset of disability resulted in all carers becoming more conscious and aware of what it really meant to have a disability:

I think it really brought home the meaning, the true meaning of the word healthy child. ...Today they mean a hell of a lot more when you've gone through an experience like this, you realise what it means to have a healthy child. (Sameer Gokhani, p16)

This meant having to deal with the issue of disability from a personal perspective as opposed to something that only happened to other people:

...I wasn't expecting it. I felt very alone; you think this thing happen to other people, not you. (Sheetal Soni, p4)

The majority of carers upon being told the diagnosis or having had their worst fears confirmed experienced acute episodes of initial anxiety:

And they said that he would need to attend a special needs school and our minds, well we were very upset...It was a total shock...We lost sleep altogether. We cried so much that we almost halved in size. (Anant Laxman, p2)

### **Coming to terms?**

The experience of coming to terms with disability has often been compared with bereavement. Mackeith (1974) writes that parents of 'handicapped children' experience feelings similar to those of bereavement at the loss of a normal child they expected. These include feelings of anger, grief and adjustment. It is reported that adjustment can only come about as a result of working through the various stages of shock, denial, anger and depression (Albrecht, 1976 in Oliver, 1981). Gujarati Hindu carers in this study experienced similar feelings and found it hard to accept the diagnosis and spoke of crying for days on end, particularly if the child looked 'normal' or if the prognosis was reported as being poor. Female carers caring for sons felt that their husbands had more difficulty accepting that their son was disabled than they did, resulting in limited support from their

husband. However, although it is reported that eventual adjustment will occur (Albrecht, 1976 in Oliver, 1981) the current study revealed that carers were far from adjusted to their situation. Instead, they were experiencing feelings of 'chronic sorrow', where there was continual mourning for the loss of hopes and expectations for the child [*or person*: my addition] (Olshansky, 1962 in Mutch, 1997). Carers used the phrase, 'Why me?' questioning why they were in that predicament. On the other hand, some continued to live in hope that the cared-for person would, one day, be fit and well again. Madhu Gokhani for instance said: "I mean I think at the back of my mind, I hoped it was all a mistake, they [doctors] were wrong, and that at some point things were going to get back to normal." Sometimes, despite years of intensive 'hands on caring' carers hoped that one day their son, daughter or spouse would be completely cured. Belief in such 'miracles' is not a defining feature of the religious beliefs of minority ethnic communities alone. As Vosey (1975) argues, for all groups, 'Miracle acts as a residual explanatory category for phenomena that science 'can't explain' and their possibility gives hope in the context of an otherwise uncertain future.' (p169).

In the hope of cure or improvement, carers were prepared to go to great lengths. Although western medical healthcare is generally favoured by minority ethnic communities (Bowes and Domokos, 1993), notions of health are often culturally defined (Mares et al, 1985). Different ideas about management and cure, attitudes to disability and the role of alternative therapists, for instance, influenced carers' views about disability. In a bid to find a cure, Gujarati Hindu carers (often at considerable expense) turned to alternative therapies in Britain or abroad, alongside conventional treatment. These findings were not documented in Katbamna and Bhakta's (1998) large study.

Shanta Hari, for instance, cared for her 'physically and medically handicapped' son. They lived in a terraced house in the inner city. Shanta Hari had been caring for twenty seven years. She said she would be prepared to sell her home if a cure could be found for her son.

She had tried a variety of treatments and therapies both conventional and alternative:

We used to have *asha* [hope] that he would become well. He was 10,12 years old then and we kept thinking he'll get better, he'll get better...We took him to India for a short while and we gave him *vedic*<sup>16</sup> treatment. You know, we thought, maybe he might improve a little. (p18)

Shanta Hari came to Britain in 1963, and at the time, had had very few close relations in Britain to support her. However, despite there being very few relatives, when it became known that she and her husband wanted to take their son for treatment at an institute for brain injured children, and that they were in need of financial support, relatives rallied round and made contributions towards costs. They enrolled on a programme where Shanta Hari was taught a technique of "patterning", where limbs had to be moved in a certain order. However, the technique had to be done several times a day and required more than one person to do it. A rota system was developed for differing techniques to be carried out throughout the day, each day. She managed to organise support from neighbours and relatives for a few months. However, over the months, the support diminished. People were unable to commit the time or provide financial support on a long-term basis. They subsequently withdrew from the programme as they were unable to meet costs, continue patterning on their own and then lost interest. However, a few years later, Shanta Hari took their son to America to try out yet another programme of therapy reported in a television documentary, which they financed themselves.

This is an interesting case, illustrating two important issues. Firstly, it illustrates that Shanta Hari was continuously searching and hoping for a cure. Several years passed before she found out what was wrong with her son. She had little knowledge and no information to see her through the worst moments. Yet, hope of a possible cure for her son enabled her to continue caring. However, her desperation was such that she enrolled on programmes of treatment at great financial cost which she was not in a position to meet. Secondly, although she was able to enlist support from relatives and neighbours, it was

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<sup>16</sup> *Vedic medicine* focuses not only on the health of the individual but also on the health of the environment and the wholesomeness of society. It prescribes treatments that create harmony and balance using all avenues of a person's life including one's diet, daily routine, relationships, sleep, exercise, living environment, music and spiritual life. Vedic medicine describes nearly every possible influence on a person including the best (and worst) food, water, buildings, music, and plants, permitting people to adjust their lifestyle for maximum longevity by eliminating unwholesome stresses, wear and tear, toxic foods and environments. (Lancaster Ayurveda Medical Centre, 2003)

short lived. These issues were also pertinent to other carers in the study and are addressed below.

Others did similar things, creating an added financial burden that they were often not really in position to take on:

We'd actually got a place in Somerset, cos they've a way of treating what they call brain injured children and we were gonna have to pay for this treatment and it was like £500 initially and then it went on £100 every month, which we were prepared to do, but we had to get the money together, so there was that expense.

(Madhu Gokhani, p18)

This financial impact is important because there was evidence of comparative material disadvantage among carers in this study in terms of housing, income and health (also see chapter one and appendix five for a description of carers' circumstances and characteristics).

A variety of treatments or alternatives to conventional treatment were tried out by carers. They were involved doing *malliss* therapy of the whole body or what can best be described as aromatherapy for the affected part. Alisha Ram, for instance, mentioned placing her mother-in-law's hand in a bowl with warm water, lemon and oil on a daily basis to encourage movement. Carers learnt techniques or sought advice from individuals in the wider community who were known to be 'experts' in the field. With the exception of Anant Laxman and Sameer Gokhani, it was generally female carers who spoke of seeking or carrying out alternative therapies. Anant Laxman felt that if they did *malliss* [massage] his son would not have to be so dependent upon drugs as it would improve his blood circulation. Similarly, Sameer Gokhani said he would sometimes massage his son before bed or before bathing to try and stimulate him.

Other carers sought out formal organisations. Radha Nayan regularly took her daughter to a special needs gym class. Shanta Hari and Madhu Gokhani, in addition to doing massage also sought help from other specialist institutes catering for brain injured children. Whatever form of therapy carers had opted to try out, it was relentlessly carried out on a regular basis (daily in some cases) in addition to their normal caring responsibilities and at added cost.

For some carers, then, it was hope that enabled them to continue caring, with adjustment being somewhat episodic and dependent on their circumstances at the time.

An important finding from the current study was the way in which attitudes concerning disability among minority ethnic communities laid an expectation on carers that they should not 'give up hope'. There was pressure from relatives and the wider community, particularly on mothers of disabled children, to be seen to be doing all they could to 'cure' their child. These pressures to believe that a cure might be found or that the condition could improve included views that parents should take their child to a faith healer, spiritual healer or abroad to try out remedies and therapies that were non-conventional. In addition, despite years of 'trying out' different methods, there would be an expectation that if anything 'new' was discovered, treatment would, once again, be sought. Thus, there would be continuous pressure to be seen to be doing all the right things in the eyes of the community and a firm belief that parents, for instance, should have *shradhaa* [faith] if they were to expect a cure or improvement in the condition. Those carers that eventually gave up hope or failed to engage in curative practice could expect to be talked about within the community as not having enough *shradhaa*, resulting in the continued disability of a child.

In one isolated case, difficulties in coming to terms with the disability resulted in services that were offered being declined:

In the beginning it was really hard because you sort of can't accept it, and they offered it us [pushchair] and I thought no, no, no it's okay, I'll manage.  
(Radha Nayan, p2)

Radha Nayan felt that by 'giving in', it would prevent her daughter from learning to walk independently as she would get used to being pushed. Further, the larger than average sized pushchair offered to Radha Nayan by the occupational therapist would inevitably be a constant reminder of her child's difference from other children. Her reaction was similar to that reported by Charmaz (1983).

Based on a qualitative study with 57 chronically ill persons with varied diagnoses, Charmaz, (1983) writes that an initial coping strategy may be an attempt at 'normalisation' whereby a person continues to act as normally as possible, by minimising the significance of activities associated with the technical management or adjustment to the disability (Charmaz, 1983).

It was not only carers of children who were disabled at birth who found it difficult to come to terms with the disability. Those caring for someone who was otherwise fit and healthy who subsequently became disabled found it equally distressing. In these cases, carers made references to how the cared-for person was before the onset of the disability or impairment. It has been argued that a fundamental form of suffering for chronically ill persons is 'the loss of

self', where the person observes their former self-image crumbling away (Charmaz, 1983). However, it could be equally distressing for carers to observe the progressive deterioration of the cared-for person's personality and physical health:

My mum wasn't my mum anymore, she was like a friend to me...I felt like one of my best friends had gone...After she'd lost her memory she didn't even remember me, she can't even remember my name. (Madhuri Krishen, p14)

All carers expressed concern about the future welfare of their loved one and were extremely worried about who would care in the event of something happening to them (the carers).

As reported earlier, carers' accounts revealed that periods of adjustment were episodic. Adjustment was linked to other significant events that were taking place (for instance, if the carer was ill or if there was a wedding approaching) and carers' emotional state at the time of the event. It was on occasions when carers were feeling particularly vulnerable or stressed, that fears and anxieties about the future welfare of the cared-for person re-emerged.

### **Finding a cause**

A secondary reaction to disability was to try and identify its cause. Carers' beliefs about the cause of the disability were not necessarily linked to beliefs in the supernatural or witchcraft, as commonly reported (Commission for Racial Equality, 1993). Indeed, there was limited evidence to this effect in this study. Only one carer expressed the belief that certain types of people possessed supernatural powers [of witchcraft] which she felt were used on her husband, resulting in his mental health problems. Priya Thakrar said: "Sometimes I think, you know, somebody must have done something to him".

However, beliefs about disability linked to cultural and religious beliefs were evident. This, however, was much stronger among relatives and the wider community with whom carers had contact rather than carers themselves.

A central tenet of Hindu philosophy is the idea of the immortal soul and reincarnation<sup>17</sup> imbedded within principles of *Karma*<sup>18</sup>. Shanta Hari cared for her adult 27 year old son who was 'physical and mentally handicapped'. She believed that disability was fated. Thus the

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<sup>17</sup> *Reincarnation*: a belief in the cycle of birth and rebirth (Teasdale, 2000)

<sup>18</sup> *Karma*: Which form or condition one is reborn depends on the principles of Karma. The principle exerts that we are morally and existentially responsible for all our actions, thoughts, and words -- even our emotions. According to this principle, each action, thought, emotion, and word has either positive or negative consequence. The nature of the consequence depends on the moral quality of the action, thought, emotion, or word. Everything we do, say, think, and feel thus affects our next life (Teasdale, 2000)

future of the cared-for person had been predestined or prewritten before birth and was meant to entail living a life with disability and the carer a life devoted to caring. She said: “It was our *naseeb*, [fate] *lakha-you-has-sae* [prewritten: predestined] that we’ve got to work really hard. And that’s what we’ve been doing” (p18). However, she felt that being new to the county and not being able to communicate in English was also a contributory factor as nursing staff did not understand her when she tried to explain to them that she sensed that something was not quite right with her newborn baby who had turned blue.

Although, the above example is dated, issues concerning communication and not being taken seriously by health professionals are as present and pertinent today as they were then. Addressing these concerns remains an important part of effective health service delivery and is discussed further in chapters seven and eight.

Others believed that disability was something that could happen to anyone. For example, Shivam Ranchord described imperfections in society overall and referred to having a disabled child as both chance and God’s wish.

On occasions, partners blamed each other in a bid to try and identify which side of the family the disability could have come from. A few mothers blamed themselves and wondered what they had done ‘wrong’ that resulted in them having a disabled child. Feelings of inadequacy at reproduction have also been reported by other commentators (Hicks, 1988). As discussed later, mothers in particular were blamed by the family and the wider community for causing the child’s disability. This was an additional burden for female carers to shoulder.

However, carers’ predicament was often compounded by the inability to access information, and inadequate explanations concerning the cause of disability. There was an apparent lack of knowledge concerning the cause of the disability and its manifestations among the majority of carers. Prabha Laxman, for instance, believed that her son developed side effects four years after routine injections were administered when he was three years of age (her son suffered from encephalitis at the age of 7 years). Many of these issues are discussed further in chapter seven but have implications here, because if carers are not clear about what is wrong, what the expected outcome is likely to be, and information is not relayed to them on a continuous basis as their circumstances change, this will invariably affect their ability to cope and come to terms with the disability. Further, as described in chapter five the majority of carers were not fluent in speaking English. Only six interviews were conducted in English, all of which were younger carers. Although the ability to speak English did not break down all communication

barriers, those carers not able to speak English were disadvantaged further. They were unable to communicate their concerns, were not taken seriously by professionals and often lacked knowledge about support services available.

## **CARING EXPERIENCES**

The analysis revealed that carers in this study were involved in providing similar types of personal and practical support as reported in the white carers' literature (Parker, 1993; Twigg and Atkin, 1994). However, lack of support from immediate and extended family and carers' socio-economic circumstances and material deprivation were worse.

### **Personal care**

Dealing with personal care activities for adults was reported to be the most difficult and distressing aspects of all caring activities and this supports the work of other researchers (Parker, 1993; Twigg and Atkin, 1994; Katbamna and Bhakta, 1998). This was largely due to inhibitions about touching and nakedness. Many carers found tasks such as toileting, dealing with incontinence, handling soiled clothing and commodes, and, in particular, dealing with menstruation caused the most discomfort. Both male and female carers found it "embarrassing" and "hard" providing personal care but, more often than not, women were primarily responsible for these tasks. Despite some carers being heavily involved in caring over many years, carrying out personal care activities did not get easier over time. Rather, carers felt drained by it, not only because it required physical strength but mentally it was not something that one could 'get used to'. The odour and contact with adult bodily excretions was problematic and carers frequently commented that it was 'not the same' as caring for a baby that needed to have its nappy changed. Carers spoke of feeling repulsed and nauseated at times, yet they had to manage:

It's the smell from the nappies [pads] really... It's too much. Your whole head spins because of the smell. (Priya Thakrar, p8)

Carers found it stressful and spoke in terms of being tied up all day and night with the task of dealing with incontinence. Consequently, in a bid to try and spare a little time to get other chores done, the first thing carers did upon waking in the morning was to meet the toileting needs of the cared-for person. However, some carers were dealing with incontinence very frequently. The findings of the current study support those of Twigg and Atkin (1994) who report that carers' difficulties are intensified by the fact that personal care tasks cannot be accumulated and have to be performed on demand.

Intensive caring tasks had become more problematic and difficult to manage in cases where both cared-for person and carer had aged. Moreover, carers often had health problems of their own to contend with. A number suffered from back or other health related problems, thus their own disabilities impeded their ability to provide care, especially when it involved lifting, carrying and handling. Further, when the cared-for person was not feeling well, the same task was reported as being much more demanding.

Personal caring activities involve aspects of taboo as tasks are not only of an intimate nature, but also cross the boundaries between what men and women should see or do for each other (Ungerson, 1987). Relationship and gender will thus have a bearing on the meaning of personal care as different relationships imply different expectations requiring techniques of social distancing (Twigg and Atkin, 1994). In Katbamna and Bhakta's (1998) study, it was reported that providing care for daughters was not problematic to male carers if their daughter was still a child (under seven years of age). For Gujarati Hindu carers, however, even this support was not available to women and they received little or no support from their husbands or immediate family. Male carers were not prepared to provide personal care where daughters were concerned, as it was viewed as inappropriate to be involved in intimate caring tasks:

He helps with feeding her, but he won't give her a bath, change her nappy, I have to do it all, he won't even touch her. (Sheetal Soni, p7)

Although female carers said they would have welcomed support with personal care for their daughters, on further questioning, they admitted that they had a preference for their husbands not to be involved.

However, where personal care was concerned, it was not only cross gender caring that was problematic. It was just as distressing to provide personal care for someone of the same sex as the carer. Daughters caring for mothers and mothers caring for daughters found it equally difficult, and more so when the cared-for person felt embarrassed:

I felt a bit different as well cos I had to do things for her like giving her a wash.  
When I give her a wash and everything, that's what, that's what hurt me cos she's my mum and she don't like it...She felt really embarrassed and everything.  
(Madhuri Krishen, p10)

As discussed later, some carers had no option but to care as there was no one else who could take on the responsibility or because ties of duty and obligation made it difficult for them to get out of the situation. This included both male and female carers. In one case, this resulted in a male carer marrying. For Mital Popat, washing and dressing his mother who was still

young (46) at the time he was involved in caring for her, made it very difficult to carry out tasks. He spoke of having “a very bad” feeling about being involved providing intimate personal care. In addition, being involved in cross-gender personal caring activities made it impossible for him to disclose the matter to his relatives or his general practitioner and get support. Lack of knowledge that he might be able to get support for personal care did little to ease matters. Within a year, he felt unable to continue and decided to get married. He was therefore able to discharge his caring responsibilities over to his wife (Qureshi and Walker, 1989).

Further, contrary to the popular notion that the intimacy shared by married couples makes it less problematic to perform tasks of an intimate nature as it is a normal extension of marital duties (Borsay, 1990 in Parker, 1993), the findings from this study revealed the contrary. Being married to the person requiring intimate personal care did not make it any easier. Rather, inhibitions concerning personal care applied equally to spouse carers, supporting Parker’s (1993) findings. Vikesh Anand gave a detailed account of the type of personal care he provided for his wife. He mentioned that it was not only embarrassing but it was also a difficult issue to deal with on a daily basis and several times a day. It was equally problematic for him trying to explain exactly how he was feeling and what he was going through:

That’s the hardest, I find that hard, everyday you know, cleaning her up, sometimes she soiled herself, and I change her, and then bathing her, it’s hard. It’s very difficult for me. (p10)

It’s especially during the night time, you know, ‘cause you’re half asleep yourself, and you have to get up and change her, to sit her up. I used to get up two or three times a night, so I’d just feel knackered all the time...She’s my wife so...well if I have to clean her up with water, then, then you know, I feel, you know, Well I don’t know. (p14)

In the case above, Vikesh Anand had no choice but to provide care as there was no one else present in the home that could have ‘potentially’ helped. Further, there was no alternative but to continue as his wife objected to having outside support, including nursing support.

On the whole, female carers had greater responsibility, providing care during the day as well as seeing to the needs of the cared-for person (male or female) during the night. A few carers, usually parents, reported that they worked together, sharing the workload equally between them. However, Pritesh Krishen and Madhuri Krishen were brother and sister. Both cared for their parents and constantly referred to themselves as being a ‘team’ and on a number of occasions declared that all tasks were divided equally between them. However, where personal care was concerned, Madhuri Krishen saw only to her mother’s needs, as her father would not allow her to touch him. Pritesh Krishen, however, was involved in providing

personal care for both his mother and father. Their father was still mobile, able to speak and was still largely independent and was therefore able to refuse help from his daughter as he was not happy with the arrangement. Their mother, on the other hand, was totally dependent on her children to wash, dress and feed her, unable to speak or communicate other than show emotion by crying. Their mother may have not been happy with her son providing personal care, but was unable to communicate this and had limited choice in the matter. Further, given that both parents required a lot of assistance both Madhuri Krishen and Pritesh Krishen had to overcome barriers of cross-gender caring and simply get on with tasks.

### **Practical support**

Not all caring tasks were strenuous. Some were more of a practical nature. This included tasks such as giving medication, putting up intravenous feeds, cutting food into small pieces, giving drinks and keeping the cared-for person occupied. These types of activities, although not strenuous, continued to impinge on carers' time, leading to frustration. Efforts to meet needs were compounded by lack of knowledge concerning availability of services and access to basic equipment such as dycem mats, drinking beakers and specially shaped cutlery. Further, for those carers involved in washing and dressing the cared-for person, none had been shown how to make dressing easier, (for instance, by using bigger size clothes).

Further, in addition to providing personal care, physical and practical support and keeping an eye on the cared-for person, carers also had to combine their caring activities with other chores. These included cooking and cleaning, seeing to the needs of other family members, keeping up with suggested therapy, meeting social obligations, keeping hospital and general practitioner appointments, as well as general property and car maintenance. Juggling all of these activities resulted in many carers feeling drained and shattered because they had to "do every single thing" (Madhuri Krishen).

### **Watching over**

Another feature of caring involves 'keeping an eye' on the cared-for person or 'watching over'. There is ample evidence stating that these activities are stressful and taxing for carers. The intensity, duration or degree of watchfulness required is dependent on the severity and nature of illness or condition of the cared-for person (Hicks, 1988; Twigg and Atkin, 1994). The analysis here revealed that carers' experiences were broadly similar to those reported in the white carers' literature. However, there were some important differences particularly in terms of carers' own attitudes towards disability.

A number of carers were involved in keeping an eye on the cared-for person. Madhuri Krishen cited several instances concerning her father where he had put himself or them in danger as a result of him smoking. Her brother, Pritesh Krishen said: "He's a hazard to our family." Those carers looking after persons that had limited awareness of danger experienced considerable difficulties:

Oh yeah she's gotta be looked after all the while...we cannot put this fire on when she is here playing about unless she's on the chair ... because she doesn't know the dangers, any dangers, even if she hurts herself she will probably go there again...So 24 hours a day she's gotta be looked after. (Shivam Ranchord, p6)

'Keeping an eye' on the cared-for person was reported as being stressful and difficult to deal with on a daily basis because it was emotionally and physically draining. It involved a process of constantly being 'on guard', avoiding potentially dangerous situations from occurring or maintaining the safety of the cared-for person. Consequently, although carers were able to snatch some time away to get on with other chores, for instance, if the cared-for person was busy 'playing' by flicking through magazines, carers continued to 'pop in' to the room to make sure that the cared-for person was alright and that everything was still in order. Shanta Hari for instance, mentioned that said she would 'pop in' at least ten times whilst trying to cook a meal.

The safety of the cared-for person was thus always on carers' minds. This created a situation where carers were never able to get away from caring. If carers were not physically providing care, their mind would be. Carers' own attitudes towards disability, however, also influenced how much of their time was devoted to caring and watching over. In a few cases, carers themselves created tiresome routines. Parental carers of adult children, in particular, and on occasions spouse carers too, described their experiences of providing care very much in terms of care that would otherwise be provided for a baby. For instance, they spoke of giving feeds, changing nappies, making sure their son or daughter had been 'winded', positioning, putting the cared-for person to sleep comfortably. A few carers prepared special meals which were separate and different from those consumed by the rest of the family, and not necessarily because the cared-for person required a special diet.

One particularly interesting finding was that a few parents continued to have their adult children sleep in the same room as them. The need to have the cared-for person in the same room was justified on the ground that they could respond to their needs immediately and maintain safety. Carers had an inbuilt fear that something would happen to the cared-for person whilst the carer was asleep and that they would not hear them:

[his bed] it's in our bedroom... Because he isn't aware of how to cover himself up. It's very difficult...but if he wakes up he'll make a noise... I'll be awake...whatever happens to him I'll be up straight away. (Shanta Hari, p13)

Although this level of concern is understandable in cases where the cared-for person requires a great deal of care, parental carers were keeping their adult children in an extended childhood. Carers' concern for their adult child's needs resulted in both carer and cared-for person losing the privacy they would otherwise have had. The more engulfed (Twigg and Atkin, 1994) carers were in meeting the needs of the cared-for person the greater the impact on daily life. Adult children sleeping in the same room as their parents is a new finding, not previously documented even in Katbamna and Bhakta's (1998) large-scale study. It illustrates a need for continuous information and effective communication between professionals and engulfed carers in particular. Carers need professional advice about the importance of allocating some time for themselves. Understanding needs to be enhanced to enable carers to appreciate that devoting just a small amount of time in activities that are of interest to them can enable them to be more effective. Caring should not involve putting one's life on hold nor should carers become overridden with guilt because they feel they should be seeing only to the needs of the cared-for person. Carers need support to enable them to appreciate that their needs are equally important to those of the cared-for person. Carers in this study devoted day and night to meeting the needs of the cared-for person, allowing little or no time for themselves to get involved in other types of activities.

### **Feelings about caring**

As we have seen above, some carers were involved in carrying out tasks requiring considerable strength and energy on a daily basis such washing, dressing, undressing, changing, feeding and positioning the cared-for person regularly and help with mobility. These tasks were carried out throughout the day and frequently at night as well:

Well, she [daughter] is totally dependent on me. She can't feed herself, she makes a lot of mess, and then she wears nappies. I give her a bath, feed her, you know, just like a baby. She can't talk, she can't do anything... she asks for food or whatever she wants by eye contact and distracting you, she's totally dependent. (Sheetal Soni, p7)

Although carers' experiences differed according to their own individual circumstances, their experiences were in many respects similar to those experienced by white carers (Hicks, 1988; Parker, 1993; Twigg and Atkin, 1994). Often, the entire day was spent seeing to the needs of the cared-for person and many reported that caring was time consuming, monotonous and taxing. As a consequence, the majority reported that, although they were used to the routine of

caring, they were tired of it. Shanta Hari, for instance said, "It's always the clock, all day I'm looking at the clock. All the time, it's the clock, the clock is my life". The findings of this study supports other commentators who have described 'the daily grind' of caring (Bayley, 1973). Frustrations of 'the daily grind' were, equally applicable to male carers:

"You just get fed up, especially when there's so much housework to do, you know, cooking, cleaning and shopping and getting her ready. If I wanted to go out I have to think twice, how am I going to go out?." (Vikesh Anand, p6)

Female carers, in particular, felt as if they had no life left other than to care because they were "stuck at home all day". This was particularly evident among those who had given up professional jobs to care. Further, in the case of unforeseen eventualities, such as staying overnight in hospital, or getting up during the night to toilet and change the cared-for person, again, the responsibility continued to fall on female carers. Shanta Hari summed up the views of all female carers: "it's always me". However, the stresses of being involved in routine caring activities were not entirely gender specific. Male carers were equally stressed and 'fed up':

And it became such a tiresome routine that eventually you think "Bloody hell", you know, "How much longer is this got to go on?" (Sameer Gokhani, p12)

Yet all carers were devoted and continued with their responsibilities despite experiencing difficulties. As also reported by Beresford (1994) and Nolan et al (1996), a few Gujarati Hindu carers did feel rewarded for their caring responsibilities. Caring had enabled them to acquire knowledge about caring and disability helping them to be more sympathetic to other carers' needs.

Parental carers also spoke of the delight and happiness it bought them to see their child progress, however small the milestone. Those caring for children (young or adult) requiring a lot of care mentioned that despite their child not being able to move or do much, they could sense what the child was trying to express by the way he or she looked back at them. It was at times like this that parents felt rewarded for their hard work:

...and his eyes, you know, the way he looks back at you, it's lovely. (Shanta Hari, p16)

Carers used phrases such as "she's a delight" or "you can't stop loving her" and were happy when their child was happy. Some carers mentioned that their disabled child was 'more spoilt' than their other children, and how they bought them more clothes, toys or gave them extra little treats. A number of carers made a point of dressing their son or daughter in nice clothes and made sure they always looked presentable.

However, all carers felt that caring had resulted in their lives changing significantly. Some felt that the happiness they had hoped for had gone altogether, and that their dreams had shattered. For some, caring was depressing and they could see no way out. Caring had not bought them any satisfaction, instead they spoke in terms of feeling like “a nobody” (Madhu Gokhani) and no one being able to takeaway the *dhuk* [pain] they were feeling (Shanta Hari). Dissatisfaction outweighed any satisfaction experienced. Carers were thus unable to maintain the balance or equilibrium reported by Beresford (1994) or Nolan et al (1996). A number of female carers mentioned that they would not want their children to have a similar life to them and hoped that they would never have to care for anyone.

The study illustrates that although carers felt rewarded by unspoken gestures and smiles from the cared-for person, it was not enough. On the whole, the majority of carers were desperately unhappy. Caring had a huge impact on their lives and they were caring at considerable cost. Things had changed, overnight in some cases, and the life they once had, or hoped for had disappeared.

### **Engulfed carers**

Both male and female carers spoke of the importance of ensuring that they took care of their own health because there was no one else who could take over the responsibility of caring. However, in a few instances, it was evident that caring had taken over and carers had subordinated their life to that of the cared-for person. These few carers were *engulfed* in caring (Twigg and Atkin, 1994). Caring had become a defining feature of their identity and they were unable to detach themselves from the role:

Well at the moment we don't think about anything like that [own needs], because everything is for him. We've devoted our life to him. He is our life.  
(Anant Laxman, p6)

Parents caring for adult children and spouse carers involved in intensive ‘hands on’ care fell into this engulfment mode. They remained focused on the task of caring and meeting the needs of the cared-for person alone and did not deviate from this. The process involved a period of reflection and weighing up which issues were really important and had to take precedence over other matters. However, this meant changing priorities in order to meet the demands of the cared-for person often at the neglect of their own needs. It was hard for carers not to become engulfed when faced with the daily routine of meeting washing and dressing needs, dealing with incontinence and having limited sleep in between. This created a scenario where a few carers were unable to relinquish the role, as they felt that only they could provide ‘proper’ care, especially in terms of bathing and massage therapy. As described in appendix

18, Anant Laxman and Prabha Laxman felt that only they could provide care 'properly' or 'completely'. If the cared-for person was in pain, this further contributed to the likelihood of the carer being engulfed by the situation. Carers took measures to maintain the cared-for person's safety, and tried not to make any demands or put any undue pressures on them for fear of causing ill effects. Thus in some cases, the entire day or night was spent revolving around the needs of the cared-for person.

### **Male carers**

On the whole, although there is evidence of a few Gujarati Hindu male carers being heavily involved most still had more of a peripheral role, being responsible for activities such as organising travel arrangements for hospital appointments, paying bills, doing the shopping, keeping the cared-for person amused or occupied, maintaining safety and giving out medication. A few others did try to help around the home and had taken on roles they were not accustomed to prior to caring, such as washing up and hovering. One male carer learnt to cook basic meals (Anant Laxman). However, cooking was reported by male carers as particularly problematic for them and they were therefore usually dependent upon their sisters or daughters to help them.

### **Access to equipment, aids and supplies**

Dealing with incontinence and bathing was often more problematic due to lack of equipment or access to aids and supplies. Gopal Mithun, for instance, said his wife had been having a bed bath for over two years. She was unable to have a shower as they did not have an appropriate sized wheelchair, which would have enabled access to the adapted shower room. As a result of several strokes she was physically unable to walk and had also gained a substantial amount of weight. Therefore the original wheelchair had become redundant. Further, not being able to bath or shower for many years made his wife (and others in a similar position), feel unclean and restricted their ability to take part in religious practices. For his wife, being able to bath just once a week would have been sufficient.

Meeting the personal and hygiene needs of cared-for person's requiring 'all care' on a daily basis without equipment or adaptations to the home was very difficult. Sheetal Soni, for instance, provided 'all care' for her adult daughter. It required two people to lift her daughter, (one person to lift her legs up whilst the other held the top half of her body). Yet they did not have a hoist, which clearly would have made lifting much easier. Similarly, Shivam Ranchord described how his wife brought their 17 year old daughter downstairs, in the event that he had already left for work, as they had no stair lift:

Well, she struggles a bit coming down you know. What she does, she sits on the stairs and puts her [daughter] on her lap and slowly one step at time [brings her downstairs].  
(p7)

Problems were intensified for some carers because they experienced difficulties in accessing incontinence pads and paper pants. This inevitably made it difficult to maintain the hygiene needs of the cared-for person as well as keep their home free from the odour of incontinence. This and related issues are discussed in chapter seven and eight.

## **Housing**

It is only recently that the significance of housing within community care policy has come to be taken seriously (Department of Health, 1993; Farrell et al, 1999). Although there is ample evidence (Smaje, 1995), which highlights the deprivation and concentration of minority ethnic communities within inner city areas, there is little about their housing in terms of its suitability to meet the needs of a disabled person (Chamba et al, 1999). Yet, appropriate accommodation is one of the most important pieces in the jigsaw of provision which enables disabled people to live good quality lives in the community (Morris, 1989 in Parker, 1993) and one of the 'keys to independent living' (Harrison and Davis, 2001, p122). Adaptations to the home can make everyday activities easier. Housing adaptations can, for instance, allow people to turn on lights, open windows and have a bath if they choose to and not when someone else decides (Heywood and Smart, 1996 in Harrison and Davis, 2001).

The majority of carers in this study (as described in chapter five and appendix five) lived within the inner city, in terraced accommodation. Although a detailed survey of housing needs was not carried out, from carers' own accounts and personal observation of their housing conditions (for instance, homes being cold, narrow stairways, door frames not being wide enough to allow wheelchair access, wall paper peeling off and lack of central heating or double glazing), it is not unreasonable to state that the housing needs of Gujarati Hindu carers in this study were inadequate.

Lack of space and equipment resulted in the cared-for person being confined to one room. This was either in an upstairs bedroom, or in one room downstairs that had been turned into a combined bedroom, sitting room, washing, dressing, and toileting and eating area for the cared-for person, housing a bed, chair, commode and a few personal belongings. Mr Gopal Mithun, an elderly carer, mentioned that his wife had spent several years in the front room as she was unable to go into the living room, and moved only between the bed and a large chair. As reported earlier, not having a suitably sized wheelchair restricted her movements further.

The use of commodes is not favoured among South Asian communities (Katbamna and Bhakta, 1998). Carers in this study found that having a commode in the room made it difficult to keep the odour of urine or incontinence away. This put people off visiting the home, resulting in both carer and the cared-for person becoming socially isolated.

Alisha Ram spoke about attempts to restructure the living space so that her mother-in-law could stay downstairs and be near the rest of the family. However her mother-in-law was not willing to use the commode. This was an additional pressure, as it required considerable effort and energy to take her to the toilet. She and others like her would have benefited from having adaptations but bureaucracy or disagreements concerning what carers would have liked and adaptations that housing officials were prepared to consent to delayed matters. Although it was not the aim of this study to address housing applications and appeals, inadequate housing and lack of appropriate adaptations or equipment will clearly impede carers' ability to provide care, and require more effort on the carer's part to meet needs. Parker (1993) identified that disabled people and their carers frequently face long delays in getting the aids or adaptations they require. In the current study it was reported that applications for adaptations took several years to be processed and focused on meeting the needs of the cared-for person alone. There were also lengthy delays due to disagreements concerning what would be in the interest of the cared-for person and what carers viewed as being in the interest of them and the rest of the family. Problems were further compounded by lack of financial means to repair or maintain the property.

## **WHY CARE?**

We now move on to explore the motivations of Gujarati Hindu carers and the factors that lead to them becoming carers. Many of the factors identified in this study were similar to those reported in the white carers' literature (Hicks, 1988), however, differences were also evident. The decision to care was not always a conscious one and on occasions a number of factors were inextricably linked.

### **Lack of choice**

Both male and female Gujarati Hindu carers mentioned that lack of choice meant that they had to care. This was largely because there was no one else who could take on the responsibility, and was often driven by a sense of duty because carers were the parents or spouse of the cared-for person. Thus there was no option but to care:

She's my daughter. I have to care for her...If I don't do it, who else will do it?"  
(Sheetal Soni, p8)

This was particularly strong among parental and spouse carers, the majority of whom used the phrase: "it's my *faraj* (duty)" as a husband, mother, father or son, for instance.

If the caring situation had risen unexpectedly, this left carers with little choice in the matter:

What can you do? You have to do it, if the responsibility is thrown upon you, you have to do it. (Gopal Mithun, p9)

For some carers, their caring role developed as a result of pre-existing circumstances. This was usually because the cared-for person was already living with the carer. In one interesting case, Alisha Ram gave a detailed account of how she had been part of a large extended family that decided to buy a five bedroomed house purely on the grounds that the responsibility of caring for her in-laws could be divided between other family members. However, although the intention was to share the responsibility, in reality, once a home and carer had been identified, other family members took the opportunity to divest themselves of the responsibility and moved out. The findings support the work of Nissel and Bonnerjea (1982) who reported that once the cared-for person had settled in with one of his/her children, other children in the family contributed very little. The difference, however, was that although some carers lived within extended households (unlike white carers) and thus potentially had the support of others, the responsibility continued to fall on one person, reinforced by role expectations from the wider community, to which the analysis now turns.

### **Role expectations by society**

Like white female carers, female carers in this study also took on the bulk of the responsibility. Finch (1989) has explored whether kinship and family ties alone are a strong enough factor to encourage people to help and support relatives in times of need. She reports that the duty to care for immediate relatives is stronger than for distant relatives. In contrast, among minority ethnic communities, 'an individual's position in the family (relationship, gender, age, relative prosperity, physical health etc) carries with it a complex of duties, rights, obligations and expectations' (Ahmad, 1996, p57). This is particularly important for minority ethnic women if they are to maintain family honour and protect their moral reputation, often reinforced by the influence of the wider community. In this study, male carers were involved in caring for their wives and sons but did not get involved in caring for their adult daughters or other family members. Female carers, however, were involved in caring not only for immediate family members such as husbands, sons and daughters but also other relatives such as their mother-in-law. This would be a natural extension of the material duties of a daughter-

in-law. For Alisha Ram, not caring for her mother-in-law was not an option, as the community would have looked upon it as a result of poor upbringing and blamed her parents:

I can't sort of shout at them or say anything to them, you know, and say that I don't want to do it because...that's the way I've been brought up. And also, I wouldn't want my dad and my mum, my parents' names to be, you know, blackened really because of me. You know, it'll look as if I'm not looking after them, and I don't want them to think that. (p22)

### **Cultural and religious beliefs**

There was also evidence of some carers being influenced by religious and cultural beliefs. Thus caring was a responsibility bestowed upon them by God. Some spoke in terms of their circumstances being fated and predestined:

Perhaps, *lakha-you-has-sae* [written in: predestined] that I need to do *seva* [to care:to serve]...I feel that that perhaps it was written in my *naseeb* [fate:future], perhaps it was written in her *naseeb*. (Vikesh Anand, p4)

Prabha Laxman mentioned that she would continue to care for her son while God continued to give her *shakti* [strength]. On the other hand, Mital Popat, felt that as God had created the world, he had to give something back in return by caring.

Cultural values and beliefs played a significant part in carers' lives, principles usually deeply embedded with childhood socialisation and upbringing. This meant that carers were well aware of their responsibilities and the role they had to play in society. Caring was a tradition. "Well we tend to look after our parents and grandparents" (Shivam Ranchord, p9). It was believed that tolerating unhappiness and *dhuk* [pain] as a result of caring was part and parcel of caring and one's duty. Caring was a cultural value which had been passed on from one generation to the next, and a value which a few carers wanted to keep alive. One way to do this was to set an example to one's children. Being seen to uphold these values meant that children would learn to understand and appreciate them:

It's our religion, it's our *dharam* [tradition - cultural/religious values]. If we're able to stay in that, then we're able to bring our family up, because we're able to teach our children good values and principles...I think if they've been brought up properly by the parents, then I think they will do it [care]. They'll know that they [parents] did it like this, so they ought to do it, as well. (Vikesh Anand, p19)

### **Love and wanting to care**

Findings from this study contrast notably with studies of white carers (Briggs and Oliver, 1985), which have frequently reported love and affection as influencing the decision to care. This is not to say that Gujarati Hindu carers did not love the cared-for person. Rather, issues concerning love, emotion and wanting to care were factors reported more distantly. Carers'

religious and cultural beliefs and role expectations from society, as reported above, had greater influence. In this study only parental carers made specific reference to love and wanting to care for children. Maternal instincts were also directly associated with their feelings. Phrases such as, “because we love her” or “I wanted to do it” were commonly reported. However, those caring for their parents also made comments that could be interpreted as expressing love:

The closeness you have as mother and child...but it's just something that's from inside. My mum, she's the same blood and we felt so close to her all the time....I'll never turn my back on my parents because they need me. (Madhuri Krishen , p42)

## **THE COSTS OF CARING**

The findings from this study in relation to the costs of caring are broadly similar to those reported in the white carers literature (Braithwaite, 1990; Parker, 1993) and other available evidence on minority ethnic carers (McCalman, 1990; Katbamna and Bhakta, 1998). Carers were devoted and did all they could to ensure that their loved one was taken care of and had their needs met. However, the responsibilities resulted in all carers incurring costs of one type or another.

### **Health related costs**

As outlined in chapter four, it has been argued that the relationship between care giving and ill health remains equivocal (Parker, 1990). Evidence from carers in this study, however, suggests that certain types of health problems can be attributed to caring and supports Hirst's (1998) more recent findings.

Carers suffered from a variety of ailments and conditions such as colds, loss of voice, and generalised aches and pains. Female carers more commonly reported general ill health. Although general health problems can occur irrespective of whether one is involved in caring or not, carers did not see it like that. Unlike Katbamna and Bhakta's (1998) findings, carers in this study saw their caring role as being a cause of even generalised health problems by comparing their previous health status with their current health status. For instance, those that used to be employed before taking on the caring role spoke about how little time they used to have off sick from work but, since being involved in caring, felt as if they always had something wrong with them, such as having a cold or losing their voice. Some carers, although they were young (under 65 years of age) felt that they had aged and that their overall health status was poor. Others have reported that self perceived ill health is generally high among minority ethnic communities (Rudat, 1994; Smaje, 1995). Combined with the higher

rate of chronic illness (Modood et al, 1997), this obviously has implications for carers. Services will need to be prepared to cater not only for those that are aging prematurely but also those that migrated in the early 1960s and 1970s who will be approaching retirement (Patel, 1993). Further, the majority of carers in this study, as reported earlier, were desperately unhappy and gained little satisfaction from their role. Being ill was another factor which contributed to their unhappiness. However, not all health problems could be attributed to their caring role. Conditions such as increasing frailty, limited mobility and deafness experienced by older carers, for instance, could be put down to the ageing process.

The major health problems experienced by Gujarati Hindu carers fell into two main groups: those that affected their physical health and those that affected mental well-being.

The commonest *physical problem* reported by both male and female carers was that of backache, with combined shoulder ache for some. Carers involved in providing intensive 'hands on' care reported that they suffered from back problems which meant that they too were in pain and were taking painkillers. Yet they had to carry on caring even when they did not feel well as there was no one else to take over:

If I'm not feeling well and I want to lie down in bed for a couple of hours in the morning, I can't do that, if I'm sick, not feeling well, still I have to look after [daughter].(Sheetal Soni, p10)

Back problems were attributed to lifting and handling the cared-for person on a daily basis. In some cases carers had little time to acquire knowledge or gain the skills required concerning correct lifting and handling techniques. Further, minority ethnic people are generally smaller in stature, thus lifting was particularly problematic when the carer had aged, or because grown up children were often as big as or larger than their mother in size, or because the cared-for person was not able to help much or had uncontrolled movements.

Moreover, as reported in chapter seven many carers lacked knowledge about or were not shown or were not able to access information that would have enabled them to protect their back and prevent long term injury. Some of these carers had been caring continuously for over twenty years. Problems were further exacerbated due to lack of equipment, appropriate adaptations to the home and poor housing conditions, as reported earlier, or lack of support from informal or formal sources, as discussed later. Male carers also suffered back problems. In one case, this led to early retirement. In some cases, carers' problems were intensified by the fact they were caring for more than one person.

For some carers, their day usually started in the early hours of the morning and they had little or no time to rest or take a break during the day. Caring did not stop during the night either. The continuous demands meant that carers experienced extreme tiredness as a result of sleep deprivation:

We don't go to sleep until at least 12 o'clock at night. So how many hours sleep do you get you know, all these years I've hardly slept. (Shanta Hari, p22)

Lack of sleep was also an issue for those caring for someone with a mental health problem:

Well in the night he [husband] usually wakes up two or three times, and then he wakes me up. If he can't sleep he'll just wake me up and he'll say "come on let's go downstairs and sit". (Priya Thakrar, p9)

Hirst (1998) has revealed that caring had the greatest impact on carers' *emotional health*, especially among those more 'heavily' involved. Similar findings were evident in the current study. Some male carers even turned to smoking in a bid to relieve stress and enable them to cope. Carers used terms and phrases such as 'stressed', 'distress', 'anxious' interchangeably to describe how they were feeling. Carers were thus both physically and emotionally drained. They spoke in terms of feeling continuously stressed, run down, tired, forgetful and, at times, depressed with the situation they had found themselves in. Overall female carers were far more stressed and anxious than male carers. However, this is not surprising as they bore the brunt of the responsibility.

Heightened levels of anxiety remained with carers throughout the day and during the night: "I always feel anxious all the time because of him." (Shanta Hari, p22)

Consequently, carers felt that caring had changed them from the person they once were. All but one (Vikesh Anand) reported they were far more short tempered and became angry easily over trivial matters. Those involved in providing both personal and practical support over many years had the most difficulty controlling their anger:

I don't have even a bit of patience... I get angry just like that... It's just my temper's got worser...I think I have become very rude person sometimes. When you get, the pressure gets too much. I just can't [control temper]. (Madhuri Krishen, p23)

Although anger was often short lived, it resulted in heated arguments with spouse, children or other family members. A few carers reported depression and one carer eventually had a nervous breakdown.

Several factors influenced carers' psychological well-being. Firstly, the *workload* contributed significantly to feeling stressed. This was either because carers could see no end to the caring

or because they felt that it had impacted on their lives in many other ways. It had restricted their social life, caused marital problems and affected their home life, for instance. For those living within an extended family, the stresses were far worse. They had to combine caring with meeting the demands of other people, as well as family and social obligations:

My father-in-law and mother-in-law they like to invite people now and then...they will just do it. They don't ask me. I can't say much about it... I just have to do it [cook]. People do come round but even then it still feels like [they imply] that we are not doing that. (Alisha Ram, p24)

Another factor that caused anxiety was that of *concern for the cared-for person*, both in terms of their health status and what would happen to them in the future. Carers remained anxious about the health and welfare of the cared-for person throughout the day and night. As reported earlier, some took active measures to keep an eye on the cared-for person by having them sleep in the same room as them. Carers tried not to put the cared-for person under any undue stress, or make any demands and frequently gave in to their needs. Even those carers that were working and had the opportunity to 'get away' from caring, mentioned that they 'phoned home several times a day to check that the cared-for person was all right:

It's constantly on your mind. Even if I'm at work, I'll ring home to her and say "how did she do this morning," "did she have a cup of tea this morning," "did she have toast"? You know that it's just a worry...It's always there to me. On my mind. (Shivam Ranchord, p12)

A cause for concern and great anxiety among many carers was the future welfare of the cared-for person in the event of something happening to them. Who would look after them and what would happen to them were questions repeated throughout interviews:

...I get very depressed sometimes and think if something happened to me or my husband, what's going to happen to her? (Radha Nayan, p7)

However, as reported later, many carers did not know which services could support them. The thought of long term residential care had crossed carers' minds, but they did not know where homes were located, what type of services were available and whether the homes would be able to cater adequately for the needs of the cared-for person.

Caring had however made carers much stronger in character. This change in personality gave some the ability to challenge and question professionals. This tended to be the younger carers with children with disabilities and those that were fluent in English:

Mentally it's probably made me a bit more outspoken and I used to accept things...I used to say, well fine, carry on.....but I'm a bit more aggressive. I have, I've changed, and I'm becoming a bit more assertive, you know assertive for my rights sort of thing. (Radha Nayan, p13)

## Social costs

Parallel to findings in other studies (Lewis and Meredith, 1988; Parker, 1993; Katbamna and Bhakta, 1998), carers experienced many changes in their social life. Some of the main causes of social isolation were linked to time constraints due to the demands of care giving, restrictedness (Twigg and Atkin, 1994), limited financial resources and lack of support. Many carers experienced extreme isolation. A combination of terms was used to describe feelings of restriction such as 'trapped', 'housebound', 'can't do what you want any more'. Time constraints were one of the main reasons for social isolation among carers, especially females:

You know its time consuming because you don't have any other time, you don't get time to do any other things. (Alisha Ram, p20)

The *demands of caring* left little other spare time especially as caring often started in the early hours of the morning. Whatever time was left would then be devoted to housework. For those living within an extended household or caring for more than one person, it was a continuous cycle of caring and chores. Carers felt restricted and unable to escape from their circumstances:

Well I just think you know, my life's finished, it's ended now. I've got no other life, I'm just looking after them, and that's it...I've got no other life, other than just look after them. I don't go out, I can't go out even if I want to I can't...I have to look after them and their needs, everything comes first with them (Alisha Ram, p14)

Sometimes those who were in contact with carers assumed that, because the carer was 'only' caring, they would have plenty of time to do as they wished as they were not really working:

Even people think, oh, you know, we've got enough time, we can do the things what we wanna do, we got enough time to do things. But it's not, it's like 24 hours like I gotta keep my eye on my mum and dad. (Madhuri Krishen, p29)

Limited satisfaction in caring and difficulties participating in social activities meant that carers were dissatisfied and unhappy. They felt restricted because they were unable to do simple things that other 'normal' people would do, for instance, drink a cup of tea, watch television or go shopping:

*Bahr lage* [feeling over burdened: too much work to do], when you compare yourself with normal family...everybody's just sitting around watching television, video. I don't even get time to sit down. (Shanta Hari, p18)

Isolation was also heightened because of feelings of *restrictedness* (Twigg and Atkin, 1994). A few carers felt unable to leave the cared-for person alone at all, not even for a few moments. This was largely because of concerns for their safety. As reported earlier, some cared-for persons needed constant supervision and monitoring because they had no awareness about danger. However, other carers in similar circumstances had devised strategies that

enabled them to at least go to the local shop. Carers tried to snatch a few moments out, if the cared-for person was playing or asleep, for instance. Time was, however, very limited. Further, before venturing out, carers double checked the home to be sure that the cared-for person was going to be safe and occupied.

However, some carers who had made attempts to go out and socialise were put off because of the process of getting the cared-for person ready. This usually involved getting all the things they needed together such as a wheelchair, clothing, pads and medication and then having to meet the needs of the cared-for person at the social event. It was not only time consuming and physically exhausting but the satisfaction and rewards gained by attending the social event were not sufficient in comparison to the effort required to organise a day out. Further, difficulties were compounded by lack of wheel chair or pushchair access to buildings and lack of private facilities, particularly when changing incontinence pads of adult children. This was an issue not only when visiting relatives but also if using hotel accommodation:

The wife wouldn't feel comfortable you know of changing and bathing her in someone else's house. Even well a hotel probably be a bit of privacy yeah, but it wouldn't have the facilities there...special bath and toilet and things like that.  
(Shivam Ranchord, p16)

Loss of joint activities either between husband and wife or as a family unit was important. Carers referred back to activities or things they did pre-caring and felt saddened that they were no longer able to participate fully:

You don't have family life...Like normal people, we don't have that life.  
(Sheetal Soni, p8)

Even if carers managed to get out they could experience feelings of guilt. Going out and enjoying oneself was viewed as selfishness:

We felt very guilty for going out and enjoying ourselves 'cos you know...knowing that [son was very ill]... (Sameer Gokhani, p20)

Travel was usually restricted to local areas. In cases where it was essential to show one's presence at a function then only one member of the family would go, and carers would try and organise a lift in the car with other relatives that were attending the same function.

Consequently, long established friendships or contacts had either broken down or diminished as a result of carers' involvement in their caring role and their inability to participate in social activities. Other than religious activities, carers lost interest in taking part in activities that focused on their needs. Since caring, a number of carers had become more religious minded, thus they limited their activities by attending preaching and visiting the temple for instance:

I used to go to the pub at the weekend. I used to eat meat. But I've given all that up now...Well the friends that I've made afterwards are the ones that sort of believe in religion, and we're a big group...You know, like a family. If we want to go to *Bhajan* or *Kirtan* [attendance at functions to listen or sing religious songs] you know I'll take her with me. (Vikesh Anand, p18)

*Limited financial resources* played a significant part in the social isolation experienced by carers, particularly in terms of entertaining guests, meeting *biraderi* [obligations] and participating in *vartan bhanji* [give and take] (Ahmad, 1996). Ahmad (1996) provides a comprehensive account of the origins and meaning of *biraderi* and *vatan bhanji*. Katbamna and Bhakta (1998) in their study, used existing terminology from Ahmad (1996). However, *biraderi* and *vatan bhanji* are terms that Gujarati people would not be familiar with.

Within the Gujarati community, the term *wear waar* is used to describe both give and take and meeting one's social obligations and has the same meaning as Ahmad's (1996) *biraderi* and *vatan bhanji*. *Wear waar* is thus a term not previously documented in the literature.

Carers either limited or were not able to participate fully in *wear waar*. This had implications because other felt that carers were using caring as an excuse not to keep within *wear waar*:

Well what can you do. It is like that isn't it? Because after she's become ill I can't go out, I just have to sit in the house...Well one of my sisters she lives in the next street and even she mentioned last week "Brother, you haven't come for a year now", you know. So I said to her, "How can I come sister?" (Gopal Mithun, p12)

Financially reducing *wear waar* was noticed by relatives who then accused carers of changing from the giving person they once were:

They're saying that we have changed. You know, *amara dil* [within our heart] I am able to give them things [love], but because we have cut down [on *wear waar*] and things like that people say things like that. (Vikesh Anand, p24)

Dependency on benefits and limited resources meant that although carers welcomed guests or would have liked to have a holiday, they were restricted financially. Male carers spoke of the additional financial costs of entertaining guests, particularly as they would be dependent on ordering food from the restaurant, which was costly, and an expense they could not afford.

Goffman (1974) in comparing stigmatised with 'normal' people in social settings writes that 'normal' people either treat the stigmatised person as someone who is:

better than we feel he might be or someone worse than we feel he probably is. If neither of these tacks is possible, then we may try to act as if he were a 'non-person', and not present at all...of whom ritual notice is taken (p84)

Social isolation was more intense for female carers and in many respects their experiences were very similar to those described by Goffman (1974). Housework and caring were seen as women's responsibility, leaving female carers with a *lack of support* or sympathy from their husbands, relatives or wider community:

I had to make the sacrifice at the end of the day...but there was all the frustration, there was loneliness as well, no-one to talk to about it. When my husband got home, he didn't want to talk you know. And there's always this thing about being at home, it was always branded to me well, I work all day, because you don't work, I didn't feel as if I had a status anymore. I was a nobody. (Madhu Gokhani, p10)

These feelings were intensified and reinforced when greeted with guests, who continued to talk to other members of the household but had little to do with carers, as it was assumed that as they were at home all day they would not have anything to contribute:

And then it was like when we had people come round, they won't ask me. It was like everything I had to say wasn't important anymore because I wasn't working. They talk about work and what they were doing, and nobody sort of asked me, how are you...They just thought, I'm at home, well you know, there's nothing to ask really you know. And you just felt like a nobody really. (Madhu Gokhani, p10)

A few carers longed for company and did invite people to their home. However, people were either not willing to visit because, for instance, the 'smell' of incontinence put them off, or emotional outbursts by the cared-for person resulted in people withdrawing contact but then going on to gossip about the cared-for person within the community. Further, traditional support networks broke down. Over time, friends stopped visiting and support from relatives diminished and was non-existent. Thus carers were isolated and alone, with no one to talk to and no one to support them:

No, no, no, no. They'll [relatives] just say "*so so nae sambare*" [everybody looks after their own]. Nobody provides you with any support in this country, who will support you? (Priya Thakrar, p14)

The sentiments of Priya Thakrar were echoed by all carers. Lack of support from friends, neighbours and, in particular, relatives was an issue that generated by far the most criticism. No one offered to take over or sit with the cared-for person for even a short while to relieve the carer of his or her duty. Instead, there was an expectation that the carer should ask:

It's so easy for people to say "Oh, we'll help you, tell us if you need help, we can help you" but it's so hard to ask for help. (Madhuri Krishen, p16)

Further, Gujarati Hindu carers were reluctant to ask for help due to negative past experiences of having requested help and being refused. In some cases, they felt unable to ask for help either because they lived in a neighbourhood where they felt unable to trust anyone or because neighbours were elderly and carers felt that even keeping an eye on the cared-for

person was too great a responsibility for them. Those carers that lived with other family members who could have taken over the responsibility also felt similarly. Carers felt guilty asking for 'time off' because, for instance, sons or daughters were studying, or husbands were busy working during the day, thus being involved in caring would have been an added responsibility for them.

A break from caring would have enabled carers to participate in social activities and do other things. However, most were not able to have one or were reluctant if it meant having to take the cared-for person along, as this was not viewed as a real break. Difficulties were intensified in situations where the carer was torn between desperately wanting a break and the cared-for person objecting to using formal services and making carers feel guilty. In one instance, the cared-for person objected to having formal nursing service input and refused to use respite:

...but if I call her [nurse] then she's not happy with it...I have to do it. What else can I do? If I had the chance of not doing it [caring] then I'd have more time. I can enjoy myself. I have to *bhaugowoo pada* [tolerate/put up with situation]. (Vikesh Anand, p16)

Moreover, many carers lacked knowledge about which services were available that would benefit either the cared-for person or themselves, or if having found a service they felt would have been able to support them, felt disappointed with the service provided. Carers' experience with formal support services is discussed later.

### **Family costs**

Studies on informal care among white and minority ethnic communities have highlighted the consequences of care-giving on family and married life. It has been reported that women often feel torn between meeting the needs of the cared-for person and those of the rest of the family (Beresford, 1994; Katbamna and Bhakta, 1998). Similar findings emerged in this study. The majority of carers had to combine caring with looking after other family members, for instance, children or spouse or in-laws. This was problematic in view of competing demands and pressure of workload. Female carers, in particular, spoke of their other children being neglected and experienced feelings of guilt. However, both male and female carers considered themselves to be different from other 'normal' families. Feelings of no longer being a 'normal' family resulted in carers withdrawing and losing contact with people, often as a result of insensitive remarks and, as reported earlier, workload pressures and financial limitations. There was a general consensus that non-carers could not understand and had no insight into what caring was really like and its impact on carers' lives.

Studies that have looked specifically at the impact of caring on marriage report both positive and negative impact. Spouse carers in Parker's (1993) study reported that negative feelings could be counter balanced by positive feelings of having a much stronger relationship and being closer as a result of one spouse becoming disabled. However, Quine and Pahl (1985) suggest that caring can lead to a break down in marriage when disabled children are being cared for.

In the current study, only one carer felt that they had a stronger marital relationship since caring (Anant Laxman). However, he was one of the *engulfed* carers, (Twigg and Atkin, 1994). Moreover, his wife who was also present at the interview made no comments on the matter. As discussed in chapter five conducting a joint interview with this particular couple was difficult as Anant Laxman took the lead with Prabha Laxman rarely commenting. Secondly, comments by Anant Laxman did not 'match up' with her reactions and expressions during the interview, when she sat some distance away and cried at times. Some of his comments and statements were thus a 'public account' of what he felt should be heard or openly discussed. Although other carers had many arguments, usually after husbands returned home from work, some had been married for many years and none implied that they would rather divorce. The exception was Madhu Gokhani who was not sure whether she and her husband would continue to stay together.

So when [son] came home I was involved with his life, that [husband ] and myself didn't have a life. So of course when [son] died we had to pick the pieces up and it was difficult because we had both changed... I think we both want different things now. I think he wants it to work and I don't know, you know. I don't know anymore. (Madhu Gokhani, p41)

Caring had affected other carers' married relationships too, with female carers feeling tired and no longer interested in personal relationships and male carers feeling that, despite caring, this was one area that should not be affected:

Yes it happens [arguments], it used to happen more then. You know what men are like, they only have one thought. It doesn't matter how many children they have, men will never become old. Men's thoughts are always diverted to that and as soon as it's night time, they have only this one thought. So this would happen with us. You know, because I would just turn round and go to sleep because I have to get up in an hour. If he[son] gets up then it's always me who has to get up. (Shanta Hari, p41)

Ties of duty and obligation resulted in one female carer (Madhuri Krishen) putting her marriage "on hold" for several years because she had suddenly found herself caring for both her parents and younger brother. She was due to be married four days after the interview and spoke at length about her concerns for her brother and whether he would manage without her,

especially as their mother required personal and practical care. In addition, their father was described by them as being a 'hazard' and her brother could not cook. She eventually married but continued to 'pop' back home to check in on her parents and to make sure her brother was coping. However, regular visits to her parent's home were met with disapproval from her mother-in-law. As she was now married it was her duty as a daughter-in-law to look after the needs of her new family. This resulted in arguments with her husband as she felt unsupported when he did not defend her when his mother spoke ill of her. The marriage was short lived and both went their separate ways within months. Although this is a rare case, it illustrates how strong and deep set cultural values, beliefs and tradition are. Issues concerning one's duty, obligations and role expectations seem as paramount and as alive today as they were in the past. Migration, if anything, has reinforced and strengthened these beliefs further (Ahmad, 1996)

### **Financial costs**

The findings from this study about the financial costs of caring are broadly similar to those of existing studies (Baldwin, 1985; Cocking and Athwal, 1990; Glendinning, 1992; Katbamna and Bhakta, 1998). However, in comparison to white carers, the circumstances of Gujarati Hindu carers were compounded by: high levels of dependency on benefits, keeping up with traditional obligations, and general material disadvantage. As a consequence, carers experienced financial hardship and found it difficult to run the home.

A number of carers gave up work or significantly reduced the number of hours in paid employment. Overall this tended to be female carers. The exception was Anant Laxman who eventually left work to help his wife when she was no longer able to lift her adult son. The effect of this was a *high level of dependency on benefits*. Disability living allowance, attendance allowance and income support were the main benefits carers were in receipt of. One carer also received incapacity benefit as he had injured his back due to the pressures of lifting and caring for his wife. However, many carers experienced delays in receiving benefits because they lacked knowledge about entitlements or found out 'too late', in some cases several years after they had become heavily involved in caring. Mital Popat who cared for his mother, said, "... but I didn't know she could get disabled allowance and all this you see, I didn't know anything about that...I would just manage, just manage" (p10). The findings are similar to those reported by Cocking and Athwal (1990) almost 15 years ago.

In addition, carers had the added pressure of convincing the benefits agencies how heavily involved in caring they were before getting financial support. Alisha Ram cared for her

mother-in-law who had several strokes, a daughter with leukaemia and her elderly father-in-law. She spoke about her claim in relation to caring for her mother in law:

Well what happened at that time was they never used to give us anything at that time. Well as carer I've been looking after her for nearly four years...but it's only been the last two years that we've been given help. (p6)

As with studies of white carers, there was also the strain of meeting additional disability-related costs. These included extra telephone costs to ring for appointments, extra heating costs to keep the house warm during the day when they would otherwise be out at work, travel and taxi costs for hospital appointments, additional laundry costs (more use of the washing machine and washing powder and drying costs), the expense of buying incontinence 'pads' and additional clothing (sometimes, made to measure) shoes, air fresheners, or food. However, the high reliance on benefits and limited resources meant that carers were largely dependent on formal provision.

There was also the additional cost of *keeping up with traditional obligations* [*wear waar*] which added to the financial difficulties. Gujarati Hindu carers therefore devised strategies that enabled them to weigh up whether it was essential to be involved in *wear waar* or not. This meant that they had to think carefully about to whom (near or distant relative/friend) the money was going, in order to decide how much they could realistically spare, without embarrassing themselves in the process:

Well in terms of those sorts of things [*wear waar*] I had to cut down. You know, when I had the money we would give five or ten pounds, but now we have to think about it. You know, you have to think, should I give two pounds, or shall I give five pounds you know. I think now, that if I can manage by just giving two pounds then let's do it that way. (Vikesh Anand, p23)

For some carers there was the cost and stress of saving for weddings. For instance, it is customary for parents to give gold jewellery such as a necklace or bangles to their daughter as a gift when they marry. Carers were saddened as they felt it was not within their means to do this.

Carers' circumstances were further compounded by *general material disadvantage*. Hence, Gujarati Hindu carers that were working were employed in low paid jobs and consequently stressed but earning very little. The majority of carers did not own a car and were therefore dependent on bus and taxi services. Travel by bus was problematic because of the effort required in getting the cared-for person to hospital appointments and travel by taxi was costly. And carers did not have the financial capacity to repair and maintain their home.

## **COPING AND NOT COPING**

In this section, the analysis looks specifically at how carers coped or not with their caring responsibilities on a day to day basis. Previous research on informal caring among minority ethnic communities (Katbamna and Bhakta, 1998) did not explore coping. However, whether carers cope and the strategies used to enable the process are important, particularly as more recent research (Atkin and Ahmad, 1999) suggests that appropriate professional support can reduce stress and facilitate coping.

### **Crying**

The most common strategy adopted by female carers was that of crying. Episodes of crying were more frequent in the early stages, a period when mothers of disabled children, in particular, were feeling very vulnerable, and often feeling worse because of insensitive remarks from family, friends, neighbours or the wider community. Much, however, also stemmed from their inability to accept the diagnosis, if given, and the situation that they had suddenly found themselves in. Although it is often said that, “time is a great healer”, this was not the case with female carers in this study who still resorted to sitting down and having ‘a good cry’ when they were feeling particularly stressed.

For many carers in this study, the research interview was the first time someone had asked them about their feelings about caring. They were not used to this, as their dealings with health and social care professionals often related to the needs of the cared for person. This interest in their needs resulted in female carers crying uncontrollably at times during the interview as they talked about their experiences. In contrast, none of the male carers mentioned that they ever cried and none openly cried during the interviews. Only one male carer (Vikesh Anand) showed some degree of emotion during the interview when he became very quiet, ‘lost for words’ and had tears in his eyes when explaining how his personal relationship with his wife had changed significantly since her brain haemorrhage.

### **Self-indulgence**

Male carers, by contrast, turned to self-indulgence as a means of coping, giving themselves treats such as watching television or smoking. Sameer Gokhani said:

I like to wind down in front of the TV, that’s my way of coping with it (p12).

As mentioned earlier, some male carers who had given up smoking many years previously had turned to it again since being involved in caring. Vikesh Anand, for instance, mentioned that he knew smoking was a bad habit but said:

after just one cigarette you know, I feel better, and my mind feels *shanti* [at peace] again, because the stress goes away, then I'm able to go back to it [caring]. (p11)

Others ways of relieving tension mentioned by male carers included having 'a nice cold drink', requesting not to be disturbed, going for a drive or 'popping round' to see the neighbours. None of these strategies were mentioned by the female carers in the study. However, female carers shouldered more responsibilities thus giving them fewer opportunities to take or justify to themselves the need for a break.

### **Approaches to life**

In order to cope with the daily routine of caring, carers also tried not to dwell on their situation by "not thinking too much" and concentrating on caring alone. This involved a process of "blocking things out" and taking less interest in the activities of other families or in the community. Some carers deliberately isolated themselves from other people because of lack of understanding about what it was like for them to care and peoples' attitudes concerning disability. Carers ignored remarks in order to maintain a sense of inner peace.

### **Religion**

Religion played a significant part in some Gujarati Hindu carers' ability to cope and continue caring, and was important to both male and female carers. It provided the basis for social contact and, importantly, the opportunity to draw emotional support from like minded religious people without expectations of reciprocity or mutual exchange that are usually prerequisites of friendship or neighbourly support (Bulmer, 1987).

Visiting the temple or attending religious gatherings or group preachings enabled carers to have interaction with people that genuinely sympathised with carers and showed understanding. This made continuing to care that bit easier. Religion gave carers the strength to continue caring as well as being a source of comfort for them. For some carers, their religious beliefs had become much stronger since being involved in caring. Mital Popat, for instance, spoke of his faith in God increasing "one hundred per cent". Some felt that they were able to continue caring only because of God's support:

God gives us *shakti* [strength]. We believe in God and we've got God's support. We've got his *shaat* [supporting hand]...it's because we've got his support that we are able to do these things day to day. (Anant Laxman, p29)

Carers' increased faith in their religious beliefs meant that they were more involved in religious duties and acts than previously (before caring). The majority had a place of worship set aside in the home where they prayed and lit a *dewa* [candle], read holy books, listened to

cassettes with *bhajans and artis* [religious songs] or watched *dharmik* [religious] documentaries and films. Some carers had become devoted followers of spiritual Gurus or preachers and found strength to continue caring from listening to them preach.

Vikesh Anand, for instance, often went to gatherings when *Morari Bapu* (a Hindu priest) visited England and was preaching. He spoke how he had changed his lifestyle completely after listening to him, which he had done since taking on the caring responsibility. He said:

Yes, yes I do believe in God more... And the thing is, he's given us a lot of help as well. I try to work by *bhagwan- noo- naam- lay- nai* [remembering God's name]. But since then, I've had more faith in God. Before I used to be non-veg, drinking everything. After ten, twelve years now, I've turned vegetarian. And then afterwards in 1988 when the *katha* [listened to recitals by Morari Bapu – priest], took place, I changed completely. I decided that you know, no I have to stop this [drinking and eating non vegetarian food] and whatever I was doing was wrong. (p5)

Similarly, Shanta Hari spoke of caring being too much for her but being able to cope because of her beliefs in her Guru and his teachings. She said:

That's why I pray to God. I do God's *Bhakti* [pray] and ask him to show me the right way. Since last five years, we have found *swadhiya* [started believing in a Guru and attending regular meditation programmes and preachings]. And they say that the body that God has given us, then we ought to use that body to do good work on earth. You've been given intelligence and a body to do good work on earth. Do good deeds before you leave [die]. And whatever work you do, don't do it begrudgingly. Do it with a smile and that's what I've realised. (p20)

Some carers coped with their circumstances by accepting disability and caring as being "God's wish" and therefore believed that the situation was beyond their control and something that they just had to deal with.

Only one (female) carer spoke to the contrary about her religious beliefs. Madhu Gokhani spoke of losing all interest in God and religion. Although her family were horrified with her attitude and behaviour, for her, watching her son suffer before his death was proof that there was no God:

My mum started doing a few things like fast, I refused to do it. I mean the only time I've done it recently, was when it was a special month to remember people who had died. And I did it then, I fasted for two days for him [son]. But if it had been something I had to do for myself I wouldn't. I'd refuse to do it. I mean I would probably celebrate Diwali because of [other child] and my husband, but I refuse to do it. I refuse to believe in anything. I don't see if there was a God, why did he let [son] suffer as much as he did? He did suffer a lot, you know. I don't think there is a God. There can't be, there is no reason to let a child suffer as much as that. So no. (p40)

## **Anger**

The fact remains that 'it is much easier to look after someone for a few weeks rather than for years' (Allen et al, 1983, p74). Despite using different strategies to facilitate coping, when caring became too burdensome, these carers experienced periods of anger, frustration and unhappiness. Carers spoke of wanting to "disappear", more so when they were feeling tired and emotionally drained.

Incidents of inability to cope were reported by both male and female carers. Not coping was recognised by carers who reported being angered more easily as a sign of their inability to cope with the demands and pressures of caring. Anger was usually directed at other family members or in some cases at the cared-for person:

You get very angry, get to the point where you could throw him [son] in the cot and say, "stay there." (Sameer Gokhani, p17)

## **Abuse**

In one instance, anger eventually turned into abuse and the carer had a nervous breakdown. Madhuri Krishen was 26 at the time of interview; she had been caring since the age of nineteen for her parents. She spoke of her experiences:

You know, it's two people... My mum's not too bad... if I make her sit in a wheelchair, she'll sit there...but not my dad, he's moving around and everything and he seems to make too much mess....When he goes to the toilet he messes everything up. It's all over the place, on the floor and everything...like he's filthy and he's not clean and these kinds of things and in between my mum's nagging...she's really whingey and everything. That's when you get really angry 'cos you know here I'm cooking, my dad's messed over the toilet, my mum's crying loudly like a baby and everything...You feel like telling her to shut up but you can't because she don't understand...One thing, she'll go over and over again until we do it and those are the kind of things that really annoy you...She don't know how busy I am...so you just get angry and I'll just push her in the chair.... I think it happened once or twice and I really really hated myself badly... I think she was spitting on the floor and I said "you'd better stop that mum or I'll hit you" and I keep telling her but she don't understand and she was keep doing it and I just, I don't know what happened, all of a sudden I just gave her a slap and at that time I felt so small and really bad inside and it happened another time as well...

After the incident, Madhuri Krishen was totally guilt ridden and ashamed. Unable to cope with her actions, she sought medical advice. She was eventually referred for counselling. But this was only after she started to self harm.

In this case, the carer recognised herself that she was not coping and sought advice from the doctor. The nursing services were in place, yet she did not receive the support she deserved. It may have been that she was seen by the nurses as a young able-bodied female who was coping. However, it was precisely because she was young that she felt restricted and trapped

in the situation, unable to pursue an education, having to put her marriage on hold and having limited time to do as she wanted. Although her brother helped, her responsibilities were far greater. Whilst lack of time remains an issue for professionals, a few minutes of genuine interest and concern for the carer may avoid situations like the one above.

As some of the examples have shown, it was not until carers reached crisis point and were totally overwhelmed with their responsibilities that they were able to access the support they needed. The next section explores more closely the issue of support from formal services.

## **SUPPORT AND CARING**

Community care policy has been based on the idea of self supporting families having strong social networks of friends, relations, neighbours and the like to help and support each other in times of need (Griffiths, 1988). The move towards community based care was generally welcomed. It was assumed that this approach would not only help ease the State's financial burden but also reduce dependency on State services (Parker, 1993). However, 'it was only during the 1980s that we were 'helped to discover' that living at home was good for us' (Lawrence et al, 1987 in Nolan et al, 1996, p154). This view was based on assumptions that living with the family as opposed to being cared for in an institutional setting would be in the interest of both the cared-for person and their family (Parker, 1993). However, 'carers and cared-for persons may hold very different views about what constitutes support, and how beneficial and enduring its effects are' (Rook, 1992 in Nolan et al, 1996, p9). Dependence on a relative or partner can be 'the most exploitative of all forms of so-called care delivered in our society for it exploits both the carer and person receiving care. It ruins relationships between people and results in thwarted life opportunities on both sides of the caring equation.' (Brisenden, 1989 in Parker, 1993, p43).

As discussed in chapter three, policy and practice have taken a long time to acknowledge that carers rarely operate within the 'ideal' of a self-supporting community. This acknowledgment has taken even longer for minority ethnic carers. Instead, there has been, and remains, a generally held view among health and social service providers that minority ethnic communities do operate this 'ideal'. Living within an extended household is taken as proof that there is ample support for minority ethnic carers from within the family, (Lee, 1987). In the next section, this issue is explored by examining support from informal sources. The context is set by looking first at what the current study revealed about attitudes towards disability within the Gujarati Hindu community and its impact on carers.

## **INFORMAL SUPPORT**

### **Attitudes of relatives, friends and neighbours**

Informal support has been shown to be an important coping resource (Baldwin and Carlisle, 1994), yet widespread negative attitudes concerning disability resulted in Gujarati Hindu carers having little support from relatives, friends or neighbours. All carers had experienced negative encounters with people they had contact with. Negative attitudes concerning disability were aimed at both carers and the cared-for person. Female carers experienced greater insensitivity. Mothers of disabled children cried as they described how they were treated by relatives, friends and others, who instead of consoling mothers, blamed them for causing their child's disability and then cited religious and cultural beliefs as confirmation. Carers were bluntly told that they were 'paying for past sins'. Other examples include beliefs that the mother must have 'eaten something' or that she did not take adequate care during the pregnancy. Parents whose children became ill later in childhood also had similar experiences:

And all the time they [in-laws] used to tell us, at that time they used to blame us for my daughter's illness. (Alisha Ram, p10)

This left female carers with no one to turn to for support. Even those that were once close to carers were far from sympathetic. In addition, carers had to put up with insensitive remarks:

Asian people have said "aren't you ashamed, you should be ashamed of yourself bringing him [son] here" [social function]. You know, "how could you do that." (Madhu Gokhani, p7)

People often stared at or ignored the cared-for person, for instance by not acknowledging their presence or picking them up. At times, comments such as, "Look how she was, and look at her now" only made the carer feel worse (Vikesh Anand). Carers were hurt by people's attitudes towards them and the cared-for person and soon lost contact or significantly reduced their dealings with people. Negative attitudes were so deep set that ceremonies or functions relating to the cared-for person that were of importance to carers were not taken seriously by other people, who usually failed to attend. Many carers believed that relatives and people in society generally had a dim view of disability, often lacking in understanding both in terms of how disability affected carers and the cared-for person and the impact on their lives and that, "It's [disability] your problem, you deal with it" (Sheetal Soni).

People's views about how disabled people should be treated meant that carers also had to put up with remarks from neighbours, for example when they felt it was "cruel" when carers tried to carry out therapy when encouraging a physically disabled child to learn to walk (Radha

Nayan). Carers spoke of other people not understanding what it was like for them to care. The views of Pritesh Krishen, for instance, were echoed by all carers:

“Friends have no idea, unless you’ve been through it, you can’t understand.”

### **Support from within the home**

As shown earlier, on the whole, there was limited support for carers from within the household. Many female carers did not get the support they would have liked from their husbands, especially when a disabled child was younger, as seeing to the needs of the child was regarded as the mother’s responsibility or duty. Yet, the situation was no different years later when the child became adult. Support from husbands was on an ad hoc basis as opposed to regular. The exception was Anant Laxman, who gave up his job to help his wife in caring for their son as she found it too difficult to lift him by herself.

In terms of support from other children, carers received more support from daughters than sons. Daughters helped with cooking for instance. Those that were studying away from home helped on return from university by attending hospital appointments or by keeping an eye on the cared-for person or with housework. However, carers had reservations about asking children to support them. Many hoped that their children would not end up being carers in the future as they did not want them to have the type of life they had. Some carers, however, preferred not to involve their children in caring at all as they did not want to become too dependent upon them. This was largely because they knew that one day their children would leave home and there would be no one else to support them then. Interestingly, none of the carers discussed what types of tasks their sons helped them with. Some spoke of their sons helping with “everything” but were reluctant to specify what they did to support them.

### **Support from relatives**

Although there was evidence of carers living within an extended family household, contrary to the popular notion that the extended family cares for its own, carers’ accounts revealed that they had little or no support from relatives, friends or neighbours where personal care was concerned. Carers involved in personal caring tasks mentioned that other brothers and sisters or sisters in-law would not help in this respect but had expectations that the carer should continue doing so. Some mentioned that they received some support from relations when they initially started caring, by offering to look after other children for instance. However, this was often short lived. On the whole, the majority of carers felt that support from relatives or the community was simply not there and that they were very much on their own.

Further, there was the added pressure of meeting social obligations when guests or relatives visited. This was problematic as carers had enough to do, yet deep set cultural traditions meant both that guests expected to be entertained by eating meals or having snacks, for instance, and that carers felt obliged to live up to such expectations. This led to feelings of resentment, because carers felt they were not receiving the help and support from relatives (immediate family or distant) that they should have been given. This is important as reciprocity is the basis upon which support networks are maintained (Bulmer, 1986). However, not all carers wanted help with personal caring tasks, rather they wanted some form of practical support, whatever it might be - help with shopping for instance, was mentioned.

However, carers were also reluctant to ask for support from relatives for a variety of reasons, including past experiences of requesting help and then being turned down. For instance, Madhuri Krishen mentioned that relatives offered to take them shopping in the car when they had large amounts to buy, however, each time they telephoned to ask for a lift, the relatives made excuses as to why it was not convenient for them. When carers were fortunate enough to get some help from relatives (who usually did no more than keep an eye on the cared-for person) carers found that they then had to listen to endless commentary on their return about how stressful and terrible the whole experience was for them, or had to repeatedly express how grateful they were in order to keep the relatives happy and avoid being talked about in the wider community:

But you know with relatives they'll try and find out what is happening in your house and they'll tell everyone else and then they'll say that "oh in her house, this is what the situation is." You know, once I mentioned the pads [husband wears incontinence pads] to someone and you know that person went and told everyone that he has to wear nappies [starts to cry]. (Priya Thakrar, p14)

Further, and in contrast to what is known about white carers, Gujarati Hindu carers viewed support as something that they should not have to request but that should be offered:

It's their *faraj* [duty] just to ask you know, for instance if we ever needed any money or something. Just to let us know. If they just said that we are here for you. (Vikesh Anand, p21)

For some carers, just the gesture of support would have been enough, but even this was not forthcoming. Most carers were of the opinion that "everyone could have done something if they tried" (Madhu Gokhani, p13). Unfortunately, there was no one to support carers at the times they needed it the most. Nobody asked them how they were feeling and whether they would like any support.

The findings here are consistent with Chamba et al (1999) who reported in their study that Gujarati carers received little support from family members in comparison to Pakistani and Bangladeshi families. One can only speculate that ties of duty and obligation to support others are perhaps slightly stronger in the Pakistani and Bangladeshi communities and may be gradually dissolving within the Gujarati community who were the earliest arrivals to Britain.

### **Support from friends and neighbours**

Underpinning the philosophy of community care policy was that carers could rely not only on their family but also their wider network of friends and neighbours to support them. However, friends and neighbours do not have the same sense of obligation to care as immediate relatives (Finch, 1989; Parker, 1993). This was evident in this study from the limited support carers were able to obtain. Other than those few carers who were in paid employment, who subsequently managed to get some emotional support via their work colleagues and 'forget' about their problems for a while, the majority of carers received neither emotional nor practical support from friends or neighbours.

A few carers were, however, reluctant to ask for help from neighbours as they lived in areas where there were a number of elderly people, and therefore not able to offer support, or the area in which they lived was classed by carers as 'not safe' and one that had a high rate of crime. Feelings of vulnerability were thus an added source of stress which further isolated carers:

The area that we live in is not that brilliant, you can't really trust anybody  
(Madhuri Krishen, p32)

Some spoke of losing touch with friends and those they used to be close to. As shown above, long established friendships broke down as a result of social restrictions. The only form of support a handful of carers could rely on was from neighbours who helped by keeping an eye on the cared-for person for short durations only.

It has been suggested that families who have a greater number of support networks will be better equipped to cope with their situation (Kazak, 1986 in Smith, 1992). Carers in this study had a large network of social contacts, primarily made up of relations and people from the same community. However, as the analysis has shown, having a large network of social contacts is not proof of support; rather it is the content of relationships embedded within these social networks that is of relevance (Bulmer, 1987). Among minority ethnic communities, different relationships have different roles and expectations attached to them. This inevitably

adds to the complexity of doing what is expected, as well as doing things which may not necessarily be attached to one's role but out of the goodness of one's heart.

## **FORMAL SUPPORT**

Finally in this chapter, we turn to the issue of formal support. In relation to primary health care nursing support this issue is discussed in substantial detail in the next chapter. Here, we simply outline some of the issues carers raised relating to formal support in general.

Research has shown that the provision of formal services can enable carers to cope better with their situation (Atkin and Ahmad, 1999). In this study, there was little evidence of substantial involvement from formal services. The majority of carers were unaware of which services were available to support them or where they could be located. Difficulties were compounded by inability to access verbal or written information about available support services. The majority of carers were not referred onto other agencies or informed about other forms of outside support, such as support groups, respite services or advice centres, by those professionals with whom they had contact.

### **Support groups**

Only two carers had contact with support groups at the time of being interviewed. One carer previously attended a support group whilst another attended a local support group aimed at carers and users of mental health services. In another case, a male carer had approached a support group coordinator and made several requests for support, yet his request was not taken seriously by the coordinator, which subsequently destroyed his confidence in formal support services.

Mothers of children with disabilities in particular would have welcomed the opportunity to talk to other parents in similar circumstances. Sheetal Soni's experiences, though some time ago, illustrate clearly the type of support some carers need. Sheetal Soni had a 17 year old daughter with cerebral palsy when she was interviewed. When a young mother, Sheetal Soni desperately wanted to talk to someone else in a similar situation but was unable to get the support she needed despite having health visitor involvement:

She used to encourage me, and give me some hope for that, you know, she [daughter] might be [alright], "give her some time, she might be able to sit, and all that", it's general talk, but then, I wanted more, it was just like normal, like she was talking about a normal child, but I wanted someone to, to talk to someone who really knows you know, or who has a disabled child before to talk to me, but it was a nightmare. (p5)

### **Day care**

The most common form of support carers were able to access was day centre provision for the cared-for person. Like carers in Wright's (1986) study, day centre provision was valued by carers as it enabled them to get on with other chores around the house without the added pressure of having to constantly 'pop in' on the cared-for person. However, in some cases, the cared-for person did little other than sit in a chair at home all day. This was often because of reluctance on the part of the cared-for person to attend a day centre or to have other forms of support at home.

### **Respite care**

The importance of carers having a break and being supported is reiterated in numerous policy documents (Department of Health, 1999a), yet, only two carers had experience of using residential respite services, Shanta Hari valued the service immensely. Sheetal Soni on the other hand, felt over burdened with caring and thought that a few weeks in a year was simply not enough time to allow her to recuperate. Further she was frustrated with the system of having to book respite at least six to eight weeks in advanced, which inhibited her and her family from doing things other 'normal' families did on the spur of the moment, such as attend weddings or go on holiday. The findings support other commentators who report that carers need access to both planned and emergency respite services (Twigg and Atkin, 1994).

### **Residential and nursing home care**

Carers' limited awareness and lack of referral by professionals meant that some missed out on services that could have helped them. For example, some carers did not even know which residential homes were available locally. In one case, the carer asked the researcher to send her information about residential care homes. On the whole, however, carers in this study were reluctant to place the cared-for person into long term residential or nursing home care, although they were prepared to consider it as option when they were physically unable to meet the needs of the cared-for person themselves. This refutes Shah's (1992) suggestions that minority ethnic parents fail to see the necessity to prepare for the welfare of their disabled child because God would protect him/her. However, it is the case that, on the whole, parental carers were more positive about their relationship with their children and were the most reluctant of all groups to consider residential care as an immediate option.

Madhuri Krishen and Pritesh Krishen both cared for their parents, but they only spoke positively about their relationship with their mother. They, like the majority of other carers in the study, had negative views of residential care. Madhuri Krishen, for instance, said "We'd

rather she die here [at home].” Male and female carers were generally of the opinion that residential care was not like being at home and that “*ghar e ghar*” [home is home]. It was also felt that the quality of care provided would not compare to that provided at home by carers. Many carers felt that only they could care “properly” and that the extra attention they paid to meeting their relative’s needs, for instance, by doing *malliss* [massage] would not be provided by staff in residential care.

In some instances, carers’ negative experiences of placing their relative in a nursing home for a short time whilst the carer had a break resulted in them being totally against the idea. In the carers’ view, the cared-for person had not been taken care of properly and their physical condition was much worse upon discharge from the home than when admitted. Carers of adult daughters had concerns for their personal safety and expressed fears that their daughter might be abused whilst in care. Shivam Ranchord, for instance, said, “You can’t leave a big girl like that with strangers.” In other cases, ties of duty and obligation made it difficult even to suggest the idea of long term residential or nursing home placement.

## CONCLUSION

The evidence from this small scale study complements and supplements the data available from other studies on informal caring. It demonstrates that the experiences of Gujarati Hindu carers in this study were markedly similar to those of white carers. Areas of similarity concerned carers’ experiences of providing practical, personal and emotional care as well as issues concerning cross-gender caring. There were also evident similarities in relation to the associated health, social and financial costs of caring and, like white carers, Gujarati Hindu carers in this study also had little choice concerning the decision to take on the responsibility of caring.

Adjustment to disability was however somewhat episodic, with Gujarati Hindu carers never fully ‘adjusting’ to their situation. Instead, there was evidence of continuous mourning due to the realisation of unfulfilled expectations (Olshansky 1962 in Mutch, 1997). Hence, carers in this study turned to alternative forms of treatment (often at great expense) alongside conventional treatment in the hope of cure or improvement. This finding has not been previously documented in the minority ethnic carers’ literature. Further, the plight of mothers of disabled children was worse in that they were blamed for causing their child’s disability, a finding mirrored in previous studies (Katbamna and Bhakta, 1998). Moreover, unlike white carers, Gujarati Hindu carers experienced additional pressures from society to find and try out

new 'cures' for the disability, despite there being little scope for improvement. This is a new finding not previously reported in the caring literature overall.

The practice of having adult children sleep in the same room as parental carers has also not previously been reported in the minority ethnic carers' literature. This suggests that these types of carers would benefit from support to help them realize that allocating time for themselves will in the long run benefit them and the cared-for person.

Another new finding not previously reported in the minority ethnic carers literature concerned coping strategies. Gujarati Hindu carers in this study used a variety of approaches to help them get through their daily routine, from self indulgence to turning to religion. Religion provided much needed emotional support for many carers. Praying at home, reading books and listening to religious music enabled carers to feel more in control of their circumstances and gain inner peace. There were, however, apparent differences in the coping strategies adopted by male and female carers. Female carers, who took the bulk of the caring responsibility, were more restricted, had fewer opportunities to 'get away from it all' and were therefore more isolated. Male carers, on the other hand, were able to unwind by simply requesting not to be disturbed and asking their wives to 'take over'. This was simply not an option for female carers.

A major difference in relation to white carers was that carers in this study experienced more difficulties, as discussed further in chapter seven, because of language and communication issues, resulting in problems in accessing information and services. As a consequence carers were not able to access the support which they might otherwise have obtained because they were not able to communicate their needs, as well as not understanding what was being asked of them. Difficulties were further compounded by general material disadvantage.

Importantly, as identified in previous research (Kathamna and Bhakta, 1998; Chamba et al, 1999) Gujarati Hindu carers in this study also had little support from family, friends, neighbours or formal services. Although there was evidence of carers living within extended households they were still 'on their own' when it came to caring. The evidence demonstrates that carers would not necessarily turn down offers of support; they would have welcomed the opportunity to attend support groups and those who experienced it valued day care support immensely. Moreover, carers' reluctance to use certain services such as respite, residential or nursing home care had more to do with concerns about quality and inflexibility of service provision as opposed to their being well supported by their extended family and therefore not

needing services. This is important, because as demonstrated in chapter eight, PHC nurses did believe that minority ethnic carers were better supported by their families than white carers.

Further, the situation for carers in this study was much worse in comparison to white carers, as they not only had additional pressures of having their actions monitored by the wider community but also had to live up to expectations and meet the demands of other family members as a consequence of living within an extended family household.

These findings clearly have implications in terms of the way in which PHC nursing services are provided and the type of support PHC nurses provide for minority ethnic carers if they are to be responsive to their needs. The evidence from this chapter demonstrates that carers would benefit from support from PHC nursing services by way of access to information, as well recognition for their caring role. A means of ensuring that carers' needs are addressed could be through holistic nursing assessment. These issues are addressed in chapters seven and eight.

## **CHAPTER 7**

### **GUJARATI HINDU CARERS' EXPERIENCES WITH PRIMARY HEALTH CARE NURSING SERVICES**

#### **INTRODUCTION**

The previous chapter reported the analytical findings relating to the caring experiences of Gujarati Hindu carers, providing the context for the study's aims. This chapter reports the analytical findings, which address the core aims of the study, namely Gujarati Hindu carers' experiences with PHC nursing services to ascertain whether they felt supported by them. The findings are presented by drawing upon the earlier review or by building upon it.

Earlier it was illustrated how little influence policy had on the caring experiences of Gujarati Hindu carers and how they were caring at great cost to them selves. Their plight was made worse due to lack of or limited support from family, friends, neighbours or formal structures. As reported earlier, there is little evidence on the subject of supporting informal carers within nursing literature. PHC nurses can, however, make a significant contribution by, for instance, carrying out holistic assessments which take account of both patient and carer needs and by working collaboratively with social workers (Department of Health, 1999a; Department of Health, 2001b). PHC nurses can also support carers by providing advice and information (Twigg and Atkin, 1994) or by providing them with the skills and training to take on the responsibility of and to continue caring (Department of Health, 1999a). Policy both stipulates and endorses that nurses should offer support to carers (Department of Health, 1996; Department of Health, 2001c). The nurses' Code of Professional Conduct (1992) also states that nurses need to 'work in an open and co-operative manner with patients, clients and their families, foster their independence and recognise and respect their involvement in the planning and delivery of care'. Moreover, policy stipulates that consumers, including informal carers, should be involved in care processes (Department of Health, 1998). PHC nurses are therefore ideally suited to work in partnership with carers throughout their caring careers.

Although attempts to explore partnership working with informal carers have been made (Casey, 1995), there are no studies to date that have addressed the issue of carer involvement from a minority ethnic perspective within a community setting.

In addressing the aims of the chapter, we start by reporting the positive aspects of the PHC nursing services as described by Gujarati Hindu carers. This is followed by the analysis

relating specifically to their experiences with PHC nursing services where the core themes relating to support are addressed. Despite the rhetoric of policy intentions and nursing's claim to provide patient-centred care and holistic assessments aimed at meeting both patient and carer needs. Carers in this study felt unsupported in two core areas, those concerning access to information and PHC nurses 'patient-centred' approach to working, in its literal sense. These two issues form sections 2 and 3 of this chapter.

Difficulties were further intensified due to language and communication difficulties. Discussion of this issue forms the fourth substantive part of the chapter. As before major themes are identified by uppercase titles, second-level themes by sentence-or lower-case bold, and third level themes by italics. Given the many different issues to be covered in this chapter, conclusions are placed at the end of each main section rather than at the end of the chapter.

### **VALUED ASPECTS OF PRIMARY HEALTH CARE NURSING SERVICES**

It is important to consider the positive comments made by Gujarati Hindu carers in relation to their experiences with the PHC nurses with whom they had contact. This is because there has been a tendency within research and academia to focus on either the positive *or* negative aspects of a service alone, rarely reporting both issues together. In practice, improvements in services would be better achieved if positive comments were incorporated into strategies, which can then build upon and improve on any areas where shortfalls are identified.

The most valued characteristics reported by Gujarati Hindu carers were those concerning the nurse's **ability to be caring and sympathetic**. They described PHC nurses by using terms such as 'nice' or 'good'. More importantly, however, it was the nurse's ability to listen and take genuine interest in their concerns that was most valued.

...they often say... "if you want to talk, about anything, you talk about it to us...you don't have to work so hard with her." (Gopal Mithun, p26)

A few carers viewed the PHC nurses as more than just professional nurses and described them as their friends. For these carers, it was an opportunity to have a small amount of time each week with someone who listened to their concerns as well as meeting the needs of the cared-for person.

Well I found she was very caring, very understanding and very supportive. I felt I could talk to her. I think I see her more than a health visitor, I see her as a friend really, cos, ...I think she really did care, she cared about [son] a lot...I'm glad she was there because it was something for me to look forward to, once a week there was somebody coming that I could talk about him to. (Madhu Gokhani, p26)

Some PHC nurses left a contact telephone number and made a point of stressing to carers that they could contact them any time if they needed to talk or ask for advice. This was particularly valued and appreciated by younger female carers.

The support of DNs and health visitors was more frequently mentioned, and their services were particularly valued, more so than the input of other nursing services. This may have been because DNs and health visitors are professions that tend to have a **more ‘hands on’ approach to working**. Therefore, they would have been involved in carrying out, helping or advising about the more practical and physical aspects of nursing care. As the previous chapter demonstrated, a number of carers had been involved in providing personal, physical and practical care for many years; knowing that the nurse would support them by helping with these tasks relieved considerable stress and pressure. Madhuri Krishen, for instance, had been caring for both her parents and younger brother since the age of nineteen. Her mother had experienced several stokes and was totally dependent upon her in terms of feeding, dressing and toileting. For her, the arrival of the DNs in the morning brought a huge sense of relief. She said:

I think [feel] relief to see them in the morning...I just open the door and they just quickly get in and that's it and you get the feeling like, thank god, you know. (p40)

Further, where there was evidence of **continuity of care**, with the same PHC nurses visiting carers and the cared-for person on a regular basis, positive relationships had been developed. Madhuri Krishen and her brother, for instance, had developed a special relationship with their DN and auxiliary nurse, so much so that a system of ‘helping each other out’ had been devised between them. She said:

Yeah, they're ever so friendly to us...It's more like family now. We really get on more and like we help each other out sometimes as well. If she's struggling with something and she's got a lot to do and everything, we help each other out....we do things together, we help them out and they're ever so grateful like that. (p35)

Health visitors were also praised for **‘spotting’ problems** not recognised by parents. In one instance, the health visitor had noticed that the child had a squint (Radha Nayan) and, in another, a hernia (Madhu Gokhani). In both cases, it was the health visitors who referred the children to their general practitioners for further investigations.

## **PRIMARY HEALTH CARE NURSING SERVICES AND INFORMATION**

This section now explores the issue of support from primary health care nursing services in relation to carers' information needs. All carers need access to information if they are to feel

empowered and in control of their caring situation. Gujarati Hindu carers' information requirements were related to their individual circumstances and covered a broad range of topics. Rather than providing a detailed break down of all the different types of information these carers would have liked, the intention here is to analyse the main issues, which cut across the whole sample. This section therefore focuses on carers' information needs concerning diagnosis and prognosis, caring for and managing the cared-for person, and accessing equipment and services. The implications of not accessing information are also discussed within the relevant sub-sections.

Although this section is mainly about primary health care nursing services, PHC nurses do not work in isolation but have interactions with other service providers such as general practitioners and social services. Hence, reference is made to other personnel, where relevant.

### **Information about diagnosis and prognosis**

Irrespective of the nature of the condition or impairment, both male and female Gujarati Hindu carers expressed a need to know what was wrong with their relative. Analysis identified both what carers needed from information, and what prevented them from getting it. There are six elements to this.

Firstly, carers simply wanted *to know what was wrong* and what the cause of the condition was. Hence, they wanted information that explained the condition and prognosis and whether there was any possibility of the cared-for person ever being cured. Many had not been prepared for caring, or had insufficient understanding of what it would really entail, let alone how this might affect their lives in the long term. Some carers were given a diagnosis or told that there was something 'wrong' by medical staff at the hospital. Sometime this was after a long struggle by carers to get professionals to believe them when they suspected something was wrong in the first instance. Few carers, however, had been given any diagnosis or even an adequate explanation by their doctors. Unfortunately, these issues were also not later followed through by PHC nurses with whom carers had contact. Carers acknowledged that no one could predict the future in terms of prognosis, for instance. However, it was important for them to know what professionals anticipated might be the long term outcome for the cared-for person, how they could manage the cared-for person and the type of support available to them. Hence, those carers that were unable to obtain information or support did not find primary health care nursing services to be that useful to them:

Because I didn't feel that they were suggesting various things or helping us as much as they could have done at the time... she's (health visitor) saying yes, yes, but are you actually gonna do anything or suggest things or you know, there wasn't, I didn't find a lot of that coming out. (Sameer Gokhani, p23)

Matters could be made worse when professionals tried to 'soften the blow' concerning the diagnosis as their good intentions only added to the confusion, as the case below illustrates.

...but nothing was definitely said, and when he went to the [hospital], I remember talking to the neurologist, and he wasn't sleeping. The neurologist sort of said, "Well brain damaged children don't sleep very well", but at that time nobody actually said to me that he was actually brain damaged... and they kept saying "well you know there's a bit of abnormality, but it's nothing definite and they all said that we'd all got a bit of abnormality in it, so there was nothing said properly that he was brain damaged.....it was like 5 months later they told me he was actually brain damaged. (Madhu Gokhani, p3)

Secondly, carers needed *a sufficient level of information* and at the right time. The previous chapter reported carers' reactions to disability and how they found it difficult to come to terms with disability, so much so that many continued to live in the hope that their son or daughter would one day be cured. For these carers, information concerning diagnosis and prognosis and explanation of the condition was clearly not sufficient. Sloper and Turner (1992) similarly found that 59 per cent of (mainly) white parents caring for severely disabled children still wanted more information two years after diagnosis.

Thirdly, carers wanted *information in an appropriate form*. Given that carers in Sloper and Turner's (1992) study could communicate in English yet still experienced difficulties, it is not surprising, perhaps, that Gujarati Hindu carers, many of whom who could not communicate in English, had real unmet needs for information and advice and were constantly 'searching'. In the current study, in comparison to male carers, female carers were either not fluent in English or had limited understanding of it. This is important, because the responsibility of caring using fell on females.

However, the ability to speak English did not guarantee that carers would be given adequate explanations. Indeed, even those who had 'professional' jobs also went to extreme lengths to try and find out what was wrong with the cared-for person. Radha Nayan a mother of a little girl with no diagnosis said:

...you see, right from the beginning if they'd said to me that, this is what's wrong with your daughter, I can cope with that, but not knowing what's wrong with her, you know, if somebody said to me, well there's something wrong with her legs, then I would say right, I'll sort, sort help that way. I even got an orthopaedic, because she wasn't walking I took a back route and got one of the surgeons to look at her, you know, just to check whether her hips were all right, so I took a lot of back routes because of where I

work and who I know, sort of thing. But again, he said her hips are perfectly all right.... And you know, even now, I think, well what's wrong with her, you know, what's wrong with her. I mean if you look, if you just sort of caught a quick glance of her you wouldn't think there was anything wrong with her. (p5&6)

Fourthly, analysis identified that one of the biggest barriers to accessing information was *carers' concerns not being taken seriously* in the first instance. In a number of cases, carers had long suspected that things were not 'quite right' with the cared-for person, which led to them seeking advice from PHC nurses or their general practitioner. Carers of all types experienced difficulties trying to convince professionals that something was wrong, resulting in them being unable to get information or advice that would have helped them deal with and manage the situation more effectively. In some cases, carers' 'gut instincts' told them that things were not right: "And you know I kept feeling, you know, something was telling me, why does he keep doing this, why is [are] his fists so tight all the while" (Shanta Hari, p6). On the other hand, those carers that had children previously sensed that 'something was wrong' by comparing developmental milestones:

She wasn't responding and I thought she was a bit slow because I had my elder daughter, so I knew at about six or eight weeks she wasn't following or nothing...I contacted my health visitor and when she was born, she had a complication (displaced anus) and she had a little operation, so I was told because of her operation she might be a bit slow, so just give her time, so I gave her about three months, and still there was nothing, she couldn't even lift her head up or nothing, so I contacted the health visitor again, she said "give her a bit more time", and then I said I am sure there is something wrong with her, and then took her to the doctor's...

About three months...I went to the clinic and the doctor there said "because she was very weak after the operation, give her some time...She was poorly, and she had feeding problems when she was born. So just give her time".

I thought "there's still something wrong with her" because in other areas she wasn't responding at all.... I was saying it from the very beginning there was something wrong with her, but then all the time they were telling me to "give her time, give her some time" and after that.....(Sheetal Soni, p3&4)

This carer cried throughout the interview and we had to stop and start the interview on several occasions. She was extremely distressed, but for her and a number of other carers it was their first opportunity to tell someone exactly what they were feeling and what had happened, without fear of being judged by the listener. This is important because as reported in chapter six, issues concerning disability are highly complex and attract considerable stigma among minority ethnic communities. The example is not an isolated one; a number of carers in this study had recognised that there was a problem and yet were unable to convince health professionals. In most cases, they cried as they spoke about not being believed and then

finding out that there was something seriously wrong afterwards. In these cases, carers had a long and stressful wait before discovering what was wrong or having their doubts confirmed, and before any useful information was disclosed to them.

Fifthly, analysis showed that some carers' *access to information depended largely on the ability to go out and find what they needed themselves*. Some managed to access information through informal contacts such as friends or other carers, although this was usually limited. However, very few mentioned their relatives or social contacts as a source to obtain information. Also, none mentioned that they accessed information via their local community centre. This contrasts with Katbamna and Bhakta (1998) who found that the local community centre was an invaluable source of information for *Bangladeshi* carers. The findings here belie the notion that minority ethnic communities support each other and are self-sufficient as often assumed. Female Gujarati Hindu carers were particularly disadvantaged as they were often isolated and had limited contact not only with their own community but the 'outside world' generally. Others managed to obtain information simply by chance. This method of accessing information was clearly inadequate.

Finally, the analysis showed how some carers found it *difficult to be assertive*. Previous evidence suggests that carers have to be assertive if their needs are to be addressed (Henwood et al, 1996 in Parker, 1999). However, this proved to be difficult for Gujarati Hindu carers in this study. On occasions information was not fully understood by carers but they failed to question professionals, assuming their judgement was final and correct. Generally, those carers who had limited or no command of spoken English were more accepting of what was said by professionals. For example, Sheetal Soni provided all care for her daughter. Whilst her daughter was a child, Sheetal Soni was told not to take her daughter on holiday "as she needs all these injections, and it might damage her more" (p12). The consequence of this was that, when their daughter was a child, they never went away on holiday. Now she was a teenager it was even more difficult for her to go on holiday as she required all care and was too heavy for Sheetal Soni to manage. Professionals need to be aware that carers may follow advice literally without it occurring to them to question it again later.

### **Information about caring and managing**

The type of information Gujarati Hindu carers would have valued in this area naturally related to the type of caring they were personally involved in. Inadequacies in accessing information were identified in terms of the 'what to do' and 'how to' aspects of caring. For instance, those involved in 'hands on' caring would have welcomed information on lifting and handling

and dealing with incontinence, whereas others would have liked information on dealing with and managing people with depression or mental health problems.

Inevitably, inadequacies in information resulted in increased anxiety and was an added pressure, making caring more difficult.

I found it very difficult with his sleeping, or lack of sleeping habits. Because I was shattered myself, I was so exhausted you know, and I was really run down. There was no explanation to why he was waking up...we did all sorts of things...make sure he's comfortable, he's propped up and, you know, he had a bigger feed to sort of like settle his stomach ... I'd taken as many steps as I could and I just didn't feel that was the answer... and you know what can they tell in three months, what you've been going through. (Madhu Gokhani, p12)

Lack of information can thus result in carers feeling over-burdened, shattered and neglected. It also runs the risk that they will start to think that 'nobody else understands' what it is like for them and lose faith in professionals and their abilities. This has an impact not only on their daily responsibilities but might also affect their health in the longer-term.

Language and communication barriers inevitably caused some difficulties in accessing information. However, there were also cases where PHC nurses simply did not pass on relevant information to the person who needed it most. For instance, some carers reported that they were not shown how to operate the hoist or how to use correct lifting and handling techniques. These are very important issues. Indeed, professional nurses themselves have to undergo training in these areas. Yet the need to pass on this information, or at the very least to ask if carers knew what they were doing and were happy doing it, appears to have been overlooked by PHC nurses in some cases.

### **Information about equipment and services**

The type of information Gujarati Hindu carers wanted concerning equipment and services spanned both health and social care sectors.

First, many carers interviewed in this study were unable to access vital equipment which could have helped relieve some of the pressures of caring. For example, in chapter six we saw that appropriate eating and drinking utensils or shaped cutlery would have been beneficial for both the cared-for person and the carer and relieved some pressure during meal times. Information on *the types of equipment available and how to access them* was thus a major need.

Secondly, these carers genuinely did not know about, or had little knowledge, experience or awareness of what to expect from services, including nursing services. Hence, many rehearsed a need for information on *the roles of different professionals and the services they provide*.

Well, what their role is, what they should provide so that you know, if they going to provide equipment, well, you know, what are you going to provide, when am I going to get it (Madhu Gokhani, p36)

Many carers lacked knowledge about available primary health care nursing services or the roles of nursing professionals and how they could be supported. Ironically, even though some had been using primary health care nursing services for a long time, they were still unsure about their role and how they could be supported by them. For instance, they were unaware of the type of equipment primary health care nursing services might be able to obtain for them. They were also not aware of or had no contact with formal services such as support groups, respite or day care provision and would have valued information in these areas.

How we should go about doing it, [finding appropriate LTC provision] what sort of place we should be looking for, where we should look, who we should ask. These sorts of things you know. (Shanta Hari, p49)

PHC nurses did not seem to refer carers to services, provide information on support groups or suggest that carers make inquiries about whether local resources and community organisations could support them. It is not an unrealistic expectation that PHC nurses will be knowledgeable and proactive in seeking information for carers. Policy documents (Department of Health, 1999a) clearly state that health professionals have a crucial role in referring carers to other appropriate sources of help (p40). The findings here are in contrast to those of Gerrish (1998) who reported that nurses did offer to refer carers to other support services. Admittedly, a limitation of this study is that, unlike Gerrish (1998), the behaviour of PHC nurses was not observed. Hence, there remains a possibility that PHC nurses may have asked Gujarati Hindu carers but language and communication barriers could have resulted in carers misunderstanding or not understanding what the PHC nurse were trying to say or not realising the benefits of suggestions for support services, as they did not have any experience of them.

However, it is important to stress that none of the carers had any printed information in English or translated versions about support services. This surely suggests that PHC nurses were not as proactive as they might have been in seeking information and giving it to carers. In addition, as discussed in the next chapter, evidence from PHC nurses themselves suggests

that they were not able to keep up to date with what was happening locally and to 'keep track' of the type of support services available.

Carers themselves mentioned that information needs should be met through a service aimed specifically at meeting the needs of informal carers, provided either within the local community or situated in hospitals.

There should be some sort of body of carers. That say, for instance, if a person is discharged from hospital they inform carers about what type of services are available and what they're entitled to. For instance, about the DN, community nurses, you know, about what you get, through the occupational therapist. All these sorts of things, for instance, the nappies, the sheets, bedding. Who do you contact for these things? So there should be somebody who explains all these things to you.

(Anant Laxman, p14)

This is similar to services that are already provided by associations such as Carers UK. None of the carers in this study mentioned that they had any contact with such organisations.

Thirdly, there was a need for *information about benefit entitlements*. As reported in chapter six, Gujarati Hindu carers experienced considerable financial hardship. Their plight was often made worse due to lack of knowledge resulting in delays in receiving benefits. While welfare benefits advice is not a key part of PHC nurses' role, they could refer carers to others trained to deal with these issues. PHC nurses would perhaps benefit from training which considers how economic, health and social factors combined with race, gender, age and class to influence the lives of carers.

### **Conclusions about PHC nursing services and information**

To sum up, many Gujarati Hindu carers had limited access to the type of information about diagnosis and prognosis they would have liked. This was particularly so for condition specific information. Inability to access information produced confusion and anxiety. The ability to access information is particularly important in relation to this thesis because as reported in chapter six, many carers in this study never fully adjusted to their situation. In developing a model looking at crisis events in life, such as bereavement, Hopson (1986 in Pain, 1998) suggests that information seeking forms part of the process of transition towards acceptance and adjustment to a new situation, which enables people to cope and move onto the next phase of their transition.

A number of carers in the current study could not communicate in English and this disadvantaged them further. They were constantly searching for information that would give

them more insight into the condition and how to manage it as well as information into its cause and available support services. It is little wonder that they found it difficult to adjust to their situation, felt confused and, as reported in the earlier chapter, highly stressed. Access to appropriate information might have helped carers cope and manage their situation better, as Beresford (1994) identified in her study of white parents caring for a severely disabled child. By contrast, when carers are concerned about something, health professionals, despite having their education and training behind them, need to acknowledge that those closest to patients can also be 'experts'.

Although issues concerning access to information for informal carers are not new, this is the first study to address, in-depth, Gujarati Hindu carers' expectations of support in terms of information from PHC nursing services. Analysis showed that their needs for information cut across three areas; diagnosis and prognosis, caring and managing and equipment and services.

A number of important issues emerge. Difficulties in accessing information made caring and managing the cared-for person more difficult for carers. Lack of information meant that they lacked knowledge about which services were available, and how they could be supported. These issues were compounded by the isolation experienced by female Gujarati Hindu carers, inability to obtain sufficient information from informal contacts, communication and language barriers, as well as the inability to access literature, translated or otherwise in all the three areas identified.

Although PHC nursing staff cannot be held *directly* responsible for Gujarati Hindu carers' lack of knowledge concerning services, they could promote their services, as well as highlight any concerns about access to their Trusts. As we see in chapter eight, PHC nurses did express concern during their interviews, not only about the low numbers of minority ethnic patients on their caseload, but also that, when they did receive referrals, patients from minority ethnic communities were often in a worse state of health.

Gerrish (1998) identified that patients and carers who spoke limited English or who were reliant upon an interpreter, sought less information from nurses. Evidence from this study indicates a definite need for information, with Gujarati Hindu carers constantly 'searching' for more. This study suggests that carers' information needs were neglected from the onset of their caring role. Hence, information on simply knowing what was wrong with the cared-for person and how to manage and care for them was identified as a real need. Carers indicated preferences for both verbal *and* translated information, although verbal information accessible

via the PHC nurse was their first choice. Access to information would have helped these carers not only in their caring role but also would have enabled them to feel more empowered and in control.

However, access to translated information is not the answer for everything, especially given that younger Gujarati Hindu carers had a preference for printed literature in English. There were variations between carers in this study in their ability to write and speak Gujarati as well as English. This indicates that different types of approaches would be necessary if information is to be made accessible. After five decades, it seems that NHS services are still unable to cater adequately for non-English-speaking people.

Derdiarian (1989 in Driscoll, 2000) has examined the effects of information on recently diagnosed cancer patient's and spouse's satisfaction with care and identified that the provision of information resulted in an increase in the satisfaction with care. Given that carers in my study raised concerns about the quality of PHC nursing services, as discussed later in this chapter, this suggests that access to information (or lack of it) may have had other effects. Inevitably, lack of access to information or delays in getting information resulted in carers experiencing difficulties not only with carrying out their caring responsibilities but also emotionally.

The previous chapter discussed in detail the care-giving experiences of Gujarati Hindu carers, many of whom were involved in substantial caring activities, ranging from physical and personal care to caring for those with mental health problems. However, as we have seen here, these activities were often carried out with carers having little information, training or practical skills. In order for carers to become real partners in the provision of care, they need information about ways to provide that care and information about the help and services available (Department of Health, 1999a).

The study illustrates not only how compounding factors such as isolation, gender and language and social class have a bearing on the ability to access information but also how inadequacies in working collaboratively between health and social care sectors can lead to carers experiencing unnecessary suffering and difficulty. The findings are, further, pertinent to other ethnic groups. Hence, these broad subject areas could be used as a base upon which to develop future services aimed at addressing carers' information needs.

## **THE IMPACT ON CARERS OF 'PATIENT-CENTRED' APPROACHES TO WORKING**

This study is the first of its kind to address, in-depth, the perspective of Gujarati Hindu carers as opposed to patients in the context of primary health care nursing services. Importantly, although the aim of the study was to study carers' experiences, it has also shed new light into how 'patient-centred' care and holistic assessments both failed to address the needs of carers, resulting in lack of support. No other studies to date have addressed the carer's perspective from this theoretical standpoint. It is to this key issue that the chapter now turns.

In chapter three, the development of patient-centred approaches to nursing and the role of holistic assessment were outlined. These 'ideals' are now used as a background against which to examine the actual experiences of Gujarati Hindu carers with PHC nursing services.

In the context of this thesis, it is taken that a patient-centred approach to working, together with a holistic assessment, is one in which PHC nurses would value and respect carers' involvement and in which *their* needs would also be addressed. 'Need is defined as the ability of an individual, or population, to benefit from a specific health care intervention (Stevens and Raftery, 1994 in Vernon et al, 2000, p284), although the need for health care services is potentially limitless (Vernon et al, 2000, p284). As policy (Department of Health, 1997) stipulates more effective use of health care resources, PHC nurses are ideally suited to ensure that the needs of both users and carers are assessed through the assessment process and that any unmet needs are reported to those responsible for commissioning services. However, the findings presented here suggest otherwise, as PHC nurses adopted a 'patient-centred' approach to working in a very literal sense. For clarity, in discussing PHC nurses' 'patient-centred' approach to working in this literal sense, inverted commas will be used to differentiate between the type of patient-centred care PHC nurses claimed to practice and that described by nurse theorists.

In analysing the data, six sub-themes were identified where a narrow interpretation of 'patient-centred' practice appeared to disadvantage carers. Each is now addressed in turn.

### **Carers' assessment**

Although the Carers Recognition and Services Act (Department of Health, 1995) gave carers the right to an assessment of their own, none of the Gujarati Hindu carers in this study had requested an assessment or were aware of having had one. Such an assessment would, in the

main, be the responsibility of social services. However, PHC nurses who are already in contact with carers also have a potentially important role.

While some Gujarati Hindu carers had the input of PHC nursing services for many years, they (and others) felt that their needs had not been assessed, even less met, via PHC nurses. Although carers were acknowledged, they reported that this was more a passing gesture or a formality and often with regard to the cared-for person's needs, and there was no evidence of PHC nurses arranging independent visits especially for them. These findings are in contrast to Gerrish (1998) who reported that DNs frequently visited carers with the specific intention of addressing their needs as opposed to merely checking that they were providing care. Many if not most carers in this study simply did not know about their rights to an assessment in the first instance.

A number of themes about assessment emerge from analysis of the material from the current study. First, there is the issue of *why and how PHC nurses collected and recorded information*. This study included a mixture of different PHC nurses, and each group used their own data collection forms whilst conducting an assessment. There was, however, some overlap in the type of information collected. Information loosely covered three areas, two of which were fairly routine: general information such as name, address, date of birth and social circumstances and past medical history. Most emphasis, however, was placed on the cared-for person's current health problems and bodily functioning. This included, for instance, the patients' medical condition, why they had been hospitalised, the type of things they could physically manage to do or not, information on their medications, eating and drinking habits, sleeping problems and mobility. The findings are similar to those of Ellis (1993) who reported that practitioners had a tendency to focus their assessment on the physical functioning of the user and thereby failed to pick up carer stress.

In order to build up a picture of the cared-for person's needs, PHC nurses collected a lot of information, but they did not question its relevance for practice. For example, they sought information on the cared-for person's social circumstances; hence, details of next of kin and contact persons or carer were recorded. Yet, this information was not utilised to good effect. Information was sought and used for the purpose of identifying and recording details of a contact person, and although carers were identified as the main contact person or, indeed as the main carer, their needs did not form part of a formal assessment. Any interactions with carers, then, can best be classed as data collection as opposed to holistic assessment, which would have incorporated their needs. Secondly, there is the issue of *communication and*

*language*. The Department of Health care management guide for practitioners (Social Services Inspectorate/Social Work Inspectorate Group, 1991) suggests that staff should have appropriate communication skills, and users and carers have 'ready access' to communication equipment and interpreters and communicators. However, while communication and language created a number of difficulties for PHC nurses, they did not effectively utilise the interpreting services provided by the trust (see chapter eight). Indeed, only one Gujarati Hindu carer had experience of the PHC nurse calling with an interpreter. The inability to have a two-way conversation resulted in carers having limited involvement in assessment (or care-planning – see below) resulting in PHC nurses making decisions on behalf of carers with little consultation or negotiation. This inevitably raises questions about the quality of assessment in relation to both patients' and carers' immediate needs, and even more about whether hidden needs could be captured. It also questions the whole ethos of partnership. This issue is discussed further in the next chapter.

Thirdly, there is the issue of *carers' own health*. One of the strategic elements of the National Strategy for Carers is to 'recognise carers as individuals in their own right' and ensure that their own health needs are addressed, especially given that many health problems suffered by carers are preventable (Department of Health, 1999a, p55). It is also stated that 'health professionals locally should be aware of carers' own health needs and how best they can help' (Department of Health, 1999a, p38).

As reported in chapter six, carers in the current study suffered from both emotional and physical health problems. Yet, as PHC nurses focused on meeting the needs of the cared-for person, carers' health problems seemed to be overlooked. Some of this was related to carers not being involved in the assessment process, coupled with the limited conversations between them and PHC nurses. On the occasions when they did engage with carers, conversations were largely formal or based on 'general chit chat' with no real substance, resulting in carers' health needs not being identified or taken seriously enough. As reported in chapter six and later in this chapter too, carers' health problems were compounded by lack of appropriate equipment or advice on correct lifting and handling. Hence, some of their health problems were preventable. The health related costs of caring, especially over a longer term, were thus not taken into consideration whilst assessing, reviewing and monitoring the cared-for person.

The fourth issue is the *assumptions PHC nurses may have made about carers' willingness to care and other sources of support* for them. Twigg and Atkin's (1994) study of different types of carers and their experiences with health and social care services reported that service

providers have normative expectations structuring caring expectations and service receipt and different relationships contain different normative expectations concerning caring. These meanings and assumptions are shared by service providers and as a consequence influence the way in which they respond to situations or the forms of help they suggest or provide. Evidence from this study underlines this. For example, Alisha Ram felt that she was being denied adequate district nursing support because she was viewed as a suitable carer by nursing staff making the initial assessment. In her view, because they could 'see her' [the carer] there was an expectation that she would take on the responsibility of caring for her mother-in-law. She said:

I mean they did ask me if, I could manage her you know, in the mornings and they would send one nurse but I said that, you know, I was thinking of going for a morning job at that time, you know, so I wouldn't be able to you know and that it would only be my father in law [at home] I had to actually tell them that. And then they said, because of that they would send two [nurses] then. (p26)

In her view if she had not told them that she was looking for a job she would have not received adequate support.

The previous chapter discussed in detail the lack of support for Gujarati Hindu carers, not only from formal services but also from within the family. This raises a number of issues that should be considered during a proper assessment. These include whether the caring responsibility would be divided or taken on by one carer, carers' capacity to cope in the short and long term, whether carers had any activities other than caring, and whether they were happy with the situation in the first instance. Living within an extended family or evidence of having lots of contacts does not mean that there is enough support for carers. The findings from this study mirrored those from studies of white carers that, by and large, irrespective of other people living within one household, one person is usually singled out as a carer and shoulders the responsibility of meeting the cared-for person's needs (Nissel and Bonnerjea, 1982). Yet, as demonstrated in the next chapter PHC nurses did, at times, fall into the trap of believing that extended families and extensive contacts were proof that there was sufficient support.

Manthorpe and Twigg (1995) report that conducting separate carer assessments can be problematic in practice, as it has not been seen as part and parcel of professional practice. The findings of the current study also indicate that PHC nurses find it difficult to incorporate carer needs into the nursing assessment. This may be due to the centrality of the patient-nurse relationship in nurses' construction of nursing (Kirk and Glendinning, 1998). Indeed, PHC nurses' 'patient-centred' approach to working in its literal sense certainly indicates this.

Moreover, Gujarati Hindu carers' concerns were not unfounded, as we see in the next chapter, where PHC nurses emphasised that the patient was their main concern.

This is the first study to report the carer's perspective in the context of nursing assessment within primary care. Previous research has looked at the issue of assessment from the patient's perspective or in relation to a social care assessment (Davison, 1996; Ellis, 1993; Hardy et al, 1999). While it was not the original aim of this study to assess whether assessment met the needs of Gujarati Hindu carers, these findings have highlighted a number of important issues. Further study is needed to assess holistic nursing assessment among carers in other ethnic groups, including the white majority community.

### **Care planning**

Department of Health guidance on care-planning expects the care plan to be the result of a constructive dialogue between service user, carer, and staff (Department of Health, 1991:28). The current study found little evidence that this ideal model was employed by PHC nurses with Gujarati Hindu carers.

Once PHC nurses had collected relevant information they made notes in the cared-for person's records, which related to the proposed plan of care. They devised 'patient-centred' care plans largely based on their interpretation of the cared-for person's health-related needs and rarely consulted or asked carers for their views in devising this plan:

No, no, no. They don't you know [involve her in care planning] I just try to work out myself. You know and some of it I don't understand. But I just work it out myself. You know, they have these forms and all they do is mark it out on there... and everything she just filled it in, she didn't ask me anything... she didn't explain but she just said what they'll be doing. (Alisha Ram, p47)

This inevitably begs the question of whether Gujarati Hindu carers understood what was happening, why certain decisions or plans of action had been made, what the expected outcome was likely to be, and what their role as carer would mean or involve.

Where the patients were able to speak in English, PHC nurses concentrated on having a dialogue with them. If carers were consulted it was usually to obtain information around the three areas mentioned earlier. Hence, conversations were centred on the cared-for person's needs as opposed to the carer's. PHC nurses monitored the cared-for person's condition and progress and made amendment to their care plans. Again, however, carers felt left out. PHC nurses continued to be 'patient-centred', having a tendency to do what they had to do in terms of carrying out practical tasks or documenting events and being keen to leave soon

afterwards. Carers sensed that this was to avoid being 'caught up' with them. The exception tended to be learning disability nurses and health visitors who, because of the nature of their caseloads, tried to involve carers although, again, this was usually in relation to meeting the needs of the cared-for person.

A few carers differentiated between the junior and senior district nursing staff. Generally, untrained nursing staff (nursing auxiliary) spent less time talking to carers, as they had the responsibility of getting the practical tasks done. Senior staff on the other hand, although they did not visit as often as other staff, spent more time in the home although, again, this was usually in connection with the initial assessment or follow up visits concerning the cared-for person.

### **Emotional support and recognition**

As Bowers argues, the 'process of caring is much more complex than ... commonly used definitions would indicate and much of the stress of care giving is unrelated to the presence of tasks' (Bowers, 1987 in Nolan et al, 1995, p5). Emotional support and recognition can thus be crucial elements of support for carers.

Some Gujarati Hindu carers accepted that meeting the needs of the cared-for person took precedence over their needs when PHC nurses called and were satisfied as long as the cared-for person's needs were met. For others, however, years of caring had taken their toll and female carers, especially, expressed the need for emotional support from PHC nurses. As reported in chapter six, female Gujarati Hindu carers shouldered much of the responsibility of providing care and were at home having little interaction with other people, and therefore little opportunity for informal support. Moreover, many female carers had limited or no command of English, which contributed to their isolation. Similar findings have been identified in other studies (Cameron et al, 1988; Modood et al, 1997; Gerrish, 1998; Katbamna and Bhakta, 1998). Male Gujarati Hindu carers, on the other hand, were able to socialise through their place of employment and often did not get involved in the same types of caring responsibilities. Their needs for emotional support were, as a result, usually lower.

Carers were aware that PHC nurses were busy and had other patients to see, yet they wanted them to make time for them too. On the whole, PHC nurses were rushed, did what they had to do as quickly as possible, and tried not to get too involved with carers:

They [nurses] are not there long enough [in the carer's home]. They are usually in a rush, yeah, they're usually in a rush 'cos they've got other patients to attend and everything... She don't really have enough time to talk to me. (Madhuri Krishen, p38)

Difficulties in expressing the need for this type of support were complicated not only by communication barriers but also by PHC nurses reinforcing their 'busy-ness' as soon as they arrived and making it obvious that they were keen to go. Ultimately, this made it more difficult for carers to raise their need for support too. Carers were able to sense whether it was a good moment or not to approach the PHC nurse because body language "said it all". In such situations, carers did not disturb the PHC nurse and let her get on with her duties because it had been clear to them that the PHC nurse did not have any time to waste. Madhuri Krishen for instance said: "you can't really say anything to them as well. I never say anything to them, I just let them get on with their job."

Hence, Gujarati Hindu carers only tried to communicate with the 'approachable' type of PHC nurses. There were PHC nurses who adopted a 'patient-centred' approach to working but did spare a few moments for general chitchat. The not so approachable type made it clear that they were busy and focused on getting on with tasks. Although greetings were exchanged, conversations were usually formal and focused on the cared-for person and their needs with little interaction and involvement with carers. Experience had thus taught carers to be selective in terms of the nurses they approached and whether they might spare a few moments for them or not. Alisha Ram for instance said: "Well [it] depends on different nurses. I wouldn't talk to everybody."

Gujarati Hindu carers were thus well aware that PHC nurses did not have time for them. However, a few that the PHC nurses did not make an effort where the cared-for person was concerned either. Alisha Ram said "they don't really talk to you much. They just do their work and go. You know, they used to dress her up and that was it, they wouldn't really talk to her much."

Carers did not expect PHC nurses to stay and talk for any great length of time; rather all that they wanted was to be shown understanding and for PHC nurses to be sympathetic to their circumstances. We have seen throughout that Gujarati Hindu carers were not supported by their immediate or extended family, primary health care nursing services or other formal structures. Although some carers had gained considerable experience in terms of managing and providing practical care, they still had a need for emotional support that PHC nurses appeared to have neglected.

As reported earlier, many carers in the sample were not able to communicate effectively in English nor could they read it. This led to difficulties in obtaining support as they could not clearly express their needs to PHC nurses. Gerrish (1998) has reported that where language barriers posed a problem, DNs were unable to discuss in detail how the carer was coping with the physical and emotional burden of caring. The example below sums up the views and experiences of many Gujarati Hindu carers in this study in terms of their inability to access emotional support due to PHC nurses 'patient-centred' approach to working.

Shanta Hari, cared for her adult, physically and mentally handicapped son. She talked extensively about how communication difficulties led to her not being able to tell the learning disability nurses that she wanted someone to talk to and take an interest in her, things that she desperately needed. Learning disability nurses only took interest in her son's needs and adopted a very 'patient-centred' approach:

I'm not able to, in terms of feelings...I know she comes and she asks about [son] but I'm not satisfied because they're not able to speak in our language and because I can't speak the language to a great extent, although I do speak a little bit, but whatever she says to me I don't understand and that's my main Dhuk [unhappiness/problem]. (p46)

She was not aware of how the nurses could have supported her because when they did visit, they saw only to her son's needs. She had never been asked if she was coping, whether she wanted to continue caring or simply how her general health was. The lack of support for her, as carer, spanning many years resulted in her no longer having faith in the nursing services. In her view, the learning disability nurses came only for her son and caring for her son was the part she could manage. She wanted emotional support for herself; the type of support that had never been provided and, in her opinion, probably never would be.

When asked if she would like more practical nursing support, she felt that this was not necessary - indeed felt that it would make matters worse as it would take up more of her time, and, at the end of the day, the nurses would be interested in her son's needs rather than hers.

As reported in the earlier review, (chapter four) caring for those with psychiatric or behavioural difficulties can be more stressful than caring for someone requiring physical care (Draper, 1992), yet even these types of carers were unable to access emotional support. Priya Thakrar for instance, caring for her husband who 'heard voices' said, "well the nurses [community psychiatric nurses] don't provide any support. The nurses they just come, they'll come, they'll sit, they'll chat, they'll give the injection [to her husband] then go. They don't provide any support" (p21).

Lack of support led some carers to suggest that PHC nurses should carry out “spot checks” for carers. This could be done by telephone or a formal visit every now and then. Carers wanted someone to take interest in their needs, someone to ask how they were getting on, whether they had any concerns, how they were feeling, whether they were coping and to have a little bit of time set aside on occasions especially for them.

If somebody is coming regularly, if the community nurse was coming they know the mother is caring then really they ought to be keeping an eye on the mother as well...Nurses, they should be like, you know, how do you feel? If they are like that, then you feel better...I mean they give benefits to everyone in this country, but doctors and nurses, for those looking after the handicapped children, be it mentally or physically or if they've got learning disabilities, they ought to remember that their parents experience a lot of *dhuk* [unhappiness/pain] and because of this *dhuk* you feel ill...because they ought to be keeping an eye on carers. Not only handicapped and disabled people. (Shanta Hari, pXX)

This would not be difficult to do in practice and could be done alongside any visit that had been arranged for the cared-for person. Further, as meeting carers' needs was viewed as being part and parcel of the role of PHC nurses, Gujarati Hindu carers wanted 'carers' issues' to be incorporated in to PHC nurse training.

This study provides evidence that, irrespective of the type of caring Gujarati Hindu carers were involved in, whether physical care or meeting mental health needs, most were not coping with the demands of caring and were desperate to talk to someone. This was despite the input of relevant PHC nurses, whose duty, as part of their professional role, would have included meeting carer needs. Rather, PHC nurses reacted by distancing themselves and concentrating on meeting the needs of the cared-for person. The majority of carers felt their needs had been neglected due to PHC nurses' 'patient-centred' approach to working.

### **Failure to recognise those that were not coping**

Language barriers, limited conversations and hurried working resulted in difficulties in establishing effective carer-nurse relationships. The implication of this was that PHC nurses did not recognise that some Gujarati Hindu carers, like Madhuri Krishen for instance, whose case was illustrated in the previous chapter, were not coping with the demands of caring. Other carers, too, were not coping and yet they carried on doing what was expected of them by PHC nurses, therapy staff, family, relations and society in general.

An example of this was those who had responsibility for carrying out exercises at home, as set by therapy staff. Carers found this an added burden and strain and there were some anxieties surrounding the issue; carers worried about not doing what was recommended and whether

this might be viewed as not caring enough about the cared-for person. Yet, to do what was recommended impinged further on their time and was an additional task which, frequently, they alone had to see to.

...they don't seem to know, they don't really know. I mean I know they sort of feel that you've got to do exercises and stuff like that. But sometimes it's not possible in a day to do them, or you know, with time, you've juggling around so much you've got to keep a household going, as well as looking after another child, as well as doing care. To fit everything in is very difficult. To them, because it's their area of work, it's the most important thing that you should be doing, really, drop everything else. But I don't know, you can't always do it. (Madhu Gokhani, p34)

Problems were intensified due to lack of understanding on the part of PHC nurses and therapy staff who seemed unable to recognise the realities of the daily expectations placed on carers, often with little guidance. Madhu Gokhani said "I mean she trained, she's done some three or four years of training of how to do physio and I'm suppose to pick it up in an afternoon". Although this example relates to physiotherapy services, PHC nurses need to be working collaboratively with other health and social care personnel, liaising and communicating regularly with each other, and letting each other know if a carer seems to need further support or a break. Intervention of this sort by PHC nurses would at least reassure carers that someone was interested in their welfare too.

Madhu Gokhani carried on doing what was expected of her, and more, in a bid to be seen as someone who was coping and 'on top of things'. A poor carer-nurse relationship resulted in unmet needs and unnecessary fears about her son being 'taken away':

...and I think 'cos they're like with nurses, it's like, the hygiene as well, isn't it, they are looking at. The hygiene side, what if they think it's dirty, they might take him away, or they might say something, you know...It was always, well, just in case, you know. And I always made sure the children were clean and tidy as well, you know. ...You know that I wasn't uncaring, and on top of things really as well, you know. (p33)

### **Practical support**

Both male and female Gujarati Hindu carers reported being unable to obtain practical support and most learnt how to care for and manage the cared-for person with limited or no input from services. Some wanted help only with carrying out personal care whilst others wanted someone to help them for a few hours a day with the personal and physical aspects of caring. In other cases, support would have been welcome when there were compounding factors which prevented carers from continuing to care, such as when they were not feeling well.

...if I was ever sick, say for a week, or if I've had flu or if I need to go into the hospital and if I was finding it difficult to care for [son], well then I feel that somebody should be helping us, someone should come and help us. (Shanta Hari, p43)

Analysis identified three separate issues here: the need for generic practical support; access to equipment and services; and bathing.

### *Generic practical support*

Many of the issues identified here concern district nursing services, given the nature of their work. It is acknowledged that the material presented relates both to fully qualified district nurses (DNs) and to auxiliary staff. The abbreviation, DN, is used to cover both. Further, at times, issues are equally pertinent to other nursing professionals, in which case this is indicated by using the term 'PHC nurses'.

Those Gujarati Hindu carers involved in 'hands on' caring, encountered difficulties with district nursing services in particular, which overlooked the need to show how things should be done or demonstrate how equipment should be used, did not obtain or follow up delayed equipment, and provided limited support with the practical aspects of nursing care, such as help with personal care. Hence, many carers described themselves as being 'self taught' in terms of learning what to do and how to care for or manage the cared-for person. Most had learnt how to do things through 'observing' rather than the nurses going over issues with them. Brereton and Nolan (2000) have found that carers of stroke patients confirm the adequacy of their skills through books, as opposed to direct observation. However, many carers in the current study were unable to speak or properly understand English; this meant not only that they were unable to ask to be shown what to do but also that they did not have access to literature or resources from which they could have gained help. They described in detail feelings of inadequacy concerning the 'knowing what to do' or 'how to' aspects of practical caring tasks, as well as in relation to managing those with mental health or behaviour problems. Carers learnt by watching because there was no other alternative, and also because PHC nurses concentrated on meeting patient needs.

In some cases, carers were involved in carrying out what can best be described as skilled nursing tasks, such as putting up intravenous feeds, suctioning and giving enemas with little guidance. The following is the conversation between the interviewer (PB) and Anant Laxman and Prabha Laxman:

PB: So do you do the suctioning yourself?

Mr Laxman: Yes we do it ourselves.

Mrs Laxman: We, we taught ourselves.

Mr Laxman: Yes, we just learnt everything ourselves.

PB: So what you're saying is nobody taught you how to do these things?

Mr Laxman: No, nobody taught us.

Mrs Laxman: So if they were ever doing it, we used to look.

Mr Laxman: We've learnt everything through experience. Even postural drainage we've learnt through experience.

Anant and Prabha Laxman had been caring for many years and, like other Gujarati Hindu carers, learnt what they had to do through observing the nurses. In this case, however, inadequate information resulted in them doing more than was required, particularly in terms of observing their son's intravenous feeds. They were aware of the importance of the tube not becoming blocked and hence the need to observe the feeds. However, both woke up at five o'clock each day to get the feed started and dare not take a nap or move away from the bedside whilst the feed was running. Lack of what may appear very basic information resulted in both carers literally standing over the bedside until the feed was completed. Further, prolonged episodes of waking extremely early inevitably made them tired and caused undue stress.

It seemed that *because* they had been caring for many years, DNs overlooked Anant and Prabha Laxman's needs and never asked if they would like any help or support. This may have been because they were now seen as 'experienced' carers, who knew what they were doing and were therefore left to get on with it:

No they [nurses] don't actually help us. Nobody's ever recommended that. Nobody's ever suggested it. Up until now we've always done it, given him bath and everything [suctioning, postural drainage, put up intravenous feed, give enemas] we've done everything. ...Well, we didn't know how they could help us. We didn't know that you're entitled to these things and nobody's ever asked us so. (Anant Laxman, p24, 26)

The case does, however, illustrate that no matter how experienced carers become in their role, the need for emotional and practical support remains throughout their caring career. As discussed in chapter six, both these carers had become so engrossed in their caring role that they felt that they alone could provide the type of quality care required for their son.

A year after being interviewed, the Laxman's son died. However, even then, after fifteen years of dedicated caring, they were not able to access adequate support from district nursing services at a time they needed it most. Anant Laxman spoke about the DNs and said, "No, I didn't hear a dickey bird from them, not a dickey bird" (Fieldwork diary). Although the DNs were in contact with the family for many years, they clearly did not see it as part of their role to ask the carers if they were coping and whether they wanted any support. Sadder still, was that the nurses did not pay one last visit to a family who had been on their 'books' for many years. The house had been adapted and equipment needed to be sorted and 'given back' and both carers, because of their heavy involvement, would have many changes and adjustments to make in their lives. None of these issues seemed to have been given any consideration by the DNs, who simply left the carers to sort themselves out. This is important given that

research has identified that those carers involved in long term caring find it more difficult to create new roles and new beginnings (Aneshensal et al, 1995).

Limited support resulted in Gujarati Hindu carers devising their own systems for managing the cared-for person. Shanta Hari, for instance, cared for her adult son who suffered with incontinence. She used incontinence pads only on the days when he was incontinent more frequently than usual and only on the days after he had an epileptic fit. Like other Gujarati Hindu carers, she too felt that she had 'taught' herself how to care without any help from PHC nurses. She said:

I've taught myself, I've taught myself, nobody's taught me anything. Everything I've taught myself, nobody's come to teach me, nobody's come to tell me...(p26)

The community nurse has been coming for a long time now. It must be ten years now but none of them, you know, but they've never taken any deep interest in us... They've never helped us. (p34)

Although carers had learnt what to do and how by watching DNs, at times this led to risk because carers had not been given advice on correct lifting and handling techniques, for instance, or shown how equipment should be operated.

Alisha Ram cared for her mother-in-law who had a stroke. In sorting out discharge arrangements at the hospital, nurses went through instructions on how to operate the hoist with *male* members of her family. Her father-in-law was shown how to operate the hoist, but he was elderly and fragile himself and could not have managed it alone. Her husband was shown, but he was away at work all day, and her brother-in-law was also shown. However he worked and lived in another part of the city. Yet Alisha Ram was the main carer. She said, "But I just learnt it myself" (p43). Unfortunately, this issue was not followed up by the DNs who assumed that she must have been taught how to operate the hoist. This resulted in her getting incomplete instructions and her learning how to operate the hoist through trial and error.

#### *Access to equipment and supplies*

Another area that caused carer's difficulty concerned access to equipment. Two sub-sets of issues were identified – those specific to health services' responsibilities and those about liaison on the carers' behalf with other service providers.

The *health services' responsibilities* that caused most difficulty concerned incontinence supplies. Access to pads and pants was based on PHC nurses estimating how many would be

required on a monthly basis. This was the amount that would be then be supplied. However, if carers ran out of supplies, they were unable to access any more:

... but they only provided two [disposable pants] so in terms of changing it would be difficult because at least twice a day he would soil them so what can he wear then?...so we went over to the health centre but they said that they can only give it us after a month because they should last a month.” (Priya Thakrar, p16)

Disposable pants are made from paper and tear very easily. In the case above, sending the carer person away without anything to manage until the next ‘due date’ is simply bad practice and caused considerable inconvenience.

Further, as illustrated in the earlier chapters and the literature review, many Gujarati Hindu carers were experiencing financial hardship and were dependent on benefits, and were therefore wholly dependent on formal services to provide otherwise expensive supplies. If it was within carers’ means to buy pads themselves then they did so. For example, health visitors had been visiting Anant Laxman and his family for many years but had not informed the family about their entitlement to free nappies until spotting the terry nappies on the washing line, when the boy was seven. Up until this time the family had been managing as best they could with nappies purchased from the local shops.

Carers’ financial circumstances seemed to be an area that PHC nurses could not fully appreciate, being unable to match economic and social circumstances to the need for formal support.

In other cases, health visitors who had been in contact with the families for a considerable length of time and would presumably have noticed children getting bigger did not offer the suggestion of supplies of extra large size nappies.

However, not all carers experienced difficulties and much was dependent upon the type of carer-nurse relationship that had been developed. Madhuri Krishen, for instance, had developed a very close relationship with particular DNs. For her, running out of pads was not problematic as she only had to call the nurses before they arrived to see her mother. The DNs then collected the pads for her and delivered them to her. This suggests that PHC nurses within the same NHS Trust were inconsistent in their behaviour, with some putting the responsibility onto carers and others doing things on their behalf. Perhaps PHC nurses were here operating as Twigg and Atkin (1994) have also described, using their discretion to judge who was ‘deserving’ of this type of additional support from them.

Some carers did not have even basic equipment or advice that could have helped them in their caring role, as well as promoting independence for the cared-for person. This included equipment such as dycem mats, beakers, shaped cutlery, advice on dressing practice and purchasing larger clothes for the cared-for person with a stroke, and dietary management.

The second issue around equipment and supplies was *the role of the PHC nurse in liaising with other service providers*. Gujarati Hindu carers' inability to access equipment concerned both nursing and social care services. They spoke of equipment taking longer than anticipated to arrive or being 'promised a lot of equipment but not getting it'. While waiting months for equipment to arrive is not an unusual experience for carers, some in this study seemed to wait longer than normal because their case was not followed up. For instance, in the case of Gopal Mithun, not having the correct size wheelchair meant that his wife was unable to have a 'proper' bath for two years as she could not be wheeled into an already wheelchair accessible and adapted bathroom. Further, inadequate information, coupled with language and communication barriers, resulted in this same carer having to meet a bill for £1000 when the occupational therapist suggested that he could order chairs suitable to meet the needs of his wife. He went ahead and ordered them without realising the cost implications.

Carers' anxieties or difficulties could have been alleviated if they had been given adequate information and realistic dates of when equipment was likely to arrive, as well as being re-referred, if necessary, to occupational therapy or social services. Although following up equipment ordered by other professionals is not part of the PHC nurse's role, it is within their role to liaise with staff from other sectors and bring the matter to their attention. Moreover, given language and communication difficulties Gujarati Hindu carers would have found it difficult to take on the role of coordinating equipment and supplies themselves, which white carers might have been in a position to do.

Boundary issues concerning professional roles resulted in fragmented services and carers tolerating unnecessary difficult situations. The impact this had on their lives was discussed in chapter six. In order to avoid these sorts of situations, it is vital that PHC nurses look beyond their role and work collaboratively with other professional staff and services.

### *Bathing*

PHC nurses' roles have changed significantly in recent years, resulting in their no longer routinely bathing patients unless there is a health related need. The following section looks at the issue of bathing from the perspective of three Gujarati Hindu carers. Although the views are based on a small number of carers in this instance, they do provide some interesting insight on this subject. Two main issues emerged from the analysis here.

First, these carers cared for people who were severely disabled and also had other health problems and did therefore fall into the category of having health related need for support with bathing from nursing services. However, this was an area that caused considerable dissatisfaction, largely because whether the cared-for person had a bath or not was determined by workload commitments and whether DNs could 'fit' a bath in during the visit. The drawback was that many months could pass without the cared-for person having a bath. If requests for help were made, carers reported that DNs made them feel uncomfortable; they implied that carers were being over-demanding and made it clear that they could not help because they had other patients to see. Madhuri Krishen talked of her experiences of asking for help to give her mother a bath:

My mum was in a right mess and everything and she was messed up completely in bed, the toilet and everything and because it was since last night, I didn't realise cos she was sleeping. She was in mess in the morning. I would have liked her to have a bit of quick bath and they just said "no". So I didn't say much or anything. (p37)

You know, sometimes some nurses do things like and like we ask too much, that's how they feel that we're asking too much....And you can't really say anything to them as well, I never say anything to them, I just let them get on with their job, do what they do and the rest. If I'm not happy with it, I do it myself. (p37)

Although Gujarati Hindu carers accepted that a full 'proper' bath could not be given regularly due to time restrictions, an occasional bath would have been welcome.

Cultural considerations were also woven through this issue. A 'bed bath' was regarded as particularly unclean and distasteful. Gopal Mithun spoke about his wife and said: "Well, she's been having a bed bath for the last two years now. They just wash her in bed, but what can you do in bed [how can you get clean?]" In a few cases, not being able to have a proper bath resulted in the cared-for persons not fully participating in religious activities because they did not feel 'clean.' Although district nursing staff did try to meet the cultural needs of the cared-for person during special occasions, there was still a general feeling among Gujarati Hindu carers that PHC nurses lacked knowledge concerning their cultural and religious beliefs.

I think it would be nice if they knew about our culture...you know the nurses, they don't even understand, it makes it difficult for them. (Madhuri Krishen said, p46)

Meeting the spiritual needs of the cared-for person is part and parcel of holistic nursing (Dossey, 2001) hence, PHC nurse training was identified as in need of improvement.

I think in the nurse training, when they go for their first nurse training, I think they need to be more culturally aware of what the different services, what different types of clients they're likely to come across...If they haven't got that cultural awareness when they

come across Asian clients or with any different clients, they're not going to be able to respond to them...They're not gonna have that appreciation of how differently that client might see things...I think everybody needs re-educating. (Sameer Gokhani, p33)

The second issue here was carers simply not being aware that they could get support with bathing, whether from DNs if there was a 'health' need or via social services. As reported later, Gujarati Hindu carers were unable to differentiate between different grades or types of PHC nurses or knowledge of their role. As a result some, perhaps, had unrealistic expectations of support with regard to bathing. However, the DNs could have clearly indicated if bathing did not fall within their remit, pointed carers in alternative directions, and informed them that there might be a charge for social care support with bathing. It would then be up to carers to determine whether they wanted or could afford to take up offers of social care support. In one case, for instance, a young male carer said he would have liked nursing support to help bath his mother. He found the task embarrassing, knew of no other way of getting support, and resorted to marrying so that his wife could take on the responsibility.

Similarly, Gopal Mithun's problem with not having a wheelchair to use in the bathroom was not *technically* a nursing problem. However, his wife was eligible for a 'health' bath, which begs the question of how the DNs involved saw their role in ensuring that adequate equipment was available to make this possible.

### **Quality of service**

PHC nurses were also criticised by Gujarati Hindu carers in terms of the quality of services provided.

First there was the issue of the *range of tasks undertaken* during visits, such as emptying catheter bags or meeting toileting needs. Again, many of these issues were particularly pertinent to DNs. For example, although DNs called to put Alisha Ram's mother-in-law to bed each night, they did not see to her toileting needs:

All they [nurses] do is dress her up [change into nightclothes] and that. And then they go, you know, and they don't even put her on the toilet or empty her bag [catheter bag]. (Alisha Ram, p29)

As a result, soon after her mother-in-law had been put into bed and the DNs had left, the carer would have to see her mother-in-law's toileting needs.

Secondly, carers assessed *how things were done*, compared to their own caring input, especially in relation to personal care. Madhuri Krishen for instance, gave a description of the routine she and her brother had when putting her mother to bed:

Like when we put mum into bed, we give her a good wash, bottom wash and everything and get her changed and you know, give her a proper wash and put her in bed just the way she's comfortable. (p33)

This was in contrast to what the nurses did or were prepared to do. Consequently, some carers felt that they 'did a better job' than the DNs. This finding is mirrored in other studies too (Twigg and Atkin, 1994). Although it is acknowledged that DNs would be working under different constraints and Gujarati Hindu carers would have developed expertise through their role, carers 'demands' were those normally to be expected of PHC nurses. For instance, making sure the cared-for person is clean and left in a comfortable position is not something that can be classed as being overly demanding.

The third issue was *the timing and reliability of visits*. Carers referred to PHC nurses calling too late, too early, never being on time or not turning up at all. Such inconsistencies in the service made it difficult for carers to plan and organise the day. This left them feeling frustrated, and in some cases, they were unable to continue with other tasks until the cared-for person had their needs met. Problems with the timing of visits resulted in some carers turning the nurse away when she did eventually call.

Once, we were waiting for them [DNs] and it was quarter past ten and I had even gone upstairs, and I was shutting the curtains, and then the nurse you know parked outside. So we told her, you know, well now she's gone to sleep already, you can go. (Gopal Mithun, p22)

In other instances, carers felt nurses came too early to put the person to bed and this was unacceptable, as the nurse would not call again until late the next morning.

We booked it for between half past eight and nine, they used to come at seven o'clock in the evening to put her to bed and that's too long for her, we don't really like her to go to bed that early. It's like she stays in bed for a long time, they used to come at the wrong time when she was eating and afterwards she likes to sit down for a bit, not go straight into bed. (Madhuri Krishen, p33)

Carers who had no other source of support were particularly vulnerable. Gopal Mithun, for instance, was himself elderly and frail and was unable physically to lift his wife onto the commode. This resulted in her having to stay in soiled clothing and pads for the entire day and most of the evening as district nursing staff only called twice a day.

She'll be sat there all day, and then they'll come in the evening, and they'll clean her up. Then they'll pick her up and put her to bed....So if she wants to go [to the toilet] then she just has to wait [either to have pads changed or to be put onto the toilet]. ...they've already been allocated other patients to see so they're not able to come.

He went on to talk about his experiences of when the nurse did not turn up:

Nobody came, and she was screaming because she wanted to go to the toilet but who can lift her you know....So we phoned her and she said she wasn't down to come but then she eventually came at ten o'clock [pm].

As the example above demonstrates, for Gujarati Hindu carers, the most frustrating aspect of having primary health care nursing services was *not* having a service. This was largely because the PHC nurses did not arrive as expected and at times gave no prior warning that they would not call.

Like on Saturday, we never got any services at all on Saturday afternoon, nobody came in the afternoon. We just waited and waited and they didn't turn up.  
(Alisha Ram, p31)

In a few cases, inconsistencies in district nursing service resulted in some carers asking that the number of visits made by the DN be reduced.

A fourth issue experienced by the majority of carers was the fast *turnover of PHC nurses*. Carers found this problematic as it became difficult to establish effective carer-nurse relationships and resulted in continuity of care being affected when the 'nurses kept changing'. Carers thus became involved in a lot of repetition in terms of the cared-for person's overall health, progress and care. Madhuri Krishen, for instance, spoke about this issue with respect of the DNs.

So we have all different nurses coming in all the while, we never get a regular one coming in, only for a few months and at the end it just seems too much stress. I just wanted somebody to take a bit of pressure off me, come home, do things what they need to do in the way we would like them to do it and everything but instead of that everyday, different ones. We had to go over everything, explain them...when somebody else is coming, I find it a bit difficult then 'cos sometimes in the morning I just open the door, they just do what they have to, but if somebody else comes then you have to go through all the routine, where we keep things and everything and what we do and we've gotta tell them how we do them. (p34&37)

Fifthly, there was the considerable upset caused by nurses' *untidy approach to working*. District nursing staff were felt to be untidy and that they did not clean up after themselves. As a consequence, carers resented their involvement because it meant additional work. DNs were reported not to have disposed of used incontinence pads appropriately by putting them in bags, not putting things back in their place and leaving tasks for carers to do after they had finished:

...they don't put things like powder, cream and clothes and everything, they just leave it everywhere, they don't really bother cleaning that up and powders all over the place and they're just messy. I find them messy. (Madhuri Krishen, p35)

Further, knowing that the DNs were busy, some carers tried to help the district nursing staff by getting things ready before they arrived.

...but when they come I usually have everything complete [ready]. So I get everything ready, I move everything and make sure everything's ready for her, for when she comes. I'll have all her clothes ready you know, and I move the table and get everything ready for her. (Gopal Mithun, p19)

Carers reported that this support to the nurses was overlooked by them.

For some carers, the mess left behind by the district nursing staff and their attitude and behaviour resulted in them wanting to cancel the service altogether. Female carers, in particular, were critical of district nursing staff's lack of willingness to support them other than by carrying out tasks that had been written down in the nursing notes. Tidying up afterwards, for instance, was something which carers felt should be part and parcel of the care provided for the cared-for person, and not something that should be passed on to carers.

If they're [nurses] just gonna leave it [things] lying around there's no point having the service is there?" (Alisha Ram, p35)

Finally, all carers in receipt of district nursing services were particularly critical of the *weekend service*. This was an unexpected finding. It is acknowledged that there would be more limited district nursing services during the weekend. However, it would be generally assumed that irrespective of whether care is provided at the weekend or during the week, services would be of the same quality. All the issues reported above were much more problematic during the weekend but, overall, lack of consistency with weekend nursing staff caused the most difficulties for carers.

### **Conclusions about PHC nurses' 'patient-centred' approach**

All types of Gujarati Hindu carers in this study felt that they were not being supported while, as we see in the next chapters, PHC nurses and managers expressed the view that minority ethnic carers had higher expectations of what PHC nurses could do for them than did white carers. In writing about role theory, Gross et al (1966 in Coulson, 1972) define role as a set of expectations, or a set of evaluative standards applied to the incumbent of a particular position. A person's occupation affects the way others behave towards him or her (Banton, 1965, p33). Gujarati carers' lack of knowledge about the roles of different PHC nursing professionals and

services and how they could be supported by them might, thus, have provided some explanation for these contradictory views.

However, the analysis did not reveal any real evidence to this effect. Gujarati Hindu carers had expectations that PHC nurses would give or supply information, obtain equipment or provide emotional or practical support – all activities of a type that *do* fall well within the professional boundaries of PHC nurses' role.

Previous research in this area has been contradictory. Cameron et al. (1988), for example, suggested that DNs failed to support informal carers, while Gerrish's (1998) observational study of district nursing practice suggested that DNs *did* attribute importance to supporting carers and were attentive to their needs, irrespective of ethnic background. Both these approaches were evident in the current study. PHC nurses did attach some importance to meeting the needs of informal carers and did not overlook them altogether. However, as we see in chapter eight, they also stated that the needs of the patient were a priority and therefore tried not to get 'too involved' with Gujarati Hindu carers. Indeed, as we shall see, carers' attempts to establish relationships were thwarted by PHC nurses who used strategies to distance themselves, as opposed to creating partnerships.

The current study is different, then, because the analysis revealed that, although PHC nurses acknowledged Gujarati Hindu carers, they did not support them adequately because they appeared to practise a restricted model of 'patient-centred' working. It was this that resulted in carers not being provided with practical and emotional support. The next chapter shows that PHC nurses did see meeting the patient's needs as their central concern. Hence requests by carers for support may have been viewed as impinging on time their patients were deserving of and, given the constraints they were working under, PHC nurses consequently tried not to get too involved with carers.

The conclusion here, then, is that much of carers' disappointment seemed related to PHC nurses' 'patient-centred' approach to working, which led to carers' needs being neglected. Despite nursing philosophy and policy promoting partnership, equality and a relationship based on negotiation, collaboration, consultation and shared decision making there was little evidence of this in practice for most of these carers.

Similarly, while modern primary health care nursing claims to conduct holistic nursing assessment which would incorporate carers' needs, in practice, assessment continues to focus

on the needs of the patient. Further, PHC nurses did not question the implications of some of the information gathered.

It is concluded, then, that true patient-centred care in combination with the holistic assessment remains an ideal. Further, it is unlikely that either of these approaches will have any impact on the lives of carers unless PHC nurses begin to seriously consider carers as partners and value not only their contribution but also their need for support.

The quality of assessments and care-planning carried out by PHC nurses was not assessed in this study. However, given the evidence based on interviews with carers, it is suggested that this area warrants further investigation.

It can be argued that PHC nurses and carers have the same agenda, which is to ensure that the cared-for person has their needs met. However, this can only be achieved if PHC nurses see carers as more than just a resource (Twigg and Atkin, 1994). Twigg and Atkin (1994) suggest that carers' needs could be incorporated into practice by adopting carers as 'co-workers'. This model could be used to ensure that primary health care staff and social care agencies work alongside the informal care sector, by interweaving their support with that of the carers. It aims to encompass all the potential sources of help in the community from friends, neighbours and kin. As we have seen, however, Gujarati Hindu carers had very little, if any, support from family, friends, neighbours or even formal services. In terms of this thesis, then, a model where carers are seen as co-clients may be more useful. This would ensure that carers were recognised as individuals in need of help in their own right. Services would then be aimed at relieving the carer's situation and enhancing their morale, for instance by, arranging short-term residential respite care. It is particularly useful for the highly stressed and heavily burdened carers (Twigg and Atkin, 1994).

In practice, the model that is adopted will depend on a carer's individual situation and circumstances. However, irrespective of models used to support carers, effective carer-nurse relationships are pivotal if partnership working is to be successful.

## **COMMUNICATION AND LANGUAGE BARRIERS**

As seen throughout the earlier parts of this chapter, provision of support for Gujarati Hindu carers was complicated by language and communication barriers. These included carers being unable to express needs clearly to PHC nurses, not understanding what the PHC nurse was trying to tell them, not understanding the benefits of proposed treatment plans, not

understanding what was expected of them as carers, as well as having little understanding of the roles of PHC nurses and how they could support them. Inevitably, this created a situation where PHC nurses were in a 'naturally' dominant and powerful position in comparison to the non-English speaking Gujarati Hindu carers. There was little evidence of carers being involved in the planning of care or effective partnership working.

Without adequate interpretation services carers were *unable to express their needs*. Only one carer in the study had experience of using an interpreter, when a learning disability nurse took another member of staff with her to the carer's home. For a variety of reasons PHC nurses did not make full use of the professional interpreting services provided. Their rationale for this is discussed in more depth in chapter eight. Gujarati Hindu carers tried to overcome communication difficulties by, for instance, asking relatives to interpret, taking their children to interpret at appointments or asking them to interpret when the PHC nurse called. However, using children to interpret could lead to information not being accurately understood and misinterpreted. In addition, it could be highly embarrassing for the child to interpret and discuss sensitive issues. Pharoah (1995) and Gerrish (1998) have made similar observations.

Barriers to communication also played a part in Gujarati Hindu carers' *not understanding what they were being told*. Although the ability to communicate in English did not guarantee understanding, those carers unable to communicate in English found their situation much worse. They were unable to ask for advice or information, remained uninformed verbally by primary health care nursing staff, and were not provided with any translated material. While information translated into Gujarati was felt to be valuable, carers' first preference was for the PHC nurse involved with their family to provide information directly or point them in the right direction for help. These findings are similar to those of Beresford (1994) who identified that parents preferred personal communication. In such circumstances, translated and printed information would act as a resource that carers could use to explore issues in more detail, such as specific conditions, for re-checking information or to complement what PHC nurses had told them verbally.

Language and communication barriers could also result in the carer *not understanding the benefits of proposed treatment plans and their role in treatment*. In one case, unclear communication resulted in a carer asking for therapy to be stopped. Shanta Hari cared for her adult 'physically and mentally disabled' son. Nursing staff at the day centre commenced massage therapy on her son without consulting her. Instead, a note was written in her son's

diary informing her that massage therapy was being carried out. She felt this to be inadequate and said:

I mean they wrote us a little message but with a little message what, you know, what understanding can you gain from that? (p52)

Shanta Hari, could not understand the rationale and benefits of massage therapy for her son. In her opinion, it aggravated his behaviour so she requested that it be stopped:

He won't relax, if he has a massage, he doesn't relax, he becomes too active, he goes the opposite way. ...So then I started observing that he wouldn't be sleeping and we kept on noticing, noticing, noticing and then afterward we got fed up and we wrote a letter to them [to stop massage]. (p52)

This situation could have been avoided if the learning disability nurses had made attempts to explain through an interpreter why it had been decided to start therapy and what the potential benefits might be.

On the whole, however, Gujarati Hindu carers, including Shanta Hari, did what was asked of them, often without questioning the authority of a professional. The findings support the view of Pearson (1989) who argued that minority ethnic people may be reluctant or unable to complain about the quality of services especially if they feel ill or vulnerable, let alone further jeopardise relationships by challenging professionals.

Shanta Hari, for instance, painstakingly kept a diary of her son's fits and food intake. Other carers too, generally did what was asked of them - carried out exercises as suggested by therapy staff or carried out tasks that can be classed as skilled nursing care, as in the case of Anant and Prabha Laxman.

Communication and language barriers also restricted *understanding of the role of PHC nursing services and how they could support carers*. Even those who had contact with PHC nurses knew little about their professional role, let alone about services provided by other types of PHC nurses. For instance, Madhuri Krishen, as mentioned earlier, had a special relationship with particular district nursing staff, yet, despite this and many years of having nursing involvement, she still lacked knowledge about the different grades and types of staff and what their roles were. She said:

No, I don't know nothing about it. Still I don't. Honestly. All I know is, who ever comes in the morning is an auxiliary, they not a nurse. They not nurses, they not qualified to do some of the things what, you know the monthly visit we have. The levels and that, I still don't know a thing about it kind of thing. (p43)

At times Gujarati Hindu carers did not understand why staff had called and many were unable to differentiate between the roles of different grades of staff within the same profession. Those carers who had children had some awareness of the role of health visitors through their own experiences of contact via their young children. A few had some insight into the types of tasks district nursing auxiliary staff were unable to do. For instance, they referred to the auxiliary nurses as the ones that were 'not trained' and not allowed to give medications. It is, perhaps, significant that carers were told clearly about the types of things PHC nurses were *not* prepared to do, yet PHC nurses gave little away in terms of how they *could* support them.

That's why I'm saying to you about the community nurse, I don't know about her, I don't know what her job is. The one that comes, you know, I don't know what the community nurse's job is, what her role is, we just don't know. All I know is they come for [son]. (Shanta Hari, p51)

Lack of knowledge about services in the first instance also delayed access to PHC nursing services. Hence, a few carers felt they had 'missed out' on nursing support at a time when they most needed it. In once case, the carer was under the impression that professionals may have deliberately blocked services:

Well about nursing services, we found out about nursing services very late... But who do you find out from, even that we don't know... not up until now, But we, we weren't aware, you know, what, whose role is what. Which services they may have blocked we don't know. You see what's happened is, it's through personal experience that we've learnt about everything and found out about things. (Anant Laxman p14 & 23)

There was only one case in which the carer knew about district nursing services but turned down an offer of support. In this instance, pressure from the cared-for person resulted in Vikesh Anand having no option but to care for his wife without any outside support. After many years of dedicated caring for his wife, involving washing, dressing, feeding and toileting, he was now desperate for support and a break. The following are his thoughts about how DNs could have supported him:

Well, if the nurses had come, then it would have given me that much of a break you know, for an hour or two... Well, they could have got her ready, for instance, given her a bath and that. Because of the time that I would have, my time would have been taken up you know, in getting her ready you know....during that time I could get something else done instead...I could cook a little earlier. If somebody was at home then you know, I could go shopping, and in that way it would have made a difference.

Well, I tried to make her [wife] understand that I wanted to keep somebody here, you know, in that it would have given me that extra time, so I wouldn't have to suffer all that pressure and stress and that, and everything you know, and that if somebody is offering to come and help, you shouldn't say "No", you should take their help.

...people did come and ask and ask her [wife], you know, if we wanted help but she just said no, she didn't want anybody else to come and do it. It didn't matter if they were coming to do it free...and because of that reason even I had to leave work. (p25,26,38)

Carers suggested that PHC nurses might benefit from training in which the curriculum included sensitivity to cultural awareness. However, they did not indicate a preference for only Gujarati Hindu nurses or South Asian nurses to meet their needs. Rather, irrespective of the ethnicity of the PHC nurse, carers wanted recognition and some appreciation for their efforts. Although 'matching' might help overcome language and communication barriers, as well as being useful in developing stronger relationships through exchanging views on shared cultural values, it remains a controversial tactic. Problematising minority ethnic needs as being 'special' can lead to minority ethnic communities being viewed as deviant groups not fitting in with the majority (Blakemore, 1998). Blakemore (1998) suggests that 'it is not so much that 'special' needs are being addressed but rather that existing inadequacies and common problems are being recognised' (p271).

Evidence from this study is limited in that only two carers discussed the issue in-depth. What emerged however, was that 'ethnic matching' of PHC nurses was valued only in that it was thought of as being useful to overcome language barriers. Moreover, despite language barriers, both carers still indicated a preference for white nurses over South Asian nurses.

There used to be an Indian nurse that used to come a long time ago, but I told them not to send her again and to send Diana instead. (Gopal Mithun, p25).

### **Conclusions about communication and language barriers**

One way of involving carers is for nurses and carers to discuss openly and negotiate a relationship within which involvement can operate in a way that both feel comfortable with and in a way that endorses the principles of good practice, for instance, those relating to communication and power (Walker and Dewar, 2001). Robert and Krause (1990 in Casey, 1995) describe a three way process of negotiating care with clients (and carers, my addition) which begins with eliciting requests and expectations, followed by interaction, consensus and finally decision making based on a shared view of the problems. Given the language and communication barriers identified in this thesis, there was little room for negotiations, let alone eliciting carers' requests or expectations.

Evidence from this study identified a definite need for PHC nursing services, yet many carers in this study had been in Britain for more than ten years, and still had limited knowledge about which PHC nursing services were available. The findings mirror those of Modood et al (1997).

The findings from the current study also mirror those of Blakemore & Boneham (1994) who argued that people do not necessarily want to be cared for someone from the same community just because they speak the same language. The ethnicity of the PHC nurse was not important because Gujarati Hindu carers wanted, more than anything, simply someone to turn to. The findings are contrary to evidence from earlier studies that addressed social care needs where it was argued that the provision of specialist services would be better able to meet the needs of minority ethnic people (Farrah, 1986). Given that there are no large scale studies to date that have looked at 'ethnicity matching' in the provision of primary health care nursing services, it is suggested that this is an area that would benefit from further research.

## **CHAPTER 8**

### **PRIMARY HEALTH CARE NURSES' EXPERIENCES WITH MINORITY ETHNIC CARERS**

#### **INTRODUCTION**

The previous chapter demonstrated the different ways in which Gujarati Hindu carers were supported or not by PHC nursing services. The aim of this chapter is to look at the perspectives of PHC nurses in terms of their experiences with minority ethnic carers. As reported in chapter five, the initial intention of this study was to adopt a case study approach whereby the views of PHC nurses and 'their carers' would have been sought. However, PHC nurses were reluctant to discuss individual cases which would have enabled triangulation of views; it was not therefore possible to obtain PHC nurses' views in relation to specific Gujarati Hindu carers. Hence, the findings reported here are based on PHC nurses' retrospective accounts of their experiences with minority ethnic carers, as in South Asian carers, more generally, including those from different communities. Where appropriate, examples relating to the patient (rather than the carer) have been included for clarity and context. However, in reporting from a PHC nursing perspective, the word 'patient' is used as opposed to 'cared-for person'.

Obtaining the views of different parties adds to the complexity of the thesis. However, the earlier review (chapter three) identified that partnership with carers is one approach PHC nurses can adopt to support carers. Indeed, partnership with carers is a key aspect of policy, as well as being central to the philosophy of nursing. It was thus essential to obtain the views of both carers and PHC nurses not only to improve understanding but also to facilitate awareness of what the key issues were from both perspectives. Moreover, this approach has been neglected in previous research in this field which has often obtained the views of one party only.

This chapter is divided into three sections. The first looks briefly at PHC nurses' experiences with minority ethnic carers. The second section takes an in-depth look at PHC nursing services in practice. The final section looks at the impact of structural factors on PHC nursing practice and how these impinged on their ability to meet needs. As with chapter seven, because of the range of issues considered here, conclusions are included at end of each main section.

## **PRIMARY HEALTH CARE NURSES' EXPERIENCES WITH MINORITY ETHNIC CARERS**

### **Positive experiences**

PHC nurses enjoyed working with minority ethnic patients and carers. Some would have liked more minority ethnic patients on their caseload whilst some even suggested that they had a preference for working with minority ethnic families over white families.

Working with minority ethnic patients and carers was viewed positively because of the sociable and hospitable nature of the community. Minority ethnic families were reported to be polite and pleasant. PHC nurses were made to feel welcome and frequently offered Indian food, snacks and drinks and more so during festive periods such as Diwali. There was a general consensus that when visiting minority ethnic patients, PHC nurses would rarely leave the home without having tasted or tried 'something' to eat or at the very least been offered tea, coffee or a soft drink.

As soon as you walk through the door, you are made to feel very welcome.  
(Clinical supervisor Likisto, p15)

Some PHC nurses particularly enjoyed working with minority ethnic families because they were respected as professionals by them. They described carers as being cooperative, who listened to what the PHC nurse had to say, appreciated professional input and advice, turned up for appointments and as being 'eternally grateful' for whatever the PHC nurse did for them. PHC nurses associated this with their ability to 'open a lot of doors' for carers with regards to accessing services. Some even spoke of finding it easier to work with minority ethnic communities, although perhaps not always for the right reasons. Health visitor Faygate, for instance, spoke about how she enjoyed working with minority ethnic patients because they were polite, always asked questions, had the greatest respect for professionals and 'they do exactly as they are told' (p6).

Minority ethnic carers' were reported to have limited awareness about which PHC nursing services were available. Learning disability nurses, for instance, expressed concerns about not having enough minority ethnic families on the 'books', despite it being an area in which the majority of the population was South Asian. However, once minority ethnic families had entered into the system, they did generally use the services provided by them. Similar findings have been reported in other studies (Twigg and Atkin, 1994).

This limited awareness resulted in PHC nurses receiving referrals for minority ethnic patients who were often in a much worse state of health than would be the case for white patients. District nurse Dobcross, for instance, commented that referrals for people who had a stroke always reached them too late, by which time the client had deteriorated because of lack of activity and there was little the nurses could then do. Concerns about minority ethnic patients being much older by the time PHC nurse received referrals were also expressed.

It's the age of the people, you know, with Asian people when the referrals come through... you might find that you have people in their 40s that are accessing our service now. I mean I don't know how they have found out about it but obviously they have been caring for that person with the learning disability for all those years and they have had no help.

(Community nurse Startley, p46)

### **Knowledge about minority ethnic communities**

Contrary to previous evidence (Bhakta et al, 2000) in which it has been reported that PHC nurses lacked knowledge about minority ethnic communities, the analysis from this study revealed that PHC nurses had, indeed, acquired some general knowledge concerning minority ethnic communities. Much of this had been acquired whilst working in the community with different client groups. PHC nurses were knowledgeable in three distinct areas: the structure of minority ethnic households, factors influencing the decision to care and the issue of stigma.

Based on their experiences of visiting minority ethnic patients and their carers, PHC nurses were aware that extended family households were a common feature. Male members were recognised as having overall responsibility for meeting the needs of the family and taking decisions. PHC nurses were also aware that it was common for the daughter-in-law to take on the responsibility for caring. Difficulties of living within an extended family were also recognised, particularly concerning differences of opinion between parents and grandparents.

PHC nurses recognised that cultural and religious beliefs influenced carers' decisions to care and that carers were often guided by the principles of *Karma*. This knowledge was often gained through carers who had mentioned to PHC nurses that if they continued to care in this life, their next life would be better.

It was recognised that disability and mental health carried considerable stigma within minority ethnic communities. PHC nurses were aware that mothers of disabled children in particular were often not well supported, irrespective of living within an extended family household. Others gave examples of carers not wanting relatives and neighbours to find out

that the patient had a mental health problem. This inevitably resulted in these families being isolated from the community.

You know I have had carers of users who had been on treatment for twenty years right and the treatment would be, say, schizophrenia right and they're totally isolated, for twenty years the carer didn't know what the illness was, why he was having treatment, what are the side effects, what are the long term effects, totally isolated as well from the family because of the stigma then [from] the community as well. They live in a totally isolated world. (Community psychiatric nurse Mathern, p3)

Despite this general awareness about minority ethnic communities, PHC nurses were still unable to differentiate and link beliefs and practices between and within minority ethnic groups. Partial understanding resulted in some of the knowledge acquired being at times misunderstood. For instance, some PHC nurses believed that it was carers' beliefs in *Karma* that resulted in non-compliance.

Another family told me quite clearly that their belief system was, the more they suffered in this life through caring for their son, and their next life would be better. And I was demonstrating behaviour techniques, which would actually make their son's management easier, and I did demonstrate to them that, you know, you could control his behaviour but in fact they weren't motivated to control his behaviour, for the reasons I've just said. (Clinical supervisor Jaywick, p5)

### **Conclusions about experiences and knowledge**

PHC nurses in this study enjoyed working with minority ethnic families and those that worked in a predominantly South Asian area expressed concerns of the low numbers of minority ethnic patients on their caseload. Contrary to previous evidence, this study identified that PHC nurses had indeed, acquired some general awareness concerning minority ethnic communities in distinct subject areas, much of which had been learnt 'on the job'.

## **PRIMARY HEALTH CARE NURSING IN PRACTICE**

### **SUPPORTING MINORITY ETHNIC CARERS**

PHC nurses provided three distinct types of support for carers; providing advice and information, coordination and referral to services and emotional support.

PHC nurses described providing a range of different types of information and advice to carers. This included information on, for instance, respite and day service provision, advice about transitional changes, information about the toy library and advice about how to make the best use of the GP surgery. Filling in forms or writing supporting letters for housing was also mentioned. Benefits claims forms were recognised as being difficult for anyone to complete hence, on occasions, PHC nurses spent time going through forms and filling them in on behalf of carers.

PHC nurses also described themselves as being the “middle man” or the “liaison person,” coordinating between all the other agencies that carers had contact with, for example, social services, schools, clinics and hospitals. This involved enabling carers to access equipment such as waterproof mattress covers, liaising with other agencies such as the Red Cross and referring to services, such as day care. Health visitor Elgin felt her role was to ensure that everyone that should be visiting was visiting. She described it as “knitting things together.”

Building up a trusting relationship was also described as a key aspect of their role. This was important as minority ethnic carers were reluctant to take a break.

It's very very difficult because you see these parents just disintegrating in front of you and if they won't accept any help there's nothing you can do about it.  
(Health visitor Golant, p12).

PHC nurses also recognised that at times, the patients manipulated the situation and made carers feel guilty for wanting to take a break without them. Enabling carers to talk about their concerns and allowing them the opportunity to “offload” was regarded as essential part of practice. PHC nurses described themselves as being skilled listeners whom carers could turn to anytime. It was also recognised that carer's needs could easily be overlooked.

I feel that my role is to make sure that everybody is visiting who should be, they've been referred to who they should be and they're having that sort of support in that way and we would then support the parent, more of listening, letting them talk about the problems, how they're feeling, because it's often the carer that gets left and they've probably got a lot of emotional needs that they need to talk through.  
(Health visitor Elgin, p10)

However, more often than not, PHC nurses reported providing support for carers via the telephone or leaving their contact details for patients and carers. This suggests that PHC nurses did provide carers with some support; however it does lead to the question of what type of support PHC nurses were able to provide over the telephone. For example, evidence from a recent survey (Chamba and Ahmad, 2000) which looked at language and communication needs of parents with severely disabled children reported that telephone help-lines whether in English or another language, were not widely seen as a way of getting information. It is not unreasonable to suggest that trying to 'offload' over the telephone is not the same as trying to explain in person that you no longer wish to continue caring for instance.

The findings of the current study suggest that, in a bid not to get too involved with carers, providing contact details and stressing that carers could access support via the telephone was one strategy used by PHC nurses to enable them to continue focusing on the needs of the patient whilst visiting patients in the home environment. Moreover, given that many carers were unable to speak English and were criticised by PHC nurses for failing to cancel appointments, for instance, one does wonder what type and how much telephone support they provided for non-English speaking carers. This is important as minority ethnic carers may be somewhat more restricted in their ability to stop caring (Katbamna and Bhakta, 1998). Hence, when deciding whether carers should be involved or not, it is essential that PHC nurses remember that:

Informal carergivers' participation in patient care must be considered as their privilege rather than their responsibility (Laitinen, 1992, p1236).

Despite listing the range of activities PHC nurses did to support carers, when asked to give a recent example of how they had supported carers, PHC nurses were taken aback. Some could not think of anything initially and paused for a while before answering; others had difficulty describing what they did, because they 'did it all the time' [support carers]. Those that eventually managed to think of something reeled off 'text book' type responses giving long lists of what they did. More importantly, however, despite PHC nurses stating that they supported carers, all PHC nurses reiterated that the patient was their central concern. Interestingly a number of PHC nurses said they had to focus on the patient because otherwise it would in effect be classed as two separate referrals. The issue of focusing on the patient is described in the example below.

A GP [general practitioner] refers you a client so you actually go and see the client on their own. You don't go and see the whole family.  
(Community psychiatric nurse Hakin, p11)

If PHC nurses are to meet minority ethnic carers' needs, changes to the way in which caseloads are managed may be necessary, enabling them to spare some time for carers; alternatively, PHC nurses could refer carers on to other services that could provide a 'listening' service. However, if services are to be used, information and explanations about them would need to be provided in a language that carers understood, as well as being followed up in a concrete way.

Some PHC nurses were aware that the support they were able to provide was not enough. They reported the need for local support groups for minority ethnic carers and for an 'extended hours crisis worker' for those caring for someone with a mental health problem whose needs did not necessarily conform to usual 'office hours'.

### **Conclusions about support**

Evidence from PHC nurses revealed that they provided advice, made referrals and supported carers emotionally and, hence, carers' needs were not totally overlooked as reported in previous studies (Cameron et al, 1988). However, neither were they met, as reported more recently (Gerrish, 1998). Rather, the analysis revealed partial and somewhat distanced support, for instance, via the telephone. Hence, PHC nurses endeavoured to meet carers' needs to an extent, but still kept their distance and tried not to get too involved with them because meeting the needs of patients was their priority.

### **LANGUAGE AND COMMUNICATION**

Despite positive experiences, PHC nurses did experience a number of difficulties in their day to day encounters with minority ethnic carers. By far the main difficulty concerned language and communication problems. Indeed, district nurse Dobcross spoke with sarcasm when asked if she encountered any particular difficulties whilst working with minority ethnic carers as if language and communication barriers should have been obvious. As also identified by Murphy and Clark (1993), communication difficulties resulted in immense frustration as well as uneasy and poor carer-nurse relationships as neither the Gujarati Hindu carer nor the PHC nurse really understood each other. Building up rapport with carers proved problematic where language and communication barriers existed. On the contrary, rapport with English speaking carers was identified as being 'more special' as it enabled carers to be at ease and 'open up' (NA Badby, p1). On occasion, difficulties in communication resulted in PHC nurses feeling helpless and inadequate.

The language, yes frequently trying to make them understand what I want. That is the biggest problem....I have stood in houses feeling very frustrated because I just don't

know what is going on. I find that dreadful, you know people are crying, wailing, shouting, talking and I am just standing there, haven't got a clue....sometimes I feel useless. (District nurse Dobcross, p17)

Her frustrations were such that she went on to say, 'I just wish they [minority ethnic people] all spoke the same language' (p24).

One of the biggest problems experienced by PHC nurses where language and communication problems were present concerned conducting holistic assessments as they were reported to be more time consuming because of the need for constant clarification. However, PHC nurses involved in conducting bilingual assessments also experienced difficulties in trying to find appropriate words to explain to carers what it was they wanted them to do. This issue is discussed in more detail later in this chapter.

In their attempts to overcome language and communication difficulties, PHC nurses used techniques such as miming, or 'sign language' often combined with English to try and explain what they were doing. Despite difficulties, '*muddling through*' was viewed as acceptable practice under the circumstances. On the whole, this approach enabled PHC nurses to get by to a certain extent, usually where it involved practical tasks or when PHC nurses were paying a visit specifically in connection with the patient.

Another strategy used to overcome communication difficulties involved '*making do*' by using family members, usually a male relative, second generation sons and daughters brought up and educated in England, other relations, children or neighbours to interpret. Although PHC nurses reported that this was not ideal, it enabled them to 'get by' sufficiently and was viewed as acceptable, especially as some carers 'brought their own interpreters'. Given the availability of an English speaking relative or neighbour, this was felt acceptable under the circumstances:

We aren't supposed to in general. Obviously if I went to a patient's house, and wasn't aware that there was no English and there was a daughter there who spoke English I am not just going to walk away from the situation. I am going to get on with it the best I can. (District nurse Dobcross, p16)

In discussing communication issues, health visitor Golant claimed that carers and patients actually preferred to use somebody in the family to interpret. Most worrying, however, was the view that if difficulties in communication were left long enough, someone else would set up systems to sort the problem out by the time she saw the family again.

I mean the other thing, if you're getting into personal details they don't always want some stranger that they don't know as an interpreter they'd rather have somebody in the family. But as I say, usually by the time they get to us there's some system set up, sort of thing...because as I say usually by the time they get to us they've either got their own or they've got enough English on a day to day basis. (p20)

The use of family and neighbours as interpreters raises concerns about whether sensitive issues can be adequately addressed. Using a third party to interpret, be it a family member or an interpreter, proved to be wholly inadequate when emotional support needed to be provided for carers: "You can't counsel somebody through somebody else [interpreter], you know, well you can't". (Health visitor Golant, p20)

There is also the issue of how much of what is asked is actually transmitted back or edited. Using others to translate could result in carers accessing only information which the English speaking person passed on. This is important as previous studies have identified that even husbands often did not pass on relevant information to their wives. Yet they were ultimately involved in caring for the child (Chamba et al, 1999). Other studies have also rightly been critical of professionals using family members to interpret (Richter et al, 1979; Cameron et al, 1989; Gerrish, 1998).

Despite the language and communication barriers, interpreting services were used but usually only for the initial assessment. However, PHC nurses did talk about why they had reservations about using interpreting services. These issues are discussed later in the chapter.

### **Consequences of language and communication barriers**

Despite well meaning intention, the practice of 'muddling through' and 'making do' resulted in difficulties in practice for all PHC nurses, and more so when complex information, advice or therapeutic strategies that needed to be carried out at home had to be conveyed to carers. First, learning disability nurses and health visitors experienced problems in *giving advice and supporting carers around sexual development and marriage*.

PHC nurses experienced difficulties in discussing physical developmental changes with carers, and more so because many carers found it difficult to comprehend that their son or daughter, irrespective of disability, would still go through puberty and experience the same changes with their bodies as other children. Issues relating to menstruation, puberty, pregnancy and masturbation were found to be the most problematic to explain due to language barriers.

Discussing the issue of marriage concerning 'adult' children with learning disabilities was also a problematic area. Learning disability nurses and health visitors expressed considerable concerns as carers of people with learning disability asked their opinion as to whether the patient should marry. Some carers apparently felt that marriage would 'cure' the cared-for person of their disability. PHC nurses expressed concerns largely because they felt unable to alter carers' belief patterns.

In fact, if somebody has the belief that if their son gets married and they have children, even though he's got a profound learning disability, then he will become somehow normal, you know, I can't shift that idea...I can't really do very much about altering their belief systems can I? (Clinical supervisor Jaywick, p4)

PHC nurses also cited arranged marriages as the cause of problems. There was considerable anxiety that people with learning disabilities would be taken to India and 'married off' without fully consulting the bride to be, who would then become a carer:

some people do think that you know, if they can get them married off, it'll sort out their problems [gives example in detail] ...cos you can imagine it can't you?, when its arranged, people don't meet too often before do they? It can be arranged one meeting and then marriage from what I understand. (Clinical supervisor Kindle, p24)

This is an area that has not been researched before and it is difficult to suggest that such views are widespread among minority ethnic carers. Evidence from chapter six does indicate that carers continued to hope that the cared-for person would one day be cured, that carers tried different types of treatments in the hope of cure and that adjustment was episodic. None, however, indicated that they believed that marriage would cure the cared-for person's disability. This is a new finding about PHC nurses views not identified in previous research. Given the limited evidence and the sensitivity of the topic to be addressed, this is an area that would benefit from further research.

The analysis revealed that providing explanations and advice proved more problematic for learning disability nurses, community psychiatric nurses and health visitors. Interestingly, these professions are less involved in the practical tasks often associated with district nursing services and more with 'talking' forms of support. The strategies adopted, although alleviating some of the difficulties in the short term, raise questions as to how much carers actually understood.

Secondly, learning disability and community psychiatric nurses also expressed concerns about *lack of compliance* when advice, monitoring exercises, diary keeping and programmes of

therapy that they had suggested were not followed up at home by carers. The view expressed by one community psychiatric nurse summed up the views of other PHC nurses:

There is no clear boundaries to what responsibilities belongs to them and how much they need to do in order to better the situation.  
(Community psychiatric nurse Hakin, p8)

Consequently, this led to minority ethnic carers being viewed as people that listened politely, agreed to lots of things but found it difficult to act upon what had been suggested. PHC nurses did however provide contradictory views at times. On the one hand, for instance, they reported how much they enjoyed working with minority ethnic carers because they complied with treatment and suggestions and on the other hand, claimed that they did not do as they were asked. Despite the contradictory views it was possible to identify key issues through development of themes and sub-themes. This approach proved useful in making sense of the data enabling conclusions to be drawn, even if only tentative at times.

Evidence from the carers' chapter identified that carers **were** generally compliant. Moreover, it was not that carers deliberately did not comply but rather that barriers to effective communication resulted in them not understanding what was being asked of them or fully understanding what the rationale for the suggested treatment was. Some of this could have been overcome had an interpreter been used.

*Making appointments over the telephone* was identified as a third problematic area as carers could not understand what PHC nurses were trying to say to them. Ironically, some PHC nurses could not see how this might be just as problematic for carers, and expected carers to telephone them if appointments needed to be cancelled, claiming that carers were well aware of how to contact them and that it was an 'easy' enough task (Health visitor Elgin).

They (minority ethnic carers) don't think to ring. (District nurse Carie, p5 )

Finally, the majority of PHC nurses believed that *minority ethnic carers lacked awareness about PHC nurses' roles* and what they could realistically do for them, and that this was particularly prevalent among those carers who did not speak English or were elderly. Carers also lacked awareness about the specific roles and responsibilities of different types and grades of PHC nursing staff and how they differed in the way in which they could support them. As a result, carers were unable to differentiate between different PHC nurses and hence had expectations of them to do things which did not necessarily fall within their role. Learning disability nurses and community psychiatric nurses, for instance, both mentioned that carers assumed that they were 'general' (Registered General Nurse) trained and therefore able to

provide 'hands on' type of support. And a nursing auxiliary (NA Badby) spoke about her experiences when she refused to give medication to a patient because she was not trained to administer drugs. Due to language barriers she found it difficult to explain to the carer that she could not give out medication. Misunderstandings resulted in the carer feeling that the NA was refusing to give medication because she simply did not want to do it.

### **Conclusions about language and communication**

The findings from this study indicate that it was not lack of compliance but rather lack of awareness coupled with communication barriers that resulted in carers not knowing what was expected of them as carers, as well as not knowing what support they could expect from PHC nursing services.

It was not only carers who experienced difficulties in understanding, however; bilingual PHC nurses also experienced difficulties in getting information through because, for instance, of the difficulties involved in translation and interpretation and 'words' not being available to explain medical terminology in a different language. Given that carers did not fully understand and PHC nurses also found it problematic to provide advice and explanations to non-English speaking carers, communicating in a language other than English is far more complex than often envisaged. Findings from this study suggest that being bilingual and having a 'health' background does not necessarily overcome communication difficulties.

This new finding suggests that overcoming communication difficulties to discuss complex and sensitive issues will require innovative thinking and new strategies if difficulties are to be resolved. Having trained interpreters is at least one step forward in terms of bridging the language and communication gap. However, there may be variations in the spoken language used by younger generation South Asians and older patients and carers with whom PHC nurses have contact. It is also highly probable that there may be variations in the language used by British born South Asians and those brought up in India for instance. Hence, further research could, for instance, identify language used by different generations in relation to specific nursing, medical and health related conditions as well as establish whether having a condensed 'dictionary' at hand would prove useful in practice.

### **CULTURAL AND RELIGIOUS BELIEFS**

As demonstrated earlier, PHC nurses had acquired some knowledge concerning ethnicity, culture and religious beliefs, much of which was learnt 'on the job' whilst out in the community. However, despite this knowledge they still encountered some difficulties in

meeting needs in practice. Areas where difficulties were identified concerned carers' attitudes to disability, the use of alternative therapies and religious beliefs, particularly among Muslims.

### **Attitudes to disability**

One area that caused difficulty in practice concerned carers' attitudes to disability which were viewed as being different to those of white carers. Based on their experiences health visitors and learning disability nurses reported that carers did not follow advice or did more than was necessary resulting in over-dependency in the patient, especially where children were concerned. District nurses on the other hand reported that minority ethnic patients often stayed in bed for prolonged periods when there was no real need. There was a concern that this contributed to other health related problems such as chest infections. Although there was a general consensus among PHC nurses that cultural beliefs influenced the decision to care, PHC nurses also associated non-compliance with cultural beliefs.

I think sometimes from a cultural point of view we are quite restricted in that carers sometimes have a different opinion. We'll perhaps ask them, if it's for someone with a behavioural problem, we'll ask them to take a certain line with that person either from the point of view of being more strict or whatever and some carers find that very difficult because cultural[ly] that's not what's expected of them.

(Clinical supervisor Likisto, p11)

Evidence from chapter six does substantiate PHC nurses' views that cultural and religious beliefs influenced carers' decision to care. There was however, no evidence of cultural beliefs being associated with lack of compliance for treatment for the cared-for person. Indeed, lack of compliance is also commonly reported in the general literature (see for instance, Fielding and Duff, 1999) rather it is suggested that PHC nurses associated lack of compliance as being some how connected to minority ethnic culture and ignored other contributory factors such as lack of understanding.

### **Use of alternative therapies**

PHC nurses were aware that carers believed in the use of traditional medicines and faith healers. This is not an issue particular to minority ethnic communities; there is ample evidence in the general literature of people turning to alternative forms of treatment. When alternative therapies were used in conjunction with western medicine, so long as the patient's safety was maintained, PHC nurses did not find this too problematic. One health visitor, for instance, spoke of her experiences of when a carer gave 'holy' water at set times. She respected the carer's wishes because it caused no harm to the patient. However, PHC nurses

became anxious when carers turned to alternative forms of treatment or therapy that militated against 'conventional' approaches and when carers opted to use **only** alternative forms of therapy, preferring not to continue with western treatment. On these occasions PHC nurses had to reiterate to carers the importance of treatment and taking medication even though carers were reluctant because a faith healer had told them otherwise.

Yes, it plays quite a big part because often you will get carers and patients expressing that they don't want to take medication that is prescribed and that they want to go and see a faith healer or wanted that for a certain amount of days because this is what they believe will get rid of the illness. Oh, yeah it's a struggle because you are talking about a struggle between peoples' beliefs to, you know, versus medical model.  
(Community psychiatric nurse Hakin, p13)

Compliance with western treatment or therapy was even more problematic when religious convictions turned into delusions. Hence, compliance became a "struggle." Community psychiatric nurse Hakin, for instance, gave an example of a lady who was experiencing thoughts that meant that she had to pray more often and for longer periods in order to become a good Muslim. Although the lady was already praying five times a day, her thoughts were restricting, and preventing her from doing other things.

### **Difficulties in meeting the needs of Muslim patients**

While the focus of this study was Hindu carers' experiences with PHC nursing services, interviews with PHC nurses revealed that in practice meeting the needs of Muslim patients was more problematic with regards to fasting, prayer and washing. PHC nurses were able to associate fasting with religious beliefs although they were unable to fully understand why people deemed it necessary to fast. However, they were genuinely concerned that fasting would result in ill health because medication was not taken.

During Ramadan, diabetics don't eat and that's difficult for me because it's their health and you should eat. (District nurse Carie, p6)

Recent evidence does support PHC nurses' concerns. Aadil et al. (2004) for example, report that patients with chronic disease often insist on fasting during Ramadan even though under Islamic rules they are permitted not to. Also, patients with acute illness are allowed to stop fasting and make up for it after Ramadan. Their study concluded that fasting from dawn to dusk during Ramadan could cause problems with drug dosage regimes for Muslim patients.

Prayer was another area that caused difficulties in practice. Again, PHC nurses were aware that people's religious beliefs would mean that they would be involved in prayer at certain

times; however lack of understanding combined with difficulties in managing workloads resulted in frustrations. For instance, PHC nurses expected patients to 'stop' praying when they called; if patients continued to pray, PHC nurses felt ignored and frustrated.

We have got one man who you can't go to between 12-2 on Friday and if you walk in on him praying he won't stop, just totally ignore you and carries on... When you cover the whole of the city, this is the problem. I deal with a big area and if you're in the next street then you are going to go to the patient there aren't you, you can't come all the way back half an hour later. They don't always appreciate that, the patients don't. (District nurse Dobcross, p11).

Some PHC nurses just could not see the relevance of praying. Clinical supervisor Jaywick, for instance, although acknowledging that prayer could be a source of inner strength, felt it inappropriate for carers to be involved in the practice as 'they already had enough to do'.

If the Guru says, you know, that you've got to get up and do so many prayers, you know at certain times, or you've got to do certain tasks we might look at it as "oh surely mum's got enough to do without having to do this additional thing" you know. (Clinical supervisor Jaywick, p17)

He failed to see that praying was perhaps the only activity that enabled the carer to continue caring.

One activity which caused considerable anxiety and concern was that of children with learning disabilities being encouraged to read the Koran. This was largely because it was thought to put undue pressure on the children.

Oh, yes, we've had one or two, where the lads have been taken off to the Mosque to learn the Koran, when they were really not up to learning their own name and it put pressure on the lads because they were kept up and not getting the sleep and they've been tired, you know and fretful. (Health visitor, Golant, p18)

For district nursing services, meeting patients' washing needs proved to be the most problematic area in everyday practice. It was reported that washing involved lengthy, time consuming techniques. Hence, in some instances, district nursing services were withdrawn because services could not meet demands.

He's a Muslim, and he likes to wash with one flannel, throw it away [replace it] get another one, change the water constantly, that's the way he does it. We haven't got time to do all that. We'll change the water but can't spend that length of time the way he likes to be washed. [e.g., wash one arm three times, then the other three times, then the body] ...but it was difficult for nurse because he wasn't willing to compromise, it's his way or not. So this service was not offered. His wife washes and nurses toilet him. (District nurse Carie, p5)

Nursing auxiliary Badby commented that washing was “so symbolic that you’d be there till Christmas”. Consequently, she felt that some of the demands and expectations were more than she could meet so she “had to knock it on the head.”

The findings of this study are in stark contrast to those of Gerrish (1998) who reported that there were many observable instances where nurses modified their practice to take account of cultural needs. This was especially so with Muslim patients. However, one reason for this might be that Gerrish’s (1998) study was conducted in the north of England where there is a large Pakistani Muslim population. In contrast, this study has been conducted in a region with a predominantly Indian population. It may be that PHC nurses in the north are more accustomed to dealing with Muslim patients and have therefore made adjustments in the way in which they practice.

It is not suggested that PHC nurses in this study did not meet Muslim patient’s needs; rather they found meeting needs problematic and frustrating. Hence, it is suggested that further research is need to identify why there are evident differences, and secondly to identify examples of good practice and how they were implemented. This will enable other regions to learn from them, implement changes or modify practice accordingly.

### **Conclusions about cultural and religious beliefs**

Minority ethnic carers’ attitudes to disability were recognised as being different from those of white carers. However, PHC nurses also saw cultural beliefs as being the ‘root’ cause of their difficulties when they encountered situations of non-compliance or over dependency.

In practice, many of the difficulties reported by PHC nurses in meeting needs related to meeting the needs of Muslim patients and carers. PHC nurses were genuinely concerned when patients insisted on fasting during Ramadan. However, praying and washing were two areas that frustrated PHC nurses. Some of this was due to lack of understanding on the part of the PHC nurse and some due to already demanding workloads. Trying to meet needs by, for instance, avoiding Fridays or helping with washing as requested was reported as being problematic in practice.

### **THE HOLISTIC ASSESSMENT**

One means of supporting carers is through assessment. Although primarily aimed at the patient, carers’ needs should be incorporated, as formally recognised within policy and nursing philosophy. The advantage of using this approach is that if need is identified action can be taken to enable carers to access appropriate support. PHC nurses can be influential in

referring carers to other generic services as well as requesting a formal assessment for carers through a care manager, if required.

Irrespective of profession, all PHC nurses described conducting holistic assessments. It was reported that this approach enabled them not only to gather general background information but also help identify the health and nursing needs of the patient as well as meet carers' needs at the same time.

Oh yes, I mean you look at the social, physical and psychological. There is a reason why we've gone in and that is obviously where you start. You then look at the whole picture...whether the patient is coping, whether the carers are coping, whether the situation works. (District nurse Dobcross, p7)

The importance of identifying and meeting carer needs was acknowledged by all PHC nurses. A variety of reasons were identified as to why this was felt to be important. These included for instance:

- The nature of their caseloads meant that PHC nurses **had** to work with carers (for instance, where children and people with profound learning disabilities were concerned)
- The role of PHC nurses was to help carers find their own answers
- Enable PHC nurses to establish what kind of relationship carers had with the patient
- Without carers, the patient would have constant relapses
- Carers made PHC nurses' jobs easier because they took on a lot of responsibility.

As different PHC nurses formed the sample group in this study, the depth and types of information collected or documented varied between professions. There was, however, consistency across the differing professions in terms of some of the basic information that was gathered. This usually concerned general biographical data, address, diagnosis, present health status and health problems or conditions such as diabetes, social circumstances, past medical history and language spoken. Some PHC nurses reported that specific nursing models were not used to guide the assessment, whilst other reported that models suitable for their profession did not exist; hence they used 'their own' or 'bits of models' to inform the assessment process. Other PHC nurses, although they said they used models in practice, were unable to specify which one they were using. The assessment was referred to by some as a "checklist" and might take several visits to build up an accurate picture of the patient's needs. The staging of the assessment process over several visits might indeed prove beneficial in terms of meeting the needs of the patient. However, evidence from carers, as reported earlier, and PHC nurses themselves suggests that PHC nurses neglected to fully incorporate **carers**

into the equation or utilise opportunities that would have enabled them to address carers' concerns through assessment, care-planning and monitoring. Further, PHC nurses did not make effective use of the information gathered, to question what it really meant to document the name of a carer as a contact person, or what impact caring had on their lives.

There are parallels here with Worth's (2001) study that looked at the assessment needs of older people by district nurses and social workers. In addressing whether social needs were addressed, when interviewed, district nurses all said that social aspects were integral part of their assessment, including family relationships, support and the need for company. Yet in observed assessment, social needs received less attention in district nurses' than social workers' assessment.

### **Holistic assessment and care planning in practice**

From the carer's perspective as explored in seven, the assessment was often no more than a form filling exercise which overlooked their needs from the onset and throughout. This inevitably begs the question of whether carers' needs were acknowledged at all. The simple answer is yes. The analysis of PHC nurses accounts revealed that carers were not overlooked totally, but usually their involvement was in connection with the needs of the cared for person. When conducting holistic assessments, PHC nurses did not always involve carers from the onset. Rather, they used their own professional judgement and discretion to determine whether carers should be involved or not. For instance, in the case of children, or people with profound learning disabilities, PHC nurses did involve carers. Indeed, in these instances, it was regarded as imperative. However, a danger of this method of working is that it can undermine carers as opposed to supporting and empowering them, and is removed from the ethos of equality in partnership and a relationship based on negotiation as promoted in policy documents (Department of Health, 1998a).

For example, one of the reasons cited for involving carers was because it was recognised that carers would in effect be the ones carrying out the suggested treatment or therapy.

I rely on them...because through them we provide my care, the package of care that I've planned. (Community psychiatric nurse Mathern, p2)

Hence carers were viewed as an essential resource, as identified by Twigg and Atkin (1994), rather than 'clients' in their own right.

However, PHC nurses also cited reasons for not wanting to get too involved with carers. One reason for this was because the patient was their priority and central concern.

I think that is a difficulty that you have to try and keep that very separate knowing that the carer might be facing a problem but you are not actually going to see the carer. You are actually going to see the patient or the client that has initially been referred to you. (Community psychiatric nurse, Hakin, p5)

PHC nurses across the disciplines expressed similar views:

I say our primary concern has always been the patient, we're a patient centred service and that's the kind of service we'd like to continue to offer. (Clinical supervisor Likisto, p26 )

There were two examples of when the PHC nurse concerned 'kept an eye' on the carer 'informally'. In one instance, the carer also had mental health problems which made it difficult for her to care at times; that carer was also in effect a 'patient'. In the second example, clinical supervisor Kindle described how he called in to see one family where the patient was blind. Yet, providing emotional support for the carer resulted in the PHC nurse feeling like a "fraud"

So really I haven't offered much but they said just talking is enough. Somebody outside of the family we can talk to, have a grumble because they have no other input really. I feel a bit like a fraud basically, cup of tea and a chat. (p34)

Carers were thus, acknowledged to a degree and were not totally over looked. However, evidence from PHC nurses illustrates that involvement was usually in connection with the patient. When discussing assessments Clinical supervisor Likisto, for instance, spoke about how assessment forms had several categories. One of them was to record what the referring agent felt the needs of the patient were. Yet this was given as example of meeting carer needs. PHC nurses seemed to find it difficult to move away from meeting only the needs of 'the patient' to a situation in which carers' needs would also be recognised and met. When asked to identify situations in which they might involve carers, again examples given often related to the needs of the patient.

Obviously, the sort of main focus is that I go in looking at the patient as they are referred to our team. Carers' information does come into it, but it would be secondary to the patient's needs. I often speak to carers generally to get a bit more information. To get a bit more understanding of how they perceive the problem to be or the problems, you know, that are for the patient. (Community psychiatric nurse Hakin, p4)

It was no surprise then that the practice of making separate appointments or the allocation of some time specifically for carers was virtually non-existent. A number of PHC nurses made it clear that they did not really assess carers' needs because the patient was their priority.

We never write about the carer unless there's a problem. Our records focus on the child. (Health visitor Faygate, p4)

The findings support the views of carers in the previous chapter.

PHC nurses were also reluctant to get too involved with carers because, for instance, they were reported to take over or wanted to talk about themselves instead of the patient, carers expectations of needs did not match with those of the patient, or because carers were reported to make negative comments about the patient. Hence, carers were in a 'no win situation', criticised if they tried to get involved by talking about the cared-for person and criticised if they tried to talk to PHC nurses about themselves. Yet many carers, especially long-term carers, will have amassed a considerable amount of knowledge about the cared-for person's needs and wants which should be tapped into by PHC nurses.

PHC nurses preferred instead to use their own judgement to build up a picture of the situation when conducting an initial assessment. Interestingly, some PHC nurses felt that by involving carers, this would somehow blinker their judgement of the actual situation.

It is quite plausible that carers may have made negative comments concerning the patient, especially given the evidence in chapter six, which illustrated that some carers found it difficult to cope and many would have liked PHC nurses to provide them with emotional support. Unfortunately negative commentary was not taken on board by PHC nurses as an indication of carers' inability to cope. Alternatively, it is also possible that PHC nurses realised that carers were still not at that point where they were no longer able to cope at all, hence they preferred to distance themselves because structural factors such as workload demands made it difficult to meet needs in any case. Certainly, some PHC nurses spoke in terms of 'those that shouted the loudest' being able to access their services. Similar findings were identified by Twigg and Atkin (1994).

It depends on the needs of the carers. If the carers cope, not always so soon. If the carers make enough noise we get in. If the carers get on with it then sometimes we don't. (District nurse Dobcross, p15)

Care-planning is another channel whereby carers can be included as part of the on-going assessment. PHC nurses did discuss issues concerning the patient and said they tried to work with carers to negotiate care concerning the patient; however, some did not practice joint care-planning. Reasons for this included, for instance, workload demands, time constraints and difficulties associated with conducting a bilingual assessment.

No I don't practice joint care-planning. I'm not able to.

Moreover, some PHC nurses did not even write the care-plan out in the carer's home. Rather, PHC nurses gathered essential information and wrote their notes up at base. Other than district nursing services, PHC nurses did not leave care-plans and notes at carer's homes. One reason for this was because the type of information shared with colleagues was at times different from that shared with carers. The care-plan was therefore used as means to document any concerns with regards to the patient. Occasion when this might have happened were when PHC nurses had concerns about the patient's safety, for instance.

### **Problems encountered by primary health care nurses when conducting holistic assessments**

Conducting holistic assessments proved problematic in practice for both white and minority ethnic PHC nurses and was reported to take much longer than when visiting white families. Analysis revealed specific issues for white nurses, for minority ethnic nurses, and issues shared by both. These are dealt with in turn.

One particular frustration for white nurses concerned *inadequate information being provided on the initial referral forms*. This is important because not only does policy make clear the importance of collaborative working between and within sectors (Department of Health, 1997; 1998a; 1999b ) but because acute sector nurses play an important role in providing adequate information on referral forms when discharging patients into the community setting. Yet, evidence from this study identified that the language spoken by patients was often not recorded on referral forms. Inevitably, when white nurses had not been forewarned that the patient did not speak English, this resulted in a tremendous waste of resources and time. PHC nurses spoke of their experiences when, for instance, they had 'turned up at the door' only to find that the whole family did not speak English. This meant PHC nurses having to go back to their base and rearranging their visit with an interpreter, if possible. Yet accessing an interpreter also proved to be problematic and more so if a referral had come through during the late hours of the evening, for instance. District nurse Carie spoke of her experiences when she 'turned up' to find that the family did not speak English. The family tried to help by asking neighbours to translate but before she knew it "half the neighbourhood was there." Previous studies have also identified poor referrals (Robinson and Street, 2004) and difficulties with communication across the primary and secondary care interface (Gerrish, 1998) as causing difficulties in practice for community nurses and as being detrimental to the continuity of care.

*Traditions of hospitality and expectations of social interaction* meant that minority ethnic PHC nurses were often offered snacks and drinks. Being involved in social interactions naturally impinged on their time. The giving of 'background' information is also a common feature of minority ethnic tradition, and minority ethnic nurses were well aware of these expectations. It is not uncommon within the Gujarati community, for instance, to be asked by someone you've only met the first time, where your parents originated from 'back home', where you were brought up, where you live and so on.

PHC nurses did generally divulge a lot of background information about themselves, for instance, information about whether they were married and had any children, gender of the children, their ages and so on.

I try to stay professional but with our Asian community its very difficult because a lot of families are so warm and caring, they like to know about your background, where you live, your family, how many children you've got, that sort of thing, so that's part of the culture. (Community psychiatric nurse Mathern, p4)

Despite this sharing of background information, PHC nurses drew the line at giving their home address and telephone numbers, even though families requested them at times, because they felt that this would result in them working all sorts of hours and refusal allowed them the autonomy to remain professional.

Conducting *bilingual holistic assessments* was identified as being particularly problematic because they took so much longer. Hence, PHC nurses had to be very descriptive, and often had to reinforce several times over what they were trying to do because literal translations could not be carried out because the words simply did not exist. This was particularly problematic when trying to describe or give advice concerning mental health issues or learning disabilities. Based on their experiences, minority ethnic nurses reported that the level of understanding among the minority ethnic community was very poor in these two areas in particular.

The use of a 'Eurocentric model' of nursing assessments was also reported to be problematic. One community psychiatric nurse made the following comments about why this was so:

It happens a great deal that you are having to reassess your boundaries with people and a bit of that sort of comes back to the sort of Eurocentric model that we work in. I think it is easy to define to a white client and say, okay, eight sessions I am going to offer you, this is what we are going to do, Whereas when you are actually speaking to Asian patients because they have never worked in that boundary or because they have not

worked on a psychological [programme] basis it's far more difficult to put that model into practice. (Community psychiatric nurse Hakin, p11)

This study was conducted in an area with a large minority ethnic population. In a bid to meet the needs of a diverse population bilingual PHC nursing staff had been especially recruited. However, these PHC nurses found *their role was very demanding*. It was reported that they took on the vast majority of minority ethnic referrals. Moreover, when compared to the ratio of staff employed to cover other geographical localities, minority ethnic PHC nurses found themselves working with fewer staff covering a much wider remit, largely in response to having to take on the majority of minority ethnic referrals.

As a result, these PHC nurses felt particularly pressured and stressed. It was mentioned several times during interviews that their caseloads were too big for them to deal with on their own, and that there was only so much they could do. Further, they had the added burden of accompanying their colleagues for visits and acting as translator. This is what one PHC nurse had to say:

There is a great gap in the service because I'm the only one with the level of skills. I do a lot of specialist work like transcultural therapy, individual work as well.... I feel that there's a lot of pressure on me but I do say now or encourage them [other colleagues] to use the interpreter but I can't just take on every case where there is a language difficulty. It's a very political issue [using interpreters].  
(Community psychiatric nurse Hakin, p22)

Both white and minority ethnic nurses spoke of *difficulties in trying to access information from minority ethnic families* whilst conducting a holistic assessment. It was reported that minority ethnic carers "did not give the full story". This was largely because carers had concerns about the community finding out that the patient had a mental health problem, for instance. It was felt that once carers had crossed that hurdle, things became much easier for everyone. Hence, PHC nurses ability to remain professional was as important as maintaining confidentiality which often had to be stressed several times over.

Holistic assessments with minority ethnic families were reported as being problematic because they were often carried out in *the presence of other members of the family*. It was reported that there was always somebody else present, such as a mother-in-law or husband and that "they never completely go away." PHC nurses found this method of working difficult because it was viewed as being restrictive for patients, resulting in them not being able to discuss personal issues. In contrast, when visiting white families, assessments were usually carried out with the patient alone.

### **Holistic assessments and collaborative working between health and social care services**

Changes in policy (Department of Health, 1997, Department of Health, 1998, Department of Health, 1999b) should have resulted in changes in the way in which PHC nurses and social workers practised. Policy now makes clear that there should be more collaborative working between PHC nurse and social care staff, with social workers identified as having a lead role where assessments are concerned. The intention of policy was to make clear who would be responsible for which service, hence bathing became classed as a social care responsibility unless there was a nursing and health need for bathing. PHC nurses would now only be responsible for providing nursing care.

These clarifications, however, were viewed with hostility in the current study, and were a particular “bone of contention” among district nursing staff. On the whole, district nurses did not have good working relationships with social workers. Inevitably, poor working relationships resulted in district nurses experiencing difficulties working across the social care sector. Relationships were described as being problematic, tense and at times fraught with difficulties.

District nurses felt angry and resented this new method of working because the reality of working collaboratively with social workers was different to that portrayed within policy documents. Social workers were, for instance, reported to refuse referrals despite district nurses assessing the patient as having social care needs.

Many of my Asian ladies and gents are bed bound a lot of them. Social services states that if a patient is in bed they won't wash them, they will only wash them in a chair. Now my patients are bed bound because they choose to be bed bound so they are quite capable of sitting in a chair so really they need social care but because they're in bed they won't take them, they fall on us and that is a big problem.  
(District nurse Dobcross, p30)

Moreover, resentment continued to build largely because social workers were reported to refuse patients on the basis of inflexible questioning techniques. District nurses were, for instance, quizzed over the telephone as to whether patients were ‘bed bound’ or ‘chair bound’. Hence, district nurses felt that social workers did not really assess the patient in a true sense and this method of refusal caused much anger. District nurses were of the opinion that if social workers saw the patient for themselves, they would immediately realise that the person did in fact have social care needs.

Some of the resentment expressed by district nurses, however, related to the fact that they had already carried out an assessment and made an informed decision by seeing for themselves that the patient needed to have social care support, only for the patient to be assessed again by social workers. District nurses claimed that they experienced difficulties “nearly all the time” in terms of handing patients over to social care services and reported that “there was never any compromising” with social workers.

Changes in working practice resulted in district nurses feeling that they no longer had the degree of influence they had in the past. Social workers were now viewed as ‘having more clout’ (District nurse Carie). Moreover, as social workers now played a lead role in assessment, this resulted in district nurses feeling ‘threatened’ by social workers as they were treading on roles which they effectively viewed as belonging to them. District nurse Carie, for instance, gave a detailed account of how in the past they, as district nurses, were involved in conducting assessments. Now, however, social workers made the assessments often without involving the district nurses and then telephoned the district nurse to let them know what they felt needed to be done for the patient.

You always, when you go in there you have got to do the assessment to decide what the problem is and I think that is, got to be our role. Take that away from us and we’ve lost our jobs. You know anybody can do anything. I mean so much so now social services has taken over... None of us like it. (District nurse Dobcross, p30)

The findings of this study contrast with those of Worth (2001). In a qualitative study, the process of assessment of the needs of older people by district nurses, social workers and care managers was explored. District nurses reported considerable satisfaction related to their role in care provision as a consequence of the changes in policy. In contrast, social workers reported that assessment and case management had led to a loss in their provider role as they were no longer involved in casework and therapeutic involvement with clients.

### **Conclusions about holistic assessments**

Holistic assessments and the importance of meeting carer needs were reiterated as being central to practice, yet it was generally assumed that minority ethnic carers were well supported and that their need for support was not as great compared to that of white carers. Although carers were not completely overlooked, in practice, meeting the needs of the patient took precedence.

Evidence from this study suggests that PHC nurses were aware of carers’ needs yet made conscious decisions not to get too involved with them, due to the patient being their priority,

and workload demands. Hence, their 'patient-centred approach' to working played a significant part in carer needs being neglected. The findings of this chapter substantiate carers' views from the previous chapter that their involvement was limited and usually only in connection with the needs of the cared-for person. Although PHC nurses claimed to practice holistically, evidence suggests that assessments are far from holistic and that change can only come about if there is a shift in attitudes and changes in practice, from focusing only on the needs of the patient to recognising and valuing the contribution of carers.

The current study is based on a small sample of district nurses. Although practice was not observed, evidence from both carers and PHC nurses suggests that carers' social and emotional needs were overlooked in a bid to meet the needs of the patient. The findings also shed new light on some of the difficulties that district nurses experienced in terms of working with social workers and provides evidence of how little collaborative working actually took place. The findings thus contrast with those of Gerrish (1998) in which district nurses generally had a good working relationship with social workers. Given the small sample size, it is suggested that this is an area of research that would benefit from being conducted on a larger scale to assess, for instance, what impact poor relationships between PHC nursing staff and social care staff have on carers' ability to access resources or other forms of support.

## **DIFFERENCES AND DIVERSITY**

This section addresses issues relating to differences and diversity. The following areas are explored: PHC nurses' views about services provided, issues relating to interpreting services, PHC nurse training and resources for PHC nurses.

### **'The same for everyone?'**

PHC nurses were asked to sum up the type of care they provided for minority ethnic carers and patients. There was some inconsistency in the responses with PHC nurses stating on the one hand that they provided care that was individualised and tailored to the needs of each patient and on the other hand stating that they provided care that was the same for everyone. Hence, when asked if they would find training to discuss minority ethnic issues useful, a few stated that further training was not necessary.

Because the needs of the clients are gonna be the same whichever group of people you've come from. (Clinical supervisor Jaywick, p23)

If care is provided on the basis of it being the same for everyone, then it is assumed that 'one service fits all'. Moreover, the services provided were viewed as being 'good enough'. Some

PHC nurses were also of the opinion that it was not always necessary to provide culturally appropriate services.

you'd be negotiating for ever and a day then, wouldn't you, if you were to bend over backwards all the time to pander to every single whim and need and prejudice.  
(Clinical supervisor Kindle, p17).

He went on to suggest that, instead, there should be greater equality between sexes and that men in general, would not be treated any differently if they were in hospital.

'cos if you go into a general hospital you find the bulk of the nurses are female. So, if you're a man and you're gonna be bathed, the chances are you'll be bathed by a female, you wouldn't have a male nurse...I mean I have done some pretty intimate things with females, but you always ask first, "Do you mind?". Now whether people feel they can't really refuse, you know, "Oh I'm not comfortable". But I mean you can't, you can't go over board, 'cos you have to get on with your work, don't you?  
(Clinical supervisor Kindle, p17)

These attitudes are in essence similar to those outlined in chapter two, when assimilation and integration strategies were used in health care, when it was argued that minority ethnic culture was the 'cause' of problems and hence it was the responsibility of minority ethnic people to 'fit in' and use what was available. Hence, some PHC nurses adopted an ethnocentric approach to delivering services.

### **Interpreting services**

Gerrish et al (2004) found that PHC nurses from most disciplines, lacked awareness of the range of interpreting services available and were unsure how to access different types of service. PHC nurses in the current study, by contrast, were well aware of the availability of local interpreting services and also knew how to access them. However, other than community psychiatric nurses, all of whom were bilingual in South Asian languages, PHC nurses across the disciplines had reservations about using the services and preferred, as we saw earlier, to 'muddle through' or 'make do' or ask bilingual colleagues to accompany them on visits. They thus deliberately chose not to use the services provided.

My auxiliary nurse is Asian, Gujarati...I just grab her by the arm and take her with me.  
(District nurse Dobcross, p27)

That's why its good now we have one of our nursing assistants and to be honest on a new referral I tend to take her with me if I know that it's sort of an Urdu or Gujarati speaking family...To be honest we don't use them [interpreting services] because we tend to use our own nurse and we've got another nurse in another department who we can use as well. (Clinical supervisor Likisto, p8)

Difficulties in accessing the services and concerns about the quality of services provided were the two main reasons why PHC nurses had reservations about the services and preference for using in house staff if available.

Overall PHC nurses expressed that *access to an interpreter* was extremely problematic because there were simply not enough interpreters to meet demands. For instance, at the time of the study, the mental health trust had only one interpreter working office hours for the entire trust. This service was viewed by community psychiatric nurses in this study as being wholly inadequate. Other local trusts on the other hand, were reported to have access to interpreting services via a central resource centre. This method of accessing interpreters was viewed as being more beneficial and one which community psychiatric nurses felt should be developed within mental health.

Yet, even those PHC nurses that could access their interpreters via the resource centre still experienced difficulties in accessing services.

It would be nice if there were one [interpreter] readily available...but that would be a big pie in the sky. (Health visitor Golant, p15)

PHC nurses had to book in advance if they wanted interpreters to accompany them on visits, for instance. This system of booking in advance proved difficult in everyday practice and was often impractical. This was quite simply because the nature of PHC nurses workload meant that they often received 'last minute' referrals such as late in the evening when interpreting services were closed. Other than health visiting, PHC nursing services were provided 24 hours each day of the week, although a limited service operated during the weekends. By contrast, 'out of office hours', there were no services available which would have enabled PHC nurses to access an interpreter. Hence, the system of booking interpreters in advance was only really useful in situations where PHC nurses had more control over their diaries and could plan ahead, for instance, in time for an out-patient appointment which was several weeks away. Even then, bookings had to be made several weeks in advance.

Having to wait until, you know, four weeks on Monday sort of thing.  
(Health visitor Golant, p20).

Moreover, limitations on resources meant that access to interpreters was restricted. For instance, those who worked with other bilingual colleagues were told to "use them" (Community nurse, Startley, p25). Further, use of interpreters was limited to initial

assessment only. Hence, only qualified senior PHC nurses involved in assessments were able to access an interpreter in any case. Nursing auxiliary Badby, for instance, commented that as junior member of staff she would not have access to an interpreter because “the sums wouldn’t stretch” (p1). Thus in reality, PHC nurses just had to manage. Restricted access to interpreting services led to bilingual PHC nursing staff becoming frustrated with the system which was felt to have an impact on the service offered to minority ethnic patients.

So you can imagine the standard of service they’re [patients] getting. Tokenistic that’s all I can say. But it’s a political and management issue. I don’t get bogged in because it’s not my problem (Community psychiatric nurse Mathern, p2)

Gerrish et al (2004) also identified that PHC nurses tended to draw more upon interpreters when dealing with complex or sensitive issues. Again, the findings of this study are in direct contrast. Rather *the quality of the interpreting services* was cited by PHC nurses as a major reason for not using them. For example, discussing complex ‘medical’ issues via interpreters was problematic as they often had no medical/health based knowledge or insight. PHC nurses were aware that literal translations were problematic and linked interpreters’ lack of medical insight with the often irrelevant and distorted information provided to them through interpretation. Translations often did not match up with expected responses, being too far removed from what was originally asked. PHC nurses were further concerned that discussions had not been interpreted accurately or that amidst the translation and interpretation process, information had somehow got lost or filtered.

Many PHC nurses consequently felt that interpreters should have access to formal medical based training as part of their role.

It was, however, recognised that using interpreters to discuss personal issues was problematic not only for nurses but for carers and patients too.

It’s bad enough having to tell someone quite a personal problem but having to say it and then wait for someone else to explain it for you, who’s not got a clinical background or a medical background in anyway can be very difficult.  
(Clinical supervisor Likisto, p7)

PHC nurses were also wary about not being able to police the discussions that took place. For instance, it was reported that on occasions, long in-depth conversations took place between the interpreter and patient, but when the PHC nurse asked what the patient said the interpreter would reduce the entire conversation to a few words.

Like other studies (Bhakta et al, 2000; Gerrish et al, 2004), the findings of this study demonstrate that PHC nurses chose to use family members to help with interpreting. However, in contrast to previous studies which have reported lack of awareness among professionals as a reason for not using services (Gerrish et al, 2004), evidence here shows that PHC nurses deliberately chose not to use the services and thereby compromised the support they were able to offer carers. This suggests that awareness about services does not always translate into uptake for interpreting services by PHC nurses. One means of improving uptake could be through collaborative working between PHC nursing services and interpreting services to discuss anxieties and apprehensions as well as means of overcoming them. This could be through training of interpreters about health and nursing issues, for instance, as well as training for PHC nurses outlining the benefits of using the services.

### **Training and education**

PHC nurse training was reported to be inadequate, leaving PHC nurses feeling ill prepared to work with minority ethnic patients and carers. Difficulties were identified in terms of 'basic' training specific to each speciality, as well as training after qualifying.

#### **Basic training**

Many PHC nurses felt their 'basic' training was inadequate for working with minority ethnic communities. Hence, they felt ill prepared to work with them. PHC nurses talked of their experiences in terms of not knowing what to expect or how to meet needs once out in the community. They felt their knowledge to be inadequate when minority ethnic culture was seen to be so different from their own. District nurse Dobcross, for instance, commented how she had worked as a community nurse for fifteen years but when she went to work in a predominantly minority ethnic community, "it was like starting all over again".

Inadequacies in preparation resulted in some PHC nurses viewing minority ethnic culture as the cause of all 'the problems'. For instance, it was reported that westernised families were less trouble than 'non-westernised' families. The westernised ones wore western clothes, spoke English, had professional jobs and gave their children both western and Asian foods. The troublemakers, on the other hand, were non-English speaking, non-westernised and often elderly:

The Asian people that live in the county are usually very westernised. The non-English speaking ones usually live in the City. I don't know whether that's a reasonable rationale but I would say that that was to be said. The westernised ones don't give us any problems because they are very, English in their ways, you know what I am saying. Whereas the Asians that live in the inner city live in their own culture, they still live in their own little way, they have got their own shops and they do their own thing and they

don't speak English so they're isolated and they're the ones that I find the problem with because I can't communicate with them. (District nurse Dobcross, p26)

Some PHC nurses classed their training as being ethnocentric. It was reported that not enough time had been allocated during lessons and throughout the curriculum to adequately address issues pertinent to minority ethnic communities, their culture or ethnicity. As the amount of time allocated to discussing these issues was severely restricted, PHC nurses did not gain much from the training, as issues were not discussed in any depth. Some PHC nurses mentioned that out of a course spanning several years only one or two days had been allocated to discuss minority ethnic communities in general.

Two days were set aside to look at some of these issues. It was a very basic introduction towards race and ethnicity basically and I mean I was so, it was appalling the standard was appalling in terms of how it was delivered because it was very, very basic. ..As I say, two days for the three years training that we do, it's pretty poor really. (Community psychiatric nurse Hakin, p21)

Previous research also suggests that 'the hidden curriculum' in nurse education may be partly responsible for preventing delivery of culturally appropriate care (Hills, 1982 in Thomas and Dines, 1994); that educational materials may be responsible for imparting cultural stereotypes (Robinson and Kyle, 1982 in Thomas and Dines, 1994) and that the amount of time allocated to certain subjects reveals implicit messages (Hargreaves, 1978 in Thomas and Dines, 1994).

Ironically, despite very little time being allocated to discuss these issues, PHC nurses spoke of colleagues on courses raising considerable objections at having **any** time allocated specifically to discuss ethnic minority communities.

A lot of my colleagues were very angry after the whole day, extremely angry with all this attention paid to what ethnic minorities needs are. This was just for one day yep to give us more awareness about what to do, it just created an influence, a few of them were very angry at the amount of attention it was getting. (Health visitor Faygate, p10)

#### Access to training after qualifying

It was reported that much of what PHC nurses knew concerning minority ethnic communities was learnt through 'trial and error', by working within the community, rather than through any formal training. Very few PHC nurses had been on any formal training courses or had the opportunity to attend seminars or conferences on issues concerning ethnicity and race. A few had attended the 'multicultural mosaic' course, a local course which gave an overview of minority ethnic issues. Those PHC nurses that had the opportunity to attend such a course found it to be useful and spoke about how they tried to modify the way in which they practised, for instance, dressing appropriately depending on whom they were visiting.

Other than for the learning disability nurses, who appeared to be able to access courses without much difficulty, access to courses or conferences was problematic for PHC nurses and particularly so for junior staff. Nursing auxiliary Badby, for instance, spoke about how she wanted to attend the course on cultural awareness that the Trust offered, but she felt that because of her status she was the least likely person to be selected. In her view, the only courses nursing auxiliaries could go on were the ones on lifting, handling, manoeuvring and hoist training; the courses that were in effect 'to cover the Trust', as opposed to being part of staff development. Her view was not totally unsubstantiated, as a similar view was expressed by a manager who spoke of mandatory training having priority over courses concerning ethnicity and race (see chapter nine).

A number of PHC nurses felt strongly that the induction course for all new staff should cover issues pertinent to minority ethnic communities. They felt that it was essential to have some background training which would have so much impact in every day practice. An example given was knowing that minority ethnic people might prefer to shower as opposed to sit in a bath full of water.

#### Training to deal with death

Training on the subject of death and dying from a minority ethnic perspective was also inadequate. Coupled with difficulties in accessing resources, and language and communication barriers, PHC nurses often had limited awareness on the subject and therefore found it difficult to support minority ethnic carers.

PHC nurses were often in a dilemma as to what the most appropriate course of action would be for them when a minority ethnic patient had died. For instance, PHC nurses found it difficult to judge whether it would be appropriate for them to visit a family when a patient had died or whether they should attend funerals or not. Seeing large numbers of people at carers' homes, however, led to further feelings of inadequacy and not knowing what to do for the best, with some choosing not to visit families because, as discussed later, it was felt that carers had enough support from their own community.

However, it may be that it is in this very situation that carers are able to express their emotions and feelings to an 'outsider', because as demonstrated in chapter four, it is the quality of relationships that matter (Bulmer, 1987).

## Resources

PHC nurses reported that there no official structure for them to tap into to obtain information, hence they turned to colleagues, if necessary, for advice. Inability to access resources suitable to use in everyday practice caused difficulties for PHC nurses across all disciplines. They did not have access to translated material, updated literature, documents or resources to turn to for clarification or information. It was recognised that translated information was not the answer to everything, but having translated literature was felt to be useful in terms of backing up what PHC nurses had explained to carers. This would then enable carers to read through the literature at their leisure and ask questions on the subsequent visits.

I think the general information about the sort of major mental health difficulties that people encounter...it is always essential to back that up with background reading. Patients' fact sheets, for example, where you can actually give out and say look after I have gone read through it and it will make more sense in terms of what we have talked about. (Community psychiatric nurse Hakin, p17)

A need for translated information was identified in the following areas:

- Literature which described various medical conditions
- Literature which described what learning disability and mental health problems meant
- Literature which explained the different types of PHC nursing services available
- Literature which described the role, duties and responsibilities of different types of PHC nurses
- Literature which explained what type of support carers could expect from different types of PHC nurses

Calling cards to be made available in different languages were also suggested, as nurses reported that visits were often wasted because patients and carers were out. Hence, it was felt that cards which had the PHC nurse's name and contact details on should be made available.

I want a calling card, you know, that the district nurse called while you were out. I don't bother leaving cards because they are all in English, not many of them can read English even if they can understand some English. I have been saying all along that I could do with some. (District nurse Dobcross, p27)

It was, however, suggested that access to translated literature should be made available not only to PHC nurses but patients and carers via their general practice surgery. Some PHC nurses felt that videos would be another useful method of overcoming communication barriers, as well as workshops or events specifically for carers which addressed what types of services PHC nursing services provided.

Another difficulty for PHC nurses was that they were unable to keep up to date with what was happening in the local community. This was because voluntary organisations often closed down soon after they had opened. Many PHC nurses were unaware of which local support groups or organisations were available to support minority ethnic carers. Indeed, one PHC nurse suggested that she would find it very useful if the researcher could compile a list for her.

### **Conclusions about differences and diversity**

Although there was some inconsistency in terms of PHC nurses responses to the type of care provided, what was evident was that some PHC nurses adopted an ethnocentric approach to service delivery and believed that the services provided were good enough to meet the needs of all clients and carers.

Communication difficulties were identified as a particularly problematic area, yet PHC nurses did not make effective use of the interpreting services provided and deliberately choose not to use the services. Instead strategies such as 'muddling through' or 'making do' were used. As identified in previous studies, PHC nurses opted to use family members to interpret.

There was a general consensus among PHC nurses that they needed better access to training, study days, workshops or conferences which might cover issues relating to ethnicity, race and culture, death and dying as well as 'general' information about minority ethnic communities. Some PHC nurses also felt that race and ethnicity issues should be better built in to the nursing curriculum whilst others suggested that there needed to be more equality in accessing courses between grades of staff. It was also reported that study days or seminars should be based locally if possible, giving PHC nurses more of a chance to attend, as well as reducing costs.

The evidence suggests, then, that there is a clear need for PHC nurse training to take a more in-depth look at issues pertinent to minority ethnic communities. Nurse theorists such as Leininger (1981) advocate transcultural nursing as one means of doing this. This has been defined as:

A formal area of study and practice that focuses on a comparative analysis of cultures and subcultures with respect to diverse health-illness caring beliefs, values, practices with the goal of generating scientific and humanistic and culture-specific or cultural-universal therapeutic nursing care practices (p366)

However, critics of Leininger argue that the approach will not necessarily translate into practice and provide culturally competent practice, as it involves looking back at earlier traditions that may not be relevant today (Price and Cortis, 2000). Instead, it is suggested that practitioners need an understanding of ethnicity, race, culture and the processes of acculturation, as well as an awareness of how their own position and general orientation might view another as inferior (Price and Cortis, 2000). Gerrish and Papadopoulos (1999) make a number of additional suggestions for nurse education to prepare nurses for transcultural competence:

- Develop culture specific and generic competence of knowledge and skills concerning minority ethnic groups
- Understand the clients' (carers') perspective
- Understand socio-economic and political influences
- Provide learning opportunities to put theory into practice

Difficulties in meeting carers' needs were hampered due to PHC nurses' inability to access resources to help them in everyday practice. An area that caused particular problems concerned wasted visiting. Hence, a need for calling cards in different languages was reported.

### **MEETING NEEDS?**

Here, PHC nurses' stereotypical views concerning minority ethnic carers are reported. Two areas are addressed: perceptions of carers having ample support because of belonging to a 'caring community' and carers having higher expectations of support.

#### **Belonging to a 'caring community'**

There was a general consensus among all PHC nurses that the minority ethnic community as a whole was more caring and supportive towards its members. Based on their experiences of nursing in the community, PHC nurses made direct comparisons with what they felt the situation to be in the white community; this was particularly in relation to attitudes towards residential care and the support of the extended family. PHC nurses reported, for instance, that minority ethnic carers had a much higher tolerance level than white carers. This resulted in them continuing to care under very difficult circumstances because they were prepared to endure a lot more 'suffering' in order to keep the patient at home as opposed to be cared for in a residential care setting. In contrast, it was reported that a white patient with the same severity of disability or illness would have been admitted to residential care long before reaching a similar stage.

They do devote a lot of time and effort with their family...overall the majority of Asian carers are really good and suffer a lot of difficulties as well and have a much higher tolerance level than the white carers. Some of the cases I've got are severe cases and they are still at home, and if you compare them with white carers they would've been in residential care years ago. (Community psychiatric nurse Mathern, p5)

As the support of the extended family and the community as a whole was much greater than for white carers, it was felt that minority ethnic carers were able to access support, either from the wider community or the temple. Perceptions of ample support resulted in a few PHC nurses believing that minority ethnic carers had a lesser need for support from PHC nurses compared to white carers, especially for emotional support.

with the Asians, they don't want us [nurses], because they have got [support]. I mean their bereavement is quite a big thing...I am aware that everybody comes and they really don't want us there in the house. (District nurse Dobcross, p22)

Other PHC nurses believed that services such as respite and district nursing services were either not requested or used, primarily because carers had the support of the extended family.

Because of the extended family they don't request services. (District nurse Carie, p6)

Moreover, seeing large numbers of people at funerals was 'proof' that minority ethnic carers were better supported.

when it comes to the funeral rites and things like that, the whole community is there for them, they are supportive, you know...We see coach loads of the community arrive, which is very different to some, you know, some English situations where perhaps there's just the mother, you know, and the community nurse, you know. So that speaks for itself doesn't it, how the support is there for some communities and not for others. (Clinical supervisor Jaywick, p14)

However, assumptions regarding allegiances and networks must be scrutinised and challenged if PHC nurses are to be responsive to the needs of minority ethnic carers. Rather, PHC nurses must begin to appreciate that '[u]nderstanding of black people in Britain must move beyond the crude essentialism implicit in multicultural approaches. Identity is not a 'fixed core,' (Watters, 1996, p121) but shifts in a context in which 'cultural identities are simultaneously cultures in process' (Brah 1992, in Watters, 1996, p121).

### **Higher expectations**

In contrast to Gerrish (1998) who reported that South Asian patients and their carers in particular were perceived as less demanding and more self-resourceful due to the role of the extended family, evidence from PHC nurses in the current study suggests that they felt that minority ethnic carers had higher expectations of what they could realistically do for them,

compared to white carers. Carers were reported to ask PHC nurses to do things which they felt could have been sorted out by either the carer or their family and, hence, carers were too dependent upon PHC nurses. Carers approached PHC nurses to do 'little' things which PHC nurses felt were not their responsibility, for instance, making telephones calls, picking up tissues from the floor, moving chairs. These requests resulted in PHC nurses feeling frustrated.

There is these areas that because you are a nurse or because you are a community mental health worker or because you are involved, full stop, that you should sort everything out for them. (Community psychiatric nurse Hakin, p8)

I think their expectations that as having a community nurse that they expect that you will be able to sort out everything and that you are there for them all the time so any little thing that may need sorting out, you might need a phone call, could you just ring up so and so and do this for me, when actually they should be able to do it themselves. (Community nurse Startley, p23)

Hence, PHC nurses felt that minority ethnic carers were demanding, fussy and had expectations that were 'over and above' those of white carers. For example, district nurse Carie gave an example of how an elderly male carer looking after his wife wanted the district nurses to stay so that that his wife's toileting needs could be dealt with. However, the district nurses felt that it simply was not practical to have someone sitting on the commode for half an hour in the hope of getting things 'sorted', just because they happened to be there.

These feelings also concerned carers' expectation of lengthy washing techniques, as reported earlier, and access to equipment. For instance, it was reported that if equipment was requested for the patient, carers had expectations that the PHC nurse would be able to access equipment immediately, did not understand the logistics behind ordering and obtaining equipment and continuously asked when it was going to arrive. Evidence from carers themselves suggests that this was true to the extent that carers had little knowledge of how 'the system' actually worked. However, carers often had a considerable wait for equipment which, at times, was not chased up by PHC nurses. This suggests that carers did not have higher expectations in terms of accessing equipment but rather they lacked understanding about how services were provided, resulting in repeated questioning and requests for the same item. Moreover, PHC nurses' views about 'social need' suggest that this was no longer viewed as their responsibility.

I mean it it's more to do with social need or whatever, that's more to do with Social Services anyway. (Clinical supervisor Jaywick, p23)

While PHC nurses cannot be held responsible for delays in equipment arriving, it would be part of their responsibility to work with social care colleagues to ensure that action taken was followed through.

Some PHC nurses were clearly of the opinion that carers did not do enough.

But there are times when you feel like saying to carers, but surely there's a bit more you should be doing for the person you are caring for ... (Nursing auxiliary Badby, p6)

Minority ethnic men, in particular, were viewed as not being 'caring enough', especially by district nursing staff who found them reluctant to be involved in 'hands on caring'.

I find that male Asians are very reluctant to care, care as in giving them a wash or toileting them. They don't feel it is the man's role, you know even if there is an able bodied man in the house there is nobody to look after her, if it is a woman that is the sick one. If it's the wife that's ill and her husband is able bodied he won't care because it's not his job. He wouldn't wash her or do things for her. Whereas in other religions [communities] you would find that the man would get on with it. The Asian men are very reluctant to do that sort of thing. (District nurse Dobcross, p18)

Yet, evidence suggests that this reluctance is also common among white carers (Parker, 1990). Moreover, Parker's (1990) study identified that ties of marriage do not necessarily prepare people to be involved in intimate caring tasks, nor do they make it any easier.

Other nurses reported that minority ethnic carers tried to get more from PHC nursing services than they deserved:

I mean sometimes folk will latch on because they do see you as a meal ticket to get things, you know. Let's be negative for a minute about things. I mean it happens. (Health visitor Golant, p12)

Moreover, some PHC nurses suggested that by trying to meet the needs of minority ethnic carers and patients, this disadvantaged other families. Hence, it was necessary to "work the system" so that it would be "fair" for everyone (District nurse Carie). A similar view was expressed by management (see chapter nine).

Given the constraints on the NHS and limited resources, it is accepted that services may be allocated on the principles of fairness and equity (Gerrish 1998). However, it is suggested that the views held by PHC nurses and managers in this study - of minority ethnic carers being demanding in terms of resources - only served to reinforced negative stereotypes. This is especially so as other evidence from the study indicates that lack of knowledge played a significant part in carers asking for services when they knew little about which service

provider resources came from and had little knowledge about how 'the system' (National Health Service and social care) worked in the first instance.

There is ample evidence which illustrates that professional's own views of deservingness influence people's ability to access services (Lipsky, 1980; Ahmad and Husband, 1993; Twigg and Atkin, 1994). PHC nurses in this study, too, used their discretion to judge whether they would or would not help carers:

From a mental health point of view, you can go in to support, you can go in to monitor, you can go in and advise [the] client what to do. There seems to be this high expressed need coming from a carer that may feel that you should do everything for them... it happens a great deal that you have to sort of reassess your boundaries with people. (Community psychiatric nurse Hakin, p8/10)

There was, however, some variation in terms of what PHC nurses said they would do or not do for carers and the manner in which they actually practised. For instance, PHC nurses said they would not deliver incontinence pads to carers, yet evidence from one carer, as reported in the earlier chapter, demonstrates that much was dependant on the type of relationship carers had with PHC nurses.

As minority ethnic carers were viewed as too dependent upon them, PHC nurses used strategies such as 'reassessing boundaries', as shown above. They also used 'distancing' and 'being firm' to overcome this perceived dependency.

*Distancing* involved PHC nurses behaving in a 'matter of fact' and professional manner, getting on with tasks at hand without getting side tracked by getting too involved with carers. This is not to say that carers were ignored totally, rather PHC nurses weighed up whether carers were coping and if they were, they "pulled back" and left contact details. This was often necessary to make their caseloads more manageable. Moreover, PHC nurses felt they could not afford to visit those lonely carers who "just wanted a cup of tea and a natter".

I do try and get out of situations when they want to just talk about nothing [anything], because there are people who want to express their problems and talk about them... There are some people who are just lonely, who just want to talk for talking sake, and that's when you have got to try and get out sometimes because they may be lonely but I'm afraid I can't sit there all day talking to them because they want talk to somebody. (District nurse Dobcross, p9)

Ironically, it was probably these very carers who were in desperate need of someone to talk to and on the border line of not coping. Yet, PHC nurses, when they sensed that carers wanted to 'just talk' did their best to get out of the situation as soon as possible.

It is acknowledged that PHC nurses would not have the time to 'sit and chat' for hours, but as part of their professional practice they could make time to support carers, and if necessary refer carers on to services where they would be able to obtain the emotional support they needed and were searching for. The evidence suggests that PHC nurses 'knew' that carers wanted them to stay and talk and hence did their best to make sure that carers also 'knew' that they did not have time for them. The findings of this chapter demonstrate that carers' claims of not being provided with emotional support are not unfounded.

*Being firm* with minority ethnic carers was only reported by one PHC nurse. However, it is important to report this, as this strategy was also identified by management as being essential to practice when dealing with minority ethnic carers. This issue is discussed further in the subsequent chapter. This nurse reported that it was necessary to be assertive and firm when dealing with minority ethnic carers and clients because they saw her as "their skivvy" and that sometimes "they would see if they get away with it and ask" [her to do something] (Nursing auxiliary Badby). However, this same PHC nurse reported that she might do things for older carers but not younger ones. In her mind, younger carers were less deserving of support from PHC nursing services because they should be able to do things for themselves. Yet the costs of caring affect all carers, irrespective of age and probably more so for younger carers who may have a lifetime of caring ahead of them.

### **Conclusions about meeting needs**

PHC nurses in this study expressed a number of stereotypical views concerning carers, who were viewed both as having lower levels of needs because of their membership of a 'caring community' and having higher expectations of services. Hence, PHC nurses used a variety of strategies to curtail demand.

As practice was not observed it is not possible to know whether these stereotypical views had any impact on practice. However, this is not a new finding as previous research has reported that, where health professionals hold negative stereotypes about minority ethnic people these, in turn, affected the care they received (see for instance, Foster, 1988; Cameron et al, 1989; Ahmad et al, 1991; Bowler, 1993; Watters, 1996). The exception is Gerrish's (1998) study in which it was observed that although district nurses did express stereotypical views this did not affect the care provided for minority ethnic patients and carers. However, what is clear from the current study is that carers' needs, at least in the area of the country studied, were not met.

## STRUCTURAL DIFFICULTIES IN MEETING CARERS' NEEDS

The findings reported in this chapter have highlighted some of the shortcomings within PHC nursing. However, this final section reviews evidence about the structural issues that also resulted in PHC nurses not being able to address minority ethnic carers' needs. These difficulties were often out of the jurisdiction and control of PHC nurses. They concerned referrals, insufficient minority ethnic staff and implications of the NHS and Community Care Act (1990).

As reported earlier, meeting the needs of patients took precedence. Moreover, practice which focused largely on the patient was viewed as acceptable because meeting carers' needs was classed as warranting two separate referrals. It is ironic that, on the one hand PHC nurses claimed to practice holistic assessments which would encompass carer needs, yet the patient was clearly their central concern. This would suggest that, if carers' needs are to be addressed, then general practitioners, for instance, would need to start making separate *referrals* for carers. This is important because from the total sample of PHC nurses in this study, only two referrals were specifically for carers.

PHC nurses from all disciplines and gender expressed an urgent *need for more qualified minority ethnic staff*. There was a general consensus that there were not enough minority ethnic staff working in the community to meet the demands of a large minority ethnic population being served by PHC nursing services. Particular concerns were raised by learning disability nurses and community psychiatric nurses. Although this is a relatively small study, these findings support those of other national studies in which it has been identified that there are too few bilingual minority ethnic nurses overall (Beishon et al, 1995), and fewer still in specialist areas (Atkin and Lunt, 1993; Cassidy, 1995) where most nurses would be appointed on a much higher pay scale. Evidence suggests that employing a culturally diverse workforce partially resolves some of the difficulties experienced by the NHS in providing accessible and responsive health service provisions (Department of Health, 1993).

The *NHS and Community Care Act (1990)* was identified as having a significant impact on PHC nurses' workload. PHC nurses across all disciplines reported their caseloads as being much heavier and larger. Many struggled to meet the demands of existing patients hence carers' needs were seen as secondary. The number of referrals to PHC nursing services for patients had also increased, therefore cases were opened and closed more quickly. However, PHC nurses often received inappropriate referrals which were not relevant to their profession. This resulted in them redirecting referrals to other disciplines within PHC nursing services.

General practitioners' lack of awareness about the roles of different PHC nurses was identified by nurses as the root cause of the difficulties they experienced.

Larger and more technical workloads resulted in PHC nurses having little time for carers; the majority mentioned that they did not have time to meet the needs of carers because of workload pressures relating to patients' needs:

Too much to do, too much to do a lot of the time...The door is never shut. It's not like a ward you can say I've got my 40 patients I'm full. We are never full. (District nurse Dobcross, p6)

Lack of time resulted in PHC nurses concentrating on the tasks that needed to be done for patients:

but who is going to go and sit and talk to someone?  
(Nursing Auxiliary Badby, p2)

Combined with lack of time and difficulties in managing caseloads, PHC nurses prioritised and limited their services for patient needs on the whole. In view of the difficulties they were having in meeting patient's needs, they tried not to identify needs which they knew they did not have the resources to meet needs, especially as there were too few PHC nurses in some disciplines in the first instance.

It's no use targeting it if there's no facilities or resources for them. It's no use going to the elderly and picking up problems if there's nothing you can do about it.  
(Health visitor Elgin, p9).

### **Conclusions about structural difficulties**

Structural factors that affected PHC nurses' ability to provide support were out of their control, hence there was little that they could have done about them. What was evident however was that these structural factors had a significant impact on PHC nurses' ability to meet needs. With lack of minority ethnic staff, heavier workloads and more technical workloads and lack of time, PHC nurses focused their energy on meeting the needs of patients as that was whom the referral was for in the first instance.

Evidence from this chapter, then, demonstrates that nursing philosophy and policy continue to remain ideals which have yet to be implemented fully into practice for carers.

## **CHAPTER NINE**

### **MEETING THE NEEDS OF MINORITY ETHNIC CARERS A MANAGEMENT PERSPECTIVE**

#### **INTRODUCTION**

This study was undertaken during a period when in the interest of promoting market efficiency and accountability, the purchaser and provider functions in the provision of health services were still operational. It was the responsibility of the purchasers or commissioners, as they are now known, to identify needs and priorities within and between populations, channel resources towards services that would meet those needs and well as manage the performance of those providing services. Fund holding practices and District Health Authorities had the responsibility of purchasing community nursing services whilst the responsibility of providing services rested with National Health Service Trusts or Directly Managed Units which were managed and contracted to both the Health Authority and the Trusts (Atkin and Lunt, 1993).

For this thesis, commissioners from the Health Authority and providers of community nursing services from National Health Service Trusts were interviewed. The issues explored in this chapter were not researched in Katbamna and Bhakta's (1998) study. Obtaining the perspective of health managers (many of whom had nursing backgrounds) thus adds a new dimension in attempting to meet the needs of minority ethnic carers. This is important as research has tended to focus on carers' views about specific services without providing accounts of the views and experiences of those managing services.

Provider Trusts included those that provided learning disability services, mental health and community district nursing and health visiting services. The views of both provider managers and commissioners have been grouped together to provide an overall management perspective. However, where appropriate, the views of commissioners are reported separately to enable distinctions to be drawn. Also, because of the nature of managers' work, the findings reported here are retrospective accounts based on interviews with managers relating to South Asian minority ethnic carers as a whole as opposed to Gujarati Hindu carers specifically.

As the previous chapter demonstrates, the practice of 'patient-centred' care together with holistic assessments resulted in carers not being supported. However, factors beyond PHC

nurses' control also played a part in their inability to meet needs. This chapter focuses on the management perspective of meeting minority ethnic carers' needs. It starts by providing a managerial account of why meeting carers' needs was deemed important and how holistic assessments were identified as being a key tool for meeting needs. The second section looks at the support available to PHC nurses to enable them to meet needs.

## **VALUING CARERS**

The importance of meeting carers' needs was recognised throughout the management hierarchy and across the provider and purchaser boundary. Several key factors were identified as to why meeting carers' needs was felt to be important. Firstly, valuing and recognising carers' contribution was reiterated as being part and parcel of Trusts' philosophies:

It's very much part of our philosophy as a Trust that any staff visiting at home do an assessment which is holistic which should incorporate the needs of carers.  
(Manager Ullock, p2)

It was also recognised that carers were an important asset because PHC nurses were reliant upon them to 'take over' the caring responsibilities. Moreover, without carers, Trusts would simply not be able to cope with demands on PHC nursing services due to limited resources.

And we do rely on carers an awful lot. The district nurses can't be there all day...We couldn't exist out there without them. We don't have the resources to do what carers do.  
(Manager Niddrie, p34)

Hence, carers were viewed as an important resource (Twigg and Atkin, 1994). Moreover, it was reported that if carers' needs were not addressed, then the care for the patient would in essence break down.

The philosophy is that you need to look after the carers as well, that you need to take their care into consideration because otherwise you end up admitting the patient as an emergency because the care had broken down because of the carer.  
(Manager Ticknall, p23)

Therefore, managers believed it was important that PHC nurses were able to recognise whether carers "could deliver their part of the bargain." (Purchaser Sontley, p11)

## **IDENTIFYING NEEDS**

### **Holistic assessments**

The holistic assessment was identified by managers as a means of identifying and addressing carer needs and concerns. There was a general consensus that every patient had a holistic assessment of need undertaken by PHC nurses. The holistic nature of the assessment would therefore "automatically" pick up on carers' issues as the assessment would look not only at

the whole person but also their environment. “Carers would always be a consideration because, from the beginning of the holistic assessment” (Manager Tugby, p6).

The holistic assessment would cover many important aspects including whether carers were coping or wanted to care and were happy caring.

But obviously while you’re doing that assessment you are taking into consideration, customs, religions, it’s a holistic assessment. To support carers and to teach carers, to advise them on health and safety and issues like moving and handling. Listening to carers and watching their stress levels. (Manager Niddrie, p34)

Many managers were of the opinion that identifying carers’ needs was not problematic as conducting holistic assessments was an important part of the role of PHC nurses and that despite PHC nurses being busy, they still made time for carers. Moreover, as PHC nurses were visiting patients in their own homes, this enabled them to establish effective relationships with carers. They thereby became “part of the family”, which enabled carers to “open up” and discuss any issues with them. Further, if needs were identified, PHC nurses would be well placed to refer carers on to local community resources, as they had considerable knowledge concerning both local and national organisations and structures that could support carers. This was even more so because PHC nurses were involved in discussions with these local organisations in any case. If, on the other hand, PHC nurses were not sure which services were available locally, or they needed advice, they were said to be very resourceful and thus usually able to find out from colleagues. Alternatively, they could always turn to their managers for support, or search Helpbox, a computerised database listing information about relevant community organisations for instance for guidance.

Managers thus reiterated that carers’ needs were automatically assessed through the holistic nursing assessment.

So I’d expect community nurses or any nurses to be identifying carers, offering them an assessment, and to make sure that it isn’t just a one off thing, ’cos needs change, carers’ needs change, and that they’re discussing those. (Purchaser Sontley, p 12 )

Manager Ticknall went as far as to say: “I think the better nurses make time [for carers]” (p8).

## **ENABLING PHC NURSES TO MEET NEEDS**

Access to interpreting services, translated information, access to the services of a local resource centre and training for PHC nurses were identified as means to support PHC nurses to meet the needs of minority ethnic carers. Each is discussed in turn.

### **Interpreting services**

Managers across the board expressed many positive views about the local interpreting facilities provided by their Trusts. Indeed, within some trusts it was firm policy that interpreters be used (Manager Ullock). There was high regard for the services as they catered for many languages, could accommodate any 'need' and provided a very good service overall. Moreover, access to the services was not thought to be problematic, as the process of accessing an interpreter was relatively "easy"; all it required on the part of the PHC nurses was for them to book an interpreter when they needed one.

It should be fairly easy to access an interpreter because we have mainstream and sessional workers. It shouldn't really be difficult for them [nurses] to access.  
(Manager Westwell, p4)

It was however acknowledged that, at times, PHC nurses might have to wait one to two weeks on occasions before an interpreter could be made available. However, the issue of having to wait was justified both on the grounds that interpreters had to be 'tracked down' from a list of sessional workers and on PHC nurses' inability to book in advance.

If they [nurses] tell us [in advance], they won't have to wait a week or two. If they have to wait there are very good reasons...I don't have a Chinese [Chinese interpreter] sat here. (Manager Risley, p3)

Only one manager expressed a contrary view, feeling that PHC nurses lacked knowledge of how to access interpreting services (Manager Tugby). Others were of the opinion that it was not a matter of lack of knowledge about the services, rather PHC nurses did not use the services provided. Manager Veness, for example, reported that PHC nurses did not trust the interpreters; hence a link worker system would be more appropriate.

I think that system is ideal. If you call an interpreter from a service, they are not known and not trusted and not part of the team. The development of the link worker system is a good one and would help the staff, community and carers. (p9)

However, two managers (Oldpark and Zennor), both of whom favoured the use of 'in house' staff, supported PHC nurses' decisions not to use the interpreting services:

The difficulty we have is interpreters understanding what learning disabilities are as well as interpreting and what our difficulty is... with the sensitivity of learning disabilities because of the way that they sometimes explain things and that's the difficulty..so you've not just got the cultural difference and language, you've also got difficulty of the barrier of learning disabilities...So it's almost like 2 or 3 hurdles we have to jump across and if there is that simple barrier of language, well we just have to sit there and accept what's being said is accurate. And we don't know whether they're feeding it back correctly or they're passing it across the way that we'd like it

emphasised...Yeah, I think the staff have more confidence in our own nursing assistants....I think the reality is , as anything, people tend to rely on the people that they know and feel that they've got a trust. (Manager Oldpark, p7)

Commissioners, on the other hand, were aware that the basic structures of having interpreting services were in place. However, they reported that it was the responsibility of the Trusts to overcome obstacles in a planned way (Purchaser Sontley).

### **Translated information**

It was reported that PHC nurses had access to a range of translated information. This included, for instance, the front cover the district nurse's folder that outlined how district nursing services could be accessed, as well translated literature which outlined the patient's charter and complaints procedures. There were, however, concerns about having 'too much' information translated because of fears of it not reaching the target population, due to the diversity of the population that needed to be served. However, as identified in the previous chapter, the type of translated information available was not much use to PHC nurses in everyday practice.

### **Resource centre**

All PHC nurses as well as managers themselves had access to the services offered by a local resource centre. The centre was viewed as an important resource which not only provided access to translated information and interpreters but also put on exhibitions, and provided advice, information, and courses relating to minority ethnic issues. As the centre had a lot to offer it was felt that PHC nurses should be able to address any difficulties concerning minority ethnic communities via the centre.

### **Training for PHC nurses**

When discussing training, managers confirmed the views of many PHC nurses that statutory training such as lifting and handling would have priority over courses or study days concerning race and ethnicity. There were also no formal study days provided by the Trusts which at looked meeting the needs of carers in general. Further, study leave to attend courses would only be granted if the course concerned was felt to be appropriate to the field in which the PHC nurse worked. Manager Niddrie summed up the views of a number of managers who said:

It's no good sitting here now and deciding, right this year we're gonna train staff in ABC, unless it's a very generalised subject...Generalised things yes, I mean like through the year staff have attended moving and handling, things like this. To make sure you're up to date and doing the right thing. (p27)

Moreover, attending a course on, say, ethnicity was viewed as having low priority, especially if the population being served by the requesting PHC nurse had very few minority ethnic people residing in it. It was reported that the PHC nurse would 'forget' what was learnt by the time it became necessary to implement it in practice.

I mean yes, you could go on study leave for a day, but because you're not dealing with that clientele, by the time you come into contact with that clientele, you may have forgotten the thing that you'd learnt today. (Manager Niddrie, p26)

However, managers stressed that there were opportunities for nurses to attend courses relating to ethnicity and that a course on race equality issues was currently being provided to all grades of staff. The course was being rolled out using a 'top down' approach. However, it soon became apparent that the course had actually been in operation five years but due to various difficulties could not be run on a regular basis. At the time of interviewing, the course had cascaded down only to community general management level over a period of five years which suggests that junior staff would have a considerable wait to access the course. Moreover, although it was reported that all grades of staff had equal access to courses, it was acknowledged that the selection process was a bit vague.

In contrast, some trusts operated a system of 'individual performance review' (IPR). This method enabled PHC nurses to identify any training issues and bring the matter to the attention of their team leader, who in turn informed the manager. The IPR system worked well, where used, and was appreciated by PHC nurses too, a number of whom had attended the multicultural mosaic course as a result of this system in which their training needs were identified.

Commissioners, on the other hand, reported that it was the duty of the Trusts concerned to address training issues to ensure that PHC nurses were properly trained. However, if training was identified as being problematic, it would be appropriate for commissioners to specify in the service agreement what types of standards they expected and how they intended to monitor the situation.

## **SUPPORTING MINORITY ETHNIC CARERS IN PRACTICE**

### **Patient priority**

Despite managers reiterating the importance of meeting carers' needs as reported at the beginning of this chapter, upon further questioning, evidence from managers in this study illustrates that practice was very different. Like PHC nurses, managers expressed the view that meeting the needs of patients was their main concern.

Professionals and carers work together in the interest of the patient or client, at the end of day it is the patient or the client who is the most important person, so the emphasis is on the patient. (Manager Woolwich, p5)

This was more so because PHC nurses had demanding enough caseloads: “But the reality is that we can hardly meet the needs of the clients” (Manager Zennor, p5). Moreover, meeting carers’ needs was not fully taken on board by Trusts because expectations from commissioners were that patient needs would be met. When discussing the issue with commissioners, there was some inconsistency between the two commissioners on the subject. Purchaser Sontley, for instance, spoke positively of the community care reforms and reported that the Act would act as a stimulus to think about ‘who did what’, for instance. Also, despite the issue of carers issue effectively ‘belonging’ to social services, negotiations had already taken place with their local providers.

Oh, well its been implemented locally....it essentially relates to local authorities who have a statutory duty now to identify carers needs, but what we’ve done is recognised that it may not be mandatory but it’s good practice. If our social service colleagues are in the community identifying carers needs then it makes sense for us to do the same and to work alongside them. So even though it isn’t a national essential we’ve put it on our agenda locally. (Purchaser Sontley, p14)

Purchaser Rochester, by contrast, made it clear that carers’ needs were not viewed as a health issue.

The health service as yet hasn’t been required to do as yet by law for carers. If it’s not required to do it by law, it’s very slow to do it, it’s very slow to do it. It’s like local authorities they weren’t required to assess the needs of carers until recently and now they are, so, they do. I think that’s what is required, a greater push, a greater emphasis for [the]Health Authority to make it part of our business to assess carers. (p14)

When asked to clarify how carers’ needs were to be met by providers, there was effectively little by way of policy or strategy that suggested that carers’ needs were considered a health issue by providers. Moreover, a number of managers expressed the view that if carers had any concerns it was easy enough for them to raise issues with the PHC nurse involved in the patient’s care. Further, accessing services was not viewed as problematic because carers would approach their general practitioner as their first port of call in any case. Consequently, it was felt that it was up to carers to speak up and inform PHC nurses and the trusts about the type of services they wanted in order to be responsive to their needs. Manager Woolwich, for instance said:

In order to support carers, we need to find out what sort of support carers would like...raise awareness about what constitutes ethnic minority problems and encourage them [carers] to let us know that they what. (p6)

A few managers were cautious about saying that carers' needs might not be adequately addressed and therefore referred to it as something they would like to establish in the future or said that it was in the "pipeline".

There was little representation of carers on committees, or reference to them in in-house policies, strategies, documents or charters which would encompass their needs. Managers stressed, however, that although there was no structured consultation process with carers, meeting their needs was part of the service. Yet policy (Department of Health, 1999a) stipulates that health services providers should also be involved in identifying and establishing links with carers as part of their service, as well as involving carers in the strategic planning of service provision and development. Past research (Barnes and Wistow, 1993 in Rogers and Barnes, 2003) in which carers have been involved at a strategic level has reported that carers felt valued because they were at last recognised as having expertise that was valuable to paid service providers. Braye (2000 in Rogers and Barnes, 2003, p129) suggests that a 'democratic model of participation is about participation with the purpose of achieving greater influence and control'. Hence, 'it is equally important to feel that your voice is being heard and valued, and to feel that it is possible to influence change as well as see change in practice' (Rogers and Barnes, 2003, p129). Given the evidence, one wonders how managers in the current study felt this would be achieved if, firstly, there were no policies in relation to carers' needs or identification of those needs and secondly, there were no strategies in place to ensure compliance, or means to monitor effectiveness.

The evidence demonstrates that, although policy (NHS and Community Care Act, 1990) made clear that helping carers access the support they needed was now to also be regarded as a health concern, this had not been taken on board by managers in this study. These findings mirror those of Twigg and Atkin's much earlier study (1994).

All Trusts were working towards 'The 12 Point Check List' (appendix 19), a strategy developed by the Health Authority aimed at improving accessibility, acceptability and appropriateness of services for minority ethnic patients. None of the Trusts in this study were, however, prepared to say how far down the list of 12 points they had reached or what had been achieved in relation to its objectives. ". Indeed, purchaser Sontley felt that the 12 point check list had not been highly successful, and therefore smaller targets had to be set by

commissioners for the trusts. A number of other innovative schemes and ideas had been put in place in order to reach minority ethnic communities in general, none however, focused specifically on carers' needs<sup>19</sup>. Further, available documentary evidence that had been collected also did not mention carers and how their needs could be addressed (see chapter five).

## MEETING NEEDS?

A few managers, like the PHC nurses, reported that minority ethnic carers had higher expectations in terms of what PHC nurses could realistically do for them and the resources they could access. Manager Peplow for instance, gave a detailed example of where a family wanted sterile syringes to administer medication for their son.

They are lovely people and they care for him beautifully but they want 520 syringes a month in order to administer his medicines, down his gastrostomy tube. Now they don't need those number of syringes because the syringes can be washed... the gentleman does not want his wife to wash the syringes because he says that she has enough to do as it is and he thinks she should have a new syringe every time, of course they've got hundreds of syringes, like a shipping order, even though we have tried to explain that he doesn't need sterile syringes ...but he won't budge one quarter of an inch and still demands his syringes. (p10)

As a consequence, managers gave PHC nurses clear messages to ensure that they were firm when dealing with minority ethnic carers.

A lifestyle where they're used to having servants. I think its hard for them (minority ethnic carers) to lose that, they seem to see the nurses and other people in the same light...Yes, yes, it just means everybody's got to be firm and everybody's got to be giving the same message. Because if you get one nurse that says, "Oh, I'll do it" [this would lead to problems]. (Manager Niddrie, p10)

However, as reported earlier, the majority of carers lacked awareness about how PHC nurses could support them and had little knowledge about the role of PHC nurses, many were not able to differentiate between what aspects of care and provision fell into the health care remit and what fell into the social care arena. Moreover, in situations where minority ethnic carers were found to be demanding, it does beg the question of whether an interpreter was used to make things clear. This is important as evidence from the carers (chapter seven) identified that very few actually had any experience of using an interpreter.

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<sup>19</sup> These included for instance, radio broadcasts about mental health, health promotion days, links with temples and other community organisations, learning disabilities nurses 'going to the community' to identify possible clients and community psychiatric nurses visiting general practitioners to explain their roles.

## **Access**

Managers' views concerning access were touched upon earlier. Although there was a general consensus that access was not problematic for carers, there were concerns about people with learning disabilities and mental health problems not accessing services and, hence, people were "missing out". Managers recognised that mental health in particular carried a lot of stigma within the minority ethnic community. Examples were given of people with mental health problems not wanting to be collected from outside their home because of the stigma of having a 'labelled' van outside, because mental health was 'not the same as breaking a leg'.

Two main causes of inability to access services were identified. Firstly, a number of managers had strong beliefs that general practitioners did not refer people with learning disability and those with mental health problems, in particular, to services. General practitioners' lack of knowledge about the roles of different PHC nurses was viewed as a contributory factor to this. This study did not set out to look at referral patterns; however, evidence from PHC nurses in the previous chapter and managers in this chapter does lend tentative support to the findings of earlier studies. Cameron et al (1988) for instance, in trying to 'make sense' of why there were too few minority ethnic patients on district nurses caseloads reported lack of referral by general practitioners as a strong possibility as to why this might be so.

Secondly, minority ethnic people's culture was also believed to be linked to inability to access services. Manager Zennor for instance, said, "Females with depression, we're not getting them. That we see as a cultural thing." Others identified social class as being more significant in terms of ability to access services:

Some social classes access services better than others, whether they're ethnic minorities or not doesn't matter. It's more social class really and they don't access the service. We perhaps constantly need to be targeting those groups. (Manager Quatt, p7)

## **The same for everyone?**

As minority ethnic carers were viewed by some managers as having higher expectations, managers, like PHC nurses spoke in terms of trying to provide services on a fair and equitable basis which were 'the same for everyone'. However, treating everyone in a like fashion assumes that no 'special' treatment is given to any individual and hence the service is 'fair' (Roys, 1988). However, this approach fails to take account of cultural differences and presents services provided for the white majority as the norm and acceptable. Ahmad (1993) argues that if equity is to be achieved within health care and health status, the basic prerequisites of health such as decent housing and access to jobs and a good education are

essential. This also means being able to access and use services as full citizens. Tudor Hart (1971) argued that those in greatest need should be targeted for more resources. As reported in chapter five and six, minority ethnic communities experience considerable socio-economic disadvantage. This would suggest that if anything, minority ethnic carers should be targeted for more resources if their needs are to be addressed. Yet restricted budgets resulted in managers struggling to meet the needs even of patients.

On the whole, there were very few complaints from minority ethnic patients or carers. Manager Zennor gave an example of a complaint about racial discrimination concerning the management of a black youth with mental health problems. He spoke about how the youth and his family had been treated in the same way that anyone else would have been under the circumstances. Yet he felt it was important to stress that in their attempts to meet needs, normal practice procedures were followed and that black nurses were present at the time. In his view, the action taken concerning the black youth was justified. He added:

You wouldn't get away with it because there are so many black nurses on here! (p7)

Yet, surely it was more important to convince the family in this case that there was nothing that the Trust was trying to get away with?

Evidence from this study identified that 'fears' of racism resulted in some highly inappropriate decisions being taken at senior management level. In relation to the earlier example of the family who wanted sterile syringes, manager Peplow went on to say that demands might be met for fears of the trust being branded racist:

The trust will back off and give him the syringes I expect. Because if you don't, it looks as if you're being difficult, people are frightened of being labelled racists. They are, there is no two ways about it, I mean there is nothing racist about it because it wouldn't matter whether he was blue, pink, brown, green you know, the principle's the same, they don't need a sterile syringe each time. (p11)

Similarly, manager Ticknall spoke of extra nursing resources being allocated to one family because "otherwise they would have got complaints about racial discrimination" (p19).

Yet, at the same time, manager Ticknall believed that the allocation of extra resources was not justified on the grounds that it disadvantaged other - white - families.

Really I think the nurses were trying to go too much the other way [trying to 'over' please the family], in detriment to the white families down the road (p9)

Given the scarcity of PHC nursing services as a resource, should these not be provided only on the basis of need, as opposed to a 'trying to please' approach?

Evidence from this section demonstrates that there was misunderstanding among senior managers concerning minority ethnic culture and racism. This resulted in some inappropriate decisions being taken. This is important because discussing these issues proved problematic when conducting interviews with managers. Many were 'cagey' and 'cautious' and, at times, 'thought' carefully before responding, whilst others were simply offended.

We have got some very skilled people. We know what we are doing, any decisions made, are made with ethnic minorities in mind, it's the way we see it, it's part of our life.....there is the race element, people saying about the way we provide a service based on a racist point of view, euro centric perspective which I find very offensive. (Manager Zennor, p6)

If senior managers find it difficult to discuss these issues, how can carers with little or no command of English or knowledge of 'the system' make their views known without them being labelled 'demanding'?

## **STRUCTURAL ISSUES**

Managers referred to the provision of services being guided by policies issued by the Department of Health and that these were then implemented locally. However, despite attempts to implement policies, structural difficulties made meeting the needs of carers problematic. For instance, many managers reiterated that the role of PHC nurses had changed considerably. District nurses for instance, were now providing care in the community for more highly dependent people with complex health needs. Patients were also discharged more quickly than in the past. Moreover, the push for care in community meant that more people were now being cared for in the community as opposed to in institution-based care. Other structural difficulties concerning lack of minority ethnic staff, joint working and lack of financial resources added to the problems. These are discussed in turn.

### **Lack of minority ethnic staff**

There was a general consensus among managers that the number of minority ethnic staff employed in the community was significantly low in comparison to the population being served. In a bid to overcome these difficulties, Trusts did take positive steps to encourage minority ethnic nurses to apply for positions. For instance, some positions advertised were aimed specifically at minority ethnic people. On the issue of problematic recruitment, managers stressed that they did not positively discriminate. However, some managers were resigned to the fact that no amount of advertising would solve the problem as it was more a case of minority ethnic people not applying to train as nurses because their families objected.

But the problem is that the community don't see nursing as particularly a job for females to undertake. It's not, it's not considered to be something which females should go into (Manager Ticknall, p6)

In contrast, manager Westwell felt that it was unacceptable to hide behind the culture that recruitment was problematic, and that it was up to the schools of nursing to think of innovative approaches to attract more people from minority ethnic communities into the profession. Manager Ticknall on the other hand, did not express any concerns because the area covered within that patch was predominantly white, hence it was believed that the 'need' for minority ethnic nurses specifically was not there.

Although, the percentage of minority ethnic staff employed was low, there were no strategies in place to try and retain the few they had. Further, while ethnic monitoring of staff was in place, commissioners did not monitor applications received to assess what percentage applied and were successful from minority ethnic backgrounds.

### **Joint working**

Changes in working affected not only PHC nurses, but also health and social care managers. With the drive to provide a seamless service and 'joined up' working, health service managers too had adjustments to make in terms of the way they worked with their social care colleagues. A few managers viewed this new method of working in a positive light. Indeed, this approach was reported to have created stronger working relationships and constructive negotiations had occurred as a result.

However, tensions still remained, especially in terms of drawing divisions as to what constituted a health need and what fell into the social care boundary.

What is health and what is social care, the old chestnut that gets thrown up all the time. (Manager Ullock, p7)

Passing cases over to social care was also reported to be problematic.

Yes they [nurses] could be thinking, "Right this person is a lot better now, it's social care they need now", and then, we can't get through that brick wall, trying to pass it over to social services. (Manager Niddrie, p18)

As reported by PHC nurses in the previous chapter, some managers were also of the opinion that the nursing assessment was, in a sense, being done twice and the reality was that joint working between nurses and social workers was problematic.

The division between health and social need I think has resulted in people spending a great deal of time doing assessments only for that process to be done again by social services, and I think that nurses feel frustrated in the amount of time that's given in that ...things aren't clear cut as perhaps first appeared and I think for staff there's this frustration at the time they spend trying to get to know who is actually doing what. (Manager Tugby, p4)

Managers repeatedly stressed that the boundaries between health and social care were not clear-cut and that there must be easier ways of working. Manager Oldpark for instance, reported that the relationship between social workers and nurses was no longer constructive and went on to say: "To be quite honest, the delivery of care in the community is zero for people with learning disabilities". Hence, improving joint working was reported as the way forward.

The key is for better joint working between the health authority and social services and health and there should be more to encourage, facilitate, developing working together to assess needs. (Purchaser Rochester, p15)

## **Resources**

Walker and Ahmad (1994) point to the difficulties of administering effective community care services for vulnerable groups such as minority ethnic carers, when resources are restricted. Similarly, Twigg and Atkin (1994) argue that as a result of such resource issues, carers experience double pressure - because services are operating within a low-budget area of a constrained service sector.

Managers in the current study indeed identified that working with limited resources made it difficult to meet the needs even of the patients.

So I think that legislation and social policy needs some degree of financial backing to make it work really. With the best will in the world, you can't make a silk purse out of a sow's ear. (Manager Zennor, p5)

They also acknowledged that lack of financial resources affected both commissioners and providers. However, manager Peplow, expressed the view that: "they [commissioners] want us to do more and more for the same amount of resources which is very difficult...you can't get a pint into a quart pot, you can only do so much". Commissioners, on the other hand, argued that everyone wanted more resources but their job was to "listen to all of that and with the resources that are made available to us we'd have to make the most sensible and best effective use of those resources" (Purchaser Rochester). It was, however, mentioned that, at times, Trusts did not put forward their cases for extra resources effectively enough. This

rather begs the question of what role the commissioners were playing in trying to place carers higher up the provider Trusts' agendas.

In a bid to provide services within limited budgets, providing services that would cater for the needs of the majority was viewed as the most sensible use of resources.

If you're working with limited resources what you're trying to do is provide services that will meet the needs of all clients which in terms of provision I'm thinking of with respite, the most efficient way of doing this is within a project. We wouldn't have the money to provide services at home [as requested by minority ethnic carers] but we would be able to provide the services in another area so that more children can use that service. ( Manager Tugby, p5)

## **CONCLUSION**

The evidence from this chapter demonstrates that the many of the concerns aired by PHC nurses about interpreting services, and the difficulties experienced on the 'ground' as reported in the previous chapter were not recognised by managers. Although interpreting services were in place, difficulties subsumed within the services provided resulted in managers overlooking difficulties experienced by PHC nurses. Moreover, the type of information that was translated was of little use to PHC nurses in practice.

This study has identified that there was variations between Trusts as to how training needs of PHC nurses were monitored. Cotgrove (1970) in discussing occupational roles, role strain and role conflict, writes that in many large scale organisations (such as the National Health Service), it is the organisation which defines and spells out the daily activities of the individual. The rules of the organisation provides the script, defines tasks and the goals expected to be pursued by the actor (employee). The employee determines how this will be played according to his or own role style. However, the role played will be shaped not only by his or her characteristics but will also depend on the skills and capacities he or she has for carrying out the tasks which the role requires. Yet, as reported by PHC nurses in the previous chapter, and as confirmed by managers in this chapter, emphasis was placed on ensuring that PHC nurses accessed mandatory courses. Training that would have heightened PHC nurses' awareness of issues such as race, ethnicity and culture and the socio-economic circumstances of minority ethnic groups had little priority but would have helped PHC nurses in their day to day practice.

The evidence from this chapter also demonstrates that although managers valued carers, in reality, meeting patient needs took precedence. Managers had expectations that PHC nurses would meet carer's needs as part and parcel of the holistic assessment of need, yet they

provided PHC nurses little by way of support in terms of access to resources or training to realistically identify and meet carers' needs. Moreover, misunderstanding of needs resulted in misrepresentation of needs and, as consequence, inappropriate decision making. In the midst of limited financial resources, meeting the needs of patients took priority and carers' needs continued to be viewed as a responsibility not 'belonging' to health. Hence, carers received little support in reality. Davies and Challis (1986 in Twigg and Atkin, 1994, p22) suggests that this is because 'horizontal target'<sup>20</sup> efficiency' is so poor that 'vertical target efficiency'<sup>21</sup> is almost total.

Although policy has placed greater emphasis on collaborative working and implied that divisions concerning what constitutes 'health' and what constitutes 'social' need were clear, evidence from this study suggests that collaborative working remained problematic; boundary issues were not as clear cut as implied in policy, resulting in difficulties in passing cases 'over' to social care providers.

In summary then, there was a general mismatch between managers' views about how carers could be supported and the reality of PHC nurses' day-to-day experience. In practice, meeting patient needs took precedence. However, like PHC nurses, managers reported minority ethnic carers as having higher expectations, suggesting a shared level of stereotyping. But overall, managers believed that it was structural difficulties that were key in their inability to meet carers' needs.

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<sup>20</sup> The degree to which individuals in the target category receive the intervention

<sup>21</sup> The degree to which individuals who receive the intervention fall within the category

## **CHAPTER TEN**

### **CONCLUSIONS AND RECOMMENDATIONS**

#### **INTRODUCTION**

The central aim of this thesis was to explore whether Gujarati Hindu carers felt supported by PHC nursing services. The decision to focus on Gujarati Hindu carers' experiences with PHC nursing services was based on several factors: the literature review which identified that this was an area that warranted further investigation as there were a number of evident gaps; my experiences of nursing that led me to question whether PHC nurses' views concerning minority ethnic people would be as negative as those held by colleagues in an acute setting and whether they would be working under similar constraints; prior knowledge that the large-scale South Asian carers study (Katbamna and Bhakta, 1998) had previously been unsuccessful in obtaining carers' views about their experiences with PHC nursing services and, lastly, personal experiences of having a disabled child in a community in which disability is stigmatised and women in particular are blamed for having a disabled child.

Hence, this study aimed to fill an important gap in knowledge, not only in terms of the minority ethnic carers' literature but also in relation to PHC nursing in general. The specific intention of the thesis was to explore the areas carers felt supported by PHC nursing services and if they did not feel supported, to find out why carers felt this to be the case.

From the outset it was decided that the views of PHC nurses would also be sought, as previous research had focused on obtaining the views of one party, for instance, those of PHC nurses (Gerrish, 1998) or carers (Katbamna and Bhakta, 1998). The decision to be as inclusive as possible in terms of recruiting different types of carers to the study proved beneficial as the process enabled me to obtain not only the views of different types of PHC nurses but subsequently, also, the views of different types of managers. The design therefore enabled complex and sensitive issues to be addressed from different perspectives and levels and importantly, highlighted how institutional racism infiltrated through the National Health Service in a much broader sense. The approach adopted for this study made carrying out the research complex and, at times, difficult. It does, however, add to the originality of the thesis and makes a contribution to the field of PHC nursing knowledge and the minority ethnic carers' literature.

As mentioned in the introductory chapter, the literature was reviewed from different theoretical standpoints. Adopting an eclectic approach to reviewing the literature not only enabled a much wider dialogue with the findings but also enabled a diverse range of issues to be explored which otherwise would have been limited and restricted had I focused on one particular discipline or subject area. Importantly, the study identified how little influence policy had on carers' day to day caring experiences and how in reality they received little support from PHC nursing services. The varied findings of this study complement and contribute to the existing knowledge base as the study identified not only similarities with previous studies but also new and contrasting evidence.

The specific questions this thesis aimed to address were reported in the introductory chapter and the findings relating to those questions were reported in the earlier results chapters. As demonstrated in the results chapters, a number of major issues were identified in this study, many of which are original to this study alone. This thesis therefore makes a valuable contribution to an otherwise under researched area. Table 9 provides examples of areas of *originality* emanating from this research study not previously documented in the associated South Asian carers study (Katbamna and Bhakta, 1998).

**Table 9 : Examples of areas of *originality* identified in the research study**

Carers experiences of caring and support: chapter 6	Carers experiences with PHC nursing services: chapter 7
<ul style="list-style-type: none"> <li>• Coming to terms with disability was episodic and there was continual mourning of the loss of hope or expectations.</li> <li>• Carers turned to alternative forms of therapy or treatment in the hope of cure or improvement.</li> <li>• Carers had additional pressures from the 'wider community' to contend with and had to be seen to be doing all the right things and 'trying out' new found therapies or treatment.</li> <li>• Carers continued to have 'adult' children sleep in the same room as them.</li> <li>• Carers used strategies such as, crying, self-indulgence, adopting different approaches to life, turning to religion to enable them to cope.</li> <li>• Female carers more restricted in their ability to take up the same coping</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulties in accessing information from <i>PHC nursing services</i> resulted in difficulties in caring.</li> <li>• PHC nurses operated a restricted model of 'patient-centred' approach to working which <u>did not</u> fully incorporate or meet the needs of carers.</li> <li>• PHC nurses did not always involve carers from the outset in the assessment process.</li> <li>• 'Ethnic matching' of PHC nurses by carers identified as not being an essential requirement to meet needs.</li> </ul>

strategies.	
<b>PHC nurses experiences with minority ethnic carers: chapter 8</b>	<b>A management perspective: chapter 9</b>
<ul style="list-style-type: none"> <li>• PHC nurses did offer telephone support.</li> <li>• Being bilingual and having a 'health' background did not necessarily overcome language and communication difficulties because, for instance, of the complexities involved in interpretation and translation.</li> <li>• PHC nurses deliberately chose not to use the interpreting services provided.</li> <li>• PHC nurses found it frustrating and difficult meeting the needs of Muslim patients.</li> <li>• Holistic assessments focused on the needs of the <u>patient</u>.</li> <li>• PHC nurses stated that the needs of patients were their central concern and said they did what they had to for the <u>patient</u>.</li> <li>• PHC nurses used techniques of distancing, reassessing boundaries and being firm to avoid being 'caught up' with carers.</li> <li>• PHC nurses reported minority ethnic carers as having higher expectations.</li> </ul>	<ul style="list-style-type: none"> <li>• Holistic assessments identified as a means to identify and address carer's needs.</li> <li>• Meeting the needs of the <u>patient</u> identified as main concern.</li> <li>• Ethnic minority carers viewed as having higher expectations.</li> <li>• Inappropriate decision making due to heightened awareness of racism and the need to promote equality.</li> </ul>

**Table 9 continued.**

This chapter will not dwell on the issues identified in table 9, as discussions on these issues have already been reported earlier; rather, the aim here is to provide a synthesis of the major issues arising from the separate results chapters. However, before moving on to this, it is important to give some consideration to the appropriateness of the methodology used for this study.

## **REFLECTIONS ON THE METHODOLOGY**

### **Timing**

This small-scale study was carried out using a pragmatic qualitative approach. The fieldwork took place between October 1996 - August 1997. This inevitably makes interpreting the findings difficult as the Conservative government was still in office when the fieldwork started but the New Labour government had been in office four months before the fieldwork

was completed. Hence, the findings need to be viewed from within this changing political context. Much of the fieldwork thus took place when the Conservative government was in office and the Carers Recognition and Services Act (1995) was introduced not long after, as reported in the earlier review (see chapter three). It was however, the New Labour Government's victory that paved the way for more concrete recognition for carers (see for instance, Department of Health, 1999a). Despite the uncontrollable nature of the historical time frame within which this research study was conducted, it is still possible to draw inferences which relate more specifically to the contemporary policy literature, PHC nursing practice and literature concerning informal caring in general. Evidence from this study, for instance, identified that despite the changes in government and policy for carers, in reality, policy had little impact on carers' day to day experiences of caring, resulting in them feeling over burdened and unsupported not only by family, friends and neighbours but by also by PHC nursing services.

## **Methods**

Reasons for adopting a pragmatic qualitative approach and the use of in-depth interviews as the method of data collection were discussed in chapter five. A discussion on the limitations of the chosen methodology and an examination of methods adopted by previous researchers in the field were provided in the same chapter. The use of retrospective accounts based on in-depth interviews as a method of data collection for this study proved worthwhile as it enabled the detailed perspectives of different groups of participants carers PHC nurses and managers - to be obtained. This paid dividends in that the findings confirmed from three different perspectives that carers' needs continue to be secondary to those of patients and that, despite policy intentions to view carers on a more equal footing with patients, this was clearly not happening within the context of PHC nursing and health service management.

The decision to include different types of carers enabled the perspectives of PHC nurses from different disciplines to be explored and identified how some issues such as meeting the needs of Muslim patients was problematic across disciplines. If the views of PHC nurses from only one discipline been explored, this important finding would have been overlooked. The findings confirm, yet again, the importance of not viewing the needs of different minority ethnic groups as being the same. Operating a system of one service to suit all is clearly inadequate. The findings are in direct contrast to those of Gerrish (1998).

Chapter five provides a comprehensive account of the research methodology and reports how factors influencing the research process, such as addressing sensitive topics and the concept of

power were addressed in practice. Some consideration was also given to factors which might otherwise influence the research. Throughout the study I had to be mindful that these and other factors could potentially influence the results. My own ethnicity was one notable factor. In this study the use of different participant groups further added to the complexity of conducting the research. I do not feel my ethnicity or, indeed, the fact that I was of a different 'caste' to the carers in this study had any negative consequences whilst interviewing carers. Rather, as the accounts in the earlier chapters demonstrate, the interviews with carers were rich and detailed. Further, as reported in Part C of the methods chapter, many carers valued the opportunity to discuss their side of the story with a stranger whom they had no connections or ties with, as it enabled them to speak honestly about their experiences and provide accounts 'from the heart'.

By contrast, as discussed in the methods chapter, my ethnicity undoubtedly influenced the research whilst interviewing PHC nurses and managers, albeit with only a few of them. It is not possible to know whether a white researcher would have encountered similar difficulties or whether they would have obtained similar findings. This type of research would be useful from a methodological point of view. Although interviewing managers on the subject of race, ethnicity and informal carers was problematic, it was clear that some of these difficulties concerned 'loyalties' to their employer and the need to illustrate that their organisation as a whole 'was on top of' issues concerning equality and meeting minority ethnic people's needs overall.

In the early stages of data collection my professional status as a nurse had an impact on the type of information I was able to access. Although it was important that PHC nurses did not view me as threat, the fact that they began to view me as 'one of them' affected the amount of information they disclosed to me, as it was assumed that I would be well aware of difficulties experienced by them or how issues affected them in practice. This resulted in PHC nurses using phrases such as "you know what I mean" which restricted the depth of information I was able to gather. In light of these difficulties, I refrained from further disclosing my nursing background to PHC nurses, as discussed in Part C of the methods chapter.

In summary, then, adopting a pragmatic qualitative approach with the use of in-depth interviews as a means of data collection proved beneficial as it allowed the exploration of the participants' perspectives and unearthed issues that otherwise would have been missed had any other approach been used. The evidence generated is rich and clearly demonstrates and supports carers' claims of being unsupported by PHC nursing services because of their

‘patient-centred’ approach to working. Moreover, the evidence illustrates in detail the complexities involved in researching minority communities and how the process is not as simple as often made out in research reports (Burgess, 1984).

### **Generalisability**

The thorough and detailed methodology chapter documents not only the entire research process but also the dilemmas encountered whilst conducting the study. This additional information not only enhances reliability and validity but also strengthens the credibility of the findings. Importantly, as Altheide and Johnson (1994) argue, the analysis presented in this thesis relates only to my interpretation of the situation as I saw it. The area being studied was under researched, hence it is suggested that further research is still needed which either supports, complements or lends further insight into this subject area.

It is acknowledged that it cannot be claimed that this small-scale pragmatic study enabled wide-scale generalisable findings to be obtained. However, it has been argued that if the sample is well defined, then it can be generalised to the population at large (Hinton, 1987 in Carr, 1994). My own view is that, given the methodology adopted and research questions to be addressed, it is possible to draw theoretical inferences which relate more specifically to the population of minority ethnic informal carers and more broadly to PHC nursing. This is important, as this study was by nature largely exploratory; hence, one of the aims of this study was to make recommendations for practice. This has been done by interweaving the literature and the findings to identify areas for future research. It is acknowledged, however, that as this study obtained only the views of one community of informal carers, it does not provide all the answers.

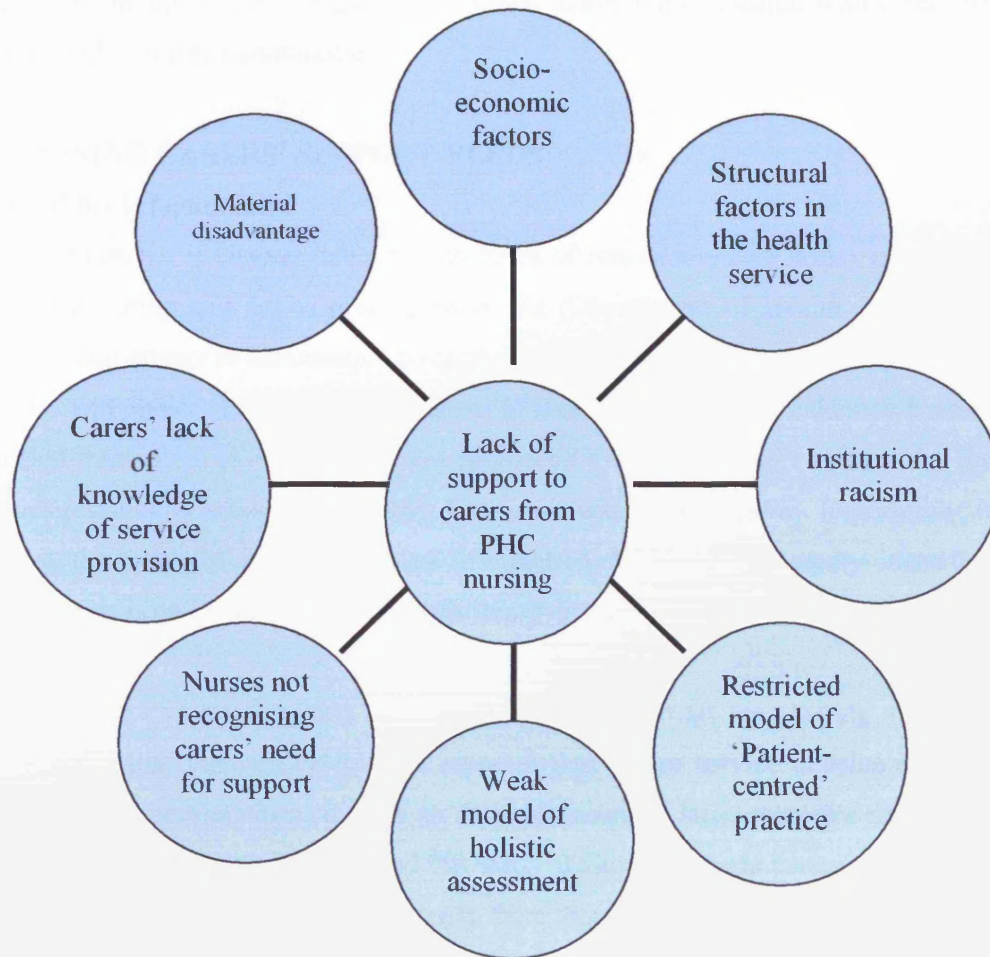
### **REFLECTIONS ON THE RESULTS**

We now move on to the conclusions relating more specifically to the results chapters. As described in table 9, there were a number of new issues to arise from this study, some of which were pertinent to individual chapters alone; others cut across another one of the results chapter whilst some issues cut across the three main results chapters.

This final chapter concentrates upon key issues identified across the main results chapters - addressing carers’ support needs, inadequacies of the patient-centred approach to caring and holistic assessments, and institutional racism - and fits these and the other issues into a tentative theoretical model explaining Gujarati Hindu carers’ lack of support. This section

also relates findings to more recent policy development that has occurred since the fieldwork for this project was carried out.

### **TOWARDS A MODEL EXPLAINING LACK OF SUPPORT FOR GUJARATI HINDU CARERS**



**Diagram 1. Model explaining lack of support for Gujarati Hindu carers**

The current study has indicated a number of factors that, acting together, seem to explain why Gujarati Hindu carers largely felt unsupported by primary health care nurses. First, there were the socio-economic factors and carers' general material disadvantage that made their role more difficult. These are generic social issues that the health service and its practitioners cannot address directly but which need to be acknowledged when developing and delivering services. Secondly, there was carers' lack of awareness about service provision, coupled with PHC nurses' lack of recognition of the need for support, especially emotional support.

‘Patient-centred’ practice and a weak model of holistic assessment, compounded by communication barriers, made up the third set of factors, while the broader influences of institutional racism and structural issues in the health service were the fourth. Together these four sets of factors served to disadvantage carers. While some of these might also be experienced by white carers, others would not. This summary theoretical insight, derived from the evidence generated by this study, is shown in the model in diagram 1. The explanatory value of the model could be explored in future, larger scale research with carers from both majority and minority communities.

## **ADDRESSING CARERS’ SUPPORT NEEDS**

### **The need for information**

As reported earlier in chapter three, a main thrust of community care policy is to enable carers to continue caring and not to give up their role (Department of Health, 1989). Policy also stipulates that access to information to help carers in their caring role and to make informed decisions and choices is crucial (Department of Health, 1999a). Yet, evidence from this study identified that access to information was problematic for carers and confirms the findings of previous research (Cameron et al, 1988; Katbamna and Bhakta, 1998). Importantly, however, although the issue of inadequacies in information has been repeatedly identified in the literature, this is an issue that still warrants improvement.

As reported in chapter five, this study was carried out in an area having a large minority ethnic population. Pharoah (1995) has reported that where service development occurs for minority ethnic communities, it does so in areas having a large minority ethnic population. One might have expected, then, to find the needs of Gujarati Hindu carers in the current study to have been well catered for. The evidence from this study demonstrates that Gujarati Hindu carers’ need for information was for ‘basic’ general information and information that could have been provided by PHC nursing services: for example, the need to know what is wrong with the cared for person, the need to know how to care and the need to know which services are available and how they can provide support. While information concerning diagnosis and prognosis would usually fall within the remit of a doctor, the type of information sought from carers in this study concerned information about how certain illness or diseases might affect someone, information which PHC nurses could have easily passed on.

This is important, as some carers in this study did not even know what was wrong with the cared-for person, and were therefore ‘caring in the dark’. Unlike previous research (Katbamna and Bhakta, 1998), this study identified that adjustment to disability was episodic and many

carers had never fully adjusted or come to terms with disability. It is not unreasonable to suggest that this new finding was closely associated with carers' inability to access information.

Many carers had limited knowledge about the roles of different PHC nursing services and how they could support them. This difficulty could perhaps be overcome by the use of video tapes describing the role of PHC nurses loaned to carers by PHC nurses on the initial visit.

In the context of this thesis, it is plausible that carers may have turned to PHC nurses for information, as the PHC nurse was probably the professional person with whom they had most contact. Yet, workload pressures resulted in PHC nurses using strategies to avoid being caught up with carers. As a result carers felt unsupported by PHC nursing services.

PHC nurses, by and large, used interpreters only for the initial assessment. It may be more beneficial to use interpreters on a staged basis or at least more than once. Although a lot of ground would be covered during an initial assessment, if carers had any questions, they would probably only come to light after the PHC nurse and the interpreter had left the carer's home and usually only after the carer had experienced some of the associated 'costs' of caring. It is acknowledged that access to interpreting services for PHC nurses may have resource implications for health service managers; however, if carers' information needs are identified early and carers are put in the picture about roles and responsibilities of PHC nurses, for instance, the long-term gains could outweigh the initial costs. Carers were not asking for changes to the entire workings of the National Health Service to be made; rather, their needs were small and could be accommodated within existing practice.

Inability to access appropriate information either verbally, translated or in another format caused carers difficulties, unnecessary anxiety and confusion. There was evidence that PHC nurses were not as proactive as they might have been in terms of sourcing information or in sparing the time to explain things to carers; many even lacked knowledge about which services were available locally to support carers. The findings are contrary to policy (Department of Health, 1999a), which suggests that PHC nurses should be knowledgeable about local sources of support for carers. Moreover, leaflets have been published by Carers UK, which were funded by the Department of Health, and British Gas jointly on carers rights, benefits and breaks in an easy to use format. These leaflets would be accessible to PHC nurses or at the very least PHC nurses could inform carers that these leaflets are available through the Carers UK organisation. Recent policy (Department of Health, 2006a) also

clearly spells out the need to strengthen relationships with both users and carers to offer meaningful choice and person-centred values. This suggests that PHC nurses need to provide good information about different interventions and outcomes for instance. This is only possible however, if both users and carers are consulted and informed. One means of supporting carers is through the National Expert Carers Programme (Department of Health, 2006b). However, carers will only be supported if assessments are truly holistic and carers' needs are incorporated.

It would be easy to lay all the blame for carers' inability to access information with PHC nurses especially as the Carers (Equal Opportunities) 2004 Act has been developed further and requires local authorities to develop an information strategy to ensure that carers are being told of their right to an assessment for instance (Department of Health, 2005a). However, obtaining the views of PHC nurses showed that they did not have access to literature, which explained specific conditions or illnesses. Resources which they needed to help them in their day to day practice and resources not otherwise provided by the resource centre, as identified by managers in the study, would be one means of supporting PHC nurses. It is up to health service managers to work together with PHC nurses and local organisations to address how the information needs of PHC nurses can also be addressed. Where systems already exist for promoting knowledge about services there is a need to fill evident gaps. Where such systems do not exist, structures need to be set up, and awareness raising among PHC nurses about where they can access different types of information may be useful.

### **Barriers to communication**

Carers' need for support from PHC nursing services was complicated by language and communication barriers, as also identified in previous studies (Cameron et al, 1988; Murphy and Macleod Clark, 1993; Katbamna and Bhakta, 1998; Gerrish, 1998). However, unlike other studies, this study highlights how barriers to communication caused difficulties for both carers and PHC nurses. Importantly, it was identified that despite nursing philosophy and policy for carers spelling out the need to recognise and value the contribution of carers, ineffective communication resulted in little partnership working with carers and, as a consequence, PHC nurses were naturally in a more powerful position. There was little evidence of partnership working as endorsed by academics such as Nolan et al (1995) especially with regards to the holistic assessment, which PHC nurses claimed they practiced. This issue is discussed in more detail later.

Like other studies (Pharoah, 1995; Gerrish, 1998; Katbamna and Bhakta, 1998) the current one identified inadequacies with interpreting services. However, in contrast to previous

research (Gerrish et al, 2004) which identified that PHC nurses lacked knowledge about the availability of and access to interpreting services, evidence from this study suggests that PHC nurses, despite being well informed, deliberately chose not to use the interpreting services because of concerns about the quality of services and difficulties concerning access.

The evidence from carers illustrates that the use of interpreting services would have been highly appropriate in a number of instances. However, only a handful of carers had experiences of using the interpreting services which would have helped overcome some communication and language barriers. Many carers had limited understanding of the English language and could not express their needs or fully comprehend what they were being requested to do by PHC nurses. Carers therefore resorted to doing what they were told to do, based on their interpretation of what was being asked of them. Their difficulties were compounded by their inability to access information.

Evidence from PHC nurses identified that barriers to communication caused considerable difficulties in practice for them, especially in terms of giving advice and information. Despite the difficulties experienced, PHC nurses still had a preference not to use the interpreting services, and therefore resorted to using a variety of strategies to overcome communication barriers. These included the practice of muddling through, making do with available family members and taking other bilingual colleagues on visits with them. The practice of muddling through inevitably questions how far carers can be expected to understand and follow the advice given by PHC nurses, especially when they are only able to make sense of a small portion of a conversation. Further, the use of family interpreters has been widely criticized in a number of previous studies (Gerrish, 1998). In this study PHC nurses 'made do' with family interpreters based on their assessment of whether it was acceptable practice or not, given the situation they found themselves in at the time. The practice not only undermines carers' rights to access an interpreter (Department of Health, 1999a) but also prevents carers from making an informed choice in the decision to use an interpreter. This is important because, although carers may have called upon their neighbours to overcome communication difficulties, it is probable that this was done out of necessity to help the PHC nurse as opposed to a desire to share their health problems with their neighbour, especially given that carers were reluctant to ask for help and support from family, friends or neighbours because of concerns about gossip. Lastly, the use of bilingual colleagues to interpret imposes a situation upon them where they cannot refuse to help their colleague and then end up being overburdened with their own workload.

Overall, PHC nurses deliberately chose not to use interpreting services, a view also endorsed by some managers for the reasons mentioned earlier. Strategies need to be developed to address some of the shortfalls with the interpreting services. One way forward could also be to 'loosen' the criteria of when an interpreter can be used by PHC nurses as opposed to limiting access to initial assessment visits only. In addition, health service managers and PHC nurses need to work collaboratively with the interpreting services to improve upon the areas where deficiencies were reported. This could also involve the services operating on a more flexible basis perhaps by having an out of hours service, by the development of an 'on call' system. Names and contact details of those willing to interpret out of office hours should be made available, either through a central location or via Trusts where PHC nurses are based. The recent announcement by NHS Direct which provides a 24 hour telephone health advice and information service that it will now also be providing a telephone interpreting and translation service for its callers (NHS Language and Translation Framework, 2004) is clearly a great leap forward in terms of meeting the language and communication needs of minority ethnic patients and carers. It is up to managers and PHC nurses now to 'try out' this new service and accept that changes in practice are sometimes necessary. An important new finding emanating from this study is that being bilingual and having a 'health' background did not necessarily overcome all communication difficulties, particularly when it involved discussing issues around learning disabilities and mental health, as commonly used words or phrases to described therapy or conditions did not exist or PHC nurses were unsure how to explain things as they were not familiar with the words. As suggested earlier, further research to identify how, for instance, mental health conditions are explained by professionals in the South Asian countries is needed and the findings adapted and implemented here.

In contrast to previous research (Gerrish, 1998), this study identified that PHC nurses and managers both believed that the expectations of minority ethnic carers of what PHC nurses could do for them were higher than those of white carers. Communication and language barriers and inability to access information only added to this perception. As demonstrated earlier, it was not that carers had higher expectations, but their lack of understanding and lack of awareness about how the national health system and social care system operated resulted in PHC nurses and managers believing they had higher expectations.

Barriers to communication resulted in poor relationships between carers and PHC nurses. Coupled with evidence from the earlier chapters, it is not unreasonable to suggest that support for Gujarati Hindu carers from PHC nursing services was compromised. If PHC nursing

services aim to meet carers' needs they need to appreciate the carer's perspective and address their communication and information needs.

It is suggested that further study is needed to assess whether white carers, who would not experience the same communication difficulties, would be disadvantaged in the same way as minority ethnic carers.

## **INADEQUACIES OF THE PATIENT-CENTRED APPROACH AND HOLISTIC ASSESSMENT IN MEETING THE NEEDS OF INFORMAL CARERS**

The earlier review identified the importance of meeting carers' needs from both a policy and PHC nursing perspective and how little research has been done in this field previously. The importance of a patient-centred approach and the use of a holistic assessment to identify need as being crucial to the delivery of high quality care were also reported. By interviewing, in-depth, carers, PHC nurses and managers, this study breaks new ground as inadequacies in meeting the needs of carers have been identified from three different perspectives, an approach neglected in previous research with minority ethnic carers.

Firstly, there was evidence that the broader influences of policy did have an impact on the way PHC nurses practised. The NHS and Community Care Act (1990) for instance, saw their caseloads increase not only in terms of numbers but also in terms of the complexity of the cases they had to deal with. Moreover, structural difficulties made it difficult to meet the needs of patients. Meeting the needs of carers was viewed as being an additional burden which they felt that they did not have the resources to meet. This view was endorsed by management. However, as evidence from the carer chapter demonstrates, meeting carers' basic needs would not have required a huge amount of financial resources; rather a shift in attitudes and changes in the way in services were delivered would ensure that carers' emotional needs, at the very least, were addressed. As evidence from chapter seven shows, carers had a definite need for this type of support, in addition to practical support. Female carers were certainly the most disadvantaged, as a number of them were isolated and could not understand or express their needs. In 2001, the Department of Health announced that it would provide £300m injection of funding to address the issue of 'bed blocking' as patients were waiting to get into and out of hospital. As a consequence there was a national drive for the early discharge of patients into the community. The subsequent Community Care (Delayed Discharges etc) Act, 2003; made particular reference to taking carers needs into consideration where hospital discharge processes was concerned. The Act made clear that 'Where the carer has asked for an assessment, the social services authority must assess and,

after consultation with the NHS body, determine what services it will provide for a carer when the person they care for is ready for discharge'. There are several implications here for carers, firstly, it may result in PHC nurses having even less time to address carer needs as the turnover concerning their caseload may increase further. Indeed, Holzhausen (2001) in a recent survey reported that out of 2215 carers, 45% of carers reported that their ideas and concerns were not taken into consideration and that they were not involved in the discharge planning process. Further, although there are a number of potential benefits of early discharge services, such as reduced admission rates, carer satisfaction is reported to be lower (Holzhausen, 2001). Importantly however, where minority ethnic carers are concerned, they may find themselves in a situation where they are not only unable to request an assessment because of language barriers, but are also unsupported because their needs have not been taken into consideration. This is important given ultimately, it will be the carer who will be doing the caring.

However, policy alone cannot be singled out as the root cause of carers being unsupported. Rather, as evidence from the earlier chapter demonstrates, the use of a restricted model of the patient-centred approach and inadequacies in the way in which the holistic assessment was carried out resulted in PHC nurses being less sensitive to the needs of carers than they perhaps could have been, resulting in carers feeling and being unsupported.

The earlier review (chapter three) argued that the professional ideology of patient-centred care as promoted within nursing is one in which carers are considered partners and that the use of holistic assessments should ensure that carers are involved in the assessment and planning of care (Nolan et al, 1995). However, evidence from this study identified that PHC nurses operated different versions of both the patient-centred approach and holistic assessments to that portrayed and promoted within nursing literature. This was despite partnership with carers being central to nursing philosophy. The evidence from this study was obtained from three perspectives, not carers alone, and each group provided further clarification and confirmation that carers' needs were, indeed, secondary to those of the patient.

While practice was not observed directly, interviews from three perspectives confirmed that meeting the needs of the patient was central to PHC nurses' day to day practice. This study therefore makes a unique contribution in understanding PHC nurses' views about carers and identifies how they operated. Despite having some knowledge and insight about issues affecting carers, PHC nurses did not practise the patient-centred approach, as promoted in the

literature (McCormack, 2004). There was also little evidence of recognition, trust and respect for carers as suggested by Kitwood (1997 in McCormack, 2004).

Although there was evidence of carers being involved in the holistic assessment process, much was dependant upon on the situation at the time and the discretion of the assessing PHC nurse. Moreover, carer's involvement was largely in connection to the needs of the cared-for person, not to identify and address their own needs. PHC nurses and managers both identified the holistic assessment as the means to identify and address carers' needs but, in practice, these needs were rarely addressed within the holistic assessment. The study illustrates that both managers and PHC nurses knew that the holistic assessment was the best tool by which to incorporate and identify carer's needs, yet, it was also accepted that the patient was to be the priority and carers' needs were always likely to be secondary to those of the patient. An effect of this method of practising was that carers were disadvantaged because, for instance, they had little say in how or what needed to be done. Rather, PHC nurses designed care-plans and laid the foundations of what needed to be done and by whom with little involvement from carers. This approach to practice serves to undermine carers further as it is assumed that the assessment as carried out by the PHC nurse and the strategies needed to meet needs as devised by them are prudent, effective and without failure (Cox, 2000, p184). If carers' needs are to be truly met, it is essential that PHC nurses begin to see carers as partners and incorporate meeting their needs into their day to day practice. There also needs to be a shift from viewing meeting the needs only of the patient as being central to nursing practice. Since the data were collected for this study, the National Service Framework for older people (Department of Health, 2001e) introduced the single assessment process (SAP) to be implemented locally from the year 2002. It was designed specifically to enable health and social care professionals to work together to deliver better services to avoid duplication of assessments. With information being collated and stored in one jointly shared file. This included information such as basic personal information, contact information and specialist assessment information such as occupational therapy assessment or carer assessment information. How far, the SAP has been effective in terms of meeting the needs of minority ethnic patients and carers' remains to be explored more fully.

Managers too, need to accept that meeting the needs of informal carers is part and parcel of health service duty. A recent improvement leaders guide (NHS Institute for Innovation and Improvement, 2005) for instance, gives clear guidance to managers in terms of the tools and techniques that can be applied in order to involve patients and carers in every aspect of service improvement. Previous research (Gerrish, 1998; Worth, 2001) identified that when practice is observed, behaviour is different to that reported verbally. Gerrish (1998) reported

that practice was not affected by expressed ethnic stereotypes and Worth (2001) that district nurses, although verbally claiming to take account of patients' social needs, paid little attention to them when observed. Further research is needed to assess whether observation of practice would result in carers' needs being addressed and incorporated into practice; to provide further clarification of PHC nurses' and health service managers' interpretation of the concept of patient-centred care and holistic assessments; and to assess their interpretation of who the responsibility of meeting carers needs should 'belong to'. This is important because, although policy may have spelled out the duties of health services in meeting carers' needs, evidence from this study suggests that there is some way to go before it becomes a reality, not only within PHC nursing but also within health service management. The findings of this study complement those of Simon and Kendrick (2001) who reported that general practitioners and district nurses saw themselves as providing only a reactive role as opposed to being proactive in terms of supporting carers. Further, 32 per cent of district nurses reported that it would be impossible to provide proactive care.

It remains to be seen what impact the recent combined policy guidance (Department of Health, 2005a) has on carers support needs especially as one of its principle recommendation is that of improving cooperation between authorities and taking carer needs into consideration when planning services. Further, it is suggested that 'hidden' carers also need to be reached and carer assessments must now include whether the carers wishes to work or not, and whether the carer wishes to participate in any training or leisure activities.

If policy recommendations are to become a reality, it is up health services managers to develop strategies and implement changes. It will also require a shift in attitudes from all involved in delivering care to patients to achieve a situation in which carers' needs are incorporated in to day-to-day practice.

Since the Labour government came into office, the nursing profession overall has gained recognition and become more empowered in a number of areas. The establishment of primary care groups and trusts within primary care (Department of Health, 1997) for instance, witnessed PHC nurses taking on new roles in assessing the health needs of the local community and being involved in purchasing services to address those needs. PHC nurses now have the opportunity to play a greater role in decision making, and their roles are changing in light of developments such as NHS walk-in centres, NHS direct and the 'Expert Patients' Programme. One of the aims of the NHS Plan (Department of Health, 2000) is to reduce inequalities and PHC nurses are seen to have a role here. The Plan, for instance, made

clear that power and resources would be devolved to front line staff who deliver care, thereby enabling PHC nurses to be innovative and make changes for the benefit of the local communities they serve. The importance of working with the local communities is emphasised, as it is recognised that health inequalities are part of a pattern that often combines low income, poor health and poor access to services (Department of Health, 2003), all issues that affect minority ethnic carers. PHC nurses are ideally placed to focus their efforts on prevention and tackling inequalities. Indeed, policy and guidance (Department of Health, 2001, Department of Health, 2002) talk about how PHC nurses can be involved in providing better quality care, how they can involve patients and carers in that care, how they can engage with the local community and, importantly, their role in reducing inequalities by focusing on priorities such as reducing death rates and addressing issues such as stigma.

The current study served to highlight the inadequacies of both the patient-centred approach and the holistic assessment in addressing inequalities. Rather, it appears that the 'inverse care law' operates as access to services for carers was restricted due to communication and language barriers, and compounded further by their caring circumstances and the socio-economic and general material disadvantaged experienced by them.

The findings from this study are also far removed from the policy intentions of enabling carers to feel empowered and in control and from the philosophy of nursing promoting partnership with carers and relationships based on equality. Moreover, although holism is promoted as an approach to the delivery of care in which nurses comprehensively assesses the patient by involving significant others, and as appropriate in subsequent stages (Ham Ying, 1993; McCormack, 2004) evidence from carers and PHC nurses in this study identified that this was not how PHC nurses practised and carers' need did not form part of the holistic assessment.

The findings demonstrate that Gujarati Hindu carers were not supported by PHC nurses as well as they might have been because there was little flexibility in the way PHC nurses practised and because they focused their attention on meeting the needs of patients alone. Importantly, management tacitly accepted this method of practising. Further research is needed to identify whether incorporating the needs of white carers into day-to-day practice is just as problematic for PHC nurses or not and, if not, why not. For instance, can the difficulties experienced by PHC nurses all be put down to cultural and linguistic barriers?

take this on board and acknowledge that providing the same experience of choice will not work as different people will need different support (Reid and Phillips, 2004). One means of doing this is through effective collection of information on ethnicity, for instance, through ethnic monitoring and utilising of that information to ensure that services are tailored to meet the needs of local people.

This final section looks at the workings of institutional racism and how it served to leave minority ethnic carers unsupported by PHC nursing services. The earlier review (chapter two) identified that institutional racism encompasses two themes: ignoring difference and diversity, and misrepresentation of needs (Atkin, 2003).

The table below provides examples of these themes as identified in this study.

**Table 10: Examples of institutional racism identified in this study**

IGNORING DIFFERENCE AND DIVERSITY	MISREPRESENTATION OF NEEDS
<ul style="list-style-type: none"> <li>• Information and communication needs not met.</li> <li>• Lack of involvement in the holistic assessment.</li> <li>• PHC nursing services provided on a basis of the same service for all.</li> <li>• PHC nurses feeling ill equipped to meet needs</li> </ul>	<ul style="list-style-type: none"> <li>• Evidence of myths such as ‘they care for their own’.</li> <li>• Cultural views used by PHC nurses as a basis to understand lack of compliance</li> <li>• Access to support from PHC nursing services dependent upon discretion of the PHC nurse.</li> </ul>

Difficulties in accessing information, communication barriers and carers not being involved in the holistic assessment are all issues which were influenced by institutional racism in one way or another. As an in-depth discussion of these areas has already been documented, this section will concentrate on highlighting the consequences of institutional racism for carers by focusing on the remaining examples as reported in table 10. As reported in chapter eight, there was evidence that some PHC nurses held views which suggested that the one service equates to an equal service for all (Atkin, 2003) and consequently delivered their services based on an ethnocentric approach. PHC nurses provided the same type of service for everyone and thereby failed to engage with difference. Moreover, using Macpherson’s (1999) definition of institutional racism - whereby institutional racism can be seen or detected in processes, attitudes and behaviours which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping, which disadvantage minority ethnic people (para.6.34) - leads us to question whether PHC nurses were unwitting/ unintentionally being ‘institutionally racist’ when they deliberately excluded carers in the assessment process, and chose not to make use of the interpreting services.

## **THE BROADER INFLUENCES OF INSTITUTIONAL RACISM**

Addressing institutional racism is now central to the government's objectives. Indeed, under the Race Relations (Amendment) Act, the NHS has a legal duty to improve services for minority ethnic patients and carers. In 2004, Sir Nigel Crisp, published the Race Equality Action Plan for the NHS. It stated that the health service must give greater prominence to race equality in terms of both leadership and tackling equality and diversity issues in order to improve health. The need to focus on chronic diseases where morbidity is high and addressing health inequalities was made clear. PHC nurses are therefore ideally placed to involve minority ethnic patients and carers in service improvement for instance, by seeking their views about how services could be improved and asking them what type of support they would like from PHC nursing services. More recently, the Department of Health has published its 2005-2008 race equality scheme, which focuses on race equality in designing and delivering health and social care services. Again, there is a clear message that minority ethnic patients and carers need access to information in order to make informed choices about their health and health care. Translated information is also available through the patient information bank. It is up to managers to provide training and support for PHC nurses to access this information and encourage them to pass information onto families.

Moreover, improvements in the health of minority ethnic patients and carers will only come about if institutional racism is tackled and if PHC nurses change the way in they currently practice. Differences and diversity need to be recognised and welcomed. Managers will thus have to ensure that PHC nurses are competent in cultural awareness issues and have the skills to meet the needs of a diverse population.

A fundamental part of improving health concerns understanding what is happening to you when you are ill, especially in relation to mental health as mental illness causes distress and not knowing what is happening because of language issues makes it worse (Reid and Phillips, 2004). NHS walk in centres have also now been developed to supplement the work of general practitioners, PHC nurses could direct minority ethnic patients and carers to this new service to ensure that they are able to get support when they need it most.

As part of NHS drive to improve services overall, it has made a commitment to offer greater choice to the public. It is essential that language issues be addressed if minority ethnic patients and carers are to be involved in choice of service provider for instance. Evidence from this study identified that minority ethnic carers did want to be involved in the decision making process. Others have also reported that the experiences of minority ethnic people of bureaucracies making decisions for them, of telling them what is best for them, has not delivered them equity (Reid and Phillips, 2004). It is essential that managers and PHC nurses

This definition also leads us to question how seriously the notion of tackling institutional racism is taken on board by health service managers, given that they too were in favour, for example, of using in-house staff to interpret and restricted use of interpreting services to initial assessments only.

Many PHC nurses reported feeling ill-equipped to meet the needs of minority ethnic patients and families, again bringing into question the importance managers placed on ensuring that PHC nurses had access to appropriate training to meet those needs. This is important because, as documented in chapter eight, although PHC nurses had some knowledge and insight into minority ethnic culture, there was evidence of confusion, with nurses associating cultural beliefs with lack of compliance when lack of understanding due to communication barriers may have been a significant factor.

A consequence of being ill-informed is that myths concerning minority ethnic carers continue to spread and regenerate. It was certainly the case that there was a widely held belief among PHC nurses that minority ethnic carers were well supported because of the extended family. However, as demonstrated in chapter one, household structures are changing (Modood et al, 1997) along with the views and attitudes of younger generation South Asians towards caring. Moreover, as argued by Ahmad (1993) the assumption that minority ethnic people are well supported because of the extended family is far too simplistic. It is, then, perhaps not even the real issue. As Atkin and Rollings (1996) argue, '[t]he assumption that extended South Asian families have the necessary material, emotional and social resources to cope with chronic illness, with limited professional support is at best misguided and at worst racist denial of their support needs'. These types of views further perpetuate beliefs and reinforce negative stereotypes about minority ethnic carers and deprive carers of their rights to support from PHC nursing services, especially as PHC nurses used their own discretion in determining which carers they supported or not. The findings mirror those of other studies (Lipsky, 1990; Twigg and Atkin, 1994).

Both PHC nurses and managers also strongly believed that minority ethnic carers had higher expectations in terms of the support they received from PHC nursing services. Yet, as demonstrated earlier, many carers lacked knowledge about the roles of PHC nurses and how they could be supported by them. At the same time, PHC nurses were not as proactive as they might have been in promoting their services and providing information to carers that would have provided them with information about how they could have been supported and whether the PHC nurse was the right professional to approach. This resulted in a situation where carers were left uninformed and PHC nurses and managers viewed all minority ethnic carers in the

same light – as having higher expectations compared to white carers. The evidence demonstrates how PHC nurses' own views about minority ethnic carers coupled with structural factors, often beyond the control of PHC nurses, contributed to carers not being supported by PHC nursing services. More importantly, these views were also shared by managers.

The evidence from this section illustrates how the wider influences of institutional racism served to disadvantage carers in this study in their ability to access support from PHC nursing services. Moreover, it illustrates how when difference was recognised, it only served to further disadvantage carers (Atkin, 2003), because linguistic needs were not adequately met, cultural views confused and religious needs found to be too difficult to meet in practice. However, it has to be remembered, as reported in chapter four, that there are also many similarities between minority ethnic carers and white carers. Carers' experiences of caring and the costs incurred are, for instance, very similar to those of white carers. Similarly, although ethnicity is reported to be a contributory factor in accessing services, evidence also suggests that if services are improved generally, this can often improve support for minority ethnic populations at the same time (Ahmad, 1993).

## **RECOMMENDATIONS FOR POLICY, PRACTICE AND RESEARCH**

This study, like others, illustrates the urgent need to take carers' issues forward, particularly when those carers experience other aspects of disadvantage. Although the research was carried out in a predominantly South Asian area, services were still not able to meet needs. If changes are to come about, services will need to be provided so that they are not only accessible but equitable and responsive to the needs of the population being served.

Throughout this thesis the deficiencies and shortfalls in meeting carers' needs have been highlighted and ways in which policy has failed to meet carers' needs have also been reported. Recommendations for policy, practice and research have also been made throughout. These will not be repeated here; rather a summary of the main issues concerning policy, practice and research is provided.

### **Policy**

Although policy now is beginning to take carers' issues more seriously (Department of Health, 1999a), evidence from this study illustrates the many shortfalls in terms of turning the rhetoric of policy into reality. The most notable areas in need of improvement concern:

- The need to consider carers' issues as a health service responsibility.

- The need to provide information and improve communication.
- The need to recognise and value the contribution of carers from a PHC nursing perspective.
- The need to give consideration to the disadvantage experienced by minority ethnic carers in terms of access to services, how material and socio-economic circumstances can affect caring and how factors such as race and ethnicity serve to further disadvantage carers.
- The need to tackle institutional racism.

### **Practice**

A shift in attitudes and working is needed so that carers become part and parcel of day-to-day practice. Meeting carers' needs should not be viewed as an additional task, rather accepted as a PHC nursing responsibility. PHC nurses have an obligation to provide an equitable service. This cannot be achieved if carers' needs are ignored. Moreover, as carers had limited awareness about who did what, it is imperative that PHC nurses act as gateways to other service providers. Both initial and subsequent training are key issues here, but so is the support of those who manage PHC nursing services.

### **Research**

Evidence from this study suggests that the appropriateness of the patient-centred approach and holistic assessments is questionable in meeting carers' needs. It was not the original intention of this study to address these issues, as the research was, by nature, largely exploratory. A larger study is warranted to look at the meanings PHC nurses attached to the concepts of patient-centred care and holistic assessment, to assess the importance PHC nurses attached to meeting carers' needs in practice and to obtain their views about what actually happens in practice.

This study was limited in that it focused only on Gujarati Hindu carers. Further research is warranted which includes other minority ethnic groups and a comparative sample of white carers, to assess the issue of support from PHC nursing services from a carers' perspective and the issue of providing support from a PHC nursing perspective. The inclusion of other groups in the sample will help to identify if, for instance, there are differences between groups in terms of the type of support received from PHC nursing services as well as identify the areas that are problematic for PHC nurses in meeting any carers' needs. Such research would help to confirm or challenge the explanatory model developed in this final chapter of the thesis.

## APPENDIX 1

### Letter to carers

Dear

I am a postgraduate student at the University of Leicester - Nuffield Community Care Studies Unit. I am currently involved in a study, which looks at the needs of male and female carers from the Gujarati community in Leicester. The study aims to explore the needs and experiences of different types of carers either caring for children or adults with physical, mental, chronic ill health or impairments. In addition experiences if any, with nursing services will also be explored.

Would you be willing to take part in this study which would involve taking part in a taped interview at your convenience?

My identity can be confirmed at the University with Professor Gillian Parker (Head of Department) at the above address.

If you are able to support me with this study I would be grateful if you return the tear-off slip in the pre-paid envelope provided as soon as possible. A payment of £10 will be made to cover any expenses.

Yours sincerely

Mrs Padma Bhakta  
Postgraduate student

-----  
**Name**.....

**Address**.....  
.....

**Telephone No.**.....

(If you wish to take part in the study please could you state a contact number to enable me to arrange an appointment with you at your convenience)

I wish to take part in the study [ ]

શ્રીમાન / શ્રીમતિ, .....

હું લેસ્ટર યુનિવર્સિટીના નફિલ્ડ કમ્યુનીટી કેર સ્ટડીઝ યુનિટમાં રિસર્ચર છું. અમે લેસ્ટરનાં ગુજરાતી સમાજમાં દરેક પ્રકારનાં કેરરની (દેખભાળ રાખનાર) જરૂરિયાતો વિશે પ્રોજેક્ટ કરીએ છીએ; જેવા કે માનસિક દર્દીઓ, અપંગો અને લાંબા સમયથી પિડાતા માદગી વાળા વ્યક્તિઓની દેખભાળ રાખનાર.

તમે આ પ્રોજેક્ટમાં ભાગ લેવા ઈચ્છતા હો તો તમારું ઈન્ટરવ્યુ તમારી અનુકૂળતાએ લઈ શકીએ ? તમે જણાવેલી બધી માહિતી ખાનગી રાખવામાં આવશે.

મારી પહેચાનની જરૂર હોય તો તમે પ્રોફેસર જીલીયન પારકરનો ઉપરના સરનામે સંપર્ક કરી શકો છો.

તમે આ પ્રોજેક્ટમાં ભાગ લો તો તમારા ખર્ચ માટે તમને ૧૦ પાઉન્ડ આપવામાં આવશે.

તમારી ઈચ્છા હોય તો તમો આ સાથે મોકલેલા કવરમાં તમારું નામ, સરનામું અને ફોન નંબર લખી રવાના કરો તો હું તમારી ઘણી આભારી રહીશ.

તમારી શુભેચ્છક,

પદ્મ ભક્ત  
રીસર્ચ એસોસીએટ

નામ .....

સરનામું .....  
.....

હું આ પ્રોજેક્ટમાં ભાગ લેવા ઈચ્છું છું [ ]  
મારી આ પ્રોજેક્ટમાં ભાગ લેવાની ઈચ્છા નથી [ ]

## APPENDIX 3

### Consent Form

(Carers consent form to contact primary health care nursing staff)

I -----

Of -----

-----  
-----  
-----  
-----

agree to Padma Bhakta to contact the individual nurse who has been caring for me and my family, as part of her study which looks at the needs and experiences of Asian carers, patients, nurses and management.

**Date**

-----

**Time**

-----

**Signature**

-----

**Witness (Padma Bhakta)**

-----

**Consent Form**

**(Carers, primary health care nurses, provider managers and purchaser managers)**

**I** .....

**Of** .....

.....  
.....

agree to participate in the study undertaken by Padma Bhakta. I understand that the study aims to look at the needs and experiences of Asian carers, patients, nurses and purchasers and providers of healthcare.

I agree to take part in an in-depth interview that will be tape-recorded. The material will be treated in the strictest confidence and the identity of any individuals will not be disclosed.

**Date** .....

**Time** .....

**Signature of interviewee**.....

**Witness (Padma Bhakta)** .....

**APPENDIX 5**
**Characteristics of carers that took part in the study**

*Carers Name and arrival to Britain	Relationship	Age Group	**Condition/ Diagnosis of the cared-for person	Type Of Housing And Location	No. Of People Living In House	Car Ownership	Employment Status	Benefits Received	Family Type
Prabha Laxman (1973) Anant Laxman (1973)	Mother Father	40-50	Son (21) /Encephalitis-Mentally And Physically Disabled, double incontinence and no speech	Terraced House Inner City	4	Yes	Full-Time Carers	Attendance Allowance (AA)	Nuclear
Sheetal Soni (1973)	Mother	31-40	Daughter (17)/Cp-Mentally & Physically Disabled, incontinence, breathing problems, asthma, hernia, limited speech	Semi-Detached City	5	No	Pt/Transport	Disability Living Allowance (DLA)	Nuclear
Madhu Gokhani (Born in Britain) Sameer Gokhani (1967)	Mother Father	21-30	Son (18mths (Died)/ AVSD, Quadriplegic, CP, limited sight, hearing and speech.	Terraced House Inner City	3	No	Pt/Clerical Officer Ft/Personnel Officer	AA + DLA	Nuclear
Radha Nayan (1969)	Mother	31-40	Daughter (3)/ No Diagnosis? Ld	Semi-Detached City	4	No	Pt/RGN	Mobility Allowance And Income Support And Severe Disability Allowance	Nuclear
Shanta Hari (1963)	Mother	51-60	Son (27) Mentally &Physicallyhandicapped, epileptic and incontinence	Terraced Inner City	5	No	Full-Time Carer	Disability Allowance	Nuclear
Gopal Mithun (1970)	Husband	65+ (80)	Wife/Stroke/ Shaking, blood pressure and incontinence	Semi-Detached (Son's) Inner City	5	No	Full-Time Carer	Disability Allowance	Extended

\* all names are fictitious \*\* as described by the carers Key: cp/cerebral palsy; LD/learning disability/m-in-law/mother in law; f-in-law/father in law; ns/not stated; pt/part time; ft/full time; NA/nursing assistant

**APPENDIX 5**
**Characteristics of carers that took part in the study**

*Carers Name	Relationship	Age Group	**Condition/ Diagnosis of the cared-for person	Type Of Housing And Location	No. Of People Living In House	Car Ownership	Employment Status	Benefits Received	Family Type
Priya Thakrar (1972)	Wife	51-60	Husband/Hearing Voices	Terraced Inner City	2	No	Full-Time Carer	Disability Allowance	Nuclear
Alisha Ram (1981)	D-In-Law	31-40	M-In-Law/Stroke Daughter (6) /Leukaemia/ F-In-Law/Elderly	Detached House County	7	Yes	Pt/Check Out Operator	Carers Allowance	Extended
Shivam Ranchord (1962)	Father	51-60	Daughter (15) Cp/Epilepsy	Terraced Inner City	5	Yes	Bus Driver	DLA and Invalidity Benefit	Nuclear
Madhuri Kishen (1984) Pritesh Kishen (1984)	Daughter/Son	21-30	Parents: M-Stroke/Epilepsy/Diabetes And Father / ?Ld, Mental Health Problems	Council/Semi-Detached Inner City	4	No	Pt/Na Ft/Crisp Packer	DLA and Carers Allowance	Nuclear
Vikesh Anand (1975)	Husband	41-50	Wife/Stroke/ Epilepsy	Town Inner City	4	Yes	Full-Time Carer	DLA and Incapacity Benefit	Nuclear
Mital Popat (1972)	Son	31-40	Mother/ Depression And Arthritis	Terraced Inner City	7	Yes	Trainee Driving Instructor	Invalid Care Allowance And Income Support	Extended

## APPENDIX 6

### Topic guide: carers

#### *Experiences of caring*

- \* how long have you been caring and how did you become a carer?
- \* what were your thoughts when you first became a carer?
- \* how do you feel about it (caring)

Can you describe your role in caring for your relative on an 'average' day?

- \* are you able to leave the person alone?

Are there certain caring tasks that you alone have to deal with?

Are there any particular things you find difficult to do?

- \* washing and bathing - getting the person ready
- \* getting other things done - housework
- \* getting time to have a rest - sleep

#### *Culture, ethnicity and religion*

It is often said tradition in the Asian community that 'we look after our own' (eldest son cares for ageing parents etc.)

- \* views on this
- \* views about disability

#### *Why do you feel you care?*

- \* love, marriage vows, religion
- \* how would you describe your relationship with the dependent?
- \* if you had the opportunity would you choose to 'stop' caring?

#### *Costs of caring*

Has caring affected you:

- \* health
- \* financially
- \* social
- \* any other costs?
- \* negative/positive effect in your life

Do you feel that your caring role has changed you as a person?

- \* in what ways

#### *Support from others*

Is time an issue for you? why?

Are there any other people who help you in your caring role?

- \* relatives, neighbours, friends,
- \* type of support provided
- \* type of support preferred

***Future***

What expectations did you have for your life

How do you see your life in the future?

- \* do you think your children will care for you?

***Access to services***

Have you have heard of any of the following nursing services

- \* district nurse, community psychiatric nurse, health visitor, practice nurse

What do you know about their role?

Can you describe how you come into contact with the service?

- \* where did you find out about nursing services
- \* did you have access to any written information
- \* type of referral, professional, self-referral, word & mouth

Were there any particular problems in terms of accessing nursing services?

***Experiences of using nursing services***

Can you describe your experiences of using the nursing services that you are in contact with:

- \* what kind of support do they provide?

Did you find the nurse's input was of any benefit to you/dependent?

Have you ever used nursing services but stopped using the service?

Can you describe any instances in which nursing staff have not been as helpful to you as you would have liked?

Do you feel you should be treated '*differently*' because you are Asian?

Have there ever been any occasions when you would have liked to have used the service but didn't? why not

Do you feel that you are able to turn to the nurse if you wanted advice or information?

What do you do before the nurse arrives?

- \* make sure everything is 'neat and tidy' in the house?
- \* why do you do these things?

***Improvements to nursing services***

What are your expectations of the nurse in terms of the type of support she should provide?

Are there any other means by which existing services can be improved?

- \* more information needed: about the roles of professionals?
- \* professionals: education and training?
- \* improve access to services?

How have you found the interview?

Is there anything else you would like to say before we end the interview

### Topic guide: primary health care nurses

#### **Background information**

- \* qualifications (nursing and other)
- \* which country did you do your training?
- \* type of employment (full-time part-time job-share)
- \* employment history (nursing and other- past and present)
- \* any 'important' achievements i.e. awards, scholarship
- \* type of client group (elderly, young , mixed - Asian )

#### **Nursing input and role**

- \* what sorts of things do you normally do on an average day?

#### **Assessment**

- \* how are patients referred to you?
- \* what form of assessment do you use?
- \* are carers/patients consulted in the assessments/care-planning?
- \* how frequently and by whom is the evaluation done?

#### **Relationship with carers**

- \* do you get many self-referrals from carers?
- \* things done for carers

#### **Experiences with minority ethnic carers and patients**

- \* what are your experiences of working with EM carers/patients?  
- are there any particular problems?
- \* views about Asian carers/patients
- \* how do you try and deliver care to EM?
- \* how are non-English speaking patients and carers assessed?  
(are interpreters used? who is used - family, friends, qualified interpreter)
- \* were there any particular issues that come to mind

#### **Experiences of working in a primary healthcare team**

- \* type of relationship with organisation
- \* what are your views about working in such a 'set up'?
- \* how does the team operate usually?
- \* do you feel that PHCT's share a common purpose
- \* differences in what you think your role should be and what the organisation thinks
- \* can you think of any benefits to carers and patients because of the PHCT?
- \* do you feel more supported this way? (how/why not)
- \* do you get opportunities to discuss any problems?
- \* do you feel that PHCT acknowledges the needs of EM carers adequately?
- \* do you feel that you can fulfil your role as a professional adequately?

#### **Training and education**

- \* were 'carers' part of the curriculum ?
- \* were culture, race and ethnicity covered in the curriculum ?
- \* have you ever attended study days/seminars in past 12 months? - ethnicity and culture?  
is funding an issue?
- \* any restrictions resulting in difficulty in getting training
- \* do you have any concerns about meeting PREP requirements?
- \* how do you see your future role ?

#### **Improvements to services**

- \* how do you feel your own needs can be met to help you in caring for EM?
- \* access to information/communication?

How have you found the interview?- Is there anything else you would like to say?

## APPENDIX 8

### Topic guide: provider managers

#### *Background information*

- \* professional qualifications
- \* employment history
- \* role as manager (within hospital/community)

#### *Management and nursing*

- \* your role in relation to nurses
- \* geographical areas
- \* training and support for nurses

#### *Nurses role and ethnic minorities*

- \* nurses role in relation to carers/patients from EM

#### *Employment*

- \* nurse recruitment
- \* any monitoring system?
- \* strategies to encourage and retain minority ethnic staff
- \* any occasions when you specifically employed EM bilingual staff

#### *Quality*

- \* how are standards (quality) of nursing care monitored?
- \* any established published procedures for making complaints

#### *Purchasing of nursing services*

- \* nurses role
- \* impact on nurses role - CC Act, health of nation targets, purchaser/provider split

#### *Relationship with purchaser*

- \* accountability to purchasers
- \* relationship/sharing knowledge- information

#### *Providing for minority communities*

- \* ensuring equality for client/carers
- \* information on what proportion of residents are EM?
- \* meeting local needs (advisory group within the unit)
- \* documents on meeting the needs of EM
- \* type of service provided for EM

#### *Providing for minority ethnic carers*

- \* meeting carers needs
- \* guidance for nurses in meeting carers needs/meeting the needs of minority ethnic carers and their families
- \* review system which monitors the experiences of EM clients/carers
- \* ethnic monitoring - who collects data/why and how is the data used

#### *Improvements in nursing, carer and patient services*

- \* training issues
- \* the way forward
- \* access to services –

#### *Future developments*

- \* predict any changes in management role/nurses role

## APPENDIX 9

### Topic guide: purchaser managers

#### ***Background information***

- \* professional qualifications
- \* employment history
- \* role as purchaser
- \* areas of responsibility

#### ***Management and nursing***

- \* your role in relation to nurses
- \* geographical areas
- \* training and support

#### ***Nurses' role and minority ethnic communities***

- \* nurses role in relation to carers/patients from EM
- \* meeting the needs of non-English speaking clients/carers
- \* any particular nursing demands that are difficult

#### ***Employment***

- \* nurse recruitment - equal opportunity statement requirement
- \* ? any monitoring system
- \* strategies used to encourage and retain minority ethnic staff

#### ***Quality***

- \* how are standards (quality) of nursing care monitored?
- \* complaints
- \* strategies for staff levels

#### ***Management and purchasing of nursing services***

- \* role in relation to community nursing services
- \* impact on nurses role - CC Act

#### ***Relationship with providers of nursing services***

- \* extent and type of relationship with providers of nursing services
- \* criteria used to determine which nursing services will be purchased
- \* establishment levels

#### ***Purchasing for minority communities***

- \* views on policy documents/acts
- \* ensuring equality for client/carers
- \* information on what proportion of residents are EM
- \* meeting local needs met?
- \* policy / documents on meeting needs

#### ***Purchasing for minority ethnic carers***

- \* guidance for nurses
- \* ensuring services are acceptable, appropriate, equitable to all users
- \* links with local community - consultation
- \* use of review system which monitors the experiences of minority ethnic carers/families
- \* system of ethnic monitoring?

#### ***Improvement in nursing, carer and patient services***

- \* training issues
- \* improving access to services
- \* the way forward?

## APPENDIX 10

### Background information: carers

Date:

Time started:

Time ended:

-----  
**Preamble: identify self, purpose of the study, assurance of confidentiality**

### General data

Name of carer.....

Age group 18-20 [ ] 21-30 [ ] 31-40 [ ] 51-60 [ ] 61-65 [ ] 65+ [ ]

Sex male [ ] female [ ]

Religion Hindu [ ] Other (specify).....

Mother tongue Gujarati [ ] Other (specify).....

Preferred language for conducting interview Gujarati [ ] English [ ]

Were you born in UK yes [ ] no [ ]

If no:

When did you come to Britain?.....

Marital status: married [ ] single [ ] divorced [ ] widow [ ] widower [ ]

No. of adults in household .....

Relationship to dependent.....

How many children do you have?.....

How many children live at home with you?.....

How many children live away?.....

Type of housing: detached [ ] semi-detached [ ] terraced [ ] bungalow [ ]

Household tenure: owner occupier [ ] privately rented [ ] council housing [ ]

Household location: county [ ] inner city [ ] city [ ]

Level of education of carer.....

Country where education was received: UK [ ] India [ ] Africa [ ]

other [ ] (specify).....

Is the carer employed: full-time [ ] part-time [ ] not employed [ ]

Occupation (now).....

Occupation (previously).....

Does the dependent live with you? yes [ ] no [ ]

Age of dependent.....

Type of disability or illness.....

.....

.....

Benefits received by carer:

.....

.....

.....

.....

**Example of a 'quick reference profile': carer**

**Sheetal Soni**

- Young mother [31-40] age group caring for 17 year old daughter with cerebral palsy
- Interview in Gujarati and English
- Came to UK in 1973 from Africa
- Lives with husband and two other children –all at home
- Live in semi-detached house which they own in the city
- Big guard around fire. Sat on floor for the interview.
- Works part time now in transport? (did not elaborate on this). Used to work full time in a factory before but had to give it up.
- Receives disability living allowance

**Notes**

Good interview about her experiences of caring and costs. Has to do everything. Talked mainly about the health visitor. Tearful throughout the interview. Said at the end of the interview that the study should have been happened a long time ago. Had to leave the room at one point to compose herself and come back because she was so upset. Community have not been supportive at all.

## APPENDIX 12

### Indexing guide for carers

- 1.0 Experiences of caring**
  - 1.1 personal care
  - 1.2 practical care/support
  - 1.3 difficulties experienced
  - 1.4 cross gender caring
  - 1.5 daughters as carers
- 2.0 Why care**
  - 2.1 lack of choice
  - 2.2 duty/obligation
  - 2.3 religion/culture
  - 2.4 society expectation
  - 2.5 love/feelings/wanting to care/preparing to care
  - 2.6 'paying back'
- 3.0 Caring**
  - 3.1 thoughts/views/feelings about (i.e., giving personal care)/own health/break
  - 3.2 caring for someone else /thoughts about others caring
  - 3.3 rewards
  - 3.4 nothing gained
- 4.0 Attitudes to disability and carers**
  - 4.1 carers attitude
  - 4.2 society attitude
  - 4.3 disability and gender
  - 4.4 relationship /positive
  - 4.5 relationship/negative
  - 4.6 religion/culture/tradition
- 5.0 Coping strategies**
  - 5.1 self reliance
  - 5.2 cry
  - 5.3 religion
  - 5.4 hard/tolerant
  - 5.5 other (anger/work)
- 6.0 Not coping**
  - 6.1 impact on carer
  - 6.2 impact on DP
- 7.0 Future**
  - 7.1 views and thoughts about residential/nursing home care
  - 7.2 concerns about DP
  - 7.3 concerns about carer own future
- 8.0 Impact of caring**
  - 8.1 health
  - 8.2 financial
  - 8.3 social
  - 8.4 personality
  - 8.5 impact on family
  - 8.6 religious views
  - 8.7 career/education

- 8.8 life in general
- 8.9 marriage and personal life
  
- 9.0 Support for carers**
  - 9.1 immediate families
  - 9.2 relatives/friends/neighbours/carers
  - 9.3 support groups/voluntary organisations/counselling/respice
  - 9.3 views about support
  
- 10.0 Access to Information/services**
  - 10.1 informal sources
  - 10.2 professionals
  - 10.3 organisations
  - 10.4 difficulties because of lack of information
  - 10.5 control of information
  
- 11.0 Experiences of using nursing services**
  - 11.1 positive
  - 11.2 negative
  - 11.3 carers views about nursing/nurses
  
- 12.0 Primary health care services**
  - 12.1 positive experiences
  - 12.2 negatives experiences
  - 12.3 views
  
- 13.0 Improving nursing services**
  - 13.1 access
  - 13.2 information/communication
  - 13.3 training/education
  - 13.4 type of nursing services wanted
  - 13.5 raising awareness in the Asian community about carers
  - 13.5 support for carers/parents (sharing or workload between professionals and carers)
  - 13.6 manager awareness

## **Indexing guide for primary health care nurses**

- 1.0 Nurses role in caring for carers and patients**
  - 1.1 supportive/listening/counselling
  - 1.2 liaison person between other agencies and professionals
  - 1.3 carer and patient advocate
  - 1.4 form filling
- 2.0 Relationship between carers and patients**
  - 2.1 professional/ keeping a distance
  - 2.2 friendly/good relationship
  - 2.3 weigh it up
- 3.0 Assessment**
  - 3.1 patient centred
  - 3.2 joint - patient and carer 'holistic'
  - 3.3 patient then carer
  - 3.4 carer first
- 4.0 Care-planning**
  - 4.1 patient centred
  - 4.2 joint care-plan: patient and carer
  - 4.3 views/do not use care-plans/models
- 5.0 Delivering care**
  - 5.1 patient centred
  - 5.2 patient first - then carer needs
  - 5.3 patient and carer needs considered jointly
  - 5.4 deserving and non-deserving cases
  - 5.5 based on euro centric model/same for everyone
  - 5.6 individualised
  - 5.7 ethical
  - 5.8 timed visits
- 6.0 Evaluation**
  - 6.1 by the nurse
  - 6.2 with the patient only
  - 6.3 with the patient and carer
- 7.0 Closing cases**
  - 7.1 one or two visits after bereavement
  - 7.2 as soon as it is felt that the carer can cope
  - 7.3 afford to visit?[money, time, staff]
  - 7.4 discharge
  - 7.5 other
- 8.0 Support for nurse [information/advice/emotional]**
  - 8.1 outside organisation: carers centre
  - 8.2 other colleagues
  - 8.3 management
  - 8.4 documents etc.
- 9.0 Inequalities in nursing**
  - 9.1 experiences and views of junior staff
  - 9.2 experiences and views of senior staff
  - 9.3 experiences of part time staff

- 10.0 Caring for minority ethnic carers and patients**
  - 10.1 culture/religious practices/beliefs of minority ethnic communities - nurses' experiences
  - 10.2 nurses positive experiences of caring for minority ethnic communities
  - 10.3 nurses' negative experiences of caring for minority ethnic communities
  - 10.4 nurses feelings about not being able to meet needs
  - 10.5 views
- 11.0 Constraints for nurses in meeting carer and patient needs**
  - 11.1 staffing issue
  - 11.2 time/workload
  - 11.3 referrals
  - 11.4 resources
  - 11.5 communication
  - 11.6 training/ knowledge
  - 11.7 lack of support from management
  - 11.8 relatives not supportive
- 12.0 Collaborative working**
  - 12.1 nurses positive experiences of working within PHCTs
  - 12.2 nurses negative experiences of working within PHCTs
  - 12.3 health and social care divide
  - 12.4 views about phct
  - 12.5 discharge/hospital collaboration
  - 12.6 other agencies
- 13.0 Influence of policy and CC Act**
  - 13.1 changes in role
  - 13.2 workload patterns
  - 13.3 changes in working practice
  - 13.4 nurses views about changes in NHS
- 14.0 Improving services**
  - 14.1 for nurses
  - 14.2 for carers and patients
  - 14.3 PHCT
  - 14.4 research ideas
- 15.0 Other issues**
  - 15.1 job satisfaction
  - 15.2 reaching carers
  - 15.3 personal safety
  - 15.4 difficulties for carers

**Indexing guide for provider managers**

- 1.0 Nurses role**
  - 1.1 patient centred approach
  - 1.2 holistic approach
  
- 2.0 Supporting nurses**
  - 2.1 any problems -come to me
  - 2.2 keeping nurses informed
  - 2.3 consultations with nurses on documents
  - 2.4 clinical supervision
  
- 3.0 Enabling nurses to meet needs**
  - 3.1 interpreting services
  - 3.2 translated information
  - 3.3 staff awareness of local needs and resources
  - 3.4 access to training for staff
  - 3.5 skill mix within the community
  
- 4.0 Experiences and views about minority ethnic communities**
  - 4.1 positive
  - 4.2 negative
  - 4.3 other issues
  
- 5.0 Meeting the needs of minority ethnic communities**
  - 5.1 views about meeting needs: up to carers/pts to tell us what they want/problem pts/lack of awareness
  - 5.2 involving users and carers
  
- 6.0 Impact of policies and CC Act on nurses**
  - 6.1 increased workload
  - 6.2 poor relationship between ssd and nurses
  - 6.3 providing more skilled nursing care
  
- 7.0 Purchasing nursing services**
  - 7.1 historical accounts
  - 7.2 current practice
  - 7.3 relationship with purchasers
  
- 8.0 Primary health care service**
  - 8.1 difficulties for nurses
  - 8.2 difficulties for trusts
  
- 9.0 Equal opportunities/recruitment/policies**
  - 9.1 minority ethnic staff
  - 9.2 ensuring quality [EOP, recruitment, complaints, ethnic monitoring, standards, documents]
  
- 10. Future services**
  - 10.1 suggestions for improving services

**Indexing guide for purchasers**

- 1.0 Expectation of nursing staff**
  - 1.1 assess/discuss/review carer & pt needs
  - 1.2 access interpreters
  - 1.3 keep up to date
  - 1.4 accountability
  
- 2.0 Trusts: expectations and relationship**
  - 2.1 training issues
  - 2.2 providing equitable, accessible services, quality services
  - 2.3 relationship with trusts
  
- 3.0 Purchasing**
  - 3.1 historical outlook
  - 3.2 consultation
  - 3.3 Process and decision making
  - 3.4 finance
  - 3.5 awareness of nursing role
  - 3.6 views about purchasing
  
- 4.0 Purchasing for minority ethnic communities, nurses and carers**
  - 4.1 myths, assumptions and stereotypes
  - 4.2 awareness of needs
  - 4.3 meeting needs
  - 4.4 policies and charters
  
- 5.0 Impact of policies and legislation**
  - 5.1 nurses
  - 5.2 carers and patients
  - 5.3 within primary health care
  
- 6.0 Primary health care teams**
  
- 7.0 Improving services**

**Example of a coded transcript**

**PB:** In our community often, if you're not able to fulfil social obligations then some people have experienced that they've been talked about, I mean do you have any experiences like that?

**PL:** We don't, we don't look at anything like that. We, we don't take to much concern. All we do is just look after our son's needs. [4.1]

**AL:** Those that are understanding are understanding. [4.3]

**PL:** Well they don't actually say it but even if they did we would ignore it. 'Cos for us .. he is everything for us. [4.3/3.1]

**PB:** So have you had any experiences like that, where you've realised that you have been, been talked about?

**AL:** We just turned a blind eye to it. We just don't bother with them. [5.5/3.1]

**PL:** Well we think that, that it doesn't really matter if people do say things like that because we're just not going to bother with it because if we start being concerned about what other people are feeling then we won't be able to care for his needs. Because our health will be affected and if our health becomes affected then we won't be able to look after our son's needs. [5.4/3.1]

**PB:** So you, what you're saying is, that you feel that you yourself have to remain healthy?

**AL:** Yes, we have to stay healthy. Usually between one and three we usually, we tend to keep our telephone off the hook and we try and rest for at least two hours because we have to get up at least four to five times during the night. So for about an hour and a half to two hours we try and sleep. Because our sleep has been disturbed during the night and if we don't sleep during the day then obviously we'll be tired during the night. And we have experience of that. [4.1]

**PB:** And do you feel that there's anything else that has, that has affected your caring role?

**AL:** Well .. well we just look after his needs and, and that's it. Besides that. [4.1]

**PB:** So you feel

**AL:** Well it is our duty to look after him. [2.2]

**APPENDIX 17 : EXAMPLE OF CHARTING USING THE FRAMEWORK APPROACH : Nurses experiences of caring (10.0)**

Nurse's name	10.1 Culture and Religion	10.2 Positive Experiences	10.3 Negative Experiences	10.4 Feelings about not being able to meet need	10.5 Views about minority ethnic carers and patients
	"Asian people are just people that have always looked after their own isn't it" They find its their duty, their sort of custom, if they don't look after them its like they're not doing their job"p6	"Some of them do rely on me because I do open a lot of doors for them...they are so grateful because they have never had any help"p4	washing is so symbolic, you'd be there till Christmas p4  feels like saying to carers "do more"	finds it uncomfortable - its all very light hearted- mimes to try and communicate with patients	ethnic minorities not aware of nurses roles... they obviously get what they need, the more they know the more they demand "many times they just want a natter" p11
	EM want their children to marry - LD Religious beliefs gives them strength, Guru says pray -but we think "surely she's got enough to do"		it takes longer, give back ground, people are always present, confidentiality, having to be descriptive		EM missing out on services - referrals received much later= sometimes it was too late by then
	with the Asian culture their are a lot of beliefs that are quite strange and still quite upheld saying their illness is related to which craft or magic...p6	There was another women who was so eternally grateful to me, it was really pleasant, always provided food and drink and when you walked in the door you're made to feel really welcome"p15	I think people think that because you are a nurse, you are trained in all aspects of nursing... demand much higher/ letting go	language problems - muddle through but very frustrating  Feels 'sorry' for these can't speak any English p29	"I think the need for emotional support is less from us than perhaps an English family who has no community..."p13
	views about family dynamics ....p11 "oh yes oh yes, we have got one man that you can't go to on Friday between 12 and 2 and if you walk in on him praying he won't stop, he totally ignores you and carries on"	"thoroughly enjoy it because they are very polite, <b>they do exactly as they are told!</b> , they will always ask and have the greatest respect for health professionals"	Asian people take to their bed - finds this very frustrating... p14, p15 "They don't ring the doctor, they don't like to bother him but they bother us"		"As far as carers concerned I do find that the Asian families look after their patients a lot better than the English people do... they care basically, with the English people, I am talking about the white British people, a lot of the old people go into old peoples homes. p1
	"more regulated by custom and tradition"  ..you have to wait until they finish praying <b>and</b> you have to take your shoes off		language problems - before she knows it half the neighbourhood was in the house, can't talk about personal issues and nurse finds this difficult Expectations are over and above ..you can't be there for ever and "quite fussy"p7,p8 "They don't think to ring" - appts p5		Good family networkp3 they don't request services p6  more elderly people living on their own  Men could do more p13

### Engulfed carers and 'proper care'

The example below illustrates how some carers felt only they were able to provide 'proper care'. This is how Anant Laxman and Prabha Laxman's described their role:

**Mr Laxman:** So we give him full sponge bath, we get him ready, **proper**, everything. You know, put all his clothes on **proper**, brush, and **completely** get him ready. So it takes us till about 8.30 to get him ready and as soon as they've taken him (day centre) we start to do other things that need doing. So we start working on his bed...cleaning...kitchen...

After 3 o'clock our life starts again. We have to do chest tapping, to do postural drainage on him, **proper** as soon as he arrives.

**Mr Laxman:** Well at the weekend, it is a little bit more relaxing. We tend to get up at 6 o'clock instead of 5 o'clock. We give him his tea and then say about 8.30 we lie him down on the floor and we massage his whole body and then we massage him **completely** and then we give him a shower. What we do is give a salty water shower, so in the bucket we put a little bit of salt in it and give him a **complete** shower and wash so his whole body is relaxed.

**Mr Laxman:** It's just the massage that we do on Saturday and Sunday. The bath is seven days a week. We have to keep him very clean, so in the morning we give him a **sponge bath Monday to Friday**, about 3.30 o'clock we give him a **proper** shower.

**Mrs Laxman:** So that is everyday, everyday, no matter how late it is.

**Mrs Laxman:** ...the massage itself takes us an hour and then bathing for another hour. You know its done **proper**. You know, we bath him, we shampoo his hair and for him, you know, we've kept, especially for him, baby items like shampoo because you know in our shampoo it's got chemicals in it.

**Mrs Laxman:** if he's had a bath and he's been made ready **proper** then usually it takes us at least an hour.

**12 POINT CHECKLIST**

The provider will demonstrate that steps are being taken to improve accessibility, acceptability and appropriateness of services to the minority ethnic population of [Name of town]

Particular attention should be given to the following:-

- (1) Translated materials will be available in the form of leaflets, cassettes and videos which will reflect the needs of the minority ethnic population of [ x x x ] Innovative methods of dispersing information should be implemented, i.e. via appropriate media.
- (2) Sign posting will reflect the ethnic mix of [ x x x ]
- (3) Non - English speaking users will have ready access to trained interpreters with an emphasis in the following service areas:-  
  
Heart specialities, diabetes, renal specialities, haemoglobinopathy services, mental health services, antenatal services, palliative services, child health services, family planning services.
- (4) A non - denominational place of worship will be available in hospitals and day centres for prayer and meditation.
- (5) Catering and dietary services will meet the needs of the minority ethnic population of [ x x x ]
- (6) Provider units will ensure that there are arrangements for complaints and suggestion procedures which are accessible and appropriate to minority ethnic patients and carers.
- (7) Provider units will demonstrate ways in which service delivery and planning has evolved as a result of No. 6.
- (8) Provider units will ensure that client / patient records / careplans reflect cultural sensitivity throughout.
- (9) The provider will ensure the implementation of Race Equality training with on - going monitoring, review and feedback mechanisms.
- (10) The provider will demonstrate that positive action is being undertaken in the recruitment, retention and promotion of staff from the minority ethnic population.
- (11) The provider will demonstrate that ethnic monitoring data has been analysed and utilised in terms of service provision and planning.
- (12) The provider will ensure the implementation of the Equal Opportunities Policy ( Which complies with Section 20 of the Race Relations Act ) and CRE Codes of Practice.

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