

URINARY INCONTINENCE IN INDIAN WOMEN IN LEICESTER

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by

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Abstract

Background

Urinary incontinence affects people of different ages, gender and ethnic backgrounds. Current review of literature shows very that very little work has been done with regards to urinary incontinence in ethnic minority groups. At Leicester there is a high ethnic minority population comprising of different ethnic groups, the largest in inner city Leicester being the Indians that migrated from the state of Gujarat in India.

Observations of clinic attendees, and unpublished data from the Medical Research Council Leicester Incontinence Study, lead us to believe that significant numbers of Indian women have continence problems but do not make use of currently available services.

Aims

To explore inequality in health, barriers towards accessing continence care and to further understand how best to provide continence services to this group the research program was formulated comprising of:

- Prevalence study
- Cultural context study
- Patients' journey through primary care study

These will address the various aspects of the influence and interaction of ethnic origin with incontinence care.

Methods

This project uses a mixed method approach combining both quantitative and qualitative research methods. The quantitative arm of the study uses validated self administered questionnaires to determine the prevalence and quality of life scores in women suffering with urinary incontinence in the community. The qualitative arm of the study uses focus groups and interviews to further explore women's coping strategies, the effect of migration in their symptoms and help seeking behaviour, the impact incontinence has on their lives and their attitudes towards available continence care, including suggestions for improving services.

Results

The South Asian named women in our research reported higher rates and severity of urinary symptoms, with a corresponding greater impact on their quality of life when compared to White British named women and Indian women in Gujarat. It highlights some of the barriers in effective continence care. None of these women were referred to secondary care immediately, unlike their White British counterparts within the same primary care setup. Management of incontinence in primary care is inadequate and doesn't comply with the recommendations made in the NICE guidelines.

Conclusions

This research project is a unique opportunity to study the impact of ethnic origin upon urinary incontinence. The inequalities in healthcare that have been highlighted together with the suggestions of service improvement that have come from the service users has resulted in the development of a strategic framework of continence care for ethnic minority women. This will aim to ensure accessible and acceptable care for these patients.

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For my Father,
Love you always

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List of abbreviations used

BME	Black and Minority Ethnic
DOH	Department of Health
EMIS	Egton Medical Information System
GP	General Practitioner
ICIQ-SF	International Consultation on Incontinence Questionnaire-Short Form
ICS	International Continence Society
IIQ	Incontinence Impact Questionnaire
LIS	Leicester Impact Scale
LREC	Local Research Ethics Committee
LUSQ	Leicester Urinary Symptoms Questionnaire
LUTS	Lower Urinary Tract Symptoms
MORI	Market & Opinion Research International
MRC	Medical Research Council
NHS	National Health Service
NICE	National Institute for Clinical Excellence
ONS	Office of National Statistics
OPCS	Office of Population Census and Survey
PFE	Pelvic Floor Exercises
RCOG	Royal College of Obstetricians & Gynaecologists
UI	Urinary Incontinence

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Chapter 1: Introduction

1.1 Introduction

Urinary incontinence affects people of different ages, gender and ethnic backgrounds.

In Leicester there is a high ethnic minority population. There are different ethnic minority groups but the largest group in inner city Leicester is the Indians. The Leicester Urogynaecology Unit caters to this population, and from a brief review of the continence clinic workload during an audit of our services (2003-2004), we found that only 15% of our patient population was from an ethnic minority background. It appears that fewer women from South Asian ethnic groups attend than we would expect. We have no information of why this might be so, but these are some of the possible reasons:

- South Asian women do not suffer from incontinence problems.
- They must be seeking help from sources other than their GP.
- They are less likely to be referred by their GPs but are being managed out in the community.
- These women are not being managed by the GP, nor referred.
- South Asian women are referred as often as Caucasian women, but do not make use of hospital services.

A review of the literature revealed very little information about urinary incontinence (UI) in women from ethnic minorities in the UK. Most epidemiological studies of UI have used populations composed mainly of white women (Hunskaar et al., 2003). To address our queries and to enable us to understand how best to provide continence services to this group the research program was designed to address the following objectives:

1. To determine the prevalence of urinary incontinence within the South Asian population.
2. To understand the cultural context of urinary incontinence and the community perception of UI and barriers to help seeking.
3. To understand barriers in the continence care pathway in primary care.

The research program comprised the following studies to meet the above objectives:

1. Prevalence Study

The prevalence of urinary incontinence in women is difficult to estimate, and more so in the ethnic minority population. Studies have shown that only a quarter of the women affected by urinary incontinence consult a doctor for their symptoms, despite evidence of effective treatment and better management of the condition in primary care (Seim et al., 1995).

To assess prevalence of the condition in the community we will approach one of the larger primary care health centres in the area and use their assistance to send out questionnaires to patients registered within their practice (1000 questionnaires to White British women and 1000 questionnaires to South Asian women). These questionnaires will ask questions on occurrence and impact of urinary incontinence on the individual.

2. Cultural Context

2 a) UK

The aim of this study was to explore the views and experiences of women in the South Asian Indian community in Leicester about urinary incontinence and their perceptions of available care.

Some of the areas that will be explored are; reasons for not seeking help either in primary or secondary care, use of alternative care pathways, awareness of the services available, and the acceptability of these services.

2 b) India

To further understand the effect of culture on health and to be able to provide culturally competent care, we will carry out a cross cultural study with women in Gujarat. As vast majority of the Indian women in Leicester originate from the state of Gujarat in India, this part of the study will be done in conjunction with the Shri Sayaji General Hospital, Maharaja Sayajirao University Baroda India.

We will then compare the findings between the two groups to understand the impact of culture on help seeking behaviour and provide strategies for improved awareness within our local Asian population.

3. Patients' journey through primary care

3 a) Health Provision

This part of the project aims to explore the care pathway of a patient suffering with urinary incontinence from the time they present to primary care until they are referred to secondary care.

Case notes from both the Asian and White British women suffering with incontinence will be identified from an inner city GPs practice. We aim to explore the following:

- To examine retrospectively the treatments offered to women seeking continence advice from their GP.
- To examine the pattern of referral to hospital care.
- To compare these treatments and referrals between women of White British and Asian origin.

3b) Patients' experience

To further explore the patients' experience in primary care purposive sampling in the form of one to one interviews will be carried out using qualitative methodology with a select number of Indian patients to:

- Explore the attitudes of these women to their incontinence.
- Examine why and how they seek help for their incontinence.
- Examine the social, religious and cultural influences on this behaviour.
- Their satisfaction with the care that was provided.
- Suggestions for service improvement.

Expected Outcome

Observations of clinic attendees, and unpublished data from the Medical Research Council Leicester Incontinence Study, lead us to believe that significant numbers of Asian women have continence problems but do not make use of currently available services. We believe that our research provides a unique opportunity to study the cultural and socioeconomic impact of ethnic origin upon urinary incontinence. This in turn, will increase our understanding of the social and cultural influences on disease presentation, allowing us to improve the quality of care we offer our patients. It will hopefully lead to innovative ways of providing continence care for different ethnic groups, which could become a stimulus for other clinicians to follow our lead.

1.2 Thesis outline

Section I

Chapter 2

This chapter introduces the concept of ethnicity and aims to differentiate it from race and culture and its use in literature. It provides an overview of the study population from an epidemiological, religious and linguistic perspective. The latter part of the chapter explores causes into inequalities in health in ethnic minority population.

Chapter 3

This chapter explores the prevalence, causes and the impact of urinary incontinence in women. It gives an overview of the barriers that most women face in help seeking and the coping strategies they adopt. Investigations and treatment options that should be instigated in primary care according to the National Guidelines are highlighted.

Chapter 4

This chapter discusses the methodology used in this research project, the reasons for choosing them and the advantages and disadvantages of each. The research in this thesis uses a mixed methods approach, which involves a combination of quantitative and qualitative research techniques. It also highlights the role of qualitative research in urogynaecology.

Section II

Chapters 5-7

These chapters discuss in great depth the various studies that form this research project. They are presented as aims, method, results, discussion with an overall summary for each of the studies.

The studies include those carried out in the community, in primary care as well a cross cultural study done with participants in India.

Section III

Chapter 8

This chapter lists the key findings of the research. It also highlights the strengths and limitations of the study and finally provides recommendations for service improvement and further research. A personal reflection on the entire research process will conclude this thesis.

Chapter 9

Bibliography and Appendices.

Section I

Chapter 2: Ethnicity

2.1 Ethnicity

2.1.1 Definition

The word “ethnicity” is derived from the Greek word “ethnos” meaning a nation (Weber 1922 cited in (Guibernau and Rex, 1997)).The definition of ethnicity is controversial because ethnic identification is subjective, multi-faceted and changing in nature as there is no clear consensus on what constitutes an ethnic group (Salt and Clarke, 1996) (University of Cambridge, 2004).

The core concept of ethnicity is a subjective belief of the individual of common origins, without the necessary existence of genetic linkage or physical similarity. The main reasons for such perceptions of self identity are certain shared characteristics, including physical appearance, geographical and ancestral origin, cultural tradition, religion and language (Bhopal, 2004). Therefore the most widely accepted notion of ethnicity is a multi-dimensional concept that includes different aspects of a group’s identity in relation to kinship, religion, language, shared territory, nationality and physical appearance (Senior and Bhopal, 1994). The characteristics that conceptualise ethnicity are not fixed or easily measured so ethnicity is considered a subjective and fluid concept (Senior and Bhopal, 1994).

It is important to differentiate between the concepts of culture, race and ethnicity though differences between them maybe subtle (Table 1.1).

Table 1.1: Differences between race, culture and ethnicity

Concept	Primary characteristics	Origin	Associated Perceptions	Example
Race	Inherent, Biological Physical, Natural	Genetic - Descent	Permanent	Caucasian Mongoloid Negroid Australoid
Culture	Behavioural expression of preferred lifestyle	Upbringing- learned	Capable of being changed	Chinese Indian African Mediterranean
Ethnicity	Identity, multi faceted, political	Socially constructed	Situational negotiated	British Indian British Chinese

Adapted from CEEHD – Ethnicity, Health and Diversity

Culture and ethnicity

Culture is a complex social phenomenon comprising of shared beliefs, values and attitudes that guide the behaviour of a group of people. Some researchers assume that culture is relatively static but at the same time believe that people can easily change learned habits if they want to (Wikan, 1999).

Race and ethnicity

Race is defined in the Cambridge English Dictionary as “a group, especially of people, with particular similar physical characteristics, who are considered as belonging to the same type, or the fact of belonging to such a group” (University of Cambridge, 2004). Current race classifications remain influenced by ‘biologically rooted’ racial stereotypes (Graves, 2002; Graves, 2003) and the concept of ‘race’ is still strongly used in many countries such as the US, when subdividing populations according to their ancestral origins (e.g. Blacks, Hispanics, Whites).

In order to overcome the biological determinism in the term 'race' and to include other non biological factors the concept of race has been abandoned in favour of ethnicity. This, however, should not lead to both terms being used inter-changeably (Bhopal, 2004).

2.1.2 Measurement and Classification

Despite the recognised complexity, subjectivity and fluidity of the concept 'ethnicity', it is necessary to categorise ethnicity in order to be able to measure it routinely. The classification that has become the UK standard is what has been used in the two most recent UK Census (1991, 2001: See Appendix 1).

The 2001 Census classification addressed some of the omissions in the 1991 census relating to the categorisation of ethnicity. Questions were further added to include mixed ethnicity and a further breakdown of the white category (Rankin and Bhopal, 1999). A voluntary question on religion was also added onto the census questionnaire. However, the 2001 classification has been criticised for continuing to stress the importance of skin colour across the whole classification (Aspinall, 2000b), e.g. Black African, Asian (Aspinall, 2000a), White (Peach C, 2000), or others (Connolly and Gardner, 2005) and fails to acknowledge heterogeneity within the groups.

Plans for the UK 2011 census are already under way. The Office for National Statistics (ONS) tested a full questionnaire for England and Wales in May 2007 (ONS, 2006a). This consultation reflected on how to differentiate between colour, nationality and ethnicity as well as questions around inclusion of community language in the census questionnaires. This resulted in a total of 19 ethnicity categories, 16 from the 2001 list, plus a new breakdown of White into English and other British, and two new categories of Arab/Gipsy/Romany/Irish travellers. Furthermore, the test questionnaire also

included two new multiple response questions on language spoken and national identity (ONS, 2006a) and a question on religion and country of birth [Appendix 1]. Interestingly mechanisms to assist those with a difficulty (i.e. language, literacy) in filling the forms were discussed.

2.1.2.1 Issues with official ethnicity classification

There are three major problems with the way which ethnicity is currently officially recorded. First, ethnicity is usually measured as a single variable, an ethnic group into which an individual self assigns his or herself from a classification of numbered classes with no scope to express the multi-faceted nature of self identity. The second problem is that pre-set ethnic classifications are used as opposed to an open question allowing self classification (ONS, 2003a), and these may not reflect the complex heterogeneity found within each group (Connolly and Gardner, 2005); (Rankin and Bhopal, 1999). The third problem arises from the method of determining ethnicity by self assessment (Bhopal, 2004) as opposed to it being assigned by a third person or a computer according to some established measurable criteria. As a result of self-classification, the ethnicity reported by the same person can vary through time since perceptions of individual and social identity also change over time (Aspinall, 2000a) and are influenced by the type of ethnicity question asked (Arday et al., 2000) and the definition of categories offered (Olson, 2002). In addition, there is a lack of routine collection of ethnicity data in most government or public service data sets.

2.1.2.2 Limitations of ethnicity data in the UK

Despite the UK census providing a standard for the collection of ethnicity information, ethnic group is still not recorded in most public sector datasets, including the Population register (e.g. birth, death, electoral and health general practice registrations) (LHO, 2003). In health care, the collection of ethnicity data has been mandatory for hospital admission statistics since 1995 (NHS Executive, 1994). Data coverage is still

only 70% of all episodes (LHO, 2005) and the data are of poor quality when compared with other research sources (Bhopal, 2004).

Many studies use categories such as Black or South Asian to describe the ethnicity of those studied (Chaturedi and McKeigue, 1994). It is important to recognize that such categories are heterogeneous, containing ethnic groups with different cultures, religions, migration histories, geographical and socio-economical location. For example, South Asians may have Punjabis or Bangladeshis included in the classification, which can be potentially misleading, because the findings of one ethnic minority group in a particular location may become generalized to others hence the potential for the difference between them to be ignored (Bhopal et al., 1991b).

2.1.3 Ethnic Data Collection

One of the reasons why services have failed Black and minority ethnic groups in the past is the lack of information available about them (Smith GD, (2000)). Much of the information that is currently collected is not broken down by ethnic group. Minority ethnic communities make up a small proportion of the population, making their representation in many surveys so low, as to make it difficult to use the results with confidence. The resulting lack of detailed local and robust data that covers the whole country means that it is often difficult to adequately diagnose problems and target policies better (SEU, 2000).

A British Medical Journal editorial pointed out that the categories of ethnic group used in health related research are often undefined and inconsistently used (McKenzie and Crowcroft, 1994). For example, because country of birth is recorded on death certificates and used in the census, much of the published data according to country of birth, this tends to be used as a surrogate for ethnicity, a strategy that is clearly inadequate.

In the 1991 census over half of the population in the black category were born in the UK, as were half of those giving their ethnic group as Pakistani, 42% of Indians and 32% of Bangladeshi. It is now estimated that less than 40% of the Black and minority ethnic populations (BME) can be identified by birthplace and increasingly few by the birthplace of their parents (ONS, 2003b; ONS, 2003c).

2.1.3.1 Primary Care

In 1990, the Department of Health in England proposed that a patient's ethnicity should be stated in General Practitioner (GP) referral letters (Department of Health, 1990), the rationale being that ethnic group data would be collated at the patients' first point of contact with the NHS. The vast majority of the population are registered with, or regularly consult with a general practitioner, or have regular contact with local primary care services. This gives an opportunity for capturing ethnicity data on a large proportion of the population, with general practices having been given a small financial incentive to do so. This is important as opportunities to promote health rather than treat diseases may be more realistic in primary care and targeting such services would benefit from ethnicity data.

Professionals may have knowledge of the ethnic make-up of their local population that may be of more value than statistical sources (Johnson, 1996), particularly where there is a rapid change in the configuration of the population possibly through recent relocation or migration, for example, an influx of Eastern Europeans into Leicester. However, practitioners may not be able to differentiate sub-groups very accurately, for example, Punjabi Indians and Punjabi Pakistanis (Coldman et al., 1988).

Although GP records in the UK do not routinely state ethnicity, it is common for people from certain ethnic minority groups to be registered with GPs from similar ethnic backgrounds who may be able to identify their needs (Cooper, 2003).

2.1.3.2 Secondary Care

Ethnic monitoring was introduced in all hospitals in England in 1995 (NHS Executive, 1994). Collecting valid data on ethnic groups of people using hospital services has proven difficult even when ethnic monitoring is national policy. Generally the information remains incomplete and of variable quality making interpretation difficult (Atkinson et al., 2001). This incompleteness may be due to lack of awareness or relevant training, reflecting variable commitments to collecting data. Staff may not like to ask questions about ethnicity because of fear that they may be perceived to be seen as racist (Bhatti-Sinclair and Wheal, 1998).

2.2 Ethnic Health

2.2.1 Potential benefits of race and ethnicity concepts in healthcare

Studying ethnic and racial variations in health can potentially help to understand disease aetiology, tackle inequality, assess need, make better health plans and direct resource allocation (Nazroo, 1997).

The interest in ethnic minority evolved from identifying unusual diseases initially to attempting to understand the impact their culture had on health and finally comparing their health to that of the indigenous population (Johnson et al., 2000).

Even now the aim is to adapt policy and services to meet specific needs rather than to try to ensure that the NHS as a whole is primed to meet the challenges of multi-cultural healthcare. Thus despite the multi-ethnic and multi-cultural nature of modern Britain, and notwithstanding the enormous efforts of both institutions and individuals, NHS

healthcare provisions and training are still largely based on the concept of a relatively homogenous British population (Culley, 1996).

Whilst there have been attempts to adapt services to take into account Britain's multi-racial, multi-cultural and multi-faith society, inequitable healthcare for ethnic minority communities continues as a consequence of linguistic difficulties and a social and cultural difference between patients and staff (Bowler, 1993). Throughout the UK many projects on ethnic health and healthcare start and stop each year and their subject is usually basic e.g. communication (usually health promotion projects or services) (Bhopal, 2007). In spite of this, basic services such as translation have not yet become an integral, effective and accountable parts of routine NHS care. Such barriers to equity of access and quality of care undermine the assumption "NHS free for all therefore equitable to all" (Dixon et al., 2003).

2.2.2 Explaining Patterns of Health

Senior and Bhopal identified problems with the concept of ethnicity in epidemiology, which are equally applicable to race and other quantitative health disciplines (Senior and Bhopal, 1994).

- *Problems of heterogeneous populations*

The populations identified by current methods of defining ethnicity are often too diverse labelling them into White, Indian and Pakistani ethnic groups. This diminishes their heterogeneity, reducing the value of ethnic categorisation as a means of delivering culturally appropriate healthcare and understanding the causes of ethnic variations in disease (Bhopal et al., 1991a). For example, a study postulating the role of diet in the aetiology of coronary artery disease, compared the risks of Indians and non-Indians, but gave only limited insight, since Indian diets are very diverse (Qureshi, 1990). The importance of social class and education variations in ethnic groups also needs to be

considered. Thus research techniques should incorporate all these variables when researching ethnic groups or else misleading conclusions may be drawn.

- *Problems of ethnocentricity*

The standard approach to ethnicity in health research is ethnocentricity, “an inherent tendency to view one’s own culture as a standard against which others are judged.” For example, Marmot and colleagues (Marmot et al., 1984), compared and contrasted the performance of other ethnic groups to that of the majority population. This can lead to less emphasis being given to diseases where the indigenous population has an excess in relation to the minority population or those conditions where there is no difference. Senior and Bhopal advocate identifying common health problems confronting individual ethnic groups (Senior and Bhopal, 1994).

2.3 Ethnic Minorities in the UK

2.3.1 Population

In the 2001 census 6.7 million people in Great Britain or 11.8% of the total population were from ethnic minorities (CRE, 2007). Of these, 4.6 million (or 8.1% of the total population) were from non-white ethnic minorities. This represents an increase of 53% from just over 3 million (or roughly 5.5%) in 1991, when a question about ethnicity was asked as part of the census for the first time. Forecasts based on the current population growth rate figures put the non-white ethnic minority population in 2011 at between 6-7 million people, representing 11-12% of the projected population of Great Britain. This estimate does not take into account changes in birth rates, levels of migration or the ways in which people might classify themselves.

Ethnic Groups

The 2001 census used five broad groups of ethnic category: White or mixed ethnic background, Asian or Asian British, Black or Black-British, Chinese or other ethnic backgrounds (ONS, 2003c). These were further sub-divided into 16 sub-categories in England and Wales. Indians made up 1.8% of the total population of Great Britain in 2001 and formed the single largest ethnic minority group. They were followed by Pakistanis at 1.3%, White-Irish 1.2%, mixed ethnic backgrounds 1.2%, Black-Caribbeans at 1%, Black-Africans 0.8% and Bangladeshis at 0.5%. Around half of Great Britain's non-white population in 2001 described themselves as Asians of Indian, Pakistani, Bangladeshi or other Asian origin and a quarter have been from the Black-Caribbean, Black-African and other black groups. In Great Britain in 2001, 674,000 people said they were from mixed ethnic backgrounds.

Country of Birth

Of the UK population in 2001, 8.3% or 4.9 million were born abroad (almost double the proportion in 1951) (CRE, 2007). Around 53% of the population born elsewhere were from the white groups, and the next largest ethnic groups were Indian's at 570,000, Pakistani's at 336,000, Black-African's 322,000, Black-Caribbean 238,000, Chinese 176,000 and Bangladeshi at 152,000. Among the population born elsewhere, the country of birth did not always correspond closely with ethnicity, for example, 38% of people born in Africa were black, 31% were white and 20% were Indian.

Language

Best estimates are that there are more than 3 million speakers of other languages in England and Wales, but probably only 1% of these have no ability in English (CRE, 2007). The remainder may have only a basic understanding of spoken English. Recent estimates suggest that over 300 languages are used as "mother tongues" in London

(Baker and Eversley, 2000). Current data on South Asian minority ethnic women, especially in the Muslim cultural groups, found that they may not be literate in their “mother tongue” and were least likely to speak or read English (Schott and Henley, 1996).

2.3.2 British Asians

British Asians make up 50.2% of the UK non-European population. In the 2001 UK census, there were 2.33 million British Asians making up 4% of the population of the United Kingdom (ONS, 2003b; ONS, 2003c). This was further sub-divided to 1.05 million of Indian origin, which is 1.8% of the population. Of this, 747,000 are of Pakistani origin (1.3%), 283,000 are of Bangladeshi origin (0.5%) and 247,000 from other Asian origins (0.4%; largely of Sri Lankan origin). British Indians tend to be religiously diverse with 45% Hindu, 29% Sikh and 13% Muslim, while their counterparts of Pakistani and Bangladeshi origin are much more religiously homogenous with Muslim’s accounting for 92% of each group (Connolly and Gardner, 2005).

2.3.3 Leicester and its Ethnic minority population

Leicester has just over 100,000 ethnic minority residents out of a total population of 280,000 (Table 2.1). Indians form the bulk of the total Asian population (84,000) and make up 1 in 4 of all Leicester residents. Pakistanis and Bangladeshis however are only slightly over-represented against the national average. The city also has over 5,500 residents who defined their ethnicity by ticking the “Asian other” box in the 2001 census. Many of these are likely to be Kenyan and Ugandan Asians.

Table 2.1: Ethnic Composition of Leicester from 2001 Census

Ethnicity Breakdown (%)	Leicester	England & Wales
White	63.9	91.3
Mixed	2.3	1.3
Asian	29.9	4.4
Asian or Asian British: Indian	25.7	2.0
Asian or Asian British: Pakistan	1.5	1.4
Asian or Asian British: Bangladeshi	0.7	0.5
Black	3.1	2.2
Black or Black British: Caribbean	1.7	1.1
Black or Black British: African	1.2	0.9
Other	0.8	0.9

2.3.4 History of South Asians in Leicester

By the 1960s there was already a large Asian population in Leicester, many of whom had migrated from the Punjab and Gujarat regions in India, and from Pakistan to work in the UK. These migrants were followed by East African Asians, who began arriving in large numbers in the 1960s following events in several newly independent African countries. The number of East African Asians in the UK rose dramatically from 6,000 in 1965 to 31,600 in 1967 after African Governments announced intentions to restrict the entry and residence of non-citizens (Patel, 1972).

Although ten times less numerous than the Asian population, Black people are also represented in Leicester at a level above the national average with 3.1% of the city residents compared to 2.3% for the whole of England. Leicester's mixed race population is also proportionately higher than average totalling 6,500 people. It is one

of very few places outside London where the White and Asian mixed group begin to approach 1% of the total population. Leicester is widely predicted to become the first city in Europe with a majority non-white population in the next five years (CRE, 2006). According to the 2001 census, only 60.5% of the city's residents describe themselves as White-British.

2.4 Health Service Provision for Ethnic Minorities

2.4.1 Health Inequalities

Policy document such as NHS and Community Care Act, Department of Health 1990 and the NHS Plan 2000 (DOH, 2000), have shown the Government's intention to set national health inequalities targets to make health services more responsive to all sections of the population and to involve local communities in evaluating the effectiveness and accessibility of local services.

For many groups of BME women, healthcare continues to be inaccessible and inappropriate and the reason for this may be multi factorial. Ethnic minorities may have different ways of thinking about health illness and healthcare. Failure to recognise this will make the care offered inappropriate to their needs as will the discriminatory practices that may be built into the services themselves and their mode of delivery (Nazroo, 1997). All these factors can be exacerbated by poverty and general social deprivation making it more difficult for some women from minority ethnic groups to get optimal care from the NHS.

It is significant that some of the major pieces of legislation and attempts have been made by Health Authorities and Trusts to involve Black service users in this process, however they have often been half-hearted and there are few examples of the

systematic involvement of Black women in new policy initiatives (Whitehead et al., 1992).

Health service provision may offer a poorer service to ethnic minority groups for the following reasons:

- An individual member of staff treats the patient unequally because of racial prejudice.
- The policies of services are based on the needs of ethnic majority population and not those of the minority population, thus creating inequity of care.
- Health services are planned and managed largely by members of the majority population, on the basis of limited understanding of the needs and preferences of the users of the service. Therefore, people from poorer less articulate groups are likely to receive poorer care, due to an under-represented voice.
- The specialist resources required to meet the needs of ethnic minority groups simply do not exist even though they are recognised by policy makers.

The key obstacle to improving access to healthcare lies in the lack of priority and recognition given to accessing healthcare for BME groups. This can lead to people not having proper treatment on the NHS and often can act as a barrier to people seeking help. Sometimes the whole encounter with the health service for whom people whose first language is not English, is so full of anxiety that they tend not to discuss all of their health problems (Bhugra and Bahl, 1999).

The Department of Health's own patient survey revealed a consistent pattern of higher level of dissatisfaction with NHS services among some minority ethnic groups, when compared with the White British majority (Commission for Health Improvement, 2004). For example, those responding to the survey from Pakistani, Indian and Bangladeshi

backgrounds reported significantly poorer experiences as hospital inpatients than White British or Irish respondents, particularly on questions of prompt access as well as their experiences of involvement and choice. As mentioned earlier the evidence base is limited because of the failure of the NHS Institutions to collect ethnicity data on patients, both at hospital and primary care level.

Access to healthcare compared with service provision

Appropriate access to healthcare for a diverse population requires more than just simply providing the service.

A review on access to an uptake of NHS services by ethnic minorities has recommended the following (Atkinson et al., 2001):

- Equal access via appropriate information.
- Access to services that are relevant, timely and sensitive to the persons needs.
- Being able to use the Health Service with ease and having confidence that you will be treated with respect.

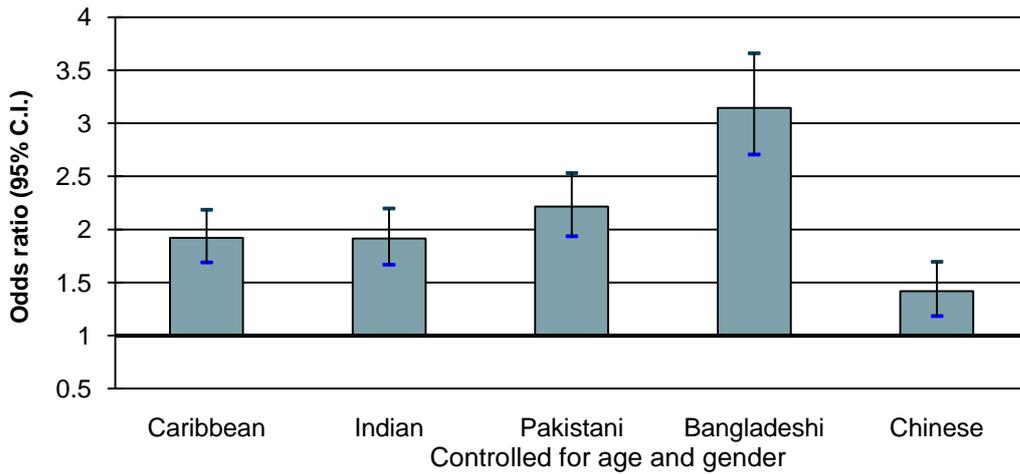
This should form the basis of any health service provision not just for ethnic minority groups but for the population as a whole.

2.4.1.1 Existing Studies

Ethnic inequalities in health have become an increasing focus of research attention in Britain since the early 1970s, reflecting a growing public policy concern with the health of and quality of healthcare provided for ethnic minority groups (Nazroo, 2003). Figure 1.1 shows the odds ratio of people that have reported bad or fair health in the health survey for England by ethnic groups, compared with the White British majority. It is striking to notice that the people from groups such as the Caribbean, Indian,

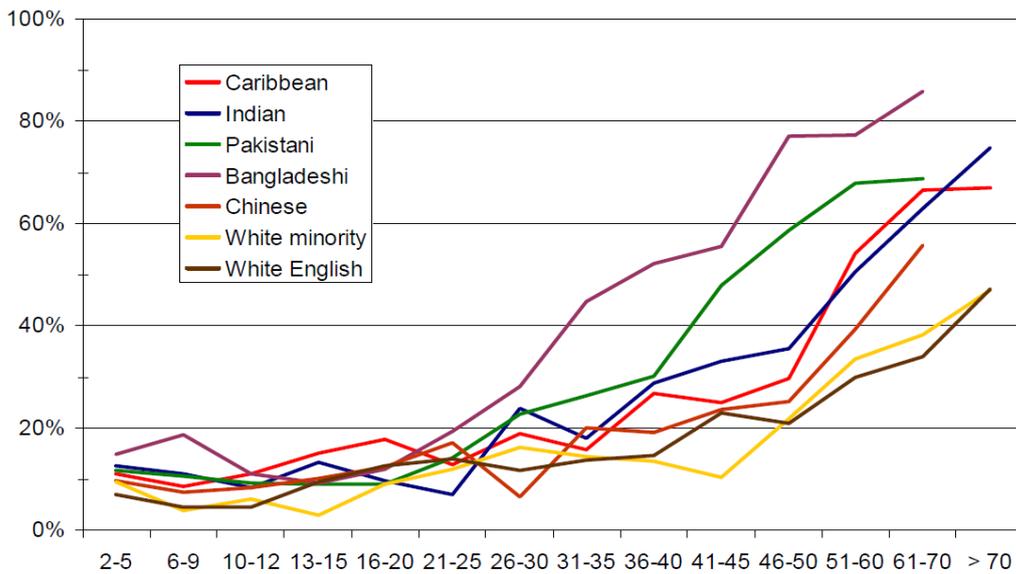
Bangladeshi or Pakistani ethnic groups reported bad or fair health 2 to 3.2 more often than that of the White British majority (DOH, 2001). This status of poor health gets worse as the population ages [Figure 2.1].

Figure 1.1: Odds of reporting fair or poor health compared with White English



Health Survey for England 2004

Figure 2.1: Reported fair or bad health by age



Health Survey of England 1999

A review of literature to identify studies involving Asian women in Leicester revealed a study by McAvoy et al, exploring Asian women's family planning needs. Over 80% wanted a female doctor, 37% could not read English family planning literature, 5% did not understand it, 55% preferred to discuss family planning in their mother tongue and 20% wanted information available in the workplace (McAvoy and Raza, 1988). McAvoy and colleagues also identified that Asians made up 22% of the population studied but accounted for 32% of all births in the city. Their fertility rate was higher, 13% versus 5% for the UK in that year. Their contraceptive use was lower than that of Caucasians but was not affected by religion. This raises issues about barriers in accessing appropriate healthcare services.

Explanations offered by researchers for reported disparities in access to health services fall into two main groups. The first group is linked with intrinsic personal factors, which include the particular needs of ethnic minority people. The second group is associated with extrinsic or organisational factors. These focus on the organisation itself and its healthcare delivery and planning systems. Each will be considered in detail below.

2.4.1.2 Intrinsic or Personal Factors

Cultural differences

People identify themselves with a social group on cultural grounds, and that the diverse racial and ethnic groups may have different health beliefs and behaviours (Brach and Fraser, 2000). Other cultural factors include religious practices that may affect access to healthcare and compliance with treatment offered. Gender of the healthcare professional especially for female patients maybe an obstacle to service access. Patients may have a different way of somatising symptoms that may lead to misunderstanding, misdiagnosis or incorrect referrals. Patients may be shy and

believe that help should only be sought at a certain stage of the illness. Other cultural factors, such as family dynamics, may mean people cannot easily attend or take up services without the support of family members (Atkinson et al., 2001). Health professionals need to take into account these types of cultural beliefs and values when communicating with patients or users (Stewart et al., 1999).

Language, Literacy and Communication

Poor linguistic competence is a major barrier to access. Interpreting services may be required to facilitate the adequate diagnosis, consent and treatment of these people. For example in South Asian groups in the UK, there is evidence that ability to speak English is lower for women than men, and is much poorer for those born outside of the UK and declines with increasing age (Johnson et al., 2000; Modood et al., 1997).

Language skills are important for effective communication between ethnic minority patients and healthcare personnel (Diaz, 2002a). Many may feel hindered because of their lack of ability at expressing their feelings due to language and reading difficulties (Lipton et al., 1998). The inability to communicate in what is not their mother tongue inevitably leads them to struggle to express their inner feelings, ask questions or to represent themselves or their families (Hatfield et al., 1996). Poor language skills also have an adverse effect on the confidence of the patient. This causes additional emotional stress and discomfort to the normal stress that accompanies medical consultation. Language difficulties can have a detrimental effect upon the physician's attempt at obtaining vital medical history resulting in improper diagnosis and treatment as well as the patients' ability to comprehend proposed treatments is hampered resulting in a detrimental result (Williams et al., 1995).

Differences in literacy might be another important factor. Although people may be able to speak English they may not be able to read it. Estimates differ but there is a general

agreement that fewer than one third of older Bangladeshi and Pakistani women (aged 50 – 75), and fewer than two thirds of older men can read English (Johnson et al., 2000). Even if a letter or patient information leaflets are translated, people may not be able to read their own language. Over half of all Bangladeshi and Pakistani women (and about 20% of older men) are illiterate in any language (Rudat, 1994).

Cultural Competence

It is not only language barriers but various other cultural factors that can influence successful healthcare delivery to ethnic minority populations (US National Center for Cultural Competence). Cultural differences are likely to influence health beliefs and how the ethnic groups perceive illness. Their attitudes towards healthcare providers can affect their help seeking behaviour. This is important as are the views of those delivering healthcare.

Thus, healthcare organisations and their staff need to be culturally, as well as linguistically, competent, to provide equitable access to healthcare services for diverse populations (Szczepura, 2005).

Translation

Ethnic minority patients often use friends, their spouse, children or other family members as interpreters (Watt et al., 1993). These often lack the necessary skills to fully communicate the message, and may make little difference to the consultation process (Watt et al., 1993). The presence of a professional interpreter can improve the quality of the conversation whilst at the same time providing the patient with more coherent explanations of the case through face-to-face dialogue, improving patient rapport (Diaz, 2002a; Diaz, 2002b). Use of interpreters is not without its problems. Some patients are concerned about the accuracy of the translated information and

there maybe reluctance of patients to reveal to the interpreter confidential information (Jirojwong and Manderson, 2002; Jirojwong, 2002).

Perceptual attitudes towards health services and personnel

Disapproving perceptions and attitudes with regard to health services and personnel can act as a barrier. This is especially apparent when ethnic minority do not see the benefit of health services (Garrett et al., 1998; Smith et al., 2000).

Demand in health services is influenced greatly by the consumer. Ethnic minority patients may see providers as rather distant with traditional overpowering respect for medical personnel. This may in turn prevent them from asking important questions about medical instructions, or organisational access. This higher respect and a feeling of subordination prevents them from questioning authority (Lipton et al., 1998).

Knowledge about physiology and disease

People may have a limited and different understanding of the workings of their body (El-Kebbi et al., 1996). Non-recognition of medical needs by patients is a reason for not presenting with a problem (Garrett et al., 1998) which may also lead to the patient not receiving optimal care. For example patients of certain ethnic minorities think that pre-natal care is only required in cases of past or present problems with the pregnancy (Sokoloski, 1995). Therefore this attitude is applicable to urinary incontinence because they consider it to be a normal process of aging. This is no different from what white people think (Mittiness and Barker, 1995).

Source of Advice and Regular Sources of Care

Healthcare practitioners believe their patients to be strongly influenced by recommendations and stories from families or friends which may not always be entirely true (Jenkins et al., 1996). This belief may make patients resistant to

recommendations from health professionals, for example, reluctance to increase their medicine dosage based on the view that the illness might worsen or there may be complications (Lipton et al., 1998). Thus having a regular source of care and information is important to provide preventative healthcare (Jenkins et al., 1996; Jenkins CNH, 1996).

Knowledge of health services and how to use them

Unawareness of service availability or a lack of knowledge about the services can act as a barrier to the use of health services (Moon et al., 1998). If the ethnic minority patient has no knowledge of the function and availability of primary care workers, knowledge being restricted to the GP, then the use of primary health care services will inevitably be restricted and inappropriate (Jirojwong and Manderson, 2002). For example, screening services, i.e. breast and cervical screening is low among ethnic minorities due to a general lack of knowledge about these services and a different understanding of the nature of preventative care. However, this is contradicted as immunisation rates are generally high among ethnic minorities (Smith et al., 2000).

Perceived illness, perceived cause

Ethnic minorities' different perceptions of the severity of the symptoms can act as a barrier. Some ethnic minorities maybe more concerned about the symptom, for example, pain and are more prone to seeking immediate care. Also, some ethnic minorities are more prone to seeking immediate care for an ailing child (Smith et al., 2000) thus putting pressure on health service providers.

2.4.1.3 Extrinsic factors

Medical procedures and practices

Invasive medical procedures can act as a barrier to the use of health services (Sokoloski, 1995). The performing of certain medical tests and examination can act as a barrier if ethnic minority patients are frightened especially if the procedure has not been explained adequately (Gray et al., 1995).

Female patients may be embarrassed by physical examinations especially if performed by male physicians. Pelvic and vaginal examination cause the maximum amount of embarrassment and shame (Byrd et al., 1996).

Communication Skills

Weak communication skills and misunderstanding between patients and doctors can act as a barrier (Bhui et al., 2003) leading to an inappropriate consultation. There is tendency of the primary care physician to refer the patient more quickly to a specialist if it becomes difficult to diagnose the concerns of the ethnic minority patient (Blais and Maiïga, 1999), or alternatively to ignore the patients symptoms. This is shown in patients from certain ethnic minority groups who have a complex pathway to specialist mental health services as opposed to people from other ethnic minority groups or ethnic majority. These patients are less likely to be referred to a specialist service due to the unlikelihood of recognizing a psychiatric problem (Bhui et al., 2003).

Questioning patients about missed appointments or other forms of non-compliance may result in future non-attendance as the healthcare provider is seen in an unsympathetic authoritative role. For example the fear in ethnic minority pregnant women that if one did not attend the obstetric clinic then forthcoming delivery assistance may be withdrawn (Spring et al., 1995).

Being bi-lingual without the skills to fully articulate ones views can act as a barrier. Bi-lingual physicians face substantial language difficulties that can lead to communication breakdown (Perez-Stable et al., 1997). Although some physicians are able to care for patients without translators, clinical interaction about complex issues requires advance levels of language fluency for an effective patient/physician communication (Snowden et al., 1995).

Translation

The vast majority of care providers prefer a word-for-word translation and only a small minority prefer the interpreter to focus on the content of the consultation (Singy, 2003).

Medical consultations with an interpreter are challenging and require a longer period of time than that assigned to patients in primary or secondary care. This needs to be taken into account when patients from ethnic backgrounds are booked for consultation (Gargan and Chianese, 2007).

Linguistic and communication barriers

Communication in the patients' native language can be done with the help of relatives or friends as interpreters, professional medical interpreters or bi-lingual staff. Most often informal or ad hoc interpreters are used. Family or friends can be asked to accompany the patient to a healthcare facility to interpret for them. In the Netherlands, 60-82% of Turkish and Moroccan patients use this strategy (Verrept, 1998). This is similar to the situation in Austria where 60% of hospital staff stated that accompanying persons are used often or nearly always (Pöchhacker, 2000).

Friends and family are not trained to interpret and are therefore likely to edit messages. In addition, they are not accustomed to medical jargon. Patients on the other hand

may not always express themselves openly because they feel uncomfortable in the presence of a third party. This is especially the case for children but also with adult patients who are dependent on their own children (Verrept, 1998). Furthermore, the language skills of small children may not always be adequate for medical encounters. In some healthcare settings, non-medical bi-lingual staff is asked to interpret during medical encounters. Since they are not trained to interpret the same pitfalls regarding mis-interpretation may occur as with the accompanying friends and family.

A study in California highlighted pitfalls, when bi-lingual nurses were observed treating ethnic minority patients. They tended to treat the patients as subordinates when there was a difference in socio-economic status (Marshall and Richards, 1989). Some nurses attempted to mis-interpret information from the patient in order to confer with the physicians' views.

This contradicts the findings by Seijo et al who suggested that a bi-lingual health professional may be an effective solution to avoid mis-interpretation (Seijo et al., 1991). They reported that Hispanic patients communicating in Spanish with their doctors had a better recall and a better understanding of the information, asked more questions and had better patient–doctor interaction. Some of the strategies identified to avoid miscommunication as shown in Table 2.2. Using simple sentences, which could be partly understood by the patient and used in summaries allows for possible feedback about the interpretation. Use of non verbal signals is also important. Full interpretation by the nurse interpreter instead of leaving out information encourages patients to tell more about their problem (Marshall and Richards, 1989).

Table 2.2: Communication methods in the first language of the patient

With help of	Advantages	Disadvantages
Accompanying persons	<ul style="list-style-type: none">• Close to patients	<ul style="list-style-type: none">• No training in interpreting and medical jargon• Shame for taboo subjects• Dependency on volunteers
Accompanying (small) children	<ul style="list-style-type: none">• Close to patients	<ul style="list-style-type: none">• Language skills not yet adequate• Affects child-parent relationship
Bilingual non-medical staff	<ul style="list-style-type: none">• Easy at hand• Same culture	<ul style="list-style-type: none">• Editing messages• No 'cultural' translation• Low hierarchic position
Bilingual health professional	<ul style="list-style-type: none">• Always present• Same culture	<ul style="list-style-type: none">• 'Culturalisation' of complaints
Professional medical interpreter or advocates	<ul style="list-style-type: none">• Trained interpreters in health• Same culture	<ul style="list-style-type: none">• Low hierarchical position in care setting• Own position in cultural group

Adapted from (Schaafsma et al., 2003)

Cultural Knowledge

Lack of cultural knowledge can act as a barrier (Garrett et al., 1998). Cultural knowledge about, for example, traditional family patterns and values, are regarded as essential to the provision of health promotion and preventive care (Garrett et al., 1998).

Family Involvement

Ethnic minority patients' have strong and traditional family values (Miranda et al., 1996), which may influence their health seeking experience (e.g.: Latinos, Asians). Within the hierarchical nature of a traditional family pattern it is usually the father or husband who is the most powerful family member. He makes most of the major decisions and provides the financial emotional stability. Therefore, he should be included in the discussions about treatment of other family members (Lipton et al., 1998). Neglecting the influence of the family through non-involvement can act as a barrier.

Parallel sets of beliefs and practices

Ignoring the existence of parallel set of beliefs and practices can act as a barrier to the use of health service. The belief in or commitment to additional practices does not hinder the perception that Western healthcare can be very beneficial too. Ethnic minority patients may have parallel sets of beliefs and practices. On one hand, they may be committed to Western health practices and on the other hand sometimes travel to their country of origin for non-Western practices (Ma, 1999).

Potential barriers at organizational level

Western medical practices can act as a barrier as they are based upon a biomedical explanatory model of health illness and healing methods. Some ethnic minority patients are dissatisfied with this model as the dimensions of religion and culture on health and healing are not recognized. Ethnic minority patients seem unable

to convey their inner feelings and needs and as a result these patients lack the confidence to ask important questions especially when they feel isolated for example when they are admitted to hospital away from family and friends (Hatfield et al., 1996).

The referral system can act as a barrier as some patients feel uncomfortable with procedures that hinder them from obtaining adequate care (Panos and Panos, 2000). For example, in their own country, they would usually go directly to a health specialist, rather than seeing a general practitioner, and the treatment they have received from healthcare workers in their own country, may influence their attitude to accessing services here (Jirojwong and Manderson, 2002). Decisions are also based upon the nature of the illness and the effect of previous treatment, as well as the cost of the treatment itself (e.g. prescription charges).

Consultancy Appointments and Waiting Times

Difficulties in accessing health services stems from the making and obtaining of appointments. Patients with limited English communication skills may find it difficult to ring to make an appointment (Knipscheer and Kleber, 2001). The unavailability of an appointment at a convenient time, long waiting times for appointments and during visits to clinic hinder the patient from using the services, however much of this has been addressed by the 18 week pathway implemented by the NHS (Barrett et al., 1998). Patients of certain ethnic minority groups have to wait longer for specialist intervention, for example in the management of chronic heart disease South Asians patients had to wait twice as long as their European counterparts for specialist intervention (Shaukat et al., 1993). Where this barrier occurs is not clear.

Length of Consultation and Treatment

Short consultations are perceived to be abrupt and can act as a barrier (Barrett et al., 1998). Patients' fear that their condition is not perceived to be important or serious enough to warrant medical attention. This undermines the trust, which is essential for improved relations to occur between patient and provider.

Printed material and other forms of media

The lack of appropriate translated information and educative materials can also be a hindrance, particularly when information and education is critical to the needs of adequate patient management. Information and education with regards to ethnic minority patients must take into account the varying levels of literacy within the ethnic minority sub-groups. It must acknowledge the value of traditional practices, explaining technical procedures and their rationale, address the concerns reported by the patient and inform them of their legal right (Spring et al., 1995).

2.4.2 Healthcare Access and Utilisation

Ethnic differences in utilisation may reflect differences in demand for services as well as inequities in supply.

In Acute Services

Balarajan (1991) examined ethnic patterns using data from the Office of Population Censuses and Surveys (OPCS) General Household Survey (1982-1987) in the self reported utilisation of acute inpatient and outpatient services (Balarajan, 1991). Of the 3,500 from ethnic minority groups which the investigators divided into Indian, Pakistani and West Indian based on self reported ethnicity, they found that Pakistani women had significantly higher levels of utilisation than White women in the 16 to 44 age group, being more than twice as likely to have used acute inpatient services, even after adjusting for differences in age in socio-economic status. The investigators suggested

that the higher level amongst younger Pakistani women probably reflected a greater use of maternity services due to high fertility. Outpatient attendances were lower than Whites for both male and females in the 0 – 44 age range for all ethnic minority groups. In the 45 – 64 age range outpatient attendance was higher for all minority ethnic groups but only significantly so for Indian males and females.

GP and Primary Care Healthcare Services

McCormick and Rosenbaum (1993) described ethnic patterns of GP consultations from the third National GP Morbidity Survey, which is based upon data from 25 General Practices in England and Wales (McCormick and Rosenbaum, 1993). Consultations were 13% higher in men from the Indian sub-continent than the general population after adjusting for differences in age. Men and women from the Indian Sub-continent had higher consultation rates for endocrine, nutritional and metabolic disorders, respiratory disease, skin disease, disease of the digestive and musculo-skeletal systems and for symptoms, signs and ill defined conditions but significantly lower consultations for mental disorders.

Little attention has been paid on the utilisation of community health services by minority ethnic populations. Research in Bristol by Hek (1991) found that fewer Caribbean and South Asian people received care from District Nurses than would be expected on the basis of population estimates (Hek, 1991). This finding was attributed to lack of information and knowledge about the services among the older minority ethnic people and the attitudes of the nurses themselves.

Differences in utilisation would be expected on the basis of the age and gender structure of the population of interest as well as their socio-economic structure and patterns of morbidity. The precise impact of belief in knowledge about health and health disease between ethnic groups is unknown (Free and McKee, 1998). Perhaps

the most striking findings for most studies is the degree of broad similarities with the Western medical model of disease exhibited by minority groups (Howlett et al., 1992) and a general confidence in the principles of Western medicine. Respondents tend to under-report beliefs which they may feel are regarded as quaint or unworthy of reporting. Howlett et al (1992) analysed the health beliefs of 129 Asians and 94 Afro-Caribbeans in comparison to samples of White respondents matched for age, gender, social class. They found that Asians perceived health in relation to their ability to perform daily activities and illness a matter of luck, as compared to Whites who saw health in terms of strength and fitness and illness a fault of the individual. Bhopal (Bhopal, 1986) interviewed 65 South Asian people chosen randomly from records of a General Practice and found that their knowledge was rooted in the Western medical model and they were generally scornful of many traditional South Asian beliefs. Many were poorly informed about health issues, particularly the older people and those who were less familiar with the English language. Understanding the degree of knowledge displayed by ethnic groups of the services available to them and their attitudes to these services can help to explain patterns of service use.

In the West Midlands study, Johnson (1984) found that South Asian and Caribbean patients were less likely than Whites to refer themselves directly to the Emergency Department than generally awaiting referral from their GP (Johnson, 1984). This may partially explain the high levels of GP consultation. In other areas of primary and preventative service provision, lower levels of utilisation are generally mirrored by less knowledge of these services (Donaldson, 1986).

Overall, therefore, it appears that the GP is a more crucial point of contact with health services for people from ethnic minority populations than is the case for majority populations. Several studies have investigated the factors investigating the choice of GP and their implications for the success of the doctor patient relationship. The

difficulties of language and communication exist affecting the choice of a White or South Asian GP and where women consult with a male GP. Earlier studies in the West Midlands suggested that the key determinant of GPs choice was proximity and that factors such as ethnicity of the GP were less important (Jain, 1985) although clearly there is a considerable co-incidence between areas of South Asian residence and the availability of South Asian GPs. Some more recent studies have suggested that difficulties in communication may not be a major problem. For example, Rashid and Jagger (1992) found that only 6% of the sample of South Asian patients in Leicester found it difficult to explain their symptoms in English (Rashid and Jagger, 1992). On the other hand considerable problems in English fluency have been reported amongst elderly South Asians in Leicester (Donaldson, 1986) and Pakistanis in Bradford (Ahmad et al., 1989).

Gender of GP

There are conflicting data on the choice of the GP by gender. It is often suggested that South Asians, particularly Muslim women, are more reluctant to consult with a male doctor where physical (especially vaginal) examinations may be involved (Chapple, 2001). This is not entirely supported by the evidence which suggests that most South Asian women consulted male doctors and relatively few (10% – 30%) expressed a preference for women (Rashid, 1992). Ahmed et al (1989) found in their Bradford study that 62% of Pakistani women in Bradford said that they would object to being examined by a male physician.

2.5 Summary

Race, culture and ethnicity are complex, intertwining, powerful, and dynamic concepts that are used by individuals and societies to identify and evaluate social groups and individuals. Measurements of ethnicity have become increasingly standardized through the wide adoption of official ethnicity classifications in public datasets. However, such classifications have a series of problems. They fail to reflect the multi-dimensional nature of ethnicity, they are restricted to just a few predefined coarse categories and they are subjective to the variability of self assignment of ethnicity. Moreover, the lack of routine collection of ethnic information and its low quality and comparability across datasets and periods of time presents major short comings for researchers and public policy decision makers. Race and ethnicity are important in health and healthcare, particularly in demonstrating inequalities.

The potential value of ethnicity and race in modern multi-ethnic societies will be achieved only when understanding an application of these concepts such that their advantages exceed their weaknesses.

“To understand a person’s behaviour, one must have knowledge of the environments from which the person came and the behaviour patterns encouraged by these environments” (Dyck, 1992).

Chapter 3: Urinary Incontinence

3.1 Introduction

Urinary incontinence is a common symptom that can affect women of all ages across different cultures and races, with a wide range of severity having an influence on the physical, psychological and social wellbeing of affected individuals. The impact is not only on the person but also on the families and carers of those suffering with it.

Published prevalence rates vary widely due to differences in definitions used, populations surveyed, survey type, response rate, age, gender, availability and efficacy of healthcare (Hunnskaar et al., 2004). According to the International Continence Society (ICS), the definition of urinary incontinence is:

“the complaint of any involuntary leakage of urine”.

The ICS defines the symptoms of stress urinary incontinence as the complaint of involuntary leakage on effort or exertion, or on sneezing or coughing. Urge urinary incontinence is a symptom of involuntary leakage accompanied by, or immediately preceded by urgency. Mixed urinary incontinence is a symptom of involuntary leakage associated with urgency and also with exertion, effort, sneezing or coughing (Abrams et al., 2002).

3.2 Risk Factors

Most of the studies of risk factors have included cross-sectional studies, with the best studied factors being parity, age and obesity (Bump and Norton, 1998; Dwyer et al., 1988). Racial or ethnic factors are an understudied area. Most studies report white women to have increased prevalence of urinary incontinence (Burgio et al., 1991) especially stress incontinence (Bump, 1993). Age has been strongly associated with the prevalence of incontinence (O'Donnell et al., 2007), (McGrother et al., 2004).

However incontinence should not be inferred as an inevitable consequence of aging in women, but rather that the contributing factors to incontinence are increased with age as well. Vaginal delivery seems to be the most important risk factor for lifetime incontinence. About 30% of women become incontinent after a first vaginal delivery (Farrell et al., 2001). Other risk factors include functional and cognitive impairment (Hunskaar, 2000), family history (Hannestad et al., 2004) and genitourinary prolapse (Samuelsson et al., 2000).

3.3 Prevalence Rates

Literature suggests that urinary incontinence affects 1 in 4 women over the age of 50, with prevalence rates going up to 50% among institutionalised women (O'Donnell et al., 2007). Prevalence rates vary depending on the study population, the gender, age, ethnicity, co-morbidities and whether the target population is institutionalised or community dwelling.

Numerous epidemiological studies show that the incidence of urinary incontinence increases with age (Hampel et al., 1997; Thom et al., 1997). Despite high prevalence rates, urinary incontinence is not a static condition. Rather, it is a dynamic condition whereby significant incident rates are associated with equally significant remission rates and the patients move back and forth from continence to incontinence (Hunskaar, 2000).

In a UK community study, the prevalence of urinary incontinence known to the health and social service agencies was 0.2% in women aged 15 to 64 years and 2.5% in those aged 65 and over (Thomas et al., 1980). A concurrent postal survey showed a prevalence of 8.5% in women aged 15 to 64 and 11.6% in those aged 65 and over. Incontinence was described as moderate or severe in one fifth of those who reported it

and even amongst these less than one third were receiving health or social services for the condition (Thomas et al., 1980).

Where the most inclusive definitions have been used (ever, any, at least once in the last 12 months) prevalence estimates in the general population range from 5 – 69% in women 15 years average range being 25 - 45% (Shaw et al., 2006c). There appears to be less variation in the prevalence of more severe urinary incontinence and estimates in the general population range between 4 and 7% in women under 65 years and between 4 and 17% in those over 65 for daily urinary incontinence (Shaw et al., 2006c). The Leicestershire MRC Incontinence Study found that whilst 34.2% of women reported urinary incontinence at times, only 3.5% experienced symptoms on a daily basis, 11.8% weekly, 7.3% monthly and 11.6% yearly (McGrother et al., 2004). 33.6% of the population reported significant urinary symptoms but only 6.2% found these troublesome and 2.4% both troublesome and socially disabling. Of the population surveyed, 3.8% (1 in 9) of those with clinically significant symptoms felt the need for help with their symptoms (Dugan et al., 2001) (Perry et al., 2000).

Stress incontinence appears to be the most common urinary incontinence type and overall 50% of incontinent women in the EPINCONT survey reported this as their only symptom. 11% described only urge incontinence and 36% reported mixed urinary incontinence (Hannestad et al., 2002).

However, the prevalence of urge and mixed incontinence increases in those aged 50 years and over (Minassian et al., 2003). The Leicestershire MRC Incontinence Study found an overall prevalence of overactive bladder syndrome in women aged 40 and above to be over 21.4% (McGrother et al., 2006).

3.4 Incontinence in Ethnic Minority Populations

Although data and research on this issue are scarce, there is some literature which has been published. A study by Wilkinson (Wilkinson, 2001) conducted in the United Kingdom looked at the perceptions of Pakistani women with incontinence. Pakistani women were less likely to report that they had incontinence as they feared that divulging this information could have detrimental effect on their access to religious activity. Similar findings have been reported by other authors (Rizk et al., 1999) who reported that 90% of United Arab Emirate women stated that urinary incontinence interfered with their ability to pray. There is very little literature published from within the country of origin of Asian women (i.e. South East Asian countries), with those that do quoting prevalence ranging from 6.2% to 13% (Pan Asia Incontinence Society).

Lara *et al* (Lara and Nacey, 1994) reported a higher prevalence of urinary incontinence in Maori women (46.8%) compared with Pacific Islanders (29.2%) and European women (31.2%). Two American studies have shown that urinary incontinence was higher in White women (23-32%) compared to Black women (16-18%) (Burgio et al., 1991) (Tennstedt et al., 2007). It is also known that White women have higher prevalence of urinary incontinence compared with Black and Hispanic women with rates of 41%, 31% and 30% respectively (Sze et al., 2002). Data obtained as part of the Leicestershire MRC Incontinence Study, found that 36.5% of Asian Community-dwelling men aged >40 years described at least one significant lower urinary tract symptoms compared to 29.0% of white men. Reported levels of bother and felt need were the same in both population groups, but actual help-seeking was significantly less in the Asian group. Only 25.0% of Asian men had actively sought help, compared to 53.1% of white men (Taylor et al., 2006).

3.5 Understanding incontinence needs of women

If clinicians and administrators understood women's reasons for, and barriers to continence care seeking, it would contribute to their ability to bring symptomatic yet untreated individuals into the healthcare system earlier in the disease process at points where intervention might prevent higher levels of morbidity and loss of quality of life. Incontinence care seeking rates have been surprisingly low for affected individuals. 71% of continent persons believe that incontinence would have a great deal or fair amount of effect on their lifestyles. If incontinent, 95% of continent subjects would go to their doctor and only 15% thought they would feel embarrassed by doing so. In contrast, only 36% of incontinent sufferers feel that their condition had a great deal or fair amount of effect on their lifestyle. However, only 52% of incontinent sufferers consulted their doctors upon realising that it was a problem (Brocklehurst, 1993). According to Hunskar, both epidemiological and qualitative incontinence research should be encouraged in order to understand cultural, religious or other reasons for help seeking behaviour worldwide (Hunskar, 2000).

3.6 Attitudes towards Urinary Incontinence

Whilst the attitudes to urinary incontinence have changed over recent years, some of the following myths are listed below (Tseng et al., 2000). People still believe that urinary incontinence is:

- Part of the aging process.
- Part of being a woman and having children.
- It is untreatable.
- A condition that will get better by itself.
- Uncommon, no one talks about it.
- Not a serious medical problem, hence not to be discussed with the doctor.

Previously published work on Pakistani women has alluded to similar beliefs about the aetiology behind urinary incontinence (Wilkinson, 2001). Currently only 10% of incontinent people in the UK seek help for their condition (Shaw et al., 2006a).

The majority of urinary incontinence sufferers prefer to self-manage using coping mechanisms that aim to conceal leakages in order to maintain self esteem (Locher et al., 2002).

3.7 The Effects of Incontinence

Incontinence affects people socially, physically and financially, causing social embarrassment to the patient and costing them emotionally and financially (Johnson et al., 2000). It can lead to social isolation affecting the patient's quality of life (Burgio et al., 1994); (DuBeau et al., 1999). Herzog outlined the psychosocial effects of incontinence stating that the stigma attached to this condition has retarded research into this area (Herzog et al., 1988).

Whilst research into incontinence and its effects have been conducted, the views that were previously held by patients and physicians have not changed much. Both patients and healthcare providers need to better understand the effects that urinary incontinence has on the sufferers and devise a management strategy that will not only be effective but also be acceptable to sufferers to ensure adherence to treatment.

3.7.1 Psychosocial Effects of Incontinence

Various studies have attempted to correlate the effect that psychosocial behaviour has on disease outcomes, including research amongst people with urinary incontinence (Lam et al., 1992; Yu et al., 1991). The psychosocial consequences of incontinence vary depending on the individual and the severity of their symptoms. However, even though the symptoms can have a profound effect on the sufferer's life, many do not

seek medical help (Holst and Wilson, 1988) (Shimanouchi et al., 2000). Literature on the help seeking behaviour of incontinent people varies with some researchers reporting that only 10 – 15% of incontinent people seek medical attention (Voelker, 1998), whilst others report that up to 50% seek help (Malmsten et al., 1997). In adult women with urinary incontinence, 60% avoid going away from home, 50% feel odd or different from others and 45% avoid using public transport. 50% also report avoiding sexual activity through fear of incontinence (Norton et al., 1988). Serious psychiatric morbidity has been reported in one quarter of women attending hospital for urinary incontinence (Macaulay et al., 1987). For carers, urinary incontinence offers a major reason for breakdown of the caring relationship, with financial cost to patients and carers (Thom et al., 1997).

3.7.2 Coping Mechanisms

Incontinence coping mechanisms are those behaviours that incontinent people employ in an effort to deal with or conceal their condition. Various authors have documented these mechanisms (Diokno et al., 2006); (Shaw, 2001).

Examples of coping strategies are:

- Adjusting their daily routine (e.g. avoiding going out, or only doing short distances, going to the toilet often to avoid leak)
- Reducing their fluid intake before going out or going to bed
- Reducing physical activities in order to minimise accidents (avoiding exercise, or walking)
- Identifying locations of toilets (toilet mapping)
- Use of absorption devices/frequent changing of undergarments

Urinary incontinence pads are a passive way of coping with the condition. Studies have reported that incontinent patients who use pads do not consider themselves

incontinent because they do not leak onto their undergarments (Mittiness and Barker, 1995). Satisfaction with the product may influence whether the patient seeks treatment or whether they continue trying to cope with the embarrassing symptoms of urinary incontinence. The severity of the patients' condition and the extremities of the coping mechanisms may influence their decision to seek treatment (Burgio et al., 1994).

3.7.3 Help Seeking Behaviour

Health planners need to know the factors that influence help seeking behaviour so they can develop and provide appropriate services and intervention, particularly since people with mild urinary incontinence are less likely to seek help than those people with severe urinary incontinence (Dugan et al., 2001). If help can be provided to those people with mild urinary incontinence, they can achieve better health outcomes with less invasive treatment.

A study by Dugan et al (Dugan et al., 2001) found that healthcare providers did not ask patients with urinary incontinence about their symptoms and 70% of patients suffering didn't bring up the topic either. Severity of symptoms prompted consultation and people tended to wait till their symptoms were severe before they sought help. However, Kinchen et al (Kinchen et al., 2003) reported that 90% of overactive bladder sufferers who sought help initiated the topic themselves. Other studies have reported that whilst 71% of incontinent women seek help within the first 2 years of symptom onset, 23% delayed their treatment for at least 5 years (Valerius, 1997). Therefore the type, duration and severity of symptoms influences help seeking behaviour with women experiencing a greater impact on quality of life more likely to seek help than those who felt urinary incontinence was not a major concern (Burgio et al., 1994).

3.7.4 Cultural barriers to help seeking

The perception of illness and health are influenced by patients' culture and stigma attached to that illness (Dyck, 1992). Hence, when addressing the issue of help seeking behaviour it is important that the cultural aspects of the condition are taken into consideration, particularly if there is shame attached to the condition as there is with incontinence. Shame is one of the negative emotions identified by people suffering with incontinence (Dugan et al., 2001). It is important that an understanding of this emotion is clear with relation to the medical interview especially since only 10-15% of women with incontinence seek medical advice (Minassian et al., 2003).

Patients may fear being ridiculed or experience shame at having to divulge personal information, but during a medical interview the patient must be probed about their beliefs of the condition, the methods of treatment and the prognosis. (McGrother et al., 2004).

3.7.5 Financial Implications of Urinary Incontinence

The impact of urinary incontinence on health care costs is substantial and increasing. The condition imposes a significant financial burden on individuals, their families and healthcare organisations. It is only in the last 20 years that researchers have looked into the impact that urinary incontinence has on the quality of life of sufferers (Kelleher et al., 2006) with various questionnaires developed to measure the impact of urinary incontinence on the patients' quality of life.

Estimating the economic cost of urinary incontinence requires a standardised definition of urinary incontinence and whilst many studies attempt to calculate the economic cost, the definitions are different making a comparison across studies difficult. Hu and Wagner (Hu et al., 2004) have summarised methods and definitions used to determine

the economic costs associated with urinary incontinence. These methods of defining the economic cost of urinary incontinence are of particular importance in policy development and resource allocation. It is evidence from studies that attempts have been made to estimate the total economic cost of urinary incontinence but determining the intangible cost of urinary incontinence is difficult. Intangible cost is the value of pain and suffering with decreased quality of life experienced by the patient. It has been estimated that 20% of people aged 40 years and over representing around 5 million people in the UK have a healthcare requirement (McGrother et al., 2004). This figure increases up to 36% in women aged at 80 and over.

Most studies focus on the direct cost, which include diagnostic and treatment costs, routine care costs and consequential costs (NICE, 2006). However, more studies now include the indirect cost of urinary incontinence which includes the loss of wages by urinary incontinence sufferers and their care givers, loss of productivity, loss of wages from receiving healthcare and travel costs for the patient and/or carer to obtain healthcare (Lose et al., 2001).

Studies from the US have reported that direct healthcare costs an individual at 65 years of age and older amounted to approximately \$8.2billion in the 1980s and \$16.4billion in the 1990s (Wagner and Hu, 1998). In Sweden, the estimated cost of urinary incontinence was 1.8billion Swedish Crowns in 1990, or approximately 2% of the total healthcare costs (Milsom, 2000). Data from the MRC study estimates the annual cost of the NHS to treating clinically significant urinary incontinence at £536million (£233million for women). The total annual service costs, including costs borne by individuals, were estimated at £743million (Papanicolaou et al., 2005; Turner, 2004)

3.8 Care that is available

UK statistics indicate that 36 out of 10,000 of the population per annum consult a general practitioner for incontinence. However, this represents only 7% of adults who self report such consultations (O'Brien et al., 1991). The geographical variation of service provision and access is well recognised within the UK. Some primary care continence nursing services operate walk in open referrals, but this practice is not widespread. The NHS guidance states that initial treatment for urinary incontinence should be in primary care (NICE, 2006). Unfortunately variations in service delivery means that patients may be treated extensively within primary care with behavioural and medical therapies or be referred at an early stage to specialists, including Neurologists, Geriatricians, Urologists and Gynaecologists.

The MRC Incontinence Study estimates 6.2% of people aged 40 or over are using incontinence aids of some kind (McGrother et al., 2003). Provision of containment products is rationed by some continence services and there is evidence of wide variations in waiting times for assessments of products. This may force women to buy products over the counter at their own expense. However, waiting lists exist for diagnostic and surgical procedures as well as more comprehensive pelvic floor training programmes in secondary care. There has also been a steady increase in the number of prescriptions for drugs used exclusively for incontinence in recent years.

3.8.1 Managing Incontinence in Primary Care

Given the high prevalence of urinary incontinence, early access to care is important especially in countries like the UK where waiting lists for secondary care exist. Initial treatment should therefore be commenced based on fairly simple diagnostic criteria that can be performed in every physician's office (Abrams et al., 2002). However, structural aspects of the health care system are only one determinant of treatment

seeking behaviour. Cultural differences in practice, style and patients perceptions as well as expectations are also important to consider (Deveugele et al., 2002). Where women have attended their doctor, studies have shown that GP management of women with urinary incontinence is suboptimal.

Of women who had discussed their incontinence with their GP, 50% had not been assessed for over a year and 30% had never had any form of assessment (O'Brien et al., 1991). Indeed, few GPs refer to the continence advisory service even when the accessibility and success of it has been well established (Briggs and Williams ES, 1992). Analysis of data from a MORI poll suggests that medication is often prescribed even though a clinical examination has not been carried out and a diagnosis may not have been made (Brocklehurst, 1993).

Algorithmic methods have been described for the assessment and management of women with urinary incontinence and have shown that 60% of invasive investigative procedures carried out on elderly women with urinary incontinence "could be eliminated with minimal loss of diagnostic accuracy." (Jolleys et al., 1994).

The current NICE guidelines on urinary incontinence (2006) sets out an algorithmic pathway of diagnosis and management of urinary incontinence. The guidance has a section on assessment and investigation which helps to categorize the condition into stress, urge or mixed incontinence (Table 3.1).

Table 3.1: Initial assessment and conservative management of UI by trained and competent staff

NICE clinical guideline recommends the following (NICE, 2006).

- At the initial clinical assessment, the woman's UI should be categorised as stress UI, mixed UI or urge UI/overactive bladder syndrome (OAB). Initial treatment should be started on this basis. In mixed UI, treatment should be directed towards the predominant symptom.
- The use of multi-channel cystometry, ambulatory urodynamics or video urodynamics is not recommended before starting conservative treatment.
- Absorbent products, hand held urinals and toileting aids should not be considered as a treatment for UI. They should be used only as a coping strategy pending definitive treatment, as an adjunct to ongoing therapy or for long-term management of UI only after other treatment options have been explored.

The conservative management of UI in women includes:

- Lifestyle interventions.
- Pelvic floor muscle training.
- Bladder training.
- Drug treatment if bladder training is ineffective.
- Bladder catheterisation for women in whom persistent urinary retention is causing incontinence.

Electrical stimulation and/or biofeedback for women who cannot actively contract their pelvic floor muscles. However, current availability is limited in some areas, so commissioners may wish to consider commissioning services from specialist regional teams.

Treatment recommendations include:

- Routine clinical history taking for urinary incontinence should include medication review, enquiry as to bowel problems (in particular constipation and faecal incontinence), functional ability to reach the toilet, appropriate fluid intake and sexual dysfunction.
- Lifestyle changes, such as changing how much a person drinks and losing weight
- Initial assessment of a female patient with urinary incontinence should include urinalysis and pelvic examination.
- At least three months of pelvic floor muscle training. Pelvic floor muscle exercises should be the first choice of treatment offered to patients suffering from stress or mixed incontinence. Referral should be to a specialist physiotherapist or trained Primary Care clinician
- At least six weeks of bladder training.
- A trial of an anti-muscarinic should be given to patients with significant urgency with or without urge incontinence assuming no contra-indications exist.
- Using a validated quality of life and incontinence severity questionnaire to evaluate and audit the impact of urinary symptoms and effectiveness of any management strategy
- Patients should be referred to secondary care if previous surgical or non-surgical treatments for urinary incontinence have failed or if surgical treatments are being considered.

It is important to evaluate the adherence to this policy and impact it will have on service provision. However, looking back to the Consensus conference on urinary incontinence in adults (Conference, 1989) most health care professionals ignored the problem of urinary incontinence and provided inadequate diagnosis and treatment.

Various studies have shown the reasons for not practicing in accordance with recommendations are lack of time, staff, diagnostic tools and competences, and low motivation of health professionals (Lose et al., 2001; Viktrup and Bump, 2003). The obstacles mentioned are found in many countries and indicate a potential need for local initiatives for implementation of guidelines to improve quality of care for UI patients both in primary and secondary care (Hilton and Stanton, 1981).

Nurse led clinics have shown a significant improvement in the patients' symptoms in 68% of women attending their clinics and it is advocated that this may be the way forward in first line management of urinary incontinence in primary as well as secondary care (O'Brien et al., 1991).

3.9 Summary

Urinary incontinence is an embarrassing problem for many women, with an under reported prevalence, and even lesser data on women from ethnic minority background. In spite of government initiatives and recommendations service provisions remains poor and these need to be addressed to ensure appropriate information and management tools are available for those that suffer and those that manage this condition.

Chapter 4: Methodology

The studies in this research program use a variety of mixed research methods. We have used both quantitative and qualitative methods as outlined below, with the rationale for selecting the appropriate research method for quality data collection.

4.1 Mixed Method Approach

Mixed methods research is an approach that combines the collection and analysis of quantitative and qualitative data (Creswell et al., 2004). Quantitative data are data in numerical form, often derived from questionnaires or structured interviews. Qualitative data is descriptive data from observation or unstructured interviews (Taylor and Bogdan, 1998) pg 632. The use of mixed methods research has seen a growth in popularity driven by the increasing complexity of research problems relating to human health.

Mixed methods involves the planned mixing of qualitative and quantitative methods at a predetermined stage of the research process, either in the initial study planning, during the process of data collection, or data analysis and reporting, in order to answer the research question effectively.

4.1.1 Advantages

Bryman et al (Bryman and Burgess, 1994) pg126 suggests that combining qualitative and quantitative methods brings together the strengths and benefits of each while reducing their respective weaknesses and limitations. For example, a large-scale survey may yield useful quantitative data about certain aspects of a prevalence, incidence, objective cure, but cannot explore in depth their underlying beliefs and perceptions.

“If the only tool researchers have is a hammer, they tend to see every problem as a nail. An appreciation of both quantitative and qualitative approaches can enhance a

researcher's ability to answer complex questions in a manner which is efficient, internally valid, and generalizable" (Stange and Zyzanski, 1989).

4.1.2 Disadvantages

While there are demonstrated benefits to the mixed methods designs, there are several limitations and challenges as well. Qualitative data lose their depth and flexibility when they are quantitized. Qualitative codes are multidimensional, meaning they can and do provide insights into a host of interrelated conceptual themes or issues during analysis (Bazeley, 2004). Codes can also be revisited during analysis in an iterative analytic process to allow for the recognition of emergent themes and insights. Quantified data however are fixed, one-dimensional and cannot change in response to new insights in analysis. Another challenge to mixed methods research, commonly expressed by quantitative researchers, concerns the limitations of quantified qualitative data for statistical measurement (Roberts, 2000).

4.2 Quantitative methods

The ICS has recommended that outcome measures in clinical trials be standardised and that quality of life be measured in studies of urinary incontinence (Abrams et al., 2002a). Interest is focused on developing condition specific measures for incontinent patients in the hope that they will be more sensitive to change in intervention studies than generic measures.

4.2.1 Quality of Life Questionnaires

Urinary symptoms affect different women in different ways and have a variable influence on their physical psychological, social, domestic and interpersonal lifestyles. The assessment of disease severity, treatment efficacy and the treatment selection for urinary incontinence have traditionally been performed on objective findings obtained by urodynamic examination and the pad test (Gotoh, 2007). However, since 1987 various quality of life assessment questionnaires have been developed for patients with urinary incontinence and in recent years subjective symptoms and quality of life have become more important than objective findings. Quality of life is usually measured with questionnaires completed by the patient or their carer and although many different questionnaires are now available each conform to the same basic structure. The questionnaires consist of a variable number of domains or sections which gather information focused on particular aspects of health and quality of life. Quality of life assessment may prove to be important for health services research and for the allocation of financial resources within an already over utilised and underfunded health service. Two major types of quality of life questionnaires are available, namely generic and disease specific (Streiner, 1993).

Generic questionnaires widely test varying states of health and therefore lack specificity towards a particular condition. Disease specific questionnaires aim to overcome this problem and are designed to assess with great complexity and accuracy the impact of specific medical complications. A number of condition specific questionnaires have been designed for the assessment of urinary incontinent women (Barber, 2007)

Relationship of quality of life with clinical measures

Assessing the impact of urinary incontinence on the wellbeing of individuals can be accomplished using a symptom impact evaluation or quality of life questionnaire. Symptom impact questionnaires measure the degree to which a patient is bothered by the presence of a symptom rather than measuring whether a symptom is present or absent. Comparing symptom impact and symptom presence is an important concept. In a study by Jolleys et al (1994), the prevalence of symptoms did not correlate with their degree of bother. For example, whilst only 14% of patients had nocturia, 67% found it bothersome. In contrast, 78% of patients had terminal dribbling but only 19% found it bothersome. View of bother varies significantly and is affected by many different factors. The objective degree of symptom severity such as number of pads worn or the amount of urine lost may not be as important as an individuals' overall outlook on the problem. This is an important concept when assessing condition specific questionnaires which address the impact of specific symptoms. If the impact of symptoms is to be used to compare individuals with different urinary problems, then a system of weighing the significance of the individuals' symptom is essential in order to make any valid comparisons between different diagnostic groups. It would for example be difficult to compare the symptom impact for women with predominantly overactive bladder symptoms to that of women with predominantly stress symptoms when both are scored on the same scale.

4.2.1.1 The Leicester Impact Scale (LIS)

The Leicester Impact Scale is a questionnaire which assesses the impact of storage symptoms with and without incontinence in a community sample of men and women with a wide variation in symptom severity (Shaw et al., 2004). It extends the knowledge base by providing psychometric data on an interview administered questionnaire which is potentially useful in clinical situations as well as in the research context. This questionnaire was developed following a literature review and

discussions with clinicians and people who experienced urinary symptoms. Three areas of impact were identified, impact on activities, feelings and relationships. A score of two was assigned for a lot of impact and if the urinary pattern had stopped activity, one for little and zero for not at all. If the respondent did not do the activity for other reasons the item was treated as missing, as was a non response or a don't know/not sure response [Appendix 2]. This questionnaire provides a useful tool for the assessment of impact of lower urinary tract symptoms and quality of life having all the characteristics for good measure as proposed in the classic principles of item measurement theory, i.e. coverage, reliability, validity and responsiveness (Testa and Simonson, 1996).

4.2.1.2 Leicester Urinary Symptoms Questionnaire (LUSQ)

The Leicester Urinary Symptoms questionnaire was designed as an outcome measure for a series of clinical trials of service provision and specific drug and behavioural treatments, (Perry et al., 2000) as well as acting as a descriptor of severity of symptoms in an epidemiological context. The questionnaire was developed from a review of the literature and discussion with clinicians, epidemiologists, social scientists, statisticians and patients undergoing treatment for urinary symptoms. It focuses on storage symptoms including urgency, frequency and nocturia as well as incontinence. It is a tool that is appropriate for use in people with a wide range of severity symptoms. It was validated in 930 consecutive patients taking part in a randomised controlled trial of a nurse led continence service (Williams et al., 2000). The reliability of the instrument over time (test re-test reliability) was examined by administering the questionnaire on two separate occasions by the same interviewer. Reliability across interviewers was assessed using different interviewers on each occasion [Appendix 2].

4.2.1.3 International Consultation on Incontinence Questionnaire: Short Form (ICIQ-SF)

The original ICIQ short form included ten questions on the frequency of urinary incontinence, degree of hindrance, frequency in the use of napkin, type of napkin, subjective assessment of the amount of urinary incontinence, influence on daily life, influence on social life, influence on sexual life and quality of general life. Moreover, age, gender and a subjective assessment of the cause of urinary incontinence was also included in the ICIQ short form. During the verification of the ICIQ short form, considerable duplications were observed amongst the questions. Therefore it was amended so that the final edition only had 3 questions related to the frequency of incontinence, the ordinary amount of urinary incontinence and the influence on daily life. Since the assessment of the cause of urinary incontinence is important for clinicians, a question related to the subjective assessment of the cause of urinary incontinence was included in the final edition. However, this question was not scored. The scores of the 3 questions were summed and the resulting total ranged from between 0 and 21 points. The ICIQ short form was developed for all patients with urinary incontinence regardless of gender and age, the validity, reliability and the responsiveness of the ICIQ short form was verified and it has been translated into 27 languages including Japanese, Dutch, Spanish and Swedish (Gotoh, 2007). However, there is no translated version in any Indian regional languages [Appendix 2].

4.2.2 Selection of questionnaires for this research project

Several scales have been developed to measure the quality of life in people with urinary symptoms. The Incontinence Impact Questionnaire (IIQ) (Shumaker et al., 1994) is the most similar to the Leicester Impact Scale as it includes subscales related to activities and feelings but was only originally developed for women with incontinence only. It has a greater emphasis on the impact on activities and having relatively few

items concerning emotion. Another well validated questionnaire is the Kings Health questionnaire (Kelleher, 2000). This questionnaire has proved to be a valid and reliable tool for the assessment of condition specific impact in people with urinary symptoms. It is appropriate for use across primary and secondary care settings and will allow comparisons across gender and between different diagnostic conditions. However it concentrates on the degree of impact on the symptoms rather than measuring clinical severity.

As urinary symptoms are common in older and more disabled patients, it is not always possible to use self completion questionnaires but there is little information in the literature concerning the psychometric properties of interviewer based methods for measuring the effects of urinary symptoms on the quality of life (Guillemin et al., 1993). There are few studies in the literature that have examined the issue comparing self and interviewer administered questionnaires. The presence of an interviewer may provide the individual with a more structured framework for her response and may help the subject to give more information. However, studies have shown a high agreement between self administered and interviewer administered questionnaires (Durant and Carey, 2000; Kaplan et al., 2001; Siemiatycki, 1979).

The only questionnaire recommended by the ICS that was designed as an interview measure is the Incontinence Severity Index (Sandvik et al., 1993). It includes questions only about leakage with a summary score based on frequency and the amount of leakage.

Both the Leicester Impact scale and the Leicester Symptoms questionnaire have the added advantage of being validated in community dwelling women and therefore were chosen for the study as that was the population that was to be studied. The added advantage of using them as interviewer administered questionnaires made it a

favourable choice over other questionnaires, as we anticipated that the participants in the study may have difficulty completing self administered questionnaires due to language barriers.

4.2.3 Translated Questionnaires

Authors such as Hansen (Hansen, 1987) discuss at length the implications of translation in developing data collection instruments when using quantitative methods of research. The literature regarding research using quantitative methods describes three key concepts which have implications for equivalence in translation:- source language, target language and back translation (McDermott and Palchanes, 1994).

All three questionnaires used in this study were translated and back translated by Translation India (2006). They were then piloted in 40 bi-lingual women to test for cultural understanding and acceptability. Hindi and Gujarati were the two languages that this was done in because these were the two common languages spoken by the studied population [Appendix 3].

4.3 Qualitative Methods

4.3.1 Qualitative research in urogynaecology

This section has been published as an editorial piece in BJOG 2007 [Appendix16]

Lower urinary tract dysfunction is a common and distressing problem. With functional, psychological and social sequel, it can have far-reaching effects on everyday life for individuals affected and others. Over 25 years ago, Patrick Bates coined the phrase 'the bladder is an unreliable witness', meaning that no matter what the underlying patho-physiology, the bladder has a limited means of expressing its own pathology. But what about those to whom these bladders belong? There is increasing recognition that what matters to most women with chronic illness is how well they are able to function and how they feel about their day-to-day lives. Understanding patients concerns, expectations and requests is important for the measurement of healthcare quality, the delivery of health services and the costs of care.

What is qualitative research?

A qualitative 'approach' is a general way of thinking about conducting qualitative research. It describes the purpose of the qualitative research, the role of the researcher(s), the stages of research and the method of data analysis. Qualitative research, like quantitative research, embodies a number of different theoretically based approaches (Holloway, 1997) (Table 4.1). Qualitative research is distinguished by an emphasis on trying to look at things from the perspective of those being studied. Qualitative methods can be particularly useful in areas where little research exists. The systematic observation of everyday behaviour, interactions and talk is especially useful in studying health issues because it allows researchers to examine what people actually do rather than relying on reported behaviour. This is something a quality-of-life questionnaire attempts to measure but does not succeed in its entirety (Little, 1998). For example, urgency, defined as the compelling feeling of impending incontinence that is difficult to defer (Chapple et al., 2005), is the cornerstone symptom of overactive

bladder. Unfortunately, controversy continues to surround this term, its definition and its relationship to the normal urge to void. Qualitative research would be the ideal tool to unravel these uncertainties to explore the relationship of the symptom to existing measures of bladder function and symptom severity.

Table 4.1: Theoretical Approaches to qualitative research

- Ethnography is research which emphasis on studying an entire culture. Originally, the idea of a culture was tied to the notion of ethnicity and geographic location, but it has been broadened to include virtually any group or organization.
- Phenomenology is a school of thought that emphasizes a focus on people's subjective experiences and interpretations of the world. That is, the phenomenologist wants to understand how the world appears to others.
- Grounded theory is a complex *iterative* process. The research begins with the raising of *generative questions* which help to guide the research but are not intended to be either static or confining. As the researcher begins to gather data, *core theoretical concept(s)* are identified. Tentative *linkages* are developed between the theoretical core concepts and the data.

Where is the qualitative research?

Qualitative research continues to become more prominent in medicine and health services research. Recent editorials have advocated a larger role for qualitative research as a way to address both 'clinical' and 'bio-psychosocial' phenomena (Berkwits and Aronowitz, 1995), (Inui, 1996), (Jones, 1995), and increasing numbers of papers reporting qualitative studies have begun to appear in prominent journals. However, only 16 of 3146 abstracts accepted at International Continence Society annual conferences over the past 5 years (2002–2006) presented findings from qualitative research despite a range of areas of investigation where qualitative work would offer a valuable insight. A similar picture can be seen from examining the abstracts presented at the International Urogynaecology Association meeting of 2007. Only 3 (0.6%) of the 497 abstracts (oral podium, oral poster, non-discussed poster and videos) were presentations of qualitative research.

So, what is the place of qualitative research in urogynaecology?

The potential purposes for which qualitative research might be used in relation to urinary incontinence are multiple:

Generating/Clarifying the hypothesis

Clinical measurement is at the heart of biomedical research, but what if the measurements are not as reliable as we suppose? We generally accept that the 1-hour pad test is an objective measure of urinary incontinence, although its reliability has been challenged (Matharu et al., 2004). The same is certainly true of the standard urodynamic test. There may be a paradoxical situation, as seen in clinical practice, where urodynamic tests that are thought to be objective may be found to be unreliable, and so of little clinical value (Whiteside et al., 2006), while urinary symptoms assessed by the women that are thought to be subjective may be found to be reliable, and so of greater clinical value.

Exploring new ground/theories

While qualitative and quantitative research may well investigate similar topics, each will address a different type of question. For example, in relation to adherence to drug treatment, a quantitative study will be used to determine the proportion and demographic characteristics of women taking a certain percentage of prescribed drugs over a given period. Questions about the reasons for variations in adherence and the meaning of drug treatment in the lives of women may be best investigated by a qualitative approach (Britten et al., 1995). Such investigation becomes very important if you want to understand the reason for non-compliance to anti-cholinergic medications or Duloxetine (drug for stress incontinence), for example.

Understanding quantitative study findings

Researchers can use qualitative findings to better understand quantitative results and to enhance the validity of the study as a whole. The real value is the in-depth understanding that qualitative work can give us. While qualitative data can answer 'what?' and 'how many?' quantitative methods can really get at 'why?' questions. All qualitative data can be quantitatively coded in an almost infinite variety of ways.

Numbers in and of themselves cannot be interpreted without understanding the assumptions that underlie them. All quantitative data are based on qualitative judgement. Let us take, for example, the International Consultation on Incontinence Questionnaire Short Form (ICIQ SF) questionnaire. The question on 'Overall how much does leaking urine interfere with your everyday life?' which is to be answered on a scale of 0–10, requires the participant to make a judgement about what the numbers mean. We cannot really understand this quantitative value unless we dig into some of the judgements and assumptions that underlie it and explore them.

Understand perplexing results

Qualitative research may explain why the results of quantitative research based on large groups of women may be irrelevant to subgroups or individuals. Ethnography can be applied to urogynaecology as a way of accessing beliefs and practices, allowing these to be viewed in the context in which they occur and thereby aiding understanding of behaviour surrounding health and illness (Boyle, 1994). This is particularly valuable as women's views and experiences of illness or delivery of service become increasingly central to a 21st century healthcare system. Ethnography can show, for example, how the effectiveness of therapeutic interventions can be influenced by women's cultural practices (Prout, 1996) and how ethnocentric assumptions on the part of professionals can impede effective health promotion (Kingfisher and Millard, 1998). This could be useful in understanding prevalence, attitudes and help-seeking behaviour in women with urinary incontinence from different ethnic backgrounds. Qualitative research may help explain contradictory results not by determining which is correct but by explaining why they differ.

Assessing the outcomes of treatment

Outcome evaluation has been seen primarily as the preserve of quantitative research. Owing to the subjective symptomatic nature of the quality-of-life impact associated with voiding dysfunction and incontinence, there is no gold standard for outcomes assessment. Patients' perceptions of their condition, physicians' analyses of therapy (with or without investigator bias) and the real probability of incomplete symptomatic response to intervention each contribute to the difficulty of evaluating the success of any therapy. For women to have a realistic expectation of outcome, it is important to understand their expectations and priorities beforehand (Brubaker and Shull, 2005). Existing studies suggest that women regard improved symptoms and quality of life as the most important outcomes of treatment (Tincello and Alfirevic, 2002). Most women want 'a good improvement so that symptoms no longer interfere with their life'

(Robinson et al., 2003). This might suggest that good patient perceptions can be obtained without achieving total continence. But how are we to find this if we only use objective assessments to define cure?

Choosing the most effective treatment for urinary incontinence is not necessarily going to result in a satisfied woman if they are unprepared or if their expectations remain unfulfilled, and qualitative research can provide information to help in the counselling of women about these issues. This in turn may improve patient satisfaction and long-term compliance. We need a broad spectrum of information if we are to understand not only which treatments work but also how and why they work (or do not work).

Complementing quantitative research

Qualitative research can both inform and complement quantitative research. For example, interviews are frequently used in questionnaire development to check the meaning of words or terms to be used or to validate individual questions. This preliminary research is often a vital stage in survey research. Thus, all quality-of-life questionnaires must have been developed after extensive qualitative research to make them robust and user friendly.

Qualitative methods can improve service provision

Qualitative methods can help plan the locations or settings for intervention, especially if the intervention is to be community based or mobile, where the precise location of the service is crucial. For example, it is important to understand the targets populations' profiles, needs and help-seeking-related experiences, before setting up a service, especially among hard-to reach groups.

By using a multi-indicator approach, qualitative methods can complement quantitative and monitoring research to address the three key questions often asked in process delivery — is the service being delivered? Is it being delivered as planned? Is it reaching the target population? Interviews with both staff and clients can gain insight into the barriers and facilitators of service delivery as well as gaining measures of satisfaction. It can be readily seen how this kind of information can help integrated continence services around the country to provide appropriate and cost-effective care.

So, why has qualitative research struggled?

Despite offering a valuable insight into other chronic illness over the course of several decades, qualitative research has struggled to penetrate urogynaecology. One reason may be that clinical scientists have had difficulty in accepting the research methodologies of the social sciences. Publication and dissemination of the results of qualitative research have often been difficult, partly because different formats are required. A narrative, as opposed to numerate, account of an investigation may not fit into a typical biomedical journal or into a 10-minute presentation at a scientific meeting. The assessment of proposals for qualitative research and of papers submitted for publication is likely to have been hampered by a lack of agreement on criteria for assessment. Most referees are more familiar with the concepts of quantitative research (including generalisability and a large sample) and may simply transfer these thought processes to their assessment of qualitative research, although this is inappropriate. It

is possible, however, to provide clear guidance to reviewers how to assess qualitative research (Holloway, 1997).

The future

Urinary incontinence and lower urinary tract dysfunction are common conditions, and no one would deny that much more knowledge into appropriate patient-centred assessment outcomes and ultimately prevention is required. There are many goals to research, including to improve the care of women, and also to promote understanding of the disease process. Gilchrist and Engel (Gilchrist and Engel, 1995; Salganik and Heckathorn, 2004) wrote that 'qualitative research answers questions for clinicians that quantitative research cannot. These are questions about individuals' motivations, perceptions, expectations, and meaning'.

The ultimate goal is to produce credible research, and the bottom line is that quantitative and qualitative data are two sides of the same coin. To ask which is 'better' or more 'valid' ignores the intimate connection between them. To do credible research, we need to use both the qualitative and the quantitative data.

4.3.2 Data Collection

I identified various Asian community associations as well as Women's Health Centres from the Leicester City Council database. These were then approached with meetings arranged between the Heads/Leaders of these organisations and the research was outlined. Prior to inviting people to the study, a urinary incontinence awareness talk lasting 20 minutes was given. At the end of the talk women were informed about the research that was being undertaken and were invited to participate. They were advised to contact the group leader/lead of the association/women's centre if they were interested in taking part. The group leaders then contacted me, and a convenient time for the focus group was arranged (Halcomb et al., 2007).

Contrary to the researchers perception that women would require a lot of convincing to participate, women readily volunteered to take part in these focus group discussions and at times there were more women than the room could accommodate.

Recruitment also utilised snow-ball sampling (Salganik and Heckathorn, 2004) where previous participants were asked to refer other women who would possibly want to be involved in the research. The advantage of this method was that the person recommending participation contacted potential participants. I felt that this method of recruitment would possibly increase the recruitment rate as potential recruits were more likely to have more confidence and or trust in their friend or acquaintance.

Participation of women recruited through associations/women's centre/religious community centres was greatly improved by scheduling focus groups before or after other functions the women were attending at the same venue. None of the women participating in these focus group discussions had any qualms about the discussions being recorded. These women did not require any financial incentive to participate.

4.3.2.1 Focus Groups

Focus groups are semi-structured interviews that aim to explore a fixed set of issues. They were originally used within communication studies and are a popular method of assessing health education messages and examining public understand of illnesses and health behaviours (Basch, 1987). They are widely used to examine peoples' experiences of disease and health services and are an effective technique of exploring the attitudes and needs of staff (Denning and Verschelden, 1993).

Patton (1990) has described the focus group as being useful in basic research to contribute to fundamental theory and its knowledge, as well as in applied research to

determine the effectiveness of the programme. The idea behind the focus group method is that people can explore and clarify their views in ways that would be less easily accessible in a one-to-one interview. This is useful when the interviewer has a series of open ended questions and wishes to encourage research participants to explore the issues of importance to them in their own vocabulary pursuing their own priorities.

There are many advantages in using focus group interview techniques but there are also disadvantages.

4.3.2.1.1 Advantages and Disadvantages

Researchers Morgan and Stewart (Morgan, 1997; Stewart et al., 2007) found that the greatest advantage of using focus groups in studies are:

- They are particularly suitable for groups with strong oral tradition and low levels of formal education.
- They are time efficient, many people may be questioned in the same amount of time as it takes to interview one person.
- The groups provide instant verification of the data because of the in-built checks and balances of viewpoints.
- A skilled facilitator can build on a single response to develop a rich source of data.

The disadvantages are:

- Only a limited number of questions can be addressed.
- Questions cannot be explored in detail, nor can interesting leads be adequately pursued.
- The facilitator needs special skills.

- Two researchers are needed at times, one to facilitate and the other to observe and take field notes about group dynamics.
- Some people do not interview well in group situations whilst others tend to dominate, rather than their views being recorded only two or three sets of views may be reflected in the data.
- The public rather than private views of individuals tend to be documented.

Sampling and Group Composition

Data collected through qualitative research is not representative of the entire population (Ambert et al., 1995). However, selecting participants who can confirm or reject theories may improve the quality of data.

The recommended sample size for focus groups is 6 – 12 participants per focus group discussion (Stewart et al., 2007) pg 57. This size is large enough for the researcher to probe whilst allowing all of the participants a chance to express themselves (Beaudin and Pelletier, 1996). The number of focus group discussions held will depend on when data saturation, i.e. no new research themes is reached. The average size of the focus group discussions were 6-8 participants.

As mentioned earlier, on one occasion double the number of women originally invited for the focus group attended and had to be turned away. However, this situation was managed as certain members of the original focus group were quite happy to return at a later date in time to take part and they were replaced by some of the newcomers. This highlights the unpredictable nature of conducting focus groups and potential participant attendance can never be guaranteed.

Another focus group that I ran had eight confirmed participants. However, when I showed up for the focus group discussions, only two people attended. The other participants had unfortunately not informed of their absence.

Consideration should be given to group composition specifically with respect to gender and age. In some cultures, it is considered rude for a younger person to voice a different opinion from that of an older person, or one who is considered more senior in importance. This may also occur when there are females in a group of males especially in an ethnic setting (Davies, 1999).

Focus Group Guide Development

The development of a question route to guide the focus group enhances the consistency of data obtained between groups and assists in efficient high quality data analysis (Kreuger, 1988). The aim of the question guide is to first introduce the discussion with an introductory question that would stimulate group discussion (Morgan, 1997). The questions that follow gradually narrow the focus of the discussion until the key question which represents the core of the research interest are asked (Kreuger, 1988). Napolitano et al identified that the planning of questions is very important especially when conducting focus groups with culturally and linguistically diverse backgrounds (Napolitano et al., 2002). Questions that are too open ended would fail to yield answers that are meaningful. Therefore it is suggested that questions are kept short yet not closed ended (Stewart et al., 2007).

4.3.2.1.2 Focus group research with culturally and linguistically diverse groups

An increasing number of studies demonstrate the utility of the focus group method in conducting health related research in culturally and linguistically diverse populations (Devlin et al., 2006; Huer and Saenz, 2003; Whitaker and Orzol, 2006). This method is important as it gives access to marginalised groups of people with inadequate literacy or language in the dominant culture to participate in research, which traditional methods (i.e. quantitative, questionnaires) did not. It is only through culturally sensitive modifications to the traditional focus group method that the voices of participants from culturally and linguistically diverse backgrounds can be heard (Strickland, 1999).

Whilst some cultures might readily embrace the focus group method as it fits in with their already predominant oral culture (Strickland, 1999) other cultural groups such as the Chinese might find the idea of gathering a group of people together to discuss issues alien to their cultural norms (Willgerodt, 2003). Another important consideration of the focus group technique is the consideration of group dynamics. It is possible that some participants feel that they cannot disagree with leaders in a group, or present an alternative view to the group (Clarke, 1999). The presence of other research participants is a double edged sword. To some the group situation facilitates expression of views whilst in others the presence of other participants inhibits disclosure because of fear of lack of confidentiality (Kitzinger, 1994).

Some cultural groups may find audio-taping of sessions confronting and not within their cultural norms (Sim, 1998). In the investigation of rural women in India (Vissandjee et al., 2002) reported that many participants had not seen a tape recorder before. During one focus group in this research project (Cultural context study Chapter 6a, focus

group no 3) a participant asked for the recording to be ceased before she could truthfully answer a question.

Linguistic Difficulties

Evidence from studies such as one undertaken by (Neile, 1995) to examine the maternity needs of the Chinese community in Central England indicated that non-English speakers were inaccurately and inadequately studied due to language difficulties.

Marshall et al (Marshall and While, 1994) highlighted the difficulties of undertaking semi-structured interviews with respondents for whom English was their second language. Where English is not the first language of informants, it is appropriate for researchers to use the language of the participants to obtain an understanding of health experiences and perceptions of health care.

In the literature reference is made to face-to-face communication which allows for clarification between the researcher and the participant, however issues can arise when the data are translated, which then are difficult to clarify (Temple and Young, 2004).

4.3.2.1.3 Focus groups in the study

As we have suggested we felt that it was important to ensure that all group members understood that although the group should be committed to maintain confidentiality, this could not be guaranteed. It became clear that as a researcher, I had limited control over the process of disclosure and of course had no control over the maintenance of confidentiality.

Contrary to our belief that women would not be happy to share personal stories about their incontinence, many women actually did reveal personal information about their suffering in silence with the condition.

At the beginning of the focus groups and at the end it was reiterated that there would be no identifying markers to the discussions and name alias would be used if the quotes were to be used in future publications.

Sessions in our research were run in a relaxed, comfortable setting, usually at a participants' home or the community centres. It was felt that if the participants were familiar with the venue they would be less likely to feel intimidated and would feel more able to speak freely, as well as the fact that they would not need to travel to various locations. Most of the focus groups were either conducted during lunch hours, when the interviewees were free or after working hours when these women attend the various organisations. Refreshments were provided.

The seats for the focus group discussions were arranged in a semi-circle around a table with the facilitator seated in front of the participants. Before each focus group all participants were informed of the study purpose and confidentiality issues around the discussions. The focus groups were all tape recorded and participants were advised that if they wished to leave the discussions at any time, they were free to do so.

Once the focus group had been seated, the facilitator introduced the topic and then ran through the ethical issues of confidentiality and anonymity and the right of each individual to withdraw from the group at any point without penalty and the right not to respond to any questions. The facilitator then explained the aim of the focus group to encourage people to talk to each other rather than address themselves to the researcher. As the session progressed the researcher adopted a more interventionist

style urging debate to continue beyond the stage it might otherwise have ended and encouraging the group to discuss inconsistencies both between participants and within their own thinking.

Assuring the participants that question time would be allowed at the end of the focus group reduced the chances of interruptions with questions from participants. Most of the focus group participants kept to these instructions and usually I spent an additional 30 minutes after the focus group discussions answering questions pertaining to individuals suffering urinary storage symptoms. The researcher facilitated all the focus groups that were held in either English or Gujarati/Hindi/Punjabi as the principal investigator was multi-lingual. Women were happy that this research was being conducted and especially in a language that they were comfortable with and therefore were happy to recruit other women with similar problems. The focus group discussions ran for approximately an hour and half. Participants were assured of name aliases if their data was used in any publication from the focus groups. This seemed to put the women at ease.

The focus group discussion guide was reviewed by me and one of the supervisors after a couple of focus group discussions. This was due to unanticipated information collected from the participants and to probe into other areas which the initial focus group guide had not taken into account. The focus group discussion guide was modified (for example, there was no question in the original focus group guide on traditional practices, as this was highlighted by the women in the first two focus groups , the focus group guide was revised to include questions on this).

After the focus group discussions some women wanted to speak to the facilitator privately about urinary incontinence. This could indicate the sensitive nature of the topic and highlight one of the drawbacks of data collection through focus group

discussions, or the fact that these women were not comfortable talking about urinary incontinence in the presence of other women.

One of the most challenging parts of data collection with Indian women was their tendency to all speak at once. The women were constantly being reminded that transcribing the audio tape would be difficult if they all spoke at the same time rendering the whole process fruitless.

4.3.2.2 Interviews

Interviews are one of the most commonly recognised forms of qualitative research method. There are three main interview structures: informal, guided and structured (Britten, 1995). Informal interviews occur largely as an adjunct to participant observation and are spontaneous and based on interaction between researcher and respondent. Information that is often relevant to the research question may emerge in this casual general conversation. Guided interviews comprise of a set of broad ranging questions derived from previously researched theoretical aspects. The structure, phrasing and placement of these questions in the interview process are at the interviewer's discretion. The major purpose of guided interviews is to provide a minimal directive framework which enables both researcher and informant to access and identify key areas for further investigation.

Structured interviews consist of administering structured questionnaires and interviewers are trained to ask questions in a standardised manner, example: "is your health excellent, good, fair or poor?" Semi-structured interviews are conducted on the basis of a loose structure consisting of open ended questions that define the area to be explored at least initially and from which the interviewer or interviewee may divert in order to pursue an idea in more detail.

Clinical and qualitative research interviews are very different. Although the doctor may be willing to see the problem from the patients' perspective, the clinical task is to fit that problem into an appropriate medical category such that a management plan is initiated. Due to time constraints in most medical consultations open ended questioning needs to be brought to a conclusion swiftly (Britten et al., 1995).

Interviews aim is to discover the interviewees own structure of meaning and the researchers task is to avoid imposing their assumptions and beliefs as much as possible. The researcher needs to remain open to the possibility that the concepts that emerge can be very different from those that might have been predicted at the outset of the research project.

Good qualitative interviewing is hard, creative work that requires a great deal of planning (Holstein and Gubrium, 1995).

4.3.2.2.1 Interviews in the study

Interviews were used in the patients' experience of primary care study and those in India. (Chapter 5b and 7b). The interview guides were developed and based on the information collected via participant observation, informal interviews and the literature review. The guide was produced from the focus groups conducted in the earlier part of the study and a review of literature.

Interviews lasted on average 35 minutes and took place at the participants' homes. The interviewee was asked to select the venue, because choosing a venue convenient for the interviewee helped to reduce the chances of women declining to be interviewed and may also have helped the women feel comfortable in their environment, thus increasing the chances of them speaking openly. The number of interviews that were to be conducted was not predetermined, but it was decided that cessation of the

interview process would occur when data saturation was reached. Data saturation level is reached when the information gathered from the different sources does not add depth to the research purpose (Morse and Field, 1995) or if all resources have been exhausted or irregularities in the data start to appear (Hoepfl, 1997). I found that by the tenth interview (Study on patients' experience of management in primary care Chapter 7b) saturation was reached and hence stopped interviewing.

4.4 Data Analysis

There are a number of stages in the analysis of qualitative interview data. It is important to familiarize oneself with the data by reading and re-reading the transcribed information, constantly organising, integrating, interpreting and comparing the data as it becomes available (Polit and Hungler, 1999). This process can be cumbersome when conducting research with an ethnic group to which a researcher does not belong and it requires numerous translations and back translations. Some researchers transcribe all data collected verbatim, including information given by participants which does not relate to the topics being discussed (Field and Morse, 1985); (Twinn, 1997). The inclusion or exclusion of these data is dependent on the researchers. Some researchers may argue as to why this information should be transcribed when it has nothing to do with the topic (Seale and Silverman, 1997). Others argue that this so-called "waffle" may help in developing new concepts and or themes (Twinn, 1997). We used the following data analysis approach as described by Morse and Field (Morse and Field, 1995) and Polit and Hungler (Polit and Hungler, 1999):

- **Comprehending**

It is during this process the researcher aims to gain a deeper understanding of the data determining the presence of new phenomena.

- Synthesizing

That is sifting through the data, placing all the pieces of the puzzle together and determining the norms (recurring themes) and the outliers (themes different from the bulk of the data).

- Theorising

It is during this process the researcher aims to determine if there could be any other explanation for the conclusion being drawn.

- Recontextualizing

Here the researcher attempts to develop a theory so that the theories presented can be generalised to other groups.

Discussions of similar recurrent and important themes are drawn together and compared and their relationship to variables within the sample population examined. These repeated themes are grounded in the data and not imposed onto the data by the researcher. One method of analysis that can be used is rating teams or issues by independent raters chosen on the basis of their general knowledge of the topic. In content analysis of the transcription, raters identify emerging themes and patterns concerning the product or service being evaluated. Other methods of analysis include tabulation of word or phrase frequency, construction of grids summarising the content of group interviews and quote mapping of interviews (Knodel, 1993).

It is important that differences between individuals are analysed and should be explored especially those that do not fit with into the general themes.

The impact of the groups' dynamics and specific comments, jokes, anecdotes, questions, censorship, changes of mind, deferring to the opinion of others are all

equally important. Quotations must not be taken out of context if the analysis is to be true to the data.

4.4.1 Grounded Theory

Grounded theory is an approach that develops the theory from the data collected, rather than applying a theory to the data. This can be a popular approach for people exploring a new area of research.

Grounded theory requires an interpersonal interaction on the part of the researcher with both the data and participants in the study. The researcher must not only observe the participants but observe self behaviour and so make visible one's own preconception values and beliefs (Hutchinson, 1993). The most critical aspect of grounded theory which differentiates it from other qualitative research methods is its emphasis on theory development (Strauss and Corbin, 1998). Theory is said to be grounded when it emerges from and generates explanations of relationships and events that reflect the life experiences of those individual groups and processes we are attempting to understand. Denzin (Denzin and Lincoln, 2000) describes four functions that all data serve and contribute to theory development. Grounded theory is considered to be particularly appropriate when little is known about a topic and there are few existing theories to explain a particular phenomenon (Hutchinson, 1993). We chose this as there is very little knowledge of urinary incontinence in the population that we wished to study and we wanted to gather data without any preformed opinions.

4.4.2 Constant comparison method

This is widely used approach to qualitative research (Green, 1998). It involves checking the consistency and accuracy of interpretations and especially the application of codes by constantly comparing one interpretation or code with others both of a similar sort and in other cases and settings. This is to ensure both consistency and

completeness in analysis. Previously coded text also needs to be checked to see if the new codes created are relevant. Constant comparison is a central part of grounded theory. Newly gathered data are continually compared with previously collected data and their coding in order to refine the development of theoretical categories. The purpose is to test emerging ideas that might take the research in new and fruitful directions.

Constant comparison also involves looking for variations and differences across cases, settings or factors which affect the phenomena that are being studied. Such variations might include the influence of age and gender. This was addressed with focus groups run with different age groups in the study.

4.4.3 Coding of data

Strauss and Corbin (1998) suggest there are 3 stages in analysis in grounded theory: open coding, axial coding and selective coding. During open coding the researcher reads the text and asks questions to identify codes that are theoretical or analytical, e.g. what is going on behind what the person interviewed says rather than just coding literally what is said.

Coding Line-by-line

Line-by-line coding, literally means coding each line of an interview. This approach is intended to be an analytical process not being influenced by preconceived ideas. The next step is to check the codes against the text again and see how they can be improved. The codes are also linked with each other and with more general codes.

The next step after this initial line-by-line coding is to refine the actual codes and to link code together in a meaningful way according their importance. So there may be main

code with sub-codes relating to that topic (Coding tree for Cultural context study UK and patients' experience of primary care management) [Appendix 4 and 5].

4.4.4 Data quality and reliability in qualitative research

Schatz and Walker (1995) state that the researcher cannot help but be a co-participant. The researcher has had previous experience with South Asian women, being involved in consultation for general obstetrics and gynaecological problems as well as having a special area of interest in urinary incontinence in women. In keeping with the philosophy of accepting the researcher as a co-participant, I have been explicit and transparent in my role as an interpreter of the data collected through the various triangulation methods used in this research.

The debate about criteria for good quality

In natural science findings are validated by their repeated replication. If a second investigator cannot replicate the findings when they repeat the experiment then the original results are questioned. If no-one else can replicate the original results then they are rejected as flawed and invalid. Natural scientists have developed procedures and designs to ensure that experiments can be replicated.

In social research there are two problems with adopting this approach. First, there is no widespread agreement about whether there can be any procedures that ensure research and analyses produce the right answers. Second, replication is seldom possible and in most cases doesn't make much sense. When observed or questioned again, respondents in qualitative research will rarely say or do exactly the same things. Whether results have been successfully replicated is always a matter of interpretation.

Inter-rater reliability

If more than one person or team is coding then it is possible to compare how they have coded the same passages. The coding of the same data by a primary coder and secondary coder is compared to see where there are areas of agreement and disagreement. Disagreements can then be discussed and a new agreement reached about a codes definition, improving consistency and rigour. This is commonly used by teams where individuals may be coding parts of a large data set and it is important that codes are applied consistently. In this case inter-rater reliability helps refine the coding definition to one which the team agree on.

Reliability

One way to demonstrate reliability is to include evidence in the analytic reports. Usually, this takes the form of quotations from interviews and field notes, along with detailed descriptions of episodes, events and settings. A danger, when using quotations, is to use too many and to make them too long forcing the reader to make their own interpretations of the data. On the other hand quotations that are too short can become decontextualised and, again, without explanation they will lose their power.

Generalisability/Transferability

Generalisability or transferability refers to how these findings can be applied to other people, times and settings other than those actually studied. By defining, in detail, the kind of settings and types of people to whom the explanation or theory applies data can be used for wider interpretation.

4.4.5 Triangulation

Data triangulation refers to the use of numerous sources in order to validate the conclusions drawn from research (Polit and Hungler, 1999). Data triangulation aims to take into account the time span over which the data is collected, the site in which the data is collected and the sources of that data. The aim is to elucidate data which takes these variations of factors into consideration whilst ensuring data consistency. Data triangulation was utilised in this project. Both qualitative and quantitative methods were used to answer the research question. Data were collected from women who had been in the UK for a long period of time and these was compared with data from women from different age ranges as well as women who are still in their country of origin.

Investigator triangulation uses more than one person to analyse and interpret the data. This aims to reduce the chance of bias in the data interpretation. In addition, investigator triangulation helps to highlight issues that the investigator may not be aware of for improving the quality of data. This process can prove quite cumbersome particular when conducting research which requires the translation of collected data. Whilst I conducted the interviews and focus groups, the data collected was reviewed by myself and one of the supervisors to ensure reliability.

Method triangulation (Foss and Ellefsen, 2002) refers to the use of more than one data collection method to address the same research question. This ensures that the data collected are not influenced by the method selected.

As this research uses mixed methods tools, various questionnaires and qualitative methods have been used to triangulate data and ensure a complete understanding is reached.

4.5 Ethical approval and consideration

The Cultural Context Study (Chapter 6a) recruited women from the various women's group, religious centres and community organisations. Advice was sought from the local research ethics committee (LREC) about whether formal ethical approval was required. At the time the study commenced, the role of the LREC was to assess research involving NHS patients and staff, or other research taking place in the NHS premises. Thus, we were told that formal approval was not necessary for this community-based study, and that assessment was outside the remit of the LREC. Furthermore, at that time our institution did not have a system for formal review of studies falling outside the remit of the LREC.

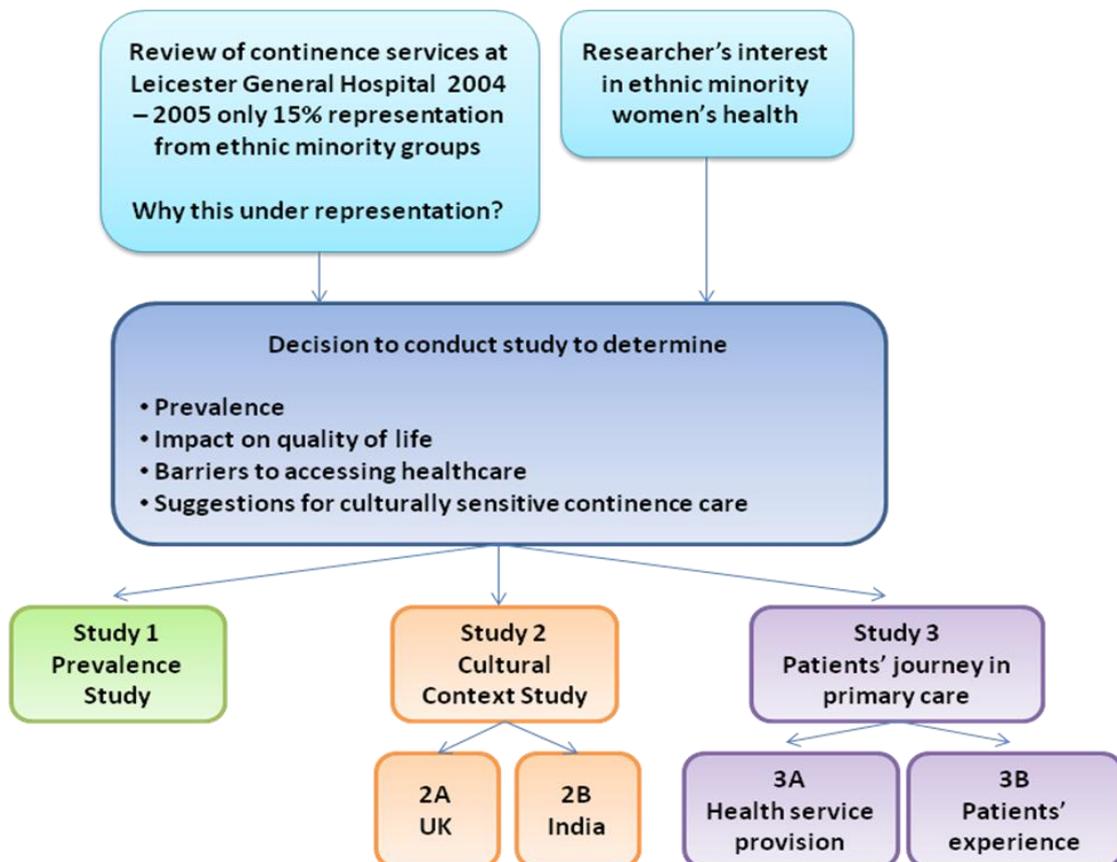
However, we decided to conduct the study to the same standard with which we have conducted other focus group-based studies which have been approved by an LREC, in order to protect the rights of the participants as much as possible. By the nature of focus group studies, participants give consent by participating and are free to withdraw from the discussion, or indeed the entire group, at any time.

For the remaining studies ethical approval was obtained from the relevant ethical committees [Appendix 6].

Section II

This flow chart gives an overview of the studies undertaken in this research project

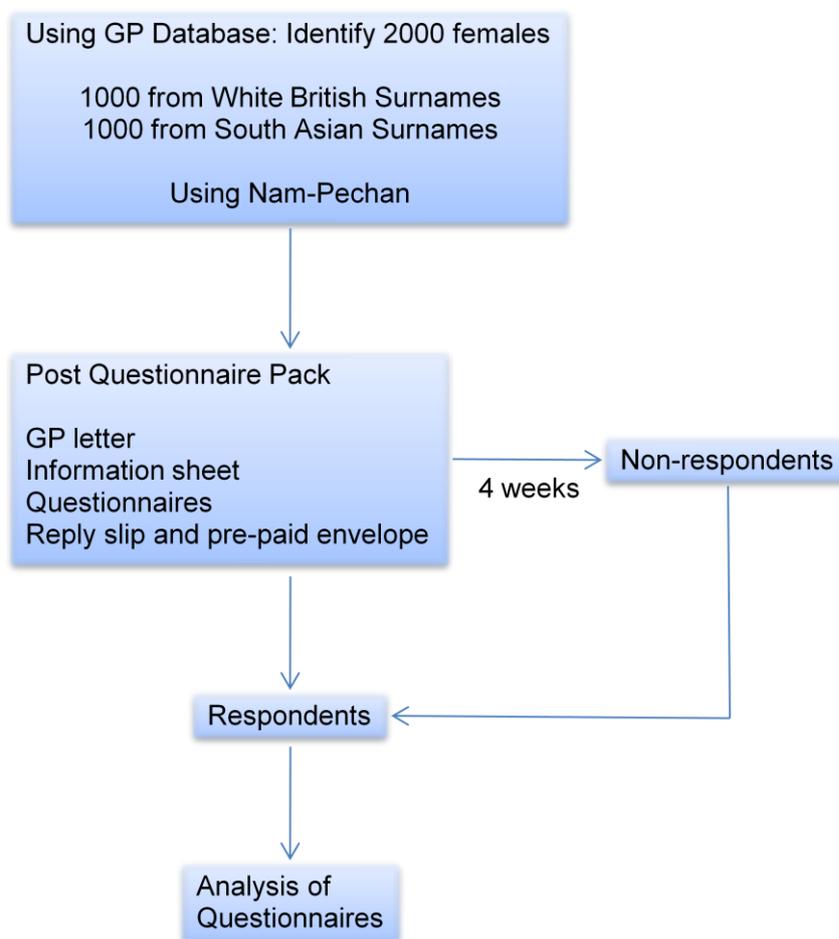
Figure 4.1: Overview of research project



Chapter 5: Prevalence Study

This study explores the prevalence of lower urinary storage symptoms within the community. The flow chart (Figure 5.1) shows how participants were identified and recruited. The questionnaires used in this part of the study are enclosed as Appendix 2. Data were analysed using SPSS v14 (QSR International, Chicago IL USA). Results are presented as comparisons between the Asian named and White British named respondents.

Figure 5.1: Overview of Prevalence Study



As I highlighted in Chapter 3, urinary incontinence is a significant health problem with potentially serious physical, psychological and social consequences. The prevalence estimates range from 14% to 71% among Caucasian women. However, little data exist on the prevalence or impact of urinary incontinence in harder to reach groups such as the elderly, institutionalised and ethnic minorities. Despite Britain's growing "Asian" ethnic minority population the pattern and prevalence of urinary symptoms experienced by these women has not been described.

5.1 Aim

The aim of this study was to estimate and describe the type of lower urinary tract symptoms (LUTS) experienced by Asian women in Leicester, and the bother they cause. We compared these to the White British population, to establish any differences in symptoms, bother or help-seeking.

5.2 Methods

Women registered with an inner city Leicester general practice were invited to participate in the study [Appendix 7]. We selected a practice which catered to a high Asian population, with approximately 50% of the 6000 patients being from an ethnic minority background.

Identification of Asian women was not straightforward. Ethnicity is not routinely recorded in general practices' patients list. However South Asian names are distinctive and their use has long been recognised as an alternative approach to ascertaining ethnicity (Nicoll et al., 1986), (Cummins et al., 1999), (Harding et al., 1999). Thus we used the Nam Pechan Program to identify South Asian names from the register. The program, developed by Bradford Health Authority and the City of Bradford Metropolitan

Council has been in use since the 1980s and was validated on West Yorkshire populations during its development phase with a sensitivity of 90.5% and a positive predictive value of 63.2%.The software contains a dictionary of South Asian names which it attempts to match against the complete name or the name stem (usually the first five characters of an individual's name) in order to provide a list of South Asians together with a language and religion marker for each person (Cummins et al., 1999).

Questionnaires

The questionnaires used in this study were those developed in the MRC Incontinence study to explore symptoms and impact of urinary incontinence in community dwelling women (Perry et al., 2000).Questionnaires used were the Leicester Symptoms Questionnaire, Leicester Impact scale and ICIQ-SF ,these have been described in detail in Chapter 4.

1000 postal questionnaires were sent to women with Asian sounding names aged 18 years and over registered with the practice. Gujarati and Hindi translated versions of the questionnaires were available on request (translation performed by Translation India 2006: Appendix 3). A further 1000 questionnaires were sent to White British women identified from the same register to compare the prevalence and degree of bothersome of urinary symptoms between the two ethnic groups. An invitation letter from the GP explaining the purpose of the study and inviting women to participate was sent with the questionnaires. Repeat questionnaires were sent to non responders four weeks later [Appendix 7].

Basic demographic details were collected including: age and parity. The invitation letter was translated into Hindi and Gujarati and had information on whom to contact if further assistance or a translated version of the questionnaires was required.

Data were analysed using the SPSS software version 14 (SPSS Inc, Chicago, IL, USA). Symptom prevalence and bother for each group was compared using the chi-square test. Results are presented as number (%), mean+/-standard deviation or median (range). Differences are presented with 95% confidence intervals (CI).

5.3 Results

The response rate was poor, despite mailed reminders. 432 women returned completed questionnaires: 169 questionnaires were returned uncompleted from the Asian group (women with asian sounding names) and 69 from the White British group with a note stating that they did not suffer from the condition. The response rate from White British group (29.4%) was significantly greater than from the Asians (13.8%), and the Asian women were younger than the Caucasian women (Table 5.1).

The Asian women returned higher scores from the ICIQ-SF (Table 5.1). Examination of the individual scores of the ICIQ-SF showed this difference to be due to differences in the bother reported on a 10-point visual analogue scale (question 3 of the ICIQ-SF). Median bother was 1.5 [0-10] for the Asians and 0 [0-10] for the Caucasians ($p<0.0001$) with a higher proportion of Asians reporting high scores (Figure 5.2). Scores for both the impact and feelings subscales of the LIS were higher for Asian women (Table 5.1; Figs 5.3 & 5.4).

Table 5.1: Responses from White British and Asian named women

	White British women	Asian women	p value or % difference
Response rate	294 (29.4)	138 (13.8)	15.6
(n(%))			(95%CI: 12.0, 19.2)
Age	57.1±17.9	40.8±11.7	<0.0001
Primary presenting symptom (urinary)	22	34	0.182
ICIQ-SF score	3.0 [0-21]	5.0 [0-21]	0.001
(median [range])*			
LIS activity**	0 [0-18]	3 [0-18]	<0.0001
LIS feelings***	0 [0-21]	2 [0-24]	<0.001
UI prevalence†	131 (48.7)	82 (59.4)	10.7
			(95%CI: 0.5, 21.0)

* n= 126 Asians, 303 White British

** n= 125 Asians, 299 White British

*** n= 127 Asians, 304 White British

† “yes” response to the question “Do you leak?” from the LUSQ; n= 138 Asians, 269 Caucasians

Figure 5.2: Incontinence bother by race (from ICIQ-SF)

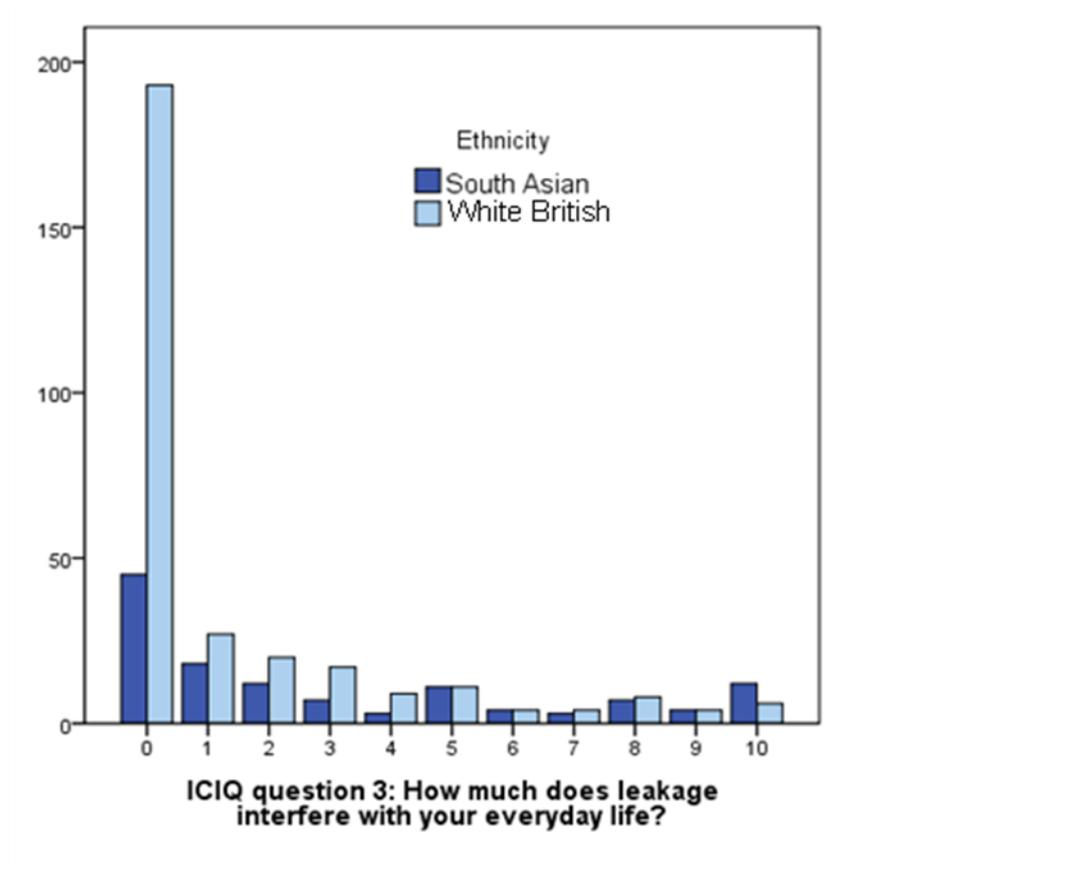


Figure 5.3: Leicester Impact Scale: activity subscale scores

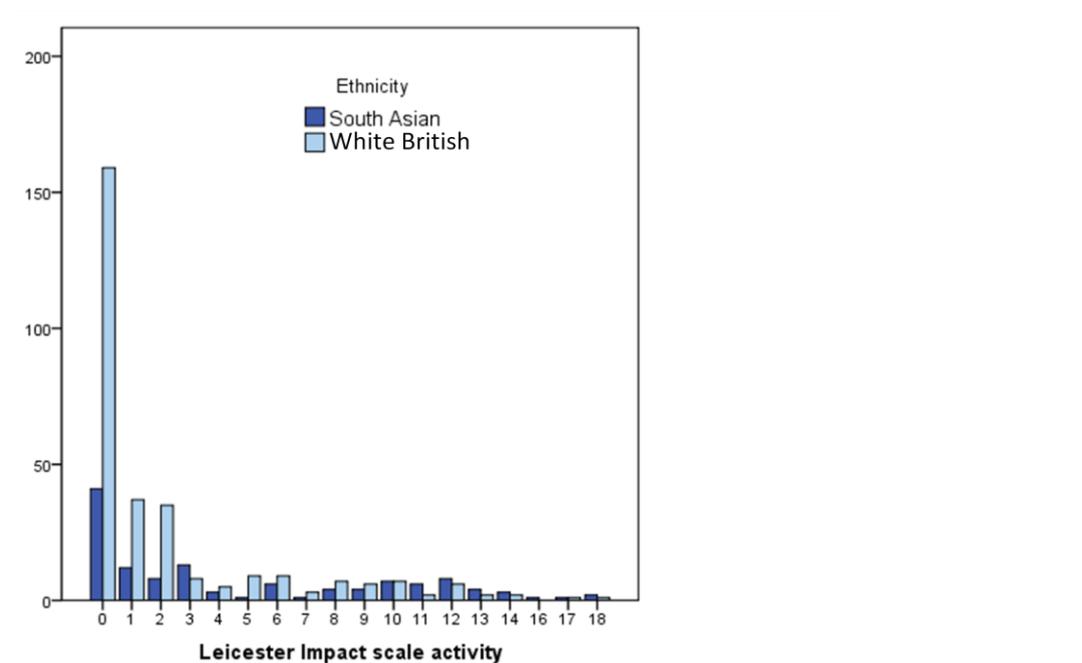
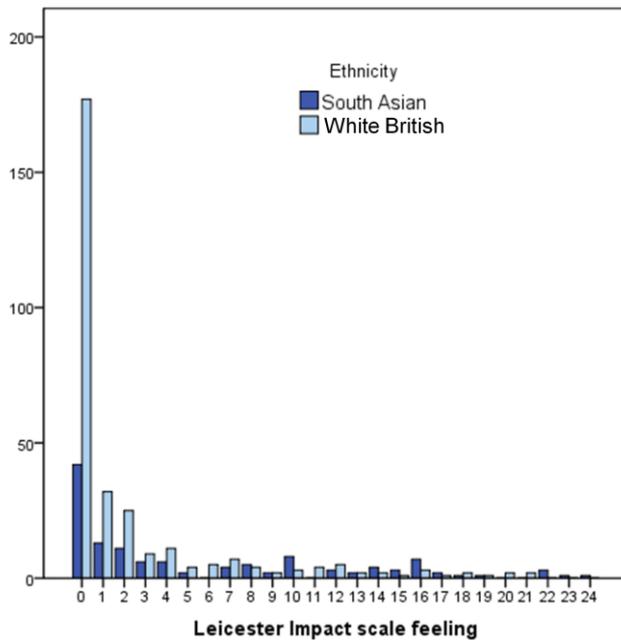


Figure 5.4: Leicester Impact Scale: feelings subscale scores



The LUSQ demonstrated that the prevalence of urinary incontinence (as inferred from a “yes” response to the question “Do you leak?”) was higher among the Asian named women (Table 5.1). It was also clear that Asian named women reported urge incontinence more often than White British named women (Table 5.2). The sensation of urgency was stronger in these women, with a high proportion of them describing it to be strong or overwhelming (Table 5.3). Asian named women had difficulty holding urine once they felt the sensation (Table 5.4). Larger leaks were reported by the Asian women in the study (Table 5.5 & 5.6). Daytime frequency was more in the Asian group (Table 5.7) although there were no reported differences in the frequency of stress leakage, or nocturia (data not shown).

Table 5.2: Urge Incontinence

	White British women (n=311)	Asian women (n=145)	P
Never	131 (42.1)	57 (39.4)	
Occasionally	101 (32.5)	25 (17.2)	0.0003
Sometimes	58 (18.6)	46 (31.7)	
Most of the time	21 (6.8)	17 (11.7)	

Question 3 of LUSQ : “When you have the urge to pass urine, does any leak before you get to the toilet?”

Table 5.3: Urge Sensation

	White British women (n=290)	Asian women (n=138)	P
No sensation	4 (1.4)	1 (0.7)	
Weak	13 (4.5)	6 (4.3)	0.005
Normal	175 (60.3)	73 (52.9)	
Strong	60 (20.7)	23 (16.7)	
Very strong	33 (11.4)	22 (16.0)	
Overwhelming	5 (1.7)	13 (9.4)	

Question 7 of LUSQ : “When you first feel the need to pass urine how strong is the urge to go usually?”

Table 5.4: Holding onto urge symptom

	White British women (n=290)	Asian women (n=138)	P
Most of the time	47(16.2)	39(28.2)	
Sometimes	55(18.9)	46(33.3)	0.000003
Occasionally	93(32)	21(15.2)	
Never	99(34)	33(23.9)	

Question 8 of LUSQ : “Do you have difficulty holding urine once you feel the urge to go?”

Table 5.5: Amount of Leak 1

	White British women (n=212)	Asian women (n=106)	P
A few drops	102(48.1)	63(59.4)	
A dribble	91(42.9)	29(27.3)	0.010
A stream	18(8.5)	10(9.4)	
A flood	4(1.9)	1(0.9)	

Question 4 of LUSQ : “How much do you leak usually?”

Table 5.6: Amount of Leak 2

	White British women (n=205)	Asian women (n=107)	p
Almost dry	73(35.6)	35(32.7)	
Damp	101(49.2)	43(40.1)	0.041
Wet	28(13.6)	23(21.5)	
Soaked	3(1.4)	6(5.6)	

Question 5 of LUSQ : “How much do you leak usually?”

Table 5.7: Frequency

	White British women (n=275)	Asian women (n=135)	p
Half hourly	5(1.8)	11(8.1)	
Hourly	43(15.6)	15(11.1)	0.021
One and half hourly	37(13.5)	20(14.8)	
2 hourly	195(70.9)	54(40)	
More than 2 hourly	85(30.9)	35(25.9)	

Question 9 of LUSQ : “How many times do you go to the toilet to pass urine during the daytime?”

5.4 Discussion

This study examines the prevalence and severity of UI in community women. About half of the Asian named women who returned the questionnaires had UI. They were more bothered than the White British women by the symptoms as shown from the ICIQ-SF scores, and reported more disturbance of impact and feelings (LIS). Also some symptoms were more common or severe (LUSQ).

The reason for choosing three questionnaires was to triangulate the results to give a complete assessment of symptoms and the effect on quality of life. The Leicester Symptoms Questionnaire assesses only symptom severity but doesn't address the issues of quality of life. This information is complemented by the Leicester Impact Scale which assesses the effect of symptoms on activities and feelings. As mentioned earlier there is no quality of life questionnaire for urinary incontinence that has been validated in any Indian language. This study group is in the process of validating the ICIQ-SF in Gujarati.

The high impact of urinary incontinence in these women would lead to the assumption that there would be a high help seeking rate. This has not been shown in our initial audit at the beginning of the project, whereby only 15% of our patients were from an Asian ethnic background. This raises the possibilities of barriers to care. Several studies have, in fact suggested that women with UI often do not seek medical care because of incorrect beliefs or inadequate knowledge about UI. For example 81% of women with UI failed to seek medical care because they did not view UI as abnormal. This was the most common cause of failure to seek appropriate care (Holst and Wilson, 1988). Similar issues have been highlighted in the cultural context study (Chapter 6a).

Identification of the Asian woman from the primary care database was challenging as not all registered patients have their ethnicity coded although ethnic group should now be routinely recorded by hospitals in England (NHS Executive, 1994). In the absence of information on self ascribed ethnic origin, the analysis of names either with the help of programs such as Nam Pechan or manually offers a feasible alternative for the identification of South Asian residents and the method has been used in a number of studies (Donaldson, 1986), (Barker and Baker, 1990), (Swerdlow et al., 1995) including this one. Thus in this study where Asian women are mentioned, these are women identified from the register to have Asian sounding names, The ethnicity was not confirmed by the participants.

The low response rate from the Asian group in our study raises important issues about ethnic minority participation in medical research. An observation made from those who contacted me was that women from Asian backgrounds were not at ease in completing the questionnaires. This could be due to mistrust with the origins of the document and divulging of personal information. In our study the Asian women were younger than their White British counterparts. This may be a bias in the data collection, as it is possible that younger women who were more literate were more likely to complete and return the questionnaire than the older age group. We may have thus missed an entire cohort of women, and this needs to be addressed. Those from the older group may have had the questionnaires completed by younger members in their residence, which raises a whole different issue about informal translations and its reliability. We tried to address this by choosing questionnaires that were validated in community dwelling women, a population that we were interested in exploring rather than selecting a data set from primary or secondary care from women who had presented with UI. With the flexibility of using the questionnaires as interviewer administered we hoped that we would gain data from our ethnic population who may find understanding the questions

difficult. However not many women made use of the service with few requests for translated questionnaires or speaking to an interviewer.

5.5 Summary

These findings show a significant burden of disease among Asian women in Leicester (identified by their Asian sounding names), raising the possibility of barriers of accessing healthcare. The epidemiology of urinary incontinence in a growing ethnic minority population is important from a socio economic point of view. It provides information for future planning of care as the delivery of culturally competent care is essential in today's health care environment, where patient satisfaction and financial liquidity have become imperative (Davidhizar et al., 1998).

Chapter 6: Cultural Context

Chapter 6a: UK

This study explores the views of women in the community in regards to urinary incontinence and the flow chart below (Fig 6a.1) shows the process of recruitment, data collection and analysis. A similar study was carried out in India to further understand the influence of culture on health, namely urinary incontinence and how this influences the help seeking behaviour (see Chapter 6b).

Figure 6a.1: Overview of Cultural Context Study - UK



Data from this Chapter has been published in Family Practice 2007

[Appendix 16].

6a.1 Aim

This qualitative study to explore the views and experiences of women in the South Asian Indian community in Leicester about urinary incontinence and their perceptions of available care.

6a.2 Methods

I identified various Asian community associations as well as Women's Health Centres from the Leicester City Council database. These were then approached with meetings arranged between the Heads/Leaders of these organisations and the research was outlined. .

Contrary to the my perception that women would require a lot of convincing to participate, women readily volunteered to take part in these focus group discussions and at times there were more women than the room could accommodate.

Participation of women recruited through associations/women's centre/religious community centres was greatly improved by scheduling focus groups before or after other functions the women were attending at the same venue. The focus group discussions were held at various organisations meeting rooms. It was felt that if the participants were familiar with the venue they would be less likely to feel intimidated and would feel more able to speak freely, as well as the fact that they would not need to travel to various locations. None of the women participating in these focus group discussions had any qualms about the discussions being recorded. These women did not require any financial incentive to participate.

Focus groups were felt to be an appropriate choice of method when seeking to explore women's views and experiences of incontinence and continence services (Wilkinson, 2001). In this study each focus group included six women. This size was large enough for me to probe whilst allowing all of the participants a chance to express themselves.

The older women only spoke in their native language of Hindi, Gujarati and Punjabi. Many of the younger, second-generation Indian women were bi- or multi-lingual. Care was taken to recruit women of similar age and linguistic ability in the same focus group to encourage discussion. The discussions were conducted in the participants' chosen language and facilitated by myself, as I can speak several of the Asian languages mentioned above. This encouraged the non-English speaking women to discuss issues in their own language in a comfortable environment. The focus groups were run as described in Chapter 4.

The focus group discussion guide was reviewed after a couple of focus group discussions. This was due to information collected from the participants and to probe into other areas which the initial focus group guide had not taken into account.

After the focus group discussions some women wanted to speak to me privately about urinary incontinence. This could indicate the sensitive of the topic and highlight one of the drawbacks of data collection through focus group discussions, or the fact that these women were not comfortable talking about urinary incontinence in the presence of other women.

The development of the focus group schedule was informed by the main research questions, review of the literature and discussions within the research team. The schedule had broad questions which the moderator used to guide the discussion. The schedule was used flexibly and the emphasis was on gaining the perspectives of the women themselves (Table 6a.1).

Table 6a.1: Schedule of focus group discussion

Schedule of content of focus group discussion (exact content and order varied according to participants' responses). Prompts such as 'why?', 'in what way?' and 'can you say a bit more about...?' were used to explore initial responses in more depth.

Questions asked by facilitator:

1. Have you heard about anyone having urinary incontinence?
 2. How did you or they (relatives or friends who suffer from urinary incontinence) cope with it?
 3. Why do you think incontinence occurs?
 4. Do you know of any treatment available for incontinence?
 5. Would you be willing to try alternative therapies?
 6. Who would you like to see if you developed this condition and why?
 7. Why do you think most women don't seek help for this problem?
 8. How do you think we can increase awareness within the community about incontinence?
 9. How do you think we can improve the services provided in the NHS for managing women with incontinence?
 10. If any of the participant answered that they or a family or friend suffered from incontinence, they would be asked if they would be willing to share the experience with the group, including issues around access to care, treatment and how satisfied they were with the received care.
-

The main areas explored in the focus groups were as follows:

- awareness of incontinence;
- quality of life issues;
- seeking help for urinary incontinence;
- awareness of treatment options; and
- suggestions for better service provision for women from ethnic minorities.

Women were not asked to disclose whether or not they had experienced symptoms of urinary incontinence. All focus groups were tape-recorded and transcribed verbatim into English. Name aliases were used on all transcripts. Any colloquial words and phrases that could not be translated verbatim were replaced with an English phrase carrying the same meaning.

6a.3 Analysis

Hand coding was carried out with data from the focus groups and a systematic and iterative method of analysis based on the constant comparative method was used (Forrest Keenan et al., 2005; Glaser, 1965).

The data were read and re-read. Initially, 'open codes' were applied to the data representing the significance of sections of text. Initially, this was done independently by myself and my supervisor and then discussed together. Open codes were then grouped into organizing categories or overarching themes (Forrest Keenan et al., 2005). The coding was partly influenced by the research questions but more particularly by ideas arising during data collection and analysis (Bowling, 2002) known as grounded codes, whereby prejudices, presuppositions and previous knowledge of the subject area are put aside and the concentration is instead on finding new themes in your data.

Quotations are provided as illustration of the themes, each identified by focus group number.

6a.4 Results

Four focus groups were held. After the first focus group, it became clear that generational differences may be important in formulating views and experiences of incontinence and therefore two focus groups were held with women aged 30–60 years (Groups 1 and 3) and two with women aged 60–85 years (Groups 2 and 4) (Table 6a.2).

Table 6a.2: Characteristics of focus groups and participants

Focus Groups	Number of Participants	Age Median (range)	Interview Language
1	6	50 (47 – 56)	English and Gujarati
2	6	70.5 (56 – 82)	Punjabi and Hindi
3	6	44 (36 – 47)	English, Gujarati and Punjabi
4	6	74 (68 – 80)	Gujarati and Hindi

The focus groups worked well and in all groups women discussed the issues around incontinence and continence care freely. The following overarching categories were identified from the analysis:

1. normalization/management of symptoms;
2. help seeking/access to health care; and
3. suggestions for improved service.

Each category is discussed below. Some categories contain subsidiary themes within them and these are identified by subheadings.

Normalization/ Self management of symptoms

Overall, women felt that urinary symptoms such as leakage, frequency and nocturia were a normal part of the ageing process, and so not considered to be serious symptoms of a disease state. So, they were unlikely to regard these symptoms as something to be concerned about:

I don't think that was a problem, just like Seema was saying, that I thought it was part of getting old and not really a problem (Focus Group 1).

Because symptoms were considered to be a part of the ageing process, they tended to be normalized. All of the women who took part in the discussions had a very accepting attitude towards these changes, with the overall feeling that little or nothing could be done:

I used to think that going to the toilet many times was OK. Maybe I have drunk too much or because it's cold (Focus Group 1).

The problem is that there is more than one problem, like heart and diabetes, so there are many problems and this may not be so important. When we get older diseases engulf us, so there is little we can do (Focus Group 2).

Most of the women had formed explanations for the cause of their condition:

Part of the reason is that muscles have gone weak, and we feel there is no cure for weakness, it has to happen so it will, we are old, nothing can be done (Focus Group 4).

Some women recalled that they had suffered with these symptoms for years so that it had become a part of their daily lives and they had developed management strategies to incorporate these symptoms in their everyday life:

I used to avoid going out, my husband is so sweet, first thing he would do is try and find out where the toilets were, and we would sit near to the toilet, as I could just not control it (Focus Group 1).

I cut down drinking during the day because of my job as a visiting officer. I didn't want to use the customer's toilets. I would have a cup of tea in the morning and then not drink anything for the next 5–6 hours but it made my bladder condition worse (Focus Group 1).

It was apparent that in spite of the difference in the ages of the women from the focus groups and that the younger women were bilingual with good understanding of both written and spoken English, all the women had heard or read little about the subject of continence:

We say that we are educated but you don't realise and I didn't realise how big a problem this is and that something can be done about it ... I've lived in this country all my life, I was educated here and I didn't think that this was a problem, so I never saw a doctor about it (Focus Group 3).

Help seeking/access to health care

Five women in the groups had sought help for their incontinence symptoms, but the majority felt that the symptoms were not that important to prompt a consultation with the GP (or family doctor), even if they were seeing their GP for other symptoms:

I never thought it was a problem to go see the GP (Focus Group 2).

I thought it was a small problem and it would go away, maybe I drank too much water, never thought it was such a big problem with so many people affected.

You don't go to see your GP for small problems (Focus Group 2).

The women in the older age focus group put their urinary symptoms down to side effects of the medications that they were on (e.g. diuretics for hypertension):

I take tablets for hypertension and cholesterol, so during the day I go every hour but during the night am OK, only get up once, I drink plenty because I have kidney problems as well (Focus Group 4).

Interaction with health care professionals

Although many women had not sought medical help, the women who had approached their GP felt that they had not received any valuable advice to manage the condition, with some saying that the GP had reinforced their belief that nothing could be done:

The doctor said that because you have so many children your womb has dropped and said you're getting old, it will get better, didn't give me any medication (Focus Group 2).

He said I was going through the menopause and this was normal, he made me feel like 'what are you complaining about, woman, just get on with it' (Focus Group 3).

Embarrassment

Women across all the focus groups commonly reported feeling embarrassed when going to see their GP for personal reasons such as incontinence. The reasons given for this were mainly the gender of the GP and the sensitive nature of the problem:

I'm embarrassed to see the doctor, I have a male GP, but if I tell him he will refer me to the female GP, but I don't want that because they will examine me and I don't want that (Focus Group 4).

In discussing their interactions with their GP, several women felt that the GP was embarrassed to address continence issues:

I think I make him (GP) uncomfortable, he realises it's embarrassing and he tries to make it easier, he doesn't look at me either when he talks about the problem (Focus Group 3).

My GP was more embarrassed than I was, probably because he is an elderly male GP and I felt I couldn't talk to him openly about the problems I had (Focus Group 1).

Characteristics of health professionals

During the focus group discussions, we tried to explore further whether women had a preference for the gender of the medical professionals they saw and whether this made a difference in their health-seeking behaviour. In all focus groups, there was an

expressed preference to be seen by a female doctor, for ease of discussing sensitive subjects:

With a lady doctor it's different, you can be a bit more open than with a male doctor (Focus Group 4).

I think having a female makes it easier to talk about your personal problems especially those down below, because it's embarrassing (Focus Group 1).

In addition, there was strong opinion that women would prefer to see an allied health professional (i.e. continence nurses, district nurses, practice nurses, physiotherapists and health care visitors) rather than the GP. This was partly because of an assumption that allied health professionals would be female:

I have a practice nurse and when we make an appointment they say 'whom do you want to see?' and I say 'the nurse, I don't want to talk to the doctor' (Focus Group 3).

Nurses are females and they have more time (Focus Group 4).

Especially for older women, nurses who visit at home would be better, because then we don't have to leave the house, problems with transport and waiting in the GP surgery (Focus Group 2).

Women also suggested that having GPs from similar ethnic backgrounds would be preferable, because they would have a better understanding of cultural issues affecting them, besides being able to communicate in the patients' own language:

The other thing I've noticed is that Asian people tend to go to Asian doctors. They think that there will be no language or cultural issues (Focus Group 2).

Like when we were young my parents changed to a muslim GP, because somebody said that when you die they do this and they do that and if you have a muslim doctor then he understands the procedures and my mum and dad thought 'excellent, let's change to a muslim doctor' (Focus Group 2).

Treatment options.

A majority of the women in the younger focus groups had heard of pelvic floor exercises, but many of them felt that these were only to be done after having a baby. They expressed dissatisfaction at the way they had been taught pelvic floor exercises, highlighting that no one had actually told them the significance of performing these exercises or their long-term benefits:

They told me to do pelvic floor exercises when you have a baby, they don't exactly say it's for your bladder, they just said 'you have had a baby and it will help with your muscles', it was not said 'if you don't do this you will have bladder problems later' (Focus Group 3).

The problem is not knowing if I am doing the right pelvic exercises (Focus Group 1).

No one emphasised it, what you could end up suffering if you didn't do them (pelvic floor exercises). All they say is 'just do it to strengthen your muscles', not that you could end up in nappies, that would be frightening (Focus Group 3)

In contrast, most of the older women had not heard of pelvic floor exercises. When asked if they had been taught these after childbirth, they said that they had delivered their babies in countries other than the UK, where it was not a routine post-natal practice.

Complementary therapy

During the discussions, women also talked about their experiences of alternative therapies. On the whole, the younger age group women were more likely to consider alternative therapies, including herbal medication. The older women tended to prefer to use medication as prescribed by their doctor. Concurrent use of both Western and traditional approaches were considered to be contradictory by the majority of the women:

I would take the hospital's medicine; my son is a doctor you see (Focus Group 4).

I would take the doctor's medicine or herbal medicine, I wouldn't mix and match. I don't think it would help, sometimes I would take herbal medicines if the problem was small (Focus Group 4).

Use of interpreter services

When asked about the importance and use of interpreter services, members of all four focus groups preferred to use family members rather than the interpreting services offered by the GP surgery or the hospital.

I wouldn't feel comfortable, again it would be a complete stranger and you end up talking to two people who you don't know. The interpreter may go home and talk about it and they come from the same community (Focus Group 2).

A friend of mine's an interpreter and she went to a GP surgery because she was asked to sit in on an appointment and the lady who she had to translate for lived two doors down the road from her, and they know each other, can you imagine how difficult it must have been for that lady to sit with someone who lives down the road and talk about such a personal issue? That is why I wouldn't be comfortable with an interpreter, I would just demonstrate, even if I didn't speak the language (Focus Group 3).

Only one of the 24 women who took part would have preferred an interpreter, because of fear of family members finding out about her condition.

Suggestions for improving services

Increasing awareness

In the UK, several charitable organizations such as the Continence Foundation have run campaigns to increase continence awareness within communities. Unfortunately, it did not seem that any of the women from the focus groups had heard of these, nor had they received any leaflets on the subject.

I haven't seen that many articles but to be honest I haven't really been that interested in this (Focus Group 2).

At the end of each focus group, we asked the women to suggest ways of increasing awareness within the community and improving existing services. Their responses were analysed and are reported under the following themes: professionals, opportunistic screening and publicity.

Professionals

The women felt that health professionals should use a more direct approach in addressing the problem. They felt that if they were directly asked they were more likely to discuss their problem:

If they ask you are happy to answer back, rather than you tell them (Focus Group 2).

There was the feeling that if urinary symptoms were asked about by health professionals then they must be of some significance, and so women would be more likely to talk about their condition:

If the nurse asks you then it's like it's recognised, it's not just something you have, it's an issue, that's why she has brought it up and because it affects so many women (Focus Group 3).

Publicity

Women in all four focus groups felt that talk-based awareness campaigns were more likely to be successful than written ones. It was interesting to learn from these women that a large majority of these monolingual speakers are not literate and are unable to read the printed material, even in their native languages:

Asian community is a lot of word of mouth (Focus Group 1).

My mother in law can't read so I have to translate it for her. Talks are the way forward (Focus Group 1).

We also noted that the younger generation of women were unable to read their ethnic languages:

English would be good so that my daughter can read it, she can't read Gujarati (Focus Group 4).

Women felt that to overcome the taboo of talking about incontinence, others who have the problem should be encouraged to come forward and share their experience:

If you have champions within the community it has to be someone who has been through it (Focus Group 3).

Women felt that small group discussions, rather than large groups with health care professionals, would be more valuable than printed leaflets to enable them to gain a better understanding of the nature of the problem and available solutions:

Small community centres that these elder women go to and give them talks, in a small group they are more likely to be receptive, not 100%, but if they know a little bit about it they will talk, better than you giving a talk in a large group (Focus Group 1).

I don't think leaflets help, we hardly ever read. We bring them and then throw them out, sometimes we don't understand them (Focus Group 2).

Like the leaflet explains how to do pelvic floor exercises, but how do you know that you are doing them right (Focus Group 3).

Most women participating in our focus groups subscribed to media channels catering specifically to ethnic minorities (e.g. SABRAS radio, BBC Asian network and MATV) and they felt that these were very strong media to disseminate awareness within the community by having programs in local languages addressing this problem:

BBC radio is good; once a week they have a health program ... that will be good (Focus Group 1).

Program on TV, in a casual manner, like two women near a temple, make a joke about it and then how it was sorted. So then people will know there is treatment (Focus Group 3).

6a.5 Discussion

Understanding the reasons why women do or do not seek treatment for incontinence is hampered by the ethnic homogeneity of the existing data (primarily white Caucasian) and the lack of comparative data from ethnic minority populations. Most previous work suffers from selection bias, studying patients recruited from within the health service environment. We have explored continence needs and attitudes to health care access among South Asian Indian women in the community.

We confirmed the existing knowledge about the sensitive nature of the problem and demonstrated that typical coping mechanisms used by these women were similar to a Caucasian sample (Shaw, 2001). The participating women considered their symptoms to be an inevitable consequence of ageing and childbirth, and normalized their symptoms, resulting in the adoption of management strategies to minimize the impact of the incontinence upon their lifestyle (Diokno et al., 2004). A consequence of this was that most women had not considered attending the GP to discuss an issue which they thought was unavoidable, or a side effect of other treatments. Women also held the belief that no treatments were available, a finding similar to that reported by others, among women of Caucasian origin (Holst and Wilson, 1988). Adult Asians are known to attend general practices more frequently compared with European patients (Balarajan et al., 1989). Assuming this to be true for the women in our study who had attended the GP for other medical conditions, they still did not feel that incontinence was an 'important' enough symptom to discuss with the GP.

It is of significance that women identified considerable difficulties in discussing continence issues with their GP. Some women felt that their GP dismissed their concerns and was not aware, or not prepared, to consider definitive treatment for the condition. A lack of consultation and management skills in continence care has been

identified by others (McFall et al.), (Dovey et al., 1996). Eriksen et al (1990) found that >50% of cases of incontinence were inadequately managed. Swanson et al (2002), showed that only 34.6% of family physicians felt very comfortable dealing with urinary incontinence.

The women in our study did report that their GPs appeared to be embarrassed to discuss continence with them, and most of the women were registered with practices staffed mostly by male doctors. Embarrassment among patients is known to be an issue for continence care (Samuelsson et al., 1997), but we are not aware of other work which has explicitly identified perceived embarrassment among health professionals as a barrier to effective care delivery. Although we did not interview the GPs, it is possible that social stigmata among the South Asian population contribute to the difficulty which they may have in discussing continence care with their patients. The preferences of the women we studied were for female doctors or nurses to discuss their problems with, which suggest that these gender issues are also playing a significant role. There was also a preference for a doctor or nurse from the same ethnic group, which suggests that cultural issues and taboos were important to the women.

The issue of interpreter services is frequently discussed in relation to ethnic minority groups, and translating and interpreting services are now considered to be a pre-requisite for a comprehensive service in a multi-ethnic area (CRE, 2003). A systematic review of the impact of medical interpreter services on the quality of health care (Flores, 2005) found that optimal communication, highest patient satisfaction, better outcomes and the fewest errors of potential clinical consequence occur when ethnic minority patients had access to trained professional interpreters or bilingual health care providers. Additionally, the quality of care for ethnic minority patients was often inferior when untrained, *ad hoc* interpreters (including family members, friends, medical and non-medical staff and strangers) were used.

However, our study has revealed some interesting insights based upon the women's preferences which would not have been identified in the systematic review. The majority of women preferred to attend with a bilingual family member to translate, rather than to make use of hospital provided translators, which appeared to be a consequence of the close-knit communities in which these women tended to live. They were keen to avoid situations where they may encounter a social contact in a medical setting and reveal sensitive or personal information in that situation. In contrast, patients from Chinese and Vietnamese Asian backgrounds preferred using professional interpreters rather than family members, and preferred gender-concordant translators, (Ngo-Metzger et al., 2003) which suggest that there may be culture-specific differences and that generalization is unwise.

Our focus groups provided an opportunity to compare attitudes and opinions between women of different ages, who were either immigrants (the older women) or second-generation Asians born in the UK (the younger women). We found no difference in the level of awareness about the prevalence of continence problems, available treatments or in the women's tendency to accept and normalize their symptoms. Both age groups identified embarrassment in themselves and in their GPs, and both preferred female and non-medical health care input. Younger women did, however, seem to have greater knowledge about pelvic floor exercises and were more likely to consider complementary therapies.

In contrast to Caucasian populations who find written leaflets helpful (Gates et al., 1993), our women thought that conventional leaflets would not make an impact in increasing awareness within their community and were much more enthusiastic about talk-based media in the form of short advertisements and educational talks on the local (culturally relevant) media and small group discussions. Ideally, these discussions

would involve a member of their own community who had experience of the condition and its treatment (Turner and Shepherd, 1999).

6a.6 Summary

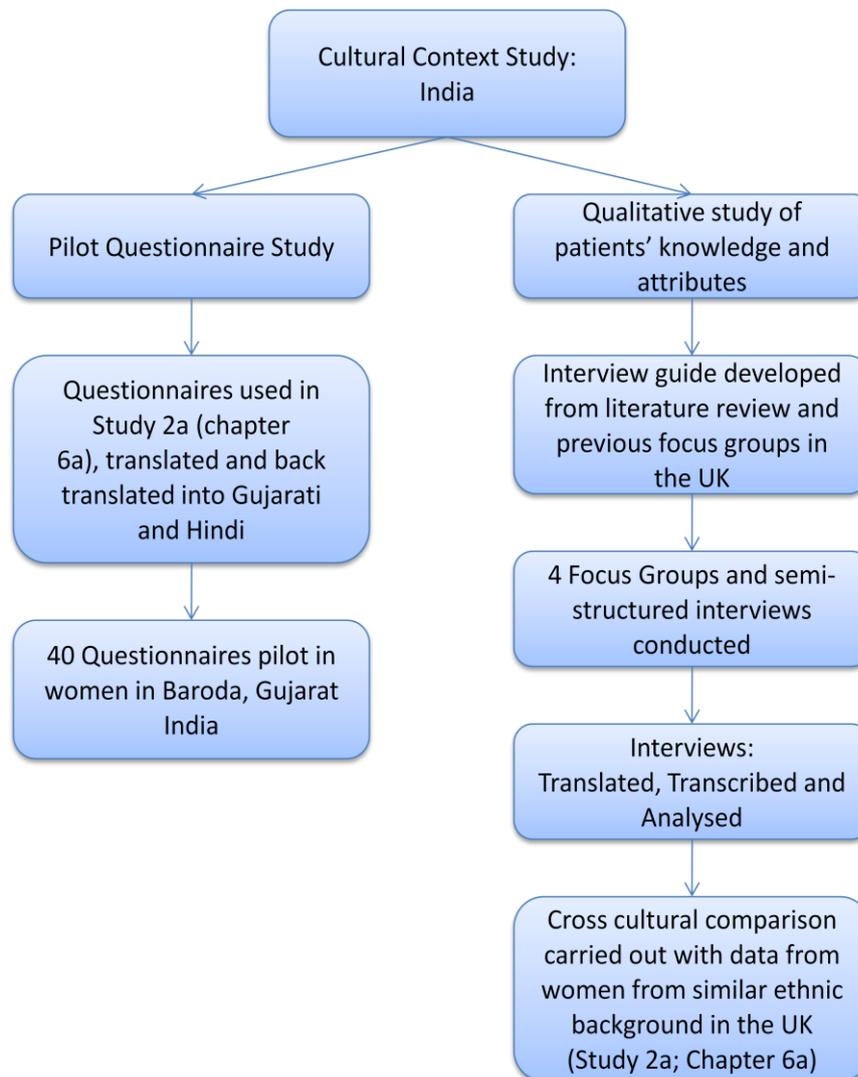
Understanding the philosophy of a different culture and integrating this understanding into the provision of clinical care is challenging and complex. It is important to realize the effects which culture, religion and family background have on patients. A deeper understanding of these effects will inform the development of a service which would cater to the needs of a specific population. We have gained valuable understanding of the continence needs of South Asian women and have received suggestions from our focus groups on appropriate ways to develop a service that will provide not only cultural sensitive care but also be a focal point for improving awareness of incontinence within the community. This study involved a self-selecting sample of women and it is not clear how widely the findings are generalizable. However, it has laid the groundwork for further research towards gaining a better understanding of urinary incontinence in an ethnic community and educating ourselves as the health care providers about implementing culturally sensitive care.

Chapter 6b: Cultural Context Study – India

This study is a cross cultural research project with the SSG Hospital, University of Baroda India, to explore the influence of culture on awareness, impact and help seeking behaviour of urinary incontinence. Focus groups and interviews were conducted in women in India and the data were compared with that obtained in study 2a (the above chapter 6a).

The recruitment and analysis is represented as Figure 6b.1.

Figure 6b.1: Overview of the Cultural Context Study - India



The UK has a comparatively large and increasing black and minority ethnic (BME) population which has risen from 4.2% of the population in 1981 to 7.9% (4.6 million) in 2001 (Census 2001). The South Asian group is the largest, accounting for about half of the total immigrant population (2 million people). Migration has become an integral part of economic and social development everywhere. The trends in international migration have important implications for healthcare systems globally, including the United Kingdom (UK).

Studies of the Health of Migrants

Study of the health of migrants poses numerous significant methodological challenges. Studies of migrants are prone to mistakes in conclusions possibly because no research design is capable of controlling the myriad of environmental variables that may influence health status (Greenwood, 1985). Furthermore, selection factors that may occur amongst migrants, healthy and younger individuals, than to migrate as well as reasons for migration and the historical time of migration may bias conclusions reached. Most migration studies are epidemiological in nature with a cross section designed to measure health status in terms of incidence and prevalence at a specified period of time. These observational studies are important to give us an idea about the health status of immigrant groups. These studies are also helpful in providing us with information about risk factors and their association with particular health problem. Despite many arguments in favour of the cohort nature of migration studies to get a more complete picture of the migration process and health outcomes, very few examples can be seen in the literature where attempts are made to get the information by using this approach. To study the impact of migration on health it is imperative to examine the immigrant groups in the context of origin and destination (Kliewer, 1992).

Recently conducted surveys on diabetes prevalence in India and Pakistan are in accordance with the prevalence rates among immigrants to the UK and other European

countries denouncing immigrant status as being the only explainable variable for the high prevalence. Therefore it is difficult to formulate a linear relationship between health and immigrant status. We need to develop a more complex descriptive model to discuss the issues relating to migration and health in terms of environmental and genetic interactions, behaviours, responses and interpret different mechanisms like social class, education and cultural aspects.

Existing data showed greater morbidity among migrants especially concerning mental health problems, depression, post-traumatic stress disorder, psychosomatic complaints and anxiety and certain chronic diseases such as diabetes and infectious diseases such as tuberculosis and hepatitis B (Syed and Vangen); (Bhugra and Bahl, 1999); (Thomas and Thomas, 2004). There is a lack of consistency in the findings on migrant health. Some studies showed that the morbidity patterns among migrants are not markedly different from the background population in the recipient country. Other studies indicate a lower prevalence of certain diseases among migrants compared to the background populations in the recipient countries, for example, depression (Ingerslev, 2001).

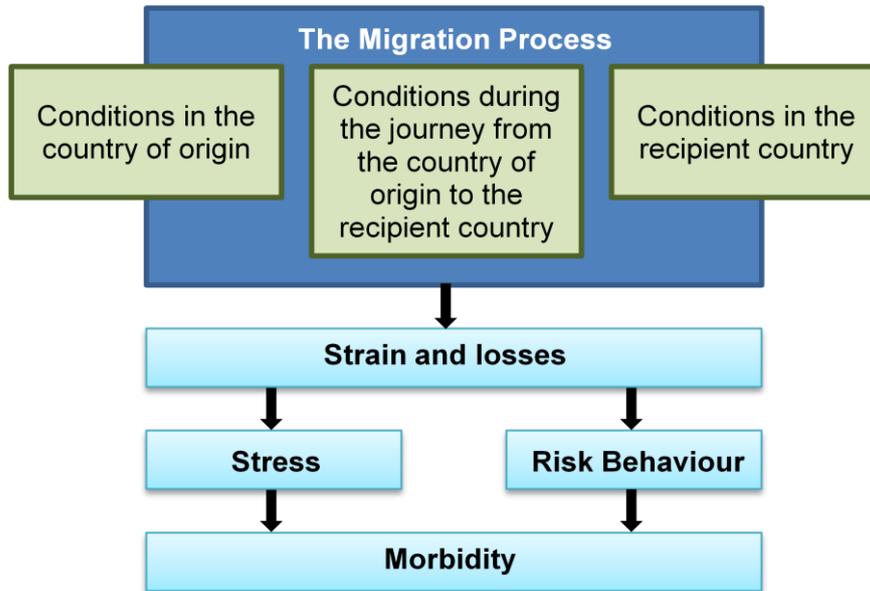
Morbidity patterns amongst migrants will approach those among the background population of the recipient country over the course of time. Migrants often live in a social context where new social political and language realities result in great demands on coping skills and adaptability. Social networks may be especially important to migrants' mental health and health behaviour. Lack of social support, larger geographic distances to members of the social network and high expectation from relatives in the country of origin and sometimes additional stresses leading to mental health problems and risky health behaviour among migrants (Bhugra and Bahl, 1999). It is not only the first generation migrants who face substantial demands on their coping

capabilities, second generation migrants also experience stress due to the challenges they face when adapting to the surrounding society (Bhugra and Bahl, 1999).

Behaviour often changes as a result of adaptation to a new culture following immigration. This is termed “acculturation”, a process in which members of one cultural group adopt the beliefs and behaviours of another group. This phenomena has been studied in relation to prevalence of chronic illnesses and utilization of health services. Aspects of the lifestyle of particular cultural groups (e.g., dietary habits, patterns of physical activity) may affect the development of specific diseases. Beliefs about causes, treatment, and prevention of illnesses may affect the utilization of health services. For example, immigrant women living for 10 years in an adopted country show behaviour in response to cancer screening which converges with the behaviour of the host population (Mercer and Goel, 1997).

The deterioration of some positive health characteristics soon after arrival in the destination country to levels that are similar to those in the host population also known as the "healthy immigrant effect", is believed to result from a combination of socio-cultural, behavioural and environmental changes (e.g. increased body mass index, altered glucose metabolism) and behavioural changes (e.g. use of tobacco, alcohol or other substances) following arrival which may increase the risk of adverse health outcomes [Figure 6b.2].

Figure 6b.2: Influence of migration process on migrants' morbidity



(Kristiansen et al., February 2007)

6b.1 Aims

We sought to understand the experience of living with urinary storage symptoms among women from Gujarat, India and to compare with previous research exploring experiences of a migrated Asian population originating from the Indian subcontinent and settled in Leicester (study 2a). As mentioned earlier in chapter 2, Leicester has the highest proportion of the population from minority ethnic groups. Nearly 25% (65,000 inhabitants) are of South Asian origin; originating from India, Pakistan and Bangladesh, commonly via the East African Countries of Kenya, Uganda and Tanzania. The predominant Indian population originates from the Gujarat state in India.

Study 2a (Chapter 6a) has shown that Indian women living in the UK commonly normalised symptoms of urinary incontinence, attributing them to the ageing process or consequences of childbirth. Help seeking behaviour was hindered by feelings of embarrassment in discussing sensitive problems, especially with male health professionals, but also the perceived embarrassment felt by doctors. Women reported a lack of available information in culturally sensitive media. These findings were important in informing how culturally competent care may be developed in the UK. The aim of this study in Gujarat was to conduct a similar, community-based study to explore whether women had similar experiences of incontinence and help seeking. It allowed us to explore the views and experience of women in Gujarat and then compare with findings among women of Gujarati origin in the United Kingdom.

6b.2 Methods

The study methodology was chosen to closely match the UK community based study (Chapter 6a). Ethical approval was granted by the Department of Obstetrics and Gynaecology, SSG Hospital, Medical College Research Department, Baroda. Data collection took place in December 2006 [Appendix 6.2].

Study population

The target population for this study were women from a varied range of socioeconomic and educational backgrounds living in Baroda, a city in the Gujarat region of India. Gujarat was selected because the vast majority of Indian women in Leicester originate from this state. Baroda has a tertiary level hospital providing care to women with reproductive health problems. However, there are no specialised continence services available to these women.

Women were recruited by the research associate in India from community groups, social clubs, those living in low income areas of the city through a self employed women's association (SEWA), as well as hospital attendees (either relatives of or patients presenting to the hospital for symptoms other than those of urinary incontinence). All the women recruited to take part were given a short introduction about and the aims and objectives of the study, either by me or the research associate who helped with the study and interviews. Those recruited from the social and community groups were then asked to attend at a specified time and location for the focus groups [Appendix 8].

Attempts were made to match the India sample with the UK sample (Study 2a) in terms of socioeconomic and educational level. Matching the groups in terms of socioeconomic status was inevitably difficult, and so the indirect indicators of socioeconomic status such as education level, employment and occupation were used to match the two groups.

Focus groups and Interviews

The hospital focus groups took place in a quiet room within the hospital. When it was not possible for participants to travel back to the hospital, individual interviews were carried out to ensure women living more distant from the hospital and from all socioeconomic groups could be included. The remaining focus groups were arranged at a location convenient to the women, usually at the home of one of the participants, or a place convenient to all participants. All the focus groups and interviews were conducted in the participants' chosen language (Gujarati, /Hindi/English) and facilitated by myself.

The development of the focus group and interview schedule was informed by the main research questions, review of the literature and the schedule used in our Study 2a (Chapter 6a). The four main areas explored in the focus groups were: awareness of incontinence; quality of life issues; seeking help for urinary incontinence; awareness of treatment options.

All focus groups and interviews were audio-recorded and transcribed verbatim into English. Name aliases were used on all transcripts. Any colloquial words and phrases that could not be translated verbatim were replaced with an English phrase carrying the same meaning. (e.g. there is no Gujarati word for incontinence and this has to be translated as “loss of urine”).

6b.3 Results

A systematic and iterative method of analysis based on the constant comparative method was used as before (Green, 1998). The data were read and re-read. Initially, ‘open codes’ were applied to the data representing the significance of sections of text. Open codes were then grouped into organising categories or overarching themes. The coding was partly influenced by our previous study 2a, but more particularly by ideas arising during data collection and analysis. Quotations are provided as illustration of the themes.

Four focus groups and ten interviews were conducted. Each focus group included six or seven women. Characteristics of the participants are presented in Table 6b.1.

Table 6b.1: Demographics of participants

Participants	No	Age (Mean)	Parity (Median)
Focus Group 1	6	42.6	3
Focus Group 2	8	38.3	2
Focus Group 3	7	47.1	3
Focus Group 4	6	52.4	4
Interview 1	1	33	2
Interview 2	1	46	3
Interview 3	1	52	1
Interview 4	1	38	4
Interview 5	1	47	2
Interview 6	1	28	1
Interview 7	1	29	2
Interview 8	1	26	2
Interview 9	1	78	7
Interview 10	1	69	5

Data from the interviews and focus groups proved very rich, and the following themes were identified:

Awareness and coping strategies

Various reasons were given for people not seeking help or advice for their incontinence problem. Norton *et al* (2006) found patients were unsure where to seek help and advice. Patients thought symptoms were normal and had low expectations of the benefits of treatment. There was the stigma of shame and embarrassment and fear of an accident happening at any time. This fear restricted and altered their pattern of life (e.g. never being too far from the toilet, avoidance of fluids, the need to wear pads,

feeling odd or different and affecting their work. When women discussed the causes of urinary incontinence, there was some awareness of the aetiological process; however, broadly incontinence was considered to be part of ageing, familial patterns or as a result of childbirth, all of which were considered unavoidable:

People who have many children especially if they have not had hospital deliveries then they are more likely to have problems as they have been in labour for a very long time (Focus group 1).

I'm not sure if it runs in families, my mother had similar problems and then my sister had it as well; don't know if I will get it (Focus group 1).

'Coping strategies' play an important role for managing incontinence and include changes in lifestyle, protection and aids. By the time women sought medical advice for urinary incontinence they had usually tried various tactics to either limit the leakage or protect themselves from it. The most common tactics include fluid restriction, regular toileting, and pads that are often home-made and unsuitable.

I know of someone I used to work with who used to wear a thick petticoat when she went out (Focus group4)

I remember that lady, who was very modern, that lived on the same street as us, she used to swallow blotting paper, she said it would absorb the urine so she wouldn't have to go often (Interview 4).

We drink a lot of water, which is probably why we need to go to the toilet often (Focus group 4).

Help seeking and barriers

Most women had accepted living with urinary incontinence; small amounts of leaks were thought to be normal and would only seek help when the condition became worse such as when they had no control on their bladders:

When it becomes embarrassing and I can't control my urine at all then I will show a doctor otherwise I will cope (Interview 6).

I felt ashamed.....it started as a little drop now and again and I thought it will go away. I was shy to tell anyone...now I have little control over it (Focus Group 2).

When you get old you have lots of problems...lots of women problems and this is one of them....if it happens a lot then see a doctor otherwise its normal (Focus Group 1).

No it only happens when I cough...not all the time...so I took some medicines for the cough (Interview 6).

Barriers

Most women participating in our study found that accessing healthcare was an issue especially in those from the lower socio-economical background. Although those that could afford private healthcare still did not seek help for urinary incontinence:

Don't know what to do, don't know where to go (focus group 2).

When I had the problem initially I went to the government hospital, but I got tired of running back and forth, they told me go to no 4 consulting room then no 10. Then for scan and they couldn't understand what was going on, they gave me

medicines and I didn't get better, then my sister in law went to this clinic and got operated so I went there and the medicines worked for me (Interview 8).

Healthcare professionals

Women found that those they turned to for seeking help with their sensitive problem were not very forthcoming and this reinforced the belief that incontinence was not a major problem and something that they had to live with:

They look at other problems more than leaking urine, if they find something else that is wrong then it is treated first (Interview 3).

This bladder problem is not going to kill you that is why they (doctors) think it is not very important (Focus Group3).

*I go for my check up and the doctor never seems to ask
(Focus Group 2).*

Gender preferences

Most felt that the gender of the doctor did not really matter; it was more the expertise of the doctor. They were used to seeing male physicians in a hospital setting (childbirth/surgical consultations):

A doctor is a doctor whether male or female; he should be good and know how to treat the problem (Focus Group 1).

*It has to be a good doctor who knows, then I don't mind if its male or female there are more male doctors in the hospital and one has to go for treatment
(Focus Group 3).*

I would like to see a female doctor. I would feel shy otherwise, and wouldn't show if it were a man (Interview 7).

However it was apparent that religious beliefs played a role in the choice of their physicians' gender:

Muslim women tend to want to see female doctors, I personally don't mind (Focus Group 3).

Allied professionals

Healthcare provision in India is very different from that in the UK. Although a primary care system is available most women present to the hospital or visit a private institution. It was apparent that in the city the doctors played the major role of providing healthcare, whilst in the rural areas, where nurses were in the forefront of providing primary care, most women turned to them for advice:

In the villages it's the nurses, in the town it is the doctor. In the village the nurses are close to the people as they provide immunization and other care (Focus Group 3).

Government hospitals aren't good ...we have to run here and there to get seen it is a lot of hassle.

I: what about private hospital.

R: treatment is good ...we pay money... (Focus group 2).

Treatment options

Various conservative treatment options are available for the management of urinary incontinence however when we asked about these the vast majority of them had either not heard of the options feared that surgery would be the inevitable outcome.

Pelvic floor exercises

Most women had heard of pelvic floor exercises, but were not sure how to do them. Those who had had children in the cities were informed of the benefits of pelvic floor exercises, but those that had delivered in the rural areas, by traditional birth attendants did not:

I was taught where I went for yoga (Interview 2).

Post delivery they are taught but they don't really remember
(Focus group 3).

Interviewer: Have you heard of pelvic floor exercises?

All say no. (Focus group 4).

Complementary therapies

Most women preferred to use western medication, a few had tried ayurvedic (traditional Indian medicine). There was also a concept of black magic which had caused the problem and women had seen traditional healers and holy men to cure them of this:

I think its bua (evil spirit), I told her to go see that priest
(Focus Group 4).

If it becomes an embarrassing disease I wouldn't take ayurvedic treatment: ayurvedic treatment works but it takes a long time and doesn't have side effects... (Focus Group 3).

Suggestion for health promotion

Health promotion is the process of enabling people to increase control over their health, it's determinants, thereby improving their health. We asked the participants to suggest culturally appropriate and cost effective methods of promoting continence awareness in the community, in medical, behavioural, educational, public policy and empowerment frameworks.

People will read posters rather than leaflets, large posters with pictures (Interview 7).

TV is better; people can see and understand better. Yoga has become popular because of TV (Focus Group 1).

Like AIDS, no one used to come and now people do, there is a lot of propaganda and people are no longer ashamed, so they come to be checked, they need to be told that this is nothing to be ashamed of, it's not a bad disease and is curable (Focus Group 2).

I'm not so sure about leaflets I tend not to read them, if they are colourful with little written on them then we are likely to read, we aren't in the habit of reading too much you see (Interview 5).

I can't read or write so pictures would be nice (Interview 9).

If there is a play or a film on TV, if it's on TV it is important , if you tell people some may listen but all may not understand, they can't read so leaflets are useless , plus if they think if it's on TV it is important that is why it has been shown (Focus Group 3).

6b.4 Discussion

Socio-economic and cultural factors are undoubtedly linked with health and health behaviour but the literature on acculturation has received critical review as it tends to be a “catch-all construct” (Salant and Lauderdale, 2003) and models tend to be linear and unidirectional meaning that complex systems of meaning and action are missed. Rather than adopt a model of acculturation and compare a migrant population with the host population we sought to conduct a cross-cultural study to compare views and experiences around incontinence for women in migrated population with those in country of origin.

This qualitative study explores the attitudes of Gujarati women in India towards urinary incontinence and helps to understand the cultural beliefs that could influence their awareness of the condition, coping mechanism and accessing healthcare for the problem. We sought to compare our findings with those from women living in the UK (Study 2a).

In our study conducted in Gujarat we found that women in India expressed similar beliefs about urinary incontinence as their counterparts in the UK, believing this condition to be something that one had to live with very little information about treatment options. Our UK study had shown that in spite of living in the UK for over a decade most of the women were unaware of the condition, and sought to normalise their symptoms or attribute it to childbearing or old age. A consequence of this was that most women had not considered attending the GP to discuss an issue which they

thought was unavoidable, or a side effect of other treatments. Women also held the belief that no treatments were available, a finding similar to that reported by others, among women of Caucasian origin (Holst and Wilson, 1988).

This is an interesting finding as the vast majority of the women in our UK study had lived in the UK for a long period of time, and in spite of available healthcare and awareness campaigns, their perception of the condition was not greatly different from the women in India, where such services are not readily available to the vast majority. Although there is a difference in availability of protective continence devices between countries, women in India adopted coping mechanisms, which in principal were similar to those in the UK.

A lack of consultation and management skills in continence care has been identified by Eriksen *et al* (1999) who found that >50% of cases of incontinence were inadequately managed. Swanson *et al* (2002) showed that only 34.6% of family physicians felt very comfortable dealing with urinary incontinence. In spite of their being differences in healthcare provision, it was interesting to note that from the participants perspective, women felt that healthcare participation in managing this condition was poor. They felt that healthcare professional didn't give urinary incontinence importance and this reflected in their consultations and treatments offered. They highlighted the need for health care professionals to take the lead in addressing the problem, as the impression was that significance of a condition depended on the emphasis that healthcare professionals put on them. They gave examples of immunization, diabetes being important because they were continually being promoted. This suggests that there may be a universal apathy amongst healthcare professionals in addressing and managing health needs in regards to urinary incontinence.

Women in India were divided on the gender and level of healthcare professional they wished to see. They saw the doctor as a professional, the gender of whom was secondary to their competency. Those interviewed in the rural areas were happy to see the nurses or health visitors as the vast majority of health promotion is carried out by the allied health professionals. This was different in the city where the majority wanted to see a doctor. This is different from the women in the UK who would prefer to see allied healthcare professionals, partly because they felt they had more time than their GPs and were most likely to be female, whom they felt comfortable talking to (Doshani et al., 2007).

The presumption that women in India would favour the use of alternative therapies over western medication was refuted. Women in India preferred to try western therapies and reverted to traditional ones if these failed in a similar fashion to the UK women we studied.

Health promotion is an important aspect in bringing sensitive conditions like urinary incontinence into the highlight and the participants provided valuable information on ways that would be acceptable to them. This was important as the key to increasing awareness and breaking the barriers in accessing care is promoting health that is efficient, culturally sensitive and effective.

Women in Gujarat felt that conventional leaflets would not make an impact in increasing awareness within their community, and that talk-based media in the form of short advertisements and educational talks on the local (culturally relevant) media and small group discussions would be a better way of increasing awareness (Turner and Shepherd, 1999). This finding was similar to those in our previous study 2a (Chapter 6a) with women in the UK and further reinforces the need to use these in developing health promotion programs for ethnic minority women.

6b.5 Summary

In conclusion, our study has identified evidence of lack of acculturation about incontinence, insofar as the beliefs about inevitability and treatment were concordant between the Gujarat women and our UK sample. Further, the cultural tendency to prefer media based information giving seemed resistant to migration.

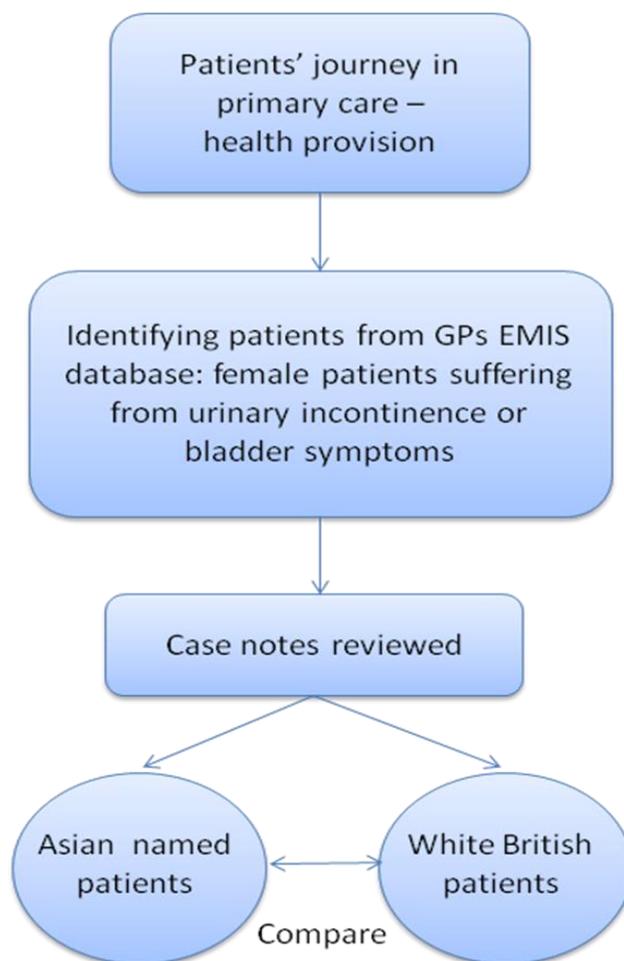
The results of this study adds valuable information on the diversity of urinary incontinence experience and helps us to understand cultural and health beliefs of our women, which are fundamental to the development of a strategy to address 'culturally competent' services .This emphasises not only clinically effective services but also the linguistic, cultural and religious preferences of individuals receiving the care illustrating the need of a proactive healthcare system to address the variability of need within a group.

Chapter 7: Patients' journey in primary care

Chapter 7a: Health Provision

In this study women diagnosed with Lower urinary tract symptoms (LUTS) were identified using the Read codes in EMIS (Egton Medical System). The records were then reviewed and data collected to chart a patient's journey in primary care with urinary incontinence. Ethnic comparisons were then carried out comparing the treatments offered. The study process is shown in Figure 7a.1 below.

Figure 7a.1: Overview of patients' journey in Primary Care Health Provision



There are evidence based clinical practice guidelines published worldwide for initial assessment management and treatment for UI (Woodford and George, 2007). A Department of Health report recommended that the initial management of incontinence is carried out in primary care and that a systematic approach be adopted (Department of Health). The report emphasized the need for a suitably trained health professional to carry out the assessment, followed by first-line treatments of pelvic floor exercises (PFE) for stress incontinence, bladder training and anti-cholinergic medication for urge incontinence. It was also recommended that all incontinent individuals be identified by proactive questioning of those at risk, such as pregnant and post-partum women, older people and their carers, people with disabilities, school age children and menopausal women. More recently, recommendations for treatment of women with urinary incontinence have been published by the National Institute for Clinical Excellence (NICE), which address assessment and treatment in both primary and secondary care (NICE, 2006).

Chronic conditions like asthma, diabetes mellitus type 2, and hypertension have shown a greater burden of disease among ethnic minority groups (Lanting et al., 2005) (Agyemang et al., 2005). Possible explanations for these may range from genetic predisposition to access to healthcare (Bonds et al., 2003). We hypothesize that the latter maybe the case in urinary incontinence.

7a.1 Aim

The aim of this study was to chart out patients' journeys through primary care, exploring the time taken to present to a primary care health professional, and the investigations and treatments offered in primary care before being transferred to secondary care. These were to be compared with the guidelines set out in the NICE document in regards to managing urinary incontinence (NICE, 2006). These data was compared by ethnicity.

7a.2 Methods

To obtain information on the care received in primary care we used the electronic patient record database. The prime function of the medical record is to support patient care (NHS Executive, 2000). The general practice record is based on an individual and is a contemporaneous list of entries about that person's health. Record entries in computerised general practice systems generally consist of a mixture of text and Read codes. Together these form the narrative structure and content of the electronic patient record.

There are thousands of Read codes and new codes are released bi-annually with the introduction of new techniques and suggestions by users. Approximately 87% of medical practices are computerised, and of these 80% use Read codes, a figure which is expected to rise to above 90% in the next three years. The advantage of the Read codes is that they are simple to implement and can aid searches. They also allow GPs to record data more consistently, retrieve it more easily and analyse it thoroughly (NHS Information Authority, 2000.).

We performed a retrospective study of female patient records registered on the Egton Medical Information System (EMIS) in an inner city GP practice. Read codes for

urinary incontinence were ascertained and used to identify these women. Women over the age of 18 years were included in the study.

Ethnicity coding had only been introduced in 2005 and therefore a manual search of all identified women suffering from incontinence was carried out to separate those of Asian origin on the basis of surname recognition (Cummins et al., 1999).

Data recorded, included [Appendix 9]:

- Time to presentation (number of years/months before patient presented to GP)
- Presenting symptom (primary or secondary symptom for consultation)
- Plan of management in primary care (investigations/treatment)
- Referral to secondary care (time and reason).

To determine if there were differences in presenting and treatments offered due to ethnic differences in the patients at the practice, a matched number of case notes of Asian (based on surname recognition) and White British women were identified. We drafted the common treatments that should be provided in primary care from the NICE guidelines on UI (see Table 3.1).

7a.3 Results

300 patients were identified using the Read codes, of whom 70 (23%) were Asian. On reviewing the notes only 30 Asian named patients were identified to be suffering from urinary incontinence. The remaining had urinary problems not pertaining to incontinence (e.g. urinary tract infection, prolapse) and were excluded from the study. Forty consecutive case notes of White British named women were matched to these.

The mean age and parity in both groups was similar (Table 7a.1). The average time to presentation in Asian and White British women was 750 and 910 days respectively. More Asian women were diagnosed with overactive bladder symptoms whilst White British women had mixed urinary incontinence (Table 7a.1).

We found no difference in the number of consultations for urinary incontinence between the two ethnic groups (Table 7a.1). In the vast majority of patients the appointment was made for urinary incontinence.

The number of women referred to secondary care varied between the two groups. Asian women took a median of 105 days to be referred compared to 30 days in the White British group.

Further analysis showed GPs were more likely to refer White British women to secondary care on the first consultation 40% compared to 0% in the Asian group ($p=0.002$) (Table 7a.1).

Table 7a.1: Demographics, Consultation, Referral in Primary Care

	Asian	White British	P
Number	30	40	
Age	53 [42-64]	59 [44-63]	0.087
Parity	3	2	0.240
BMI	29 (22-43)	27 (18-44)	0.649
Symptoms			
OAB	19	14	
Mixed	6	16	0.059*
Stress	5	10	
Referred on first visit	0	15	0.0002
Time to referral	105 [7-1275]	1 [0-30]	0.002
No of consultations	87 (+/- 47)	104 (+/- 50)	0.149

* Chi square test for distribution list

Data are presented as numbers , median (range),mean(+/-standard deviation)

The investigation and treatments carried out in the GPs practice were analysed by diagnosis and ethnicity (Table 7a.2 & 7a.3). Fewer than 10% had their urine tested for infection. 4% were given advice on pelvic floor exercises, and only one patient was given advice on weight reduction. 10 out of 70 (14%) patients were referred to the district nurse. Nearly half were given anti-cholinergic drugs. Interestingly one out of eight to whom the drug was prescribed did not suffer from overactive bladder symptoms or mixed urinary incontinence. There was no difference by ethnicity in the treatment offered, except for the referral to secondary care.

Table 7a.2: Procedures performed in Primary care

	Asian (%)	White British (%)	Total	P Value
MSU	3 (60)	2 (40)	5	
Pelvic Floor Exercise	1 (33.3)	2 (66.7)	3	
Bladder Advice	1 (33.3)	2 (66.7)	3	
Refer to District Nurse	3 (30)	7 (70)	10	
Refer to consultant	8 (44.4)	10 (55.5)	18	0.857*
Anticholinergics	14 (46.6)	16 (53.3)	30	
Reduce Weight	0	1 (100)	1	

* Chi square test for distribution list

Table 7a.3: Procedures in Primary care by diagnosis

	Stress	OAB	Mixed	Total
MSU	0	3	2	5
Pelvic floor exercises	3	0	0	3
Bladder advice	0	3	0	3
Refer to District Nurse	3	4	3	10
Refer to Hospital	5	7	6	18
Anticholinergics	4	16	10	30
Reduce weight	0	0	1	1
Total	15	33	22	70

7a.4 Discussion

This study is the first of its kind in charting the patients' journey through primary care in women with urinary incontinence from an ethnic minority background. We found a very low rate of reported and recorded urinary incontinence, which supports work by others showing that urinary incontinence is frequently underreported (Cardozo et al., 2000).

The higher incidence of overactive bladder symptoms diagnosed in Asian women is in keeping with findings from studies that have reported a difference in incidence rates between ethnic groups (Thom et al., 2006).

Asians took an average of 160 days longer to present than their White British counterparts. This supports the findings in study 2a (Chapter 6a), where we found that women tended to normalize their symptoms and this together with other barriers to accessing healthcare delayed their presentation.

Those that did present made the appointment primarily for their urinary incontinence as a secondary symptom. This is similar to the data from Diokno et al (2004) whereby 43% of Caucasian women in USA spoke to their general practitioner about incontinence. 85% of those women who talked to a physician stated that they rather than the physician had initiated the conversation. 35.4% recalled that the visit was for a medical condition other than incontinence and 5.3% recalled the visit was for routine postnatal care. Only 7.6% reported that the visit was scheduled specifically to discuss incontinence. This published data and our own findings suggest that physicians need to proactively ask patients about their urinary symptoms. This is important if we want to encourage silent sufferers in the community to seek help.

An important finding of the study is the lack of immediate referral to secondary care in Asian named women, as compared to White British women. This highlights the health

inequalities faced by ethnic minorities in healthcare, and further exploration of this finding is needed, to ascertain if this finding is pertinent to just urinary incontinence or other conditions as well.

The NICE guidelines suggest simple diagnostic and management modalities (e.g. bladder advice, pelvic floor exercises) for urinary incontinence. These have been shown to be non-invasive and cost effective in primary care (Table 4.1).

Our findings suggest that overall management in primary care was basic. Although there was no difference in management by ethnicity, the treatments offered were not in accordance to those recommended by NICE (NICE, 2006), for example, a simple test to differentiate urinary incontinence from urinary tract infection entails a urine dipstick or midstream urine. This should be carried out in all of the patients attending with lower urinary tract symptoms (LUTS). Our study found only 7% of patients had this test.

Simple effective treatments of bladder advice, pelvic floor exercises and weight reduction were suboptimal. There appeared to be a tendency to simply refer the patients onto district or specialist nurses or the hospital. These findings agree with the consensus conference on urinary incontinence in suggesting that most healthcare professionals tended to ignore the problem of urinary incontinence resulting in inadequate diagnosis and treatment (Resnick and Ouslander, 1990). The GPs tended to manage urinary incontinence with anti-cholinergic drugs with 30 out of the 70 patients being prescribed one. A study by Hamm et al (Hamm et al., 1996) showed that drug therapy was readily used by GPs often as a trial prior to referral or whilst waiting for a secondary care appointment.

This study also raises the issue of validity and reliability of electronic health records, and especially coding of ethnicity and clinical conditions. I had difficulty in identifying

Asian patients from the GPs register because ethnicity coding had only been introduced five years ago and only a proportion of the newly registered patients had been coded.

In spite of identifying 300 records by Read code for LUTS, only thirty of the seventy identified to be Asian had them. The remaining conditions were urinary tract infection, prolapse or pathology unrelated to the urinary tract.

Barriers to clinical coding have been identified (de Lusignan and van Weel, 2006). Recording data in consultation takes time and skill and is largely dependent on the motivation of the person entering this information. It is important to overcome these barriers to enable data to be identified easily and used meaningfully.

7a.5 Summary

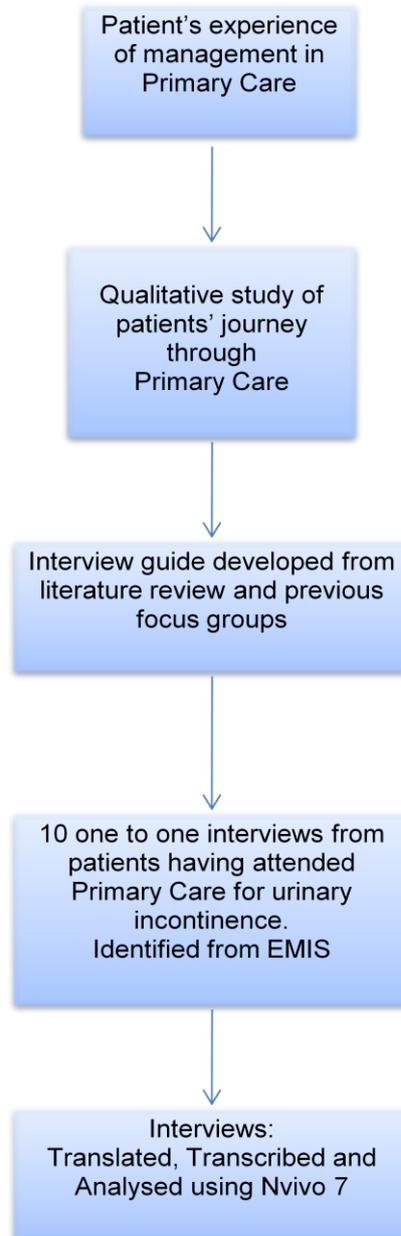
In conclusion, there appear to be several issues acting as barriers to optimal treatment for urinary incontinence in primary care. Management practices are inconsistent and generally unsystematic with high referral to secondary care. This is costly to both the National Health Service and the patients (in terms of quality of life costs). Access to specialist nurse-led continence services was variable and often underutilized. Referral patterns to secondary care are also based on ethnicity and these health inequality needs further exploration.

The inadequate reporting and management of LUTS in primary care highlighted in this study reflects non adherence to NICE guidelines, raising issues about compliance as well as about the barriers to implementing these recommendations. Further exploration of these barriers are needed to be able to implement changes in the current management practice of urinary incontinence in primary care.

Chapter 7b: Patients' experience

This study aims to explore the Indian woman's experience of management of urinary incontinence in primary care. The flow chart below Figure 7b.1 shows the recruitment process for the women who took part in one to one interviews. These were translated and transcribed. Analysis was by constant comparative method using NVivo 7 (QSR International 2006).

Figure 7.1: Overview of patients' experience of management in Primary Care Study



When patients with UI seek professional help in many European countries such as the UK, they will first present to the general practitioner (GP) (O'Donnell et al., 2007). Around 6–8000 adults experience regular incontinence in an average Primary Care Trust (London). There is evidence however that most people who have consulted their GP in the first instance find treatment provision to be poor. One study reported that while most women seeking help for stress incontinence received some form of treatment or advice, only 35% received recommended treatments (Shaw et al., 2006c).

7b.1 Aim

To further understand the Asian women's experience of assessment and management in primary care in regards to urinary incontinence.

7b.2 Methods

Women were identified and invited from the GPs register [Appendix 10]. Once they had agreed to take part in the study, they completed a consent form [Appendix 11]. The interviews were carried out in the similar way as the focus groups (Chapter 4), maintaining confidentiality and giving the women the option to withdraw at any time. These qualitative interviews were carried out in the women's chosen regional language and then translated and transcribed. Thematic analysis was performed and themes identified. The analysis was based on the constant comparative method derived from the grounded theory (Strauss and Corbin, 1998). A coding frame was developed for the main concepts, which were then broken down further into sub codes creating a hierarchical coding tree. A field diary was kept by me to note additional information on theoretical explanation and thoughts on themes and operational issues. To help manage the data systematically NVivo 7 a qualitative data software package was used

to help code each transcript (QSR International 2006). Data collection was stopped when data saturation was reached.

7b.3 Results

10 women were interviewed. Thematic analysis was performed and the following themes were identified:

- Feeling towards treatment options offered and care received.
- Choice of health professional and their gender.
- Barriers to effective consultation.
- Suggestions to improve service.

The themes are presented with supporting data from the interviews in the form of transcript excerpts with participation identification in brackets. Demographic details of the participants are presented in Table 7b.1 and the coding tree derived from the analysis is shown in Appendix 5.

Table 7b.1: Participants demographics

Participants	Age	Parity
Interview 1	44	3
Interview 2	48	1
Interview 3	52	2
Interview 4	49	0
Interview 5	45	1
Interview 6	35	4
Interview 7	31	1
Interview 8	76	7
Interview 9	78	6
Interview 10	66	5

Feeling towards treatment options offered and care received

The women interviewed were confused about the treatment received in primary care. They felt that not much could be done in primary care. The GPs had insufficient knowledge or seemed to be uninterested in their condition resulting in them being referred to the hospital or specialist nurses.

GPs are useless all they did was to give me antibiotics and paracetamol, he didn't even examine me (HP).

I don't think GPs are interested in these kinds of problems, because it's not really like an illness is it? It's not a major illness, it's just something you have developed (LP).

I feel GPs can't do much about this problem that is why they refer you to the consultant in the hospital (SS).

The women were frustrated with both the lack of plan of management and the delay in referral to a specialist. This had a psychological and financial impact, as they had to take time off work.

She gave me a leaflet in the beginning about exercise, then I went a couple of times and then she referred me to the hospital (ZB).

My GP is female, she told me I have infection so she gave me antibiotics sometimes I leak in bed, and they don't give me pads so I put a black plastic bag you know the garbage bag. I went to them and said I need nappies for night time (JP).

I was hoping they would have sorted it out the second time, it's very frustrating because you have to go to appointments and for that you have to take time off work and that's not easy (LP).

Choice of health professional and their gender

Eight out of 10 women interviewed felt that they would prefer seeing a nursing health professional than a doctor. They felt comfortable talking to nurses about their incontinence because they were female and had more time to discuss the problem.

I don't think they (doctors) are really interested I think nurses take a slightly different approach maybe because they are women or have had a slightly different training from doctors (LP).

I would prefer the doctor, but the doctor referred me to the nurse (PS).

I would see the practice nurse, because I think she sees lots of women and has more experience. She knows how to talk to women and deal with women. I felt more confident with the practice nurse than with the GP because of the way she talked to me. She explained everything well (LP).

Women were divided in the gender of health professional that they would prefer to see for this condition. If given the choice two third of the women would have preferred to be seen by a female physician. Those that did not mind said the experience of having a male obstetrician during childbirth influenced their decision.

Many of the women in our community may not go to see their GP; many surgeries in this area don't have a female doctor. I was comfortable because I had a female doctor (SS).

If I had a choice I prefer a woman but when you have kids there are male doctors you can't stop that (HD).

Barriers to effective consultation

Issues with communication were highlighted as barriers to effective consultation. All of these women had lived in the country for over ten years, some for as long as 40 years. Although some of them could speak English they felt that their vocabulary and understanding was limited when it came to understanding medical terminology.

I can speak little English but when they talk more I can't understand (HD).

Those who couldn't speak English had to rely on family and friends due to inconsistencies in interpreting facilities. This caused inconvenience to the patient, as well as poor utilization of resources.

I went on my own and there was no one with me so no one could speak so then I had to go home and had another appointment when I took my daughter (LT).

We explored the role of interpreters in facilitating the communication process during the interviews. The women were again divided as to whether they would want an interpreter for the consultation. All women felt that communication was important but were divided as to whether they would prefer an interpreter or a family member to interpret on their behalf. Some felt that information revealed during a consultation would be confidential if an interpreter was used as compared to a friend or family member.

I think they would feel comfortable with a stranger if it was me I would feel comfortable with a stranger, I wouldn't want my family to know about my personal life, but I don't know what others might think. It's confidential with an interpreter and it won't go out into the community (PT).

Others felt they were more likely to trust a family member with such sensitive personal information and would not be comfortable talking through a stranger about it.

This is a private problem that is why it is difficult to talk to this with an interpreter however it's easier if it's a knee problem (GL).

If I had my daughter at home I would take her. It's awkward talking about your personal things with someone, its private. With my problem I'm even shy to talk to my husband about it. You have a limit about how personal you can get (LP).

They also commented that by using the same member of family they did not have to explain their condition repeatedly. However this was not the case with the health professionals. They were frustrated at times because they would have to tell their “story” from the beginning every time they saw a new doctor, at each visit.

I would trust someone from home rather than interpreter. We try to speak English but at our age it's difficult. I would take my husband who would know my story so I don't have to tell everything from the beginning (GH).

I don't know I'm fed up, you go there but nothing happens you see a new doctor each time and each time you have to tell the whole story (PT).

Other communication issues were highlighted with the women not being confident to ask the health professional questions about their condition and treatment. This was because either they were frightened to question authority or felt they had inadequate linguistic skills to carry out a medical consultation.

Interviewer: Do you feel confident asking questions to the health professionals
L: Not all the time, sometimes I feel am I asking the wrong thing, should I be asking this? (SS).

Management options

We explored the procedures carried out in primary care from the perspective and understanding of the patients. They highlighted that minimal intervention was done in primary care and the vast majority were referred to the practice nurse or to the hospital for further evaluation and treatment. Common treatments offered in primary care was repeated courses of antibiotics, in spite of the low level of tests performed to diagnose this as shown in our previous study (Study 3, patients' journey in primary care), where less than 10% had their urine tested for an infection.

Another course of antibiotics (GB).

Interviewer: Did the GP do any test before referring you to the hospital

J: no he didn't (LP).

When I saw the GP he referred me to the nurse and said she would examine me. She thought I had the prolapse of the womb and she said I can see it and thought that it might be causing the problem and pelvic floor exercises weren't working so she referred me to the hospital for pelvic floor exercises (LT).

Suggestions to improve service

The women interviewed were open about their condition and were keen for others to learn from their experience to avoid suffering in silence. They made suggestions about the use of audio-visual services, over written leaflets. These services could be placed in areas visited by these women (e.g. temples, schools, community centers). The leaflets if used would have to be in English as most of the women could not read their mother tongue.

Yes I would read them but I can't read Gujarati it would have to be in English. It can be in the surgery or in schools if it's interesting about health, people will read it. Put posters in community centres, temples, gurdwaras, where women can discuss it with other women and they can help them (PT).

I prefer to listen to the radio. I think with listening you take more in, but with reading your mind is elsewhere. And you can listen while you're doing the housework (SS).

Not sure we get many leaflets and we throw them out.

Leaflets in Gujarati would not be useful as women can't read (LP).

They also suggested that healthcare professionals should be proactive in asking about urinary problems, in a way similar to the emphasis given on conditions such as hypertension and diabetes. They commented that at each visit to the GP for any symptom, they were always asked about these, which made them think that they must be important.

What they should do is every time they see the women they should ask the women what things they are suffering from. Ask them is your bladder alright. Once it's mentioned the person will think oh it's mentioned so let me tell them about it. Maybe they would open up (AD).

7b.4 Discussion

In spite of the NICE guidelines being published in 2006 to optimise UI treatment, there seems to be a lack of management strategy for UI. This may be a reflection of the training or the understanding of UI in primary care. The failure to manage UI actively results in suboptimal care and increases patient dissatisfaction (Viktrup and Bump, 2003).

The women in this study felt that GPs had limited knowledge and training on managing urinary incontinence, this together with time constraints for consultation acted as a barrier to seeking help for their condition. This is supported by literature on the variability of GPs knowledge and views on urinary incontinence (Shaw et al., 2006b).

The women felt that allied health professional such as the practice nurses had more time and were comfortable discussing their condition with them rather than the GP. Practice nurses may be better placed to discuss urinary incontinence with patients than GPs, given their established role in health promotion and longer consultation times (Gott and O'Brien, 1990). Most women preferred to be referred to nurses, however there appeared to be a poor referral rate to nurse-led continence care or community continence care, as shown in our study no 3a (Chapter 7a). Most of the women were referred to secondary care, this finding is supported by the study in primary care (Chapter 7a), whereby patients were readily referred to secondary care. This could be the result of lack of availability or lack of knowledge of local services.

Communication with health professionals was a recurring theme. This related not only to the language of the consultation but terminology. Some women spoke reasonably good English but felt they had inadequate vocabulary and understanding for a medical consultation. Studies of health, race and ethnic minorities tend to deal with language differences only in terms of interpretation and translation (Smaje, 1995): patients can or cannot speak English; they either need an interpreter, or they do not. Yet the issue is not so straight forward. Even relatively fluent speakers of the dominant language have differences in accent and communicative style which make it harder to process meaning accurately.

Women reported they preferred to see a female physician for their symptoms a finding supported in literature where irrespective of ethnicity, women highly preferred a female physician for visits that require gender specific examinations such as gynaecological examinations (Ahmad et al., 2002).

This study adds to the findings of study no 2a (Chapter 6a) shows a consistent theme of preference for audio/visual materials. These have been found to be of increasing value to minority ethnic groups. For example, participants in Chew-Graham's study (Chew-Graham et al., 2002) identified the potential for using Asian Sound radio to disseminate information about mental health. This was similar to Mclean et al's (2003) study, where members of the African Caribbean community suggested informal support networks and African Caribbean radio stations to spread information relating to mental health provision and provide informal referral services. Therefore future development of educational material for this group should encompass a talk based approach rather than a written one, to be successful.

Drug therapy was more readily used by GPs according to the women and this was similar to studies done elsewhere (Shaw et al., 2007). There appeared to be no distinction for the indication of the use of anticholinergic drugs, irrespective of diagnosis of overactive bladder symptoms or stress incontinence patients were prescribed these medication. This is also shown in our primary care casenote study where one in eight women were prescribed these drugs inappropriately.

7b.5 Summary

This study highlights the lack of adequate management in primary care and the barriers both personal and institutional that exist and need to be addressed. Women expressed the need for effective linguistic consultation and a proper management plan, to avoid the frustration and psychosocial impact that UI has on them. Suggestions for improving services need to be taken on board. The need for female physicians, nurses and interpreters have been explored.

Although some incontinent women may not feel they need or want medical treatment for incontinence, it is important that women who want to consider treatment are able to receive accurate information from their healthcare providers to make informed decisions about their options. The women preferred talk based audio-visual methods of receiving information.

Section III

Chapter 8: Conclusions

8.1 Key Findings

As this is the first study to our knowledge exploring the prevalence of UI in South Asian women in the UK, we had very little literature to compare our findings with others. The various studies conducted have met the objectives set out in the introduction and have enabled us to obtain information towards developing a culturally sensitive continence care package. We have explored the prevalence of the condition within this ethnic minority group, and investigated issues around the condition from within the South Asian community, to those having sought help for their incontinence. Barriers to accessing care were explored and importantly ways in which they can be addressed from the users' perspective.

Findings of similar prevalence to that of the White British women confirmed our initial beliefs that there must be other barriers to accessing healthcare as reflected in the low representation from South Asian women in our outpatient clinic population. It was interesting to note that the impact UI had on South Asian women reflected in both the quantitative and qualitative studies were more than that in the White British women. This further confounds the fact that the barriers must be so overwhelming that in spite of the condition having a greater effect on their lives they still did not seek help.

The average age of the women in the prevalence study (No1) in the South Asian group was much younger than I had expected based on the anecdotal findings from practice, where much older patients present to secondary care. This may reflect the need for care in much younger women, who may be suffering for long periods of time, adopting various coping strategies, before seeking help.

The vast majority of women that had attended primary care had initiated the conversation about their incontinence themselves. The women that presented to their

GPs were just a small proportion of those suffering with the problem and because of the social embarrassment and stigma attached to the condition, it was suggested both in the cultural context study and the patients' experience in primary care (chapter 6 and 7) that more needs to be done to promote awareness of the problem (e.g. health professionals need to be pro-active in questioning about these symptoms like they do for conditions such as diabetes and hypertension).

Effective communication is a key tool in providing health care, ethnic minority health being no exception. This research explored issues around interpreting services that were ad hoc and reliance on using family and friends to interpret for them. The women were divided in their preference of using a professional or a family member to interpret, with issues around confidentiality and acceptability. Majority of the women preferred to be seen by a female health professional, with preference of seeing a nurse rather than a doctor. These findings should be taken into account when services are planned.

Considerable resources are spent by the NHS on translating existing leaflets into regional languages. Our study shows that this is culturally not acceptable to these women who would prefer audio-visual aids to promote health awareness and dissemination of information. This is an important finding as it was shown in two separate studies carried out in this research project, and consideration should be given to this modality of information relay. Understanding culture was vital to comprehend why traditional health promotion approaches have not been successful. The study of women in India enabled us to delve into these cultural issues, resulting in suggestions from the community in ways to improve culturally sensitive access and treatment.

Management in primary care was basic, with patients being frustrated with the lack of management plan and referral to secondary care. The interesting finding which highlights inequalities in healthcare was the difference in referral to secondary care by

ethnicity. None of the South Asian women seen in primary care were referred immediately to secondary specialist care. This requires further exploration, as this maybe a reflection of practice in relation to ethnicity in general rather than being specific for this condition.

The research project confirms our observation that South Asian women do suffer with urinary incontinence and the impact it has on their quality of life is significant. Both personal and organisational barriers to effective healthcare need to be addressed if we are to improve services for these women.

8.2 Strengths

This study is the first of its kind to explore in depth the prevalence, symptoms and impact of UI on women from a South Asian background. The study with women in India is novel in improving our understanding of culture and beliefs that affect health and the influence migration has on these. This has not been shown before in the area of urinary incontinence.

This study uses a mixed methods approach, with triangulation of the data to reach the end results. This has been beneficial as it has allowed us to explore in depth areas that may not have been possible if a single research method was used. By using both quantitative (questionnaires) and qualitative (focus groups and interviews) we were able to ascertain the prevalence, objective as well as subjective impact of UI on these women, and explore the barriers to accessing healthcare. All this would not have been possible in a single method study.

The advantage of having the researcher being multi-lingual ensured that information was not 'lost in translation'. Contrary to traditional beliefs of cultural shyness women

were keen to talk about their LUTS and this has helped us immensely in obtaining the data, which would have otherwise been impossible.

8.3 Limitations

This study explores the experiences of South Asian women (mainly Indian) with urinary incontinence and although there are bound to be similarities with other South Asian women (Pakistani, Bangladeshi), the findings should not be generalised to all Asian women. Socioeconomic status and educational levels were assessed by me, but there was no formal assessment of these variables.

The identification of both Asian and White British women from the Primary care database was done based on surname recognition, as ethnicity was not routinely coded. This raises issues on the validity of ethnic data collected and is an important aspect which the majority of ethnic health research suffers from due to lack of ethnic data monitoring.

The response rate from the questionnaire study was poor in the South Asian arm. We may have to explore other means of collecting data from this ethnic group for future research, as these women were probably not comfortable completing postal self administered questionnaires. This is also reflected in the questionnaire part of the study whereby younger women (average age of 40 years) returned completed questionnaires. Thus a whole cohort of older women may have been missed in this part of the study. However efforts have been made to include them in the qualitative parts of the study by actively recruiting older women for some of the focus groups.

The questionnaires used in the study (LUSQ, LIS, ICIQ-SF) have not been validated in any South Asian language. We translated and back translated the questionnaires to ensure that they were culturally appropriate and retained the meaning, and validation of the ICIQ-SF is underway.

The way participants respond to questions may be influenced by perceptions of the role and status of the interviewer (Richards and Emslie, 2000). Some of the participants in the study knowing of the facilitator's medical background wanted a dialogue rather than supplying information for the research and this had to be addressed (e.g. time was allocated at the end of the focus groups for participants to talk about specific medical problems)

Barriers from an organisational perspective were explored and the triangulation from primary care audit and the interviews from users of service highlighted the inadequacy in diagnosis and management of urinary incontinence in primary care and efforts should be made to address those if we are to improve services for these women.

It is equally important that we explore the experiences and challenges of primary healthcare providers in managing women with urinary incontinence from various ethnic backgrounds. None of the Asian patients were immediately referred to secondary care, and this needs to be further explored, to determine if this is a referral pattern in the individual practice studied or a general one in practices across the county. To understand referral pathways further, research is needed to see if the findings of our study are duplicated with other medical conditions within the practice studied, to establish whether the discrepancy in the referral pathway was due to the medical condition or ethnicity.

8.4 Recommendations

As this thesis explores urinary incontinence in the context of ethnicity, the recommendations from the research findings are towards a culturally sensitive continence care strategic framework.

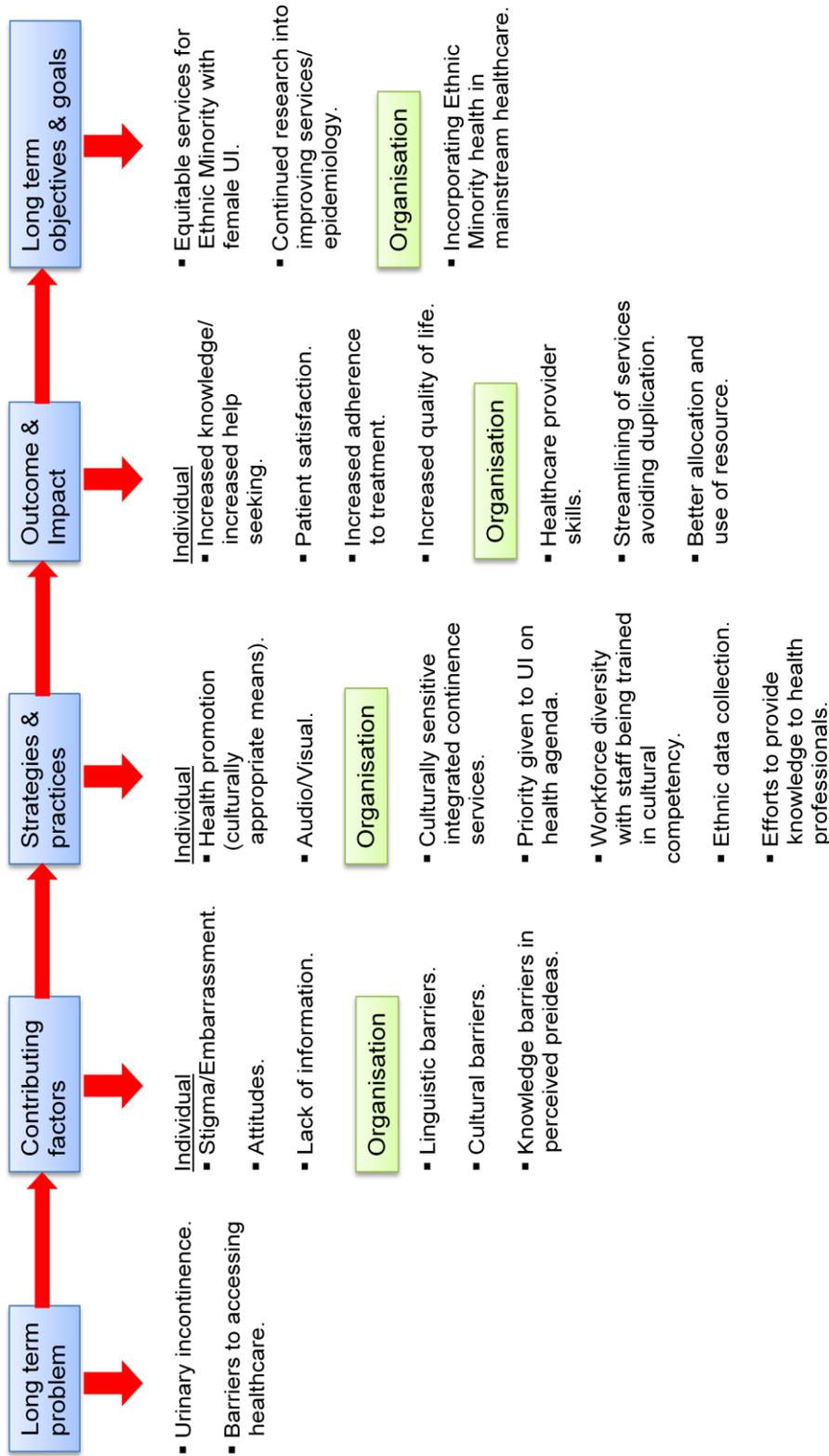
The issues which are of concern to South Asians are not dramatically different to those which the literature identifies as concerning many white women suffering with urinary incontinence. The interrelationship between ethnicity, race, class and gender is complex and dynamic and these variables may compound the impact UI has on their health.

However, we must remember as (Atkin, 2004) argues “not every problem or difficulty a person encounters as they attempt to gain access to appropriate service delivery can be attributed to their ethnic background”.

Despite having thought that culture might explain differences in presentation in secondary care (the original spur for the research), the thesis actually found sub-optimal care in general practice and a failure to refer to secondary care was a key issue. These seem to be the most significant findings and merit further investigation.

Some of the suggestions from the research are highlighted below, and outlined in a strategic framework (Table 8.1) to provide culturally sensitive continence care.

Table 8.1: Strategic framework for culturally sensitive continence care



Integrated Culturally Sensitive Continence Care

Continence care is 'the total package tailored to meet the individual needs of patients with bladder and bowel problems' (DOH, 2000a) .

Good Practice in Continence Services (DOH, 2001a) calls for integrated continence services that are cohesive, comprehensive equitable and effective for all. The emphasis is placed on primary care teams to be proactive in identifying all people with incontinence, offering initial investigations and treatment. The commissioning of continence services will be the responsibility of the Primary Care Trust ensuring that there is a fully integrated service providing seamless care for individual patients within health and social care settings (DoH, 2001b). These services should encompass the cultural and linguistic needs of the population they cater to.

The NICE guidelines on urinary incontinence (NICE, 2006) should be implemented and monitored to ensure compliance and identify barriers to its use. To ensure implementation awareness and training sessions should be introduced into primary care. The practice should be audited and problems with compliance addressed.

Ongoing comprehensive risk assessment, community outreach, appropriate management, interpreter services, and health education should also be integral components of the service model. Provision of outreach activities facilitates access for women who traditionally are difficult to engage in care or who drop out of care. Strategies to improve access to care should incorporate facilities for running clinics in areas and at times convenient for patients (e.g. day centres, evening clinics). This was suggested by the women who took part in Study 2a (cultural context study) as well as those in Study 3b (patients' experience of management in primary care) who felt better access would facilitate attendance and compliance to treatment.

An important aspect of the care process is ongoing evaluation. Quality of care should be an important outcome measure. Methods to document and track access and health status outcomes in addition to measures that reflect minority women's concepts of health and wellness must be included in the evaluation process (e.g. patient satisfaction as shown in the proposed strategic plan, keeping the cultural background of the service users in context).

Ethnic data monitoring

Monitoring of ethnic data is important to provide information on ethnic patterns on incidence, treatment outcomes and to ensure proper allocation of resources and effectiveness of service provision. These data should be recorded sensitively and areas of non compliance to recording should be addressed as ethnicity is mandatory information for all health and social service agencies. Barriers to ethnic coding should be addressed, for example, the introduction of ethnic monitoring kit and communication guide to support planning and implementation of patient ethnic data collection (e.g. Equality and Diversity Information Program NHS Scotland).

Increasing awareness

Information systems should be redesigned to produce health information by ethnic group. Health education materials and national campaigns for health promotion in urinary incontinence should take explicit account of the needs, culture and language of the ethnic group and be produced in the appropriate media. As this research highlights Indian women preferred audio visual aids as means of receiving information and these should be used as a method of disseminating information. To avoid duplication and unnecessary expenses, there should be a central repository of health information materials, thereby reducing the cost of translation and production as well as unifying the information to be given. For example this information could be put on the Patient UK website where it can be monitored, updated and easily accessible to the public. I

have found during the research that the best way of ensuring that we get the message right is to involve service users in the production of this information material, as shown in the production of a CD outlining the findings to this research in Gujarati for those unable to read or understand English [Appendix 13].

Interpreting facilities

Reliable confidential interpreting services that are culturally acceptable are needed to ensure that users have equitable access to care and make consultation meaningful for both the patient and the healthcare provider. This language support should be consistently provided and monitored and research undertaken to assure its efficacy in reducing inequality. Participants in the research highlighted the ad-hoc arrangements of interpreting facilities and the short time of consultation that the doctors had as compared to the nurses. Consultation times should accommodate the time needed for interpretation and understanding the information (an average 7 minute GP consultation may not suffice).

Healthcare professionals

Training of health professionals is twofold, one the understanding of ethnicity and its effect on health and two the understanding of urinary incontinence and its management.

Training of all staff involved is needed in the issue of ethnicity and health including understanding population size and structure, living circumstances, lifestyle, language spoken and read, religions practiced, and the implications of all of this for modification of care. Cultural competency training has been shown to be a promising strategy for improving knowledge, attitude and skills of health professional. This training in cultural competence should be developed and rolled out for all sectors of healthcare workforce

and in all clinical areas, to enable them to provide culturally sensitive care (e.g. NHS Education for Scotland have e-learning educational material on cultural diversity).

Proactive recruitment of staff with particular language skills or cultural understanding is important to be able to provide cultural competence.

We need to work to remove the stigma that faces urinary incontinence, not just from a patient's perspective, but that from the health professionals as well. Educational tools need to be developed to educate primary care health professionals, nurses, midwives and health care assistants to be proactive in asking women about their symptoms and initiating first line management. Conservative management in primary care, within an integrated continence care pathway, with initiatives such as one stop culturally sensitive nurse led clinics need to be implemented as they have shown to be effective in reducing patients journey time with satisfactory management (Oliver et al., 2009).

Ethnic minority research

As ethnicity is dynamic, research findings may rapidly come out of date, and results cannot be generalised across time, generations and migrant populations. Attention must be paid to within group variations which exist in the broader 'ethnic groups' categories.

Where there is evidence of high disease prevalence or under utilization of service, research programs should be set to target these communities to further understand the issues. Similar to this research carried out in the area of UI many issues remain unexplored in hard to reach groups (e.g. cervical screening uptake, menopause, menstrual disorders). To ensure success of these research programs it is important to empower ethnic minority groups to be an active part of the research process. This should be in collaboration rather than passive consultation. During this project a patient

and public involvement user group was set up to advice on the research and patient information material. The group were also involved in recruiting participants for the focus groups as well as translating the findings of the research onto a CD in Gujarati. Those involved in the research both as advisors and participants have been hopefully empowered to seek further information and help for their condition. This active involvement of user group should be encouraged in all research projects, for their involvement makes research more relevant to people's needs and concerns.

All health and healthcare policy and service development/implementation documents should contain background information on and a plan of inclusion of ethnic minority populations. The key is to ensure that meeting the needs of ethnic minority groups is an integral part of the mainstream healthcare and public health function, rather than an add-on to the system.

Future research/resources

An audio CD of the main research findings has been produced so that users, participants and ethnic women in the community who don't read English are able to understand the findings of the research they have participated in, thus improving future participation, as they can see the result of the their contribution. This is available in Gujarati [Appendix 13].

As the women who participated in the study suggested written information should be minimal and the use of pictorial representation should be encouraged for conveying information. I have taken these suggestions on board and working with an artist from De Montfort University in Leicester, have built a pictorial representation resource for urinary incontinence to be used in future health promotion [Appendix 12].

Development of an educational DVD is underway, incorporating the suggestions made by the study participants in the two common South Asian languages in Leicester (Gujarati and Hindi).

A diagnostic and management tool is also being developed for use in primary care to facilitate assessment and treatment in primary care for health professionals. It is hoped that this will be incorporated into existing electronic medical records systems for health professionals to use in routine practice.

This research has given us an understanding of the experiences and barriers to accessing healthcare in South Asian women in Leicester suffering from LUTS. We now need to move forward to translate these findings into practice, by implementing these into service provision and evaluating the outcomes.

8.5 Reflection

This research program has been a journey into understanding the impact urinary incontinence has on quality of life of ethnic minority women. In spite of having managed women with incontinence for several years, I am humbled by the stories that women who participated in the various studies within the research project have shared with me, and I thank them for letting me into their homes and their lives.

The whole concept of culture, race and ethnicity has been fascinating to explore, and although it still remains a minefield, it is important to differentiate ethnicity within groups and be wary of grouping them together, as individuals groups may have different needs. I soon realised the heterogenous Asian population of Leicester (Indians, Pakistanis, Bangladeshis, from different religious backgrounds), and decided to target the largest group i.e. the Indians to participate in this project.

As a clinician, I have always looked at incontinence from a disease perspective that needs treating either by medication or surgery, knowingly well that all sufferers cannot be cured. Yet very little attention is paid to those that don't get better or those that never seek help because of stigma or embarrassment.

As I come from a similar ethnic background as the women participating in the study I had to be careful not to let my own beliefs both cultural and professional influence the collection and analysis of the data. It was important to position the participants as experts and it was their experience that were important not the medical knowledge of the facilitator.

This research has brought to light how little awareness there is in the community about incontinence and this leads to women taking drastic measures at times to cope with the condition. Extreme examples that come to mind are the lady in India who swallowed

blotting paper, or the women who slept on a garbage bin liner at night. Have these communities not been targeted by the various continence organisations or is the way in which information is disseminated not culturally acceptable?

This research project has also enabled me to develop skills in qualitative research. An area as a clinician I would have probably never ventured into, but now feel is a very important part of any research project involving health and people. I have realised it is not just important to know if something works (i.e. medication or surgery) but equally important is the patients perception of the treatment and service provision. I advocate that all studies should incorporate a qualitative arm within the research program.

It was interesting to explore the effect migration has on the help seeking behaviour and attitude towards urinary incontinence. This study is the first of its kind in this area and I am grateful to the RCOG for the Ethicon Travel Award that enabled me to spend time in Baroda, Gujarat to carry out this part of the study and to Dr Nandita Maitra, Associate Professor and her team at SSG Hospital Baroda for facilitating this part of the project. This was important to understand what we actually mean by culture and to experience it first hand in the country that they have originally migrated from. As mentioned in the thesis, people “hang” on to their cultural and health beliefs for many years after migration. Although the health system in India is very different from the NHS, the women’s’ knowledge, fears, coping strategies are very similar.

The study exploring the women’s journey through primary care was probably the most disheartening. In spite of the vast amount of money spent on urinary incontinence we still don’t seem to have an integrated service that works to the satisfaction of these women. As the study highlights this could be because of organisational or individual (healthcare professionals/patients) barriers. This is an important area that needs to be addressed if we are to provide culturally sensitive continence care.

Finally, I would like to thank the University of Leicester for organising the Festival of Postgraduate Research (2008), which enabled me to present the research findings to the general public [Appendix14]; an opportunity that would be reserved usually for scientific meetings. This enabled the research participants to come and see how their contribution had helped in shaping the project and to feel an integral part of the project. We took comments these women made on board and had the poster presented at this meeting translated into audio (Gujarati and Hindi), which was available for those women who were unable to speak or read English. I also worked with a student from De Montfort University Art School to produce visual guides to promote continence within the community.

I hope this study has contributed to the field of ethnic women's health and aims to improve continence services for these women.

Chapter 9: References and Appendices

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Appendix 1: Census Question on ethnicity 1991, 2001, 2011

1991 Census	2001 census	2011 census (proposed for England)
0 White	White	
1 Black- Caribbean	A British	A White English
2 Black –African	B Irish	Other British Irish
3 Black-Other	C Any other white	Any other White
4 Indian	Mixed	
5 Pakistani	D White and Black Caribbean	B Mixed White and Black Caribbean
6 Bangladeshi	E White and Black African	White and Black African
7 Chinese	F White and Asian	White and Asian
8 Any other ethnic group	G Any other mixed	Any other mixed
9 Not Given	Asian or Asian British	
	H Indian	C Asian Indian Pakistani Bangladeshi Chinese
	J Pakistani	Any other Asian background
	K Bangladeshi	
	L Any other Asian background	D Black or Black British Caribbean African
	Black or Black British	Any other Black background
	M Caribbean	
	N African	
	P Any other Black background	
	Other Ethnic Groups	
	R Chinese	E Other ethnic groups Arab Gypsy/Romany/Irish /Traveller
	S Any other ethnic group	Any other ethnic group
	Z Not stated	Not stated

Appendix 2: Leicester Impact Scale Questionnaire

Does your urinary pattern interfere with, or affect the way that you do any of the following activities?

Activity	A lot	A little	Not at all	Don't do this activity for other reasons	Urine problem stopped this activity
				Not applicable (NA)	
a) Making short journeys	2	1	0	(NA)	2
b) Making long journeys	2	1	0	NA	2
c) Shopping	2	1	0	NA	2
d) Overnight stays	2	1	0	NA	2
e) Visiting people	2	1	0	NA	2
f) Having visitors	2	1	0	NA	2
g) Interests/hobbies	2	1	0	NA	2
h) Social life	2	1	0	NA	2
i) Family life	2	1	0	NA	2

Does your urinary pattern make you feel any of the following ?

Feelings	A lot	A little	Not at all
a) Embarrassed	2	1	0
b) Depressed	2	1	0
c) Anxious	2	1	0
d) Frustrated	2	1	0
e) Angry	2	1	0
f) Fearful	2	1	0
g) Tired ^a	2	1	0
h) Worried	2	1	0
i) Ashamed	2	1	0
j) Guilty	2	1	0
k) Fed up	2	1	0
l) Less attractive	2	1	0

Appendix 2: Leicester Urinary Symptoms Questionnaire

1. Thinking over the last 12 months have you ever found you leak urine/water when you don't mean to

[Yes, No]

2. Do you ever leak urine when you do the following:

Sneeze;

Exercise;

Cough;

[Yes, No]

Laugh;

Bend;

Stand up.

3. When you have the urge to pass urine, does any leak before you get to the toilet?

Most of the time

Sometimes

Occasionally

Never

4. How much do you leak usually?

A few drops

A dribble

A stream

A flood

5. How much do you leak usually?

Soaked

Wet

Damp

Almost dry

6. How would you describe the amount of urine you leak?

Not noticeable

Noticeable to yourself only

Potentially noticeable to others

Noticeable to others

7. When you first feel the need to pass urine how strong is the urge to go usually?

Overwhelming

Very strong,

Strong,

Normal,

Weak,

Do you have no sensation

8. Do you have difficulty holding urine once you feel the urge to go

Most of the time

Sometimes

Occasionally

Never

9. How many times do you go to the toilet to pass urine during the daytime?

About every half an hour

about every hour,

about every hour and a half,

about every two hours,

OR number of times (insert no)

10. How often do you get up at night to pass urine, if at all?

[Not usually

once a night,

twice a night

three times a night,

four times or more a night

Appendix 2: ICIQ-SF

Many people leak urine some of the time. We are trying to find out how many people leak urine, and how much this bothers them. We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

1. How often do you leak urine? (Tick one box)

- never 0
about once a week or less often 1
two or three times a week 2
about once a day 3
several times a day 4
all the time 5

We would like to know how much you think leaks.

2. How much urine do you usually leak (whether you wear protection or not)?
(Tick one box)

- none 0
a small amount 2
a moderate amount 4
a large amount 6

3. Overall, how much does leaking urine interfere with your everyday life?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

ICIQ score: sum scores 1+2+3

4. When does urine leak? (Please tick all that apply to you)

- never – urine does not leak
leaks before you can get to the toilet
leaks when you cough or sneeze
leaks when you are asleep
leaks when you are physically active/exercising
leaks when you have finished urinating and are dressed
leaks for no obvious reason
leaks all the time

Appendix 3: Translated questionnaires

Gujarati Version

આ પ્રશ્નોતરી ભરવા માટે સંમતિ આપવા બદલ આપનો આભાર

આ પ્રશ્નોતરિઓ અનામી છે અને કોઈપણ વિગતોની તમને પરત જાણ કરવાનો કોઈ માર્ગ નથી.

આ પ્રશ્નો પરથી એકત્રિત માહિતી, સમાજની સમસ્યાને સમજવા માટે ખૂબ મહત્વપૂર્ણ બનશે અને નજીકના ભવિષ્યમાં વધુ સારી સેવા પૂરી પાડવામાં મદદ કરશે.

તમારો સમય લેવા બદલ આભાર.

તમારા વિષેની કેટલીક વિગતો

વય (જન્મ તારીખ ન લખવી)

તમારાં બાળકોની સંખ્યા

તમે કોઈ દક્ષિણ એશિયન ભાષા બોલો છો
(તેની આસપાસ કુંડાળું કરવું)

ગુજરાતી

પંજાબી

બંગાળી

હિંદી

ઊર્દૂ

અન્ય ...

આમાંની કોઈપણ વિગત તમે વાંચી લખી શકો છો. હા/ના

૧. તમને છેલ્લા ૧૨ મહિનામાં તેમ કરવાની ઈચ્છા ન હોય ત્યારે તમને પેશાબ/પાણી પડ્યું હોવાનું ક્યારેય માલૂમ પડ્યું હતું કે કેમ તે વિચારવું
(હા, ના)

૨. તમે નીચેની કામગીરી કરતા હોવ ત્યારે તમને ક્યારેય પેશાબ થઈ ગયો છે :
છીંક;
કસરત;
ઉધરસ; (હા, ના)
હસવું;
વળવું;
ઊભા થવું.

૩. તમને પેશાબ કરવાની ઈચ્છા થાય ત્યારે તમે શૌચાલયમાં જાવ તે પહેલાં પેશાબ થઈ જાય છે ?
મોટાભાગના સમયે
કેટલીકવાર
પ્રસંગોપાત
કદાપિ નહીં

૪. સામાન્ય રીતે કેટલો પેશાબ થઈ જાય છે ?
થોડાક ટીપાં
ટીપે ટીપે ટપકવું
પ્રવાહ વહેવો
પૂરજોશમાં

૫. સામાન્ય રીતે તમને કેવો પેશાબ થાય છે ?
તરબોળ કરે
ભીનું
ભેજવાળું
લગભગ સૂકો

૬. તમને ટપકી જતાં પેશાબના પ્રમાણનું તમે કેવી રીતે વર્ણન કરશો ?
ધ્યાનપાત્ર નહીં
માત્ર તમારા ધ્યાનમાં આવે
બીજાઓને પણ ધ્યાનમાં આવવાની શક્યતા
અન્યને ધ્યાનમાં આવવાપાત્ર

૭. તમને સૌ પ્રથમ પેશાબ કરવાની લાગણી થાય ત્યારે તે ઈચ્છા સામાન્ય
રીતે કેટલી તીવ્ર હોય છે ?
નિવારી ન શકાય તેવી
ખૂબ તીવ્ર,
તીવ્ર,
સાધારણ,
થોડીક,
તમને કોઈ સંવેદના ન થાય

૮. તમને પેશાબ કરવાની એકવાર ઈચ્છા થાય ત્યારે તેને રોકવામાં તમને
કોઈ મૂશ્કેલી પડે-
મોટાભાગે
ક્યારેક
પ્રસંગોપાત
ક્યારેય નહીં

૯. દિવસ દરમિયાન પેશાબ કરવા તમે કેટલીવાર શૌચાલયમાં જાવ છો ?
લગભગ દર અડધા કલાકે
લગભગ દર કલાકે,
લગભગ દોઢ કલાકે,
લગભગ બે કલાકે,
અથવા અનેકવાર (ના દાખલ કરો)

૧૦. પેશાબ કરવા રાત્રે તમે કેટલીવાર ઊઠો છો ?
સામાન્ય રીતે નહીં
રાત્રે એક વખત
રાત્રે બે વખત
રાત્રે ત્રણ વખત
રાત્રે ચાર કે વધુ વખત

નીચેની કોઈપણ પ્રવૃત્તિઓ તમે જે રીતે કરો તેને તમારી (યુરિનરી) પેશાબ પદ્ધતિ આડબીલીરૂપ થાય, કે તેને અસર કરે ?

પ્રવૃત્તિ	ખૂબ	થોડીક	બિલકુલ નહીં	અન્ય કારણોસર આ પ્રવૃત્તિ ન કરો	પેશાબની સમસ્યાથી આ પ્રવૃત્તિ અટકાવી દીધી હોય
ક) નાની મુસાફરી કરવી	૨	૧	૦	લાગુ પડતું નથી.	૨
ખ) લાંબી મુસાફરીઓ કરવી	૨	૧	૦	લાગુ પડતું નથી.	૨
ગ) શોપિંગ	૨	૧	૦	લાગુ પડતું નથી.	૨
ઘ) રાત્રિ રોકાણ	૨	૧	૦	લાગુ પડતું નથી.	૨
ચ) મુલાકાતે આવતાં લોકો	૨	૧	૦	લાગુ પડતું નથી.	૨
છ) મુલાકાતીઓ હોવા	૨	૧	૦	લાગુ પડતું નથી.	૨
જ) રસ/શોખ	૨	૧	૦	લાગુ પડતું નથી.	૨
ટ) સામાજિક જિંદગી	૨	૧	૦	લાગુ પડતું નથી.	૨
ઠ) પારિવારિક જિંદગી	૨	૧	૦	લાગુ પડતું નથી.	૨

તમારી પેશાબ વિષયક પદ્ધતિથી તમને નીચેની કોઈ લાગણી થાય છે ?

લાગણી	ખૂબ	થોડીક	બિલકુલ નહીં
(ક) ગૂંચવણ થવી	૨	૧	૦
(ખ) હતાશ થવું	૨	૧	૦
(ગ) આતુર	૨	૧	૦
(ઘ) નિરાશ	૨	૧	૦
(ચ) ગુસ્સો	૨	૧	૦
(છ) ભયભીત	૨	૧	૦
(જ) થાકવું	૨	૧	૦
(ઝ) ચિંતા કરવી	૨	૧	૦
(ટ) શરમાવું	૨	૧	૦
(ઠ) ગુનેગારનો ભય	૨	૧	૦
(ડ) કંટાળવું	૨	૧	૦
(ઢ) ઓછા આકર્ષક	૨	૧	૦

કેટલીકવાર ઘણા લોકોને અનાયાસ પેશાબ ટપકે છે. કેટલાક લોકોને પેશાબ અનાયાસ ટપકે છે, અને તેઓને તેથી કેટલી ચિંતા થાય છે તે શોધી જાણવાનો અમે પ્રયત્ન કરીએ છીએ. છેલ્લા ચાર અઠવાડિયા તમે સરેરાશ કેવા રહ્યા હતા તે અંગે વિચારીને નીચેના પ્રશ્નોના જવાબ આપશો તો અમે આભારી થઈશું.

૧. તમને કેટલીકવાર અનાયાસ પેશાબ ટપકે છે ? (એક ચોકઠામાં નિશાની કરવી)

ક્યારેય નહીં	<input type="checkbox"/>
અઠવાડિયામાં એકાદ વાર કે તેથી ઓછું	<input type="checkbox"/>
અઠવાડિયામાં બે કે ત્રણ વાર	<input type="checkbox"/>
દિવસમાં લગભગ એક વાર	<input type="checkbox"/>
દિવસમાં અનેકવાર	<input type="checkbox"/>
હંમેશા	<input type="checkbox"/>

અમે જાણવા માંગીએ છીએ તમને કેટલીકવાર અનાયાસ પેશાબ થઈ જતો હોવાનું લાગે છે.

૨. સામાન્ય રીતે તમને કેટલો પેશાબ થઈ જાય છે (તમે રક્ષણ વસ્ત્ર પહેરો છો કે નહીં)? (એક ચોકઠામાં નિશાની કરવી)

ના	<input type="checkbox"/>
થોડાક પ્રમાણમાં	<input type="checkbox"/>
મધ્યસર	<input type="checkbox"/>
ખૂબ મોટા પ્રમાણમાં	<input type="checkbox"/>

૩. એકંદરે, આ અનાયાસ થતા પેશાબથી તમારી રોજિંદી જિંદગીમાં અવરોધ ઊભો થાય છે ?

૦ ની સંખ્યાથી (બિલકુલ નહીં) ૧૦ (મોટા પ્રમાણમાં)ની સંખ્યા વચ્ચેના આંકડા પર કુંડાળું કરવું.

૦	૧	૨	૩	૪	૫	૬	૭	૮	૯	૧૦
બિલકુલ નહીં										મોટા પ્રમાણમાં

આઈસીઆઈક્યૂ સ્કોર : સ્કોરનો સરવાળો ૧+૨+૩

૪. ક્યારે પેશાબ થઈ જાય છે ? (તમને લાગુ પડે ત્યાં નિશાની કરવી)

કદાપિ નહીં - પેશાબ થઈ જતો નથી	<input type="checkbox"/>
સંડાશ જાવ તે પહેલાં થઈ જાય	<input type="checkbox"/>
તમે ઉધરસ કે છીંક ખાવ ત્યારે થઈ જાય	<input type="checkbox"/>
ઊંઘમાં પેશાબ થઈ જાય	<input type="checkbox"/>
શારીરિક રીતે સક્રિય/વ્યાયામ કરતા હોવ ત્યારે પેશાબ થઈ જાય	<input type="checkbox"/>
પેશાબ કરવાનું પતી જાય અને કપડાં પહેરી લો ત્યારપછી પેશાબ ટપકી જાય	<input type="checkbox"/>
પેશાબ અનાયાસ થવા માટે કોઈ સ્પષ્ટ કારણ ન હોય	<input type="checkbox"/>
કોઈપણ સમયે પેશાબ ટપકે	<input type="checkbox"/>

Hindi Version

इस प्रश्नावली को भरने पर सहमत होने के लिए आपका धन्यवाद।

ये प्रश्न बेनामी हैं और इसके बाद आपके बारे में जानकारी हासिल करने को कोई तरीका नहीं है।

इन प्रश्नों से प्राप्त जानकारी समाज में इस समस्या को समझने के लिए बहुत महत्वपूर्ण होगी और निकट भविष्य में हमें बेहतर सेवा उपलब्ध कराने में मदद करेगी।

अपना समय देने के लिए आपका धन्यवाद।

आपके बारे में कुछ जानकारी

उम्र(जन्मतिथि न लिखें)

आपके बच्चों की संख्या

आप कौनसी दक्षिणी एशियाई भाषा बोल सकते हैं
(कृपया गोला लगाएं)

गुजराती

पंजाबी

बंगाली

हिंदी

उर्दू

अन्य.....

क्या आप इनमें से कोई भाषा पढ़ और लिख सकते हैं

हां/नहीं

1. पिछले 12 महीनों के बारे में सोच कर बताइए कि जब आप नहीं चाहते उस समय आपको मूत्र/पानी का रिसाव होता है
[हां/नहीं]
2. जब आप निम्नलिखित कार्य करते हैं तो क्या मूत्र निकलता है:
छींकना:
व्यायाम करना:
खांसना: [हां/नहीं]
हंसना:
झुकना:
खड़े होना:
3. जब आप की पेशाब करने की इच्छा होती है, तो क्या शौचालय में जाने से पहले आप का पेशाब निकलता है?
अधिकांशतः:
कभी-कभी:
किसी किसी मौके पर:
कभी नहीं:
4. अक्सर आप का कितना मूत्र निकलता है?
कुछ बूंदें:
थोड़ी मात्रा:
पूरी धार:
बहुत अधिक मात्रा:
5. प्रायः रिसाव का क्या होता है?
सोख लिया जाता है:
गीला:
नमी रहती है:
लगभग सूखा:

6. रिसने वाले पेशाब को मात्रा का वणन अप कैसे करेंगे?
 पता नहीं लगता:
 केवल आपको पता लगता है:
 अन्य लोगों को कम पता लगता है:
 अन्य लोगों को अधिक पता लगता है:
7. जब आपको पेशाब करने की पहले पहल इच्छा होती है तो आपको सामान्यतः कितनी उत्तेजना होती है?
 अत्यधिक प्रबल:
 काफी प्रबल:
 प्रबल:
 सामान्य:
 कम:
 क्या आपको कुछ अनुभव नहीं होता:
8. क्या एक बार पेशाब करने की इच्छा होने पर आपको पेशाब रोकने में मुश्किल होती है?
 अधिकांशतः
 कभी-कभी:
 बहुत कम:
 कभी नहीं:
9. दिन के समय आप कितनी बार पेशाब करने जाते हैं?
 लगभग हर आधे घंटे बाद:
 लगभग हर एक घंटे बाद:
 लगभग हर डेढ़ घंटे बाद:
 लगभग हर दो घंटे बाद:
 या कितनी बार(संख्या दर्ज करें)
10. यदि आप रात्रि में पेशाब करने उठते हैं तो अक्सर कितनी बार उठते हैं?
 प्रायः नहीं:
 रात में एक बार:
 रात में दो बार:
 रात में तीन बार:
 रात में चार बार या इससे ज्यादा:

क्या आपका मूत्र पैटर्न निम्नलिखित में से आपकी किसी गतिविधि को रोकता या प्रभावित करता है?

गतिविधि	बहुत अधिक	थोड़ा सा	बिल्कुल नहीं	अन्य कारणों से यह गतिविधि नहीं करते	पेशाब की समस्या के कारण यह गतिविधि रूक गई
a) छोटी यात्राएं करना	2	1	0	लागू नहीं	2
b) लम्बी यात्राएं करना	2	1	0	लागू नहीं	2
c) खरीदारी करना	2	1	0	लागू नहीं	2
d) रात में बाहर टहरना	2	1	0	लागू नहीं	2
e) लोगों के पास जाना	2	1	0	लागू नहीं	2
f) लोगों को बुलाना	2	1	0	लागू नहीं	2
g) रूचियां/शौक	2	1	0	लागू नहीं	2
h) सामाजिक जीवन	2	1	0	लागू नहीं	2
i) धरेलू जीवन	2	1	0	लागू नहीं	2

क्या आप अपने मूत्र पैटर्न के कारण निम्नलिखित में से कुछ अनुभव करते हैं?

अनुभव	बहुत अधिक	थोड़ा सा	बिल्कुल नहीं
a) हीनता	2	1	0
b) अवसाद	2	1	0
c) व्याकुल	2	1	0
d) व्यग्र	2	1	0
e) क्रुद्ध	2	1	0
f) भयभीत	2	1	0
g) थका हुआ	2	1	0
h) चिंतित	2	1	0
i) शर्मिंदा	2	1	0
j) अपराधी	2	1	0
k) उकताया हुआ	2	1	0
l) कम आकर्षक	2	1	0

कई लोगों का मूत्र कभी कभी रिसता है। हम यह पता लगाने की कोशिश कर रहे हैं कि कितने लोगों का पेशाब रिसता है और इससे उन्हें कितनी परेशानी होती है। यदि पिछले चार सप्ताहों के दौरान अपने बारे में सोचते हुए आप निम्नलिखित प्रश्नों के उत्तर दे पाएं तो हम आपके आभारी होंगे।

1. आपका पेशाब प्रायः कितनी बार रिसता है? (एक पर निशान लगाएं)

कभी नहीं
सप्ताह में एक बार या कम
दिन में एक बार
एक दिन में कई बार
हर समय

हम यह जानना चाहेंगे कि आप रिसाव(लीक) के बारे में कितना सोचते हैं।

2. आपका पेशाब प्रायः कितना रिसता है? (आप सुरक्षा या प्रोटेक्शन पहनते हैं या नहीं)?
(एक बॉक्स पर निशान लगाएं)

कुछ नहीं
केवल कुछ मात्रा
सामान्य मात्रा
भारी मात्रा

3. कुल मिला कर, आपके रोजमर्रा के जीवन की गतिविधियों पर पेशाब के रिसाव का कितना असर पड़ता है?

0 1 2 3 4 5 6 7 8 9 10
बिल्कुल नहीं बिल्कुल नहीं

4. पेशाब कब रिसता है? (उस पर निशान लगाएं जो आप पर लागू होता है)

कभी नहीं- पेशाब कभी नहीं रिसता
आपके शौचालय जाने से पहले रिस जाता है
जब आप खांसते या छींकते हैं तो निकल जाता है
जब आप सोते हैं तो निकल जाता है
जब आप शारीरिक गतिविधियां/व्यायाम करते हैं तो रिसता है
जब आप पेशाब करना समाप्त करते हैं और झडकते हैं तो रिसता है
बिना किसी ठोस कारण के रिसता है
हर समय रिसता रहता है

Appendix 4: Coding Tree Study 1

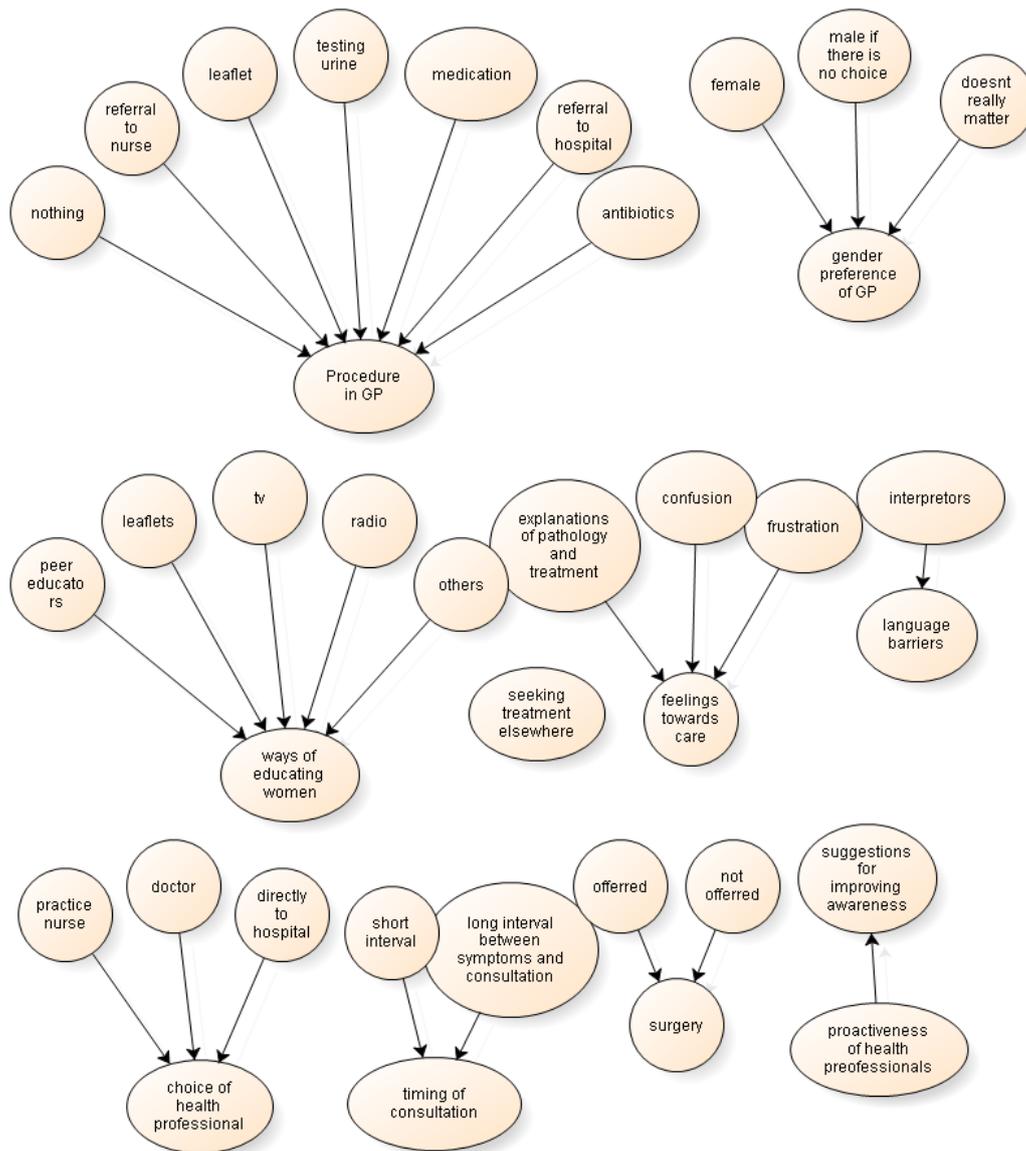
Level 1		Level 2	Level 3	
1.1 Awareness of incontinence	What did women know about the condition			
		1.1.1 normalisation of symptoms		
			1.1.1.1 part of ageing process	Associated with other medical problems
			1.1.1.2 part of child bearing process	Attributed to tears or difficult deliveries
			1.1.1.3 part of the menopause	Associated with weakening of the muscles
		1.2.1 limited awareness		
			1.2.1.1 younger womens' views	Felt it was a condition of old age.

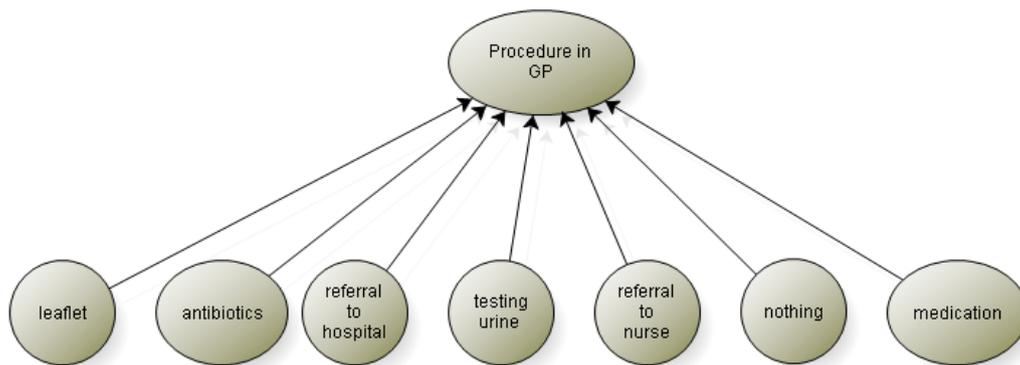
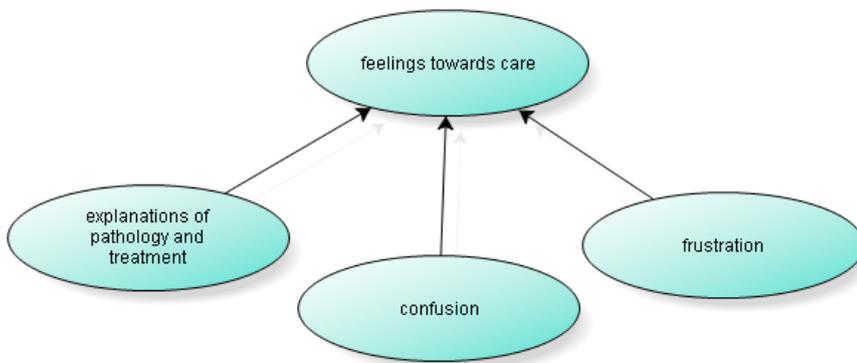
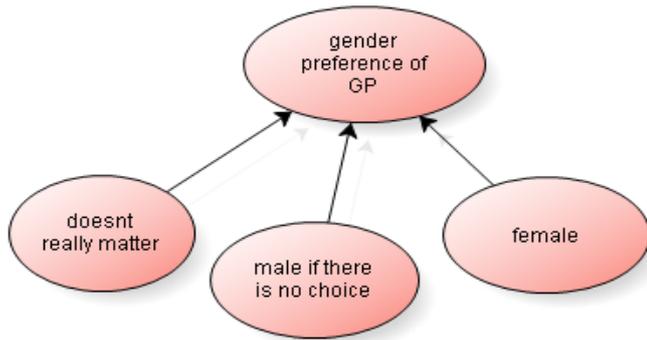
2.1 Quality of life issues	How did the condition affect the women			
		2.1.1 limitation of activities		
			2.1.1.1 travel	Short trips Avoiding long journeys
			2.1.1.2 drinking	Reducing amount of fluid intake Cutting down on caffeine
			2.1.1.3 exercising	Avoiding going to the gym
		2.1.2 feeling of being unclean		
			2.1.2.1 effecting prayer rituals	Unable to carry out religious duties
			2.1.2.2 feeling of being unattractive	Loss of confidence
			2.1.2.3 depression	Compounding feelings of loss of self esteem

3.1 Barriers to accessing care	Why women did not seek help			
		3.1.1 Seriousness of condition	3.1.1.1 women's perception of condition	Not serious enough to seek help and be deserving of healthcare
			3.1.1.2 part of multiple disease process	Side effect of other drugs like diuretics.
		3.1.2. Interaction with health professionals	3.1.2.1 interaction with GP	GP not interested, reinforce belief of helplessness.
			3.1.2.2 fear	Fear of wasting time of GP Fear of gynaecological examination
		3.1.3 Embarrassment	3.1.3.1 of the condition	Talking about symptoms with family members
			3.1.3.2 of talking to health professional	Talking to GPs, nurses usually as a secondary complaint
		3.1.4 Characteristic of health professional	3.1.4.1 GP versus nurses	Preference to see nurses more time, better understanding
			3.1.4.2 gender of GP	Male vs. female GP
		3.1.5 Interpreting services	3.1.5.1 using relatives	Advantages and disadvantages
			3.1.5.2 using interpreting services	Availability, reliability and confidence issues

4.1 Awareness of treatment options	What did women know about treatments on offer			
		4.1.1 no treatment		
		4.1.2 treatments available	4.1.2.1 pelvic floor exercises	Unsure of benefits, how to perform, limited advice from health professionals
			4.1.2.2 surgery	Fear of, belief that only form of treatment
			4.1.2.3 complementary therapy	Herbal versus western medicine
5.1 Suggestions of improving services	How could we improve the service provision			
		5.1.1 increasing awareness	5.1.1.2 role of continence foundation /other organisations	Most women had not heard of these organisations
		5.1.2 publicity	5.1.2.1 newspaper/ magazines	Read by a few, articles in these would be helpful
			5.1.2.2 leaflets	Pointless in regional languages as women had literacy issues in those languages
			5.1.2.3 radio and television	Preferred media for health promotion
		5.1.3 health professionals	5.1.3.2 proactive questioning	By staff when presenting with gynaecological problems.
			5.1.3.3. opportunistic screening	Questions postnatal or at cervical smear testing

Appendix 5: Coding Tree Study 4.





Appendix 6.1: Ethical Approval Letter



Nottingham Research Ethics Committee 1

1 Standard Court
Park Row
Nottingham
NG1 6GN

Telephone: 0115 912 3344 ext 49435
Facsimile: 0115 9123300

30 August 2006

Dr A Doshani
Clinical Research Fellow/specialist Registrar Obs/Gyn
Leicester General Hospital
Research Office
Dept of Women's Health & Perinatal services
Gwendolen Road
LE5 4PW

Dear DR DOSHANI

Full title of study: Qualitative study South Asian women in Leicestershire exploring social issues and barriers to access to continence services.
REC reference number: 06/Q2403/105

Thank you for your letter of 20 July 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		07 June 2006
Investigator CV: Educational Supervisor		
Investigator CV: Chief Investigator		
Protocol	1	17 May 2006
Summary/Synopsis	1.0	17 May 2006
Letter from Sponsor		19 July 2006
Peer Review		05 June 2006
Questionnaire: Leicester Symptoms	2.0	17 July 2006
Questionnaire: Leicester Impact Scale	1	17 May 2006
Questionnaire: ICIQ	1	17 May 2006
Letter of invitation to participant: Reminder Interview	1.0	17 May 2006
Letter of invitation to participant	1.0	17 May 2006
Letter of invitation to participant	2.0	17 July 2006
Participant Information Sheet: Interview	2.0	17 July 2006
Participant Consent Form: Interview	2.0	17 July 2006
Response to Request for Further Information		20 July 2006
Questionnaire Introduction	2.0	17 July 2006
Reminder to return questionnaires	1.0	17 May 2006
Case Note Audit	1	17 May 2006

Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q2403/105	Please quote this number on all correspondence
---------------------	---

With the Committee's best wishes for the success of this project

Yours sincerely



Dr K Pointon / Ms L Ellis
Chair / Committee Co-ordinator

Email: linda.ellis@rushcliffe-pct.nhs.uk

Appendix 6.2: Ethical approval letter India

No.MCB/UG/¹⁸⁴⁶²⁻⁶⁵/06,
Office of the Dean,
Medical College, Baroda.
Date: 22/11/06.

Sub:- Elective Study.

Ref:- Your Application dt.02-11-2006.

Vide above subject & reference, you are directed to do Elective Study in the subject you have mentioned in your application for the period from 12-12-2006 to 04-01-2007 (Obst. & Gynae.) in anticipation the clearance from The Secretary to the Govt. of India Ministry of Health & Family Welfare, Nirman Bhawan, New Delhi, vide letter No. MCI-39(10)/2006-Med./17737 dt.13-11-06 from Secretary, Medical Council of India appended herewith.



**Dean,
Medical College, Baroda.**

✓
To,
Dr. Anjum Doshani

Copy to the Head & Prof. of the Dept of Obst. & Gynae., Medical College Baroda.

Copy f. w. c. s. to :- The Secretary, Medical council of India, Pocket-14, Sector 8 Dwarka, New Delhi .

- The Secretary, Govt. of India, Ministry of Health and Family welfare, Nirman Bhavan New Delhi, With request to necessary clearance details of the student are send herewith.

Appendix 7: Invitation letter From GP



THE EAST LEICESTER MEDICAL PRACTICE
UPPINGHAM ROAD HEALTH CENTRE
131 Uppingham Road
Leicester LE5 4BP

Telephone:
(0116) 295 8282
Facsimile:
(0116) 295 8284

Partners:
Dr S Longworth
MB ChB., M Sc
(Sports Med), MRCGP,
DM- S Med, DPCR,
FSOM

Dr L S Levene
MA, MB, B Chir.,
FRCGP, F.P. Cert.

Dr A Farooqi
MB ChB, FRCGP,
DCH, DRCOG,
F.P.Cert.

Dr R J Moriarty
BMBS, PhD, MRCGP,
DCH, F.P. Cert.

Dr R K McKinley
MD, MRCP, FRCGP

Associates:
Dr T Stokes
MA, MBChB, PhD,
MRCGP, DFFP, DFPH

Dr S K Sahota
MBBS MRCGP DRCOG
DFFP

Dr A Mawby
MBBS, BSc, DFFP

Dr A Bayford
MBChB, MRCGP

Practice Nurses:
J Mears RGN
E Curley RGN
R Pertab BA BSc RGN RM
J Sexton RGN

Practice Manager:
A Rawal BSc, MIHM

Quality Manager:
S Glennon

IT Co-ordinator:
L Silvester-McIntosh

Practice Pharmacist:
R C Simmons MRPharmS

Dear Ms

I am writing to ask if you would be willing to help with a research study.
The practice is working with the Continence Care Team at the Leicester General Hospital.
We plan to carry out a survey which will give us an idea of the bladder problems in women within the different communities of Leicester.

All you have to do is complete the attached short questionnaires and return them in the pre-paid envelope.
All the information collected from these questionnaires will be confidential and there will be no way of identifying you from the answers you have given.

We hope that with your help we will be able to gather information on bladder problems within the communities in Leicester to develop a better service to provide care for this very common problem.

We are also looking for volunteers who would like to share their experience of living with bladder problems.
We will be conducting private interviews to understand the problems relating to this sensitive subject.

Each interview will take about an hour, and will be confidential. If you are interested to take part, please complete the reply slip with your details and one of us will contact you and arrange a convenient time to see you.
If you would like some more information before filling in the forms or reply slip, you can contact Dr Doshani the principal investigator who is working with us on 01162525884.
Thank you for your interest in our work.

Dr Farooqi
GP

DR A DOSHANI
Principal Investigator

MR TINCELLO
Local Investigator

University Hospitals of Leicester

NHS Trust

Leicester General Hospital
Gwendolen Road
Leicester
LE5 4PW

Tel: 0116 2490490
Fax: 0116 2584666
Minicom: 0116 2588188

South Asian Women in Leicestershire Incontinence Study

Thank you for agreeing to fill in this questionnaire.

These questionnaires are anonymous and there is no way of identifying any details back to you.

Information collected from these questions will be very important in understanding the problem in the community, and will help us provide a better service in the near future.

Thank you for your time.

Some details about yourself

Age (do not write date of birth)

Number of children you have

Which South Asian Language do you speak

(Please circle)

Gujarati Punjabi Bengali Hindi Urdu

Others

Can you read and write any of these Yes/No

If you are unable to complete the questionnaire and would like to talk to someone about it please call 0116 252 5884

तमने आ प्रश्नपत्र भरवामां मुश्केली पडती होय अने तमे आना विषे डोर्षनी साथे वातचीत करवा मांगता हो तो डॉ. होसाणीनो फोन द्वारा (०११६ २५२ ५८८४) संपर्क करी शको छी.

अगर आपको प्रश्नोत्तरी भरनेमें कोई मुश्केली(दीक्कत) हो या इसके बारेमें कोई भी जानकारी या बातचित करना चाहते हो तो डॉ. होसाणीको फोन द्वारा (०११६ २५२ ५८८४) संपर्क कर सकते हैं ।

Quest intro:
version 2.0;17.07.06

Trust Headquarters, Glenfield Hospital, Groby Road, Leicester, LE3 9QP
Tel: 0116 2583188 Fax: 0116 2563187 Website: www.uhl-tr.nhs.uk
Chairman Mr Philip Hammersley CBE Chief Executive Dr Peter Reading

Appendix 8: Pictures from Baroda, India



The Department of Obstetrics and Gynaecology at the SSG Hospital.
A beautiful building which exudes history.



Dr Nandita Maitra and her team who were extremely helpful in making my research project happen. Thank You!!!



Women queuing up in a gynaecology clinic.



The research assistant with a patient in the gynaecology clinic



Women waiting for antenatal check ups.



Focus group held in an urban low socio-economic community



Focus group with a 'sevika' (peer educator from within the community) on the right (in the pink sari).

Appendix 9: Data collection Proforma

CASE NOTES AUDIT

Demographic data:

Age

Weight

Parity

Type of Delivery

Gynaecological surgery

Hysterectomy *Abdominal*

Prolapse Repair *Vaginal*
Anterior
Posterior

Continenence Surgery *Vault*
Burch Colposuspension
TVT /TOT

Others

Medical Problems :
Diabetes
Hypertension

Medication:

Urinary Symptoms

When was the patient seen at the Practice for the problem?

Symptoms prior to attending GP

Frequency

Urgency

Stress Incontinence

Urge Incontinence

Cystitis

Dysuria

Nocturia

Others

Duration of symptoms

Reason for attending Practice

Main symptom at attendance

Frequency

Urgency

Stress Incontinence

Urge Incontinence

Cystitis

Dysuria

Nocturia

Others

Management in Primary Care

Dates

1. Referral to continence nurse
2. Referral for physiotherapy
3. Leaflets given
4. Bladder advice given
5. Anticholinergic medication prescribed
6. Referred to hospital.
7. MSSU sent
8. Referred for urodynamics
9. Duloxetine prescribed

10. Vaginal oestrogen prescribed

11. Other

Appendix 10: Invitation letter GP for interview

University Hospitals of Leicester 
NHS Trust

Leicester Royal Infirmary
Leicester
LE1 5WW

Tel: 0116 254 1414
Fax: 0116 258 5631
Minicom: 0116 258 6878

Invitation to join

SOUTH ASIAN WOMAN INCONTINENCE STUDY

We are inviting you to join our research study, and we want to be sure that you understand why we are doing this research and what we would ask you to do.

So please read this information carefully. Show it to your friends and family if it helps. Ask as many questions as you want. Take time to decide whether you want to help us or not.

If you decide not to join our study, we won't ask why. Your decision won't affect the care you get from your family doctor.

Asking for more information does not mean you are agreeing to help us. You haven't joined our study until you have returned the reply slip and been contacted by the team.

Even if you do join, you can leave our study at any time without giving any reason.

Thank you for your interest in our work.

If you have any questions, please don't hesitate to call us.

Principal Investigator

Dr Angie Doshani

Co Investigators

Dr A Farooqi

General Practitioner, East Leicester Medical Practice

Mr D Tincello

Consultant Gynaecologist, Leicester General Hospital

Ms J. Townsend

Continence Nurse Specialist, Leicester General Hospital

Mr C Mayne

Consultant Gynaecologist, Leicester General Hospital

You may Contact Dr Angie Doshani Tel no: 01162525884

Trust Headquarters, Gwendolen House, Gwendolen Road, Leicester, LE5 4QF
Website: www.uhl-tr.nhs.uk
Interview info; Version 1.0; 17.05.06
Chairman: Mr. Martin Hindle Chief Executive: Malcolm Lowe-Lauri

Information about

A qualitative study on urinary incontinence in women from South Asian ethnic background in Leicestershire

What is the purpose of the study?

We want to find out how much of a problem bladder weakness (urinary incontinence) is among women who attend your doctor's surgery. We are particularly interested in finding out if women from different ethnic groups have more or less of a problem. Most research which has been done before in the UK has only looked at white British women.

Here in Leicester we are interesting in finding out more about this so that we can ensure that everyone is able to receive the best treatment. This study will help us make sure that we provide help in a way which all women can make use of and find suitable.

Why do you want me to join your study?

You have been identified by your doctor as possibly being suitable for this study.

We know that you have had bladder problems and have been seen by the doctors at your surgery. We want to explore how you felt about the problem and help which was available.

Do I have to take part?

It is up to you whether or not you want to help us. If you decide not to help we won't ask why and your decision won't affect the care you get from the family doctor.

If you decide to help us, you can still leave the study at any time you want, without saying why.

What will happen to me if I take part?

We will arrange for you to come for a single interview. The interview will be conducted in your own language. It will last up to an hour and a half, at a place convenient to you.

The interview will cover how you felt about your bladder problem, what you did about it, and how you felt about the treatment you were offered. The interview will be tape recorded. The recording will then be typed out and stored on a computer, after which the tape will be erased. When we type everything out, we will change your name so that it will no longer be possible to identify you from what was said.

You will not be identified in any of the material that is written. The information we collect will be presented in meetings and in medical journals, but it will not be possible to identify you in any way.

What are the benefits of me taking part in your study?

There are no direct benefits to you for taking part in the study, although you may find it helpful to talk about your experiences. The information we gather will help us to develop and improve the way we offer treatment for bladder problems to patients like you in the future.

Where can I go for more information

If you have any questions, you can talk to the lead researcher Dr Doshani, who works in the Continence Care Team. Or if you prefer, you can talk to Dr Farooqi or a GP in your practice.

DR DOSHANI

DR FAROOQI

TEL NO 01162525884

TEL NO : 0116 2958299

Appendix 11: consent form

University Hospitals of Leicester 
NHS Trust

Leicester General Hospital
Gwendolen Road
Leicester
LE5 4PW

Participant Identification Number for this study:

Tel: 0116 2490490
Fax: 0116 2584666
Minicom: 0116 2588188

INTERVIEW CONSENT FORM

Title: South Asian Women in Leicestershire Incontinence Study

Name of researcher: Dr. Anjum Doshani

1. I confirm that I have read and understand the Participant Information Sheet for the above study(version 2.0 17.07.06) and have had the opportunity to ask questions
2. I understand the interview will be tape recorded. I give permission for this
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reasons. My care will not be affected in any way
4. I agree to take part in this study

(Name of participant) (Signature) (Date)

(Name of person taking (Signature) (Date)
consent if different from researcher)

(Researcher) (Signature) (Date)

(one copy for the participant, one copy for the researcher)

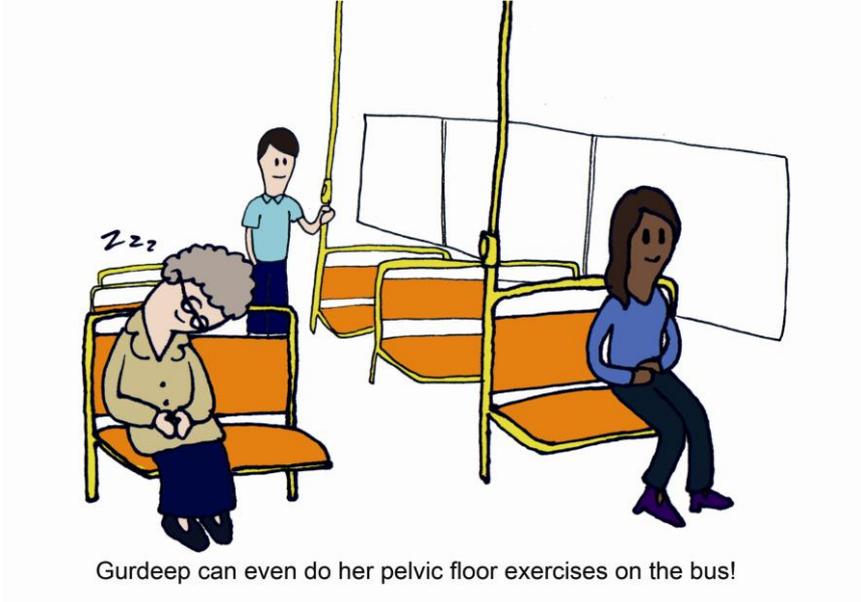
Interview consent form
Version 2 17.07.06

Trust Headquarters, Glenfield Hospital, Groby Road, Leicester, LE3 9QP
Tel: 0116 2583188 Fax: 0116 2563187 Website: www.uhl-tr.nhs.uk
Chairman Mr Philip Hammersley CBE Chief Executive Dr Peter Reading

Appendix 12: Pictorial tools developed from focus group Study 1



I'm going to have to use the men's toilet if they don't hurry up!



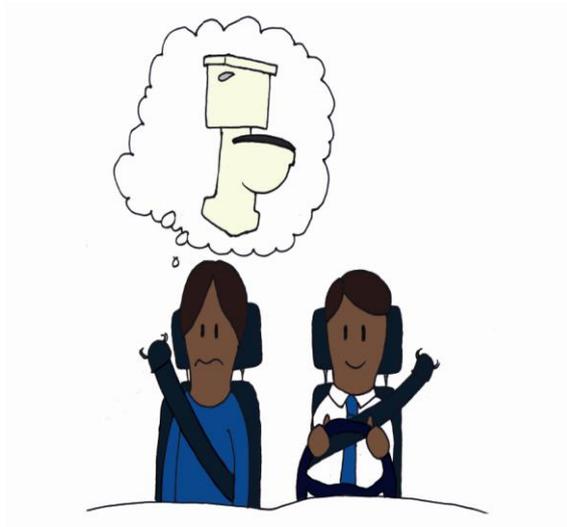
Gurdeep can even do her pelvic floor exercises on the bus!



TOO LATE!

10 miles to the next services

Can't you drive any quicker!!!



Must remember to do those pelvic floor exercises





I'm so glad ASDA is doing a special price on these, I'm going through a box a week!!!



I can't go on like this. I'm in the toilet every half an hour!

Appendix 13: CD of Research Findings in Gujarati

[Enclosed in sleeve at back of Thesis]

Appendix 14: Festival invite and Postgraduate research poster



University of
Leicester

Graduate School

You are warmly invited to attend the
Festival of Postgraduate Research
Thursday 26th June 2008



Explaining the real world implications of research projects at the University of Leicester

Exhibition: 11am – 1pm (Belvoir Suite, Charles Wilson Building)

Award Ceremony: 2pm – 3.30pm (Ken Edwards Lecture Theatre 3)

For further information contact:

Postgraduate Events Team
on pgevents@le.ac.uk or 229 7697, or visit the Festival of Postgraduate Research website
at www.le.ac.uk/gradschool/festival/

Appendix 15: Publications from Research

The published articles [p. 268-280] are not available in the electronic version of this thesis due to third party copyright restrictions.

The full version can be consulted at the University of Leicester Library.

Appendix 16: Published Abstracts

Doshani A, Pitchforth E, Maitra N, Mayne C, Tincello D. Does migrating to the UK make you incontinent? *Int Urogynecol J* 2007; 18 Suppl 1:S21-2

Doshani A, Pitchforth E, Maitra N, Mayne C, Tincello D. Influence of migration on the understanding and help seeking behaviour of Indian women with urinary incontinence. *Int Urogynecol J* 2007; 18 Suppl 1:S126-7.

Doshani A, Pitchforth E, Tincello D, Mayne C. A qualitative study to explore help-seeking and access to continence services among South Asian women in Leicester. *Int Urogynecol J* 2006;17 Suppl 2:S172-3.

Doshani A, Pitchforth E, Tincello D, Mayne C. Urinary symptoms and quality of life in South Asian Women in Leicester. *Int Urogynecol J* 2006;17 Suppl 2:S315.

Appendix 17: Conference Proceedings

Doshani A, Pitchforth E, Farooqi A, Mayne CJ, Tincello DG. Patients' journey through primary care. IUGA conference 2009 PP371

Doshani A, Pitchforth E, Farooqi A, Mayne CJ, Tincello DG. Differences in prevalence and impact of urinary symptoms by ethnicity? A survey of Asian and Caucasian communities in Leicester. *Proc UK Cont Soc* 2008;OP13.

Doshani A, Pitchforth E, Mayne CJ, Maitra N, Tincello DG. Does migrating to the UK make you incontinent? *Proc UK Cont Soc* 2007;TO26. (**winner best oral presentation**)

Doshani A, Pitchforth E, Tincello D, Mayne C. Urinary symptoms and quality of life in South Asian women in Leicester. *Proc Int Cont Soc* 2006;436.