

**HOW IS FIRST EPISODE PSYCHOSIS
AND EARLY INTERVENTION
UNDERSTOOD BY PAKISTANI FAMILIES?**

**Thesis submitted for the degree of
Doctorate in Clinical Psychology
at the University of Leicester**

By

Elizabeth Penny

**Department of Clinical Psychology
University of Leicester**

June 2005

UMI Number: U213139

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



UMI U213139

Published by ProQuest LLC 2014. Copyright in the Dissertation held by the Author.
Microform Edition © ProQuest LLC.

All rights reserved. This work is protected against
unauthorized copying under Title 17, United States Code.



ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

Declaration

This thesis constitutes original work by the named author. It has not been submitted for any other qualification, or to any other institution.

Acknowledgements

Bismillah.

I would first of all like to thank the participants in this study, who were so generous with their thoughts, their honesty and their time.

I would particularly like to thank my field supervisor Dr Lizzie Newton, who introduced anxiety and deadlines early in the process, and allowed me to keep ahead as a result. I am very grateful. Also thanks to Alison Tweed, my course supervisor, for the balance of encouragement and criticism. Thanks lastly to my interpreters and translators for all the hard work.

I am grateful to my family and friends, for all their support and encouragement. Special thanks to Belal, for all the sacrifices he made and encouragement he gave both through the research, and training itself.

Word Count

	Excluding References	Including References
Literature Review	7846	9446
Research Report	12000	13321
Critical Appraisal	4210	4526
Total (excluding appendices)	24056	27293
Appendices	3271	
Total (Including Appendices)	27327	30564

The literature review (Section A) has been written in accordance with the guidelines of the Journal of Mental Health (Appendix I). Referencing therefore follows APA guidelines.

The research report (Section B) follows the general style of the British Journal of Clinical Psychology. Referencing therefore follows BPS guidelines.

Contents

	Page number
Thesis Abstract	8
SECTION A: Literature Review	9
1. Abstract	10
2. Introduction	11
3. Materials and Methods	12
4. Asian Patients' Experience of Mental Illness	13
5. Beliefs in Asian Communities About Mental Illness	14
6. Cultural Differences in How Services are Viewed	17
7. Schizophrenia and Psychotic Illness	18
8. Psychosis in Asian and Other Minority Communities	22
9. Beliefs About Mental Distress by those who Experience it	25
10. Carers Perception of Services	27
11. Carers from Ethnic Minorities	30
12. Methodological Implications	33
13. Suggestions for Future Studies	35
14. REFERENCES	37
SECTION B: Research Report	46
1. Abstract	47
2. Introduction	48
3. Method	51
4. Results	57
Theme 1: Story of the Illness	58
Theme 2: A Social Illness	63
Theme 3: Treatment and Change	70
5. Discussion	79
Theme 1: Story of the Illness	79
Theme 2: A Social Illness	82
Theme 3: Treatment and Change	84
6. Clinical Implications	87
7. Critique and Limitations	89

8. Further Research	91
9. Conclusion	91
10. REFERENCES	92

SECTION C: Critical Appraisal **99**

1. Origins and Planning	99
2. Qualitative Methodology	100
3. Participants and Recruitment	101
4. Interviewing Non-English Speakers	104
5. Approaches to Interviews and Confidentiality	105
6. The Reflective Process	107
7. Analysis and Writing Up	110
8. Learning Points	111
9. Conclusion	112
10. REFERENCES	113

SECTION D: Appendices **115**

Appendix I: Publishing guidelines for the Journal of Mental Health

Appendix II: Ethical Approval letter

Appendix III: Participant information and participant consent sheet

Appendix IV: Participant family trees

Appendix V: Interview schedule

Appendix VI: Translators confidentiality form

Addendum: A copy of all transcribed interviews

List of Tables

Page number

Table 1: Participants	53
Table 2: Analysis	57
Table 3: Conventions Used in Transcripts:	58

How Is First Episode Psychosis And Early Intervention Understood By Pakistani Families?

Thesis submitted for the degree of Doctorate in Clinical Psychology by Elizabeth Penny

Abstract

The thesis consists of three independent sections:

Section A: Literature Review

Title: How are Mental Health Problems and Mental Health Services Understood in British Asian Communities?

The review outlines literature relating to Asian communities in Britain and their beliefs about and experience of mental illness, particularly psychosis. It particularly examines the experience of Asian service users and carers.

The review highlights cultural differences in the understanding and treatment of mental illness. It also suggests specific difficulties these communities have in accessing services.

Section B: Research Report

Title: How Is First Episode Psychosis And Early Intervention Understood By Pakistani Families?

Aims

The report aims firstly to better understand the beliefs held by Pakistani carers towards their family member's psychotic illness. Secondly, it explores Pakistani carers' attitudes towards an Early Intervention for Psychosis Service, accessed by their family member.

Methods

Eleven participants (Pakistani in origin) whose close family member was accessing the Early Intervention Service are interviewed. Interpretative Phenomenological Analysis is used to qualitatively analysis transcripts.

Results

Three Superordinate themes are evident: "Story of the Illness" "A Social Illness" and "Treatment and Change". These describe the impact that their family member's illness has on participants' lives, and their complex understandings of causes and treatment.

Conclusions

The study expands our understanding of participants' complex and multi-layered understanding of psychosis, its causes and treatment, as well as their experience of services. Implications and suggestions for further research are discussed.

Section C: Critical Appraisal

The critical appraisal is a reflection on the process of doing the research, based on a research diary. It includes a critique of the methodology selected and development of the research from design to write up. Areas of difficulty are highlighted, including recruitment, confidentiality and the use of interpreters. The influence of the researcher on the work is considered.

SECTION A: Literature Review

**How are Mental Health Problems and Mental Health
Services Understood in British Asian Communities?**

1. Abstract

Background

The South Asian communities make up about half the ethnic minority population in Britain. However, studies about mental health and attitudes towards mental illness in this population are limited and defuse.

Aims

This review outlines the literature relating to Asian communities in Britain experience of mental illness, particularly psychosis. It examines literature relating to rates of illness, beliefs about illness and attitudes to treatment. The review will discuss understandings of service users and carers in particular, and will focus on the Pakistani community.

Methods

Papers have been included from the last twenty years (1985-2005) and the focus is UK based studies, although some relevant international studies are included.

Results

Two primary areas of literature are highlighted; perceptions and beliefs about mental illness within Asian communities, and access to and experience of mental health services for Asian people.

Conclusions

The review highlights cultural differences in the understanding and treatment of mental illness. It also suggests difficulties for services in accessing these communities. The review calls attention to the lack of research into Asian understandings of psychotic illness, the role of carers, and perceptions of newly set up services. Suggestions for further research are made.

2. Introduction

There has long been debate in the literature regarding ethnic and cultural differences in the prevalence of mental health problems, particularly Schizophrenia. However, literature on how cultural difference may influence the understanding and experience of psychological distress is more limited. For example, there is a significant amount of literature about the overrepresentation of black patients in acute services, but there is a dearth of information about how patients experience diagnosis, and mental health services. Research about the Asian communities is particularly limited. The focus of this review will therefore be the experiences of Asian communities in Britain. However, literature regarding black and other minority communities will be cited where relevant.

This literature review will focus on gaining an understanding of a number of interrelated issues. Firstly, research regarding cultural differences in how mental health services are perceived will be examined. The study will then focus on the particular case of psychotic illness. Literature regarding psychotic illness, service provision and Early Intervention Services (EIS) will be summarised. The research on prevalence of psychosis in different ethnic groups and pathways to care amongst these groups will be mentioned. The study will then focus on how the experience of mental illness, in particular psychosis, is understood in Asian communities in general, and by those who experience it.

As people with acute mental illness are increasingly cared for in the community, the importance of the family and informal carers has grown. Therefore, the experience of carers and their role in treatment will be considered. These findings will be examined specifically with relation to the literature regarding ethnic minority carers. Lastly, areas where further research is needed will be highlighted.

3. Materials and Methods

Search Strategy

A number of key words were used to form the search strategy for this review:

psychosis/schizophrenia, mental health/distress, culture, ethnic*, Asian/ethnic minority/Pakistan*, carer/family.

Searches were performed using the “PsychINFO” “Embase” and “Medline” search engines. Manual searches were also performed, including searching the internet and searching references from relevant collected papers.

Papers have been included from over the last twenty years (1985-2005), although most cited studies are from the last ten years. Studies from the USA have been included, but UK based studies are focused on. It is recognised that the experience of cultural groups differs in different countries, and service issues are also different. The search found diverse areas of research literature; concerning prevalence from the medical journals, and some studies about attitudes and beliefs from the sociological and psychological literature. Overall the literature was diffuse and fairly sparse, particularly in relation to British Asians.

Defining Terms

The term “Asian” is used to define people whose families originate in the Indian sub-continent, including India, Pakistan, Bangladesh and Sri Lanka. When American studies are cited the difference in terminology will be addressed. “African-Caribbean” will be used to refer to people of African or Caribbean decent, although the term “black” will also be used. “White” refers to indigenous British people. The inadequacies of such terms, and the vast differences in the peoples defined by them are recognised. The Pakistani population will be

the focus of the study because of the significant cultural, religious and socio-economic differences within the British Asian populations. However, differences between those defined as Pakistani are also acknowledged.

4. Asian Patients' Experience of Mental Illness

There is more research into the experience of Asian patients with non-psychotic mental health problems than psychotic illnesses. Firstly, there are suggestions in the literature of differences in access to services. As with black populations, Asians are less likely than whites to be recognised as suffering from a mental health problem when they present to their GP (Commander *et al.*, 1997b). A practice-based cross-sectional survey in East London found that prescribing rates for antidepressants and anxiolytics were lower in Asian areas, indicating either lower levels of depression and anxiety, or lower recognition rates (Hull *et al.*, 2001).

A clearer understanding of why lower diagnosis occurs is needed. There is evidence that Asian patients both express psychological distress differently, and are less likely than white Patients to be diagnosed by their GPs. In an elegant study by Wilson and MacCarthy (1994) all patients attending five London health centres were screened for non-psychotic mental illness. Forms were available in English or Gujarati. GP's were asked to complete rating forms on all patients who scored highly at this screening. No differences were found in rates of mental illness between the Asian and white patients. However, Asian patients scoring above the cut off point for psychiatric morbidity were significantly more likely to be seeing the GP for a physical reason alone. Asian patients in psychological distress were, as in other studies, much less likely to be recognised as such than white patients. GPs identified 49% of white cases reporting high levels of psychological distress, but only 19% of Asians experiencing the same level of psychological distress.

This result is supported by a study by Bhui *et al.*, (2001). The study used Punjabi speaking and English GPs, and both a British and Asian mood scale. Again they found that rates of common mental health problems were not significantly different between the populations, but that both Asian and white GPs were less likely to recognise symptomatology in the Punjabi sample.

These studies together imply that distress may be perceived and communicated differently by Asian and white subjects, and further that GPs were less able to identify Asian patients' psychological distress. The significance of this finding is amplified by research that suggests that the Asian population is less likely to know about mental health services, or how to access them, thus are more reliant on their GP for psychological help (Hatfield *et al.*, 1996). Thus Asian patients experiencing psychological distress are likely to access professional support only through the GP, who in turn is less likely to recognise the problem.

Asian patients are therefore likely to describe mental distress differently to white patients, and that this may lead to inadequate diagnosis and treatment. The possibility that Asian patients also describe psychotic symptomatology differently, and that this also may have an impact on services, needs to be considered. This research leads one to consider not only how distress or mental illness is expressed differently, but also differences in how it is understood.

5. Beliefs in Asian Communities about Mental Illness

Beliefs about the causes of mental illness

Malik (2000) used a survey approach to examine how depression is perceived by the Pakistani community. In this study 120 British Pakistanis were given a vignette portraying a “depressed” man, and asked what they felt were the causes. Causes were generally considered to be external to (happening to, not within) the individual and ideas of self were emphasised

less than has been found in studies of white people. Many respondents saw symptoms of depression as indicative of spiritual weakness. Faith and worship were considered necessary to regain lost balance. A recent review of depression in Asian women suggests that there are differences between different Asian groups in understanding and defining depression, and services are often not utilised and not appropriate (Hussain & Cochrane, 2004).

A survey of perceptions of mental illness in an Asian community (Hatfield *et al.*, 1996) found that people listed three main causes of mental health problems. These were social stress, family problems and the will of God. The study found a strong belief in the need for spiritual as well as psychosocial support for mental illness. These factors are supported by a number of qualitative studies (e.g. Greenwood *et al.*, 2000 & Malik, 2000).

Currer (1986) examined Muslim Pathan women's perceptions of mental illness. The women in this study observe purdah (an interpretation of Islamic law in which women wear a complete veil and restrict their contact with male strangers), and have little contact with western society. The women interviewed saw health and illness, and happiness and unhappiness as inevitable and from God, therefore out of their control. Further, while some were described by the authors as depressed, they did not in general view themselves as ill. Although these studies provide useful information about culture, the research methods are not made explicit, and it is not therefore clear whether the participants' or author's ideas are dominant.

A further survey (Tabassum *et al.*, 2000) in a socially deprived Pakistani community found that stress at home and unhappiness were the most common reasons given for mental illness, however, more than 25% of participants also thought supernatural forces could cause mental illness. This study found that most participants would consider accessing traditional faith

healers alongside doctors, supporting Weiss's (1995) theory that Asian patients can hold different models of mental illness simultaneously.

Is mental illness stigmatised?

Many Asian families (in 60 semi-structured interviews, Li & Browne, 2000) believed mental illness is untreatable, and therefore preferred to classify emotional distress as physical illness. It was also felt by many that such issues should remain a family secret; this may be due more to beliefs about privacy than stigma however. The study is limited in its relevance as it was Canadian and includes diverse "Asian" groups, including Chinese, Indian and Filipino participants.

Qidwai and Azam (2002) surveyed over 300 patients attending a family doctor's clinic (not necessarily for mental illness) in Pakistan. Three-quarters of this population reported that mental illness is stigmatised, and they would be reluctant to seek out help. The research used a standardised questionnaire, and detailed information regarding participants' views is not available. Research utilizing quantitative and qualitative techniques in Bangalore, India, (Raguram *et al.*, 2004) found that stigma was greater when the family member had symptoms of suspiciousness and inappropriate sexual behaviour, and where families believed the illness was due to heredity or previous bad deeds. This suggests that stigma may be a changeable concept; dependent on the individual circumstances of the patient. These studies reflect perspectives in Asian countries, and these views may therefore be different to those held by Asian people in the UK.

One survey (Tabassum *et al.*, 2000) found that in general Asian respondents in the UK were reluctant to closely engage with people with mental health problems, but it is unclear whether different results would be found in a white sample. While these studies do suggest

that stigma may be an issue in Asian communities, the meaning of this has not been fully examined, and stigma about mental illness exists in many cultures.

6. Cultural Differences in How Services Are Viewed

Significant differences between African Caribbean and white groups in satisfaction with services were also found by Parkman *et al.* (1997). Second generation black patients had consistent and significantly lower levels of satisfaction with services. The study was not able to question why this might be, because of the quantitative techniques used. There is also evidence that ethnic minority patients and carers sometimes perceive services as racist (McGoven & Hemmings, 1994). Importantly, no large UK study on satisfaction with services has included Asian participants.

There is evidence suggesting that Asian populations may view mental health services differently. In an anthropological study of Pakistani women in the UK, Wheeler (1998) argues that within Pakistani culture a woman's role in the family is central to her identity and status. Because of patri-lineal structures women are often isolated from their own families and support. She hypothesises that in Pakistan and India mental hospitals are places of last resort and signify to others that the problem is permanent. Hospitalisation is felt to be stigmatising because of these connotations, and because it takes women away from their families. Wheeler interviewed a number of women who describe the loss of status and respect as a result of hospitalisation. This highlights the deeper meaning that treatment may hold, and the role that gender plays in the experience of treatment.

The research reviewed suggests cultural differences in understandings of mental illness, and views about services. It is important to examine whether this is also the case with schizophrenia and psychotic illness specifically.

7. Schizophrenia and Psychotic Illness

Schizophrenia is defined as a psychotic disorder, characterised by major disturbances in thought, emotion and behaviour (DSM IV, American Psychiatric Association, 1994). It includes the experience of both “positive” and “negative” symptoms. Positive symptoms are commonly delusions, hallucinations, disorganised speech or behaviour. Negative symptoms are often more long lasting; these include anhedonia, flat affect, and a lack of energy. Schizophrenia usually presents in late adolescence or early adulthood. Prognosis is varied, but approximately 75% of sufferers’ symptoms will continue or return throughout a significant part of life. Psychosis is an umbrella term used to describe Schizophrenia and other conditions with similar symptoms, where the patient seems to have lost touch with reality. It is sometimes used in preference to Schizophrenia where a formal diagnosis has not been given, particularly in young people, where diagnoses frequently change in the first few years.

Prevalence of Schizophrenia

Universally, incidence rates for Schizophrenia are similar worldwide, with a lifetime incident rate of between 1 and 2 % of the population (World Health Organisation, Sartorius *et al.*, 1986). However it is suggested that poverty, urban living and social stresses are all risk factors for psychotic illness (Boydell et al., 2001) therefore rates vary through the UK. For example, in the inner city area of Birmingham the annual incidence of psychosis is more than double the ‘text book’ level at 55 new cases per 100 000 population per year (Newton & Birchwood, 2005).

Prevalence and prognosis in Non-White Communities

Although worldwide incidents of schizophrenia are similar, there are cultural differences in prognosis, both internationally and within the UK. Internationally, in developing countries

prognosis is considerably more favourable, at two and five year follow up (Sartorius *et al.*, 1986). A multi-centre study in India supported this finding; a higher proportion of patients meeting initial diagnostic criteria for Schizophrenia had not had a relapse of symptoms at two year follow up than found in British and American trials (Gupta, 1992).

Better prognosis in developing nations does not however equate to a “protective” factor when populations move to developed countries. In contrast to the worldwide picture, in the UK (and other western countries) African-Caribbean patients’ incidence rates of psychotic illness, and their prognosis has been notably poorer than white patients (Bhugra & Bhui, 2001).

There has been a significant amount of research in the UK looking specifically at differences between ethnic groups. Overall, Schizophrenia is diagnosed significantly more often among African-Caribbean people than other ethnic groups (Bhui *et al.*, 2003). There has been significant research and debate into the causes of this difference. Recent studies have indicated that being a cultural minority itself may increase the risk of developing a psychotic illness. A population study in South London found that the incidence of Schizophrenia in non-white ethnic minorities increased significantly as their proportion in the local population fell (Boydell *et al.*, 2001). Thus the experience of being a minority may itself be a risk factor for psychotic illness. This emphasises the importance of social and environmental factors in psychotic illness. However, there remains very little research, or conclusive findings, regarding the diagnosis of psychosis in Asian populations.

Cost to individual and health services

Psychotic illness has significant long-term effects on the sufferer, his or her family and the wider community. People diagnosed with Schizophrenia are more likely to commit suicide, more likely to be homeless, and less likely to have a job, or maintain a relationship than the

general population (McKenna, 1994). Not only is the human cost vast, it has also been calculated that in England alone the annual financial cost of Schizophrenia to the nation is £2.6bn (Knapp *et al.*, 1997).

There are therefore significant reasons for the National Health Service (NHS) to prioritise the treatment of psychotic illness. Current research suggests that treatment during the initial stages of a psychotic illness (typically seen between the ages of 16 and 35) is critical in the long-term prognosis of the condition (Newton & Birchwood, 2005). A delay in treatment also increases the likelihood that the patient will have to be admitted for treatment under section rather than voluntarily. As well as causing significant distress for the individual and family (Johnstone *et al.*, 1986), this leads to increased distrust with and disengagement from services (McGovern *et al.*, 1994).

The National Service Framework (NSF) was introduced for the NHS in 1999 (DoH, 1999) to set national standards of mental health care based on the available evidence. The NSF has introduced seven standards of care. At least four of these focus on issues relevant to the needs of patients with psychosis (mental health promotion and reduction of stigma, access to services, effective services for people with severe mental illness and caring for carers). The need for early intervention into psychosis was further recognised by the NHS Plan (DoH, 2000) which established the need for all young people with a first episode of psychosis to receive early and intensive support.

Role of Early Intervention

The NSF states that anyone with a first episode of psychosis between the ages of fourteen and thirty-five should be treated within an early intervention service (EIS). The role of these services is to provide easily accessible specialist treatment in the initial stages of the illness, which is believed to improve long-term prognosis. To do this services have three aims: early

detection of psychosis, reduced delay in treatment and a sustained intervention through the critical first three years. EIS uses an assertive outreach model; they work to increase compliance and aim to support patients within the community where possible.

Ethnic Minority Patients in Early Intervention

Since the 1960s mental health care has been moving towards care of the acutely ill in the community. Many studies suggest that non-white patients in particular have experienced institutional care negatively; it is vital therefore that these errors are not repeated in community services, which rely on the engagement of clients. The Department of Health's paper "Delivering Race Equality" (2003) reports "clear evidence" of inequitable treatment of ethnic minority service users and their families, within services.

The need for community engagement is particularly important with newly set up initiatives such as assertive outreach and early intervention in psychosis services. One of the primary aims of these services is engagement with the client and their family. Through developing relationships with service users EIS aim to increase compliance with treatment, facilitate quicker intervention when symptoms reoccur and reduce risk (Birchwood *et al.*, 2002).

Initial studies suggest that community services may not always engage ethnic minority communities as effectively as white patients. A study by Bae *et al.*, (2004) used a longitudinal design to assess ethnic variations in prospective treatment outcomes in a community based psychosocial rehabilitation interventions in the US, over a twelve-month period. The study concluded that African-Caribbean participants were less likely to improve in social functioning. Change in other areas was the same.

Mental health policy now emphasises equality in care provision. The NHS is also now legally liable if services are discriminatory (Race Relations [Amendment] Act, 2000). The primary aim of community services therefore has to be provision of an equitable service for all users within the community (Sashidharan, 2001). To do this, services need a better understanding of different cultures social norms, beliefs and expectations about services.

Current research regarding ethnic minority, and particularly Asian, patients' experiences of services and beliefs about psychotic illness will therefore be reviewed.

8. Psychosis in Asian and Other Minority Communities

Differences in Pathways to Care

A number of studies have shown that black patients have more complex pathways to care before accessing specialist services (Commander *et al.*, 1999, 1997a). This means African-Caribbean patients see more specialists, and generally take longer to access the appropriate level of care than white patients. Data on Asians' access to care is both sparser and more contradictory than that on the African-Caribbean community (Cole *et al.*, 2000, Tabassum *et al.*, 2000). However, Asian hospital patients with psychotic illnesses were also found to have more complex pathways to care than white patients prior to addressing their problem (Commander *et al.*, 1999). Asian patients were also less likely to perceive themselves as having a mental health problem and were less likely to feel they needed to come into hospital.

Commander *et al.*'s (1997a & 1997b) valuable studies tracking pathways to care of newly admitted patients found that the most significant problem for Asian clients was not diagnosis at General Practitioner (GP) level, but referral on to specialist services. However, the results of the study should be treated cautiously as patients who didn't speak English were excluded, and more Asian participants refused to take part than white participants. If referral from GP

is the issue for Asian patients this would be consistent with the pattern seen in African-Caribbean groups. There is evidence that African-Caribbean patients are less likely to be referred to specialist services after visiting the GP than white patients (Cole *et al.*, 1995). Part of the explanation for this seems to be that GPs are less likely to recognise a psychiatric problem in a black patient (Bhugra *et al.*, 1999).

Not all studies agree that Asian patients have difficulty accessing specialist services. A smaller study in London indicated no difference between whites and Asians in referral to specialist services (Bhugra *et al.*, 1999). Birchwood *et al.* (1992) found that young Asians accessed help more quickly. They hypothesise that, as young Asian people are more likely to be in close contact with their families than young whites or African-Caribbeans, family members may notice psychotic symptoms sooner and the young person is encouraged to seek help more quickly.

Differences in use of specialist services

The evidence is also unclear regarding whether black and Asian patients maintain contact with services as well as white patients (Bhui *et al.*, 2003). McGovern and Hemmings (1994) show that African-Caribbean people with Schizophrenia are much more frequently lost from services. Literature for Asians remains inconclusive. One study (Gupta, 1992) found that at follow-up nearly twice as many Asian as white patients were not accounted for, nor registered with any GP. This could be an indicator of Asian clients' dissatisfaction with services, although this has not been fully explored.

When referred to psychiatric services, Asians are more likely to be admitted to inpatient care than white patients but less likely than African-Caribbean patients (Commander *et al.*, 1997, Goater *et al.*, 1999 & Koffman *et al.*, 1997). Compulsory admission is generally agreed to be significantly higher for black patients than either Asian or white patients. Of three studies

that have examined this two found compulsion was less common for Asians than white patients (Birchwood *et al.*, 1992 & Crowley & Simmons, 1992), but the sample sizes were small. The police were more likely to be involved with admission for Black patients than white, but Asian patients too are more likely than white patients to have police involvement at admission (Bhui *et al.*, 2003, Commander *et al.*, 1999, Thomas *et al.*, 1993,).

Asians may be less likely than other ethnic groups to be admitted to secure wards or to be readmitted (Birchwood *et al.*, 1992, Gupta, 1992). One study (Sheikh, 1985) finds no difference in number of admissions or length of stay on the ward. However, he did find that Asians with a diagnosis of Schizophrenia were more likely to be given ECT than matched white controls.

Birchwood *et al.* (1992) hypothesise that social and family support is better among Asian clients with psychosis, and this is frequently linked to improved prognosis. Evidence for better prognosis is found in a cohort study, followed up at 5 years, (Gupta, 1992) which found that first generation Asians diagnosed with a psychotic illness had shorter admissions and spent less time on average in hospital at five year follow up. These results are difficult to interpret, because of significantly greater difficulty in following up Asian patients, and because it is difficult to know if this reflects better health, or a reluctance to access services.

The contradictions in the literature regarding Asian's access of secondary services may partially reflect regional differences. While this has not been examined in the UK, a cohort study of two American counties (Snowdon and Hui, 1997) showed distinct differences in American Asians' (including South Asians') utilisation of secondary services. In areas where culturally sensitive community services were developed ethnic minority clients were significantly more likely to use them; where these services did not exist access was much lower than population norms.

Implications for services

Services are increasingly expected to consider the wishes and beliefs of both service users and their families. Mental health services have been accused in the past of insensitivity to cultural difference (Sashidharan, 2001). The research on psychosis in Asian communities suggests there exists differences in access to specialist services. Further, it indicates that Asian service users and their carers may have different beliefs about psychotic illness, which need to be understood, but have not so far been adequately researched.

These issues are particularly relevant to EIS, because they relay on the engagement of clients and their families. EIS also emphasise the need to help clients re-engage with, and gain support from, their communities. An understanding of their patients', their patients families' and the wider communities' beliefs about psychotic illness and treatment is therefore vital.

9. Beliefs About Mental Distress by Those Who Experienced It

A number of studies have examined how mental distress is understood by those in the Asian communities who are experiencing it. Fenton and Sadiq-Sangster (1996) in their review of mental distress in South Asian women argue that often research assumes women do not receive mental health services because they are not aware of their own depression, or because they somatise it. However, this ignores the possibility that they are experiencing psychological distress in different ways, and finding different solutions to white people.

The universality of diagnostic criteria was questioned in an Indian study by Weiss *et al.* (1995). A structured clinical interview for DSM IIIR was given to 80 outpatients. Patients emphasised their somatic symptoms to a far greater extent than seen in Western studies, and more than 50% received a non-specific or dual diagnosis. This questions the "fit" of western

constructions of mental illness used in non-western cultures. Of course, the issue may be more complex in Britain, where people's cultural views are influenced to different degrees by their original and host culture.

Weiss *et al.*, (1984) highlighted the use of traditional healers and beliefs in astrology, karma and the effect of humeral relationships among (mainly Hindu) psychiatric inpatients in India. In this study many participants gave more than one reason for the problems they face. The study indicated that people might be able to hold seemingly conflicting (and competing) views of mental illness (such as western and Ayurvedic) at the same time.

Krause (1989) emphasises the importance of the meaning ascribed to symptoms and illness within a culture. She describes one explanation of illness given by Bedford Sikh and Hindu Punjabis, through the term; *dil ghirda hai* "sinking heart". This term was also the main one used by Sikh and Muslim Punjabi women experiencing psychological distress in a qualitative study in Bristol (Fenton & Sadiq-Sangster, 1994). Krause compares this term, which describes psychological distress with physiological symptoms, to western concepts of physical and psychological distress. The study found that "sinking heart" had multiple social, physical, and personality causes and treatments. Again, this study suggests differences in the experience of and the explanations given for mental illness in Asian cultures.

No study was found which examined specifically the beliefs of Asian people with a diagnosis of psychosis about their illness. The studies that asked about "mental health" generally focussed on symptoms that fit into a western model of depression or anxiety. A study that asked specifically about hospitalisation (Wheeler, 1998) suggested that psychotic illness was classified differently by Asian communities than other types of distress. A deeper understanding of the meaning of psychotic symptoms to Asian service users and families is therefore needed.

10. Carers' perception of services

Informal carers (usually the family) of people with severe and enduring mental health problems have become increasingly important as service provision moves away from institutionalisation to community based care. 40% of people discharged from psychiatric units return to live with family members, another 30-40% stay in close contact (Johnson, 2000). Families have been shown in many studies to have potential positive and negative effects on the mental well-being of the cared for person. For example, good family support can lead to improved prognosis for people with psychosis (Birchwood *et al.*, 1992) whereas high expressed emotion and criticism within a family environment is related to higher relapse rates and increased hospitalisation (Kuipers & Raune, 2002).

Studies have also shown that the burden imposed on families through caring can be significant. Carers have been shown to suffer “associated stigma” and feelings of shame. In a population study of 156 carers of people experiencing their first admission to a psychiatric hospital (Phelan *et al.*, 1998) around 50% concealed the hospitalisation from other family or friends. This was more likely if the patient was female and if the family were educated. The quantitative methodology used in this study makes it difficult to access why carers felt shame and stigma. Ethnic minorities were under represented and issues of race and culture were not explored.

A number of studies have used qualitative techniques to further examine these issues, providing a richer understanding of the complex concerns and views of carers. An American study used qualitative methods with large numbers of carers to examine areas of concern for families, and to see how these differed with regard to gender, class and race (Johnson, 2000). Interestingly, this US study supported findings in India and the UK (Phelan *et al.*, 1998 &

Thara & Srinivasan, 2000) in indicating that stigma was higher among the middle classes. Family members often felt excluded by professionals. Carers were more likely to have a positive attitude towards caring if they received support from other family members and if they accessed support through religion. This may be because this gave them an increased sense of competence and meaning in the caring role. The Johnson (2000) study was organised through a carer's support group, with mainly white, middle-class members. Non-white participants were therefore not accessed sufficiently, and both non-white and "lower-class" participants were significantly more likely to refuse to take part, this may well have led to biases.

A UK study which examined written comments taken from quantitative assessment tools (Saunders & Byrne, 2002) found similar themes. Carers felt overwhelmed with (usually negative) emotions, which did not fade as the diagnosis became more familiar. They also discussed the importance of support from family and friends, and difficulties with stigma within communities. No information about ethnicity or social background was given.

A further study from America (Crisanti, 2000) examined four mothers' experiences of involuntary hospitalisation of their child diagnosed with Schizophrenia. Phenomenological analysis of these interviews indicated that mothers found the experience demeaning, and left them feeling baffled, victimized, anxious and judged. Although a small sample, the study sheds light on the ways health care professionals can improve relations with carers, who are often central to the well being of patients. The study suggests further work should be done with other family members, and with those experiencing the first hospitalisation of a relative.

Another American study using phenomenological analysis (Tuck *et al.*, 1997) examined parents' experiences of caring for an adult child with Schizophrenia. This gave a longer-term perspective of the difficulties faced by parents. The study describes parents' sense of loss, for

the imagined future for their child, and the losses in their own identity. They describe the caring process as a journey with no conceivable end. There is a need to make sense of their experiences, and this includes finding meaning through, and sometimes reassessing, their views about the nature of the world and their spiritual beliefs. The concept that carers need to create an understanding of what the change in their relative is and means has been shown in this and other studies, and cultural factors are fundamental to this understanding (Milstein *et al.*, 1995). The implications are limited because participants are all middle class (mainly white) carers, caring for son's with a diagnosis of Schizophrenia. The authors suggest the experience of other cultural groups, and those caring for daughters may well be different.

One qualitative study from the UK was found (Barker *et al.*, 2001). This used narrative techniques with eight clients and their family members. As with many studies, the majority of the carers were women and the patients were mainly men, in this case they all lived away from their parents. Although the study was carried out in South London (an ethnically diverse area) culture of participants is not mentioned. The study found similar themes to Tuck *et al.*, (1997) above; participants discussed their experiences as a journey that has not finished. They describe childhood, pre-diagnosis as normal, and perceived the onset of symptoms as a catastrophic disruption to this. It also supports Crisanti, (2000) in suggesting hospitalisation and early experiences with professionals can be negative.

These studies, although limited in number, agree on some themes of caring. The importance of support from other family members is stressed, commonly carers also feel disregarded by professional mental health staff. The search for meaning is emphasised by many carers; there is a need to understand the illness and its implications through an individual's cultural, ethical and spiritual framework. Although these studies have not looked specifically at cultural difference, these themes suggest culture may play a role in the caring experience.

11. Carers from Ethnic Minorities

Carers from non-white groups

A number of American studies have examined caregiving by black and white families of mentally ill children and siblings (i.e. Horwitz, & Reinhard, 1995, Milstein *et al.*, 1995 & Stueve *et al.*, 1997). There has been a consistent finding that black siblings and parents report lower levels of “caregiver burden”, defined as the perceived stress of caring. These differences remain after control for income, gender, age, diagnosis and perceived stigma. The studies also suggest that cultures that emphasise family obligation, and have greater extended family support have less voluntary use of mental health services and less reliance on professionals. One survey of carers (Milstein *et al.*, 1995) found that a much greater percentage of African-Caribbean and Hispanic parents cared for adult children with mental illness at home, and a larger percentage of white respondents reported that they would like their child to live elsewhere if this were possible. This finding suggests there may be cultural differences in the understanding and experience of care giving.

Milstein *et al.* (1995) asked carers if they knew their child’s diagnosis, and if they agreed with it. Non-white participants were less likely to know the diagnosis and to accept it. They were also asked for their explanation of the problem. White participants emphasised heredity as the most likely cause of the problem, Hispanics and African-Caribbean people emphasised external events such as relationships or a traumatic event. Hispanic people were more likely to describe the problem as one of emotions, rather than a medical problem. This supports the theory that non-white people are less likely to share the medical model of mental illness, and may therefore be less likely to agree with professionals regarding diagnosis. It also adds weight to the view that collectivist cultures are more likely to see distress as due to social rather than internal factors.

Asian carers

Studies looking at carers of people with mental illness have, in general, not accessed the opinions of Asian carers. Yet there is evidence that Asian clients are more likely to be living with parents and other family, and to be married (Birchwood *et al.*, 1992, Commander *et al.*, 1999). Thus family involvement is likely to be greater.

With particular reference to carers, Thara *et al.* (2003) examine the perceptions of carers towards their diagnosed family member, particularly in relation to stigma. Two important findings are relevant here. Firstly, levels of stigma and feelings of shame and guilt were various, not uniformly high. Stigma was found to be significantly higher where the patient and family were Hindu rather than Muslim or Christian and where the patient was female. Thus within group differences in the Asian communities may be as important as between group differences.

A further study in India (Thara, Kamath & Kumar, 2003) interviewed 75 carers regarding their beliefs about their family member and assessed caregiver burden using the Burden Assessment Schedule. This study suggested high levels of distress and a negative view about the future, due in particular to concerns about long term care. Participants were also concerned about financial support.

There are however some methodological weaknesses that limit the significance of these studies. Interviews were structured around carers' levels of stigma or level of burden. Many other issues of importance to carers, for example positive feelings, may have been ignored. One example of this is shown in qualitative studies (e.g. Tuck *et al.*, 1997) which indicate carers can experience conflicting and complex feelings about the person defined as ill, and that there may be positive feelings as well as negative. Doctors, who could be viewed as

authority figures, were the main interviewers. Carers might have discussed their difficulties more openly with an interviewer not involved in the patient's care.

In a UK study, Greenwood *et al.* (2000) used grounded theory to study the views of 12 Asian patients from acute wards settings and their main carer. Patients were mainly Pakistani. Interviews were carried out in English, Urdu or Punjabi, by a Pakistani researcher. This is important in accessing the voices of those often excluded from research. However, as the authors point out, a researcher from the same cultural group may mean some loss of objectivity.

A number of core themes were found. The first was about "being Asian". This meant very different things to different people; some saw culture as central to their identity and mental health, while others saw it as irrelevant to their treatment. Both patients and carers often felt unable to fully express their needs, partly due to translation issues. The issue of interpreters was interesting, some respondents felt judged by them, partly because they came from their own community. Religion was seen as helpful and supportive by many (as is seen with white carers) and hospitalisation often led to difficulties for patients in practising their religion.

Many carers recognised there was a problem but did not want to describe this as mental illness. Mental illness was equated with madness and violence and was seen as permanent. Finding appropriate language to describe their understanding of the problem was important. Participants often applied both Asian and Western explanations to their problems. For example, a common explanation (as with Thara *et al.*'s (2003) participants in India) was stress, worry and pressure, which in some cases was due to family and cultural issues. However, participants also mentioned punishment from God, black magic and the evil eye.

Participants sometimes accessed both western treatment and traditional healers or religious figures, and most made it clear that they did not inform medical staff of this. Patients felt that it was possible to combine these approaches (for example, by explaining that the medication is given to us for our use from Allah). Patients and carers therefore did not always perceive Western and personal cultural explanations of mental illness in competition with one another, but as complimentary.

Qualitative research methods seem able to examine the complexities of opinions, and to uncover findings that are not predicted. In particular, this study emphasises the robust and humane approaches to caring for mentally ill family members supported by some Asian cultural values.

12. Methodological Implications

Quantitative studies have clearly indicated differences between the Asian and white British populations in access to services and pathways to care. However, findings are at times contradictory and not able to fully answer questions regarding patients' perception of services, or reasons why access might be different.

There are some significant difficulties in understanding Asian service users' experience from a purely quantitative perspective. Practically, sample size for Asian groups is often too small to find significant differences. Papers varied in their classification of ethnic groups, not clearly defining inclusion criteria. No study looked at differences between Asian communities, despite clear evidence of significant demographic differences in income, education, language and social position. Most studies ignored confounding variables such as age, class, gender and religion (e.g. Bhugra *et al.*, 1999).

There are other methodological difficulties with some quantitative studies reviewed, which influence their validity. There are obvious limitations in using quantitative methods with people whose first language is not English. Standardised questionnaires are not well validated with different cultural groups (Commander *et al.*, 1997b). Many studies had significantly lower uptake from Asian clients (Commander *et al.*, 1997a), leading to possible sampling bias. Further, studies often either actively excluded those who did not read English (Commander *et al.*, 1997a) or did not mention what was done in these cases (Goater *et al.*, 1999). This is in the context of high levels of illiteracy and poor spoken English among the Pakistani and Bangladeshi communities.

Further, measuring the extent of mental health problems in ethnic minority communities and comparing it to a white “norm” risks misunderstanding or ignoring the reasons behind the differences. As Sashidharan (2001) puts it: “*within psychiatric practice, minority ethnic groups continue to be deemed as deviant from the white norms one way or another, either as requiring or receiving too much or too little psychiatry*” (p.245.) Further research and qualitative data are needed to allow a more complex and complete understanding of these issues.

Qualitative methods have been instrumental in gaining a richer understanding of these complex issues. Qualitative methods used well can be more open to the participant’s perceptions, and allow them more control over the interview process (Greenwood *et al.*, 2000). They are therefore particularly useful for carers and ethnic minorities, as both groups may be suspicious of services and both groups views are often not heard. Qualitative methods may also be able to examine the between-group differences, which seemed to be very important among the Asian communities (Greenwood *et al.*, 2000).

There is a need within qualitative research to be clear regarding the techniques used. Some studies were not explicit regarding their methodology. Some, for example, used

structured interviewing and did not tape-record responses (Kai & Hedges, 1999 & Tabassum *et al.*, 2000), this can decrease the influence of the participants over the final text, and increases the interpretative role of the interviewer. Sampling is also important. Accessing community members was sometimes difficult so a ‘snow balling’ technique was commonly used. In other studies selection was through personal or professional contacts (i.e. Tabassum *et al.*, 2000). Both these techniques can lead to limiting the differences in the voices heard.

In all studies it is important to bear in mind that a researcher’s age, sex, ethnicity and social status will influence what is said by participants (Kai & Hedges, 1999). Many studies have intentionally used people of the same or similar cultures to carry out interviews. This has many benefits, particularly with language and with understanding cultural perceptions. However, one must not assume that cultural origin equates to shared cultural values. Interviewers and translators will always have their own beliefs regarding an issue and participants’ comments will be filtered through this (Temple, 2002). Concern about confidentiality or about shared taboos may lead clients to say less to a professional of their cultural origin. In one study (Tabassum *et al.*, 2000) a Pakistani psychiatrist was chosen to carry out interviews in a deprived Pakistani community. Her status as a doctor, and as someone known to the community, may in fact have limited participants’ ability to be open, but this is not mentioned in the study. Good qualitative research should allow the researcher to take a reflective approach to these issues, and allows a better understanding of their influence on the process.

13. Suggestions for future studies

The study of cultural difference in beliefs about mental illness is a new and expanding area and there is currently a paucity of research in this field. There are two particular areas of deficit, which would benefit from further study. The first relates to the experience of Asian

service users with severe mental illness. While there is still much research to be done looking at the overrepresentation of black patients in services, research into prevalence of psychological distress in Asian communities, pathways to treatment, and attitudes towards mental illness is in its infancy. Of 35 studies examining pathways to treatment reviewed by Bhui *et al.* (2003) only 8 looked specifically at Asian patients. Commander *et al.* (1999) comment when reviewing the research; “*The literature relating to ethnicity and service use for people with severe mental illness largely overlooks the experience of Asian people in the UK.*” (p. 484). As Asians now make up 50% of our ethnic minority population (Reid-Galloway, 2003) more needs to be done to understand their needs within mental health services.

Secondly, there is a need to examine the attitudes of service users and their carers from different cultures towards community care services. If beliefs about illness are different, as has been suggested in the literature, then there is also likely to be differences in expectations from services.

A study of Asian carers of people with serious mental health problems, their attitudes towards mental illness, caring and formal services would be an interesting way of looking at some of the research deficits. Asian patients are more likely to live with family than other ethnic groups. Little is known about the impact on the patient and family of this. Studying families of patients involved in EIS would be particularly useful, as these services aim to engage communities and families (Birchwood *et al.*, 2002), yet there has been little research examining responses to this.

14. References

- American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Addition. (DSM IV)*. Washington DC: APA
- Barker, S., Lavender, T. & Morant, N. (2001). Client and family narratives on schizophrenia. *Journal of Mental Health, 10*(2), 199-212.
- Bhugra, D. & Bhui, K. (2001). *Cross-Cultural Psychiatry: A Practical Guide*. London: Arnold
- Bhugra, D., Corridan, B., Rudge, S. Leff J. Mallett R. (1999). Early manifestations, personality traits, and pathways into care for Asian and white first-onset cases of schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 34*, 595-599.
- Bhui, K., Bhugra, D. Goldberg, D., Dunn, G. & Desai, M. (2001). Cultural influences on the prevalence of common mental disorder, general practitioners' assessments and help-seeking among Punjabi and English people visiting their general practitioner. *Psychological Medicine, 31*(5), 815-825.
- Bhui. K., Stansfield, S., Hull, S., Priebe, S., Mole, F. & Feder, G. (2003). Ethnic variations in pathways to and use of specialist mental health services in the UK: A systemic review. *British Journal of Psychiatry, 182*, 105-116.
- Birchwood, M., Cochrane, R., Macmillan, F., Copestake, S., Kucharska, J. & Cariss, M. (1992). The influence of ethnicity and family structure on relapse in first-episode schizophrenia: A

comparison of Asian, Afro-Caribbean and White patients. *British Journal of Psychiatry*, 161, 783-790.

Birchwood, M., Fowler, D. & Jackson, C. (2002) *Early Intervention in Psychosis: A Guide to Concepts, Evidence and Interventions*. Chichester: Wiley

Boydell, J. Van Os, J., McKenzie, K. Allardyce, J. Goel, R. McCreadie, R.G. & Murray, R.M. (2001). Incidence of schizophrenia in ethnic minorities in London: Ecological study into interactions with environment. *British Medical Journal*, 323(7325), 1336-1338.

Cole, E., Leavey, G., King M., Johnson-Sabine E. & Hoar A. (2000). Pathways to care for patients with a first episode of psychosis: A comparison of ethnic groups. *British Journal of Psychiatry*, 167, 770-776.

Commander, M.J., Cochrane, R., Sashidharan, S.P., Akilu, F. & Wildsmith, E. (1999). Mental health care for Asian, black and white patients with non-affective psychosis: Pathways to the psychiatric hospital, in-patient and after care. *Social Psychiatry and Psychiatric Epidemiology*, 34, 484-491.

Commander, M.J., Sashidharan, S.P., Odell, S.M. & Surtees, P.G. (1997a). Access to mental health care in an inner-city health district. I: Pathways into and within specialist psychiatric services. *The British Journal of Psychiatry*, 170(4), 312-316.

Commander, M.J., Sashidharan, S.P., Odell, S.M. & Surtees, P.G. (1997b). Access to mental health care in an inner-city health district. II: Association with demographic factors. *The British Journal of Psychiatry*, 170(4), 317-320.

- Crisanti, A.S. (2000). Experiences with involuntary hospitalisation: a qualitative study of mothers of adult children with schizophrenia. *Schizophrenia Research*, 45, 79-81.
- Crowley, J.J. & Simmons, S. (1992). Mental health, race and ethnicity: A retrospective study of the care of ethnic minorities and whites in a psychiatric unit. *Journal of Advanced Nursing*, 17, 1078-1087.
- Currer, C. (1986). Pathan women in Bradford – factors affecting mental health with particular reference to racism. *International Journal of Social Psychology*, 30(1-2), 72-76.
- Department of Health. (1999). *A National Service Framework for Mental Health*. London: The Stationery Office.
- Department of Health. (2000). *The NHS Plan*. London: The Stationery Office.
- Department of Health (2003). *Delivering Race Equality: A framework For Action*. London: The Stationery Office.
- Department of Health and Home Office (2000). *Race Relations Amendment Act*. London: The Stationery Office.
- Fenton, S. & Sadiq-Sangster, A. (1996). Culture, relativism and the expression of mental distress: South Asian women in Britain. *Sociology of Health and Illness*, 18(1), 66-85.
- Goater, N., King, M., Cole, E., Leavey, G., Johnson-Sabine, E. & Blizard, R. *et al.* (1999). Ethnicity and outcome in psychosis. *The British Journal of Psychiatry*, 175(7), 34-42.

Greenwood, N., Hussain, F., Burns, T. & Raphael, F. (2000). Asian in-patient and carer views of mental health care. *Journal of Mental Health*, 9(4), 397-408.

Gupta, S. (1992). Psychosis in Asian immigrants from the Indian sub-continent. *Social Psychiatry and Psychiatric Epidemiology*, 27, 242-244.

Hatfield, B., Mohamad, H., Rahim, Z. & Tanweer, H. (1996). Mental health and the Asian communities: A local survey. *British Journal of Social Work*, 26, 315-336.

Horwitz, A.V. & Reinhard, S.C. (1995). Ethnic differences in caregiving duties among parents and siblings of persons with severe mental illness. *Journal of Health and Social Behaviour*, 36(2), 138-150.

Hull, S.A., Cornwell, J., Harvey, C., Eldridge, S. & Bare, P. (2001). Prescribing rates for psychotropic medication amongst East London general practices: Low rates where Asian populations are greatest. *Family Practice*, 18(2), 167-173.

Hussain, F. & Cochrane, R. (2004). Depression in South Asian women living in the UK: A review of the literature with implications for service provision. *Transcultural Psychiatry*, 4(2), 253-270.

Ineichen, B. (1990). The mental health of Asians in Britain: Little disease or underreporting? *The British Medical Journal*, 300, 1669-1670.

Johnson, E.D. (2000). Differences among families coping with serious mental illness: A qualitative analysis. *American Journal of Orthopsychiatry*, 70(1), 126-134.

- Johnson, S. & Orrell, M. (1996). Insight, psychosis and ethnicity: A case-note study. *Psychological Medicine*, 26(5), 1081-1084.
- Kai, J. & Hedges, C. (1999). Minority ethnic community participation in needs assessment and service development in primary care: Perceptions of Pakistani and Bangladeshi people about psychological distress. *Health Expectations*, 2, 7-20.
- Knapp M. (1997). Costs of schizophrenia. *British Journal of Psychiatry*, 171, 509-518.
- Koffman, J., Fulop, N.J., Pashley, D. & Coleman K. (1997). Ethnicity and use of acute psychiatric beds: one-day survey in North and South Thames regions. *British Journal of Psychiatry*, 171, 238-241.
- Krause, I.B. (1989). Sinking heart: A Punjabi communication of distress. *Social Science Medicine*, 29(4), 563-575.
- Kuipers, L. (1993). Family burden in schizophrenia: Implications for services. *Social Psychiatry and Psychiatric Epidemiology*, 28, 207-210.
- Kuipers, E. & Raune, D. (2002). The early development of expressed emotion and burden in the families of first-onset psychosis. In: M Birchwood, D. Fowler & C. Jackson (Eds.), *Early Interventions in Psychosis* (pp.128-142). Chichester: Wiley
- Li, H.Z. & Browne, A.J. (2000). Defining mental illness and accessing mental health services: Perspectives of Asian Canadians. *Canadian Journal of Community Mental Health*, 19(1), 143-159.

McGoven, D. & Hemmings, P. (1994). A follow-up of second generation Afro-Caribbeans and white British with a first admission diagnosis of schizophrenia: Attitudes to mental illness and psychiatric services of patients and relatives. *Social Science Medicine*, 38(1), 117-127.

McKenna, P.J. (1994). *Schizophrenia and Related Symptoms*. Psychology Press: East Sussex

Malik, R. (2000). Culture and emotions: Depression among Pakistanis. In: C. Squire (Ed.), *Culture in Psychology* (pp. 147-162). London: Routledge

Milstein, G., Guarnaccia, P. & Midlarsky, E. (1995). Ethnic differences in the interpretation of mental illness: Perspectives of caregivers. *Research in Community and Mental Health*, 8, 155-178.

Newton, E. & Birchwood, M. (2005). Early intervention in psychosis: From research to reality. In D. Sallah & M. Clark (Eds.) *Research and Development in Mental Health*. London: Elsevier.

Parkman, S., Davies, S., Leese, M., Phelan, M. & Thornicroft, G. (1997). Ethnic Differences in satisfaction with mental health services among representative people with psychosis in South London. *The British Journal of Psychiatry*, 171(9), 260-264.

Phelan, J.C., Bromet, E.J. & Link, B.G. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin*, 24(1), 115-126.

Qidwai, W. & Azam, S.I. (2002). Psychiatric morbidity and perceptions on psychiatric illness among patients presenting to family physicians. *Asia Pacific Family Medicine*. 1(2-3), 79-82.

- Raguram R., Raghu, T.M., Vounatsou, P. & Weiss M.G. (2004). Schizophrenia and the cultural epidemiology of stigma in Bangalore, India. *Journal of Nervous & Mental Disease*, 192(11), 734-744.
- Reid-Galloway, (2003). *Mental Health of the Asian Community*. London: Mind Information Unit.
- Sartorius, N., Jablensky, A., Korten, A., Ernberg, G., Anker, M. & Cooper, J.E. (1986). Early manifestations and first-contact incidence of schizophrenia in different cultures. *Psychological Medicine*, 16, 909-928.
- Sashidharan, S.P. (2001). Institutional racism in British psychiatry. *Psychiatric Bulletin*, 25, 244-247.
- Saunders, J.C. & Byrne, M.M. (2002). A thematic analysis of families living with schizophrenia. *Achieves of Psychiatric Nursing*, 16(5), 217-223.
- Shaikh, A. (1985). Cross-cultural comparison: Psychiatric admission of Asian and indigenous patients in Leicestershire. *International Journal of Social Psychology*, 31, 3-11.
- Snowden, L.R., & Hu, T-W. (1997). Ethnic differences in mental health services use among the severely mentally ill. *Journal of Community Psychology*, 25, 235-247.
- Stueve, A., Vine, P. & Stuenkel, E.L. (1997). Perceived burden among caregivers of adults with serious mental illness: Comparison of black, Hispanic and white families. *American Journal of Orthopsychiatry*, 67(2), 199-209.

Tabassum, R., Macaskill, A. & Ahmed, I. (2000). Attitudes towards mental health in an urban Pakistani community in the United Kingdom. *International Journal of Social Psychiatry*, 46(3), 170-181.

Temple, B. (2002). Crossed wires: Interpreters, translators, and bilingual workers in cross-language research. *Qualitative Health Research*, 12, 844-854.

Thara, R. & Srinivasan, T.N. (2000). How stigmatising is schizophrenia in India? *International Journal of Social Psychology*, 46(2), 135-141.

Thara, R., Kamath, S. & Kumar, S. (2003). Women with schizophrenia and broken marriages - doubly disadvantaged? Part II: Family perspective. *International Journal of Social Psychiatry*, 49(3), 233-240.

Thomas, C.S., Stone, K., Osborn, M., Thomas, P.F. & Fisher M. (1993). Psychiatric morbidity and compulsory admission among UK born Europeans, Afro-Caribbeans and Asians in central Manchester. *British Journal of Psychiatry*, 163, 91-99.

Tuck, I., du Mont, P., Evans, G. & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing*, 11(3), 118-125.

Weiss, M.G., Raguram, R. & Channabasavanna, S.M. (1995). Cultural dimensions of psychiatric diagnosis. *British Journal of Psychiatry*, 66, 353-359.

Weiss, M.G., Sharma, S.D., Gaur, R.K., Sharma, J.S., Desai, A. & Doongaji, D.R. (1986). Traditional concepts of mental disorder among Indian psychiatric patients. *Social Science and Medicine*, 21(4), 379-386.

Wheeler, E.L. (1998). Mental illness and social stigma: experiences in a Pakistani community in the UK. *Gender and Development*, 6(1), 37-43.

Wilson, M. & MacCarthy, B. (1994). GP consultation as a factor in the low rate of mental health service use by Asians. *Psychological Medicine*, 24, 113-119.

SECTION B: Research Report

How is First Episode Psychosis and Early Intervention Understood By Pakistani Families?

1. Abstract

Aims

- To gain an insight into the beliefs held by Pakistani carers towards their family members' psychotic illness.
- To gain an understanding of Pakistani carers' attitudes towards an Early Intervention for Psychosis Service, accessed by their family member.

Methods

Eleven participants were interviewed from six families, using a semi-structured interview. Contributors were all British Pakistanis with a close family member referred to the Early Intervention Service. Interviews were recorded and transcribed. Interpretative Phenomenological Analysis was used to qualitatively analyse transcripts.

Results

The analysis revealed three Superordinate themes: "Story of the Illness" "A Social Illness" and "Treatment and Change". These describe the impact that their family member's illness had on participants' lives, and in response to it, their complex understandings of causes and treatment. The themes are explored using extracts from participants' interviews.

Conclusions

The study expands our understanding of participants' complex and multi-layered understanding of psychosis, its causes and treatment as well as their experience of services. The study provides a better understanding of the role services can play in supporting families, and recommends changes to service provision to better meet the needs of Pakistani communities. Other implications and suggestions for further research are discussed.

2. Introduction

Psychosis and Early Intervention

Psychotic illness is estimated to have a lifetime incidence rate of between 1 and 2% of the population (World Health Organisation, Sartorius *et al.*, 1986). Although its prevalence is therefore lower than other mental illnesses such as depression, it often has a far greater impact on the individuals affected, and those around them. People diagnosed with a psychotic illness are at significant risk of having symptoms reoccurring throughout life, which influence many aspects of functioning (McKenna, 1994). The National Service Framework (DoH, 1999) has emphasised the need to focus care for those experiencing psychotic illness.

Research indicates that early and appropriate treatment during the initial stages of a psychosis may improve long-term prognosis (Newton & Birchwood, 2005). Early Intervention Services (EISs) are designed to specifically address the needs of younger people experiencing psychotic illness. The NHS Plan (DoH, 2000) stated that by 2004 every young person with a first episode of psychosis should be treated within a dedicated EI team, and currently EISs are being set up throughout England.

Providing Care to All Communities

Engagement with the service is central to EISs work (Birchwood *et al.*, 2002). Further, services attempt to support patients to re-engage with their communities, and families should be a key part of this, as stated in the NHS plan and NICE guidelines. In the NHS document “Delivering Race Equality” (2003) this role of services to specifically engage ethnic minority carers is highlighted; “*There is clear evidence of the need to transform the services and outcomes experienced by these [ethnic minority] users and their relatives and carers.*”

Mental health services, and particularly institutional care, have in the past been accused of being insensitive to cultural difference (Sashidharan, 2001). There are differences in how ethnic minority patients access services (Commander *et al.*, 1997 & 1999, Gupta, 1992 & Tabassum *et al.*, 2000). There is also evidence to suggest that ethnic minority groups are less satisfied with the service they receive (Parkman *et al.*, 1997). The NHS is now legally responsible for ensuring that services are not discriminatory, and provide equitable and appropriate care, (Race Relations [Amendment] Act, 2000). Community services such as early intervention, therefore, need to understand the needs and expectations of the diverse communities they serve (Bhugra, 2002).

Asian Families and Beliefs About Mental Illness

Approximately 13% of the UK population is from an ethnic minority, and nearly half of these are “Asian” (Reid-Galloway, 2003). The term Asian is used in this context to describe people from India, Bangladesh, Pakistan or Sri Lanka. Many studies have excluded Asian communities from research (e.g. in a review of papers examining pathways to treatment for different cultural groups, 27 out of 35 studies excluded Asian service users, Bhui *et al.*, 2003). There has been little research done to understand the views or experience of Asian communities about psychotic illness, or mental health services (Commander *et al.*, 1999).

The studies of attitudes towards mental illness and depression that have been conducted indicate that there are distinct differences in how Asian people understand mental illness. In particular Asian respondents reported that mental illness was caused by external, social factors more than internal emotional causes, and that acts of worship, such as prayer, were important in recovery (Greenwood *et al.*, 2000, Hatfield *et al.*, 1996, Malik *et al.*, 2000). There is also evidence that Asian participants often hold more than one model of illness, for example accessing both medical and spiritual explanations (Tabassum *et al.*, 2000). Thus there

is some evidence that Asians (including patients and carers) view mental illness differently from the majority population.

Carers

There is evidence that Asian people with mental health problems are more likely to live with their families (Commander *et al.*, 1999), and therefore the families' understanding of the illness may be highly significant. Informal carers (usually the family) of people with severe and enduring mental health problems have become increasingly important as service provision moves away from institutionalisation to community based care. About 70% of all EISs service users live with family (Stirling *et al.*, 1991). Evidence suggests that good family support can lead to improved prognosis for people with psychosis (Birchwood *et al.*, 1992).

Studies of other cultural groups have suggested that attitudes to caring, as well as understandings of mental illness, may be culturally determined (Milstein *et al.*, 1995 & Stueve *et al.*, 1997). Only one study (Greenwood *et al.*, 2000) appears to have examined the views of carers of in-patients with psychotic illness. This study highlighted the complexity of cultural definitions, and the difficulties families had expressing their needs and wishes. Carers often rejected the label of mental illness, and defined the problem in terms of behaviour.

Aim and Implications for Current Study

This study will aim to fill the significant gaps in recent research regarding community care for Asian communities. There is no research examining the views of carers to the newly set up EISs. Further, while there is evidence that Asian communities have different ways of understanding mental illness, this has not been examined in depth with relation to psychotic illness. This study will examine the interface of these issues; how Asian carers understand psychotic illness and how they experience EISs.

Many studies have attempted to understand Asian communities as a whole. However significant differences exist between these groups in terms of religion, culture, migration experience, education and class (Hussain & Cochrane, 2004). This study will recruit participants from the Pakistani community, which is one of the largest and most economically deprived populations (Modood *et al.*, 1997).

The study will use a qualitative methodology. The question is more suitable to a qualitative methodology because it is exploratory, and attempts to understand the participants' perspectives and experienced meaning, rather than testing hypothesised relationships (Elliot, 1995). Questionnaire based approaches are limited by the researchers preconceptions, and quantitative methods are not designed to access this kind of complex, rich and contradictory data (Shaw, 2001).

3. Method

Qualitative methodology was used to examine families' attitudes towards an early intervention service, and their beliefs about psychotic illness. Interpretative Phenomenological Analysis (IPA) bases its analysis on psychological theory, and through this aims to understand participants' underlying cognitions and beliefs (Smith, 1995 & 1999, Willig, 2001). IPA was selected as a qualitative methodology over other approaches (such as Grounded Theory) because it is designed to explore the meanings constructed by a person about their situation and social world, rather than exploring or theorising about an event or issue (Smith & Osborn, 2003) and therefore is ideally suited to the research question. Further, IPA is designed to be used with one cohesive population and was therefore well suited to the study, which focuses solely on the Pakistani community of one city. Lastly, issues relating to

examining culture have been studies to a greater extent using in IPA than other qualitative methodologies (Shaw *et al.* 2003).

The researcher carried out all interviews, transcription (except for translated sections) and all analysis. This allowed for consistency of approach and closeness to the data. The researcher had experience in working with people with psychotic illnesses and their families. She was familiar with Pakistani culture and had some understanding of the Urdu and Mirpuri languages.

Recruitment

Participants were taken from an inner city early EIS. Referrals for the service are accepted for people between the ages of 16 and 35 in their first year of treatment for a psychotic illness.

Ethical approval was sought and gained from West Birmingham Local Research Ethics Committee. An ethical approval letter is included in the appendix (appendix II).

Participants were family members of current service users (SUs). The names of all SUs who had accessed the service for at least a year, and who described themselves as Pakistani, were accessed through a manual search of all current files. The service has a very culturally diverse population, and the majority of SUs belong to an ethnic minority.

Families of both male and female patients, who had accessed different key workers, were selected. Key workers and the patient's Responsible Medical Officer were contacted to ascertain if contacting the family might damage the relationship between the service, family and client or if there might be significant risks in visiting the family. No other selection criteria were used.

The patient's key worker initially contacted families. The aims of the research were explained. If interested, families were then contacted by telephone or visited by the researcher, and written information about the research as well as a consent form was given (Appendix III). Where participants did not speak English an interpreter explained the patient information and consent sheets. Translations of the sheets were not used due to high levels of illiteracy in first generation Pakistanis.

Explicit, detailed information regarding anonymity was given to participants. It was explained that transcripts would be anonymised and that tapes would be destroyed after use, or sent to the participant if preferred. The independence of the research from the service was also clarified.

Six families agreed to participate. All participants lived with SUs. The families are represented in figure 1 and in diagrams 1-6 (appendix IV). Family members are identified by a pseudonym (i.e. Mrs Saeed, service user Saeed) to maintain anonymity.

Table 1: Participants

Family No	Participant Name	Relationship To Service User	Language of Interview	Sex Of Service User
1	Mrs Saeed Appa ¹ Saeed Sister Saeed	Mother Older sister Older sister	Mirpuri English English	Male
2	Mr Miza	Father	Mirpuri	Female
3	Mrs Rehman	Grandmother	English	Female
4	Mrs Shah Miss Shah	Mother Older sister	Mirpuri English	Male
5	Mrs Khan Mr Khan	Mother Father	English English	Female
6	Mrs Ahmed Mr Ahmed	Mother Father	Pashtu English	Male

¹ Appa is a title given to the oldest sister in Pakistani families. It is used here and in the data to differentiate between the two sisters

Materials

Each interview was recorded using audiotape for later transcription and analysis. The interview schedule (Appendix V) was reviewed by a psychologist who was experienced in working with carers and with using IPA. It was designed to allow a broad and open discussion about the participant's experience of the EIS, and their beliefs about their family member's illness and future.

Interviews

Eleven participants were interviewed. In two families only the primary carer chose to be interviewed. Participants were interviewed in their homes, except in one case (Miss Shah) where the participant preferred to be interviewed at her work place.

Three interviews were carried out through interpreters, and one (Mrs Shah) through a family member, as she did not want to use an interpreter. Two interpreters were used, they were both female and had experience of mental health interpreting. They had the same duty of confidentiality, and this was stressed to the participants. Interpreters were met 30 minutes before sessions, in order to discuss fully the nature of the interviews. They were also debriefed after each interview.

It was explained to participants that interviews would be about their experiences of the EIS, and about their understanding of their family member's difficulties. There was an untranscribed pilot interview with an interpreter and one family to assess the schedule and process of working with and interpreter. Revisions were then made to the order the questions were asked, putting the question regarding how their family member came into contact with the service first. The wording of one question (what is it like to be a family member to x) was simplified.

The interview was semi-structured; how questions were asked and their order was dependent on the interview, to follow the lead of the participant. This approach allowed participants greater freedom to address the question from their stance, while giving a helpful structure to those participants who were less able to express themselves, and for whom open questions could be difficult to answer.

Analysis

Interviews were transcribed verbatim. Interpreted interviews were professionally translated and transcribed, translators were asked to sign a confidentiality clause (appendix VI). Transcripts were analysed using IPA, using the method described by Smith et al. (1999) and Smith (1995).

Step 1: Initial Coding

Each transcript was read and re-read a number of times. In the left column of each transcript the participants' concerns and experiences were noted, using their own language. Phrases or "codes" were selected which summarised each of these. Coding aimed to organise data and identify patterns within it by picking out recurrent experiences, terms and objects.

Step 2: Identifying Themes Within and Between Transcripts

Transcripts were reanalysed in light of the initial coding, to group together codes into "emergent themes". Themes are simply the grouping of codes, through interpretation of the text, in order to describe the structure and relationships between codes. This was done by first returning to the text and using the right hand column of each transcript to note commonalities between codes. These emergent themes were noted separately for each participant, along with relevant quotes. During this stage the analysis becomes interpretive, as inferences are made about the meaning and context of each participant's experiences.

These initial themes were then examined in light of what constituted the shared aspect of the participants' experience (Smith *et al.*, 1999). Through comparing themes for each transcript shared themes were found and the relationship between these themes was considered. This allowed a better understanding of a hierarchical structure to the themes and superordinate themes emerged.

Step 3: Sharing Analysis and Validity

The themes and analysis were shared with another researcher, who was experienced in IPA research. Alternative interpretations of the original data and themes were discussed. Data was also validated through taking transcripts and analysis to a peer review group. This allowed the researcher to examine the interpretations she was making, and consider alternative ways of understanding the data. This produced a final list of superordinate and subordinate themes.

Step 4: A Written Account

A narrative account was constructed around the superordinate themes. This account was illustrated with selected verbatim extracts from the transcripts. These should allow the experiences of the participants to remain transparent while ensuring that the researcher's interpretation is visible to the reader.

Evaluation of Research

All research needs to have clear, explicit criteria for its evaluation. In common with quantitative methodologies there is a need to ensure that research meets certain well known criteria, for example in its explicit purpose and contribution to knowledge, clarity in methodology and respect for participants. However, there are also criteria that relate specifically to qualitative research. During the process of data collection and analysis there is a need for the researcher to own their own perspective, situate the sample and provide

credibility checks. Within the report themes must also be grounded in examples, be coherent and resonate with the reader. (Elliott et al., 1999)

4. RESULTS

Three superordinate themes emerged from the interviews. The themes were “Story of the Illness” “A Social Illness” and “Treatment and Change”. Subordinate themes were identified.

These themes reflect primary concerns for families; the impact of the illness on the individual and family, the meaning they have made of the SU’s illness and lastly their understanding of treatment and change. All three themes are linked by a few key understandings for families. These relate to the primacy of social experiences and issues of loss, hope and family responsibility.

Table 2: Analysis

STORY OF ILLNESS	A SOCIAL ILLNESS	TREATMENT AND CHANGE
i) Sudden realisation	i) Illness has a social cause	i) Treatment needs to be social and relational
ii) Hope disappointed	ii) Illness defined through social interaction	ii) Faith and spirituality
iii) Worry and loss	iii) Absence of Psychiatric Explanation	iii) EIS is just about medicine
		iv) Care is the families’ responsibility

Table three is presented to clarify symbols used in the quotes. Where interpreters were used their contributions are included, and all text has been translated.

Table 3: Conventions Used in Transcripts

Symbol	Meaning
(...)	Text has been omitted
...	A pause in speech
[text]	Explanation used to clarify the participants comments.
Text in italics	A question asked of participant, either by the interviewer, or the interpreter.

Theme 1: Story of the Illness

The first theme is primarily phenomenological, outlining participants' journey through the illness. Participants described a chronological story of the development of the illness, even where this was not requested. Within these stories there are features shared by all families. The subordinate themes represent the families' chronological journey from first contacting services to the current situation. They also describe families' change in perception about the illness and its implications, which seems to be a parallel process to the development of the illness. This can be summarised as a journey from confusion and optimism to a loss of hope and worry in nearly all families.

The exception is the Khan family, whose daughter experienced one psychotic episode and has not experienced significant symptoms since. All others had experienced some persistent symptoms and/or relapse of their mental illness. While the Khan family could be described as a "deviant case", because of their less negative experience of illness, and of the service, they do share many of the same beliefs and concerns with the other participants. These similarities and differences will be highlighted through the analysis.

i) Sudden realisation

Most families described a moment when they realised that their family member was ill, even if behaviour had changed before this. This realisation was normally due to significant changes in the service user's behaviour, but may also have represented a shift in interpretation of behaviour:

Interviewer: *what was it that first made you, and your mum worried about your brother?*

Miss Shah: ... Er, it all happened very quickly, it didn't build up, it was just that one day when everything ... it's quite difficult to explain now, but he was all, he just took, it came out of nowhere really. So ... (34-37 interview with Mrs Shah)

Miss Saeed: I think it's, it happened all so quick.

Interviewer: Umm

Miss Saeed: You see what I mean? One minute he was at college, then he left college, and after that he was working at the shop, and after that he just started getting depressed.
(10-14)

Further, families suggest that referral to services occurred when they felt that behaviour was no longer containable within the family. This, and the severity of symptoms described, suggested that difficulties might not have occurred before this point. On reflection some participants recognised that addressing the problem earlier might have been helpful:

Interviewer: *OK, and if you were going to advise other Asian families with the same problem, what would you say to them?*

Appa Saeed: Before it gets too worse just sit down and talk to your brother or sister.

Interviewer: *Umm*

Appa Saeed: If you think they're behaving slightly like, out of their place or whatever, or if you think something's wrong, don't ignore them. Sit down and talk to them, never ever ignore them. Never. Don't think – you know what Asian families are like – “Oh, yeah, he's done this, or whatever, leave it” they don't sit down and they never talk. (140-147)

ii) Hope disappointed

After the initial realisation families describe a loss of hope over time; in contrast with initial hopes for complete recovery. Initial over-optimism was seen by some participants as encouraged by the EIS, participants felt the service thought that complete recovery was likely. If families were given alternative perspectives about prognosis, this was not reported in the interviews:

Miss Saeed: There was a time you know when it started, there was a time when we thought, oh yeah, two more months, three more months, that's what they used to tell us at the early intervention centre, oh just give it another two months, it's not totally up to them but, you know, its like it goes on and X isn't really happy (...) (106-110)

Participants describe a shift in expectations, from hoping for recovery to slow change or maintaining improvements. Participants refer to the SU needing to “take it slow” and a shift in perception to seeing the SU as permanently ill or vulnerable:

Miss Shah: Um, well, he came out of hospital in May and said he was wanting to go back to education. So, um, I wasn't quite sure about that, but er his key worker said I mean, it's all right, he thought he was fit enough to go back, and we just said so to him to take one subject or maybe two, just leave it for now. And take it easy, take it like a mock year (...) (87-90)

This concern with “not taking on too much” was even the case in the Khan family, despite perceptions that Miss Khan was better:

Mr Khan: She going for the full time, she still asking about full time. I'm not pleased with that, I said leave it, half a day, part time. You know like er,

Interviewer: *Why do you think that part time is better?*

Mr Khan: You know, less hours, there is all day to day, there is more kids and it's too much isn't it.” (25-28)

For many families there appeared to be an altered attitude about what was expected of the SU, in their education, work and life. The SU had been given the role of a sick person who should avoid stress or pressure:

Mr Ahmed: So first think that you are a sick man, a sick person. Don't take too much pressure on your back. Go easy. No matter what you do, but go easy. Be happy all the time. You go to school or work, I am not bothered about it. You stay in England, if you want to go back to Pakistan it's alright.” (124-128)

Thus the SU, no matter how much they recovered, continued to be viewed as unwell or even disabled.

iii) Worry and loss

When reflecting on their current situation, all families describe some degree of continuing worry about the service user. Family members did not generally define what they worried about, but described a need to keep the person close to them, and depicted worry as a natural and permanent state for the family. As Mr Ahmed put it; “*if you have a kid, and there is something*

wrong with them, it's not normal, wouldn't you worry?" (142-143). Participants generally recognised this worry as something that affected the whole family. Mr Mirza, who did not talk much about the family's distress, nonetheless described how worry for his daughter's illness permeated the whole of his family:

Interviewer: *How has her illness affected the family?*

Mr Mirza: It has affected the family, as it upsets us, and when there is a healthy child in the house, it gives us peace of mind. But now, we don't have that, which make me feel bad knowing that she isn't that well.

Interpreter: they are worrying about her, because um, she's got ill and she's not well, and he feels bad thinking about her.

Interviewer: *Do other people in your family worry as well?*

Interpreter: *Do everyone else in the family, children and wife, worry as well?*

Mr Mirza: I'm talking for myself, but obviously it upsets us all, as when we sit in a room together and are quiet, we are all thinking about the same thing and about her ... (51-61)

Family members described a sense of loss; a change from how their family had been, and a change in future expectations. Mothers in particular remembered their children before the illness in a very positive, perhaps idealised, light, and contrasted this with their child now:

Mrs Saeed: He used to be a boy of such beautiful character who has changed which is really painful to me. There wasn't anyone like him around. Look at what has happened to him.

Interviewer: *Umm. What do you think about the future for X?*

Mrs Saeed: He hasn't got a future ahead of him. ... I don't know what to think anymore about it ... [tearful] There's a lot of difficulties [tearful] (137-146)

Mrs Ahmed: He was so good at his studies in school (Allah forgive me ²) he was really good. Now when he comes back he sits on his own and thinks to himself. I ask myself what's happened to him? (144-147)

Older participants also mention the role they had hoped the SU would take in caring for them as they get older; this is a further loss:

Mrs Saeed: (...) When I used to get worried about him, he'd reassure me by saying, "mum, I'll take care of you when I am older", but now, he doesn't do anything.

Interpreter: (...) When she used to be worried, he would say, "don't worry mum, I will grow up and look after you". Now he doesn't do nothing.

Mrs Saeed: When I went for Hajj³, he came with me and we saw a lady there whose son was helping her to perform Hajj. I just thought that if I was in the same situation, would my son do the same? (...) The poor thing, it's not his fault at all, not at all (506-512)

Theme 2: A Social Illness

The second theme is both phenomenological and interpretive. It describes a framework for understanding how the problem, acknowledged in the first theme, is defined. Participants described their concerns beginning when their family member's behaviour fell outside culturally accepted limits. Behaviour retains an important role in families' understanding of the illness. Participants endeavoured to explain abnormal behaviour through familiar beliefs and models, such as social stress or black magic, rather than using terms such as psychosis or schizophrenia. It is striking that none of the participants used these diagnostic terms at all in

² Muslims dislike praising others. Sometimes people will ask Allah's forgiveness when they believe they have said something denoting excessive praise.

³ Hajj is the annual Muslim pilgrimage to Mecca in Saudi Arabia.

the interviews, or often describe psychotic symptoms such as delusions or voices. Instead participants defined the illness primarily in terms of social deficits.

i) Illness has a social cause

Participants consider shorter-term social stressors, and longer-term family difficulties as pivotal factors in causing their family member's difficulties. A number of participants mentioned recent changes in the SU's life, for example stress at school, as possible causes. Miss Shah suggested that she *"didn't know at the time what to think, I thought maybe it's stress, ... I did tell him to take it easy, coz he did take on quite a few um subjects, in A-levels."* (33-34)

Families also consider longer-term social and familial factors. Many older participants implied that being within British society may have had a negative and corrupting influence. This was an explicit explanation for the Ahmed family; both parents thought that watching pornography caused their son's illness:

Mrs Ahmed: He use to watch dirty films dirty, dirty films he used to watch. He's my good son. Now he has become wrong. That's what's done it. He would pressure, on his brains, he wouldn't go to sleep he would watch, which has affected his brain. (380-383)

The pressures of living in a society with conflicting social values to that of the family is suggested by other participants; the Saeed family for example mention "bad" friends (who encouraged him to drink) as a stressor (Mrs Saeed, & Miss Saeed).

A number of families feel family itself may have been a cause, especially in not "being there enough" for their child. Participants felt that the company of others, especially family was important:

Interviewer: *Did A [key worker] talk to you about why he was ill and what it was?*

Mr Ahmed: ... A didn't say anything, but she knows, you know, I know, everyone can, in this country, especially – it's loneliness. I mean, if he had a brother or sister around him it would be alright.

Interviewer: *Ok. So being on his own?*

Mr Ahmed: His own. I used to go to work, and the wife used to go, ... sewing and Quran Sharif⁴ ...(79-85)

Mrs Rehman and Miss Shah Families considered that absence of fathers might cause problems for the SU:

Interviewer: And you mentioned that he had taken on a lot of subjects at school, and that was maybe one thing that caused it, can you think of anything else?

Miss Shah: yeah the family.

Interviewer: umm

Miss Shah: God, where do I start! Um, my parents divorced when he was about two. And, he, well my mum's never stopped any of us from contacting our dad, whatever, but I don't know whether he wanted to, or doesn't want to hurt her feelings like? (115-122)

ii) Illness has a spiritual cause

Another explanation given by families was black magic. Within Pakistani culture black magic is an accepted cause of many unfortunate or unexplainable events in people's lives (Karim *et al.*, 2004). Mrs Saeed, Mrs Ahmed and Mrs Rehman mention this as being a possible cause of their child's difficulties. Possibly because this is not a belief felt to be shared with the non-Muslim community it was often addressed in interviews tentatively:

⁴ She attended classes to study the Quran. Quran Sharif mean honoured Quran, the Quran is the Islamic Holy book.

Mrs Saeed: All the relative and I know that it could be black magic, as it has been done to a lot of people.

Interpreter: She goes it could be, because it's like, well known, that there is black magic...

Mrs Saeed: This woman, A [a nurse] she was really helpful and said that, give the medicine to your son and also consult with a molvi [religious teacher] so that he would blow some religious verses on him and do other things like that.

Interpreter: She says that someone came from the city hospital, an Asian lady, she said that – have the medication, and also take him to a, you know, holy man, molvi. So, you know, when they blow on him, and do like that.

Interviewer: *What did she think of that?*

Interpreter: *What did you think of that?*

Mrs Saeed: I was very worried at around that time and obviously, not knowing what to do, whichever way someone would tell me to walk, I'd do it. I didn't know what to think... (360-376)

The belief that there may be a spiritual cause for illness is intrinsically tied up with treatment.

Later in the interview Mrs Saeed says she took her son to Pakistan for a year in order to access treatment by a molvi.

iii) Illness defined through social interaction

As the cause for the SU's difficulties is described primarily socially, so the problem itself is defined in social terms. Participants refer to the SU's difficulties in terms of their behaviour in relation to others. Little reference is made to the SU's internal social world, moods, or beliefs. Mrs Saeed for example described her son's behaviour as without reason:

Interpreter: *When did you start thinking there was a problem, before you found out?*

Mrs Saeed: Other than this, he started to reject going to school and eating food.

Interpreter: He stopped eating, he wouldn't go to school.

Mrs Saeed: He wouldn't sleep a wink at night, and he'd spend the night awake watching a film.

If he couldn't do that, he'd just stare at the ceiling, which would worry us.

Interpreter: Many times he woke up in the night and would just be looking at the ceiling. And he wasn't sleeping and they were very worried about him,

Mrs Saeed: His eyes would just fill up with so many tears, and he would just keep crying, without a reason." (31-42)

Mr Ahmed also described his son's illness in terms of behaviour:

Mr Ahmed: He just grow, like wild, grow his beard and hair, and like wild. If I say anything, he runs. They put er, people working there [points to outside the window] on the roof. They put er scaffolding, one day he on the top! So I went, you know. And he run away, start swearing at me. One day he took some knife with him, he put in some knife. So we thought, we need to do something now with him. (27-32)

While some of these concerning behaviours were no longer present, participants were still worried about the SU's lack of communication with the family and their cultural and social isolation. Some participants mention that the SU was no longer following important social conventions:

Mrs Rehman: I don't know how, how she behave. Which is, her behaviour is not bad, she's ok, um, when she goes there, you know like in our culture, people come and say "salaam alaikum"⁵ and say "how are you", but she's quiet, she doesn't say anything. (275-277)

⁵ The Muslim greeting, meaning peace be upon you. It is considered rude in Muslim societies not to return the greeting.

Some participants commented that the SU was not able to communicate even their fundamental needs to the family and they stressed the importance of communicating basic practical needs for the SU's recovery:

Mrs Saeed: He's not talking which is like half his illness, not talking about things. He doesn't even ask for things, not even for food. If he was going to start speaking about things, that might help him to get better, rather than keeping it in. (574-577)

Participants also viewed communication as an indicator of how well the SU was recovering:

Miss Shah: So, yeah, he's doing really well. He's communication with the outside world.

Interviewer: *And is that something that is important, as far as you are concerned?*

Miss Shah: Um, its how he used to be. He's very sociable, like. He's very good with communicating and he gets on with everyone, so. He wasn't someone who would shy away and hide. And that's what he ended up doing. (99-104)

iv) Absence of Psychiatric Explanation

The illness was much less frequently described with reference to the internal world, beliefs or feelings of the service user. No participant used the terms schizophrenia or psychosis in describing the problem, even though all SUs were accessing an "Early Intervention for Psychosis" service. However, some participants used the term depression. One explanation for this is that families were not given (or did not absorb) the service's bio-psycho-social model of the illness and this lead to a stronger reliance on the social model. When prompted, participants in general did not feel that EI workers explained the illness to them, often describing only on a more superficial, or social level:

Interviewer: *And has anyone tried to talk to you about what they think the problems are?*

Mrs Khan: ... I don't know, they just sort of chat. (76-77)

One participant, Miss Shah, remembered that the family were given some information by the service about their family member's illness, but this was at first referral, and the family had difficulty taking it all in:

Interviewer: *...I wonder if the people at the early intervention team have talked to you about what happened then, and why it happened, what the problem was?*

Miss Shah: They did, I think there was a talk, but I can't remember it now, so, coz I just got so much to, you know ...(71-74)

Psychiatric labels may also be incorrectly translated to families which could increase stigma. For example, within these interviews the interpreter used the term "pagal" which means madness or craziness, to describe "mental illness":

Interviewer: *And you said the doctor saw him and he said it was a mental illness?*

Interpreter: *The doctor said he was mental [pagal]?*

Mrs Saeed: Yes

Interviewer: *Have they told you more about that?*

Interpreter: *Have they said anything more than that?*

Mrs Saeed: No (227-233)

The subordinate themes are linked by the role that social and communal factors have in understanding the illness. This is related to the absence of a diagnostic model.

Theme 3: Treatment and Change

This theme describes participants' complex and seemingly contradictory responses to the illness. The subordinate themes all represent things that family members think can be done to overcome or deal with the SU's difficulties. Participants viewed the combination of approaches, rather than one thing alone, as helpful in aiding recovery.

i) Treatment needs to be social and relational

Theme two showed that families hold social understandings of what has occurred, and it is therefore not surprising that they also privilege social solutions. All participants stress the benefit for service users of being active in the community. A number of participants mention that being at home doing nothing is bad for you. Many also suggest that sport, work or other social activity are beneficial and they suggest that the EIS should take their family member out:

Mrs Rehman: The only other thing would be if er, like, they [EIS] would take her out you know. Coz she doesn't want to go with me, I don't know why. Or her mother, like er, ... activity like sport thing, where she can keep the mind busy. (262-264)

They are also concerned by their family member's isolation, Mrs Saeed says; "*I want him to have good company as that's like medication*" (565) stressing the therapeutic or restorative nature of companionship. The Ahmed and the Saeed parents also mention that they are considering marriage for the SU. This was seen as providing a further social tie, and also as a way of assuring their son is looked after when they are no longer able, as Mrs Saeed says: "*maybe he will get better, a wife's love is different. Plus, he will have kids as companions thereafter. It could make him change and help him and when I go, his wife, his companion, could take care of him.*" (319-322). As

previous themes show that families consider the illness is a social illness, a social cure is considered of primary importance.

ii) Faith and spirituality

Many family members describe religion as a way of coping and making sense of what had happened, and also giving them hope in the possibility of change. Religion links the person into their cultural and social world. Religious beliefs were referred to frequently, and meaning was given to difficulties through the language of belief. For example, many participants said “InshaAllah”⁶ whenever they mentioned hopes for the future.

Some participants seemed to find belief empowering, because they felt they could have some influence on what happened. Although they described Allah as ultimately in control, they also believed they may influence what happens through prayer, pilgrimage, reading or using the Quran:

Mrs Saeed: InshaAllah he will get better, I have dreams that I am at Mecca⁷, and that Allah is saying, don't worry, he will get better. Allah will help.

Interpreter: She says, he will get better, she's praying for God's help and she said that she feels that he will get better,

Mrs Saeed: With Allah's help, I am not in need for anything else. (461-466)

While a discussion of religion was more common in parents, younger participants too sometimes referred to their belief that while medicine only made small changes, it was only their faith that gave them hope things could significantly change:

⁶ Meaning “If Allah wills it”. Muslims use this to remind them of the belief that everything is in Allah's power.

⁷ Mecca is the place of Muslim pilgrimage. Within Islam dreams are believed to sometimes be from Allah.

Appa Saeed: Yeah, I am not really happy with the medicine. The only thing we can believe in now is Allah (57-58)

Participants linked a belief in religion to black magic and possible treatment; visiting a molvi (religious man) who is skilled in dealing with black magic, often in Pakistan. The Saeed, Rehman, and Ahmed families all sought spiritual treatments. The same families also took their children to Pakistan where they felt they might be happier and more able to change:

Mrs Saeed: When we went there, [Pakistan] the molvi at the mosque whispered some things on the water which was given to him. He was really happy and very calm with that.

Interviewer: Umm

Interpreter: *And have you given him more of it since?*

Mrs Saeed: It finished then but I'm thinking of going again as he likes it in Pakistan.

Interpreter: He was happy there

Interviewer: *While he was in Pakistan?*

Interpreter: Yeah, he was happy there.

Interviewer: *What do you think made him happy there?*

Interpreter: *In your opinion, what made him happy in Pakistan?*

Mrs Saeed: All the children relax there and enjoy themselves. It could be that he took the water from the molvi's. (390-395)

This is particularly interesting as Mrs Saeed links spiritual treatments with social treatments. Families do not need to accept a purely spiritual cause for the difficulties to believe that they could be helped by spiritual treatments. Mrs Rehman for example, accepts that the cause for her granddaughter's difficulty is medical, but she still feels that spiritual treatments could help:

Mrs Rehman: This illness, I accept this is an illness, and you want to go some sort of, something to read or something like that, give something which is, which I give to X, either, they do this sugar, or salt or honey and they just pray something on it, and give to the girl⁸, I can do that, because I trust God. (329-333)

Mr and Mrs Ahmed described going to see a molvi first for treatment before they accessed medical help, and it was the molvi who suggested contacting a doctor. Again this suggests older participants at least view medical and spiritual approaches to illness as complementary.

iii) EIS is just about medicine

There were some key requirements that all families felt should be delivered by a mental health service, but they differed in whether they felt the EIS provided them. The family who were most happy with the EIS were the Khan family, who were also the only family who described their child as completely recovered.

Even amongst those who were happy with the service, participants often commented that the service was only, or primarily, focused on giving medication. Mr Khan was asked about whether the service talked to him about the problem, he said “*They cross here, you know ... they just really give the medication.*” (57). While most families thought that medication was needed, it was not considered the cure they had initially hoped for, and this links to “disappointed hope” identified in theme one.

Interviewer: *And you feel the medication helps her?*

Mrs Rehman: it help her, it help her yeah. It help her because it seems to be, she is getting better, but it's very, very slow. (116-118)

⁸ Mrs Rehman is describing two common forms of religious treatment; giving certain parts of the Quran for the person to read or wear on their person, or reading prayers and Quran over food and giving the food to the person to eat.

Some families, like the Saeeds, took the SU off the medication for a while, because it didn't bring the person back to how they were before:

Interviewer: *can you ask her why they decided to take the medication away?*

Interpreter: *why did they take the medicine away?*

Mrs Saeed: Because the pills affected his body. I thought the pills will help him to become the way he was before; when he used to talk enthusiastically about going to college, or doing Law. Going without medication was thought to be the best thing for him. (193-198)

The Saeed family were most negative about the medication, partly because their family member experienced bad side effects from it:

Appa Saeed: Two things; he wet himself, and he's gone very slow in the head as well. All to do with the medicine. So what is the medicine? The only thing it's helping him is to calm down. Even drink calms him down. (200-202)

While most families felt the medication was necessary, no participant saw it as sufficient. Even the Khan family mentioned family support and social change as part of recovery. Family members seemed happier with key workers when they were perceived as having a relationship with the SU, rather than just giving medication:

Interviewer: *What is it that she [key worker] does that you think helps?*

Mr Ahmed: Oh she talks with him very soft and nice talk. Like a friend, you know. She tells him she is like a friend. Or keep secret, I don't know what secret he's got! Just joking with him really! (155-158)

There is often an absence of communication between the service and the family. Some participants felt the service only talked to the family when it was in its interest to do so. Communication was particularly hard for those who don't speak English, as they felt the service only provided interpreters when they needed information from the family, not to provide information:

Interviewer: *Yeah. So have people from the service come to talk to you, your mum or you, about your brother's difficulties?*

Miss Shah: There have been a couple of times, but it was for them. Um, when they were doing surveys and things so. It was for them, not for us, yeah.

Interviewer: *So they come to get you to answer questions, but they haven't come to talk to you about the illness?*

Miss Shah: Yeah.

Interviewer: *Did they give you any explanations, about what the matter is, what will happen?*

Miss Shah: I don't think they did, really, ... I can't think.

Interviewer: *And when they come, do they ever bring people who can speak your mother's language?*

Miss Shah: Um ... never. Never, coz I used to be home then and I could, I was always there.

Interviewer: *Yeah. And could you ask your mum, what that was like, not being able to speak to the workers?*

Miss Shah: *how was it for you when the workers didn't speak your language to you?*

Mrs Shah: I was hoping that a person can speak to me in my language, directly to me and not using someone to translate (Mrs Shah, 168-184)

There was a difference between generations in the role participants thought the service should have with the family. While all participants wanted the service to communicate with them about care, younger participants felt that the family's perspective should be listened to, as they are in a position to see how well their family member is:

Interviewer: *Do you think it would good for them to talk to you as well as him?*

Appa Saeed: Yes definitely. I mean if X would understand them it would be really good if they could come and talk to X, but if X didn't want that I think they should come and speak to whose ever, brothers, sisters or parents or whoever.

Interviewer: *If you could advice them about what to do to improve the service, what would you say to them?*

Appa Saeed: Emm ... like keep the family informed. Like, ok, he's been on this medicine for this long and, ask us if he's changed or improved or anything like that, ask us. (124-131)

Parents however often saw the service (especially the doctor) as the decision maker:

Interviewer: *Do you think she should carry on with the medication?*

Mr Khan: Ah, depends doctors you see, you know, what they say. If they say carry on then carry on. If they say stop it you try it, then, you know. That's the best thing. You know, I can't say, you know like, er... the doctors know better than us. (45-48)

iv) Care is the families' responsibility

The health and well being of the SU was central to participants' lives. The family feel responsible for change, and in some ways care is the only thing left which families feel able to do. This links with the loss of hope seen throughout. The family (not the service user themselves, or the service) were felt to be primarily responsible for the welfare of the service

user. Thus parents especially are looking for ways of helping and making things better. A number of parents used the phrase “we’ll do anything for them”. Mrs Rehman’s statement is typical; *“I would do anything I can to help her, to get her back to where she was before.”* (78-79).

Indeed, many families made significant sacrifices for the SU, for example as Mrs Saeed stated; *“(...) we dropped everything for a whole year and we took him to Pakistan to see if it could help”* (385-386). Mr Ahmed also left his work to take his son to Pakistan for medical (and possibly spiritual) treatment. In the two families in which service users had been hospitalised, both sets of parents attempted to visit every day, even though in the case of the Shahs this was a 200 mile round trip:

Miss Shah: We were always like worried, but gradually he was, he started getting back, back on track and he’d like say um, you don’t like me and that’s why you leave me here [in hospital], and that made my mum upset. So that’s why she tried to go up every day. [tearful]. ... four hours on the trains and the buses, and it was hard. ... (170-174)

Participants even felt responsible for making sure the service provided the medication to them on time, and for ensuring that the SU took it:

Mr Ahmed: No, no she [the key worker] never forgets. Anyway, I don’t let her forget, I ring. When medicine is finished. If medicine is finished on Tuesday, I ring on Monday. You know? (240-241)

Miss Shah: Just the medication; sometimes I do worry, coz sometimes he feels he doesn’t need the medication, (...) And he does tend to skip. And I have spoken to his key worker, but they said as long as he isn’t missing too much, it’s OK. But that’s why I wanted to see,

um the doctor, if he can reduce the amount he is taking, like maybe one dose a day or something? (204-210)

Parents also reported that a central part of their role is “keeping them happy”. Where communication was poor this meant trying to guess the SU’s needs and wants, often in meeting day-to-day needs such as food and comforts:

Mr Mirza: We just keep her happy by talking to her constantly, by checking if she wants to eat anything more recently, asking her if she wants to go and visit her sister, and things like that. (172-174)

Interviewer: (...) *If you knew someone else, another family, who had the same problem, what would you advise them?*

Mr Ahmed: I would advise them to do the same thing, keep him happy, you know, let him do what he wants. Just keep eye on him, so you know what he wants. You know, so when they happy, they feel a bit better. And him now, sometimes, we have argument, he loses temper but I try my best to keep him happy but even so sometimes he loses temper. (184-190)

It is possible that this indicates a shift from hoping the person might change to changing the social environment around the SU. This may be all that parents feel they are able to do when hopes about the person’s recovery have faded, and is connected to them seeing their child as vulnerable and ill, as described in the first theme.

5. DISCUSSION

The study was designed to examine families' attitudes towards an early intervention service, and their beliefs about psychotic illness. The results show that participants understand the problem in complex but interrelated ways. Families privileged social explanations for distress, and social models for treatment, but also accessed both medical and spiritual approaches. Different approaches were generally viewed as complementary. The research also highlighted a lack of communication with the EIS, and a belief that its role is limited to medical intervention.

Theme 1: Story of the illness

Participants describe family members difficulties as a journey, from realisation, through a loss of hope to their current position. This representation of carers' experiences as a journey is found in other qualitative studies (Barker *et al.*, 2001 & Tuck *et al.*, 1997). Barker *et al.* found that carers of people with psychotic illness described their experiences as a journey that has not finished, and perceived the onset of symptoms as a catastrophic disruption to previous normality. However, Barker *et al.*'s participants found a sense of meaning and understanding through diagnosis. Diagnosis was not mentioned at all by the participants in this study and this may suggest cultural differences in the value and meaning of diagnostic terms, although it may also indicate service differences.

That families focus on telling the story, even when that was not what was asked, may also indicate a reliance on a safer narrative, and avoidance of discussing the more emotional or personal experiences of their difficulties. Literature describes patients and carers using avoidant coping to deal with the difficulties they have experienced. This type of coping has

been described as “sealing over” in patients with schizophrenia, and it is possible that families have similar coping styles (Tait *et al.*, 2004). There is evidence in the interviews that families had not previously discussed the issues raised, and found them uncomfortable.

Sudden realisation

While participants describe symptoms as coming on suddenly, they also describe longer held concerns about the person and their behaviour previous to the time of referral. There is evidence that suggests Asian families refer children earlier than other families (Birchwood *et al.*, 1992), and this study’s findings are inconsistent with this. However, it is possible that families in this study do not refer to the prodromal period as part of the illness. Services should therefore consider that patients may have been ill for longer than families suggest. There is also anecdotal evidence to support Commander *et al.*’s (1997) study, which found that Asian families did access the GP, but delay occurred before they were referred on to specialist services.

Hope Disappointed

While the journey from initial optimism to a loss of hope may be a common part of the long-term carers’ experience, nonetheless it is interesting that some participants felt the EIS encouraged this optimism. While this may have been helpful where recovery occurred (for example for the Khan family) for others it seemed to increase the sense of disillusionment with the service.

Many families increasingly placed the SU in a sick role. This was apparent in parents’ changed expectations and concerns that the service user should “take it easy”. It is also shown in the third theme, where families describe their new role as “keeping them happy”. While this can be helpful for the family, as it places the SU in a role with which they are familiar, it may not support SU’s recovery. In a study of Asian EI service users (Latif *et al.*,

2004) SUs described families as unable to recognise recovery, and found this permanent sick role constraining and frustrating.

Worry and Loss

Participants described a strong sense of worry for the SU, which permeated family life. Further, parents in particular experienced significant loss and sorrow both for the service user's present and future life, but also for themselves and their lost hopes. These feelings are not unique to these participants and are similar to the descriptions given in other studies by families living with schizophrenia. Saunders and Byrne (2002) for example described carers' "overwhelming feelings" of depression, bewilderment, devastation and hopelessness. Tuck et al's (1997) American study indicated parents grieved for the loss for themselves as well as their child.

The construct of chronic sorrow seemed to fit well with families' experiences. Originally used to describe the situation of people experiencing terminal illness (Mayer, 2001) more recently it has been applied to their carers and to the carers of people with learning disabilities. This construct describes sorrow and loss, which is repetitive and progressive in nature and likely to intensify following initial feelings of disillusionment, loss or apprehension. It is partly the lack of a predictable outcome that is difficult for people experiencing this. The construct also fits with families' understandings because it is seen as a normal response (unlike depression) to the loss of normality in the life of the impaired individual or caregiver. These carers' experiences of schizophrenia do hold many similarities with the experience of carers of people with other long-term difficulties. As services begin to consider support for carers models such as that of chronic sorrow may be useful.

Theme 2: A Social Illness

The families described the SUs' problems as both primarily caused by, and defined through, social interaction. Participants also identified that black magic could be a factor in illness, and that prayer and spiritual approaches were important. In a community survey researching Asians beliefs about mental illness, Hatfield *et al.* (1996) found very similar themes. Participants believed mental illness had three main causes; social stress, family problems and the will of God; closely reflecting the beliefs of participants in this study. This also reflects Malik's (2000) and Tabassum et al's (2000) findings that Pakistanis are more likely to view mental illness as caused by external events, and many believed that faith and worship was an important part of treatment.

Illness Has a Social Cause

We can hypothesise two reasons for participants privileging a social cause for what is occurring. The first is that this fits with their general model of illness. A number of studies highlight social explanations for distress prioritised over medical explanations within the Asian communities (Hatfield *et al.*, 1996, Tabassum *et al.*, 2000).

Alternatively, families may not be familiar with the EIS's model of psychosis. They are therefore using explanations familiar to them to understand what has happened. Families did not in general describe being given explanations by the EIS. One participant (Miss Shah) did feel she was given an explanation, but this was at the time of first diagnosis, and this may have been too much information to take in. It seemed that for this information to be beneficial it would have helped to repeat it at a later time.

Absence of Psychiatric Explanation

In the interviews families described the difficulties in terms of the SU's social interaction and behaviour more than, for example, experience of delusions and hallucinations. There are a number of possible reasons why this might be. It may be that behavioural symptoms were viewed as more important. There is evidence that different cultural groups present with different symptoms of distress (Bhugra *et al.*, 2000). Within Pakistani culture there is an emphasis on young people conforming to set social norms and a focus on the importance of the individual's integration within the community, as opposed to their internal emotional world (Furnham and Malik, 1994). Families therefore may simply be focusing on the aspects of the SU's behaviour that are most difficult for them to understand, or are most important to them. Greenwood *et al.* (2000) and Tabassum *et al.* (2000) also noted a preference within the Pakistani community for defining "mental illness" as behavioural problems or depression. Further, social isolation and lack of communication may also be the most difficult problems for families in the longer term. Studies suggest that it is the negative and social elements of psychosis which families often find hardest to understand or cope with (Scazufca & Kuipers, 1997).

Milstein *et al.*'s (1995) American study indicated that non-white carers are 50% less likely to use the term schizophrenia to describe a relative's problem. One explanation for this is that this term doesn't fit with language. The term for madness in Urdu/Mirpuri is "pagal", which means "a lunatic" or "crazy". It is a stigmatised term that also indicates permanence (Wheeler, 1998). Those labelled as "pagal" are often isolated from family discussions and normal roles. It may be therefore that families avoid describing symptoms that would be seen as describing pagal. This also may explain why terms such as mental illness and schizophrenia are not used by older participants, as these are often translated as pagal.

This difficulty with language seems to have been compounded by the EIS's lack of communication regarding what they mean by "mental illness". Carers had very little understanding of the service, despite the fact that one of the primary aims of the EIS is to engage, educate and support families (McGorry *et al.*, 2001). Services need to make steps to communicate with families, and further be aware of the differences in language and understanding about mental illness.

Theme 3: Treatment and Change

Families considered a range of apparently contradictory treatments. Research suggests that within Asian cultures different causes and treatments are viewed as complementary, and part of a holistic whole, rather than in conflict (Weiss *et al.*, 1984). Participants support this view; they not only considered and accessed spiritual and medical treatments, but they also considered that the illness could have concurrent medical, social and spiritual causes. For example, the Ahmed family first took their son to see a molvi, and he suggested they should also go to the doctor. The Saeed family took their son to Pakistan for a year to seek spiritual treatment, but made sure he had access to medication whilst there. Other studies have found similar attitudes to treatment Hatfield *et al.* (1996) for example, found that families support religious based treatments as well as asking for social support. It is important for services to be aware therefore that some Pakistani families will access medical treatment alongside not instead of other forms of treatment.

Treatment and support through faith

Older participants in particular located religion as central to their understanding of what had happened, and as support and treatment. Treatment using Islamic methods was advocated and tried by a number of families; it was seen as a way of addressing inexplicable problems, partly because most families did not feel that medication provided a "cure".

Previous studies indicate that Asian patients in the UK will advocate and access traditional or spiritual treatments (Dein & Sembhi, 2001 and Hatfield *et al.*, 1996). As in Greenwood *et al.*'s study (2000) carers did not perceive medical explanations and their cultural explanations of mental illness in competition with one another, but as complementary.

Religious belief may also be an outlet for some family members' distress. Evidence suggests carers with spiritual beliefs can find caring less stressful (Johnson, 2000, Mir & Tovey, 2003). Where families consider that the illness is caused by black magic they may be able to view the problem not as meaning some deficit within the individual or family, but as due to a malicious external force. Further, this alternative model of causation may allow families to maintain hope in the possibility of recovery through spiritual or religious cures, where medical treatments do not appear satisfactory.

EIS is just about medicine

Younger participants in particular wanted better communication and more of a dialogue with the EIS. This fits with the model of early intervention, which is meant to view families as "*allies in the fight against a potentially severe but treatable mental illness*" (Linszen & Birchwood, 2002 page 271). However, this is not how families viewed current service provision. Families described the EIS as primarily (or totally) about medicine. As medicine was not viewed (except by the Khan family) as "curing" the problem, the service too was only seen as partially effective. A significant role for EISs is engaging patients in meaningful social activity and providing family support (NICE, 2002). Participants did not seem to be aware of what the EIS should offer. While some participants were offered social activities, or given this at first, they didn't feel that this continued or was sufficient. No family reported being offered any formal family work. It is not clear whether this was the case only for Asian families or more universally within the service.

Some families expressed difficulty with communication and access to interpreters. Mrs Khan did not want an interpreter, but would have liked a worker who was able to speak her language. This request was also found by Greenwood *et al.* (2000). The study suggests that in most cases family members were relied on rather than interpreters or bilingual workers, which can put significant strain on younger family members. Appa Saeed and Miss Shah both described taking significant responsibility for their brothers and liaison with services because their mothers did not speak English.

There are other studies that indicate Asian patients may be less satisfied with mental health services, for a number of reasons, including some of the concerns mentioned by our participants. Parkman *et al.* (1997) found that Black patients born in the UK were significantly less satisfied with services than white patients. McGoven (1994) suggested that Asian service users are less engaged with services. This study suggests that new community based services may also be failing to engage minority communities.

Care is the families' responsibility

All families discussed the support of close family more than extended family. Some even found extended family unhelpful. This supports the findings of Katbamna *et al.* (2004) who found Asian carers often report a lack of social support, and challenges the widespread assumption that Pakistani families can draw on a wide range of extended family support.

The concept of family responsibility could link to the subordinate themes of worry and loss. Families' perception that the SU's recovery is their responsibility could lead to self-blame and anxiety. Other carers also describe this sense of responsibility (Tuck *et al.*, 1997). However, carers in Tuck *et al.*'s study also emphasise their own needs and loss of identity, and these themes are absent in this study. Rather, parents in particular seemed to be subsuming their own needs into the needs of the SU. Cultural differences in the role of family and

expectations about care (especially from women) may be significant here. Lastly, this sense of families taking responsibility may in part be due to a lack of choice. Participants did not feel that the EIS communicated with them and they were unaware of other support or services.

6. Clinical Implications

These findings have important implications for EISs in particular, and for mental health services in general. Participants highlight some concerns that are likely to be general to all carers, and others that reflect different cultural perspectives and issues.

Dissatisfaction with the EIS was based around lack of communication, both about what it could offer, and about what to expect of the illness. Communication with carers is often highlighted in research (Saunders & Bryne, 2002) and is vital regardless of culture. Better communication with families might have included sharing the service's bio-psycho-social model of illness. Participants either did not know the service's model, or felt it was purely medical. Participants favoured a social explanation of the SU's difficulties, which might have fitted well with the EIS's philosophy, if this had been adequately explained. This lack of communication with families meant less support for the EIS from carers, which might have had an impact on SU compliance.

Some difficulties with communication seemed to be specifically cultural. Services are obliged to provide access to interpreters, and to attempt to reach hard to access groups, such as non-English speakers. The Government's paper "The Duty to Promote Race Equality" (2002) states that organisations have a duty to ensure that; "*(...) everyone, whatever their racial group, can get information about your authority and its services. In practice you may have to identify and focus on people who do not appear to know about your work or your services, or who face barriers accessing it, such as language barriers.* (p. 46)

This study found when interpreters were used it was mainly to gain information, not to inform or support families. This has a number of implications. Firstly, this meant that the EIS was in many cases ignorant of the concerns and needs of families. Further, in many cases the service relied on female siblings to communicate with the family. Not only was this difficult for them, but younger family members often held different models of illness and beliefs about treatment than their parents. Thus non-English speaking family members were isolated still further from the service and from the service's understandings, and in turn the service was ignorant about their views.

Communication and a shared understanding of the illness between carers and the service is essential in ensuring consistent support for the SU. The lack of trust and communication between families and the EIS seems to have impacted on this. In some families carers even encouraged the SU to not take medication. Thus the carers' influence on the SU's treatment should not be underestimated.

Many families in this study experienced great difficulties due to the SU's illness, and participants were experiencing significant loss and sorrow. It is important for EISs to be aware of the level of responsibility which families take, and the stress this might place on family members. EISs are meant to support families, and offer therapeutic approaches, and this may have been helpful for many of the participants. However, no participant mentioned this as occurring.

The routine use of interpreters who are familiar with the needs of the service would support better communication with families. Ideally, recruitment of workers from Asian backgrounds would support families who feel reluctant to use an interpreter. Further, all EIS

staff need to be aware of the needs of this client population, and the beliefs of their carers. Support and explanations should be offered to all family members.

Clinical Psychology works both with patients and their families, and is an important part of the EIS approach. However, no participant had heard about psychologists' role. Many participants mentioned the value in talking about what had happened, both for the SU and the family. However, it also seemed that in many families there were difficulties in talking about these issues without support. Psychology would be beneficial in addressing this and Clinical Psychologists should consider their role in trying to help meet the needs of this group.

7. Critique and Limitations

The research as a whole was considered in light of criteria set down for good qualitative research (Elliott *et al.*, 1999). The research clearly contributes to knowledge in a field where there has been little research. It has implications for services, and for our understanding of ethnic minority carers. The methodology and aims of the study were also clearly defined. Care was taken to ensure the informed consent and confidentiality of participants.

Qualitative methodologies accept that the research is the product not only of the participant, but also the subtle interplay between all involved in the interview. The researcher's own understandings and perspective will therefore influence the analysis of the data. The researcher, as a visibly Muslim woman, was aware of the impact her faith, gender, cultural and social background would have on the process and reflected on this through the use of supervision and the research log. This is examined in more depth within the critical appraisal.

Information about each participant and a detailed family tree was used to situate the sample. A number of credibility checks were used, particularly “auditing” the analysis through a research group and through supervision. Given further time it would also have been useful to have discussed the research findings with the participants after analysis. Within the report themes were clearly grounded within examples from the text and it is hoped the thematic analysis provides a coherent account which makes sense for, and resonates with the reader.

The study was able to gain a rich and complex understanding of families’ views about psychosis, and their attitude towards early intervention services. The qualitative methodology was well suited to accessing this kind of complex understanding. Families cannot be said to be representative of other Asian, or even other Pakistani carers. Nonetheless, the study’s themes have been supported by other research, and share some important similarities of experience and perception.

There are difficulties and risks associated with using interpreters in interviews, and with using translated data. It is arguable that during this process the participant’s voice is altered, and the meaning can be influenced. However, without using interpreters four of my participants would not have been heard in this research. By translating all the texts, rather than relying on the interpreter’s summary a better understanding of the participants’ view was possible. These participants provided an understanding of the experience of carers who cannot communicate directly with the service, and are reliant on their family to filter information. These carers also contributed to a deeper understanding of many of the themes, especially the role of faith and worship.

8. Further Research

This is an area that deserves further research. A parallel study has been undertaken to examine the views of Asian service users, (Latif *et al.*, 2004) and it will be useful to consider the findings of the two studies together. It also would be interesting to extend this study by examining the views of carers from different cultural groups, and the implication of different needs and beliefs to service provision. There are important initial ideas in this study about how different understandings of psychosis can aid or hinder coping, for example in how hope and a sense of control was maintained for some carers and not for others. A better understanding of this could influence how services explain psychosis (and other long term conditions) to families, and the kind of support they offer.

9. Conclusion

Overall, the research has begun to fill a substantial gap in the literature. The study aimed to examine the view of carers from the Pakistani community towards psychotic illness and its treatment through an EIS. Although the findings cannot be said to be representative of all Pakistani families, steps towards a better understanding of these issues were made. The data have tapped a rich source of understanding both in the differences and similarities in Pakistani carers' beliefs. The research has implications for our understanding of psychosis and the language of mental illness. It also provides practical information about how services can better access and support carers from minority communities. In an increasingly multi-cultural Britain this type of research allows a better understanding of different community views, requirements and strengths.

10. References

- Bhugra, D. (2002). Ethnic factors and service utilisation. *Current Opinions in Psychiatry*, 15(2), 201-204.
- Bhui. K., Stansfield, S., Hull, S., Priebe, S., Mole, F. & Feder, G. (2003). Ethnic variations in pathways to and use of specialist mental health services in the UK: A systemic review. *British Journal of Psychiatry*, 182, 105-116.
- Birchwood, M., Cochrane, R., Macmillan, F., Copestake, S., Kucharska, J. & Cariss, M. (1992). The influence of ethnicity and family structure on relapse in first-episode schizophrenia. A comparison of Asian, Afro-Caribbean and White patients. *British Journal of Psychiatry*, 161, 783-790.
- Commander, M.J., Cochrane, R., Sashidharan, S.P., Akilu, F. & Wildsmith, E. (1999). Mental health care for Asian, black and white patients with non-affective psychosis: Pathways to the psychiatric hospital, in-patient and after care. *Social Psychiatry and Psychiatric Epidemiology*, 34, 484-491.
- Commander, M.J., Sashidharan, S.P., Odell, S.M. & Surtees, P.G. (1997a). Access to mental health care in an inner-city health district. I: Pathways into and within specialist psychiatric services. *The British Journal of Psychiatry*, 170(4), 312-316.
- Commander, M.J., Sashidharan, S.P., Odell, S.M. & Surtees, P.G. (1997b). Access to mental health care in an inner-city health district. II: Association with demographic factors. *The British Journal of Psychiatry*, 170(4), 317-320.

Dein, S. & Sembhi, S. (2001). The use of traditional healing in South Asian psychiatric patients in the U.K.: Interactions between professional and folk psychiatries. *Transcultural Psychiatry*, 38(2), 243-257.

Department of Health (1999). *A National Service Framework for Mental Health*. London: The Stationery Office.

Department of Health (2000). *The NHS Plan*. London: The Stationery Office.

Department of Health and Home Office (2000). *Race Relations Amendment Act*. London: The Stationery Office.

Elliot, R. (1995). Therapy process research and clinical practice. In M. Alverlene & D.A. Shapero (Eds.) *Research foundations for psychotherapy practice*, (pp. 49-72). Chichester: Wiley.

Elliott, R. Rischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for the publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.

Furnham, A. & Malik, R. (1994). Cross cultural beliefs about "depression". *The International Journal of Social Psychology*, 40(2), 106-123.

Greenwood, N., Hussain, F., Burns, T. & Raphael, F. (2000). Asian in-patient and carer views of mental health care. *Journal of Mental Health*, 9(4), 397-408.

- Gupta, S. (1992). Psychosis in Asian Immigrants from the Indian Sub-Continent. *Social Psychiatry and Psychiatric Epidemiology*, 27, 242-244.
- Hatfield, B., Mohamad, H., Rahim, Z. & Tanweer, H. (1996). Mental health and the Asian communities: A local survey. *British Journal of Social Work* 26, 315-336.
- Hussain, F. & Cochrane, R. (2004). Depression in South Asian women living in the UK: A review of the literature with implications for service provision. *Transcultural Psychiatry*, 4(2) 253-270.
- Johnson, E.D. (2000). Differences among families coping with serious mental illness: A qualitative analysis. *American Journal of Orthopsychiatry*, 70(1), 126-134.
- Katbamna S., Ahmed, W., Bhakta, P., Baker, R. & Parker, G. (2004). Do they look after their own? Informal support for South Asian carers. *Health & Social Care in the Community*, 12(5) 398-406.
- Katbamna S., Bhakta, P., Ahmed, W., Baker, R. & Parker, G. (2002). Supporting South Asian carers and those they care for: The role of the primary health care team. *British Journal of General Practice*, 52(477), 300-305.
- Karim, S., Saeed, K., Rana, M.H., Mubbashar, M.H. & Jenkins, R. (2004). Pakistan mental health, country profile. *International Review of Psychiatry*, 16(1-2), 83-92.
- Latif, S., Newton, L. & Larkin, M. (2004, July). *Asian service-users' views and experience of early intervention*. Paper presented at the Interpretative Phenomenological Analysis (IPA) 6th Conference, Nottingham, UK.

- Linszen, D. & Birchwood, M. (2002). The early phase of psychosis and schizophrenia: A critical period for patients, families and the profession. In M. Birchwood, D. Fowler & C. Jackson (Eds.) *Early intervention in psychosis*, (pp. 261-280) Wiley: Chichester.
- McGorry, P.D., Yung, A. & Phillips, L. (2001). Ethics and early intervention in psychosis: keeping up the pace and staying in step. *Schizophrenia Research*, 51(1), 17-29.
- McGoven, D. & Hemmings, P. (1994). A follow-up of second generation Afro-Caribbeans and white British with a first admission diagnosis of schizophrenia: Attitudes to mental illness and psychiatric services of patients and relatives. *Social Science Medicine*, 38(1), 117-127.
- McKenna, P.J. (1994). *Schizophrenia and related symptoms*. East Sussex: Psychology Press.
- Malik, R. (2000). Culture and emotions: Depression among Pakistanis In C. Squire (Ed.) *Culture in psychology*. (pp. 147-162). London: Routledge.
- Mayer, M. (2001). Chronic sorrow in caregiving spouses of patients with Alzheimer's Disease. *Journal of Aging and Identity*, 6(1), 49-60.
- Milstein, G., Guarnaccia, P. & Midlarsky, E. (1995). Ethnic differences in the interpretation of mental illness: Perspectives of caregivers. *Research in Community and Mental Health*, 8, 155-178.
- Mir, G. & Tovey, P. (2003) Asian carers' experiences of medical and social care: The case of cerebral palsy. *British Journal of Social Work*, 33, 465-479.
- Modood, T., Berthoud, R., Lakey, J., Nazroo, J., Smith, P., Virdee, S. & Beishon, S.

(1997). *Ethnic minorities in Britain: Diversity and disadvantage*. London: Policy Studies Institute.

National Institute For Clinical Excellence (2002). *Schizophrenia: Core interventions in the treatment and management of schizophrenia in primary and secondary care*. London: NICE.

Newton, E. & Birchwood, M. (2005). Early intervention in psychosis: From research to reality. In D. Sallah & M. Clark (Eds.) *Research and development in mental health*. London: Elsevier.

Parkman, S., Davies, S., Leese, M., Phelan, M. & Thornicroft, G. (1997). Ethnic differences in satisfaction with mental health services among representative people with psychosis in South London. *The British Journal of Psychiatry*, 171(9), 260-264.

Reid-Galloway, (2003). *Mental health of the Asian community*. London: Mind Information Unit.

Sartorius, N., Jablensky, A., Korten, A., Ernberg, G., Anker, M. & Cooper, J.E. *et al.* (1986). Early manifestations and first-contact incidence of schizophrenia in different cultures. *Psychological Medicine*, 16, 909-928.

Sashidharan, S.P. (2001). Institutional racism in British psychiatry. *Psychiatric Bulletin*, 25, 244-247.

Saunders, J.C. & Byrne, M.M. (2002). A thematic analysis of families living with schizophrenia. *Archives of Psychiatric Nursing*, 16(5), 217-223.

Scazufca, M. & Kuipers, E. (1997). Impact on women who care for those with schizophrenia. *Psychiatric Bulletin*, 21(8), 469-471.

Shaw, R. (2001). Why use interpretative phenomenological analysis in health psychology? *Health Psychology Update*, 10(4), 48-52.

Shaw, R., Wallace, L.M. & Bansal, M. (2003). Is breast best? Perceptions of infant feeding. *Community Practitioner* 76(8), 299-303.

Smith, J.A. (1995). Semi-structured interviewing and qualitative analysis. In J.A. Smith, R. Harre & L. Langerhove (Eds.) *Rethinking methods in psychology* (pp. 9-26). London: Sage.

Smith, J.A., Jarman, M. & Osborn, M. (1999). Doing interpretive phenomenological analysis. In M. Murray & K. Chamberlain (Eds.) *Theories and methods* (pp. 218-240) London: Sage.

Stirling, J., Tantum, D., Thonks, P., Newby, D. and Montague, L. (1991). Expressed emotion and early onset schizophrenia. *Psychological Medicine*, 21, 675 – 685.

Stueve, A., Vine, P. & Stuenkel, E.L. (1997). Perceived burden among caregivers of adults with serious mental illness: Comparison of Black, Hispanic and White families. *American Journal of Orthopsychiatry*, 67(2), 199-209.

Tabassum, R., Macaskill, A. & Ahmed, I. (2000). Attitudes towards mental health in an urban Pakistani community in the United Kingdom. *International Journal of Social Psychiatry*, 46(3), 170-181.

Tait, L., Birchwood, M. & Trower, P. (2004). Adapting to the challenge of psychosis: Personal resilience and the use of sealing-over (avoidant) coping strategies. *British Journal of Psychiatry*, 185, 410-415.

Temple, B. (2002). Crossed wires: Interpreters, translators, and bilingual workers in cross-language research. *Qualitative Health Research*, 12(6), 844-854.

Temple, B. & Edwards, R. (2002). Cross language research. *International Journal of Qualitative Methods*, 1(2), 2-22.

Tuck, I., du Mont, P., Evans, G. & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing*, 11(3), 118-125.

Weiss, M.G., Sharma, S.D., Gaur, R.K., Sharma, J.S., Desai, A. & Doongaji, D.R. (1986). Traditional concepts of mental disorder among Indian psychiatric patients. *Social Science and Medicine*, 21(4), 379-386.

Wheeler, E.L. (1998). Mental illness and social stigma: Experiences in a Pakistani community in the UK. *Gender and Development*, 6(1), 37-43.

Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University Press.

Section C: Critical Appraisal

My reflections about the process of the research form the basis of this critical appraisal.

The main source for this is my research diary, which was kept throughout the process and included initial ideas and preconceptions, immediate responses to the interviews, transcription and analysis, as well as reflections on my influence on the research.

1. Origins and Planning

The Early Intervention Service themselves highlighted the need for research, because they were aware that Asian families were not accessing their services in the same way as English families, and wanted to know why. Doing research to investigate this cultural group and their response to services interested me mainly because it seemed that the service was open to considering the implications of the findings and I consider it of primary importance that research is used to influence service provision.

Research in this area also attracted me because I have some familiarity with the participant groups. I worked with people with a diagnosis of schizophrenia before clinical training. Further, I have always had an interest in working with minority communities. During training I became aware that ethnic minority communities, and the British Asian community in particular, have not always been able to access Clinical Psychology services in a way that meets their needs. Therefore research into the needs of this group appealed to me.

The role of carers is increasingly important in the NHS, but my clinical experience suggested that it was often only the more articulate or assertive carers who were able to access support from services. I also found that there was little research into the needs of carers from ethnic minorities. The participants in this study therefore were a very poorly researched

group. While it was challenging to research an area that was so little understood, it was also an exciting proposition.

2. Qualitative Methodology

Although I did not have previous experience of using qualitative methods, it became clear that this was the most relevant methodology for the research question. Practically, this is an area where very little research has been done, and therefore a methodology that avoids prior assumptions was seen to be more appropriate (Reid *et al.*, 2005). Also it was both impractical and inadvisable to use measures standardised on a white English population on a non-English speaking and culturally different population, (Turpin *et al.*, 1997). Lastly, I felt convinced that qualitative methods are more suitable to researching people's complex and sometimes contradictory understandings of an event (Shaw, 2001).

Different qualitative techniques suit different research questions, and Interpretative Phenomenological Analysis (IPA) seemed particularly well suited to my area of interest. The focus of IPA is the meanings constructed by a person of their situation and social world, rather than attempting to understand an event itself (Smith, 1996).

IPA has an open epistemological stance, but suits a "critical realist" position (Madill *et al.*, 2000). IPA used in this way finds a balance between a purely "realist" and a social constructionist position; it is able to acknowledge the role of the interaction between participant and researcher and consider the process, but also accept that a "real" experience that is being described (Reid *et al.*, 2005). Therefore, unlike Discourse Analysis, the model allows for application of findings at a clinical level. This also worked well with my personal epistemological position.

In order to become familiar with the model I attended an IPA conference, which gave me a greater understanding of the process from interviewing to analysis, and allowed me to consider the epistemological considerations. There were also pragmatic reasons for choosing IPA, due to my field's supervisor's expertise in the area. The disadvantage of using IPA was that, although it is the method of choice in a number of Clinical courses, Leicester trainees use it relatively rarely.

3. Participants and Recruitment

Most studies of carers have accessed the "primary carer" (e.g. Greenwood, 2000); this often means accessing mainly older women. However, I was interested in considering the impact of psychotic illness in the family on different generations and genders. This decision seemed to have been supported by my research findings, which suggests differences between generations and within families. It also highlighted the roles and responsibilities often taken by service users' sisters, especially in families where English was not spoken confidently by parents.

I had planned to interview at least eight participants, from at least four families, as eight is the recommended minimum standard for doctoral qualitative research (Turpin *et al.*, 1997). As in most families it was difficult to access more than one or two family members, I had trouble accessing enough Pakistani participants. If more participants from each family had been accessed this might have enabled a more detailed understanding of intra-family differences. At one point I had to consider accessing families from different Asian backgrounds. I resisted this, as I felt that a major critique of previous research was the assumption of a universal Asian culture. Studies suggest that there are in fact significant cultural, religious and social differences between these groups (Hussain *et al.*, 2004). In IPA, as opposed to Grounded Theory, it is recommended to attempt to sample a fairly cohesive

population. By accessing a different key worker I contacted the final family I needed, and was able in all to access eleven participants.

The main difficulty I encountered in recruitment was in accessing male participants. This was particularly the case with brothers of service users, who were generally less involved in care, and seemed to be perceived by other family members not to understand, or have a useful contribution to make to the research. This can be seen in the following conversation with Mr Mirza, where the researcher is asking him if his sons might also be interested in being interviewed:

Interviewer: *Would be it be possible for me to come back and talk to one of his sons?*

Interpreter: *Can she talk to any of your sons at a later date?*

Mr Mirza: Yeah, but they work. They have bus duty.

Interpreter: He says he will ask his son, if they want. He works on the buses.

Interviewer: *I can come at any time really. I will leave some information for your son to read*

–

Mr Mirza: He speaks English

Interpreter: He says his sons -

Mr Mirza: He is useless with helping as he know nothing about this, so he won't be helpful.

Interpreter: He won't be able to help you about the service, because he doesn't know about it.

Mr Mirza: When he is free from the bus duty, he just goes out and won't be helpful.

Interpreter: He says that he goes to work on the buses and when he comes home he just goes out with his friends and he won't be able to help you much.

A number of factors seemed to contribute to the difficulty in accessing men. Although this was not explicitly said, I felt that the caring role was viewed by many as primarily a female

role, and also family concerns were felt to be the domain of women. However, fathers I interviewed did seem very concerned about their children, and took an active role in planning their care. Practically, in many of the families men were self employed and worked long hours; they may therefore have been reluctant to sacrifice their limited free time to do an interview. Further, Muslims are often reluctant to be interviewed by someone of the opposite sex, especially if this means being alone with them. Other researchers have found using an interviewer of the same sex as participants is necessary (e.g. Hatfield *et al.*, 1996). It might have been beneficial therefore to have used a male interviewer with some participants.

The extract from Mr Mirza's interview above highlights a further issue that affected recruitment, which was the role of senior family members in deciding who should be interviewed. It was important for me, despite my keenness to talk to more people, to reflect on the reasons why family members might be reluctant to be interviewed. I was clearly asking participants to consider and discuss issues that were very difficult for them, and in some cases they had not talked about before. I had to consider the impact on families of pushing them to discuss their feelings, or to express different views from each other, when I was aware they did not have access to formal support. Further, some families felt that they did not have, or did not want to describe, different perspectives, but instead wanted their views represented by one family member. These beliefs had to be respected.

I was aware that qualitative research can be a slow process and therefore began interviewing in March 2004; the interviews were finished just before the Muslim holy month of Ramadan in October 2004. It was felt to be important to finish before this month, as families are busy during this time; people are mainly fasting in the day, eating together and going to night prayers in the evening. Finishing interviewing early also allowed me enough time to get the non-English parts of transcripts translated, which was a time consuming process. Further, it gave me longer to complete and reflect on my analysis.

4. Interviewing Non-English Speakers

A decision was taken early on in the process not to exclude non-English speakers. Large numbers of Pakistani people do not speak English, or speak only little. They are more likely to be older and more likely to be female. In four out of the six families I interviewed at least one of the close family members did not speak English; excluding them would have been to lose an important and often un-heard voice. While this has to be balanced with both the practical and theoretical difficulties of doing qualitative research using interpreters, it seemed to me that these were people whose perception would otherwise never be accessed by research or by services.

The need to give people the choice to be interviewed in their first language is supported in the literature. In one study (Fenton & Sadiq-Sangster, 1996) one Asian participant comments about being interviewed in her own language: *“I can explain myself in English somewhat but I can’t tell you how I am feeling – what is in my heart – as I am doing to you now – all the small things in our language. I can’t say how I am feeling in my heart ... I can’t get the right words.”* For participants to describe complex and emotionally loaded issues in their own language is difficult, but in a second language it is far harder. In my interviews, despite translation, some of the most eloquent interviews are those using an interpreter. This contrasts with some of the first generation participants who chose to use English, (such as Mrs Rehman or Mrs Khan) whose interviews are more stilted.

Using interpreters did make the research more complex and time consuming. This was particularly the case as I decided to translate the texts. As well as considering the issue in supervision, I discussed the methodology with a qualitative researcher who had published IPA with non-English speakers (Rachel Shaw). She agreed that using translated texts would

allow a richer analysis of the data. Having the translated version and the interpreter's version of what was said also gave a better understanding of confusing or difficult phrases used by participants. Further, it allowed the researcher to see the extent to which the interpreter departed from what was said by the participants.

I also had to plan extra time to arrange for interpreters and translation into my timetable. Funding had to be agreed with the NHS trust, as the course was unable to cover the substantial costs of getting texts translated. Finding suitable translators and interpreters also took time. The agency used by the NHS trust for translation did not seem to fully appreciate the importance of confidentiality, and suggested the translator could listen to the interview on a tape while in a public office! I therefore chose to use other translators, and asked them to sign a confidentiality form. I also decided to pay translators for the time they took, rather than by line translated. This was in order to encourage them to take their time and ensure more accurate translation.

5. Approach to Interviews and confidentiality

While interviewing I had to be very sensitive to, and reflective about, my position as both a researcher and a guest in Pakistani family homes. As a Muslim and a psychologist I was deeply aware where these roles conflicted, and discussed these concerns in supervision. For example, families would offer me tea and sometimes food, which I did accept, and on one occasion a child came and sat on my lap. Allowing this to occur might be viewed as compromising my position as a researcher. However, to reject these things would have been viewed by families as very rude.

Further, some participants (particularly older people) seemed to need to know a little about me before the interview. This may have been partly because they were sharing so much

about themselves and partly curiosity. However, it also seemed to me that it was on some occasions also about confidentiality. As a Muslim interviewer, participants may have been concerned about whether I might be connected with their local community. Therefore people often asked me if I was married, if my husband was Pakistani and where we lived. Although I did not volunteer information, I was happy to inform participants when asked that both my husband's family and I lived outside Birmingham, and this did seem to reassure people.

Within families maintaining the individual confidentiality of interviews was my greatest challenge. While I discussed with participants my concern that interviews should be private, this was often difficult. Firstly, many family homes were small and I was interviewing in the main living area. Secondly, families did not in general hold the western perspective on individual privacy, possibly because they felt that information should not be private from other family members. In fact, sometimes other family members would be consulted, or would add comments, as this extract from the interview with Appa Saeed suggests:

Interviewer: *It's meant to be only for people who are young, that get that service.*

Appa Saeed: OK. No, I don't think they are good at all then, I'm sorry, you can put that down in black and white! [speaks in Urdu to mother] They don't even come down, ask, or anything. Blood tests and medicine, that's it.

Interviewer: *Yeah.*

Appa Saeed: That's the only thing. [Answers mothers question in Urdu] Yeah, she's saying, you know like with the team, she reckons that he - if anything he's just gone worse...

During interviews people came in and out of the room, and on some occasions this included the service user. On one occasion (the Shah family) this clearly limited what they and I felt able to talk about, and I therefore offered to interview outside the home. With other families it seemed unlikely that participants would have been willing or able to be interviewed

elsewhere, due to family commitments. The limitations brought by lack of privacy therefore need to be balanced against accessing participants who might otherwise be reluctant to be interviewed.

I was asked to discuss cross-cultural interviewing in a symposium about cross-cultural research at the IPA conference (Nottingham, July 2004). As this took place while interviews were ongoing, it allowed me to reflect further on the process of interviewing.

6. The Reflective Process

It is important in qualitative research for the researcher to own their personal and intellectual position with regards to the research (Elliott *et al.*, 1999). As a British Muslim I felt a strong affinity to the community I was interviewing, which was increased by my family connections with the Pakistani community. I held an expectation that culture and spirituality was likely to be important in participants' understandings of mental illness. Through my clinical experience I felt that cultural difference was often not fully considered by NHS services, and that this has led to minority communities not fully accessing or benefiting from services. I also believe that minority communities should be able to access mainstream services, rather than relying on voluntary community services. This perspective was one of the reasons I was interested in the research, and will also have influences how I understood participants' experiences. During the research process I was constantly aware of the dynamic relationship between my own perspective and the participants' views, which impacted on what was said in interviews and how I interpreted this.

However, through the research, I was also aware of my differences from my participants, in my experience as a white woman and in my position as a psychologist and "professional". This was most evident to me in considering families' perception of the role of black magic in

mental illness, which was not something I initially understood. During analysis I was very aware of my own interpretive framework, and this led me to question my role in the construction of my findings. This was especially the case in areas where I held strong views, such as the role of spirituality.

I also often considered in supervision how participants might view me and the impact this might have on the research. I emphasised to participants that I did not work for the Early Intervention Service, yet I was a professional. I was not Pakistani in origin, but was visibly Muslim, and that may have influenced how some participants saw me. Older female participants often took an interested, almost protective stance towards me. Mrs Rehman insisting I call her when I reached my home, as the interview was in the evening, and Mrs Ahmed commented (in Pashtu) to the interpreter “*She is a nice woman too, because she is a Muslim Alhamdulillah [praise God]*”. Thus there was, as is always the case with cross-cultural research, an interplay between our similarities, differences, and how we chose to view these (Egharevba, 2001).

It was important for me to think about these issues from a reflexive perspective; considering how I as the interviewer influenced the participants’ responses both in how I appeared and what I chose to say or not say (King, 1996). My position as a Muslim may have engendered more trust in me as a researcher for some participants. It is possible that topics such as black magic and prayer might not have been brought up if the interviewer had not been Muslim. However, how families viewed me might also have limited what participants told me, for example, not wishing to say anything which sounded irreligious.

The study also highlighted to me issues of power difference. I have mentioned the role of gender in recruiting participants, and gender also seemed to play a role in how the interviews were experienced. There seemed to be a familiarity and comfortableness for most female

participants in discussing family difficulties with another woman. This was especially the case with younger women, and interviews often felt more natural with this group. Interviews with men were more formal; male participants seemed less willing to open up especially about emotional responses, and this may have been in part because of gender differences, as well as cultural understandings of gendered roles.

Class and cultural differences also played a significant part in the research. My ethnic background, professional status and education could make participants feel intimidated, or increase their feeling that I would not understand their situation. The fact we were meeting in participants' homes, which in many cases were in deprived areas, to discuss issues which were very private and (some participants felt) potentially shaming to them gave me access to a lot more information about them than they had about me. This again put me in a very powerful position and may have impacted on how participants felt about the research. Considering these power imbalances allowed me to better understand families' need to control who I talked to, and to find out more about my personal situation, as mentioned above.

During and after the interviews participants' stories affected me significantly. Participants were often deeply upset and, even when this was not expressed in words but in silences, this affected me. In fact, in some of the interviews I felt as an interviewer that I was unable to ask difficult questions due to the distress and discomfort of the participants. The experience of transcribing the interviews was also very emotional, and this was useful for me in reflecting about the families' experiences during analysis. It also seemed likely to me that many family members had not talked about their feelings to anyone, and this itself was important. Reflecting on these issues and how they might have impacted on the interview process and analysis was important for me.

7. Analysis and Writing Up

Initially I felt anxious about the analysis. I was apprehensive because it was the first time I had undertaken qualitative research and also because I was very concerned to accurately reflect (as much as that is possible) the participants' views. While at first I tried to include all sub-themes in the analysis, after time, space and returning to my original codes, my core themes emerged relatively easily, and I felt confident that they reflected the central issues in what had been said.

I found the process of writing up a little more testing, as it was very difficult constraining myself to the word limit. I found it frustrating that the word limit included quotations, especially as this was only confirmed after I had started my analysis. I found it hard to let go of the quotes I had selected, and would also have liked to add more depth to the analysis. However, the process of writing up did help me further consider and develop my themes.

Because I had taken time over the analysis, I found the results and discussion section sprang fairly naturally from this. I had enough time to step back from and reassess my results. The fact I had this time was largely due to the support (and occasional bullying) from my field supervisor, Lizzie Newton, who is experienced in qualitative research and so knew how long it took. With her guidance I gave myself a series of deadlines throughout the research process, which allowed me to stay on schedule.

8. Learning Points

I learnt a great deal about research and my own strengths and weaknesses through this process. Despite the hard work involved, I found doing qualitative research very satisfying. The results felt more connected to the participants than I had found in quantitative studies. I certainly feel more confident in the approach and I hope to do qualitative research again.

The research has helped me reflect on the needs of carers and those people around the service user. As a psychologist often working with individuals only I was reminded of how important carers can be to the service user. I also realised how much one person's illness can affect those around them. The interviews shifted my perspective about working with carers away from considering only how to help them care better, to thinking about their needs more broadly, especially the importance of listening to carers' beliefs about the illness.

The research reinvigorated my interest in trying to initiate dialogue between services and ethnic minority communities. It gave me a new insight into the difficulties families face in dealing with services that, even when they are designed to be accessible, can seem distant and confusing. The study particularly helped me to consider the difficulties for services in meeting the needs of non-English speakers. As a western psychologist I had certain preconceptions about what the families might believe and might request. The participants lead me to question my understanding of what is supportive for families and re-consider how differently other cultures might view mental illness.

I hope this research can contribute to the process of changing services in some little way. Firstly, I hope to feed the results of this research back to the EIS team, in a way which might enable them to consider the specific needs of this group and change practice to better meet them. Further, I aim to publish the findings of this research. I hope that this will add to the

now growing research on cultural differences within understandings of mental health. My research has made me consider the importance, especially for Clinical Psychologists, of learning about different cultures' models of mental illness and ways of coping, rather than simply comparing ethnic minorities' experiences to a white "norm".

9. Conclusion

Before beginning Clinical Psychology training I was uncertain of the advantages for trainees in completing such a long-term and complex piece of research. With the benefit of hindsight however I do feel that the study has taught me a great deal about carrying out research while you work. I believe that Clinical Psychologists are in a good position to produce research that can have a positive impact on understanding our client groups. I hope that this report goes some way towards meeting that goal. The study and I have come a long way, and I feel very grateful to my participants from whom I have learnt a great deal.

10. References

Egharevba, I. (2001). Researching an-'other' minority ethnic community: reflections of a black female researcher on the intersections of race, gender and other power positions on the research process. *Social Research Methodology*, 4(3), 225-241.

Elliott, R. Rischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for the publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.

Fenton, S. & Sadiq-Sangster, A. (1996). Culture, relativism and the expression of mental distress: South Asian women in Britain. *Sociology of Health and Illness*, 18(1), 66-85.

Greenwood, N., Hussain, F., Burns, T. & Raphael, F. (2000). Asian in-patient and carer views of mental health care. *Journal of Mental Health*, 9(4), 397-408.

Hatfield, B., Mohamad, H., Rahim, Z. & Tanweer, H. (1996). Mental health and the Asian communities: A local survey. *British Journal of Social Work* 26, 315-336.

Hussain, F. & Cochrane, R. (2004). Depression in South Asian women living in the UK: A review of the literature with implications for service provision. *Transcultural Psychiatry*, 4(2) 253-270.

King, E. (1996). The use of the self in qualitative research. In J.T.E. Richardson (Ed.) *Handbook of qualitative research methods for psychology and the social sciences*. (pp. 175-188). Leicester: BPS Books.

Madill, A., Hordan, A. & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, 91, 1-20.

Reid, K., Flowers, P. & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18(1), 20-23.

Shaw, R. (2001). Why use interpretative phenomenological analysis in health psychology? *Health Psychology Update*, 10(4), 48-52.

Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychological and Health*, 11, 261-271.

Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J.A. & Walsh, S. (1997). Standards for research projects and those involving qualitative methods: Suggested guidelines for trainees and courses. *Clinical Psychology Forum*, 108, 3-7.

SECTION D: Appendices

APPENDIX I

Instructions for Authors:

[Click here to check your article status](#)

*****Note to Authors:** please make sure your contact address information is clearly visible on the **outside** of all packages you are sending to Editors.***

Journal of Mental Health is an international journal adhering to the highest standards of anonymous, double-blind peer-review. The journal welcomes original contributions with relevance to mental health research from all parts of the world. Papers are accepted on the understanding that their contents have not previously been published or submitted elsewhere for publication in print or electronic form.
Evaluation Criteria of Qualitative Research Papers.

We strongly encourage electronic submissions to the *Journal of Mental Health* at e-mail address: jmh@iop.kcl.ac.uk

Manuscripts should be sent to Executive Editor, Professor Til Wykes, Department of Psychology, Institute of Psychiatry, De Crespigny Park, London, SE5 8AF, United Kingdom. It is essential that authors pay attention to the guidelines to avoid unnecessary delays in the evaluation process.

To expedite assessment, three complete copies of each manuscript should be submitted along with an electronic version on disk. The names of authors should not be displayed on figures, tables or footnotes to facilitate blind reviewing.

All books for reviewing should be sent directly to **Martin Guha**, Book Reviews Editor, Information Services & Systems, Institute of Psychiatry, KCL, De Crespigny Park, PO Box 18, London, SE5 8AF.

Manuscripts should be typed on one side of paper, double-spaced (including references), with margins of at least 2.5cm (1 inch). Good quality printouts with a font size of 12 or 10 pt are required. The first page should show the full title of the paper, a short title not exceeding 45 characters (to be used as a running title at the head of each page), the full names and affiliations of authors and the address where the work was carried out. The corresponding author should be identified, giving full postal address, telephone, fax number and email address if available. To expedite blind reviewing, no other pages in the manuscript should identify the authors. All pages should be numbered.

Abstracts . The second page should also show the title, together with a structured abstract of no more than 200 words, using the following headings: Background, Aims, Method, Results, Conclusions, Declaration of interest. The declaration of interest should acknowledge all financial support and any financial relationship that may pose a conflict of interest. Acknowledgement of individuals should be confined to those who contributed to the article's intellectual or technical content.

Keywords. Authors should include up to five key words with their article, selected from the American Psychological Association (APA) list of index descriptors, unless otherwise agreed with the editor.

Text . Follow this order when typing manuscripts: Title, Authors, Affiliations, Abstract, Key Words, Main text, Appendix, References, Figures, Tables. Footnotes should be avoided where possible. Manuscripts should not exceed 6,000 words unless previously agreed with the editor. Language should be in the style of the APA (see *Publication Manual of the American Psychological Association* , Fifth Edition, 2001).

Style and References . Manuscripts should be carefully prepared using the aforementioned *Publication Manual of the American Psychological Association* , and all references listed must be mentioned in the text. Within the text references should be indicated by the author's name and year of publication in parentheses, e.g. (Hodgson, 1992) or (Grey & Mathews 2000), or if there are more than two authors (Wykes *et al.* , 1997). Where several references are quoted consecutively, or within a single year, the order should be alphabetical within the text, e.g. (Craig, 1999; Mawson, 1992; Parry & Watts, 1989; Rachman, 1998). If more than one paper from the same author(s) a year are listed, the date should be followed by (a), (b), etc., e.g. (Marks, 1991a).

The reference list should begin on a separate page, in alphabetical order by author (showing the names of *all* authors), in the following standard forms, capitalisation and punctuation:

a) For journal articles (titles of journals should *not* be abbreviated):

Grey, S.J., Price, G. & Mathews, A. (2000). Reduction of anxiety during MR imaging: A controlled trial. *Magnetic Resonance Imaging*, 18, 351–355.

b) For books:

Powell, T.J. & Enright, S.J. (1990) *Anxiety and Stress Management*. London: Routledge

c) For chapters within multi-authored books:

Hodgson, R.J. & Rollnick, S. (1989) More fun less stress: How to survive in research. In G.Parry & F. Watts (Eds.), *A Handbook of Skills and Methods in Mental Health Research* (pp. 75–89). London: Lawrence Erlbaum.

Illustrations should *not* be inserted in the text. Three copies of each should be provided separately, numbered on the back with the figure number and the title of the article. All photographs, graphs and diagrams should be referred to as 'Figures' and should be numbered consecutively in the text in Arabic numerals (e.g. Figure 3). The appropriate position of each illustration should be indicated in the text. A list of captions for the figures should be submitted on a separate page and should make interpretation possible without reference to the text. Captions should include keys to symbols. It would help ensure greater accuracy in the reproduction of figures if the values used to generate them were supplied.

Tables should be typed on separate sheets and their approximate position in the text should be indicated. Units should appear in parentheses in the column heading but not in the body of the table. Words and numerals should be repeated on successive lines; 'ditto' or 'do' should *not* be used.

Accepted papers. If the article is accepted, authors are requested to submit their final and revised version of their manuscript on disk. The disk should contain the paper saved in Microsoft Word, rich text format (RTF), or as a text or ASCII (plain) text file. The disk should be clearly labelled with the names of the author(s), title, filenames and software used. Figures should be included on the disk, in Microsoft Excel. A good quality hard copy is also required.

Proofs are supplied for checking and making essential corrections, not for general revision or alteration. Proofs should be corrected and returned within three days of receipt.

Early Electronic Offprints: Corresponding authors can now receive their article by e-mail as a complete PDF. This allows the author to print up to 50 copies, free of charge, and disseminate them to colleagues. In many cases this facility will be available up to two weeks prior to publication. Or, alternatively, corresponding authors will receive the traditional 50 offprints. A copy of the journal will be sent by post to all corresponding authors after publication. Additional copies of the journal can be purchased at the author's preferential rate of £15.00/\$25.00 per copy.

Copyright. It is a condition of publication that authors transfer copyright of their articles, including abstracts, to Shadowfax Publishing and Taylor & Francis Ltd. Transfer of copyright enables the publishers to ensure full copyright protection and to disseminate the article and journal to the widest possible readership in print and electronic forms. Authors may, of course, use their article and abstract elsewhere after publication providing that prior permission is obtained from Taylor and Francis Ltd. Authors are themselves responsible for obtaining permission to reproduce copyright material from other sources.

APPENDIX II



"A City" Local Research Ethics Committee
Address (removed for anonymity)

Ms E Penny
Name of service (removed for anonymity)
Address of service

5 January 2004

Dear Ms Penny and Ms Bahia

LREC 03/10/705 - Asian service users and Asian families experiences of early intervention for psychosis

The Chairman on behalf of the (*Name of NHS Trust*) Ethics Committee has considered your response to the issues raised by the Committee at the first review of your application on 21 November 2003, as set out in our letter dated 1 December 2003. The documents considered were as follows:

- Application form
- Patient information sheet

The Chairman, acting under delegated authority, is satisfied that your response has fulfilled the requirements of the Committee. You are therefore given approval for your research on ethical grounds providing you comply with the conditions set out below:

Conditions of approval:

- (Where approval is given before receipt of CTX) Please let the LREC have a copy of the CTX when it is available. If changes to the protocol are required by the MHRA (Medicines and Healthcare Products Regulatory Agency), the LREC approval will become void until those changes have been made and the revised protocol will need to be approved.
- You do not undertake this research in any NHS organisation until the relevant NHS management approval has been received.

You do not deviate from, or make changes to, the protocol without the prior written approval of the LREC, except where this is necessary to eliminate immediate hazards to research participants or when the change involves only logistical or administrative aspects of the research. In such cases, the LREC should be informed within seven days of the implementation of the change. Likewise, you should also seek the relevant NHS management approval for the amendment, or inform the NHS organisation of any logistical or administrative changes.

- *You complete and return the standard progress report form to the LREC one year from the date of this letter and thereafter on an annual basis. This form should also be used to notify the Committee when your research is completed and should be sent to the REC within three months of completion.*
- *If you decide to terminate this research prematurely, a progress report form should be sent to the LREC within 15 days, indicating the reason for the early termination.*
- *You must advise the LREC of all Suspected Serious Adverse Reactions (SSARs) and all Suspected Unexpected Serious Adverse Reactions (SUSARs).*
- *You advise the LREC of any unusual or unexpected results that raise questions about the safety of the research.*
- *The project must be started within three years of the date of this letter.*

'Lead' LREC – other local submissions

Where this LREC is taking the role of 'Lead' LREC, it is your responsibility to ensure that any other local researchers within the (*name of*) Health Authority seek the approval of the relevant LREC before starting their research. To do this you should submit **one copy** of the following documents to the relevant LRECs:

- This approval letter
- Locality form
- LREC-approved version of the patient information sheet and consent form, in the appropriate local format (ie on pertinent headed paper and showing pertinent local contact details)
- Principal (local) investigator's CV.

No other documents are required by the LREC to consider locality issues.

NHS LRECs are compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the conduct of trials involving participation of human subjects.

Your application has been given a unique reference number, please use it on all correspondence with the LREC.

Yours sincerely

Administrator
(Name of trust) Local Research Ethics Committee

APPENDIX III

Finding Out About the Early Intervention Experiences of Asian Families in *(name of city)*

We would like to invite you to take part in a research study. Before you decide whether you will be able to help us out with our research project, please take the time to read this information sheet.

What is the study about?

Our project aims to gain a greater understanding of the young people and their families who come into contact with our Early Intervention Service. In particular, we would like to learn more about the needs and concerns of families from Asian communities. We are interested in hearing about your opinions and experiences, and would welcome any input that you would be able to give us. We want to ask families about how their relatives came into contact with the service, and how they feel about the treatment that they have received.

What are the benefits?

We are doing this research for three main reasons: firstly, to find out more about the people who we are trying help; secondly, to find out how helpful our services are; and finally, to find out what we should change about the services that we provide. By asking you about your experiences we will be able to improve the services that we provide for young people, and their families, from the Asian communities.

What are the risks?

There are no risks associated with taking part in this study.

What will I have to do?

If you decide to take part in this research you will be asked to attend a meeting with a female researcher. The meeting can either be conducted in your home, or we can arrange transportation to and from one of our centres. An interpreter can also be provided. This meeting will last for approximately one hour. Family members will be interviewed individually, but we are happy to interview more than one family member.

At the meeting, the researcher will ask a few questions to enable you to discuss your experiences of the Early Intervention Service and to talk about how your family member came into contact with them. The meeting will be recorded on a tape recorder so that the research team have an accurate record of what is said. Only members of the research team will have access to the tapes, and all information will be kept confidential.

What happens to the information?

The research team will study the tapes, and they will make detailed notes about what you have told us, using your own words. In the notes, and in the research reports that we write about them, we will use what you tell us to help us to develop a plan for improving our service. Although we will often use *your* words, *we will not reveal your identity*. In all of the reports and documentation for the research project we will

refer to you by a false name. We will also be careful to alter or remove any specific information that would identify you. The audiotapes will be returned to you to keep after we have finished this process.

What if I do not want to take part or I change my mind during the study?

It is important to remember that it is up to you whether or not you take part. Even if you decide to take part, you are still free to change your mind and withdraw from the project at any time, and without giving a reason. This is a research project, and it has no direct link to the standard of care that you and/or your relatives receive. Whether you decide to take part in the study or not, is up to you, and it will not affect the treatment that you or your relative receive.

Who else is taking part?

We are contacting the families of all Asian patients who are treated by *(name of city)* Early Intervention Service for more than one year to see if they would like to take part. We would like to speak to the mothers, fathers, sisters, brothers, husbands and wives of our service users.

What happens at the end of the study?

At the end of the study you can choose to have a meeting with the researcher in which she will tell you about the results of the research or we can send you a leaflet describing our findings.

What if I have more questions or do not understand something?

If you have any questions or do not understand something we would be happy to meet and discuss these. We can provide an interpreter to help to explain in more detail.

Contact name and number

If you have any questions or concerns about this project, however, please do not hesitate to contact Elizabeth Penny on *(number given)*.

If you have concerns about this study and wish to contact someone independent you may telephone *(R&D department name omitted)* on *(number given)*.

Thank you for taking the time to read this information .

Centre Number
Study Number
Patient Identification Number

CONSENT FORM

Title: **Asian Carers and Early Intervention**

Name of Researcher: Elizabeth Penny

Please initial box

1. I confirm that I have read and understand the information sheet
for the above study and have had the opportunity to discuss
details with and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to
withdraw at any time, without giving any reason, without my medical
care, the care of any family member, or my legal rights being affected. ☐
3. The nature and purpose of the interview have been explained to me and
I understand what will be required if I take part in the study. ☐
4. I agree to take part in this study ☐

Client

Date

Signature

Person taking consent

Date

Signature

Researcher

Date

Signature

APPENDIX V

Interview Schedule

How are mental health problems (generally) and psychosis (in particular) understood by Asian families of service users? (Beliefs and meanings ascribed to family members' illness)

How are mental health services (in general) and early intervention (in particular) construed by Asian families of service users?

- *How did x come into contact with early intervention? (participants psychosis "Framework")*
 - who did you see first (family, GP, other prof, community or spiritual leader) name key worker and doctor where necessary
 - what made you *first think* that X might have some difficulties?
 - Interpretation: what did u think was wrong at the time?
 - why did they access professional help (who thought they should/should not?)
- *What is it like to be a family member to x?*
 - how are they now and what do you think the future might bring?
 - What do you think helps x to stay well/happy? (Things you do and things x does ie: work, family, friends, community, religion, herbal medicine, food etc)
 - How has what's happened impacted on x? What's been good and bad?
 - How has what's happened impacted on you and your family – good and bad?
- *What did the early intervention team do?*
 - who did you see
 - how frequently (too little/ok/too much)
 - was x given medication (views)
 - other interventions (views)
 - what treatments did you think were helpful and what were not
 - what help did the family receive
 - how did it feel talking to professionals?
 - what do you think x's Dr/key worker think x's difficulties are? (do you agree) did you feel your view was taken into account? (ie use of term psychosis if mentioned)
- *Are there things that you feel that the early intervention could have done differently?*
 - If you had to give the team advice on helping other Asian service users and their families what suggestions would you give them?
 - Was the service what you expected – what was helpful and what was unhelpful?

APPENDIX VI

Confidentiality Form

The interview being transcribed is confidential.

This means that:

- You must inform the researcher if you know, or think you might know any participant in the interview, or anyone referred to in the interview.
- You must not share the interview's content, or any information about its participants, with anyone else.
- All data and material belongs to the researcher. All data, word files and sound files on which the interview is stored will be returned to the researcher and deleted from computers.

If you have any questions regarding these conditions please discuss them with the researcher before signing below.

I understand that the interview and material related to it is confidential and I agree with the conditions above:

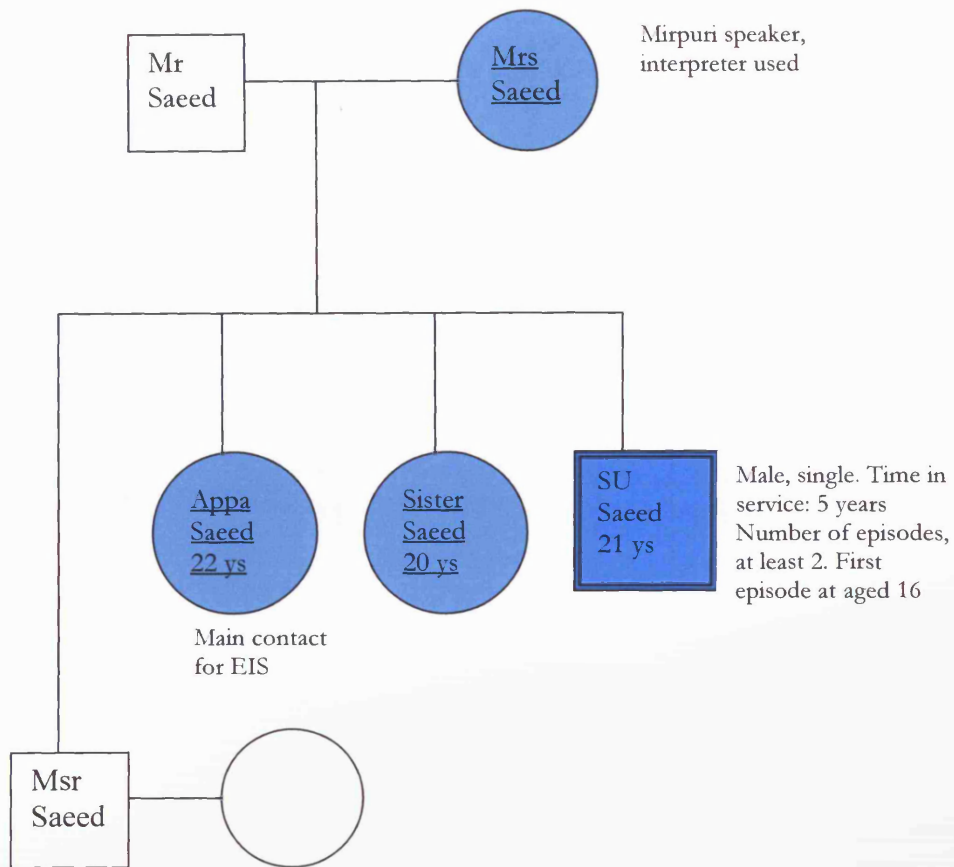
Name:

Signature: Date:.....

Researcher's signature: Date:

APPENDIX IV

Diagram 1: The Saeed Family



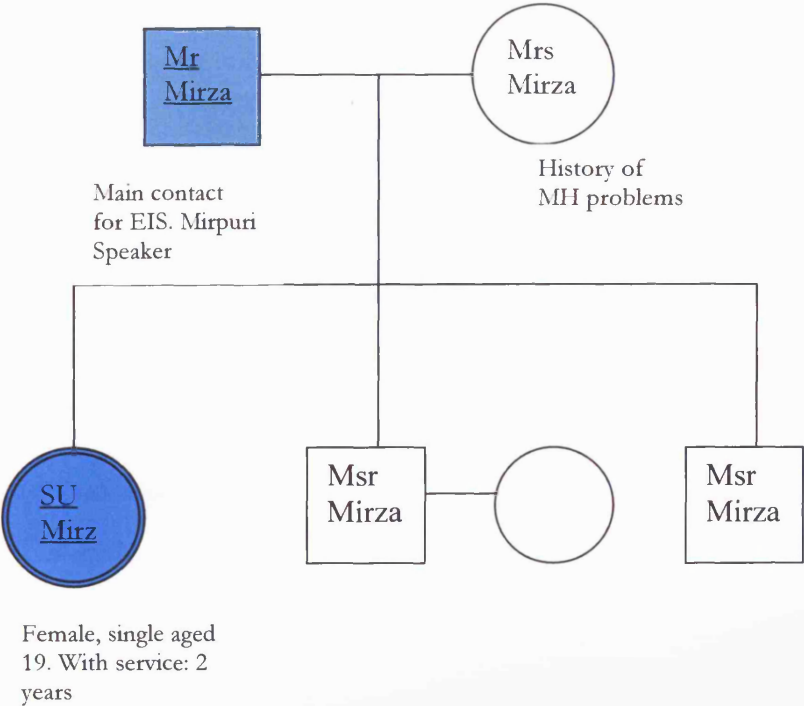
Key:

Green = interviewed

Blue = service user

White = family member, not interviewed

Diagram 2: The Mirza Family



APPENDIX IV

Diagram 3: The Rehman Family

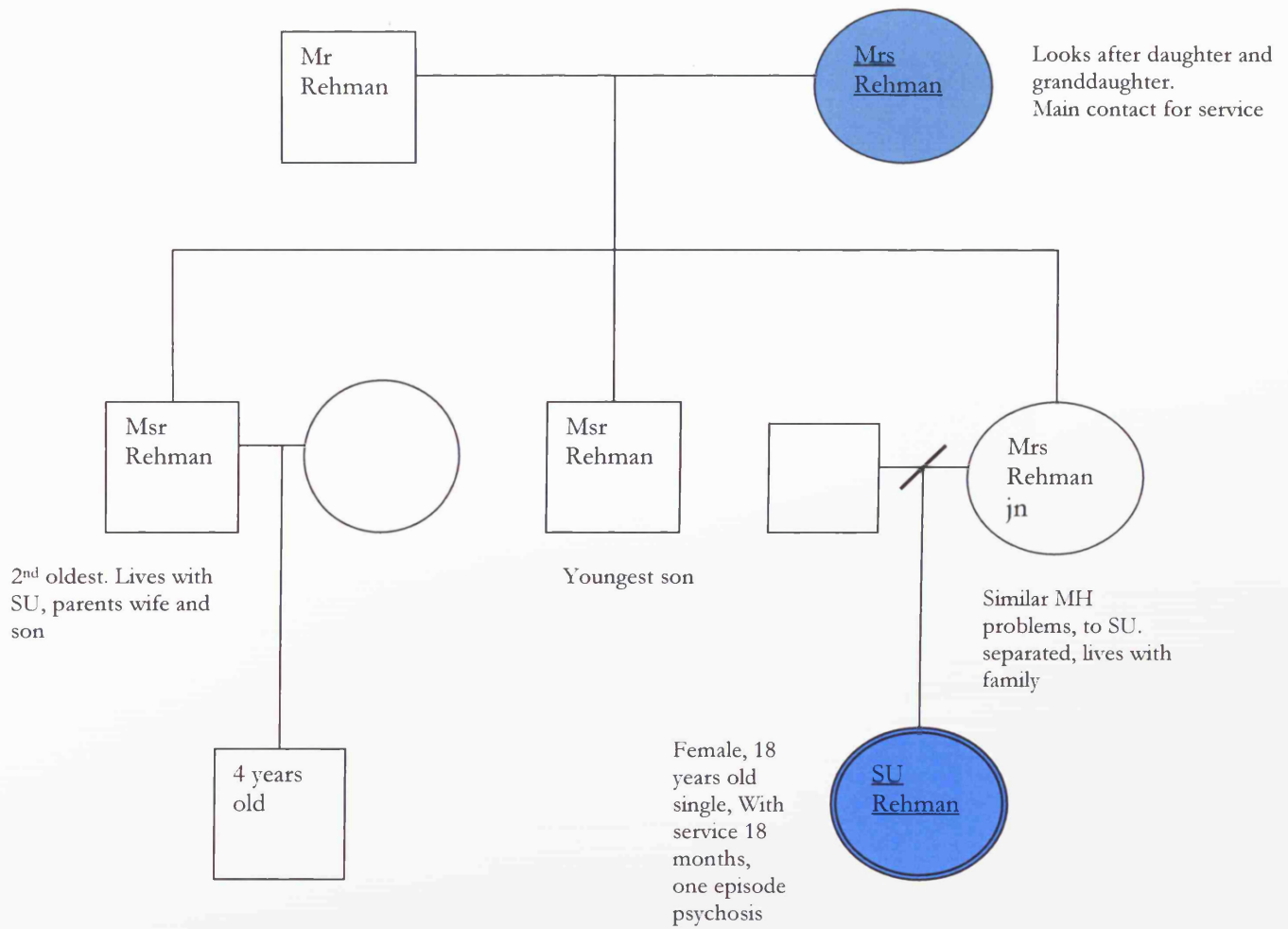


Diagram 4: The Shah Family

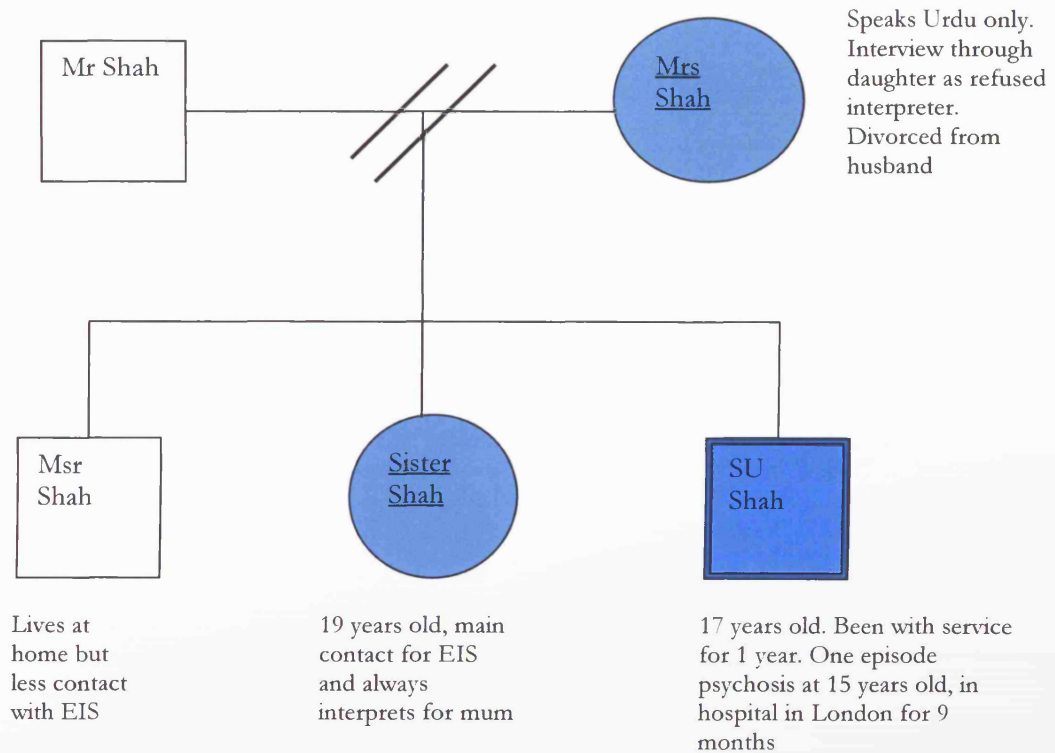
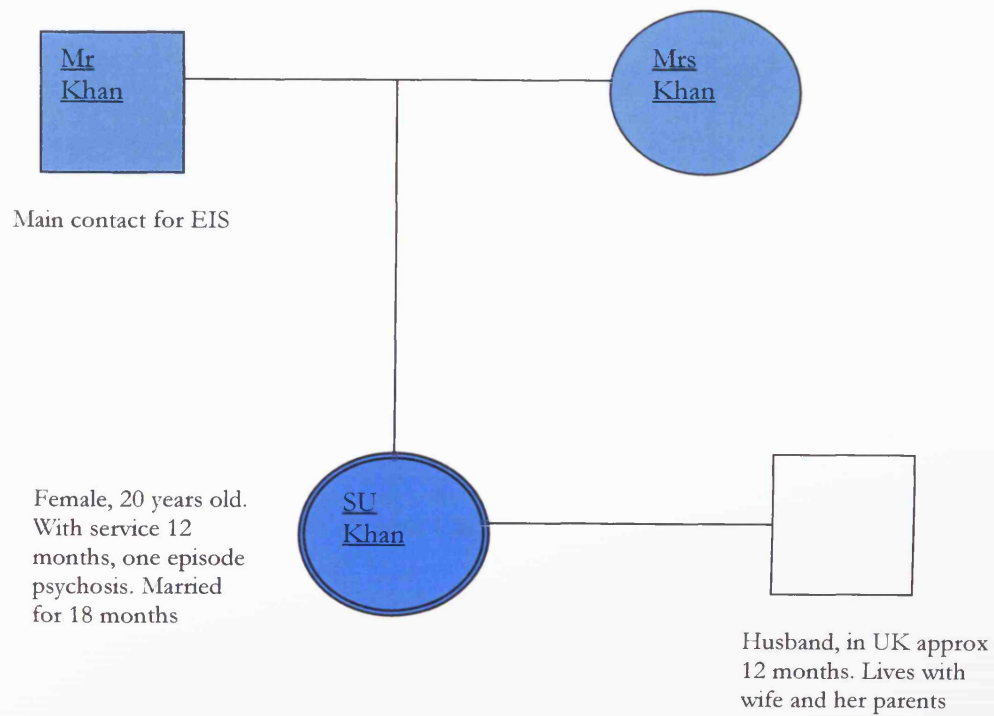
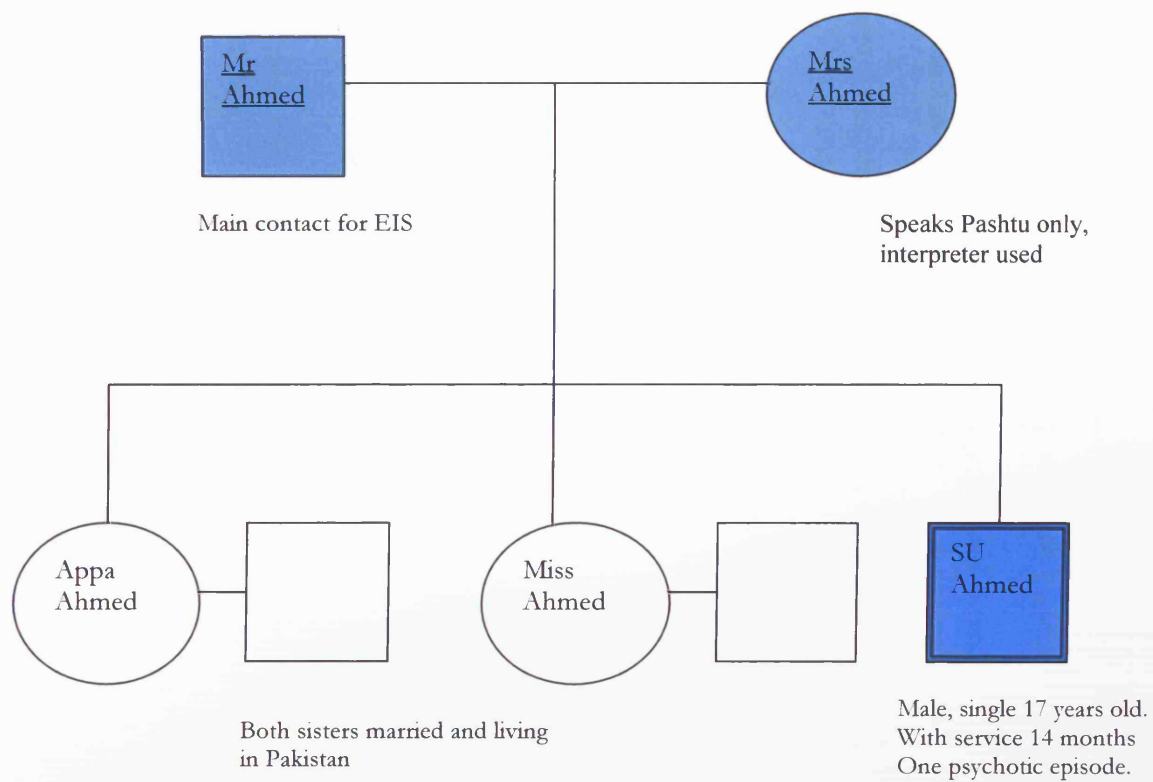


Diagram 5: The Khan Family



APPENDIX IV

Diagram 6: Ahmed Family



Mrs Saeed

THEME	COMMENTS	QUOTE
Behaviour is focus	<p>Personality change – to aggressive</p> <p>Behav isolated from emotions (defence?)</p>	<p>people from the family and his friends have said, oh he has changed, they noticed the changes in him, in his behaviour. She said I told him to go to school and he says I'm not going. Then she says get changed and he says I don't want to get changed 4-7</p> <p>he used to make a lot of noises to himself and be rowdy. We used to think why he would make these noises himself. He said that children are jeering at him and being rude to him. 240-43</p> <p>His eyes would just fill up with so many tears, and he would just keep crying, without a reason. 41-2</p>
Problem has multiple (social) causes		<p>If it was one thing, I'd say so easily. 46</p> <p>all the relatives and I know that it could be black magic, as it has been done to a lot of people. 359-60</p>
Loss of trust and blame		Especially since he left hospital, he has acted, behaved in an angry way towards me, and more towards me than anyone else. 154-5
Loss	For him and for her	<p>He used to be a boy of such beautiful character who has changed which is really painful to me. There wasn't anyone like him around. Look at what has happened to him. 137-9</p> <p>When I used to get worried about him, he'd reassure me by saying, 'mum, I'll take care of you when I am older', but now, he doesn't do anything. (Interpreter)</p> <p>P: when I went for hajj, he came with me and we saw a lady there whose son was helping her to perform hajj. I just thought that if I was in the same situation, would my son do the same? (Interpreter)</p> <p>P: the poor thing, it's not his fault at all, not at all (...) 497-510</p>
Loss of hope		<p>He hasn't got a future ahead of him. (...) I don't know what to think anymore about it [tearful] 145-6</p> <p>With medicine, he did change a bit, but that finished. We just feel helpless, but what can we do? 296-7</p>
Medicine	Calms him	<p>P: Going without medicine didn't help him. He changed.</p> <p>Interp:... How didn't it help?</p>

		P: He spoke to himself and was really upset. The pills helped him. 185-90
	But lost old self	I thought the pills will help him to become the way he was before; when he used to talk enthusiastically about going to college, or doing Law. 195-97 The medicine he has been taking makes me feel that he is just so different to how he used to be. 284-5
Isolation	Need to talk – to meet needs, to express yourself and to be part of family Family try to work to his wishes	He's not talking which is like half his illness, not talking about things. He doesn't even ask for things, not even for food. If he was going to start speaking about things, that might help him to get better, rather than keeping it in. 577-81 He used to sit with everyone and eat and now he prefers sitting alone upstairs when eating. I don't like it, but I have to deal with it especially because that's the way he wants it. 297-300 Maybe he could get a good friend and things could get better if he forgets about his illness. 558-559 I want him to have good company as that's like medication. 564
Fear for future need to be cared for	Search for end to isolation, which might be solution (linked to isolation theme and hope theme)	When I die, no one will take care of him. I am always wondering about his situation, as for his sisters, that's another story. They won't be able to look after him in the same way as I do. I sometimes think that maybe if he gets married, he will change and it might help. But then, I think, will he be able to deal with marriage properly and would it possibly make him better? 305-10 maybe he will get better, a wife's love is different. Plus, he will have kids as companions thereafter. It could make him change and help him and when I go, his wife, his companion, could take care of him.

Will try anything to help		<p>I was very worried at around that time and obviously, not knowing what to do, whichever way someone would tell me to walk, I'd do it. I didn't know what to think...</p> <p>(interp...)</p> <p><i>E: did she take him to anyone?</i></p> <p><i>Interp: did you take him to see anyone?</i></p> <p>P: Yeah, we dropped everything for a whole year and we took him to Pakistan to see if it could help. 373-384</p>
Hope in Allah		<p>God willing, he will get better, I have dreams that I am at Mecca, and that Allah is saying, don't worry, he will get better. Allah will help. 460-62</p>
Want non-medical treatment		<p>when we went there, the moulvi at the mosque whispered some things on the water which was given to him. He was really happy and very calm with that. 389-91</p> <p><i>Interp: what can they do to help now?</i></p> <p>P: anything, other than medicines, medicines, and more medicines, his stomach has become very big because of it and so anything really (...) 484-487</p>
Denial of illness?		<p>He stayed at the first hospital for 2 days only as there were rather disturbed people there, which he did not like. 169-70</p>

Theme	Comments	Quote
Social pressures cause illness	Social and family pressure causes depression, if this is not talked about becomes MI	Yeah, we recon you know, its like mum was in Pakistan you know, when he got in trouble with the police. You know if your mum's not here E: <i>yeah.</i> P; we recon it's that, that's why he got depressed. 251-256
Illness defined by behaviour	Stigma to behaviours, behaviours not understandable	And then at one time he started walking round in circles in the garden and started crying, so we knew something was wrong then. 19-21
Social causes and social cures	Talking helps at early stage, going out doing productive things helps	It would have been different if we had talked to start with, but we didn't know. He was going to go through all this. Because depression does, er does end up like if it gets worse, you could go, like, mentally ill. 216-9 If only we had noticed it first, and sat there and talked to him. 36-7
Loss of hope and loss of trust	Initial optimism over time it goes	We got used to it. We always had our hopes, we still got a hope. We always had a hope, at the beginning it was like – its only for a little while, he's going to get better. But after four years, its like you have still got a hope but. Living with him, everyone knows his moods. 53-57
	Loss of trust in drugs	His body is used to it. His brain is used to it. I- I I recon we made the biggest mistake putting him on it in the first place. 66-8 two things; he wet himself, and he's gone very slow in the head as well. All to do with the medicine. So what is the medicine? The only thing it's helping him is to calm down. Even drink calms him down. 272-5

	Feeling its too late	I used to have, well everyone's got a hope, but, I'm thinking – a miracle
	Only Allah can help – you have to hope	Yeah, I am not really happy with the medicine. The only thing we can believe in now is Allah 76-8
Family expectations not met	Family as experts and want dialogue with service	...keep the family informed. Like, ok, he's been on this medicine for this long and, ask us if he's changed or improved or anything like that, ask us. 176-9
	Service not reliable and service only gives drugs	A, they hardly – they normally come and drop his medicine off, but sometimes it would be late. So he could go into a relapse and all the rest of it. B, they're like, they won't come and explain to you, OK you know like they should come down and explain to you or ask how W is getting along and all the rest of it. They just give oh, its just another patient and that's it, another patient to their list really. 132-9 Its just the medicine and that's it. Its been like four years, that's all. 160-61

Theme	Comments	Quote
Social stress causes illness and makes it worse	Able to hold two views (social/head injury together 258-66)	<i>What makes him more ill or more depressed?</i> Oh, if he hears like an argument going on, or someone upset, or something happened in the family, that's affecting all the family 127-9
MI not understandable	All experience depression but MI harder to understand	laughing, Just laughing for no reason, and crying and um, and that was it really, it just came more 20-1 well I thought, we wasn't sure, I wasn't not sure. I didn't know whether it was just him wanting <i>attention</i> or whether it was true or not 33-5
Personality change	Most diff for family no longer part of emotional life of family	Now he's just like really quiet, he will talk when he feels like it <i>E: Hmm</i> <i>P; only if its something meaningful; I want this or I want that and</i> <i>E: Umm</i> <i>P: and then if anything needs cooking or getting.68-74</i>
Disappointed hopes in services	Feel don't listen Feel don't keep promises	So we told them, we said to them, could you just lower the dose? But they were like, its only another two more years. They'll always have it their way, they'll never listen. 146-9 I want them to listen to us. It's like your talking to them, and they're sitting there and they listen to you going yeah, yeah I understand, this that and the other, once they are out that door everything that was in their head, its <i>gone</i> . You see what I mean? 298-303 We'll take him out, this that, but nothing happens. They've even made like appointments, oh you know, Saturday this time or Monday that time and its never <i>ever</i> ever happened. Nobody on the day has taken him out. And their <i>always always</i> late for dropping off their medication. <i>All</i> the time. We have to check, chase them, leave a message. 167-74
Disappointed hopes in recovery	Better but not how he was	yeah, he's better than when it started, but not the same as before, this, before the illness, before he became depressed. He's more quiet, and before he was like really giggly and bubbly and always talked to everyone. 66-8 there was a time you know when it started, there was a time when we thought, oh yeah, two more

		<p>months, three more months, that's what they used to tell us at the early intervention centre, oh just give it another two months, its not totally up to them but, you know, its like it goes on and W isn't really happy, and whatever we want them to do, its never like that. 138-42</p> <p>yeah so, I don't know, now its just hope. We do hope that he will get better, but its taking so long its like, five or six years now.</p>
Once on medication its too late	Once on med have to stay on it Once illness gone this far talking doesn't work	<p>Now its too late. Because even if we want to talk to him, he doesn't want to really talk back to you. 46-8</p> <p>Because, I mean there are times when you, you do go through this sort of illness, but, you do get out of it don't you? But once your on the medication, I think your stuck with the illness, because when you, if you ever try to stop taking them, you, your body and mind so much used to them that you have to, depend on them. See what I mean? 233-9</p>
stigma		<p>you see someone like the way W is, OK, he's not totally, you know, (...) like you'd call mental he's got, he's, when they see someone like W they wont really want to hang around with him and all that, will they 95-9</p>
Shift from medicine to social treat		<p>so, yeah it probably would be good. At least he's going out, getting out of the house, he's always stuck in his bedroom. 223-5</p> <p>At that time, you don't know. I think, half of the illness goes by talking to a person. Getting to know how they feel, you know what I mean? That's what we should have done. 275-278</p>

THEME	COMMENTS	QUOTE
Ill and unhappy		<p>she just got ill, and started annoying everyone she wasn't happy at all 17-18</p> <p><i>what did they say what the problem was?</i></p> <p>P: they say it is depression 146-147</p>
Don't know why		<p><i>Inte: what did you think was the problem around that time?</i></p> <p>P: I didn't know what to think, as my other children are absolutely fine. 22-23</p> <p>I don't understand why she is ill. 181</p>
Medicine, family and going out help		<p>We treat her with more love and the medicine helps which she takes in the morning, and going to the centre. 38-39</p> <p>I would say the best thing is to keep her happy, speak to the doctor who could help. 209-210</p>
Help by doing things for her		<p>we just keep her happy by talking to her constantly, by checking if she wants to eat anything more recently, asking her if she wants to go and visit her sister, and things like that. 215-219</p>
Isolated	This is how she has always been so less of a change	<p>She stays ok but she doesn't talk too much. She has always been quite quiet since childhood, but that part of her hasn't changed that much, as she has always remained shy. 52-54</p>
Loss for family		<p>It has affected the family, as it upsets us, and when there is a healthy child in the house, it gives us peace of mind. But now, we don't have that which make me feel bad knowing that she isn't that well.</p> <p>Interp: they are worrying about her, because um, she's got ill and she's not well, and he feels bad thinking about her.</p> <p><i>E: do other people in your family worry as well? (interp)</i></p> <p>P: I'm talking for myself, but obviously it upsets us all, as when we sit in a room together and are quiet, we are all thinking about the same thing and about her (...)</p>

		66-77
Can't plan or hope take each day as it comes	powerlessness	<i>E: and what do you think about the future for your daughter?</i> P: nothing. Just talking each day as it comes. (...)
Positive if she has plans or independence		<i>you think, for her health, she can do anything that would help her?</i> P: she doesn't have that much ambitions. She does ask to be taught to drive, that was last night. In that way, she does say at times what she wants to do (...) 88-92
Imp for service to be reliable		he's, he's fine because they come on time with the medication, they come on time to talk to his daughter, and if they can't come they ring. 235-7

THEME	COMMENTS	QUOTE
What is the prob?	<p>Accepts Ill but why is she ill?</p> <p>First symptoms social withdrawal, behav symptoms</p>	<p>she was ill, um, and we found, she needed someone, like a professional. 6-7</p> <p>And um, she came here, and she was so quiet and I sit her down on the sofa and I go and sit next to her, and cuddle her, and I says, N could you tell me anything about it, what's going wrong? Why are you so quiet? And she burst into tears, you know.</p> <p>E: um</p> <p>P: she didn't say anything, and, just she was crying you know? And after that she was like er, (...) Crying and begging and calling, she says call my aunties, my other daughter, call the cousins, and call the everybody. 112-121</p>
Caused by being different	<p>Maybe because she sees mum is ill and because she is on her own</p>	<p>This illness, this illness is, I think the mother was ill, it could be she, she <i>thinks</i> about the mother as well.</p> <p>E: <i>right.</i></p> <p>P: Er, because why is my mummy like this? ...</p> <p>E: <i>what do you believe about why N is suffering from this, and why she is ill?</i></p> <p>P: (...)I couldn't say, (...) it could be the mother's side. Because she was ill and she thinks, and the father is not here – and why is my father not here? She doesn't talk with others, she don't have any friends. Which is, you should have a friends. 218-231</p>
How to care	<p>Should push them</p> <p>Medication helps but slow</p>	<p>29-47</p> <p>E: <i>and you feel the medication helps her?</i></p> <p>P: it help her, it help her yeah. It help her because it seems to be, she is getting better, but its <i>very, very</i> slow. 144-146</p>

	Recovery is slow – need for patience	<p><i>if you were talking to another family, who were having these problems, just starting to have these problems what advice would you give them?</i></p> <p>P: Just be patient. And er, take care of the person, and er, (..) take help if you can get it from the doctors, from the families, and help to the person as well. And take it gradually, as it comes. 456-61</p>
--	--------------------------------------	---

<p>Need for social stuff</p>	<p>Plus doesn't fit in</p>	<p>the only other thing would be if er like, they would take her out you know. Coz she doesn't want to go with me, I don't know why. Or her mother, like er, (...) activity like sport thing, where she can keep the mind busy. Things more, wider things, you know, like how you can help yourself and, this is the main thing. 343-48</p> <p>Is she stopped her medicine, or if you take N out, (...) I don't know how, how she behave. Which is, her behaviour is not bad, she's ok, um, when she goes there, you know like in our culture, people come and say salaam alaikum and say how are you, but she's quiet, she doesn't say anything. If a child, even I, my grandchild, she doesn't want to play with him. 361-66</p>
<p>Would do anything to help</p>	<p>But what can I do? Don't know what she wants</p>	<p>I would do anything I can to help her, to get her back to where she was before.</p> <p><i>E: yeah.</i></p> <p><i>P: but I don't know if I can. 100-104</i></p> <p>yeah they [service] talk to me, yes they do talk to me – if I need any help, and er, money wise or – but I am ok, I told them if I need it I will let you know. But at the moment, its ok, I am helping, this is my granddaughter, I do anything for her, which way to help her, to get back on own feet. 265-9</p> <p>If she wants to watch the TV she should talk about it, that's the thing, she don't say anything.</p> <p><i>E: right. So, would it help her to be able to talk about what she wants?</i></p> <p><i>P: it will help her. It'll help her. And er, I will be, everybody will be happy and everybody thinking about her, because we are concerned. She's a lovely child, lovely girl .. 329-333</i></p>

<p>Ability to care for self is route to recovery (and role)</p>		<p>But them main thing she can look after <i>herself</i>, get some education you know, <i>E: umm.</i> <i>P:</i> and er, (...) do some responsibilities, like you know, like a house work, cooking, um, again do bits and pieces, er and after that depends on her, what she want to do.</p> <p>I would just say to her N (..) if you could help yourself it would be better, and you can do what you want to do and er you can like, she was saying she wants to learn to drive, if she can, learn the driving we will get you a car, and you can take your mum, and yourself, go on holidays, go and do shopping, do what you want to do. And er, then you take me as well, coz when I get old I have no one to look after me. 305-11</p> <p>but she will get better, hopefully InshaAllah. Er, if she goes to the college and learn something and go to the job and then see how she copes. Get married, settle in her own house. They wanted the separate house we get them a house across the road. But unfortunately N is not well to look after herself, at the moment. 396-401</p>
<p>Drive and asking for self</p>	<p>Sign that getting better, wants child to ask for what they want</p> <p>Choices – what she wants</p>	<p>But she's, appetite increases, coz she doesn't eat very much, but now she can ask for it, she want this and she want that. That's the change she gets. And er, she want to do some sort of courses now. 156-159</p>
<p>Hope but worry</p>		<p>the future is hoping she gets better ... which is InshaAllah, hopefully, um I don't know how long it will take. 165-8</p>

		its just the worries. Brings worries to everyone. Is more like, er, (...) thinking about <i>her</i> (...) like I mean when she, if we go away, I don't know, what is going to happen? 358-60
Lack of communication		it could be, could be. That's my opinion, I don't know about it. Because if she talks, then you know. But she doesn't talk. E: So is it hard for you to know what she is feeling? P: that's it, that's what I would like to know, if once in her lifetime she could say something. 296-301
Role of Allah in cure	Even if cause is medical cure can be w Allah	This illness, I accept this is an illness, and you want to go some sort of, something to read or something like that, give something which is, which I give to N, either, they do this sugar, or salt or honey and they just pray something on it, and give to the girl, I can do that, because I trust God. I don't trust everyone, but I just trust because it's the writing, which is right, that has come from Quran Sharif – that's alright. 434-440
	Tarveez as something other ppl believe helps	Sometimes my husband thinks about this, that its maybe somebody doing something, and he talks about using tarveez. And I say, if you want to go somewhere you can go, ask them. 408-11
Service	Good but need interp	they helped us with a lot. They helping, but er sometimes, it's a language problem, not like myself but er, some of the English, not good, then they can't tell them what is the problem. That's the only thing. 465-468

APPENDIX 7: Miss Shah		(line references refer to transcripts used for analysis not transcripts in addendum)
THEME	COMMENTS	QUOTE
Trauma of onset	Happened suddenly Vivid memory of day first ill Interview is also traumatic – coping by not talking	Line 57-77 don't know, coz um, I think we've just got on with things, um, just put it to the side. Um, no-one talks about it, like I've said. E: <i>it must have been a bit hard me coming and asking all these questions</i> P: yeah! (...) E: <i>is there any support that you would like or that you think services could offer you?</i> P: (...) um, I just don't like it al being dragged back 286-294
paranoia	Frightening – don't know what's happening	He was saying um, the whole school was plotting, something against him, and they were going to hurt the family and put the house on fire. He was talking like that, I became a little scared of coz I didn't know what was happening. 29-33
Cause	Maybe stress: But not sure Lack of male role model and family probs	didn't know at the time what to think, I thought maybe its stress, (...) I did tell him to take it easy, coz he did take on quite a few um subjects, in A-levels. So. 42-44 <i>And you mentioned that he had taken on a lot of subjects at school, and that was maybe one thing that caused it, can you think of anything else?</i> P: yeah the family. E: umm P: God, where do I start! Um, my parents divorced when he was about two. And, he, well my mums never stopped any of us from contacting our dad, whatever, but I don't know whether he wanted to, or doesn't want to hurt her feelings like? 153-162
Road to recovery		He has improved a lot, he's not a hundred percent, but I'd say he was there. 90-91
Need to take it easy		um, well, he came out of hospital in May and said he was wanting to go back to education. So, um, I wasn't quite sure about that, but er his key worker said I mean, its all right, he thought he was fit enough to go back, and we just said so to him to take one subject or maybe two, just leave it for now. And take it easy, take it like a mock year, and um, yeah, he did that and I think um at the beginning he was a bit shaky, about getting back into education and um, that routine again. But, since he has improved, yeah. 112-120
Communication and social skills as mark of recovery	Social skills is sign he is getting back to how he used to be	So, yeah, he's doing really well. He's communication with the outside world. E: <i>and is that something that is important, as far as you are concerned?</i> P: um, its how he used to be. He's very sociable, like. He's very good with communicating and he gets on with everyone, so. He wasn't someone who would shy away and hide. And that's what he ended up doing. But now he's more, (...) more outgoing. Like he used to be. 128-136
medication	Reduction is mark of recovery	
Not talking	Good or bad?	I don't know what about his feelings and thoughts were, coz he did keep that to himself. We didn't really talk about it. 165-167 <i>do you think if he had been able to talk about his problems that would have helped?</i> P: yeah. I think it would. But if you are not that kind of person that, coz he tries to take on everything, you know, so. I wouldn't be sure. 191-195 E: <i>And how does it impact on the rest of you, you and your mum and the rest of your family?</i> P: no-one talks about it, its like, we don't go there. Um, but I think we are kind of over it, its moving on you know. E: <i>so yeah, what helps you guys to be ok?</i> P: (...) I don't know, coz um, I think we've just got on with things, um, just put it to the side. Um, no-one talks about it, like I've said.
Anger and rejection	Getting better leads to anger with family Family responds by trying to do more	at first he didn't, like I said he couldn't um recognise us. We were always like worried, but gradually he was, he started getting back, back on track and he'd like say um, you don't like me and that's why you leave me here, and that made my mum upset. So that's why she tried to go up every day. [tearful]. (...) four hours on the trains and the buses, and it was hard. (...) 223-228
Team get don't give back	Take history but don't give explanation	they just listened to our side of the story, but I don't think they really um, did give a reason why. 105-6
Want to know more		I think we would tell them right from the start what happens and make them understand, coz a lot of people doesn't understand. I'm not sure if I'm making sense, but we would tell them exactly what happened, and the treatment he is getting, and more about the illness, and then maybe. E: <i>what misunderstandings do you think people have about it?</i> P: (...) Don't know actually. Coz it's very rare isn't it? Coz I, I didn't know anything about this before. And, (...) it's a lot to take in as well. (...) 233-242
Taking responsibility	Sister's role Empathy for brother Don't let staff sort out, need to do it self	Just the medication, sometimes I do worry, coz sometimes he feels he doesn't need the medication, but like um, you know I can understand how he feels, like if I was on a course or something, and I had to complete it I don't usually do that, so I can understand where he is coming from, taking medication is hard. And he does tend to skip. And I have spoken to his key worker, but they said as long as he isn't missing too much, it's OK. But that's why I wanted to see, um the doctor, if he can reduce the amount he is taking, like maybe one dose a day or something? 265-274

Theme	Comments	Quotes
Problem was with sleeping – medical problem	Physiological problem, no ones fault, no stigma?	ah, she's not sleeping well. And er, that's why we took to early intervention service. E: um. Mum: and they give her sleeping tablets, I think. She sleep two, three days alright, then she can be better. 4-8
Nothing you need to do except take the meds – out of patients hands		E: <i>and I was wondering, if you had, if you had friends who had similar problems, you know they had a child with the same kind of problem, what would you tell them to do?</i> P: (...)nothing to do really. Yeah. 105-8
Service only give meds		they come every two weeks and give tablets, that's it.
Haven't thought about impact of illness before		
Team don't talk about illness w parents		<i>and has anyone tried to talk to you about what they think the problems are?</i> P: (...) I don't know, they just sort of chat.
Nothing to worry about now		E: <i>How about the future. What do you think about the future with this difficulty, and what's going to happen?</i> P: I think she's alright. Nothing to think about really.
Not up to her up to daughter		E: <i>and what about medication, will that need to carry on?</i> P: I'm not sure, that is up to her, probably she will stop it, but I don't know.

Theme	Comment	quote
Symptoms: change in behav		she's not, not sleeping, and talking too much, and you know, like going fast. And er, (...) worried you know, these kind of things.81-2
Caused by worry		you know she was worried about the entry visa for her husband, that thing. E: <i>oh yeah.</i> P: yeah, you know its like stressful. And then you know when he come, she picked it up again. You know. E: <i>yeah.</i> P: you know, that's what I think actually did that, yes. 12-18
Effect on family		well you know, first day we actually worried, what's going on. You know, like she's normal, friendly, and she never really gets sick, it worried everybody you know. And afterward, when she take two or three days sleeping tablets and er she back to, picking up 86-90
She ok now – back to normal		she's alright. That time, when she married, you know, like, she wasn't happy when you know he's not coming here. And er, you know, she's back to normal and everything, yeah.6-9 alhamdulillah, (praise God) she's back alright, we are very happy. That's the main thing.
Living normal life helps		...And you know she'll be going work, and going out with her husband, you know, that's no problem. E: <i>so doing things and going out, is that good?</i> P: yeah, you know if you are sitting at home all the time, it's a bit, and you are bored. You know that. 25-9
Still need to take it easy		She going for the full time, she still asking about full time. I'm not pleased with that, I said leave it, half a day, part time. You know like er, E: <i>why do you think that part time is better?</i> P: You know less hours, there is all day to day, there is more kids and its too much isn't it. 29-34
Family support helps		What she needs, we'll help 25

		<p>Family supporting is the main thing. I know there are lots and lots of people on the streets, and if you look after, parents yeah, and they are coming up and look how well she is, you know. 127-131</p> <p>Parents look after their kids you know. They will get better quicker. If instead you leave in the hospital, whatever, it causes more depression. 137-9</p>
Not her fault she is ill- nothing she can do		She has never done anything wrong! She's my kid, I have brought her up and she's ok. 45-6
Doctors know best		<p><i>E: do you think she should carry on with the medication?</i></p> <p>P: ah, depends doctors you see, you know, what they say. If they say carry on then carry on. If they say stop it you try it, then, you know. That's the best thing. You know, I can't say, you know like, er... the doctors know better than us. 53-8</p>
EIT just give meds don't talk about probs		they cross here, you know (...) they just really give the medication 67-8
Service ok Reliable		<p>Everything is fine. They are alright you know. Them peoples alright, you know. 77-8</p> <p>yeah its good. Coming when they ask for appointments, you know they give you an appointment and come at the right time, you know, that's good, and no complaints I don't think, no 162-5</p>
Daughter's voice dominant		<p><i>E: so you think those stresses are what made your daughter a bit ill, unwell?</i></p> <p>Daughter: not stress, I just wasn't getting enough sleep.</p> <p>P: that's it, not enough sleep and er, after it she you know, she got medication and afterwards no problem</p>

THEME	COMMENTS	QUOTE
Hope in God	Only God can make him back to how he was	I hope God fixes him 2 oh my little child that was the only thing that we was looking for and hope god makes him better 299
	If I pray Allah will help my son – my role – can do something	Mum: now uhhh Allah gives us help who needs a taweez? Allah is here, and I do my prayers and make dua (supplication) for my son and read the quran.you know...
Only God who heals		but what kind of help would they give them? Mum: Allah will give, what can we give? (laughs) Allah will help, Allah has the power... 549-552
Medicine helps		yes now the medication is helping him, now he's become a little better 150-1
Service good because of personal relationships		Mum: C and my son get on really well and she really Interp: she likes C, Mum: good, nurse – good, nurse She is a real good women.
Signs of illness: first not going to school	? school attendance now shows he is better	First thing, he didn't go to school for his studies. Thank goodness, now he goes to school 6-7
Behav diff to understand	Mum's difficulty explaining it echoes this? Alien, strange behav	that's it (...)he used to sit in the room. Something happened to him, erm (...)he used to laugh stand in the door, (unclear) Motorway....motor noises he hears. 11-3
Role of others and how they see behaviour		well I don't know, the Punjabis, the neighbour opposite are Punjabis, they use to tell me that your son when he sits on the wall he speaks and shout at himself. Then how does he go to school? 30-2
	Husband as family representative	56 – went to see teacher
Role of Nazah	Can be unintentional	He was so good at his studies in school (Allah forgive me) he was really good.56-7
	Happened because son was talented	Something just happened. He would go to his French lessons, karate lessons, and people talked. Something happened to him. 439-41
No explanation from service		<i>did C explain things to you on why S is ill?</i> Mum: she use to ask a lot of questions, she asked a lot of questions, she did enquire a lot, 386-8

Loss	Son had so much and that is gone so quickly Also disgust at his role in illness – creates distance between them?	He was so good at his studies in school (Allah forgive me) he was really good. Now when he comes back he sits on his own and thinks to himself. I ask myself what's happened to him. 56-9 He's the only one that we were having hopes for ..ahh. 261 poor thing. He was nice and hard working. The medication, medication made him better. My son. I couldn't look at him.
Isolation from world	Thinking too much, not communication,	He use to think a lot. He had a blanket over his head and blanket would cover his face. 71-2
		I would be happy if god gives him kids, a job and that someone is with him in the house. I hope god gives something. 250-2
Can hold two models of diagnosis and treatment		<i>Interp: is the maulvi a doctor also?</i> Mum: doctor and also a maulvi. he said show him to a doctor there is something wrong. 101-110 Interp: the women is saying in your mind what is helping him to get better? Mum: Allah. Allah will help him. He takes those medicines. Those medicines
	When in Pakistan get medical and tarveez treatment	in Pakistan we admitted him to the hospital. A psychiatric hospital (unclear) He wouldn't take his tablets, you know and the tablets made him calm down (...) (unclear) We also did the vital important prayers over him. 123-6
	Son's refuses both approaches	Interp: They spent a week, but err, he wouldn't take his medication. I think the maulvi at (place) had prescribed him something as well, the homeopathic doctor.

Influence of western society	Marriage issue	We wanted him to get married but he was very ill. He always use to say that he wanted to get married, we didn't know what was going on, why he was saying that. 234-6
	Cinemas and going out is bad for him	don't let him watch film. I don't like films myself, I would like him to do his prayers. 353-4 Mum. When he's in the house he is ok when he goes outside he suffocates. Interp: she was, he's fine when he's in the house, but when he goes on the outside, it suffocates him – she's using the word like suffocate, that's how it is in Pashto, but she means like, that he's not right, he is back to, you know, how he is or whatever. 360-66
	Films on internet made him paranoid	He use to watch dirty films dirty, dirty films he used to watch. He's my good son. Now he has become wrong. That's what's done it. He would pressure, on his brains, he wouldn't go to sleep he would watch, which has affected his brain. 477-81
Worry is normal		He's my little child of course I worry about him 292

THEME	COMMENTS	QUOTE
Help seeking	Maulvi first 25	some people tell her, somebody, one woman, her daughter was sick, they went there. Another woman, her son was like him, they went there. So, I say ok, we go there. (...) we went there.
	Maulvi sends to GP <i>Medical and spiritual cures- poss to have 2 beliefs about illness</i>	then he said, you better take him to doctor. But he, did, it's a good thing, so next day, I took him to the doctor. 297-9
		very cleaver man. Very good man. A lot of people come to him. A lot of people get better there
Forcing – balance between compulsion and care	Services here can't. Pak calm him down <i>treatment –either med or maulvi could work but son doesn't engage</i>	so I took him Pakistan, put him into psychiatrist hospital. They put him down. (...) They were not bad, they put him down, the way they treat him, is too much. Its very, hard – tired him up and (...) anyway, I anything I would do for him, for his benefit
Service role blurred	Key worker as a friend	Oh she talks with him very soft and nice talk. Like a friend, you know. She tells hims she is like a friend. Or keep secret, I don't know what secret he's got! Just joking with him really!
	Team good as reliable	
Feel responsible for care		No, no she never forgets. Anyway, I don't let her forget, I ring. When medicine is finished.
Nature of Illness: Deception and denial		So he started using it in a bad way. He staying three o'clock, four o'clock morning, watching those bad things. I didn't know. And he made a fool of us. 132-5
	Can't see medication helps	I said, everybody get ill, they get medicine and they get better. And he take medicine, before

	101-5	this. But he saying, it he say no, won't work. And he says no I am telling the truth, it won't work on me.
		"So I said why you not, you take the exam? He said I did exam, I did exam" 8-9
Nature of Illness: Odd paranoid behaviour	Need to observe son 15-19	Then I start getting notice, when he walked to school he look down. He go, and kept looking back, like this. You know? So I went there, I followed him...its fifteen minutes walk, he took nearly three-quarters
Nature of Illness: wild and disobedient	40-41	He just grow, like wild, grow his beard and hair, and like wild. If I say anything, he runs.
Causes	Depression	
	Someone caused it	I can be that somebody did something to him, bad, bad you know, you see. And he said, send him to the doctor, he said its something, depression you have. 27-9
Cause is this society	Loneliness 119-21 this society and family not around	you know, I know, everyone can in this country, especially – its loneliness. I mean, if he had a brother or sister around him it would be alright. well, community can't provide him a friend. He want friends. 251-2
	Bad for sexual/emotional dev 155-7	I think. I think that was bad for him. And then, (...) when I say that because all of a sudden you know he is talking about getting married. I say you are only a baby, no – no I want to get married.
Not recovered but on road to recovery	Not alright but better Need to go easy	So he's alright, better now. He's not alright but he's better. So now he's going back to his college...He want to do more but I said "go easy". 108-12

Go easy chronic ill role		So first think that you are a sick man, a sick person. Don't take too much pressure on your back. Go easy. No matter what you do, but go easy. Be happy all the time. 181-4
	Flexible – can do whatever 171	You go to school or work, I am not bothered about it.
	Make him happy by putting his needs first 211-8 and 355-7	you try your best to be with them all the time. We try our best to be, to keep him happy. (...) I mean, anything we do we do for S.
Worry natural	206-7	if you have a kid, and there is something wrong with them, its not normal, wouldn't you worry?
	197 role to get kids set up	Dad: so, I don't know. This is it really. This is our only one son. In fact we got two daughters in Pakistan, get married and they finished from me. You know, they got their own life. So.