University of Sheffield

Approaches in Considering Cultural Issues in South Asian People with Learning Disabilities and their Families; The Experiences of Pakistani Muslim Maternal Carers of Adults with Learning Disabilities

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Declaration

This work has not been submitted for any other qualification or to any other institution.

Thesis Abstract

This thesis is divided into three sections:

Section 1 –

Literature Review: Approaches in Considering Cultural Issues in South Asian People with Learning Disabilities and their Families

This review focuses on two areas of the literature, highlighting service issues surrounding South Asian people with learning disabilities and their families, and considering the perceptions and experiences of people with learning disabilities and their carers. It concludes by reflecting on the cross-cultural implications of the research and identifying deficits within service provision for this population.

Section 2 –

Research Report: The Experiences of Pakistani Muslim Maternal Carers of Adults with Learning Disabilities

This study aimed to detail the experience of maternal carers of South Asian descent living in Britain who care for an adult with a learning disability. Eight Pakistani Punjabi or Mirpuri speaking mothers or maternal carers of adults with learning disability were interviewed. Interviews were translated into English and Interpretative Phenomenological Analysis was employed to explore experiences and examine beliefs surrounding learning disabilities within this population in order form interpretations of the participants' experiences. Three super-ordinate or master themes emerged from the data. These are 'Faith, Destiny and Understandings', 'Maternal Obligation' and 'Stereotypes and Assumptions'. These themes and corresponding subordinate themes are explored with detailed extracts from participant interviews. Insight into the multi-dimensional experiences of the participants has been gained in order to increase the knowledge base in this under-researched area. Clinical and further research implications

are discussed.

Section 3 –

Critical Appraisal

The critical appraisal includes commentary and reflection on the process of conducting this research taken from a research diary written during the course of this study. It includes initial ideas, planning and negotiating issues, difficulties and overall learning from the research process

Acknowledgements

Bismillah

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Word Count

	Excluding References	Including References
Literature Review	6007	6882
Research Report	12,282	13,492
Critical Appraisal	2347	2446
Appendices		9703
Total without Appendices		**22,820**
Total with Appendices		**32,523**

The Literature Review has been written in accordance with the guidelines of the Journal of Applied Research in Intellectual Disabilities - Jarid (Appendix Ia).

The Thesis is submitted under **Option A** guidance (Appendix Ib)

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4. Appendices

SECTION 1

Literature Review

Cultural Issues in South Asian People with Learning Disabilities and their Families

Cultural Issues in South Asian People with Learning Disabilities and their Families

ABSTRACT

Background. The aim of this review is to outline the literature on issues of culture concerning people of South Asian origin with learning disabilities and their families.

Materials and Methods. Papers have been included from over the last ten years (1994-2004) and only UK based studies are reviewed.

Results. This review highlights two areas of the literature: service issues surrounding South Asian people with learning disabilities and their families, and considering the perceptions and experiences of people with learning disabilities and their carers.

Conclusions. Reflections on the cross-cultural implications of the research are made and deficits within service provision for this population have been identified.

Keywords: Learning Disabilities, South Asian, Culture, Carers, Services.

INTRODUCTION

Background

There are approximately 1.4 million people with learning disabilities in the UK (Department of Health, 2001). The Government highlight in the White Paper, 'Valuing People' (DOH, 2001), that this group is the most vulnerable and socially excluded in society. It proposes the principles of "Rights, Independence, Choice and Inclusion" to enhance mainstream service provision for all people with learning disabilities[1] (LD) and their families. It also identifies that person-centred planning should be at the heart of service provision for individuals with LD, and that carers should be supported both financially and through local agencies. Independence within daily living, and increasing opportunities for work and education are also emphasised.

People of non-White origin make up approximately 13 percent of the population of England (Census 2001). South Asians consist of approximately 2.7 percent of the UK population, with people of Pakistani origin making up approximately a third of that amount (Census 1991). In a report to the Department of Health, Mir and Nocon (2001) recommend that further principles of "Partnership, Advocacy, Independent Living and Empowerment" as necessary in providing an inclusive service for ethnic minority groups with LD. Consultancy of and partnership with local ethnic minority groups is necessary in order to ensure appropriately planned services considerate of their differing needs and values. Advocacy is highlighted as a method of working with families, as well as individuals, and its importance is recognised in promoting independent living. However, this 'independence' must be both mindful and respectful of the context of close family networks that can exist in many minority communities. The report underlines the importance of empowerment in terms of choice and involvement in

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[1] Within this literature review, the terms 'learning disability', 'learning difficulty' and 'intellectual disability' have been considered interchangeably'.

decision-making, and in accessing support for people with LD and their families. Service uptake can be encouraged by allowing access to bilingual staff and interpreters, thereby reducing communication difficulties for service-users and families. Only with increased cultural sensitivity and continuity between home and service environments, can ethnic minority communities enjoy a fully inclusive service (Mir & Nocon, 2001).

The Hester Adrian research report (Hatton et al, 1996) identified the needs of Asian people with LD and their families, particularly highlighting low levels of access to services and challenges within services of providing appropriate support. There is evidence to suggest British Asians face substantial inequalities and discrimination. For example, they are more likely to live in sub-standard housing in inner city areas, have semi-skilled jobs or be unemployed compared to the indigenous White population (Modood et al, 1997; Kaur & Routledge, 1998).

'Cultural Issues'

This literature review aims to consider the cultural issues surrounding people of South Asian origin with learning disabilities and their families. The term 'culture' has been described as a 'poorly defined' construct (Hatton, 2002) and one which is often used along side or instead of the terms 'ethnicity' and 'race'. Culture has been considered to be a shared world-view, belief or value system held by a group of individuals. Ethnicity has been defined to be a group of individuals who share an identity, common heritage and language, whereas race is based on genetically transmitted physical features such as skin colour (Hatton, 2002). For the purposes of this literature review, the overlap between the two constructs of ethnicity and culture will be considered within the framework of 'cultural issues'. Whilst acknowledging, however, there are some specific factors, which relate only to ethnicity, such as ethnic identity and bilingualism, and specific to culture, such as perceived social class (Hatton, 2003).

There is a small amount of research exploring the experiences of people with disabilities of ethnic minority origin in the UK. In one of the few reviews carried out, Ali et al (2001) reviewed literature concerning the views on disability of White and ethnic minority children and young people with and without disabilities. The authors highlight that Black and Asian people and their carers experience disability differently to the indigenous population. They found the literature to centre around three major themes: identity and self-image, attitudes towards childhood disability within minority and majority communities, and the perception of appropriateness of services (social care, health, education and advocacy) provided to families. The papers reviewed consider the issues of discrimination and racism young people may experience along with their disability. They also identify that ethnic minority language, culture and religions can be neglected in service provision which can lead service users feeling that their needs are disregarded (Ahmed et al, 2000). They further comment that the experience of individual racism and institutional racism can impact on identity and self-image of disabled young people. Poor communication between services and carers can result in carers feeling confused, ridden with guilt and disbelief (Shah, 1997). Although providing a useful insight into culturally sensitive issues, this review does not consider learning disabilities as a separate issue and does generalise between minority communities.

Hatton (2002) reviewed literature from the US and UK on ethnicity and learning disabilities. He identifies that significant research attention has been directed towards the experiences of children from ethnic minority communities and their families, however much less attention has been directed towards adults. This review considers the literature in a number of themes and studies the conceptual framework of the research within the context of cross-cultural psychological theory (Berry 1999, cf: Hatton 2002). 'Absolutism' assumes that human behaviour is the same across all cultures this implies, for example, psychological measures developed within one cultural group can be translated, if necessary, and used with another group. 'Relativism' (also referred to as emic) assumes that human behaviour is unique and culture-specific, therefore cross-cultural comparisons cannot be made. 'Universalism' is the cross-over between these two positions (also referred to as etic), that is that basic human characteristics are universal however culture influences their presentation within different populations. This view can be tested empirically and cross-cultural differences between groups are rooted in a combination of variations in biological, economic and cultural factors. This approach aims to establish cross-cultural equivalence of the theoretical constructs that exist within a particular theoretical framework and develop measures that are also equivalent (Hatton, 2004).

Hatton concludes that much of cross-cultural research with people with LD has taken an absolutist position, either by excluding people of ethnic minority origin from research, or by not presenting culture or ethnicity as a potentially relevant variable within theory and research findings. Hatton states that the universalist position seems to be the most appropriate to increasing knowledge and understanding of ethnic minority people with LD. He also notes that previous research that has taken this perspective fails to consider differences with ethnic groups in detail, but also does not explore the variation within ethnic groups, which is especially important when testing hypotheses.

This review will have a two-fold focus. Firstly, exploring what services exist for South Asian people with learning disabilities and their families and whether cultural issues are addressed. Secondly, considering the perceptions and experiences of carers and people with learning disabilities, which has been highlighted by Ali et al (2001) to be a different experience to the indigenous population. Throughout this review, South Asian has been considered to include people from India, Pakistan and Bangladesh; however some studies reviewed also include people of Indian origin who have lived in East Africa.

MATERIALS AND METHODS

Search Strategy

A number of key words were used to form the search strategy for this review: intellectual/learning; disabilit*/difficult*; culture; cross-cultur*; Asian; carer; family; ethnic minorit*; ethnicity.

The search engines utilised are listed below:

- PsychINFO
- Medline
- Webspirs/ Web of Science
- Manual search for papers, including searching the internet and using references from collected papers that were relevant.

During the manual search for papers, it was noted that many papers from the 'grey' literature have been included in previous literature reviews. These papers have been included in this review and their implications are further addressed in the 'discussion' section. Papers have been included from over the last ten years (1994-2004) and only UK based studies are reviewed in order to gain a picture of the experiences of South Asian people in the UK and relate this to service issues. Papers from other Western countries have been excluded because of the possibility of different cultural and service issues.

RESULTS

Prevalence of Learning Disability in the UK South Asian Community

There have been few studies examining prevalence of learning disability in this population. Emerson et al (1997) attempted to measure prevalence and range of learning disability in the Asian populations of three metropolitan boroughs by contacting various services and identifying people as having learning disabilities, and by using a case register to identify Asian and non-Asian people with learning disability. They found that there were fewer people of Asian origin with mild learning disabilities in comparison to non-Asian people. However, in five to thirty-four year olds, the prevalence of severe learning disabilities was three times more likely in the Asian population when compared to the non Asian.

An equivalent finding has also been found in a recent study (Kerr, 2001) which found severe learning disability to be markedly higher in those of South Asian descent and that they were more likely to have a sibling with a learning disability. However, sample size in this study was relatively small. A recent study, considering prevalence of learning disability in Leicestershire amongst Asian and White adults, found that it was approximately equivalent in both populations. However, this study considered mainly people of Indian origin whereas the previous studies may have included more participants of Pakistani origin (McGrother et al, 2002). This study has been discussed by Emerson and Hatton (2004) who consider there may be significant differences in age and social deprivation between Indian and Pakistani populations which may account for the reported discrepancy in prevalence. A recent report to the Department of Health, using epidemiological trends, suggests that there will be a considerable increase in Asians within the UK with severe learning disabilities over the next 20 years (Hatton et al, 2002).

a) Exploring service issues

Few studies have considered how many clients of Asian ethnicity currently access services. One study used the 1991 Census and Department of Health statistics to monitor number of people from ethnic minority background within residential services. It concluded that young Asian men and women were significantly less likely to be placed in residential provision than their peers from other ethnic backgrounds (Emerson & Hatton, 1998).

Other studies have focused on specific aspects of service provision. Chaplin et al (1996) retrospectively compared the use of out-patient Psychiatry services in Leicester between Asian adults with LD and White controls. Data collection involved the use of the Learning Disability Register, which contains information on medical check-ups, socio-demographic details, ethnicity and other health and social issues. Service records were reviewed to indicate the number of service-users within the identified year of study. Each Asian service-user was matched (by age and sex) with two White controls who had also accessed the service within that year. Case notes were analysed to gain information about service-users such as, for example, cause and severity of LD and psychiatric diagnosis determined by ICD-9 and the pattern of service use was indicated by number of contacts within the year of study. Thirty-eight Asian people were identified with 76 White controls. The authors found that over all Asian people were under-represented on the Learning Disability register. However, once in contact with services, Asian patients were as likely to be referred to specialist psychiatry services, mainly by medical practitioners such as GPs. The study found a greater proportion of Asian service-users with a psychiatric diagnosis (96%) compared to controls (78%) and that the Asian group contained more people with a diagnosis of functional psychosis. The authors relate this finding to a number of explanations, particularly highlighting the relationship between ethnicity, economic adversity and social class with increased psychiatric morbidity. Any conclusions drawn, however, must be viewed as tenuous, as this study was conducted retrospectively and with use of case-notes which are often written by a number of record-keepers and contain variations in level of detail. Nevertheless, this study does indicate a potential gap in service provision and the need for future research.

O'Hara and Martin (2003) carried out a retrospective study over five years examining gaps in service provision of a Community learning disability health team (CTLD) for English and Bangladeshi clients. Cases were identified on the current case load and through previous case notes of clients who were no longer receiving services (54 people were identified, 22 English; 4 male, 18 female; 30 Bangladeshi; 15 male, 15 female). Although a small sample was considered, the authors note that there was a difference in marital status between both groups of men, only two English men either were married or cohabited compared to all fifteen Bangladeshi men, although the wives of three men were still in Bangladesh. Due to a specialist service, (Bangladeshi Parent Advisor Service), the authors were able to collect outcome data on the children of Bangladeshi fathers. They found that the many of the Bangladeshi men had fathered more than one child and many were living in the traditional family environment. However, they highlight that the CTLD had offered little psychosocial support to the fathers with learning disabilities. Service provision had mostly been concerned with supporting mothers with LD and this did not include the non-disabled wives of clients with LD and their children. The study indicated a difference in marital relationships as all of the Bangladeshi women were married (although two subsequently separated) whereas only seven English women were married or cohabiting. The authors also note that the age of the Bangladeshi mothers was younger than the English women, and previous terminations of pregnancies were higher in the English group. This paper particularly highlights the increased number of children living at home with the Bangladeshi mothers, 85 percent compared to only 29 percent in the English group. Furthermore, despite Bangladeshi mothers having significant disabilities and a proportion had a referral to psychiatric services following concerns for their child, none of the children were on the child protection register.

This study is a snap-shot of services provision and does not give a comprehensive comparison between groups, as only in-depth information about the Bangladeshi group was available due to a specialist service. Nevertheless, it does highlight important issues for service provision. O'Hara and Martin indicate the challenge of empowering clients with learning disabilities to consent to sexual relationships within the context of a Bengali culture that sees marriage as an entry into adulthood for a person with LD. It is also highlighted that a significant premise of services is an expectation that extended family networks will support these mothers (O'Hara & Martin, 2003).

Individual case studies have further identified issues for services. Hepper (1999) discusses the case of a 27 year old Bangladeshi woman, given the pseudonym 'Amina', with moderate intellectual disability and epilepsy and considers the issues of offering appropriate psychological and social support to her. This case is considered because of the dilemma Amina presented to services after her marriage to a cousin in Bangladesh and the subsequent decline in her mental and physical health, which required admission to a medical ward. Although this is a single case and the results cannot be generalised, Hepper highlights the challenges faced by professionals when trying to understand the cultural and societal influences which led to Amina's illness, which they saw as a traumatic response to her marriage. The author interviewed her parents to gain an understanding of their beliefs and attitudes about Amina's condition.

This case raises serious questions about Amina's ability, for example, to make decisions concerning her marriage particularly around the sexual relationship and in taking on domestic duties. It also highlights the appropriateness of services that are aiming to determine her level of understanding. For example, Hepper outlines that guidelines used to teach people with learning disabilities about sexuality are rooted in the Western feminist perspective and may impose those ideals on what a consenting sexual relationship should be, thereby failing to allow for cultural differences. It seems important to note that Hepper interviewed Amina's parents and little information is present from Amina herself.

Some research has been conducted around specific aspects of service provision for South Asian families. Hatton et al (2003) explored the impact of the process of disclosure to parents that their child has severe intellectual disabilities, where parents are often presented with the initial challenge of adjusting to their child's disability. The authors divide the challenges resulting from disclosure into two categories, either viewed existentially, that is, as 'problems of meaning and acceptance' and or seen within practical terms, that is the 'day-to-day adaptations to their child's disability'. Previous literature, from studies with White families, indicates that increased parental satisfaction with the disclosure process is related to both these areas being addressed (Sloper & Turner 1993a cf: Hatton et al, 2003). For example, existential challenges can be addressed by allowing enough time for consultation and offering emotional support, and giving parents enough information and support with finances could tackle practical challenges. The authors suggest that South Asian families are more likely to experience these challenges as crises due to not having English as a first language and the possibilities of the added experiences of racial discrimination and poverty.

This study employed both quantitative and qualitative methodologies over three phases. Hatton et al interviewed 26 South Asian families with a child with severe intellectual disability, from these interviews they created a structured interview which they carried out with 136 parents, including those who participated in the first phase. Following this, they re-interviewed those who participated in Phase 1 and 2 (20 out of 26) using a semi-structured interview aiming to check the information gathered. The families originated from a number of countries, India, Pakistan, Bangladesh, East Africa and spoke a range of languages: Urdu, Punjabi, Pashtu, Bengali, Gujarati, Swahili and English. Phase 2 consisted largely of information gathering about the disclosure process, whereas Phase 1 and 3 explored how disclosure was perceived. Phase 2 identified disclosure occurred early in childhood, for example, that almost half of the parents had suspicions that their child had a disability before formal medical disclosure took place. Phase 1 and 3 indicated that parental acceptance of their child's condition was aided by receiving information in an appropriate language, gaining some of the medical knowledge about the disability and giving the disclosure in an emotionally sensitive way. There was a general level of satisfaction with disclosure within this study. However, when results were compared to previous studies with White participants, there were key differences: diagnosis was received much later for families in this study and there were issues around language, for example, disclosure and written information not always being provided in the families' preferred language. The authors highlight that poor disclosure can have a long-term impact on many factors, including family acceptance of the child, uptake of benefits and use of services (Hatton et al, 2003).

Some work has been done to try and improve information to Asian carers. One such project looked at providing information about autistic spectrum disorders to Asian families in Bradford (Dobson et al, 2001). The researchers trained bilingual workers to present a case vignette of a person with autism to three groups of participants (12 per group), each speaking a different language (Urdu/Punjabi; Bengali & Gujarati). They then interviewed the participants about their views, knowledge and beliefs about the disorder. They found that there was confusion about the difference between autism and other disorders, and uncertainty about its cause. Many families felt that autism was curable through socialisation rather than medication or diet. There were also wider implications found relating to how the family may be viewed in the community, for example, the effects on the marriage prospects of siblings and shame or embarrassment for the family. The authors attempted to use these views as a basis for planning their information pack. They found difficulties in translating the pack into Asian languages, for example, there is no equivalent word for autism. The English descriptions of autistic spectrum disorders are not easily translated to comparable words in the Asian languages. They cite an example of an information leaflet in Urdu, where the word 'disorder' has been translated as 'deformity'.

Shah (1997) has produced good practice guidelines when working with Asian families and children with disabilities. She highlights that there is a deficit in the system of early diagnosis and identification of difficulties in Asian families. The gap in this service provision slows down the offering of appropriate interventions which in turn impacts on the child's development. In line with previous literature, issues around language are described, highlighting the importance of interpreters who are appropriately trained. She also outlines the necessity of culturally appropriate counselling and support for families and cites examples of good practice, e.g. the Parent Advisor Scheme in Tower Hamlets (Davis, Buchan & Choudhary Ali, 1995).

b) Views, perceptions and experiences of people with LD and their families

Some studies have focussed on the experiences of people with disabilities and their families. Chamba et al (1999) surveyed 600 ethnic minority (Black, Afro-Caribbean and Asian) parents of a severely disabled child. They compared this to a previous study with the general population carried out by Beresford et al (1995). Black and ethnic minority carers within this study experienced many inequalities in social needs including: low incomes, lower uptake of disability benefits and substandard housing which was inappropriate for their disabled child. The survey also identified that parents, particularly non-English speakers, were poorly informed about their child's impairment. It also highlighted that not all families had extended families who could be called upon for extra support, and those that did, had less than their White peers. They concluded that there were high levels of unmet need and stereotyping and myths need to be replaced with more competent service provision.

There is evidence to suggest that South Asian carers of people with disabilities face culturally-specific difficulties. Katbamna et al (2001) in a qualitative study interviewing 105 carers (either individually, within a focus group or both) considered the views on disability and care-giving of South Asian carers. The authors struggled to separate attitudes towards disabled people and those towards their carers, as negative comments about disabled people were often directed towards their carers. These negative perception were often held by people known to the carers, and were rooted in lack of understanding about cause of disability, fear and stigma. Carers' views were influenced by various factors including religious beliefs, nature of disability and gender differences. The authors noticed different caring issues according to gender of child, for example, carers seemed concerned about their daughter's reputation within society particularly with respect to marriage and social inclusion. Differing religious affiliations impacted the views on disability. Some Hindu and Sikh carers held beliefs that the disability and their caring role was a 'karmic' response to past sins, or they were settling 'debts', that is their bad deeds from a previous life, whereas Muslim carers believed that their role was their destiny and accepted disability as God's will. Katbamna et al (2001) also highlight the differences between female carers and male carers, where female carers often held multiple roles within the family and struggled to gain support from other relatives and services.

Although, the above papers outline general issues surrounding caring for a person with disabilities, they do not deal with learning disability as a specific issue. One study has looked specifically at the South Asian carers of adolescents and adults with learning difficulties (Hatton et al, 1998). The researchers interviewed the main carer in 54 families of South Asian descent, with the majority being of Pakistani and Muslim origin. Their aims were to identify the support needs of the families and to consider the stresses of the main carer and their service requirements. They found the main carers to be mostly mothers of the person with learning difficulties. They used a translated version of the Malaise Inventory (Rutter et al, 1970, cf: Hatton et al, 1998) to identify risk of developing psychiatric problems. Although the face validity of using this measure was checked, the internal validity was not, therefore possibly questioning the quality of the questionnaire. Nevertheless, they found 78 percent of Asian carers to be at risk of developing psychiatric difficulties. They compared this result to previous studies of parents with other disabilities and found this sample to be the most distressed. Regarding service provision, most carers reported being unaware about services and felt there were few members of staff who could speak their language.

There is evidence to suggest that carers of South Asian origin may experience higher levels of psychological distress. Emerson et al (2004) carried out a study to examine the impact of child-related factors, ethnicity and levels of neighbourhood socio-economic deprivation on levels on psychological distress reported by family carers of children with LD. Information was collected by postal questionnaire or interview for those that did not have English as their first language. The authors collected a variety of information including: basic demographic information of the young person with LD, developmental delay and other impairments, level of deprivation, and information on the child's mental health needs through measures given to carers. Carer psychological distress was measured by GHQ-12. Using regression analysis of variables, the authors found 47 percent of primary carers scored above the threshold for psychological distress on GHQ, and this was related to emotional and behavioural needs of the index child, ethnicity and severity of delay in child. However, these results were influenced by a low response rate and this may have an impact on the associations made between level of psychological distress and variables. The level of social deprivation or social support experienced by the participants may have influenced the psychological distress experienced, therefore the associations between the variables and distress must be viewed with caution. Nevertheless, this study indicates a strong association between being in the South Asian ethnic minority community and carer psychological distress. This result is not affected by the method of data collection (that is, interview or questionnaire), although it may be influenced by social deprivation, as previous literature suggests significant links between ethnicity and social deprivation (Modood et al, 1997).

As highlighted earlier, there is some literature to suggest that parents of Asian descent have differing beliefs about learning disabilities to their White counterparts. There is evidence to suggest this may impact on how services are accessed. Fatimilehin and Nadirshaw (1994) compared the views of Asian and White British families, about their adult son or daughter's learning disability in the context of their culture and belief systems. A structured interview was designed from an unstructured interview carried out with a small number of families. The unstructured interview aimed to look for similarities and differences in views between both groups with regards to culture and religions. For example, questions were asked about their son's/daughter's problem, its cause, feelings about the disability, religion, service usage etc. Parents were also asked about other family members' views and what things could be done to help their son/daughter. Twelve families from each group were questioned using the structured interview derived from the earlier interview and the differences were analysed between groups.

This study indicates that there were significant differences between the groups. Children were older within the Asian group than the White group when families became aware of the disability. Most Asian families had contacted a holy person as well as medical practitioner whereas only one of the White families had done so. Also significant, more White than Asian families had received a medical explanation for their child's difficulty. Although there were no statistical differences between groups in terms of service utilisation, fewer Asian families had accessed services. A greater picture of patterns of service use could have been gained if the study had included a larger sample size. More Asian than White families felt their doctor and religion would help their son/daughter improve and more Asian families described themselves as religious. The difference in social support received from family was statistically significantly more in Asian families than White. White families indicated that they wanted their child to be cared for in a community home if they were no longer able to provide care whereas most Asian families wanted a relative to care.

Although there few participants in the comparative groups, this study highlights that Asian families are less well informed about the cause of their son's/daughter's learning disability when compared to White families. The authors also indicate that beliefs held about disability may have an impact on how Asian families access and utilise service. The authors suggest increasing the use of interpreters in order to successfully provide information about disability and consider religious needs in care services offered to individuals with LD (Fatimilehin & Nadirshaw, 1994). Other evidence suggests that if carer need for information and practical support is not met, it can adversely affect the individual with disability by carers holding negative views of disability (Mir & Tovey, 2003).

When appropriate to level of impairment, few studies have interviewed people with disability in order to gain a picture of their views. Hussain et al (2002) interviewed 29 young people with disabilities (17-30 years old) of Muslim and Sikh origin (as no Hindu participants could be found), and 14 parents and 15 siblings of the young people. They were interviewed on how they saw themselves, their attitudes, perceived barriers to their needs, and whether discrimination was experienced. They explored other influences of how they saw their impairment and the potential influences of religion, ethnicity, culture, gender and age. Participants felt that they were denied opportunities and had experienced social discrimination for example at work and in their education. Many participants felt that they had a different cultural identity to their parents; although, they thought their religion was important to them but often access to religious events was a problem.

Azmi et al (1997) considered the views of South Asian adolescents and adults with LD on their day service, accommodation, service support, friendships, relationships and ethnic and racial identity. The authors interviewed 21 participants in their first language, the majority of who were of Pakistani origin. Interview data was content analysed and a trained rater was asked to indicate satisfaction on a five-point scale. Regarding day services, for example, interviewees reported although they were satisfied with them at a general level, some felt they did not receive religiously appropriate food, or their religious or cultural festivals were not recognised. The interviews also explored views on experiences of racism and stigma. Sixty-three percent of participants felt that they were treated badly because of their ethnicity and fifty-seven percent felt they were stigmatised because of their disability. Participants felt satisfied with their family and home life, with many receiving significant support from parents and other family members and few expressing preferences to live independently. However, there was some evidence to show living with families may be imposing restrictions on the participants, for example, participants reported that they only went out with family members and would have liked to go out more.

DISCUSSION

This literature review highlights an emerging picture of the cultural issues surrounding the experience of learning disability within Asian families. The research base is beginning to grow in size and take together the studies do provide some key themes, which are largely recognised by the papers reviewed. Although this review has been presented as containing a two-fold focus, it is apparent that both the issues of service access and provision, and experiences and views of those with learning disabilities and their carers, are inextricably linked.

There have been several links made between people of South Asian origin and social deprivation, which may have a significant impact on the prevalence of learning disability within this population. Low levels of service access and uptake have been highlighted as a cause for concern by several studies particularly within residential service provision. There are suggestions that issues with service are mediated by difficulties with language, particularly as Asian families without English may view day to day difficulties with caring for a person with LD as crises (Hatton et al, 2003).

The literature has also indicated that services have needed to adapt and think about issues of South Asian culture. This has consisted of exploring the views of individual service users and carers or families. There are few studies that involve service users themselves; however these studies indicate the presence of perceived 'double discrimination' due to having learning difficulties and being of minority ethnic origin. Issues of marriage, sexuality and child rearing have created dilemmas for services and resulted in perceptions, views and belief systems around disability being explored in order to provide a more culturally competent service. Also highlighted, is the psychological distress experienced by carers, in particular primary carers who usually are mothers. However, there has been no research looking at the experiences of mothers caring for their son or daughter with LD.

In considering the conceptual framework presented by Hatton (2002), it has become clear that the literature does not seem to reflect on the cross-cultural meanings of their findings. Within the methodologies, some of the literature takes the 'absolutist' position, for example, in studies using psychological measures, such as the GHQ and Malaise Inventory, as measures of distress within the Asian population (Hatton et al, 1998; Emerson et al, 2004). However, a proportion of studies do seek to make cross-cultural comparisons thereby assuming the 'universalist' or etic position (e.g. Fatimilehin & Nadirshaw, 1994), which is in line with Hatton's (2002) own conclusions. He further identifies that studies have described differences between ethnic groups but have stopped short of explaining these differences and exploring the variation within ethnic groups, which is the case with the studies reviewed here.

The literature reviewed is far from providing a comprehensive picture. The participants who have been studied often are from differing cultures all considered under the banner of 'South Asian'. Few studies have reflected upon the differences within their mixed samples. There have been few quantitative studies and those that have been carried out have had small sample sizes whilst the prevalence rates of LD suggest there are more potential participants than the literature reflects. Although more literature has used qualitative methodology, the assumptions underlying the research questions have not been made explicit and there have been deficits in depth and breadth of analysis carried out (Yardley, 2000). This may be due to seminal studies largely originating from grey literature and not peer-reviewed journals which may have more of an emphasis on methodological competence.

In order to adhere to the good practice service principles outlined by Mir and Nocon (2001) there needs to be further research into the context of close family networks that can exist in many minority communities and sense those families make of LD. No research has looked specifically at the Pakistani community, although it has been identified to be the group which is the most socially deprived and may therefore have a higher prevalence of learning disability. For the 'partnership' model to be truly successful there needs to be greater understanding between services, their clients and those who care for them.

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SECTION 2

Research Report

The Experiences of Pakistani Muslim Maternal Carers of Adults with Learning Disabilities

The Experiences of Pakistani Muslim Maternal Carers of Adults with Learning Disabilities

ABSTRACT

Objectives. To gain a detailed view of the experiences of maternal carers of Pakistani origin living in Britain who care for an adult with a learning disability.

Methods. Eight Pakistani Punjabi or Mirpuri speaking mothers or maternal carers of adults with learning disability were interviewed. Interviews were translated into English and Interpretative Phenomenological Analysis was employed to explore experiences and examine beliefs surrounding learning disabilities within this population in order form interpretations of the participants' experiences.

Results. Three super-ordinate or master themes emerged from the data. These are 'Faith, Destiny and Understandings', 'Maternal Obligation' and 'Stereotypes and Assumptions'. These themes and corresponding subordinate themes are explored with detailed extracts from participant interviews.

Conclusions. Insight into the multi-dimensional experiences of the participants has been gained in order to increase the knowledge base in this under-researched area. Clinical and further research implications are discussed.

INTRODUCTION

Background

People of non-White origin make up approximately 13 percent of the population of England (Census 2001). South Asians, usually considered to be people originating from India, Pakistan and Bangladesh, consist of approximately 2.7 percent of the UK population with people of Pakistani origin making up approximately a third of that amount (Census 1991). There have been few studies examining prevalence of learning disability (LD) in this population[2]. Emerson et al (1997) found that there were fewer people of Asian origin with mild learning disabilities in comparison to non-Asian people. However, in five to thirty-four year olds, the prevalence of severe learning disabilities was three times more likely in the Asian population when compared to the non Asian. An equivalent finding has also been found in a recent study (Kerr, 2001) which found severe learning disability to be markedly higher in those of South Asian descent and that they were more likely to have a sibling with a learning disability. McGrother et al (2002) found prevalence was approximately equivalent in both White and Asian populations; however, this study considered mainly people of Indian origin whereas the previous studies may have included more participants of Pakistani origin. Emerson and Hatton (2004) consider there may be significant differences in age and social deprivation between Indian and Pakistani populations as factors which may account for the reported discrepancy in prevalence. Recent projected population figures for LD within the South Asian population suggest prevalence will considerably increase over the next 20 years (Hatton et al, 2002). This further highlights the importance of research interest in South Asian people with LD and their families.

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[2] Within this study, the terms 'learning disability', 'learning difficulty' and 'intellectual disability' have been considered interchangeably.

South Asian Carers of People with Learning Disabilities

There is little overall research exploring the experiences of South Asian carers, however, there is evidence to suggest that they face culturally specific difficulties. Fatimilehin and Nadirshaw (1994) compared the views of Asian and White British families about their adult son or daughter's learning disability, in the context of their culture and belief systems. They found that parents of Asian descent have differing beliefs about learning disabilities to their White counterparts and there is evidence to suggest that this may impact on how services are accessed. The study highlights that there were significant differences between the groups. Children were older within the Asian group, than the White group, when families became aware of the disability. Most Asian families had contacted a holy person as well as medical practitioner whereas only one of the White families had done so. They also found that more White than Asian families had received a medical explanation for their child's difficulty. This study suggests fewer Asian families accessed services generally, although a greater picture of patterns of service use could have been gained if the study had included a larger sample size. The authors included a mixed sample of Asian people from India and Pakistan with differing religious orientations (Sikh or Muslim). Although more Asian families described themselves as religious, the impact of different cultures on the views about a person with LD is unclear. Nevertheless, more of the Asian sample felt that their doctor and religion would help son/daughter improve.

Despite there being a small number of participants in the comparative groups, this study highlights that Asian families are less well informed about the cause of their son's/daughter's learning disability when compared to White families. The authors suggest increasing the use of interpreters in providing information about disability and considering religious needs in care services offered to individuals with LD (Fatimilehin

& Nadirshaw, 1994). Other evidence suggests that if carer need for information and practical support is not met, it can adversely affect the individual with disability by carers holding negative views of disability (Mir & Tovey, 2003).

The way families have been told about the learning disability itself has been reported to be a major distress to them (Shah, 1996). Hatton et al (2003) explored the impact of the process of disclosure to parents that their child has severe intellectual disabilities, where parents are often presented with the initial challenge of adjusting to their child's disability. The authors divide the challenges resulting from disclosure into two categories: either they are viewed existentially, that is, as 'problems of meaning and acceptance' or seen within practical terms, that is the 'day-to-day adaptations to their child's disability'. Previous literature from studies with White families indicates that increased parental satisfaction with the disclosure process is related to both of these areas being addressed (Sloper & Turner 1993a cf: Hatton et al, 2003). For example, existential challenges can be addressed by allowing enough time for consultation and offering emotional support, and giving parents enough information and offering support in tackling financial issues could address practical challenges. The authors suggest that South Asian families are more likely to experiences these challenges as crises due to not having English as their first language and the possibilities of the added experiences of racial discrimination and poverty also are suggested.

There was a general level of satisfaction with disclosure of diagnosis within this study; however, when results were compared to previous studies with White participants, there were key differences. Diagnosis was received much later for families in this study and there were issues around language; for example, disclosure and written information was not always being provided to the families in their preferred language. The authors highlight that poor disclosure can have a long-term impact on many factors, including family acceptance of the child, uptake of benefits and use of services (Hatton et al, 2003).

There is literature to suggest that Asian families experience high levels of material deprivation in terms of inadequate housing, poverty and unemployment (Hatton 1997, cf: Kaur & Routledge 1998, Chamba et al, 1999). Modood et al (1997) reported Pakistani and Bangladeshi families to experience the most social and material deprivation. Shah (1996) identified that only a minority of Asian carers have been found to speak or write English. Interestingly against a stereotype, very few Asian families report extended family members or siblings in the family available for informal support. As a result, almost 80 percent experience high levels of stress and additional health problems (Shah, 1996).

South Asian carers may experience higher levels of psychological distress. Emerson et al (2004) carried out a study to examine the impact of child-related factors, ethnicity and levels of neighbourhood socio-economic deprivation on levels of psychological distress reported by family carers of children with LD. Information was collected by postal questionnaire or interview (for those that did not have English as their first language). Using regression analysis of variables, the authors found 47 percent of primary carers scored above the threshold for psychological distress on GHQ, and this was related to emotional and behavioural needs of the index child, ethnicity and severity of delay in child. However, these results were influenced by a low response rate and this may have had an impact on the associations made between level of psychological distress and variables. The level of social deprivation or social support experienced by the participants may have influenced the psychological distress experienced; therefore the associations between the variables and distress must be viewed with caution. Nevertheless, this study indicates a strong association between being in the South Asian ethnic minority community and carer psychological distress. This result is not affected by the method of data collection, (that is, interview or questionnaire), although it may be influenced by social deprivation, as previous literature suggests significant links between ethnicity and social deprivation (Modood et al, 1997).

Although there are a number of studies that have considered the views of South Asian carers, few have reflected on the different cultures within their samples. Hatton (2002), in an extensive literature review, identifies that cross-cultural studies have described differences between ethnic groups but have stopped short of explaining these differences. There has been little or no exploration of the effects of the ethnic and cultural variation of South Asian participants within a sample who may originate from different countries, speak different languages and hold differing religious beliefs and cultural identities.

In considering the conceptual framework presented by Hatton (2002), it has become clear that the literature does not seem to reflect on the cross-cultural meanings of their findings. Some of the literature reviewed has taken the 'absolutist' or emic position, for example, in studies using psychological measures, such as the GHQ and Malaise Inventory, as measures of distress within the Asian population (Hatton et al, 1998; Emerson et al, 2004). However, a proportion of studies do seek to make cross-cultural comparisons thereby assuming the 'universalist' or etic position (e.g. Fatimilehin & Nadirshaw, 1994). Hatton states that the universalist position seems to be the most appropriate to increasing knowledge and understanding of ethnic minority people with LD.

Maternal Carers

Research has indicated that mothers are more commonly the primary carers of people with LD, and some literature has focussed specifically on their experiences although not particularly with mothers of South Asian origin. Emerson (2003) carried out a study of mothers of children and adolescents with LD. Using the Office of National Statistics survey data, he looked at the social-economic status of mother who were caring for a child with LD compared to those who were caring for children without LD. He also sought to identify negative psychological outcomes associated with raising a child with LD, as well as the variables that contributed to these negative outcomes. He found that those supporting a child with LD were significantly economically disadvantaged. The mothers of children with LD experienced a greater psychological impact, although socio-economic status moderated this effect. The gender of the child also had an effect on the mother, in that having a boy with LD adversely affected the mental health status of the mother. Kim et al (2003) compared mothers of a child with LD and mothers of adults with mental illness, with a focus on coping and psychological well-being, measured over a three year period. They found that mothers of children with LD used problem-focused coping more than the comparison group and this was associated with an increase in psychological well-being.

Katbamna et al (2001), in a qualitative study, considered the views on disability and care-giving of South Asian carers. The authors highlight the differences between female carers and male carers, where female carers often held multiple roles within the family and struggled to gain support from other relatives and services. One study has looked specifically at the South Asian carers of adolescents and adults with learning difficulties (Hatton et al, 1998). The researchers interviewed the main carer in 54 families of South

Asian descent, with the majority being of Pakistani and Muslim origin. Their aim was to identify the support needs of the families, consider the stresses of the main carer and their service requirements. They found the main carers to be mostly mothers of the person with learning difficulties. They also found 78 percent of Asian carers to be at risk of developing psychiatric difficulties. They compared this result to previous studies of parents of people with other disabilities and found this sample of Asian carers to be the most distressed. Regarding service provision, most carers reported being unaware about services available and felt there were few members of staff who could speak their language.

Culture, Ethnicity and Religious Beliefs

Different ethnic and cultural groups have been indicated to hold differing views about disability. Previous research has linked ethnicity, disability and stigmatisation (Azmi et al, 1998, Hussain et al 2002). Saetermoe et al (2001) suggest that there may be attitudes towards disabilities that vary across cultures. They found that (East) Asian-American participants were more likely to stigmatise people with disabilities than African-American, Latin-American or European-American participants.

Katbamna et al (2001) found that negative comments about disabled people were often directed towards their carers. Often these negative perceptions were held by people known to the carers and were rooted in lack of understanding about cause of disability, fear and stigma. Carer views were influenced by various factors including religious beliefs, nature of disability and gender differences. This study noted different caring issues according to gender of child, for example, carers seemed concerned about their daughter's reputation within society particularly with respect to marriage and social inclusion.

Differing religious affiliations have also been shown to impact upon views held about disability (Masters Glidden et al, 2001). For example, previous research has indicated religion as a factor in ameliorating some of the difficulties associated with having a child with disabilities (Blancher, 1994 cf: Masters Glidden et al, 2001). Katbamna et al (2001) found that some Hindu and Sikh carers held beliefs that the disability and their caring role was a 'karmic' response to past sins, or they were settling 'debts' (that is their bad deeds from a previous life). Muslim carers in contrast, were found to believe that this was their destiny and accepted disability as God's will.

Interpreters and Translation

Much of the previous literature discussed has employed methodology which has involved translation of data collection materials (e.g. Hatton et al, 1998; Emerson et al, 2004). Temple (2002) further discusses the implications of using translators in the research process. She describes two methodologies; where in the first, interpreters are used as vehicles to obtain data and are ignored in the research methodologies. In the second, they are considered part of the research process and their views have an influence in the discourse in which they participate. Temple emphasises the importance of considering and reflecting on the impact of interpreters on the research process, rather than them being seen as 'shadowy figures' who do not affect data collection methods. She expounds that if researchers are going to use translators, they must not be viewed as a 'cultural expert' and a wide consultation must be sought.

Previous research has highlighted other difficulties in translation into the Asian languages. One project (Dobson et al, 2001) looked at providing information about autistic spectrum disorders to Asian families in Bradford and found that English descriptions of autism spectrum disorders were not easily translated to comparable words in the Asian languages. They cite an example of an information leaflet in Urdu, where the word 'disorder' has been translated as 'deformity'. Few studies have considered training bilingual facilitators to conduct interviews with participants. Neufeld et al (2002) trained bilingual interviewers in interviewing skills in the context of qualitative methodology and ethical issues, and found this process of recognising interviewers in the research process allowed for greater accuracy in the data collection method (Esposito, 2001).

Aim and Implications of Current Study

Previous literature, which has employed a South Asian sample, has failed to consider the implications of having a possibly culturally heterogeneous group. An attempt will be made to obtain participants of Pakistani Muslim origin who have been recognised to be one of the most socially deprived groups in the UK (Modood et al, 1997). The current study aims to work within the gap of the current literature, in exploring the experiences of mothers or maternal carers of adults with LD. This has many implications in exploring how supported women may feel, the wider implication of having a learning disability within their family and what may help or hinder access to services. Qualitative methodologies will be used, as these will provide a detailed insight into the experiences of the participants that is necessary to increase the knowledge base in this under-researched area. Quantitative measures would only answer very specific research hypotheses and therefore may miss some of the depth of the experiences. By asking broad, non-directive questions and studying the particular themes that emerge from the interviews, qualitative analysis will allow a fuller picture of the participants' belief systems and perceptions of their son or daughter. An attempt will be made to enable participation of non-English speakers in order to provide access to people who may not usually be able to express their views and feelings. Similar to the literature, it could be that non-English speakers may have different ideas about their son's/daughter's disability than those that can get access to information about their condition.

METHOD

Design

A qualitative methodology was employed to explore participants' experiences. Although there are many types of methodologies, Interpretative Phenomenological Analysis (IPA, Smith, 1995, 1999; Smith and Osbourne, 2003) was chosen for this study due to the assertion that IPA can access a person's underlying cognitions, including beliefs and attitudes. This approach allows the researcher to gain an insider's perspective into the essence or nature of the phenomena of study, that is, individual experiences (Willig, 2001). As there are few studies which have examined beliefs surrounding learning disabilities within this population, IPA was deemed appropriate in enabling the researcher to draw interpretations of the participants' experiences that are rooted in psychological understandings. In using IPA, which emphasises a broad, open and non-directive approach, the intention was to gain a perspective of how participants' experiences fit in their life-worlds, rather than identify the social processes that account for the phenomena such as within Grounded Theory (Willig, 2001).

Participants

An attempt was made to recruit between eight to ten participants, a number deemed appropriate by previous literature to allow for sufficient participant consensus and a level of theme replication, when using IPA (Jarman, Smith & Walsh, 1997). Although there were some difficulties in recruitment, eight participants were recruited but due to equipment failure one interview could not be used. Information from seven participants is presented within the results section.

Criteria for Inclusion

1. All participants were Pakistani Muslim mothers or maternal carers[3] of adult children between the ages of 18 – 60 years who have a learning disability.
2. All were resident in the UK and had a degree of acculturisation in the UK. Level of acculturisation was considered to be 5 years or more.
3. Participants were chosen who did not have English as their first language in order to access people for whom Pakistani culture is central to their lives.

The influence of having a son or daughter with learning disability was considered in selection and an attempt at including an equal number of families with adult males and females with learning disability was made. However, difficulties with recruitment made this difficult and therefore all people eligible for selection were included.

Table 1 indicates the gender, age, and level of learning disability of their adult child, using pseudonyms as identifiers the participants. Specific details about the participants and their families have not been included, in order to maintain anonymity. Level of care is indicated by three categories, low, moderate and high. This information was gathered from the carer and categorised by the researcher.

Table 1.

Name	Type of Maternal Carer	Gender of Adult with LD	Age of Adult with LD	Level of Care Required	Years in UK (approximate)
1. Fahima	Mother	Male	19	Moderate	28
2. Kareema	Mother	Female	25	Moderate	18
3. Afiyah	Grandmother	Female	19	Low	38
4. Sayyida	Mother	Female	45	Moderate	28
5. Huda[4]	Mother	Female	18	High	6
6. Sultana	Step-mother	Male	32	Low	5
7. Halima	Mother	Female	18	High	19
8. Khadija[5]	Mother	Male	26	High	27

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[3] Initially mothers of adults with LD were only included, however this was extended to maternal carers due to difficulties in recruitment.

[4] Although this participant's interview did not record (due to equipment failure), notes from her interview have been used as an external check of themes.

Ethics

An initial research protocol was internally peer reviewed the University of Sheffield Department of Clinical Psychology Research Sub-committee. Following this, ethical approval was granted by North Sheffield Research Ethics committee, and research governance by Sheffield Health and Social Research Consortium[6]. In the event that participants were significantly distressed, it was agreed that a list of contact details of local services for them and or their son/daughter was made available, or steps would be taken for participants to meet with support staff, or if necessary their GP. This process was followed for one participant who was found to be significantly distressed and an appointment to see their GP was made.

Procedure

Potential participants were recruited through two local voluntary agency support services for Pakistani clients with learning disabilities and their carers, and through a local specialist Learning Disability Psychology service. Initially, information sheets with details of confidentiality and participant anonymity were first summarised to participants either in person or over the telephone and verbal consent was obtained. Participants were given a choice of where they would like to be interviewed, either in the community centre where the support groups were held or at home. All participants chose to be interviewed at home. Participants were then given a copy of the information sheet in their chosen language. Many participants who could not read or speak English chose an information sheet in English for other family members to read. Prior to interviewing, the information sheet was read out to participants and written consent was obtained[7].

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[5] Although, Khadija's first language was Punjabi, she was the only participant to speak fluent English and her interview was conducted in English.

[6] Ethical approval letter is included in Appendix II.

[7] The information sheets and consent forms in English and Urdu are included in Appendix III.

Research Team

The principal researcher is a practicing Muslim woman of South Asian descent, who has an interest in issues of cross-culture, particularly the South Asian community within the UK. Although an Urdu speaker, she was not able to do the interviews herself due to not being sufficiently fluent in Punjabi. A facilitator, who spoke Urdu, Punjabi and Mirpuri fluently, was recruited and trained to carry out the interviews. The facilitator who was a psychology graduate and had worked in the local learning disability service was already familiar with qualitative methodology. The principal researcher discussed the methodology of IPA with the facilitator and practiced the interviews[8] prior to meeting with participants. The facilitator was debriefed by the researcher following each interview.

Interview Schedule

The interview schedule was constructed in a semi-structured format that fits IPA (Smith, 1995), the data collection and analysis methodology chosen for this study.

The interview questions centred around four topic areas[9]:

- Background demographic information – participants were asked about demographic information (e.g. language, years in the UK, area of origin, religious identity, number of individuals in the family, who lives in the house with them and details about their son/daughter - age, gender and their disability).
- Relationship between mother/maternal carer and child – participants were asked retrospectively about the birth and development of the adult they care for.
- Impact of learning disability – participants were asked about what life was like being a parent or a carer.

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[8] The facilitator was briefed on confidentiality and signed a contract regarding this. The Confidentiality Agreement is included in Appendix IVa.

- Belief systems – participants were asked why they thought their son/daughter had this condition, what their family thought about their son/daughter and what the future held for them.

Analysis

Interviews were tape-recorded and then translated by two translators, who recorded their translation onto tapes[10]. They were asked to highlight any words which they struggled to translate or which may have had several meanings. The transcripts were then checked by the researcher listening to the tapes and following the translation. The external language consultant was asked to check sections of the tapes which the translators had highlighted. The translated interviews were then transcribed by someone independent to the research.

The analysis consisted of reading each transcript repeatedly with the researcher noting down anything which appeared striking or significant in the left-hand column of the transcript. Comments about the transcripts were made in order to make links, summarise or make initial interpretations. These 'emerging themes' (Smith, 1999) were listed in a table with the corresponding quote and index number from each transcript ensuring that themes could be tracked back to their origins in the text. Possible connected themes and quotes from each transcript were added to the table. The themes were then clustered to form major or 'super-ordinate' themes. The process was cyclical and some themes were dropped in preference of those that were deemed more useful or prevalent. During this process, a bilingual research consultant of Asian origin was approached to consider the translated meanings of the interviews and the subsequent emerging themes. Supervisors were also involved in checking that themes listed could

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[9] The interview schedule is included in Appendix V.

be connected back to the original transcript. Once all transcripts were analysed, a master list or index of super-ordinate themes and clusters was produced. The interpretations made from this have included verbatim examples from the transcripts.

Validity and Quality Control

It is important that steps are taken to maintain validity to conduct good quality research (Elliot et al, 1999). Stiles (1993) has identified several key concepts underpinning reliable and valid qualitative research. In order to enhance reliability, empathy and clarification between interviewer and participant were considered as crucial to gaining the 'insider view'. A significant threat to this was having the interviews becoming a three-way process, in having the participant, facilitator and researcher in the room. This was remedied by the facilitator becoming the primary interviewer and the principal researcher taking a secondary role, keeping notes during the interview and occasionally asking for clarification via the facilitator to the participant.

An attempt has been made to keep the interpretation 'coherent', in keeping a close-knit chain between data and interpretation and providing relevant examples for all interpretations. It is also important that researchers openly disclose their ideas and theories, as these preconceptions may allow what participants say to 'resonate' with them in different ways (Lincoln & Guba, 1990; cf: Stiles, 1993). This has been followed in this research, as many of the insights into participants' belief systems have been seen through the researcher's and the facilitator's own biases as Muslim women. Stiles (1993) also proposes a method of triangulation, where interpretations drawn from the data are convergent across all data sources. Part of this process included involving supervisors in checking the analysis of transcripts to gain some degree of consensus in

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[10] The translators were briefed on confidentiality and signed a contract regarding this. The Confidentiality Agreement is included in Appendix IVb.

themes. A research journal was therefore kept to ensure the study could be repeated in the same way.

A significant threat to validity is the use of translated material within the analysis of this study. The researcher was present at the interviews to ensure IPA data collection procedures were followed and to check translation/interpretation. Consultation was sought from researchers who speak Urdu and Punjabi during the translation of the interviews, prior to theme clustering, in order to reduce misinterpretations that could occur. Yardley (2000) suggests that the researcher should have an extensive grounding in the relevant literature. She also emphasises the importance of considering participants' socio-cultural setting, which is central to this study.

RESULTS

The experiences of Pakistani Muslim maternal carers were summarised into three super-ordinate or master themes which emerged from the analysis. These are 'Faith, Destiny and Understandings', 'Maternal Obligation' and 'Stereotypes and Assumptions'. Although some of the women's experience was deemed to be wider than these themes, it was felt that the majority of the interpretations made from the data were conceptualised by the identified themes. The analysis involved considering each master theme in turn, with underlying subordinate or sub-themes. The sub-themes are illustrated by verbatim text from the interview data, whereas the master themes include the overarching sense or meaning made from the data. Although many themes and sub-themes could have been produced, only material that related to these three themes has been presented here[11].

Table of Master Themes and Sub-Themes

I ***Faith, Destiny and Understandings***	*II* ***Maternal Obligation***	*III* ***Stereotypes and Assumptions***
Tests and Personal Strength	Connection	Here and There; Them and us
External Negative Influence	Daily Responsibility	Community Assumptions
Making meaning	Pain and loss	

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[11] The initial analysis which includes the collation and linking together of the extracts from the interviews has been included in Appendix VI.

I Faith, Destiny and Understandings

This master theme highlights the influence of the Muslim faith as an underlying belief system to many ideas held about LD and the participants' role as a carer. The belief that this role was a test from God was also linked into this, however, some women expressed a sense of inevitability about their role, feeling that their life was out of their control and Allah or God had decided their destiny. The participants felt that there was an underlying cause for their son/daughter's difficulty. This is highlighted by the beliefs that there had been something negative influencing the person they care for. There is also a feeling that doctors do not know the real cause and religious and cultural understandings are helpful in filling the gaps in knowledge regarding LD.

Many words that are related to cultural and religious beliefs have not been translated[12].

Tests and Personal strength

The feeling that caring for a person with a learning disability was a God-given test was a shared view from a few women and this belief seems to be a source of support in providing a higher purpose to their role. However Khadija for example, took this test to be linked to her own behaviours, whether God was testing her because she has done something wrong.

> I feel that God's testing me and my husband, how we're going to manage and how we're going to cope with, erm, but there were so many things, er, thrown at us in a way, questions but I think, I don't personally think I've done something wrong but you cannot one hundred percent say that, look I'm innocent, erm, I haven't done anything wrong because only God knows who's done right and wrong, and at the end of the day, I think if God's given us this, it's some sort of

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[12] A glossary has been provided in Appendix VII.

> a test for us, and how we're going to manage and cope, and I think for twenty six years, it's not been bad. [Khadija] (498-507)

Some participants felt that Allah had given them strength in order to deal with the challenges of caring.

> Allah's given me so much strength even though I'm ill, probably because of my kids, so that I can look after them. [Halima] (364-366)

The participants expressed a view of hope within their faith and recognised that life could be worse. One participant felt that Allah had done best for her granddaughter and that Allah would continue to do so in the future.

> We do think that maybe Allah will have mercy on her, we do think but what can we do. What Allah will want for her will happen. Maybe Allah will do best for her. That is what I think, when you look at the world, I think that maybe Allah has done best for her. I pray after 'X'[13] that Allah will do best for her future as well. He will do best for her, we have hope in Him, He will open the doors for her. All we can do is pray. [Afiyah] (171-177)

> It's not good really, but I thank Allah because she could have been worse, she could have been disabled and been without a limb or a leg, not eating or drinking, or going to the toilet. She's much better than children in those situations and I'm grateful for that. [Kareema] (99-103)

External negative influence

The sub-theme of external negative influence includes views on black magic (jadoo), spirit beings (jinn) and amulet (taweez), which have been seen as both positive and negative. These views exist within traditional mainstream Islamic understandings, however, the women describe specific practices which seem particular to Pakistani culture, although it is difficult to separate this out.

Participants felt that other people had practiced these negative forces on their son/ daughter or that a spirit had possessed them. Many participants discussed attempting to 'cure' their son/daughter of their disability. However some participants, such as Sayyida, do come to a conclusion that they may not be able to do this.

> I do feel for her, sometimes in my mind comes these thoughts that someone has done a taweez on her, then I think maybe she has something (jinn[14]) with her. I have tried curing her of these but it hasn't made a difference. I tried getting taweez for her, she's got one in her neck, I got it from Rawalpindi, after taking her to a pir/faqir (holy man), but it hasn't worked. I think it must be with her mind. [Sayyida] (81-88)

Halima, presented below, who cares for three adults with learning disabilities within her family, attempted to try and reconcile the differing ideas she has about the cause, particularly in disproving ideas about genetics presented to her by doctors. She also linked this with her faith, similar to other participants, questioning why she has this responsibility.

> They don't know why, the doctor's say it's because you get married with your cousins, that's why the children are like this, but other people who are not

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[13] 'X' is included where son/daughter's name has been removed.

[14] Words in brackets within the text have been added to enhance clarity.

> relatives, their children are like this as well. Sometimes we think, why did Allah want this for us, three children exactly the same. Somebody wants this for me. My husband was good with his parents, financially looked after them as well, looked after his relatives financially as well. He helped every family of his relatives, be it with money or something else. My husband is good with everyone. We just talk amongst ourselves about it, we tell God because he is the one who put us in this situation, you can only tell the person who put you in this situation. When we go to people of knowledge, they say it's because of jadoo (black magic) when we have them taken out. They say when they were in the mum's tummy then someone did this jadoo. [Halima] (279-293)

However, views about black magic also seemed to make the most sense for many participants, and along with this view, the carers have found ways to be active in their son/daughter's care, in trying to remove the magic or exorcise the jinn.

> She's got a "saya" (shadow) with her. Her arms will go like this, no matter how high she is, she'll jump down. Yes, it's Jadoo (black magic). We have them taken out, but after four/five months they're back, as soon as someone knows they put them back on her, we have taken out constantly. They don't do it on her, what has she done to anyone? They do it because of us, the parents, because they're our children, our blood. So it's affects us on our heart and mind. What has 'X' said to anyone? She's a silent flower, she hasn't said good or bad to anyone, it's to get to us, us the parents. We'll get fed up and start arguing, that's what they want. [Halima] (96-106)

For some participants, using their traditional religious leaders or scholars was found to be helpful.

> Then we would be visited by Maulvi, Qari saab (men of Islamic knowledge). He used to read some things for him and we did as well, everyday in the morning, then slowly, slowly, with Allah's help, he began to get better. [Fahima] (158-161)

Making meaning

All participants tried to make sense of why their son/daughter may have a learning disability. Many participants felt doctors were unable to provide an explanation for the cause of LD. Many presented as resigned to the fact that they may never know the cause and this may limit how much they could do for their son/daughter.

> What do I don't know, not even the doctors can really tell me why she's like she is. Only God knows why she is as she is, there's nothing anyone can do, not me or you. [Kareema] 2 (135-137)
>
> The doctors can't seem to understand what's wrong with my son, his problem. [Fahima] 1 (157-158)

One participant did offer an explanation, which made the most sense to her.

> The doctors don't understand, I think there is something with her tongue and that is why she isn't talking but the doctors don't understand.... The doctors don't understand but I know there's something stretching her tongue. The reason why she talks like she does. The doctors don't understand. [Afiyah] (98-105)

II Maternal obligation

This master theme highlights the significance of the participants' role as a carer and how this role was viewed as a duty or obligation. There seemed a general consensus amongst the participants, who were the mothers of the person with LD, that they would always have the responsibility of caring. Furthermore, participants identified their struggles in trying to have a break from this role. The women anecdotally disclosed difficulties within their caring role and reflected on their health problems, which encompassed them and resulted in their needs not being met.

Connection

Participants detailed their experience of always being connected to their caring role. Participants vary in how much they felt other members of the family also shared this responsibility.

> I feel that as long as I am alive, his brothers and sisters will want to help him but when I'm not around then nobody will be helpful towards him, not his brothers or his sisters. [Fahima] (243-245)

> It's just that there's a daughter and a mother, and the mother feels it's her duty to care for her child [Kareema] (91-92)

> A brother or a sister may be concerned but other outsiders won't be bothered, it's not their problem, it's a problem concerning the immediate family and no-one else really. What's it to them? [Kareema] (145-148)

Some participants indicated that the role of caring begins and ends with the mother. In having this idea, participants suggest that the person with the learning disability is only their responsibility to manage. The women repeatedly illustrated their reliance on Allah and prayer as a way of coping; however, they also presented as feeling like they had little control over their future, which they believe has been predestined by Allah.

> I pray Allah doesn't make me rely on anyone. I always pray after namaz (daily prayer), oh Allah, as long as my kids have life, make my life long as well, but I don't know, Allah will do what he wants, He won't listen. People are like this, (*i.e. have LD*) it's not Allah's fault. [Halima] (368-371)

> Yes, her mum, dad, we all are worried about her. She won't be staying all her life with us, nobody will stay (with her). Allah's her protector for the future. [Afiyah] (84-85)

> **R: How do you feel about the future?**
>
> S: It's all thanks to Allah, our provision is written, maybe because we're looking after him. Allah's providing for us as well. Allah knows best, it becomes obligatory for the parents to look after their children. [Sultana] (174-178)

Khadija, for example, illustrated her beliefs around parents being responsible for their son /daughter with LD. Not only did she see her son as connected to his parents, she also wished his life to be within her lifetime. She presented as taking ownership of his difficulties, that is they were only for herself to cope with and not for anyone else. She further identified that providing a high level of care, such as she does, can result in 'suffering' and having 'family problems'.

> But, I just want him to go before we do. Because I think, even though sisters love him and, er, I, I don't want them to, er, I don't want to rely on my daughters

> because, er, it's alright for them now but at the end of the day when they get married, they have families of their own, I don't want anybody suffering because of him and having family problems. I think his future is with us and, erm, I don't know, I mean, up to now, I'm saying this because I know they don't have very long lives. Er, somehow I think, everything's got a life and I'd prefer him to have a shorter than having a long life because I...... he's not going to have any other achievements in life. [Khadija] (534-547)

Some participants related incidents of them feeling distant from Pakistan and not being able to disconnect from their caring role to be able to visit Pakistan, particularly when relatives are unwell.

> When I went to Pakistan and I had to leave him behind, was hard at the time. And I remember it was very hard. I had to round about tea-time, drop him off at respite and I just couldn't cope with it. I mean, he was going to respite normally, if that's fine. When I'm, I'm here I can ring up, check up on him and they can ring and let me know that, if there's anything wrong or, or if they need anything, and, er, because I was going and leaving him for 7 weeks and that was the hardest. [Khadija] (408-417)

For example, Fahima details this experience, but also presents with a feeling of being trapped within her caring role.

> It was like qiyamat (judgement day) inside (our house). For two years we weren't aware of what was going on outside our family. My uncle passed away and I found out six months later. Even now, it's difficult. My father passed away in Pakistan, and my mother passed away. When my father died, I was able to go to Pakistan. My mother-in-law, she telephoned asking me to come, she said,

> please come and meet me, I'm going to die soon and I want to see you before you die. But because of my son, I was unable to go. But then my mother-in-law kept on insisting, so I went just for ten days. When I came back, after four or seven days, my mother-in-law passed away. Exactly what they said would happen, happened. If my son was well and healthy, like my other children are, then I wouldn't have had to come back so soon, I could have stayed for two months and it wouldn't have mattered. I wish that my son was well so that I wouldn't have to live in this country. Fahima (255-269)

Only one participant reflected on letting go of her maternal obligation to be able to engage in using respite services for her son.

> And the thing is I, I never wanted to send him to respite because he used to go, he used to come back upset. And I just could not understand what to do about it, at the end of the day like, they all find we need a break at the end of the day. And if he goes away for four to five days to this other place, and there was a time when I used to dread these weekends coming up when he's going to go away but now, time is like that now that I actually feel that it doesn't come soon enough. [Khadija] (104-110)

However she later added, although she recognises her own need for a break to relax, she still experienced the connection with son when he is at respite.

> And I think when he goes away with them for a break, even though mentally I'm always sort of getting up at the same time, er, you just hear these voices in your head during nights, even though, if he's not here, theres no rushing around because I have heard a cry, and things like that but, the thing is, now I feel that I've got less energy in me, that's how I feel. It comes to a certain stage where

> you think that's it, just want to just sit back and relax yourself. [Khadija] (111-118)

Negotiating daily tasks

Within this sub-theme, the participants illustrate how they manage the day to day tasks of caring for their son or daughter. For example, Sultana, indicates how sometimes meal times can be difficult but this is reconciled by her beliefs that it is an obligation for parents to look after their children.

> He doesn't trouble me. Well, sometimes he does of eating, he'll go here, he'll go there. I told you if you put songs on for him, he'll sit there all day. Well, you know children like him, their brain is like that. We are his parents so we have to look after him. Nobody else can look after him. [Sultana] (84-89)

Halima illustrated this belief of the mother's obligation to care by discussing her response to outside help within an everyday task.

> I brush her teeth myself, if they've given helpers I don't rely on them. I still brush her teeth again myself. She doesn't brush them properly as well so I brush them myself. I know if plaque sticks then you won't be able to get rid of it. The dentist says their teeth are very clean. [Halima] (152-156)

Sayyida identified the difficulties she has with her daughter at home. She gave examples of her checking her daughter for safety pins and matches, and outlined concerns and sense of responsibility for her daughter's safety.

> She doesn't understand anything. Sometimes she'll take a matchbox and say, I'm going to on the gas (cooker), this room gas is automatic but in the other room she'll say, I'm going to on the gas, she'll say to me. It's dangerous, have to

> be careful in case she knocks against something and the match drops, she doesn't know at all, there could be a fire. Sometimes she'll see pins in shops (*safety pins*) but we be careful, we're always checking her. At night we check her so many times, we'll check her pockets. [Sayyida] (161-169)

Other participants discussed negotiating more complex situations with their son/daughter and the difficulties that arose from these resulted in them feeling isolated from others. Fahima illustrates this within the extract below.

> We had problems on the plane because he kept wanting to hit people, and we kept on having to apologise to them. Other people don't realise that he's ill, he kept bothering people sat behind him or in front of him. For the whole of the journey I had to hold his hands, we didn't eat or drink anything during the journey. The aeroplane staff didn't offer us anything and then I didn't ask either. I just held onto my son. Two people stayed with him and then when we got there, he was aright. [Fahima] (218-225)

Pain and loss

Within this sub-theme, participants identify their own health needs and resulting physical pain. However, amongst this references were made to experiencing emotional pain within the role of caring for their son or daughter with LD. The women identified areas of loss within their expectations for their future and highlight their needs, particularly, in feelings of loneliness or isolation experienced by carers, indicated in references made about not having people to talk to or look after them.

> Hard, we lead a hard life, I worried all the time. I suffer from arthritis, when I'm in pain I want someone to look after me, and talk to me, I need someone to look

> after me. Despite all of this, I still think of her, I think what will become of her. She is forty five, forty six now, people of her age look after people, they look after someone, she can't look after anyone. [Sayyida] (92-97)

Some participants described giving up some of their caring responsibilities for other family members to do.

> My husband does a lot, he puts S in the chair and on the toilet, and then he wakes me up. He gives 'X' weetabix and puts her in the chair, and then says to me to get up, that I've put her and you can wash her now. He helps me a lot with her, when she comes he'll help me as well, he'll take her out of the wheelchair, he doesn't let me pick her up because the doctors have told me not to, because I've already had angina attack twice. [Halima] (253-259)

> My daughter helps me a lot, if she knows I'm ill she'll come running, nobody else can look after them like that. I'm a sugar patient and a heart patient, how long can I live? If I become invalid who will look after me?[ ] My daughter-in-law cooks and cleans but you still have to do so much for them (son/daughters with LD), sometimes I can't even get up, who's going to look after me? [Halima] (361-364)

> Sometimes it's really difficult. Now I don't really care for him, my daughter does. I have problems with my arms, I can't lift them very high. They've put three rods in three places in my arms and this makes it difficult for me to do much. When I used to be at home on my own, I used to hate it, I used to cry a lot. I used to have to change my son's nappy using my feet, that's how I used to (tie it) and move it away. I wasn't get getting any help, I really felt that.

> [Fahima] (90-97)

Fahima, for example, identified losses for her other son and daughters who also participate in the duties of caring for her son.

> I had to spend a lot of time in hospital with him, with my other daughter. This affected the other children, they weren't able to study, I wasn't able to concentrate on them. A friend of my daughter's said that she wanted to be health visitor or a nurse but she (daughter) wasn't able to study or train for anything. My other son didn't study, or my other daughter. My eldest daughter hasn't been able to study. This is because she's having to care for her brother and help me with him. When they grow up, they'll probably blame their brother and say it was because of him that they weren't able to study. [Fahima] (276-287)

Sayyida linked her worrying to her health, recognising that nothing is gained by worrying but that she has no other options other that worrying about her daughter.

> I get ill, I told you I've got arthritis, I don't feel well. It is not within our control. By worrying nothing can be gained. If I worry and cry nothing can be gained, we can't do anything. Say if it's a mother or father, we can't do anything but just worry. What can we do, what are we going to do? [Sayyida] (128-132)

III Stereotypes and Assumptions

This master theme outlines participants' perceived differences, either between themselves and the indigenous English White population, or between themselves and the wider Pakistani community. Within this theme, there are nuances of participants feeling that service providers, who they see as part of the White community, do not understand their needs or the needs of their son/daughter. This theme suggests that the stereotypes and assumptions made about the women, and those the woman make about the outside world, leave the women isolated from society.

Here and There, Them and Us

This sub-theme indicates that participants have experienced services as not being able to support their son/daughter appropriately. Fahima illustrates this, when discussing an application for housing and being offered a one bedroom flat for her son. She describes wanting services to recognise the roles of herself and other sons/daughters in her son's care. She implies that 'White people', within services, do not see they have a responsibility to the rest of the client's family, particularly the mother, as she is the one who most looks out for the person.

> White people don't think like this, they think that one room for somebody is enough, for the ill person. Theres no-one dearer than one's mum...... There is no responsibility to the rest of the people (like brothers and sisters). They're just concerned with the person who is ill. They can provide the room but they can't look after him. If he was on his own he could fall. There wouldn't be anybody around to give him any food or drink. I follow him around making sure that he eats a bit in the day, that people help him, offer him water, do things for him. If he was on his own this help wouldn't be available, but English people don't do that, do they? [Fahima] (114-128)

Khadija highlights a situation related to respite, where she felt assumptions were made about her having lots of extended family to help with the care of her son.

> Lots of English people, erm, erm, think Asian people have, erm, family help or, or they've got, they're surrounded by family and they get almost all the help from family but it, I think it's not one hundred percent true. Er, there might be a chance of them coming to your help but there is a time when all families have got their little problems to cope with, and they can't just turn up. And I remember when I used to go to X's school and I had a meeting about short-term fostering or, erm, short-term care and people who go on holiday and things you need, children need some of family to, and, er, whenever it came down to me, they used to have, er, what happens with Asian families they've got families within the community so they don't need it. But that wasn't true then until I got really sick of listening to this and I ended up telling them all - Do you know what, you people think that we've got families who do this and that. [Khadija] (35-53)

Some participants related incidents which resulted in them viewing services negatively. Sultana described an episode where her step-son was taken to a residential unit after accusing his father of hitting him.

> Once he wasn't home and it wasn't the same, it felt like darkness. He was saying my dad hits me. They took him where they keep children, he stayed there. But his father didn't touch him at all, nor have I ever touched him. At night they came to take his clothes, his father said, you should ask me, he's my son, not yours. Take a look, has he got any marks anywhere, he hadn't, so my husband said, you know his mind's not normal, so why did you take him? I'm his guardian, so they believed us and 'X' was saying he doesn't want to go.

> **R:** **How long did he stay?**
>
> 6: Only one night. He came back, nobody made dinner or ate, it wasn't the same without 'X'. He is a child after all. [Sultana] (178-194)

Some participants described not being listened to when they had concerns about their son/daughter. Khadija related her worries about her son when he was born. She described trying to tell hospital staff about her concerns and felt they were not taken seriously. Khadija, however, highlights language as an important divide between her and support from services.

> I know I was, I was ever such a young age that I didn't understand what was going on, and then, er, I remember later on that his neck was turning in such colours, a blue, yellow, purple and then red, he was changing colours and, er, his eyes had rolled back and all you could see was the white and all that. And I tried telling the midwife she wouldn't take any notice, er,... I do feel angry but some, sometimes I think, maybe I didn't have enough knowledge, maybe if I had the language, erm, I could have helped myself. [Khadija] (247-257)

Community assumptions

This sub-theme outlines the position of the women within the periphery of the Pakistani community. The participants describe people within the community making assumptions about what it means for them to have a person with LD in their family. For example, one assumption made by the community is that people who have a child with a disability are financially better off.

> Some people say to me, oh, if you've got a child like this you can get extra money but what's money. Someone could take the whole payment book from me. I don't want money......[Fahima] (82-87)

> And every morning we get up, it's a routine, we get up in the morning, we've got to go through and wait for transport to come, and yet we get him carers and I'm still feeling drained. Er, you know but lots of people think that, er, having a disabled person in the family, er, means that you get benefits or it's an excuse for the family to, not to do this and that, not to take part in things. I think, unless you've been through it, you don't understand what the situation is, and lots of our (Pakistani) people don't realise any of that. [Khadija] (136-146)

Marriage is viewed as extremely important within Islam and Pakistani culture. Participants considered the effects of their son/daughter not being able to engage in this process and how they may be removed further from their community.

> We think whatever he's like, Allah's made him like this. People can't do anything. Sometimes he'll say himself, I'm ill. If someone asks him, 'X', are you okay? He'll say, no, I'm ill. We feel sorry for him, but Allah's made him like this. His brothers and sisters are all married, if he was aware of things, of the world then? [Sultana] (137-142)

Afiyah identified that people within the Pakistani community did arrange marriages for people with LD, but highlighted the impact this would have on both parties.

> I wish that Allah had made her like other children, then we wouldn't feel like this. All the others are ready for marriage now, and she's not so we do think about this.... .... Yes, she's the first. She's got younger sisters ready for marriage and she's not. Now we'll see what Allah will do for her, he will do what's best for her. I've seen worse mentally than her and they've got married....... You can get partners but you have to think about their life. You want to find someone who will help her get on with her life. [Afiyah] (153-155)

The issue of feeling ostracised or marginalised by the community runs deep within this sub-theme. Khadija illustrates this by relating the pressure she feels from the community. She also links this to the earlier theme of 'external negative influences', arguing that the community views disability as a curse or jinx and therefore isolates families containing a person with LD.

> And I think sometimes you get more pressure. I, I keep well away from, erm, all community, apart from my sisters, brothers, I don't keep much contact with people because there is more bother going on then actual help. And it plays with your head sometimes and you just want to break away because you only want to sort out family problems, your own children and you don't want to have to think about anything else.
>
> **R: Is that the community are pressuring you?**
>
> **K:** Yeah. Erm, what happens with them is, erm, if they need a help, er, they rely on you to turn to them but if you need help they turn their backs on you, and in some way they think, erm, a person with a, er, disabled or a child with learning difficulties, erm, some sort of a curse or a jinx on the family. Erm, but sometimes it separates the family cleanly away from the community and it, it's just that I, I felt I don't, I, I'm not ashamed of him, with a son like that. I believe there is a God and the God has given me this, actually as some sort of a destiny. [Khadija] (65-87)

DISCUSSION

This qualitative study aimed to gain an insight into the experiences of Pakistani Muslim maternal carers of an adult with a learning disability. The three super-ordinate themes that emerged incorporate detailed illustrations of the participants' views which add to the literature about South Asian carers of people with LD living in Britain.

I Faith, Destiny and Understandings

This research highlighted the Muslim faith as a central tenet throughout all the themes, as references were made to Allah in other areas other than this particular master theme. This theme highlighted beliefs about the caring role as a test or trial from God. This ideology has been related by other ethnic minority groups. Research carried out with Hispanic families, indicated that similar views about having a child with a disability was a God-given test of their worthiness (Heller et al, 1994). This view has been similarly viewed as a comfort within this population and has been found to be associated with a reduced burden of caring within the Hispanic population when compared to the non-Hispanic population (Heller et al, 1994).

The women within this research often made associations between their faith, hope and being able to get on and cope. However, they also made references to their own good deeds, like being good to their parents, when questioning why they had been given the test or destiny of having a son or daughter with LD. Previous literature has indicated some cultures viewing a child with a disability as a punishment for a sin (Groce & Zola, 1993).

This theme also highlighted the carers' significant reliance on traditional Pakistani understandings, particularly spirit possession and black magic, to explain the cause of their son/daughter's LD. These beliefs are common in Pakistan particularly in understanding mental illness (Mubbashar, 2000). In holding these beliefs, participants related that they had approached traditional healers to receive help for their son/daughter's disability. Hussain et al (1998, cf: Mubbashar, 2000) carried out a study in Pakistan and found that more women then men were inclined to believe that traditional healers could help people whom physicians could not help. Hussain et al also noted an inverse relationship between level of education and holding this belief. Previous research has identified the search for a cure and fatalism are reasons given by workers why Asian parents may not be interested in seeking help through services (Fatimilehin & Nadirshaw, 1994).

There were many cultural explanations offered for causes of learning disability by participants, and a shared view that doctors did not know about why their son or daughter had a LD. This was also reflected in the way some participants referred to their son or daughter with LD, for example, as 'ill' or 'not normal'. Davis et al (1995) highlight language barriers, lack of knowledge about LD and limited knowledge of services, as reasons for isolation of families and low uptake of services. Hatton et al (2002) recommend that the disclosure procedure should be well-conducted. This involves ensuring coordination between support provided by an ongoing key-worker, and family support groups that are necessary for increasing parental acceptance and understanding of the child's condition.

II Maternal Obligation

The participants shared a strong sense of duty and obligation to care for their son or daughter. Many women spoke of receiving help from other family members, particularly other daughters or daughters-in-law. This suggests that there may be a gender specific expectation to assume responsibility for caregiving (Neufeld et al, 2002). There may also be an increased burden of care because of an absence of relatives who would normally help (George, 1998). There are cultural South Asian traditional concepts, such as 'Dharma,' which refers to the notion of fulfilling one's duty (George, 1998). This concept involves the idea that family needs take priority over individual ones, which seems to be the case in the present study, where there seemed to an expectation that other sons/daughters would assist in the caring responsibility. Some participants, however, discussed other children blaming them for missed opportunities, for example in education due to having to help with the care of a sibling with LD.

The women identified many of their own health problems and expressed a desire to be cared for themselves, which may be associated with those carers who were older and who had significant health problems. Rates of psychological distress have been shown to be very high amongst South Asian carers; this is also mediated by social deprivation (Emerson et al 2004).

III Stereotypes and Assumptions

This theme touched on participants' experiences of services. Some women identified that they had felt that there were differences between what they wanted and what was offered to them by 'White' service providers and that they felt stereo-typed. Chamba et al (1999) disagreed with the stereotype that all Asian families had extended families that could be called upon for extra support. They found that those families that did have support, had less then their White peers. They concluded that there were high levels of unmet needs, and stereotyping and myths needed to be replaced with more competent service provision.

The experience of stigma from within one's own ethnic minority group has been well documented (Saetermoe et al, 2001; Hussain et al, 2002). In the present study, the women referred to other members of their community not understanding their situation, for example, suggesting the carers were wealthier due to receiving disability benefits. Participants not being able to get sons or daughters married was also discussed as something which added to carers being on the periphery of their own community. Two participants disclosed that they had thought about arranging the marriages of their daughters who had mild LD. Katbamna et al (2001) noted that Asian carers seemed concerned about their daughter's reputation within society, particularly with respect to marriage and social inclusion. Hepper (1999) highlighted the challenges faced by professionals when trying to understand the cultural and societal influences which led to an arranged marriage of an Asian client. Services may have to consider how issues of sexuality and consenting relationships may manifest in different cultures and how clients with LD can be sensitively empowered to consent to sexual relationships within the context of South Asian culture.

The majority of the participants did not have English as a first language. Language issues have been raised in previous research when considering low uptake of services. Hatton et al (1998) identified that Asian carers within their study reported being unaware about services and felt there were too few members of staff who could speak their language. Interestingly, the only English speaking participant within this study, was the only person who accessed respite services for her son.

Methodological Issues

Literature relevant to this study has been closely examined in order to show sensitivity to context (Yardley, 2000). The relationship between facilitator, researcher and participants is another context in which sensitivity is required (Smith, 2003). It is important to reflect on the effects of having two South Asian Muslim women as researcher and facilitator. For example, participants may have felt more able to share their ideas, or felt they had to respond to perceived expectations about what was required of them. Some of the comments made by participants indicated that they held assumptions about the researchers and their background. This was indicated in the texts below, here Fahima reflects on the achievements of the researcher as something she would have wanted for her children:

> Like you are all studying and trying to get ahead, that's what I would have wanted as well for my children. [Fahima] (293-294)

In another instance, Kareema distinguishes the researcher and facilitator from the 'White' service providers:

Researcher: **By doing this interview, its not that you will get help. All we are trying to do is to find out what your needs are, then it's up to the service providers to take the initiative whether or not they will provide services that families like yours need. But the responsibility isn't with us, we just want to make that clear to you.**

Kareema: No, no, I understand that, that's fine. It's the English people who work out the services, I realise that.

Attempts were made to affirm the reliability of the interview data collected by keeping an awareness of the researcher's preconceptions, particularly in understanding the data within the context of her own socio-cultural background. It is important to note that the analysis using IPA may have been coloured by the assumptions held by the researcher, particularly her identity as a Muslim women of South Asian decent. Although this potential for subjectivity is recognised within IPA, a close link was maintained with the material, regular cycling took place between the data and interpretations made, and an attempt was made to ground all interpretations with examples from the data (Stiles, 1993). Validity was considered by using supervision, and within this checking of coherence of interpretations and themes also took place. Triangulation took place by discussing findings with the facilitator and research supervisors, and a clear audit trail between data and themes was established.

Translation Issues and Limitations

Few studies have used qualitative methodologies with translated material, and a significant threat to validity is the use of this material within the analysis of this study. Temple and Edwards (2002) highlight the importance of considering reflexivity, that is, the research being a product of the researcher, including interpreter and participant. In order to minimise threats to validity, the views of the facilitator are considered to have an influence in the discourse in which they participated in (Temple, 2002). An attempt was made to develop transcripts which were clear, accurate and which sounded as natural as possible. The researcher and facilitator regularly discussed their understandings of the material to ensure contextual meaning was harnessed (Esposito, 2001). If possible within the time frame of the research, the process of back-translation would have been a useful check of cultural and contextual meaning. Consultation, however, was sought from a research consultant who spoke Punjabi and Mirpuri during the translation of the interviews, prior to theme clustering, in order to reduce misinterpretations that could have occurred. Steps could have been taken to improve validity, as member validation became difficult due to translating the interviews and creating themes in English.

Many difficulties were faced with recruitment of participants. This including refusal to participate when approached by contacts at the carer support group or day centre. Two women refused to participate when told that interviews would be audio-taped. Therefore, the small sample of women who agreed to take part in this study, questions the generalisability and reliability of the findings. The difficulties in recruitment resulted in the criteria for inclusion being widened to include other maternal carers as well as mothers. This meant that a step-mother and grandmother were also included. This could have implications for the generalisability of the study and also raises the question whether these other carers presented with different experiences to the mothers. Other variables, such as the age of the participants, may also have influenced the data as previous studies with elderly carers have demonstrated that they experience loss, isolation, ill-health and stress which are related in the themes found here (Brewer, 2001). Nevertheless, this study is in line with the conclusions drawn by previous research with South Asian carers and has some important implications for future research and clinical work.

Research and Clinical Implications

By focusing on mothers or maternal carers of adults with a learning disability, this research allows for a detailed picture of difficulties faced with the day-to-day responsibility of caring. Further study is required to determine generalisability of findings. Future research could also use insights provided by the themes to focus on developing cross-culturally valid measures of carer stress, in order to identify carers needs earlier and therefore offer appropriate support.

Few studies have reflected on the process of translation within studies, or used IPA or other qualitative methodologies on translated material. This is an important area for development within future research in order to advance research methodology, that is not only valid and reliable, but also inclusive to all people regardless of language or level of education.

Implications can be drawn for future clinical and service provision. The three master themes, of 'Faith, Destiny and Understandings', 'Maternal Obligations' and 'Stereotypes and Assumptions', allow for a detailed insight into the lives of Pakistani Muslim maternal carers of an adult with LD. The first theme highlights how carers may understand their son/daughter and their condition, for example, the women's beliefs about LD being a test of personal strength and their ideas about the cause of LD. These have important implications for clinical psychology services in thinking about how to develop a shared understanding with carers about their son/daughter's condition. It also highlights where and how carers may receive support if not through mainstream services. The second theme provides a framework for exploring the stresses and responsibilities of the women, for example, the connection the participants feel towards their role as carer, the daily stresses they experience and their own well-being. This would have an impact on how services negotiate the type of support that would be considered helpful by families and therefore improve engagement. The third theme outlines participants' views of services and indicates the need for professionals, including clinical psychology, to be more culturally aware and recognise their own assumptions.

Conclusions

This research has worked within the gap of the current literature to obtain a more detailed view of the experience of Pakistani Muslim women living in Britain, who care for an adult with a learning disability. The qualitative methodology of Interpretative Phenomenological Analysis has provided a detailed insight into the experiences of the participants that is necessary to increase the knowledge base in this under-researched area. This study has considered the level of support experienced by the women, the wider implications of having a learning disabled person within the family, and access and views about services currently available.

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SECTION 3

Critical Appraisal

CRITICAL APPRAISAL

This critical appraisal includes commentary and reflection on the process of conducting this research taken from a research diary written during the course of this study. It includes initial ideas, planning and negotiating issues, difficulties and overall learning from the research process.

Origins of the Project

My research interests have always centred around South Asian people in the UK. Previous research I have carried out includes, studying psychological distress and wellbeing within the Asian population, and comparing health protection behaviours between White and Asian women. Being a second generation British Asian person of Muslim faith, the complexities of negotiating day to day situations with many ideas, cultural influences and belief systems, usually gives me a lot to reflect on. I had a strong inclination to carry out research with this population once again, however, was unsure about which research questions to follow. In my second year of training, we received teaching on cultural issues in learning disabilities and Dr Linda Buchan spoke to us about the 'Partnership Model' (Davis et al, 1995). She discussed the difficulties faced by Bangladeshi carers and the successes of using the 'Partnership Model' in East London. We discussed approaches in working with South Asian people with learning disabilities and their families in Sheffield and the difficulties with engagement in services. I felt that if work was carried out to find out what people's experiences of services were, then this could lead to better service provision.

Planning

After deciding on the area of research, I spent some time searching through the existing literature and discovered that there were no studies specifically looking at the experiences of Asian mothers of adults with learning disabilities. I noted that previous qualitative literature had included a widely heterogeneous group of participants from many different countries with a label of South Asian. I decided to make my study specific to the Pakistani community.

Professor Gillian Hardy and Dr Linda Buchan agreed to supervise the project, and Linda suggested the Learning Disability Psychology Service for a forum to access participants. I was also given contact details of a specialist day service run by voluntary and social services for Pakistani Muslim adults, here I heard about another project set up for female carers of the clients with LD. After contacting these services, the organizers were interested in the research and offered me a platform from which to recruit participants.

Qualitative Methodology

I had used qualitative methodology in previous research, specifically using focus groups with South Asian people who did not speak English or have literacy in their mother tongue. I found this methodology not only empowering for participants but also it allowed for cross-cultural theoretical understandings and for one to take an etic perspective. During my clinical training, I had heard about IPA and thought its principles would work well cross-culturally because it would involve exploring and gaining an 'insider' view of the meanings constructed by a person of their personal and social world (Smith & Osborn, 2003). I felt this would be clinically relevant as I had heard anecdotally that local psychology services struggled to develop a shared understanding for interventions with South Asian families. I hoped this research may provide useful insights which could help professionals make sense of how a client's family may view their learning disability.

Research Proposal

I began to put together a proposal for the research ideas I had. I wondered about speaking with mothers of children with learning disabilities, however, another researcher was already doing some work in that area. Once I had decided that mothers of learning disabled adults would be my participants, I was determined to access women who could only speak their mother tongue of Urdu or Punjabi. I wanted to speak to those women who may not have been asked about their views and gain insights into their personal and social world. Upon sharing these ideas to the University Research Sub-Committee, they had many concerns about using IPA with translated material, and about how this added stage would fit into the time frame for completion. Although recognising that this was not my only opportunity to carry out research, I felt that it was important to think about ways to include non-English speakers in research. With ongoing support from Professor Gillian Hardy and from looking at the existing literature of using translated material and conveying contextual meaning within qualitative research (Temple, 2002; Esposito; 2001), I felt that this project would be possible.

In thinking about developing the interview schedule, I was conscious that the principles of IPA should permeate from the interview questions right through to analysis. I was aware of the importance of asking broad, open questions to participants in order to generate good quality data. Since I can understand Punjabi however not speak it very well, a decision was made to employ a facilitator who was fluent in Punjabi and Mirpuri (a dialect of Punjabi specific to many of the women interviewed). Eram Khan is a psychology graduate and had a great deal of experience of working with Pakistani families within the Psychology Learning Disability service. She and I spent some time going over the issues surrounding consent, the interview schedule and how questions may be translated.

Ethics and Funding

Ethical approval was obtained over the summer of 2003 from the North Sheffield Research Ethics Committee. One important question raised within the committee meeting was that of how the women would respond to people who they may see as belonging to their own community, in terms of feeling able to speak freely. Eram was also known to many of this sample due to her prior role within the Learning Disability service. I recognized the importance of being able to reflect on the influences of Eram and myself within the interview process.

Being able to involve a facilitator and have an extra translation phase required extra funding. I applied and received this through the Sheffield Health and Social Research Consortium.

Recruitment

I arranged to attend the carer's group when they met on a fortnightly basis in order to recruit and build trust with potential participants. Initially I would be ignored as an outsider to the large group which consisted of: clients, carers, support staff, health care staff, and friends of carers who attended the group as a social gathering. After spending time with the women and giving out information sheets, I began to ask whether people would like to participate in my study. Part of the recruitment process involved me being able to disclose personal details including my cultural background, my marital status and whether I had children. To the potential participants, this seemed to be the minimum they needed to know so I was not a stranger to them and they felt able to talk to me. This information, along with gaining reassurance from the Carers' group leader, (who was widely respected by all the women), seemed to allow me to be accepted by the women.

Recruitment was plagued by difficulties for many different reasons. At the service for carers, only women who had been signposted by the group facilitator as people who may participate were approached. This is because many women had been approached by the facilitator and had refused. I had also wanted to recruit from the Day service, however, my contact there was on long-term sick leave and it took me a while to make a new contact there. The new contact arranged for me to contact potential participants over the telephone to initially gain verbal consent to interview. Two women refused due to the requirement of audio-taping interviews. The Psychology Learning Disability service was also used to access participants, however many of the same participants whom I had seen or was about to see in the other settings were mentioned. Due to these difficulties in recruitment, the criteria for inclusion was widened from mothers to maternal carers.

Consent, Interviews and Difficulties

Consent to participate was verbally agreed within the Carer's group. All women requested for me to interview them at home, so formal written consent was gained in this setting. The participants met Eram prior to being interviewed. They were told about her and many had already met her in her previous roles and did not object to her interviewing them. We were always both present in every interview with my role involving taking notes and occasionally asking questions if I thought something had been missed.

The first interview that we did was a bit of trial and error, as Eram and I were working for the first time together and we felt a bit stilted. However we reviewed this at the end and by the second interview, we were beginning to develop a style that flowed more. This may have also been due to reduced anxiety of completing the first interview.

Initially the participant in the first interview was not happy about being tape-recorded and we noticed this would be a continuing theme in many of our interviews. The women did not understand why we could not try to 'remember' the interviews or just make notes instead of taping. When we explained why we needed to record, they did agree to participate, but despite this I felt they had suspicions their interview would be broadcast over the radio. In seriousness, I think the women had many legitimate worries from previous bad experiences of things getting back to their community.

Another difficulty within consent, was explaining how the information would be written up, because most of the participants could not read/speak English or read in Urdu or Punjabi. Therefore I was unable to show them what a report or thesis might look like.

Many of the interviews were both upsetting and moving for Eram and I, some participants were tearful in sessions, and I perceived this was due to the women having very few times for them as an individual, to tell their stories. I was struck by how open the women were and how warmly they welcomed us into their home, even offering an invitation to share their evening meal with them. I was particularly grateful for the amount of time the women spent being interviewed, whilst receiving nothing from us except a small box of biscuits.

Translation, Analysis and Writing up

The translation phase of this project was a particularly lengthy one. I had contacted two people I know who had experience doing translation work and agreed to carry out the translations. I had to warn them several times not to summarise the interviews, a skill interpreters become very good at, but something they had to fight the instinct to do in these interviews.

Following their translations, I had the tapes transcribed. I then spent time listening to every tape and check whether both translators had been consistent with the words they had used. I asked a medical doctor who is Pakistani, speaks Mirpuri and has many years of experience working within the Pakistani community in Britain, to be a research consultant. Part of this role included checking whether the correct meanings had been ascertained from particular phrases. Eram and I discussed whether our understandings of the interviews and the translation correlated.

I found managing all of the data a huge challenge through the analysis phase. IPA was a new approach for me, and juggling this with the difficulties inherent in developing themes left me questioning whether I was doing justice to the rich data that the participants had provided for me. However I enjoyed developing and reflecting on the themes as it felt that I was finally being able to capture some of the women's experiences. I felt quite pressured at times to get this phase 'right' because I wanted to do justice to the participants as well as their stories.

Learning Points

There were many areas of learning within this project. I have found the research work interesting and challenging. The interest for me has been to be close to the data and I was pleased that using IPA allowed me to remain well-grounded in the data. However, managing the amount of data generated within qualitative work has been somewhat difficult, as was letting go of data from less prominent subordinate themes.

Supervision and peer learning has been valuable in this process, particularly towards the end when the research has felt very overwhelming. Using a relatively new qualitative approach - although interesting, at times has felt unsupported by the University. I have found I have done most of my learning about the methodology from reading and during the research.

The timescale was most difficult to keep to within all the phases of the project. This was due to a number of factors. Recruitment difficulties began quite early on and the expected target of eight participants was only met with very late on. One of the tapes failed to record properly, so I only had seven interview transcripts and there was not enough time to go back to recruitment. Interviewing was suspended during the Muslim month of fasting, Ramadhan. As all interviews were carried out in the evenings, during this period, most participants were either preparing meals or attending special evening prayers, as were Eram and myself. The interview phase was also further complicated by Eram and myself having to find times which were suitable for the participants and both of us.

I had many challenges to contend with on a personal level. Being a third year trainee on busy specialist placements, continuing with the research, the process of finding a job and having energy for various family weddings (!) has been a complicated balancing act. I have also moved house twice in one year and in January undertook an important spiritual journey to the Muslim Holy city of Makkah for the pilgrimage of Hajj.

Conclusions

Although this research has been a challenge to manage, I have found it an extremely valuable experience. I am very grateful to the participants who shared their intimate and personal accounts of their experiences of caring for their son or daughter and I hope their views have been well-represented.

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APPENDICES

APPENDIX Ia

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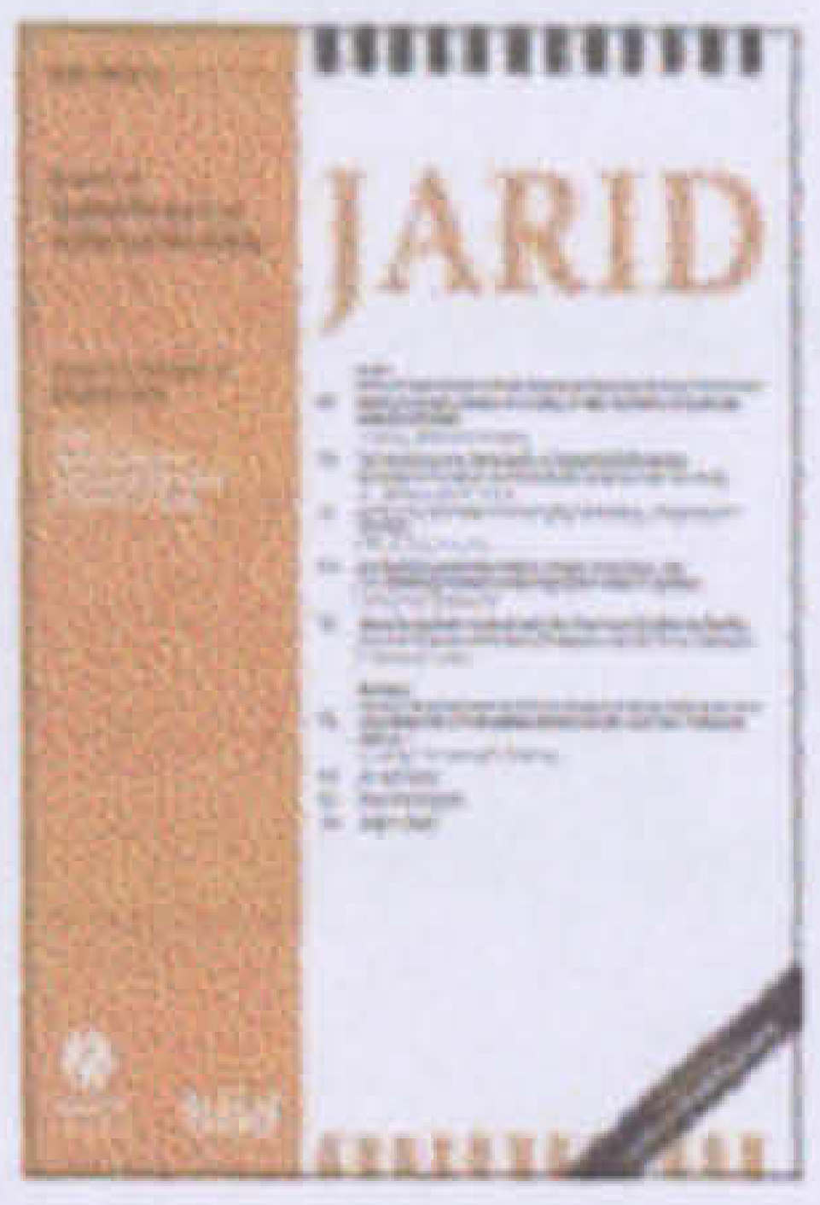

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Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities.* Cambridge University Press, Cambridge.

APPENDIX Ia

McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.
Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

Illustrations and Tables

These should be referred to in the text as Figures using Arabic numbers, e.g. Fig. 1, Fig. 2, etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number.

Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

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APPENDIX Ia

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APPENDIX Ib

THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology
Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
Clinical supervision training and NHS research training and consultancy

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TP UK
Unit Director: Prof Graham Turpin
Assistant Director : Prof Pauline Slade
Prof Gillian Hardy

Telephone: 0114 2226570
Fax: 0114 2226610
Email: dclinpsy@sheffield.ac.uk

Clinical Practice Director: Ms Joyce Scaife
Course Administrator: Carole Gillespie
Prof Nigel Beail

12th July 2004

Hena Sabir
Third year trainee
Clinical Psychology Unit
University of Sheffield

Dear Hena

I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

Literature Review: Journal of Applied Research in Intellectual Disabilities

Research Report: Option A

Please remember to bind in this letter and copies of the relevant Instructions to Authors with your thesis.

Yours sincerely

Andrew Thompson
Chair, Research Sub-Committee

APPENDIX II

North Sheffield Ethics Office
1st Floor Vickers Corridor

Direct Line: 0114 271 4894 or 271 4011
Fax: 0114 256 2469
Email: Sue.Rose@sth.nhs.uk

Northern General Hospital
Herries Road
Sheffield
S5 7AU

CMHN/AD/28/07/03

Hardy/NS2003 7 1732 **Please quote this number on all correspondence**

16th October 2003

Ms Hena Syed-Sabir
Trainee Clinical Psychologist
Clinical Psychology Department
University of Sheffield
Western Bank
SHEFFIELD
S10 2TP

Dear Ms Syed-Sabir

The experiences of Pakistani Muslim mothers of adults with learning disabilities.
NS2003 7 1732

The Chair/Honorary Secretary of the North Sheffield Research Ethics Committee has considered the modifications submitted in response to the Committee's earlier review of your application on 28th July 2003 as set out in our letter dated 31st July 2003. The documents considered were as follows:

- Protocol version 2 dated August 2003.
- Information sheet version 2.
- Consent form version 2.
- Details of indemnity arrangements with Sheffield Care Trust dated 30th September 2003.

The Chair/Honorary Secretary, acting under delegated authority, is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you the favourable opinion of the committee on the understanding that you will follow the conditions set out below.

Conditions

- You do not recruit any research subjects within a research site unless favourable opinion has been obtained from the relevant REC.

- You do not undertake this research in an NHS organisation until the relevant NHS management approval has been gained as set out in the Framework *for Research Governance in Health and Social Care.*

APPENDIX II

- You do not deviate from, or make changes to, the protocol without prior written approval of the REC, 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 REC should be informed within seven days of the implementation of the change.

- You complete and return the standard progress report form to the REC one-year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the REC when your research is completed and in this case should be sent to this REC within three months of completion.

- If you decided to terminate this research prematurely you send a report to this REC within 15 days, indicating the reason for the early termination.

- You advise the REC of any unusual or unexpected results that raise questions about the safety of the research.

A full record of the review undertaken by the REC is contained in the attached REC Response Form. The project must be started within three years of the date on which REC approval is given.

Yours sincerely

Dr C M H Newman
HONORARY SECRETARY - NORTH SHEFFIELD RESEARCH ETHICS COMMITTEE
Senior Lecturer in Cardiology/Honorary Consultant Physician

Cc Gillian Hardy, Linda Buchan, R & D Consortium

Encs

APPENDIX III

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Email: dclinpsy@sheffield.ac.uk

Unit Director: Prof Graham Turpin (26569)
Clinical Practice Director: Ms Joyce Scaife (26574)
Assistant Director : Prof Pauline Slade (26568)
Course Administrator: Carole Gillespie (26570)

INFORMATION SHEET

Research study:
The experiences of Pakistani Muslim mothers of adults with learning difficulties.
Researcher:
Hena Sabir, Trainee Clinical Psychologist

These are some questions you may have about the above research study. Please read through the information provided, and take your time deciding whether you want to take part. Please feel free to talk this over with family or friends, and if you have any questions please contact me, (my details are below).

What is the study about?

The study aims to get a more detailed view of the experience of South Asian women living in Britain who have an adult child with a learning disability. I am interested in your experience of being a mother to your son/daughter. It focuses on your views about your relationship and how you cope with their condition. I am also interested in how you manage at home, where you may get help from and what services you access.

What would I be asked to do if I take part?

You would be asked to participate in an interview with a facilitator or interviewer called ...., it will take about 1-1 ½ hour(s). If you wish to participate you will be asked to sign the attached consent form. At the end of the study, I would like to be able to contact you again to check if I have understood what you have said.

Who will know what I say?

To make sure I hear what you say, I will tape record the interview. A secretary or myself will write up the interview. The tapes will be kept in a safe and locked place and wiped at the end of the study. Your interview will be anonymised, that is your name will not be attached to it. The whole study will be written up in a report or thesis for the University of Sheffield. All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the University will have your name removed so that you cannot be recognised from it.

Where will we meet?
We can meet in a room at the local Psychology service or at the Pakistani Muslim Centre.

What happens if I want to change my mind or feel unhappy about the study?
You can always change your mind about what you say or say if you do not want to answer a question. You can always say if you don't want to take part any more. If you have any questions you can always contact me.

What should I do if I have any complaints about this research?
If you have any complaints about any aspects of the way you have been approached or treated during participating in this study, you may make a complaint through the National Health Service. Your participation in this study will not affect this process. If you have any complaints or concerns please contact the project co-ordinator, Gillian Hardy, on 0114 2226570. If this is not satisfactory, then you can also use the Sheffield Community Health Trust complaints procedure, by contacting Wendy Hedland, Complaints Officer, Fulwood House, Old Fulwood Road, Sheffield, S10 3TH or tel: 0114 2718956.

Thank you for taking the time to read this.
Hena Sabir – Trainee Clinical Psychologist Tel – 0114 2226570
Clinical Psychology Unit, University of Sheffield, Western Bank, Sheffield, S10 2TP

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Clinical Practice Director: Ms Joyce Scaife (26574)
Assistant Director : Prof Pauline Slade (26568)
Course Administrator: Carole Gillespie (26570)

CONSENT FORM

Research study:
The experiences of Pakistani Muslim mothers of adults with learning difficulties.

Researcher:
Hena Sabir, Trainee Clinical Psychologist

You should complete the whole of this sheet yourself, please ask if you need any help with the questions.

	Please circle response
Have you read the Research Information Sheet?	Yes/No
Have you had an opportunity to ask questions and discuss this study?	Yes/No
Have you received answers to your questions?	Yes/No
Have you received enough information?	Yes/No
Do you understand you are free to withdraw from the study: • at anytime • without giving a reason	Yes/No

APPENDIX III

Do you agree to take part?	Yes/No
Signed.. Date.............................. (NAME IN BLOCK LETTERS)..	
Signature of Witness...	

APPENDIX III

معلوماتی شیٹ

تحقیقاتی مطالعہ:

سیکھنے میں معذوریوں کے حامل بالغ افراد اور پاکستانی مسلم ماؤں کے ذاتی تجربات

ریسرچر (تحقیق کار):

حنا، صابر ، ٹرینی کلینکل سائیکالوجسٹ

یہاں بعض ایسے سوالات دیئے گئے ہیں جو اُوپر بیان کردہ تحقیقاتی مطالعے میں آپ پوچھنا پسند کرسکتی ہیں۔ براہِ مہربانی فراہم کردہ معلومات کو اچھی طرح پڑھیں اور فیصلہ کرنے کے لئے اپنا مناسب وقت لیں کہ آیا آپ اِس میں حصّہ لینا چاہتی ہیں یا نہیں۔ براہ مہربانی اپنے خاندان کے افراد اور دوستوں کے ساتھ اِس کے متعلق کھل کر بات چیت کریں اور اگر آپ کوئی سوالات پوچھنا چاہیں تو براہِ مہربانی مجھ سے رابطہ قائم کریں، (میرے متعلق تفصیلات نیچے دی گئی ہیں)۔

یہ مطالعہ کس بات کے متعلق ہے ؟

اِس مطالعے کا مقصد برطانیہ میں رہنے والی ایسی جنوبی ایشیائی عورتوں کے تجربات کے متعلق زیادہ تفصیلات میں جانکاری حاصل کرنا ہے جنکے کسی بالغ بچے/بچی کو سیکھنے میں معذوری لاحق ہے۔ میں آپکے اُن تجربات کی بابت جاننے میں دلچسپی رکھتی ہوں جو بحیثیت ایک ماں آپکو اپنے بیٹے/بیٹی کے متعلق پیش آتے ہیں۔ اِس میں آپکے اُس کے ساتھ اپنے تعلق پر روشنی ڈالی گئی ہے اور آپ کس طرح اُن کی بیماری سے نمٹتی ہیں۔ میں یہ جاننے میں بھی دلچسپی رکھتی ہوں کہ آپ گھر میں اِس کام کو کس طرح سرانجام دیتی ہیں آپ کہاں سے مدد حاصل کرسکتی ہیں اور آپکو کونسی سروسز دستیاب ہیں۔

اگر میں حصّہ لیتی ہوں تو مجھے کیا کرنے کے لئے کہا جائیگا ؟

آپکو ایک فسیلی ٹیٹر یا انٹرویو لینے والی جسکا نام —————— ہے کے ساتھ انٹرویو میں شامل ہونے کے لئے کہا جائیگا. اِس پر تقریباً ایک گھنٹے سے لیکر ڈیڑھ گھنٹے تک وقت لگے گا۔ اگر آپ حصّہ لینا چاہتی ہیں تو آپکو منسلکہ رضامندی فارم پر دستخط کرنے کے لئے کہا جائیگا۔ مطالعے کے اختتام پر میں آپ سے دوبارہ رابطہ قائم کرنا چاہوں گی تاکہ معلوم کرسکوں کہ آیا میں نے اُس بات کو اچھی طرح سمجھ لیا ہے جو آپ نے کہی ہے۔

APPENDIX III

جو کچھ میں کہوں گی اُس کے متعلق کس کو علم ہو سکے گا ؟

اِس بات کو یقینی بنانے کے لئے کہ جو کچھ آپ کہیں گی اُسکو میں اچھی طرح سُن سکوں، میں انٹرویو کو ٹیپ ریکارڈ کروں گی۔ سیکرٹری یا میں خود اِس انٹرویو کو تحریر کروں گی۔ ٹیپوں کو تالا لگاکر کہیں محفوظ رکھا جائیگا اور مطالعے کے اختتام پر اُن پر سے آواز کو ختم کر دیا جائیگا۔ آپکے انٹرویو کو گمنام رکھا جائیگا اور اُس پر آپکا نام درج نہیں ہوگا۔ تمام تر مطالعے کو شفیلڈ یونیورسٹی کے لئے ایک رپورٹ یا مقالے کی صورت میں پیش کیا جائیگا۔ ریسرچ (تحقیق) کے دوران آپکے متعلق اکٹھی کی گئی تمام معلومات کو انتہائی طور پر صیغہ راز میں رکھا جائیگا۔ آپکے متعلق ہر قسم کی معلومات جو یونیورسٹی سے باہر جائیں گی اُن پر سے آپکا نام حذف کر دیا جائیگا تا کہ اُس سے آپکی شناخت نہ ہو سکے۔

ہماری میٹنگ کہاں ہوگی ؟

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آپ جو کچھ بھی کہیں گی آپ اُس کے متعلق کسی وقت بھی اپنا ذہن تبدیل کر سکتی ہیں یا یہ کہہ لیں کہ آپ کسی سوال کا جواب دینا نہیں چاہتیں۔ آپ کسی وقت بھی کہہ سکتی ہیں کہ آپ مطالعے میں مزید حصہ لینا نہیں چاہتیں۔ اگر آپ کوئی سوالات پوچھنا چاہیں تو آپ ہمیشہ مجھ سے رابطہ قائم کر سکتی ہیں۔

اگر مجھے اِس ریسرچ (تحقیق) کے متعلق کوئی شکایات پیدا ہوتی ہیں تو مجھے کیا کرنا چاہئے ؟

آپ سے جس طرح رابطہ پیدا کیا گیا ہے یا مطالعے میں حصہ لینے کے دوران آپ سے برتاؤ کیا گیا ہے اگر اُس طریقے کے کسی بھی پہلو کے متعلق آپکو کوئی شکایات ہیں تو آپ نیشنل ہیلتھ سروس کے ذریعے شکایت کر سکتی ہیں۔ اِس مطالعے میں آپکی شمولیت اِس عمل پر کسی طرح بھی اثر انداز نہیں ہوگی۔ اگر آپکو کوئی شکایات یا تشویشات ہیں تو براہ مہربانی پروجیکٹ کو آرڈینیٹر جلین ہارڈی سے ٹیلی فون نمبر: 0114 2226570 پر رابطہ قائم کریں۔ اگر آپکے لئے یہ تسلی بخش نہ ہو تو آپ نیچے دیئے گئے پتے پر وینڈی ہیڈلینڈ سے رابطہ قائم کر کے شفیلڈ کیونٹی ہیلتھ ٹرسٹ کے شکایات کے طریقہ کار کو استعمال کر سکتی ہیں:

Wendy Hedland, Complaints Officer, Fulwood House, Old Fulwood Road, Sheffield, S10 3TH

یا 0114 2718956 پر فون کریں۔

اِس کو پڑھنے کے لئے وقت نکالنے کا شکریہ۔

حنا صابر- ٹرینی کلینکل سائیکالوجسٹ ٹیلی فون نمبر:0114 2226570

کلینکل سائیکالوجی یونٹ ، یونیورسٹی آف شفیلڈ، ویسٹرن بینک، شفیلڈ، S10 2TP

APPENDIX III

رضامندی فارم

تحقیقاتی مطالعہ:

سیکھنے میں معذوریوں کے حامل بالغ افراد کی پاکستانی مسلم ماؤں کے ذاتی تجربات

ریسرچر (تحقیق کار)

حنا، صابر، ٹرینی کلینکل سائیکالوجسٹ

آپکو اس شیٹ کو مکمل طور پر بذات خود پُر کرنا چاہیے، اگر آپکو سوالات کے سمجھنے میں کسی قسم کی مدد کی ضرورت ہو تو براہ مہربانی ہمیں پوچھیں۔

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کیا آپکو سوالات کے جوابات دیئے گئے؟	ہاں/ نہیں
کیا آپکو کافی معلومات دی گئیں؟	ہاں/ نہیں

APPENDIX III

کیا آپ اِس بات کو سمجھتے ہیں کہ آپ مطالعے سے علیحدہ ہونے کے لئے آزاد ہیں: ● کسی وقت بھی ● بغیر وجہ بیان کئے	ہاں/نہیں
کیا آپ حصہ لینے پر رضامند ہیں؟	ہاں/نہیں

دستخط:-- تاریخ:--

(بڑے حروف میں نام لکھیں)--

گواہ کے دستخط--

APPENDIX IVa

Doctorate in Clinical Psychology

University of Sheffield

Confidentiality Form

Research Thesis: The Experiences of Pakistani Muslim Maternal Carers of Adults with Learning Disabilities

Researcher: Hena Sabir

The interviews, which you have agreed to facilitate and translate, may contain information of a highly personal nature. This information must be kept confidential and not disclosed to others.

Should you hear anything distressing during the interviews, please discuss this with the researcher.

Declaration

I understand that:

- I will discuss the content of the interviews **only** with the researcher involved.
- I will treat the material heard as confidential.

I agree to act according to the above constraints.

Name..

Signature...

Date...

APPENDIX IVb

Doctorate of Clinical Psychology

University of Sheffield

Confidentiality Form

Research Thesis: The Experience of Pakistani Muslim Maternal Carers of Adults with Learning

Disabilities

Researcher: Hena Syed-Sabir

The interviews, which you have agreed to translate, may contain information of a highly personal nature. This information must be kept confidential and not disclosed to others.

Should you hear anything distressing during the interviews, please discuss this with the researcher.

Declaration

I understand that:

- I will only discuss the content of the interviews with the researcher involved
- I will treat the material heard as confidential

I agree to act according to the above constraints.

Name ....

Signature ....

Date ....

APPENDIX V

INTERVIEW SCHEDULE

1. Background Demography

How long have you been in the UK?
Where do you come from in Pakistan?
Who lives at home with you? Do you have other relatives nearby?

Today I have come to talk to you about …….
How old is he/she?

What does he/she do during the day?
Prompt: Do you access/attend another service or professional?
Day centre?
What is he/she like?
Prompt: What interests him/her?

2. Relationship between Mother and Child

What was it like when he/she was born?
Prompt: if appropriate, when did you first find out about his/her learning disability?

Can you tell what …….. was like growing up?

3. Impact of Learning Disability

What's life like with ……..?
Prompt: What is it like being ……..'s Mum?

Tell me about how you manage?

4. Belief Systems

Why do you think …………'s like this?
Prompt: What explanations make sense to you?
How does your family understand ………'s condition?
When people say 'learning disability' what does that mean for you?

Can you tell me what it's like when you visit Pakistan with …….?
Prompt: How do people respond?

How do you feel about ………'s future
Prompt: How do you think this has had an impact on you?

Debrief – Resource Information sheet – Thanks

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Preliminary Thoughts/ Themes	**Interview & Index**	**Quotation**
'No peace' – constant worry Collect will/identity – one hurts we all hurt	1 (67-69)	Whoever lives in this house with him, it's as if they are ill. There's no peace in this house or feeling of well-being amongst everybody else. Everyone is always anxious and worried all the time.
	1 (71-73)	When he's well and happy then all of his brothers and sisters and mum, all of us are happy but when he becomes too ill then we all become worried and anxious again.
Perceived **assumptions** and **stereotyping.** Difference in 'our' home/way/thinking **Us and them** **Assumptions** of differing expectations Pakistan – get the services we want – finance them Our people – assumed sense of belonging will be Pakistan **Differences between here and there**	8 (35-53)	lots of English people, erm, erm, think Asian people have, erm, family help or, or they've got, they're surrounded by family and they get almost all the help from family but it, I think it's not one hundred percent true. Er, there might be a chance of them coming to your help but there is a time when all families have got their little problems to cope with, and they can't just turn up ??? And I remember when I used to go to S's school and I had a meeting about short-term fostering or, erm, short-term care and people who go on holiday and things you need, children need some of family to, and, er, whenever it came down to me, they used to have, er, what happens with Asian families they've got families within the community so they don't need it. But that wasn't true then until I got really sick of listening to this and I ended up telling them all - Do you know what, you people think that we've got families who do this and that.
	1 (78-79)	In this country there doesn't seem to be any peace/help (sahoolat) for children like this and there should be.
	1 (114-128)	English (Gorey/Whites) people don't think like this, they think that one room for somebody is enough, for the ill person. Theres no-one dearer than one's mum…… There is no responsibility to the rest of the people (like brothers and sisters). They're just concerned with the person who is ill. They can provide the room but they can't look after him. If he was on his own he could fall. There wouldn't be anybody around to give him any food or drink. I follow him around making sure that he eats a bit in the day, that people help him, offer him water, do things for him. If he was on his own this help wouldn't be available, but English people don't do that, do they?
	1 (235-236)	In Pakistan, its good, you can pay people to give a massage or to help you take children, people places.
	2 (182-187)	Its good isn't it, its our country our people, she liked it……. Shopping, our people, our cars our land. Here in England we tend to have to stay in all the time but there she see cows, goats chickens etc, over there, there is everything (in front of you). Its an open space.
Negative about Pakistan	7 (203-207)	If we were here maybe the doctor wouldn't have agreed about the child but there they can't tell. I couldn't feel anything myself. I was critical when I was about to give birth to her because there aren't facilities. They were taking me to Murpur, but otherwise I didn't know at all she was going to be born like this.
God's control of **destiny** – Hope that son/daughter may get better Some element of certainty	1 (87-88)	I just want Allah to make my son better for me. I pray that Allah protects all Muslim children from an illness like this.
	1 (144-145)	Allah made him well mentally and he seemed to come back to us.
	1 (158-	Then we would be visited by Maulvi, Qari saab. He used to read some things for him and we did as well,

APPENDIX VI

that Maulvi has some cure/ or can help	161)	everyday in the morning, then slowly, slowly, with Allah help, he began to get better.
	2 (192)	I just think that Allah make her okay. That she is happy.
	3 (72-73)	How can I help her, Allah will help her. Her time is being spent, I don't know about tomorrow, what can say?
Allah's choice test	3 (84-85)	Yes, her mum, dad, we all are worried about her. She won't be staying all her life with us, nobody will stay (with her). Allah's her protector for the future.
Locus of control lies with Allah – we can't help her	6 (137-142)	We think whatever he's like, Allah's made him like this. People can't do anything. Sometimes he'll say himself, I'm ill. If someone asks him, S, are you okay? He'll say, no, I'm ill. We feel sorry for him, but Allah's made him like this. His brothers and sisters are all married, if he was aware of things, of the world then.
Strong sense of coping – in future planning	2 (135-137)	What do I don't know, not even the doctors can really tell me why she's like she is. Only God knows why she is as she is, there's nothing anyone can do, not me or you.
		You tell us, why do you think he's like this? **6:** It's by the will of Allah (swt). By looking at him, as I said before, nobody can tell, it's when he talks, he talks really fast, really fast.
Allah has given me strength Why me? **Test**	7 (361-371)	My daughter helps me a lot, if she knows I'm ill she'll come running, nobody else can look after them like that. I'm a sugar patient and a heart patient, how long can I live? If I become invalid who will look after me? Allah's given me so much strength even though I'm ill, probably because of my kids, so that I can look after them. My daughter-in-law cooks and cleans but you still have to do so much for them, sometimes I can't even get up, who's going to look after me? I pray Allah doesn't make me rely on anyone. I always pray after namaz, oh Allah, as long as my kids have life, make my life long as well, but I don't know, Allah will do what he wants, he won't listen. People are like this, it's not Allah's fault.
Other people questioning ability to cope Allah will look after when we die	8 (483-498)	They were, they were like, er, thoughts in my head at the beginning when I used to question why me? You know like, once people judge you then you start judging yourself, why and why, and then I go back, er, to a time when, er, I was barely a child myself so like people say, I was a child but you don't know rights and wrongs yourself, God's not that cruel. Then you think, if it wasn't me, it could have been somebody else but when you think about it, every God shows you, to test you, erm, whether your God is, erm, will power to cope with it and things like that because I've seen many people, they can't cope with their one normal child, two normal children. Erm, like when my husband's grandmother used to say to me that, if I've ever got no energy or if I've said I haven't got time, she used to say to me that people have ten children and they've got the time, and you've only got two or three and you think you've got no time. But there is a difference between the ten normal children and one with severe learning difficulties.
	3 (171-177)	We do think that maybe Allah will have mercy on her, we do think but what can we do. What Allah will want for her will happen. Maybe Allah will do best for her. That is what I think, when you look at the world, I think that maybe Allah has done best for her. I pray after N that Allah will do best for her future as well. He will do best for her, we have hope in Him, He will open the doors for her. All we can do is pray.
Obligatory for parents – our role is set - ownership	6 (174-194)	**R: How do you feel about the future?** **6:** It's all thanks to Allah, our provision is written, maybe because we're looking after him.

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		Allah's providing for us as well. Allah knows best, it becomes obligatory for the parents to look after their children. Once he wasn't home and it wasn't the same, it felt like darkness. He was saying, my dad hits me, they took him where they keep children, he stayed there but his father didn't touch him at all, nor have I ever touched him. At night they came to take his clothes, his father said, you should ask me, he's my son, not yours. Take a look, has he got any marks anywhere, he hadn't, so my husband said, you know his mind's not normal, so why did you take him? I'm his guardian so they believed us and S was saying he doesn't want to go. **R: How long did he stay?** **6:** Only one night. He came back, nobody made dinner or ate, it wasn't the same without S. He is a child after all.
Testing me	8 (498-507)	I feel that God's testing me and my husband, how we're going to manage and how we're going to cope with, erm, but there were so many things, er, thrown at us in a way, questions but I think, I don't personally think I've done something wrong but you cannot one hundred percent say that, look I'm innocent, erm, I haven't done anything wrong because only God knows who's done right and wrong, and at the end of the day, I think if god's given us this, it's some sort of a test for us, and how we're going to manage and cope, and I think for twenty six years, it's not been bad.
Meaning of disability	4 (99-102)	I think it was in our destiny, it was written for us. It's a test for us, a trial or I think someone has done something on her (magic) on her or there is something (force) with her, these are the things I think about, that go around in my head.
	7 (342-351)	I'm just thinking if we, mum and dad are not here tomorrow, life is in Allah's hands. He can take your life sitting and sleeping. The only thing we can think of, standing, sleeping, awake, is who will look after our children, who's going to bath them, keep them clean. If you feed them and you don't clean their face, they get agitated by it, they'll say nobody cleaned our faces. They're so clean, they'll have a bath and my little one will want perfume on, she doesn't let her hair get greasy, she'll have a shower every day, who will keep them this clean?
Own illness put aside Conflict of interests Will to look after	1 (90-97)	Sometimes it's really difficult. Now I don't really care for him, my daughter does. I have problems with my arms, I can't lift them very high. They've put three rods in three places in my arms And this makes it difficult for me to do much. When I used to be at home on my own, I used to hate it, I used to cry a lot. I used to have to change my son's nappy using my feet, that's how I used to (tie it) and move it away. I wasn't get getting any help, I really felt that.
? **expections** mother has for her old age – being looked after?	4 (92-97)	Hard, we lead a hard life, I worried all the time. I suffer from arthritis, when I'm in pain I want someone to look after me, and talk to me, I need someone to look after me. Despite all of this, I still think of her, I think what will become of her. She is forty five, forty six now, people of her age look after people, they look after someone, she can't look after anyone.
Physical pain	7 (139-144)	I had so much swelling on my face and arms. When I was washing S I couldn't move them. I have to take her to toilet, wash her, her dad can't take her. She (daughter-in-law) puts her clothes on for her. I wash her, brush her teeth, wash her face, then she comes, she puts her clothes on her. I can't bend to wash her face because my back really hurts.
Illness	7 (253-	My husband does a lot, he puts S in the chair and on the toilet, and then he wakes me up. He gives S weetabix and

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	259)	puts her in the chair, and then says to me to get up, that I've put her and you can wash her now. He helps me a lot with her, when she comes he'll help me as well, he'll take her out of the wheelchair, he doesn't let me pick her up because the doctors have told me not to, because I've already had angina attack twice
Lack of practical help or support She doesn't matter – **meaningless to everyone** else except me..? Powerless Helplessness Constant state of worry	1 (102-103)	They say there's this place available or that service, but I haven't got any help at all.
	6 (24-27)	Yes, we take him sometimes to town, shopping etc. Yes, we haven't got a car and my husband doesn't know how to drive anyway. I can't drive and my husband can't drive
	2 (169-175)	Why would they think anything about her? There, whether you're rich or poor, people don't care, they're only concerned about themselves, they're not going to think about her, even the educated they are not going to think about her or the uneducated or those whose minds aren't working. How she is doesn't matter to them, it doesn't make any difference to their lives.
	4 (128-132)	I get ill, I told you I've got arthritis, I don't feel well. It is not within our control. By worrying nothing can be gained. If I worry and cry nothing can be gained, we can't do anything say if it's a mother or father, we can't do anything but just worry. What can we do, what are we going to do?
	4 (158-160)	When she tried to put gas cooker on to warm tea, but couldn't, telling of how the gas smell was everywhere, and had to open doors and windows and put the fan on for the smell to go.
	7 (236-242)	You know how hard it is to manage in Pakistan, you have all the housework and looking after the kids as well. It was really hard to look after them. When I came here it was still all on my head, they didn't give me anyone for help. They still not doing justice here. If someone's got one child like this they've given help but if someone's got three children like this they still have only given one help.
Not getting any help They've got the money – not **bothering about us**?	7 (262-274)	It's really hard for me, even my letters from the hospital have gone to them saying why I'm not getting help even though I'm so ill. They say about me that I can't pick a child up myself, so why aren't I getting any help. The doctor send a nurse home and said, we'll look into the matter if they are not listening to you. The doctor knows of my illness so he send a nurse home to see the condition of my children, and to find out how much help we're getting, when she came she was shocked. Then she phoned them and said, it's between me and them now, I'm going to sort it out. She is going to sort it out now, they have got the money but they're not bothering. They say they have got the funding, they just can't get a person from an agency. Well, if they look for someone, they'll find someone.
Need for help	1 (107-109)	What I need is a place that is downstairs. This house is a two-storey house so some of his brothers and sisters go to sleep upstairs, and he has to stay downstairs by himself and he really feels that. He wants to be able to go upstairs and sleep as well, and be with them.
Aspirations for child/children – grief/loss of normality Not like other children – sense of abnormality	1 (82-84)	As a mother I really feel it. Like any other mother I want my child to go to college, to be independent, to go to college or school, but all of this has had to stop and be put aside.
	3 (153-155)	I wish that Allah had made her like other children, then we wouldn't feel like this. All the others are ready for marriage now, and she's not so we do think about this…. …. Yes, she's the first. She's got younger sisters ready for marriage and she's not. Now we'll see what Allah will do for her, he will do what's best for her. I've seen worse mentally than her and they've got married……. You can get partners but you have to think about their life. You want to find someone who will help her get on with her life.

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Not able for adult with LD to be part of culture/expectations	2 (76-79)	**What she quiet from the start?** **4:** Yes, from the start she wouldn't mix with people. Look how she's sitting alone now, she won't talk to anyone and she won't mix with anyone.
	3 (68-69)	……But not like a normal child, she's not alert like normal children.
	4 (89-91)	She didn't read namaz, she didn't read an Islamic book or read Quran, she hasn't kept a fast, she doesn't know at all. She doesn't know at all! Where we've come from and where we are going to or what we should be doing.
Taweezs/Jinns/Pir/Faqir First port of call	1 (146-147)	Then we tried to sort things out by taking him to see holy men (pir/faqir), and to get help from them.
Exert an influence/positive-negative Black magic We've taken it out	4 (81-88)	I do feel for her, sometimes in my mind comes these thoughts that someone has done a taweez on her, then I think maybe she has something (force/jinn) with her. I have tried curing her of these but it hasn't made a difference. I tried getting taweez for her, she's got one in her neck, I got it from Rawalpindi, after taking her to a pir/faqir (holy men), but it hasn't worked. I think it must be with her mind.
	7 (96-106)	She's got a "saya" (shadow) with her. Her arms will go like this, no matter how high she is, she'll jump down. Yes, it's Jadoo (black magic). We have them taken out, but after four/five months they're back, as soon as someone knows they put them back on her, we have taken out constantly. They don't do it on her. What has she done to anyone, they do it because of us, the parents, because they're our children, our blood. So it's affects us on our heart and mind. What has S said to anyone, she's a silent flower, she hasn't said good or bad to anyone, it's to get to us, us the parents. We'll get fed up and start arguing, that's what they want.
Community pushing feelings about curse – play with head	8 (65-87)	And I think sometimes you get more pressure. I, I keep well away from, erm, all community, apart from my sisters, brothers, I don't keep much contact with people because there is more bother going on then actual help. And it plays with your head sometimes and you just want to break away because you only want to sort out family problems, your own children and you don't want to have to think about anything else. **R: Is that the community are pressuring you?** **8:** Yeah. Erm, what happens with them is, erm, if they need a help, er, they rely on you to turn to them but if you need help they turn their backs on you, and in some way they think, erm, a person with a, er, disabled or a child with learning difficulties, erm, some sort of a curse or a jinx on the family. Erm, but sometimes it separates the family cleanly away from the community and it, it's just that I, I felt I don't, I, I'm not ashamed of him, with a son like that. I believe there is a God and the God has given me this, actually as some sort of a destiny.
Doctors don't know…. No reasons	1 (145-146)	The doctors didn't seem to know what was going on.
	1 (157-158)	The doctors can't seem to understand what's wrong with my son, his problem
	2 i(135-137)	What do I don't know, not even the doctors can really tell me why she's like she is. Only God knows why she is as she is, there's nothing anyone can do, not me or you.
	3 (98-105)	The doctors don't understand, I think there is something with her tongue and that is why she isn't talking but the doctors don't understand…. The doctors don't understand but I know there's something stretching her tongue. The reason why she talks like she does. The doctors don't understand.

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Disability and gifted	1 (161-164) (180-181)	If there was anything happening or going to happen here or in Pakistan, my son used to be the first one to know. For example, a few days ago we were going to buy a car. We didn't know what colour it would be but my son knew, he said it was a red car.... He doesn't say much now but he does know what's going to happen often. He finds out before.
Positives	3 (23-26)	......she's happy at home, she goes out with us. She goes shopping with us. In the evening she goes to mosque from 4.30 till 6.00, she reads Quran there. She also reads namaz (salah), shes good, she has started namaz.
Maternal responsibility – duty – no one else but me – only problem of immediate family	1 (243-245)	I feel that as long as I am alive, his brothers and sisters will want to help him but when I'm not around then nobody will be helpful towards him, not his brothers or his sisters.
	2 (91-92)	It's just that there's a daughter and a mother, and the mother feels it's her duty to care for her child.
	2 (145-148)	A brother or a sister may be concerned but other outsiders won't be bothered, it's not their problem, it's a problem concerning the immediate family and no-one else really. What's it to them
	6 (35-37)	His brothers/sister-in-laws come, but they've got their own homes, they work, so they can't come.
Wanting him to go before we do – we brought him into world	7 (152-156)	I brush her teeth myself, if they've given helpers I don't rely on them. I still brush her teeth again myself. She doesn't brush them properly as well so I brush them myself. I know if plaque sticks then you won't be able to get rid of it. The dentist says their teeth are very clean
	6 (84-89)	he doesn't trouble me. Well, sometimes he does of eating, he'll go here, he'll go there. I told you if you put songs on for him, he'll sit there all day. Well, you know children like him, their brain is like that. We are his parents so we have to look after him. Nobody else can look after him.
Life is with us?	8 (534-547)	But, I just want him to go before we do.Because I think, even though sisters love him and, er, I, I don't want them to, er, I don't want to rely on my daughters because, er, it's alright for them now but at the end of the day when they get married, they have families of their own, I don't want anybody suffering because of him and having family problems. I think his future is with us and, erm, I don't know, I mean, up to now, I'm saying this because I know they don't have very long lives. Er, somehow I think, everything's got a life and I'd prefer him to have a shorter than having a long life because I, he's not going to have any other achievements in life,
Impact of everyday situations, **stress and coping**	1 (218-225)	We had problems on the plane because he kept wanting to hit people, and we kept on having to apologise to them. Other people don't realise that he's ill, he kept bothering people sat behind him or in front of him. For the whole of the journey I had to hold his hands, we didn't eat or drink anything during the journey. The aeroplane staff didn't offer us anything and then I didn't ask either. I just held onto my son. Two people stayed with him and then when we got there, he was aright.
	2 (110-114)	I mean, getting out of the house, I haven't pass (the test) for the car so if I have to take her out, its difficult, for example, with this girl/daughter to the doctors, the doctor is quite near to me but if it was far than without a car I would have to arrange for a taxi. It difficult isn't it.
	2 (120-121)	And another thing, when it's frosty outside then, other children with understanding can see it. This child can slip.
'Not understanding'	4 (61-66)	She used to come out of school and go on the streets, then we wouldn't send her to school. Then the school had a taxi service for her. She used to come and go on the taxi, then the school started sending her to 'B' to learn

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struggle/exhaustion/conflict		English. Once she went on the bus to 'B' and got off on the wrong bus stop. She came home late and we were very worried.
	4 (161-169)	She doesn't understand anything. Sometimes she'll take a matchbox and say, I'm going to on the gas, this room gas is automatic but in the other room she'll say, I'm going to on the gas, she'll say to me. It's dangerous, have to be careful in case she knocks against something and the match drops, she doesn't know at all, there could be a fire. Sometimes she'll see pins in shops (*safety pins*) but we be careful, we're always checking her. At night we check her so many times, we'll check her pockets.
Check – hypervigilance Keep eye Helplessness – trapped	4 (170-181)	**R: How do you feel about this?** 4:She doesn't know what she's doing. She'll go to the bathroom and within five minutes take threads out of the mop. (*mum demonstrating what she does with threads*) Then I'll say, what you doing Z, your arms will go bad. **R: She put them on her neck?** 4: Yes, she did. If you ask her why she's doing it she'll say, shall I not? Shall I not? I say, no, you shouldn't. She'll break leaves off the plant and it dies. If I say, why did you, she'll say, shouldn't I? I always keep an eye on her, if she goes outside. She'll just pick things up like metal etc. then I say to her that you shouldn't pick things up from the floor.
	3 (14-18)	Yes, they're Pakistani but …. You've got the tape on, but they don't like N,they hit N. So let the tape record now you can ask what you want. The children have hit N about four or five times, because of this we are fed up, what can we do, where can we go……..
Family sacrifice? Regret/ guilt/? Trapped/ conflict – powerlessness – loss – **not able to meet own needs**	1 (255-269)	It was like qiyamat inside (our house). For two years we weren't aware of what was going on outside our family. My uncle passed away and I found out six months later. Even now, it's difficult. My father passed away in Pakistan, and my mother passed away. When my father died, I was able to go to Pakistan. My mother-in-law, she telephoned asking me to come, she said, please come and meet me, I'm going to die soon and I want to see you before you die. But because of my son, I was unable to go. But then my mother-in-law kept on insisting, so I went just for ten days. When I came back, after four or seven days, my mother-in-law passed away. Exactly what they said would happen, happened. If my son was well and healthy, like my other children are, then I wouldn't have had to come back so soon, I could have stayed for two months and it wouldn't have mattered. I wish that my son was well so that I wouldn't have to live in this country.
Living in country – homesick/trapped Not able to **disconnect** Blame-her/son/each other Guilt/regret	8 (408-417)	when I went to Pakistan and I had to leave him behind, was hard at the time. And I remember it was very hard. I had to round about tea-time, drop him off at respite and I just couldn't cope with it. I mean, he was going to respite normally, if that's fine. When I'm, I'm here I can ring up, check up on him and they can ring and let me know that, if there's anything wrong or, or if they need anything, and, er, because I was going and leaving him for 7 weeks and that was the hardest.
	1 (276-287)	I had to spend a lot of time in hospital with him, with my other daughter. This affected the other children, they weren't able to study, I wasn't able to concentrate on them. A friend of my daughter's said that she wanted to be health visitor or a nurse but she wasn't able to study or train for anything. My other son didn't study, or my other daughter. My eldest daughter hasn't been able to study. This is because she's having to care for her brother and help me with him. When they grow up, they'll probably blame their brother and say it was because of him that they weren't able to study
	8 (111-	And I think when he goes away with them for a break, even though mentally I'm always sort of getting up at the

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	118)	same time, er, you just hear these voices in your head during nights, even though, if he's not here, theres no rushing around because I have heard a cry, and things like that but, the thing is, now I feel that I've got less energy in me, that's how I feel. It comes to a certain stage where you think that's it, just want to just sit back and relax yourself
Ideas about researchers – appreciation/regret – ?wistful	1 (293-294)	Like you are all studying and trying to get ahead, that's what I would have wanted as well for my children.
Projection of powerlessness	2 (1-8)	**R: By doing this interview its not that you will get help. All we are trying to do is to find out what your needs are, then it's up to the service providers to take the initiative whether or not they will provide services that families like yours need. But the responsibility isn't with us, we just want to make that clear to you.** **2:** No, no, I understand that, that's fine. It's the English people who work out the services, I realise that.
Benefits – nothing is enough	1 (82-87)	Some people say to me, oh, if you've got a child like this you can get extra money but what's money. Someone could take the whole payment book from me. I don't want money……
It could be worse.. – we have to be grateful-minimising	2 (99-103)	It's not good really, but I thank Allah because she could have been worse, she could have been disabled and been without a limb or a leg, not eating or drinking, or going to the toilet. She's much better than children in those situations and I'm grateful for that
Disbelief at disclosure	7 (157-165)	She's like this from birth, S. They said from birth but you couldn't tell she got better. She could climb up the stairs and come down again. There's a film of S when we were in the other house, showing her climbing the stairs. She's shouting from the top, where are you, mummy? We couldn't believe why the doctors were saying she won't be able to walk, she was walking fine. We didn't know that when she's getting older she wouldn't be able to walk. Yes, she used to walk up the stairs, she used to go into the kitchen by holding the wall.
Genetics?? Married with cousins – not right – too painful Husband good person therefore must be black magic	7 (279-293)	They don't know why, the doctor's say it's because you get married with your cousins, that's why the children are like this, but other people who are not relatives, their children are like this as well. Sometimes we think, why did Allah want this for us, three children exactly the same. Somebody wants this for me. My husband was good with his parents, financially looked after them as well, looked after his relatives financially as well. He helped every family of his relatives, be it with money or something else. My husband is good with everyone. We just talk amongst ourselves about it, we tell god because he is the one who put us in this situation, you can only tell the person who put you in this situation. When we go to people of knowledge, they say it's because of jadoo (black magic) when we have them taken out. They say when they were in the mum's tummy then someone did this jadoo.
Reasons for disability – unsure – I think, no-one really knows	2 (141-142)	I think when she was little and she had her injections, there was something wrong, but nobody knows for sure, can they?
	6 (78-79)	Yes, it's all mentally. It's one of his veins to the brain. It's like a stroke.
	3 (91-93)	They didn't abort because the bleeding stopped. I think that because of that bleeding this girl has been affected. It affected her on her speech and on her throat.
Not being believed	8 (247-	I know I was, I was ever such a young age that I didn't understand what was going on, and then, er, I remember later on that his neck was turning in such colours, a blue, yellow, purple and then red, he was changing colours

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If I could speak English… language	257)	and, er, his eyes had rolled back and all you could see was the white and all that. And I tried telling the midwife she wouldn't take any notice, er,… I do feel angry but some, sometimes I think, maybe I didn't have enough knowledge, maybe if I had the language, erm, I could have helped myself. Erm
The eclipse makes more sense This more **meaningful**?	7 (208-220)	Yes, she did walk after five years but when she was born her feet were turned backwards. When there was eclipse on the moon, you know when they say there's a moon eclipse. We buried her feet in the earth and her feet became straight. They say until the moon clears you keep the feet buried. Me and my brother-in-law (husband's younger brother) who died, we kept her feet buried, he was in Pakistan at that time. He said, don't say she's crying, she'll get better. When the feet were becoming straight with force she was crying, they became absolutely straight and she started walking when she was five. We did it twice like this and she got better. Then here they started operating and she got worse. Her bone that's turned in her ankle, they operated but it hasn't got better.
Respite – responsibility lifted	8 (104-110)	And the thing is I, I never wanted to send him to respite because he used to go, he used to come back upset. And I just could not understand what to do about it, at the end of the day like, they all find we need a break at the end of the day. And if he goes away for four to five days to this other place, and there was a time when I used to dread these weekends coming up when he's going to go away but now, time is like that now that I actually feel that it doesn't come soon enough.

APPENDIX VII

Glossary

Allah	Term for God within the Islamic faith
Jadoo	Black magic.
Jinn	Spirit being made of smokeless flame of fire believed to have been created by Allah along with mankind.
Jinn possession	Person is 'possessed' by jinn due to a misdeed.
Maulvi	Pious man with knowledge of Islam, not necessarily a scholar.
Pir or Peer (can also be referred to as faqir)	Traditional faith healer often Sufi in Islamic orientation. They are generally well respected members of the community having a good knowledge of local customs and traditions.
Qari	Pious man with knowledge of Quran and it's correct pronunciation.
Qiyamat	Day of Judgment or Reckoning.
Rawalpindi	City in Pakistan.
Saya	Literally means shadow. A person is considered to be under the shadow of a jinn or supernatural being.
Taweez	Amulet which contains verses of the Qur'an written on a piece of paper which is usually given by a Pir to an ill or sick person. They have to wear it and it allows protection or healing. (Within this community references are also made that someone has done a 'taweez' on them – which is a local Mirpuri expression to indicate that someone has done something negative to them).