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**Genetics, Religion and Identity:
A Study of British Bangladeshis
(2004-7)**

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Introduction (Sophie Gilliat-Ray)

Based on 2001 Census data, the Muslim population of England and Wales in 2001 was 1.54 million, with about 40,000 Muslims in Scotland (Census 2001; General Register Office, Scotland). However, given that the 'religion' question in the Census was voluntary (answered by 92 per cent of respondents) and based upon the above-average birth rate among Muslims in Britain, it is likely that actual size of the Muslim population today is currently between 1.7 and 2 million.

Within this population group there are many different ethnic and cultural groups, such as Pakistanis, Bangladeshis, Arabs, Africans, Turks, and so on, and there is considerable diversity within these different ethnic groups derived from association with particular tribes, regions, or castes. There are also important differences among Muslims in terms of their culture, language, class, age, and membership of different philosophical schools of thought. Despite this diversity, Muslims around the globe often share a sense of connection to the world-wide Muslim community, the *ummah*, and despite their cultural and sectarian differences, they defend some central tenets of Islam as non-negotiable. Many Muslims living in Britain regard themselves as part of this world-wide community of faith and share a sense of belonging and identity based in Islam, regardless of their particular ethnic background.

The 2001 Census recorded 283,063 Bangladeshis living in Britain (up from 163,000 in 1991) and the vast majority are Sunni Muslims. They constitute about 17 per cent of the British Muslim population, and they are among the most homogenous, with nearly all of them originating from the Sylhet region of Bangladesh. Around three-quarters of Bangladeshis in Britain are under 35, and they are distinctive for their large household size (60 per cent comprising five persons or more). More than half of Bangladeshi women in their late thirties had four or more children (Ahmed, Latimer & Phillipson, 2001). Bangladeshis are unevenly distributed across the UK, and on the whole, the Census data reveals that they are concentrated in large numbers, but in fewer areas. For example, the London Borough of Tower Hamlets is overwhelmingly comprised of Bangladeshis, where they comprise nearly 36 per cent of the Borough's population.

Religion continues to be an important dimension of personal identity for different generations of British Muslims, including Bangladeshis. Research has indicated that Islam is becoming more rather than less significant to younger generations of British-born Muslims (Eade 1994; Jacobson 1998). Within a number of migrant communities, a new and distinctive identity as 'British Muslims' is being formed, negotiated and employed in a wide range of settings (Modood 1998; Khan 2000; Gilliat-Ray 2000), sometimes as a deliberate and strategic technique for empowerment and equal opportunities. Although the different generations of British Muslims are likely to share a belief in the central tenets of Islam, there is clear evidence to suggest that Islam is used differentially in identity-formation, and that there are different ways of 'being Muslim' in Britain across the generations (Gilliat 1994; 1998a; 1998b). Younger British-born Muslims, regardless of ethnic background, appear to have a stronger sense of being first and foremost 'Muslim', and a greater willingness to challenge what they perceive as traditional cultural practices (Jacobson 1998). A project recently conducted by one of the applicants (Latimer) indicated that religion is integral to the decision-making and identity-work of Bangladeshi Muslim women in Britain across generational groups, including the ways in which they conceptualise and act on (or don't act upon) health-related issues.

Consanguineous marriage remains common among many population groups that share a Muslim identity (but not all), principally those from the Middle East, North Africa, and the Indian sub-continent. Approximately 20-50 per cent of marriages are consanguineous (Shaw 2000), increasing the risk of recessively inherited genetic disorders. Although some young British-born Muslims are challenging this practice, it remains common.

Previous research on British Pakistanis and genetics conducted by Alison Shaw (Shaw 2000) indicated the complex role of religion in the process of decision-making about genetic screening and the 'management' of genetic disorders. An appeal might be made to Islam as justification for declining testing; caring for a child with a genetic disorder might be regarded as a 'test' of faith from God and a matter of destiny or duty; a child suffering from a genetic disease might also be seen as a 'special gift' from God. Religious discourse is used to explain, justify and legitimate matters of fate and decision-making. This research project sought to build upon Alison Shaw's work with Pakistani Muslims by examining issues of genetics within the Bangladeshi Muslim community in Britain. Comparison between two migrant groups which differ in terms of ethnicity but which share a common religious identity, enables an evaluation of the similarities and differences in the way Islam is used by each to justify, manage and legitimate decision-making about genetics. By exploring inter-generational decision-making and knowledge-transfer, the project aimed to trace important patterns of change that could have significant implications for the delivery of genetics services to population groups that share a Muslim religious identity.

Muslims from ethnic minority communities who have been referred for genetic testing are likely to be unempowered in lay-professional interaction in a number of ways (e.g. language barriers), but also on account of their generally poor knowledge about genetics (El-Hashemite 1997). Understanding how Bangladeshi Muslims from different generations speak about and understand genetic information and disorder, as this project sought to do, could help in the development of culturally appropriate resources to close the lay-professional gap, and it is hoped that specialists in the delivery of genetic services might take up the challenges posed in this project report. Given the increasing importance of religion as a reference point for identity among many young Muslims in Britain, a project which placed Islam at the centre of research questions was timely and consonant with the significance that is attached to religion, especially by a demographically 'young' and largely British-born population group.

Previous research has indicated that professionals involved in genetics services are often dismissive of lay perspectives (Kerr *et al.* 1997). This disjunction of understanding has important implications for policy decisions about genetics. Furthermore, psychosocial studies of genetics services in Britain have so far been largely blind to the ethnic and cultural diversity of the service users (Clarke 1997), with issues of religious identity even more peripheral.

It has been established that indicators of religiosity and membership of specific religious groups predict responses to attitudinal questions about genetics (Singer, Corning and Lamias 1998). This has been established in relation to Christians and Jews, but so far, there has been no systematic study that includes British Muslims. The existing research on genetics involving British Muslim participants has tended to focus upon Pakistanis in particular (Darr & Modell 1988; Bunday 1990; Shaw 2000), but even in these studies, issues of religion have not been the focus of research questions.

Patients receiving genetic counselling often identify religion as the basis for their resistance to screening or other interventions, although their decision-making is likely to reflect a wide range of other factors, such as education, socio-cultural background and so on (Clarke 1997, Shaw 2000). Our project sought to identify the significance of religion in particular, and to explore the ways in which patients use religion (or not) to negotiate and legitimate their decision making about genetic testing.

Gatrad & Sheikh (2000) note the likely risks associated with culturally insensitive maternity care for Muslim patients (including genetic and prenatal counselling) (Bowler 1993), and argue that appropriate services tailored to meet the needs of Muslims should be considered as deserving priority attention. This is particularly so because recessively inherited genetic disorders may compound social disadvantage and exclusion experience by so many Muslim groups (Modood 1997). This project thus sought to identify what these needs are and how they might be delivered. Furthermore, Darr (1999) has indicated the “dearth of culturally appropriate resources for health professionals and families to aid in the time-consuming process of genetic counselling”. The data gathered from this research will hopefully help to rectify this lack of resources by providing the data upon which might inform the development of new services or methods of service delivery.

Against the background of previous research relating to Bangladeshis in Britain, genetics and health services, and Islam in Britain, this project had a number of distinctive aims and objectives. Firstly, we wanted to know how genetic information was transmitted between different generations of Bangladeshi Muslims in Britain. What are the mechanisms by which knowledge was transferred, and to what extent did this knowledge shape subsequent or future action and decision-making? Did families ‘learn from the past’, e.g. in terms of potential marriage partners? Secondly, we were curious to discover how families made decisions about genetic information in relation to health care and religious professional opinion. To what extent was religious discourse part of this process, and how was it used to negotiate and legitimate decision-making? In particular, how (if at all) was religious language used (potentially) to disarm health care professionals? Thirdly, we sought to establish what role, if any, Islam played in shaping decision-making about genetic testing, and how religion was used as a resource in helping families to care for those affected by a genetic disorder. How did families with a history of genetic disorder “account for” this (verbally and religiously) particularly in relation to the strong concepts of family honour and reputation prevalent within many Muslim communities? To what extent did different generations of Bangladeshi Muslims find a resource within Islam for the repair of a ‘damaged’ identity or self-perception because of genetic disorders? There were also important questions surrounding the tension between conventional medical advice and action, and ‘Islamic’ medicinal approaches and courses of action. Whilst scientific medical intervention is clearly sanctioned in Islamic tradition, among devout Muslims there is also an awareness of the ultimate source of cure, who for them is God. This project report explores some of these questions, tensions, and challenges, and we hope that its findings will be of value to those most directly concerned with the delivery of genetics services to Muslims in Britain, especially those of Bangladeshi origin.

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The Research and its Findings (Santi Rozario)

1. Background to the Research

The project described here is a study of British Bangladeshi Muslim families with genetic disorders. It was directed by Dr Sophie Gilliat-Ray, with Prof Angus Clarke, Dr Joanna Latimer and Prof Stephen Pattison as co-investigators, and funded by an ESRC Research Grant.¹ I arrived in the UK and commenced field research with the Bangladeshi community in January 2005,² though as explained below the actual recruitment of families with genetic disorders had to wait for some further months. My field research was substantially completed in Feb-March 2007, although I have remained in touch with several of the families and some of the data below refers to this more recent data. The project itself concluded at the end of June 2007.

The project had several related aims (see Sophie Gilliat-Ray's Introduction). In brief, these were

- to explore the role of Islam in the lives of British Bangladeshi Muslims in relation to genetic disorders. This included seeing whether Islam plays a role in accounting for genetic disorders and in helping families to care for affected members, and studying the role of Muslim religious professionals in relation to genetic disorders.
- to understand the specific ways Bangladeshi Muslim families make sense of genetic disorders, how they share information with close or extended family

¹ I wish to indicate my gratitude to the ESRC (Grant Ref No: R000 239934) for funding this project, and to Sophie Gilliat-Ray for her on-going assistance and being there when I needed her, to Angus Clarke, Joanna Latimer and Stephen Pattison for their general support. I am indebted to Carole McKeown, Shagufta Khan, Asfa Ahmed, Angus Clarke and Tessa Liburd for their assistance with recruitment of patients. *Maulana* Kamruzzaman provided me with crucial links to several *imams* and *maulanas*. I am also thankful to Flo Ticehurst, Sally Davies, Mary Nicol, Daniella Pilz and Mary Honeyman who have provided help in other ways. Within the Bangladeshi community, I would like to thank various people associated with Bangladeshi associations, including Farida, Rehana, Shahara, Fatena, Rajma, Ruksana, Reha, Rohma and Anwara. Wahida Kent from the ABCD in South Wales also facilitated my research and I would like to thank her. Jasmin Chowdhury and Patricia Gregory provided me with initial contacts within the community and also kept me informed about various functions which became very useful for my ethnographic research. I would also like to thank Jonathon Scourfield and Marie-Jet Bekkers for putting me in touch with key community members, John King and Ken Woodhouse for making useful suggestions when facing difficulties with recruitment, and my colleagues Christine Trevett, Will Johnson, Louise Child and Roberta Bivins for their moral support. I thank Eve McKenzie for putting me in touch with her parents, and her parents for their hospitality upon my arrival and for sharing interesting anecdotes about the Bangladeshis in their city, my second field site. Alison Shaw extended moral support and shared her own experience of similar research with British Pakistanis; this was especially helpful with my recruitment strategy. I also thank my husband, Geoffrey Samuel, for his assistance and advice, both throughout the project and in relation to this report. I would specially like to thank the patients and their family members for sharing their stories, for their hospitality during my visits, and for allowing me to meet their extended family members. Without these families' cooperation, their willingness to share their life stories with me, especially the stories involving their affected children, and their patience with my often-persistent questioning, this research would not have been possible. I am particularly grateful to some of the families who accommodated me in their households during my inter-city visits. For reasons of confidentiality I am unable to name any of the families here. Finally, I would like to express my gratitude to Runu and Peter Simpson, and their two children for sharing their household with me on a regular basis and making my stay so comfortable during my field visits to their city, which became my second home for the duration of this project. They also introduced me to many key community members in their city and readily shared their knowledge of genetic disorders.

² The project duration was 36 months, but the project had been running for six months before my arrival, so that I was employed on the project (on an 80% full-time basis) for 30 months.

members, how they make decisions about genetic testing, and how they negotiate the possibly conflicting messages they may receive from health professionals and Islamic authorities.

- to build on previous work with Pakistani Muslims (in particular the work of Alison Shaw 2000a, 2000b, 2001) so as to identify the similarities and differences between these two communities.

The study also explored other cultural resources people draw on in dealing with genetic disorders. Issues of consanguineous and arranged marriages, which are prevalent among the British Bangladeshis and have implications for genetic disorders, were also explored.

The project formed part of a wider body of genetic and genomic research at Cardiff University, and was connected to it particularly through the involvement of Angus Clarke, Professor of Medical Genetics at the University. I have benefited from the presence of this wider community and from taking part in many of the workshops, forums and seminars associated with this research and from publications associated with it (e.g. Clarke 1997; Featherstone 2006 *et al.*; Featherstone *et al.* 2005).

Several publications have already emerged from this research (Rozario 2005, 2006b, 2007) and further publications are in preparation. The 2007 article, in the *Journal of Genetic Counseling*, has also been selected for use as part of the journal's on-line continuing education programme. The present report is a general account of the research and its findings, written initially for an end of project dissemination meeting on 16 July 2007.

History of the Project

When I took up the position of researcher, Local Research Ethics Committee (LREC) and Multi Centre Research Ethics Committee (MREC) approval had already been obtained. No action had as yet been undertaken, however, in relation to obtaining Research and Development (R&D) approval from the two relevant NHS trusts in the two UK cities, Cities A and B,³ where the project was to take place, which was a requirement before recruitment of patients could be undertaken through the Trusts. In fact, it was some weeks before I even learned that R&D approval was required from the individual NHS Trusts in addition to the existing MREC and LREC approvals. While I had undertaken extensive research in Bangladesh and Australia, much of it on health-related issues, I had not previously carried out research within the NHS system.

Actual recruitment of patients for the project was thus delayed substantially while pursuing R&D approval from the two NHS Trusts in Cities A and B, a process that took some five months from the time that I submitted my application. I was then informed that further approval was required from the Director of the Primary Care Directorate, and it was not until September 2005 when I was able to start recruiting patients' families. At this stage, 15 months of the project's 36 month duration had expired, and I had been working for 9 months. As I will explain, however, I had made considerable progress in other directions during this time, despite the very considerable amount of time taken up with pursuing the R&D application.

The R&D issue arose again at a later stage when I accompanied one of my families to another hospital in City B. While waiting at the hospital, which is

³ City A is in South Wales; City B is in the Midlands. I have avoided specifying them further to maintain as much confidentiality as possible for the families involved.

administered by a different NHS Trust from the two for which I already had R&D approval, I met two other Bangladeshi Muslim thalassaemia patients and their parents and began talking to them. They appeared willing to work with me, but I was not permitted to do this without undergoing a third R&D approval process for this new NHS Trust. I submitted all the relevant papers and attempted to fast-track the process, but the Trust failed to cooperate, so that my sample includes only one family with thalassaemia from City B, recruited from another source. The question of the so-called 'bureaucratic nightmare' associated with undertaking research in the NHS has received increasing publicity in recent times.⁴ I can only say that the degree of bureaucratic complexity and, at times, sheer obstructiveness that I had to deal with in obtaining approval to undertake research within the NHS had no parallel in my extensive previous research experience. It appeared to me to be wholly out of proportion to any risks involved in the kinds of social science research I was undertaking, particularly given that the research had already undergone the rigorous MREC and LREC approval process. I am sure that the present situation has successfully deterred many good researchers from undertaking work within the NHS.

While I was waiting for my R&D approval from the two principal NHS Trusts concerned, filling in numerous forms and answering a seemingly unending number of questions from a wide range of different individuals, I decided to engage in some ethnographic research with the Bangladeshi communities in the two cities involved, so as to gain a general picture of the communities and to explore some relevant issues. Through various welfare and community organisations, I was able to meet many people, especially women. I joined them in many of their regular activities, including weekly trips to the local gymnasium for running on the treadmill, swimming or Bollywood dance classes, and visits to local Bangladeshi stores for grocery shopping and the like. I was invited to attend several pre-wedding and wedding celebrations, and visited some families at home.

I held two focus group discussions with a group of British-born Bangladeshi women, and conducted individual interviews with various members of the community, to explore their understanding of genetic disorders, and their perspectives on the relationship between 'modern' medical options and Islam. In addition, I sought out and interviewed a number of religious leaders on their understanding and perspectives on genetic disorders. In doing all this, I followed traditional anthropological methods. Thus while I did ask some direct questions when I interviewed individuals, much of my time was taken up with participant observation, a process through which I learnt a great deal about the two local communities involved which was to have a bearing on my subsequent research with individual families.

I also spent much of my time during the first nine months introducing myself to the relevant medical professionals in the two cities, asking for their cooperation in the research and sometimes sitting in on their consulting sessions. I also accompanied some genetic counsellors on their home visits, not always to Bangladeshi families, and learnt a lot of the ways in which health information was collected from the patients' families and medical information or options provided to them. Thus the time spent getting the R & D approval from the NHS Trusts ended up being a productive period for me in terms of the ethnographic knowledge I acquired both of the Bangladeshi communities and of the practice of genetic counselling.

⁴ See e.g. Tony Tysome, 'Health Research Buckles Under Burden of Red Tape,' *THES* 1795 (May 25, 2007), p.1.

This period also gave me an opportunity to familiarise myself with the UK Bangladeshi community and with Sylheti dialect. Most British Bangladeshis originate from Sylhet, which is culturally and linguistically a very distinctive region of Bangladesh. While I grew up in Bangladesh, and speak both educated Bangla and several local dialects, I was not familiar with the Sylheti dialect spoken by most of the UK community. My non-Sylheti background stood out, and I struggled initially with my broken Sylheti when communicating with those who did not speak English. Nevertheless, as I hung around regularly with them in various places, they got used to me, and I developed good understanding and rapport with many of them. I was gradually accepted and began to be drawn into many of their other communal activities.

I was initially concerned that my not being Muslim might be a problem (my family background is Christian, part of a small Catholic community in Bangladesh dating back to the Portuguese presence in the 16th century). However, in practice this did not seem to be a significant issue. British Bangladeshis from Sylhet are often not aware that there is a Catholic community in Bangladesh, and people often assumed to start with that I was either Muslim or Hindu, but they rapidly seemed to accept me as an 'insider' and showed no reluctance to speak to me about religious issues.

After obtaining the R&D approval, I had further obstacles when it came to recruiting patients and their families. First, the project intended to recruit patients both retrospectively and prospectively. Unfortunately, the genetic clinic in City A does not as yet record religion or ethnicity of patients, which made retrospective studies more or less impossible and in fact raised considerable problems even in identifying Bangladeshi patients from the clinic records for prospective studies. In practice, patients in my sample were by necessity recruited some way into the process of genetic counselling and treatment, and followed where possible for periods of several months throughout successive stages of that process.

Second, the ethics guidelines that had been approved by MREC and LREC before my arrival were excessively complex and unrealistic. In practice, they left me entirely at the mercy of genetic consultants and genetic counsellors. The patients' information sheet, relatives' information sheet and consent forms were extremely detailed and difficult to follow, covering such matters as Purpose of the study, Do I have to take part? What will happen to me if I take part? Ethical and Confidentiality Matters, What will happen to the results of the research study? Who has reviewed the research? More Information, What should I do now? The official procedure was that these forms (both the original English versions and the Bangla translations which I had made) were posted to the potential participants, who were expected to read them and then volunteer to be interviewed by either calling me or sending me the consent form in the mail. The ethics regulations prohibited me from contacting the patients directly.

While I agree that all this information needs to be provided at some stage, sending it in the mail to patients' families and expecting them to read it all and then volunteer was most unrealistic, to say the least. Many of the families had limited literacy in either or both languages, and they had many other concerns that took priority over volunteering for a study with a person they had never met and knew nothing about. The information could have been given to them much more effectively in person during my first meeting, when I had the opportunity to read through the material with them.

In practice, of course, this is exactly what happened when I eventually succeeded in recruiting some families. First, however I had to waste some further

weeks waiting fruitlessly for patients' families to contact me after the genetic counsellors posted my information sheets to them. No family ever contacted me as a result of this procedure.

Eventually, at my request, a number of genetic consultants and counsellors became more proactive and agreed to call the patients after they had received the information package. In a number of other cases, I was able to accompany the genetic counsellors on their home visits to the Bangladeshi families and was introduced to them. These methods worked fairly well. I also recruited a number of families through my personal networks within the community, then asked for their consent to take part in the project after getting to know them informally. Some refused, but most were happy to take part. In these ways, I succeeded in recruiting seventeen families: twelve families of patients with moderate to severe genetic disorders, and another five who were thalassaemia carriers (see below for further details). I have also included data from three other families who did not strictly speaking have genetic disorders but from whom I gained valuable insights, making a total of twenty families.

I became closely involved with several of the families after they agreed to participate in the study. They began to enjoy my visits, many seeing me a source of moral or other support, and would ask me when I would visit them next. I visited these families (roughly half of the families of patients with moderate to severe genetic disorders) more than five times each. I often shared food when I visited, and would spend several hours with them at a time. A few families who regularly cancelled appointments or were too busy to give me more appointments I could only visit two, three or maybe four times. I usually spent two or three nights in City B during each visit there and stayed overnight with three families who were also participants in the project. During these overnight visits I got to know these families even better.

Some families have their extended families living either adjacent to them, on the same street, or just round the corner. Thus when I visited a family for an extended period I often ran into other family members visiting and had the opportunity to get to know them as well. I would talk to them about a variety of things, including the genetic disorder in the family, their attitudes towards it and their understanding of it. These family members usually included grandmothers, aunts (father's or mother's sisters) and sometimes also uncles (father's brother) of the patients. When attending social functions like weddings, I had the opportunity to observe people's behaviour with affected children and interaction between family members.

I got to know a number of families very closely. These families invited me to many family events. Two of my recruited families asked me to visit them in Sylhet when they were there on their holidays, for they knew I would be in Bangladesh at the same time. I took up the opportunity and visited one of these families (the family with a young child with Cockayne Syndrome). In this way, I found out a lot more about the extended families' attitude, their beliefs and ideas about genetic disorder. I learned about the alternative and religious treatments of which they availed themselves while there, and how they saw the differences between medical treatment in the UK and Bangladesh. I also saw how these various healers and forms of treatment encouraged family members to blame the child's mother and her side of the family.

Methodology and Sample

As I mentioned above, the approach I used to the material was essentially anthropological, reflecting my own previous training and extensive research experience. This was a change from the more sociological methodology envisaged in the original project. That had been based around the idea of a set of recorded, semi-structured interviews with each family, to be transcribed and analysed, though some freer and less structured interviews were also envisaged. The new methodology also reflected a different research situation from that originally envisaged. The initial intention was that the research assistant would gather the data, but that the analysis would be carried out primarily by Dr Gilliat-Ray and the project team. Given my own status as a senior and experienced researcher who had already carried out similar projects under my own direction, this no longer made much sense. While I met regularly with Dr Gilliat-Ray, and presented interim versions of my findings to the project team and to other gatherings on a number of occasions, the research and analysis presented here are my own.

In fact, I did not use tape recording at all. I did not feel that my interviewees would have been comfortable with it, and instead I took notes after each interview or period of interaction. Much of the most useful material came from conversation in situations of informal interaction, through which I gradually built up a sense of how the parents, other children and the wider family were dealing with their situation.

Interviews and other interaction took place in Bangla (Bengali, the national language of Bangladesh) and/or English, depending on the language in which people felt most comfortable. The British born people felt most comfortable speaking in English while those without any English conversed with me in a mixture of Sylheti and Bangla. After some initial hiccups with some of the Sylheti vocabulary, I learnt to communicate quite effectively in Sylheti.

Basic data on the families in my sample are presented in table 1 below. I have only listed members of the nuclear family here. In several cases, I learned that members of the extended family were also affected, but it was impossible to get consistent data regarding this, for reasons that will become clear later in the study. In addition, as explained below, in some cases children may be from more than one marriage.

The names here are all pseudonyms. I have deliberately avoided specifying from which city a particular family comes, to help to preserve confidentiality. In the remainder of this report, I have also occasionally been deliberately imprecise about details of occupation, residence and the like, or avoided identifying which family in the sample is being discussed at a particular point, for similar reasons. No data has however actually been falsified, apart from the names.

Sabina and Anwar	XP (xeroderma pigmentosum)	5 children, 2 affected
Aziza and Fahim	Dysmorphia, psychiatric problems	4 children, 1 affected
Ruby and Nafis	Angelman Syndrome	1 son, 1 affected
Sabnam and Firoz	TS (tuberous sclerosis)	7 children, 1 affected
Sufia and Karim	Cockayne Syndrome	1 son, 1 affected
Rani and Zafar	Undiagnosed genetic disorder	1 child (died)
Sheheli and Abdul	Carnitine Transporter Syndrome	3 children, 2 affected (1 died)
Razia and Rahman	Muscular Dystrophy	5 children, 1 affected
Shahanara and Jamil	Bardet-Biedel condition	2 children, 1 affected
Khaleda and Faruq	Beta Thalassaemia	5 children, 1 affected

Maha and Omar	Pendred Syndrome	2 children, 1 affected
Rohima and John	Neurofibromatosis 1	2 children, 1 affected

Table 1a: Families with Genetic Disorders in Sample

In addition, I interviewed five families where one or both parents were thalassaemia carriers:

Afsana and Rabi	Thalassaemia (Beta & E-trait) carrier	1 child, carrier of Beta thalassaemia
Batul	D-trait thalassaemia carrier	2 children
Fazeela	E-trait thalassaemia carrier	Son is carrier
Habiba and Rashid	E-trait thalassaemia carrier	1 child
Nazma and Fareed	Unstable haemoglobin	2 children

Table 1b: Thalassaemia Carriers in Sample

Three further families who did not strictly speaking have genetic disorders were included in the sample because they helped illuminate some of the issues dealt with in the study. These are:

Rohima and Majid	Experience of having triplets	5 surviving children, including 2 triplets (the third died)
Shireen and Kibria	Asthma and allergy	4 children, 1 affected
Sharifa and Showkat	Fertility problems, apparently genetic in origin	2 children

Table 1c: Other Families in Sample

As can be seen, the families in the first group included children suffering from a number of serious genetic disorders, and no two families had the same disorder. Brief descriptions of these disorders are given in the glossary. Most of them are regarded by biomedicine as inherited in an autosomal recessive pattern, meaning that both parents must pass on the relevant gene for the child to be affected. Since the affected genes are relatively rare in most cases, the chances of this happening are higher if the parents are genetically related, which is why the question of preferential marriage to first cousins among UK Pakistanis has been regarded in recent years as a medical issue (Darr & Modell 1988; Darr 1997; Qureshi 1997; Proctor & Smith 1997). The families in the second group (the thalassaemia carriers) were not directly affected by genetic disorders, but had the potential to pass these on to their children in several cases.

As we will see in Chapter Two, first cousin marriage is common among UK Bangladeshis, and many of the families in my sample are in fact marriages between first cousins. The reasons are less to do with a traditional preference for marriage of this kind, however, as appears to be the case for some Pakistani populations, than with the use of marriage for purposes of immigration.

At the same time, we cannot assume that these disorders necessarily 'result' in any simple sense from cousin marriage. The affected genes may not result from common ancestors of the two partners, and in any case not all of these conditions are regarded as transmitted via an autosomal recessive trait. Some may be due to random (spontaneous) mutations, and others may result from other inheritance patterns (X-linked recessive, or autosomal dominant). The following table gives a rough breakdown based on the sources used for the Glossary:

Angelman Syndrome	Usually random mutation
Bardet-Biedl Syndrome	Autosomal recessive
Carnitine Transporter Deficiency	Autosomal recessive
Cockayne Syndrome	Autosomal recessive
Muscular Dystrophy	Various mechanisms for different types; the most common form in children, Duchenne muscular dystrophy, is X-linked recessive
Neurofibromatosis (NF1)	Autosomal dominant; about half of cases are random mutation
Pendred Syndrome	Autosomal recessive
Thalassaemia major (Beta thalassaemia)	Autosomal recessive
Tuberous sclerosis	Autosomal dominant; about two-thirds of cases are random mutation
Xeroderma pigmentosum	Autosomal recessive

Table 2: Patterns of Causation for Genetic Disorders

In addition to the patients and their families, I interviewed about twelve *imams* in Cities A and B. I interviewed two of these *imams* twice, the others only once, either at their own homes in the presence of their wives (in one case I was an overnight guest), or at his work place in the case of a hospital chaplain. I also interviewed a single *imam*, whose wife was in Bangladesh, at a mosque complex just before he was to commence his evening Islamic class for local children. Thus two older children were hanging around nearby, thus ensuring the propriety of the situation. On one occasion, I was able to accompany a family in their visit to a *pir* or Sufi spiritual leader (see Appendix). I also collected a lot of information about the ways in which the patients' families used the services of the local Bangladeshi *imams* and on what they thought of them.

In this study I was dealing with a small number of families in detail, rather than gathering limited data on a much larger number. As even the above table makes clear, however, the amount of variation in the sample was quite substantial. Further important issues included the place of origin of both spouses (UK or Bangladesh), their level of education, and whether they had access to support from a locally-resident extended family. This is not the kind of study where one can arrive at statistically significant results about how Bangladeshi families will behave in relation to genetic disorders. However, the study proved to be very revealing of the kinds of issues that might arise in relation to Bangladeshi families with genetic disorders. Apart from its intrinsic interest as a study in medical anthropology and in the role of religion in society, there is much material in my data that is of practical significance. Genetic consultants, counsellors and nurses dealing with Bangladeshi families need to be aware of the ways in which Bangladeshi families might understand and respond to information about genetic diseases, and to be aware of how the families themselves approach the children's illness.

2. The Bangladeshi Population of The Two Cities

In this chapter and in Chapter Three I present some information regarding the history and nature of the Bangladeshi community and of family structures within the community. As will be seen, all this has a considerable bearing on how problems relating to health, including genetic disorders, are approached. In fact, one can make little sense of some aspects of Bangladeshi health-seeking behaviour without understanding the physical and social context of the lives of British Bangladeshi families.

Both cities have substantial Bangladeshi communities, though the community in City B is considerably larger than that in City A. Most of the Bangladeshi population in these two cities, and all of my samples of patients and most of the *imams*, originated from Sylhet, a region in north-western Bangladesh which is the place of origin of the bulk of the British Bangladeshi population.⁵ The reason for this is not so much the extreme poverty of this region as the fact that the Sylhetis already had a history of migration within the region. Geographically situated at the north-eastern hilly borderlands, adjacent to Assam, in the late nineteenth century Sylhet was administratively incorporated into Assam, although it rejoined Bengal in 1947. Various developments within the Sylheti economy, specially as a result of the British well-known permanent settlement act led to impoverishment of the thousands of tenants and influenced them to migrate to Assam. In Assam there were still opportunities to be owner-cultivators and live in relative prosperity compared to tenants without any land. As Gardner & Shukur (1994:146) argue, it was these rural Sylhetis who were able to raise the necessary capital to migrate overseas when the opportunity arose.

Bangladeshis from Sylhet began to emigrate to the UK before the end of nineteenth century. Their careers as ship-workers, often leading to their 'jumping ship' in London or New York, are well known (Gardner 1995). Many single Sylheti men landed in London in this manner and found help from fellow Bangladeshis with accommodation and contacts.

From about the 1960s Sylheti migration to Britain became more widespread. This was largely because, in response to the need for international labour for British industries, Britain was open to receiving manual workers from former colonies, e.g. South Asia and the Caribbean.⁶ Although work permits (the so-called 'labour vouchers') were introduced in 1962 to restrict entry of non-white Commonwealth migrants to the country, it was at this time that a large number of Sylhetis were able to obtain entry permits to the UK. This was possible because those Sylhetis already in the UK obtained 'labour vouchers' for their immediate or extended family members back in Bangladesh (Choudhury & Drake 2001:14). The presence of a significant number of Sylhetis already in the UK from earlier periods facilitated such chain migration.

Most early migrants found work in various factories around the country. Some gradually started their own businesses as they accumulated some capital, or took up work with other Bangladeshis, particularly in the flourishing 'Indian' restaurant

⁵ Three of the *imams* were not from Sylhet.

⁶ The migrants took up unskilled, heavy and dirty jobs that were rejected by the white workers (Choudhury & Drake 2001).

business.⁷ In recent years many Sylheti Bangladeshis are also finding taxi driving a fairly lucrative business.

As with many migrant communities, the early Sylheti migrants did not plan to live in Britain permanently. They wanted to work hard for some years, earn a lot of money, send money home, and eventually return home. However, the anxiety that immigration rules might change further, making it difficult for them to remain in Britain as workers, led many Bangladeshis to bring their wives and children over to join them from the 1960s onwards.

In the early stages, then, most men were either unmarried or did not bring their wives and children to the country. This meant that they had to do all the household work, especially cooking, traditionally only done by women in Bangladeshi families. They worked very hard in factories, lived in cramped situations with many other single men, and their sole aim was to accumulate money and remit it home. The immigrants' lack of language and lack of knowledge about housing or transport systems combined with their experience of racial discrimination and prejudice led to their setting up small "colonies in inner city areas close to the factories where they had found work" (Choudhury & Drake 2001:16). These were usually cheap, run-down parts of the cities.

In time, when these male migrants began to bring their wives and children over to join them, they found bigger houses, but more often bought another house next door or close by. Indeed there are stories of groups of men from 10 or more sharing a house, and gradually, as the number increased with new migrants joining them, buying a series of houses close to each other to create more room. Thus the current pattern in City B, which has quite a large Bangladeshi population (more than 10,000), is that the majority of the people in a particular suburb hail from a specific region of Sylhet. Many of these families are also related to each other, are from the same village or neighbouring villages. This is the consequence of the chain migration and the settlement pattern of Sylhetis who very rarely moved far away from their original residence.

Gradually these colonies became self-sufficient for most needs of the Bangladeshis. At present they have Bangladeshi grocery shops, mosques, children's schools nearby, specialised clothing shops that stock Bengali clothing for both men and women, including wedding and *mehedy* dresses, banks, jewellery shops, travel agents, as well as other businesses like small supermarkets, shops selling carpets and household goods, solicitors and doctors. Consequently, the local Bangladeshi population rarely needs to venture out to the city. Some women may have never been into the city centre. On the rare occasions when they do go to the centre they need to be escorted, and will not know how to get there on their own.⁸ Even men rarely have a need to go to cities and due to the nature of their work hours, they spend much of the daytime in bed or going shopping locally. Thus the suburbs where almost all the families in the sample live are fully provided for with all the essential needs for the Bangladeshis settled in these areas.

⁷ It should be noted that although almost all the restaurants serving so-called 'Indian' food were labelled as Indian restaurants, they were all owned and run by Bangladeshis in the UK. It is only in recent years that the restaurants gradually started to identify themselves as Bangladeshi.

⁸ A relatively young Bangladeshi widow I got know told me she had to ask a friend to accompany her to the city council office and they took a taxi. She also takes a taxi everywhere else she needs to go outside of her immediate suburb, e.g. to take her disabled brother for medical appointments. In another case, when her sick son was in hospital for a few weeks, and she was having serious marital problems with her husband who refused to drive her back and forth to the hospital, a mother had to take taxis a few times. Negotiating with public transport is a big problem for these women.

Choudhury and Drake note in relation to the Bangladeshi community of Birmingham that “the 1991 census indicated that housing conditions for the Bangladeshi community had not improved. Out of all the Birmingham’s ethnic groups Bangladeshis suffered most from overcrowding. The average size, nearly six, of a Bangladeshi household was more than twice the city average and their houses, in many instances, lacked basic amenities such as indoor toilets” (2001:19).⁹ The situation was similar in City B.

Although they never intended to settle down as permanent migrants in the UK, few of the earlier Bangladeshi migrants returned to Sylhet permanently. Instead they went back for occasional visits every few years. While some of them returned home at retirement, many elderly Bangladeshis divide up their time between their UK home where they usually have their children and grandchildren, and their home in Bangladesh. Not surprisingly, they usually spend the UK winters in Bangladesh. People associate many of their health problems with the cold weather in the UK. The consequent lack of sweating is seen as particularly unhealthy.

Like the earlier migrants, Bangladeshi men continue to send money home. Most Sylheti Bangladeshis have heavy financial responsibilities to support their families back in Bangladesh. They work long hours in restaurants or similar jobs, without any holidays, and only one day a week off. The money they earn is sent back to Bangladesh every month to support not only their parents, but also unmarried sisters and brothers, families of married brothers, and often also families of married sisters. Money sent home is also used to buy land and build houses in Bangladesh, with land ownership and in particular large and elaborate houses becoming the status symbols of ‘Londoni’ families.

In addition to spending money on families, land and housing in Sylhet, people also spend big money on weddings: there is intense competition to outdo others in the community in the elaborateness of the decorations, the cost of the clothing, venue, and vehicles (stretch limos, Rolls-Royces, horse-drawn carriages are all common). People in the British Sylheti community readily spend £30,000 to £60,000 on a wedding.

Gardner found that there were many unmarried men in Sylhet waiting to be sponsored by their relatives in the UK (personal communication). They and their families are hoping that Bangladeshi women with British visas and citizenship would be found for them to marry or perhaps that jobs can be fixed up in restaurants. Many of the women I spoke to in the UK complained how the menfolk in their families back in Bangladesh are hopeless, they do not work but simply expect their “Londoni” relative to send them money regularly.¹⁰ While these young men refused to engage in manual work in Bangladesh, if and when they finally make it to the UK, whether through marriage or otherwise, most of them nevertheless end up doing hard manual work in the restaurant trade.

An alternative route for migration to the UK for some Bangladeshi men is to enter Britain as religious professionals. Thus I came across a number of *imams* who had been trained for a minimal period of three months or so, before being sponsored

⁹ Apparently Bangladeshis only started to apply for council housing in the 1980s. 80% of my sample families however occupied council houses. In some cases this was because of unemployment of the husband, or because illness within a family had meant that a father had adopted the role of a carer.

¹⁰Gardner makes similar observations. As she notes, all this needs to be understood in terms of these families’ disdain for manual labour. Historically, the families whose members were able to migrate came from relatively better off middle class background, owned land and had abhorred working as labourers or tenants (Gardner 1995).

as *imam* for a small mosque in City B. They led prayers, and also taught Islam to children by holding regular Qur'anic classes in the mosque or by going over to people's houses for a small fee. The English language skills of some of these *imams* was almost non-existent, and their knowledge of Islam also appeared to be fairly limited.

Many members of the Bangladeshi community have limited English language skills. This is a particular issue in relation to men and women who grew up in Bangladesh and migrated as adults, either through marriage or to join a father who was a UK citizen. Lack of English is not necessarily viewed as a big problem within the community since, as mentioned above, people can get most things done locally without needing to use English. Bangladeshi men work in Bangladeshi restaurants, owned and managed by Bangladeshis. Most women do not work outside the home.¹¹

While some couples are clearly interested in getting the non-English speaking spouse to learn English, more often than not the families find it easy enough to make do without English because of the segregated situation in which they lived. There are always some individuals around who can read and write, and fill in relevant forms when necessary. There are also often interpreters when seeking medical or social help. In addition, women commence having children soon after marriage and arrival in the UK from Bangladesh, and men commence restaurant work soon after their arrival, so it is difficult for people to take advantage of any local government-provided facilities to learn English. As men work in the restaurants at night, they get home early in the morning, and spend most of the day in bed or going shopping for the family. While some community centres which provide English language classes also provide child care facilities, Bangladeshis tend to be unwilling to use these public facilities. The low level of language skills has significant implications for communication with health professionals.¹²

Bangladeshis are said to lag behind most other ethnic groups in their access and utilization of educational opportunities in the UK. (Choudhury & Drake 2001:20). Choudhury and Drake's comments, referring to the 1970s and 1980s, still apply to many of the families I worked with:

It was and is doubly difficult for the Bangladeshi children of caterers to fully benefit from an English education. The father's hours of work meant disturbed sleep in the house and made it difficult for the children to be at school punctually. Many Bangladeshi boys, when they reached secondary school age, began part-time work in a relative's restaurant. The temptation of earning regular wages meant that they often left school at the earliest opportunity, then married young and started a family, so institutionalising a cycle of low pay and few career opportunities. (Choudhury and Drake 2001:20)

This is precisely the situation that I found during my research. Fathers usually do not return home from their restaurant or their taxi driving till early morning. There are

¹¹ A very limited number of Bangladeshi women are employed at schools, supervising students or working in school canteens. Those with good English skills may work as receptionists at local GPs' surgeries, as legal secretaries, interpreters, social workers and so forth.

¹² At home people mostly watch Bangla TV channels, although young boys and girls sometimes might check out other non-Bangla channels. Some parents are totally opposed to children watching English TV channels, since they see English-language films and TV dramas as having a bad influence on the children. When I asked some teenagers about the friends they saw outside school, none appeared to have any non-Asian friends. In any case, most parents would not permit their children to go out with English friends for fear of the latter having a bad influence on them. Use of alcohol, drugs and problems associated with the opposite sex are some of the main things people are concerned about. All this behaviour, while understandable, also makes the Bangladeshi community very segregated from the wider white society.

times when they might even have a visitor drop in at that hour. Children would often be still up.¹³ It is still the case that young boys often end up working in the restaurants. Some young teenagers with whom I discussed their future aspirations also told me they will probably work in a restaurant. It seemed to be an easy choice. However, a number of young men with small children voiced their concern about this scenario with the Bangladeshi boys and told me they will make sure their sons become a doctor, solicitor or an engineer. Thus perhaps this situation will change in future. On the other hand, I found the girls were hoping to go further than year ten, although often they were married at the age of eighteen or nineteen. If they were working before marriage, their husbands would often be opposed to their continuing with their jobs.

For recreation and holidays, Bangladeshis congregate in each other's households. During a year there may be a number of weddings and pre-wedding rituals a family gets invited to. During school holidays people often hire a van or bus and take off to visit relatives in another city. Their real break comes when they can go to Bangladesh for a holiday. This only happens every few years, for it is expensive to travel with the whole family, especially since they have to buy large numbers of presents for all their relatives in Bangladesh.¹⁴ Some women told me how they look forward to going to picnics in beautiful locations when on holidays in Bangladesh. They rarely go on picnics in the UK, however. At most a busload of people, mainly extended family, might take off for places like Blackpool for a day trip.

In any case, when they are in Bangladesh, women in particular can have a real break, because the children then get looked after by other people. Many families even hire extra help when they are there especially to look after their children. As I have seen, it is reasonably common when families are in Bangladesh for couples or adults to leave children behind and go to town on their own for the day.

While the bulk of the Bangladeshi population, including all the families in my sample, come from the background described above, it is worth noting that there are other components to the British Bangladeshi community. Among the Sylhetis, in addition to those who came and found work as unskilled labourers, there were also a handful of doctors and a few ex-students who settled down in the UK. There is also by now a significant proportion of the Bangladeshi migrants who originate from non-Sylheti regions, mainly Dhaka and other urban centres. These non-Sylheti migrants are usually, though by no means always, educated and have mostly found various work in skilled sector of the economy. In addition, they have often not settled in the Bangladeshi colonies established by the early Sylheti migrants in East London, Birmingham, Manchester, Bradford, Cardiff and other cities. The recently introduced highly skilled migrants programme is also facilitating in the migration of more of this latter category of Bangladeshis into the UK.

I found a clear division between educated and non-educated Bangladeshis, coinciding to a considerable degree to the division between non-Sylheti and Sylhetis. There are numerous social organisations, networks and groups within the Bangladeshi community, but most in practice have either Sylheti or non-Sylheti members.

¹³ Working hours in restaurants interfere with many aspects of people's lives in the day time, specially in tasks which requires men's participation. Thus Hawthorne *et al.* (2003) found that Bangladeshi patients wanted to have appointments only in particular times. During my research I was lucky to have been given an appointment before mid-day.

¹⁴ One or two families in my sample have had holidays elsewhere outside of the UK, e.g. Egypt and Tunisia. The British-born younger generation are not exclusively focussed on holidays in Bangladesh, a place which they often refer to as 'overseas' or 'abroad', rather than as 'home' or 'Bangladesh'.

Educated Sylhetis might take part in non-Sylheti Bangladeshi social gatherings, but the non-Sylhetis rarely took part in Sylheti events.

This division was in part a question of class background, but it also had a cultural aspect. While the non-Sylhetis had a tendency to look down upon the Sylhetis as illiterate, rural and uncouth, the Sylhetis also suffered from low self-esteem, and maintained their distance and boundaries from the non-Sylhetis. Many non-Sylheti Bangladeshis, including medical professionals, were critical about the Sylhetis' lifestyle, their sense of hygiene, lack of 'culture' and of course lack of education. On the other hand, some Sylhetis have internalised these prejudices, whether derived from non-Sylheti Bangladeshis or from people outside the Bangladeshi community. One woman, for example, was surprised that I was trying to improve my Sylheti, and commented, "Sylheti is a dirty language".¹⁵

Family, Social Structure, Patterns of Marriage and Residence

Here I look at the structure of families among British Bangladeshis. This material is important for two main reasons. First, how a family responds to and attempts to cope with the difficult situation of having a child with a serious genetic disorder depends greatly on the existing relationships within the immediate and wider family. Family members are in most cases the most immediate people one asks for help, but they also understand and respond to the situation in various ways which can assist or worsen the situation and which are in many ways characteristic of a particular social and cultural context. For genetic counsellors, biomedical staff and others attempting to assist these families, it is important to understand ways in which the situation is viewed and made sense of (cf Featherstone 2006). For example, among Bangladeshi and North Indian families, women are generally seen as 'outsiders' marrying into a male descent line and when things go wrong they are the obvious targets for blame. I will describe some examples of this process later in this report.

Second, an important issue for the prevention of genetic disorders is whether and how far family members pass on information about genetic disorders to the extended family, particularly in relation to marriage between people who are already closely related genetically. In cases where genetic disorders may be inherited, biomedical practitioners, including genetic consultants and counsellors, aim to advise the families concerned of the possible risks. One intention is that families whose members are carriers for particular disorders will convey this information to future possible marriage partners and will use genetic testing where possible so as to avoid contracting marriages with a high risk of genetic illness. Families with genetic illness in the general UK population do not necessarily follow biomedical advice in such matters, for a variety of reasons. These may include the extent to which they understand or accept the biomedical model of the causation of genetic illness, and this is also likely to relate to their own 'folk understandings' of inheritance (Featherstone *et al.* 2006). Reasons may also include social and cultural barriers to the passing on of information.

Both of these factors apply too in the case of UK Bangladeshis, and investigating them was a major focus of the research.

Here, again, understanding the nature of Bangladeshi marriage, and in particular the process by which marriages being arranged and the reasons for the choice of particular marriage partners, is very important for understanding why information about possible genetic risk may not be passed on. Marriages between

¹⁵ *Sylheti khachra bhasha.*

close kin are often the result of debts and obligations within the extended family, and in such cases the obligation to undertake the marriage may override any considerations about possible risk of genetic disorders.¹⁶

To understand the structure of British Bangladeshi marriage, it is important to be aware of the history of the community. The older generation of men in the British Bangladeshi men migrated on their own, either as single men or, if already married, leaving their wives behind in Bangladesh. Married men in many cases lived nearly half their lives apart from their wives, while single men often went back to marry, but then left their wives in Bangladesh and returned to the UK to earn more money. In either case the husbands visited their wives occasionally, going home every few years perhaps for several months. As a result children of these earlier migrants grew up in Bangladesh and were educated in Bangladesh. Many of these children together with their mothers were later given British visas to join their fathers. Because of the way immigration rules worked, this family reunion was not extended to the older children who remained in Bangladesh.

Thus in many Bangladeshi migrant families one finds one or two siblings still residing in Bangladesh where they married and settled with their own children, many of whom are also now grown up. The members of the family in the UK feel an obligation towards their extended family members left behind, in their aspiration to migrate to the UK. Often it is this situation that leads to cousin marriages as a way of sponsoring a family member to the UK. For example, one British born woman (Sharifa) told me that the reason her marriage was arranged with Showkat, who is her father's brother's son, was because his father was the only uncle whose family members were not in the UK. "They needed help, so my brothers decided to marry me to my cousin; they couldn't help them [with money] forever! I respect my brothers, I wasn't going to go against them. They looked after me when I was small." Sharifa's father was no longer alive when she was married although her mother was still alive.

As this example illustrates, a cousin marriage may not just be a question of doing a favour to a family member back in Bangladesh. It may also be a way of ending an ongoing and financially onerous obligation to make continuing support payments to the father's brother's family, since the girl's husband can be expected to take over support of his own parents and siblings once he is himself earning money in the UK.

During the early settlement period some Bangladeshi men in the UK also married local white women. Also it was not uncommon for men to have two wives, one in the UK and one in Bangladesh and having children from both wives. Sometimes the wife in the UK might have been white, but other times both were Bangladeshis. We have to bear in mind that in Islam it is possible to have more than one wife. In a polygamous marriage a man was not permitted to sponsor to the UK his second wife but only his children from his second wife in Bangladesh. So a Bangladeshi family in the UK might consist of husband, wife and their own children, as well as the children of the husband's other wife in Bangladesh. Alternatively, a man might have two wives in the UK, be legally divorced from one, but in practice taking turns in living with both (Khanum 2001).

While all the couples in my sample were engaged in monogamous marriages, I came across several instances of polygamous marriages in their extended families. In

¹⁶ The other issue mentioned here, the extent to which British Bangladeshi families diagnosed as having genetic illness accept or disagree with that diagnosis, will be discussed later. If illness is not seen as genetically caused, then there is no reason to pass on information about it to the families of potential marriage partners. However, arguably, the amount of significance given to genetic explanations may depend on how important it is to marry a particular couple for other reasons.

one case, Akbar, in his 50s, had one wife in the UK, the other in Bangladesh and he goes back home for a few months each year. Meantime Akbar has sponsored all except for the youngest of the children from his second wife in Bangladesh. Akbar, his UK-based Bangladeshi wife, and the children from both wives live in a large (eight or nine bedroom) house. Often the age gap between siblings from the two sides is only six months. One married daughter with her husband and small child also shares this house, as does the younger brother of Akbar, his wife, and their small child. One of the married couples may move out in the near future.

In a second case, Iqbal, in his 60s, too sponsored all the children from his wife based in Bangladesh, so that children from both the wives lived together in a big house in the UK. Now most are married and moved away. In both cases I was told that the siblings from two mothers get along very well together, but I did not have the opportunity to do any real research on this aspect of peoples' lives.

The residential patterns of Bangladeshi marriages in the UK are also of significance in relation to this study. British Bangladeshi families are normally patrilocal, as in Bangladesh itself, meaning that on marriage a woman comes to live with her husband's parents. In some cases, when a British born Bangladeshi woman marries a man born and brought up in Bangladesh, her husband will come and join her family, although eventually they might move out. Patrilocal families may also break up in time, with one or more married sons moving into houses of their own. Thus British Bangladeshi families have a variety of possible forms; nuclear, consisting of a man, his wife and children; joint, consisting of a man, his younger brothers, their wives and children; or extended, with more than two generations living and pooling their resources together.

In many ways, Sylhetis have reproduced the village community of Bangladesh as much as they could in the UK. As we noted, the early migrants joined their relatives, neighbours or fellow-villagers from Sylhet and settled with them either in the same house or as close as possible nearby. Immediate relatives, e.g. two brothers with their wives, children and parents continued to share the same household until the families became much larger, when they bought additional houses, often in the same street or at most a few minutes' walk from each other. In my sample I came across row of three houses adjacent to each other belonging to members of the same family: an elderly couple with the young unmarried children in one house, a married son with his wife and children in another, and a married daughter with husband and children in another. The houses were freely accessible to all from the back of the house as they had made a common path across the back garden of the three households.

This pattern of close residence provides young families with small children with ready-made help and support from parents. Families with a sick child can also receive ready support from other family members. Even where married daughters and sons have moved away from the area and are living elsewhere as a nuclear family, the whole extended family gets together regularly at least on a weekly basis, often on Fridays, but also during the week. It is not always possible to buy houses next to each other these days, but people continue to buy houses in the same street or minimally in the same suburb, so that they are still able to maintain their family links in the same way as they would have done in Sylhet.

However, there were some families in my sample who were relatively isolated from remainder of their families. This happens when a woman is married to someone living in a different city. In the case of one of the families in my sample, Sabina married her first cousin (mother's sister's son) Anwar, who had come to the country as a teenager with a distant relative and did not return home. This marriage gave

Anwar his British citizenship. Sabina's father was a British citizen and so he was able to sponsor his wife and younger children. Sabina had come into the country when she was a teenager with her mother and did not go to school in the UK.

After their marriage, they settled in the city where Anwar used to work in a restaurant, a different city to that in which her parents and extended family live. Over the years Sabina has pleaded with Anwar to move to the city where her family lives, but he refused, even though he moved jobs and city at least once.¹⁷ Sabina's mother, who is now a widow, visits her when she can, but Sabina does not have access to the level of family support that many other Bengali women can take for granted. She has five children two of whom are affected by some serious genetic disorder and she told me many a times how she misses not being close to her mother, brother, and sisters all of whom live in another city.

Women who were born and brought up in Bangladesh and marry someone in the UK can be even more isolated than women like Sabina. In my sample, however, marriages between Bangladeshis living in the UK and in Bangladesh were arranged with first cousins, so if the bride came from Bangladesh she typically had aunts, uncles, and cousins in the community into which she was marrying. Even so, women in these families could feel isolated and excluded.

On the whole, marriage continues to be arranged by families, although not necessarily without the consent of the prospective marriage partners, whose opinion will usually be asked.¹⁸ Young men generally have more influence over decisions regarding their marriages than young women. Most arranged marriages are between British born women and men born and brought up in Sylhet. There are also marriages between men born in Britain and women born and brought up in Bangladesh. By no means all of these marriages are between first cousins, though many are. Although there is a well-known Islamic preference for a man to be married to his father's brother's daughter, I found marriages to parallel cousins on either side (i.e. father's brother's daughter or mother's sister's daughter) or to cross-cousins (father's sister's daughter, mother's brother's daughter).

According to one *imam* I interviewed, some guardians come to ask for a *tabiz* (amulet) when they are trying to arrange the marriage of their daughter or son and s/he refuses to oblige. "I then give them an appropriate verse from the Qur'an to change the feelings of the son or the daughter".¹⁹ As this suggests, there can be considerable pressure on daughters or sons to marry into a particular family. I found plenty of evidence of this in my own fieldwork. This is especially the case involving marriage with relatives from Bangladesh. I am aware of a few marriages in which the women reluctantly gave in to the family's pressure to marry their first cousins so that these could be sponsored for immigration. These marriages are not necessarily unsuccessful. Some work out well. In others, though, problems are swept under the carpet to keep the marriage going, and in other cases the marriage breaks down altogether. In fact, marital problems and divorce rates among British Bangladeshi

¹⁷ I was told by another woman that Bangladeshi husbands do not like living with or near their wives' families. This is because they feel the in-laws will interfere unnecessarily in their household affairs. One of these issues involves sending money home to husband's relatives. In this case, all of Anwar's relatives are in Bangladesh and he does send money home regularly although Sabina never complains.

¹⁸ Although some British Bangladeshis are apparently finding their partners themselves, I did not come across any such couples in my fieldwork.

¹⁹ *Guardian biye thik korchey karo shathe, kintu cheley ba meye raji hocchey na. Ami tokhon quran sharifer ekta verse dei.*

couples appear to be quite high.²⁰ This is despite the fact that much care is taken in arranging marriages.

A number of female interviewees told me that British-born women feel that Bangladeshi boys born and brought up in the UK are no good. British-born men express similar opinions about British-born Bangladeshi women. Nevertheless, I found and was also told that the younger generation of British-born Bangladeshis often prefer to marry those also born in Britain. Frequently, too, they will seek an ‘educated’ bride or groom. This may be because they have seen too many problems in marriages when one partner is born in the UK and the other in Bangladesh.

A high proportion of my sample in fact consisted of marriages between British-born men or women (most often women) and partners from Bangladesh, and it is worth examining the specific tensions involved in these families in more detail, because this again has considerable bearing on what happens when the family has a child with a genetic disorder. I have heard stories from several *imams* that I interviewed in Cities A and B, as well as from the women themselves, of marital problems among such couples.

One *imam*, Babar, commented that where the wife was brought up in the UK she was usually more ‘qualified’ (i.e. educated) than her husband. He said, “this low qualification of a husband means that he will remain under the control of his wife”. We were discussing the kinds of problems people come to see him for and he said most of the time the problems relate to conflicts (*garmil*) between husband and wife. Usually a husband will come to complain and ask for advice, although it is not unusual for a wife, accompanied by a child, to come too. On rare occasions a couple might come together. He said a husband’s complaints might include that his wife does not let him send money home, but a wife’s complaints would be the opposite, that her husband, whom she brought over on a settlement visa, sends all his money home and does not listen to her. Often, according to Babar, these ‘settlement husbands’ come from poor backgrounds and their parents depend on them to send money home. Wives who are born and brought up in the UK, and whose parents are in the UK often do not sympathise with their situation and complain if they send money. Babar went on to tell me that often a wife will receive the family benefit in her name and will refuse to give this money to her husband. “She spends his earning [usually from restaurant job] on household expenses while she spends the family benefit on herself, buying cosmetics (*prashadhoni*), on her own relatives, going out or other things.” In his view, the ‘settlement husbands’ have problems with language, with certificates and so on, while their wives who were born in this country can get any work, but they do not contribute to the family. “They are very uncontrollable,” he said, “and the men are oppressed”.²¹

When I asked Babar what women come to see him about, he said that sometimes a husband might spend his money elsewhere (perhaps on another woman) and the wife has to run the family either from her paid work or from family benefit. In such cases, a woman might come to ask for a *tabiz* or other assistance “to bring her husband under control”.²² Babar said that he usually advises couples to compromise, and suggests tolerance from each side. However, these marriages all too often lead to divorce. He commented that it is not unusual for the couple to want to make up within

²⁰ One *imam* claimed there is no peace among “85%” of married couples, referring specifically to marriages between girls born and brought up in this the UK and boys from Bangladesh. Another *imam* gave a similar figure.

²¹ *Tara ussringkhoh beshi ar chelera ottacharito.*

²² *Shamikey ayottey anar jonno.*

a few months, but then it is too late to get back together without going through the *hilla* (temporary marriage to another man) prescribed by Islamic law. Another *imam* I spoke to told me more or less the same things about continuous problems within these marriages concerning husbands sending money home and the British-born wives being selfish and wanting to spend all the money on herself and on the house in the UK.

I could not help feeling that I was getting a male view of the situation and of course, beside being men, they were also hearing stories mainly from men. The women's perspective is somewhat different. Some of these issues came up in my discussions with a British-born woman, Sharifa, and I was able to cross-check information with a number of my other interviewees.

Sharifa told me that when a boy born here marries a girl from Bangladesh she usually becomes a docile housewife, while the husband does whatever he likes, including womanising outside the house. But the marriage does not usually break up, because the docile Bangladeshi wife puts up with whatever condition she finds herself in. Sharifa continued that when a girl born and brought up here marries a boy from Bangladesh, she may be less tolerant of his behaviour. This is not necessarily a matter of women brought up in Bangladesh being more submissive. If such women want to object to their husbands' behaviour, they are in a weak position to do so. They are likely to be totally dependent on their husbands for their British visas, to have poor English language skills, little knowledge of their rights under English law, and little or no access to assistance outside the husband's family. Sometimes these Bangladeshi wives have no relatives in the UK other than their husband's family, and even in the case of a cousin marriage her primary identity for them is as the wife of the household, not as their niece or cousin. A British-born wife of a Bangladeshi husband is ahead of her husband at least with her English skills. In addition, her own family is in the UK and she can turn to them for support if things go wrong.

Sharifa was in agreement with the *imams* that a major source of conflict concerned the imported Bangladeshi husband being committed to sending much of his income back home to his own family. "As soon as a man comes to this country, the remainder of his family members become disabled, and they expect a continuous supply of money from the UK". This is a story I heard from many women, and I know of at least one marriage that broke up for precisely this reason. Another reason for marital problems, according to Sharifa, is when a British-born man insists on living with his parents after marriage, leading to conflicts between the wife and her in-laws. A third source of tension that she mentioned is over women working outside the house: "men do not like their wives working". Sharifa herself was prevented from working by her Bangladeshi cousin-husband. She also commented that "men from Bangladesh have a bad image of girls born in this country". Her own husband would check up on her when she was out with her girlfriends. "Men don't like women to question. She should be blind, deaf and dumb, just cooking, cleaning and washing in the house."

Although Sharifa's own marriage is working well, this is the result of continuous negotiation. She lets her husband send money home, but has convinced him to reduce the amount. She also gets him to help her with looking after their children and some housework. At least once a month, however, he "forgets or falls back on his habitual male chauvinism or something. He doesn't see the point of talking things through."

On the whole, it seems true that British-born Bangladeshi women like Sharifa are in a stronger position in relation to their husbands. Even so, their situation is not

easy and things do not always work out. If things go really bad, the wife does not only have to deal with the trauma of her own marriage break-up, but also has to deal with her husband's family members, who may be her own relatives. She may be seen as causing dishonour for her own family in relation to the extended family, and her re-marriage may be difficult. I know of two such difficult cases.

A perceptive middle-aged man commented on the difficulties of these intercultural marriages:

The husband grows up in Bangladesh and the wife grows up in the UK. Their values and ideas are different and there is lack of understanding between them. Perhaps the husband says his *namaz* regularly, the woman doesn't. The husband thinks his wife should not go to the bazaar, but wife goes to the bazaar. The husband is of the belief a woman should be modest in her behaviour and dressing, but his wife might wear tight trousers and shirt. Husbands usually work in restaurants at night and sometimes their wives also work during the day – so they barely spend any time together. There are major problems in marital life due to this routine of husband and wife.²³

Nevertheless, because marriage is a must for Bengali women, and mature women have no social position outside of marriage (Rozario 1992, 2002a), it is understandable that most women will try to make their marriage work, even if it means a great deal of compromise on their part. In addition to marriage itself, it is important that a wife becomes a mother soon after marriage and gradually gives birth to many more children. Large families (four to seven children) are the norm with Bangladeshi families. One or two child families are not common unless there are health problems within the family. One woman with two children told me how other women often asked her why she does not have more children, and whether they are having some marital problems. Some families in my sample were early in their marriage and therefore still had one or two children. However, Phillipson *et al.* (2003) in their study of 100 Bangladeshi women in the Tower Hamlets found that the average number of children was 5.2, and two-thirds of the women had five or more children.

The story of a British-born woman, married to her first cousin, who did not have any children during the first twelve years of her marriage is revealing of what it means to be a childless woman in Bangladeshi culture (see Appendix One). She was perceived as inauspicious and not made welcome in other people's wedding rituals, her husband was told to marry again, her husband, his relatives and other Bangladeshis felt she had some problems, not the husband. Her mother kept taking her to numerous *maulanas* (learned religious specialists) in an effort to cure her of any problems she might have had. In desperation they tried IVF, which was unsuccessful, but at the end they had twins without any medical intervention. In cases where a couple fails to have children, it is automatically assumed that the problem must be on the woman's side.

²³ *Dampotto jiboney ei nieye khub oshubidha.*

Educational Background and Language Skills

In all the cases I studied women were the primary caregivers. This meant that their ability to assert their opinions and concerns in relation to their husbands, health professionals and the wider society in general was a critical issue. In this connection, their education background was an important issue, as was their knowledge of English.

In my sample of twenty families, the women's educational background and language skills was quite varied. Seven were born in the UK, and an eighth came as a young child, and all of these were fluent in English language. Two of these women had gone to university; one had a full-time professional job, the other worked part-time. Two had completed twelve years of schooling and were employed in part-time jobs as a social worker and an interpreter. The remaining four had limited education (up to ten years, sometimes less), and were full-time mothers and housewives.

Three of the women in my sample came to the UK as young teenagers or adult and they did not attend any schooling here. Consequently, their English is either very limited or (in one case) non-existent. The other nine women came to the UK after marriage and therefore their education was in Bangladesh, and even then pretty limited. These women have hardly any English language skills.

The educational level of the Bangladeshi men in my sample was similar.²⁴ Most were employed in restaurants; all but one of the remainder drove taxis. One man had a clerical job. Five of the men were born and brought up in the UK, but they mostly had limited education and had taken up jobs in restaurants immediately after leaving school. The remaining men were born and brought up in Bangladesh. Many of these had at least ten years of schooling, and one had a bachelor's degree, but most had very little or no English. Only two of these men spoke good English.

As I noted above, the women born and brought up in this country were on the whole better off in relation to their husbands and in-laws in the UK. Because it was often through them their husbands came to the UK, because they knew the language and to a significant extent were aware of how the British social system worked, what women's rights were in the society and in marriage, their husbands usually could not push them around. Their Bangladeshi-born husbands usually had little or no English, and they conversed in Sylheti, which the British-born Bangladeshis know better than Bangla. Overall these women were in a good position to negotiate with the outside world on their own. For example, some of them drove their own cars. In some cases, being married to a cousin also worked to their advantage, though as we will see below this is by no means necessarily the case.

Women who were brought up in Bangladesh and did not speak any English were in a much weaker position. They were totally at the mercy of their husbands, who, if not born in the UK, had at least picked up enough English to get by and negotiate in the wider society. Lack of English also means that a woman cannot learn to drive, so she has to rely on her husband to take her for weekly grocery shopping or to visit relatives and friends who do not live within walking distance. One woman was a widow and had to call on to help from neighbours in crisis situations. Medical appointments, of which there can be many during a month for families with children affected by genetic disorders, generally require driving some distance and the services of an interpreter. Often Bengali interpreters are not all that easy to come by, and husbands act as interpreters for their wives. A number of women complained that this

²⁴ One of the two women with university education had an English husband. This is "Rohima," whose story is told in Rozario 2007.

is not a satisfactory situation, both because the husbands barely understand enough English to interpret effectively, but also because husbands are reluctant to communicate information that they feel is not suitable.

A number of the women in the sample suffered from what they called 'depression' and were receiving treatment for it. Beside the sample I recruited for the project, I came across several other cases of 'depression' and it is evidently a common problem with the Bangladeshi women in the UK. One of the genetic counsellors once asked me if I knew why there were so many cases of mental illness within the Bangladeshis in the UK. I have no doubt that their vulnerable position within their husbands' households and their relatively isolated lifestyle contributes to this problem. This isolated situation is much worse during the long UK winters, when the days are short and very grey. One woman who lives in a fairly isolated situation, away from all relatives and with no English whatsoever, told me how her depression gets worse in winter. As soon as her husband goes to work (around 3.30 to 4.00 p.m.) she locks herself in their upstairs room, because she is scared to come downstairs. This same woman told me that when she was in Bangladesh she did not have any depression.²⁵

²⁵ Her husband reported that she did have some depression in Bangladesh but that it was relatively mild, and that she barely took any drugs during her three months' holiday there.

3. Islam, British Bangladeshis and Genetics

Islam was a major focus for the project. The first part of Chapter Three discusses the significance of Islam for the women and men in my sample. The second part considers briefly what Islam in general, and the Bangladeshi *imams* in my sample, has to say about genetic issues.

The Changing Significance of Islam

To begin with, it is important to note that the understanding of Islam among Bangladeshis, as among other Muslim populations, has changed considerably in recent years. Historically, Bangladeshi Muslims followed what Asim Roy has termed 'syncretistic Islam'. The core values of this religion did not contrast greatly with those of Bengali Hindus. However, particularly from the early nineteenth century onwards, there was a move among the rural Bengali population, inspired in part by connections with the Wahhabi movement in the Arab world, to assert more purist forms of Muslim identity (Roy 1986). Since then, Bengali history shows how Bengali Muslim identity has fluctuated between the "Bengali" and "Muslim" poles, in association with the socioeconomic and political climate of the region. As Blanchet (1984:8) points out, in the nineteenth century both Muslims and Hindus equated Bengali culture with that of Hindus.

The renewed surge of Islamic revivalism around the world since the Iranian Revolution has greatly influenced both Bangladeshis in Bangladesh and in the diaspora, and has led to an even more forceful effort to purify 'Bengali Islam' of any Hindu traditions, that is any Bengali cultural influence. This new Islamic identity aligns Bangladeshi Muslims to the world Islamic *Umma* and thus cuts across all ethnic and geographic boundaries. Local, 'cultural' aspects of Bengali Islam are seen as superstition and as un-Islamic and to be discarded.

There is a call for Islamic brotherhood and sisterhood across the world. The recent world events, for example, the 9/11 bombing of the twin towers in New York, the wars in Iraq and Afghanistan, all have to be taken account of in understanding the increasing number of Muslims around to world who are responding to the call for this new international Islam. So do events in the UK itself, including the burning of Salman Rushdie's *Satanic Verses*, the consequent reaction within the UK, and more recently the 7/7 and other bombing incidents. These events may at one level be seen in terms of Muslim hostility to the West, but that hostility has to be understood in relation to the on-going neo-colonial and imperial relationships between several of the Western states and the Muslim countries in the Middle East and elsewhere in the third world. These relationships continue to be largely exploitative in nature, particularly in relation to South Asia. Within such a climate, when most of the world's population, Muslims and non-Muslims, are feeling harassed, confused and bewildered, and are asking questions about their identity, the response of the Muslims to the call of the Islamic movements is not surprising.

This new purist international Islam was promoted in Bangladesh by two principal movements in particular, the Jama'at-i-Islami, a right-wing Islamic political party with links to sister parties in Pakistan, India and Kashmir, and the Tablighi Jama'at, a conservative religious movement with a purist agenda oriented about eliminating 'non-Islamic' practices (Rozario 2006a). The new purist Islam is not only about discarding elements of 'Bengali culture', which are now regarded as superstitious and un-Islamic. Gardner noted the specific developments at the Sylhet front: Purist Islam involved strictly following the five pillars of Islam including the five times of prayers, the giving of alms, keeping fasts, performing *hajj*; plus regular

recitation of Qur'anic texts and leading a pious life. Anti-Islamic activities such as dancing, non-Islamic music, gambling, drinking alcohol, taking drugs etc were strictly forbidden and women had to be secluded following Islamic rules. "Purist discourses also stress the formal acquisition of knowledge (studying the Qur'an and Hadith) as the correct means to religiosity, alongside living a pure and upright life" (Gardner 1995:237).

Within the UK Bangladeshi Muslims came in more direct contact with the new purist Islamist movements. The more educated members of the younger generation in particular began to respond to them with great enthusiasm (see Kyriakides-Yeldham 2005). Thus while the Islam that was practised by the older generation of migrants was more syncretic and many of their religious rituals were also part of the Bengali culture, e.g. the pre-wedding rituals of *gae holud* (turmeric ceremonies and so on), the younger generation saw these elements as essentially backward, "Hindu" traditions. What is important to take note of is that women played important roles in many of these so-called Bengali or Hindu traditions and by discarding them, the new purist Islamists were also depriving women of certain critical, and sometime, empowering roles (Samuel & Rozario 2006).

I turn now to consider what all this means for people's everyday lives and their attitudes towards Islam. How did all these developments affect the Sylheti group that I did my research with?

From the beginning, I was struck by the much stronger outward expression of Islamic religiosity by the British Bangladeshis than I had observed in Bangladeshi Dhaka villages in the 1980s. Thus the vast majority of Bangladeshi women in the UK wore the *burqa*, a long gown covering the hair and body, men attended mosques regularly, children attended mosques very regularly for Qur'an classes, all adults and even many children kept the fasts, and people's houses were decorated with Arabic prayers and images of Mecca, the Kaaba and so forth. Many men talked about their dream of making at least one of their sons into a Qur'an-*e-Hafiz*, someone who could recite the Qur'an as a whole. Praying five times a day was taken very seriously by most adults and almost every household had installed electronic gadgets, with connections to the main local mosque, which were automatically turned on, like an alarm system, at the times for the *azan* or call for prayer. Thus five times a day they get to hear this *azan* at home and prepare to perform the appropriate rituals before saying their prayers.

As I talked to them, it became clear to me that this group had become much more Islamic-oriented in recent years. Most women, on questioning, told me that they began to take Islam more seriously over the last eight to ten years when they began to attend Islamic classes arranged by Tablighi Jama'at and other organisations. It was also from this period that these women began to adopt the *burqa*, which they did not previously use.

I only had limited opportunity to speak to young men, but two of them told me that they began to take Islam more seriously since they have been to the college, at around age seventeen or eighteen. These young men and women's turn to purist versions of Islam arose from intensive debates and discussions with other more learned Islamists, as well as from reading Islamic texts closely and asking questions. In my sample, both men and women found much solace and help from following Islam in this way, as I will show.

Like most Bangladeshis in Bangladesh, Bangladeshi migrants in the UK are Sunni Muslims. In the earlier years after their migration people had set up small mosques in private houses, but since then Bangladeshi mosques have sprung up

almost in every area where they settled. Thus Birmingham was already said to have some ten Bangladeshi mosques in 2001, and by now their number has undoubtedly increased further. These are serviced for the most part by Bangladeshi *imams*, brought from Bangladesh especially for this job.

As in Sylhet, children in the UK too attend Islamic classes to learn to read the Qur'an, preferably to recite the Qur'an by heart. Sometimes an *imam* or someone learned in Islam will come to the house to teach children to read Qur'an. One *imam* whom I interviewed had initially come to the UK to guide prayers in a small local mosque. He used to teach Qur'an in the evenings in the mosque. But he decided to be more entrepreneurial and bought two houses adjacent to each other, then expanded the back of the houses, where he now holds Islamic classes for several groups of children. He also employs two men to help him teach the thirty or so children. They divide up the class in groups and teach them for two and a half hours each day in the late afternoon. During my visit I noticed a young girl of about four or five with a cute little headscarf who was being dropped off by her father for the Islamic class. This *imam* also collected and dropped off children for some families as part of his service. His own daughter, only seven, was being taught to recite the whole Qur'an by heart. She attended the group class, but she has additional private classes three or four times a week with a female teacher at home. The aim was for the daughter to be able to read the whole Qur'an before they all go to Mecca for their big *hajj*.²⁶

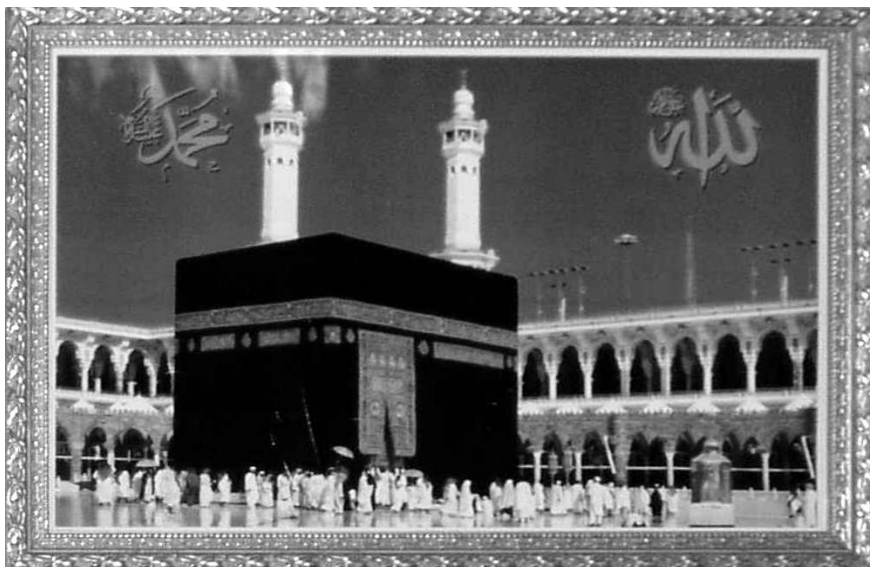


Fig. 1: Framed Print on Wall of Sylheti Household

It is important to be able to read and write Arabic, i.e. the Qur'an, because utterance of Arabic is sacred and a source of power. Thus families both in Bangladesh and in

²⁶ The trip would cost them (parents plus their daughter) around £10,000-£12,000. This is because three of them were going for four weeks and also because, as his wife said, "I will have to buy presents, gold, for all the relatives". I visited them again some time after they had been to the *hajj*. When I asked what they had brought, they showed me a large Pepsi-Cola bottle which contained some water from the Zamzam spring. This water has been distributed among their relatives. I was told that people sometimes add more water to the Zamzam water, so as not to run out of it altogether. But she added, she will keep some unmixed pure Zamzam water. As we will see later, this water is used for various health problems, and even well people will take some.

the UK are particular about making sure their children are literate in Arabic.²⁷ Gardner, who worked in a Sylheti village from which a large number of people had migrated to the UK notes, “Written Arabic is used to gain closeness to God, and to ward off forces antithetical to Islam... Amulets with citations from the Qur’an are key to healing and protection against *bhut*. Paper with Arabic writing is also pasted above doors to protect households from evil spirits.” (1995:238).



Fig. 2: Framed Print on Wall of Sylheti Household

I noticed that, in almost all the Sylheti households I visited, the living room walls were totally void of anything other than various images of Mecca, particularly the black Kaaba surrounded by thousands of people, and a number of framed items (large wall clocks, or simple paper on hardboard) with Arabic prayers written on them. Again, one of the practices of the UK-based *imams* is to give out lots of *tabiz* (amulets) inscribed with Arabic prayers, usually for health problems, but often for social problems. The *imams*' use of Qur'anic *sura* or *ayat* to blow over supplicants (a practice known as *fu*), and to consecrate water and oil to be used by people for sickness, is also viewed as powerful and effective.

Ninety per cent of the women I interviewed used the *burqa*. When I asked about this, most said that they had taken up the *burqa* voluntarily. In some families, one sister might wear the *burqa* while the other sister might not. This situation suggests that the women indeed have made their own choice. Yet, in one or two cases at least, it was clear that women were wearing the *burqa* to conform to the family's and community's expectation. Many young men these days look for brides who will adopt the *burqa*. One woman told me that two of her brothers were planning to go to Bangladesh to find brides because they thought the women in the UK will not wear the *burqa*. One woman said she hates wearing the *burqa*, for it makes her head feel hot, and she can't even keep it on when she is saying her *namaz*. So she also finds doing her *namaz* regularly troublesome. Nevertheless, she told me that her husband, who is very religious and had spent years in Saudi Arabia before coming to the UK,

²⁷ As Gardner points out, the outward expression of religiosity, including being able to send children to *madrasahs* to learn to read and write Arabic, giving regular donations around *Eid* times, sacrificing animals and distributing meat to the poor, donations to mosques, performing *hajj*, keeping women in strict *purdah* (seclusion) is a costly affair and naturally reflects people's class position. Indeed, as she argues "one has to be rich to be a good Muslim" (Gardner 1995: 237).

likes her to use the *burqa*. Also, she is concerned that one of her relatives might see her when she is out without a *burqa*. There is some tension between her and her husband regarding these things. She said that when she says her *namaz*, her husband is happy and will help her around the house. Consequently she has to wear the *burqa*. By and large though, wearing the *burqa* is part and parcel of new purist international Islam and in most cases the young, educated women are adopting it voluntarily. As is well known, this has become a common phenomenon among large numbers of Muslim women all around the world in recent years (Ahmed 1992; Rozario 1996; 1998b).

During the Islamic month of Ramadan almost all adults keep the fast. What I was surprised about was the children's interest in fasting. Thus a number of mothers told me proudly about their school-aged sons or daughters (starting from age eight) were keeping the fast, although they cannot often continue for the whole month. The mothers are happy that they were at least trying. However, older children, from fifteen upwards, keep their fasts regularly.

In relation to other Islamic practices, I found that many families have already undertaken *umrah hajj*, and were hoping to go to the full *hajj* in the future.²⁸ Many others were planning to do the *hajj*. Going to *hajj* is expensive, but this is something most Bangladeshis would not have been able to undertake if they lived in Bangladesh. It is much easier for Bangladeshis in the UK, and often families do the *hajj* en route for a holiday in Bangladesh. Men who have been to *hajj* often adopt the title of *hajji*. *Hajjis* enjoy high status in the community. Interestingly, in Bangladesh, the norm would be for old men or women to do the *hajj*. But from the UK Bangladeshis often take the whole family, and sometimes a whole extended family will make the trip together. Recently a couple with four children told me they are planning on a *hajj* in the near future.

All of my sample families have donated or performed *sadaqah* several times, typically through donating money to the poor, or sacrificing animals and distributing the meat to the poor. These things are usually done through family members in Bangladesh, where there is no shortage of poor people.

Some Bangladeshi Muslims also resort to *istikharah*, asking Allah for guidance, when making important decisions in life, e.g. marriage and regarding health problems in family. Ruby, a well-educated woman born and brought up in the UK, told me that she did an *istikharah* when she was faced with the choice of marrying her husband, her mother's sister's son. When I asked her what this meant, I was told it was about asking guidance from Allah when faced with a difficult decision. This was the first time I had heard about this Islamic concept. Later I found the following text about it:

Istikharah is to seek guidance from Allah when one is faced with a problem to which no solution is apparent. Whenever a person is faced with a difficult problem, or becomes hesitant in making a decision and his knowledge of the matter is insufficient to to guide him then after seeking advice from trusted friends he should turn to Allah and beseech His grace. He should willingly and with an open heart and mind supplicate for divine guidance and ask for direction so that the problem is solved in his own best interest. The *du'a* at such an occasion is called *Istikharah*... In the Masnoon *Istikharah*, after one has carried out his responsibility as best as one can, one should hand over the entire matter and oneself to the limitless knowledge of

²⁸ The *umrah hajj* or "Lesser Hajj" can be done at any time of year, and involves a series of ritual acts around the Kaaba in Mecca, often combined with a visit to the Mosque of the Prophet in Medina. The "Greater Hajj" has to be done at a particular date in the Islamic calendar, when Muslims assemble at Mecca from all round the world for its performance, and involves a series of further ritual acts.

Allah Ta'ala. By resorting to *Istikharah* one is now relieved of making decision on his own. Now there can be no perplexity. Only that will happen which Allah Ta'ala wills and which is good for one's own although one may not be able to see it immediately. It is not necessary that one must experience or see an evident change or vision. Allah Ta'ala alone knows which is best for His servants. It is related in that Hadith that "Success and good tidings for the son of Adam (Insan) is in performing *Istikharah* and his misfortune lies in not making *Istikharah*."²⁹

From the beginning Ruby told me that she was very religious, and that it was her religion that kept her strong with her son's serious health problem. She had a responsible full time job as well as having to give a lot of time to her small son's special needs. She told me that she had to be strong and cheerful for her son, but it was really Allah who helps her in everything. So for Ruby to be asking Allah for guidance in a major decision in her life, whether or not she should go ahead with the marriage desired by her parents, is understandable. It was a difficult decision for her to make. Initially she did not seem to be interested in the marriage, but she knew there was a family obligation. She told me that after she performed *Istikharah* there was no explicit sign for her as such, but she started to feel very good about her future husband. She was staying for a week with his family in Bangladesh at the time and spending a lot of time talking to him and discussing various things. She said, "I knew then this was *the* man I will marry, no-one else but him". Indeed, despite the severe health problems of their son, they seemed to be a very happy, and relatively relaxed couple.

Later I spoke to a young Bangladeshi man who also told me about *istikharah* and mentioned that people sometimes resort to this. As far as I know, this practice has not been common among Bangladeshi Muslims in Bangladesh, and I wonder whether its adoption by young British Bangladeshis owes something to the new Islamic movements.

In any case, there is no doubt about the increased religiosity of the Bangladeshis in the UK, and it is also evident that it is not the traditional religion from Bangladesh that they are going for, but the new purist Islam. However, as we will see later (see Chapter Seven in particular), while people's behaviour and actions are influenced by the new purist Islam, in times of crises they still often resort to traditional Islamic sources for assistance. In other respects too one can exaggerate the impact of modernist versions of Islam on the families in my sample. People's ideas about such matters as gender roles within the family are still very much guided by ingrained Bengali (Bangladeshi) cultural values which have little to do with modernist Islam. The same is true in relation to their ideas about illness and heredity, as we will also see in later chapters.

Finally, we have to bear in mind that Bangladeshi Muslims' religious behaviour is to a certain extent also influenced by the wider socio-political climate within which they are living in the UK. As we have seen above, they are very much a marginal and vulnerable community, and are sometimes directly subjected to racial abuse. Thus one woman said that "soon after 9/11 we used to be critical of the people who had done it, the suicide bombers and so on. But these days we feel sympathetic to them." She was referring to the suggestions in the media that all Muslims are terrorists, and also to people she knows who have been abused in the streets by non-Muslims. Her own son had also been harassed by white boys in a local park. He had been involved in a fight, and the police were involved. All this, no doubt, makes

²⁹ "Q & A: Istikharah" by Mufti Ebrahim Desai, posted 27 May 2001 on the Albalagh web site (<http://www.albalagh.net/qa/istikharah.shtml>), downloaded April 2007.

Bangladeshis, who are identified and identify themselves as Muslims, feel bitter about their situation in the UK. For solace and solution they turn more and more to Islam, and the Islamic communities world wide.

In addition to the problems of direct racism, Bangladeshi people in the UK also express concern about the relatively un-Islamic social climate in which they have to live and bring up their children. At least in their own segregated areas there are plenty of *halal* food shops, so buying *halal* food is no longer a big problem. However, this still remains a problem at other public places such as hospitals and schools. In my sample, parents, in particular the fathers, were often concerned that their child might be fed non-*halal* food when taken out by welfare workers to give the parents a break. Then there are the problems of alcohol, drugs, sex before marriage, and what was seen as the general immorality of Western cultures. All these problems are typically seen as ‘Western problems’ and people guard their children against mixing with non-Muslim children because of this.

Thus one mother of a child affected with a life-limiting genetic disorder told me that their child is disabled despite all the care they took during her pregnancy. She said that her husband in particular had been extra-cautious while she was pregnant. He apparently said, “This is English country, a bad country,” referring to problems with alcohol, drug, sex. She was told they had to say extra prayers to ensure that their son will not be spoilt in this country. So they “prayed and prayed”. She said she also did not watch much TV, only religious programmes and perhaps some documentaries, but avoided music, dance and all the “English shows”. Of course they also followed other rules of purity and pollution. During this time she said that she once asked her husband to bring some prawn curry from the restaurant where he worked, for she had a craving for prawn curry cooked by someone else. However, her refused to bring any prawn curry from the restaurant, for that would not be the *hok* (right) thing to do. He works there and gets paid, but bringing food not paid for would not be right, especially when she was pregnant with their son, and it might have an adverse effect on their baby. So he merely bought her some prawns from the market and she had to cook them herself.³⁰ All these precautions were because they were in this un-Islamic country.

It is perhaps not surprising that Sadaf Rizvi, a PhD student at Oxford University, found in her research with teenage Asian students in Muslim faith schools that faith and religion played a more prominent role in their lives than ethnicity. One example that she gave me was that when questioned about their future aspirations, most of them wanted to become *ulemas* and be able to teach Islam (personal communication).

I found that whether or not people were actually doing everything according to the prescriptions of purist Islam, they were at least always full of Islamic explanations for almost every aspect of their lives. Certainly, as mentioned above, when I observed them, their overt behaviour was demonstrably Muslim. Later we will see how these Islamic ideas and practices entered into the question of how they dealt with the genetic disorders of their children.

Islam and Genetics: Theological and Juridical Positions

For any mother or father of a child afflicted by a genetic disorder, the question of why it is their child who has been affected is difficult to escape. Genetics may give an

³⁰ Her husband actually worked as a chef but refused to cook at home, even when his wife was sick.

explanation of the biological process, but, even if people understand the genetic explanation, which is by no means certain, it does little to answer the question of the personal meaning of what has happened. For Muslims, as believers in a personal God, Allah, the question of Allah's role in what has happened is a natural one.

In an article some years ago discussing Muslim perspectives on health and suffering, Abdulaziz Sachedina pointed out the impossibility of thinking of Islamic views on any theological matter in monolithic terms.

In fact, plurality in belief and practice is inherent to Islam which, like Rabbinical Judaism, invests the power of interpretation and decision-making not in an institution like a church, but in the person of experts in religious matters, the *ulama*. (Sachedina 1999: 65).

At one level, Islam would seem to give a straightforward answer to the question of Divine responsibility. As Alison Shaw comments,

For Muslims, health, illness and misfortune are ultimately the consequence of Allah's will, a belief which lends itself to a fatalism which may itself be a source of comfort in cases of terminal and incurable illness. (Shaw 2000a: 98)

This assertion is founded on well-known verses of the Qur'an, such as *Sura* 64, verse 11: "No affliction befalls, except it be by the leave of God" (quoted in Sachedina 1999: 67). The corollary to the idea of affliction visited by a loving God is that those who have patience in the face of misfortune will receive their reward:

Surely We will try you with something of fear and hunger, and loss of wealth and possessions, death, and the loss of fruits of your toil. Yet, give glad tidings to those who are patient who, when they are visited by an affliction, say, 'Surely we belong to God, and to Him we return.' Upon those rest blessings and mercy from their Lord, and those are the truly guided. (*Sura* 2, vv.155-57, cited in Sachedina 1999: 69).

As Sachedina notes (1999: 66), there is a cryptic character to the Qur'anic reference, which leaves considerable room for divergence as to how the presence of misfortune and evil in the world is to be understood and how active or passive one should be in response to it. The *hadith*, the traditional accounts of the sayings of Muhammad, which, along with the Qur'an, form the basic source of Muslim law, are nevertheless on the whole very positive about the appropriateness of medical care:

The *hadith* literature overwhelmingly regards illness as an affliction that needs to be cured by every possible legitimate means. In fact, in these traditions, the search for cure is founded upon unusual confidence generated by the divine promise reported in one of the early traditions that 'There is no disease that God has created, except that He has also created its treatment.' Hence, the purpose of medicine is to search for cure and provide necessary care to those afflicted with diseases. [. . .] Thus a physician's role as a healer is regarded as spiritually and morally commendable and a collective duty among the religious obligations, in that medicine is a religious necessity for society. (Sachedina 1999: 71.)

Yet the parents of a child with a serious genetic disorder may be faced with the fact that, according to the medical authorities who are advising them, there is no available cure for the condition. This brings them back up against the question of why this misfortune has happened to them, and is also likely to bring into action another kind of possible explanation for the disorder, based on the idea that it has arisen as the result of the action of malevolent spirits (*jinn*) or other related forces such as envy (*nazar*, the 'evil eye'). This provides a further set of responses, in that the action of *jinn* and *nazar* may be countered in various ways, but also raises further questions, since *jinn* and *nazar* are only thought to be able to afflict a child as a result of negligence of some kind on the part of those who are caring for it, in particular the

child's mother. In addition, this is an area where modernist versions of Islam are of relevance, since they often contest the Islamic legitimacy of the various counter-measures against spirit-affliction.

The various responses of the parents and family members in my sample include elements of all these ideas. Thus I was told many times that having a child with a genetic disorder should be understood as a gift from Allah: "Allah has given this for a good reason" or "Allah has given this for our own good".. One of my interviewees, Khaleda, put it like this: "Allah gave this to test us. People say that Allah gives [suffering] to those who can bear it".³¹

One of my male interviewees told me too, much in the words of the *hadith* which I cited above, that Allah has created the medicine before he has given the illness.

The opposition to testing during pregnancy (via amniocentesis) and to the termination of pregnancy in the case of an affected foetus of many of my interviewees can also be seen in terms of the idea that one should not oppose Allah's will. I was often told by parents that if they were to have more children with the same problem, then, "Let it be. I will accept it." Thus Shahanara told me that it was against their religion to terminate a pregnancy. "Allah's gift, whatever Allah does. Have *iman* in Allah, He will be kind".³² Another time Shahanara said "We are Muslims, we don't want to destroy babies. It's Allah's wish if there is a miscarriage, but we never want to destroy it ourselves."³³

In fact, Islamic legal authorities are not unequivocally opposed to the termination of pregnancy, though the conditions in which it is seen as appropriate may be framed fairly narrowly, and there is no unified position on the legitimacy of termination in the case of a foetus affected by a serious genetic disorder. Instead, there is a variety of juridical opinions delivered by experts in Islamic law, which people may be informed about to varying degrees. Often these opinions (*fatwa*) are delivered as responses to a specific question. Here we return to Sachedina's point about plurality of belief and practice.

Vardit Rispler-Chaim, in a study based mainly on *fatwa* by Egyptian and Saudi authorities (muftis), looks at the question of a child's "right not to be born" in a situation such as that of genetic disorder where it cannot be assured of a reasonable quality of life (Rispler-Chaim 2003).

The general Islamic attitude toward the pursuit of knowledge and "scientific research" is very favourable, so Muslims need not object to the prenatal tests themselves. Abdel Rahim Omran [a US-based scholar whose *Family Planning in the Legacy of Islam* studies the juridical literature on these issues] even states that "Muslim children have the right to be born with no actual or potential genetic disorders," emphasizing the awareness that genetic disorders can be identified during pregnancy, and sometimes even prevented. The real problem arises when the tests suggest that an abortion is in order.

Abortion is a complex subject in Islamic law and constitutes an action that is legally judged "reprehensible." This means that it is permitted only when a "good" reason can be furnished, and only up to 120 days into the pregnancy, which is the stage before ensoulment. Only when the continuation of pregnancy endangers the mother's life is abortion permitted later than 120 days of pregnancy. The muftis debate extensively about what is a "good" reason and what is not. Genetic fetal disorders are

³¹ *Allah porikkhar jonno dichey. Manush boley jey shajja kortey parey Allah tareyi dey.*

³² *Allahr deya, Allah ja korey. Allahr upor bhorosha koro Allah doya korbo.*

³³ *Amra Muslim, amra chai na baccha nosto kortam, Allahr iccha - jodi miscarriage hoy, kintu nijer chaina kuno shomoy.*

part of this debate. Should an impaired foetus be aborted? (Rispler-Chaim 2003: 84-85).

This 120-day period is derived from the *hadith* rather than the Qur'an, but it has become an established part of Shari'a law, which considers that after 120 days the foetus becomes, in effect, a person with rights of its own, and abortion is a crime against the person (Kyriakides-Yeldham 2005: 216). In practice, Rispler-Chaim notes, the muftis are more willing to encourage contraception to prevent impaired fetuses from being conceived than to counsel abortion once they are conceived. Contraception is fairly generally permitted by these Egyptian and Saudi authorities, although most of the families in my sample were under the impression that it was un-Islamic, and a minority of muftis permit the sterilization of carriers of genetic diseases (2003: 86-87). I discuss some other sources on these issues in an article from 2005; these present a similar picture (Rozario 2005: 193-4).

The Views of the Bangladeshi Imams

I have already discussed the view of several of the Bangladeshi *imams* whom I interviewed early on in my fieldwork at some length in my 2005 article (see especially pp.193-4). Further encounters with *imams* did not substantially alter the picture given there, though I have used some of this more recent material from *imams* elsewhere in this report. Rather than repeat this material at length, I will give a brief summary here.

Imams at Bangladeshi mosques in the UK are in my experience Bangladeshis who have been trained in Bangladesh or elsewhere in the Muslim world and have come to the UK as adults. Among my interviewees, three *imams* were well educated and learned in Islam. Others did not appear to be very learned. One of the three educated *imams* told me that most of the Bangladeshi *imams* in this country were not well qualified. After their *madrassa* training, they do a short three months course and then they become *imams*. They often do this so as to be qualified to come to this country.

This might explain the reservations of one of my informants about many Bangladeshi *imams* in the UK. Shahanara said that she had heard a lot of stories about *imams*: "Some *imams* aren't good, they say incorrect³⁴ things in Islam's name: this is Islamic or this is not Islamic". She gave the example of many *imams* who are opposed in the name of Islam to women going outside the house. She said that this was not correct: "Our Prophet said women can go out with *parda* [i.e. wearing the *burqa*], but some *imams* are saying that women can't go out at all, can't work. Good, really big *imams*, they want women to study and to work."³⁵

None of the *imams* whom I interviewed had appeared to understand anything about of the nature of genetic illness, and none of them had been approached for advice regarding genetic illness.³⁶ While the families did go to see *imams*, it was mainly to ask them for amulets and other consecrated items that would help protect their child from attack by spirits (*jinn*). According to the *imams* themselves, people mostly went to see them for minor health problems, and for various social and marital problems. We have already seen something on their views in this area in Chapter

³⁴ *Faltu*.

³⁵ *Bhalo, boro boro imam - tara chuy meyera porashuna korbey, chakri korbey*.

³⁶ One man, considering termination of a foetus if found to be injured or damaged, apparently consulted an *imam* about the matter.

Two. People might also go to see certain special *imams* or *maulanas* for divination rituals when they wanted to find out if bad *jinnns* were involved in a problem.

When I asked the *imams* nevertheless for their opinions on issues of prenatal testing, abortion and contraception, they generally supported prenatal testing but differed on the question of termination of pregnancy. One said that it was permissible up to 120 days; others regarded it as not allowed under any circumstances, or allowed only if there was a risk to the mother's health. They mostly allowed contraception, though they tended to be more restrictive than the current Islamic literature in this area.

I also asked them for their views on cousin marriages. They all felt that it was allowed, though one stated that Islam neither objected to it nor encouraged it. They were clearly unaware of any possible genetic problems with cousin marriages.

4. Encounters with the British Medical System

Because of the nature of the genetic disorders my interviewees have had dealings with numerous health professionals. These include GPs, hospitals, paediatricians, genetic counsellors and consultants, as well as various other specialists. In this chapter, I explore some of what the research revealed about the nature of these interactions.

General Complaints.

On the whole, people told me that they fared quite well with the medical system. Most of my interviewees initially claimed to be happy with the medical treatment they were receiving for their children. Certainly, they did not appear to have any major complaints in relation to genetic counsellors or consultants. Almost all of the families had regular contact with genetic consultants and counsellors. Only one had rejected the genetic consultant's services outright: "These doctors can't tell us anything we don't already know" said one man, whose child had recently died at two months of age, apparently due to a genetic disorder.

When I probed further, two families complained they had never received any letters from their genetic consultants explaining their situation since their last visit, 12 to 18 months previously. Another woman said that she was still anxious to find out the outcome of the blood tests that had been done for her daughter some two months ago. She was not clear what the test was about and had heard nothing since it had been done. However, in assessing the relative lack of complaints in relation to genetic consultants and counsellors, we should recall that the families' interaction with these people is relatively limited. Typically, they may see a genetic consultant once or twice within a few years whereas they need the services of other professionals on a much more frequent basis.

Thus, many families however had some complaints or grievances in relation to other health and welfare workers with whom they interacted. These included general practitioners, hospitals, paediatricians, community health workers and other service providers such as social workers, community nurses, schools or housing associations. Some of these were related to people's expectations from the medical system. Others concerned their understanding of the particular disorder that their child was suffering from, or genetic disorders in general. This raises a series of issues regarding how families actually understood genetic illness, which I shall deal with later in the chapter.

A regular theme in parents' stories about the diagnosis of their child's disorder was how long the process took and how anxious they were during this waiting period, which in some cases lasted up to eighteen months. Thus Sabnam, the mother of the child with tuberous sclerosis, told me that she had noticed that her son had some problems when he was only a few weeks old, but it was not until when he was 12 months that he began to receive appropriate medical care for this:

Sabnam said she noticed when Nasim was only a few weeks old that he had "shakes". He used to experience shaking in one hand and often, as he started to sit upright, he would fall down on one side when he had these shakes. Sabnam mentioned the problem to their GP but he did not pay any attention and said 'It's nothing, it will sort itself out'. Sabnam also tried to explain this problem to the health visitor, but she added "I did not know how to explain this". When Nasim was about one year old, the health visitor came to their house to check up on Nasim. Sabnam was giving Nasim a bath and at that time he had a shaking fit in front of the health visitor. The health visitor wrote to the hospital immediately, Nasim had a brain scan done and then began to see his paediatrician every two or three months. Sabnam said that ,after the health vsitor wrote to the hospital, things moved on quickly and she has

been happy with all the medical services. Now they can get medicine to deal with her son's problems (one medicine for weakness and one for epilepsy). Before this, she was completely in the dark, and did not know how to explain things to the GP. Sabnam has seen a genetic consultant only once, when Nasim was aged five, and reports that she was satisfied with her consultation.

Some genetic disorders involve obvious physical symptoms and can be diagnosed within a few months after the delivery of the babies. Also, if a couple already had an affected child, and if tests are available, it is possible to diagnose a baby soon after delivery. But in most cases, as reported by my interviewees, diagnosis was a long and anxious process. Thus the families affected by NF1, XP and Cockayne Syndrome also reported varying degrees of problems with diagnosis. Often it appeared that the parents knew well before the GPs or specialists that there was a genuine problem with their child, but found it difficult to be taken seriously by the health professionals. It was only when an official diagnosis was finally obtained, often after going back and forth between a variety of medical services and professionals, that any action was taken.

Thus Rohima, the woman with NF1 whose daughter was also eventually diagnosed as having NF1, told me that having had NF1 herself she knew instinctively that her daughter was born with NF1. She herself had received no help as a child, since her parents never acknowledged that she had a medical problem, and she was only diagnosed as an adult. She was determined that her daughter would receive proper treatment, but had considerable trouble in achieving this. The following is from her written narrative (see Rozario 2007).

The GP showed complete ignorance about NF1, as have most specialists. Where NF1 is concerned it is not an issue. Except for the genetic counsellor, I cannot say that I and most importantly my daughter have had any active help. My GP does not even stick to the very basic medical guidelines for NF1 patients. He started vaguely following it because I have provided it, the same with my paediatrician. When my daughter was born I knew she had NF1, partly because she was born with a big lump on her nose, but also because I knew instinctively before she was born that she would be affected. I told the paediatrician (after she was born) during her first check up that she had NF1, they just told me that I was hysterical and should go to sleep. When I went for her six-week check to the paediatrician she started developing café-au-lait marks, these looked like bruises on her fair skin. The paediatrician started asking me if I had been hitting her, fortunately I was prepared and reminded him about the diagnostic criteria of NF1 and what it was.

I have to call her paediatrician and her eye specialist and remind them as to how often they should see her. Also according to the medical guideline she should be getting psychological support to help her with the progressiveness of the condition and the potential disfiguration, she should be seeing a dermatologist, an educational psychologist should also be involved as should a physio, she has seen none of these people. My daughter has problems in all these areas, i.e. low self esteem because of the NF1, some mild disfiguration, dyspraxia, learning problems and social problems. I think it would be easier to rebuild Hadrian's Wall than to get all these professionals to help us.

The stories of the families with TS and NF1 reflect their frustration with the GPs and other health professionals and inefficiency or ineffectiveness of the NHS medical system to deal with such problems. Rohima, a university educated woman, was clearly very knowledgeable about the disorder through her own experience, as well as through research. Sabnam did not have university education, although she had no language problems, and was simply frustrated that no one could diagnose the problem for her son.

Many of the actions people took and the comments they made in relation to

their children's genetic disorders need to be understood in terms of the difficulty they had, both emotionally and intellectually, in accepting the medical verdict that the condition was either permanent or, even worse, life-limiting. Consequently, they keep looking for possible solutions and are open to all kinds of suggestions from others. A number of parents told me that they had considered going for private medical care outside the NHS. In some cases, someone in their extended family or in the community had suggested this; others had thought themselves that perhaps a cure could be found in this way.

Often, they thought that there must be some sort of medical cure for their child's illness, but that the NHS was unwilling to provide it because it was too expensive. Thus Karim's relative asked, "Why don't you go private with him?". Other parents also talked about the possibility of going 'private' and finding out if there was indeed a cure. However, to my knowledge no one has actually done this, although two families did enquire with their genetic consultant or paediatrician whether it would help. They were both told that perhaps their child might be seen a little earlier by a private practitioner, but, unfortunately, there would not be any difference to the diagnosis nor was there any expensive drug out there in the market which could cure their child.

The concern of Bangladeshi parents about whether the public system might not be giving the best service to their children may at least partly stem from their experience, or their families, of the public medical system in Bangladesh. In Bangladesh the public health system is dysfunctional in many respects. It is supposed to be free, but in practice hardly anything is free. Doctors employed at public hospitals rarely attend to their duties, rather they spend their time working in private clinics and chambers, where they charge high fees to those who can afford to come to see them. This situation is well known by the Bangladeshi public and may well affect the way in which these families approach the NHS.³⁷

Families also have concerns about schools, social workers and housing associations. Families with children with genetic disorders have to constantly negotiate with various service providers how best to look after their children. Children with genetic disorders are provided with special care at school, and more often they are sent to special schools for children with special problems. Often a supervisor is assigned to look after the child while s/he is at school. Social workers, community nurses and occupational therapists call in both at home and at the children's schools to check for special needs, advising the parents and caretakers at school.

As a consequence, parents spend a great deal of time negotiating with all these service providers. It is maybe not surprising that many of their complaints and grievances concern these service providers rather than the medical professionals.

Thus the family with two children affected by XP were constantly worried that their children were being exposed to sunlight at school, that no one was checking to see if the children were wearing their protective hats and so on. I was told that the older child's condition has deteriorated rapidly because of his school's negligence. The father was concerned too that the children were not provided with *halal* food. The mother's concern was more that her severely disabled son (Azim) was not eating properly at school and becoming weak.³⁸ They were both very worried when Azim

³⁷ I have done some research on health care in Bangladesh myself, mainly in the context of work on childbirth with Bangladeshi women. A similar situation unfortunately also prevails in much of South Asia (Rozario 1995; 1998; Ram 1998; Jeffery et al 1988).

³⁸ Children not feeding properly, at school or at home was a constant worry of many mothers in my sample.

started to fall down and cut himself several times at school, sometimes requiring hospital treatment. This happened as he was gradually becoming weaker on his feet. By now, he is totally confined to a wheel chair.

Experiences of Genetic Counselling

As I have noted, most families claimed to be satisfied with their encounters with genetic consultants and paediatricians. This does not however mean that the consultants and the families were communicating fully and effectively about the nature of the genetic disorder. As we will see, there were problems both with the actual situation of communication, and in the extent to which families were able or willing to accept or understand what they were told. I begin with the first set of issues, relating to practical aspects of the situation of communication. Here I am relying in part on my own experience when observing a number of these interactions between medical staff and families, and in part on what the families told me about their experiences.

Questions, Language Issues and Gender Dynamics

Within Bangladeshi culture, there is a large gap between doctors and most lay people. People look up to doctors, whom they see as being educated and as in a position to cure the patients. It is not customary to question a doctor's opinion or to ask any questions about the treatment being provided.³⁹ In my experience, I found parents often asked questions about their child's condition and what to expect of their child, but rarely asked about the type of drugs or treatment being provided.

In one case, the child's mother asked a question of this kind, but was stopped by her husband. Sufia was concerned that their child was weak, and wanted to ask their paediatrician if he could be given some vitamins. Sufia does not speak any English, so she had to ask her husband to communicate this message to the doctor. Her husband refused, saying that he felt that the doctor was taking very good care of their child and if there was any need she would tell them about giving the child vitamins, without them having to ask.

Sufia's husband told me later that he had felt that asking about the vitamins would indicate that they did not have faith in their doctor treating their child well. As it turned out, I accompanied them to their next visit to the paediatrician, and I asked Sufia if she would like me to ask the question about vitamin for her. The paediatrician was not at all put off by the question, and instead took upon herself to contact the local community nurse about this. In fact, the paediatrician was pleased to have had a direct question from Sufia and encouraged them both of ask her any questions they have. I could not help feeling that the paediatrician's especially attentive and kind manner was appreciated, but had also led to the father being somewhat in awe of her, so much so that it prevented him from asking questions which he thought might seem inappropriate.

³⁹ Those with experience of doctors in Bangladesh itself also know that doctors are very busy people who rarely speak to patients, and only interact minimally with their guardians. The main expectation is for the doctors to prescribe drugs, and it is receiving the piece of paper with the prescription that is regarded as the significant part of the consultation, rather than any dialogue between the patient, family and doctor (Callan 2007).

At the same time, I found that the parents were constantly asking questions about things like “Will he ever walk? Will he grow more?” or about the kind of impact the disorder would have on their children. Thus perhaps we need to make a distinction between the kind of questions parents will readily ask and the questions they would feel it is not appropriate to ask.

The incident of Sufia and her husband brings up another issue, that of interpreting between Bangla (or rather Sylheti dialect) and English. It will be clear from what I wrote earlier about the families’ educational background and language competence that there are often likely to be problems in this area. Also, it is common for one partner to speak much better English than the other, particularly where one has been brought up in the UK and the other came over as an adult. As we have seen this can put the non-English speaking partner at a disadvantage, especially if this is the wife.

Bangla interpreters are often difficult to find, especially at short notice, and in these cases one is dependant on one’s spouse for interpreting. The details of each of these situations vary, and my experience is fairly limited, but it is worth considering two common scenarios in some detail.

In the first scenario, as with Sufia, a husband who speaks some English (not necessarily with great fluency) interprets for his wife. Here, typically, husbands appear to dominate. They do not usually interpret what is said in detail for their wives, and may avoid interpreting things that they feel are not appropriate or important for their wives to hear. In this situation, there is no real communication between the wives and the medical professionals. This is not because the medical professional is not interested in consulting the wife, but because the husband does not see any need for the wife to be consulted and resists interpreting what she says to the doctors.

Sabina had at least some English, but her situation was parallel to Sufia’s. Sabina expressed her frustration to me about her husband refusing to have interpreters for consultations with doctors, social workers, community nurses and the like. She told me that her husband thinks that he can speak and understand English, but she knows that he cannot. She believes that they missed out on a number of opportunities for helping their child because of his misunderstandings of what was being said. She was very appreciative of my presence, since I would often turn up when she needed an interpreter, to negotiate the situation at school, to review their two sick children’s overall welfare with groups of social workers, the medical team and so forth. Like Sufia, Sabina complained that her husband would refuse to say things that she wanted him to say to social workers or to medical staff.⁴⁰

A third example is from a family that I did not officially recruit. I met the wife, Rani once however when accompanying a genetic counsellor on a home visit. The genetic counsellor was visiting to obtain some information. She wanted to know about the history of Rani’s pregnancy, which had involved various problems, and also wanted to check about the extended family to see if there were signs of genetic disorders elsewhere in the family history. The husband was not at home.

In this case, the family’s three-month-old daughter had died. She was a Caesarian baby, was never brought home from the hospital, and had various health problems including a blocked passage to pass urine, along with other ‘abnormal’ physical features suggesting this might be a case of a recessive genetic disorder.

⁴⁰ When Sabina said a few things in English I felt that her English was not bad and that with some encouragement and scope to practice she could probably speak better English than her husband. Her husband clearly picked up functional English as he had been dealing with the outside world a lot more, working in restaurants, driving taxis and so on.

However, the husband had been avoiding going to see any genetic counsellors. When I called up to ask if they would be interested in taking part in my project his response was: “I don’t think it would help Rani to talk about these things again, now that she is finally trying to come to terms with it all [i.e. loss of her baby]”. However, he agreed that I could call him on the phone to ask some questions.

One day he told me over the phone that they were not interested in visiting any more specialists about their situation. “There were many letters about counselling. We don’t need counselling from strangers. They will ask personal questions and we will have to talk about personal matters. We don’t need this. If we knew them, then that would be something. I have done my research on the internet and I understand that this problem is very rare for girls [they lost a daughter], it usually happens to boys.” He also said that his sister, who had a still-born child, understands and “gives us advice.”

Rani’s husband’s rejection of any help from genetic counsellors is understandable. This was the couple’s first baby and the episode was undoubtedly traumatic for Rani. He made the decision to shelter her from any more hurt. However, I am not sure that if Rani were to be made fully aware of the situation that she would necessarily agree with his decision. Rani had no English whatsoever. She was clearly very young, probably less than twenty years old, and had arrived in the country very recently. Her husband was born and brought up in the UK.

The second scenario presents the reverse situation. Here a British-born wife with fluent English interprets for a husband with little or no English. This seemed to work much better, at least from my limited observation. In one consulting session I was present, both the genetic consultant and the wife made sure that everything was being interpreted. The wife interpreted her husband’s questions and concerns to the consultant. I did not feel that there was any attempt on the wife’s part to leave her husband out of the consultation. Indeed, she seemed to be trying very hard to ensure that he understood everything that was going on.

Of course, the family dynamics in these situations cannot be reduced simply to whether one or the other partner knew English. All four couples were marriages between first cousins, but their personal histories and backgrounds varied considerably. I got to know three of these couples quite well, though I have much less information on the fourth, Rani and her husband.

Sufia’s husband had ten years of schooling, but he was very good with languages, had spent many years in the Middle East, knew Arabic and Urdu and was generally quite worldly-wise. He was also fairly learned in Islam. His wife had only a few years of schooling, and although she can read the whole Qur’an, spoke no English whatsoever. In fact her only language was spoken Sylheti dialect; she did not speak Bangla, the official language of both Bangladesh and West Bengal in India. Sufia was treated as ignorant and ‘uncultured’ by her husband, and as not worth consulting on any important matters.

By contrast, while the woman I gave as an example of Scenario 2 was a university-educated professional, her husband was also reasonably well educated. His schooling was all in Bangladesh, however, and he had very limited English language skills. This couple appeared to be operating very much as a team. The wife always seemed concerned about the special needs and wishes of her husband, who is relatively new in the country. The husband too respected his wife’s values and beliefs, although they did not necessarily agree with his own. His wife was much more religious than he was, and he valued her decision not to want to have any genetic testing. He shared in the household and childcare duties, although they were both

employed full-time.

Sufia's and Sabina's situation was quite different. In both cases, their husbands worked as chefs, but they did no cooking at home, even when their wives were unwell. Nor did they do much housework. The wives complained frequently to me about the lack of support and help from their husbands with their heavy domestic workload, carrying out most of the housework as well as looking after sick children. In these relationships, the husbands dominated, although in both cases they owed their British visas to their wives.

These varying family dynamics can have a substantial bearing on the ability of parents to understand and respond to the suggestions and information provided by genetic consultants and counsellors or paediatricians. I am not suggesting that all couples can be reduced to 'Scenario 1' or 'Scenario 2'. The point is rather that it might help if medical staff, social workers and others interacting with Bangladeshi families in these and similar situations were more sensitive to issues of this kind and their possible consequences.

The Families' Understanding of Genetic Illness

In discussing the families' understanding of genetic illness, we need to bear in mind that communication between medical professionals and the families can often be quite problematic for reasons such as those discussed above. This aside, understanding the meaning and implications of genetic illness is far from simple for people without a technical knowledge of medical genetics, however carefully it is explained.

The complexity of the diagnosis and of the genetic disorder meant that people often had very little understanding of the real nature of their child's problem, or of what this would mean for the child in the long run. Their understanding of the implications if they planned to have more children in the future was also generally quite limited, as we will see. The term 'genetic' meant very little to most people, and they kept finding other causes for their children's ongoing illness. Often, they assumed that the problem was the negligence of the medical system. Sufia, whose only son was affected by Cockayne Syndrome, told me at length that when her son was born, the hospital in question did not do all it could have to help him. She felt that hospital B, where baby was delivered, was much inferior to hospital A, where her cousin gave birth.

My sister [cousin] had twins (*joor baccha*) twelve years after she got married. The babies weighed two pounds each. They are now three years old and they are fine. She went to hospital A, and they kept her there for one week. I went to hospital B, and that was not good. When my baby vomited, they did not do anything. When my cousin's babies vomited they immediately took the babies down and tested their blood pressure, urine, and maybe blood.

Apparently, her own baby was 5lbs at birth and he was kept in the hospital for only three days, as against the one week for her cousin. Sufia again said that "the hospital [B] could not do a hearing test for our son, but hospital [A] is really good, they did all the tests for my cousin's babies." In this story, it is clear the mother was concerned that perhaps something had gone wrong or at least something could have been done to prevent her son becoming sick, as he was now.

Indeed, her husband Karim shared this misunderstanding of what could have been done and perhaps also believed that the hospital staff had neglected their son. He told me several times that if Kiran's case had been taken seriously from the beginning

by the medical staff, something could have been done. Both the parents felt that things had been neglected.

For example, one day Sufia and Karim wanted me to watch a video of their son Kiran, who was then three years old, when he was one year old. According to them, his condition at that time had been much better. Part of the video was done on Kiran's 1st birthday. Kiran was shown sitting by himself leaning against the couch. Later we saw scenes of Kiran lying on the couple's double bed, rolling from one side to the other, or lying on his stomach. Then we saw that Kiran had a walker at that time. He was helped to stand up and he held on to the walker on his own. Sufia told me that he used to move the walker from one end of the room to the other end by himself and added that he used to say *amma* (mother), *abba* (father) and so on (he was unable to speak when I knew him). They compared Kiran's situation with his present condition, saying that he had become weaker and lethargic.

After we watched the video, Karim asked me thoughtfully, "I have been thinking for quite some time, why couldn't the medicine or doctors retain the 'brain' he had at that time".⁴¹ From my conversation with him, right from the beginning, he had told me that, because of Cockayne Syndrome, Kiran "may have many other health problems - brain problems, problems with everything". So he was assuming that there was a relationship between Kiran's various physical disabilities and his brain. He commented after the video, "It seems to me that Kiran had some 'brain' then, for he was doing more things, but I don't understand why the doctors couldn't retain the 'brain'?" Later, when he was leaving for his *namaz*, he asked, "Do you think I should say something to the doctor about this?" What he meant was that he wanted to know why Kiran's condition had deteriorated. Perhaps it had gone from bad to worse, but clearly he had had some 'brain' at an earlier stage. I said that if he had some questions, he should ask the doctor, who could give him a proper explanation.

Nevertheless, I said something about how life-limiting conditions like this usually deteriorate with time. His response was, "But the doctors said he was born with this problem." He was trying to say that if he was born with this problem, then why should he be worse now than when he was one year old? I understood him to be saying that if there was some limited problem, either the doctors should have been able to deal with this and make him better, or at least they should have been able to prevent further deterioration of his brain through medicine or in some other way.⁴²

Labelling Genetic Disorders

An important issue for the medical treatment of genetic disorders is to identify and label the particular disorder which a child suffers from. However, distraught parents find it difficult to deal with these labels for genetic disorders, particularly when, as sometimes seems to have occurred, they were told about these labels without much consideration of the likely impact of this information. I will cite two case studies here.

The first comes from Ruby, whose son, Liakot, was diagnosed as having Angelman Syndrome. She told me

I don't believe he [Liakot, their son] has Angelman's Syndrome. I did some internet research. They found one or two symptoms and labelled him with Angelman's Syndrome. First they labelled him with Prader-Willi syndrome' because of his

⁴¹ *Ami onek din thekey chinta korchi, daktari ouishodey brain dhorey rakhtey pareni keno.*

⁴² Sufia said that she was the one who instigated the video project. Karim was not in favour of it for religious reasons.

overweight. Now that his weight is 'static', they took blood test. Then Dr S [a paediatrician] informed me through letter that he has Angelman's syndrome.⁴³

She added during this conversation,

They just say that your child has this, has that, we get upset, my husband was very upset after our last visit to Dr S. After our last visit with Dr S I have decided that it's in the hands of God.

Elaborating on her problems with this particular doctor, Ruby said

Dr S first said my child was blind because he had a squint in one of his eyes, but as it turned out he is not blind. Then he said he could not hear. His first test failed [meaning it showed that Liakot could not hear]. We said the test failed because Liakot was upset and suggested we do the test following experts' own method and they could watch us from behind the screen [see-through]. We did the test and he passed. We did the test second time and he passed again. Dr S kept saying 'no', but he keeps failing his tests. Next he said 'he will never be able to walk.' But he now can walk [albeit by holding on to things, he is even going up and down the stairs]. She also said 'he will never ever talk.' My husband was so upset that this was the last short straw. She is very rude, very direct. We have another appointment with him ... but we will ring and say we will not go.

The first time that Dr S talked to Ruby, she went alone with Liakot, and she became very upset and started crying.

All Dr S could say was 'I think it's best you bring your husband next time for support.'⁴⁴ He just makes you feel so small every time you go to see him. That's why I don't want to go...He just spends about 15 minutes with us. He looks at his notes, asks can he do this, can he do that - then just sits there and writes notes.⁴⁵

I was never present during Ruby's consultation with Liakot's paediatrician, so I am in no position to judge what actually went on, though the reference to the 15 minute consultations suggests that there may have been some substance to Ruby's complaints. I know from my attendance at consultations with other paediatricians that their behaviour was completely different from Ruby's description. They were very humane, attentive, and dealt patiently with every little question raised by the parents, without looking at the clock ticking away. But what is clear is that the parents were very upset and that they felt that their feelings were not being taken into consideration when Dr S gave out information about their son's condition, and about what he could or could not do.

I recall one genetic consultant telling me that it is pretty common for patients to hate the person who first breaks the bad news to them. This consultant went on to tell the story of a patient's mother who said explicitly that she hated a particular doctor, even though there was nothing that this doctor did was wrong. 'I need to hate someone,' she said, 'and she was the one who gave me the bad news'. In Ruby's case, my guess would be that there may have been some of this, but it seems possible too that the paediatrician, who may have been overworked, was trying to cut corners, and simply gave out the information as held in the files without considering the impact it would have on the parents.

⁴³ Apparently there was no letter from the genetic consultant since her last visit several months earlier.

⁴⁴ It would seem that Ruby experienced Dr S's behaviour as unsympathetic and matter-of-fact, lacking any tactfulness in his communication.

⁴⁵ However, Ruby likes the physiotherapist from Dr S's surgery. It seems that this physiotherapist has helped Liakot to walk with aid.

All parents find it difficult when their child is labelled with a health condition that is life-long or life-limiting. In Ruby's case, she was educated and knew what the label Angelman Syndrome entailed. She was clearly upset by having it handed down when they were still hopeful that their son would get better. In Sufia's case, with hardly any education and no English whatsoever, she did not really understand what Cockayne Syndrome was. She heard the English word 'disabled' being mentioned in various contexts in relation to her child. For her 'disabled' meant someone who could not walk or talk. Her son, at age three, still could not walk or talk, but she was hopeful that he might walk one day. Then one day during the visit of one of her cousins, in passing she mentioned the word 'disabled', comparing Sufia's son's condition with someone else. Sufia was very upset about this, although she did not tell her at the time. After Sufia's cousin left, we had the following exchange:

Sufia: Do you know what Sharifa said about my son?

Santi: What?

Sufia: She said my son is 'disable'.

Santi: What do you think she meant by this?

Sufia: That he will not get better, never walk and talk

Santi: The word 'disabled' is used to refer to all sorts of people or children, who can't walk, talk, hear, see and have many other problems.

Sufia: Won't my son ever walk?

Santi: Do you recall what Dr [paediatrician] said? She thought it is unlikely that he will walk?

Having visited a couple of paediatricians with my interviewees, I appreciate the kind of difficult questions that they have to constantly deal with from parents of children suffering from serious genetic disorders, when no real hope of cure can be provided. Thus Sufia was repeatedly asking the community nurse and the paediatrician about their son. "Will he ever walk or talk?"

The concerns of mothers like Sufia and Ruby are understandable. No parent wants to give up hope of a cure and this is not only because Bangladeshi parents might be irrational or uneducated. We note from Featherstone *et al.*'s 2006 findings that white British patients or parents may express similar hopes and sentiments to my Bangladeshi interviewees. Thus Featherstone 2006 reports that one of her interviewees, Matt, who was suffering from MD, told her although he knew he would end up in a wheelchair one day, he was also given hope by his doctor who told him "It's not a problem. There will be a cure within ten years'. Matt said, 'That was thirty-one years ago. Obviously there wasn't but I'm very glad he told me that because it was a positive, rather than a negative, if you see what I mean ...'" (Featherstone *et al.* 2006:116). Indeed, some hope, however remote, may help the patient or their parents in coping with the condition. One of my interviewees, the mother of a child suffering from MD, an educated woman who had clearly done some internet research on her son's condition, told me, "One day there may be a cure for him." She explained how there was some gene missing in his body, and how the doctors were talking about trying to find ways through which the protein that is leaking out can be stopped, or forms of gene therapy by which the missing gene might be reinserted. She said, "Five years ago there was no hope, but now a lot of disease is cured by gene therapy ...".

Research with non-Bangladeshi patients also showed that people are constantly negotiating with their genetic consultants in an effort to 'evade the genetic

explanation' as well as to maintain the hope that medical scientists might still come up with a cure. Thus one of the interviewees in Armstrong *et al.* (1998: 1657) was quoted as asking the genetic consultant "I want to know if it's possible to trace the gene that causes it and maybe like in cases I have heard in cases of like spina bifida that they've now traced the gene and so they can sometimes halt it." This example has parallels to all the three case studies above: Ruby refusing to accept the paediatrician's announcement that her son will never walk; Sufia's constantly asking whether her son will ever be able to walk or talk, and Sufia and her husband's feelings that something actually might have been done when Kiran as a baby to halt further deterioration of his brain and so his motor skills, and the mother of the MD patient hoping that a new cure that might still be found through things like gene therapy.

Other Common Misunderstandings of Medical Concepts

Abbreviations

The abbreviations for labels given to genetic disorders, such as AS (Angelman Syndrome), TS (Tuberous Sclerosis), CS (Cockayne Syndrome), etc, could also cause confusion, even for parents whose language is not a problem. For example, the mother of the child with Tuberous Sclerosis told me during my first visit that her son was found to have TB. I tried to explain that I thought it was TS, not TB. At a later date, she again asked me about the distinction between TB and TS. This mother spoke very good English and had completed ten years of schooling. In my experience, most parents did not use the label, but discussed the actual symptoms of the disorder their children were affected by.

Statistics and Probabilities

There was widespread misunderstanding of what it meant to say that there was a 25% or 50% probability of a foetus being affected. Thus the family with two children affected by XP told me that they did not understand why two out of their five children were affected. This is more than 25% of the total number of their children, indeed more like 50%! They had thought that one in four children would be affected, rather than that there was a one in four chance for each birth that the child would be affected.⁴⁶ Again, when discussing this issue with the mother of a child with Bardet-Biedl syndrome, it was clear she too thought that because they already had one affected child and one well child, their next two children would not be affected. They were planning to have more children on this understanding.

On the other hand, an educated mother with a child affected with AS told me that she was not planning to have a child in a hurry as there was 50 to 75% chance of their next child also being affected. She was not prepared to take this risk, because she was opposed to the ideas of genetic testing and termination. The couple adopted a Bangladeshi child.

Misunderstanding of these probabilities is fairly common across the board, regardless of ethnic or language background (Featherstone 2006:86). I noted when I

⁴⁶ I noted from a letter from their genetic consultant that they were asked when they only had two sons, the second one having been affected, if they were planning to have more children. According to the letter Anwar said they were not planning to have more children. I wonder if their misunderstanding about the 25% led to them having more children since then.

accompanied genetic counsellors in their home visits that they are at pains to explain this probability rate, by repeating the same information, by drawing diagrams and so on. The diagrams appeared to have worked for one father. In this case, the genetic counsellor explained that with each birth there was 25% chance of them having their child affected with CS. The father found it difficult to understand, and the mother was barely concentrating as she did not understand the language being used (Urdu). So the counsellor drew up pairs of genes for parents (one damaged, the other fine for each) and showed the four different combinations which can be passed on to their child (at each birth): (a) the fine gene from both parents; (b) the damaged gene from father and the fine gene from the mother; (c) the damaged gene from the mother and the fine gene from the father; (d) the damaged gene from both. In these combinations, if the child gets (a), then it will be perfect, not even a carrier; (b) and (c) means it will be a carrier of a damaged gene, but not affected; (d) means it will be affected with CS. All this seemed to make sense to the father. In any case, they were planning to access the medical services for genetic testing and termination if it became necessary with their next child.

During this meeting, the genetic counsellor also explained what was involved in having genetic testing. However, I felt that the mother did not understand anything much about the procedure, except that there might be a small chance (1 to 2%) of miscarriage while performing amniocentesis.

Being Affected and Being a Carrier

Another general confusion concerned the distinction between being ‘affected’ by a particular genetic disorder and being a ‘carrier’ of that disorder. These terms appeared to mean very little to people. I will give two short case studies below to illustrate people’s confusion, but also to show how the complexity of the disorders means people do not bother sharing information with most family members.

The first case concerns Khaleda, a relatively young woman in her mid thirties, and her husband Faruq, in his mid sixties.⁴⁷ Neither had much education; Faruq had been in the country since he was a young man, had mainly worked in restaurants and has some functional spoken English. Khaleda came to the UK sixteen years ago. She is Faruq’s niece, twice removed; they married after Faruq’s first wife had died. Out of Faruq and Khaleda’s five children, their fourth child, a daughter, was affected with thalassaemia, which was diagnosed when she was eight months old.

In this case, they had had an interpreter during their consultation. Khaleda told me “Thalassaemia is a bad thing, this eats up the blood, the blood degenerates, the blood does not increase”.⁴⁸ Faruq commented, “I too have thalassaemia, she [referring to his wife sitting in the room] too has it. This is why the child got it. The doctor said there is no problem if the man has it, but if a woman has it, then the child gets it.”⁴⁹ I can imagine that they were told that if only one of them was a carrier, then the child would not be affected and that Faruq misinterpreted this comment.

⁴⁷ Faruq’s first wife died before his second marriage, and they had four children, one of whom died, and the other three are now grown up and settled with their own families. Khaleda and Faruq have five children, aged from two to sixteen years of age.

⁴⁸ *Thalassaemia kharap jinish, eta rokto khaiya halay, rokto khoy oiya juy, rokto barey na.*

⁴⁹ *Amaro thalassaemia achey, taro achey - ejonneyi bacchar hoichey. Daktar koichey beta mansher holiey kuno oshubidha nai, beti mansher oiley bacchar oy.*

However, later on Khaleda said, “We both have problems, it is both our problems that got to our child”.⁵⁰ It would seem that Khaleda understood the situation a little better than Faruq did. Khaleda kept talking about how thalassaemia has four groups. She did not know which one affected her step-daughter, who was a woman about own own age and married with three children). Unfortunately, despite my perseverance, I was not able to interview Faruq’s daughter by his first wife. Apparently this daughter is given saline or blood transfusions on a regular basis. I was not clear which, for Khaleda mentioned she received blood transfusions while Faruq said she received saline.

During one visit Khaleda and Faruq talked about some operation that could be performed for her daughter’s thalassaemia. I never heard about this possibility for thalassaemia before and I am not sure where this information come from. However, they said they were not sure if the operation would cure their daughter.

It is clear that there were various misunderstandings about the cause of thalassaemia for their daughter and about whether and how it might be cured. Khaleda told me that she did not know before that marriage between relatives can lead to having sick children, but she has been informed of this by some medical staff.

Still on the issue of misunderstanding the concept of carrier, I move on to another thalassaemia family. Afsana and Rabi are a young couple with only one daughter, who is aged two. Their mothers are sisters, so that they are first cousins. Afsana was born and brought up in the UK, and finished her schooling. Rabi had also completed 12 years of education in Bangladesh. According to their files, Afsana is a carrier of Hb J. Meerut trait and Rabi is a carrier of Beta Thalassaemia trait; their daughter Asma is a carrier of both Hb J and B. Thalassaemia trait, but is not herself affected. However, there is 50% chance of Asma passing these traits to each of her future children. She will need genetic counselling when she is about 16 years of age and it is important that her future husband is also tested.

Apparently Rabi was initially not tested for anything, but he voluntarily had some tests done, including a blood test, just before they took off for a long holiday in Bangladesh. While they were in Bangladesh, a letter came to their address in the UK and was opened by Afsana’s sister. She phoned Afsana and Rabi to tell them that Rabi had Thalassaemia. I asked Afsana if her sister actually read out the letter to them. She said that she did, but the phone line was bad, and all they could pick up was that Rabi had thalassaemia. When Rabi heard this, he did not know what thalassaemia was, but he thought there was something terribly wrong with him and that he was going to die, and he apparently fainted at the news. They went to numerous doctors in Bangladesh trying to find out about Rabi’s thalassaemia and what could be done. More tests were carried out in Bangladesh, but the doctors found nothing. Rabi said that the doctors did not seem to know much about thalassaemia anyway, and that the news caused them much headache during their stay in Bangladesh.

It was only after they returned to their homes in the UK and went to see their genetic counsellor, who had sent them a letter regarding counselling, that they found out there was nothing wrong with Rabi. He was a carrier of the Beta thalassaemia trait, but is not affected.

However, it appears that they are still confused about what being a ‘carrier’ meant. When I asked Afsana if she was worried about her daughter, she said that she used to be worried, but now that she sees that Asma is doing everything normally, she is not worrying much. Later on she said, “She seems to be OK intellectually. She

⁵⁰ *Duijoneri dush achey, dujionerdush gia baccharey paichey.*

must be OK, mustn't she?" Then she asked, "What would the problem be called when a child of two is quiet, does not talk, or walk, and sits quietly in a corner?". She seemed to be comparing her daughter with another child she knew. Her daughter seemed to have been doing much better and she seemed happy. In this case, Afsana did not really have to worry about Asma for she was not affected, but I found that it was common for mothers of sick children to constantly compare the condition of their children with the condition of other sick children.

Complying with the Doctor's Instructions

Patients did not necessarily follow the instructions that they were given by medical staff. In the case of the four-year-old girl with thalassaemia, her mother once stopped using the pump at night for a week because the daughter had a temperature (*tap*). Consequently her iron level became very high, and the hospital staff told them that Leila has to use the pump every day of the week (Monday to Friday). Without this, her iron level goes up. Her mother said, "When the iron level goes up she does not eat, see how she looks more like a two year old rather than four".⁵¹ So now they have come to terms with this, but in the beginning they used to skip days here and there if the child was not feeling good. The father said that now their daughter will come and remind her mother to attach the pump on her before she goes to bed!

In another case Sabnam, the mother of the child affected by Tuberculous Sclerosis, told me that the paediatrician instructed her to increase the dose of her son's medicine if he has more big fits. Sabnam said that when she does that, Nasim sleeps a lot, and it's difficult to keep him awake. Consequently she does not like giving him extra dose. However, Nasim has continued to get 'big' fits and during their next visit the paediatrician gave strict instruction to increase the dose and pointed out sleepiness was not related to that particular drug. His dose of drug was increased, and now he is a lot better. I was told he has not had any big fits, only very short ones since increasing the dose.

Again, the parents of the child with Cockayne Syndrome occasionally decided to ignore medical instructions not to expose their child to sunlight, especially when they were on holidays in Bangladesh. When I visited them in Sylhet, I saw them placing their son in the lovely wintry sun outside of their bedroom. I asked if this was good for him. His father just shrugged his shoulders. Indeed, the child seemed very happy lying exposed to indirect sun, playing with his hands above him. It was rather cold and dark inside the room. I felt perhaps that the parents had decided that if their son's life was to be very limited anyway, they might as well let him enjoy the little pleasures of life.

A retired Bangladeshi GP also told me that Bangladeshis do not always take doctors' advice seriously. As we will see later in the report, Bangladeshi Muslims were very particular about seeking medical help and also by and large followed their instructions. However, within the socio-cultural milieu of the community, it is common for them to seek help from elsewhere at the same time as they are using biomedicine. Similarly they are also happy to bypass one of mode of healing if they feel that is not working or perhaps hindering the person's wellbeing in other ways.

⁵¹ *Iron bari geley khuy na, dekhon na char bochorer bhaccha dui bochorer moto lagey.*

Risks and Tests in Cases of Recessive Disorders

I came across a number of families where there were children affected with recessive disorders which were planning for further marriages with first cousins. Not only this, but people were rejecting the idea of having blood tests or other genetic tests of possible marriage partners so as to avoid marriage with another carrier of the same gene.

As we have seen the idea of a ‘carrier’ was often poorly understood. There are other issues however involved in these decisions. Thus in one case a woman (Fazeela) reported that her brother was a carrier of Beta thalassaemia, as was their father. When discussing the risk factor of her brother getting married to someone who might also be a carrier, Fazeela seemed very keen that her brother’s fiancée should be tested before marriage. However, I heard later that her brother had gone to Bangladesh and that they would not be asking the fiancée to be tested. Fazeela explained that in order to ask a future bride to be tested, his brother would have to reveal to them he was himself a ‘carrier’ of Beta thalassaemia. As people do not understand the difference between someone being a ‘carrier’ or being ‘affected’, this revelation might be interpreted as him being sick with Beta Thalassaemia. This, of course, would also have implications for the whole family, and the marriageability of other siblings might also become an issue.

In another case, a family where the parents were first cousins and two children had been affected by a recessive genetic disorder were planning another consanguineous marriage. The wife’s younger sister (Hasina) was to marry the husband’s younger brother. Hasina was initially offered a blood test by a visiting genetic counsellor, well before her plan to get married. She told the genetic counsellor she would think about it, but later when I asked her she kept putting it off. Just before her marriage when I asked her again she said, “Is it really necessary to have the blood test?” When I nodded, she said, “Perhaps my husband and I could have the test done together after we got married.”

In a sense, Hasina did not have much to gain from having the test done. The fact is, she was getting married to her first cousin anyway. It had all been arranged and there was no turning back. Hasina was taking a risk by marrying someone who might be a carrier, when she could also be a carrier. But I did not get the feeling that she was at all concerned about this, nor were her parents, or her married sister with two affected children. The genetic disorder in this case was not life-limiting, and can be reasonably well managed. I am not clear whether this was a conscious part of their decision, or whether they simply did not believe that the condition was genetic. For example, when discussed about genetic testing during pregnancy, I was told by both the sisters that they were opposed to it as it was not Islamic. I was also told that, in any case, it was really Allah’s wish whether a child would be affected or not.

In another case, that of a girl affected with Beta thalassaemia, we were discussing whether the parents were concerned about the marital prospects of their daughter. Khaleda said they were worried about Leila’s marriage prospects. I asked Khaleda whether when the time came for Leila to marry, would they tell the potential groom and his family about her thalassaemia? She said, “We have to tell, otherwise there will be problems later”. However, she went on, “Let her grow up, we will see, perhaps we will marry her with a relative or something”.⁵² When I asked if the future groom will be tested, she said that he will have to be tested. I asked whether if she

⁵² *Janani lagbo, nailey porey oshubidha oibo. . . . Boro hoke, dekha jabey, hoyto ba kutumer majheyi biya dimu.*

marries someone from Bangladesh, there were facilities there for such tests? She said that this illness is also there in Bangladesh, implying by this that the tests must also be available.

In this case, Khaleda was concerned that her daughter should not marry anyone who might be a carrier and felt that it was important that the future groom should know of her status before they get married. However, at the same time, reflecting on the fact that there may be problem in finding someone to marry Leila under the circumstances, she thought that marrying her to a relative would be the answer. Thus she was prepared to take the risk of marrying her to a relative, despite the possibility that this might increase the chances of genetic disorders among their children.

People's willingness to take genetic risks in terms of marriage, their opting out of tests and so forth, might be related to the fact that, as we have seen, they do not necessarily accept that consanguineous marriage has anything to do with genetic disorders. It might also reflect the fact that they have a duty to their extended families in Bangladesh and that this gets priority over concerns there might be about possible 'sickly' children. After all, the risk may be seen as not that high. Many of these disorders, although permanent, are not life-limiting or severe, and can be managed pretty well with the help of drugs, blood transfusions and regular medical attention. Many of the children affected with genetic disorders probably would not have lived beyond a few months or a few years if they were in Bangladesh, but the British Bangladeshis are fortunate in that they have access to the excellent health care facilities to look after the sick.

Another important reason, as we have seen with Fazeela's brother, is people's unwillingness to reveal their 'faulty' genetic identity. This might also be an unwillingness to acknowledge that there might be something not quite right which is genetic and which is 'in the family' from way back in the past. Thus a common refrain from many of my interviewees was, "We have never had anything like this in our family before". Another common refrain was that "it is Allah who decides" who is born with a genetic condition and who is not. Together these imply that the family's descent line as such is not at fault.

Here, Armstrong *et al.*'s notion of 'revealed identity,' referring to a genetic identity that a patient is provided with in the process of genetic counselling, is useful in understanding Bangladeshi people's behaviour. Families will avoid if at all possible telling others that their child's problem is familial, hereditary or genetic. Genetic disorders implicate the whole family, both the older generation and younger generation. So, by saying, 'We have never had anything like this in our family before,' people are perhaps trying to protect the unspoiled identity of their family and to treat the child's disease as a one off thing. It is something given to them by Allah to test them, or because He loves them.⁵³

On the other hand, if they accept the genetic counsellors' suggestion, and ask for a potential bride or groom to be tested before marriage, then they are drawing attention to their own spoiled identity, and in the process revealing that it has already been spoiled in the past.

⁵³ See Chapter Seven for the widespread idea that a disabled child is a special gift from Allah.

Reflections on Bangladeshis and Genetic Counselling

Sitting through home visits with the genetic counsellors, I sometimes felt that a family was being offered rather too much information to take in from one meeting. For families with little or no education, it is not surprising that they were confused. Also, on the whole, there is a tendency for Bangladeshis in Bangladesh and in the UK to think that they do not need to understand much, what is important is to follow the instructions. They rely on the medical profession to tell them what to do and not to do.

I feel that this has implications for the preferred Western model of genetic counselling and consulting sessions. Such sessions are supposed, ideally, to be relatively objective, neutral and hands-off affairs. It is not the responsibility of the counsellor, on this model, to tell the patient's family what should be done. As Clarke (1997:9) points out "it is, after all, the clients who will have to live with the consequences of their decisions." Individuals, or individual families are given out all the information, all the questions are answered, and then they are told that it is up to them to decide what they want to do or do not want to do.

This is supposed to be most proper and ethical way of operating in these sessions, but it may not fit well with the expectation of the families of Bangladeshi patients, which is that the counsellor or doctor will take a much more directive role, and will tell them what they should do. I felt at times that families would rather that the counsellors and consultants became more involved in the families' decision-making. With my visits to paediatricians, once or twice I came across statements from them along the lines of "If it was me, I would do this, or would not do this ..." and I felt that the families actually appreciated this kind of frankness.

In Chapter Six, I move from the relationship with the medical profession to another critical relationship for Bangladeshi parents whose children have genetic disorders: the relationship with their own extended family. As we will see, the extended family can be a valuable source of support, but it can also be the cause of many problems and difficulties.

5. The Role of the Wider Family

As we have seen earlier, British Bangladeshis live in varied and complex family structures. Nuclear families are often quite large and may include co-resident children from different marriages. Members of the extended family often live in the same household or within houses that are only a few yards away from each other. Even where they do not, interaction between the nuclear family and members of the extended family elsewhere in the UK may be often much more frequent and intense than is the case for many White British families. In addition, all families have active ongoing link with members of their extended family who are residing in Bangladesh.

British Bangladeshis, like Bangladeshis in Bangladesh, define themselves and understand themselves in relation to their extended family much more than is the case for many White British families. The discussion in this chapter will, therefore, include material on the families in this wider sense, including extended families both in the UK and in Bangladesh. We will see that while people expect to receive support from their families, and often do receive much valuable support, the extended family could also cause many problems for parents, in particular mothers, of children with genetic disorders.

It is important to understand, though, that families can be in very different relationships to their extended family. In Bangladesh and North Indian villages, the normal marriage pattern is for a woman to come to live with her husband's extended family, typically in a different village to her own. The woman is thus an outsider in relation to the extended family. This may be less true in the case of a cousin marriage, in that a woman will typically have some relatives within her new household, but young women are always to some extent outsiders in relation to their husband's family and cannot necessarily rely on it for support. This continues to be the case, to some degree at least, until they have adult sons of their own.

In the British situation, there can be a variety of possibilities, since a woman may be living with or close to her husband's relatives, she may be living close to her own relatives, or she may be within easy reach of both or of neither. The various kinds of cousin marriage also lead to different patterns of relationship between wife, husband and extended families.⁵⁴ In my sample, there were only three nuclear families who, for geographical or other reasons, were relatively isolated from other extended family members in the UK. While several other couples lived in a nuclear family household, all except for these three, had members of their extended family living in the same house, an adjacent house, on the same street or in the same neighbourhood within a few minutes walk.

Many families also had relatives in other UK cities or region, and all had some extended family members in Bangladesh. It is normal for members of the extended family to visit each other regularly, sometimes on a weekly basis but often more frequently. Particularly where retired parents live nearby, they visit almost every day. This can be a good source of moral and practical support for women with sick children.

⁵⁴ Like many non-Western kinship systems, Bangladeshi kinship makes a strong contrast between relatives on the mother's and father's side. For example, mother's brother, mother's sister's husband, father's brother and father's sister's husband all have specific terms rather than being merged into a generic terms such as "uncle". The same is true of other relationships that are grouped together in British nomenclature. All this reflects the fact that these are seen by Bangladeshis as qualitatively different types of relationship, and there are different expectations about how one behaves to, and is treated by, people in each of these relationships.

The few families with no family members living within the locality were at a considerable disadvantage, and had to make do with occasional visits to relatives living in other cities. One or two families did not enjoy good relationships with their extended families, and lacked support for this reason.

Isolated Families

It is not surprising that it is these women in isolated nuclear families who found it most difficult to cope with one, in some cases two, seriously ill children. In most cases, they appeared to receive very little help from their husbands. The isolation of these families also made the women more vulnerable. The men were much more mobile than their wives, and often went out, leaving their wives to care for their children. In times of conflict between husbands and wives in these families, there is no one to intervene, and no support for the wives, and I heard of occasional domestic violence against these women. Marital problems are not uncommon in other families, but the stress both parents have to deal with in caring for one or two severely disabled children makes the women in these families exceptionally vulnerable. It is true of course that men also worry and are anxious for their children. When things get too difficult, however, a husband is liable to put his hands up and say "That's enough, I can't cope any more". It is then up to his wife to carry the burden on her own, including negotiating with various service providers. In one of the families, there were threats of desertion and divorce by the husband during my fieldwork, leading to a formal mediation process, instituted by a fellow Bangladeshi man, as the wife's extended family was in another city.

While all the mothers were anxious about their sick children, and suffered quietly watching their children's pain and suffering, the two mothers who shared most of their suffering and pain with me were isolated from their parents and siblings (who were in Bangladesh in one case, elsewhere in the UK in the other) and also had children with severe life-limiting conditions (Cockayne Syndrome and XP).

One of these was Sufia, the mother of the three-year-old boy with Cockayne Syndrome. She told me several times, "No-one's sickness is as bad as my son's sickness". At other times she would remark, "If only he could walk..." One day, when I was staying with her, she had visits from two of her female cousins, both with two children each. One had twins of about three years of age, the other's children were also about three and four years old. One cousin had come from another city and was staying with her relatives that night.

The four children ran around, ate and made a mess, doing the usual kind of things that children do. When they all left in their cars, Sufia and I went out to say goodbye. When we returned her son, Kiran, had a big vomit and Sufia cleaned up. As we sat down to have our tea together she was teary and talked about how the three of them (she and her two female cousins I had just met) were almost the same age, and how the other two had nice healthy children, while her son about two and half years of age was so sick and would soon die. She said, "This is why my husband does not take me out. Whenever I see other people with children I get upset."

On another occasion, she had been talking on the phone to a 'grandmother' (actually a distant relative), and after she got off the phone, she told me that this grandmother's two daughters had also married their cousins, and they both had good, healthy children, "but our son is so sick." She would often ask me what was wrong with the next patient I was going to see. One night, as I was sitting at my computer, she came into my room looking glum and said, "If only he [Kiran] could walk". Sufia

has been preoccupied with the thought of Kiran not being able to walk or talk ever since I have been seeing her. These two issues kept coming up whenever she had the opportunity to raise these with visiting health staff or when they went to see the paediatrician.

It was clear also that Sufia was constantly asking herself what could have gone wrong and why their son had become sick. For example, one day she told me, “I kept all the fasts when I was eight months’ pregnant, even though the doctor told me [through an interpreter] that I should not fast.” I asked whether her husband had told not told her not to fast, and she said that they had both decided that she would fast for the welfare of the child. She went on, “We thought that Allah would be angry⁵⁵ with us if I don’t fast”. It seems that they did not know that as a pregnant woman she was exempted from fasting in Islam. But Sufia said, “I am only saying this because even though I kept all my fasts and did another extra six days’ fasting,⁵⁶ we now have a sick⁵⁷ son.”

Similarly, Sabina, who had two children affected with Xeroderma Pigmentosum, constantly worried about them. The older sick child (Azim, about fifteen years old at the end of the study) deteriorated drastically even during the twenty months I knew the family. Twenty months ago, he used to be able to say a few words, and although I hardly understood him, his parents did. He used to call me Auntie, and became very cheerful when he saw me. At that stage, he could walk, although with some difficulty, and he bumped into things now and then. He could do things with his hands, and could feed himself, walk to the toilet and so forth, although he needed help with many things such as bathing and sometimes dressing.

Sabina’s daughter Nasima, about seven years old at the end of the study, was less affected. She was fairly independent in most ways, although her speech was unclear, she did not speak much, and she was unable to write her own name. She could walk fine however, though tiring easily, and could use her hands without any real problems. Sabina told me that she felt guilty at not being able to give any attention to Nasima’s needs as she was too preoccupied with Azim’s. He now has to use a wheel chair, and has to be fed through a pipe through his nose every few hours.

Sabina has three other children, all healthy and one only two years old, so she is kept extremely busy with her household chores and looking after the children. Her husband, Anwar, who is also a full-time carer, does the shopping, drives the children to school, and bathes Azim once or twice a week. Lately, he also has to take him to the toilet and clean after him as well.⁵⁸

Azim has been hospitalised several times in recent months, initially after having several falls at school and at home, then for arranging a new feeding arrangement through the pipe and various related issues. After Azim had returned home from the hospital, Anwar was given the responsibility of feeding him three to four times daily, which involved cleaning some equipment each time with a syringe, but apparently he soon became fed up with this and started to get angry with Azim and with Sabina. Sabina then had to feed him for a few days before Anwar decided to take over again.

⁵⁵ *Beraj*.

⁵⁶ Fasting for the welfare of one’s children is a very common practice among South Asian women of all religious communities.

⁵⁷ *Berami*.

⁵⁸ At this age, even mothers are not supposed to look after their sons’ physical needs; these need to be performed by a man. This is the only reason why Azim is taken to the toilet by his father, not his mother.

Ever since I have known Sabina she has been complaining about various aches and pain, specially around her shoulders and back. As she did not feel comfortable discussing her problems with workload at home when accompanied by her husband, she asked me to take her to their GP. On this occasion, she openly discussed her personal problems with the GP, only sometimes needing some interpreting help from me. She told the GP that she does not get any relaxation at home and she realises her shoulder pain has a lot to do with this. She was given the name of a booklet that she could obtain from the local library on how to be assertive with one's partner. Unfortunately, I was not able to obtain the booklet to translate or read with her. However, we had some good discussions of various strategies she might adopt to get Anwar assist her more with her household duties.⁵⁹

These families' situation was often made more difficult by some families' reluctance to take advantage of the services provided by the specialist schools for 'disabled' children, or the respite care services who would take the children away for a few hours or for a family holiday over a long weekend, also organised by the social workers. Usually, the men were opposed to these services. Their reasons included the possibility that the child might be given Western and particularly non-*halal* food at holiday places, and lack of trust that the children would be looked after well by respite carers or at specialist schools.

The Wider Family as Support

Relatively isolated families like Sufia and Sabina's are in a particularly weak position in terms of getting support from the wider kin network. Most families are better placed. Indeed, Sufia did receive support from one of her female cousins immediately after her delivery. Sufia told me that immediately after the birth of the baby, her cousin, Sharifa (Sharifa's mother, Sufia's mother and Karim's mother are siblings) took her to her own house. Sufia and the baby stayed with them for forty days.

Sharifa already had her own twins a few months earlier. Sufia said, "She [Sharifa] showed me everything, how to feed, how to bathe, change and put on nappies". Apparently Sufia's midwife also visited her at Sharifa's house. So Sufia, a woman with no English and very little education from Bangladesh, was totally dependant on her cousin during this period. Her husband of course was around, but this is supposed to be women's business. In fact, Sufia's own brother (twenty years older than Sufia) failed to extend any real help to her. When Sufia's husband asked him and his wife explicitly if they could take Sufia to their house after the delivery, they said they could not, as they were too busy. Sufia's brother's family live some twenty minutes' drive from Sufia and Karim's house. According to Karim, they have not been of any help to them whatsoever, and hardly ever visit them, although Sufia and Karim visit them when they can.

For a contrast with Sabina and Sufia we can look at Ruby, a British born woman, with plenty of family members living nearby. She has had extensive practical and moral support from her husband, her mother and her extended family. Ruby told me proudly that they have a close-knit family. Her parents, her unmarried siblings, and one of her married brothers live in two houses adjacent to her own and they have ready access to each other's households from the back of their houses.

⁵⁹ Interestingly, Sabina told me that she did not want to learn to drive, because she knows that if she is able to drive, Anwar will soon leave some of the outside work to her, including transporting children to schools daily.

Her mother often dropped in to see her grandson Liakot. She had dropped in twice during my visits and I noted how caring she was with her grandson, who also clearly looked forward to her visits. Ruby also had regular visits from other relatives and the family got together once a week, often on Fridays after the *jumma namaz*. Of course they also got together on festivals like *Eid*.

Ruby and her husband took their son for a holiday during the time that I knew them and they were accompanied by Ruby's younger unmarried brother and sister, who looked after their nephew to give Ruby and her husband some time to relax. I have seen some pictures of them all having a good time during their holiday. So it is clear that Ruby received a level of family support much greater than that available to Sufia and Sabina.

In addition to the support of her immediate and extended family, Ruby was also better placed in terms of her education. I felt that this made a lot of difference to the way she coped and handled her son. Unlike Sufia and Sabina, who were full-time housewives, Ruby had a responsible professional full-time job and so found the situation of having to cope with her severely disabled son very trying. Unlike the children of Sufia and Sabina, Ruby's son's disorder (Angelman Syndrome) was not life-limiting. Nevertheless, to cope with a disabled hyperactive toddler was a full-on job and the knowledge that he would never be cured of his condition was no doubt heart-breaking. I was impressed by the way Ruby was coping and handling Liakot's health problems. She was quite lively and not seemingly depressed. She talked a lot about how she would not swap her son for anything. Ruby always looked for positive signs and tried to build on that. She said "He is so lively and a happy child." She also spoke of how things had improved with her son, although the improvement did not seem very evident to me.

It was interesting to have in-depth discussions with Ruby about her feelings regarding her son's illness. She told me that she thought that she needed to think and feel positively about life, because if she was depressed, then her son would pick it up from her. Then she would say, "I have to admit, it is hard work, I am always very busy. Liakot needs a lot of attention all the time. There is no time whatsoever to relax, to read or do anything. I try to do some work [related to her job] when he is asleep." Ruby said she does not like to shut the door and lock Liakot out. She wants to give him time when he is awake.

Sheheli was British-born and while not as educated as Ruby she spoke excellent English and was surrounded by her own near relatives. Her husband came to the UK by marrying her, as did Ruby's husband.

If we compared the situation of Sabina and Sufia on the one side with that of Ruby and Sheheli on the other, we can see how the latter two are much better placed with plenty of support from family members. They also had good education or at least very good English language skills and were in much better position to negotiate the British social and health system. In Ruby's case, her educational background would have enabled her to come to terms of with her son's condition in ways, not possible by the other mothers. By contrast, Sabina and Sufia's lack of education and English language skills were also significant issues, in addition to the lack of support from their husbands in their nuclear family structure. A comparative table may help to highlight the contrast.

Sufia, Sabina	Sheheli, Ruby
UK citizens, but came to the UK either as a teenager or an adult	Both British born
Both first cousins of their husbands, who got their visas through the marriage	Both first cousins of their husbands, who got their visas through the marriage
Neither has good English language skills (one has no English at all)	Both have excellent English language skills
Both have little or no knowledge of how British health and social services work	Both have knowledge of how British health and the social services work
Both full-time housewives	Ruby with higher education and a professional job, Sheheli a housewife
Genetic condition of their children life-limiting	Genetic condition of their children not life-limiting, but Ruby's child's condition is much more severe than that of Sheheli's children
Families in UK in both cases, but in one case in different city, in another relationship not good with her brother	They both had plenty of family members in the UK
They both live in nuclear family set up – away from any family members.	They both lived next door to their own family members.

Table 3: Comparison Between the Four Mothers

In general, British-born women like Sheheli and Ruby who married men from Bangladesh and who lived with or close to their own families could rely on extensive support from their families. In my sample, other British born women such as Sabnam, Sharifa, Razia, Shireen, Afsana, who had their families living in the UK and whose husbands came from Bangladesh, were in a similar position to Sheheli (none of them had Ruby's level of education).

I will briefly consider two other family situations. (1) There were some families where the husbands were born and brought up in the UK and the wives came from Bangladesh. Unfortunately, I did not get to know them closely enough to find out how the couple were faring. Often the husbands dominated the discussion when I was visiting, and it was also these families that kept cancelling appointments, reflecting the decision being taken by the men, more than by the women (e.g. Fahim).

(2) In some families, neither partner had much in the way of English language skills. One couple, Shahanara and Jamil, was a first cousin marriage in which neither partner spoke much English when I knew them, although Shahanara was improving rapidly and her English already seemed somewhat better than that of her husband Jamil, who had had been in the UK much longer than Shahanara. Jamil had come to the country as a teenager with his mother and younger siblings. The couple was living with Jamil's mother and his younger siblings. Shahanara did not complain much explicitly. She said she got along fine with the family "I don't have any problems - it's just like home". Their daughter, who has Barbet-Biedl Syndrome, gets some attention from the other family members.

There were some other families in which husband and wife both lacked English but again I do not have in-depth information about the way they were coping (e.g. Rohima and Majid) However, none of these families had children with severe genetic disorders; these were either carriers of Beta thalassaemia or other genetic disorders which were not life-limiting or severely disabling for children.

The Extended Family and the Question of Blame

Above, we have seen that extended families can be a real source of support for a couple with affected children. However, often it is these same family members who engage in gossip and look for ways of blaming the parents, usually the mothers, for the health problems of their children.

Within Bengali culture, marriage is primarily about reproducing children, and a married woman's main duty is to give birth to children. In Bangladesh, the preference is often for more male children than female children, although within the UK context this preference was not that explicit with my sample.⁶⁰ However, I found that when something goes wrong with the norm of a married woman reproducing children, then the blame is often placed on the shoulder of the woman. Certainly if a couple do not have children, the blame is placed on the woman (see Appendix).

When a child is born with a genetic disorder (or some ongoing permanent illness), the situation may be more complex. Here, the blame may not be placed blindly on the mother, but relatives nevertheless have a tendency to shift the blame on the mother. At the same time, people are equally concerned about safeguarding the reputation of 'healthy' and 'pure' status of their family or lineage (*bangsha* or *gusthi*). This is an important issue, as we will see, when it comes to arranging their children's marriages. Admitting that a brother or sister has a child with a genetic disorder could potentially have a very serious impact on their own children's marriage prospects. As we will see below, concerns of this kind can also underlie people's reluctance to disclose the presence of genetic disorders, including a child being the carrier of a recessive disorder, when arranging a marriage.

For now, I want to show how people within families have a tendency to put the blame on the incoming wife. Here it is important to appreciate that normally in a South Asian marriage the wife's lineage or *bangsha* is different from her husband's, so that she is an outsider from the point of view of her husband's kin group. In a first cousin marriage, the two may be of the same *bangsha*, but this is not necessarily the case since *bangsha* is reckoned through the male line.⁶¹ In the following case study, I show that even when a couple are first cousins, people tend to blame the mother of the child for not having followed appropriate rules and regulations and so laying the child open to supernatural attack. The theme of supernaturally-caused (*upri*) illness will be discussed further in Chapter Seven. For the present, the important point is that if the disorder is seen as caused by *upri* factors, typically as a result of the mother's negligence, the responsibility is twice deflected away from the *bangsha*: the illness is caused by *jinns* (spirits) rather than stigmatising the blood or genes of the *bangsha* itself, and the moral fault which led to the child being vulnerable to attack is that of the mother, not of a *bangsha* member.⁶²

The case study I present again refers to Sufia and Karim, the couple with the Cockayne Syndrome child, Kiran. Recently they went to Bangladesh for the first time since the birth of Kiran, who is now three years old. Kiran was receiving regular medical treatment and the family had already consulted several well-known *maulanas*

⁶⁰One couple in my sample recently had their seventh child, their only daughter. I was told that when they went to *hajj* to do *dua dorod* for their affected son, they, particularly the husband, also asked Allah to give them a daughter. The wife was somewhat embarrassed about having her seventh child and consequently did not have all the initial pregnancy check-ups done.

⁶¹ Thus the groom and bride will belong to the same lineage only if their fathers are brothers or are otherwise members of the same lineage.

⁶² In practice people do not necessarily speak directly of *bangsha*, using expressions such as "her side" or "his side" and their Bangla equivalents, but the implication is present.

(Islamic holy men believed to have healing powers) who were visiting the UK in the hope of finding out what the problem might have been with Kiran. I discuss some of these incidents in Chapter Seven. Here I am concerned with events that took place during their visit to Bangladesh which illustrate some of the family dynamics that can be set off in such situations.

I had the opportunity to visit this family in Sylhet during their visit there and was able to talk to Sufia's mother-in-law, sisters-in-law and other family members who reside in Bangladesh.

Sufia told me that her mother-in-law blamed her for Kiran's illness. The mother-in-law said that Sufia went out shopping, leaving Kiran alone in the house. Sufia's sisters-in-law also told me that there may be 'something in Sufia's family' – for there is nothing on Karim's side of the family.

When I discussed Kiran's problems with Sufia's mother-in-law, she told me "Sufia has problems".⁶³ She meant that Sufia has problems with *upri*, more specifically that *jinn*s had possessed her before Kiran's birth. Sufia's mother-in-law told me that she had sent a silver *tabiz* (amulet) for Sufia to wear during her pregnancy and give to her son after his birth, but she wondered if Sufia had really worn it. "If she had done this, there would not have been any *upri* problem." She continued, "If the baby was with me here, I would have looked after him. I looked after the four children of my eldest son". She mentioned her grandson by her second son, who had been apparently having some health problems. "He has only been saved by many *fu*,"⁶⁴ referring to the practice of blowing (*fu*) over the child while an *imam* or a pious person chants special prayers (*dua*). She also said that Sufia did not breastfeed Kiran either and claimed that when Sufia did housework, e.g. cooking, downstairs, she left Kiran on his own upstairs. All this implied that she had not cared for him properly and so had left him open to supernatural attack.

Sufia's mother-in-law also said that since Sufia had been in Sylhet for her holidays, she had spent some time when Kiran got diarrhoea at her own mother's house. Sufia was always going out, leaving Kiran behind and not paying enough attention to him.⁶⁵ At the same time, Sufia also complained that the servant woman and her mother-in-law did not look after Kiran properly when she and Karim were out.

Sufia's new sister-in-law⁶⁶ also said that *jinn*s first possessed Sufia and that because Sufia had *jinn*s, Kiran has them too: "*Jinn*s blend into the blood and cannot be cured.... This is what happened to Kiran."

Everyone in Karim's household in Sylhet said about Kiran's illness that they had never seen anything like this before. When I asked the elder sister-in-law (*bhabhi*) directly if in Islam it is said that parents' sin is reflected on their children, for example through illness, she said, "People say like this". Then she added, "People say Sufia's brother's son is a cripple, Sufia's son is a cripple. So they say there is

⁶³ *Sufiar dush achey.*

⁶⁴ *Fu dieye dieye takey bachaichey.*

⁶⁵ During my stay for three days with the family, Sufia and Karim twice left Kiran with Karim's mother and a maid and then went out with me. Apparently, Sufia and Karim have done this several times before. Clearly they were taking the opportunity of being home and surrounded by extended family who could keep an eye on Kiran when they went out. This is something they were never able to do in the UK, as they lived in a nuclear set-up. However, Karim's family were critical of this behaviour. They were not critical of Karim, of course, but of Sufia, for as a man Karim is expected to go around.

⁶⁶ Karim's younger brother's marriage had taken place with Karim and Sufia's financial help during their holiday in Sylhet.

some problem in Sufia's family." ⁶⁷ Then she said. "Perhaps when Kiran woke up suddenly with a bad dream, Sufia was not there, then he lost consciousness".

Most of Karim's family and most of Sufia's extended family members are still in Bangladesh. Hence it is understandable that the family reaction and the consequent dynamics came to the fore on their visit to Bangladesh. In the UK they have a few first cousins and some other relatives, but they do not live close to Sufia and Karim. One of their cousins, who had provided Sufia with much support after her delivery, told me, "People say there is disability in the family now that Kiran also has problems." She was referring to Sufia's brother's son's disability. Then she added, "Even I think there is something wrong in the blood in this family."⁶⁸

While Sufia and Karim were in Bangladesh, a divination ritual performed by an *imam* provided an opportunity to confirm suspicions that Sufia had been possessed by *jinns*. This ritual was performed some days before I visited them in Bangladesh so my information is based on accounts given to me by several family members and by the girl who was used as a medium.

The *imam* got a young unmarried girl of about fifteen or sixteen years of age to be a medium between him and the *jinns*. The only ones present during the ritual apart from the *imam* and the girl were Sufia, Kiran, Karim and Karim's mother; all other relatives were told to leave the room.

The *imam* told the girl to sit on a *namaz* (prayer) mat. She was made to hold *tazbi* (prayer beads) on both hands and she was blindfolded. He then did some Islamic *dua*, and asked the girl to say what she could see. He asked her if she could see some *maulanas*, and how many, to which she said she could see six *maulanas*. Then he asked the girl if she could see any sweets, she said yes, they had six boxes of sweets in their hands. She was asked if she could see a park, and she replied that she could. Karim wanted to know if there was a name of the park. The *imam* apparently said, "It is not necessary to ask about the name, there may be problems", but Karim nevertheless asked the girl to see if she could see the name of a particular park in the city where he lived in the UK. She replied that she could see this name.

As a result of this ritual, the *imam* decided that some six *jinns* from the park had possessed Sufia and that there has been problems ever since as a result. He said that it was from the mother that the son was also possessed by these *jinns*. His treatment included doing *fu* (ritual blowing over) for both Sufia and Kiran, offering six kilograms of sweets to the *jinns*, two *tabiz* for Kiran to wear on his neck and hand, one *tabiz* for Sufia to wear on her body, *tel pora* to massage Kiran with, and *pani pora* for Kiran, Sufia and Karim to drink for fourteen days.

In addition he gave them fourteen pieces of paper with *dua* (Islamic prayers) written on them. They were instructed to wrap one piece of paper per day for fourteen days in cloth, dip it in the *tel pora*, burn it in fire, and let Kiran and Sufia inhale the smoke from these. When I visited them they were still using the water and inhaling the

⁶⁷ Sufia has a brother, much older than her, who has lived in the UK for some 35 to 40 years. One of his sons is apparently 'disabled'. I never got to meet him or his family as Sufia and Karim did not feel comfortable about taking me to their house. The relationship between them was not that good. It was never clear to me whether the condition of Sufia's brother is genetic or not. I was told the disabled son of her brother was perfectly normal until he was about seven or eight when he suddenly came down with high temperature, which led to other problems. He is now totally dependent on his parents for his all his physical needs.

⁶⁸ It is interesting that this first cousin of Sufia, to whom she is related through her mother, was readily distancing herself from Sufia's 'family' and 'bloodline' when telling me that she believed there was something wrong in Sufia's family. As Featherstone et al (2006:146) found from their research with White British patients and families, "Individuals' and families' ideas about the biological origin of a genetic disorder are not necessarily congruent with those of a genetic specialist." Yet, as both my findings and Featherstone's findings show, these ideas are very powerful and can, for example, be the basis on which one side of the family holds the other responsible for a problem.

smoke. The *imam* was paid Tk.1500 (£15.00) altogether for sweets, candles etc. The *imam* was going to buy and take the sweets for the *jinns* to a particular spot in the village.

Sufia said that Karim was not in favour of going for the *imam*'s treatment. He does not believe in all this. However, his mother, brother and Sufia took the initiative and arranged for the treatment.

I do not have detailed information of this kind from other families, and as it can be imagined people are not in any hurry to share information of this kind. I came to know this family more closely than most and also had the opportunity to interview the wider family members in Bangladesh as well as in the UK. I assume from my experience and understanding of Bengali culture that such consultations and processes of blaming the in-marrying woman are very common among British Bangladeshi families and their kin back in Bangladesh.



*Fig. 3. Plastic Bottles containing Pani Pora and Tel Pora
(Consecrated Water and Oil)*

Communication of Genetic Information

Here I discuss reasons for non-communication or miscommunication of information regarding genetic disorders of their children between the parents and other members of the extended family. In general, there are at least five factors that may be operating to limit effective communication:

- 0) the parents of the patients may not themselves understand the nature of the disorder, how it works or what carrier status means;
- 0) even if they have some understanding themselves, they may feel that older people (such as the father and mother's own parents) would not understand these things and that there is no point in trying to explain;
- 0) there may be complete denial, or refusal to accept, that the disorder is genetic;

- 0) there may be a belief and insistence that such disorders are given by Allah, and that the results of any medical intervention are entirely dependent on Allah's will;
- 0) there may be the insistence that there has never been anything like this in the family before.

We have already considered several issues relating to the parents' own understanding (point 1) in Chapter Four. We saw there that parents' understanding of the messages of genetic counsellors was often partial and confused. Point 2 is obvious enough, and we will see some examples below. Points 3 and 4 relate to the non-medical modes of explanation to be discussed in Chapter Seven. We have already met point 5, the insistence that nothing like this has happened in the family before.

Points 4 and 5 become particularly relevant when there is the question of communicating a risk factor to a future spouse and family in the context of arranging the marriage of a family member. This relates to people's fear of being identified and stigmatised as a family with some problem in their 'blood'.

Within my sample, many told me that their immediate and extended family, meaning their own parents, their own siblings, their spouse and children all knew about the genetic disorder of their child or children. Sometimes they might say that their aunts and uncles, first cousins, and their children were also aware of the problem. However, when discussing this aspect of sharing information, it became clear that parents did not often give the full story, and in particular might not explain that the problem was 'genetic' (Featherstone *et al.* 2006).

Given that parents often themselves did not understand what a particular disorder really was, and themselves did not accept that the condition was genetic, it is understandable that they would not be passing on such information to their extended family, although immediate relatives, such as parents and sometimes siblings, might be informed. However, even here, it is rare that people really understood and communicated the relevant information about recessive genetic illnesses to their relatives. With recessive disorders, the concept of someone being a carrier is important in understanding how the so-called 'faulty gene' (Clarke 1997) is passed on, but as we saw in Chapter Four, this concept was rarely clearly understood. Thus when I asked Afsana if she told her parents about her daughter Asma being a carrier she said, 'No, they would not understand really'.⁶⁹ When Afsana was in the kitchen making tea, I asked her mother if everything was OK with her granddaughter Asma. I was trying to get a sense of if she knew anything about her being found to be a carrier of trait E and B thalassaemia from her parents. Afsana's mother said "She walks, she talks, everything seems to be OK, isn't it?".

In addition to the problem of lack of understanding of these concepts, there is the issue of stigma associated with making the presence of a genetic disorder explicit. This is another reason why people are quite secretive about what actually is the nature of the medical condition of their child. Thus Sufia, who told me she was given much help by her cousin Sharifa after her delivery, failed to communicate to Sharifa that the problem with their son had been diagnosed as genetic. Sharifa told me, "They never told me anything". She said that she only found out much later, when it was well and truly clear that Sufia's son had some real problem.

⁶⁹ As noted above, Afsana's husband Rabi is carrier of Beta Thalassaemia trait; their daughter Asma is carrier of both Hb J and B. Thalassaemia trait, but not affected. However, there is 50% chance of Asma passing these traits to each of her future children.

Often the way the extended family gets to find out about a special problem with a child is by comparison with other children in the family. If a child does not start to crawl, stand up, walk or talk by a certain age, a relative might ask why this is the case. For example, in the case of a child affected with Carnitine Transporter Deficiency combined with some hearing problem, the father was in Bangladesh and had not seen her for nearly eighteen months. By then, his daughter was three years old and she was still not talking. When the father came from Bangladesh he said, “She should be talking by now, why isn’t she talking as yet?”. At that stage, no diagnosis had taken place for this child. Indeed, it was not until after their second affected daughter died in infancy that some investigation took place and the elder daughter’s problem was diagnosed.

In another family, a child diagnosed with Angelman Syndrome had a first cousin only twenty-one days older. When the extended family got together, they began to compare. Liakot’s aunt would say to Liakot’s mother, “Why can’t Liakot do this or that, my son can”. Often such family gatherings bring into the open the problem that a child might have. Liakot’s mother said that her sisters and other family members now understood what the problem was and that they were very supportive. However, at the beginning, when even she was unclear as to what was going on with her son, she found their comments quite upsetting. Other families also reported upsetting experiences like this, when their children’s disability to perform at the expected level for their age was constantly pointed out by their relatives at family gatherings.

The question of communicating a person’s genetic disorder or carrier status becomes critical when his or her marriage is arranged. In my sample, except for one of the carrier families, all patients were children and their marriage was not yet being discussed. Still I asked people what they were planning to do when the time came. Thus, I asked Afsana and Rabi whether they had thought about their two-year old daughter’s future. When I asked, Rabi agreed that it would be difficult to discuss this issue openly with a prospective groom and his family. This was because people would automatically label Asma as sick and would not want to form a marriage with her. A couple of similar cases have been cited in previous chapters.

In another case, however, Sabina, with two children affected by XP (Azim and Nasima), told me that her brother’s in-laws knew all about Azim. After I had spent some three days attending the elaborate wedding rituals of Sabina’s brother, I somewhat tentatively asked Sabina if her sister-in-law and her parents are aware of Azim and Nasima’s health problems. She replied, “Yes, we took Azim [whose condition is much worse than that of his younger sister Nasima] for a visit to their [sister-in-law’s] house before the wedding and they were very nice to him”. I prodded Sabina further, “Was there any hesitation on the part of the bride and her family on the grounds that perhaps there is something wrong in the family?” She said, “No, you see, we Muslims believe this illness is not caused by people,⁷⁰ but by Allah”. What Sabina was trying to say was that there cannot be anything in the family as such. In my own observation during the wedding rituals, Azim was very much part of the wedding. He was dressed up a like any other boy of his age, and his father fussed about him a lot. At that stage, he was not confined to his wheelchair, but could walk reasonably well. His cousins visiting from Bangladesh for the wedding were very considerate and caring about him.

⁷⁰ *Manusher teuri na*. By ‘not caused by people’ she implied that it was not in the family (gene) or in the blood of people in the family.

This example is interesting, in that the bride and the groom were both born and brought up in the UK, the marriage took place in the UK and not in Bangladesh, and the affected children were on the groom's side, not the bride's side. Given the priority of young women to marry in time while the pressure on men to marry is not as great, this might have influenced the bride's family's decision.⁷¹ Another factor that might have some significance is that, although the marriage was apparently arranged, there was a gap of several months between the time that the bride and groom were introduced to the actual wedding. During this time the bride and the groom got to know each other and seemed to like each other a lot. Thus by the time the bride and her family met and was told of Azim, this was perhaps not taken as seriously as it might have been earlier. However, the point to take note of is how, by shifting the cause of the children's disorder to Allah, the families have avoided entering into discussion about its genetic⁷² origin and the consequent question as to whether Sabina's brother was a carrier.⁷³

Discussion

People's reluctance to share information with future in-laws about their children being a carrier, or being affected by a particular genetic disorder where the affected person does not appear to be disabled as such, has to be understood in terms of marriage being an essential and important rite of passage for all Bangladeshis (Rozario 1992; Chattopadhyay 2006). Also, marriage is not only about two individuals, but about two families. Each family is interested in establishing alliance with another 'respectable' and 'good' family, or better still, enhancing its own respectability and status by marrying into more respectable or reputable family. 'Respectable' and 'good' can be linked to one's class and religious background (also caste in the case of Hindus), which in turn is also linked to people's moral and bodily purity. For example, in relation to kinship system in West Bengal, Inden and Nicholas (1977) argued how in Bengal, the code of conduct of a particular clan or family (*bangsha*) is thought to be embedded in the bodily substance shared by the persons in each clan or family and is inherited by birth. I found that this line of thought also influenced people's choice in the marriage market in Bangladesh. Families look first for other 'good' families, then the individuals (Rozario 2001). People's health status of course

⁷¹ In rural Bangladesh most families marry off their daughters soon after they reached their puberty, at age fourteen to sixteen. In the urban centres and in educated families, girls might marry after they have completed their higher school certificate (twelve years of schooling) and sometimes beyond. But by and large if a young woman is not married by the time she is twenty or older parents start worrying, as extended relatives and the wider community constantly comment: 'When will you marry your daughter? It's getting late'. Here people are concerned about women being able to guard their purity, including their virginity, for losing this would bring great dishonour for the whole family. A pregnancy resulting outside of marriage makes it impossible for a girl to ever find a suitor. It also makes it almost impossible for her sisters, and sometimes makes it difficult for her brothers, to find marriage partners. However, men can remain unmarried until they are aged thirty or over, and their 'purity' is hardly ever questioned (Rozario 2001). Thus, in the few cases of which I knew where marriages of girls had taken place in the UK, most of the girls were younger than twenty when they married. Interestingly, a few girls commented that they do not trust the boys born and brought up in the UK.

⁷² People use the term *bongshagoto*, 'hereditary'.

⁷³ It is true that I might not have been told the whole background story, yet as I have got to know this family so closely and as Sabina confided in me about many intimate stories concerning her difficult relationship with her husband, I feel confident that she would have at least given me a hint that her children's illness was a potential problem for her brother's marriage. But this issue never came up during all the time I spent with her.

is critical here too, for a 'sick' person in a family can mean the 'blood' of the whole family is corrupted and liable to be sick. In Bengali thought, the main bodily substance that people share with each other in a consanguineous kin group is blood. Thus even talking about people's non-health issues, e.g. moral behaviour, one might say the 'blood' of a particular lineage is bad as a way of explaining someone's immoral behaviour. In Bangladesh I also heard things like "it's in her blood" when explaining some sexual 'misbehaviour' by a woman. With serious and on-going disease, purity of blood is of course of more direct concern. It might be interesting to note here that lay English perception of inheritance is parallel to this Bengali thinking about blood, hence people's reference to blood relationships (Richards 1997:189).⁷⁴

Anyway, with the Bangladeshis, disclosing information about the fact that a groom or bride to be is a carrier of something which is actually 'in the family', people would also be drawing attention to the whole family and its potentially 'impure blood', so no one would want to marry into the family. Chattopadhyay (2006), in a study of thalassaemia in West Bengal, discusses whether a West Bengali mother who was arranging to marry her older daughter, a carrier of thalassaemia, would disclose her carrier status. It was clear that the mother's main concern was to marry her daughter even though she appreciated there is always a risk that the groom would turn out to be a carrier as well. When Chattopadhyay pointed out that it might be difficult to hide her carrier status, since a younger daughter had thalassaemia,

she responded that this was all the more reason not to disclose (her status) because having an ill sibling would already put her in a disadvantageous position in the marriage market. If the truth might seal her daughter's fate for good (by not being able to marry), it was a price that neither she nor her husband were willing to pay (Chattopadhyay (2006:2665-6).

Chattopadhyay had more examples along the same lines. The children of my interviewees were still very young so their parents were not faced with that question just yet. However, they knew very well the risk that disclosing carrier status or the actual disorder would mean no marriage, if a daughter, and perhaps not a very suitable marriage, if a son. Women face much greater problems than men at the marriage market within South Asian societies, even without any genetic disorders (Rozario 2001, 1998a).

Chattopadhyay reports how her respondents, like my own interviewees, said things like, "I do not know where she got this disease from! No one in my *bangsa* (lineage) has it" (2006: 2667). Many of my interviewees commented that they do not understand the genetic disorder their child has, as they never had anything like this in their family. Such statements were perhaps a way of showing pride of one's lineage and its bloodline. Chattopadhyay argues that "the stigma associated with it [thalassaemia] is exacerbated because of the cultural interpretation of *Rakter Dosh*" (bad or corrupted blood, 2006: 2667). I have not heard this expression from my British Bangladeshi interviewees, but certainly the implication has been there when they made statements like, "We never had anything like this in our family", or "Something is wrong with the family". They were either guarding the incorruptibility of their blood or stigmatising another family's blood being corrupted.

As we saw from the story of Sufia's ritual divination in Sylhet, the complement to "We never had anything like this in our family" is to blame the trouble on the woman's family, on the incoming wife, who does not necessarily share the

⁷⁴ Richards (1997:189) comments that "there is a common belief that blood donations from those who carry a genetic disease may present dangers for the recipients".

same blood. Whether the *imam* was conscious of what he was doing or not, his diagnosis of Kiran's disease as *upri* had the effect of freeing the family of any *dosh* or fault in their gene or blood and placing the blame on the un-Muslim *jinns*. Moreover, by diagnosing Sufia as having been possessed when she was outside of the house, in or near some park in the UK, the blame was being placed squarely on her shoulder, for not behaving as a proper Bangladeshi *pardanshin*⁷⁵ wife should. Streets are public spaces, part of the men's world, and parks with lots of trees are places which attract bad *jinns*.⁷⁶ In her recent research with Sylhetis in Bangladesh, Alyson Callan sees many of the 'sorcery' rituals (similar to the *upri* rituals discussed above) as face saving mechanisms (Callan 2007). I would argue that while Karim's family was interested in finding out a cure for Kiran, they were also going through the exercise as a way of saving their 'face', that is, safeguarding the status of their family as not sick, so that they could continue to claim that there was no fault 'in their family'. Although, in private, Sufia's sisters-in-law blamed Sufia's family, saying that there was some serious disease in her family, and pointing to her brother's son's serious health problems, in public they all talked of *upri* or *jinns* as the cause of the problem.

Scholars working with Pakistani families, whose practice of consanguineous marriage is much more extensive and routine than that of Bangladeshi families, have argued that families readily shared information with relatives (Amra Darr 1997). However, as I have discussed above, even with families where the couple were consanguineally related, communication between family members were not necessarily very open. Similarly, my material contrasted with Naddem Qureshi's (1997) findings with Pakistani families, in which in-married wives with affected children received support from their mothers-in-law because they are, after all, also their aunts. Modell (1997) too noted that a woman who marries her cousin has blood ties in her own right with her mother-in-law or father-in-law and therefore is well placed within that family. Thus, for these Pakistani wives, being away from their own parents and siblings was not a real problem. Again, in my limited sample, I found that while this might be the case with some families, in others it was definitely not. Bangladeshi family patterns appear to be fairly varied and the situations which women find themselves in depend on a variety of factors, including nuclear or extended family living arrangements, whether one is living with one's own parents, is educated or not, has English language skills or not and so on. I found that, as in the case of Sufia's child's illness and Sharifa's childlessness, there is a tendency even in cousin marriages to place the blame for anything that went wrong to the woman and her side of the family. Thus it is by no means always the case for Bangladeshi families that cousin-marriages provide support to women. Admittedly, in my examples, the consanguineally-related wives who had been having difficulties were actually living in nuclear family households, not with their aunts or in-laws. However, in both examples, the women faced much criticism and blame from their husbands' families when they visited them in Bangladesh.

In my sample, the cousin-marriages in which the women had support from their wider families were those where women were born and brought up in the UK, were living with or close to their own immediate families, and were educated, or at

⁷⁵ The term refers to women dressing and behaving modestly, covering themselves up when they have to go out and refrain from hanging around parks and streets.

⁷⁶ Two women and a number of imams pointed out that bad *jinns* cannot enter places or households where people keep their fasts and say their *namaz* regularly. The implication would be that the parks and streets are fair game for bad *jinns* while households where people generally pray and fast are relatively safe.

least had fluent English skills as well as a knowledge of the way British health and social system operated. Thus Ruby and Sheheli enjoyed good relationships and they were not blamed, but Sufia and Sabina's situation was the opposite. Sharifa (see Appendix), was a British-born woman, but her parents were not alive, her brothers were settled with their own families, and she was living in a nuclear set up with her cousin husband. She had control over her immediate family situation, but was constantly blamed by her husband's family and community members for not being able to have a child.

Consanguineous Marriage and its Prevalence

In my findings, cousin marriages were very common. Most couples in my sample (14 out of 20) were first cousins.⁷⁷ Outside of my sample, from my discussions with members of the Bangladeshi community in the two cities, it was evident that there are significant levels of marriage with cousins or other close relatives. In addition to the pragmatic need to sponsor a relative to the UK, there is also the issue of family solidarity and the need for the two families (bride's and the groom's) family to get on, for them to share similar values and understanding. Cousin marriages can be seen as a convenient way to achieve this.⁷⁸

In one case, a young woman was preparing to marry her first cousin, the younger brother of sister's husband. Her sister and her husband had two affected children, and another had died from Carnitine Transporter Deficiency, but this fact did not in any way influence the family against another marriage taking place within the same family. The issue of testing came up only when I asked, and the bride-to-be did not seem to be interested or concerned as such. There is some parallel here with Alison Shaw's findings about British Pakistani families. Shaw's interviewee, Shamima, who had several children affected with a serious genetic disorder leading to their death, was not deterred and was planning to marry her daughter to some relative (2000:100).

Another reason for cousin marriages can be found in the stigma of genetic disorder and the consequent difficulty in families finding a suitor outside their family. Thus, as already shown in an example above, the mother of the daughter affected with Beta thalassaemia thought they could at least marry her with a relative. However, she also thought that she would disclose the problem and have the groom tested. One other mother with an affected son indicated that although they did not anticipate any real problems in marrying him, there was always the option of marrying him to some relative.

For reasons mentioned above, men affected with genetic disorders are likely to face less of a problem than women in the marriage market, especially if the condition is not really severe and the disability not very obvious. Generally, if people can get

⁷⁷ In one case at least, the older brother of the bride was initially opposed to the marriage of his sister to their mother's sister's son. Apparently he was concerned about potential problem with children.

⁷⁸ A British-born woman told me that in their family there have been cousin marriages in her parents and uncles' generation but no cousin marriages in her generation. She thought the incidence of cousin marriages was now decreasing. When I suggested that people mainly engaged in cousin marriages to bring people over from Bangladesh, she agreed, but said that "Cousin marriages are also very safe – knowing who the people are, you know what to expect". This came up after we discussed problems with her brother's marriage only two months before. She also mentioned that one of her sister's marriage did not work out due to incompatibility between the couple and the two families, leading to her divorce. So she was implying perhaps that cousin marriages at least did not have these problems.

away with hiding disability or genetic disorder during marriage, they will try to do so. Thus I have been told a story whereby a severely disabled UK Bangladeshi man in his forties was married to a young girl from Bangladesh. The woman telling me the story said that, “The poor girl’s only role as wife became one of full-time carer of her husband”. I understand the man was later institutionalised. In this case, it would seem that the prospect of coming to the UK may have influenced the parents to give their daughter into marriage to this disabled person.

Thus the tendency for the families who have been affected by some recessive genetic disorder, and who are already married with cousins, is to plan further cousin marriages for their young siblings or for their children. This suggests that either (1) they understand what is going on but prefer to take precautions in terms of testing the future partner, or at least having appropriate prenatal tests (amniocentesis) done when the time comes; or (2) they do not understand the real significance; (3) or they do not believe what the geneticists say to them.

My discussions about consanguineous marriages with people who were not affected might be helpful in getting an insight into people’s way of thinking on this issue.

One of the educated *imams* whom I interviewed told me “From our religious perspective we do not agree with the scientific explanation that cousin marriages result in handicapped children.”⁷⁹ He then went on to talk about how there were so many white disabled people and said this was because “the girls slept with some street people”. So, for him, the existence of a genetic disorder was Allah’s wish, or to do with non-appropriate sexual behaviour, and in any case nothing to do with cousin marriages. All other *imams* whom I interviewed also said that consanguineous marriages were allowed in Islam. However, most of them and most of my sample also did not see any link between cousin marriages and genetic disorders and mostly referred to Allah’s Will in all this.

I asked a British-born woman, Suraya, not in my sample, about her or her family’s views on cousin marriages. I was asking about people’s reaction to the British MP Ann Cryer’s campaign in late 2005 against cousin marriages among British South Asians.⁸⁰ Suraya said, “They think that if they are willing to marry their cousins, it should be up to them who they marry. Even in this country people [referring to British born Bangladeshis] marry their cousins.” When asked what people think about the risks of marrying cousins from the point of view of genetic disorders, she said that people would give examples of other related married couples (cousins) with completely well children, so “why so much fuss?”⁸¹ Citing the example of someone we both knew, who had married her cousin and had two healthy children, Suraya said “at the end of the day, it’s up to Allah”.

Suraya, who was part of a focus group discussion with me on perspectives on cousin marriages and genetic disorders, told me that after our focus group she had raised the topic with her aunt and uncle who were related as first cousins. They were not convinced that cousin marriage makes any difference to children being sick or

⁷⁹ In Bangla, what he said was “*Sciencey jey boley cousin-marriage korley cheley meye handicapped hoy, dharmiyo dik thekey amra agree kori na*”.

⁸⁰ See e.g. <http://news.bbc.co.uk/1/hi/programmes/newsnight/4442010.stm>, story from 16 Nov 2005, downloaded June 2007. I am grateful to Angus Clarke for prompting me to raise this question with my interviewees, since it elicited some interesting responses.

⁸¹ Suraya apparently got to know a couple (non-Sylheti) who were cousins, and who kept losing their babies, through still-births or in other ways. This was “a highly educated couple”. Later she found out that cousin marriages may give rise to problems with children.

well. They gave the example of her uncle's brother, who married someone who is not related to him, but had a child who has thalassaemia.⁸² She ended by saying, "What can you say then? People always have examples." Such reactions on the issue about consanguineous marriages reflect most people's misconceptions about how recessive disorders work, and their lack of awareness that these disorders can appear with children of both related and un-related couples.

However, some of the young women whom I interviewed seemed to be taking on board the fact that cousin marriages pose potential risks, although they may not be clear how and why this can be a risk. One young woman, Nabila, told me that her first cousin married another first cousin (*chachato bhai*), and that they could not have any children. This was apparently put down to genetic issues by a genetic counsellor. Nabila said that since then, "We as a family decided that we will not arrange any marriage with relatives". When asked about who within the family decided this, she said that her parents do not see cousin marriages as a problem for they might say "why, people have always married cousins, what's the problem?" It is really her generation who have decided that they would not marry cousins. She said that she has also read Islamic books on cousin marriages and is aware this practice is permissible by Islam. However, interestingly, she added that people are instructed to have their partners tested before marriage.

Rohima, who married her mother's brother's son, had triplets, one of which died at the hospital after some weeks while the other two had numerous health problems. I asked if she had heard from anyone that perhaps 'cousin marriage' was the cause. Rohima said that she had never heard that cousin marriages lead to any problems until Nabila, a Bangladeshi social worker, mentioned this to her. "I know so many other families like ours [e.g. couples who are first cousins], but their children have no problems. Now there will be no more marriages with relations."

As we have seen, a regular theme among the families I knew was an unwillingness to fully accept genetic explanations for their children's disorders. In the final chapter, Chapter Seven, I look in more detail at the non-medical explanations for genetic illness and how these affect the ways in which the families in my sample thought about illness and how they dealt with their children's disorders.

⁸² This family live in Bangladesh.

6. How Do Bangladeshi Families Understand and Respond to Genetic Disorders?

This last chapter of the report brings together many of the issues which have been discussed in the report so far to illustrate how Bangladeshi families understand and respond to genetic disorders.⁸³

This chapter is based on a single extended case study of a family who have already featured extensively in the report so far, that of Sufia and Karim and their young son with the severe life-limiting disorder Cockayne Syndrome. I will supplement this with data from other families, when necessary, to analyse people's understanding and coping mechanisms, and the kinds of assistance they seek as appropriate for their children.

I will show how the families distinguished between illnesses as either medical (*daktari*) in nature or as something caused by *jinn*s or spirits (*upri*). Although *upri* problems can generally be treated only by *imams* or other spiritual practitioners, and medical problems by doctors, in practice there is no sharp dividing line between these, and both kinds of treatment may be pursued for the same disorder. I discuss the treatment people receive from *imams* and the various other Islamic practices they engage in for the welfare of their children. Finally, I discuss the role that families attribute to Allah in deciding and giving a genetic disorder to a particular child, and consider their faith (*iman*) in the ultimate power of Allah in relation to the power of *jinn*s, *imams*, and medical treatment in curing a genetic disorder.

I came across references to *upri* in relation to problems of genetic disorders very early on during my field research with British Bangladeshi families. Initially I did not know what people meant by *upri*, even though my research in rural Bangladesh had made me very familiar with people's routine association of particular health problems with *bhut* (i.e. evil spirits) (Rozario 1998c, 2002b; Spiro 2005; Wilce 1997, 2004; Blanchet 1984; Islam 1980). Very soon I realised, that *upri* is parallel to *bhut* and to another term used in rural Bangladesh, *kharap batash* ('bad air') and like them referred to illnesses and problems caused by malevolent spirits. *Upri* was used particularly by the British Bangladeshis, who came largely from the Sylhet region of Bangladesh. Rather than *bhut*, the standard Bangla term for evil spirits, Sylhetis tended to use the Arabic-derived term *jinn*, but their ideas about these spirits were very much the same as those I was familiar with from rural Bangladesh in relation to *bhut*.

In rural Bangladesh, people associate such problems as children's diarrhoea, young women's white discharge, children getting scared, excessive crying of babies, or babies not breast-feeding, with *bhut* and sometimes with *nazor* (evil eye) (Bhopal 1986). We will see from my examples below that this was very much the case with British Bangladeshis as well. However, in addition to all this, many of my interviewees also considered *upri*, i.e. interference of *jinn*s, perhaps through the blood or something, as possibly underlying their children's illnesses, although these had in most cases already been diagnosed as genetic disorders by the medical personnel.

⁸³ An earlier version of some of the material in this chapter was given as a seminar paper, 'How British Bangladeshi Families Understand Genetic Disorders: Daktari Problems and Upri Problems,' to the Cardiff-Cambridge Genetic Discussion Meeting, Centre for Family Research, Cambridge, and the Institute of Medical Genetics, Cardiff, in July 2006. A revised version was presented at the Biennial Conference of the European Association of Social Anthropologists in Bristol, September 2006, and to the Medicine and Society Research Interest Group, Social Sciences at Cardiff University, October 2006. I thank all those who provided comments on these occasions.

Bangladeshis generally believe that illnesses caused by *bhut* or *upri* cannot be cured by medical doctors, but have to be dealt with by traditional folk-healers or religious leaders (*imams*). In this chapter, I discuss how patients' families dealt with their anxiety that *jinns* (i.e. *upri*) might have caused their children's genetic disease. We will see that families did not choose between medical treatment, religious or other folk treatment. Rather, they usually sought medical treatment side by side with treatment from *imams*, and sometimes from other sources as well. Such behaviour is quite a common occurrence in Bangladesh itself, as well as South Asia in general and other such situations of medical pluralism (Nichter & Nicheter 1996; Connor & Samuel 2000; Rozario and Samuel 2002, Rozario 1998c). However, the point to emphasise here is that to my interviewees there was no real conflict between religious forms of healing and medical (*daktari*) treatment. That is, there is no sharp dividing line between *daktari* and *upri* problems, and families will use a combination of ways of understanding and attempting to remedy their children's condition.

Introduction: Kiran and His Family

I was introduced to this family early in my study by a local genetic counsellor during her home visit. I visited them regularly and was often their overnight guest on my inter-city trips. Thus I got to spend a lot of time with both Kiran's parents, and was able to take part in some of their regular activities such as shopping and visiting other families. Kiran's mother (Sufia) and father (Karim) are first cousins. They are both relatively new migrants to the UK, Karim having been here eight years and Sufia four years.

Kiran suffers from Cockayne Syndrome in what I was told was a moderate to severe form. At the time when I first met the family, Kiran was close to two years old and he has never been able to walk or talk. His hearing was also very limited. In the time that I have known the family, for over a year, his condition has deteriorated and his weight has hardly increased. At nearly 3 years of age, he is the size of a normal one-year-old baby.

The Genetic Diagnosis and Treatment of Kiran's Condition

Depending on the particular problem, most British Bangladeshi families confronted by a health problem initially look to the medical system for a solution. Religious factors may not necessarily be central at this stage. Here I discuss in brief the history of Kiran's diagnosis as suffering from a genetic disorder.

When Sufia was pregnant with Kiran, her first child, she had a check up at three months, then at six months, and a scan at nine months. Sufia said, "They [medical staff] didn't find anything."

Karim told me the story of the diagnosis. "From day one Kiran started to vomit after feeding and also at other times. The midwife, the GP, all said that the baby was OK, it [vomiting] is normal for newborn babies. Then when the baby was three months old, the GP prescribed some 'baby Gaviscon'. Then when Kiran was about six months old his milk was changed from Cowgate [which Kiran was fed since he was about one week old] to some other milk." When I asked about breastfeeding, Sufia said that she could not breastfeed as Kiran was not sucking properly. Some gadget was given to her to express breast milk for feeding him, but Sufia gave up after a few days.

When Kiran was about one year old, apparently an MRI scan was carried out and it revealed some abnormality. Karim said, "From then on every month, or every

two months, the health visitor kept coming to our house, showing us how to feed the baby and all that.⁸⁴ The baby's weight would be taken regularly, but his weight increased very little. We were told, 'Sometimes this happens.' Then an ECG was done when baby was about fourteen months old, which was apparently normal. Then they did a hearing test in the computer, they couldn't find anything in the computer. We had to take him twice, the first time they could not conduct an effective test because they said, 'The baby has to be deep in sleep'. The second time the baby was deep asleep, but even then they couldn't find anything. The test was repeated, still no result. After that, there were no further tests." Karim and Sufia think that Kiran's hearing is getting worse.

Karim explained that because of Kiran's Cockayne Syndrome, "he may have many other health problems - brain problems, problems with everything. He cannot walk or talk." Then he told me how Kiran had been hospitalised several times for complications.

During my first visit, when I accompanied their genetic counsellor, I learnt that the parents had only received the unfortunate news of their son's life-limiting condition a few weeks before, in other words when Kiran was around 18 months old. When I was with the genetic counsellor, she explained to Karim and Sufia that with each birth there was a 25% chance of them having their child affected with Cockayne Syndrome. Karim found this difficult to understand, so the genetic counsellor drew up pairs of genes for the parents (one damaged, the other fine for each) and explained the four different combinations which could be passed on to a child. If the child had a damaged gene from one side, it would be unaffected, but would be a carrier; if it received the damaged gene from both sides, it would be affected with Cockayne Syndrome. This seemed to make sense to Karim. Although I was not sure that he really understood the concept of a 'carrier'.

The genetic counsellor also explained that if they planned to have another baby there were tests available during pregnancy to ascertain whether or not the foetus was affected by the same condition. She emphasized the importance of them contacting the relevant medical staff as soon as they knew of Sufia's pregnancy. Then when Sufia was about nine weeks' pregnant, a scan would be done (dating the pregnancy). The test (amniocentesis) to check if the foetus was affected by CS would be done exactly at eleven weeks. Further the genetic counsellor explained the procedure involved in the test (amniocentesis) and the 1 to 2% risk of miscarriage associated with it.

While Sufia was taking very little notice of what was being explained, Karim was clearly very concerned that the timetable of the tests was such that the amniocentesis result would not be available within three months of pregnancy. His understanding was that in Islam one was not allowed to terminate foetus after three months pregnancy. The genetic counsellor explained that as far as she knew in Islam one was allowed to terminate foetus within the 120 days of pregnancy, i.e. four months. At the same time she advised Karim to check with the *imam* at the Central mosque, the Shariah Council or his local *imam* about this. Karim was surprised to hear about the 120 days limit but seemed to accept the genetic counsellor's explanation. When I asked a few months after, however, Karim still had not checked with any Islamic authorities, even though they were now planning to have a baby. Much later he told me that he had checked with an *imam* who had said that if the

⁸⁴ From the beginning Kiran has been fed through a special feeding machine, pumping the milk product through a thin tube to Kiran's nose.

mother's condition was so bad (Sufia suffered from depression) then it would be fine for them to terminate a damaged foetus.

During my first few visits, Sufia was not interested in another pregnancy. She seemed to be overwhelmed with the day to day routine of cleaning up after Kiran's vomiting, taking Kiran frequently to various health professionals, cooking, and cleaning. She would also feel anxious that something might go wrong with Kiran when Karim was at work during the evenings.⁸⁵ Sufia's English was non-existent, while Karim spoke reasonably good English, so she had to rely on her neighbour, a British-born Bangladeshi woman, if an emergency happened when Karim was not in the house.

On top of all this, Sufia had developed problems of depression since her pregnancy. When the genetic counsellor was there, and also afterwards, Sufia kept saying that she already had problems with depression, she could not cope with her present sick child, and that the tests would be too much of a hassle. She was not interested in having more children or in having any pregnancy tests.

I also had the feeling that Sufia was still unclear about the nature of her son's condition and that it was a life-limiting condition. She was hopeful that Kiran will get better and she kept asking the genetic counsellor and subsequently the paediatrician, "Will he [their son] ever speak? Will he ever walk?" Karim, by contrast, has been interested in having another child from the beginning, but was concerned about Sufia's depression. However, over the last nine to ten months Sufia changed her mind and the couple began to plan to have another child. Initially they told me that they planned to get all the pregnancy tests, including amniocentesis, done. As we will see, they later changed their minds about this.

During my first visit, Karim said spontaneously both to the genetic counsellor and to myself that their son was "God's gift". During my subsequent visits, he repeated this many times, and I will discuss this later on.

Karim and Sufia were on the whole reasonably satisfied with the medical treatment with which their son was being provided, e.g. through the community nurses, dietician, paediatricians and so on, although they had some discontents with their local GP and with the hospital where Sufia delivered her son. They were very meticulous about keeping all the medical appointments and seemed to have accepted the medical (*daktari*) diagnosis given for Kiran. However, despite the fact that their child was under continual treatment by the UK medical system, Karim and Sufia also sought religious treatment for him, and as we have seen have now decided to trust in Allah rather than biomedical testing in relation to a possible further child.

Upri, Nazor and Treatment

In many cases, British Bangladeshis will assume from the nature of the problem that *upri* ('supernatural') factors may be involved. In Islamic terms, this involves the action of *jinn*s (spirits) and families will look to a specialist in *jinn* (who may be a Muslim cleric, *imam*) or an independent specialist) for assistance. If the specialist confirms that *jinn*s are involved, *upri* treatment may go on in parallel to *daktari* treatment.

In Karim and Suzia's case, some of these issues had already come up shortly after the birth, as a result of Suzia's inability to breastfeed Kiran, who would not

⁸⁵ Karim worked in a restaurant and was away from home from 3.30 pm till nearly 1am six days of the week.

suckle properly. She said, “People talked about *nazor*,”⁸⁶ meaning that the baby was subjected to some evil eye or *nazor*. So Sufia saw a Bangladeshi woman who did a *dudh pora* for her (consecrated her breast milk). For this problem they also brought *pani pora* (consecrated water) and *tel pora* (consecrated oil) from another *maulana*, but none of this succeeded in getting Kiran to breastfeed.

As Karim and Sufia were waiting for the medical diagnosis for Kiran’s illness, and even after a medical diagnosis was provided, they pursued other non-medical causes and treatment for their son’s illness. First they went to see a *maulana* visiting the UK from Malaysia. It seems that this *maulana* told them that some *jinn* had possessed Kiran because his father wanted to make him a *Qur’an-e-hafiz* (one who knows the Qur’an by heart).⁸⁷ He gave them a *tabiz* (amulet),⁸⁸ *pani pora* (consecrated water) and *shuta pora* (protective cord). They were charged some £60 for all this. Also Sufia said they gave him some of their brand new clothes. She said, “I thought, it’s all for my son.” They used the protective cord for a little while around Kiran’s neck, fed him some of the water and also used it to bathe him. However, his condition did not improve.⁸⁹

Karim told me they also went to see another very well known *maulana* who was visiting the UK from Bangladesh. This *maulana* said that Kiran’s condition was nothing to do with *jinn*, but that “it is a gift from Allah, Allah is testing you.”⁹⁰ He added, “This illness is *neyamot* (a special favour from Allah),” and added, “Do not take notice of what doctors say about Kiran’s *hayat* [how long he will live]. Only Allah knows what his *hayat* is.”

Karim added that *maulanas* and also lay people say that sinless patients like Kiran can deliver *dua* (prayers) to Allah on behalf of others. So when someone goes visiting such a sick person, one might ask him to say *dua* to Allah for him or her. This *maulana* also gave him some consecrated water, oil etc. They used the water in the usual manner, and the oil to massage Kiran with. Apparently, the outcome of their consulting this Maulana was that the *maulana* put down Kiran’s condition in the realm of *daktari*, not *upri*.

I have already told, in Chapter Six, the story of Karim, Sufia and Kiran’s visit to Bangladesh, and the divination ritual that was performed for them on that occasion, which led to Kiran’s illness being attributed to *jinn* from a park near their house in the UK, and to Sufia being blamed for leaving him open to attack by the *jinn* through her neglectful behaviour.

⁸⁶ *Mainshey koichey nozor laigzey.*

⁸⁷ He asked if I knew that a *Qur’an-e-hafiz* can take ten *dujogi* (people in hell) people to heaven (*behesto*) by requesting Allah. Perhaps these bad non-Muslim *jinn*s did not want to lose ten people from hell and hence the attack! Karim said that in the UK many men become *Qur’an-e-hafiz*; they usually memorize the whole Qur’an. A person who can also explain the Qur’an in Bangla (in addition to memorizing it in Arabic) is called *Tafsiri Qur’an*.

⁸⁸ One night when Kiran’s jacket was taken off, I noticed two *tabiz* hung on a square flat brass holder which had Arabic prayers written on it.

⁸⁹ A couple of months ago, I learned that Karim and Sufia also called this Malaysian *maulana* after he had returned home from his UK visit. He had told them to call him if the treatment he had given them did not work. When they called him, the *maulana* apparently did an *upri* divination ritual over the phone. For this ritual, the child had to be left alone in a room for ten minutes while the parents waited outside the house. Sufia was apparently scared in anticipation that the bad *jinn* would come out of the house after leaving Kiran.

⁹⁰ I asked Karim in what way Allah was supposed to be testing him. He replied, “How we are taking it, whether we are still calling on Allah, whether we are happy with Allah or whether we are blaming Allah.”

Ideas of *upri* and *nazor*, and the use of various consecrated items to counter them, were very common among the other families I interviewed and who had children affected with genetic disorders. This did not mean that these families neglected biomedical care for their affected children. My interviewees were meticulous about seeking medical treatment for the genetic conditions of their children. They accepted, by and large, that the genetic conditions of their children were ‘medical’. Many of them too were aware that Islam not only allowed but required them to pursue medical treatment for their children. I was told by several parents that it is *faraz* (obligatory) in Islam to seek medical help for illness.

However, for on-going, severe, and life-threatening health problems, most families, like Karim and Sufia, also considered the possibility of their child’s condition being caused by *upri* or evil *jinn*s. For example, the grandmother of a toddler affected with a severe genetic disorder, a condition which is explained in terms of translocation of chromosomes number 15 and 4, told me that perhaps *jinn*s have interfered with the child’s blood. In my presence she told her daughter to take the child to a well-known *imam* of her acquaintance, so that he could check if *jinn*s had anything to do with her grandson’s problem.

Many common health problems may be explained in terms of *upri* or *nazor* or ‘evil eye’. *Nazor* literally means ‘sight’; the idea is linked to envy and jealousy, and it is thought that people can cast an evil eye (*nazor*) without being aware of the power of their *nazor*. Thus, a seemingly innocent comment or praise about a child’s good looks, can lead to its diarrhoea or something. A childless woman might feel envy about another woman’s newborn baby.⁹¹

Problems caused by *nazor* include stomach problems and vomiting, excessive crying of babies, refusal to eat and so on. Illnesses considered as *upri* include psychiatric problems, diarrhoea, abdominal pain, scary dreams, excessive crying of babies, refusal of food by a baby or child, chest pain etc. All these can also be related to *nazor* (evil eye) and it is not easy to make a distinction between *nazor* (where a person might have voluntarily or involuntarily cast an evil eye) and *upri* (evil spirits) related illnesses.

One measure used commonly by British Bangladeshis to ward off both the evil eye (*nazor*) or evil spirits (*upri*) is a black thread tied around a child’s neck or waist. In Bangladesh people often place soot on a child’s forehead. Elsewhere in South Asia, eyes are often blackened and black thread worn on the wrist or the body to ward off these dangers (Spiro 2005; Teerink 1995: 98-99).

Among my British Bangladeshi Muslim interviewees the belief in *nazor* was strong and many (80% of my sample) obtained *tabiz* for their children to ward off *nazor* as well as evil spirits.⁹² Children’s stomach problems in particular were often attributed to *nazor*. In addition to Sufia, whom I discussed above, two other interviewees mentioned having *dudh pora* done. One of them said her baby stopped drinking his whole bottle of milk for some days and they thought it was because of

⁹¹The idea of *nazor* (*najar*, etc) is widespread among populations of South Asia, the Middle East (including North Africa) and Southern Europe. “The evil eye is fairly consistent and uniform folk belief complex based upon the idea that an individual, male or female, has the power, voluntarily or involuntarily, to cause harm to another individual or his property merely by looking at or praising that person or property” (Dundes 1981, quoted in Bowie 2002:236). Alyson Callan (2007) found from her recent research with Sylhetis in Bangladesh that *nazor* was commonly thought to be the cause of many minor physical illnesses.

⁹² I also found in my earlier research in Bangladesh that Muslims routinely obtained a series of *tabiz* from *imams* or local healers for the same purpose (Rozario 1992).

nazor. Many of my interviewees also obtained consecrated black threads from the *imams* to tie around a child's waist or neck to ward off evil eyes and evil spirits.

Whatever the case, it is common for families to consult an *imam* or traditional healer in relation to other illnesses which are not necessarily categorised as *upri*, and for which they are already receiving medical treatment, to check if *any* evil spirits (*upri*) or evil eye (*nazor*) have anything to do with the health problems. This especially happens with on-going medical problems. This, together with the incomprehensibility of the nature of genetic disorders, might explain why most of my interviewees, in addition to seeking medical treatment, also consulted someone to ensure that *upri* was not the cause of their child's condition.⁹³

Of course, if it is believed to be *upri* one has to seek help from a reputable *imam* or traditional healer. So while they continued medical treatment, most families consulted one or more *imams* to check if their child's condition had anything to do with *upri*. In most cases, *imams* declared the condition was not *upri*. There have been cases, like Kiran above, when *imams* declared the condition to be caused by *upri*. Whether a condition was declared as linked to *upri* or not, *imams* usually gave some protective measures for all their clients to engage in. Typically, these included giving amulets inscribed with some special Qur'anic words, performing the ritual of *fu* or blowing on the child, giving consecrated thread for the child, and sometimes the mother, to wear on their bodies, giving consecrated water to drink and consecrated oil to massage).

An elderly woman told me

There are *jinn* with some people. There are good *jinns* and bad *jinns*, and bad *jinns* pick on people, cause harm and distress.⁹⁴ *Jinns* can cause someone to become *pagol* (mad). It can happen in your everyday living, you can step on the *jinn*.⁹⁵

When discussing *nazor* with the same woman she said to me, "Some people's eyes are good, some people's eyes are bad." As evidence, her daughter (the child's mother who was born in the UK) proceeded to give an example of how once her son had stopped eating when on holiday in Bangladesh and the problem was diagnosed as *nazor*. A female healer rubbed a dry chilli on her son's stomach and then burnt it on fire, when no pungent smell came off burning, indicating the presence of *nazor*.⁹⁶ The child's mother told me that after the female healer left, she burnt another dry chilli on fire and it gave off a really pungent smell, making her cough for a few minutes. This experiment made her believe her son was afflicted with *nazor*.

A third category that overlaps with *upri* and *nazor* is *jadu* or *chalan*, best translated as 'magic' or 'sorcery'. For example, another British-born Bangladeshi woman told me of her being sick for three out of the five weeks of her holiday in Bangladesh. She said, "You will probably laugh, but it was *jadu* [magic]". She meant that someone deliberately tried to harm her by use of *jadu* or magic. Apparently she received treatment from her doctor for several weeks, but it was a Pakistani *maulana* who cured her. He gave her four *tabiz* (with Qur'anic words inside), one to wear around her neck and three to soak and drink the water from.

My interviewees, as well as Bangladeshis in Bangladesh in general, quite frequently referred to *jadu* or *chalan*, both forms of magic or sorcery, used by some

⁹³I was told by a British born Bangladeshi woman that an illness is *upri* when it is sudden and unexplainable. She was in fact referring to her mother-in-law's heart attack.

⁹⁴The Qur'an is explicit that some *jinn* are Muslims, and others are wrong-doers (Sura 72).

⁹⁵See also Gardner 1992.

⁹⁶Bhopal (1986:103) in his research with British Asian communities also found that exactly the same ritual of burning chilli was also used for *nazor* related health problems of children.

people with the help of evil spirits to inflict illness or other kinds of harm on their enemies or those they envy.⁹⁷ I had numerous stories from British Bangladeshi *imams* and my interviewees about how they or some family member had been subjected to *chalan* or *jadu* leading to problems of diarrhoea, mental illness etc. One of the genetic counsellors who made regular home visits to Asian families told me that many families told her that their children's disability was caused by some black magic.

I was told that not all *imams* engaged in proper *upri* treatment, which involved the ritual of divination, calling the evil *jinn*s (or other spirits) responsible to come forward and speak through the patient/s or the medium, asking them why they took possession of the sick persons, then the healer coming to some agreement with the evil *jinn*s whereby the latter will leave the sick persons. These exorcism rituals can be very elaborate (in Bangladesh referred to as *jhara*, meaning to sweeping away), and are not always successful. Exorcism of evil spirits is performed only by a few *imam* or healers, as it is a dangerous and scary business.⁹⁸

In the case of Kiran, when the *imam* in Bangladesh declared he was possessed by *jinn*s, because Kiran was a mere baby, a young girl was asked to take his seat during the divination ritual. In Kiran's case the six *jinn*s who were said to have possessed the mother during her walk in the park close to her house in the U.K. and then in turn possessing little Kiran, asked for some sweets. In other cases, I heard of evil *jinn*s or spirits asking for a chicken or a goat.⁹⁹

Evil spirits (*bhut* or *jinn*s) are said to be able to take any form or shape to come near a victim, and usually reside in jungles, in big trees, and dirty places. In different parts of Bangladesh people refer to *batash* (bad wind), *batash lagse* (attacked by bad wind), *upardosh* (attacked from above), *upri*, (from above) *bhutey dhorchey* (possessed by evil spirit), *jinn* (bad Islamic spirits) and *poris* (female spirits as causes of various diseases or illness) (Gardner 1991). In my own work, as well as in the work of Thérèse Blanchet, it is clear that all these terms refer to the same category of dangers, i.e. evil spirits. Blanchet (1984:117) found in her work in a rural area of Northern Bangladesh, that "good Muslims are not supposed to believe in *bhut*. Moreover, I have heard that people are sometimes frightened to mention *bhut* lest they retaliate." As Blanchet suggests, the use of more impersonal words such as *batash*, *upordosh*, *upri* circumvents this problem. This might explain why most of interviewees used the term *upri* referring to evil spirits (*jinn*s or *bhut*). They also use the terms *batash* and *batash lagche*.¹⁰⁰

⁹⁷ Thus Karbani et al report the story of an educated man who said he "Had been a great object of envy in his community when a second son was born and when he won the scholarship to study abroad. He worried that when he left Pakistan, he had left his family unprotected and exposed to the envious curses of those around" (Karbani et al 1997:160).

⁹⁸ One Maulana I interviewed in the UK told me "I do not deal with *upri*, because those who tackle *upri*, they always need some force, *jinn*. Some *jinn*s remain under their control. There is a technique for controlling *jinn*s, but I do not know this. With the force of these *jinn*s they move or exorcise other *jinn*s. However, these *jinn*s under their control can also harm them." He continued "to exorcise bad *jinn* one needs to control bad *jinn*s. If anyone comes to me with problems of *upri*, if it's 'normal' problems, I will give *pani pora*, *tel pora*, *fu* and read certain *ayats* from the Qur'an. There are specific *ayats* in the Qur'an for specific things." I think by 'normal' he meant relatively simple health problems: e.g. headache, stomach problems, children crying, getting scared etc, not serious health problems. He added that not everyone he gives treatment to gets better – it is Allah's wish.

⁹⁹ I wondered why it was six *jinn*s, rather than one *jinn*. Perhaps the severity of Kiran's condition could be understood by the combined evil force of the six *jinn*s.

¹⁰⁰ Thus the mother of a child affected with Xeroderma Pigmentosum (XP), a condition which gets aggravated when the child is exposed to sun and day light in general, told me that when they were on holiday in Sylhet, people told her that her child had *agni batash* (fiery or hot air).

It is not a surprise that the evil *jinn*s who were supposed to have attacked Sufia got hold of her from a park, full of big trees. While in theory evil spirits (or *jinn*s) can attack men or women alike, in practice women are thought to be much more vulnerable to their attacks than men. A British Bangladeshi *imam* told me how in order to avoid attack of evil spirits appropriate behaviour is important. Some of his examples included how women should dress appropriately and cover their hair and watch where they go. He said *jinn*s reside in “bad, dirty, messy places, e.g. you find them in jungles. *Jinn* will never take shelter where one says his *namaz*, keeps his fast.”¹⁰¹ Such statements were also made by a number of families whom I interviewed. They imply that being attacked by *jinn* is not morally neutral; it is usually to some extent the fault of the victim or, in the case of a small child, of its guardians. As in Sufia’s case, a child’s mother is the person most immediately at risk of being blamed.

Other Religious Measures

Alongside *daktari* (medical) treatment and *upri* treatment, most British Bangladeshi families dealing with a serious medical situation will also employ a variety of Islamic practices which they hope will increase the chances of a cure or improvement. These include special prayers (*dua*), extra fasts, *Qur’an-e-khattam* [recitation of the whole *Qur’an*], *sadaqah* (*sadga* in Bangla, animal sacrifices with donation of the meat to the poor, monetary charity to the poor, etc). Families will also ask for consecrated water (*pani pora*) and consecrated oil (*tel pora*) from *imams*. *Imams* are also regularly asked to provide amulets (*tabiz*), which usually contain set prayers (*ayats* from the *Qur’an*) for particular health problems. Often these will be brought over from Saudi Arabia (from Mecca and Medina)¹⁰² when someone goes to the Islamic pilgrimage (*hajj*), or from some famous *maulana* in Bangladesh. When they can afford it, families will take their child to *hajj*.

As for Karim and Sufia, they engaged in most of the above religious activities for their son. They sent money home to Bangladesh so that a cow could be sacrificed. They engaged a number of *imams* to read the whole *Qu’ran* in Karim’s house in Bangladesh. Karim’s brother, who lives in Saudi Arabia, went to *hajj* so that Kiran’s illness would get better.¹⁰³ Sufia told me, “We have water and [sacred] soil from the house of Allah [meaning from Mecca and Medina]. I put the soil inside the pillow, it’s still there.” Sufia used the water to feed and bath the baby. She also drank some for her depression and other health problems, but Karim did not have any as he did not have any health problems.

Sufia said they also do extra prayers (*dua dorud*) and extra fasting. Sufia’s sister obtained some special prayers (*dua*) from a well-known *maulana* in Sylhet (Moulvi Bazaar) and sent it to Sufia in a letter. Sufia has been using them since.¹⁰⁴

¹⁰¹ Almost all the stories I heard of someone having been possessed by some evil spirit involved the person apparently having been at some inappropriate place and at inappropriate times. Certain times of the day and night are also not appropriate for people to be outside of the house, especially for new brides, pregnant women, and new mothers.

¹⁰² Water from the Zamzam well at Mecca is famous for its apparently healing power. So it is very common for people who go to *hajj*, to return with bottles of this ‘sacred’ water and share with relatives and friends. Recently Zamzam water was also being sold in London, although it was apparently found to be contaminated with high levels of arsenic (*The Muslim Weekly*, Issue No 130).

¹⁰³ *Bemar komey*.

¹⁰⁴ There is a tendency for British Bangladeshis to rate the *maulanas* and *imams* based in the UK lower than the ones based in Bangladesh. Thus Sufia said that the *imams* in the UK are no good, they take too

She said, “People say that the prayers of parents are the best [for a child].’ One *Maulana* told her “cry when you pray.”

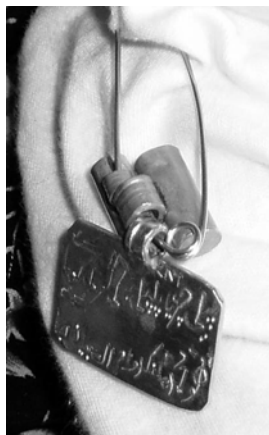


Fig. 4: Brass plate with two tabiz attached to child's clothing

Kiran was also sent a special *tabiz* set in a little brass plate from Bangladesh, which he wears on the sleeve of his shirt (see Fig. 3). During the family's holiday in Bangladesh Kiran received two more *tabiz* from yet another *Maulana* after the divination ritual referred to above.

In addition to all these above religious measures when the opportunity arises many families visit the shrines of Muslim Sufi Saints. One of the more famous ones is the shrine of Shah Jalal in the Sylhet region, where the vast majority of the British Bangladeshis come from and where all my interviewees also come from. Sylhet is in fact well known for shrines of Sufi saints. There are hundreds of them around the whole region, and many others in Bangladesh.

The most famous of all the Sufi saints' shrines in South Asia is located in Ajmer in India. Most of my interviewees knew about this and some hoped to visit the shrine one day, including Karim. When in Bangladesh for their holiday Sufia and Karim took Kiran to the famous local shrine of Shah Jalal. Sufia placed Kiran on the floor adjacent to the wall linked to the grave of the pir and did *dua*. Karim's mother had already visited the Shah Jalal Shrine and a number of other shrines a few times, begging the saint to make Kiran better.

Like Sufia and Karim, every family I interviewed performed *sadaqah*, *Qu'ran-e-khattam*, as well as saying extra prayers, keeping extra fasts etc. For example, the mother of the baby affected with Carnitine Transporter Deficiency told me that recently when her son was hospitalised and operated upon for a serious chest problem, she immediately decided to undertake three lots of *Qu'ran-e-khattam*. She stayed at the hospital with the baby and finished reading the whole *Qu'ran* once and then read it once more after her child was released from the hospital. Meantime, her husband called his mother in Bangladesh and asked them to get some *imams* to undertake *Qu'ran-e-khattam*. I met the husband's mother when she was visiting and she told me how they performed this ritual in two hours as ten *imams* divided the sections among themselves. They also distributed a sweet dish to people. This is the common pattern with other families too. Usually they get the *Qu'ran-e-khattam* and *sadaqah* done by family in Bangladesh.

Discussing why they do *sadaqah* in Bangladesh, one woman said, “There are more people in Bangladesh, there are no poor people here.” Usually people undertake these extra religious measures in times of crises, such as sudden hospitalisation or the first diagnosis of the condition being life-limiting or life-long. One female interviewee with a toddler son affected by a severe genetic condition, said, “It is my religion that made me strong in this situation”. She and her husband performed a *sadaqah* for their son a number of times, and she told me, “I feel that when the poor pray that might have an effect on my son, maybe he will get better.” The mother of a

much money, e.g. £60-£70 for *pani pora* or *dua pora*. Another woman told me, “It is not right to get amulets and so on from the imams who come to this country... they are not like the *imams* back home.” Her husband added, “Once they come here, they [*imams*] become greedy for money. People are not getting any benefit, they are taking amulets, *pani pora* but the effect is opposite. We have heard a lot [of stories?].” Asked if they consulted any *imams* or obtained any *tabiz*, *pani pora* etc. they said no.

five-year old son with a life-long genetic condition also told me they have been doing *sadaqah* every year. She told me that after the animal sacrifice, “Firoz [her son] gets better for a while.” She thought her son gets the blessing of the poor who get their help. Later she added, “I do not think medicine helps as much as these religious things do.”

Except for one or two individuals in some families, all those I interviewed performed the regular *namaz* and fasts, as well as engaging in many extra fasts, *duas* or prayers, asking *imams* to say special prayers and undertook various other Islamic practices to improve the chances of their children getting better.

Allah is the Scientist of the Scientists



Fig. 5: Explanatory Frames

For Karim and most other interviewees, beyond all these modes of treatment, medical treatment, treatment by *imams* for *upri* problems and the various Islamic practices (special prayers, *sadaqah*, *Qu’ran-e-khattam* etc) lies Allah, since their success or failure is ultimately according to His will. My interviewees would place the responsibility for the illness as well as the power of cures both on Allah. It is Allah who gives the problem to certain individuals in certain families, not all individuals and not in every family. This outer frame of explanation particularly comes into play when none of the three other approaches appears to be working. At this stage, families may go on pilgrimage to Mecca and Medina (*umrah* or *hajj*) or to shrines of Sufi saints in Bangladesh, India or elsewhere, in the hope of a “miraculous” cure.

Thus it is very common for families to say about their child’s illness: “This is Allah’s gift”, or “Allah is testing us”, or “This illness is *neyamot*” [a special favour from Allah]. As mentioned above, Karim told me right from the beginning how Kiran’s illness was “Allah’s gift” and he was told by the second *maulana* he consulted that Allah was testing him, and that his child’s illness was a special favour from Allah.

One morning as we were sitting in their living room, with Kiran sitting as usual in his little chair with the feeding pipe attached to his nose. He had vomited twice since he woke up, and Sufia was despairing about the condition of her son. This led to the following dialogue between her and Karim:

Sufia: “Why has Allah given us such problems?”

Karim: “It’s the will of Allah. He gave us this problem for our own good. If we look after him he will take us to heaven. Allah gives problems to those He loves most; to those who say their prayers and keep their fast regularly.”

Sufia: “People say, ‘Allah has given you this [sick child] because you are good people’.”

From such conversations and from other people's statements, it was clear that Karim and Sufia gained consolation by placing the responsibility on to Allah. Thus when once he was making plans for their pilgrimage to Mecca with little Kiran I asked him what he expects from his pilgrimage. He said, "Now that the doctors have given up on Kiran, we thought it's a good thing to take him to Mecca, there is a hope we might be blessed by some miracle by Allah." He then related a story (see below) of a miracle gained by one of his friends after having gone to *hajj*.

I asked Sufia what she expected from the *hajj*, and she replied "I will pray to Allah and see what He does." Sufia talked about how she would make a *niyot* (contract) with Allah, for example that if Allah cures Kiran she would perform more *sadaqahs* and so forth. At this Karim protested and said that it was not possible to make any *niyot* or contract with Allah. He reminded Sufia of an excerpt from the Qur'an: "Be happy with what I have given you." Karim continued, "Everything depend on *iman* (faith).

Another day, reflecting on his son's severe life-limiting condition, he said

Death is not really death. We are now in this world, after death we will go to the next world. Allah does not do anything without a reason. He [the son] is sinless, if he or other sinless children like him pray [when in heaven], their prayers will be more effective. Their parents are lucky because their sinless children will pray for them.

He said similar things on other occasions. Karim also had a dream about going to the famous Sufi shrine of Khawaja Muinuddin Chishti in Ajmer in India. As a young child he had heard songs about this shrine: "No-one returns empty-handed from the *darbar* [court] of Khwaja Baba (saint)".

It looked, however, as though none of these dreams would come to fruition for Karim. In 2006 the family had hoped to go to *umrah hajj* but could not, nor could they go to Ajmer for reasons that are beyond the scope of this report to discuss. In fact, while in Bangladesh, a *maulana*, a relative by marriage, pointed out to Karim that it was better to go to *hajj* to pray directly to Allah rather than to go to any Sufi shrine, such as Ajmer. Other people in Bangladesh and in the UK also told him that it was better to go to Saudi Arabia to the *hajj* rather than to Ajmer.

In June 2007, I had a phone call from Sufia. She told me that they were going to Saudi Arabia for a holiday. "Do you mean that you are going for the *umrah hajj*?" I asked. She said yes, they were. I was surprised since I had spoken to them three or four weeks before and they had no plans at that stage. "We have been thinking about going there on and off," said Karim. "Now is probably a good time." He told me that he had left his job so that he could go to Mecca and Medina. When I asked if there was any special reason, he said, "We have to do it some time. Why not now?". Karim explained that they had had a meeting a few days before with their paediatrician who had asked if they were liaising with the genetic counsellor about Sufia's possible new pregnancy. Karim had apparently told the paediatrician, "All this is not necessary. These tests, and then termination, these are not good."

"But I thought you were going ahead with the tests?," I said. Karim replied, "I am becoming stronger now, I am learning more about Islam and I have been speaking to more people. Everyone says that these are not good." He added, "Allah tests people with many things. Whatever Allah does it is for our own good. They said that these genetic tests and termination are not Islamic."

"But what if your next child turns out to be affected?," I asked. Karim's response was, "We have been thinking that there are two of us [meaning him and his wife]. We should be able to look after two [disabled] children. Maybe we can bring someone from Bangladesh to look after them. We might also go back to Bangladesh

to live”. I referred back to our earlier discussion regarding termination, when he had appeared pleased to learn that it was legitimate under Islamic law to terminate a damaged foetus up to four months. “Yes,” he said, “but it’s not right to abort a *baccha* [foetus] because it has a leg missing or some other problem”. His argument now was that abortion was only permissible if the situation was impossible to manage otherwise, but he and Sufia could manage to care for two disabled children. “Allah feeds all of the 18,000 types of living beings,” he said, meaning that if Allah to give them another disabled child, He would help them to look after it.

So it seemed that their sudden decision to go on the *hajj* was no coincidence. They had been thinking about this business of having another child and about the hassles of genetic tests and termination. Although they had told me earlier that they would definitely go through with all these for they could not possibly cope with another child like Kiran, they have changed their mind after discussing the issue with other learned Muslims around. Even though Karim did not tell me this explicitly, it was clear to me that they were going to the hajj, both to ask Allah for a healthy foetus, and of course also for some miraculous cure for their existing son. Sufia said, “There is 75% chance of us having a healthy child”. Karim added, “I have always said that all this is Allah’s order (*hukum*), although Sufia did not always accept it.” So, their trip to Mecca and Medina is to do “some *dua dorod* [special pleading to Allah]” in a holy (*pobitra*) place. Karim said, “Let us go there, and do *dua dorod* to Allah”.

Karim told me of a story he had heard the day before of an ‘English’ [meaning ‘white’] man who had apparently been to the moon and when on the moon had heard the *azan*, the call to prayer. After that experience he had apparently converted to Islam, saying that “Islam is the only true religion”. Karim was impressed by this story, also mentioned being impressed by seeing an English man saying his *namaz* at his local mosque. He asked me, “From all your research and experience, which do *you* think is the best religion?” Karim had clearly been searching and talking to many people, both in the UK and when in Bangladesh, about true Islam and Islamic values. He seemed genuinely to want to follow what is Islamic, even if this means more disabled children for him and his wife.

My own reading of the situation is that it was largely Karim who had been searching and doing the research and who had then influenced Sufia to accept his position. Sufia was delighted that they were going on a holiday to Saudi Arabia, and it was clear that for her this was as much a ‘holiday’ as a *hajj*. For her, this was mainly a wonderful break from her everyday routine of sitting at home and looking after her sick son. For Karim, though, who spent most of his time outside the home, working at restaurants or shopping, it was primarily about *umrah hajj*. My reading is that Sufia had accepted the idea of not going through the genetic tests (amniocentesis etc) both because she was concerned and even scared about the whole procedure but also because she was instead offered the opportunity to go to Saudi Arabia, to Mecca and Medina. We recall that Sufia has always been somewhat sceptical about placing all the responsibility and depending 100% on Allah. She was more inclined to take the line of making a contract (*niat*) with Allah, and it was she who told me that they had done all the right things by their religion and by Allah when she was pregnant and still were given a sick son. So she is not necessarily ‘happy’ with Allah for having given her a sick son, and does not really accept the suggestion that this is some kind of special favour (*neyamot*) from Allah, even though she does gain some consolation when other people say that “Allah gives such sick children to those He loves most”.

It was clear from my discussion with the other families too that for them their ultimate saviour was Allah, for it is He who gives the illness and it is He who has the

power to cure. Like Kiran's parents, many other parents and family members told me in relation to the disorder of their children that "Allah is testing us" or "He is Allah's gift to us, I believe in Allah". One woman said, "We believe he [son] was meant to be like this, he was meant to be born to us, this is meant to be a test of Allah. My son [when he dies] will go straight to heaven and with him his family too will go to heaven. I don't care what other people say. . . but those who are religious, advise us to pray and to have *iman* [faith]." Such sentiments were very common with almost all my interviewees.

Like Kiran's family, many other of my interviewees have been dreaming or planning to go on *hajj* (pilgrimage). Going on *hajj* is one of the five pillars of Islam in any case, but for families with a sick child (with genetic disorder), the pilgrimage is specifically to ask *dua* to Allah for their children. In one case, a mother reported that after she and her husband had taken their little son to *hajj* he has become much better. "He used to have speech problems, now he can talk properly, he used to have more fits, now he is a lot better."

Here too I was told stories of miracles related to *hajj* or to items brought from Mecca. Kiran's father Karim told me about a friend whose wife had a baby within a year after he returned from his pilgrimage to Mecca. This was their first baby and they had been married for seven years. It seems the couple were having problems in having a baby. When the baby came it was taken as Allah's blessing because Karim's friend had gone to the *hajj*. In another case, one woman had a baby after some ten years of marriage. I was told that this happened after she ate some wheat that was brought from Mecca.

As with Kiran's family, items (water, oil, soil) brought from Mecca or Medina were also popular with many other interviewees. Usually relatives or friends will bring them over if the families cannot go to *hajj* themselves.

One of the mothers I interviewed told me at length how she was very unhappy with her paediatrician and was planning to cancel her son's next appointment with him. Explaining how the paediatrician made her and her husband unnecessarily upset through his rude behaviour, she said, "After our last visit I have decided that it's now in the hands of God." Later she told me that they were planning to take their son to *hajj* in the near future.

Given such faith of people in Allah, it is not surprising I was told again and again by both the *imams* and the parents or family members of sick children that unless Allah wills it, a patient will not get better. It does not matter how famous or reputable a doctor or an *imam* are. I was told a number of stories such as the following:

An old man had cancer. The 'big' [famous, well-known] doctors in town gave up on him and told his relatives to take him home and feed him whatever he liked to eat, as he would not live very long. He was brought home and his two educated sons were by his side. Then a plain village healer (*kabiraj*) came by and enquired after the old man's welfare. When he was told that he could not be treated by the 'big' doctors, he asked if he could try. The son laughed, thinking "What can he do?," but he nevertheless let him give some treatment. The herbal pills given by the village healer cured the old man's cancer and he lived after that for another fifteen years.

At the end, the story-teller, an *imam*, told me, "If Allah wishes, he will cure. That He would cure him through this simple herbal thing, it is beyond imagination."¹⁰⁵ Then he said, "One should seek medical advice. But keep in mind if Allah does not will,

¹⁰⁵ *Allahr iccha holey Allah bhalo korben. Allah jey shamanno lota patar madhomey bhalo korben ta toe kolpanar bairey.*

medicine will not work. If Allah wish He can cure someone without medicine... Allah is the Scientist of the Scientists.” Thus, all forms of treatment become mere medium through which Allah might or might not cure a patient.

Discussion and Analysis: Daktari and Upri Problems

The rather fluid movement between the various modes of explanation we see in this case study are quite common in Bangladesh and the rest of South Asia, and perhaps elsewhere as well. Thus Rensje Teerink, in a study of ideas of disease causation in a Gujarati village (1995), refers to the American anthropologist George Foster,'s distinction between 'personalistic' and 'naturalistic' medical systems. Foster suggested that medical systems characteristically emphasised either 'personalistic' modes of explanation, in which diseases are seen as caused by a quasi-personal agent (whether human or 'supernatural') or naturalistic modes, in which disease was seen as deriving from the bodily system being somehow out of balance (Foster 1976). Teerink notes that personalistic and supernatural modes of explanation dominated in the village she studied, but adds that this "does not do justice to the complex realities of popular medical discourse" (1995: 101):

It is not possible to make a clear distinction between the personalistic and naturalistic medical systems. In fact, the very distinction between both aetiologies seems erroneous since the villagers' discourse evades these Western-derived binary oppositions. Rather, the cause of disease is often explained somewhere between the naturalistic and personalistic pole and shifts in emphasis from one pole to another, never to be quite pinned down.

There is a parallel in the way my interviewees, British Bangladeshi Muslims, distinguished between illness which could be understood in *daktari* terms, while there were others which fell outside of this *daktari* or medical realm, and they were usually caused by some evil spirits (evil *jinnns*), or by the *nazor* or evil eye of a person. I would agree with Teerink, too, that the western-derived binary division between the two aetiological systems does not accurately capture the ways Bangladeshis in Bangladesh or the Bangladeshis in the UK view things. For my interviewees, like Teerink's Gujarati villagers, "the cause of disease [. . .] shifts in emphasis from one pole to another, never to be quite pinned down."

This does not rule out the fact that to start with people (including religious and traditional healers) will usually associate certain types of health problems with the 'medical' (naturalistic) realm and others with *upri* or *nazor*, *jadu* or *chalan* (i.e. personalistic aetiologies). Thus, a family with a child affected with a serious genetic disorder might for a while settle down with the idea of their child's problem being 'medical'. However, one then finds the same family seeking help for *upri* from some *imam*. This can happen at the suggestion of a family member, or to take the opportunity of a famous visiting *imam* to the U.K. or often during the interviewees' holiday in Bangladesh.

Similarly, for a health problem a family might start off by assuming it is due to *upri*, or *nazor* and thus seeking help from extra-medical sources, and then if the problem persists, the family might also turn for medical help. Such to-ing and fro-ing was a reasonably common pattern with the families I interviewed, as with Kiran's parents.

At the same time, as we have seen, people will always say that their first and last resort is in Allah. Whether a sick person is cured or not ultimately depends on the

will of Allah. In the concluding section, I would like to problematise this situation a little.

Conclusion

I was struck in this research with people's absolute faith in Allah in relation to whatever healing and medical options they might adopt. Perhaps, though, it is worth asking why the idea of Allah's ultimate responsibility carried so much conviction. In saying this, I do not mean to demean or dismiss the religious convictions of the families I studied, but to contextualise a little the situation in which they made these statements about Allah.

There are two ways in particular in which one could look at people's tendency to make Allah the ultimate saviour and decision-maker in relation to their children's illnesses. Each seems to me to help in understanding why this idea had such strength and potency for them.

First, treating the illness as the will of Allah can be seen as a way of coping with the stigmatisation involved in the idea of genetic illness. In Bangladeshi culture, any form of on-going sickness of a member in a family runs the risk of stigmatising the individual and sometimes the whole family. Such stigmatisation might stand in the way of marital alliances with other families (Rozario, 2007). We have seen examples of these issues in earlier chapters. Moreover, there is also blaming of one side of the family or the other for illness.

By shifting the responsibility for their child's illness to Allah, any possibility of stigma or blame for the parents is undermined. Indeed, the illness can be seen as a special 'gift' from Allah and as an indication that they are in some special way particularly close to Him.

Most of all, having a child with permanent disability or life-limiting condition is difficult for anyone, regardless of religious background. Finding consolation with God or the divine is a feature of other religious groups in South Asia as well as the Muslims. For example, in similar situations, Christian Bangladeshis might also say, "Everything is God's will".¹⁰⁶ Kalpana Ram, from her work with Hindu and Christian Tamil populations in India shows how "illness and possession [evil spirits] are both a curse and a blessing... serious bouts of illness are an affliction, but also key opportunities to experience the power of the divine in the form of surrender and faith. Illness is therefore a pathway to prove faith and receive grace, as well as being one of the symptoms of love" (Ram 1991:57).

Secondly, I would also argue that commitment to Allah is an identity issue for Bangladeshi Muslims. As I mentioned in Chapter Three, Bangladeshi Muslims in the UK, like Muslims all around the world are now taking a renewed interest in Islam, and are becoming much more committed to their religion and to the world Islamic *umma* (community) (see also Glynn 2002, 2003; Ahmed 2005). This increased interest in Islam has been explained in terms of recent world and local events, starting with the Iranian revolution of 1979, the burning of the *Satanic Verses* in Bradford, and the 1991 war in Iraq, and the continuing to the more recent events of 11 September 2001, followed by the wars in Afghanistan and Iraq. All these events placed Muslims on the defensive in relation to the Western world (Rozario 2005).

This renewed interest and increased level of commitment to Islam is greater with diasporic Muslims, the younger generation in particular. With Bangladeshi

¹⁰⁶ *Shob esshorer iccha*.

Muslims in the UK, this new Islamism gives them an alternative identity to their marginal position in British society as the most backward of major ethnic and religious groups. Their renewed commitment to Islam is more than just praying five times a day and, for women, wearing the *burqa* or *hijab*. The new international political climate has the effect of creating a ‘us’ and ‘them’ division between the ‘west’ and the Islamic world (i.e. the Muslim people). Many things labelled as ‘western’ are avoided by ‘good’ Muslims. Generally speaking western values are seen as leading people astray, so that one needs to abide by Islamic values as closely as much as possible.

I often wondered, when some of my interviewees told me they were opposed to genetic testing (amniocentesis), termination, or contraceptives, saying these were not Islamic, whether they actually knew their Islamic sources or whether what they were saying was better understood in terms of an emotional commitment to Islam as against the West. In other words, because these solutions were being offered by the biomedical system, as precautions in order to avoid having another child with genetic disorder, were they shunned as ‘western’ and therefore as no good for ‘good’ Muslims?¹⁰⁷

It is perhaps not surprising that the *imams*, whom the British Bangladeshis went to see for any health problems, emphasised the role of Qur’an in the healing process. One *imam* said, “Qur’an is like medicine”.¹⁰⁸ Another *imam* told me that people who come to see him, usually got better with Qur’anic treatment, saying he built up mental strength of patients through Qur’anic language. What is perhaps more significant is the way in which lay British Bangladeshi Muslims used Islam, Islamic text, and even Islamic countries as their anchor. Thus one of the families I interviewed had a short holiday in a Middle Eastern country when the husband took their son swimming in the waters of the Red Sea. The mother told me that the Red Sea waters had cured their son’s skin problems, and that some patches on his skin had cleared up since their holiday. Similarly, as mentioned above, people routinely brought items such as soil, water, wheat and oil from Mecca and Medina, the holy lands, and have told me these helped them or their children’s genetic condition. Going to *hajj* in person was often seen as opening up the possibility of a miraculous cure. People also thought that following various Islamic practices were critical to their children getting better.

If we return to Karim’s decision to go on the *hajj* and appeal to Allah rather than to pursue testing and possible termination in relation to his wife’s pregnancy, we can see some of these factors operating. At one level, Karim’s action can be seen purely in Islamic terms, as a statement of commitment to Islam. If we were to try to understand what exactly underlies his and therefore also his wife’s change of heart about genetic testing and termination of a possible damaged foetus, I would suggest that his search for identity and for a sense of belonging was also a critical factor. He did not want to deviate from a crucial Islamic injunction and to have to live with the knowledge that he had sinned and that Allah might not accept him into heaven. Externally, he also wanted to remain and be acknowledged as someone who is a good and pious Muslim. He was already considered a very good practising Muslim,

¹⁰⁷ In most cases women (and men) were opposed to the ideas of genetic testing (amniocentesis) and opposed to termination. Many women were also opposed to contraceptives. Yet it is never clear in advance what women would really do when they had to make the decisions. As we have seen from Kiran’s family, the parents can move back and forth between the biomedical option of testing and possible termination, and the rejection of biomedicine in favour of faith in Allah.

¹⁰⁸ *Qur’an sharif ekta oushod sharup.*

although sometimes he was also criticised for his over-religiosity by some of his relatives, who do not necessarily say their *namaz* five times a day and go to the mosque every day like Karim does. The stories he told of the 'Englishmen' becoming good Muslims were also significant. It was as if he needed some re-assurance from the Englishmen to whose country he has migrated, many of whom denigrate Islam and Muslims. The religiosity of the Englishmen inspired him more towards his own religion and his religious identity. If he wanted to remain a good Muslim, he could not go through with the genetic tests and termination of the foetus.

As I said, I do not intend by these comments to dismiss Karim and Sufia's religious faith, or that of any of these families. It has obviously been a great support for them in what are often very difficult and painful situations. My intention is only to point to some of the contexts that may have helped to shape and to strengthen that faith. For those people in British society who want to understand, and even more for those involved in helping, these Bangladeshi Muslim families who are coping with children afflicted with genetic disorders, I think it is important also to become as aware as possible of the conditions in which they are living, and the ways in which they themselves make sense of and try to deal with their situation. I hope that this report has contributed a little to this process.

Appendix: Two Short Case Studies

I include two more short case studies here that illustrate further issues mentioned above but not discussed at length. The first is the narrative of a couple who had fertility problems, and illustrates how infertility in Bangladeshi culture invariably becomes blamed in one way or another on the women. The second describes a visit to a *pir* or Sufi holy man who is believed to have healing powers.

1. Problems with Fertility

British-born Sharifa married her father's brother's son Showkat from Bangladesh when they were both eighteen. She said that during the first few years after her marriage she didn't try to have a child, though she wouldn't have minded having one. But then she realised that this was becoming a big problem for her, and that she was being talked about. She said that she was labelled as *olokhi* (inauspicious) and so she was not welcome at *mehedy* ceremonies (henna ceremonies before marriage). "When I went to parties [Bangladeshi gatherings] you could tell that people were looking at you, having thoughts, you could read their thoughts. So I avoided parties apart from my immediate family parties [her brothers and their wives]." She said, "I stopped going to weddings, *mehedy* and so on. Then I started to think, I never took any pills. In 1995-6 we both went to see our GP who referred us to a hospital." Apparently, Showkat had a low sperm count. Then her mother died. "I nearly had a breakdown – the closest person I had was my mom, I lost track of life, I had depression. All I did was cry."

"I used to know a female Qur'anic teacher who had no children," she said. "When her husband died she was helpless. People used to say, if only she had a child. Seeing this made me desperate to have a child. I could actually feel her pain. I went to the doctor again. The doctor said my depression stopped me from getting pregnant. I was referred to a hospital – lots of tests were done. Showkat's sperm count was low, but that was not supposed to be a real problem. After a couple of visits they suggested IVF. Our area was not covered by NHS, so the IVF would not be covered by the NHS and would cost me £2500. I had no money and was too depressed. I have four brothers and four sisters-in-law. I was a little close to the youngest sister-in-law who grew up here in the UK, less so to the other wives who were from Bangladesh. I don't have any sister."

Sharifa said that eventually the four brothers helped her pay for the IVF treatment. However, she said, the IVF success rate was only 20%, and their treatment was not successful. Sharifa wanted to have another go, but the doctors advised her not to do it. She would have children anyway, they said. However, it was another four years before she had her twins. Sharifa said that beside her immediate family, no one else knew that she had IVF.

Sharifa said "I felt there was a hollow in our marriage during that four years. My husband's family never respected me because I didn't have children. When they talked about family matters, they neglected me."

"In my family, my mother took me to a *maulana* in Bangladesh. He said that my Fallopian tube was not in the proper place. The treatment for this was to place a biggish clay pot, cut in half by a woman, filled with oil and covered, on my belly button. My stomach would swell up. After about ten or fifteen minutes dirt from my Fallopian tube would come out. The funny thing is, a lot of dirt did come up from nowhere. A whole lot of black stuff on my belly button, the whole

pot filled up with dirt.” This treatment took place about five years after her marriage, when Sharifa was about twenty-three.

Her mother apparently kept taking her to whomever people suggested. It seems that some *upri* problem was suspected. But Sharifa said, “I only went because my mom pestered me, I wasn’t interested in it, it was all bullshit.” So in the UK she was taken to another *maulana*. This one took a piece of string and measured half her waist, then measured the other half of her waist. Apparently he found one half of the waist to be shorter than the other half and declared that the stomach had moved to one side. He then read something from the Qur’an and rubbed under her arm. “It was so painful, I never went back. I was supposed to go back three times.”

Sharifa said “I told one *maulana* about my husband’s low sperm count. He said “Bullshit,” and told us not to go back to the doctor. He said, “Men can never have problems”. He gave her *pani pora* to drink and *tel pora* with which to massage her stomach for a month. After that she was supposed to go back, but Sharifa said that they never went back.

Apparently, the doctors also checked Sharifa’s Fallopian tubes. She said, “I believe what the doctors say, that it’s in the genes. The doctors say that if you are related, pregnancy might be delayed, but that sperm count being low is not really significant”. She thought that in 5% of cousin marriages pregnancy may be delayed. “My mom married her cousin and had her first child seven or eight years later.”

Sharifa said that when her mother was alive, she wanted them to adopt a child. Apparently it was arranged for them to adopt some Bangladeshi child in the UK, who had been brought by a family and left behind when they returned, was arranged to be adopted, but at the last moment her husband refused. “No, I won’t be able to see it as my child. It’s Allah’s *hukum* (order).” Sharifa said that he had faith that they would have children one day.

Some relatives and other community members, and a couple of *imams* told Showkat to marry again, both in Bangladesh and in the U.K. even though his sperm count was low, and nothing was found wrong with Sharifa. She said, “No one told me to marry again, but they told my husband to do so in front of me.”

“Eventually, when I did become pregnant, I was depressed because my mom wasn’t alive to see me have children. People thought that I wasn’t happy being pregnant.”

Sharifa said that they had never sought any *tabiz* (amulets) or anything of that kind. But five years ago, when they had gone to Bangladesh on a holiday, they went to see a well known *maulana* in Dhaka. “A week later, Showkat went to Dhaka again, and apparently he was advised not to re-marry. He was told that if it’s not going to happen, it will not happen. I used to feel that perhaps he didn’t marry again because if he didn’t have a child with the second wife, people would point the finger at him. He never accepted that he had any problems. I felt he thought I had the problems.”

“People talked behind my back. Bangladeshis automatically think it’s the woman’s problem. They would not tell both of us to go to the doctor, but for me to go to the doctor.”

2. A Visit to a Pir

Karim had agreed to take me to visit this *pir*. But he asked Sufia to get ready so she could take Kiran, their sick child, with them. I realised that he had wanted to take Kiran for a while, but that Sufia was not interested. She said that he scolds and screams at her.¹⁰⁹ Apparently Sharifa too went to see him once and did not like him because of his rough speech and scolding.

When I asked Karim why people call him *pir*, he said, “He who is called a *pir*, he has some miraculous power, that is why he is called a *pir*”.¹¹⁰ It seems he is known to have cured some people. Karim added that this *pir* doesn’t take money, but his speech is rough (*korkosh*). But it seems that Karim thinks he tells the truth, since other people say this about him.

When we were in the car, Karim warned me that if *pir shaheb* opens the door, I should walk by placing my right leg inside the door first, followed by the left leg. Last time, he was apparently scolded by him for putting his left leg first. Sufia said that she knew about this rule and had told Karim to put his left leg first!

When we went in, no one else was there. Apparently there is often a queue of people waiting to see him. We were lucky and got to see him immediately.¹¹¹ He was sitting on the floor of his living room: a newspaper was spread on the floor and over it a wooden chopping board. He was chopping onions and potatoes as he talked. When asked by Karim if he would take some food if they brought it, he said he would not.

Apparently he cooks for himself, usually very simple vegetarian food; he has fish or meat once in a while. He said that meat is not good, and that one should boil meat before cooking and throw out the water. Apparently Sufia does this too. He said that if meat is not boiled people get cancer, particularly lung cancer. When I asked Karim later why they need to boil meat, he said Sufia boils it to get rid of fat.

The *pir*’s wife left him a long time ago. He has a grown up son in Bangladesh, and a daughter in the UK. Sufia later told me that the *pir* did not like sleeping with his wife, he slept downstairs and she slept upstairs. The wife got fed up and left.

He does not charge people any fees for his advice, so he is very popular. He also does not give any *tabiz* (amulets). He came to the UK forty-five years ago. For twenty years, he used to take Qur’an classes twice a day.

Karim started to talk about Kiran, saying he is not getting better, there is something wrong with his brain. The *pir* said that something is wrong with his kidney too. When Karim asked why Kiran’s condition had occurred, he said it was because his parents had done something wrong. Either the parents made love when Sufia was menstruating, or Karim put pressure on Sufia when pregnant and they were making love. He said that maybe the mother ate something very hot when she was pregnant. Karim and Sufia both objected, saying that they did everything right, and followed all the rules. I talked to Sufia about this afterwards, and she said that this was true.

Karim said that the doctors have said that Kiran will not live long (*hayat beshi nai*). The *pir* said something like, “That’s good, he will return for his parents.” I asked Karim later what he meant. Karim told me, “When a small child like Kiran dies, they leave this world for the other world.¹¹² There is a special place in the other world to which these children go. There is a prophet there and he teaches them everything, better than he would have been taught in this world. On the last day of judgement, the

¹⁰⁹ *Uni galagali koren.*

¹¹⁰ *Oloukik shakti.*

¹¹¹ While we were there he had three phone calls from other clients, two Bengali and one Urdu-speaking person. All called him “*babji*”.

¹¹² In Bangla, go from *ihakal* to *porokal*.

child goes and stands by his parents and asks Allah to take them to heaven. Allah listens to these children.”

At the end, Karim asked the *pir*, “Won’t he get better?”¹¹³ The *pir* said that he will get better, but it will take time.

I asked the *pir* about *jinn* (spirits). He said, “I am the father of people, and also the father of *jinns*. Recently I converted four *jinns* to Islam. They live in my house, like a bodyguard.”¹¹⁴ There are apparently three types of *jinn* (*tin jater jinn*): these three types are found in mosques, graveyards and toilets. He said that the graveyard and the toilet *jinns* are dangerous.

Karim was waiting for a new Bangladeshi passport, and he asked whether his passport situation will be resolved or not. The *pir* said that it will take four to eight weeks. When Karim said that they were thinking about going to *hajj*, the *pir* dismissed the significance of *hajj*. He said that if people can say their *namaz* regularly, especially the early morning *namaz* which most people find difficult to get up for, this is as good as going to *hajj*.

The *pir* was very critical about TV and radio shows, comparing these to a toilet. Like some of my other informants, he linked many of the health problems in this country to the fact that people do not sweat here because of constant cold weather. It is believed that when you sweat a lot of illness comes out of the body.

At one stage he told Karim and Sufia to say “*Subhan Allah*”. I asked Karim about this afterwards and he said, “This is a form of *dua*, a praise of Allah. When you see a nice thing you praise Allah. Thus although Kiran is clearly sick, he has special gift, and Allah is testing you.”

Karim also asked the *pir* about Sufia’s depression: He said, “Actually depression is not an illness”.¹¹⁵ He gave some *ayats* [Qur’anic verses]. Later I checked with Karim what the *pir* meant by saying that depression was not an illness. Karim said that depression arises from some sort of mental pressure.

One of the *ayats* was for Kiran and one for Sufia’s depression. He recited them and Karim wrote them down on a small piece of paper he had given them. Karim was having a little difficulty with this, but Sufia seemed to know the *ayats* by heart too, so she helped Karim to write them down in Bangla script. The *ayat* for Kiran was to be recited over some water and blown over. Then water would be *pani pora* (consecrated) and would be fed to Kiran. Sufia will do her own too and drink the water. She said Karim would not be able to do it, for he forgets, so she will do the *pani pora* for both of them. This arrangement was partly because Karim and Sufia did not bring bottles for the *pani pora* (Sufia told me they took *pani pora* from him last time they visited him) and partly because the *pir*’s own *fu* (blowing over the water) would be too strong, according to the *pir* himself. “If I do the *fu* [ritual], it will be strong, the child’s brain will be burnt out.”¹¹⁶

He said about people unable to have children, that those who are greedy (*laloshi*) for money, they do not have children. When I asked him why people have genetic conditions (I said, were born with some on-going health problems), he answered. “*shongodushey hoy*”. He was referring to not following rules when making love. At one point he said “*Quran boro daktar*” (Qur’an is the big doctor).

¹¹³ *Bala oito na ni?*

¹¹⁴ *Ami manshero baba, jinnero baba – ami er majhey charta jinre muslim banaichi, amar ghorey ahey – body guard.*

¹¹⁵ *Asholey depression beram na.*

¹¹⁶ *Ami diley strong oibo, fu hard oiya jaibo – fu diley brain joila jaibo.*

Genetic Disorders and Other Related Vocabulary

N.B. The descriptions here of the genetic disorders which are referred to in the report are intended as a general guide only. They are condensed from descriptions given on the Contact a Family web pages at <http://www.cafamily.org.uk/>, the U.S. National Library of Medicine's Genetics Home Reference pages at <http://ghr.nlm.nih.gov/>, the Orphanet database at <http://www.orpha.net/> and the Laurence-Moon-Bardet-Biedl Society website at <http://www.lmbbs.org.uk/> I would like to thank Sasha Henriques of Contact a family for her assistance.

Angelman Syndrome. A neurodevelopmental disorder that was first described in 1965. The main signs and symptoms of Angelman syndrome are learning disability, jerky movements, a tendency to seizures and a happy, sociable personality. Children with Angelman syndrome usually present with a delay in reaching their developmental milestones and often do not learn to sit until around one year of age. Adults with Angelman syndrome remain dependent on others, but can acquire a variety of skills to help with daily living. Most cases of Angelman syndrome are not inherited, particularly those caused by a deletion in the maternal chromosome 15 or by paternal uniparental disomy. These genetic changes occur as random events during the formation of reproductive cells or in early foetal development. Affected people typically have no history of the disorder in their family. Rarely, a genetic change responsible for Angelman syndrome can be inherited. For example, it is possible for a mutation in the UBE3A gene or in the nearby DNA region that controls gene activation to be passed from one generation to the next.

Bardet-Biedl Syndrome (or Laurence-Moon-Bardet-Biedl Syndrome) is a rare, recessively inherited genetic disorder that affects approximately 1 in 100,000 babies born. It involves visual impairment, caused by rod-cone dystrophy, a progressive eye condition which is often diagnosed as Retinitis Pigmentosa. This first shows itself as impaired night-vision and can lead to tunnel vision, and ultimately blindness. Other consequences include obesity; extra fingers and/or toes (polydactyly) and/or partially fused digits (syndactyly); underdeveloped genitals in males; developmental delay, speech and co-ordination problems, and often, learning difficulties. Other health problems may occur, most frequently kidney (renal) abnormalities.

Carrier. A person who has received the gene for a recessive genetic disorder from one parent only. Such a person does not suffer from the disorder, but may transmit the gene to his or her children.

Carnitine Transporter Deficiency (also known as **primary carnitine deficiency**) is a genetic disorder that prevents the body from using fats for energy, particularly during periods without food (fasting). Typically, initial signs and symptoms of this disorder occur during infancy or early childhood and often include changes in brain tissue (encephalopathy) resulting in functional abnormalities; an enlarged, poorly pumping heart (cardiomyopathy); confusion; vomiting; muscle weakness; and low blood sugar (hypoglycemia). Serious complications such as heart failure, liver problems, coma, and sudden unexpected death are also a risk. Severe illness due to primary carnitine deficiency can be triggered by periods of fasting or illnesses such as viral infections, particularly when eating is reduced. This condition is inherited in an autosomal recessive pattern.

Cockayne Syndrome. First described in 1936. In its classical form it presents with premature ageing and neurological deterioration. The facial features show progressive ageing with thinning of the skin, deep sunken eyes, hair loss and dental decay. There may be loss of motor and intellectual skills with changes in the white matter of brain (leukodystrophy) on an MRI brain scan. Deafness and visual problems due to retinitis pigmentosa will develop. The bones show thinning and the back becomes curved and there will be joint contractures. The age of the onset of symptoms and the progression of the disease is variable. One of the hallmarks of the syndrome is sensitivity to the sun leading to blistering and excessive reddening of the skin. This has led to the recognition that in Cockayne syndrome ultra violet (UV) light can cause damage to the DNA. In fact, the underlying cause is known to be a defect in the enzymes that repair DNA after UV damage. The sun sensitivity can be reduced by avoiding exposure to UV light and the use of sun block creams. However, there is no treatment for the progressive neurological degeneration. The disorder is inherited as an autosomal recessive trait.

dominant trait: a genetic disorder which is inherited as an autosomal dominant trait may appear as the result of a single gene from one parent.

Dysmorphia. A general term for abnormalities in bodily shape, possibly caused by a genetic disorder.

Muscular Dystrophy. Muscular dystrophies are a group of genetic conditions characterized by progressive muscle weakness and wasting. Myotonic dystrophy, the most common form, affects about 1 in 8000 people worldwide. It is characterized by progressive muscle wasting and weakness, particularly in the lower legs, hands, neck, and face, and is inherited in an autosomal dominant pattern. The features usually develop in early adulthood though they can occur at any age and in some cases they may appear at birth. Two further types of muscular dystrophy, the Duchenne and Becker types result from mutations in the DMD gene. They primarily affect the skeletal muscles, which are used for movement, and the muscles of the heart. Duchenne muscular dystrophy is the most common form of muscular dystrophy in children. These types of muscular dystrophy are inherited in an X-linked recessive pattern, and mainly affect males. Females who carry one copy of a DMD mutation may have some signs and symptoms related to the condition (such as muscle weakness and cramping), but these are typically milder than the signs and symptoms seen in affected males. A further, rarer type, Emery-Dreifuss muscular dystrophy, also chiefly affects muscles used for movement (skeletal muscles) and the heart (cardiac) muscle, and almost always leads to heart problems by adulthood. This is also usually inherited in an X-linked recessive pattern but in a small number of cases is inherited as an autosomal recessive trait.

NF1 see neurofibromatosis.

Neurofibromatosis (NF). An inherited genetic disorder causing tumours on nerve tissue anywhere in the body and often other effects. There are two main types of neurofibromatosis: NF1 caused by a defect on Chromosome 17 (ninety per cent of cases) and NF2 caused by a defect on Chromosome 22. The disorder is inherited as an autosomal dominant trait, but fifty per cent of cases result from spontaneous new mutations in families with no previous history of the disorder. Complications of NF1 are mainly cosmetic, but in about a third of cases complications of varying severity may occur, including plexiform neurofibromas (deeper nerve growths), scoliosis (curvature of the spine), pseudarthrosis (stiffening) of the long bones, optic glioma (eye growths, often without symptoms), spinal neurofibroma, hypertension due to renal artery stenosis and pheochromocytoma (a usually benign adrenal gland tumour). The majority of children with NF1 have an intelligence within the normal range. However, a substantial proportion have learning difficulties which can be specific, such as dyslexia, or generalised, such as intellectual disability. Compared with their peers, children with NF1 can have difficulty with concentration, co-ordination affecting both fine and gross motor skills, memory, visuo-motor and visuo-spatial skills, organisation and processing. Social and language problems have also been documented. NF1 is a variable and unpredictable condition which imposes a psychological burden that is difficult for both parents, affected individuals and those professionals engaged in their care.

Pendred Syndrome. A genetic disorder typically associated with hearing loss and goitre (enlargement of the thyroid gland). Hearing loss is often evident at birth, but in some cases it does not develop until later in infancy or early childhood. Some affected individuals also have problems with balance. Additionally, abnormalities of the inner ear are common in Pendred syndrome. The disorder is inherited in an autosomal recessive pattern.

recessive trait: A genetic condition which is inherited as an autosomal recessive trait only appears when an individual receives genes from both parents.

Thalassaemia: a group of genetic disorders. **Beta thalassaemia** is a genetic disorder that reduces the production of haemoglobin, and is caused by mutations of the HBB gene. Symptoms of beta thalassaemia occur when not enough oxygen gets to various parts of the body due to low levels of haemoglobin and a shortage of red blood cells (anaemia). This disorder is classified as thalassaemia major (also called Cooley's anaemia) or thalassaemia intermedia depending on the severity of symptoms. Of the two types, thalassaemia major is more severe. Signs and symptoms of thalassaemia major appear in the first 2 years of life. Infants have life-threatening anaemia and become pale and listless. They also have a poor appetite, grow slowly, and may develop yellowing of the skin and whites of the eyes (jaundice). The spleen, liver, and heart may be enlarged, and bones may be deformed. Adolescents with thalassaemia major may experience delayed puberty. Thalassaemia major and thalassaemia intermedia are inherited in an autosomal recessive pattern. Most often, the parents do not show signs and symptoms of the disorder. Sometimes, however, carriers of the altered HBB gene have a mild anaemia referred to as thalassaemia minor. **Other thalassaemias:** There are several related genetic disorders and conditions, of which two are referred to in the report. **D-trait** carriers inherit a normal haemoglobin gene (Hb A) from one parent and a haemoglobin D (Hb D) gene from the other parent. Haemoglobin D disease involves Hb D genes from both parents but is relatively mild. **E-trait** carriers similarly inherit a normal gene from one parent and the E gene from the other. Children with

Hb E genes from both parents do not have symptoms, but those with an E gene and a beta thalassaemia gene may have disorders resembling thalassaemia minor, intermedia or major, with similarly life-threatening consequences if severe.

TS see Tuberos sclerosis

Tuberous sclerosis is a genetic disorder characterized by the growth of numerous non-cancerous tumours in many parts of the body. These tumours can occur in the skin, brain, kidneys, and other organs, in some cases leading to significant medical problems. Tumours on the face (facial angiofibromas) are also common, beginning in childhood. Neurologic symptoms can include seizures, behavioral problems such as hyperactivity and aggression, and mental retardation or learning disabilities. Some affected children have the characteristic features of autism, a developmental disorder that affects communication and social interaction. Kidney tumors are also common in people with tuberous sclerosis; these growths can cause serious problems with kidney function and may be life-threatening in some cases. Additionally, tumors can develop in the heart, lungs, and the light-sensitive tissue at the back of the eye (the retina). TS affects about 1 in 6,000 people. It is inherited in an autosomal dominant pattern. About two-thirds of cases result from new mutations and occur in people with no history of tuberous sclerosis in their family. In the remaining cases, an affected person inherits an altered TSC1 or TSC2 gene from a parent who has the disorder.

Xeroderma pigmentosum (XP). XP is a group of rare inherited conditions that is characterised by defective repair of DNA damaged by ultraviolet light, particularly from the sun. There are at least eight different subtypes recognised, which are referred to as complementation groups A to G and XP variant. Each subtype has a different genetic abnormality and capacity to repair DNA. The subtypes show different degrees of severity. The condition leads to variable degrees of pigmentary change such as freckling, skin dryness, premature skin ageing and early skin cancers. The eyes can also be affected with photophobia, conjunctivitis and damage to the cornea and conjunctiva. Neurological abnormalities occur in some patients with learning disabilities, spasticity, poor co-ordination and deafness. XP patients may be of small stature and show developmental delay. XP is inherited in an autosomal recessive pattern.

X-linked recessive trait A condition is considered X-linked if the mutated gene that causes the disorder is located on the X chromosome, one of the two sex chromosomes. In males (who have only one X chromosome) one altered copy of the gene in each cell is sufficient to cause the condition. In females (who have two X chromosomes) a mutation must be present in both copies of the gene to cause the disorder. Males are affected by X-linked recessive disorders much more frequently than females. Fathers cannot pass X-linked traits to their sons; the mutation is either inherited from the mother or results from a new mutation.

XP see Xeroderma pigmentosum.

General Glossary

azan Muslim call to prayer

ayat verse from Qur'an; verses are often used for ritual purposes, to bring about healing etc

bangsha lineage, descent reckoned through the paternal line

batash literally means air or breeze. However, when people attribute the cause of a particular health problem to *batash*, they are referring to evil spirits or *jinn*s. Blanchet (1984) noted that people are frightened to mention *bhut* (see below), lest they provoke their action. "The use of a more impersonal, less definite word such as *batash* or *upordosh* [or *upri*] circumvents this problem" (Blanchet 1984:117).

batash lagche This implies someone has been attacked by some evil spirit, e.g. *bhut* or *jinn*s (see *batash*)

behesto heaven

bhabi Bangladeshi Muslim kinship term for elder sister-in-law

bhut malevolent spirit; illness and misfortune are often attributed to *bhut*; *jinn* may be used as an equivalent term by Bengali Muslims

burqa long garment worn by Muslim women, covering the entire body and hair

chalan form of witchcraft or sorcery performed out of jealousy by one person or family on another.

daktari (from *daktar* = doctor); biomedical; used of illnesses which can be healed by conventional medicine

du'a intercessory prayer, additional to regular *namaz*

du'a dorod additional prayer with expressive emotions, like crying, while asking for special favour

dudh pora consecration of breast milk

dujog hell

Eid One of the chief Muslim religious festivals

faraz prescribed, obligatory duty of Muslims

fu blowing on something or someone to bring about healing; commonly carried out by *imam*, or other pious persons.

gae holud turmeric ceremony; part of traditional Bangladeshi wedding ceremony among all communities, including both Muslims and Hindu

gusthi see *bangsha*

hadith sayings attributed to the Prophet Muhammad; the *hadith* along with the Qur'an are the principal sources of Muslim law

hajj pilgrimage to the Muslim holy places of Mecca and Medina

hajji title used by someone who has gone on *hajj*

halal allowed for Muslims (of food)

hilla Muslim temporary marriage

hok rightful, just

imam Muslim religious specialist; employed by mosque as leader of prayer; carries out minor ritual healing services

iman faith (in Allah)

istikharah prayer for divine guidance

jadu magic; bringing about action through spiritual power

Jama'at-i-Islami Islamic political party in Bangladesh (there are related parties in other South Asian countries); affiliated organisation in UK

jinn spirit; the Qur'an mentions good (Muslim) and bad *jinn*; *jinn* can cause illness and misfortune

jumma namaz Friday mid-day *namaz*

LREC Local Research Ethics Committee

maulana Muslim religious specialist, particularly one resorted to for spiritual healing

mehedy henna; pre-wedding gathering to put henna on the bride

MREC Multi-Centre Research Ethics Committee

namaz one of the five regular daily prayers obligatory for Muslims

nazar (*nozor*) 'evil eye,' envy; illness and misfortune are often attributed to *nazar*

niyat contract, agreement

pani pora blessed water, used for healing; may be obtained from an *imam* or prepared according to the directions of an *imam*.

pir Muslim religious specialist; Sufi spiritual authority; generally believed to have healing powers

Qur'an holy book of Islam

Qur'an-e-hafiz someone who has learned the Qur'an by heart and can recite it

Qur'an-e-khatam entails the complete reading of the whole Qur'an, preferably in one sitting, commonly undertaken for the welfare of sick children. This is usually done by getting one or more *imams* to read the whole Qur'an from the beginning till the end. But sometimes mothers of sick children also performed this over a period of a few days.

sadgah (< Arabic *sadaqah*) donations of money or sacrificed animal meat to poor people

tabiz amulet, usually for healing or protection; generally obtained from *imam* or *pir*

Tablighi Jama'at International Islamic religious movement with large membership in Bangladesh and other South Asian countries; affiliated organisation in UK

tel pora blessed oil, used for healing massage; may be obtained from an *imam*.

ulema Islamically learned men

ummah International community of Muslims

umrah a shorter *hajj* of about two weeks' length. This can take place any time during the year, while the annual *hajj*, usually four weeks' length, falls on a particular time of the year and attracts a much larger population from around the world.

upordosh 'Something evil from above', see *batash* above.

upri 'from above' is used to refer to attack by bad *jinn* (see also *batash* above), e.g. in the case of illnesses which cannot be healed by conventional medicine and for which one may resort to the services of a *imam* or *pir*.

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