

Research papers

Genetics, religion and identity among British Bangladeshis: some initial findings

Santi Rozario PhD

Senior Research Fellow, Religious and Theological Studies, Cardiff University, Wales, UK

ABSTRACT

This paper presents initial findings from an Economic and Social Research Council (ESRC)-funded project 'Genetics, religion and identity: a study of Bangladeshis in the UK'. The aim of this interdisciplinary study is to explore the role of Islam among UK Bangladeshis in relation to genetic counselling, and to understand how Bangladeshi Muslims in the UK make sense of genetically related diseases. In particular, the intention is to find out how Bangladeshi Muslims in the UK made decisions about genetic testing, and how (if at all) information about possible genetic risk factors are transmitted from one generation to the next in Bangladeshi Muslim families. In addition the project aims to

explore how British Bangladeshis negotiate the possibly conflicting messages they may receive from health professionals and Islamic authorities, and whether Islam plays a role in accounting for genetic disorders and in helping families to care for affected members. This paper presents the results of some preliminary discussions with British Bangladeshi women and with Bangladeshi imams (Muslim clerics), which have yielded valuable information regarding opinions about and knowledge of genetically related disease.

Keywords: British Bangladeshis, genetics and religious belief, Islam and genetic disorders

Introduction

This paper provides a preliminary report about a study that is intended to explore issues to do with genetic disorders and genetic counselling among two UK Bangladeshi communities, in South Wales and the West Midlands, including the ways in which Islam affects how the community deals with genetic issues. I begin with some background issues to the study.

In the 2001 British census, a total of 280 830 people gave their ethnic identity as Bangladeshi. Almost all of these were Muslims, making up the second-largest Muslim community in the UK. Only 1.26% gave another religious identity, although 0.43% gave 'no religion' and 5.83% did not state their religion (National Statistics, 2005a,b).

The history of the migration of this community has been covered in detail by other authors (e.g. Gardner and Shukur, 1994; Gardner, 1995, 1997; Eade, 1999; Glynn, 2003) and I will not discuss it here except to note that the UK Bangladeshi community is today one of the most disadvantaged ethnic groups in the UK. Bangladeshi men have the highest unemployment rate

(18%) of any of the ethnic groups specified in the census, and Bangladeshi women have the highest female economic inactivity rate (77%). Bangladeshis also have the highest percentage of people of working age with no educational qualifications (48% of women and 40% of men). As might be expected, health indicators for the Bangladeshi population are also poor (National Statistics, 2004).

Health administrators are not in a position to do much about issues of social disadvantage, and it is often tempting in such a situation to blame the community itself for its health problems. Certainly, this seems to have happened in relation to UK Pakistanis, who are in a similar situation in many respects. Shaw (2005, personal communication) noted some years ago that doctors in hospitals in and around Oxford saw the Pakistani community as a medical problem because of the high rates of consanguineous marriage, that is marriage between close relatives. She went on to carry out an anthropological study of genetic counselling in relation to UK Pakistanis, demonstrating

that the linkage between marriage practices and community health indicators is far from straightforward (Shaw 2000a, 2003a). UK Pakistanis come from a variety of quite different backgrounds in Pakistan. While some groups indeed have high rates of consanguineous marriage, these need to be understood in relation to a variety of contemporary economic and social factors, including the use of marriage as a way of bringing over family members to this country (Shaw, 2000b, 2001).

In addition, it is less than clear how far the practice of consanguineous marriage leads to high rates of genetically related illness. Referring to research on North African, Middle Eastern and Asian populations where consanguineous marriage is also common (Bittles *et al*, 1991; Jaber *et al*, 1998), Shaw notes that 'epidemiological evidence from these populations shows consistently that parental consanguinity is associated with an increased risk of recessively inherited disorders and with higher rates of infant mortality and morbidity' (Shaw, 2000a). Bunday and Alam (1993) studied 4934 babies, of whom 956 were from the UK Pakistani community, in a Birmingham study. They found a dramatic increase in adverse birth outcomes for children born to consanguineous parents. Christianson and Modell (2004) argue, on the basis of Bittles *et al* (1991), that 'available data indicate that the birth prevalence of infants with recessively inherited disorders rises by about 7.0/1000 for every 0.01 increase in the coefficient of consanguinity (F)'. They calculate that, on the basis of the Birmingham birth study, F for British Pakistanis is about 0.0431, compared with about 0.003 for most North European populations.

While this sounds clear enough, it is only with the more straightforward recessively linked disorders such as thalassaemia and haemophilia that there is clear and well-understood linkage between high rates of consanguineous marriage and a higher incidence of genetic disorders. Many genetic disorders are not inherited in this way, and in these cases consanguineous marriage does not necessarily affect the incidence of the disorder, particularly where the alternative is likely to be marriage to another member of the same community. In addition, the identification of a genetic disorder is often much less straightforward than in cases such as thalassaemia or haemophilia. The diagnosis of genetically related illness, as with other forms of diagnosis, is the result of complex clinical processes, and is often far from certain (Shaw, 2003b; Atkinson, 2005).

This is particularly true in relation to the diagnosis of developmental disorders. Whether a child has a developmental disorder or not is a difficult question of clinical judgement. It can be difficult to disentangle the effects of poverty and social disadvantage from those of a possible genetic problem. It seems likely that

awareness of Pakistani marriage practices has led to some medical authorities being over-ready to identify unspecific developmental disorders among Pakistani children, and to see them as resulting from inter-marriage within the community. In other words, it is arguable that often health issues among Pakistanis and similar populations are being seen as genetic problems, where the real difficulties are elsewhere in socio-economic deprivation, poor access to healthcare because of language and other difficulties, discrimination and disadvantage in the education system. Ahmad (1995, cited in Darr 1997) comments that 'the fascination with consanguinity in the NHS owes more to racism than to science'. Thus, for example, a study of birth outcomes in the Pakistani community in Bradford argued that 'consanguinity ... is not the main factor associated with adverse birth outcome in Bradford Pakistani families', and suggests that 'epidemiological and clinical obsession with consanguinity as the principal cause' is in itself a major problem (Procter and Smith, 1997; see also Darr, 1997; Stacey, 1997).

It is also worth noting that the increased risk of recessively linked disorders may be offset by other, more positive, features of consanguineous marriage, especially in the migrant situation. Shaw (2003a) describes the Pakistani preference for cousin marriages 'as a means of reducing the social risks of marriage outside the family'. Women enjoy a better status within consanguineous families compared to women married to non-related families (Modell, 1997; Shaw, 2000b). Modell (1997) comments that in Pakistani marriages 'a daughter is not perceived as a burden because a balanced sex ratio is desired within the extended family'. She goes on to point out that according to Aamra Darr 'consanguineous marriage can strengthen the power position of women because when it is common, patrilineal families are also to some extent matrilineal. A woman who marries her cousin has blood ties in her own right with her mother-in-law or father-in-law' (Modell, 1997). In addition, consanguineous families may be at a distinct advantage when it comes to coping with their disabled members (Modell, 1997; Shaw, 2003a).

Researchers should be cautious about seeing consanguineous marriage among UK Pakistanis as a major health issue for the Bangladeshi population. Both Pakistanis and Bangladeshis in the UK are socially disadvantaged populations, and a narrow focus on genetic issues may divert attention from more significant problems elsewhere. In any case, Bangladeshi attitudes to consanguineous marriage, genetic illness and genetic counselling cannot be viewed purely in biomedical terms. They need to be understood within the wider social context of UK Bangladeshi society.

Genetics and family structure among British Bangladeshis

So far, there is little reliable information about consanguineous marriage among Bangladeshis, either in Bangladesh or in the UK. One unpublished study (by Khan *et al*, 1985, cited in Hussain and Bittles, 2004) reported rates of 6.7% and 17.9% for two populations in Bangladesh. This is a much lower rate than those reported from Pakistani populations in Pakistan and in the UK, which range from 35% to 60% (Shaw, 2001; Hussain and Bittles, 2004). However, this is only a single study, and it does not refer to Bangladeshis in the UK, or even to the region of Bangladesh (Sylhet), from which most British Bangladeshis originate. The study by Bunday *et al* (1990) in Birmingham included 216 Bangladeshi mothers, and reported that 13.4% had related parents (compared to 68.7% of the 956 Pakistanis in the study). This is roughly consistent with Khan *et al*'s (1985) Bangladeshi study, but the sample is not large (Bunday and Alam, 1993).

From discussions with members of the Bangladeshi community in Cardiff and Birmingham, the two primary locations of our study, it is evident that there are significant levels of marriage with cousins and other close relatives among British Bangladeshis. Sometimes, cousin marriages are preferred as a way of bringing family members to the UK. Also, as with the Pakistanis, cousin marriages may be seen as desirable to maintain bonding and solidarity with relatives after family property has been divided up and families have begun to fend for themselves. Bangladeshis, especially in the migrant situation, feel it is better to 'marry your own' so that individuals know that they can rely on their in-laws and that their behaviour and values will be similar. Here it is worth recalling the argument presented by Inden and Nicholas (1977) that 'the code of conduct of a particular clan, family, or sex is thought to be embedded in the bodily substance shared by the persons of each genus and to be inherited by birth'. There are, however, suggestions that cousin marriage is less common for the younger generation (age 20 years or below), with marriages more likely to take place within the UK Bangladeshi community than with kin back in Bangladesh.

There are a number of other structural factors that have a bearing on any study of genetic counselling among UK Bangladeshis. These include non-standard family and household arrangements, often, particularly among the older generation, arising from strategies adopted to deal with immigration rulings in relation to polygamous marriages. Thus a Bangladeshi man might have a wife in the UK and another in Bangladesh, and have children from both. While he can sponsor his children from the wife in Bangladesh

for migration, he cannot bring their mother over. 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). Such household structures and kinship patterns clearly have implications for women's position and status within these families and the community in general. They also have implications for the attitude of members of these families to genetic diseases and genetic counselling.

Another significant factor is social class and status differentiation among the UK Bangladeshis. The major divide here is between the well-off Bangladeshis, most of whom are non-Sylhetis, and the relatively less well-off and less educated families, most of whom originate from Sylhet. This division is by no means clear-cut in that there are some well-off, educated Sylheti families. While most of the earlier Sylheti migrants originated from rural and uneducated backgrounds, some of the more recent migrants come from urban backgrounds, often starting off as university students before settling down in the UK. These groups maintain considerable distance from each other (Khanum, 2002), a factor that has implications for healthcare, since many Bangladeshi social workers, health workers, interpreters or translators come from elite, non-Sylheti backgrounds.

I have written elsewhere at length about the situation of women in Bangladeshi society (e.g. Rozario, 2001, 2002a,b), and this also has a bearing on the study of genetic illness among the UK community, since there is considerable continuity between the situation in Bangladesh and in the UK (Khanum, 1999). In Bangladesh, women are still second-class citizens. This means that they take second place within the household and community, and have to accept men's authority at home and outside. This authority is linked to women's perceived dependency on men economically and culturally. In the Bangladeshi patriarchal kinship system, a woman always leaves her parents' household to join her husband and his parents to live in their household. For a Bangladeshi woman marrying a man resident in Britain, this means leaving behind all her relatives in Bangladesh and joining her husband's family in the UK. However, it is not uncommon for British-born Bangladeshi women to marry their cousins or non-related men from Bangladesh. In this situation, the woman is typically much better off, because she is likely to have better language skills, and often better education, than her husband. One imam in Birmingham thought that these women tended to be very powerful in relation to their husbands.

The position of Bangladeshi women in the UK is not easy, but the migrant situation can also open up opportunities for them that they never had before, and allow them to do things that they were not allowed to do in Bangladesh (Ahmed, 2005). In particular, it may make it possible for women to become economically independent from their husbands, even if this means relying on government social security provision. All these factors lead to a form of empowerment for women. Despite this, it has been found that most women feel isolated and alienated, and feel even more dependent on their husbands and families in the UK. The reasons for women not being able to gain control over their lives are many. They include lack of education and language, but sometimes even when women are educated and have English language skills, their husbands and in-laws control their income, whether from social security or from their employment (Khanum, 1999; Phillipson *et al*, 2003).

Above all, the primary role of a Bangladeshi woman is to produce children, so that marriage is as essential for UK Bangladeshis as it is for women in Bangladesh itself. Even on my limited acquaintance so far, it is common for women to have three or more children. This is true even for relatively young women born and brought up in the UK. Phillipson *et al* (2003) found that among their 100 Bangladeshi informants in the Tower Hamlets, 'the average number of children was 5.2, with just 8% of women having two children or less ... Two thirds of respondents had five or more children'. Children are the primary symbol of a woman's worth, and having several children may be linked both to community attitudes and to recent religious revivalism in which contraceptives may be seen by many as un-Islamic. Yet in urban Bangladesh, by contrast, most families now will have one to three children, and any more are seen as too many. Even in the rural areas, family planning programmes are making it possible for poorer families to curtail the number of children they have, as a way of coping with their poverty-stricken situation.

Increasing levels of commitment to Islam are also a significant factor within the UK Bangladeshi community (Glynn, 2002, 2003; Ahmed, 2005). Muslims all around the world are taking a renewed interest in Islam, and are becoming much more committed to their religion and to the world Islamic *ummah* or community. This change has generally 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 in 1989, and the 1991 war in Iraq, and 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. A widespread response has been increased levels of religiosity

on the part of both Muslim men and women, along with behavioural changes such as women adopting some form of veiling or *hejab*. Much has been written on this new Islamism and its implications for women, debates to which I have also contributed (Rozario, 1996, 1998). The term 'Islamism' is preferred to 'fundamentalism' by many scholars writing in this area, as distancing themselves from simplistic and reductive analyses. However, some scholars find 'Islamism' itself problematic, for example because it groups together apolitical Islamic groups, Islamic liberal reformers as well as politically oriented groups with conservative or fundamentalist agendas (Moghissi, 2000). I use it here as the least problematic term.

This new Islamism is much more influential among the younger generation, particularly those from relatively middle-class backgrounds. As Glynn has shown for Bangladeshi Muslims in the Tower Hamlets, it is educated young people who are being drawn to the call of purist international Islam (Glynn, 2002, 2003). Elsewhere, I have argued in relation to Bangladeshi women in Bangladesh that the new Islam and the veiling is particularly attractive to middle-class, often university-educated women, and that this can be understood in terms of local problems with socio-economic development and to these women's sense of being disadvantaged within the new Western-driven development scene (Rozario, 2006, unpublished). Glynn cites reasons of alienation from the mainstream society, linked to problems of housing, unemployment, violence and drug addiction that affect the young more directly than the older generation (Glynn, 2002, 2003). However, this new international Islam also creates a tension between the young Islamists and their parents, for the new international Islam makes a clear distinction between culture and religion. This means the young Muslim radicals are critical of their parents' Islamic practices, which they see as contaminated by non-Islamic and Hindu influences.

The renewed commitment to Islamic values goes far beyond outward changes such as the adoption of Islamic dress modes. It shapes how many Muslims think and react in every aspect of their lives. As we will see below, this may affect the attitudes of UK Bangladeshi Muslims, particularly in the younger generation, towards issues arising in relation to genetic disorders, such as the appropriateness of contraception, prenatal testing, or the termination of pregnancy. We should be careful to refrain from simply labelling Muslims' attitudes to such issues as 'Islamic culture'. As Strathern (1997) has noted, it is too easy to read *difference* in terms of *culture* which can easily become a way of pigeon-holing and dismissing other people, and avoiding the need to see them as beings as complex as ourselves.

Aims and methods

This study is organised by a team at Cardiff University and I am the main researcher. The aim of the study is to find out what Bangladeshi Muslims in Britain know about genetic disorders, and how they deal with them. The research is particularly concerned with the roles of both health professionals and Muslim religious professionals, imams, in relation to genetic disorders. The design involves using qualitative and ethnographic methods, primarily in-depth semi-structured interviews and fieldwork observation to gather information from about 20 Muslim Bangladeshi families, who have been referred for genetic counselling, in Birmingham and Cardiff. Participants will be contacted through the genetic counsellors and consultants. The research will include not only the patients themselves but also members of their extended families who are living within the same household or nearby. An ethnographic approach with Bangladeshi communities in Cardiff and Birmingham in general will be used to complement work with the patients and their families. This approach will facilitate understanding and contextualisation of the issues and problems of the Bangladeshi population affected by genetic disorders. Since I am a native Bengali speaker familiar with Bangladeshi regional dialects, I am able to work without an interpreter in Bangla, the Sylheti dialect, and English, and I find that I can communicate effectively with virtually all members of the Bangladeshi community in the UK.

I commenced work at Cardiff in January 2005 but could not begin the study until it had been approved by the university ethics procedures. In addition, I obtained research and development approval from the two NHS trusts involved, in August and September 2005. As a result, interview work with patients and families is still in very early stages at the time of writing.

While waiting to commence research with patients and their families, I worked on getting to know the local communities in Cardiff and Birmingham on an informal basis. The present article derives from these informal discussions, primarily with a group of Bangladeshi women, and with four imams. The women were initially contacted via community workers in the health or other sectors, and I have since spent time with several of them in a variety of informal contexts. The imams were contacted through a Muslim hospital chaplain. Their backgrounds were quite varied, in terms of degree of formal education, extent of religious learning and class backgrounds, and they also vary in terms of regional origin and periods of residence in the UK.

As with any social research, the gender positions of the interviewer and interviewees have a bearing on

data collection, as do other factors such as class and religious background. I originally come from a poor rural family in Dhaka district, where I still have many poor relatives. This, combined with my ongoing research experience with rural Bangladeshis, puts me in a good position to build up rapport with the disadvantaged group of Bangladeshis in the UK, who are themselves mostly of fairly poor rural origin.

As a Bangladeshi woman myself, albeit from a different class position at present, I was able to develop good rapport quite easily with the women. Interaction with Bangladeshi men has been more limited, largely because I need to be mindful of the rules of sex segregation and I am therefore cautious about spending more time with the Bangladeshi men. I have met many educated Bangladeshi families socially. In these families sex segregation is not very strict, and talking to men is unproblematic. With less educated families, initial contacts tend to be primarily with the women, but it is usually possible after a while to interview men in the presence of their wives. However, the four imams, who were all men, were happy to meet me and to spend some time talking, and I found these meetings very productive. The interview situations varied. In one case I met the imam at his workplace, while in two cases I met imams at their homes in the presence of their wives. The wife of the remaining imam was still in Bangladesh, but I met him when his students were beginning to arrive at his residence for their daily afternoon lessons.

Perceptions of genetic disorder among British-born Bangladeshi women

The following is based on a series of discussions with a group of British-born Bangladeshi women of Sylheti origin who varied in age from mid-20s to early 30s. The women met together regularly as part of a community project. All were married with children, and most of them had some kind of part-time employment. All were fluent in English as well as Sylheti, and educated at least to secondary school level in the UK. All but one wore some kind of head-covering, and appeared to take their Islamic identity quite seriously.

Like other British-born Bangladeshi women of this generation, these women had at least some awareness of the possibility of genetic disorders. I heard from several sources about women in this generation who had effectively resisted their parents' attempts to arrange marriages with close relatives (cf. Phillipson, Ahmed and Latimer's study of Tower Hamlets, Phillipson *et al.*, 2003). At the same time, I am not sure how much these women really understood about

genetic disorders. Certainly there was little or no familiarity with specific genetic disorders such as thalassaemia or Down's syndrome. This might be compared with one of Phillipson's informants, who replied to her mother's suggestion that she marry her cousin, 'I don't want to have spastic children' (Phillipson *et al.*, 2003).

They were conscious of an unwillingness to share information about genetic problems among the older generation of Bangladeshis, though they felt that their generation was more open. Secrecy about genetic disorders is not surprising among Bangladeshis, since a reputation for having sick children would have drastic implications for the marital prospects of other children in a family. Genetic counsellors with whom I have spoken have commented on the unwillingness of Bangladeshis to share information about being affected by thalassaemia even with members of their extended family. Similarly, families may decline the services of a Bangladeshi interpreter because of their concern that other community members will get to know about their genetic problems through the interpreter. People will happily discuss their problems of heart disease and diabetes openly, although these too may have a genetic component, and yet will not talk about their children's disabilities. This secretiveness about genetic problems seems to contrast with findings from Pakistani families in the UK. We know from research with UK Pakistanis that when the illness is caused by consanguineous marriages the family will readily share the information with their *biradheri* (their extended family) (Modell, 1997).

I am not in a position to offer a conclusive explanation for this difference. Consanguineous marriages are less common among the Bangladeshis, and they do not typically have the enclosed, largely endogamous *biradheri* groupings typical of Pakistani communities. Also, because there has been much less concern by health authorities about genetic disorders among UK Bangladeshis, and little so far in the way of active community intervention, families with one or two affected members may remain isolated and be unaware that many other families have similar problems. There might be something to be said for introducing the kind of support groups and community interventions that have been trialled among UK Pakistanis (Darr, 1997), if only as a way of making people more aware of the existence of genetic disorders.

Since genetic counsellors often need to communicate with members of the extended family of affected individuals, secrecy clearly creates a barrier to their work. It also, of course, makes my own study more challenging and difficult.

Despite this, one of the striking features of my conversations with young, British-born Bangladeshi

women was their positive attitude towards children with genetic disabilities. Disability for these women was seen as a problem, but not as something that the family could not deal with. One woman spoke of her 29-year-old disabled cousin, who had the mental capacity of a three year old, but 'is dearly loved by her mother, her five brothers and other relatives'. She mentioned another disabled child and her wonderful smile when her mother played with her: 'That mother has poured ten times more love on this child than any other mother would for their child'. The same woman argued that if there was something really wrong with a child, the mother's body would automatically reject the fetus and it would not be born alive.

This readiness of families to look after disabled members is also found among Pakistanis (Shaw, 2003a). Religion is a big issue here: Allah has given for a reason (cf Atkin and Ahmed, 2000; see also Panter-Brick, 1991 for Saudi Arabia). The women's attitudes to prenatal tests and to termination of pregnancy on genetic grounds revealed more about the role of religion in their attitudes, and indicated that these women, like many other young Muslims in the UK, had moved towards the new, purist and international modes of Islamic commitment discussed earlier. Such forms of Islamic commitment contrast with the relatively syncretistic and relaxed forms of Islam traditionally found in Bangladesh.

Thus one of the British-born young women in her mid-20s was opposed to the idea of amniocentesis because it is against Islam. Her friend joined in to say that the test causes miscarriages. Both of them were also opposed to abortion: 'a lot of us would not go for it because it is against Islam'. They commented that one of their friends had decided to continue her pregnancy to term, although she had medical advice that the baby was affected with a severe genetic disorder and would most probably be dead at birth. To her, it was all Allah's wish: whatever He wants will always happen. For these women, sterilisation was also not allowed in Islam. As one woman commented, 'On the day of the *kiamat* [judgement] the child will come and ask you, why didn't you let me have a life?'

I see the attitudes of these British-born Bangladeshi women as a reflection of their active and conscious identification with the new purist Islam. These women were Western educated and able to manage their lives within the British context with much more ease than women who had migrated as adults and had often received very limited education in Bangladesh. Their attitude to genetic issues was a reflection of their identity as veiled and practising Muslims. It was part and parcel of their solidarity with the world Islamic *umma* (community), which many Muslims understandably regard as being under siege by the West.

Islam and Bangladeshi imams: perspectives on genetics

I interviewed four UK imams of Bangladeshi origin in order to get some idea of their attitudes to genetics. I expected to get a more informed view of genetic issues from this group than from the women, since questions of genetic disorders and appropriate Islamic responses to them have been actively debated by Islamic scholars in recent years (see below). However, my impression from my interviews with the four imams was that they had little or no understanding of what *genetic disorders* might be. After I explained what thalassaemia was, one imam said he sometimes gave a lift to a Bangladeshi family who live close to him to go to a hospital for blood transfusion for their three-year-old son. However, he had never enquired in detail as to the boy's problem, and when I asked whether the child, for example, used a pump during the night to deal with the excess iron in his blood he did not know. Another imam responded to my questions about the Islamic perspective on genetic disorders by saying, 'Islam says not to go near people with contagious diseases'! A third, more educated imam said he has been in his position in the UK only for a year and has not come across any cases of genetic disorder.

The fourth imam too did not know what thalassaemia was, but when I explained the symptoms he said he knew of a young boy who used to go to the hospital for monthly blood transfusions. However, the family never came to see him for any advice or help. Later on, this same imam told me a story of a Bangladeshi man having come to see him when his baby son was in the hospital, having to be kept alive by a machine. It was not clear what the problem was, but the doctor had told the man that they could take the baby home and let it die in its own time, or let the hospital keep it alive by machine, for a certain period. The man was obviously torn as to whether to take the baby home and let nature take its own course. The imam also found this a very difficult decision. Eventually, the man asked the imam, 'What would you have done if it was your own son?'. The imam said, 'I would have taken it out of the machine and let nature take its own course on my son'. So the man too finally did this, and the son died soon after he brought him home. It is possible that this baby was affected by some genetic disorder, but the imam clearly did not know. This is the only case I came across where an imam was possibly being asked for advice in relation to a genetic disorder.

I find it puzzling that, with the possible exception of this last incident, none of the imams had been asked for advice or help in relation to the genetic disorder of a family member. This was so even with the one imam

who worked as a hospital chaplain. When asked about his role as a Muslim chaplain, he said 'It's religious, spiritual and pastoral care. Bangladeshi families find me as a friend, interpreter, social worker'. Yet all of the imams had many clients coming to see them regularly for other health problems. For the most part, these were health problems that people attributed to *jadu* (magic), *nazar* ('evil eye') or *jinn* (evil spirits). People believed that health professionals could not treat these problems, only religious leaders or other folk healers could do so.

Although none of the imams had been approached by anyone seeking their advice on genetic-related illness, I asked for their perspectives, or the perspective of Islam, on prenatal testing, termination of pregnancy, contraception and consanguineous marriages. None of the imams saw any problems with prenatal testing. One qualified this by saying that it is allowed in Islam to check that everything is in order, but that this should be done by a female doctor if possible. When a female doctor is not available, it is permissible for a male doctor to check up.

The four imams differed on the issue of termination of pregnancy in relation to genetic disorders. One of the more educated imams, who had arrived about a year ago after spending some 20 years in Saudi Arabia and Kuwait, said, 'Islam is about people's wellbeing; Islam does not allow destroying life'. But then he added, 'Life begins after 120 days of pregnancy'. Thus termination is not a problem up to 120 days of pregnancy, because the fetus is not considered to have life. I asked him whether, if a couple came to him asking for his advice in relation to a genetic problem in their unborn baby, he would be happy to give them this same explanation. He said that he would. However, the other three imams argued that Islam does not allow termination of pregnancy under any circumstances. One commented that 'destroying the baby because it will be a burden to parents is not allowed in Islam' and that 'in Islam, it is a sin to kill anything that is alive'. For him, the *Qur'an* stated that 'life begins with sperm'. Only one of these three, the imam who was also a hospital chaplain, added that termination was allowed if the baby was a risk to the mother's health.

These opinions appear to reflect differences in the wider Islamic community on these questions. Thus the Deobandi scholar Mufti Allie Haroon Sheikh says in his *Islamic Principles on Family Planning* that:

Attitudes and opinions differ. Some persons feel that a new life has been created when the sperm and the egg merge. Others feel that the foetus becomes a human being when it assumes a human shape and appearance; others when the pregnancy reaches 28 weeks of gestation and the foetus becomes capable of independent survival; still others feel that it is a human being only after birth, when the foetus has severed its parasitic circulatory connection with the mother (Sheikh, 1999).

However, Modell and Darr (2002) note that 'a fatwa [an authoritative ruling on a point of Islamic law] that accepts abortion for genetic reasons in the first trimester has been issued in several Islamic countries, including Pakistan and Iran'. Similarly, the Saudi Arabian authority Mohammed Ali Albar notes that:

The fatwa of the Islamic Jurisprudence Council of the World Islamic League at its 12th session (10–17 February, 1990) in Mecca, agreed by a majority vote to allow for the option of abortion under certain specific conditions. The fatwa determined that an abortion may take place only if a committee of specialized, competent physicians has decided the foetus is grossly malformed, and that its life would be a calamity for both the family and itself. The malformation must be untreatable, unmanageable and very serious, and the abortion may only be carried out prior to the 120th day of conception (Albar, 1999).

This 120-day period derives from texts in the *Qur'an* and *hadith* that are interpreted as meaning that the soul is breathed into the fetus after 120 days (Sheikh, 1999). On recent opinions and debates among Islamic authorities on these issues see also El-Hashemite, 1997; Albar, 1999; Hussain, 2005; Kyriakides-Yeldham, 2005.

In relation to contraception, one of the imams said that it is allowed when a woman has a small baby that she needs to look after, or when her health is poor, but that she should consult a Muslim doctor. He said that *azal* [coitus interruptus] is permitted, and so is the use of condoms. However, permanent contraceptive methods are not allowed. Nor is contraception allowed 'to keep one's body pretty, or for reasons of money'. When I asked about poor families in Bangladesh who might feel they cannot feed so many children, his comment was 'These people do not work hard, that's why there is no food in their house'. He said that Allah already provides a source of food, before he allows a baby to come into the world, and gave mother's breast milk as an example.

Two other imams also emphasised that sterilisation was not allowed in Islam, but that other methods may be adopted if the mother's health is an issue. However, the current Islamic literature on contraception is less restrictive than the Bangladeshi imams' perspective. Albar notes that '[i]n Islam it is acceptable to use temporary means of contraception, if the couple is agreeable, and if no harm is likely to result. However, sterilization is not acceptable, unless the health of the mother would be endangered by pregnancy' (Albar, 1999).

In relation to consanguineous marriages, all four imams thought that cousin marriages were allowed. They all had a list of blood relatives (14 or 10 in number) with whom one could not enter into matrimony. This list is based on the *Qur'an*, Surah al-Nisa 4:23. One imam said, 'Islam does not object to cousin

marriages, nor does it encourage them'. Albar, however, says that:

Islam discourages first-cousin marriages. It is narrated that Omar Ibn Al-Khatab, the second khalifa, noticed that the progeny of the tribe of Bani Assayib had become weak and unhealthy because of intermarriage of cousins. He advised the tribe to avoid close-cousin intermarriage and to seek wives and husbands from tribes further afield, saying: 'Marry from far away tribes, otherwise you will be weak and unhealthy' (Albar, 1999).

In conclusion, it is striking that both the imams and the British-born Bangladeshi women are taking positions that are more restrictive than current Islamic fatwas would require on issues such as termination of pregnancy and contraception. Some of this may be a matter of lack of awareness, since many UK Bangladeshi imams come from village backgrounds and may have limited exposure to international Islamic scholarship and legal opinions. It is also possible, however, particularly with the British-born women, that identity issues may be leading them consciously to take positions that they see as 'Islamic' and as contrasting more strongly with current Western practices. I was struck by the similarity to attitudes I found among young women university students in Bangladesh, where identity issues of this kind again seemed significant (Rozario, 2005).

However, we should be wary about generalising regarding the attitudes of British Bangladeshi Muslims to genetic disorders. As among the wider British community, individuals and families have differing opinions, and I expect to find more evidence of such variety as my research proceeds. What is already clear is that the provision of relevant and appropriate health services in this area can only be helped by more knowledge of how people within the British Bangladeshi community understand genetic issues and of what they feel is an appropriate response to genetic disorders.

ACKNOWLEDGEMENTS

The research reported on here derives from an ESRC-funded project, 'Genetics, religion and identity: a study of Bangladeshi Muslims in Britain', by Dr Sophie Gilliat-Ray (principal investigator), Professor Angus Clarke, Professor Stephen Pattison and Dr Joanna Latimer. An earlier version of this material was presented to the half-day conference, *Living and Working with Sickle Cell and Thalassaemia*, Future Inns Hotel, Cardiff Bay, 7 July 2005. I would like to acknowledge the assistance of Dr Sophie Gilliat-Ray and also of Roiyah Saltus Blackwood of the Sickle Cell and Thalassaemia Research programme at the University of Glamorgan who organised the conference. Professor Geoffrey Samuel read through the paper in detail and

provided valuable editorial assistance. Comments from Professor Angus Clarke and from two anonymous reviewers were also helpful in strengthening the paper.

REFERENCES

Ahmad W (1995) Consanguinity and related demons: science and racism in the debate on consanguinity and birth outcome. In: Samson C and South N (eds) *The Social Construction of Social Policy: methodologies, racism, citizenship and the environment*. London: Macmillan, pp. 68–87.

Ahmed N (2005) Women in between: the case of Bangladeshi women living in London. In: Meenakshi T (ed.) *Transnational Migration and the Politics of Identity*. New Delhi, London, California: Sage Publications, pp. 99–129.

Albar MA (1999) Counselling about genetic disease: an Islamic perspective. *Eastern Mediterranean Health Journal* 5: 1129–33. emro.who.int/Publications/EMHJ/0506/06.htm (accessed 28 November 2005).

Atkin K and Ahmad WIU (2000) Family care-giving and chronic illness: how parents cope with a child with a sickle cell disorder or thalassaemia. *Health and Social Care in the Community* 8:57–69.

Atkinson P (2005) *The Clinic in Transition: tradition and innovation*. Seminar for the School of Social Sciences, Cardiff University, 17 February 2005.

Bittles AH, Mason WM, Greene J and Appaji RN (1991) Reproductive behavior and health in consanguineous marriages. *Science* 253:789–94.

Bundey S and Alam H (1993) A five year prospective study of the health of children in different ethnic groups, with particular reference to the effect of inbreeding. *European Journal of Human Genetics* 1:206–19.

Bundey S, Alam H, Kaur A, Mir S and Lancashire RJ (1990) Race, consanguinity and social features in Birmingham babies: a basis for prospective study. *Journal of Epidemiology and Community Health* 44:130–5.

Christianson A and Modell B (2004) Medical genetics in developing countries. *Annual Review of Genomics and Human Genetics* 5:219–65.

Darr A (1997) Consanguineous marriage and genetics: a positive relationship. In: Clarke and Parsons (eds) *Culture, Kinship and Genes: towards cross-cultural genetics*. New York: Martin's Press, 1997, pp. 83–96.

Eade J (1999) Roots and routes: British Bengalis and questions of homeland. In: Weil S (ed) *Routes and Routes: ethnicity and migration in global perspective*. Jerusalem: The NCJW Research Institute for Innovation in Education.

El-Hashemite N (1997) The Islamic view in genetic preventive procedures. *The Lancet* 350:223.

Gardner K (1995) *Global Migrants, Local Lives*, Oxford: Clarendon Press.

Gardner K (1997) Identity, age and masculinity amongst Bengali elders in East London. In: Kershen A (ed.) *A Question of Identity*. Aldershot: Avebury, pp. 160–78.

Gardner K and Shukur A (1994) 'I'm Bengali, I'm Asian, and I'm living here': the changing identity of British Bengalis. In: Ballard R (ed.) *Desh Pardesh: the South Asian presence in Britain*. London: Hurst and Company, pp. 142–65.

Glynn S (2002) Bengali Muslims: the new East End radicals? *Ethnic and Racial Studies* 25:969–88.

Glynn S (2003) *The Home and the World: Bengali political mobilisation in London's East End, and a comparison with the Jewish past*. PhD dissertation, Department of Geography, University College London.

Hussain AA (2005) Ensoulment and the prohibition of abortion in Islam. *Islam and Christian–Muslim Relations* 16:239–50.

Hussain R and Bittles AH (2004) Assessment of association between consanguinity and fertility in Asian populations. *Journal of Health, Population and Nutrition* 22:1–12.

Inden RB and Nicholas RW (1977) *Kinship in Bengali Culture*. Chicago: University of Chicago Press.

Jaber L, Halpern GJ and Shohat M (1998) The impact of consanguinity worldwide. *Community Genetics* 1:12–17.

Khanum S (1999) 'Gateway to Hell': the impact of migration on Bangladeshi women's territory, position and power in England. *Empowerment* 6:1–18.

Khanum S (2001) The household patterns of a 'Bangladesh village' in England. *Journal of Ethnic and Migration Studies* 27:489–504.

Khanum S (2002) Anthropology at home: some methodological dilemmas in migration research. *Social Science Review* 19:225–34.

Kyriakides-Yeldham A (2005) Islamic medical ethics and the straight path of God. *Islam and Christian–Muslim Relations* 16:213–25.

Modell B (1997) Kinship and medical genetics: a clinician's perspective. In: Clarke and Parsons (eds) *Culture, Kinship and Genes: towards cross-cultural genetics*. New York: Martin's Press, pp. 27–39.

Modell B and Darr A (2002) Genetic counselling and customary consanguineous marriage. *Nature Reviews* 3:225–9.

Moghissi H (2000) *Feminism and Islamic Fundamentalism: the limits of postmodern analysis*. Dhaka: The University Press Ltd.

National Statistics (2004) *Focus on Ethnicity and Identity: summary report, January 2004*. www.statistics.gov.uk/statbase/Product.asp?vlnk=10991 (accessed 28 November 2005).

National Statistics (2005a) *Datasets for ER1 Ethnic Group by Religion*. www.statistics.gov.uk/statbase/ssdataset.asp?vlnk=6891&More=Y (accessed 28 November 2005).

National Statistics (2005b) *RE2 Religion by Ethnic Group*. www.statistics.gov.uk/statbase/ssdataset.asp?vlnk=6892&More=Y (accessed 28 November 2005).

Panter-Brick C (1991) Parental responses to consanguinity and genetic disease in Saudi Arabia. *Social Science and Medicine* 33:1295–302.

Phillipson C, Ahmed N and Latimer J (2003) *Women in Transition: a study of the experiences of Bangladeshi women living in Tower Hamlets*. University of Bristol: The Policy Press.

Proctor S and Smith I (1997) Factors associated with birth outcome in Bradford Pakistanis. In: Clarke and Parsons (eds) *Culture, Kinship and Genes: towards cross-cultural genetics*. New York: Martin's Press, pp. 97–110.

Rozario S (1996) Community and resistance: Muslim women in contemporary societies. In: Coslett T, Easton A and Summerfield P (eds) *Women, Power and Resistance*:

an introduction to women's studies. London: Open University Press, pp. 209–23.

Rozario S (1998) On being Australian and Muslim: Muslim women as defenders of Islamic heritage. *Women's Studies International Forum* 21:649–61.

Rozario S (2001) *Purity and Communal Boundaries: women, and social change in a Bangladeshi village* (2e). Dhaka: University Press Limited.

Rozario S (2002a) Poor and 'dark', what is my future?: identity construction and adolescent women in Bangladesh. In: Manderson L and Rice PL (eds) *Coming of Age in South and Southeast Asia: youth, courtship and sexuality*. Richmond, Surrey: Curzon Press, pp. 42–57.

Rozario S (2002b) Gender dimensions of rural change. In: Toufique KA and Turton C (eds) *Hands Not Land: how livelihoods are changing in rural Bangladesh*. Dhaka: Bangladesh Institute of Development Studies, pp. 121–30.

Rozario S (2005) The new burqa in Bangladesh: empowerment or violation of women's rights? *Women's Studies International Forum*.

Shaw A (2000a) 'Conflicting Models of Risk': clinical genetics and British Pakistanis. In: Caplan P (ed.) *Risk Revisited*. London: Pluto Press, pp. 85–107.

Shaw A (2000b) *Kinship and Continuity: Pakistani families in Britain*. Amsterdam, London: Routledge.

Shaw A (2001) Kinship, cultural preference and immigration: consanguineous marriage among British Pakistanis. *Journal of the Royal Anthropological Institute* 7:315–34.

Shaw A (2003a) *The Impact of Genetic Risk on UK Pakistani Families*. www.wellcome.ac.uk/en/genome/geneticsand/society/hg14f005.html (accessed 28 November 2005).

Shaw A (2003b) Interpreting images: diagnostic skill in the genetics clinic. *Journal of the Royal Anthropological Institute* 9:39–55.

Sheikh MAH (1999) *Islamic Principles on Family Planning*. Karachi: Darul-Ishaat.

Stacey M (1997) About genetics: aspects of social structure worth considering. In: Clarke and Parsons (eds) *Culture, Kinship and Genes: towards cross-cultural genetics*. New York: Martin's Press, pp. 231–44.

Strathern M (1997) The work of culture: an anthropological perspective. In: Clarke and Parsons (eds) *Culture, Kinship and Genes: towards cross-cultural genetics*. New York: Martin's Press, pp. 40–53.

CONFLICTS OF INTEREST

None.

ADDRESS FOR CORRESPONDENCE

Dr Santi Rozario, Senior Research Fellow, Religious and Theological Studies, Cardiff University, Humanities Building, Colum Drive, Cardiff CF10 3EU, Wales, UK. Tel: +44 (0)29 2087 0122 or (0)29 2064 1241; fax: +44 (0)29 2087 4500; email: rozarios@cardiff.ac.uk

Received 1 September 2005

Accepted 14 November 2005