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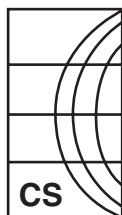
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Decision-Making and Ante-Natal Screening for Sickle Cell and Thalassaemia Disorders

To What Extent do Faith and Religious Identity Mediate Choice?

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abstract: When making decisions about prenatal diagnosis, couples not only draw on their understanding of the condition but also broader aspects of their cultural identity. This article looks at how faith and religion mediate attitudes towards screening, prenatal diagnosis and termination of pregnancy for sickle cell and thalassaemia disorders. The article specifically reports on a qualitative study, which used focus groups from a variety of faith communities (Muslim, Sikh, Hindu and Christian), at risk of haemoglobin disorders, living in England. Our findings suggest that the decision about whether or not to have diagnostic testing generally related to attitudes towards the termination of pregnancy. The consequences of the condition were as important as religious beliefs to most people. More generally, faith beliefs emerged as negotiable and contingent: realized within a broader moral framework. Religion was felt not to be prescriptive and reproductive decisions were seen as personal. When making decisions, people utilize faith within a broader context of individual, family and social relationships.

keywords: ethnicity ✦ prenatal diagnosis ✦ religious identity

The UK government is committed to implementing an effective screening programme for women whose pregnancy is 'at risk' of a sickle cell or thalassaemia disorder. Women and their partners can then be offered prenatal diagnosis with the option of either continuing or terminating the pregnancy. This, however, involves difficult and complex choices, in which couples not only draw on their understanding of sickle cell and thalassaemia but also broader aspects of their identity.

Knowing who we are and seeking legitimacy for this understanding of ourselves is at the heart of social life (Jenkins, 1996). To this extent, faith and religion assumes importance when making sense of a person's identity (Habermas, 2006), specifically reflecting changes in how ethnic identity becomes known to us, as we continuously reassess our understanding of what constitutes a multicultural society (Kymlicka, 2001). UK social policy, for example, is slowly beginning to recognize this. The 10-year census now asks about ethnic origin and religious affiliation. Government policy and the growing emphasis on culturally competent practice gives further expression to the importance of considering religious identity when developing appropriate and accessible service delivery (Popadopoulas et al., 2004). Such initiatives are facilitated by a broader sense of 'social inclusion', in which the state recognizes a plurality of interests, fostered through networks and partnerships (see Home Office, 2004). The potential for transformation, however, remains confused by the various discursive practices that aim to resolve and manage 'the problem' of ethnic diversity (Atkin, 2004).

Our article, by looking at how faith and religion mediate attitudes towards prenatal diagnosis and termination of pregnancy for sickle cell and thalassaemia disorders among various ethnic minority populations, makes sense of current tensions in policy and practice. Faith is believed to mediate the decision-making process and therefore represents a good case study from which to explore the broader sociological issues raised by religious identity. In doing so, the article not only provides insights into decision-making and ante-natal screening but also the relevance of continuity and change in understanding the experience of ethnic minority populations.

Religious Identity and Decision-Making

Religious identity is a notoriously difficult concept to define (see Bradby, 2003), although in some ways the multifaceted way in which it is known to us has many advantages. If nothing else, it reminds us of the complex and shifting nature of religious identity, as it comes to reflect an ongoing dialogue between culture, nationality and a shared heritage, in addition to religious belief (Modood et al., 1997). Some Muslim young people

whose families originate from the Punjab, for example, criticize their parents' interpretation of Islam as embodying cultural practices that have nothing to do with faith (Atkin and Hussain, 2003). Parents themselves express concerns that their children's religious values have become corrupted by western practices (see Ahmad et al., 2002). Indeed, Muslim young people do seem to have a more flexible approach to Islam than their parents and emphasize the more personal aspects of their religious beliefs, known as personal prayer or *dua* as opposed to formal ritualized prayers or *salat* (Modood et al., 1997). Religion, however, is still an important way of life for a Muslim young person, providing a moral structure that has implications for their whole life (Hussain et al., 2002). This broader process of social change also partially explains why Hindu and Sikh young people, although just as likely as their parents to acknowledge the importance of religious identity, are more likely to emphasize the importance of private spirituality (Modood et al., 1997).

Beyond this, religious identity is increasingly seen as a political symbol, defining exclusion by a powerful majority in which institutional cultures and racisms sustain inequalities, disadvantages and discriminations (Huntington, 2004; Weller et al., 2004). Religion can also be a source of pride and belonging (Parekh, 2006): in other words, a mobilizing resource which enables minority ethnic populations, as an 'imagined' moral community, to celebrate their difference and make legitimate demands as citizens (see Anderson, 2006; Husband, 1996). This is perhaps why, for many South Asian people living in the UK, religion and ethnicity often reinforce each other, especially among first-generation migrants. This, however, does not seem the case for African-Caribbean young people: the importance of religious identity is less strong for this group of young people when compared to their parents (Modood et al., 1997).

Much of European social policy, however, continues to associate religious identity with the essentialized 'other' (Atkin, 2004) and this explains why policy and practice struggle to make sense of difference and diversity (Ratcliffe, 2004). A focus that overemphasizes difference between the dominant and minority cultures emerges (Chattoo and Ahmad, 2003). Religious identity becomes stripped of context, subject to stereotypes and mythologies, rather than an expression of a person's negotiation of multiple identities within specific social and political contexts (see Bauman, 1992).

After outlining some of the theoretical themes relevant to our article, we now turn to the empirical literature, exploring the specific influence of faith and religion on decisions about prenatal diagnosis and termination. First, few studies specifically explore how a person's religion influences decision-making and those that do usually focus on Islam or Christianity. We know little about how other South Asian religions, such as Sikhism or Hinduism, influence people's decisions. Further, much of the literature

presents little more than descriptive accounts, devoid of context. Consequently, our understanding of how religion is mediated by other aspects of people's lives, such as personal experience, perceptions of the condition's severity and attitudes of the wider family, community or society is poor (Cinnirella and Loewenthal, 1999; Erikson, 2003).

Religious convictions are often presented as a reason for declining prenatal diagnosis and termination of pregnancy, especially among Muslim people and African and Caribbean populations who follow Christianity (Alkuraya and Kilani, 2001; Durosinmi et al., 1995; Lewando-Hundt et al., 2001; Obeng-Gyimah et al., 2005; Rozario, 2005; Zahed and Bou-Dames, 1997). Decision-making about prenatal diagnosis, however, is multifaceted and it is impossible to generalize (Ahmed et al., 2000; Atkin et al., 1998; De Montalembert et al., 1996; Modell et al., 1997; Parker et al., 2002; Tsianakas and Liamputtong, 2002). Even among Muslim populations, who demonstrate even greater reluctance to terminate pregnancies than other religious groups, one study has shown that 67 percent say that they would consider termination following a prenatal diagnosis of thalassaemia (Hewison et al., 2004). This suggests religious belief is more important to some people than others (Erikson, 2003: Raz, 2004).

Responsibilities for one's own future, as well as family and personal relationships, are seen as more influential when making a decision to seek prenatal genetic testing than religion per se (Remennick, 2006). In other words, when making a decision about prenatal diagnosis, people tend to consider the impact a disabled or chronically ill child would have on their future opportunities as well as the impact such a child might have on other family members. The influence of faith on a person's decision seemed to be mediated in relation to these concerns. Previous experience of the condition and judgements about its severity also seem equally influential during the decision-making process (De Montalembert et al., 1996; Henneman et al., 2001; Zahed and Bou-Dames, 1997). The literature further reminds us how religious identity is constructed within the context of social relationships (see Tsianakas and Liamputtong, 2002). South Asian populations are sometimes portrayed as making health care decisions following discussions with authoritative figures in the family, community or religious networks (Bottorff et al., 1998; Shaw, 2000), although the role of religious leaders on people's decision to accept prenatal diagnosis is complex and fraught with potential contradictions, between beliefs and eventual action (Kagu et al., 2004; Raz, 2004; Rozario, 2005).

Doing the Research

In the interests of reflexivity, it is worth discussing the reasons why the UK National Health Service (NHS) Haemoglobinopathy Screening

Programme commissioned this study, particularly since they reflect several of the theoretical tensions outlined in the preceding section (see Alvesson and Sköldberg, 2004). By acknowledging the considerable evidence suggesting that British organizations are institutionally racist, the Department of Health has long-standing anxieties about its ability to develop policy and practice that reflect the multicultural nature of British society (Department of Health, 2005). The commissioners' initial focus on religious beliefs and their influence on people's decisions represented an attempt to address this concern. A further policy agenda, however, informed the research focus: 'community cohesion' and 'social inclusion' (see Home Office, 2004). Reflecting on the pluralist nature of British society, the Department of Health wished to explore the potential of developing more meaningful ways (such as the use of religious and community leaders), of engaging with ethnic minority populations, particularly given its previous difficulties of facilitating successful dialogue. We refer to the validity of these assumptions throughout our analysis.

In practical terms, the study employed a qualitative methodology, involving focus groups with a variety of faith communities (Muslim, Sikh, Hindu and Christian) from different ethnic minority groups (Pakistani, Indian and African-Caribbean), at risk of haemoglobin disorders, living in England. Given the social context within which religious identity is constructed, the fieldwork had two distinct phases. Phase one examined different faith communities' attitudes to screening and prenatal diagnosis by talking to people of reproductive age about the influence of religion in making reproductive decisions. Phase two explored the potential role of community and religious representatives in influencing people's decision-making.

The material was collected through focus group discussions. The use of focus groups allows for speculative enquiry, while exploring normative values and assumptions, in relation to specific examples (Kruger, 1994). Focus groups are especially useful in accessing the views of people who are rarely asked their opinion on sensitive topics, where legitimation occurs within a social context (see Bloor et al., 2001). Focus groups are also useful in collecting detailed material, in a purposeful and manageable way, over a short period of time (see Carter and Henderson, 2005).

In exploring the four 'faith' communities' attitudes to prenatal diagnosis and termination of pregnancy, we conducted eight focus groups. These included Muslims of Pakistani origin; Hindus of Indian origin; Sikhs of Indian origin; and Christians of African-Caribbean origin. Separate focus groups were conducted for men and for women. Participants were recruited through community contacts. The inclusion criteria required participants to be between the ages of 18 and 45 years and to identify themselves as belonging to one of the four faith communities. All the

focus groups were conducted in community settings and ranged from four to nine participants. Written consent was obtained and anonymity and confidentiality assured. The focus groups lasted between 45 and 90 minutes. Focus groups with Pakistani Muslim, Indian Sikh and Indian Hindu participants focused on thalassaemia major and the focus groups with the African-Caribbean Christian participants focused on sickle cell disorders.

We then held four focus groups with formal religious and community representatives, such as religious scholars, priests and imams and key NHS Trust informants, such as chaplains. Potential participants were identified via known religious organizations. Most participants had little if any direct involvement with sickle cell and thalassaemia disorders, but did have a general view of religious interpretation of prenatal diagnosis and termination as well as direct experience of community politics. Focus group participants were identified as belonging to one of the four faith communities (Christian, Hindu, Muslim and Sikh). These focus groups included men and women, ranged from three to seven participants and were held in English.

We used a similar topic guide for each of the two phases, to allow for comparison between different faith groups and different stakeholders. Each focus group explored the influence of religion on an individual's attitudes to screening; the influence of others, such as family, community and religious leaders; and the influence of other factors such as severity and gestational age. Each focus group was audio-taped, transcribed verbatim and back-translated (where appropriate), on the basis of conceptual rather than literal meaning (see Atkin and Chattoo, 2006).[1] All transcripts were organized and coded using N-Vivo (Nudist-Vivo 1.2; Sage Publications). Analysis explored concepts, established linkages between concepts and offered explanations for patterns or ranges of responses or observations from different sources (see Brewer, 2000). This involved understanding the meaning of actions, beliefs, attitudes and relationships from the range and frequency of participants' views (Silverman, 2000) as well as consistent cross-referencing, which looked for similarities and differences among groups from different faiths (see Karlsen and Nazroo, 2006).[2] More generally, our study deliberately asked respondents to make hypothetical decisions rather than reflect on their actual lived experience.

Finally, in analysing our material, we were aware that responses to hypothetical questions do not always correlate with actual behaviour. They do, however, have the advantage of reflecting the broad underlying values and normative assumptions that inform the decision-making process. We consider this further in our discussion.

The Process of Decision-Making

Using Religious Belief to Make Decisions about Prenatal Diagnosis

When asked about the role of religion in prenatal diagnosis, the faith groups usually changed the focus of the discussion to religion's stance on termination. This is perhaps understandable but offers a reminder of how policy and practice need to reflect the experience of those it offers support to, rather than its own carefully articulated definitions (see Dyson and Brown, 2006). More generally, religion offered a framework in which to make sense of and legitimate experience. It was rarely seen as prescriptive: providing a rigid sense of right and wrong, but realized in a broader moral framework. This, as we see later, is a central theme of our analysis and one that explains the complexity of people's beliefs and values.

The Indian Sikh and Indian Hindu focus group participants emphasized that although taking a life might be regarded as 'a sin', this had to be balanced against 'preventing suffering'. According to the participants, this is why God gave people free will. As one Hindu man observed, 'if there is no free will, there is no need for God'. The Pakistani Muslim and African-Caribbean Christian groups came to similar conclusions, despite initially stating that termination of pregnancy was prohibited by their respective religions. This, however, was seen as negotiable, as long as such negotiations did not obliviously undermine core religious values or beliefs. The importance of 'free will' was once again mentioned as was prevention of suffering. A Pakistani Muslim man explained:

> It's not a robot religion it depends on the situation. We are not like robots. We can make our own decision. He [God] has shown us the right path and the wrong path and he says we can make our own decision.

An African-Caribbean Christian woman agreed:

> Follow the spirit of God and he will guide you and lead you because no one is perfect in life.

Most of the Muslim and Christian group participants felt that since God gave them 'free will' their reproductive decision would be based on their personal judgements and beliefs. This is how morality and religious belief become interrelated and, consequently, difficult to disentangle.

The Influence of Religious Beliefs

All the faith groups, except the African-Caribbean Christian group, agreed that they would want to know their religion's stance on termination. The African-Caribbean group's response did not reflect a lack of interest in the subject, but more a belief that they already knew their religion's stance and

further discussion was, therefore, pointless. The other groups placed different levels of emphasis on their desire for such information; the Pakistani Muslim groups were the keenest, for reasons we return to. Nevertheless, all the faith groups agreed that while they may explore their religion's stance on the issue, it would not necessarily influence their decision about termination of pregnancy. An Indian Hindu man explained: 'You would see what religion says but ultimately it's your decision.' Religious representatives and leaders – as we see later – tended to agree with this.

There were, of course, diverse opinions in every faith group and several people would not consider termination of pregnancy. Such attitudes, however, were related to individual beliefs rather than to religious values per se. This is perhaps not surprising. As we have seen, religious beliefs were not regarded as offering an absolute moral code but more of a framework in which to make decisions in a way that allows for individual interpretation: religious beliefs occur within a broader moral framework. This is why it is impossible to provide generalized accounts, common in policy and practice, that explain the religious behaviour of ethnic minority populations (see Atkin and Chattoo, 2006). Reconciling diverse interpretations becomes the key to successful policy and practice (see Dominelli, 2004). This requires considerable reflexivity on the part of health care professionals, as the following discussion illustrates.

Some Islamic states have generated *fatwas*, permitting the termination of pregnancy following a prenatal diagnosis of thalassaemia, before 120 days of gestation (see Abdel Haleem, 1993). These *fatwas* are sometimes used by health care professionals working in the UK, during their discussions with Muslim clients about prenatal testing. Muslim participants, however, still interpret such *fatwas* within the context of their own beliefs and experiences. In the focus groups, both men and women welcomed such *fatwas* in helping them come to a decision about prenatal diagnosis. Others, however, stated that they would not consider termination an option because of their own moral beliefs. Several also added that *fatwas* could be interpreted in various ways. For example, some participants pointed out that they had been produced in developing countries (which from their point of view included Lebanon, Saudi Arabia and Pakistan) and may not be applicable to western countries, given that treatment for thalassaemia is more readily available and that children are less likely to suffer.

Changing contexts were also reflected in the responses of the other focus groups. When prompted, some of the African-Caribbean Christian men associated the role of religion in reproductive decision-making with members of the older, 'more traditional', generation and suggested that younger generations were less likely to be religious. The Muslim, Sikh and Hindu groups did not make such a strong distinction and although

they felt there were differences between their religious values and those of their parents, such values were important to them (see also Modood et al., 1997). Cultural reconstitution, therefore, occurred in which parental attitudes are reinterpreted within the context of changing circumstances and social relationships (see Parekh, 2006). This process, however, did not make religious values any less relevant to a person's life, but simply different (see also Hussain et al., 2002).

Some participants in the Pakistani Muslim groups placed an emphasis on what would be permissible by Islam, and therefore stressed a preference for early screening so as to allow termination of pregnancy within the first trimester. This illustrates how health care professionals can work with a person's religious values and beliefs, when offering medical interventions. This, however, is not as straightforward as it seems. One of the main reasons why focus group participants – of whatever faith – would reject prenatal diagnosis was if it were offered too late. The possibility of termination during the second trimester was unacceptable to many people, whether or not they use religious beliefs as part of the decision-making process (see also Green and Statham, 1996), although this is often misunderstood by health care professionals (see Anionwu and Atkin, 2001). Some participants attributed this to their religious beliefs, while others simply said it reflected a personal moral preference: a late termination was regarded as unfair to the unborn child as well as being psychologically stressful for the mother. This is another example of the difficulties when trying to disentangle religious beliefs from other personal and moral values. The juxtaposition of the two and the emphasis an individual places on them reflect the complexity of the decision-making process and a further warning not to oversimplify individual beliefs when formulating policy and practice.

Beyond Religion?

Religion, although relevant to an individual's decision-making process, is not the only factor that mediates reproductive decisions. A person's religious (and moral) values – as we have seen – are negotiated and interpreted within a much broader social context. Our focus group discussions suggest that the perceived severity of the condition was equally if not more important than religious beliefs. The Indian Hindu, Pakistani Muslim and Indian Sikh groups generally believed that since thalassaemia resulted in 'a lifetime of suffering' it warranted termination. This response from an Indian Sikh man was typical of the different faiths: 'No one in their right mind would say they . . . want to let the child suffer.' For some, the prevention of suffering was more important than religious strictures, as the response of this Pakistani Muslim illustrates:

> Religion wouldn't come into it really. It would be my own ethics. I wouldn't
> want to put a child through all that pain and suffering.

For such people, 'severity' was the main reason for accepting prenatal
diagnosis and considering termination, although for some prevention of
suffering could be reconciled within their religious values; providing
another example of the complex relationship between individual moral
preferences and religious values.

The African-Caribbean Christian groups agreed that they would be
more likely to opt for termination of pregnancy if they were certain that
the baby would have a form of sickle cell disorder that caused the child to
'suffer'. They remarked, however, that decisions about termination were
complicated by the uncertain prognosis associated with the condition. An
African-Caribbean Christian woman explained:

> It is quite difficult to make that decision about termination because you don't
> really know how ill that baby could be, but then it's also scary because you
> think it might be too ill and rather than bring a baby into the world and suffer
> then you can choose to terminate, but it's hard when you don't know.

This is perhaps why people's previous experience of the condition is an
important factor when making decisions about termination, especially if
someone with the condition is a family member or friend (see Atkin,
2003): although the values of the broader society in defining the 'conse-
quences' of the condition might be equally important (see Stacey, 1996).[3]
We return to this in our discussion.

Before moving on from this debate, it is perhaps important to note that
'severity' acquired a broad meaning in people's narratives. Clinical con-
sequences were, of course, an important element in people's decision-
making. Severity, however, also became bound up with ideas about the
impact of the condition on an individual's life and their existing family
relationships as well as how the broader society treats people with chronic
illness and disability. It is difficult to disentangle these elements when
making sense of people's responses. Individuals make decisions about
screening within the broader context of their lives, in which ideas such as
'severity' assume an emotional, social, moral and political meaning (see
also Rhodes et al., in press).

The Role of the Family

Health care decisions usually involve the family (Bottorff et al., 1998) and
our faith group discussions confirmed this. Families, however, seemed to
have little direct influence on a person's decision to accept prenatal diag-
nosis or agree to termination. Once more, people – irrespective of their
faith – interpreted their family's advice within the context of their own
values and beliefs, although of course these personal values are mediated

by the broader process of socialization. Nonetheless, reproductive decisions were regarded as a private matter.

African-Caribbean Christian men had diverse opinions about whether they would discuss prenatal diagnosis with family members, other than their partner. They agreed, however, that the decision about termination of pregnancy was personal. The African-Caribbean Christian women said that they may consult a female relative, initially their mother and/or sister, but this would be for emotional support and there would be a mutual understanding that the decision was the woman's and not the family's decision. Similarly, African-Caribbean Christian women said that the option to pursue prenatal diagnosis would be a joint decision with their partner, but the ultimate decision on whether to go for termination would be their own.

The responses of Indian Hindu, Pakistani Muslim and Indian Sikh groups suggest they are more likely to consult a family member. There was, however, considerable diversity among the participants, with Indian Hindu and Pakistani Muslim men placing greatest emphasis on involving family members, particularly their parents and their parents-in-law. This was largely 'out of respect' but also in case the family could provide useful advice. Family members seem more likely to be involved in the decision-making process if the couple is living with the in-laws; if the couple is young and/or newly married; or if the parents are strict, have control over their children and are used to making decisions on their behalf.

Part of the decision to involve the family may also be dependent on the extent to which they would be involved in supporting the mother in caring for the child, although the Pakistani Muslim groups acknowledged that the involvement of the wider family could make the decision harder:

> Your parents, they are expecting a grandchild and there's pressure there, especially if it's their first grandchild. I mean they would be like 'No way, you're not terminating the pregnancy, no way it's my first grandchild.'

Other participants – irrespective of faith – commented on possible differences between the generations. Prenatal diagnosis and the possibility of termination were seen to be more acceptable to the younger generation than parents and grandparents. This, however, was attributed to differences in cultural rather than religious beliefs.

The decision to consult a family member did not necessarily mean that Sikh, Muslim or Hindu group participants expected families to be involved in the decision-making process. Like the African-Caribbean Christian focus groups, reproductive decisions were seen as personal, although potentially involving greater negotiation with other family members, which might reflect different expectations of family obligation (see Atkin and Chattoo, 2007). Nonetheless, all groups, irrespective of faith, distinguished between

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'informing' and 'involving'. Most focus group participants said they would do what they thought best, even if this meant upsetting the family. Like African-Caribbean Christian men, Muslim, Sikh and Hindu men accepted that the final decision to terminate was the woman's decision, as she was the one carrying the child.

The Role of Religious Representatives and Community Leaders

UK policy on community engagement tends to conflate the role of religious representatives and community leaders. The narratives of the focus group participants, however, did not. Whatever ambivalence people might feel about 'religious leaders', all, irrespective of faith, were dismissive and critical of community leaders. They were described as 'self-proclaimed', and working for their own personal interests. If there was a role for community leaders, it was dealing with issues such as immigration, housing, education, schooling and litter. They were seen as having no role to play in offering advice on prenatal diagnosis or termination of pregnancy. The role of religious representatives, on the other hand, was a little more complex.

All faith focus groups identified potential difficulties when consulting religious representatives about prenatal diagnosis, although in articulating these problems individuals are attempting to legitimate the role of religious representatives in the decision-making process. Concerns included the potential bias of religious representatives' opinions, when compared to the supposed 'objectivity' of medical knowledge. Health care professionals were seen as being a more appropriate source of advice. Many participants commented that religious representatives would not be in a position to judge the severity of the condition or its impact on the family. This is an interesting view, particularly since parents who have experience of prenatal diagnosis make similar observations of the medical profession (see Atkin, 2003). Do people's views, therefore, reflect a more general concern about gaining advice, which is difficult to reinterpret in relation to their circumstances and makes it difficult to gain control over the situation? For example, people seemed concerned that advice from religious representatives might be too prescriptive and therefore difficult to ignore, without compromising their religious beliefs. They will seek advice, but want to use it to come to their own decisions.

Most of the participants believed that religious representatives, irrespective of their faith, would advise against termination, rather than provide information allowing people to make their own decisions. An Indian Hindu woman remarked: 'A priest will say don't do it.' A Pakistani Muslim man said: 'Some of them probably will try to influence your decision.' Such comments reflect a broader tension between people and their

religious representatives. Religious representatives, for example, were criticized for being 'out of touch' with young people's needs. Muslim participants specifically commented on how many formal religious representatives are not necessarily scholars and any advice they might offer is, therefore, potentially flawed. Muslim religious representatives agreed.

The imaginings of the focus group participants, which suggested that religious representatives might have a less flexible approach to termination, did not find support among religious representatives themselves. The workshops of religious representatives, irrespective of religion, perceived religious belief as a personal matter, between an individual and God. These representatives emphasized that their role was to support people rather than tell them what to do. The onus, therefore, is on the individual to make a decision, which they can justify and live with. A Sikh religious scholar said:

> At the end of the day, no matter what the interpretation, it's going to be down to the individual.

A Muslim chaplain remarked:

> I take every person as an individual with many dimensions. We do not have a hard and fast rule or a protocol to say we will do this.

Interestingly, some religious representatives commented on how religious belief can become corrupted by cultural values; something raised by our focus group participants and in more general discussions about ethnic identity, in which confusion between religious and cultural practices is a feature of policy discourses (Atkin, 2004). Our religious representatives regarded culture as restrictive and religion as flexible. A Muslim chaplain explained:

> The flexibility of Islam is not something a lot of the older generation may think about, because culture overrides religion. The younger generation are turning to the Muftis for more of their religious rulings because you'd be surprised, when you look at religion it's more flexible than what the culture is.

Religious representatives were also aware that other influences would mediate the advice and support given by their colleagues and this explains why there is no single view on prenatal diagnosis, termination and religion. Different temples, mosques and churches, for example, are associated with different social class, education and castes. Further, there are individual differences and geographical/regional variations in how faith is practised and interpreted (see also Rozario, 2005). Context, therefore, is important in understanding the potential role of religious and faith leaders.

More generally, health care professionals were seen as a more appropriate source of advice on prenatal diagnosis than religious representatives, although some religious representatives felt health care professionals

could not offer spiritual support and this is why some advocated greater joint-working. The Pakistani Muslim religious representatives also discussed raising awareness about Islam's stance on termination of pregnancy at sermons in mosques. Some participants felt this would enable people to feel more comfortable about approaching a religious representative. Others, however, expressed concern that raising awareness about such complex issues in a general way could lead to misconceptions about Islam's stance on the issue:

> Not all issues can be discussed on the pulpit. As somebody who would lead a sermon myself, people sometimes don't understand, so you can't take delicate issues and present them in public, because people take a snapshot and they take that back and they make something out of it and it's not what you said.

Other faith representatives expressed more general concerns about the involvement of religious leaders in what they regarded as a health matter. Hindu religious representatives felt they had no role in offering advice on health matters:

> We shouldn't be training religious leaders on health issues. It's just being politically correct. If there is just the sense that a religious leader has been included then that's ok.

Muslim representatives agreed:

> Sometimes I think it's a bit unfair that the religious leader is the answer to everything. Like I said about my Christian colleagues, they wouldn't be faced with something like this. We can't expect them [Islamic religious leaders] to be experts on everything.

Such views seem to undermine Department of Health policy about the potential role of religious and community leaders in disseminating advice on prenatal diagnosis and genetic conditions. A possible tension, therefore, emerges between engagement with a disadvantaged group, whose voice rarely informs policy and of encouraging the idea of the 'other', which requires different forms of communication to the majority population. Formal religious representatives, although important to some people, were not generally seen as a source of advice or as having a collective role in influencing debates about genetic testing or prenatal diagnosis. They were simply one voice among many and how seriously this voice was taken depended on an individual's interpretation of the role of religious belief in their life. This would suggest that communication between the state and minority ethnic populations might not be all that different from the general population. People, irrespective of ethnic origin, use a variety of sources, depending on context, to make decisions about prenatal diagnosis.

Religious representatives pointed out that raising community awareness in minority ethnic groups should not be seen as different to the

process for raising awareness in the 'white' community. A participant in the African-Caribbean Christian workshop said:

> Communication should not be any different for the African Caribbean community as it is for the mass community. It [emphasis on community leaders] doesn't happen in the white society so why should it happen in the black society?

A person in the Sikh workshop agreed:

> It's always the minority communities which suddenly have community leaders.

The faith workshops were especially concerned that a reliance on religious and community leaders could absolve the British state of a more meaningful engagement with ethnic minority populations. A participant in the African-Caribbean Christian workshop said:

> It's convenient to speak to one person or a small group of people and then it appears as if they have communicated to the masses.

Discussion

The views and experiences of those participating in the study, irrespective of ethnic origin, suggest that their cultural and religious identity is not something fixed or predefined. It is produced and negotiated within a particular social context, which embodies individual interpretation and preferences in relation to the values of significant others. To this extent, there was no particular script predefining how religious norms and practices would mediate the decision-making process. Faith beliefs emerged as flexible, negotiable and contingent: a resource that could be used creatively to support and legitimate a person's decision. This has implications for how our findings are interpreted.

We have already mentioned the potential discrepancy between what people 'say they will do' and 'what they actually do'. Our analysis focuses on the underlying values and assumptions informing decision-making rather than the experience of people who have had to make or are currently faced with making decisions about prenatal diagnosis and termination. Our concern is to highlight the broader normative context in which screening policy is enacted. As part of this reflection, we should mention that the speculative nature of our work meant our analysis has not explored geographical/regional variations in how faith is practised and interpreted (Rozario [2005] highlights the potential importance of this). Nor were we able to explore how social class mediated people's responses (Hill [1994], for example, suggests this might be a feature of people's experience, when making decisions about termination). Further, we have little to say on how other ethnic groups, such as African populations (who

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might be Muslim or Christian) respond to prenatal diagnosis, or how religion mediates the decision-making of the broader white majority (and in some cases, minority) population.

A broader tension, at the heart of our work, is the extent to which formal religion can be distinguished from faith (belief or religiosity). In the UK context, religious identity tends to reinforce ethnic identity (see earlier) and our sampling strategy reflected this. This might not always be the case and it would be interesting to explore the experience of people of the same religions, but of different ethnic groups. There is then the issue to which people are *actually* religious. People who adopt an orthodox or more fundamentalist view of their faith might respond differently to prenatal diagnosis than other individuals or have a less reflective view of their religious affiliation.

This brief proviso is not meant to invalidate our findings, but offers a reflexive engagement, which can form the basis for further enquiry: especially important in such an emerging (and misunderstood) area (Alvesson and Sköldberg, 2004). Our purpose was to provide a broad framework in which to make sense of how religious values mediate decisions about prenatal diagnosis. To this extent, the decision about whether or not to have diagnostic testing generally related to attitudes towards the termination of pregnancy. Many different factors mediated this. Religious conviction was important but not the only influence. Perceived 'severity' of the condition, previous experience of the condition, the offering of testing during the first trimester and the consequences of having a chronically ill child for existing family relationships were seen as equally important. The social context in which 'severity' and the 'consequences' of the condition come to be defined can be particularly significant (Anionwu and Atkin, 2001). This means that people's perception of quality of life for someone with a sickle cell or thalassaemia disorder can change over time, according to developments in medical technologies as well as the broader values of society, as it defines, interprets and responds to the social consequences of chronic illness and disability. Perceptions of the condition, therefore, are contingent, existing in time and space, defined by medical technologies, societal values and individual interpretations of their situation. This perhaps explains the broader process in which a complex interplay could sometimes emerge, with individuals taking comfort from their religion when it seemed to support their decision. To this extent, religious values become supported and sustained within the broader context of a person's moral beliefs.

Consequently, negotiated practices, in which faith beliefs become embedded in conditional acceptance derived from and sustained by the broader social context (including family relationships), informed the decision-making process. Understanding this is fundamental in facilitating

successful policy and practice, particularly since it reminds us about the importance of avoiding essentialized accounts of religious identity that are devoid of context and allow no room for individual interpretation. This has particular resonance in the development of the 'new genetics' (see Calnan et al., 2006) within a multicultural society (Atkin, 2003). Making sense of this requires public policy 'to recognize a wider range of cultural identities than it does at present' (The Parekh Report, 2000: 242).

The idea that identities are situational and flexible is, of course, not new (Ahmad et al., 2002; Papastergiadis, 1982). Our findings suggest that in making sense of genetic screening, people's decision-making reflects multi-identifications, some held more strongly than others and many becoming particularly salient in certain circumstances, contexts and places. Not surprisingly, religious identity is complex, fluid and negotiable. Generational relations, migration histories, social class, gender, ethnicity as well as religion represent important identifications and the interrelationship between these identifications remains complex and intimately connected to questions of power, structure and history (see Werbner, 1997). This description of the processes of diversity suggests that religious identities are contingent because of their responsiveness to context (Giddens, 1991). Consequently, religious identities become cultivated and negotiated within a variety of structures and ideological frameworks (Hall, 1996). Such identities have different meanings to different people, in different contexts. Nor are these identities fixed and immutable but will themselves change over time and with changing circumstances. As Karl Marx observed in *Towards a Critique of Hegel's Philosophy of Right*, religion does not make the people; rather people make religion. Religious identity assumes meaning within the context in which it is expressed and by doing so, becomes 'a fact of social life' (Parekh, 2006: 327).

Notes

1. All the focus groups were conducted in English, except the Indian Sikh women's group and the Hindu men's group where English and Punjabi were used interchangeably. The female focus groups were conducted by a bilingual female researcher of Pakistani origin and the male groups facilitated by a white male and bilingual male of Pakistani origin.
2. A previous paper describes the responses of the faith groups in more detail (Ahmed et al., 2006). The article presented here contextualizes their experience in

relation to the comments of faith and religious scholars, interviewed as part of the research. This article also has greater theoretical intent and makes sense of faith and religious belief, within the context of broader debates about multiculturalism.

3. Medical advances in treatment might also mediate the decision-making process; the development of the oral chelator as a replacement for a syringe-drive pump could alter drastically the experience of those with thalassaemia (and sickle cell disease) having regular blood transfusions (see Anionwu and Atkin, 2001). We explore this further in the discussion.

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