

The influence of faith and religion and the role of religious and community leaders in prenatal decisions for sickle cell disorders and thalassaemia major

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Objectives Religion is believed to have a significant impact on individuals from minority ethnic groups when making decisions about prenatal genetic screening, prenatal diagnosis and termination of pregnancy. This study aimed to explore the views of individuals from South-Asian and African-Caribbean communities towards termination of pregnancy for sickle cell disorders and thalassaemia major and the influence of (1) faith and religion, (2) perceived severity of the conditions, and (3) religious and community leaders.

Methods The study explored the views of (1) individuals from four faith communities (Pakistani Muslims, Indian Hindus, Indian Sikhs, African-Caribbean Christians), using eight focus groups, and (2) parents of children with sickle cell disorders and thalassaemia major, using two focus groups and three interviews.

Results Participants' accounts suggest that they generally considered religion and faith as an important factor in the decision-making process, but the perceived severity of the condition would play a more important role. Religious and community leaders were believed to have little role to play in the decision-making process.

Conclusion The findings emphasise the importance of recognising diversity within different faith groups and moving away from stereotypical views based on people's ethnicity or religion, and to consider the beliefs and preferences of individuals. Copyright © 2006 John Wiley & Sons, Ltd.

KEY WORDS: termination; religion; sickle-cell; thalassaemia; decision-making

INTRODUCTION

The NHS Sickle Cell and Thalassaemia Programme in the United Kingdom offers screening to women and their partners to identify couples at risk of an affected pregnancy. Sickle cell disorders and thalassaemia major are inherited blood conditions that mainly affect people of African, Caribbean, Middle Eastern, Asian and Mediterranean origin. Couples identified at risk of having a child with sickle cell disease or thalassaemia major can then be offered prenatal diagnosis with the option of either continuing or terminating an affected pregnancy. This, however, involves difficult and complex decisions, in which the couple draw on a variety of different frames of reference (Ahmed, 2001). These not only include their understanding of sickle cell disorders and thalassaemia major but also broader aspects of their identity such as cultural values and beliefs as well as family attitudes (Atkin *et al.*, 1998; Ahmed, 2001). This is likely to be true for any couple undergoing prenatal diagnosis for any condition; however, religion is traditionally believed to be particularly salient to people from groups that are likely to be most affected by sickle cell disorders and thalassaemia major (Anionwu and Atkin, 2001).

A number of studies around the world suggest that attitudes toward prenatal diagnosis and termination of pregnancy for the haemoglobinopathies are related to religious convictions. For example, a Nigerian study that comprised 53 mothers and 48 fathers of children with a sickle cell disorder (Durosini *et al.*, 1995) found that 92% of the mothers and 86% of the fathers would opt for prenatal diagnosis and that 63% of the mothers and 51% of the fathers would opt for termination of an affected pregnancy. Participants cited religious convictions and fears of complications during termination as the two main reasons for opposing termination. Attitudes towards termination of an affected pregnancy were related to the parents' experiences of managing their child(ren)'s condition. In a Parisian study of 53 parents of children with a sickle cell disorder (de Montalembert *et al.*, 1996), only 58% of parents said that they would request prenatal diagnosis. The study showed that this choice was related to ethnic origin and religion, where Africans were more likely to opt for prenatal diagnosis than Caribbean people, and Christians were more likely to opt for prenatal diagnosis than Muslims. In a Lebanese study of 83 couples with at least one child with a haemoglobin condition (Zahed and Bou-Dames, 1997), mainly thalassaemia major (90%), 18% of couples (all Muslim) said that they would not opt for prenatal diagnosis on religious grounds.

More recent studies in Muslim populations show that education about religion's stance on termination of

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pregnancy results in higher uptake of prenatal diagnosis and termination of affected pregnancies for sickle cell disorders and thalassaemia major (Ahmed *et al.*, 2000; Alkuraya and Kilani, 2001). These studies used a Fatwa (Islamic ruling), which stated that termination of pregnancy is permissible if the fetus is affected with a serious condition and termination is within 120 days of gestation. For example, in a Pakistani study (Ahmed *et al.*, 2000), where at-risk couples were informed about the Fatwa, 300 at-risk Muslim couples opted for prenatal diagnosis over a period of three and a half years. Forty-seven of 53 women carrying an affected fetus terminated their pregnancy, while 6/53 declined on religious grounds. Overall, these studies highlight the importance of religious beliefs and education of the target population when offering sickle cell and thalassaemia screening. However, findings from such studies should be interpreted with caution if generalising to UK populations because of a number of differences, such as health service provision, social environments, education and secularism. For example, parents in Pakistan may be more inclined to opt for termination of pregnancy than Pakistanis in the United Kingdom because the former would have to pay for the treatment of a child with thalassaemia major.

Overall, the literature suggests that religious convictions are often the main reason given by Muslim populations for declining prenatal diagnosis and termination of pregnancy. However, none of these studies on attitudes towards prenatal diagnosis and termination of pregnancy for sickle cell disorders and thalassaemia major included the role of faith and religion within the broader context of people's lives. For example, studies in American, European and Jewish populations highlight perceptions of the severity of the condition, particularly the burden of the condition for the child, as one of the main factors influencing decisions on reproduction (Wertz *et al.*, 1991; Evans *et al.*, 1996; Henneman *et al.*, 2001; Zlotogora, 2002). In addition, within the context of such decision making and religion, the focus seems to be on Muslim populations and there are no such studies in other faith communities at high risk of having a child with a sickle cell disorder or thalassaemia major, such as Sikh or Hindu populations.

The literature's emphasis on religious convictions in communities most likely to be affected by sickle cell disorders and thalassaemia major raises questions about the role of religious leaders in the prenatal decision-making process. For example, a recent study looking at the acceptance of prenatal diagnosis of sickle cell disorders in Nigeria (Kagu *et al.*, 2004) also cited religious convictions for declining such procedures and highlights the importance of educating religious leaders. The present study was funded by UK policy-makers (the NHS Sickle Cell and Thalassaemia Screening Programme, Department of Health) to specifically explore the role of religious and community leaders in prenatal decisions.

Within the context of prenatal screening, prenatal diagnosis and termination of pregnancy for sickle cell disorders and thalassaemia major, this study aimed to:

- (1) explore how ideas about faith and religion mediate attitudes of individuals from South-Asian and African-Caribbean communities;
- (2) explore the role of perceptions of severity of the conditions in relation to the role of faith and religion; and
- (3) explore perceptions of the role of religious and community leaders.

The study aimed to explore the attitudes of individuals from four 'faith' communities—Pakistani Muslim, Indian Hindu, Indian Sikh and African-Caribbean Christian—and the attitudes of parents with a child with a sickle cell disorder or thalassaemia major.

MATERIALS AND METHODS

The study was conducted in the North of England using focus group methodology. The study was carried out in two phases.

Phase 1—faith communities

This involved exploration of attitudes of individuals from four 'faith' communities to prenatal screening, prenatal diagnosis and termination of pregnancy, in the following eight focus groups:

1. Pakistani Muslim men
2. Pakistani Muslim women
3. Indian Hindu men
4. Indian Hindu women
5. Indian Sikh men
6. Indian Sikh women
7. African-Caribbean Christian men
8. African-Caribbean Christian women

These groups were selected because of the high prevalence of either sickle cell disorders or thalassaemia major within them, and to explore the similarities and differences between these groups due to faith or religious beliefs. The researcher (SA) recruited participants via community organisations in Leeds, such as local community resource centres, including the Milun Women's Centre and Shantona Women's Centre. The inclusion criteria for this part of the study were that participants were between the ages of 18 and 45 years old and identified themselves as belonging to one of the four faith communities (Pakistani Muslims, Indian Sikhs, Indian Hindus and African-Caribbean Christians). All potential participants were given an information sheet, which stated that focus group discussion would be on how faith and religion influence decisions about 'testing in pregnancy for thalassaemia and sickle cell disorders', and 'decisions about continuing with the pregnancy if the baby has the disorder.'

Individuals in the four faith groups were divided into groups of men and women. The men's groups were conducted by a white male researcher (KA). The women's groups were conducted by a Pakistani female researcher (SA), fluent in English, Urdu, Punjabi and

Mirpuri. Therefore, ability to speak English was an inclusion criterion for the men's groups but not for the women's groups. All the focus groups were conducted in English, except the Indian Sikh women's groups, where English and Punjabi were used interchangeably.

All the focus groups were conducted in community settings and ranged from four to nine participants. Prior to attending the focus groups, participants were given information sheets about the study and booklets about the conditions. Written consent was obtained and anonymity and confidentiality were assured. The focus groups were conducted for 45–90 min. Each focus group was audiotaped and transcribed verbatim, and all the transcripts were reviewed for accuracy by the researcher (SA).

Focus groups with Pakistani Muslim, Indian Sikh and Indian Hindu participants were about thalassaemia major alone, and the focus groups with the African-Caribbean Christian participants were about sickle cell disorders alone. The discussions were guided by a detailed 'facilitator's guide', which explored attitudes toward prenatal screening, prenatal diagnosis and termination of pregnancy for either sickle cell disorders or thalassaemia major and the role of (1) faith and religion, (2) perceptions of the severity of the condition in relation to the role of religion, and (3) perceptions of the role of religious and community leaders.

Phase 2—parents of children with a sickle cell disorder or thalassaemia major (parents)

The inclusion criterion for this part of the study was that participants were a parent of at least one child with either a sickle cell disorder or thalassaemia major. Two focus groups were held, which included (1) mothers with a child with thalassaemia major and (2) mothers with a child with a sickle cell disorder. In addition, three fathers were interviewed—two with a child with thalassaemia major and one with a child with a sickle cell disorder.

Parents were recruited via two voluntary organisations and interviews and focus groups were carried out on their premises. These organisations (Sheffield Sickle Cell and Thalassaemia Foundation and OSCAR (Organisation for Sickle Cell Anaemia Relief and Thalassaemia Support) Birmingham) are support groups for individuals and families affected by sickle cell disorders and thalassaemia major, with no religious affiliation. The interviews and the focus group discussions were guided by a modified version of the facilitator's guide used in phase 1, and the addition of a question on the extent to which their attitudes had changed over time.

The fathers were interviewed by a white male researcher (KA) and the focus groups with the mothers were conducted by a Pakistani female researcher (SA). All the interviews and focus groups were conducted in English, except the group with mothers of children with thalassaemia major, where English and Mirpuri were used interchangeably. The focus groups with the parents were conducted in the same way as the community faith focus groups and lasted between 25 and 70 min.

The interviews and focus groups were audiotaped and transcribed verbatim.

Analysis

All transcripts were organised and coded using N-Vivo (Nudist-Vivo 1.2; SAGE Publications). The qualitative data were analysed using the framework approach (Silverman, 2001). Key themes were identified from the facilitators' guide to form the coding framework as well as new themes that emerged from the analysis of the transcripts. The transcripts from the two phases were coded using this coding framework. The data coded under each theme reflected the diversity of views and the majority view within the groups. Most importantly, analysis explored concepts; established linkages between concepts implied in the formulation of the research question and the topic guides; and offered explanations for patterns or ranges of responses or observations from different sources (Denzin and Lincoln, 1998). Analysis involved understanding the meaning of actions, beliefs, attitudes and relationships, from the range and frequency of participants' views on particular issues. Analysis also involved consistent cross-referencing within and between phases, for similarities and difference between the different faiths, conditions and gender.

Presenting the findings

The findings from phases 1 and 2 (faith communities and parents) are presented together. Where possible, the findings are cross-referenced to draw out the similarities and differences between the different faith groups, and to explore the extent to which the views of the faith groups were similar to those of parents of a child with the condition.

FINDINGS

Demographics

Table 1 describes the focus groups within the faith communities and parent groups, the condition discussed, the number of participants in each group and participants' mean age.

Owing to time constraints, only three fathers were recruited, hence the method used was interviews rather than a focus group. One father (29 years old) had a child with a sickle cell disorder and two (42 and 34 years old) had a child with thalassaemia major.

All the parents of children with a sickle cell disorder were of African-Caribbean origin and identified themselves as 'Christians', and all the parents of children with thalassaemia major were of Pakistani origin and identified themselves as 'Muslims'.

The role of faith and religion

Everyone in every group agreed that their religion or faith would not influence their decision about prenatal

Table 1—Focus group demographics

	Condition discussed	Number of participants	Mean age of participants (years)
<i>Faith communities</i>			
Pakistani Muslim men	Thalassaemia major	5	27.8
Pakistani Muslim women	Thalassaemia major	4	29.8
African-Caribbean Christian men	Sickle cell disorders	5	24.0
African-Caribbean Christian women	Sickle cell disorders	5	34.6
Indian Sikh men	Thalassaemia major	9	26.8
Indian Sikh women	Thalassaemia major	6	34.8
Indian Hindu men	Thalassaemia major	6	28.2
Indian Hindu women	Thalassaemia major	9	36.4
<i>Parents</i>			
Mothers—sickle cell disorders	Sickle cell disorders	5	36.8
Mothers—thalassaemia major	Thalassaemia major	3	38.6

screening, mainly because it was a simple blood test and did not involve any controversial issues. When asked about the role of religion in prenatal diagnosis, the groups usually changed the focus of the discussion to religion's stance on termination of pregnancy. Therefore, the findings presented from hereon are for termination of pregnancy.

Both the Indian Sikh and Indian Hindu groups explained that termination of pregnancy was not specifically prohibited by their religion and that it was an individual's decision:

Indian Hindu man: '[religion] teaches you should have a mix of everything ... it boils down to your conscience.'

Indian Hindu man: 'Hinduism is a way of life ... and it's up to you the way you want to conduct your life. That's what Hinduism means actually, them three words, 'way of life'. You all choose your own paths.'

The Indian Hindu groups added that their belief in *Karma*, reaping what you sow, would enable them to come to the right decision. The Indian Sikh groups emphasised that Sikhism specifically teaches 'prevention of suffering', and that this would be an important factor in decisions about termination of an affected pregnancy.

The Pakistani Muslim, African-Caribbean Christian and the parents groups considered that termination of pregnancy was prohibited in Islam and in Christianity respectively. However, like the Indian Sikh and Indian Hindu groups, most of the participants added that, their reproductive decision would be based on their personal moral judgements and beliefs:

African-Caribbean Christian woman: '... it's between you and God. If I choose to make a decision that maybe is not within the church, then God is my judgment'

Pakistani Muslim woman: 'Islamic religion isn't that strict or that bad that it won't allow for different sacrifices ... I think it's your personal opinion and personal choice'

Father of a child with thalassaemia major: 'We don't have to bring religion into this... it's the individual's decision, it's the parents'.'

There was also much ambivalence in the Pakistani Muslim groups and the mothers of children with thalassaemia, where they believed that termination of pregnancy was prohibited, but also generally agreed that they could not put a child through 'pain and suffering', so they would seriously consider the option of termination:

Pakistani Muslim woman: 'I believe it (termination) would be wrong but it would be something that I would have to do ... sometimes I think... if God had decided that this is the pains you go through and this is the child you should have, maybe I was destined to have that child and I interfered with it but I've got two minds on that'

Researcher: 'you would have a termination even though you personally believe this is not allowed by Islam?'

Pakistani Muslim woman: 'I would yes'

All the faith groups, except the African-Caribbean Christian groups, generally agreed that they would want to know their religion's stance on termination of pregnancy. The groups placed different levels of emphasis on their desire for such information, where the Pakistani Muslim groups were the keenest. Nevertheless, all the faith groups generally agreed that while they may explore their religion's stance on the issue, particularly the Pakistani Muslim groups, it would not influence their decision about termination of pregnancy. All the groups generally agreed that religion was not prescriptive and that they would make their own decision. At least one person in each group suggested that there were right and wrong paths that could be taken and that they as individuals had to make their own decision and, therefore, would give precedence to their own beliefs and values:

Pakistani Muslim man: 'it's not a robot religion, it depends on the situation ... we are not like robots, we can make our own decisions. He (God) has

shown us the right path and the wrong path and he says we can make our own decision'

African-Caribbean Christian woman: *'...I do class myself as a religious person, God fearing, but it would have to be a decision I came to on my own but spiritual'*

Mother of a child with thalassaemia major: *'Allah gives you knowledge... he gives us free will of choice and education... if you're blessed with that, then you have to make choices'*

There were diverse opinions in every faith group, where a number of people would not consider termination of pregnancy, and such attitudes were related to individual beliefs and values rather than to religion. For example, in the Pakistani Muslim groups, following information about fatwas permitting termination of pregnancy for thalassaemia, some people stated that they still would not consider it because of their own moral beliefs. The Pakistani Muslim groups added that fatwas could be interpreted in various ways. For example, they have been produced in developing countries (Lebanon, Saudi Arabia, Pakistan) and may not be applicable to Western countries for thalassaemia, given that treatment is more readily available and that children are less likely to suffer in the same way as in developing countries.

Unlike the other groups, most of the parents of children with thalassaemia major stressed a preference for prenatal diagnosis and termination of pregnancy within the first trimester, and clarified that this preference was related to religious beliefs:

Father of a child with thalassaemia major: *'In my religion, we're not allowed to do this after three months... after three months it's like killing'*

Overall, all the faith groups and parents placed emphasis on the relationship between the individual and God in making decisions on reproduction. In addition, the Pakistani Muslim groups also placed emphasis on what would be permissible by Islam, and therefore, stressed a preference for early service provision so as to allow termination of pregnancy within the first trimester. All the groups generally agreed that religion was important, but it was not the main factor that would influence their reproductive decisions.

The role of perceived severity of the condition

The Indian Hindu, Pakistani Muslim and Indian Sikh groups generally believed that thalassaemia major resulted in a lifetime of suffering for the affected child and, therefore, warranted termination of pregnancy. A child with thalassaemia was also perceived to have an adverse impact on parents and siblings:

Pakistani Muslim woman: *'I've seen people with thalassaemia and I've known they have been very poorly through thalassaemia, blood transfusions, it's not been easy, it's been painful all the way*

through and are constantly on medication which has side effects as well. So their quality of life has been really isolated I think, so I think I would have to terminate.'

Indian Sikh man: *'no-one in their right mind would say they want to have a child and want to let the child suffer and suffer with the child for that long, especially if they use a pump, like you say six hours with an injection in there, that is suffering'*

The prevention of a child's suffering was perceived as more important than becoming a 'sinner' through opting for termination of pregnancy:

Pakistani Muslim woman: *'it's non-Islamic to have an abortion...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'*

Indian Sikh woman: *'I don't consider it to be a sin to have termination for such a child who is ill. You shouldn't keep such a child. You would watch the child suffer. The mother would be thinking about her child all the time, go into depression.'*

Similarly, most of the parents of children with thalassaemia major said that they would opt for termination of pregnancy:

Mother of a child with thalassaemia major: *'If it happened now, I would terminate. I wouldn't hesitate... I cannot bear to see my child have a lifetime of pain... I could not bear to put another child through that'*

Father of a child with thalassaemia major: *'you don't know how long they're going to live, six months, six years or sixty years, if they don't have their medication on time. You're always worried as parents, you don't know the consequences... our children are suffering, so we are suffering along with them. We know how hard it is.'*

The African-Caribbean Christian groups agreed they were more likely to opt for termination of pregnancy if they were certain that the baby would have a form of sickle cell causing the child to 'suffer'. However, they agreed that the decision about termination of pregnancy was complicated by the uncertain prognosis of sickle cell, and would decide against termination of pregnancy if there was a possibility that the child may not have the serious form of the condition:

African-Caribbean Christian woman: *'...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.'*

In the faith groups, attitudes toward termination of pregnancy for sickle cell were more likely to be based on experiences of the condition, and within the groups these

ranged from mild, hence negligible impact, to severe, where the condition resulted in constant illness and long periods in hospital:

African-Caribbean Christian woman: ‘...my friend’s daughter, she is only 10 years old and she’s probably been out of hospital this year alone twice, and the last time she just came out a few weeks ago and she was on morphine and pain killers and it was awful actually to experience it and see her mother. You know, there’s nothing you can do as a mother, it mentally drains you’

Unlike the faith groups, the five mothers of children with a sickle cell disorder unanimously agreed that sickle cell disorders were not serious enough to warrant termination of pregnancy. This was because of the variability of the condition, and while experience of the condition within the group varied from mild to severe, all the mothers believed their children had lengthy periods of ‘normal’ life:

Mother of a child with a sickle cell disorder: ‘...children have periods of healthiness and they if they are looked after properly they can lead a good length of life’

Overall, the findings suggest that perceptions of the severity of the condition and its impact on the affected child would have a greater influence on parents’ decisions about termination of pregnancy than religious beliefs, and that thalassaemia major was perceived as having a greater adverse impact on the affected child and family than sickle cell disorders.

The role of religious leaders

All the groups usually identified the ‘priests’ of their respective religious organisations as religious leaders. All the groups agreed that they would not consult a religious leader for advice on prenatal diagnosis and termination of pregnancy. They stated that this was because religious leaders were more likely to provide biased opinions than advice based on medical knowledge, and that religious leaders were unlikely to be aware of the severity of the conditions and of their impact on the affected child and family:

Father of a child with thalassaemia major: ‘...they look normal, the only disease they’ve got is this thalassaemia, this blood problem, but only we know how bad this is and those Allamas (priests), they don’t know, unless they have a child suffering with them, they don’t know what it’s like. . . We don’t have to bring religion into this. . . it doesn’t matter what they (priests) say, it’s the individual’s decision, it’s the parents’.’

Most of the participants believed that religious leaders would advise against termination and state that religion prohibits termination of pregnancy, rather than provide information to allow people to make their own decisions:

Indian Hindu woman: ‘...it doesn’t say anywhere. A priest will say don’t do it.’

Pakistani Muslim man: ‘Some of them probably will try to influence your decision . . .they should present you with the options’

Indian Sikh man: ‘You might go pray for forgiveness for doing it. . . but you won’t talk to someone else. . . that’s between you and God’

Some of the Indian Hindu women added that priests would tell them that it was all to do with their *Karma*, that is, they are reaping what they have sown in a past life, and that this situation is God’s will:

Indian Hindu woman: ‘...a priest or someone would say ‘it’s your karma’, whatever you have it’s to do with what you have done previously . . .if it’s not to be, God will get rid of it.’

Many of the groups explained that they would pray for guidance themselves, because they could obtain spiritual guidance equally as well as religious leaders:

Pakistani Muslim woman: ‘...for your own sanity you need spiritual guidance . . .You read the Namaz and do dua (pray) . . .our prayers are being answered the same as theirs [religious leaders] . . .They’re not better than us. . . They are not more superior than us.’

In addition, the Pakistani Muslim groups and fathers of children with thalassaemia believed that religious leaders would be unable to provide guidance because of their poor knowledge of thalassaemia, hence their inability to understand individuals’ personal situations. They also believed that different religious leaders were likely to give different advice, possibly because they are from different countries and/or sects of Islam. Religious leaders were also seen as ‘out of touch’ with young people’s needs:

Pakistani Muslim man: ‘I think there are a lot of problems with the young generation and the religious community is not in touch in this country’

The Pakistani Muslim groups and African-Caribbean men also acknowledged that their views may be specific to younger generations, and that older generations were more likely to consult religious leaders:

Pakistani Muslim woman: ‘But the older, like I’m talking about my mother in law having a baby . . .she would go to somebody and say ‘You do a dua [pray] for me. . .’ she wouldn’t go to a medical professional.’

The Pakistani Muslim women related this behaviour to the history of religious leaders, where they were also perceived to be the religious scholars, but clarified that this may no longer be the case:

Pakistani Muslim woman: ‘...about 40/50 years ago, they were the knowledgeable ones . . .so they

were the scholars at that time. So that's why people still believe, like first generation they still believe that if we go to them [religious leaders], they know better than us.'

All the groups agreed that while they would not approach a religious leader, they might seek factual information about their religion's stance, for example, by searching the Internet:

Pakistani Muslim woman: 'These days you can go on the internet and Islam is everywhere ... I wouldn't go to anybody. I would look up a few different people on the net and a few different views on the net'

However, it was clarified that this did not imply that the information would be used to make reproductive decisions:

Indian Hindu man: 'You would see what religion says ... but ultimately it's your decision ...'

Similarly, none of the parents had ever approached, or intended to approach, a religious leader for advice about reproductive matters:

Father of a child with a sickle cell disorder: 'I'm a Christian. ... He's going to say that if you do this, it's going to be like killing and God says that you can't kill and you know, blaa, blaa, blaa. But I think differently. We are the parents of the baby and we'll have to make the decision. ... I think it's not going to be important for me really to speak to him.'

Overall, none of the groups believed that there was a role for religious leaders in the reproductive decision-making process because this was a very personal issue that was between the individual and God.

The role of community leaders

All the faith groups were generally dismissive and very critical of community leaders. The focus groups identified community leaders as local council candidates, organisers of events, managers of community centers/religious organisations, or people in a position of power within the community. All the groups generally described community leaders as 'self-proclaimed', representing their own personal interests, and working for their own prosperity with hidden agendas. The African-Caribbean Christian and Pakistani Muslim men added that community leaders had little contact with the communities that they claimed to represent:

African-Caribbean Christian man: 'How can you be a community leader if you don't communicate with the people who you are working for'

Pakistani Muslim man: 'There are self-proclaimed community leaders in our community. ... when something happens they just go ahead themselves and say they are representing you but they are not they are representing their own interests ...'

'I think most of the community leaders are all fake ... have their own different agendas'

The groups described community leaders as suited to dealing with issues relating to immigration, housing, education, schooling and litter. However, all the groups unanimously agreed that they would not consult a community leader for advice on prenatal diagnosis or termination of pregnancy:

African-Caribbean Christian woman: 'I can't think of many people who I think fit into community leaders or whatever but it would never dawn on me to go to any such people any way'

Indian Sikh man: 'They are there to give you advice on things, more cultural, but definitely not in your private life'

All the groups unanimously agreed that if they were at-risk of having a child with sickle cell or thalassaemia, they would definitely consult their GP and possibly their midwife or a genetic counsellor, more so than religious or community leaders. Health professionals were perceived as having the ability to give objective, non-judgmental advice based on medical expertise.

DISCUSSION

In our study, people were recruited to the faith groups if they identified themselves with the respective religion. Participants were not asked how religious they were, because of the difficulties in measuring individuals' religious convictions, although it is accepted that some people are more devout than others and that this might mediate the decision-making process. It could be argued that the study is biased because people with more conservative views were unlikely to take part. Conservative views, indicating an unwillingness to consider prenatal diagnosis or termination of pregnancy, were expressed within every focus group, albeit in the minority. Nevertheless, this paper presents a diversity of views within each of the four faith groups.

The recruitment of individuals from defined organisations could have influenced the results of the study as these members may have more similar views, be more vocal and have beliefs that may differ to individuals who would not attend such organisations. Ideally, participants could have been more randomly recruited, such as women attending their first prenatal clinic appointment for Phase 1. However, given that this study was funded for six months, women for Phase 1 were deliberately not recruited via NHS organisations. This was to avoid any delays that would be incurred in obtaining ethical approval and in satisfying research governance requirements, a fear that was confirmed by our initial recruitment strategy for Phase 2. That is, we intended to recruit parents of children with thalassaemia major and sickle cell disorders via consultant paediatricians treating such children, but the process of obtaining relevant approval for recruitment via the NHS took 5 months. Therefore, after 4 months of pursuing various approvals, a decision

was made to recruit parents via support groups. Other studies have had similar or worse experiences with NHS ethics committees and Research Governance procedures (Hunter, 2005; Galbraith *et al.*, 2006).

A small scale study is, of course, not able to control for all possible confounders, one of which might be thought to be level of education of participants. However, in a recent comparative study of over 400 white and Pakistani women in the United Kingdom, looking at social and ethnic differences in attitudes toward prenatal diagnosis and termination of pregnancy, we found that education was not related to attitudes to termination of pregnancy in either white or Pakistani women (Hewison *et al.*, 2004). Therefore, the relationship between educational level and attitudes was not explored in this study.

The mean age of the women's groups was higher than the men's groups, which could have had an impact on the findings. However, this is unlikely given that the findings were similar for the two genders. Furthermore, this article presents the views of young men from minority ethnic groups on the subject of prenatal testing and termination of pregnancy, a new generation whose voice has not been presented previously in this area.

We recognise the speculative and small-scale nature of this work; however, this does not distract from the validity of our findings. These findings can start an informed debate, in an area that is dominated by rhetoric rather than empirical evidence.

Given the literature, which suggests that Muslim and African-Caribbean populations are most likely to decline prenatal diagnosis and termination of pregnancy because of their religious convictions (Durosinmi *et al.*, 1995; de Montalembert *et al.*, 1996; Zahed and Bou-Dames, 1997; Ahmed *et al.*, 2000; Alkuraya and Kilani, 2001; Kagu *et al.*, 2004), it is understandable that policy makers/service planners are likely to believe the same for similar populations in the United Kingdom. However, participants' accounts in this study suggest that people may consider religion when making decisions about prenatal diagnosis and termination of pregnancy, but this is not the overriding factor. The decision-making process is individually based, but occurs within the context of broader social relationships, of which faith and religion are but one aspect. Participants would make decisions based on their own moral values, beliefs and judgements, which in turn would be based on experiences of and information about the impact of the condition on the child and family's quality of life (Wertz *et al.*, 1991; Snowdon and Green, 1994; Henneman *et al.*, 2001). Such findings highlight the need for balanced information about conditions for which prenatal screening is offered on what it is like to actually live with children with these conditions. A website containing such information has recently been developed specifically for prenatal screening, known as AnSWeR (Antenatal Screening Web Resource, <http://www.antenataltesting.info/>), but does not contain any information on sickle cell disorders or thalassaemia major. Given that prenatal screening for sickle cell and thalassaemia is now offered as national policy in the United Kingdom, there is an urgent need for the aforementioned information, so that parents

can make the best decisions for themselves and their families.

All the groups generally agreed that they would not approach a religious leader for advice relating to decisions about prenatal diagnosis or termination of pregnancy. At most, some of the Pakistani men may approach them for factual information on Islam's stance, but would not discuss any personal information. There was agreement within all the groups that health professionals would be consulted, because of their ability to provide factual information about the conditions, their severity and impact on the affected child and family. This highlights a need for health professionals to be better informed about the haemoglobinopathies (Dyson *et al.*, 1996), and to be more confident and willing to talk to people from minority ethnic groups about reproductive issues. In addition, health professionals should be aware of the availability of NHS faith chaplains within their region. For example, the chaplaincy teams in the Acute NHS Trusts in Leeds and Bradford comprises chaplains who represent the Christian, Muslim, Jewish, Buddhist, Sikh and Hindu faiths. Many of these chaplains are not only scholars within their own faith, but are also likely to have experience of health related issues, hence the ability to provide objective faith-based health advice (see <http://www.eurochaplains.org/uk.htm>).

Religious leaders do not have an important role to play on a one-to-one level with people, because the findings show that most people would not consult them about their personal reproductive issues. However, given that religion still contextualises decision making about termination of pregnancy for some people, it is important for policy makers/service providers to consult religious 'scholars', such as NHS Faith Chaplains, in order to be aware of this context. For example, unlike any of the other groups, the parents of children with thalassaemia (all Muslims) were aware of fatwas permitting termination of pregnancy within 120 days of gestation, and therefore, like others (Modell *et al.*, 2000), suggested that services should aim to make prenatal diagnosis available to all at-risk couples in the first trimester of pregnancy. Muslim scholars are likely to be aware of such fatwas and could advise accordingly during service planning.

As other studies have found, factors influencing people's decisions are generic (Tsianakas and Liamputtong, 2002) and could apply to people of any ethnic origin. There were differences between the faith groups' attitudes toward the role of religion in termination of pregnancy for sickle cell disorders and thalassaemia major, but the striking similarities between the groups indicate that specific minority ethnic groups should not be singled out as the 'others' who 'won't terminate because it's against their religion'. Our findings suggest that there is a need to recognise diversity within these groups and that people should not be categorised as behaving in certain ways based on their ethnicity or religion. There are no easy solutions, but health professionals should not revert to simple cultural generalisations to explain people's behaviours. Health professionals should treat people as individuals and not make judgements.

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