

# Decisions About Testing and Termination of Pregnancy for Different Fetal Conditions: A Qualitative Study of European White and Pakistani Mothers of Affected Children

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**Abstract** The aim of this study is to explore reasons for and against prenatal testing and termination for a range of conditions in women from two different ethnic backgrounds. A total of 19 Pakistani and European women in West Yorkshire, UK, who either had a child with a genetic condition or had terminated a pregnancy for one, completed a questionnaire about their attitudes regarding prenatal testing and termination for 30 different fetal conditions and were interviewed about their reasons for their responses. There were more similarities than differences between the

Pakistani and European white women. The most important factor in most women's decisions about termination of pregnancy was their perception of the quality of the life of a child with the genetic condition, in particular, whether the child would be "suffering." This was described as either physical suffering, as a result of medical treatment, or as emotional suffering, as a result of psychological and/or social factors. These findings highlight the need for detailed information about the potential quality of life for the child and the child's family to enable parents to make informed choices, particularly the extent to which the child is likely to suffer, the nature of such potential "suffering" and the extent to which the child could lead a "normal" life. The findings also challenge stereotypes about cultural differences in attitudes about termination of pregnancy.

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## Introduction

Unlike other screening programmes, antenatal screening provides information to facilitate reproductive choices, typically whether to terminate an affected pregnancy. Many researchers have explored attitudes toward termination of pregnancy for specific conditions, mainly in western populations at increased risk of the disorder: cystic fibrosis (Denayer et al. 1992; Henneman et al. 2001; Lafayette et al. 1999; Murray et al. 1999), fragile X (Murray et al. 1997; Skinner et al. 2003), breast cancer (Lodder et al. 2000), achondroplasia (Gollust et al. 2003), adrenoleukodystrophy (Costakos et al. 1991). Some have compared attitudes regarding termination for different conditions, for example, among parents of

children with cystic fibrosis (Wertz et al. 1991), students (Milner et al. 1998), and a Finnish sample (Hietala et al. 1995). These showed that parents are more likely to consider termination for conditions perceived to be more burdensome for the child, particularly those resulting in severe mental retardation, substantial physical disability, or fatal in early childhood (Drugan et al. 1990; Evans et al. 1996; Mansfield et al. 1999; Zlotogora 2002).

Studies exploring attitudes toward termination in non-white populations have usually been conducted outside the UK and predominantly for haemoglobin disorders: France (de Montalembert et al. 1996), Lebanon (Zahed and Bou-Dames 1997), Nigeria (Durosinmi et al. 1995; Kagu et al. 2004), Pakistan (Ahmed et al. 2000) and Saudi Arabia (Alkuraya and Kilani 2001). Much of this literature suggests that Muslims and people of African-Caribbean origin are most likely to decline termination of pregnancy because of their religious convictions. However, our studies with Pakistani Muslims in the UK (Ahmed et al. 2006a, b) show that while religion and faith are important factors in the decision-making process, the perceived severity of the condition and the perceived quality of life of the child also play a significant role. Moreover, Awwad et al. (2008) suggest that cultural backgrounds influence prenatal decision-making, and that acculturation may have a further impact. To our knowledge, there have been no previous studies comparing different ethnic groups' attitudes towards termination of pregnancy for a range of genetic conditions.

There is also evidence for differences in attitudes toward termination of pregnancy for genetic conditions between people who do or do not already have a child with a genetic condition. For example, some studies have shown changes in people's attitudes toward termination of pregnancy for a specific condition after having a child with the condition (Ahmed et al. 2006b; Atkin and Ahmad 1998; Sawyer et al. 2006). In these studies, parents are more likely to opt for termination of an affected pregnancy, mainly because of their experience of the impact of the condition on their child, particularly if this is perceived to result in 'suffering'. However, these studies are limited to specific conditions, such as sickle cell and thalassaemia (Ahmed et al. 2006b; Atkin and Ahmad 1998) and cystic fibrosis (Sawyer et al. 2006), and specific ethnic groups.

Overall, little is known about how people's attitudes regarding testing and termination for one condition relate to their views of testing and termination for other conditions, i.e., similarities and differences held by individuals for different conditions, particularly if they already have experience of a genetic condition. This paper is based on of the qualitative findings which form part of a larger study by Hewison et al. 2007 (referred to from here on as the main study). The main study surveyed attitudes about prenatal testing and termination for 30 different conditions in 420

new mothers living in the UK (198 Pakistani and 222 European white), and interviewed 60 of these mothers. The main study showed that, overall, Pakistani women held more favorable attitudes regarding prenatal testing, but less favorable attitudes about termination, than their European white counterparts. Both groups were most in favor of termination for the description of the same four conditions: anencephaly, trisomy 13 or 18, quadriplegia, Duchenne muscular dystrophy. There was considerable individual variation for these conditions, but many women who were generally against the idea of termination, made an exception for one or more of these conditions. Overall, the major conclusion of the main study was that people's view varied depending on the condition.

Given that direct experience has been shown to influence attitudes concerning prenatal testing, even though the direction of the effect seems to be variable (Kreuz 1996; Wertz et al. 1992), the study was conducted with a new sample of 19 Pakistani and European white women because of their prior experience of a genetic condition. These women either had a child with a genetic condition or had terminated a pregnancy for a genetic condition within the last 5 years. This paper presents the qualitative findings obtained from interviews with the 19 women, that is, their perceptions of what would influence their decisions about prenatal diagnosis and termination of pregnancy, and highlights similarities and differences between the ethnic groups where possible.

## Method

### Sample and Recruitment Procedure

Women were recruited via an NHS Genetics Department who either had a child with a genetic condition or had terminated a pregnancy for a genetic condition within the last 5 years. Participants were selected and initially contacted by the genetic counselors, to give approximately equal numbers from each ethnic group (defined in terms of family origins in the UK for the European white group and family origins in Pakistan for the Pakistani group). Genetic counselors asked potential participants if they would agree to being approached by a researcher. If so, a researcher explained the project in the woman's preferred language, and sought informed written consent to participate. Twenty-two women were invited in order to obtain the sample of 19. Prior to participant recruitment, the study was approved by the appropriate Local Research Ethics Committees. All participants completed the questionnaire and were interviewed. The study was conducted by two researchers (Pakistani and European white), who each interviewed women of both ethnic origins. The Pakistani researcher interviewed all Pakistani women unable to speak fluent English.

## Materials

### *Questionnaire*

A self-completion questionnaire was devised, which contained brief descriptions of 30 real conditions (described in, and appended to, Hewison et al. 2007). These conditions included those affecting sensory, mental or physical functioning, and varied in levels of severity. The descriptions were devised by a group consisting of a geneticist, an obstetrician/gynaecologist, a midwife, an epidemiologist, and psychologists with specialist knowledge of genetic disorders. The conditions were purposely not named, to minimise the influence of preconceived ideas and because some names would be unfamiliar to participants. For example, cystic fibrosis was described as “child would have problems with lungs and digestive systems, require a lot of medical care throughout life and have a shortened lifespan (death probably before 40 years of age)”, and Huntington’s disease was described as “child would develop an incurable condition by age 40, which has both severe mental and physical deterioration, require constant looking after and medical help and have a shortened lifespan”. Participants were asked to assume that a hypothetical test carried out early in pregnancy, using routinely collected blood, would tell them definitely whether the baby had the condition in question. For each condition, women were asked two questions: whether they would (1) want a prenatal test and (2) consider termination should the baby be affected. For each of these questions, women were asked to choose one of three responses—yes, no, not sure. The questionnaire was designed to be self-completed in the main study, but was administered face-to-face with all the women in the study presented in this paper. Where appropriate, the questionnaire was administered verbally in English, Urdu, Punjabi or Mirpuri to the Pakistani women by a member of the research team who was fluent in these languages.

### *Interview*

A semi-structured interview guide was devised to explore the factors that the participants took into account when forming their views, in particular, why certain conditions were perceived as similar and others as different for the purpose of prenatal diagnosis and termination of pregnancy (see [Appendix](#)). Participants were not asked to express their views for each of the 30 conditions separately, although many of them used the questionnaire as a reminder of the conditions and their responses.

Only the Pakistani women were prompted about the role of their faith in decisions about termination of pregnancy because, overall, the literature suggests that religious convictions are often the main reason given by Muslim populations for declining prenatal diagnosis and termina-

tion of pregnancy, unlike the Northern European white populations (Ahmed et al. 2000; Zahed and Bou-Dames 1997).

### *Analysis*

*Quantitative* Data management and simple statistical comparisons looking at difference between the groups’ responses to the questionnaire items were conducted using SPSS version 10.0 (SPSS Inc. 1999).

*Qualitative* All transcripts were organized and coded using N-Vivo (Nudist-Vivo 6; Sage Publications). The qualitative data were analysed using the framework approach (Silverman 2001), developed by researchers at the UK National Centre for Social Research. Framework analysis was chosen because: (1) it allows the researcher to be guided during analysis by a list of core issues considered important for the scope of the study, without being either too rigid or too immersed in raw data; (2) it allows the researcher to incorporate new relevant issues emerging from the data, and (3) makes the analysis of large amounts of data more manageable. A hierarchical thematic framework was developed and used to classify and organise data according to key themes, concepts and emergent categories. Key themes relating to attitudes toward prenatal diagnosis and termination of pregnancy were developed both from the research questions and from the narratives of research participants. Data analysis involved familiarisation with the data, which was achieved by listening to the tapes and reading the transcripts in their entirety, with the aim of immersing in the details and getting a sense of the interview as a whole before dividing it into more manageable sections. Analysis also involved consistent cross-referencing within and between the groups for similarities and difference between them. All data were analysed by the same experienced qualitative researcher (SA). All names used in the results and discussion are pseudonyms.

## Results

### Sample Characteristics

The sample consisted of 19 women: nine European white (five educated above GCSE level) and ten of Pakistani origin (four educated above GCSE level). Sixteen had at least one living child with a genetic condition. The Pakistani women had children with ambiguous genitalia, albinism, ataxia, congenital adrenal hyperplasia, deafness, methylmalonic academia, primary ciliary dyskinesia, or spinal muscular atrophy. The European white women had children with

achondroplasia, congenital adrenal hyperplasia, Becker muscular dystrophy, cystic fibrosis, Duchenne muscular dystrophy, fragile X, or myotubular myopathy. Two Pakistani and two European white participants had two children each, with the same genetic condition. The age of the affected children ranged from 7 months to 9 years. Three participants (two Pakistani and one European white) had terminated a pregnancy for a genetic condition. Table 1 presents demographic data.

Fifteen of the participants completed the questionnaire in English and four of the Pakistani women completed the questionnaire in Urdu. Fifteen interviews were conducted in English, two in Urdu, one in Punjabi and one in Mirpuri.

#### Attitudes About Prenatal Testing and Termination of Pregnancy: Questionnaire Findings

All 19 women in this study indicated that they would have opted for termination of pregnancy for at least one condition on the questionnaire. From here on, names of conditions will be used rather than the scenario descriptions.

Similar to the main study, there was more interest in prenatal testing than termination of pregnancy for most conditions, particularly in the Pakistani women. Unlike the main study, there was more interest in termination of pregnancy in the Pakistani women compared to their European white counterparts.

#### Attitudes About Prenatal Testing and Termination of Pregnancy: Interview Findings

During the interviews, women were asked what influenced their responses to the questionnaire items, including: the quality of life of the affected child and of family members; impact on the main care giver of an affected child, available resources and rewards; whether the condition was treatable and the nature of that treatment; religious beliefs; and opinions of others. Women were usually prompted about

these various influences, and were asked direct questions if they did not mention them. It was evident from the interviews that all 19 women perceived quality of life of the child as the main factor in their decisions about termination of pregnancy:

Anmol (Pakistani participant): "...child is number one priority, what the child has to go through."

Lorna (European white participant): "...I was thinking more about what quality of life the child would have rather than how bad it would impact on me as a parent... if I decided that I didn't think their quality of life would be good enough, that's when I would say 'yes' (to termination of pregnancy)."

Some women also said that it was difficult to judge the quality of life for a child with any condition of which they had no experience:

Hazel (European white participant): "...it's difficult for us to assess what is going to be the quality of life for the child with any condition—how can you decide before a child's born what their quality of life is gonna be like ... what makes my life quality might be different from somebody else."

Nevertheless, when deciding whether to opt for termination of pregnancy, women generally made judgements about the quality of life for a child with the various conditions in the questionnaire. They described good and poor quality of life based on their perceptions of suffering and normality. The women placed considerably less emphasis on the impact on the main care giver of an affected child, available resources and rewards, or opinions of others. Therefore, the presentation of findings in this paper will focus on deconstructing the concept of "quality of life" by looking at what it means to people in terms of "suffering" and of "normality"; how and why perceptions of the concept differ among people; and how perceptions of the concept impact decisions about termination of pregnancy. The analysis will also cover other factors that the women considered in their decision-making, such as, whether the condition was treatable and the nature of that treatment, and religious beliefs, and explore changes in their attitudes toward termination after having a child with a genetic condition. Where possible, comparisons will be made between women's attitudes for specific conditions, and between European white and Pakistani women.

#### Poor Quality of Life: The Suffering Child

##### *Perceptions of Pain*

Twelve of the Pakistani and European white women associated pain with suffering for the child, hence poor

**Table 1** Demographic Characteristics of the Study Participants

		European white	Pakistani
Place of birth	UK	9	5
	Pakistan	—	5
Religion	None	1	—
	Christian	7	—
	Islam	—	10
	Other	1	—
Regional origin in Pakistan	Mirpur Dist., Kashmir	—	8
	Nowsera/Peshawar Dist.	—	1
	Punjab	—	1
Age in years	Mean (SD)	36 (2.8)	26 (4.9)
	Range	32–40	21–37

quality of life, and said that they would terminate for a condition resulting in “pain”:

Lorna (European white participant): “...that’s a trigger word for me, ‘pain’, which links to quality of life...”

Pain was described as resulting in physical and emotional suffering for the child. Physical suffering for the child was often related to women’s perception of pain caused by treatment for the condition:

Meredith (European white participant): “...a child that would need numerous operations, a child that sort of, going to be suffering, erm, suffering pain.”

Holly (European white participant): “... (resulting in regular blood transfusions and medical treatment throughout life) ...if it’s gonna be something that causes them pain then yeah, I don’t think it’s, fair to the child to put them through it.”

Six of the women were also unsure about termination for conditions that would require treatment. This was mainly because they were unsure of how much pain the child would have to endure:

Lorna (European white participant): “If I thought I was going to be having a child who’s gonna have a condition where they had to endure hellish treatment time after time after time, you know, really, really painful treatment erm that would make me really think carefully about whether I would terminate because that is quality of life...”

Women described different types of emotional suffering for a child, depending on the condition. For example, in a condition where the child was mentally well, but extremely limited physically:

Anmol (Pakistani participant): “I wouldn’t want a child who couldn’t enjoy the life they were living ...If the child doesn’t understand what they’re living or why they’re living it, or get any pleasure out of it, what is the point? ...I would never ever want to give birth to a child like that... who couldn’t do anything for himself or herself, couldn’t enjoy anything, physically do anything and sit there and watch others enjoy themselves, not get any enjoyment out of the life they’re living, and go through all that pain and distress.”

### *Perceptions of Disfigurement*

Disfiguring conditions were described by women as resulting in emotional suffering caused by other people’s adverse reactions. For example, seven women mentioned the “world” as a “cruel place” when talking about

neurofibromatosis, and said that they would terminate for this condition, depending on the size of the lumps and type of disfigurement. This was mainly because the condition was believed to cause people to stare at and/or bully the disfigured child:

Holly (European white participant): “...probably aren’t going to be in pain but it’s just the fact that they’re going to have stares... It could be suffering mentally though, couldn’t it, with the abuse.”

Noor (Pakistani participant): “The world is a very cruel place... the child would suffer because everyone would pick on him or her, like at school... laugh at him or her. That’s like making the child suffer.”

Four women were unsure about termination for neurofibromatosis because they were unsure about the extent to which the lumps would be disfiguring and whether the lumps could be removed/cured:

Saeeda (Pakistani participant): “...there’s all sorts of things doctors do these days like plastic surgery ...it’s a cruel world out there as well. You get people calling you names and everything but, it depends to what degree they are and what could be done about it.”

However, ten women imagined neurofibromatosis to be less severe, treatable with plastic surgery and, therefore, would not consider termination for the condition.

Heather (European white participant): “You could probably have an operation for that (disfiguring large lumps on the head and face)... and cure it.”

Researcher: “Right, and if it isn’t curable?”

Heather (European white participant): “Depends how severe it is—if they (child) can live with it then fine.”

Overall, perceptions of disfigurement were key to women’s decisions about termination of pregnancy. All women who believed that the condition would be disfiguring, said that they would consider termination of pregnancy, mainly because of the implications for the affected child.

### *Poor Quality of Life: Early Death*

Conditions resulting in death before or soon after birth were seen by all the women as severe, both because the child was seen as having no life or a short lifespan in which the child would be suffering, and because of the perceived inability of the parents to cope with the death of their child:

Noor (Pakistani participant): “I think it’s stupid to go through all that (pregnancy). ... It’s not fair on the child if they are going to be ill and then die young. It’s also too much for the parents.”



Edna (European white participant): "...there's no quality there at all and I don't feel I would want to have a baby for a few months that was severely disabled knowing that it's going to die. I don't think I could cope emotionally with that at all."

Hazel (European white participant): "...I'm not sure I'd be able to give that child a good quality of life... they'd (baby) not be aware really, if it had no brain. There wouldn't be a quality of life there at all, so therefore, to terminate early might be a better thing, than to put myself and the rest of the family through the birth and dying."

However, one Pakistani and two European white women said that they would not terminate for the description of anencephaly, because it was better to have the child for a short time than not at all, the suffering would be short-lived, the baby would have been given the chance to live, and it would allow the parents to go through the grieving process:

Zorah (Pakistani participant): "...it'll only be for a few months and at least you're lucky to have a child. Even if the child is suffering, it'll only be for a few months ...those few months you can look after a child ... if it's short (lifespan,) then you can somehow manage... at least you have a chance to hold the child in your arms."

Clover (European white participant): "...if a child's going to die at birth anyway then, it's really awful, but I can just go through that pregnancy and then we can breath for we've let it try to live, even though we know it's not going to, but we still let it try to live, and when it's died, we can go through that grieving process."

Similarly, eight women said that Duchenne muscular dystrophy was severe, because it was seen as resulting in suffering for a child with a short lifespan, followed by death in childhood:

Zakiyah (Pakistani participant): "...if a child has lived for about 10, 15 years there's no point if he will suffer from that (Duchenne) and can die at the end."

Saeeda (Pakistani participant): "... child starts suffering at 11, 12. That's a very young age, and then if they die ...it's very difficult. It'd be very difficult to cope with... 10 years goes flying in life anyway... and before you know it'll be 11, 12 and start having problems. Don't mind looking after the child but then losing it is the most difficult part of it. Yeah, so I don't think I'd be able to cope."

Seven women were unsure about termination for Duchenne muscular dystrophy, because they believed that

the child could have good quality of life for a number of years, but then the child would suffer before death as a teenager:

Audrey (European white participant): "...they may have a quality of life, you know good few years, then again I don't know... I know somebody who had that, but he was a lot older, so he had had a good life and then suffered later on."

Meredith (European white participant): "...if a child was dying in infancy... I would more or less say 'I'd definitely terminate that'. Then because the child's got a slightly longer life, it gets a bit more difficult."

Four women said that they would not terminate for Duchenne muscular dystrophy because the child's life period was perceived as a long time to live, and similar to anencephaly, they believed that it was better to have a child for this period than not to have the child at all:

Fizza (Pakistani participant): "No (to termination of pregnancy), because they've had a good 12 to 13 years with their mother."

Overall, most women would opt for termination of pregnancy if they believed that a condition would result in physical or emotional suffering for the child, and if the child would die in childhood, particularly soon after birth or within a few months.

#### Perceptions of "Normality"

Women indicated that they would not consider termination of pregnancy for conditions that they perceived as resulting in the child having some quality of life, which in turn was associated with having a somewhat "normal" life, i.e. where the child could be happy, able to "cope" with the condition, and able to lead an independent life. Within this context, women usually referred to the descriptions of achondroplasia, autism, blindness, cleft lip and palate, cystic fibrosis, deafness, epilepsy, Klinefelter's syndrome, mild learning difficulties, and Turner's syndrome:

Saeeda (Pakistani participant): "...they could just carry on as normal life, they know what's going on, they know what's happening in life, they've got their own lives, they've still got opportunities in life... my friend in school used to have regular fits, epilepsy, and it didn't bother me. ...she was just normal."

Lorna (European white participant): "I could cope with that ...if I thought the child was having a good quality of life and they were happy."

Audrey (European white participant): "...I'd think about what the child's going to have to cope with....if

it's something they can cope with, I could cope with it, but if it's something they can't cope with then I couldn't cope with it."

Sinah (Pakistani participant): "... his legs are weak or whatever, but he can look after himself. He can feed himself, he can dress himself..."

Edna (European white participant): "...lots of people function very, very well with very mild learning difficulties and live independently."

Eighteen of the women believed that a child with blindness or deafness could have a normal, happy independent life:

Heather (European white participant): "I think they can have quite a good quality of life. They still can lead a normal life, independent of other people."

Fizza (Pakistani participant): "[talking about her own, living child]...he (blind son) can go to the toilet himself, eat and drink. He is not a burden on anyone."

Saeeda (Pakistani participant): "...what's he called, Blunkett, I just thought of him, and I thought 'look at him he's got every opportunity' ...a lot of people out there that are blind and living normal lives ...they can learn, they can do everything."

Eleven women also said that they would not terminate for cystic fibrosis. This was again because they believed that the child could lead a normal, independent life, but also because s/he was believed to be mentally well:

Lorna (European white participant): "...although it is a serious disease (cystic fibrosis) and it requires treatment and he's obviously gonna have a shortened life expectancy, his quality of life, you know apart from needing physio and the nebuliser, is fantastic. So he is kind of like any other little boy of his age."

Saeeda (Pakistani participant): "...the brain's still active, they're a normal child that's just got like a medical... these days there's so many medical conditions. They've got their opportunity, their brain's active, the child knows what's happening, they're still independent."

Another mother of a child with cystic fibrosis said that she would terminate for the condition because she believed the condition to have more serious consequences. She gave similar reasons for termination to those mentioned earlier, i.e. she believed that the treatment for cystic fibrosis resulted in pain for the child, hence suffering, that the child could die in childhood, hence suffering for the parents due to loss of a child:

Heather (European white participant): "...not really fair on the child with the amount of medication and

hospitalisation that they'd have to go through. I don't think it's fair on them, having a daughter that's got CF ...one child can live to be one, the other can live to be 30. You never know and you're living with that everyday, not knowing whether you're going to bury them next year or, whether they're going to carry on and grow up into adulthood... we didn't have a choice because we didn't know it was in the families, but having the choice, I think it's fairer on the child (to have a termination). ...you wouldn't even notice (that the child has cystic fibrosis), but when you go to hospital, you can see them and they can't breathe, and that isn't a life for a child, and you don't know how severely they've got it until they're born."

Heather indicated that her default in the face of uncertain prognosis was to opt for termination of pregnancy, and this related to her belief that cystic fibrosis resulted in suffering for her child. In contrast, Hazel indicated that she would not opt for termination of pregnancy in the face of uncertain prognosis and this decision appeared to be related to her experience of her child with a mild form of fragile X:

Hazel (European white participant): "...there's no way I would terminate if I found out I was having another child with fragile X, cos it can be very mild, hardly effect them at all ...if I knew it was going to be very severe, that might be different..."

Returning to perceptions of "normal," none of the women would terminate for conditions resulting in their child being unable to have children, or conditions that could be cured by surgery such as cleft lip and palate:

Sinah (Pakistani participant): "...not being able to have children is serious, but people can adopt, they can foster."

Anmol (Pakistani participant): "...that's treatable (cleft lip and palate)—wouldn't affect the child. I wouldn't see the need to terminate a child with that condition."

Fourteen women also stated that they would not consider termination for late onset conditions. This was because 40, 50, 60 years was seen as a long enough lifespan to achieve various life milestones, such as having a childhood, getting an education, and having a family:

Noor (Pakistani participant): "I don't agree with termination of pregnancy for conditions where the person would die at about 40 years old or when they are older because in that time you can have a good childhood, get an education, get married and have children. Lots of people die young, like heart attacks in late thirties..."

Saeeda (Pakistani participant): "...heart attacks (before age 50) are quite common these days... yeah so it

wouldn't really bother me ...well 60's quite an age... they've lived a life."

#### Other Factors in Decision-making About Termination of Pregnancy

Other factors in decision-making about termination of pregnancy included religion and the gender of the child. These factors were of concern mainly to the Pakistani women. That is, unlike the European white women, most of the Pakistani women spontaneously mentioned religion within the context of termination of pregnancy. When prompted, all the Pakistani women said that Islam did not allow termination of pregnancy, however, all of them also added that they had personally come to the conclusion that termination of pregnancy was justifiable for severe conditions:

Anmol (Pakistani participant): "...the way our religion sees it is, it's a human being, you are literally a murderer, but at the end of the day, if that child is not going to have any quality of life, you're in the wrong for bringing that child into the world ...you're even cruel by bringing that child into the world. ...you've got to think realistically and morally, and I think religion goes out the window there."

Noor (Pakistani participant): "...I used the will that Allah gave me to decide that I wanted to have termination of pregnancy, that I didn't want to have a baby that would suffer and die soon after birth anyway... I don't think that it would be Allah's will to put me through nine months of pregnancy to give birth to such an ill baby..."

Within the context of a child needing extra care, three Pakistani mothers mentioned the significance of the gender of the child. They explained that having a son with a condition requiring extra care was worse than having a daughter with the same condition, because the mother would be the main care giver and that difficulties would arise when a son went from being a boy to a man:

Sinah (Pakistani participant): "...if it's a boy, it'll be harder because there's a certain age a mother can look after the boy up to, cos' a boy does change into a man, then a mother can't look after a man you see, especially if it's her son..."

#### Changes in Attitudes Toward Termination of Pregnancy After Having a Child with a Genetic Condition

While some women said that having a child with a genetic condition did not change their view about termination of

pregnancy, 11 women said that it did change their views. Some women who would not have considered termination of an affected pregnancy in the past, who now had a child with a condition that required extra care, said that they were more likely to opt for termination of subsequently affected pregnancies. The women acknowledged that this was because of their own experiences of caring for a child with a severe genetic condition, and because they believed that they could not cope with another child with the same condition, requiring extra care:

Anmol (Pakistani participant): "Now I'd have it (termination of pregnancy) because I've had a piece of the cake ...I think if I hadn't, I would have said 'no' (to termination) ...but because I've seen what it's like and seen how hard it can be, then I'm saying 'yes'."

Audrey (European white participant): "... I was having this baby come what may ...but there is a lot more to consider when you've already got another child... every single time he's unwell, he has to go in to hospital for treatment."

Hazel (European white participant): "...with two children that already need extra care, if I found out that I was going to have a third that was going to need even more care, it would be a very difficult decision."

A Pakistani woman's experience of her child with a metabolic condition was so profound that she was prepared to terminate her next pregnancy at 18 weeks gestation if prenatal diagnosis was not available for that condition. That is, she would rather have terminated an unaffected fetus than take the chance of having another baby with the same condition. Her description of the implications of the condition for her 2 1/2-year-old son show why she was prepared to take such action:

Zakiah (Pakistani participant): "...he feels sick every single day ...this (condition) can lead to coma as well, can lead to die as well, can delay development as well."

Holly's son already had Duchenne and she did not say that she would terminate for this condition possibly because of her loyalty to her son:

Holly (European white participant): "...I've got (son) and I always think if I knew that I was going to have him (with Duchenne), and I had him terminated, then I would have missed out on so much. Before I had (son), I would've maybe thought differently, I probably would have had a termination."

However, she was unsure about whether she would opt for termination for another child with the same condition,



because of whether she would be able to cope with providing extra care for two children with Duchenne:

Holly (European white participant): "...can I cope with two children in wheelchairs and that's the big thing, could you cope with it really."

Lorna added that thinking about having another child with cystic fibrosis was different to thinking about having another child with other conditions, because a second child with cystic fibrosis could reduce the life expectancy of the first child with the condition, due to increased chances of infections:

Lorna (European white participant): "You're very much trained as a CF parent that you ideally shouldn't bring them into contact with other CF children... keep him away at all costs from other CF children because of the risk of infection ...most of our discussions about whether we would want to have another CF child and whether we would be prepared to terminate are 90% thinking about (son with cystic fibrosis) really."

In addition, 14 women mentioned concerns about what would happen to a child with a severe condition needing extra care when they themselves died:

Anmol (Pakistani participant): "I wouldn't want to leave a child that would need constant looking after ... not knowing that if I could be there for the rest of their lives for them. I wouldn't be prepared to do that."

### Completing the Questionnaire

Some women commented that the questionnaire was difficult to complete because it was hypothetical:

Edna (European white participant): "Difficult really. ... they (questions) are hard unless you're in that situation, because what you think you'd do and what you'd actually do is often two totally different things... I think a lot of it's circumstantial... depends on how your life is at that time, whether you'd feel you could cope with it, a disabled child, that's difficult."

Nevertheless, the decision to terminate was not taken lightly by the women in this study. Many women commented that they thought it was hard to make a decision. As Lorna explained:

Lorna (European white participant): "I don't like the thought of termination and that's why it would be a real big, big decision where I would need the information and I'd need to be fully informed and I would need to sort of decide whether it was the right thing to do, but it would be a very big decision for me. It wouldn't be 'ok they've got Down's, well I'm

terminating' type of thing. It would be 'they've got Down's, ok what does that mean? Let's find out about it. Could I do this? Should I do this?'"

### Discussion

This study was conducted with women who either had a child with a genetic condition or had terminated a pregnancy for one. The main finding of this study was that the most important factor in most women's decisions about termination of pregnancy was their perception of the quality of the life of the child. In particular, whether the child would be "suffering," either physically or emotionally. These findings show why women are more likely to say that they would terminate for conditions such as anencephaly, trisomy 13 or 18, quadriplegia, and Duchenne muscular dystrophy. Women believed that these conditions resulted in suffering for the child, but also in distress for parents caused by the death of a child. However, there were differences in attitude for these conditions, for example, for anencephaly where some women expressed a need to have the baby and go through the grieving process. Furthermore, the literature on "quality of life" shows that as well as meaning different things to different people, "quality of life" can also mean different things to the same person over the course of a disease (Sprangers and Schwartz 1999).

Women were less likely to terminate for conditions perceived as resulting in a somewhat "normal" life for the child. There was much variation in what women perceived as normal, but there was a consensus about some core factors. Many women believe that the child could have a normal life, if s/he would be happy, able to cope with the condition, and/or could live an independent life. Overall, the decision to terminate was not taken lightly by the women, and they often indicated that they were unlikely to consider termination unless the condition was perceived as resulting in suffering for the child. Overall, women's notion of quality of life in this study was broad. As well as physical quality of life, their notion included social quality of life, i.e., whether the child would be able to do things that other children can do.

The findings of the present study also challenge a number of stereotypes about cultural differences in attitudes about termination of pregnancy. There were more similarities than differences between the Pakistani and European white women. The main difference between the two groups was the role of religion in decision-making. One European white woman spontaneously mentioned religion, compared to most of the Pakistani women who spontaneously mentioned that Islam does not allow termination of pregnancy. This interpretation of Islam's stance on termination of pregnancy is a misconception, which Ahmed

et al. 2000 suggest is due to the difficulty people have in distinguishing between their religious and traditional or cultural beliefs. In fact, a number of Islamic states have ruled that termination of pregnancy for a foetus with a serious disorder is permissible, but before soul-breathing (ensoulment) occurs at 120 days of gestation, and even beyond this point if the pregnancy endangers the mother's life. For example, in February 1990 the Islamic Jurisprudence Council in Saudi Arabia ruled that "...abortion is allowed within the first 120 days of conception if it was proven beyond doubt that the fetus is affected with a severe malformation that is not amenable to therapy and if his life after being born will be a means of misery to both him and his family and if his parents agree" (Alkuraya and Kilani 2001). Nevertheless, similar to other studies (Ahmed et al. 2006a), all the Pakistani women in this study indicated that perception of the child's quality of life was the first and foremost factor in decisions about termination of pregnancy, and although religion was important, they had decided that it was justifiable for severe genetic conditions, resulting in "suffering" for the child.

#### Practice Implications

Genetic counselors should be aware of variations in perceptions of quality of life, both between people and within the same person over time, and understand the reasons for this, in order to respect reproductive choices made by parents. Genetic counselors should also be aware that experiences of a genetic condition alone may not make women pro or anti prenatal diagnosis/termination of pregnancy, but that attitudes may also be influenced by experiences of a child's disability. In general, genetic counselors should remain cognizant of the fact that decision-making is a very individualized process, so even when the same factor (e.g., quality of life) is being considered by two different patients, they may view it quite differently and reach different decision outcomes. Genetic counselors should work to help parents realize that termination decisions are complex—influenced by several factors—and help patients consider the various factors identified in this study as being involved in prenatal decisions.

Given that women are likely to accept or decline termination of pregnancy based on their perceptions of the child's potential quality of life, it is essential to provide them with balanced and sufficiently detailed information about what the condition would be like for the child and the child's family to facilitate informed consent and enable parents to make truly informed choices (Parens and Asch 1999). Although we acknowledge that this is more difficult for some conditions, such as Down syndrome where the prognosis is variable, compared to other conditions with more definitive prognoses, such as beta-thalassaemia. Nevertheless, most leaflets for antenatal testing contain

information that is overwhelmingly medico-clinical in nature and little about the condition (Bryant et al. 2001; Loeben et al. 1998). There is a need for more detailed information about the child's potential quality of life, such as that provided by AnSWeR (Antenatal Screening Web Resource, <http://www.antenataltesting.info/>), which was specifically designed to provide information about disability for people considering antenatal testing and/or termination of pregnancy. AnSWeR focuses on five conditions - cystic fibrosis, Down syndrome, neural tube defects, Klinefelter syndrome and Turner syndrome - and contains interviews with family members of a child, and individuals, with one of these conditions. AnSWeR could be expanded to include information about the quality of life for more conditions for which antenatal testing is available (Ahmed et al. 2007).

Overall, the findings emphasize the importance of recognising diversity within ethnic groups. Genetic counselors should remind themselves not to stereotype a given patient on the basis of ethnicity or religion, and to consider the beliefs and preferences of individuals.

#### Research Recommendations

Prenatal counseling often occurs with couples, therefore further research should explore fathers' attitudes. Further research is also needed to determine when "practical considerations" might outweigh more quality of life issues, such as, the risk of another child with cystic fibrosis jeopardizing the health of an existing child with cystic fibrosis; the family's inability to financially support a child with a particular condition; the stressors are too great on the care giver and/or family to have one or more affected children.

#### Study Limitations and Strengths

Participants responded to hypothetical situations, and their behavior might be different in real situations. Plus, the researchers read the questionnaire to participants, which raises the possibility of social desirability effects. Also, the use of 30 different genetic conditions may have limited the amount of depth/detail with which the women responded. In addition, prevalence of a theme does not necessarily mean that it is the most important theme, so further research should be done to investigate the importance of various factors.

A small scale qualitative 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 the main study, we found that education was not related to attitudes about termination of pregnancy in either European white or Pakistani women (Hewison et al. 2007). Therefore, the relationship between educational level and attitudes was not explored in this study.

We acknowledge that there is much literature on “quality of life,” however, studies usually focus on a specific genetic condition, using quantitative measures (Aalto et al. 1997; Carlsson et al. 2004; Knafl et al. 2007; Mugno et al. 2007; Page et al. 2006), and do not relate “quality of life” to attitudes toward termination of pregnancy. The aim of a qualitative study is not to make generalisations about quantitative issues, for example, how many people think this or that, but it is to identify what lies behind the relatively bare quantitative findings in order to understand better how they have come about. From this point of view a qualitative study of 19 women is an appropriate sample size. The “generalization” that takes place is at the level of saying that “these are the sorts of things that people take into account.” Our study has enabled us to explore and offer an insight into the similarities and differences between Pakistani and European white women’s attitudes toward prenatal diagnosis and termination of pregnancy, and how these relate to perceptions of “quality of life.”

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## Appendix

### Interview Guide

#### 1. Quality of life...

- a) ...of the affected child—Which conditions do you think result in poor quality of life? (Explore continuum from severe to acceptable)
- b) ...of family members—How do you think family life would be affected if you had a child with a condition resulting in poor quality of life?

#### 2. Parenting issues:

- a) ...burden of care
  - Who would be the main care giver if the child had a condition?
  - How easy/difficult do you think it will be to get help?
  - How would this change the life of the main care giver?
- b) ...resources
  - What resources do you think are available to help bring up a child with conditions mentioned in the questionnaire? (Explore awareness of paying/waiting for resources, e.g., special education, social services.)

#### c) ...rewards

- What sort of things do you think parents may gain from having a child with a serious condition? (Some women have mentioned a greater sense of love & affection, sense of achievement, and spiritual/religious rewards.)

#### d) ...opportunities and expectations

- What sort of expectations do you have of your children?
- What impact would having a child with a condition have upon those expectations?
- In what way do these issues affect your decisions about prenatal testing/TOP?

#### 3. Amenability to treatment:

- Are there any conditions where you think that the treatment is such that you would consider termination of pregnancy? (What if the child needed regular hospitalisation/injections/blood transfusions or surgery?)
- Are there any conditions where you think treatment may become available in the future and therefore reject a TOP?

#### 4. Religious beliefs:

- How does your religion influence your decisions around prenatal testing /TOP?

(For Pakistani women only)—Fatwas have been produced in different Islamic countries to say that TOP is allowed for serious conditions if it is within 120 days of gestation. How would such a fatwa affect your decisions about TOP?

#### 5. Opinions of others:

- In what way do other people’s opinions affect your choices about prenatal testing/TOP?

#### 6. Changes:

- In what way have your views changed about termination of pregnancy after having a child with XXX (name of genetic condition)?

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