

Experiences of parents with a child with Down syndrome in Pakistan and their views on termination of pregnancy

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Abstract It has been argued that Down syndrome (DS) is as much a cultural creation as a biomedical condition, yet the majority of research in this area has been conducted in ‘Western’ cultures. This study explored parents’ experiences of their child with DS in Pakistan and their views on abortion for the condition. Thirty mothers and fathers of children with DS took part in qualitative interviews. Transcripts were thematically analysed. Parents used Islamic discourse to frame positive personal meanings of their child’s condition. These were contrasted with personal experiences of stigmatisation and rejection by family and community. An ambivalent cultural stereotype was revealed that characterised people with DS as abnormal and objects of pity but also as being closer to God and bringers of good fortune. Views on termination varied, but parents were generally supportive of the availability of abortion for DS due to the social stigmatisation they experienced. The findings reveal how parents negotiated their religious beliefs alongside personal experiences to inform personal views on abortion for DS. Advice to other parents about termination was rooted in Islamic discourse but emphasised pragmatic concerns about the impact of having a family member with intellectual disability in Pakistan.

Keywords Down syndrome · Pakistan · Islam · Parents · Religion · Abortion

Introduction

Trisomy 21, the chromosomal anomaly associated with Down syndrome (DS), is a relatively common cause of learning disability across all human populations. There is no strong evidence to suggest that, once maternal age is taken into consideration, incidence of DS is related to ethnicity or geographical location. While life experiences and expectancy for people with DS varies significantly across the world, the majority of research with families who have a child with DS has been conducted in relatively affluent ‘Western’ countries.

In economically developed countries, life expectancy for individuals with DS continues to rise, and significant, if uneven, progress has been made in education provision and employment prospects for those with an intellectual disability (Glasson et al. 2002). Research conducted in Western Europe and North America shows that most (but not all) families adjust well to a child with DS and usually experience a quality of life similar to that of other families (Carr 2005; Cunningham-Burley and Kerr 1999; Goddard et al. 2000; Van Riper 2007). In contrast, the limited literature from economically developing countries tends to characterise life for people with intellectual disability and their families as burdensome and stigmatised (Ghai 2001). An Israeli study reported that people with DS were often viewed by the public as unattractive, frightening and embarrassing, evoking feelings of pity, sadness and rejection (Shiloh and Berkenstadt 1992). Palestinian children with DS have been reportedly hidden, subjected to abuse and even infanticide, especially when female (Fishman 1994). Nevertheless, Ingstad has argued that responses to disabled people in

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low-income countries are often misunderstood and that most of the problems are due to poverty, lack of social support and a lack of knowledge about what can be done rather than ‘a lack of love and negative attitudes’ (Ingstad 1995, 1999, 2007). In support of this, research conducted in Britain, Pakistan and Taiwan shows that, while raising a child with DS is experienced within a particular cultural context, there are also some experiences in common across economically and culturally diverse societies (Bryant et al. 2011; Department of Education and Skills 2006; Hsiao and Van 2011; Selway and Ashman 1998).

For some parents, religious belief can have an important bearing on causal attributions for disability, although the relationship between religion and views on impairment is not a straightforward one (Bryant et al. 2011; Bywaters et al. 2003; Croot et al. 2008; Groce and Zola 1993; Michie and Skinner 2010; Skinner et al. 2001). Religious discourse reflects cultural understandings as well as religious teaching, and each is embedded within the other (Bywaters et al. 2003; Diken 2006; Michie and Skinner 2010). The birth of a child with a disability may be perceived as ‘God’s will’ and associated with beliefs about being ‘chosen’ from a positive perspective but may also be perceived in the wider community as a divine punishment upon the parents (Bryant et al. 2011; Diken 2006; Groce and Zola 1993; Michie and Skinner 2010). Such understandings are found historically across many religions including Judaism, Hinduism, Christianity and Islam (Selway and Ashman 1998). The values that society conveys about disability can impair or facilitate parental adaptation and response to their child’s condition. Reduced levels of social interaction, self imposed social isolation and a willingness to place children in institutional care have been associated with maternal perceptions of stigma and negative attitudes towards disability in their families or community (Daudji et al. 2011; Green 2004).

A further crucial issue affecting parents in many economically developing countries is the lack of social and educational support for people with an intellectual disability. The Disability Rights Movement, which has significant lobbying power in many Western countries, has had little influence on public discourse in many low-income countries (Maloni et al. 2010). In many countries, including Pakistan, most service provision for people with intellectual disability is based on the ‘charity model’, largely dependent on local benefactors and charitable foundations (Coleridge 1993). For most parents, the responsibility for educating, supporting and caring for a child with DS resides entirely within the family, which, in turn, can result in financial and psychological stress for parents (Arif et al. 2008).

In many affluent Western countries, prenatal testing for DS has also become a part of routine antenatal care and, in Britain, for example, is free at the point of delivery. Although abortion continues to be a hotly debated issue, in

most countries where prenatal testing is made available, provision is also made for the legal termination of pregnancies found to have DS. In Pakistan by contrast, prenatal testing for DS is available only through private healthcare, and abortion is illegal (Rahman and Obaid-ur-Rahman 2005). Service providers can seek Fatwas (religious decrees) that give permission for abortion before 120 days gestation in cases where the foetus is affected by a disorder of a ‘severe nature’ (Ahmed et al. 2000). Research in Islamic countries shows that, despite the socially acceptable view of abortion as immoral, many Muslims would personally accept prenatal testing technology and may opt for termination of pregnancy for conditions perceived to be burdensome for the child (Ahmed et al. 2000, 2006; Alsulaiman and Hewison 2007; Bryant et al. 2011). However, there is very little research on how parents’ experiences and perceptions of disability relate to these attitudes. This paper reports on a study that explored experiences of parenting a child with DS in Pakistan, an economically developing Muslim country in South Asia. Parental views on the use of prenatal testing and termination of pregnancy for DS were also explored.

Method

In-depth interviews were carried out by authors 1, 3 and 4. All three authors are of Pakistani origin and are multilingual in English, Urdu and Punjabi. Authors 1 and 3 are based in the UK, and author 4 is based in Pakistan.

Participants

Participants were recruited in a large city in Northern Pakistan via a centre providing schooling, speech therapy, physiotherapy and medical and psychological assessment for children and young adults with intellectual disabilities (referred to from here on as the centre). The study included a sample of 30 parents of children with DS, 15 mothers and 15 fathers, representing 19 families—both the mother and father of 11 children and the mother or father of eight children. Purposive sampling of the parents of children with DS registered at the centre was conducted for gender, education, social background, parental age and the gender and age of child with DS. Thirty-nine parents were approached, and 30 agreed to participate. All the participants were Muslims. They ranged in educational attainment from no qualifications to master’s degree and, in household income, from unemployed and dependent on charity to affluent and owning their own business. Participants’ age ranged from 37 to 61 years, and the ages of their children ranged from 2 to 30 years. All the parents in this study were given a diagnosis of DS after their child was born.

Procedure

The study was given an ethical approval by the University of Leeds Ethics Committee, and the director of the centre in Pakistan gave permission to invite parents to take part. An interview guide was devised to explore participants' experiences of the social, emotional and financial implications of having a child with DS and their advice on termination of pregnancy to prospective parents receiving a prenatal diagnosis of DS. All participants were provided with information about the study, and written consent to participate was obtained. Interviews were conducted by the researchers in Urdu or Punjabi at the centre. Interviews were carried out separately with all the participants, and mothers and fathers of the same child were also interviewed separately. The interviews lasted between 30 and 80 min, were audio recorded, translated and transcribed. Some participants became upset during the interviews, at which point consent to continue was obtained. Author 1 assured the quality of the translation and transcriptions by listening to audio-recorded interviews and conducting the analysis simultaneously.

Analysis

All transcripts were organised and coded using N-Vivo (Nudist-Vivo 8; Sage Publications). The qualitative data were analysed using the framework approach (Silverman 2001). A hierarchical thematic framework was developed and used to classify and organise data according to key themes, concepts and emergent categories. Key themes were developed both from the research questions and from the narratives of research participants. Data analysis also involved consistent cross-referencing between the participants for similarities and differences between them. All data were analysed by the same experienced qualitative researcher (author 1), who discussed the coding framework and themes with the second and third authors (authors 2 and 3) at length, then refined and discussed again to ensure consistency in interpretation of the data. During analysis, differences by gender and educational attainment were explored but not found, as shown by the demographic information preceding quotes in the next section. All names used are pseudonyms.

Findings

The quotes presented in this section are preceded by information about parents' gender, the gender and age of their child with DS and the participants' highest educational qualification ('metric' is the Pakistani equivalent to the UKs' GCSE level standard school exit academic qualification at age 16).

Down syndrome within the religious cultural context of Pakistan

All parents gave accounts of the existence of people with DS within a religious framework. Most parents talked positively about the birth of their child with DS as being the 'will of Allah', expressing their affection for their child and gratitude to God. The majority of parents described their child with DS as a 'gift from God' believing that their child was special and that they had been chosen to have this child. Some of these parents related 'being chosen' to the belief that they themselves had special qualities:

Father 3 (daughter 2 years; metric): 'They are special children of Allah. ...special parents have such children...'

Some parents expressed the belief that, by accepting the will of Allah, they were being rewarded in this world with wealth and success:

Mother 12 (son 20 years; bachelor's degree): 'My husband has had so many promotions and perhaps it's because we take such good care of (child with DS).

Parent's accounts suggested that such beliefs are reinforced by authority figures in Pakistani society, for example:

Mother 5 (son 12 years; A levels): '...doctors told us that, in the homes where such children live, they get very good luck, and Allah bestows a lot on such a child. Once a saint came to our home and said that he (son with DS) is a blessing on our home, and whatever we are getting is just because of him...we asked some scholars, and they also added that he is very lucky'.

For some parents, even though in their case they did not feel that they had been rewarded, this cultural belief was acknowledged:

Mother 2 (daughter 5 years; no educational qualifications): 'People say that Allah gives you a lot (financially) when you have a child like this, but nothing like that has happened to us'.

In contrast to their own views, parents reported that there was a belief within the wider community that their child with DS was a curse or punishment from God:

Mother 9 (daughter 30 years; bachelor's degree): 'Society also gives you agony. Society teases a lot. ...they say it is a punishment from God'.

Mother 13 (three daughters, 15, 16 and 18 years; metric): 'Some people feel pity and start asking for forgiveness from Allah aloud when they see them. ... some people say that I am cursed'.

Social encounters were described as a source of stress, particularly by mothers who were the ones most likely to experience negative behaviour towards their child with DS:

Father 7 (son 7 years; master's degree): 'People stare at him with eyes full of pity, like "what's happened to him"...they say that "this is an abnormal child. What has Allah done with you people?" ...some people are so blunt and say it to your face.... "Poor child. What kind of child is he? How do you bear this child?"'

Mother 3 (daughter 2 years; A levels): '...(strangers) look at her with mercy, pity. Just pass on by making faces.... People behave like they don't want their child to catch this...push their children aside'.

A number of parents said that other people referred to their child with DS as *Allah lok* or *Saaein* and explained why they did not like these terms. A literal translation of 'lok' is people, and *Allah lok* means Allah's people, while the term *Saaein* is usually used for people perceived to have poor intellectual ability and to be in a world of their own. Parents believed the terms *Allah lok* and *Saaein*, when referring to their child with DS, were derogatory, suggesting that their child was 'abnormal', of 'low intelligence' and 'mentally retarded':

Mother 11 (son 8 years; metric): '...when people say *Saaein* or *Allah lok*, I'm deeply saddened, I feel hurt because he is very intelligent, not *Allah lok*. They (*Allah lok*) have saliva dribbling'....

Parents explained that *Allah lok* or *Saaein* are seen as 'special' and close to God; they are believed to have power to bless or curse because God listens to their prayers. Some parents reported that their child was often approached by strangers wanting to give them money or other gifts to please them and also asked the child to pray for them.

Parents also related the will of Allah to a test of their faith. In such cases, parents equated caring for a child with DS with worship and seeing the child as a burden as evidence of poor faith:

Mother 6 (daughter 9 years; bachelor's degree): 'Allah...selects people to test them out.... This shows how genuine or fake you are...whether your faith is strong'.

Parents believed they could show that their faith was strong by accepting Allah's will without questioning or complaining. They also believed that such strong faith and worship would earn them the reward of a place in heaven. Equating love for their child with worship aroused deep

emotions for many parents during the interviews; one father began to cry as he told the following story:

Father 10 (son 20 years; master's degree): '...there was a retarded child like this and God asked the angels "how does this father treat his child?". They said "he takes care of him a lot. He loves him a lot." God said "has he ever regretted having this son, felt sorry for himself or ever said God, why did you give me this son?". They said "no he has never done this. He feeds his son first and then eats himself". Then, God asked whether the father prayed regularly. The angels said "he prays, but not regularly". Would you believe (starts crying), God said "take this man to the highest rank of paradise"'.

While almost all parents used religious attributions for their child's condition, they also referred to biomedical explanations:

Mother 7 (son 8 years; metric): '...doctor said something like chromosome, a few less or more'.

Down syndrome within the extended family context

In Pakistan, it is the norm to live in an extended family group in close proximity with a network of relatives. Many women move to the family of their husband, and so 'in-laws' have significant authority over mothers of young children. Parents provided differing accounts on how their family had responded to their child with DS. Some parents expressed the view that their family had accepted their child, for example, was supportive, helped with childcare and showed ownership by not being ashamed to be seen in public with the child. Parents also talked about the love that their child with DS has brought into their family:

Mother 1 (son 15 years; no educational qualifications): 'Someone is taking him out for an ice cream; someone else takes him for a meal. Everybody loves him'.

Mother 12 (son 20 years; bachelor's degree): 'We believe that there is a lot of love amongst our family members because of him'.

By contrast, many parents, particularly mothers, experienced not just a lack of support from their relatives but also direct exposure to negative beliefs and attitudes that they found distressing. For example, relatives who believed that their child with DS was 'mad' or had a 'bad shadow' (*saya*) and should be kept hidden:

Mother 2 (daughter 5 years; no educational qualifications): (relatives) 'think the child is bad because they are not normal; that perhaps, we will be touched by the child's bad shadow and then our children could be like

that. ...(our family) told all the relatives that (the daughter with DS) is mad...even my own sister’.

Mother 6 (daughter 9 years; bachelor’s degree): (the family) ‘don’t own her with pride.... They have a shameful feeling...(her grandmother) said that I should not tell anyone outside the family’.

Experiences where relatives had said they wished that the child had never been born or even prayed for the child to die were related:

Mother 3 (daughter 2 years; A levels): ‘(my) brother said “you should have had testing in pregnancy and had an abortion”’.

Mother 7 (son 8 years; metric): ‘...only yesterday my mother-in-law said “when will he die and we will be rid of him?”’

One participant had three daughters with DS. The following quote illustrates how she and her daughters were disowned by her entire family:

Mother 13 (three daughters, 15, 16 and 18 years; metric): ‘My in-laws said that I was being punished for my sins. ...everybody wanted rid of me. My parents didn’t want me; my husband ran away. My parents said “leave the girls, and we will take you in”. Then, I stayed at Darbar (shrine, where homeless can take refuge). ...even now when (the children) ask for something, I would die to fulfil their wishes.... His (husband’s) family said “did you give birth to these disabled girls for us? Send them to some orphanage and get married to someone else”. My brother’s wife said “if you come to our doorstep, we’ll break your legs”’.

Parents described how their attempts at coping were often undermined by family members ‘reminding’ them that they should not be happy because they had a child with DS:

Mother 6 (daughter 9 years; bachelor’s degree): ‘One gathers courage and strength to face the world, that things are fine. Then, someone comes along and ruins you with a few words (starts crying). ...people (family members) say “Allah has done so much to you, and you are still happy”. They mean to say that I should be sad; I should be broken, shouldn’t laugh or smile’.

An issue rarely addressed within the literature on parental experiences of a child with intellectual disability is concern about sexual abuse within the family. One of the mothers living within an extended family added that she was cautious about leaving her child with family for this reason:

Mother 6 (daughter 9 years; bachelor’s degree): ‘The doctor told me that they have so many such cases of special girls where they are raped by cousins, who are

4 months pregnant. ...normal girls can’t defend themselves in today’s society, so what can a special (disabled) girl do?’

Parents who had unsupportive relatives were very concerned about who would care for their child when they died:

Mother 3 (daughter 2 years; A levels): ‘sometimes I think I hope she dies when I die’.

Mother 13 (3 daughters, 15, 16 and 18 years; metric): ‘...they have nobody to call their own, while I am alive, and there will be nobody after I die.... I have begged my sister-in-laws to care for my daughters after I die...but they say “they (daughters) will pine all their lives, and no one will ever love them”’.

Parents’ advice about termination of pregnancy for Down syndrome

At the end of every interview, parents were asked to imagine that a friend who had been tested in early pregnancy and that their baby was found to have DS. Their friend was not sure whether to keep the baby or terminate and asked them for advice. What advice would they give? Some parents said that having a child with DS was the will of Allah, that abortion was prohibited in Islam and that they should accept the child:

Father 13 (son 7 years; metric): ‘It is Allah’s work. We cannot interfere’.

Father 5 (son 12 years; A levels): ‘They should keep the pregnancy; it is the blessing of Allah, do not abort it; otherwise, you will commit a murder. It is sin...it is just like the murder of an adult man’.

While almost all of the parents believed that Islam did not permit abortion, the majority of parents found termination of pregnancy personally acceptable and would advise others to opt for termination. This was mainly because of the responses towards their child with DS from extended family and community but also because of related concerns about what would happen to the child after the parent’s death:

Mother 6 (daughter 9 years; bachelor’s degree): ‘I suggest they have all the tests and (termination)... there is no doubt, it is a sin...but even then...there are so many times when you lose courage and your spirit is broken as a mother. ...because people tease you, they say it is a punishment from God (crying)... whenever you go out into the neighbourhood, people look at you and ask all sorts of different questions like “what happened to her? Is she special? Abnormal? Mad?”’.

Father 4 (daughter 7 years; A levels): ‘If he comes to this world, he has to see just pain and suffering. No one is going to love him. ...how long will the parents be alive for him? Who will care for him when his parents die?’

Discussion

The parents’ descriptions of life with a child with DS in Pakistan integrated religious discourse, cultural belief systems and personal social experiences. As other research has found, many parents living in a faith-based culture use both theological and biomedical explanations for their children’s impairment to provide a more complete and meaningful explanation. For parents in this study, a belief in the reality of God’s will provided a reason why their child had been born with DS. Most participants situated their child’s condition in a positive religious framework, and other research has identified that faith can enable parents to find meaning in the birth of a disabled child and can facilitate acceptance, coping and adaptation (Edwardraj et al. 2010; Kaye and Rahgavan 2002; Michie and Skinner 2010). Research with Christian mothers of children with intellectual disability identified a transformative process where parents move from viewing their child’s condition as a burden and a curse to seeing it as blessing or as part of God’s plan (Landsman 1999; Michie and Skinner 2010). However, not all mothers in the study who described themselves as Christian experienced this transformation, and for them, being chosen by God did not equate to a blessing. Similar perspectives on God’s will were also seen in this study.

The interviews revealed an ambivalent cultural stereotype in Pakistani society that characterises individuals with DS as abnormal, ‘cursed’ objects of pity but also as beings who are closer to God with the gift of bringing ‘good fortune’. Researchers have examined primary sources of Islamic teaching—the Qur’an and Hadith (the life example of the Prophet Muhammad as preserved in his sayings and teachings)—and concluded that the Islamic concept of disability is morally neutral and neither a divine punishment nor a blessing (Bazna and Hatab 2005). Instead, the Qur’an focuses on disadvantages for the disabled created by society and calls for the need for equity. However, these interpretations currently do not appear to have had much impact on social attitudes towards disability in Pakistan. The complex relationship between religious belief and attitudes towards disability was revealed in parent’s views on termination of pregnancy for DS. Participant’s advice to other parents was rooted in Islamic discourse but emphasised pragmatic concerns about the impact of having a family member with intellectual disability in Pakistan.

During the analysis, no evidence was found to suggest that values towards DS had changed significantly over time in Pakistan, for example, parents of older children did not suggest that society had become more accepting. However, there were some differences between parents of children of different ages in terms of the issues they raised, although these differences did not appear to be directly linked to differences in views on termination. For example, parents of younger children were concerned about their child’s intellectual development, whereas parents of teenagers were more concerned about their child’s sexual development—menstruation in girls and increased sexual awareness in boys. Older parents were the most concerned about their child’s independence and who would look after their child when they died, but this concern was not restricted to older parents. We did not gather information about the degree of physical impairment that some of the children with DS may have experienced; this may have influenced parental views on termination of pregnancy. A UK study found that, in women who had a sibling with DS, the affected sib’s physical health was not a significant predictor of their sister’s views on termination of pregnancy for the condition (Bryant et al. 2005). However, in Pakistan where there is no national health service, physical health of children with DS may have more influence on attitudes to termination.

Some parents experienced support from extended family members in caring for their child with DS, but many felt stigmatised, experiencing family rejection of their child and social isolation. The negative attitudes expressed by family members seemed to be related to both a lack of understanding of the nature of DS and a response to the physical manifestations of the syndrome in individuals. Intellectual disability was frequently considered equivalent to mental illness (‘madness’), and the accompanying ‘shadow’ and facial appearance engendered suspicion and fear. Awareness of these views and the negative events they themselves experienced led to parents being very concerned about their child’s welfare after their death. Parents believed that society did not value children with intellectual disability and that communities treat both the affected children and their parents badly. Similar to other research on the role of extended family, these findings challenge assumptions that disabled people and their carers are supported within South Asian family networks (Bruns and Foerster 2011; Katbamna et al. 2004). The negative experiences of parents in this study can be understood partially by the fact that disability rights are not embedded in Pakistani culture, and the concept of ‘political correctness’ in relation to disability is virtually non-existent (Bryant et al. 2011). Social exclusion is experienced by parents of children with disabilities of all ethnicities (Barnes et al. 1999). However, in research conducted with South Asian parents living in the UK and Canada, parents perceived the attitudes of their own ethnic

community towards their disabled child as more negative than those in the wider community (Croot et al. 2008; Daudji et al. 2011).

Practical constraints limited recruitment to a centre for children and young adults with intellectual disabilities in a major city in Pakistan. We therefore accept that parents who do not have access to such centres, living in different cities or in rural areas, may have different experiences. However, this sample represented parents from a range of educational and economic backgrounds, with children of both genders and of different ages, living in a variety of family settings. As such, we believe that it makes a valuable contribution to understanding viewpoints on parenting a child with DS in Pakistan and to understanding the attitudes of Pakistani parents towards termination of pregnancy for the condition. Many people of Pakistani origin live in other parts of the world and can be described as bicultural; that is they inherit the culture of their ethnic group alongside that of the society in which they are currently living. These findings therefore have significance for those working in antenatal and genetic services in other countries as they will help health professionals understand some of the concerns that those of Pakistani origin may have about parenting a child with DS. Assumptions are sometimes made about the unacceptability of prenatal testing technology and termination of pregnancy in Muslim women, and these findings support others in arguing that diversity of opinion occurs in this group as in many others (Ahmed et al. 2012a, b). An individual's culture or religion is not prescriptive. Ethnic origin and religious background cannot wholly explain how an individual may think or behave, but knowing more about how these factors interact can help health professionals understand how and why individuals may make certain reproductive decisions.

Conclusion

Many of the experiences reported by parents in this study support the common perception that the lives of people with an intellectual disability and their family are experienced as burdensome and stigmatised in low-income countries (Ghai 2001). However, in support of the assertions made by Ingstad (1999), the feelings of love and affection that the parent's in Pakistan expressed in relation to their children are similar to those identified in other parent studies (Bryant et al. 2006; Lassetter et al. 2007). Our findings highlight the importance of understanding the specific cultural context within which someone is raising a disabled child and the potential contrast between parental and 'public' views. They also demonstrate similarities in the feelings that the parents express for a child with DS that may not be culture specific. To our knowledge, this is the first study to relate parents'

lived experiences of DS to their views on termination of an affected pregnancy in a South Asian country. Therefore, this study provides unique evidence that will be valuable for informing those working with people of Pakistani origin in genetic and prenatal testing services in other countries. The support of informed testing-related decisions requires health professionals to have an understanding of the cultural context in which the person and their wider family are situated.

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