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Article title: 'All is done by Allah'. Understandings of Down syndrome and prenatal testing in Pakistan

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ABSTRACT

Understanding the psychosocial impact of a congenital condition such as Down syndrome on affected individuals and their family requires an understanding of the cultural context in which they are situated. This study carried out in 2008 used Q-Methodology to characterize understandings of Down syndrome (DS) in Pakistan in a sample of health professionals, researchers and parents of children with the condition. Fifty statements originally developed for a UK study and translated into Urdu were Q-sorted by 60 participants. The use of factor analytic techniques identified three independent accounts and qualitative data collected during the Q-sorting exercise supported their interpretation. In two accounts, the 'will of God' was central to an understanding of the existence of people with DS although perceptions about the value and quality of life of the affected individual differed significantly between these accounts as did views about the impact on the family. The third account privileged a more 'scientific worldview' of DS as a genetic abnormality but also a belief that society can further contribute to disabling those affected. Attitudes towards prenatal testing and termination of pregnancy demonstrated that a belief in the will of Allah was not necessarily associated with a rejection of these technologies. Accounts reflect the religious, cultural and economic context of Pakistan and issues associated with raising a child with a learning disability in that country.

INTRODUCTION

Down syndrome (DS) is a relatively common chromosomal condition of which the most significant impairment is some degree of learning disability. Advanced maternal age is the most important birth predictor and there is no strong evidence to suggest that once this is taken into consideration incidence of DS is related to ethnicity or environmental factors (Roizen & Patterson, 2003). The equitable epidemiology of DS makes the condition a useful lens through which to study cross-cultural perspectives on learning disability. As Groce noted; *“All societies have explanations for why some individuals and not others are disabled, how individuals with disabilities are to be treated, what roles are appropriate and inappropriate for such individuals and what rights and responsibilities individuals with disability are either entitled to or denied”* (Groce, 1999, pg.756). To understand the psychosocial impact of a genetic condition one has to consider the cultural context of the affected individual and their family.

Most work considering how people with DS are viewed in the society in which they live has been conducted in more affluent countries in which significant (if slow and uneven) progress has been made towards improving the rights of people with a learning disability to financial support education, healthcare, employment and social inclusion. In these countries, prenatal screening has also become part of routine antenatal care and the argument that such screening leads to the devaluing of people with DS has also entered into social debate (Edwards, 2004). There has been little equivalent work in countries where the economic situation may lead the support of people with DS to be of low priority and the rights of those with learning disabilities to be less well defined and debated (Maloni, Despres, Habbous, Primmer, Slatten, Gibson et al., 2010; Miles, 1998). The literature commonly characterizes life for people with a learning disability in developing countries as one defined by rejection and suffering, and for their families as one defined by burden (Ghai, 2001). However, some commentators have challenged the totality of

this perception, arguing that responses to people with impairments in poorer nations are complex, varied and often misunderstood (Ingstad, 2007; Ingstad & Whyte, 1995). Ingstad (1999) has suggested that most of the problems disabled people in low-income countries face, are due to poverty, lack of support and a lack of knowledge about what can be done rather than “a lack of love and negative attitudes” (p.757). Clinically-oriented papers suggest that testing for DS is broadly acceptable to parents within some low-income countries although these studies do not explore links with understandings of the condition in any depth (Arif, Fatmi, Pardeep, Ali, Iqbal, Bangash et al., 2008 ; Oloyede & Oyedele, 2008). Some have raised concerns about the ethics of introducing prenatal testing in low-income countries where condition-related knowledge may be low (Gammeltoft & Nguyen, 2007).

This study aimed to characterize understandings of DS in Pakistan, alongside attitudes towards testing and termination for the condition. Pakistan is an Islamic country in South Asia with low levels of education, high levels of poverty and a relatively high prevalence of congenital conditions associated with learning disability (Gustavson, 2005). Around 65% of the population live in rural communities where access to antenatal services is usually very limited (Government of Pakistan, 2009). Even in large cities it has been estimated that around 50% of women will have no access to prenatal testing due to the financial costs associated with the mainly private healthcare system (Rahman & Obaid-ur-Rahman, 2005). The holding of strong religious beliefs is one of the best predictors of unfavourable attitudes towards termination of pregnancy (Jelen & Wilcox, 2003). This study provided the opportunity to explore understanding of DS alongside attitudes to testing and termination in a setting where a demonstrated belief in God is the social norm. Under Pakistani law, it is illegal to carry out an abortion except if the mother’s life is in danger. However, service providers can seek Fatwas (religious decrees) from religious scholars that give permission for abortion before 120 days gestation in cases where a fetus is affected by a disorder of a ‘severe nature’ (Ahmed, Saleem, Sultana, Raashid, Waqar, & Anwar, 2000).

METHOD

This study, carried out in 2008, used Q-Methodology to identify a range of viewpoints about DS. Attitudes towards prenatal testing and termination for the condition were collected via a brief questionnaire [Insert link to online questionnaire]

Q-Methodology combines quantitative techniques and analyses with broadly qualitative approaches to sampling and pattern interpretation (Stenner, Watts, & Worrell, 2008; Watts & Stenner, 2005). The method requires participants to consider and respond to a set of statements (the Q-set) using a ranking technique (a Q-sort). Responding to the statements allows participants to express their viewpoint on things already written or said about the topic. The Q-set for this study had been used previously to explore understandings of DS in a UK based population (Bryant, Green, & Hewison, 2006). From an original collection of 400 statements extracted from a wide range of academic and non-academic sources, 50 items were selected for the Q-set. Items allowed participants to reflect on their personal views about what it might be like to be a person with DS; how society may view affected individuals and the potential impact of a child with DS on their family (see Figure 1).

Authors M and S Ahmed translated the original items into Urdu, the official language of Pakistan. Collecting data in one language and translating this for analysis and interpretation in another, can impact on the validity of the research findings if not handled appropriately (Birbili, 2000). Birbili argues that the linguistic competence of the translator(s) and their knowledge of the local culture should be explicit along with the decisions made during the translation process (Birbili, 2000, pg. 1). M Ahmed is a UK based genetic counsellor and researcher, born and educated in Pakistan whose first language is Urdu; he speaks English fluently. S Ahmed is an academic and researcher with family origins in Pakistan whose first language is English; she is

fluent in Pakistani spoken languages including Urdu. Both M and S Ahmed have many years experience as translators within the research context. Translation into Urdu by M Ahmed followed well established practices that included back translation by S Ahmed and consultation with colleagues at the research site in Pakistan (H Jafri and Y Raashid) (Birbili, 2000; Brislin, 1976). Translators discussed the translated items with the lead author to ensure that the Urdu captured the meaning of the original English. For some words and terms where there was no direct lexical equivalent in Urdu (euthanasia, 'sex life' and 'political correctness') conceptual equivalence was aimed for (Birbili, 2000).

Participants

The sample comprised three groups selected to represent both professional and parent perspectives on DS in Pakistan. Via convenience sampling parents of a child with DS (n=30) were recruited via a centre for people with learning disabilities (from here on referred to as the Centre) as were staff working at the Centre (n=6). Health professionals and researchers attending a research workshop in a local University Hospital (n=29) were also recruited to increase viewpoint diversity. All participants lived in or nearby a large city in Northern Pakistan. The parent group comprised the majority of parents with children with DS attending the Centre and they represented diversity in levels of education and socio-economic circumstance. The Centre staff represented approximately a quarter of the staff in total; all described themselves as 'psychologists'. The Centre provides schooling, speech therapy, physiotherapy and medical and psychological assessment for children and young adults with learning disability. Other large cities in Pakistan have similar facilities although there is no standardized provision of this kind across the country.

Ethical approval

The Research Ethics Committee of the University of Leeds granted ethical approval to the project. In Pakistan, the Director of the Centre gave permission to invite parents and staff to participate and the Chair of Obstetrics & Gynaecology at the collaborating hospital gave permission to invite medical staff and students to participate.

Materials

Participants received a set of numbered, shuffled cards on which the Q-items were transcribed, a sorting grid (see Figure 1) and a booklet in which to record their Q-sorting pattern and comments. A section in the booklet captured age, gender, educational qualifications, occupation, and family composition. Researchers administered a brief questionnaire on attitudes towards prenatal testing and termination for DS after the Q-sort (see online version). Materials were provided in English and Urdu to the health professional/researcher group and in Urdu to the parents and staff at the Centre.

Procedure

Q-sorts with parents and Centre staff were conducted individually at the Centre; Q-sorts with health professionals were conducted in groups at the University Hospital. Participants were required to read the items and then, in a series of steps, to rank them along a dimension from +4 (strongly agree) to -4 (strongly disagree) (see Figure 1). Participants placed each item physically into the column on the grid to represent their level of agreement or disagreement with the statement. A completed grid represented a set of ranked items (the 'Q-sort'). Participants were encouraged to discuss the placing of the items and to record comments in the booklets.

Analysis

Five Q-sorts were excluded from the analysis (4 parents, 1 health professional) due to concerns that these individuals had not understood the sorting procedure. The final sample of 60 comprised 26 parents of children with DS (14 mothers and 12 fathers), 28 health professionals/researchers (14 females, 14 males) and 6 female psychologists. The parents of children with DS reported occupations within the following groups: government service, domestic service, tailoring, teaching and 'business'.

The 60 Q-sorts were entered into a dedicated Q-methodology software package (PQMethod, V. 2.09). Q-Methodology is concerned with the relationships between Q-sorts rather than between items and uses factor analytic techniques to identify how individuals' viewpoints cluster together. The Q-sorts of respondents are analyzed to create a smaller set of factors. Each factor provides a highly inter-correlated cluster of Q-sorts, that is a grouping of Q-sorts sorted in a statistically similar way (Stenner et al., 2008). The techniques used are an inversion of the usual factor analytic approach because the participants are the variables central to the clustering process rather than the items in the Q-set. The first stage of Q-analysis is the calculation of pair-wise correlations between all the item scores for each Q-sort; the resultant data matrix is then subject to factor analysis. In this study, Principal Components Analysis was used followed by orthogonal rotation using the Varimax procedure.

A number of techniques can inform the decision about how many factors to retain for rotation. This study used an established technique called the scree test where eigenvalues are plotted on a simple line graph by decreasing value (Cattell, 1966). Those factors whose eigenvalues fall after the point where the line plateaus (factorial scree) are not retained. Using the scree test, three and four factor solutions were potentially interpretable but the three-factor solution, which explained 48% of the total variance was found to produce the best fit in terms of producing interpretable accounts recognizable from comments made during the sorting procedure.

Varimax rotation was used to maximally separate the factors. Following rotation, exemplar Q-sorts were identified using the strategy described by Watts and Stenner (2005) where only Q-sorts with a loading of $\pm .04$ ($p < 0.01$) on one factor are retained. The exemplar Q-sorts were merged to create factor arrays (a table showing the average score for each item by factor) using a weighting formula devised by Spearman (Brown, 1980). The factor arrays represent an idealized Q-sort for a particular viewpoint on the topic and are the main output of the statistical analysis taken forward for interpretation (see Figure 1).

During interpretation, particular attention was given to the placing of the 'strongly agree' and 'strongly disagree' items in the factor arrays and the statements identified as statistically distinguishing ones for each factor or account. The qualitative data, including those taken from the questionnaire on attitudes towards testing and termination were used to inform, support or challenge account interpretations.

RESULTS

Account One: A child with DS is 'the will of God' and a valued human being

The Q-sorts of 19 participants exemplified this account: 13 parents of children with DS (seven mothers and six fathers), four psychologists and two male students of health-related disciplines. Ages ranged from 20 to 57 years. Nine exemplars lived in some form of extended family group and the remainder lived as parent and child 'nuclear' families. All but two had children and family size ranged from one to seven children. Of the parents of children with DS, four fathers and two mothers were educated to degree level or above, two mothers had 'A level' equivalent education, one father had GCSE equivalent education and three mothers had finished education at 14 years or younger. Four of the mothers described themselves as 'housewives',

the remainder of parents were employed. The mean age of the children with DS was 13.4 years (range 2 to 23 years). All the children with DS had siblings. Figure 1 provides the factor array for Account One.

Central to this account was the concept of a child with DS as a valued member of the family. There was a strong emphasis on understanding DS in positive relation to religious belief. A child with DS is God's creation and to be a parent of such a child is the will of God. One parent said, *"I have such qualities that I can look after a child with DS. That is why Allah has made me this child's mother"* (56: mother of 20 year-old man with DS). There were mixed feelings therefore about whether DS is 'an abnormality and error of nature it makes sense to prevent' (Item 21) as the term 'error of nature' appears to contradict the infallibility of God's will. For example, *"It may be an abnormality but certainly not an error of nature. Allah made it this way and we should not interfere with his plans"* (24: male teacher, no children). In strong contrast to the other two accounts, some parents viewed their child with DS as *Kismet* (fate) or bringing 'good fortune': *"This child is a symbol of good luck. Maybe everything is happening because of him. There is nothing to worry about. Happiness and sadness are with every human"* (60: father of eight year-old boy with DS).

Children with DS were considered to be different (or 'abnormal'), but more like other children than not: *"It is my experience that my DS child reacts similarly to sadness and happiness like my normal daughters"* (54: mother of 22 year-old woman with DS). While a child with DS may be different, they are still valued, parents love them and they love their families. Parents expect limitations to their achievements but still feel proud of them. Participants rejected the idea that people with DS are unattractive and instead described them as "beautiful" and "lovely". Participants did not consider it appropriate to pity parents who have a child with DS or see this as a 'family tragedy' as unaffected siblings need not suffer.

This account considered 'mercy killing' of children with DS to be a grave sin. Participants anticipated that the death of an affected child would bring great sadness to parents and would not be a 'blessing' as some might suggest. Giving children with DS up for adoption was viewed as unthinkable; it was considered the child's right to stay with its parents and there were concerns that others would not care for affected children adequately; *"For me Down's kid is same as normal one... how can somebody give their child to [just] anybody?"* (58: mother of a 23 year-old woman with DS). However, participants also acknowledged the 'hard reality' of having a child with a disability; while a child with DS may not bring continual sorrow, a 'disease' cannot be the source of joy and affected people can have medical problems and a reduced quality of life. It was acknowledged (although less strongly than in other accounts) that having a child with DS was not something a parent would choose: *"Everyone would want to have a lively and healthy child. No-one likes illness"* (41: mother of a two year-old with DS).

Participants were least likely to endorse testing or termination for DS, framing their views in theological explanations: *"I would not have a termination because I would never disrupt the will of God. I trust Him and I love Him. Whatever He wills for me, whatever He decides for me I am fine with it."* (6: male medical student, no children) *"No I would never [have a termination] because such a baby is a blessing of God"* (43: mother of a 10 year-old boy with DS). However, six of the parents expressed favourable attitudes towards termination for DS. One mother who had more than one affected child said *"I would agree totally for termination of pregnancy because [it is] very difficult for the children and also for the parents to take care"* (57).

Account 2: A child with DS is 'the will of God' but a burden to their family

The Q-sorts of 18 participants exemplified this factor: nine parents of children with DS (four mothers and five fathers) and nine health professionals/researchers (five males and four females). Ages ranged from 22 to 61 years. Four exemplars lived in some form of extended family group; the remainder lived in a nuclear family situation. Five had no children, for the rest, family size ranged from two to six children. Of the parents of children with DS, four fathers and two mothers were educated to degree level or above, one mother had 'A level' equivalents one father had GCSE equivalents and one mother had left school before the age of 14. Three of the mothers described themselves as 'housewives', the remainder of parents were employed. The mean age of their children with DS was 10.4 years (range 4 to 30 years). All the children with DS had siblings.

In this account, the focus was on the negative impact of the child on the family. The birth of a child with DS was a 'family tragedy' and parents were to be 'pitied'. Affected children were seen as very different from the rest of their family with the inability to feel or understand in the same way as 'normal' people. It was felt that parents could not be proud of a child with DS because such children they 'cannot achieve anything important in life'. Having a child with DS affected how the community viewed the family. One father said, "*I cannot see any reason to be proud of a DS child. They reduce your status in society*" (55: father of a 7 year-old boy with DS).

Participants considered that a child with DS has major social impact on their siblings; a mother said, "*It badly affects other children. I have married off my children with difficulty*" (51: 30 year-old daughter with DS).

This account identified parents as having a 'burden of care' throughout their child's life and they worried about what may happen to the child in the future. While it was agreed that people with DS are a burden on the state, in Pakistan the most significant burden was on their family.

Although parents may well love their child with DS, the child brings sorrow not joy. There was

acceptance that to have such a child is the will of God, but not in a positive sense, for example, *“God gives a trial to everyone one way or another. If someone has a child with DS he will be tested socially as well as religiously on the matter of acceptance of the child”* (3: male student, no children). Participants believed that people with DS suffer as they cannot be happy and they have a poor quality of life. In addition, DS brings significant physical health problems and significant financial demands on the family.

Prenatal diagnosis and termination of pregnancy was acceptable for most individuals in Account 2. Those who did find termination unacceptable expressed a belief in God, predestination and the aversion to ‘playing with nature’. As in Account 1 there was disagreement that DS is an ‘error of nature’, for example, *“Being a Muslim I believe that all is done by Allah”* (21: Male researcher, no children). Of the 11 participants agreeing that they would terminate a pregnancy for DS, six were parents of affected children. One father said, *“A DS child should be terminated so that he does not become a burden on parents and society. For such a child, life is not pleasant for him”* (55). However, it was agreed that once a child is born, euthanasia is a grave sin and it is for God to decide what happens to the child. Most participants also disagreed with adoption of affected children, as the responsibility has to be ‘faced’ by the family.

Account 3: A person with DS is a genetic anomaly in a stigmatizing society

The Q-sorts of six health professionals exemplified this account: two male doctors, a female doctor, a female psychologist and two women in related professions. No parents of children with DS were exemplars. Ages ranged from 27 to 58 years. All but one of the exemplars (who lived with spouse and child) lived in some form of extended family group; all but one had children.

In this account people with DS were seen as 'individuals' who are capable of achievement, for example, *"If provided with that extra love and care these individuals can be positive contributions to society and can achieve well"* (28: male doctor, children). Participants disagreed that people with DS stay like children all their lives, disagreed that they are 'totally' dependent on others and believed that given the right circumstances have the opportunity to have a happy life: *"In my view, compared to other disabilities, DS children have better ability to learn and understand. They could lead a good life"* (35: psychologist, no children).

This account was least likely to strongly endorse the statement that if you had a child with DS it is because God chose you (scores ranged from -3 to +2) and very few comments in relation to religion were made in comparison to the other two accounts. The statement that DS 'is an abnormality and error of nature which is sensible to prevent' was strongly endorsed, for example, *"It is a genetic condition, extra chromosome, so with scientific developments, it could be prevented"* (35). Awareness of the significance of terminology for the condition was clearest in this account. In response to Item 33 (Having to say Down syndrome instead of Mongol is just another example of political correctness) one participant wrote, "Disagree – it is a wise correctness" (1: male doctor, children). Participants recognized that social attitudes present significant obstacles and further disable affected individuals and one wrote, *"Attitudes may be changing but it is still a long way for the public's psyche to go from 'abnormal Mongol' to 'different Down's'"* (28). They agreed that 'no one would choose to have a child with DS' and there was a rejection of the idea that having such a child in your family was somehow 'lucky'. It was anticipated that such a child would not bring joy and some thought it could be more difficult to love an affected child, although the suggestion that it may be 'better' to give up babies with DS for adoption was rejected by all but one exemplar. In comparison with the other accounts this account did not reject as strongly the idea that 'euthanasia of babies with DS is acceptable if that's what the parents want', with two participants expressing mild agreement (+1).

All participants in this account indicated that they would want to use prenatal testing, for example, *“With sensitive tests available and technology advanced I would think it would be quite imprudent not to have prenatal diagnosis”* (28). Four expected that they would terminate an affected pregnancy. One explained that, *“I would want my child to be normal so that he is acceptable to everyone, so that he can be loved by everyone because, as well as the child, the parents also have to face a lot of problems because of Down’s.”* (35). However, one participant rejected termination on religious grounds; *“I am a very religious person and would take it as God’s will. I would take it as a challenge”* (8: female doctor, one child).

Consensus items

Four items did not distinguish significantly between any pair of factors and therefore reflected common points of view. Strong agreement with items 30 and 43 reflected a view that once born, people with DS have rights in society, including the right to healthcare. For example, *“everyone has a right to live and human health is equal for both normal and DS people”* (30: female psychologist, Account 1) and, *“as human beings they have a right to all sorts of medical care”* (46: father of boy with DS, Account 2).

Responses to Item 49 reflected a general disagreement that people with DS should have a ‘sex life’, although parents of children with DS were mostly likely to endorse this item strongly. The main concern appeared to be that people with DS would themselves have affected children but there was also concern about the vulnerability of the individuals themselves to sexual abuse.

The view expressed by Item 20 (‘To know someone with DS enriches our understanding of what it is to be human’) was endorsed consistently across accounts. Participants’ comments suggested belief in a ‘higher purpose’ for the existence of people with DS; for example, *“[It]*

makes us realize the true worth of being a normal human being" (22: female doctor, Account 1); *"It reminds me of the unpredictability that is strongly associated with human life. It teaches the original meaning of what a Man is"* (9: female doctor, Account 2); "Because it is something that makes us feel thankful to God" (10: female health professional, Account 3).

DISCUSSION

The origins of the word Islam refer to the act of submitting to the will of God, and a belief in the will of Allah as the determinant of the life-course is commonly held by Muslims (Murata & Chittick, 1994). Most participants in this study, with the exception of some of those exemplifying Account 3, strongly endorsed the item 'If you have a child with DS it is because God chose you' although interpretations of the will of God differed by account. Participants in Account 1 believed that Allah 'sent' children with DS as a blessing to parents, to be a source of learning and a means to develop a positive acceptance of His will. Participants in Account 2 expressed the view that Allah sent such children as a trial so that parents might learn forbearance and acceptance of God's will through difficulty and sorrow. Studies conducted with South Asian families living in the UK have identified similar theological explanations of the birth of disabled children (Croot, Grant, Cooper, & Mathers, 2008; Maloni et al., 2010). Participants who expressed unfavourable attitudes towards prenatal testing and abortion framed their response within theological discourses while those with favourable attitudes employed discourses of emotional, financial and (particularly) social burden. Again, these different response to prenatal testing technologies have been identified previously in Muslim populations (Ahmed, Atkin, Hewison, & Green, 2006; Bywaters, Ali, Fazil, Wallace, & Singh, 2003; Croot et al., 2008). Belief that Allah determines the circumstances of the birth of a child with DS did not mean that participants rejected biological explanations of etiology; instead, theology appeared to provide a higher-level explanatory framework. The comments made in response to Item 21 identified that for many Muslims the terms 'abnormality' and 'error of nature' have different meanings; while

participants accepted that DS was a (biological) abnormality, to portray the conception of an affected child as an error challenged the infallibility of Allah.

Religion, including religious practice and a formal system of beliefs, can be differentiated from spirituality, which has been defined as the way personal views and behaviour 'express a sense of relatedness to a transcendent dimension or to something greater than the self' (pg. 231 (Kaye & Raghavan, 2002). A significant body of work has demonstrated that spirituality can provide a resource for coping with disability and illness and is integral to the search for meaning in these situations (Kaye & Raghavan, 2002). Research with (Christian) mothers of children with disabilities in the United States describes how some experienced a positive 'transformation' from viewing their child's condition as a burden and a curse to seeing it as blessing or as part of God's plan for their lives (Gail Landsman, 1999; Michie & Skinner, 2010). For other mothers (who also described themselves as Christian) such a transformation did not occur and religion did not provide a resource to coping with their child's condition; for them, being 'chosen' did not equate to a blessing and they were angered by suggestions to this effect (Michie & Skinner, 2010). Religious affiliation alone therefore cannot explain the differences in responses to disability or prenatal testing technologies seen in this study and explanations are likely to be complex and multi-factorial.

The difference that family social position and income make to a disabled individual and their family in economically developing countries must not be underestimated and much work in the area of disability and culture emphasizes this (Ingstad & Whyte, 1995; Priestley, 2001). In this study, however, only the health professionals in Account 2 referred to the negative financial impact of having a child with DS. One parent (Account 1) expressed the belief that their 'lucky' child with DS had in fact brought the family a higher income. Using the participants' education and self-reported occupation as proxies for income there was no obvious link between factor

membership - or views towards abortion - and economic disadvantage, although as income was not directly measured this cannot be known for sure. This lack of emphasis on financial aspects may have reflected limitations of the Q-set in facilitating these concerns (see methodological considerations), although other research in Pakistan has demonstrated a positive association between higher income and education and acceptance of termination for congenital conditions (Arif et al., 2008). In-depth interviews with these parent participants (to be reported in a separate paper) did consider financial implications in more depth, but lack of support and acceptance from the extended family was often seen as the factor that made life most difficult, for example, the impact of the child with DS on the 'marriage-ability' of siblings. Other work has identified the 'shame and blame' associated with genetic conditions in Pakistani families and a desire to keep knowledge of the condition within the immediate family where possible (Bywaters et al., 2003; Shaw & Hurst, 2009). The impact of an 'appearance impaired' child on the social status of a family has been identified by Weiss as central to the rejection of disabled children in Israel (Weiss, 2007). In this study, the visibility of DS may have been an important concern for those who anticipated the stigmatisation of affected children within their extended families and wider society.

In this study, parents of children with DS were exemplifiers of an account that emphasised the abnormality of the condition and the burden associated with parenting affected children. Almost half of the parents in Account 1 expressed favourable attitudes towards abortion for the condition despite relaying positive experiences with their affected child. In the original UK based study no participant who had a close family member with DS expressed such views (Bryant et al., 2006). The difference between the studies may partly reflect the lack of support available for people with DS in Pakistan compared to the UK. Despite being aware of the disadvantages that people with learning disabilities experienced in Pakistan, only Account 3 appeared to recognize a socio-historical context that was both open to challenge and had the potential to change. The

expectations that society holds about the social role that a disabled person can play affects attitudes towards the education, integration and independence of those individuals (Groce & Zola, 1993). Only Account 3 identified a potential social role of *adults* with DS in Pakistani society and there was very little awareness of the ideas associated with Western social models of disability, for example, that structures within society disable those with impairments. A lack of social explanations for disability have also been identified in South Asian families in Britain (Bywaters et al., 2003). This appears at odds with the belief expressed across all accounts that 'People with DS have a right to be heard within society especially when it comes to decisions that affect them', but may suggest that this does not equate directly to Eurocentric ideas of disability rights. In many economically developing countries 'disability' is not a recognized concept and it has been argued that in this context the "meaning of impairment must be understood in terms of cosmology and values and purposes of social life" (Ingstad & Whyte, 1995) pg. 10).

Methodological considerations

In this study, practical constraints limited recruitment to participants who were all located within or close to a major city. The proportion of participants with educational qualifications was greater than would be expected in the general Pakistani population, as was the proportion of those on higher than average incomes. Due to living in a large city, parent participants had access to a school and support centre for their children. It is therefore accepted that other viewpoints may well exist, for example, in those who live isolated from health and special educational services, and those living in deprivation (Miles, 1998). The implications of using the Q-set in a more diverse Pakistani sample are unknown but as there is no direct translation of Down syndrome in any South Asian language and many Pakistanis may not recognize it as a condition, the statements would have had to reflect a more general construct of learning disability (Shaw, 2009).

Some of the concepts behind the items did not translate easily into Urdu, for example, the item concerned with 'political correctness' of the terminology for DS was seen as irrelevant by many participants or was misunderstood. There is no real concept of political correctness in this context in Pakistan where the term 'Mongol' is generally considered an acceptable descriptor. While the majority of items translated in a relatively straightforward way, these findings demonstrate the importance of collecting qualitative data to support interpretation and to help identify differences in the meanings of items. The Q-set was devised for use within a British study and it did not contain some items that may have been important in understanding DS in Pakistani society. Only one item made a direct reference to God, which limited expression of religious belief although comments made in response to other items often had a religious content. Items related to financial implications of having a child with DS and to the response of the extended family were not included, as discourse around these topics were not identified during the development of the British Q-set. Concerns about children with DS being vulnerable to sexual abuse within the family network were also raised in the Pakistani parent interviews but the original Q-set did not allow direct expression of these concerns. Finally, the requirement to read, consider and juxtapose a large number of statements was challenging for some parent participants, even with support from the researchers. Future cross-cultural research should consider how best to facilitate the Q-sort procedure in the target group and should involve pilot work to ensure that the Q-set reflects issues important to the study population.

Conclusion

The findings of this study support those of previous research, for example, the stigma associated with having a disabled child in a Pakistani community, the co-existence of theological and biomedical explanations for disability, and the rejection of abortion on religious grounds for some, but not all Muslims. Whereas previous research has tended to consider these

religious and cultural elements as themes across a population the use of Q-methodology has allowed the contextualization of these elements within distinct 'clusters of like-mindedness' that co-exist within a population. For example, we can see that in spite of stigma and the lack of integrated educational and support services in Pakistan some parents greatly value their child with DS and see them as a blessing from God. For them, spirituality and the experiencing of disability through a 'religious lens' may be the central organising theme in their pattern of thinking (Michie & Skinner, 2010). It is also apparent that education and a relatively good income do not necessarily ameliorate perceptions of burden, lack of parental reward and disadvantage; religion may also not provide a positive resource to those who share this way of thinking. The different viewpoints identified resonate with findings from research in more economically developed countries although the detail of individual responses may be different (Bryant et al., 2006; Gail Landsman, 2009; Lawson, 2006). It is important that those working in antenatal and genetic services in other countries understand some of the concerns that those of Pakistani origin may have about parenting a child with DS. While understandings of DS and views on abortion often incorporated theological explanations, there was no clear causal relationship between viewpoint and 'religion'. Instead, religious beliefs reflected and reinforced a wider worldview of disability and the role of prenatal testing technologies within the participants' perceptions of their economic and socio-cultural context.

References

- Ahmed, S., Atkin, K., Hewison, J., & Green, J. M. (2006). The influence of faith and religion and the role of religious and community leaders in prenatal decisions for sickle cell disorders and thalassaemia major. *Prenatal Diagnosis*, 26, 801-809.
- Ahmed, S., Saleem, M., Sultana, N., Raashid, Y., Waqar, A., & Anwar, M. (2000). Prenatal diagnosis of beta-thalassaemia in Pakistan: experience in a Muslim country. *Prenatal Diagnosis*, 20, 378-383.
- Arif, M. O., Fatmi, Z., Pardeep, B., Ali, T., Iqbal, H., Bangash, H. K., et al. (2008). Attitudes and perceptions about prenatal diagnosis and induced abortion among adults of Pakistani population. *Prenatal Diagnosis*, 28(12), 1149-1155.
- Birbili, M. (2000). Translating from one language to another. *Social Research Update*, 31, 1-7.
- Brislin, R. W. (Ed.) (1976). *Translation: Applications and Research*. New York: Gardner Press.
- Brown, S. R. (1980). *Political Subjectivity: Applications of Q Methodology in Political Science*. New Haven: Yale University Press.
- Bryant, L. D., Green, J. M., & Hewison, J. (2006). Understandings of Down's syndrome: a Q methodological investigation. *Social Science & Medicine*, 63, 1188-1200.
- Bywaters, P., Ali, Z., Fazil, Q., Wallace, L. M., & Singh, G. (2003). Attitudes towards disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: considerations for service providers and the disability movement. *Health & Social Care in the Community*, 11, 502-509.
- Cattell, R. B. (1966). The scree test for the number of factors. *Multivariate Behavioral Research*, 1, 245-276.
- Croot, E. J., Grant, G., Cooper, C. L., & Mathers, N. (2008). Perceptions of the causes of childhood disability among Pakistani families living in the UK. *Health & Social Care in the Community*, 16(6), 606-613.
- Edwards, S. D. (2004). Disability, identity and the 'expressivist objection'. *Journal of Medical Ethics*, 30(4), 418-420.
- Gammeltoft, T., & Nguyen, H. T. T. (2007). Fetal conditions and fatal decisions: Ethical dilemmas in ultrasound screening in Vietnam. *Social Science & Medicine*, 64(11), 2248-2259.
- Ghai, A. (2001). Marginalisation and disability: experiences from the Third-World. In M. Priestley (Ed.), *Disability and the Life Course: A Global Perspective* pp. 16 - 37). Cambridge: University of Cambridge Press.

- Government of Pakistan (2009). Pakistan Demographic Survey 2007. Islamabad: Federal Bureau of Statistics.
- Groce, N. (1999). Disability in cross-cultural perspective: rethinking disability. *The Lancet*, 354(9180), 756-757.
- Groce, N., & Zola, I. (1993). Multiculturalism, chronic illness, and disability. *Pediatrics*, 91(5), 1048.
- Gustavson, K. (2005). Prevalence and aetiology of congenital birth defects, infant mortality and mental retardation in Lahore, Pakistan: a prospective cohort study. *Acta Paediatrica*, 94(6), 769-774.
- Ingstad, B. (1999). The myth of disability in developing nations. *Lancet*, 354, 757-758.
- Ingstad, B. (2007). Seeing disability and human rights in the local context: Botswana revisited. In B. Ingstad & S. R. Whyte (Eds.), *Disability in Local and Global Worlds* pp. 237-258). Berkeley: University of California Press.
- Ingstad, B., & Whyte, S. R. (1995). Disability and culture: an overview. In B. Ingstad & S. R. Whyte (Eds.), *Disability and Culture* pp. 3-32). Berkeley: University of California Press.
- Jelen, T. G., & Wilcox, C. (2003). Causes and consequences of public attitudes toward abortion: A review and research agenda. *Political Research Quarterly*, 56(4), 489.
- Kaye, J., & Raghavan, S. K. (2002). Spirituality in Disability and Illness. *Journal of Religion and Health*, 41(3), 231-242.
- Landsman, G. (1999). Does God give special kids to special parents? Personhood and the child with disabilities as gift and giver. In L. Layne (Ed.), *Transformative motherhood: on giving and getting in a consumer culture* pp. 133–166). New York: New York University Press.
- Landsman, G. (2009). *Reconstructing Motherhood and Disability in the Age of "Perfect" Babies*. New York: Routledge.
- Lawson, K. L. (2006). Expectations of the parenting experience and willingness to consider selective termination for Down syndrome *Journal of Reproductive and Infant Psychology*, 24, 43-59.
- Maloni, P. K., Despres, E. R., Habbous, J., Primmer, A. R., Slatten, J. B., Gibson, B. E., et al. (2010). Perceptions of disability among mothers of children with disability in Bangladesh: Implications for rehabilitation service delivery. *Disability and Rehabilitation*, 32(10), 845-854.
- Michie, M., & Skinner, D. (2010). Narrating disability, narrating religious practice: reconciliation and Fragile-X syndrome. *Intellectual and Developmental Disabilities*, 48, 99-111.

- Miles, M. (1998). Development of community based rehabilitation in Pakistan: bringing mental handicap into focus. *International Journal of Disability, Development and Education*, 45(4), 431 - 448.
- Murata, S., & Chittick, W. C. (1994). *The Vision of Islam*. London: I.B.Tauris.
- Oloyede, O., & Oyedele, R. (2008). Women's attitude to prenatal screening services for congenital abnormalities in Nigeria. *Journal of Obstetrics and Gynaecology*, 28(4), 406-407.
- Priestley, M. (2001). *Disability and the Life Course: Global Perspectives*. Cambridge: Cambridge University Press.
- Rahman, S., & Obaid-ur-Rahman, M. (2005). Short communication: Prevalence rate of Down's syndrome in Karachi resident women. *Pakistan Journal of Pharmaceutical Sciences*, 18(2), 61-63.
- Roizen, N. J., & Patterson, D. (2003). Down's syndrome. *The Lancet*, 361(9365), 1281-1289.
- Shaw, A. (2009). *Negotiating Risk: British Pakistani Experiences of Genetics*: Berghahn Books.
- Shaw, A., & Hurst, J. (2009). 'I don't see any point in telling them': attitudes to sharing genetic information in the family and carrier testing of relatives among British Pakistani adults referred to a genetics clinic. *Ethnicity and Health*, 14(2), 205 - 224.
- Stenner, P., Watts, S., & Worrell, M. (2008). Q Methodology. In C. Willig & W. Stainton-Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* pp. 215 - 239). London: SAGE.
- Watts, S., & Stenner, P. (2005). Doing Q methodology: theory, method and interpretation. *Qualitative Research in Psychology*, 2(1), 67-91.
- Weiss, M. (2007). The chosen body and the rejection of disability in Israeli society. In B. Ingstad & S. R. Whyte (Eds.), *Disability in Local and Global Worlds* pp. 107- 127). Berkeley: University of California Press.

Figure 1: Factor Array for Account 1

			16. A person with DS will always be totally dependent on others			
		1. Children with DS can achieve a great deal	21. DS is an abnormality and an error of nature It makes sense to try and prevent it	11. Children with DS are a burden throughout their lives		
	2. You can be as proud of a child with DS as you can be of any child	6. A problem with children with DS is that they will probably outlive their parents	27. It is wrong to treat people with DS as a group they are all individuals	14. Choosing to bring a child with DS into the world is just selfish	4. A child with DS is a family tragedy	
20. Knowing someone with DS enriches our understanding of what it is to be human	7. It's not right to submit a child with DS to cosmetic	17. People with DS remain like children all their	31. I wouldn't call DS a major health problem	19. If I had a child with DS I would be worried about people	12. Normal children are just as demanding as children with DS	5. The normal siblings of children with DS suffer as

		surgery, they should be accepted the way they are	lives		staring at us		well	
	24. People with DS have the same feelings as anybody else	13. Nobody would choose to have a child with DS	18. For people with DS the biggest obstacle is not their learning disability but the attitudes of others	33. Having to say DS instead of Mongol is just another example of political correctness	32. The medical profession paints an overly gloomy picture of what it is like to have a child with DS	23. People with DS make me feel uncomfortable	10. If a child with DS died, it might be a blessing	
9. If you have a child with DS it is because God chose you	28. I would find it as easy to love a child with DS as to love any other child	35. For me having a child with DS wouldn't be the end of the world	29. I think you are lucky if you have a person with DS in your family	34. Saying that having a child with DS is as good as a normal child is just denying reality	45. Looking after a child with DS needs certain qualities I don't think I've got	25. The world would be a worse place if no more babies with DS were born	15. People with DS are a financial burden on the state	3. If you have a baby with DS it may be better to have it adopted and try again

26. People with DS give as well as receive love	37. People with DS shouldn't be called sufferers	46. I think mixing children with DS into ordinary schools is a good thing	42. People with DS can have as good a quality of life as everyone else	41. People with DS can live very happy lives	48. People with DS are severely mentally disabled	38. I feel so sorry for people who have a baby with DS	36. A child with DS must bring continual sorrow to its parents	8. I find people with DS rather unattractive
30. People with DS should have the same health care as any other person	43. People with DS have a right to be heard within society especially when it comes to decisions that affect them	50. People with DS should mix together with other people as much as possible	44. A family with a child with DS is just like any other family	47. People with DS are just a bit different from other people	49. People with DS should be allowed to have a normal sex life like everyone else	40. You would get a lot of joy from having a child with DS	39. It must be awful to have DS	22. I think that euthanasia of babies with DS is acceptable if that is what the parents want
+4	+3	+2	+1	0	-1	-2	-3	-4

