Growing up with Disability in Pakistani Muslim Families

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Overview

- Background and rationale for the study
- Research methods
- Findings related to religion/faith and culture

Karachi, 1992
The Pakistani community in the UK

- From the literature:
  - Higher levels of poverty (3x)
  - Higher levels of unemployment (2x for men, 3x for women)
  - Poorer housing
  - Higher incidence of self-reported ill-health (2x) and disability (1.5x) across the lifespan
  - Limited English proficiency depending on age, generation, length of settlement and ‘residential density effect’
  - Prejudice based on both racism and Islamophobia
  - A lack of faith and culture appropriate provision of social and leisure activities.

(Office for National Statistics, 2011; Nandi and Platt, 2010; Khan, 2006; Modood, 1997)

Pakistani families with disabled children

- A higher prevalence of childhood disability in the Pakistani community
- High cost of raising one or more disabled children
- Less likely to receive benefits at appropriate rates
- More difficulty in accessing health and social care

- Specific issues in the Pakistani community:
  - blaming the mother for the child’s disability
  - a belief in disability as God’s punishment
  - this leads to lower levels of support received in the extended family and the community
  - therefore high levels of distress to disabled children and their primary carers (mostly mothers)

(Beresford, 1995; Bywaters et al, 2003; Chamba, 1999; Fazil et al, 2002; Hatton et al, 2004)
The study

Objectives of the study:
1. To identify the support needs of Pakistani families with disabled children and to explore how these needs can be met more effectively
2. To explore how engaging the research participants in undertaking participatory action research in groups of men, women and children can facilitate their active role in achieving objective 1.

No specific ‘agenda’ to explore religious aspects

Research Method

In Participatory Action Research the lived experience and knowledge of the participants are directly valued and central to the process.

It aims to produce knowledge and action that are directly useful to the participants and to empower them through the process of constructing and using their own knowledge.

(Reason, 1994, p6)
The use of PAR in this study

- Exploratory phase based in each of the six family’s homes – individual interviews, drawings, photography
- Separate groups for women, men and children, in which they carried out their own action research cycles
- Meetings / parties for all families together

Cultural fit of participatory research

- Affords time for being together and sharing stories
- Venue and format of meetings:
  - Women met at one of the families’ home: giving and receiving hospitality is important
  - Men met at local Mosque: public and neutral territory put them at ease
  - Children: fun and games, non–threatening, discovering shared problems

- Participatory approach enabled participants to choose the focus for the research and religion became an important aspect for the men’s and women’s groups
The researcher

• Lived and worked in Pakistan for 9 years:
  • Knowledge and insight into culture, religion and language
  • Facilitated trust to tell me “the way it is”, as there was a common understanding of the context
  • Comfortable wearing “shalwar kameez”, sitting on the floor and waiting

• Not Pakistani:
  • Easier for men to work with me as female researcher
  • Not an insider to the local community: no gossip!

• Having a personal faith:
  • Helped participants to trust I would understand their religious views, hopes, doubts

Key issues discussed in each group

• Men:
  • Noted negative attitudes towards disability in the Pakistani community
  • Asked Imams and scholars about Islamic beliefs and myths about disability, asserting themselves as the Muslim father of a disabled child, requesting support from their religious leaders.

• Women:
  • Found the initial group meetings provided mutual recognition and support
  • Tried to set up a support group to include more Pakistani mothers

• Children:
  • Wanted “to understand our disabled siblings better so that we can help them to be happier”
Findings related to religion

- The women reflected that the challenges related to raising a disabled child and family dynamics might be universal.
- Difficult to unravel religion and culture
- The particular mix of religion, culture, socio-economic status, English proficiency and level of education is unique even to each family, but common themes emerged.

Attitudes towards disability

- All families faced overwhelmingly negative reactions from extended family and community, e.g.
  - Mother / parents being blamed: punishment
  - “child will be a burden”
  - Told to cover up physical impairments
  - Girl: worries about future marriage prospects
  - Derogatory terms used, e.g. ‘pagal’, ‘langri’
  - Pity was rarely accompanied by offers of help
  - Superstition – e.g. shadow falling on baby
  - More extreme: ‘you should have had him aborted’
Isolation

- Lost contact with extended family and friends
- More so when child had learning and/or behavioural difficulties
- Not welcome at community events, such as weddings and functions at Mosque, i.e. reduced social participation for both the child and the family as a whole.
- Mostly unaware of other Pakistani families with disabled children before the project
The vase is me and the flowers are my children. And this outside the window is just optimism, what I strive for for them. The vase is transparent, but it may crack, like the walls around it. I may crack and blend in with the rest of the walls...

Faith: from punishment to blessing

- Initial shock, confusion: “in my heart was pain and regret: why was my child like this?”
- All parents talked about a process of change, despite ongoing negative responses from relatives and community members
- Divine ‘testing’ was no longer seen as punitive, but rather as an opportunity to develop stronger faith and personality: “God tests those who are good people. This is positive as well as difficult. My prayers are all for him (her disabled son)”
- Now see their child as a blessing, which has enriched their lives
Faith: God’s will and personal responsibility

- “My prayer to God is that He would make him normal.”
- “I think there’s a reason why God gave me a disabled child. If Allah wanted him to be better, he would have made him better.”
- “Don’t just say ‘God is great’ and do nothing, but make sure she gets the right treatment. God doesn’t say ‘leave it all to me’, there is also our responsibility.”

Faith: cause of disability

- Most participants used both theological and bio–medical explanations “Mmm…, there is definitely the medical explanation, but without the wish of God there is nothing. Maybe it is in our fate, but again, it is all… there is a medical system in what God has developed. Allah is the big superpower; we can’t avoid anything.”
- Also superstition, e.g. mother sleeping on her stomach during pregnancy, black magic / spells by hostile relatives, using a knife during lunar eclipse, and ominous dreams – Most participants did not believe in these now.
Islamic teaching

- Fathers explored whether negative community attitudes had any basis in the Holy Qur’an or Hadith (teachings of the prophet).
- Religious language tends to be used to express negative attitudes, e.g. God’s punishment, testing.
- Religious leaders were unsure and did not show much interest, but eventually one Imam provided information.

Relevant verses from the Qur’an

The Qur’an does not contain many specific references to disability, but much can be inferred

- **God’s will**: “Nothing on earth or in heaven is hidden from God: it is He who shapes you all in the womb as He pleases” (3:5–6)
- **Removing stigma**: “No blame will be attached to the blind, the lame the sick. Whether you eat in your own houses, or those of your fathers, …. Or any of your friends’ houses, you will not be blamed … whether you eat in company or separately” (24:61)

Qur’an translation used:
The Qur’an. A new translation by M. A. S. Abdel Haleem
Oxford University Press, 2004
• **Meeting the needs of the disadvantaged:** “Be good to your parents, to relatives, to orphans, to the needy, to neighbours near and far, to travelers in need and to your slaves. God does not like arrogant and boastful people, who are miserly and order other people to do the same, hiding the bounty God has given them.” (4:36–37)

• **Testing – disability as a 'calamity':** “We shall certainly test you with fear and hunger, and loss of property, lives or crops. But [Prophet], give good news to those who are steadfast, those who say, when afflicted with a calamity, 'We belong to God and to Him we shall return'. These will be given blessings and mercy from their Lord, and it is they who are rightly guided.” (2:155–157)

This gives the sense that God tests the patience of those with disabilities and tests others to have mercy and care for them

(unmarked source obtained from one of the local Imams).

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(ARabic text taken from http://muttaqun.com/quran/)

“…..In God’s eyes, the most honoured of you are the ones most mindful of Him:

God is all knowing, all aware

(of people's true worth and the thoughts they harbour)"

The Qur’an, Sura 49 (Al Hujraat) verse 13
Family life

- Cultural expectation for mother to “sacrifice all” for her husband and children
- Expectations of marital relationship – not necessarily close or supportive
- Strong sense of respect and loyalty
- Siblings expected to take on caring responsibilities
- Children quite protected and restricted outside the home, in view of moral values
- Two latter issues restricted siblings’ participation in clubs and friendships outside school hours.

Children’s views

- The children did not often mention faith or religion directly.
- They appeared to accept family values and practices based on their cultural and religious background and did not seem to consciously evaluate their worldview resulting from this (yet).
- Whilst they did not express their views in religious terms, Islam – and Pakistani culture – was pervasive in their life experience.
Children’s views (cont’d)

- Family life was protective and safe with an emphasis on interdependence
- Parents had little expectation regarding the development of autonomy and decision making
- Children had never been asked about their views and feelings about having a disabled sibling before
- Once they felt confident to open up they were creative in their reflections.

I'm part of project on flight
I'm supposed to attain a great height.

But unfortunately I got stuck in a tree
So it looks like I am here for the night
“Trapped in a virtual world”

Welcome banner for the Eid Party organised by the sibling group.
Conclusion

- Religion played a big and mostly positive role in the families' lives
- Negative attitudes in the community appear to have a cultural rather than religious basis, even if religious language is used to express these.
- Exploring their religious views and experiences through talk and creative methods was helpful and made participants more aware that their faith is a positive ‘resource’ for living positive lives with their disabled child

Thank you!

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Thesis online:
http://bura.brunel.ac.uk/handle/2438/4377
References