



The role of attitudes and beliefs in accessing services: a case study of consanguinity in the Pakistani community

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Acknowledgments

The research team:

- ▶ The Birmingham study with Carl McLean & Hamid Rehman.
- ▶ The Luton study with Mubasshir Ajaz (PhD Thesis) & Professor Gurch Randhawa.

Objective



- ▶ Understand the role of **attitudes and beliefs** in **accessing healthcare**.
- ▶ Using research on consanguinity with the Pakistani community in Birmingham and Luton.

The research



- ▶ **Understanding the inter-generational attitudes and beliefs towards consanguineous marriages in Birmingham.**
- ▶ Examining the sociocultural impacts of consanguinity and implications for healthcare.

Consanguinity?

- ▶ Union between people who are second cousins or closer (Bittles, 2001, Hoodfar and Teebi, 1996).
- ▶ Often incorrectly associated with Islam but not specific to any faith group—practiced by Christians, Jews, Hindus, Buddhists (Bittles, 2001).
- ▶ In Western societies often controversially associated with incest and inbreeding (Bittles, 2008, Modell and Darr, 2002).

- ▶ May 30 2011 Professor Steve Jones caused controversy with his statement that Bradford's Pakistanis were inbred.
- ▶ Phil Woolas on 10 February 2008, the then MP for Oldham East and Saddleworth who issued a statement in which he blamed the high incidence of first cousin marriages among predominantly Pakistanis as being the cause of genetic disorders.
- ▶ Supported by Anne Cryer MP who said 'this is to do with a medieval culture where you keep wealth within the family' and went on to add how Pakistanis account for a disproportionate number of children with genetic disorders.

- ▶ Type in ‘cousin marriage’ to Google and headlines include:
 - ‘is cousin marriage incest’?
 - ‘Cousin marriage can reduce IQ’.
 - ‘Inbreeding and resulting genetic disorder in Muslim community’.
 - ‘Making light: the supposed depravity of cousin marriage’.

These statements reflect the distaste with which cousin marriages are regarded in Britain (Bittles 2001).

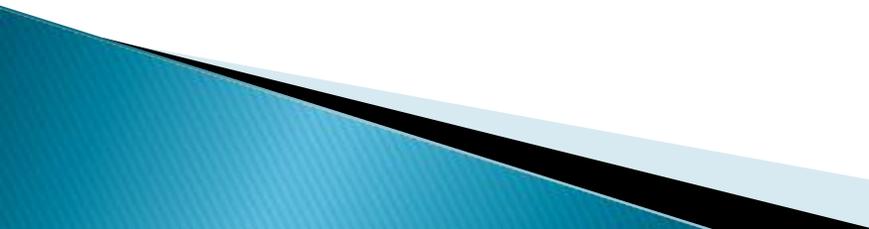
Impact on health

- ▶ Practice of consanguinity has continued among the UK's Pakistani settler communities.
- ▶ Highest rates of infant death in children of Pakistani origin and congenital anomalies are the most common cause of death in children younger than 12 months (Sheridon, 2013).
- ▶ High rates of genetic disabilities and/or abnormalities reported in the UK Pakistani community (Bittles, *et al.* 1991, Modell and Darr 2002, Khan *et al.* 2010).
- ▶ Gene variations tend to cluster in extended family groups so increasing the chance that a carrier will choose who has the same gene variant thus increasing the chance of infants born with recessively inherited disabilities and/or abnormalities (Darr et al. 2013).

Caution!!

Infant mortality is a complex interplay between deprivation, physiological, behavioural and cultural factors.

Background to the research in Birmingham

- ▶ BHWP commissioned research.
 - ▶ BHWP sought to understand the relationship between the cultural practice of consanguineous (cousin) marriages and health.
 - ▶ Part of wider programme of work trying to understand how existing social and cultural practices can contribute to current levels of infant mortality among Birmingham's ethnic minority population.
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Infant Mortality in Birmingham

- ▶ Infant mortality in Birmingham above the national average and the gap is increasing.
- ▶ Data shows that the infant mortality rate has increased in Birmingham by 13 per cent between 1998–2000 and 2002–2004 while it has fallen in other parts of the West Midlands, and across the country as a whole.
- ▶ This indicates that the gap between Birmingham and the national average has increased (Birmingham Health and Wellbeing Partnership (2006)).

Objectives of the research

- ▶ Explore general awareness and risk perceptions associated with consanguinity.
- ▶ Investigate inter-generational and gender similarities and differences in attitudes, beliefs and expectations of consanguineous marriage.
- ▶ Inform Birmingham Health & Wellbeing Partnership on ways of planning and developing future maternity provision that support members of the Pakistani community in Birmingham.

The research sample

- ▶ 8 in depth one to one interviews (in cousin unions)
- ▶ 8 focus groups (community)
- ▶ Choice of language
- ▶ Gender mix
- ▶ Age range

Depth interviews

Focus Groups	Cohort	Gender	Age	Location	Language*
1	1	Male	16-25	Springfield	English
2	1	Female	16-25	Springfield	English
3	2	Male	26-35	Springfield	English
4	2	Female	26-35	Springfield	English
5	3	Male	36-55	Springfield	English/Urdu
6	3	Female	36-55	Springfield	English/Urdu
7	4	Male	56+	Springfield	Urdu
8	4	Female	56+	Springfield	Urdu

Focus groups

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Thematic Analysis

A framework approach:

- ▶ a detailed familiarisation with the data
- ▶ identification of key themes/sub themes
- ▶ comparison across cases age/gender cohorts.
- ▶ interpretation of the findings within the context of other research as well as policy and practice considerations (Silverman, 2001).
- ▶ 4 main themes emerged.

Findings

Consanguinity and risk perceptions

- ▶ All research participants were aware of still births and children born with disabilities.
- ▶ Genetic conditions such as diabetes, visual and hearing impairments, cancer, asthma and eczema were not seen to be hereditary conditions.
- ▶ Lay confusion on the role of genetics in understanding hereditary risk/inherited diseases.

- ▶ Suspicion of statistics which illustrated that consanguinity led to an increased risk of still births and malformations.

They are just doing a lot of research and that because they know it's a Muslim thing. They don't want arranged marriages. You get mixed marriages and they [white people] love it because that's their fantasy seeing it happen. They don't want Muslims everywhere (Male, 16-25 year old).

You can stretch statistics any way you want to, you can make them fit anything you want to say. That is what they are doing (Female, 16-25 year old group).

- ▶ Rates of still births and disabilities were not seen to be significantly higher among the Pakistani community in Birmingham or nationally when compared to the White majority or other ethnic minority communities.

The other thing that comes to mind is the number of children our communities have. It tends to be on average four to five children whereas if you look at the Caucasian population they tend to stick to two children so the rate is going to be higher because obviously there are more pregnancies so the chances of having a still birth or a miscarriage is going to be higher than your normal Caucasian community (Male, 36–55 years old group).

Explanations for still births and impairments

- ▶ Majority of participants regardless of age and gender argued that still births and impairments were 'the will of God' and 'everything is written by God'. Thus notions of predestination dominated discussions.
- ▶ Black magic was referenced as a cause of stillbirths and impairments.
- ▶ Further explanations included:
 - sexual position in which the child was conceived;
 - washing after intercourse when penetration occurred more than once in one session.
 - also environmental factors poor nutrition, overworking, over reliance of prescription drugs

A Suitable boy/girl: the social and cultural context of cousin marriage

- ▶ Arranged/assisted marriages are common among many South Asian cultures including among Pakistanis in the UK.
- ▶ Arranged/assisted marriages changing over time but continue to be valued by older and younger Pakistani participants.
- ▶ Shifts in attitudes were not necessarily inter-generational or gender specific but rather based on an assessment of changing attitudes towards the practicalities and priorities of marriage.
- ▶ There was a strong emphasis on ensuring that potential partners were educated and had similar experiences which, for many participants, invariably meant marriage to UK born citizens.

- ▶ All respondents, regardless of gender or age, valued the benefits of having an arranged marriage to a cousin.
- ▶ Many respondents argued that debates on consanguinity (including this research) were a direct attack on the Muslim marriage system and a poorly disguised aggression towards the Islamic way of life.
- ▶ They argued that assisted marriages to cousins **marked** them as being separate from the majority White community and other non Muslim settlers.

- ▶ Respondents felt that ‘outsider’ perspectives on cousin marriage demonstrate that Pakistanis are seen as deviant for marrying cousins.

White people say that if you marry cousins your children are going to be born with funny feet and things like that...I've heard that said in internet forums and things like that (Male, 16-25 year old group).

I think they think it's weird because it's something different to them. They just think oh these Muslims are strange (Male, 16-25 year old group).

Providing information

- ▶ All participants wanted more medical and Islamic scholarly information on genetic risk.
- ▶ Screening services currently available.
- ▶ Information via community centres, health centres, Sure Start and the Asian media.
- ▶ Female respondents favoured genetic screening but would not terminate pregnancies—contrary to Islamic principles.
- ▶ Female respondents called for counselling to support with future pregnancy choices after a stillbirth or a baby born with an impairment
- ▶ The content of any education programme should be culturally sensitive and try to empower Muslim families to make informed choices.
- ▶ Delivered in the appropriate way by GPs surgeries and health centres and Asian media and in appropriate community languages.

Lessons from the research

- ▶ Our research mapped out the attitudes and beliefs that impact on the negotiation between the practice of consanguinity and the risk of this cultural practice to health.
- ▶ Suspicion of the link between consanguinity and genetic risk.
- ▶ Poor understanding of the link between consanguinity and genetic risk.
- ▶ Healthcare professionals have not been successful in delivering messages on the risk of consanguineous marriages and the possibility of preventative actions e.g. screening for genetic impairments.
- ▶ Attitudes and behaviour of service providers is also effected by representations of consanguinity and may influence access to services/satisfaction with services.

Service providers (Luton)

- ▶ 17 service providers from different areas of healthcare.
- ▶ 2 focus groups and 3 one to one in-depth interviews.

Some findings:

- ▶ The service providers saw high rates of infant mortality and disabilities and/or abnormalities in Luton as a result of consanguinity.
- ▶ There was overemphasis on consanguinity and little discussion of the social determinants of health deprivation as confounding factors in the pattern of health inequalities locally.
- ▶ Primary care service providers had limited/the least knowledge of genetics and genetic services, with a lack of understanding of referral patterns for these services.

- ▶ They argued that the health beliefs of the British Pakistanis created barriers in their understanding of the health risks associated with consanguinity and this impacted on their ability to deliver care.

I was talking to a patient in haematology and she it was her second child. (The) consultant said to me to do the family tree, and I started doing the family tree, and it was horrendous and (sic) five sisters married to the five brothers! (Participant 3, Female, Primary Care FG).

(You) tell them what is the risk and complications of what's happening, (but) because of the beliefs or something, it would be very rare that too many people will come up in the open (and discuss or disclose issues). It is very hard to change their beliefs, because of lack of education. (They) just don't believe that because of consanguinity this thing has happened" (Participant 7, Male, Primary Care Focus Group).

Implications for practice/access

- ▶ Help generate debate in the community.
- ▶ Provide communities that practice consanguinity with information on how genetics functions and the screening services that are currently available.
- ▶ Develop cultural competence in service delivery and cultural awareness training that focus on breaking down stereotypes and understanding consanguinity (and termination) from an Islamic perspective.

- ▶ Offer accessible counselling/support services for parents who have suffered perinatal death or given birth to children with malformations.
- ▶ Increase service provider knowledge of referral routes for consanguineous couples.
- ▶ Emphasis should be on healthcare concerns related to the practice rather than on the Pakistani/Kashmiri community thus more comparative research with other communities practicing consanguinity (Ali, Mclean, and Rehman (2012)).

Limitations of the studies

- ▶ Relatively small samples.
- ▶ Pakistani/Kashmiri and service provider views presented here may therefore **differ** elsewhere in the UK.
- ▶ More comparative research required.

Responding to the increased risk associated with consanguinity in Luton?

Salway et al, (2012)

- ▶ We have an evidence base which highlights the need for a service response and its key components.
- ▶ Interventions underdeveloped: those underway include:
 - family centred genetics services for at risk individuals and families
 - enhancement of competence of health professionals
 - community level genetic literacy

Challenges:

- sustainability of interventions
- avoid duplication
- embedded evaluation

Luton response:

- use the evidence base
- ask the community about the issues and interventions (appropriateness of the interventions) related to consanguinity.
- talk to service providers
- take a partnership approach to delivering the intervention
- evaluate the interventions

Ongoing research at the UoB/Luton

- ▶ Exploring the socio-cultural and genetic aspects of consanguinity and implications for healthcare: a case study of Pakistani/Kashmiris in Luton.
- ▶ Exploring the stigma associated with having a child with a congenital abnormality and/or disability): a case study of Pakistani women in consanguineous marriages in Luton.
- ▶ An examination of the high infant mortality rates and low birth weights among children of Pakistani and Bangladeshi origin in Luton – developing a support package for ante-natal care.
- ▶ Engaging the Pakistani/Kashmiri community in Luton on consanguinity.

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Any Questions?

