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ORIGINAL ARTICLE

Examining the family-centred approach to genetic testing and counselling among UK Pakistanis: a community perspective

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Abstract WHO advice suggests a family-centred approach for managing the elevated risk of recessively inherited disorders in consanguineous communities, whilst emerging policy recommends community engagement as an integral component of genetic service development. This paper explores the feasibility of the family-centred approach in the UK Pakistani origin community. The study took place within a context of debate in the media, professional and lay circles about cousin marriage causing disability in children. Using qualitative methods, a total of six single-sex focus group discussions (n=50) were conducted in three UK cities with a high settlement of people of Pakistani origin. Tape-recorded transcripts were analysed using framework analysis. Kinship networks within Pakistani origin communities are being sustained and marriage between close blood relatives continues to take place alongside other marriage options. Study participants were critical of what was perceived as a prevalent notion that cousin marriage causes disability in children. They were willing to discuss cousin marriage and disability, share genetic information and engage with genetic issues. A desire for accurate information and a public informed about genetic issues was articulated whilst ineffective communication of genetic risk information undermined professionals in their support role. This study suggests a community that is embracing change, one in which kinship networks are still active and genetic information exchange is taking place. At the community level, these are conditions supportive of the family-centred approach to genetic testing and counselling.

Keywords Pakistanis · Family-centred approach · Genetic testing · Counselling · Community engagement · Consanguinity

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Introduction

The baseline birth prevalence of serious congenital and genetic disorders for children of unrelated parents is 2.0–2.5 % and rises to 5 % for children of first cousins (Bundey and Alam 1993; Stoltenberg et al. 1997; Harper 2010). However, consanguineous marriage (marriage between close blood relatives) only impacts significantly on the birth prevalence of recessively inherited disorders (Modell and Darr 2002). Such rare and often severe disorders are transmitted by healthy parents who both carry the gene variant that causes the disorder. If only one parent has the variant, their children will not be affected but may be 'healthy carriers'. Couples who are both carriers have a one in four chance in each pregnancy of having an affected child. This risk is the same whether the parents are related or not.

In populations where partner choice is random, recessive genes become thinly scattered through the whole population. There is a low risk that couples will carry the same recessive gene, and the birth prevalence of children with recessive disorders is low (around 1.7/1,000) (Baird et al. 1988). In consanguineous communities, gene variants tend to cluster within extended family groups (Ahmed et al. 2002) increasing the chance that a carrier will choose a partner who carries the same gene variant. One result is an increased birth prevalence of infants with recessively inherited disorders and an increase in the prevalence of serious physical impairment (Modell and Darr 2002). With 20 % of the world's population living in consanguineous communities, this impact on health constitutes a global concern (Bittles 1990).

A decline in infant mortality has unveiled the contribution of severe recessive disorders to childhood mortality and morbidity. Estimates for the UK suggest that around 2,300 children are born annually with a severe recessive disorder, and at least 690 (30 %) are from parents of Pakistani origin (Modell, unpublished data). About a third of all affected children die before 5 years of age (Bundey and Alam 1993). Most survivors are chronically disabled and are cared for by community or specialist paediatric services (ibid) as well as needing support from their families.

Of all UK ethnic groups that favour consanguineous marriage (Darr 2009), the Pakistani origin community has the highest level of first cousin marriages (Darr and Modell 1988). In the on-going Born in Bradford birth cohort study, 63.6 % (n=3,262) of mothers of Pakistani origin (n=5,127) reported that they were related to the father of their baby (Wright et al. 2012). Of these, the considerable majority were first cousins or second cousins (80.1 %) [N. Small personal communication, see www.borninbradford.nhs.uk]. In relation to the general population, Pakistani mothers are comparatively young, have a high fertility rate (Coleman and Dubuc 2010) and most members suffer from socio-economic disadvantage (Nazroo 2001). While far from being just a health concern of the Pakistani origin community, a concentration of cases in geographic areas with high proportions of British Pakistanis can make recessive disorders an important local cause of infant and child mortality and morbidity, presenting a challenge for health services (Corry 2002; Morton et al. 2001).

Two salient health service approaches to managing consanguinity-associated genetic risk have emerged. The first focuses on the risk population and aims to reduce impairment levels by discouraging marriage between close blood relatives through promoting public awareness of the associated genetic risk. This strategy has been tried in the Middle East using media campaigns and teaching of health professionals (Samavat and Modell 2004) and in the UK as part of an outreach health promotion campaign that included a media campaign, leaflets, a video and schools roadshow (Haslam 2001). In both situations, this isolated policy of raising awareness had no detectable impact on marriage choices and prompted negative community reaction (Samavat and Modell 2004; Director, Heart of Birmingham PCT 2008, personal communication). The second strategy, a family-centred approach, focuses on identifying families at increased risk and provides them with genetic counselling and cascade genetic testing when feasible. This approach is recommended by the Eastern Mediterranean Regional Office of the World Health Organisation (Alwan and Modell 1997) which 'recognises that consanguineous marriage is an integral part of cultural and social life in many areas and that attempts to discourage it at the population level are undesirable and inappropriate'. The family-centred approach could be particularly effective in consanguineous populations, due to the clustering of recessive gene variants and the specific nature of their kinship networks. A study in Pakistan has confirmed its acceptability and potential effectiveness (Ahmed et al. 2002).

The family-centred approach (Modell and Darr 2002) starts with the diagnosis of an affected individual. This is a signal to health professionals, and the extended family, that other family members may be carriers, with an increased risk of having similarly affected children. Hence, the approach integrates the offer of information and support to extended family members, with an underpinning community engagement programme to increase the genetic literacy of the public and combat misinformation (Darr 2009). Familial links, based on blood ties and consolidated through marriage, are not only genetic links but are also potential channels for information and support (Darr 1997; Ahmed et al. 2002). The feasibility of using such links in practice depends on family networks being active and their members willing to acquire and share information about genetic risk, with a concomitant effort from service providers to facilitate these processes.

This is the first of two papers presenting the results of a qualitative study funded by the Department of Health (2006–2009) that examined the perspectives of the community, of families and of health professionals, in relation to genetic service delivery. The overall aim of the study was to explore the potential of family networks as a resource for genetic testing and counselling in a consanguineous community. Here, we report on the perspective of lay members, obtained through focus group discussions among people of Pakistani origin, conducted in three UK cities.

Research methods

This exploratory study aimed to identify community knowledge and perspectives using qualitative methods. Qualitative methods offer the best means of studying complex and contingent situations and the process by which people make sense of their lives (Hammersley 1996). Focus group discussions were selected as the most appropriate way to allow participants to explore their understanding of the topics discussed and to develop and test their views in discussion with others (Kitzinger 1995).

Fieldwork sites

Fieldwork took place in Bradford, Blackburn and Derby, three cities from the North, North West and Midland regions of the UK, respectively. They were selected for the following reasons: (1) a high concentration of people of Pakistani origin (predominantly Muslim) and (2) an increased incidence of disabling recessive disorders recognised as a major local health issue. Working with one ethnic group in three different sites mitigated against biases generated by differences in community background, configuration of local clinical services or differences in practice and ensured the broader relevance of the research findings. Access was aided by already established clinical and community contacts between members of the research team and professionals and community groups in these areas.

Selection and recruitment of participants

Six focus group discussions were held, two in each city. Single-sex groups were chosen as more appropriate in the Pakistani origin population when exploring sensitive and personal issues such as marriage and reproduction (Atkin and Chattoo 2005). Participants were recruited through community health workers, members of the Project Advisory Committee and other local contacts. In total, 50 people (27 women and 23 men) participated with group sizes varying between 6 and 11. Participants' ages ranged between 20 and 60 plus (see Table 1). Groups included grandparents, parents (both with and without disabled children) and single people. Individuals in the groups reflected a variety of backgrounds in terms of social class, age, employment and rural/urban origin in Pakistan. All group discussions were bilingual (Punjabi and English), with translation whenever required. All were facilitated by the first author and tape-recorded. The sessions began with discussion of a bilingual information sheet that contained details of the project including the aim of the discussion. Written consent to participate in the discussion, using bilingual consent forms, was then obtained from each participant. Each group discussion lasted approximately 1.5 h. All participants received £20 to cover expenses.

Bradford NHS Research Ethics Committee approved the study (ref: 06/Q1202/35). All participants gave prior written consent before the discussions.

Discussion aim

The group discussions were conducted using a topic guide that sought to: (1) elicit information on community perceptions and understanding of the consanguinity and disability debate and (2) examine the underlying factors likely to have an impact on a family-centred approach to genetic testing and counselling from a community perspective.

Analysis

All transcriptions were checked against the recorded interviews and corrected. Data were analysed using the framework approach which is particularly suited to the analysis of qualitative research data on issues related to public policy and applied research (Ritchie and Spencer 1994). This involved close examination of the data, identifying common themes that emerged within each and across all discussions. Once common themes were identified, further detailed analyses were carried out to consider these in the context of the aims and objectives of the research. The initial analysis was carried out by the first author and further developed through dialogue with team members and the project advisory group.

Table 1 Details of focus group participants

Age group	Males	Females	Total	Total UK born
20–30	3	4	7	3
30–40	4	6	10	2
40–50	6	5	11	
50–60	4	8	12	
60+	6	4	10	
Total	23	27	50	5

These discussions helped to prioritise themes and assist in interpretation.

Two meta-themes emerged:

- Community structures and social change
- Knowledge of genetics and attitudes to links between genetics and health

These were not discrete categories; for example, a sense of being a member of a beleaguered minority impacted on the credence given to health messages.

Findings

Community structures and social change

Kinship networks

Participants were asked about the nature and composition of their family and social networks to ascertain whether kinship networks were being sustained. Most families had been settled in the UK for two or more generations.

> Most of the families who lived in Mirpur now live in Derby. Nothing has changed, family wise nothing has changed. Most relatives are here, nothing has changed. They all live together, arrange marriages; they do things exactly how they used to do it. Male, Derby, 20s

Instead of kinship relationships being conducted across continents, as in previous decades, they are now focussed much more in Britain where large extended families and biraderis (wider kin grouping) may be co-located in a city or straddle cities:

> I live in [area of city] and there are thirty households and we are all related, close and distantly related, and then there are the villagers, from when my parents were young, first from Mirpur and then Sargodha. Therefore the immediate family is very large in the UK. Male, Bradford, 30s

Additional networks have also been created in Britain that consolidate kinship structures from Pakistan. One person from Derby spoke of his biraderi organising national social events annually where members socialise, acting as an informal setting for seeking marriage partners.

As well as kinship networks women respondents spoke of informal networks where they gather, sometimes weekly at local venues, to learn more about their faith and to socialise:

> In the past people did not have much interest but now these meetings are well attended, when there is a special occasion more people attend, sometimes 100 to 200 people attend. Female, Blackburn, 40s

Mosques are an important focal point for many men in the community and a proliferation of faith-based organisations are an important source of knowledge, friendship and social contact for a number of the younger participants, though not for all. Younger people also spoke of being part of broader social networks, established through work, college, university and social activities.

Marriage and social change

Participants spoke of a variety of different forms of marriage taking place. Those between close blood relatives continue. Participants, both young and older, described marriage within families as being a catalyst for a cohesive family structure with all members benefitting socially and emotionally from close relationships and shared history. But they also drew attention to the divisions created in extended families when marriages failed.

Marriage partners are also found through friendship and social networks, with some people choosing partners with minimal or no parental involvement. One anxiety was that marriage outside the biraderi would mean less extended family involvement with children. For this reason, such marriages were disliked by some older people. This was countered by a parent who felt that the concept of biraderi differed for young people who were redefining it to include people beyond their extended family.

Several participants were critical of broader, external influences on children, particularly the media which they believed was biased, resulting in young people's opposition to marriage within the family. These participants felt this alienated them from their children in an important area of their lives and denied their children the benefits that marriage within the family could offer:

> Media is poisoning our children. Our families want their children to get married in the family to keep families close, to support each other. Male, Bradford, 40s

However, older people now acknowledged that their previous authority in determining the marriages of younger family members had given way to the need to adapt to changing circumstances:

> Yes, many parents do accept them [marriages parents initially disapprove of]. How long can they stay away from their children? When they have grandchildren they accept. Children carry their blood therefore they adjust. Male, Bradford 30s

Knowledge of genetics and attitudes to links between genetics and health

Responses to health messages

Almost all participants had heard a health message they interpreted as, 'cousin marriage causes disabilities in children'. They reported this as emanating from UK health professionals and the media and to a lesser degree from the same sources in Pakistan. The message had permeated the Pakistani origin community; some participants reporting they had heard it from family members.

The typical response to this message from study participants was to reject it because it appeared illogical and confusing; they see couples who are cousins with only healthy children, and unrelated couples who have disabled children. Further, participants report that people of other ethnic groups who do not marry their cousins still have disabled children.

Participants in all the groups were vocal about the need for reliable information:

> Somebody needs to explain this. Why it happens. The impression I got is it's just cousin marriages. I thought it can't be, because there is plenty of evidence out there to show you it's not just within cousins. Male, Derby, 50s

The confusion generates considerable anxiety for families especially when marriages are being contemplated. This is most marked in families with disabled children:

> Cousin marriages are taking place here anyway, but our whole family is worried about this due to having disabled children. We do want our children to get married with cousins but we are concerned. Even when we arrange cousin marriages we are worried and concerned. Female, Blackburn, 40s

There was consternation and disappointment that health professionals, regarded as people one turns to for information and support, were amongst those relaying this information:

> I think they [doctors] can't think of anything else, that's why they say it [that cousin marriage causes disability in children]. Female, Derby, 30s

One person had been told by his doctor that his child's disability was due to cousin marriage when there was no blood relationship between him and his partner or between his parents.

Several respondents reported instances of health professionals being ill equipped to respond to people's need for information and support:

> You listen to these T.V. programmes telling you that you are carrying faulty genes. Then you go to your family doctors and they don't tell you anything. I don't think they even know anything about genetics because I probably know more than what he does. I tried to talk to him [doctor's name], he is not interested. Male, Derby, 30s

Understanding genetic risk involves unfamiliar and complex variables for lay people. One respondent, trying to grapple with information relayed to him about his nephew with thalassaemia, arrived at a mechanistic and erroneous understanding of recessive inheritance:

> They say genetic disorders are associated with Muslims, and when someone has three normal children from a marriage with a cousin then the fourth one is a disabled child. Is there any research on this topic? Male, Bradford, 60s

As well as believing that the prevalent health message is illogical and that health professionals are too quick to resort to it, there was a more general sense that this message constituted a criticism of Muslim/Pakistani culture:

> Whenever we talk about genetic, it is always associated with Muslims. I know one Hindu family who has disabled children, they don't get married in the family. Disabilities also happen in people who get married with someone from another country; even white people have so many disabilities. Male, Bradford, 30s
>
> I think this is just another thing that they punish us with, if you like, because we don't have the best name in the world, this is something else that they can point the finger at us.
> Male, Derby, 20s

Genetic testing

Knowledge about predictive testing as a preventative health intervention was varied. Generally, people were unsure about what was genetic. Some used the word 'genetic' whilst others talked about 'diseases that run in the family'. Several were aware of preventative blood tests and one related the case of a couple in Pakistan insisting on a blood test before entering into a consanguineous marriage.

Knowledge about genetic testing was, in the main, patchy or inaccurate. For example, one respondent said she knew two people who were carriers, indicating some knowledge of genetics, but then went on to say inaccurately that because they were carriers they would have disabled children. Only one man, involved in research connected with his disabled child's condition, had extensive knowledge of genetic issues and services.

The predominant opinion was that medical progress was valuable and the availability of genetic testing to alleviate disability was positive:

> Yes it is a good thing, if it happens I will be the first one to have that test. Nobody wants disabled children. To be honest, I don't see any problem; ninety per cent of people will go for it. Male, Derby, 30s

A few people noted that genetic testing could allow you to discover that you are not a carrier and therefore reduce stress:

> I think it will be good to know that if one of them is not a carrier, if both of them are carriers, their life is not going to be good. So it is better to be tested. Female, Blackburn, 20s

Other respondents were more cautious and raised the issue that although valuable, genetic testing also raises dilemmas, particularly the risk of being labelled. A major concern amongst these participants was that other people's reactions to a carrier could impact on marriage prospects:

> It puts you off before getting your son or daughter married. It puts us in a position that we have to search before we propose, so we ask them (laughs), 'Are you carrying any bad genes in your body?' You can't do that, they will say, 'Bye, see you later.' Male, Derby, 50s

For the same reason, some participants spoke of the need to keep information about carrier status or multiple disability private. There is an irony that families with disabled children felt their only chance of dealing with the stigma that resulted was for their children to seek partners from within the family, as family members were likely to be less judgmental than outsiders:

> Like our family we have so many disabled children, my sister and my brother's children are disabled and if some outsider wants to marry in our family they will think twice knowing that there is a disability in our family and children born can be disabled. I think you don't think like that in the family but if you are arranging marriage outside the family then you do. We don't do that with families. My brother's first daughter in law has a disabled brother and sisters and the youngest daughter in law has four disabled sisters, and despite this my nephews got married with them. Female, Derby, 40s

Participants, however, were not just discussing the dilemma but also seeking answers as to how to effectively communicate about personal genetic risk with others:

> If I have children and they are meeting another person, how could they ask for the medical record? Male, Derby, 40s

There were suggestions that increasing public awareness of the causes of disability, and of options available for limiting disability, would help to remove stigma and resolve dilemmas:

> I think it is important that people know what genetic means. Ninety nine per cent of Pakistani people don't know what genetic is. I only know because my family was suffering, not many people know about this because the doctors don't inform anybody. If they highlight this when you go for your blood pressure or diabetes check-ups. Any surgery that you go to, there is no information about genetic issues. Male, Derby, 30s
>
> You need the whole picture, full picture. Just having a blood sample and matching, what are you saying, what is the message given, are they defective, are they detrimental? Are you creating a fear for one another? Are you creating bad feelings, ill feelings for the future partner? Male, Bradford, 30s

Enhancing reproductive autonomy

Discussions about prenatal testing and therapeutic termination of pregnancy involved reflecting on faith as well as ethics. Some group members said that termination was not allowed even in the face of serious disability unless the mother's life was in danger. Others countered this by saying they felt there was flexibility within Islam:

> Religion tells you to go along with what is happening now in the world. If you search properly, look at the English Quran, religion tells you that if community or the world is changing you have to change with that, religion backs all the changes. Male, Derby, 40s

The issue of termination of pregnancy proved to be contentious. One person was not in favour of any type of intervention, expressing concern that this was a step on 'the slippery slope', while another stated categorically that he would not hesitate to terminate an affected foetus. There was no one dominant view. There were, however, both tensions within families and recognition that views might change over time.

> He was told by doctors that they should have a test with his wife being pregnant, 12 weeks or less. He says he should have done that, if he had known that that was what was going to happen to his kids. He'd have an abortion if it [the test] was 100% right. Every year the kids get behind and behind. Eventually nothing is working on them, but they're

still alive and he says that's a nightmare for him. Male, Blackburn, 40s

Participants discussed risk management that not only included termination of pregnancy but also marriage with unrelated partners. As two parents with disabled children commented:

I've got three children and I don't intend to marry them in the family. Male, Derby, 50s

Well it will be hard for us because it means us having to arrange marriages outside the family, for example, we will have to give our daughter to a family we know nothing about, like total strangers, it's a hard task we have to face but we have to accept the reality ahead of us. Male, Derby, 50s

Discussion

Participants showed willingness to discuss cousin marriage and disability. This was a link described as almost common knowledge within the Pakistani origin community, and one that was discussed openly within families. That discussion involved grappling with differing explanations for the cause of disabilities in the context of patchy knowledge about genetics, resulting in confusion. This situation has been recorded in numerous studies (Ahmad et al. 2000). We then have evidence of a community willing to engage with genetic issues (Shaw 2011), to address dilemmas and to avail themselves of opportunities to contribute to safeguarding the future health of their children.

Our findings indicate that while the relationship between consanguinity, genetics and disability is depicted in the prevailing public and professional discourse as a 'sensitive issue' (Buxton 2008), an 'elephant in the room' (BBC News 2008) that the presumed traditionalist and fatalistic Pakistani origin community refuses to acknowledge (Ahmad 1996a; Ahmad 1996b), the actual reality is very different. The need is not to scrutinise the Pakistani community's supposed reticence but to examine the assumptions made by those outside the community (Ali et al. 2008). Further, the mistrust of health messages about the damaging impact of cousin marriage (Darr 1997; Atkin et al. 1998) can be approached as an example of the challenges faced by professionals struggling to deliver appropriate care to diverse communities (Kai et al. 2007), rather than as a shortcoming of the Pakistani origin community.

The challenge of communicating about genetic risk, particularly with prospective partners, will become commonplace as personal genetic risk information becomes increasingly available (Forrest et al. 2003; Wilson et al. 2004). In communities where courtship before marriage is the norm, this usually just involves the couple. In communities that include arranged or semi-arranged marriages, familial responsibility for marriage arrangements necessitates that other family members also understand the implications of familial genetic risk. The need for effective communication of genetic information and support services is particularly pressing for families with children with a recessive disorder who are contemplating marriage within the extended family.

Prenatal diagnosis is available for a steadily growing proportion of recessive disorders (Modell and Darr 2002). In such situations, termination of an affected pregnancy can be offered as a therapeutic intervention. Muslim families have often been denied this service on the basis of a prevalent professional opinion that Islam forbids termination (Modell et al. 2000; Atkin et al. 2008). Our participants, however, expressed a range of opinions and interpretations, as Muslims, about the acceptability of termination of pregnancy. The discussions suggested that most participants had a general notion that termination within Islam is acceptable if the mother's life is in danger. Only a few were aware of fatwas (Islamic edicts) on prenatal testing and termination of pregnancy that state the circumstances under which termination is allowed when considering disabling conditions (Al-Aqeel 2007). Other studies have noted a complex attitude towards such fatwas that have emanated from countries outside the UK. Their applicability in the context of a different health care system in the UK is questioned by some community members (Atkin et al. 2008). This suggests a need for relevant UK Muslim bodies to examine the issue from a UK perspective.

A trend noted in this and other studies (Chattoo et al. 2004; Rozario 2005) is the increasing numbers of young people asserting their right, as Muslims, to choose their own partner. Although this suggests the possibility of a move away from cousin marriage, it is nevertheless located within the Islamic tradition of respecting elders' views, a focus on family life and discouragement of prolonged courtship before marriage.

Provision of accurate and understandable information can be a major therapeutic intervention in genetics. To understand the relationship between consanguineous marriage and genetic risk, a couple at risk for a recessive disorder needs not only to be informed about, but to understand the concept of gene transmission, of both partners being healthy carriers and the ordered sequence of steps involved in recessive inheritance (see Box 1). Discussion of the possible consequences of having children with close blood relatives (step 5) without ensuring a complete grasp of recessive inheritance (steps 1–4) is likely to be futile. Any such attempt to dilute the complexity of genetic information will be confusing and counter-productive, as

previous health campaigns in the UK and Middle East have demonstrated.

Box 1. Logical sequence for explaining recessive inheritance and the impact of marrying close blood relatives to parents of an affected child

1. You and your partner both carry the same gene variant for an inherited recessive disorder
2. When both partners are carriers, there is a one in four chance in each pregnancy that a child can be born with the disorder
3. You have each inherited this gene variant from one of your parents
4. Some other people in your family will also have inherited the same gene variant
5. If you carry a gene variant for a recessive disorder, there is a greater chance that your partner will carry the same gene variant if he/she is a close blood relative

Study findings highlighted that other people besides the immediate families of affected children were engaging with, and trying to understand, information about genetic risk. This contradicts a prevailing belief that people of Pakistani origin hide disability (Raghavan and Waseem 2007). It also underlines not only the familial need for genetic information but also the need in consanguineous communities for interventions at the community level to promote greater understanding of genetics. Our participants illustrated that these relatively close-knit communities were undergoing considerable changes but there remained a strong, shared identity as both Muslims and having Pakistani heritage. There also remain strong social networks with a continuing sense of allegiance to extended family and biraderi, even if the nature of these is evolving (Chattoo et al. 2004). Consanguineous communities, thus, can offer a resource for knowledge sharing and mutual support. This study details the experiences of lay members of British Pakistani communities, but further research is required to understand the experiences of other UK groups that favour the same marriage pattern to consolidate the applicability of the family-centred approach more broadly.

Conclusion

Public awareness of genetic issues is low not just in the Pakistani origin community, but also in the general UK population (Lanie et al. 2004). Increasing the genetic literacy of the public through community engagement is acknowledged nationally and globally as a central requirement in empowering the public to comprehend emerging debates and engage with the potential value of genetic technologies (Department of Health 2012; Reilly 2000). This acknowledgment can only benefit families when strategies for implementing comprehensive engagement programmes recognise the specific nature and needs of local communities and pay detailed attention to resource allocation and staff training.

The construction of the debate about disability around cousins having children (a cultural issue) rather than carriers having children (a scientific construct) has been a major cause of confusion for professionals and families alike (Ahmad and Bradby 2007). For progress to take place, concerns about the elevated risk of recessive disorders in consanguineous communities need to be relocated firmly in the realm of genetic service development.

Contrary to dominant perceptions of Pakistanis in the UK as traditionalists unwilling to engage in modern genetics debates, this study shows that they are discerning in their consideration of the health message that links cousin marriage with disabilities in children. The study reveals a community concerned for the welfare of their children, anxiously seeking to reconcile differing explanations of disability in a context of confusing health messages. Participants expressed a desire for accurate information and for support services. A public informed about genetics was seen to be fundamental to people being able to discuss genetic risk openly.

This study's findings suggest a community that is embracing change, one in which kinship networks are still active and genetic information exchange is taking place. At the community level, these are conditions supportive of a family-centred approach to genetic testing and counselling.

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