

Guest editorial

Cousin marriage, culture blaming and equity in service delivery

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Despite legislative attempts to ensure an equitable health service, the practice of blaming minority ethnic communities for their own ill health persists, with damaging effect. Its vociferous manifestation is reflected in media coverage of the protracted 'cousin marriage and genetics' debate, with headlines such as 'Call to end cousins marrying' and 'Muslim inbreeding in Britain causes massive surge in birth defects.' Members of Parliament (including a government minister, Phil Woolas) with limited knowledge of this complex health issue have audaciously fuelled this public debate, advocating a solution that would require individuals to alter who they choose as life partners, based solely on population statistics about genetic risk (BBC, 2005; Daily Mail, 2008).

The cousin marriage and genetics debate hinges on the rising costs of disability among Muslims of Pakistani origin, and their apparent refusal to respond to pressure and alter their marriage pattern in order to reduce disability levels. This health message has created confusion within the community of Pakistani origin, who are surrounded by couples in their family and community who are cousins but who have healthy children, as well as white couples who are not cousins but who have children with inherited disorders (Atkin *et al*, 1998; Darr, 2000).

Behind the public facade of this debate, as in previous decades (Ahmad, 1996), lie the health needs of minority ethnic groups waiting to be met. Excessive preoccupation with population statistics runs the risk of losing sight of grass-roots individual and family need. A number of very recent UK studies, adding to the previous literature, have unequivocally demonstrated the nature of this unmet need, providing the evidence for the as yet small but discernible backlash by informed academics and practitioners to the dominant media coverage (BioNews, 2005–08; Guardian, 2008).

Cousin marriage is one form of consanguineous marriage ('consanguineous' literally means 'related by blood'). It is legal in the UK, and around 25% of all cousin marriages in the UK take place among the white ethnic majority (Bittles, 2009). Cousin marriage

occurs more commonly and is customary to varying degrees among people of Pakistani, Bangladeshi and Middle Eastern origin, and also among some groups of Indian origin, Irish travellers, and some refugee populations. Worldwide, at least 20% of the global population live in communities with a preference for marrying close relatives, and at least 8.5% of all births are to consanguineous couples (Modell and Darr, 2002). The community of Pakistani origin has the highest rate of cousin marriage in the UK (Darr and Modell, 1989; Shaw, 2000).

Cousin marriage impacts only on genetic disorders that are inherited as autosomal-recessive conditions. It does not have any influence on chromosomal abnormalities, sex-linked conditions or autosomal-dominant conditions (Modell and Darr, 2002). Many rare, but severe, recessive disorders are transmitted by healthy parents who carry one gene variant for a recessive disorder. When, by chance, both parents carry the same variant, they have a 1 in 4 risk in each pregnancy of having a child affected by that disorder. A couple who are both carriers of the same recessive gene variant, regardless of whether they are related, have the same risk of having an affected child (Rose and Lucassen, 1999). In contrast to the unpredictable and thinly scattered manifestation of recessive gene variants in populations where partner choice is random, variants in communities that marry close relatives tend to cluster within extended family groups. This increases the likelihood that a carrier will choose a partner who carries the same variant. The result is an increased prevalence of infants with severe inherited disorders and an increase in the prevalence of serious disability, particularly in young populations with a high rate of fertility (Modell and Darr, 2002). The issue is not of cousins being partners, but of carriers of the same recessive gene variant being partners.

Cousin marriage creates a web of links within and between extended families. These familial links, based on blood ties, consolidated through marriage, are genetic links as well as channels for information and support. The ties have been shown to facilitate the flow

of genetic information within Pakistani-origin families in the UK and in Pakistan (Darr, 1997; Ahmed *et al*, 2002), and provide the social infrastructure to facilitate a particularly effective, integrated family and community approach to providing carrier testing and genetic counselling. This approach, recommended by the World Health Organization (1985), begins with providing accurate information on individual risk to members of at-risk families, with support to enable them to make an informed choice (Alwan and Modell, 1997). An affected person in the family is a signal to the rest of the extended family and to health professionals that some other family members may also be carriers. Hence an integral part of the approach is to offer information and support to extended family members, with an underpinning community engagement programme to increase the genetic literacy of the public, and to combat misinformation. The feasibility of this approach depends on active family networks and the willingness of their members to acquire, utilise and share information about genetic risk. Findings from the latest studies (Ali *et al*, 2008; Kingston *et al*, 2008; Darr *et al*, 2009) of at-risk families and community members of Pakistani origin show that, contrary to stereotypical assumptions, the majority of these people have considered but rejected, or are confused by, the health message that locates cousin marriage as the cause of disability. In addition, they have patchy, if any, knowledge of recessive inheritance, they want accurate information, they share health information with family members, and they wish to be active agents in determining their children's health. Currently, most lack the information and support that would allow them to make optimum use of the available services. The potential for the stigmatisation of carriers was raised by some of the participants, but this was countered by the majority, who felt that the solution was to raise public awareness of genetics. Stigmatisation of this nature is a generic issue of concern among all populations (Anionwu and Atkin, 2001; Smith, 2007).

The integrated family and community approach contrasts starkly with the strategy of discouraging people from marrying close relatives on the basis of population statistics on genetic risk. This strategy has been tried in Iran (Samavat and Modell, 2004) and by the previous Birmingham Health Authority as part of a health promotion campaign (Director, Heart of Birmingham PCT, 2008, personal communication). In both places the strategy failed to have any significant impact on disability, it prompted negative community reaction towards service providers, and it has been replaced by the integrated family and community approach.

Carrier testing has been available nationally for sickle-cell disorder and thalassaemia, which are the most common recessive disorders, for some time.

Recent advances in genetic diagnosis mean that at-risk couples can now be offered genetic testing for over 40% of recessive conditions, with this figure likely to increase rapidly in the near future (Modell and Darr, 2002).

Although crude in its manifestation, culture blaming remains a pervasive, subtle and powerful factor within the health services arena, hampering and significantly delaying development of and access to services in a diverse society. Equitable service development and delivery requires vigilance in order to recognise, swiftly combat and move beyond the time- and resource-consuming activities that culture blaming generates. The required focus is on the development of a community genetics infrastructure that is capable of responding to the needs of an ethnically diverse population that will translate technological advances in genetics into much needed services. The development of specifically designed tools for effective communication between families and professionals, training for the latter, and community engagement programmes to increase the genetic literacy of the public, emerge as priorities to meet family need.

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