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Research paper

South Asian community views about individuals with a disfigurement

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What is known on this subject

- Most appearance-related research is conducted in western cultures with individuals who have a good command of the English language.
- Stigma and shame may be experienced by the individual affected and by their family as a result of culturally specific expectations of physical appearance.
- Religion exerts powerful influences on personal perceptions, attitudes and beliefs with regard to healthcare.

What this paper adds

- Generational differences in South Asian community views about disfigurement appear to emerge from westernisation and the influence of the media.
- There is a change in the orientation of younger members of the South Asian community away from traditional religiously framed perceptions of acceptable appearance.
- Educational interventions are needed to highlight the support services available and also to dispel myths.

ABSTRACT

There is a paucity of research exploring the views of different cultural and ethnic groups about individuals with a visible difference. This research is a priority area given that issues of disfigurement, stigma and shame may be particularly bound to cultural and ethnic membership (Papadopoulos *et al*, 1999). This paper examines the attitudes of South Asian communities in the UK towards individuals with a disfigurement. It is based on thematic analysis of material generated from nine focus group interviews with South Asian community members. A number of themes emerged from the focus groups, including definitions of disfigurement, a sense of family burden and shame limiting the marriage and

social opportunities of the individual, culturally specific beliefs about the causation of disfigurement, and reactions from the community. It also emerged that there was a lack of knowledge about the support services available, and an association of visible difference with mental and physical disability. Religious beliefs and cultural practices cut across the majority of themes that emerged. These spiritually derived beliefs added meaning both to the cause and origin of the disfigurement and to the consequences of that difference. There is evidence of generational differences in views about issues such as appearance, which seem to emerge from westernisation and the influence of the media. The findings highlight the need to inform healthcare policy and implement interventions to provide appropriate psychosocial support and care for people living with a disfigurement. These include increasing knowledge and understanding of disfigurement in the South Asian community, and raising awareness of support services.

Keywords:

Introduction

This paper discusses the findings of an exploratory study of South Asian community attitudes towards individuals with a disfigurement. In the UK, people of South Asian descent (i.e. those ethnic groups originating from the Indian subcontinent) constitute one of the largest ethnic minority groups, representing 4% of the total population. This is a heterogeneous group that includes people of diverse cultural heritage, who have different religious beliefs, speak different languages and possess varying levels of literacy.

There has not been adequate research into the way in which different cultural and ethnic groups view the cause and consequences of disfigurements, and the socially constructed representations of differences within their groups. Few standardised appearance measures have been translated, so most appearance-related research is conducted in western cultures, mainly in the USA and the UK, with individuals who have a good command of the English language (Rumsey and Harcourt, 2004). Therefore it was considered a priority to conduct a pilot study designed to explore attitudes and perceptions towards appearance and disfigurement among selected minority ethnic groups. The current research is an extension of a larger multicentre research programme in the majority population supported by the Healing Foundation and led by the Centre for Appearance Research at the University of the West of England. The knowledge generated by the research programme will inform the development of a comprehensive range of health policy recommendations and interventions designed to promote positive adjustment in those affected by disfigurement. It will also facilitate the possibility of comparing the views of the South Asian sample, as observed in the present study, with white British perspectives.

Background

Cultural variations in ideas about attractiveness or unattractiveness and the reasons for our preferences have intrigued scientists and philosophers for centuries (Adamson and Doud Galli, 2009). An attractive appearance informs others of our ancestral value, whether we are potentially fertile and healthy, and whether our genes will create desirable progeny (Adamson and Doud Galli, 2009). Ubiquitous media artefacts may play a role in shaping our preferences with regard to appearance, and these ideal media representations of beauty may contribute to greater dissatisfaction with our bodies (Langlois *et al*, 1991).

Etcoff (1994) has argued that beauty may not be an arbitrary cultural convention, and it has been shown that concepts of facial beauty do not tend to vary much among races or over time (Marquardt, 2002). Research therefore suggests that our concepts of attractiveness are primal and innate.

Yet other scholars maintain that the concept of beauty is prescribed by cultural constructs and myths of all cultures, and that every civilisation studied seems to revere and pursue it (Schjedahl, 1998). Our preferences may reflect cultural and social standards of beauty which can vary with time and place, and may be specific to cultures and faiths (Haiken, 2000; Poran, 2002; Swami and Tovée, 2007). Furthermore, cultural beliefs and practices shared by specific groups of people may exert a strong influence on an individual's behaviour by defining behavioural norms, assumptions, rules and relationships (Adamson and Doud Galli, 2009). These norms give meaning to their world and govern family life, childrearing, the recognition of illness and health-seeking practices.

Indeed, the family has an important function in enforcing cultural norms and values, and thus in shaping views and perceptions (Rex, 1991). This has

particular significance for South Asian families living in the UK, in that family-based socialisation serves the twin functions of imparting religious and cultural values and countering what may be seen as the conflicting or corrupting influences of the wider society (Afshar, 1994; Anwar, 1998). The older generation of South Asian people have strong perceptions of new freedoms and views as threatening to the continuation of traditional cultural values, such as parental authority and obligations, possible changes in marriage choices, and concerns about appearance (Modood *et al*, 1994). Young people adopt their own views, seeking sources from different and often conflicting value systems. Changes to familial value systems may not result solely from a rejection (a relatively rare phenomenon) of these values (Drury, 1991), but also from partial acceptance and reinterpretation of some of them, thereby constructing hybrid identities (Papastergiadis, 1998). Alternatively, it may be that if they encounter rejection or hostility from the majority society, young people may immerse themselves in more traditional aspects of their parental culture (Cashmore, 1979).

Stigma and shame may be experienced as a result of culturally specific expectations of physical appearance. Early research found that, in initial encounters, people with a disfigurement are more likely to be negatively evaluated than physically attractive people. They may be judged to be less intelligent, less sociable, less morally upright, less likely to hold high-status jobs, and less likely to have good marriages (Rumsey *et al*, 1982, 1986). A study of interpersonal distance while waiting at the kerbside and the effects of facial appearance on seat occupancy on a suburban railway showed that facial disfigurement can lead to negative or avoidance reactions (Rumsey *et al*, 1982; Houston and Bull, 1994). Stigmatisation may also lead to social unacceptability and have an impact on the marriage prospects of those living with neurofibromatosis (NF1) among the British Bangladeshi community (Rozario, 2007). Explanations for the behaviour of others have been explored, and have included beliefs about a just world, an evolutionary aversion to anything other than perfect, and the desire to avoid anything that might be contagious (Rumsey and Harcourt, 2004).

In any society, religion exerts powerful influences on personal perceptions, attitudes and beliefs with regard to healthcare, and shapes the models of care that patients receive (McAuley *et al*, 2000; Rassool, 2000). Concepts of God play a major role in health belief systems, which constitute a holistic framework that meets the physical, spiritual and psychosocial needs of individuals and communities (Ypinazar and Margolis, 2006). For example, concepts of the origins, nature, cause and consequences of health and disease appear to be heavily influenced by strong connections to Islam and its traditional culture (Atiyeh *et al*, 2008). Strauss (1985) noted that, in Israel, western Jews, oriental Jews and Arabs differ in their explanations of the origins of birth defects, and their approaches to rehabilitation and community integration.

Therefore a disfigurement, whether congenital, present at birth or acquired later in life, may have a profound impact upon the individual and their family (Rumsey and Harcourt, 2004). The psychological and social consequences of living with a disfigurement, and the individual's experience of being visibly different, are well documented (Lansdown *et al*, 1997; Rumsey and Harcourt, 2005). For the individual concerned, it may adversely affect body image, quality of life and self-esteem, as well as social interaction (Bull and Rumsey, 1988). There is some evidence to suggest that those of 'non-white' ethnic origin worry more about the appearance of their condition and report that their appearance affects their lifestyle more than similar white counterparts (Rumsey *et al*, 2004). However, it is unclear whether South Asian communities in the UK respond and react to individuals with a disfigurement in the same way as the majority white community.

Research and observations from clinical practice have shown that the severity of a disfigurement is not an accurate predictor of distress or psychological adjustment, but is more likely to be influenced by a complex mix of physical, psychosocial and cultural factors (Clarke and Cooper, 2001). Although many people find it difficult to cope with a disfigurement, others appear to be relatively unaffected and seek little or no psychosocial support. Anecdotal evidence from the NHS strongly suggests that the uptake of support for people who have a disfigurement differs between cultural groups, and is very low among Asian and minority groups. Although most Muslims appreciate modern medicine and seek healthcare, the belief in predestination and that illness is a test from God may mean that some patients do not seek treatment (Lawrence and Rozmus, 2001). However, a recent ruling has made it clear that surgery to reshape a deformed part of the body is generally recommended in Islam (Al Jazeera Publishing, 2009). Notably, there is evidence to suggest that, as in the western world, aesthetic surgery is spreading fast in Muslim countries (Atiyeh *et al*, 2008). Scholars argue that surgery for the purpose of beautification is the result of the materialistic pattern followed by western civilisation and of standards set by Hollywood (Atiyeh *et al*, 2008).

However, the nuances of cultural and social differences in responses to visible birth anomalies and acquired differences remain largely under-researched (Rumsey and Harcourt, 2004). The aim of the present study was to explore South Asian community attitudes towards beauty and disfigurement as well as the acceptance of medical intervention and access to support for individuals with a disfigurement.

Methods

The research was undertaken between 2007 and 2008. Ethical approval was obtained from the Biomedical Research Ethics Committee at the University of Warwick. The aim of this exploratory research project was to elicit the views of selected British South Asian communities about issues of appearance and disfigurement, and perceptions of and the relevance of medical treatments. While it was acknowledged that achieving a fully representative sample of all South Asian sub-groupings was problematic, attempts were made to include people from distinct South Asian communities characterised by their religious, linguistic and ethnic attributes, in particular Bangladeshi (Bengali-speaking Muslim), Indian (Gujarati-speaking Hindu and Punjabi-speaking Sikh) and Pakistani (Urdu-speaking Muslim).

The research methodology drew upon the Social Action Research Model, which has been extensively used to explore the perceptions and understandings of ethnic minority communities, particularly in relation to South Asian health beliefs (see, for example, Culley *et al*, 2007; Lloyd *et al*, 2008; Johnson and Borde, 2009). Volunteers from within the South Asian communities were provided with quality training in aspects of social research facilitation and the issue of concern (i.e. concepts of appearance and disfigurement). In order to maximise participation and enhance linguistic and cultural sensitivity, two male and two female bilingual South Asian facilitators were recruited from the West Midlands region. The facilitators recruited natural groupings from within their specific South Asian communities, and led the focus group discussions, following an agreed semi-structured topic guide, which they helped to develop in consultation with the research team (see Box 1).

Data were collected in the West Midlands region of England. Nine single-sex focus groups were established with South Asian community members ($n = 63$). The facilitators approached participants opportunistically in community settings, including places of worship and community groups. They were allocated to groupings according to their religious and ethnic identities, gender and age. Five focus groups were conducted with women ($n = 34$) and four with men ($n = 29$), and the age range of participants was 18–70 years (see Table 1). In total, 16 participants self-ascribed their ethnicity as Bangladeshi, 35 as Indian and 12 as Pakistani. The Bangladeshi and Pakistani groups were all Muslim, and the Indian groups described their religion as Hindu ($n = 18$) or Sikh ($n = 17$). The focus groups were conducted in the preferred languages of the participants (English, Bengali, Gujarati, Punjabi or Urdu). Five discussions were tape-recorded and fully transcribed by the facilitators. Four discussions were recorded in notes compiled by the facilitators during the focus group sessions. These were translated into English by the bilingual facilitators. The facilitators were asked to use their discretion and judge whether or not it would be acceptable to the participants to tape record the discussion.

The data were analysed by a team of four analysts using a process of template analysis (Kent, 2000). A priori themes were initially defined. Initial coding of the data was then carried out, identifying those parts of the transcripts that were relevant to the research aims. If encompassed by one of the *a priori* themes, a code was allocated to the identified section. If there was no relevant theme, an existing theme was modified or a new one was created. The identified themes in the selected transcripts were then grouped into a smaller number of higher-order codes which described broader themes in the data. This template was then applied to the full data set. A group session with all study team members, including the bilingual facilitators, provided a forum in which the themes were discussed before the final analysis was accepted and completed. In the findings section that follows, key themes that emerged from the data are presented together with a discussion of the interrelated sub-themes that they encompass.

Findings

The analysis identified eight key themes relating to South Asian community views about disfigurement, namely definitions and meanings, causation, family, social and emotional reactions, social exposure, cultural differences, medical interventions, and social support.

Definitions and meanings

A range of descriptions and definitions associated with disfigurements were offered by the groups when the topic of disfigurement was introduced. These ranged from 'ugly' to any abnormality or unevenness in the colour, shape or features of the face, including scarring and birthmarks. Older male participants discussed nicknames given to people with a disfigurement, and mentioned amputation and problems with the eyes as disfigurements. Some definitions related to what was regarded as beautiful in Asian culture, and also to what God had created. Clear, fair skin, a nice nose and eyes were features that were prized and valued by many respondents. For example:

> 'In our culture beauty depends on how beautiful someone's face is.'
>
> (older Bengali man)

Box 1 Topic guide: appearance and ethnicity

Introduction

The Healing Foundation is supporting research with the University of Warwick Medical School and the Centre for Appearance Research (Bristol) into the concerns of people who have a disfigurement, or whose appearance has been changed, in order to help to understand their need for support or NHS services. We know that very few people from minority ethnic groups use these services, and we want to understand why. We are asking these questions of a selection of people from across ethnic groups, not just those who may have a disfigurement. This helps us to understand community views.

'Easy Question'

When you meet someone for the first time, what is the first thing you notice?

What do you think 'most people' look at first in a person? What is 'beauty' in *our* culture?

Does our culture place more value on any particular part of the 'look'?

What would you understand by someone being described as 'disfigured' or 'visibly different'?

Does this affect the value of that person? How might it make them feel?

Do you think this is true for the 'majority' (white) community?

Are things different in our own (cultural) community? If so, how and why?

Will this affect their taking part in (community) social events (e.g. Mela)?

What (if any) effect would it have on their ability to take part in (religious) events?

Would people feel differently about employing someone with a disfigurement?

How do you feel if you see someone who is disfigured?

Are things different in older people compared with younger people (those born here)?

Do you think that 'Western values' are affecting how people think? What about 'back home' (parents' place of birth)? Have things changed there, too? Would being 'disfigured' affect someone going back (to Asia)? And how would they be regarded there?

How about relationships within the family (e.g. attitudes of parents about marriage)? Are there any effects if someone becomes disfigured after marriage?

Is there any difference between a feature like a birthmark you are born with, and something that is acquired through an accident or as result of war (e.g. as a refugee)?

How do people explain such things? Is it 'fate' or some other cause? (ask about myths)

Are there questions of concerns about 'blame' or any 'shame/stigma'?

Does this stop a person trying to do something about the disfigurement?

What help-seeking behaviour would be acceptable or tried? (e.g. cosmetics or clothing, clinical or surgical changes, or a change in behaviour, such as avoiding certain situations)

To whom, how and where would people go for help?

Do people feel differently about 'medical' reconstructive surgery and 'cosmetic' surgery?

Last year a TV programme showed a woman having a 'face transplant.' If you saw the programme, what is your opinion about this?

There is a charity called 'Changing Faces' which works with people who have had serious accidents (burns, etc., such as Simon Weston). Have you ever heard of it? How and what have you heard?

Are there any questions you would like to ask about 'disfigurement', changing appearance and 'cosmetic surgery'? Do you think these questions would be of interest to others in your community? How should we set about helping them to get those answers? (Be prepared to offer information about help.)

'Perfect nose, eyes, slim.'

(older Pakistani woman)

'Beauty can be a number of things: beard, moustache, hat, clothes.'

(young Bengali man)

'Allah makes so many things which are beautiful.'

(older Bengali man)

Although the emphasis was on facial features such as symmetry, it was acknowledged by both men and women that beauty is subjective and can come from

Table 1 Focus group composition

Focus group	Participants (*n*)	Ethnicity	Gender	Age (years)	Religious belief	Language
1	6	Pakistani	F	≥ 35	Islam	Urdu
2	5	Bangladeshi	F	≥ 35	Islam	Bengali
3	6	Bangladeshi	F	18–35	Islam	English
4	9	Indian	F	18–35	Hindu	English
5	8	Indian	F	18–35	Sikh	Punjabi
6	6	Pakistani	M	≥ 35	Islam	Urdu
7	5	Bangladeshi	M	18–35	Islam	English
8	9	Indian	M	≥ 35	Hindu	Gujarati
9	9	Indian	M	≥ 35	Sikh	Punjabi

within. Several respondents associated a disfigurement with a physical disability such as being deaf or wheelchair bound. Other respondents linked an external disfigurement with an individual's intellectual capabilities, or used it to make a judgement about a person's character (the latter was particularly likely if the disfigurement looked as if it might have resulted from an accident or fight). For example:

> 'You always make the assumption that they are not as capable as normal people.'
>
> (young Bengali woman)

> 'If their appearance is not normal you can surmise that they are not well.'
>
> (older Sikh man)

> 'If some have [a] disfigured face, this person is not normal mentally.'
>
> (older Bengali man)

> 'If it is due to an accident or fight, people may blame him for his bad character.'
>
> (young Bengali man)

It is interesting to note the absence of any discussion of body shape, height or size, which tends to be an important aspect of the framing of meaning and the definition of beauty in white British culture. However, there is some indication that this situation is changing among young South Asian women and girls, particularly in relation to the impact of contemporary media representations of beauty in both UK and Asian cultures.

Causation

The participants offered a number of explanations for the origins of disfigurement, and in most cases these explanations were based on religious belief or cultural myth. There was a sense of fatalistic acceptance, with disfigurement being described as the will of the creator and sustainer of the world, and a belief that it should be accepted as such. This was the predominant causal explanation across the different religious groups, although some respondents regarded a disfigurement as one's destiny or a test, and others regarded it as the result of sin. For example:

> 'I feel sad, but what can we do, this is Allah's wish.'
>
> (young Bengali man)

> 'First we would have to accept it as God's will ... I would accept it as my fate and destiny.'
>
> (older Sikh man)

> 'Some people would say it's a test from God to see how that person copes with it.'
>
> (young Pakistani woman)

> 'This was God's way of punishing you.'
>
> (young Bengali woman)

Respondents mentioned that some people in their culture may attribute the origins of a disfigurement to cultural myths. Participants talked of a disfigurement being attributed to engaging in sexual activity during pregnancy, or the result of making fun of someone with a disfigurement. The superstitious avoidance of people with a disfigurement, just in case the condition was infectious, was also mentioned. Examples of such beliefs included the following:

> 'There is a common superstition about pregnant women during the lunar eclipse.'
>
> (older Bengali woman)

'You made fun of someone with a disfigurement many years ago, and now it's come back on to you.'

(young Pakistani woman)

'There are stories in our religion about these (MEATH) too. Therefore we are scared of these people. Do not go to these people.'

(older Bengali man)

The notion of individual culpability was discussed, as it was thought that the individual's past or present actions could be the reason for their difference. For example, they could have been involved in a fight or an accident, and some respondents spoke of this as the result of karma (an action or attitude in their previous life). Alternatively, others mentioned that a mother could be to blame for her past or present actions, which resulted in her bearing a visibly different child. For example:

'[if he is] disfigured due to an accident or fighting, people may blame him.'

(young Bengali man)

'People are so suspicious of how come all of a sudden this has happened to your child or what were they doing so bad that this has happened to them.'

(older Pakistani woman)

'That child is paying for their karma.'

(older Sikh man)

'The fathers along with the in-laws blame the mother.'

(older Bengali woman)

Some respondents articulated a more medical interpretation of disfigurement. It was acknowledged that genetics sometimes played a role, and that disfigurements could be inherited. This suggests that the influence of religious explanations might be weakening, although traditional beliefs still dominated the discussion.

Family

The groups spoke of an overall sense of burden and shame that would be felt by the family of someone with a visible difference. The family would wish to limit the amount of public exposure of the affected person, who would be regarded as a source of embarrassment and perhaps even suspicion. For example:

'They tend to hide them away because they see it as kind of a shameful and embarrassing thing.'

(young Bengali woman)

However, there was some indication that the South Asian community is becoming more tolerant. For example:

'A friend I know has a disabled sibling and they are not as ashamed. People are becoming more tolerant.'

(young Bengali woman)

In addition, relatives would feel a sense of responsibility to care for an individual with a disfigurement, although this would be seen as a burden, especially if the person affected was a girl. For example:

'The disfigured female in the family is terribly embarrassing.'

(older Bengali woman)

Families would be more accepting of a disfigured boy who could earn money. The importance of gender was also apparent when the groups discussed marriage. It was believed, especially by younger participants, that having a disfigurement had a negative impact on marriage prospects, especially those of a girl. For example:

'I think parents would be worried about their child's marriage if their child was disfigured.'

(young Pakistani woman)

'You are choosing the father or mother of your child ... they will not go for personality, they go for looks first.'

(young Bengali woman)

'It would affect their chances of getting married.'

(young Pakistani man)

The family is still a key social unit that replicates behaviours which are based upon feelings of shame. Therefore the individual who has a disfigurement is hidden from everyday social interaction. The interesting consequence of this restricted public exposure is the reduced opportunity for the affected person to explore alternative and more accepting cultural settings or support mechanisms. As another theme below suggests, the only outlet tends to be within a context of religious practice. Thus the individual is isolated from more tolerant communities, and may be unable to ameliorate their negative experiences as a result of what may be a form of collective collusion to avoid embarrassment.

Social and emotional reactions

Several participants discussed how they would react upon seeing an individual with a disfigurement. Some respondents said that they would feel shocked or frightened. For example:

'You might get a shock and it can make you jump.'

(young Pakistani man)

Older participants spoke of myths and religious tales. For example:

'There are stories in our religion about these people. Therefore we are scared of these people.'

(older Bengali man)

In addition, a few respondents mentioned stigmatising language used in their culture to refer to individuals with a disfigurement. For example:

> 'Even I feel scared sitting next to a disfigured person on the bus.'
>
> (older Bengali woman)

However, the majority of the respondents spoke of a sense of sorrow and sympathy, and expressed the view that they would not wish to make the person feel uncomfortable. Acts of over-compensation were discussed, as it was felt that individuals with visible differences should be protected from harm and so the community would be nicer to them. The concept of *Sewa,* or selfless service, the notion of doing something resulting in benefit to others, was also mentioned. For example:

> 'Sometimes we feel sorry for these people.'
>
> (older Bengali man)

> 'If I see such a person I feel very sad. I want these people to be treated the same as others.'
>
> (young Bengali man)

It was widely believed that a disfigurement could have a negative impact on the psychological well-being of an individual. It was thought that the person may feel marginalised and lonely, or suffer from low self-esteem. This could be as a result of keeping themselves out of the public eye, or due to the actions of others in the community. For example:

> 'They will lack confidence. They might be isolated by others but they will also isolate themselves.'
>
> (young Pakistani woman)

> 'They would probably lose the will to live.'
>
> (young Pakistani man)

> 'When he looks in the mirror he might feel different, weak.'
>
> (young Bengali man)

The social and emotional reactions of participants offered some amelioration of the strong sense of shame and stigmatisation associated with disfigurement. A willingness to advocate medical intervention was also evident. The responses reflected the expectation that individuals with a disfigurement would react to community attitudes towards them, experiencing low self-esteem and self-imposed isolation. This was thought to lead to subsequent marginalisation both within their own community and in relation to the wider UK social environment where support is available.

Social exposure

Participants thought that the community or family would try to limit the public exposure of an individual with a disfigurement in several ways. The family might attempt to do this as a form of protection as well as in response to a sense of shame. For example:

> 'We would not take them out much because people would stare.'
>
> (older Sikh man)

> 'They are considered a social outcast.'
>
> (older Bengali woman)

> 'I think other people would make it difficult for them to socialise.'
>
> (young Pakistani woman)

There was a clear differentiation between an individual with a disfigurement being accepted in a religious gathering, and attitudes towards them in situations outside this context. When attending religious ceremonies, people would be more open minded because everyone should be able to come to worship. For example:

> 'Religious events will not affect them as much, in places like that people would be more sympathetic.'
>
> (young Bengali woman)

> 'We tend to be soft hearted in religious events. So people are more broad minded.'
>
> (older Bengali woman)

It was also felt that an individual with a disfigurement would have reduced employment opportunities, and might feel pressured by society to keep him- or herself out of the public eye. For example:

> '[An] employer will not employ someone who will make the children or customer afraid.'
>
> (older Bengali woman)

> 'You will find you are stuck in the corner somewhere.'
>
> (young Bengali woman)

Participants thought that an individual with a disfigurement would find it difficult to socialise and to take part in events outside the religious context. Some participants also discussed the use of traditional clothing and make-up to conceal a disfigurement. For example:

> 'Some disguise them with clothing. ... Some would hide themselves from social gatherings.'
>
> (older Bengali woman)

The comments expressed here are, once again, culturally bounded and self-referential, since they do not encompass the possibility of alternative experiences

for the affected individual outside their immediate community setting. Despite greater religious tolerance in specific contexts, the dominant view was that the appropriate treatment of disfigured individuals is concealment. This raises questions about community awareness of both the well-being of the individual and the issues to be considered when developing interventions.

Cultural differences

A number of differences between South Asian and western white cultures were observed. It was widely felt that the western media dictates what is beautiful, and does not show images of people with a disfigurement unless the context is medical, or in order to sell products. However, several participants remarked that white western families were better educated and more accepting of disfigurements than Asian families. This supports other themes discussed above which indicate that gradual cultural shifts may be occurring within the South Asian community as they become more aware of the wider UK socio-cultural environment and consider alternative views of disfigurement. For example:

> 'Their community [white] is more aware, exposed and educated about differences.'
>
> (young Pakistani woman)

> 'They [white people] are more accepting ... they even encourage disfigured people to blend in with the mainstream society.'
>
> (older Bengali woman)

> 'As the lifestyle of both Bangladeshi and English is different, this issue is different too. They [English] treat the disabled people with respect.'
>
> (young Bengali man)

The differences noted between the cultures were also influenced by age. Younger participants commented that elders are considered to be narrow-minded and less understanding. This was evidenced by the fact that skin colour is particularly important to elders, but less so to younger people. For example:

> 'We [young people] understand how things work now, how society is, whereas they [older people] are stuck in their own times.'
>
> (young Pakistani man)

It was also mentioned that attitudes in communities back home differed, and that people there would be more tolerant of disfigurements than communities in the UK.

The influence of Bollywood, the Indian film industry, which is largely based in Bombay, was raised, and the belief was expressed that South Asian attitudes are becoming more aligned with western culture in terms of the importance attached to physical beauty. For example:

> 'With the influence of Bollywood, girls want to look more glamorous and I don't think it matters any more if they got a good personality or what sort of person you are.'
>
> (older Pakistani woman)

> 'People are more conscious about the way they look these days ... so imagine having a disability – that is a huge thing now.'
>
> (young Bengali woman)

> 'The media puts too much on people to look a certain way. You never see a disfigured person on TV.'
>
> (young Pakistani woman)

These comments suggest that the definition and framing of beauty are changing under the influence of British and Bollywood cultural artefacts, especially in the media. In this respect, the concept of beauty is becoming broader. Glamour is the focus, rather than just the face. However, it also places greater emphasis on appearance, and compounds the issue of conformity to a contemporary stereotype for those with a disfigurement.

Medical intervention

Medical intervention was considered acceptable by all groups if it was necessary for a medical reason and it was considered important to follow the advice of a doctor. It was widely thought that an individual should pursue treatment for a disfigurement, as it would improve their quality of life. However, non-essential or cosmetic surgery, pursued out of vanity, was not condoned. Numerous participants deemed cosmetic surgery to be playing God and going against God's will. A few participants stated that a person's character was linked to their physical appearance, and so one should not try to change the way that one looks. For example:

> 'It is a great sin to try to change the way of looks. Allah will punish them.'
>
> (older Bengali woman)

> 'Some people would say it's playing God.'
>
> (young Pakistani woman)

> 'Medical is necessary, and cosmetic, that is a luxury.'
>
> (young Bengali woman)

The medically acknowledged need for intervention was still qualified by traditionally held beliefs about divine retribution, although this was more likely to be asserted by elders in the community. However, it was widely articulated that remedies that can be rationalised as medically necessary could also affect mental health and quality of life in the community through

increased opportunities for social exposure and better-quality social interaction. For example:

> 'If someone's life is being drastically affected because of a disfigurement, such as marriage proposals, then they should take whatever reasonable means necessary.'
>
> (young Pakistani woman)

Social support

The participants agreed that the immediate family is the main source of support, and that shame or embarrassment may prevent families from seeking support from external sources. Families may be reluctant to ask their extended family or their community for help with a relative with a disfigurement. There was a general lack of awareness of the support services available to individuals with a disfigurement. For example, none of the participants had heard of the charity Changing Faces.

> 'The extended family stay uninvolved either due to lack of awareness, shame, or 'just can't be bothered' attitude.'
>
> (young Pakistani man)

> 'They would definitely not go to the community ... they might go to the doctors rather than ask family.'
>
> (young Bengali woman)

In several ways, this theme provides a canvas for many of the findings. The extended family is the major element of the social and cultural infrastructure that both embodies the beliefs, myths and stereotypes about disfigurement and dictates behaviours towards visibly different relatives. The family mediates a range of culturally significant attitudes towards disfigurement that comprise, among other things, shame and the process of stigmatisation, the concept of acceptable appearance, concealment of visible difference, and burden and suffering due to divine retribution. The gradual shift in cultural orientation by younger members of the South Asian community, especially women, does indicate that family dynamics may be changing. However, the lack of awareness of support opportunities and the limitation of public exposure imposed upon, and self-imposed, by those affected prevents them from seeking external social support.

Discussion

The focus group discussions revealed the value attributed to physical appearance in South Asian culture. Furthermore, it emerged that people with a disfigurement are more likely to be negatively evaluated than those who do not have a visible difference. Some respondents linked an external visible difference with an individual's intellectual capabilities, or used it to make a judgement about a person's character. Those who have a disfigurement may be judged as 'second class', and may perhaps be perceived as having 'some form of psychological disorder' (Rumsey and Harcourt, 2005, p. 12). The participants also thought that a sense of stigma and shame would be felt by an individual with a disfigurement, and that they might feel obliged to limit their presence in the community, as reported in previous studies (Gaff and Clarke, 2007). This would also limit their opportunities to access an alternative cultural referent from a wider social group, or for the affected person to be pro-active in seeking support.

Discussions also focused on the ways in which appearance played a central role in a person's life chances as well as their general well-being and levels of participation in the community. The findings support earlier research which found that attractive and non-disfigured people are favoured in a wide variety of situations, including dating, marriage, education and employment (Bull and Rumsey, 1988). The continuing custom whereby the parents arrange the marriage of their child introduces a further dimension in relation to restricted opportunities within and beyond the community. The view was widely expressed that a disfigurement would have a negative impact on an individual's marriage prospects, particularly for females. This finding supports the results of previous research that explored social acceptance and marriage in non-white communities (Rozario, 2007).

Faith and spirituality are increasingly recognised as playing an important role in people's understanding of illness, in support and coping, and in clinical care (Lambert and Sevak, 1996; Koenig *et al*, 2001). The findings of the present study show that religious and cultural beliefs cut across the majority of the themes that emerged, and were particularly implicated in beliefs about the causation and consequences of disfigurement. Some older participants felt that it was the result of a sin or that it was a test by God, and so the individual must accept it as their destiny. The findings add to the literature which shows that God plays a major role in health belief systems (McAuley *et al*, 2000; Rassool, 2000). However, it was widely thought that an individual should seek medical help for a disfigurement so long as this was not motivated by vanity (as this would be regarded as against the will of God). The findings support evidence from Muslim communities that medical intervention is accepted in Islam so long as it is undertaken for the benefit of the patient (Atiyeh *et al*, 2008).

Most of the participants felt that white western people appeared to be more educated about and accommodating towards individuals with a disfigurement. This was also the perception of the treatment of a Bangladeshi woman with NF1 in the UK (Rozario,

2007). In addition, a number of groups felt that there was cultural and generational disparity in beliefs in relation to understanding and accepting disfigurements. Younger South Asians regarded their elders as having outdated views and as being more narrow-minded than themselves (see, for example, Papastergiadis, 1998). There was also a sense that South Asian community views were becoming more aligned with western values, due to high levels of social interaction. The influence of Bollywood and changes in society back home were also considered to be significant influences on the attitudes of communities in the UK. Therefore it may be that South Asian communities will become progressively more accepting of visible disfigurement, while at the same time being influenced by the pervasive images of beauty and physical perfection promoted by the media.

In the light of these findings, an important next step is to develop appropriate information about the causes and consequences of disfigurement, and to devise effective dissemination strategies. The participants identified a number of foci for information and interventions that might reduce the negative consequences of disfigurement. These included education to dispel myths, raising awareness of sources of support, and the provision of authoritative medical explanations for disfigurements. Members of the Bengali community were particularly keen to express their suggestions for interventions to improve the experiences of those with visible differences. They identified the need to dispel myths about fetal disorders, and suggested that women's groups could be useful platforms for educating the community. They also felt that community-specific health sessions should be arranged to raise awareness, and that local government agencies could become more involved in this.

Limitations of the study

Focus groups are an invaluable research method for working in a diverse linguistic and cultural environment, and can provide rich data (Culley *et al*, 2007). We have highlighted community responses to disfigurement, and how people collectively construct meanings which may have been more difficult to discern via individual interviews (Waterton and Wynne, 1999). However, the use of focus groups has limitations and methodological implications, such as the possibility of group effects (Carey and Smith, 1994). We were also keen to collaborate with our facilitators when designing the study, in order to facilitate research *with* as opposed to research *on* minority ethnic communities (Johnson, 2006). The facilitators were given the freedom to interpret the topic guide to suit their focus group characteristics, and some of them made detailed notes throughout the group session as opposed to recording the discussion and transcribing it verbatim, although all of them had, and used, tape recorders to provide them with an aide-memoire of the discussion. This may be seen as a lack of rigour, but this approach was advised by the facilitators as they regarded it as a culturally sensitive approach in view of the characteristics of their focus group participants. Since all of the discussions were at least partly conducted in languages other than English, and language switching was common, we had to rely on the skill and interpretation of these bilingual colleagues to understand the data. Equally, it was proposed that this enabled the facilitators to contextualise the data and to provide a richer insight into the groups' response to what might be regarded as a contentious topic of discussion. Finally, there are variations in the belief systems of South Asian communities that place different emphases on the role of fate and retribution ascribed to their preferred deity. It was not possible to explore these more subtle aspects of the participating communities to inform the intervention strategies indicated.

Conclusion

This study offers a unique insight into the views held by South Asian communities in the UK in relation to how disfigurement and beauty are perceived, and it adds to the growing body of literature on disfigurement and the psychology of appearance. The findings suggest that there is a change in the orientation of younger members of the community from traditional religiously framed perceptions of acceptable appearance, to advocating a more informed and aware attitude to the causes and consequences of disfigurement. Evidence of generational differences in South Asian community views appears to emerge from westernisation and the influence of the media. The findings provide a basis from which to develop educational interventions to highlight the support services available, and also to dispel myths which may pose barriers to communities accepting and supporting individuals with a disfigurement.

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CONFLICTS OF INTEREST

None.

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