ABSTRACT

Involuntary childlessness can be a devastating experience for many women and men. The true prevalence of infertility is difficult to determine. However, an estimated one in seven couples in the UK will seek help in conceiving a child at some point in their lives. New reproductive technologies have dramatically changed the prospects for many sub-fertile couples, with the range of treatments increasing substantially in the past 20 years. Little is known, however, about ethnic differences in attitudes to fertility treatment. This paper discusses some findings from the first major study of ethnicity and infertility to be carried out in the UK, which explored the experience of infertility in British South Asian communities. The emphasis in this article is on community understandings of fertility and infertility and its causes; knowledge of and attitudes towards medical treatments for infertility; and ‘alternative’ sources of help for sub-fertile couples. In contrast to a ‘deficit’ model of the public understanding of science/technology, the data demonstrate the existence of a range of knowledges about potential causes of infertility and about treatments available to help sub-fertile couples. A case is made for raising the profile of infertility treatment within South Asian communities. At the same time, health professionals would benefit from an awareness of the broader social context of reproductive technologies. Public space needs to be created for the development of a relationship of dialogue between practitioners of the technologies and members of the lay public in a diverse range of sociocultural settings.

Keywords: ethnicity, infertility, lay understandings, reproductive technology
Introduction

This paper discusses some findings from the first major study of ethnicity and infertility to be carried out in the UK, which explored the experience of infertility in British South Asian communities (Culley et al., 2004). This NHS-funded project aimed to contribute to the development of improved policy and service provision to minority ethnic communities by investigating the social context of infertility, factors which might impact on access to infertility services at primary and secondary care levels, and the quality of service provision to minority communities.

From the perspective of access to care, lay understandings of infertility, why it arises and how it might be overcome, may have an impact on treatment-seeking behaviour. In addition, accurate, easily understood information is essential for informed choices and optimal decision making about reproductive options. This is best provided from a perspective that acknowledges existing means of understanding. An awareness of the socio-cultural positioning of clients may also assist health and social care professionals to provide culturally competent care (Culley, 2001). The project was thus concerned to map the potential impact of cultural and religious contexts on attitudes to childlessness and levels of awareness and attitudes towards infertility treatment. This paper focuses on aspects of the first phase of the project, which consisted of an exploration of the social meanings of childlessness in a sample of people of South Asian origin (Indian, Pakistani and Bangladeshi) in three English cities. The emphasis is on community understandings of infertility and its causes; community members’ knowledge of and attitudes towards medical treatments for infertility; and alternative sources of help for sub-fertile couples. It is intended that this research should not only add to the literature on a previously unresearched topic, but also provide contextual information for those providing services to minority ethnic communities.

Background

The true prevalence of infertility is difficult to determine. Studies suggest that infertility affects an estimated 9–14% of women of childbearing age in the UK, and that up to one in seven couples will seek help in conceiving a child at some point in their lives (Human Fertilisation and Embryology Authority (HFEA), 2006a). An extensive collection of studies shows that involuntary childlessness can be a devastating experience for many, with significant consequences for social and psychological well-being, for women in particular (Letherby, 1999; Monach, 1993; Pfeffer and Woolett, 1983; Souter et al., 1998; Whiteford and Gonzalez, 1994). The development of new reproductive technologies (NRT) such as in vitro fertilisation (IVF) has meant that many couples can be helped to achieve a pregnancy, although it is important to consider that for all fertility treatments, there is a less than 50% chance of successful conception (van den Akker, 2002). Notwithstanding this, new technologies have dramatically changed the prospects for many sub-fertile couples with the range of treatments increasing substantially in the past 20 years (National Institute for Clinical Excellence (NICE), 2004). The demand for fertility treatment in the UK has increased considerably, and there has been a significant increase in the uptake of medical services, both at general practitioner (GP) and at hospital level (Templeton, 2000). A major constraint, however, is the rationing of infertility treatment in the NHS and the postcode lottery of service provision. Despite the recommendations of NICE that three full cycles of IVF/intracytoplasmic sperm injection (ICSI) should be made available on the NHS, wide variations in treatment eligibility criteria and persistently high waiting lists still exist, and there is evidence that some primary care trusts (PCTs) are intending to reduce provision (Kennedy et al., 2006). This situation is clearly highly problematic for most couples, but will impact particularly on those from disadvantaged communities.

There are no data on ethnic differences in infertility per se, largely because of the inadequacies of ethnic monitoring in the NHS and in the independent sector, where much fertility treatment takes place. Population-based studies suggest that a substantial proportion of those experiencing infertility do not access services for help with their problem (Bucket and Bentick, 1997). We know from many studies that access to healthcare can be particularly problematic for some members of minority ethnic communities (Acheson, 1998), and the NHS-funded study on which this paper is based was designed specifically to explore the provision of infertility services to British South Asian communities (Culley et al., 2004). According to the 2001 UK Census, over 2.3 million people in the UK described their ethnic origin as Indian, Pakistani, Bangladeshi or Other Asian, and since these populations have a younger age structure, a significant percentage are of childbearing age. Extrapolations from the Census suggest that approximately 136 000 people who gave their ethnicity as Asian or Asian British may have fertility problems (HFEA, 2006b).

Most studies of infertility concentrate on the experiences of the affected couple. In a relatively rare study of public attitudes carried out in Canada, Miall (1994) interviewed a random sample of 150 respondents although their ethnicity was not reported. She found that a majority supported the idea that motherhood, but not fatherhood, is biologically based, and a substantial minority linked infertility to stress, coping or other psychological malfunctioning in women or
sexual malfunctioning in men. She concluded that, in contrast to the observation that social support may have a positive impact on health, the social constructs held by others may have a negative influence on their capacity to act as a source of social support for childless couples.

Many studies have identified a hegemonic pro-natalist discourse in contemporary societies, and this is seen as an important component of the stigma that is attached to childlessness and infertility (Pfeffer and Woolett, 1983). Similarly, in part because of these norms and beliefs, women with fertility problems are willing to undergo stressful, painful, expensive, and inconvenient procedures that often are unsuccessful, in order to attempt to bear a child (Stanton et al, 2002).

Those writing in the field of science and technology studies have been keen to identify the ways in which local knowledge enables, encourages or restrains people in engaging with scientific developments. Questioning the assumption that the present climate of public scepticism about science is based on a lack of understanding or knowledge, several authors argue that there are a number of additional important influences on attitudes to science and technology, among them culture, gender, risk perception, political values, religion and worldviews (Sturgis and Allum, 2004). There is an insistence on the importance of conceiving of a plurality of ‘publics’ (Wynne 1992a, b) and a need to identify the local contexts of public engagement with science and technology, including new reproductive technologies and the new genetics.

However, despite this encouragement to identify the local contexts of public engagement with science and technology (Sturgis and Allum, 2004; Wynne 1992a, b), there has been a distinct lack of research in this area, particularly with traditionally hard-to-reach communities. Surveys of public understandings of infertility in the UK are rare, and have largely ignored potential differences between ethnic groups (YouGov, 2006). Research studies in the infertility field usually focus on treatment seekers, and often samples are drawn from white, middle-class groups (Griel, 1997). At the same time, while inequalities in health between and within ethnic groups have become an increasing focus of research in the UK (Johnson, 2006; Nazroo, 1997), studies of reproduction have tended to concentrate on childbirth and contraception rather than infertility (Katbamna, 2000).

Methods

The research took place between 2002 and 2004. Ethical approval was obtained from a university Human Research Ethics Committee and NHS Local Research Ethics Committees. The aim of the phase reported here was to explore the social meanings of infertility amongst British South Asian communities. While it was recognised that a properly representative sample of all South Asian communities would be impossible to access, attempts were made to include people from diverse South Asian linguistic, religious and national-origin communities: Indian (Gujarati-speaking Hindu and Punjabi-speaking Sikh), Bangladeshi (Bengali-speaking Muslim) and Pakistani (Urdu-speaking Muslim). It is important to note the diversity of ethnicities within the category South Asian and the specificity of local communities (Ballard, 1994), both of which may limit the application of the conclusions (Payne and Williams, 2005).

Data collection was conducted in three cities in the Midlands region of the UK. Fourteen single-sex focus groups were carried out with South Asian community members (n = 93). Participants in the focus groups were invited to take part according to their ethnic and religious identities, gender and age rather than their own fertility histories. Recruitment to the focus groups was time consuming and raised many challenges for the research team (Culley et al, 2007). Key members of the communities concerned graciously acted as mediators on our behalf, publicising the project and organising times, dates and venues for the group discussions.

In order to maximise participation, including hard-to-reach groups, and to enhance cultural and linguistic sensitivity, the research team recruited a group of female and male bilingual South Asian facilitators to work with the core team. They assisted in designing research tools, carrying out focus groups and interviews, and data analysis. Semi-structured topic guides for the focus groups were developed by the research team in consultation with a research advisory group, and were subsequently translated by the bilingual facilitators for their own use. Topics for discussion included the importance of children, causes of infertility, perceptions of childless couples and knowledge of and attitudes to infertility treatment.

Ten focus groups were conducted with women (n = 67) and four with men (n = 26). Thirty-five percent of participants were aged 16–34 years, 31% were aged 35–49 years and 34% were aged over 60 years. Forty-six participants gave their ethnicity as Indian, 18 as Bangladeshi and 29 as Pakistani. The Pakistani and Bangladeshi groups were predominantly Muslim, and the Indian groups gave their religion as Hindu (n = 19) or Sikh (n = 25). The focus groups were carried out in the preferred languages of the groups (English, Bengali, Urdu, Punjabi or Gujarati). The discussions were tape-recorded and fully transcribed.

Data were analysed using a process of open and axial thematic coding (Strauss and Corbin, 1990). Codes were initially derived by two researchers on an independent basis, who then agreed a final set of codes. A group session with nine team members,
including the bilingual facilitators, was then held where the themes from the analysis were discussed before the final analysis was completed. Some of the specific methodological challenges involved in this phase of the study are discussed elsewhere (Culley et al., 2007).

Results

The overall findings from our study of the provision of infertility services to British South Asian communities and major recommendations for service providers are discussed elsewhere (Culley et al., 2006). In what follows, we discuss some of the key findings relating to understandings of infertility; knowledge of and attitudes towards seeking help for fertility problems; and perspectives on ‘alternative’ sources of help for infertile couples.

Attitudes to fertility

In order to understand attitudes to infertility, it may be helpful to set this in context by beginning with a brief exploration of attitudes to fertility and the importance of children within British South Asian communities. The findings of our project confirm the hitherto largely anecdotal view that South Asian communities are strongly pro-natalist. In South Asian communities, children are highly desired; parenthood is culturally mandatory and childlessness socially unacceptable. Social, cultural, economic and religious reasons were given for the importance of children (Culley and Hudson, 2006), and children are seen as essential for normal adult existence. Childlessness is highly visible and infertility is a heavily stigmatised condition, especially, but not exclusively, for women. As one participant commented:

’If women can’t have children, then they don’t have life. Children are life – they are the future.’ (older Pakistani Muslim female)

While several studies of white women show a motherhood mandate, others argue that increasingly some women are challenging this norm and either substantially delaying childbearing or deciding not to have children at all (Gillespie, 1999). This is much less common in the communities included in our study. In South Asian communities, marriage is almost universal and highly valued; parenthood is the natural consequence of marriage.

Although overall South Asian cultures are strongly pro-natalist, the focus groups demonstrated that there are variations in the experiences of individuals, reflecting differences in cultural, religious, economic and migration histories and educational attainment. The intensity of the pressure to reproduce was seen to vary somewhat by community, and by social class. Key informants suggested that the more educated and less traditional sections of all communities allowed young people more choice over when to have a child. However, while a delay in childbearing was increasingly seen as acceptable in some communities, particularly for young people who were in higher education or attempting to establish themselves in a career, nevertheless, it was still felt by many participants that if a child had not been produced within a relatively short time after marriage, questions would start to be asked of the couple concerned. This was more common in the Bangladeshi and Pakistani communities, with most participants reporting that pregnancy was expected to occur within the first year of marriage. This norm of early childbearing is evident in data on family structure. Women of Indian origin are similar to white women in the age at which they have children and in the total number of children in their families. Women of Pakistani and Bangladeshi origin start families earlier, complete them later and have more children than is now typical in Britain (Modood et al., 1997).

Understandings of infertility

Participants articulated different systems of understanding and a range of beliefs about who might be affected by infertility and its causes. In almost all groups, but especially in the female groups, participants described their own knowledge of infertility and how they knew, for example, that men as well as women could be defined as medically infertile. Both male and female groups made the point quite forcefully that women would be regarded as being responsible for infertility, although paradoxically many participants reported that they themselves were well aware that male factor infertility existed:

’In my family, my daughter is all right but the fault is with my son-in-law. The doctors have told them about it and now they know the real reason.’ (older Pakistani Muslim female)

However, there was also the suggestion in many of the groups that this may not be known by the wider community, particularly among the older generation.

Although many did not escape the stigma of childlessness, there was a widespread view amongst both women and men that women would be expected to take the blame for infertility so as not to expose male problems. The problem of infertility is thus consistently located with the female partner, thus reinforcing childlessness as an inherently female concern. It is possible to suggest, therefore, that rather than a lack of awareness of male factor infertility, there seemed to be a collective collusion with the public concealment or
misrecognition of a reality that was widely known privately. This was despite the fact that all of the groups, including the male groups, expressed the iniquitous and problematic consequences of always blaming the women.

The negative reaction of a childless woman’s in-laws, in particular, was an issue that came up in all the groups and was one of the consequences for women which was most strongly and frequently expressed by the participants:

‘Also the in-laws and relatives criticise, back-bite and swear at the daughter-in-law. They think because of her they can’t have grand kids. Women get really hard time especially from her husband’s family members.’ (young Bangladeshi Muslim male)

The extent of the stigmatisation of infertility, its gendered context and the attempts of younger women especially to resist this stigma are discussed in Culley and Hudson (2006).

When asked about causes of infertility, participants described various reasons why infertility may occur, including religious, cultural, behavioural or biological causes. Two younger focus group members in one discussion mentioned sexually transmitted diseases, stress and obesity as having effects on fertility. Weight as a causal factor was also mentioned in two other groups. Iatrogenic causes of infertility were also mentioned: several participants, in various groups, felt that prolonged use of the contraceptive pill would affect the ability of a couple to conceive when its use was discontinued:

‘I heard that after marriage if a woman starts taking contraceptive pills. These are harmful. They should stop it. So many women got affected by these pills. Pills are harmful. They think by taking pills they won’t have children for a while and will have a good time and will enjoy married life. On other hand these pills are harmful.’ (older Pakistani Muslim female)

In many of the groups with the older participants and in the Muslim groups especially, individuals referred to a religious understanding of fertility and conception. Whether a couple had a child, the number of children a couple might have and the sex of children were seen as determined by God. Seeing the hand of God in the process, however, did not mean that professional help should not be sought:

‘Yes of course people do go for treatment and do get a result, but to have a result the main giver is Allah. Some do gain going from treatment and some don’t, sometimes going for treatment the medicine will cure me and sometimes it won’t, there is no guarantee for that but if Allah doesn’t cure me then it can’t happen; the treatment can’t cure me.’ (older Bangladeshi Muslim female)

It was clear, especially in the groups with the Muslim participants and with the older groups, that religion had an important role to play in informing the way in which childlessness is viewed in South Asian communities. However, very few respondents in this study thought that infertility was a form of retribution for wrongdoing, although the older Sikh men felt that it could be that people were reaping the consequences of things they had done in a past life. Supernatural causes for infertility were mentioned in two groups. In one, a woman of Bangladeshi origin suggested that ‘evil spirits’ had caused her to have a miscarriage.

Data from both the focus groups and key informants suggest that while there are a variety of interpretations of what causes infertility, infertility is seen by most community members as an object of potential medical investigation and treatment.

Seeking help for infertility: community knowledge of and attitudes towards assisted conception

Participants were asked if they were aware of any medical treatments available for infertility, and the social and religious acceptability of these was discussed. Most participants felt that couples who were experiencing difficulty conceiving would ultimately seek medical help. However, few participants had given much thought to what that help might entail. As is the case in all communities, those who are not affected by a condition are less likely to have detailed information about its causes and treatments.

Several respondents suggested that some people might not wish to seek help because of problems with their GP. Many had a low opinion of their GP, and several expressed doubts about the confidentiality of consultations with Asian GPs in particular. Others argued that if the woman did not speak English she might be very reluctant to use an interpreter and might not be able to take a family member along if she did not want them to know about her fertility problems.

‘Because of language barrier they can’t discuss problem with GP and they are embarrassed to take an interpreter.’ (older Bangladeshi Muslim male)

In terms of the technology available to overcome infertility, IVF or ‘test tube baby’ was the treatment most commonly referred to amongst participants, perhaps in part as a result of media coverage of this particular technology, although some did report knowing couples who had used IVF:

‘I know about one of them, where they keep egg somewhere ...’

‘Test tube baby.’

‘Yes! They take it out with syringes and put it in there, yes! I think it’s called the test tube baby.’ (young Indian Sikh female)
The majority of participants felt that IVF would be considered an acceptable treatment, providing the resultant child was biologically related to the couple. The use of donated gametes, however, was universally regarded as socially unacceptable. It was felt that using donor gametes would be a last resort for childless couples and that if they were ‘desperate’ enough to take this option, then they would most certainly not disclose this to others.

Again, in considering treatment options, religion was introduced into the discussions by the participants as a lens through which to view certain aspects of infertility treatment. Religious objections to the use of donated sperm were most strongly expressed by the Muslim groups, though others also mentioned religion in this context:

‘It doesn’t matter if it’s a man or a woman it’s not allowed. Say for instance I go and get pregnant, mixing with a different male, in different ways, having their sperm that is haram, that is sinful in our Islam and in the eyes of the community.’ (older Bangladeshi Muslim female)

Egg donation appeared to be marginally more acceptable, perhaps due to the continued connection of the child with the ‘male line’ and perhaps due to the non-sexual connotations of this form of treatment (Haimes, 1993).

It was clear from the discussions that IVF treatment had become socially acknowledged as a procedure in overcoming infertility. This was happening in different ways in different communities, with some groups stressing the co-existence of solutions located in both medicine and religion. However, there were clear conditions about the use of IVF within marital relationships and only using the gametes of the married couple. Discussions about community perceptions of medical treatments were interspersed with discussions of alternative strategies.

Alternatives to orthodox medical treatments

Many participants suggested that women in particular might also seek advice about their fertility problems, or seek answers to fertility questions from religious sources and that some would use alternative therapies or specific foods thought to improve fertility. However, the majority felt that this would be complementary to medical assistance rather than an alternative. Seeking help from religious sources was mentioned by a large number of respondents and was linked to the fact that for some participants, infertility was seen as amenable to religious intervention. Older members in particular felt that this was an important and valid source of help. Younger members were more likely to stress the importance of medical help to assist fertility, though they did not deny that religion could play a part. Participants said that women would go to see holy men, Mawlanas (Islamic religious representatives, who have studied the Koran) and other religious people who would suggest special prayers, fasts and pilgrimages or offer amulets to increase fertility.

Many participants in all focus groups saw prayer and religious rituals as important in overcoming infertility, alongside medical treatments in most cases. Young and old, male and female participants felt that prayer, fasts and pilgrimages could have a positive impact.

Discussion

As Miall (1994) has argued, the way in which childlessness and infertility are socially constructed and publicly understood is likely to have relevance for the experience of perceived and enacted stigma. This in turn may have consequences for treatment-seeking behaviour. As this study highlights and as is reinforced by the literature, infertility is a stigmatising condition in British South Asian communities, and women bear the burden of infertility, as they do the world over (Inhorn and Van Balen, 2002; Reissman, 2000; Remennick, 2000; ). The effects of this stigmatising process may also extend to the treatment of infertility, and this may mean that couples are very concerned not to disclose the fact that they are undergoing treatment.

In contrast to a deficit model of the public understanding of science/technology, the data demonstrate the existence of a range of knowledges about potential causes of infertility and about treatments available to help sub-fertile couples. In the younger age groups in some communities, participants suggested behavioural and physical causes for infertility, including stress, obesity and sexually transmitted diseases. Older people were more likely to mention religious or iatrogenic causes, especially the contraceptive pill. Whatever the perceived cause of childlessness, it was nevertheless clear that most people saw infertility as an object of potential medical treatment, and most felt that young couples would approach their GP with this problem. However, the general level of dissatisfaction with GP services that many participants expressed reflects a growing body of work which suggests that the primary care agenda has been slow to provide accessible care, appropriate to the needs of minority ethnic populations (Atkin, 2004).

Although many people gave examples of non-medical sources of help, such as eating particular foods and herbal preparations, it was felt that most people would use these as complementary to medical help rather than as an alternative, and indeed this was borne out in subsequent interviews with those undergoing fertility treatment that were conducted in the
second phase of this study. The use of alternative medicine in minority ethnic communities is often exaggerated. A recent survey reported that most minority ethnic groups were less likely than the general population to have ever used a list of complementary or alternative therapies. Although Ayurvedic medicine was much more prevalent among Indian women and men than among the general population, only 7% of Indian women had ever used this (Sproston and Mindell, 2006).

Religion was an important factor in framing infertility and seen as important for coping with this problem. Special prayers, fasts, pilgrimages and other religious rituals were commonly reported as processes that could potentially promote fertility, and most participants felt that these would be commonly used by many community members who found themselves experiencing problems. Faith and spirituality more generally are increasingly recognised as important in understandings of illness, in support and coping and in clinical care (Kelleher and Hiller, 1996; Koenig et al., 2001). Religion was an important factor in community attitudes to infertility treatment, particularly amongst the Muslim participants. While IVF per se was regarded as permissible in Islam, the use of third-party gametes was reported as haram (forbidden). It is important to note, however, that there may well be some cultural variability in this position (Inhorn, 2006) and that religion as lived experience may vary from official religious teachings.

What is clear from this research is that the ways in which infertility and its treatment are perceived more broadly within social contexts will have implications for childless couples. Whether treatments are perceived as socially and morally acceptable will have implications for whether couples access treatment in the first instance, whether they disclose the nature of their treatment seeking, and if they do, what the reaction from others will be. This is not purely a concern for South Asian communities. There is a paucity of research generally about perceptions of infertility treatment. This subject has only recently begun to be addressed through research (for example, see YouGov (2006)), media campaigns to address these issues more broadly and debates about the implications of NRTs (for example, see the recent BBC series A Child Against All Odds presented by Robert Winston (www.bbc.co.uk/childagainstandodds)).

Most participants were keen to know more about infertility and assisted conception treatments and there is a case for more active social marketing of infertility services (French and Blair-Stevens, 2006). The current lack of public space within South Asian communities to discuss the implications of NRTs means that British South Asian women and men may have additional needs for social and emotional support from health professionals. The regulatory body, the HFEA, and infertility support groups should consider engaging with key opinion formers and other partners in minority ethnic communities, to increase awareness of infertility and treatment options. There is also a need to provide information in languages other than English (Calley et al., 2006). While there is a considerable medical literature on infertility available in clinics and on the internet, during the course of the project the team were unable to find any materials on infertility translated into any Asian language. As a result of this study the team have produced a basic information resource, Trying For A Baby, in English, Punjabi, Gujarati, Bengali and Urdu, available in booklet and audio format (www.raceforhealth.org/news_detail.php?id=64).

Conceptualising infertility as a social construct as well as a medical condition means that we must take into account how societies or communities perceive childlessness. As Miall (1994) argues, the ideas that people hold about infertility will influence how they behave towards those perceived as infertile. Community attitudes will also affect how childless couples see themselves (Miall, 1994). We cannot ignore how others perceive us, even if we do not agree with those perceptions (Goffman, 1963). Wasser et al. (1993) argue that social factors are an important component of the distress associated with infertility. In addition, reproductive health decisions are decisions that couples invariably take together rather than individually, and in some contexts decision making may extend to the wider family and community, raising issues about power in intimate relationships, gender roles, and women’s ability to negotiate outcomes with their partners and families (Beckman and Harvey, 2005). For culturally appropriate provision, therefore, health professionals and counsellors working with South Asian clients should have educational opportunities to explore ethnic diversity and consider the potential influence of the social context on understandings of infertility and on possible barriers to accessing fertility treatment. A short resource for health professionals working with South Asian clients was a further output from the project.

Conclusion

The findings of the research project from which this paper derives, and the argument proposed here, enhance the case for raising the profile of infertility treatment within South Asian communities. However, there is also a need for health professionals to be aware of the social context of access to reproductive technologies. As such, learning about reproductive health must involve not only the communities in question, but also the health professionals providing care. A social marketing approach may help to inform
REFERENCES


CONFLICTS OF INTEREST
None.

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