Debate paper

Infertility issues for South Asian women

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ABSTRACT

This article presents a discussion of some of the social, medical and psychological issues surrounding infertility for women who come from a South Asian background. Fertility is an important but often stressful subject. There is pressure to conceive, and those who fail to do so can face isolation and stigmatisation. Embarrassment is a reoccurring theme for women who are infertile and it is also a barrier to seeking treatment. Treatment is currently a postcode lottery although implementation of the NICE (2004) guidelines should mean that every woman has the same opportunity. Nevertheless there is a stigma attached to infertility treatment, and some South Asian couples use assisted conception secretly. Those women who do not speak English are at further disadvantage in that there is little translated written information. Sometimes there is also a reluctance, on the part of professionals, to offer appropriate counselling. Infertility treatments and options are ethically and practically complex, and understanding is essential. Even when fertility treatment is successful, the stress of what is often considered a high-risk pregnancy can create more problems for the couple concerned. The paper closes with a consideration of the implications of these factors for practitioners.

Keywords: counselling, embarrassment, empowerment, fertility, infertility, stigma, stress, support

Introduction

Infertility has been described as 'the diminished or absent ability to conceive or produce an offspring' (World Health Organization (WHO), 2006). The statistics for infertility vary greatly from country to country and are only an estimate due to the sensitive nature of the condition, but Vayena et al (2002) suggest that, worldwide, it is approximately 13-24%. In Britain it is estimated that approximately one in seven couples has difficulty conceiving (National Institute for Clinical Excellence (NICE), 2004). This difficulty is usually defined as taking longer than one year to conceive. In South Asia, about 4-10% of couples are affected by infertility, which appears to be a conservative figure suggesting those seeking treatment rather than those unable to conceive (WHO, 1980).

Infertility treatment is sometimes placed at the back of the health agenda and seen as a luxury; issues like reducing high maternal and child morbidity and mortality rates, or basic education are seen as more pressing. However, infertility, besides being a cause of great personal distress, can also have serious social consequences. In some societies, tremendous importance is placed on producing a child, and the failure to do so can result in stigma, ostracism and sometimes even being cast out of the family (Butler, 2003). It is usually considered to be the woman's 'fault' when there are fertility problems, the underlying assumption being that the woman has done something 'bad' to deserve divine retribution in the form of infertility (Papreen et al, 2000). Some women struggling to conceive will go on to use assisted reproductive technologies (ART) in order to have a chance of delivering a baby. These technologies are not without risks, stress or ethical considerations, and by no means guarantee a baby at the end. They also often carry a significant financial cost, which can put them out of reach of the economically disadvantaged. This paper examines the issues facing women from Pakistan, India and Bangladesh with regard to the importance of fertility, what effect infertility might have on their lives, and the social context in which infertility presents.

Fertility and social context

While there are differences between South Asian cultures and communities, they are all firmly pronatal and patriarchal in nature. Great significance is placed on marriage, with arranged marriages being the norm for most people, regardless of social, mental or health status. Marriage and parenthood confer status and recognition for men as well as women. When a woman becomes a wife, she is accorded a higher status than a single woman, but when she becomes a mother her status then has prestige and security. This might, however, be the case only when she produces sons. Widge (2005) argues that Indian women's identity comes from motherhood, and suggests that childless women are at risk of cruelty, rejection and divorce. Pressure can come, if not from the husband, from the family or wider community. This reaction, however, is less likely for those South Asians who have immigrated to Western countries (Culley et al, 2004). Nevertheless, insecurity in marriage is still a possibility if there is infertility.

Religious significance of fertility

Children, and sons in particular, have religious significance. For Hindus, the need to have a son or, failing that, a grandson, partly comes from the tradition of needing a son to perform the last religious rites at the death of the father: an important symbol of rebirth. In many conservative Muslim communities, women do not work outside the home, and child rearing is what gives purpose and meaning to life. The Qu'ran suggests that motherhood also fulfils women's religious duty (Schleifer, 1996). A child is considered a blessing, doubly so if it is a boy. Religious significance is linked to land and property tenure. Daughters often take a dowry from their birth family and become part of their husbands' families. Consequently, the birth of sons means that land, property and possessions can then stay within the family and thus provide a means of supporting parents in their old age. In this context, children, and particularly sons, are of vital importance to the survival and continuance of the family.

The system of arranged marriages imposes a duty on families to ensure that a virginal bride is delivered to the future son-in-law; he, however, is not expected to be a virgin at their wedding. It is hoped that a pregnancy will soon follow the marriage, as that is seen as sealing the union and proving that the couple are healthy. The average age of marriage is less than in the West, although this trend is declining particularly among middle-class professionals, as a good education becomes more significant (Alesna-Llanto and Raymundo, 2005).

Women are taught that sexual intercourse is a duty, and fear of this abounds according to Fisher *et al* (2003), probably because there is little or no sexual education in preparation for either the wedding or childbirth. This means that contraception may not be used until after the birth of the first child. It also means that some marriages are unconsummated – a factor that accounts for a small but steady proportion of people seeking fertility treatment (Fisher *et al*, 2003). These seem to be mainly middle class professional women who arguably have more autonomy than their less educated sisters. This suggests that economic empowerment alone is not enough to liberate from sexual fear.

Causes of infertility

There are many causes of infertility. The biggest reason for infertility, though, is unknown. For 30% of presenting couples there simply is no explanation even after all the tests (Culley *et al*, 2004). There is a high incidence of polycystic ovary syndrome among South Asian women, compounded by an earlier onset and more severe symptoms than in other groups (Wijeyaratne *et al*, 2002). This may be genetic but it could be that South Asian women are diagnosed at an earlier age because they often want to start their families earlier than others.

Other causes of infertility in women include fallopian tube damage, ovulatory disorders and endometriosis, but men account for nearly half of the causes of infertility in couples. In spite of this, Bharadwaj (2003) suggests that it is often the woman who takes responsibility for the lack of a pregnancy, while Nene *et al* (2005) assert that women cover for their sexually dysfunctional husbands in order to uphold the men's 'honour'.

In developing countries, Butler (2003) suggests the cause of infertility is often reproductive tract damage as a result of sexually transmitted infections (STIs), notably gonorrhoea and chlamydia. However, in Britain the incidence of both of these conditions is rising fast although it could be that there is just better reporting (Shahmanesh *et al*, 2000). Where men are expected to get sexual experience prior to marriage from prostitutes, widows or deserted wives, there is an increased risk of infection. This could result in an increase over the next few years in the number of people seeking fertility treatment with the resultant increased demand for ART.

Stress and fertility

Stress is generally believed to reduce fertility (Csemiczky et al, 2000), although Anderheim et al (2005) dispute this. They attempted to 'measure' stress levels during ART treatment and showed that being particularly stressed made no difference to the pregnancy rate. The study did not, however, measure effects of stress on fertility rates before ART. Nevertheless, infertility treatments are particularly stressful (Hjelmstedt et al, 2003). For some couples, the stress of infertility brings them closer, while for others it brings more conflict (Markestad and Montgomory, 1998). With the social pressure to conceive, South Asian couples have many expectations placed on them. For some, reproductive failure can lead to sexual dysfunction, for example impotence. Nene et al (2005) also suggest that the longer a couple has been trying to conceive, the less sexual intercourse they have and the higher the stress levels. For many South Asian couples trying to conceive there is a sense of having sexual intercourse simply to achieve a pregnancy, although this could be the case for all those undergoing fertility treatment.

Options for infertile couples

There are various options for the infertile couple, but all are surrounded by anxiety and are not ideal. Adoption is not an option for the majority of South Asian couples. It is very much seen as a last resort, making a private agony into a public acknowledgement of failure (Bharadwaj, 2003). Some will consider it if the child comes from within the family, so that at least there would be blood ties. Unknown genetics appear to be particularly problematic for South Asians. Adoption is also not encouraged within Islam. The child retains its father's surname but can be looked after by long-term foster parents. Hindus on the other hand are legally allowed to adopt, although Bharadwaj (2003) takes the view that, culturally, it is still not desirable.

Gamete donation, either sperm or egg, is also frowned upon in both religious and cultural terms throughout South Asia, although donor insemination appears to cause a stronger negative reaction (Bharadwaj, 2003). Nene *et al* (2005) suggest that when gamete donation can be done with absolute secrecy, and all other fertility treatments have failed, then it might be an option. However, in Britain there is an acute shortage of oocytes from Asian donors, which reduces the options for women who cannot ovulate. Mixed ethnicity is a possibility, but raises more ethical dilemmas (Culley *et al*, 2004). Widge (2005) suggests that when gamete donation has achieved a pregnancy, secrecy continues and that the child is not informed of its genetic make-up, although this is often also the case with non-Asian couples (Cramond, 1998). Confidentiality concerning fertility treatments is of paramount importance because of the fear of repercussions on themselves and their child, should the child not be seen to be the biological offspring of the parents. Where ART has used the gametes of the parents, for example in *in vitro* fertilisation (IVF), gamete intrafallopian transfer (GIFT) and intracytoplasmic sperm injection (ICSI), then it is more acceptable.

Sex selection issues

There is also the ethical issue of sex selection, which appears to often run side by side with fertility procedures. In Britain, sex selection is illegal, but in some other countries, private medicine is free to respond to demands for this. It has been suggested that in India, the higher male to female ratio reflects the importance of sons to families and the consequent practice of female infanticide in utero (Retherford and Roy, 2003). The statistics also show that girls in India or Pakistan have a 30-50% higher risk of dying under the age of five years than boys (Filmer et al, 1998) in spite of the fact that in Westernised countries, boys have a higher risk of death in the same time period (WHO, 2003). A variety of explanations is put forward to explain the high mortality of girls, including neglect, inadequate nutrition, less likelihood of having been immunised or taken for medical advice if ill (Fikree and Pasha, 2004).

Infertility treatment

It has been suggested that one couple in six will seek fertility treatment (Gunnel and Ewings, 1994). The NICE (2004) national guidelines on infertility treatments provide information and set out the options, but these are far from straightforward. Even once the figures about the likelihood of success have been explained, couples usually have high expectations of what ART can achieve (Widge, 2005). There is a huge disparity between different centres concerning fertility rates and waiting lists (Human Fertitlisation and Embryology Authority (HFEA), 2005/2006). Some regions also currently offer different services or have different financial arrangements for treatments within the NHS, although the NICE guidelines should ensure that everyone has the same access to treatment regardless of where they live. However, NICE guidelines are not legal requirements. Some health authorities are taking longer to implement the recommended one

cycle of IVF by 2005 and three cycles of IVF by 2006 for couples that meet the NHS infertility criteria. Consequently, many couples resort to private medicine in order to get the treatment they want, when they want it, but this is only an option for those couples that can afford it. Butler (2003) suggests that resources be put into developing low-cost reproductive technologies so that fertility treatment is more accessible, particularly in developing countries.

Women traditionally seek advice and help from family members regarding problems. Infertility stigmatises women and can, therefore, isolate them from their normal sources of support, leading them to consult a very wide spectrum of alternatives such as traditional healers, religious leaders, alternative therapies, healthcare providers and/or infertility specialists. Culley et al (2004), in a British study, suggested that 15% of South Asian couples used alternative therapies for infertility, although most of these were used alongside conventional medicine. It would appear that this figure could be much higher, particularly if the couple do not wish, for ethical, personal, religious or financial reasons, to access expensive and intrusive treatments like IVF. However due to the shame and secrecy surrounding infertility, women are vulnerable to unscrupulous people:

Often the infertile couple is especially vulnerable to chicanery by both traditional and conventional health care providers. (WHO 2001, p. 384)

Many people have got into debt for procedures that have either not been necessary or done badly, or have been taken advantage of with 'miracle cures' that are at best pointless (Widge, 2005).

Infertility and embarrassment

Embarrassment is a reoccurring theme for many infertile women from South Asia. Those who have immigrated to Western countries discuss embarrassment as being a big obstacle for newly arrived women obtaining treatment (Baraitser, 1999). Women are traditionally not used to talking about personal issues or sexuality, although this does not seem to be the same for second-generation South Asians (Gigi Durham, 2004). Embarrassment could stem from various causes: lack of sexual knowledge, fear of not understanding the technical terminology, or general language difficulties and being made to look stupid. Many women who cannot conceive feel inferior and worthless, and language barriers can increase this anxiety. If the general practitioner (GP) is male then there may be further obstacles to talking about trying for a baby, for modesty reasons (Katbamna, 2000). In some cases it will then be the husband who acts as the go-between, arguably further disempowering the woman. This is more of an issue for Pakistani and Bangladeshi women, as Indian women are more likely to have a female GP (Katbamna, 2000) possibly because they are more likely to be better off financially than other South Asians and so live in areas where there is a choice. Poor GP support, referral and information may be more of an issue for poorer women who live in deprived innercity areas and who are less likely to know their rights or pursue them (Atkin, 2004).

Empowerment

Empowerment is a debated issue for South Asian women in that they are traditionally not expected to make decisions or be independent (Fisher *et al*, 2003; Fikree and Pasha, 2004). It is the father and then the husband who is responsible as well as the extended family. Often the mother-in-law makes decisions that relate to the wife. This can be a barrier to seeking fertility treatment, answering personal questions and then complying with possibly invasive procedures and unpleasant treatments. This is difficult for South Asian women (South-Paul, 2003), although it could be said that anyone would find it humiliating.

There is sometimes a translation barrier to accessing services. There is limited information in alternative local languages with the NICE (2004) guidelines for the public on fertility problems being a case in point. They are only published in English and Welsh and do not mention ethnicity at all. There is now a leaflet, available in audio format, entitled Trying for a Baby, which has been translated into the main South Asian languages (Culley et al, 2004) but it is not as yet widely distributed. For couples, or one partner, that do not speak English or do not speak it well, it is imperative that professional translation is provided. Communication must be clear, with translated literature to back up what has been said, about treatments and options that are ethically and practically complex (Culley et al, 2006).

Counselling, or at least a support group, is recommended for those having infertility treatment (NICE, 2004; HFEA, 2005/2006). However, many couples, particularly South Asians, are reluctant to take up this recommendation. Only 16% of Culley *et al*'s (2004) cohort of infertile South Asian couples had used a counselling service. Some had not even been offered the opportunity. Culley *et al* (2004) suggest that the availability of more South Asian counsellors might help to increase the uptake, although there might be fear of confidentiality not being maintained. Culley *et al*'s (2004) research also found that 20% of couples relied solely on their partner for emotional support, with no one else knowing, which indicates

the isolation and fear surrounding infertility. Education is needed to help remove the stigma, although this of itself does not change the complex fertility beliefs of a community. Raising the status of women and empowerment is also needed, which raises big questions in patriarchal communities.

Pregnancy following infertility

Lastly, for those couples that suffered from infertility, used ART and were one of the minority fortunate enough to conceive, the problem does not end there. Pregnancy following fertility treatment can be considered high risk. This is because the risk of preterm delivery and a low birthweight baby is much higher, even when there is a singleton fetus (Wang et al, 1994). No one is sure of why this is, and not everyone agrees that this is the case once multiple births have been removed from the figures (NICE, 2004). But there is still an increased chance of twins, or more, which augments the risks (Gissler et al, 2004). Pre-eclampsia, gestational hypertension, placental abruption and placenta praevia have been linked with ART (Pavne, 2005). All of these conditions lead to increases in caesarean section rate as well as neonatal unit admission. The ectopic pregnancy rate is double that of natural conception rates (Strandell et al, 1999). Ovarian hyperstimulation increases the risk of ovarian cancer. However, Klip et al (2000) argue that this is due to bias in the research: the absence of controls with similar endocrine imbalance but not receiving the drugs. There is a suggested increased risk of congenital abnormalities in the fetus, although Gissler et al (2004) recognise an inconsistency in reporting. Hjelmstedt et al (2003) suggest that pregnancy following IVF has an increased effect on stress and anxiety. However, after delivery, similar stress levels were noted in those who conceived naturally. Overall, there often appears to be a price for defeating infertility.

Conclusion and implications for practice

In conclusion, there are many issues that need to be examined when looking at the subject of infertility from a South Asian perspective. The notion of womanhood is tied up with motherhood for most South Asian women as well as their sense of belonging, security and status within a community. Failing to become a mother or, in some instances, a mother of sons puts enormous pressure on a couple but particularly on the woman with whom the fault is generally considered to lie. Additionally, there are many potential barriers to accessing fertility services, including lack of knowledge, language difficulties, disempowerment and embarrassment. The NICE guidelines help infertile couples to have realistic expectations of treatments and national standards of care. Counselling is recommended as a means of exploring personal feelings and dealing with some stress, but South Asian couples are less likely to take up this service, and further research is needed to identify ways in which appropriate help can be given. For many couples, support is limited and linked with a reluctance to disclose infertility or treatment. There is also a fear of repercussions, especially if the child is not the biological offspring of the parents. Confidentiality is a high priority for South Asian couples. Even if pregnancy should take place, the assisted conception pregnancy is often at high risk regardless of ethnicity. Infertility and infertility treatments are highly stressful, and those who use the service require cultural sensitivity, kindness and support.

These issues have a number of implications for practitioners. The first concerns communication. More effort should be directed towards ensuring that South Asian people who do not speak English fluently have access to professional interpreters for any medical or counselling situation. More translated materials should be commissioned in all media, written, audio and visual, for those who cannot read English. These materials should be freely available in both health and community settings.

The second set of implications is the provision of counselling and support that is culturally appropriate and sensitive to the needs of South Asian people seeking infertility treatment. In particular, counsellors need to appreciate the stress experienced by South Asian couples unable to conceive, and the social stigma to which they may be subject.

Finally, there are implications for research about infertility, especially in areas like gamete donation and polycystic ovary syndrome, and the need to develop low-cost ART. Alongside this is the need to increase public awareness of the issues surrounding fertility, for example, through features in magazines, television and radio shows that have significant numbers of South Asian listeners. Most of all, practitioners have a role to play in encouraging the empowerment of South Asian women through education and in improving young people's knowledge about sexual issues and where to access help.

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CONFLICTS OF INTEREST

None.

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