

# **A Study of the Provision of Infertility Services to South Asian Communities**



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## **Final Report ABRIDGED VERSION**

Funded by the NHS Executive Trent, Policy and Practice Research  
and Development Programme

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## Executive summary

### INTRODUCTION:

This research project is the first major study of ethnicity and infertility services in the UK and was carried out between January 2002 and December 2003 with Gujarati Hindu, Punjabi Sikh, Bangladeshi Muslim and Pakistani Muslim communities in three English cities. It was funded by the NHS Executive Trent Region.

### AIMS:

- To examine the social meanings of involuntary childlessness amongst South Asian communities and to explore the ethnic, cultural and religious context of access to infertility services.
- To examine the experiences of South Asian couples who have been medically diagnosed as sub-fertile or infertile.
- To make recommendations for the development of policy and practice to service commissioners and providers.

### METHODS:

The research was carried out in two phases. Phase One consisted of 14 focus groups with South Asian participants (n=93) and individual interviews with key informants (n=21). Phase Two included interviews with South Asian individuals experiencing fertility problems (n=50) and interviews with health professionals providing infertility services (n=23).

### KEY FINDINGS:

- In South Asian communities, children are highly desired; parenthood is culturally mandatory and childlessness socially unacceptable. Infertility is a highly stigmatised condition with significant social consequences, especially for women.
- There is little knowledge of causes of infertility and of ways in which people can be assisted to have a child, although infertility is regarded as a problem amenable to medical help.
- Most infertility treatments including IVF are socially and culturally acceptable. However, the use of donated gametes was widely regarded as socially unacceptable across all communities.
- The needs and concerns of 'infertile' people of South Asian origin are not dramatically different from those of 'white' service users. However, differences of language, culture and religion are often important. NHS funding for IVF is limited. The socio-economic profile of the Bangladeshi and Pakistani communities in particular, places them at a disadvantage in accessing non-NHS funded treatment.
- Some dissatisfaction with primary care was evident. People experiencing problems with fertility were generally satisfied with secondary care services, but some needs were less than fully met. These included: information needs, language and communication needs and emotional support needs.

## **RECOMMENDATIONS:**

### **Infertility service provision**

- The Department of Health should ensure the full implementation of the NICE Clinical Guideline on infertility treatment at the earliest opportunity to ensure fair and equal access to NHS infertility treatment for all couples regardless of where they live.
- Further research is needed to explore the issue of access to ‘inter-ethnic’ gamete donation and the guidance of the HFEA on this issue should be clarified.

### **Data availability and monitoring**

- All relevant authorities should ensure that suitable and sensitive ethnic monitoring is in place and that regular analysis of data occurs. This would provide information on ethnic patterns of infertility incidence and prevalence, treatment outcomes and uptake of services.
- The HFEA should ensure that ethnicity data is available for all monitored treatments.

### **‘Social marketing’ of infertility treatment**

- The HFEA and other interested agencies should consider engaging with key opinion formers and other partners in minority ethnic communities to increase understanding of infertility and infertility treatment and to reassure people about confidentiality in the NHS. Approaches could be made through religious centres (Mosques, Gurdwaras, Mandirs) and community centres and should utilise bilingual community workers.
- Information about infertility should also be made available via local Asian radio and Asian television networks

### **Provision of information**

- Clinics should ensure that all patients receive appropriate written information about infertility and treatment at various stages of the treatment process.
- Clinics could conduct or commission their own research to investigate what information patients would find useful and in what form they would prefer to receive this.
- Clinics should consider providing patients with written individualised treatment plans.
- GPs and clinics should consider the use of patient-held record cards with dates and results of all tests as a means of avoiding unnecessary delays and costs of duplication of tests.
- Information about infertility and treatment should be made available in languages other than English. To avoid unnecessary expense, much of this could be provided by a central resource. The HFEA Guide to Infertility, for example, could be available in booklet form and on their Internet website in the main South Asian languages. This could be accessed by patients directly, and/or by clinics for distribution to non English speaking patients.
- Clinics should collaborate with each other and possibly with pharmaceutical companies to provide information on treatment protocols in minority languages.
- The needs of patients who do not read in their preferred language should also be addressed and material should be available in audio and video format.

- Service users and others from minority ethnic communities should be closely involved in the production of translated materials.
- The planned development of the NHS Online central depository of health promotion material could include the provision of translated material relevant to infertility. The planned extension of NHS Direct could also facilitate the provision of translated information and interpretation.

#### Interpreting services

- There is a clear need for improved interpretation services in most NHS trusts. However, this needs to happen alongside measures to increase the confidence of users in the effectiveness, cultural sensitivity and confidentiality of this service.
- It may be more practical for clinics and preferable for patients to use telephone-based interpretation (such as Language Line) on some occasions.
- Clinics should consider making the use of an official interpretation service a mandatory component of at least some consultations where one partner does not speak English, to enable shared decision-making, implement patient-centred care and ensure informed consent.
- Clinics should ensure that all staff receive training in the use of interpretation provision, including remote access services.

#### Emotional support

- Steps need to be taken to increase awareness of support counselling and the confidential nature of this service. Efforts should be made to ensure that counselling is culturally sensitive.
- Further research to investigate the reasons for the low up-take of counselling generally should be considered.
- Clinics should consider other ways in which the emotional needs of patients might be met outside of formal counselling.
- Clinics should provide patients with the contact details of infertility support groups and helplines.
- Infertility support groups should consider ways in which they might appeal more directly to users from minority ethnic communities, including producing publicity with material and imagery that is 'inclusive'.

#### Professional Education

- Health professionals should be provided with educational opportunities to explore ethnic diversity and the influence of ethnicity on health and healthcare. This may be through specific training programmes in PCTs and Acute Trusts (which should involve individuals from minority ethnic communities) and/or by accessing web-based material via e.g. the National electronic Library for Health (NeLH).

#### **OUTPUTS:**

- *Trying for a Baby*: a basic information resource for childless couples published in Punjabi, Gujarati, Bengali, Urdu and English. This is available in booklet and audio format on CD.
- *South Asian Communities and Infertility*: a resource for professionals working in the field of infertility.

# 1. INTRODUCTION

## 1.1 Background

This research consists of an exploratory study of the social meanings of infertility in British South Asian communities and the provision of infertility services to South Asian couples in three English cities. It is the first major study of ethnicity and infertility services in the UK and was carried out between January 2002 and December 2003 with Gujarati Hindu, Punjabi Sikh, Bangladeshi Muslim and Pakistani Muslim communities in three English cities.

In the UK as a whole, approximately one in six couples seek specialist help at some time in their lives because of fertility problems (HFEA 2004) and the demand for infertility services is increasing due to raised public awareness of treatment possibilities. NHS infertility treatment is highly rationed and the availability of the more advanced techniques of assisted conception such as in vitro fertilisation (IVF) varies across the UK. Most couples undergoing IVF are self-funding. In February 2004, the National Institute for Clinical Excellence (NICE) published a Clinical Guideline outlining the types of investigations and treatments that should be available to people with fertility problems (NICE 2004). A key recommendation was that three cycles of IVF should be offered to women aged between 23 and 39 who meet certain clinical criteria. The government has welcomed the NICE guidance, but has proposed a phased introduction, suggesting that all Primary Care Trusts should offer to fund at least one cycle of IVF for eligible individuals by April 2005.

Infertility is a social as well as a medical issue. Involuntary childlessness can lead to considerable distress (Letherby 1999, Pfeffer & Woolett 1983). An extensive collection of studies show that involuntary childlessness can be a devastating experience for many; with significant consequences for social and psychological well-being (Letherby 1999, Monach 1993, Pfeffer & Woolett 1983, Sandelowski 1993, Souter et al 2002, Whiteford & Gonzalez 1994). However, research has mostly been carried out with middle class, white, treatment-seekers and consistently ignored non-treatment seekers, those accessing treatments other than IVF, those in lower socio-economic groups and those from 'non-white' ethnic groups (Griel 1997).

Inequalities in health between and within ethnic groups have become an increasing focus of research in Britain (Nazroo 1997, Erens et al 2001). However, studies of ethnicity and reproduction have tended to concentrate on childbirth and contraception rather than infertility (Katbamna 2000). There is therefore, a dearth of literature on the way in which infertility might be experienced by people from minority ethnic communities, especially in the UK. A systematic review of research on ethnicity and health care access (Atkinson et al. 2001) found no reference to any work relating to ethnicity and infertility services in either published (peer reviewed) or 'grey' literature sources. There are no available data on the use of infertility services by minority ethnic groups in the UK. The collection and analysis of ethnicity data in the NHS is still patchy and much infertility treatment takes place in the private sector.

According to the 2001 Census, the size of the minority ethnic population was 4.6 million or 7.9 per cent of the total population of the United Kingdom. Over 2.3



million people described their ethnic origin as Indian, Pakistani, Bangladeshi or 'Other Asian' and a significant percentage of this population are in the childbearing age group (Census 2001). In this context, the following research aims and objectives were formulated.

## **1.2 Research Aims:**

- To examine the social meanings of involuntary childlessness amongst South Asian communities and to explore the ethnic, cultural and religious context of access to infertility services.
- To examine the experiences of South Asian couples who have been medically diagnosed as sub-fertile or infertile.
- To make recommendations for the development of policy and practice to service commissioners and providers.

This report is an abridged version of the final report. Further discussion of the literature on infertility and ethnicity and a detailed account of the methodology of the project is available in the full version of the report.

## **1.3 Method:**

Although they share a broad geographical origin in the sub-continent, South Asian communities in Britain are of diverse regional, linguistic, religious, caste and class origins. This project aimed to work with a recognition of diverse identities and experiences, which are often homogenised under the heading 'Asian'. It refers to four sub-categories: Pakistani Muslim, Bangladeshi Muslim, Indian (mainly Gujarati) Hindu and Indian Punjabi Sikh communities. An attempt has been made to recognise differences *between* communities and to consider the importance of differences of age, gender and socio-economic status *within* communities.

The project included two distinct, but linked phases. Phase One which began in January 2002, was designed to explore the meanings and context of involuntary childlessness among four main South Asian communities described above. This phase began with a literature search and review of relevant literature. This was followed by a series of focus groups with members of the South Asian communities. Phase One also included semi-structured, individual interviews with a range of key informants, including religious and community leaders, health professionals, community workers and alternative health practitioners. The insights gained from Phase One were built upon in developing the protocol for Phase Two of the project. Phase Two consisted of in-depth interviews with 50 members of the four communities who had been defined as, or who defined themselves as infertile, and 23 interviews with providers of infertility services including consultants, nurses and counsellors.

Table 1: Phases of the project

Phase One	Phase Two
Focus Group Study with South Asian Communities (n=93)	Interviews with infertile couples (37 interviews, n=50)
Interviews with Key Informants (n=21)	Interviews/focus groups with health professionals (n=23)

Focus groups: Fourteen single sex focus groups were carried out with a total of 93 participants (67 women and 26 men). These included people of Bangladeshi Pakistani Muslim, Indian Sikh and Indian Hindu origin (Table 2). Focus groups were carried out in the preferred languages of the groups, facilitated by bi-lingual researchers working with the core research team. They were tape-recorded, translated and transcribed by the trained facilitators.

Table 2: Focus group participants by sex and ethnicity

	Indian	Pakistani	Bangladeshi	Total
<b>Women</b>	33	18	16	67
<b>Men</b>	13	0	13	26
<b>Total</b>	46	18	29	93

Individual interviews with ‘infertile’ participants: Participants were offered a choice of interview and a choice of language for the interview. Twenty four interviews were carried out with women on their own and thirteen included both male and female partners, giving a total of 50 participants (Table 3).

The data from the focus groups was carried out using a process of thematic analysis. Initial coding was undertaken independently by two researchers and a final set of codes derived following discussion with the research team. Transcripts were reviewed for emergent themes in a process involving four team members (DeSantis and Tugariza 2000). Individual interviews with people experiencing infertility were tape recorded and transcribed verbatim and Ethnograph was used to organise and code the data.

Table 3: Interview participants by sex and ethnicity

	<b>Indian</b>	<b>Pakistani</b>	<b>Bangladeshi</b>	<b>Other Asian</b>	<b>Total</b>
<b>Women</b>	23	9	4	1	37
<b>Men</b>	9	2	0	2	13
<b>Total</b>	32	11	4	3	50

The research was supported by an Advisory Group, which included representatives of infertility service users, academics and practitioners. The research team consisted of university academics from three universities, plus community facilitators of South Asian ethnic origin who assisted in research design, data collection and data analysis.

## 2. KEY FINDINGS

The following key points have been selected from the main research report (Culley, et al 2004) as representing the most important issues arising from the project. There is not space here to discuss the extensive review of relevant contextual literature which is contained in the main report. The following discussion addresses the main aims of the research: the social meanings of involuntary childlessness in South Asian communities and the experiences of infertile South Asian couples.

### 2.1. Children and childlessness in British South Asian communities

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, community constructs of infertility – the ideas that people hold about infertility – will influence how people behave towards those perceived as infertile and will affect the extent to which they act as a source of social support for childless couples or a source of stress. Community constructs will also affect how childless couples see themselves. 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. An important question is, therefore, how is infertility and infertility treatment perceived in South Asian communities?

#### *Pronatalism - the social desirability of children*

To understand attitudes to infertility, it is necessary firstly to explore attitudes to fertility and the importance of children. The findings of this project confirm the hitherto largely anecdotal view that South Asian communities are strongly pronatalist. Pronatalism can be defined as any attitude or policy that is ‘pro-birth’, encourages reproduction and exalts parenthood (Miall 1994, Reminnick 2000). The focus group study, the interviews with key informants and the interviews with infertile women and men, unequivocally validate the profound impact of the motherhood mandate in British South Asian communities.

In the communities studied here, the social desirability of children is very pronounced. Marriage is highly valued and almost universal. Men and women, old and young across all ethnic and religious groups and all social classes saw parenthood as the natural and desired consequence of marriage. *Voluntary* childlessness was inconceivable for most participants in this study. This contrasts with the published evidence of the experience of white (admittedly mostly middle class) women in the UK and the USA where changing notions of parenthood, and women's roles have meant that motherhood has come into question as an essential component of women's lives and as a result some women have chosen to remain childless. This is not to suggest that involuntary childlessness does not have social consequences for white ethnic groups, but that in middle class white society at least, a childless life is much more accepted and the social repercussions of involuntary childlessness are generally less severe. Indeed as van Balen and Inhorn (2002) have argued, advocates of voluntary childlessness point out the social and economic advantages of not having children.

Child desire is multi-faceted. Focus group and key informant interviews revealed a number of reasons why children were seen as vital. Social, economic, religious and emotional reasons were advanced for having children. Understandably perhaps, older members of the communities were more likely to discuss 'social security' reasons for having children such as providing support for parents in old age. Older people were also more likely than younger people to point to the importance of children in performing religious rituals for dying parents and in offering prayers for the dead. All the major world religions embody prescriptions to encourage childbearing among the faithful (Monach 1993). In our study, both old and young discussed what Inhorn (2002) has called 'social perpetuity' desires. The need to continue the family name; the continuation of the lineage or the extended 'clan' into the future were common themes in the focus group and key informant discussions.

Interviews with people receiving infertility treatment confirmed a very strong expectation amongst their families and the wider community that married couples should produce children. Most reported feeling family pressure to produce a child (often from female members) and many of the reasons for having children given by participants in the focus groups and key informant interviews were echoed in these accounts. However, the desire for a child was not merely seen as a response to external pressure, but also expressed as a deeply held personal need, especially by women. This is consistent with the findings of most studies of infertile couples (Ulrich & Weatherall 2000; Monach 1993; Woollett 1991). Interestingly, the individual interviews revealed that for several couples, there was pressure to have more than one child. Eighteen interviewees (36%) already had a child and were seeking help to add to their family. Several of these reported the stigma of having only one child.

In some South Asian groups, large families are more prevalent. A major national study of ethnicity in the UK carried out by the Policy Studies Institute (Modood et al 1997) found that Pakistani and Bangladeshi groups had the largest families, with 33% of Pakistani families and 42 % of Bangladeshi families having four or more children. Only 4% of white families and 3% of African Asian families had more than four children while the rate for Indians was 11%. Pakistani and Bangladeshi women are more likely to start families in their twenties than Indian and African Asian or white women and more likely to continue bearing children later in life (Modood et al 1997).

Figures from the 2001 census confirm a higher family size for most South Asian groups, but also show a slight decline in size for each of the South Asian groups in the period since 1991 (Census 2001).

### *A preference for male children*

Our findings suggest that a preference for male children is also widely held across all communities. This was explicitly and spontaneously raised in several of the focus groups and reinforced by the key informants, some of whom suggested that for some families, not having a male child could be just as problematic as not having a child at all. Culturally, across the communities studied, the birth of male children was reported as a cause for celebration in a way that was not the case for female children. Religious, social and economic reasons were given for the importance of sons. A key issue is that in many South Asian communities, a daughter leaves her family of origin on marriage and enters her husband's family (in some cases with a dowry). Sons remain economically and socially part of the family and have a series of continuing obligations to their parents and siblings.

A fifth of the sample of infertile people interviewed reported pressure from families to produce a male child, although most were keen to stress that they themselves would be happy to have a child of either sex. The pressure to produce a son was particularly articulated by women, and a small number suggested that their status within the family and the community would be enhanced if they produced a male child.

A preference for sons in the Indian sub-continent has been widely reported. Bharadwaj (2003) argues that it is a widespread belief in India that the ancestors themselves are born in the form of children; the life of a man is made permanent through the agency of his son which makes the son a very important requirement according to the ancient legal codes and scriptures of the Hindu faith. Female children, however, can become a vehicle for grandsons who can act as *de facto* sons. Culturally, brothers have a particular affection for sisters and their children and are expected to look after a sister's interests after the parents have died. Research in India and Pakistan (Bhatia 1978, Bhatti et al 1999, Winkvist & Akhtar 2000) suggests a strong preference for sons, mostly for economic reasons. Although the purely economic value of children is less clear in industrial societies, in developing societies the need for children as contributors to the family economy is well recognised (van Balen & Inhorn 2002).

In the UK context, Katbamna (2000) shows a preference for sons in South Asian communities. In the Hindu religion, it is believed that unless a son perform the rituals of death, the departed person's soul does not reach heaven. Katbamna also reported that the desire for a son relates to the power of the mother in law with South Asian families. Women may desire a son, because this means that in the future they will themselves assume this powerful role and indeed the pressure on couples to have a male child was reported by Katbamna to be especially strongly communicated by mother in laws.

## *Changing community attitudes to childbearing*

In the present study, younger *and* older people acknowledged that community attitudes to childbearing were changing. A *delay* in childbearing was increasingly seen as acceptable in some communities, particularly if young people were in higher education or attempting to establish themselves in a career. Nevertheless, it was still felt that in some families, if a child had not been produced within a relatively short time after marriage questions would start to be asked. This was more commonly reported in the Pakistani and Bangladeshi communities.

Although overall, South Asian cultures are strongly pronatalist, 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. This was confirmed by the key informants. 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, although they felt that attitudes were quite slow to change in this regard.

These findings are similar to those reported in a study of South Asian women's use of family planning services. 'Non professional' women, and especially those who were not born and educated in the UK, were under pressure from the extended family to produce children and to continue until a son was born. Professional Asian women however, were more to make autonomous decisions about fertility, had few problems interacting with health services and were little different in their contraceptive behaviour to women in the general population. They expressed a strong preference for a non-Asian GP and a female health professional and were able to use skills to select a service to meet their needs (Hennick et al 1998).

Younger people in the focus groups also suggested that there was some resistance to the pressure to produce a male child. Many younger men and women stated that they did not themselves have a preference. At the same time, however, they did acknowledge that families might take a different view; as one young Bangladeshi women said "Not having a son is not going to work".

## **2.2 The stigma of infertility**

The intensity of pronatalism means that childlessness is highly stigmatised and this was a strong theme across all groups and interviews with community members. It is not merely the absence of children which can create problems for couples however. As we have seen, for a significant minority of participants experiencing problems with fertility, bearing no sons, or having only one child constituted a form of social infertility in a situation where community norms dictate that large families are preferable and that sons are essential. The pressure on South Asian couples was recognised as a significant issue by most of the professionals interviewed. In some cases it was reported that 'Asian' women were especially desperate to conceive and were often anxious to 'move things along' in treatment terms.

Infertility is a highly gendered process. The implications of childlessness were widely reported in all the focus groups as being more severe for women than men. Infertility is seen almost exclusively as a woman's problem. All participants in the study, young and old, male and female, agreed that women are 'blamed' for childlessness. 'It's always the woman's fault' was a very common theme. Many examples were given of how childless women might be gossiped about, taunted and in a few extreme cases socially ostracised and ill-treated by families. As van Balen and Inhorn (2002) have forcefully argued, it is women, the world over, who bear the burden of shame and social scrutiny for infertility; it is women's bodies which are the site of infertility treatments even when the biological problem lies with the man and it is women "who live the untoward repercussions and social backlash associated with this affliction" (p.19).

Very direct and painful questioning of women about their 'failure' to produce a child was commonly reported. This confirms the findings of Katbamna (2000) who reported pressures on women from mothers in law or other members of the husband's family in particular. This was more evident in the less prosperous Bangladeshi community than in the relatively prosperous Gujarati Hindu community. Although the single most extreme example of pressure from the extended family was given by a *professional* Bangladeshi woman. The direct and intrusive questioning of women about their childless status has also been reported in a study of strongly pronatalist Israeli society (Reminnick 2000) and in Reissman's study of South India (2000). Studies of 'white' infertile women (Imeson & McMurray 1996), also report insensitive responses from family and friends although the *possibility* of voluntary childlessness may result in a blurring which obscures the visibility of involuntary childlessness (van Balen & Inhorn 2002)

Many of the interviews with infertile individuals and couples in our study also revealed negative experiences; unsupportive reactions to infertility from family members and painful social scrutiny. Women reported avoiding occasions such as family weddings or other social events where they might be faced with comments and direct questions about their childlessness. Several women reported negative behaviour towards them from their partner's family. Some of the women interviewed felt that childlessness denied them full membership of their husband's family, and that their role in the family would not become secure until they had a child. The women and men interviewed confirmed that the female partner was always seen as the 'guilty party', responsible for a couple's childlessness.

Although negative incidents were more commonly reported, women also spoke of sympathetic and helpful responses, especially, but not exclusively, from the woman's mothers and sisters. There were examples where families of both wife and husband offered practical advice, emotional support and financial assistance to childless couples. Some women expressed surprise at the compassion and support that their mother in laws and other family members actually provided.

Men it seems, do not entirely escape stigma. Focus group participants suggested that a childless man might have to suffer taunts about his sexuality and lack of 'manhood' since infertility for men was commonly associated with sexual functioning.

Many participants in the focus groups and in the informant interviews also raised the issue of divorce. It was widely felt in the focus groups that infertility would be considered 'good grounds' for men to consider divorce or (in some communities) for the taking of additional wives and many examples of these were given. Several participants made the point that in some families, even where a husband might not wish to divorce a wife, his family might insist on this.

In the interviews with infertile participants, however, many reported that the experience of infertility had brought couples closer together. Many women reported receiving support from partners and a lack of pressure from their husbands to conceive. One third reported that their husbands had been their main source of emotional support. This finding supports evidence from a study of infertile women in Andhra Pradesh, India (Unisa 1999), which suggests that although for some women there did exist the threat of divorce or remarriage of their husband, for the majority this was not a concern, especially in situations where it was known that the infertility was treatable. However, a small number of women in our study did report a feeling of insecurity in their relationship

Pronatalism and the stigma of infertility are not, of course, confined to minority ethnic communities. Studies of white middle class participants in the UK and USA have argued that pronatalism is a key feature of contemporary ideology and that infertility is regarded as a deficient or abnormal condition. Childless women are stigmatised (Letherby 1999, Whitehead and Gonzalez 1994) and experience feelings of shame, inadequacy and failure. A study of community constructs in Eastern Canada (ethnicity unspecified), also demonstrates a pronatalist ideology. In this study however, infertility is seen as a more personal and couple centred issue (Miall 1994). In South Asian communities in the UK, infertility is highly visible.

### *The visibility of infertility*

Writers have identified infertility as an invisible stigma – a secret stigma whereby the infertile are able to pass as 'normal' (Griel 1991, Goffman 1963). Greil (1991) has argued that in American society the invisibility of infertility has transformed it from a public experience into a private one. In contrast, in South Asian communities, childlessness is *highly* visible and seen as a legitimate area of social concern, not an issue confined to the individual or couple themselves. Pronatalism means that the visibility of childlessness is more pronounced and many participants gave examples of the public surveillance of married couples in some communities.

### *Attitudes to male infertility*

Studies of childlessness around the world, confirm that women endure most of the stigma of infertility (Inhorn 1996, Miall 1994, Sandelowski 1993, Whiteford & Gonzalez 1994; Ulrich & Weatherall 2000; Remennick 2000 and Reissman 2000). The focus groups made fewer references to the effects of infertility on men, but in common with other studies (Miall 1994) a connection was made between male infertility and impotence or a failure to 'perform' sexually. Infertility was equated with sexuality for men in a way not seen with women.



The construction of male infertility was quite complex however. Almost everyone *maintained* that few people in South Asian communities knew that men could be responsible for childlessness as well as women, and this was one of the reasons why women had to bear the main burden of infertility. This was expressed in all the groups, male and female. At the same time however, almost everyone who took part in the focus groups also said that they themselves knew that male infertility existed. 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’.

Most focus group participants acknowledged then, that males as well as females could be responsible for childlessness. However, this made little difference to their insistence that nevertheless women would be blamed. This may reflect the continued linking of women with a strong reproductive role, or it may be that the stigma attached to male infertility, with its strong perceived connection with sexual failure, makes it less likely that people would attribute infertility to the man (Miall 1994). Everyone was of the opinion that even where the male was ‘at fault’, this would never be publicly revealed. Some of the female patients reported that their husbands had been reluctant to seek medical help initially and patients and health professionals gave examples of the unwillingness of some men to have their semen tested, which sometimes held up treatment. Several health professionals also commented that male denial or a reluctance to accept that they could be the source of the difficulty in achieving a pregnancy was a more common response among Asian males than others.

Several examples were given in the focus groups of men divorcing their wives who then went on to have children with other husbands. This is similar to the findings of Remennick (2000) which demonstrate the way in which in pronatalist Israeli society women were likely to take the ‘blame’ for their husband’s infertility, in order to protect ‘their partner’s ego, sense of masculinity, and sexual potency’ (p.832), which she refers to as ‘courtesy stigma’ (p.840).

### *Changing attitudes to infertility*

Although few can totally escape the potentially stigmatising outcome of childlessness, all the sources of data suggest that the extent of stigma and the possibility of being able to resist some of its effects varied, primarily according to the socio-economic and educational status of the couple and the extent to which families were embedded in more “traditional” communities. Several informants felt that the members of the East African Asian communities in particular were “more progressive” in their attitudes to infertility and many made the point that more “traditional” families may be less accepting of a couple’s childlessness. This was confirmed in the interviews. Individuals reporting very negative attitudes from in laws were more likely to come from the Bangladeshi and Pakistani communities and be of lower socio-economic status.

The Canadian study of community perceptions of infertility demonstrated strong social support for motherhood but also that women have been influenced to some extent by changing social values and the women’s movement to downplay

motherhood as the only important role for women (Miall 1994). An element of this was evident among some younger South Asian women. Focus group and key informant discussions also suggested that some women who were in education or in employment outside the home would be able to construct an alternative narrative to 'explain' childlessness, at least for a few years after marriage. This was echoed in the individual interviews, where women who were in employment reported that they were more able to resist family pressure.

### **2.3 Confidentiality and disclosure**

The process of stigma means that for those accessing infertility treatment the management of information becomes an important issue. Certainly, the focus group and key informant data would suggest that if possible, the couple would disclose the fact that they were having treatment to as small a group as possible. For some, especially those living in co-resident households, concealing treatment from the immediate family is likely to be extremely difficult. For others, it may be possible for the couple not even to reveal the problem to close family members. The key informants suggested that most couples would attempt to hide both infertility and its treatment from wider family and friends, because of the potential stigma. However, the shortage of NHS funded treatment and the high cost of private infertility treatment may require the couple to borrow money from family and thus make privacy more difficult to maintain.

Only three of the infertile individuals interviewed said that they had made information about their treatment known outside the family, one fifth reported that they had not disclosed information to anyone and one third said they had disclosed the information selectively to either family members or close friends. People were concerned about confidentiality and concerned that the wider family or community would not understand what was involved in medical treatment. There was also some concern that if people were aware that a child had been born using IVF for example, there might be implications for the way that child was treated within the community.

The health professionals also made the point that while confidentiality was an issue for many patients, it was especially important for South Asian patients and some felt that this need for secrecy meant that Asian women in particular might have fewer sources of emotional support. There is little discussion in the literature about disclosure of infertility treatment per se. In Griel's study of American couples, all but one had told parents about their infertility and the majority had told at least a few close friends, but almost no one had made it a practice to reveal their infertility routinely to casual acquaintances (Greil 1991).

There have been a small number of studies of parental disclosure to offspring of the use of donated gametes in infertility treatment. One European wide study of families who have used donated sperm has shown that the overwhelming majority of parents choose not to disclose the use of donated gametes to their offspring. This is articulated by parents as a desire to protect children from the effects of revealing non-biological parenthood and a desire to protect the father from the stigma of infertility (Cook et al 1995, Golombok et al 2002). Although none of our participants reported the use of donated gametes, it was clear from their responses and from those of our focus group

participants and infertility counsellors that non-disclosure is the norm in South Asian communities also.

## **2.4 Knowledge of infertility and attitudes to infertility treatment**

Knowledge and beliefs about infertility are likely to have an impact, alongside other important structural factors, on treatment seeking behaviour. How people explain the causes of ill health, the types of treatment they believe in and the help they seek are culturally variable (Helman 2000). An important part of the project was concerned with community understandings of infertility, attitudes to treatment in general and to some specific treatments. Most commentators suggest that in Western societies, infertility has become medicalised. That is, the medical model is becoming the dominant cognitive framework in terms of which sufferers interpret their experience (Greil 1991). Alternative understandings of infertility exist in many societies. For example, infertility may be seen as a punishment from God for wrongdoing in this or a previous life, the result of bad luck, evil spirits or a curse (van Balen & Inhorn 2002)

Data from all aspects of this study would suggest that while there are a variety of interpretations among older generations in particular, infertility is nevertheless seen by most community members as an object of potential *medical* investigation and treatment. However, knowledge of possible biological causes of infertility and treatment possibilities was very limited. The key informants were of the opinion that such knowledge was lower in the South Asian communities than in 'white' communities. It was asserted that most people have a poor understanding of male infertility in particular. It was also suggested that there was little awareness of how infertility might be treated or how treatments could be accessed. The key informants felt that the extent of infertility knowledge would vary between different South Asian communities and by social class and educational level across all communities.

A lack of awareness of biological causes of infertility was borne out to some extent in the focus groups. Levels of knowledge were slightly higher in the younger age groups in some communities where participants suggested a range of behavioural and physical 'causes' for infertility, including stress, obesity and sexually transmitted diseases. Very few people could offer any description of what might go wrong with normal reproduction to prevent pregnancy. Several participants across all groups felt that using contraceptives could affect long-term fertility, which is interesting in the context of debates around family planning in Asian communities.

A small minority of participants suggested that infertility was related to divine retribution or other spiritual or 'external' influences. A group of older Sikh men maintained that infertility was the outcome of bad deeds in a former existence. Muslim groups made the point strongly that Allah (God) ultimately was the giver of children. Nevertheless, almost all participants understood infertility as something that was amenable to medical intervention. Even where the hand of God was proposed, it was widely accepted that seeking medical treatment to correct infertility was also a religious duty. Within Islam, the purpose of marriage is to procreate and several Fatwas given in the 1980s made it clear that the use of assisted conception is permitted when the gametes are those of the husband and wife (Inhorn 2003).

Focus group participants and key informants spoke of a range of non-medical therapies and treatments that might be sought out by infertile women. The likelihood of women seeking help from religious sources and the performance of religious rituals were discussed. Childless women might visit healers, be given amulets with special prayers, undertake additional fasts or pilgrimages and/or pray to specific gods. The older members in particular discussed the use of various herbal preparations and special foods that could increase fertility. In most cases however, all such activity was seen as complementary to medical help, rather than as an alternative source of treatment, at least in the UK context. The individual interviews with infertile couples confirmed that around 15% had used 'alternative' or traditional remedies including herbal preparations, acupuncture, homeopathy and massage. This is a similar level to that found in a Dutch survey of infertility behaviour (van Balen et al 1995, cited in van Balen & Inhorn, 2002:10).

There was also considerable variation in the focus groups concerning the levels of knowledge of medical infertility treatments. Broadly speaking the older groups knew more about traditional remedies and had less in-depth knowledge of medical treatments and the younger groups knew less about traditional remedies and more about medical options. The one exception here was the Bangladeshi groups, where both older and younger women and young men were generally less knowledgeable about medical options. In all the discussions, IVF ("test-tube baby") was the only widely known treatment. Some others were aware of 'pills' might be taken.

Some health professionals suggested that South Asian patients on the whole had less knowledge of fertility and infertility than most 'white' patients, although clearly this was mediated by educational levels and what nurses and others referred to as degrees of 'Westernisation'. Some spoke of very well informed Asian patients and others who lacked even the most basic knowledge of human reproduction. Others made the point that knowledge of reproduction and infertility was generally poor in all populations.

Infertility is not an issue widely discussed in South Asian communities, although at the time of the focus groups it had emerged in one of the popular Asian TV 'soaps'. Despite the fact that childlessness causes much social and individual distress, key informants spoke of it as a 'taboo' subject. One reason for this may be the fact that infertility uncomfortably connotes sexuality – as babies are born through sexual intercourse. When couples remain childless, issues of sexual failure come to the fore (van Balen and Inhorn 2002). There was some evidence of this in the focus groups, especially with the men, who referred to infertility in terms of male sexuality. Some of the women's groups made the point that in some families it would be assumed that there was a sexual problem between partners if a couple had not produced a child soon after marriage. At the same time, however, with the exception of one group of older Bangladeshi women, most people were quite happy to get involved in what were often quite sexually explicit discussions in their single sex groups. Most of the focus groups were lively, animated discussions and there was little evidence of a reticence to touch on what we had anticipated might be 'sensitive' topics. Indeed the researchers were more concerned with ethical issues that might arise from 'over-disclosure' than any reluctance to discuss issues of reproduction and marital relations.

Many focus group participants expressed a need for more information about infertility and infertility treatments. The older groups thought that perhaps younger women

would be relatively well informed, but the younger women did not express this feeling and argued that much more information was needed about the causes of infertility, the treatment available and how to seek help. They felt that this should be available in a variety of media and in all languages. This was also echoed by the key informants, several of whom worked in a health education role. A lack of information in languages other than English was seen as particularly problematic. While most young people could read English, this was not necessarily the case for the older generation, especially the mother in laws. It was felt to be important for older family members to be well informed to enable them to support younger people. The views of the older generation are likely to be particularly important in South Asian communities, since they have considerable power and influence within the family and a very high proportion of Asian elders live with a son or daughter (Modood et al 1997).

## **2.5 Attitudes to treatment options**

The most common medical causes of infertility are ovulatory disorders, sperm defects and problems with the fallopian tubes. A significant number of couples will have more than one cause and up to 30% will have a diagnosis of 'unexplained' infertility. Assisted conception is the means by which infertile couples may be helped to achieve a pregnancy and the choice of technique depends on the cause of the problem. Although in most cases, infertility is experienced as a couple, the woman is the focus of treatment, even where male factor is the cause. Techniques include ovulation stimulation (by oral or injected drugs); artificial insemination (with partner or donor sperm) and in vitro fertilisation (IVF). More recent advances in technology have led to the use of Intracytoplasmic Sperm Injection (ICSI) with IVF for cases of impaired male fertility, whereby sperm can be surgically retrieved from the male and an individual sperm directly injected into a single egg.

Overall, there is a less than 50% chance of successful conception from all infertility treatments. Many treatments are complex, time-consuming and expensive and there are potentially harmful side effects from fertility drugs (van den Akker 2002). The success rates for IVF and IVF-ICSI vary from clinic to clinic and are highly dependent on the age of the female partner. Chances of a live birth per treatment cycle are greater than 20% for women aged 23-35 years.

There has been a significant increase in the uptake of infertility services in recent years, although this is not thought to be due to any increase in underlying prevalence. Technological advances and a raised awareness of treatment possibilities are more likely to underpin growth in treatment. Nevertheless, there is still a considerable unmet demand for treatment within the NHS. Most couples using IVF for example, are self-funding and treatment can be time-consuming and expensive, with IVF-ICSI for example costing a minimum of £3000 per treatment cycle in many clinics.

### *Attitudes to IVF and the use of donated gametes*

Attitudes to some treatments were discussed with the focus group participants and in the individual interviews with people experiencing fertility problems. As we have seen above, few participants in the focus groups were aware of ways in which infertility could be treated. Several groups mentioned IVF but few other possibilities

were known about. There was little objection to the use of IVF from participants. However, when the issue of the use of donated gametes was raised it gave rise to lively debates. The use of donated gametes was universally regarded as socially unacceptable. Most who contributed to these discussions felt that the use of any third party biological material was objectionable on social, ethical, or religious grounds. It was suggested that a child conceived in this way would not be well accepted into the wider family and community. Religious objections to the use of donated gametes were most likely to be specifically raised by the Muslim groups, where it was widely known that according to Islam, this was considered *haram* (not permissible).

At the same time, however, in some groups participants expressed the view that donated gametes probably were used by some couples, if no alternative means of achieving a pregnancy were possible. Similarly, the key informants felt that there was considerable social disapproval of the use of donor sperm and eggs, although again there was an acknowledgement that this might happen.

It was very clear from all sources, however, that confidentiality was of prime importance. It was universally felt that any use of donated gametes would be disclosed to as few people as possible. The necessity for secrecy was linked to the stigma that would be experienced by the couple and the resultant child. There were strong opinions expressed about how a child conceived using donated gametes would be treated by the family and community. Some suggested that the child might be rejected by the extended family and would face social ostracism and difficulties in obtaining a good marriage. The literature on post-assisted conception families in the UK is relatively sparse (Golombok & MacCallum 2003; Golombok et al 2001; Golombok et al 1995) and we are not aware of any that has included a consideration of ethnic differences. This issue merits further investigation.

The infertile couples interviewed reported no experience of the use of donated gametes. Around one third of those interviewed commented on this issue when asked by the interviewer and most of these were opposed to the use of donated gametes, primarily on religious grounds. A small number of individuals were more ambivalent in their response, stating that this was something they might consider as long as it was never disclosed and the child physically resembled the parents.

When discussing the possibility of using donated eggs, the concerns of our participants were generally couched in terms of 'not knowing' about the origins of the egg; concerns that eggs may be given by 'unsuitable' individuals and concerns about the social consequences if such treatment was revealed. Therefore, while there was still a general feeling that receiving donated sperm and eggs was not desirable, it might be an acceptable solution for some, although the Muslim groups and individuals rejected this option on religious grounds. As in Bharadwaj's study of infertile Hindu couples in India (Bharadwaj 2003), use of donated sperm was a possibility for some as a 'last resort' scenario, but only as long as it is kept secret so as to allow couples to claim the official, visible public status of biological parents. Several nurses mentioned that South Asian couples requiring donated sperm would initially refuse this option, but then may reappear at clinic some years later, often after having had some form of treatment in India or Pakistan.

Some health professionals also noted a reluctance of Muslims in particular to accept the use of donated sperm. However, others had experience of this being used by Muslim patients and suggested that religious issues are sometimes flexibly negotiated or “overlooked” in certain circumstances. South Asian couples are able to specify the ethnicity and religious characteristics of anonymous sperm donors and consultants reported that such requests could normally be met by providing sperm from London sperm banks, if it was not available locally. An acute shortage of egg donors from Asian communities was raised by most health professionals. Asian eggs are very rare and waiting times for Asian couples are impossibly long in most cases. Professionals reported that demand for eggs was high compared with supply. The chances of an Asian couple receiving an anonymously donated Asian egg were described as virtually zero. This issue is discussed further below.

In both the focus groups and the interviews with infertile individuals, the use of donated eggs seemed to be marginally more acceptable than the use of donated sperm. Haines (1993) noted this differential attitude to donated gametes and has argued that this may relate to the fact that sperm donation is seen as sexual in a way that egg donation is not. Bharadawaj (2003) argues that within Indian culture, the sperm is perceived as having a stronger influence on the resultant child than the egg, and that the family line is seen as transmitted via the sperm. As such, a female ‘third party’ is not seen as so invasive such a threat to the socio-political stability of the family.

Infertility counsellors reported that in their experience, couples from South Asian communities were less likely than white couples to disclose the use of donated gametes to their families and most of their Asian clients did not plan to tell the resultant child.

Donor inseminations have been in use for over 50 years in the UK, although only regulated from 1990, while the use of donated eggs or embryos is a much more recent possibility. Studies suggest that most couples who have used donor insemination choose not to disclose this fact and that they intend not to tell any resultant child (Monach 1993, Cook et al 1995, Cramond 1998). Professionals treating patients for infertility are divided in their opinions on disclosure to offspring, although most counsellors appear to favour ‘openness’.

It is clear from this study, that while the use of donated gametes is generally highly disapproved of in South Asian communities, there is also a realisation by many that it does probably occur in the case of ‘last resort’. Cultural norms are guidelines for behaviour but not predictors of it in individual cases (Henley and Schott 1999). It is important to differentiate between the rules of a culture that govern how one *should* think and behave and how people actually behave in real life. Generalisations can be dangerous, for they often lead to stereotyping, misunderstandings and discrimination (Helman 2000).

### *The use of donated eggs*

As we have seen, there is an acute shortage of eggs from Asian donors (Biljan et al 1995). For most couples therefore an anonymous egg donation is highly unlikely and the only realistic option (other than going to the US for treatment where just about any characteristic of donor can be specified) is for a couple to use a known donor. A

small number of health professionals had experience of Asian family egg donors. Some of the nurses raised concerns about possible pressure that they felt was sometimes put on female family members in this respect.

A further option of course, is the use of a 'white' egg. Mixed-ethnicity egg donation raises some interesting issues. Two consultants suggested that this would be an option they would consider making available to Asian couples, after counselling and an ethical assessment. One consultant, however, expressed concerns about 'mixed race' donation and had not offered this to Asian patients, despite the fact that Asian eggs are virtually impossible to obtain.

The practice around the country seems to be quite variable in this regard, although no firm evidence is available. This is one area where the discretion of clinics is seen to operate and variable decisions can be taken, not just in terms of the assessment of individual cases, but 'in principle' decisions on whether or not this treatment would be offered to any couple. 'Discretion' is usually exercised in the interests of the 'welfare of the child'.

The HFEA code of practice for infertility clinics contains a series of provisions related to the welfare of the child, which must be taken into consideration when deciding to treat any individual. The exercise of physician discretion in this area gives rise to inequity of treatment (Malin, 2003; Steinberg, 1997) and in this instance has serious consequences for Asian couples, given the absence of anonymous Asian egg donors. The HFEA guidelines do not give clear guidance on this specific issue, stating only that

“When discussing the selection of potential donors, treatment centres are expected to be sensitive to the wishes of those seeking treatment for information, whilst avoiding the possibility that this information could be used to select a donor possessing certain characteristics for reasons that are incompatible with or not relevant to the welfare of the child. For example, those seeking treatment are expected not to be treated with gametes provided by a donor of different physical characteristics unless there are compelling reasons for doing so.” (HFEA 2004:32-3)

This issue requires further research and consideration by the HFEA and other interested parties.

### *Egg sharing*

Egg sharing is a process whereby couples are offered free or 'at cost' IVF treatment if they are willing to donate a percentage of their eggs for the treatment of others. It is the subject of some controversy and opinion is divided about the ethics of this process (Blyth et al 2003). Commercial egg donation is not allowed in the UK, (though the practice is widespread in the US) and there is a serious shortage of eggs (especially from Asian donors). An egg-sharing facility is offered in a minority of clinics and none in our study. Perhaps not surprisingly then, none of those interviewed had heard of such schemes, since this had not been the subject of any discussion with clinic staff. Although clearly people needed time to consider this option and were actively thinking through some of the implications in the process of the interview, it is fair to say that their responses were not always negative and several participants expressed



an interest in finding out more about such schemes. Given the acute shortage of Asian eggs and the continued need for Asian sperm, it is perhaps noteworthy that no participant had been offered any information about becoming an egg or sperm donor.

## **2.6 Adoption**

The question of adoption was raised in interviews with individuals and again a varied response to this issue was evident. For those undergoing treatment, approximately one third did not want to consider the possibility of adoption. This is not surprising, since non-medical solutions are only looked to by most couples (and doctors) when attempts to achieve a pregnancy have proved futile.

Four participants ruled out adoption altogether, three because they already had one child and one because she felt that the most likely consequence of continuing childlessness for her would be divorce. A small number of women reported that they would consider adoption but this was not likely to be acceptable to their husbands. Adoption outside the family was considered to be less acceptable socially and culturally than intra-familial adoption, but most couples viewed any form of adoption as very much a last resort.

Two couples who had given the most thought to adoption were both from Muslim families and both indicated religious support for this practice. A positive view of intra-familial adoption was also echoed in the focus groups. While formal adoption (*tabanni*), where the name of the child is changed, is not permissible in Islam, if one takes care of a child as a custodian or guardian, 'adoption' is permitted as long as the child retains the name of the biological father. The key informants, including an Asian adoption worker, also argued that formal adoption is relatively uncommon in most Asian communities, but is growing in acceptability in some. The practice of formal and *informal* adoption within families was suggested as a not uncommon response to childlessness. There appears to be little literature on adoption in British South Asian communities. Informal adoption is reported among infertile couples in India (Unisa 1999), though a contrary view is expressed by Bharadwaj (2003) who found negative feelings associated with adoption in a study of Hindu couples (in India) because it is a highly visible indicator of infertility. Couples were more likely to opt for donor treatment rather than adoption. In India, adoption leaves the child and family open to stigma, especially since most available children are those abandoned by mothers because they were born outside of marriage.

Nevertheless, it is important not to over-emphasise the ethnic differences in perceptions of adoption. Studies with 'white' childless women have also shown that adoption is regarded as a last resort after medical treatment has failed (Denny 1994). It is not simply parenthood, but biological parenthood which is defined as normal. It is blood ties that are seen to bind people together (Miall 1994, Strathern 1992).

## **2.7 Accessing infertility treatment**

As we have seen, infertility is a stigmatising condition in South Asian communities. The effects of this process may also extend to the treatment of infertility. While as we shall see, most communities felt that people would seek medical help for infertility, there was also a degree of suspicion about infertility treatment, especially in the

Bangladeshi Muslim community. The use of donated gametes is highly disapproved of across all communities, and this gives rise to concerns that any form of infertility treatment might involve the use of third party biological material. Such concerns may mean that some women are discouraged by families from accessing treatment, although we have no evidence that this is the case. Accessing treatment would also, in many cases, reveal the stigmatised condition and this too might prevent people from seeking medical help. On the other hand, the stigma and humiliation of childlessness may be worse than the stigma of treatment and this may drive people to seek treatment at an early stage.

### *Experience of primary care*

In general South Asians have a high rate of consultation with family doctors. Access, however, should be thought of in terms of quality of care as well as formal access to services (Rhodes et al 2003). A range of barriers to care may exist (Rosen et al 2001, Acheson 1998).

The key informants suggested that individuals without a good knowledge of English were more likely to have poor knowledge of and access to a wide range of health and social care services. This is a common finding in the health literature (Cohen et al 1998, Chamba and Ahmad 2000, Rhodes et al 2003). Given a paucity of interpretation arrangements in primary care, non-English speakers are constrained in their choice of GP by the need to choose someone of the same language group (Modood et al. 1997). Hennink et al (1998) found that many Asian women would prefer to consult with a non-Asian female GP for family planning needs, but that many are compelled to consult a Asian GP because of communication difficulties and Asian GPs are invariably male.

The focus group participants and key informants, as we have seen, felt that most people would know that medical help of some kind was available to help with infertility. Although most people have 'access' to a GP, participants suggested that women may be reluctant to present to the GP with fertility problems. Several reasons for this were suggested. Some felt that where women had an Asian GP (common in the inner-city areas under study) women might be discouraged from speaking to their GP for fear of breaches of confidentiality. Others felt that some women and men would be too embarrassed to discuss such a sensitive issue with a male GP. Several suggested that women who had an English speaking GP and who were not fluent in English might not want to use an interpreter for such a topic, because of embarrassment or concerns about confidentiality. Katbamna (2000) found that some South Asian women are reluctant to consult a male GP from the same ethnic background because of modesty restrictions (Katbamna 2000).

Many focus group participants reported that they believed that many men would be very reluctant to go for tests, either because they saw infertility as the woman's responsibility or because they might be fearful of revealing a problem with their own fertility.

The suggestions about accessing treatment made in the focus groups, were in many cases confirmed in the interviews with infertile individuals. Almost a third of couples expressed some degree of dissatisfaction with their GP. Several felt that their

concerns had not been taken seriously by their GP or there had been an unacceptable delay in referral to secondary care. They mentioned being ‘fobbed off’ and told to ‘go away and keep trying’. Three participants specifically mentioned concerns about confidentiality of information on the part of the GP or other clinic staff. Experiences are clearly variable however, since five people made very positive references to their GP, reporting that their case was very well handled and their GP sympathetic to their situation.

Effective access to services may be less influenced by ethnicity or religion than more general educational levels, socio-economic status, and employment outside the home (Hennink et al 1998, Rhodes et al 2003). More articulate professional participants felt that they were in a better position to insist on being taken seriously than others who might find it more difficult to challenge health professionals. Referral practice in relation to infertility is variable, with some GPs carrying out investigations before referring patients, others referring to secondary care without prior tests. A minority of patients interviewed reported having had tests carried out in primary care. The clinic practice also varied in terms of their use of tests carried out by GPs. Some clinics were happy to use these, while others ordered tests to be repeated. For those accessing private treatment, this is a considerable additional cost. For some patients however, a direct referral to secondary care was preferable to having the GP carry out tests, since they felt that this would speed up the process of receiving help.

A more generalised dissatisfaction with the GP service was evident in many focus groups and in around 12% of individual interviews. This was not a consequence of lack of a common language or even of cultural misunderstandings, since many GPs referred to were themselves of Asian origin. It related to a general feeling that consultations were rushed, the doctor’s manner often brusque and patients concerns were often not taken seriously. Several of the key informants commented on what they perceived to be the often poor quality of primary care services in some inner city areas where many South Asians live (Acheson 1998). Atkin (2004) has argued that the primary care agenda has been slow to provide accessible care, appropriate to the needs of minority ethnic populations.

Having accurate information is an important pre-requisite to exercising choice and feeling some element of control over what can be a de-humanising process. Only a quarter of people reported that they had received any advice about infertility from their GP. This is a slightly lower percentage than that found in a large scale survey of patient satisfaction with infertility treatment (ethnicity unspecified) which found that over a third of patients felt that they had received sufficient information from their GP (Kerr et al 1999). None of our participants had had been given any *written* information about infertility by their GP.

## **2.8 Infertility treatment in secondary care**

The infertile individuals and couples interviewed were asked a series of questions about their experiences of accessing and receiving infertility treatment. We have already discussed the experience of primary care and in what follows we examine a number of other issues, which arose during the interviews. These include: access to information; interactions with health professionals; communication, interpretation and translation; cultural understanding; religion and infertility treatment; financial issues;

emotional support; best and worst experiences of infertility treatment. The interviewers also asked participants to give their perceptions of the worst and the best aspects of treatment and invited participants to offer advice to health professionals for improving services. This cannot be taken as some overall measure of satisfaction or dissatisfaction; that is not the objective, since responses to treatment are complex. Patients may experience satisfaction and dissatisfaction with regard to different aspects of care and even in a single infertility episode, there are many possible dimensions in which satisfaction can exist (Malin et al 2001). It is also complicated by the fact that for most people, infertility treatment takes place over a long period and involves interaction with a variety of doctors and nurses. The objective here is to have a view of what people have found helpful and what is not helpful in the context of infertility treatment experiences (Monach 1993), and this includes aspects of the availability, accessibility and process of care.

### *Access to information*

Evidence suggests that patients are more satisfied with their encounters with health professionals when they understand what is happening to them and they have had an opportunity to explain their needs (Street 1991, Monach 1993). A failure to provide accessible information about services and options can prevent people from making informed choices about their treatment. According to the HFEA, over a quarter of all couples who embark on fertility treatment will drop out because they find it too stressful. There is evidence to suggest that the more information and support patients have the more likely they are to be able to cope with their fertility treatment ([www.hfea.gov.uk](http://www.hfea.gov.uk)).

Our participants were at various stages in their investigations and treatment and so their information needs varied. Of the 37 'cases' included in the study, 14 were in the treatment process and 11 had completed the majority of tests and received a diagnosis. The majority of these patients reported feeling relatively well informed about the nature of their condition. Three quarters of those with a diagnosis had been told that their infertility was 'unexplained' and this left many feeling frustrated that they did not seem to have a specific condition which could be treated. A small number of participants expressed concern about not understanding the nature of the tests they had undertaken. In one extreme case, this left a woman about to undergo a laparoscopy (abdominal exploratory operation under general anaesthetic) in a highly anxious state.

Experiences of receiving information about treatment options were varied. While some patients felt that they had sufficient information from consultants who had spent a considerable amount of time with them, explaining their options in a friendly and helpful manner, others reported feeling that they lacked information about treatment options. Several participants said that they were relatively well informed because they had carried out their own research. Half of the participants felt that they had not been offered enough information about possible options at the beginning of the process. Many still felt unsure about some aspects of the treatment or about what options might be open to them. Sometimes, this information was only forthcoming after some 'pushing' by participants. One participant made an appointment with her GP to discuss issues that the clinic had not fully explained. Others felt that although

information had been given to them at the outset, it was a lot to take in at the time and rather daunting.

Information needs and the desire for information clearly vary between individuals and professionals have to make an assessment of how much information of what kind to give to people at various points in their investigations and treatment. However, around a half of participants felt that they had not been offered sufficient information about options at the beginning of the process and over a quarter of individuals felt that they needed more information at the point in time at which they were interviewed. For some, the information they had been given was not in a form which they could fully understand and this meant that they had “stumbled through” tests without really understanding why. This was primarily related to short appointment times and the lack of opportunity to clarify issues. Several also felt that they needed a written individual plan of care to which they could refer and which would set out the timescale for their treatment.

A minority of patients said that the language used was too technical and their consultants had not taken time to check their understanding. One participant had paid for an extra session with her consultant specifically to check through her understanding of the issues. On the other hand, one participant from a different clinic, highly praised the amount of time and care that the consultant had taken in explaining things to her in a vocabulary she could understand. Patients require access to good quality, evidence based information so they can take an active part in decisions about their health care (Thornton 2001).

Approximately one third of participants reported that they had received some form of written information about infertility and treatment and most of those were currently in treatment. Of those who were still undergoing investigations, only one patient reported having been given any written information. Of those who had not received any written information, most suggested that they would find this very useful in making sense of their treatment.

Several participants mentioned accessing information on the internet as an alternative to clinic information. The quality of this information remains variable (Pandey et al 2003). Health professionals need to be able to direct patients to sources of good quality consumer health information, including health related websites (Shepperd et al 1999). The HFEA has produced an extensive guide to infertility with real case histories to help people anticipate and plan for the practical and emotional difficulties they might face. It also has detailed medical explanations of what each different type of fertility treatment involves. There is a profile of all clinics licensed by the HFEA showing the treatments they offer, eligibility criteria and details of support services like counselling (HFEA 2004). As we shall see later, no information is provided in languages other than English.

Couples where one partner did not have good English expressed the view that it would have been very helpful to have information in the appropriate language, so that more time could be spent in translating properly for the partner. Several of the English-speaking participants also noted this as problem for those who did not speak or read English and stressed the benefits of having some written information in other languages.

These findings confirm those of previous studies that have identified a need for more information and explanation for patients. In his study of (primarily) white couples, Monach found that 40% complained of a general sense of not knowing what was happening to them or why. Satisfaction surveys have also highlighted lack of satisfaction with information giving about possible causes of infertility, drugs and the time scale for investigation and treatment (Souter et al 1998, Kerr et al 1999).

### *Interactions with health professionals*

Patient centred care means that patients should have an opportunity to ask questions and to feel involved in the decisions made about their care. Several features of the reported interaction with health professionals are worthy of discussion here. As we have seen above, there was a general dissatisfaction with primary care expressed in the focus groups, informant interviews and individual interviews with infertile individuals. Many of the latter group also had specific complaints about not being taken seriously by GPs, delays in referral and lack of information or advice about infertility.

The extent to which patients experienced patient centred care in infertility treatment varied between clinics and between individuals. Infertility is not a conventional illness. It is not life threatening and treatment is 'optional'. Many treatments have potentially harmful side effects, and most of these risks are taken by women. While some felt that options had been clearly explained to them, with a friendly approach and time given to ask questions, others felt they had not had the opportunity to hear about treatment options in enough depth because consultations were "rushed". Less than half of these felt generally satisfied that they had been fully involved in the decision making process with the opportunity to ask questions. Eight participants felt that they had not had the opportunity to ask questions or to discuss their concerns with consultants, and they attributed this primarily to the lack of time at appointments. Four participants specifically mentioned a lack of continuity of care, having to see different doctors at each consultation, which they felt had led to some inconsistency in their treatment. Several mentioned the need for a plan of what might happen and what their options would be. As we saw above, a significant minority did not feel that they had all the information they needed to be fully informed about treatment decisions. The HFEA has recognised the importance of offering a "guiding hand" to patients through the maze of different treatments, including a lay version of what treatment involves; information on success rates and patient stories. (HFEA 2004).

### *Sensitivity of staff*

Most respondents reported that staff were generally sympathetic and sensitive in their approach to couples, although a significant minority (20%) felt that staff could have been more sympathetic, especially when treatments failed. These women gave examples of unsympathetic responses when phoning the clinic to tell them that the treatment appeared to have failed. Some felt that they were treated as "just another women who wants a baby"; "another number rather than a person". Some women had built up good relationships with clinic staff over long periods while others reported a perceived lack of sensitivity on the part of clinic staff. One participant mentioned the

insensitivity of being put on a hospital ward next to a woman undergoing a sterilisation.

Some participants thought that health professionals might be de-sensitised from dealing with infertility on a day to day basis; others felt that perhaps professionals did not understand fully the emotional aspects of infertility. Some patients expressed the view that it was difficult for anyone who had not gone through the treatment to really empathise with patients. However, there were also examples of excellent care in this regard, with three women reporting what they regarded as extremely positive and encouraging interactions with particular health professionals (two nurses and one doctor).

Participants were asked if they felt that they had been treated differently because of their race or ethnicity. Six participants reported feeling that they had been subject to ethnic, religious or sexual stereotyping in some way, most commonly by medical staff. These were individuals of higher socio-economic status, though all ethnicities and religions were represented. Three felt that they had been subjected to the stereotype of the 'Asian woman.' One woman reported being told that her dislike of internal examinations was because of her "culture" when in fact she had endometriosis making internal exams painful. Another felt she was being treated as an Asian "who just wants loads of kids" and others reported being told that they could not be informed of the sex of their unborn child because they were Asian. One woman reported that she had been asked if she had returned to have a second child just because her first child had not been a boy.

Four women (two Muslim and two Hindu women) reported that they would have preferred the option of being seen by a female doctor, with two expressing considerable concern about being examined by a male doctor. Only one participant mentioned being offered the choice of a female doctor. Several studies have demonstrated the importance of offering women the option of a female doctor (Hennick et al 1998, Khan 1999, Katbamna 2000, Atkinson et al. 2001).

### *Communication, interpretation and translation*

Competent communication is crucial to accurate diagnosis and effective treatment (Bradby 2002). Ineffective communication is likely to lead to worsening health outcomes (Hornberger et al 1996). While communication clearly is about more than language alone, communicating across a language barrier presents significant difficulties for many patients in the NHS. According to a major national survey by the Policy Studies Institute (Modood et al 1997), more than three-quarters of Asian men speak English fluently or reasonably well, the highest proportion being East African Asians. There is little gender difference in this group, but in other Asian groups, women are less likely to speak English well. This is strongly linked to age, with younger people in all groups much more likely to speak English well, but also to ethnicity. In the 25-44 age group, while 92% of African Asian women were fluent in English, this was only 47% and 27% respectively for women of Pakistani and Bangladeshi origin. Substantial numbers of South Asian individuals, especially in the older age groups, while able to understand and speak English, do not necessarily regard it as their first language or preferred language. This has clear implications for health care delivery.

A quarter of the people who were currently receiving services were non-English speakers. Nine cases included one partner who did not speak good English. In five of these, the non-English speaker was the female and in two cases, the male did not speak English. The non-English speakers' languages were Punjabi (two), Gujarati (three) Bengali (one) and Tamil (one). In a further two cases, non-English speaking women attended for appointments on their own (one Bengali and one Urdu speaker).

The situation regarding use of interpreters in this study was complex. A mixture of formal and informal interpreting was reported. The two women who attended on their own had access to interpreters. One was accompanied by a Bengali linkworker, and one had access to a hospital interpreter and they did not report any problem with these arrangements. The couples however, relied on each other for interpretation. They reported that they had not been offered an interpreter since it was taken for granted that this was not required. The male partners in this situation did not report any problems with this arrangement. However, it was not possible to interview their wives separately to determine their perspectives.

The two women who were interpreting for their husbands, both expressed reservations about this. One reported that both she and her husband found this situation very difficult. Infertility patients are often dealing with issues that may be complex and difficult to come to terms with. Having the responsibility to convey information to her partner at the same time as trying to comprehend the situation herself was described as very stressful. The second female patient who translated for her husband was concerned about the quality of the information she was giving her partner, suggesting that, understandably, she found it difficult to translate the information during the consultation, but that if she waited until later she sometimes could not remember everything that had been said.

The health professionals were also asked about interpreting arrangements. This produced a range of responses. There were few instances reported of official, trained health interpreters being used. Two of the clinics reported having access to a reasonably good interpreting service, and one felt that the service was less than ideal. In many cases, members of staff from other parts of the hospital were used to interpret for patients. These included nursing staff and receptionists. Some nurses reported resorting to mime and sign language. Several reported that patients brought relatives with them to interpret. The health professionals suggested that in the cases where one partner was able to speak English, interpreters were commonly refused by couples and thus the situation of partner interpretation was accepted.

When questioned directly, many of the health professionals, especially the nurses, reported feeling very uneasy about using informal interpreters and about using partners to interpret. Discussions with patients about infertility often contain reference to sexual practices, intimate body parts, sensitive bodily processes and other highly personal details. Several nurses expressed the view that informal interpreters (including hospital staff) sometimes displayed obvious embarrassment in this situation and the nurses expressed doubts about whether they were able or willing to interpret fully and accurately. Health professionals also expressed concern about the use of partners, especially husbands, to interpret. Several nurses and two consultants expressed some reservations about the quality of the interpretation in this scenario and



expressed some doubts that a full account was always relayed to the female partner. One nurse reported that female patients often seemed anxious in this situation. Using husbands was reported as particularly problematic for women when male factor infertility was diagnosed.

Counsellors also spoke of difficulties working with non-English speaking patients. They reported rarely using professional interpreters, mainly because of patient preference. Asian couples were reported to be concerned about the confidentiality of the sessions, where very sensitive and highly personal issues were being discussed. Counsellors reported using family members as interpreters on occasions, although here too, they could see that this was not without problems. They also used partners to interpret as in the clinical sessions, but again expressed reservations about knowing just what information had been conveyed.

The use of informal interpreters such as family members may occur because couples and individuals are not offered a formal, trained interpreter or it may occur because people prefer to have someone they know rather than an unknown interpreter. This may be because they have concerns about confidentiality or because they do not wish to put an extra burden on staff in a situation where they often feel very grateful to be having any treatment at all. In the third scenario couples rely on each other for interpretation, and in our study some at least report finding this stressful and difficult, trying to come to terms with what can be painful news whilst also being responsible for communicating this to a partner. The fact that the distress which might be involved in imparting 'bad news' may render communication even more difficult has been discussed by Bradby (2001). One nurse reported that in one clinic (not in this study) a new consultant had stipulated that there should not be a reliance on partners to interpret and that an insistence on a professional interpreter was now made clear to patients.

In all cases, the health professionals and counsellors had concerns about the quality of interpretation where partners or other informal interpreters are used. The need for high quality interpreting services has long been recognised as essential to understand and meet the needs of people who do not speak the majority language. A number of consequences of communication problems have been identified: patients are less likely to consult about ill health in the first place; the development of trust between patient and practitioner is hindered; a lack of compliance with medical regimes is possible and concordance is unlikely (Rhodes and Nocon 2003). Good communication is also essential in ensuring proper informed consent to procedures and treatments.

In the case of regulated infertility treatments, the issue of informed consent and the legal requirements concerning the need to consider the 'welfare of the child' make good communication essential. Professionals need to be assured that patients are fully aware of the implications of treatment and patients need to be fully informed to make a series of important decisions about, for example, the implications of using donated gametes, the freezing and storage of embryos and their use in research.

However, the failure of the NHS to adequately address the language needs of South Asian and other minority communities is well documented (Audit Commission 1994, Johnson 1996, Nazroo 1997, Szczepura et al 1998, Chamba & Ahmad 2000, Robinson 2001, Ali et al. 2003, Rhodes & Nocon 2003). Atkin (2004) refers to the

lack of appropriate language support as an example of institutional racism. Family members speak of the difficulties in deciding how much to tell non-English speaking relatives, often wanting to 'protect them' from upsetting information. Relatives may also filter information during the consultation and (as reported in our study) try to convey the exchange at a later date. The consequence of this is that relatives may lack important information about their condition and about treatment options (Anionwu and Atkin 2000 Bhakta et al 2000). As a study of Bangladeshi diabetes sufferers showed, the lack of immediate translation, limits the capacity of people to take an active part in the consultation and prevents them from asking their own questions based on the information provided at the time (Rhodes & Nocon 2003). This too was reported by the health professionals in this study. The quality of translation is also potentially problematic; one study found a very high incidence of mis-translations, misunderstandings and omissions (Ebden et al 1988).

Using nursing or reception staff may appear to be a practical alternative where the professional interpreting service is poor, but such staff are unlikely to have formal training and skills to allow accurate and sensitive communication (Elderkin-Thompson et al 2001). 'Making do', however, also has deleterious effects and there were several examples in our study where mis-communication with clinics had resulted in women being out of the system for some time or not sufficiently understanding the details of medication so that treatment cycles had to be cancelled.

The practicalities of using interpreters for all appointments however, have to be considered. It should be possible for practitioners to pre-book interpreters for consultations where results are to be discussed and options considered. However, the nature of infertility treatment means that many clinical appointments are hard to predict and may be needed at short notice. In this case, the use of remote or telephone interpreting services should be considered. Telephone interpreting has obvious disadvantages but does at least allow some communication and may in fact be a preferred option where patient confidence in the confidentiality of a consultation is an issue, as in the present study (Pointon 1996).

The use of formal interpreters does not necessarily ensure good communication. There are examples of interpreters having insufficient specialist knowledge and skills to interpret clinical information and patients may gain misleading information about their care options (Atkin et al 1998). It is also important that interpreters are culturally sensitive and aware of the social context of the patient and it may be necessary to insist on an interpreter of the right sex. Women and men from cultures with strict codes of modesty may find it difficult to discuss intimate bodily problems in the presence of a male interpreter (Haffner 1992). It is also evident that most health professionals and counsellors have little training in the effective use of interpreters and this should be a mandatory element in health professional training. Useful guidelines are available for communicating across a language barrier (Henley 1991, Phelan & Parkman 1995).

#### Access to translated information

Infertility investigations, diagnoses and treatments are sometimes complex and patients are likely to be faced with a number of options for treatment. The social and personal implications of fertility treatment are considerable. The person treated is usually healthy and drug treatments can have harmful side effects and require careful monitoring. As we have seen, some clinics provided a substantial amount of written

information for patients about infertility and treatment and this was appreciated by those who received it. However, the project team were unable to locate *any* written information about infertility in any language other than English.

Patient information leaflets giving information about causes of infertility, treatment options and success rates, were only available in English. All consent forms were in English only. One translated leaflet was available from the HFEA, but this was limited to explaining the role of the HFEA and had no information about infertility itself. Ironically, the only written information our non-English speaking participants had seen regarding infertility was the patient information sheet and letters of introduction for the research project, which had been translated into four Asian languages.

The lack of translated material is a serious constraint on patient understanding and informed consent for non English-speaking patients. Several couples where one partner acted as interpreter, reported that they would have found it very useful to have some translated information to take away as a back up to the consultation. As we have seen, many English-speaking participants felt that they needed more information. For English speakers there are a wide range of alternative sources of information, including the internet, books, magazines and other popular literature where infertility is discussed, and these are widely used by couples experiencing fertility problems.

These alternatives are not available for non English-speaking individuals who are almost entirely reliant on information given to them by the clinicians in the course of (sometimes very short) appointments. People may take English language versions of information to be translated by other family members, but as we have seen, many couples wish to keep their treatment private from family and friends, whilst others may not have family members available who could translate technical information of this kind. Also, while some patients are able to discuss their concerns with friends, work colleagues and other acquaintances, as we have seen from the focus groups, these issues are not likely to be widely discussed within South Asian communities. Several respondents mentioned the fact that infertility was not something they could openly discuss within the family or community.

An inability to speak English does not, of course, mean that people are literate in their mother tongue (Tuffnell et al 1994), and alternative formats such as audio and video materials may be needed for some people. Since translation and production costs can be high, it would be more appropriate for this to be provided by one agency, with information available for clinicians to access from an intra-net or internet site.

If clinics are to provide translated written or audio-visual information, they need to be aware of the ethnic and language backgrounds of local populations and of patients. However, analysis of ethnicity data in the clinics was poor. While some information was recorded, there was little evidence of it being monitored or analysed. The majority of professionals interviewed had difficulty in accurately reporting even a broad estimate of the percentage of their patients of South Asian origin. There was little evidence that clinics had a clear understanding of the ethnic, religious or language profile of patients. A failure to adequately monitor and analyse ethnicity data in the NHS is well established (Gerrish et al 1996, Aspinall 2000).

Infertility treatment in clinics licensed to perform certain treatments such as donor insemination and IVF are subject to regulations determined by the HFEA. Failure to comply with aspects of these regulations can result in criminal charges being brought against the license holder. The HFEA regulations stipulate that all UK licensed clinics must supply written information to prospective patients before offering treatment. This information should give details about the services it offers, any risks involved in treatment, costs, previous live birth rates and complaints procedure. According to the HFEA guidelines, this literature should be comprehensive and easy to understand. As we have seen, at the present time, none of the clinics in the study included such information in any language other than English. The HFEA as the regulatory body also produce a range of information in booklet form and on their website. This includes detailed guidance on infertility, guidance on clinics and how to access them, eligibility for NHS funding and information on making a complaint. This is available in English only.

### *Cultural understanding*

Effective cross cultural communication requires an awareness of one's own values; a respect for difference; a knowledge of what aspects of a patient's culture might be of particular significance in treatment and an awareness of the possibility of operating with stereotyped views of 'other' cultures (Gerrish 1996, Culley 2001). Interviews with infertile individuals and couples revealed that approximately 12% reported that staff had on occasions responded to them in a stereotypical way, but this was not a strong feature of the interviews. This may have been affected by the perceived ethnicity of the (white) interviewer, although none of those interviewed by Asian interviewers expressed this concern.

Health professionals' awareness of the heterogeneity of South Asian populations was variable. Few were able to differentiate between communities in terms of ethnicity or religion, although several referred to Muslims as a distinct group. The dominant mode of differentiation used by health professionals was between 'Westernised' and more 'traditional' patients, although this was also bound up with educational levels and general socio-economic status. Health professionals broadly felt that, almost irrespective of ethnic background, the key feature in levels of understanding of infertility, attitudes to treatment and compliance with treatment was seen to be the extent of 'Westernisation' or the level of education of patients. Two professionals reported that Asian patients are more 'demanding' than white patients and have higher expectations of treatment. One consultant expressed the view that the non-English speaking patients were problematic because of the additional demands that would be made in time taken to take a history and explain treatment.

Many health professionals recognised what they regarded as the considerable additional stress that some South Asian women faced because of family pressure and several reported that they were aware that while confidentiality was an issue for many patients, it was especially important for South Asian couples.

Health professionals were asked if they felt that they were adequately prepared to meet the needs of minority ethnic groups. None of the consultants interviewed had undertaken any training in ethnicity or diversity issues and most felt that they were less than adequately informed about South Asian communities. Most of their

knowledge had been picked up experientially. A small minority of nurses had undertaken short cultural awareness training courses. All the health professionals acknowledged deficiencies in their knowledge of ethnic diversity and most expressed a desire to learn more. This was usually a desire for 'cultural' information about religious needs or specific religious festivals or a need to understand "why people need to disappear to India or Pakistan" in the middle of treatment.

Two nurses reported that they would like to learn to speak at least a few phrases of South Asian languages to help them communicate with patients. All of the counsellors felt that there was a need for more information for professionals about working with patients from minority ethnic communities. The inadequacy of health professional education on issues of diversity is well documented in the literature (Gerrish 1997, Culley 1997 & 2000).

### *Religion and infertility treatment*

The importance of religion in infertility is widely recognised (Inhorn and Van Balen 2002). Religion can be seen to play a role in the desire for children, in the aetiology of infertility and in attitudes to treatment options. As we have seen religious reasons were among the many different reasons people gave for desiring children. Few participants discussed infertility as a form of divine retribution, although the older Sikh males felt that it could be that infertile people were facing the consequences of things they had done in a past life. In the focus groups across all communities, prayer, fasts, pilgrimages and other religious rituals were mentioned as sources of help for infertile couples. It was also commented that women would seek help from molanas and other religious or spiritual individuals, although people felt that in most cases this would be alongside medical treatment not a substitute for it. The older groups were more likely to discuss the significance of religion and more likely to see prayer and other rituals as important in overcoming infertility. The will of Allah was especially important for the Muslim groups as it was seen that Allah was ultimately the giver of children. This did not however, imply a fatalism and rejection of medical treatment. Indeed, it was regarded as a religious duty to seek a cure for illness.

Over two fifths of the infertile individuals reported that religion had been important in helping them to deal with their experience and many made the point that religion had become more important to them since they discovered fertility problems. Over 10% of infertile individuals reported having consulted a religious figure for help with their infertility. Recourse to religion is an acknowledged way in which people may make sense of 'disrupted lives' (Richards 2003). We have also seen that religious beliefs can be important in the acceptability or otherwise of treatment options, particularly in relation to donated gametes.

Religious teachings within faiths such as Islam may also require certain codes of conduct that can affect treatment. Modesty rules and rules governing conduct may make the use of the health service difficult for some in the absence of appropriate provision (Katbamna 2000). A preference for female doctors for example, has been noted in the health literature (Hennick et al 1998; Khan 1999). Relatively few participants mentioned this as an issue in the interviews, perhaps reflecting the reality that this was simply not available for most couples. It could also be that in the context of the waiting lists and rationing of treatment, and the degree of discretion over which

consultants can exercise, this was something that women did not feel they could raise. Of those who women who reported this as an issue of concern, two gave their religion as Muslim and two as Hindu.

### *Financial issues*

The availability of some fertility treatments on the NHS is very limited. While many will have relatively easy access to treatments such as ovulation induction which may be provided by general gynaecology services, more complex procedures such as IVF and IVF/ICSI are highly rationed. There is postcode lottery in operation. Some Primary Care Trusts (PCTs) do not fund any IVF, others offer one, two or three cycles of NHS funded treatment. There are also variable and increasingly restrictive eligibility criteria in operation (age, existence of any previous children, marital status, sexual orientation etc). This creates extreme inequity of provision between people according to where they live. At the present time around 75% of IVF cycles are funded by patients.

In February 2004 NICE produced guidelines for the treatment of infertility, recommending that each eligible couple should receive three cycles of NHS funded IVF. The government, however, announced that this would not be fully implemented for some years, recommending to PCTs that they offer a minimum of one funded cycle of IVF by April 2005. Assisted conception treatments are costly and the financial implications of treatment are considerable. Some NHS clinics offer a self-funding service, in which treatment is provided 'at cost' and is cheaper than in private clinics, though still around £1500 to £1700 per IVF cycle, plus the costs of drugs. In some cases, PCTs will fund drug costs even where the procedure itself has to be self-funded but again this varies between different PCTs. Treatment at a private clinic (which many choose because of long NHS waiting lists, or because they fall outside NHS eligibility criteria) can cost up to £7000 for one cycle of ICSI/IVF including drugs.

Of the 18 individuals undergoing IVF in this study, 17 were wholly or partially self-funding. Sixty-six per cent of these patients gave their occupation as professional/managerial or intermediate. Of the patients who were still under investigation or on waiting list, 39% were from these higher occupational groups, with 61% from lower supervisory, semi-routine or unclassified occupational groupings (see NS-SEC categories available online at: [www.statistics.gov.uk](http://www.statistics.gov.uk)). One possible implication here is that those who go on to funded treatment are more likely to be of higher income levels, though more evidence is needed here.

Some South Asian groups in the UK suffer from economic deprivation. This is particularly acute for the Pakistani and Bangladeshi communities, where over 60% of households have incomes below the poverty line. Even the more 'prosperous' minority groups such as the African Asians are worse off than their white equivalents in income terms (Platt 2002). South Asian groups then, especially the Pakistani and Bangladeshi groups are likely to find a lack of NHS funding means that some forms of treatment may be difficult to afford and potentially out of reach.

Many participants were concerned about the financial aspects of treatment and several expressed the view that the rationing of NHS provision was unfair. There was,

however, a degree of resignation to the need to pay and some participants had chosen to pay for treatment rather than wait on an NHS list. Two participants had chosen private treatment because of a general dissatisfaction with NHS services. Only four couples said that the cost was not an issue for them. Others reported the adverse impact of the expense on their family and their lives generally. Most of those awaiting treatment expressed anxiety about the financial impact of treatment. Two people who had accessed treatment and had children reported that they were unable to consider further children because of the cost and one mentioned the considerable burden of paying off the loans they had taken out for treatment for their first child.

Strict eligibility criteria operate for NHS treatment. A key feature of this is age, with all centres operating an age range for IVF treatment. The usual concern of commentators is the upper limit, which clearly discriminates against the over 40s. This is justified by commissioners of services in terms of the sharp decline in fertility and success rates of IVF treatment in this age group (although private treatment of women in their late 40s is not uncommon). In most cases, eligibility criteria include a lower as well as an upper age limit. This is also variable around the country, but most eligibility criteria rule out those under 25 years.

For some of the South Asian groups however, a lower age limit could be problematic. The mean age of marriage for the Pakistani and Bangladeshi communities is significantly lower than that for the white community. If, as we have seen, early childbearing is also socially mandatory in these communities, then imposing a lower limit on NHS treatment will potentially differentially affect the access of these communities to NHS IVF treatment. While this may be considered a reasonable restriction for those younger people with unexplained infertility of relatively short duration, if it is a criterion applied across all clinical cases, it may well discriminate against younger couples who have medical conditions (e.g. azoospermia, blocked fallopian tubes) which mean they have virtually no chance of conceiving a child without assisted conception. The recently issued NICE guidance appears to suggest a lower age limit of 23 or infertility of three years duration.

### *Emotional support*

As many have argued, for most people infertility is an unexpected, unwelcome, and unpredictable biographical disruption and infertility treatment is an emotional roller coaster (Monach 1993, Greil 1991).

The study was not designed to explore the emotional world of the participants, but inevitably, many expressed a range of feelings about their treatment. Fears, hopes and anxieties about treatment were shared with interviewers. Several expressed fears that IVF might be unsuccessful and that their hopes of having a child would be lost. Others expressed concern about the possible mixing up of gametes or embryos, following a media report of this occurring at a UK clinic. Others found physical aspects of treatment difficult to cope with because of reactions to medication or painful injections. Others mentioned the disruption to the lives of existing children in their family; problems created for careers and jobs; a general feeling of frustration that they were not in control of their lives and of course the extreme disappointment experienced when treatment fails.

Most people relied on their partners for emotional support. Men were generally reluctant to discuss the emotional impact of infertility and more likely to stress the adverse impact on working lives. From the accounts of women, however, it was evident that men relied heavily on their wives for emotional support, perhaps adding to the burden of women who were having to come to terms with their own feelings. Women also relied on husbands for emotional support, but were more likely to have confided in family or close friends. Over 20% of couples had not disclosed their problem to anyone.

Over 20% of those interviewed (all women) felt that they would like more support in dealing with the emotional impact of infertility. They wanted to have someone to discuss their feelings with, especially those who were further on in their treatment. While several felt that they had enough support from their partner or family, others mentioned the difficulty they had in not being able to draw on the family for emotional support in the case of infertility. One participant felt that this was particularly problematic for some Asian women, because of the added strain of living in an extended family where a lot of pressure was placed on women to produce a child. The additional burden on women was also mentioned as an important theme in the key informant interviews and focus group discussions. The desire for more help with the emotional aspects of infertility is confirmed in larger quantitative studies of patient satisfaction (ethnicity unspecified) (Souter et al 1998, Kerr et al. 1999).

Counselling has an important role to play in the process of infertility treatment and some argue that counselling should be regarded as a routine part of all infertility treatment (Blyth 1999). However, most of the counselling that takes place in infertility clinics is 'implications counselling' rather than support or therapeutic counselling and some private clinics may make an extra charge for this.

The HFEA guidelines make it mandatory for clinics to *offer* implications counselling for any treatment involving donated gametes or IVF and clinicians may involve counsellors in assessing the suitability of patients for treatment to ensure that the 'welfare of the child' has been considered. Counsellors themselves are ambivalent about their role in such assessments (Blyth & Hunt 1994, Williams and Irving 1998). This counselling should be carried out by someone who is not involved in the treatment process, but she/he does not have to be a trained counsellor. The HFEA also recommend that support and therapeutic counselling should be made available to patients. The uptake of support counselling in infertility, however, is poor (Boivin et al 1999). One large scale survey reported that around 14% of infertility patients had been given help by clinics with the emotional aspects of infertility (Souter et al 1998), although a majority of respondents said they would request counselling if it were offered free (Kerr et al 1999).

Approximately 12% of our participants had not been offered counselling. These were all patients still undergoing tests or receiving non-licensed treatments and so an offer of counselling is not mandatory for this group. Others were aware that it existed, but only 16% had experienced any counselling. The counsellors interviewed as part of this study all reported a low uptake of counselling generally by South Asian couples. In contrast to the questionnaire surveys discussed above, few people expressed a positive view of counselling, as something that they felt would be helpful to them.. One felt that this might be related to the fact that they were only offered counselling



from a white counsellor. No Asian counsellors were available at any of the centres. Another counsellor felt that South Asians were generally more likely to 'keep problems to themselves' and one consultant felt that South Asian communities were not favourably disposed to any form of counselling.

Five people spoke about having at least one session with a counsellor. Three of these had undergone support counselling and saw this as a broadly positive experience, although one woman reported having to wait six weeks for an appointment with a counsellor at a private clinic. The others receiving support counselling were less satisfied with their experience and did not find it very helpful in dealing with their emotions.

Several women expressed the view that they would like to talk things over with someone, and share experiences, but not necessarily with an official counsellor. There was also a suggestion that having a counsellor involved might not meet with the approval of the family. Netto et al (2001) found a generally low level of awareness of counselling in Asian communities and a failure of mainstream counselling services to provide counselling in Asian languages.

The general uptake of infertility counselling in all populations is low (Kerr et al 1999) although there does seem to be an ethnic difference in apparent demand for counselling. A study of marital counselling in the Gujarati Hindu community demonstrated a poor knowledge of support agencies and a general sense of distrust of formal counselling services. There were also concerns about confidentiality (Goodwin et al. 1997). One city in our study did have an Asian counselling service.

#### Self-help and support groups

Other important potential sources of support for people undergoing fertility treatment are self-help groups. There are several national organisations that provide information and support to people with fertility problems or people who have had fertility treatment, many with local branches, telephone helplines, internet chat and email facilities. Only three participants reported having been given information about support groups, and there was little evidence of South Asian couples involvement in local groups.

Some participants felt that they were unsure if they would feel comfortable discussing issues in a group situation. Others however, were keen to find out more about their problems and could see the value of sharing experiences. The key informants were divided about the potential use of support groups by South Asians. Some felt that couples would be reluctant to share their experiences in a 'public' setting, but others felt that given the right circumstances, some women in particular would value talking to others in the same situation as themselves. The confidentiality of telephone helplines or internet chat rooms might be particularly important for South Asian individuals, although it would seem that these are only accessible to English speakers. We have been unable to locate any reference to Asian or other minority ethnic groups in the material produced or the websites of these groups and once again, it would appear that written information is available in English only.

### *Best and worst experiences of infertility treatment*

In the interviews with people facing fertility problems participants were given the opportunity to tell the interviewer about the negative and the positive aspects of their experience and asked for suggestions as to how health professionals could improve services.

By far the most common negative aspect of infertility treatment concerned waiting times. Reducing waiting times between appointments was also the single most quoted suggestion for improving services. Over half of all interviewees reported that they had been unhappy with the length of time they had to wait for an initial appointment or follow up appointments. These comments were received mainly about two of the three clinics in the study. Generally, people wanted the whole process to move along more quickly and to have reduced waiting time between having tests and getting results and between getting results and having treatment.

Infertility treatment is often a drawn out process and this was a source of stress for many couples. A minority of people did appear to have received less than optimum care in this regard. One couple reporting having attended a clinic for almost two years before a semen analysis was carried out. Others reported basic 'work-up' tests that had not been carried out at an early stage of investigation and several mentioned having the same tests repeated without a clear explanation of why this was necessary.

Some participants revealed a lack of understanding of the purpose of tests and of the likely time scale for investigations and treatment, reflecting a failure of communication on the part of the health professionals. The time taken for investigations to be performed and results to reach patients have been criticised in other studies (Monach 1993, Souter et al 1998). More detailed explanation and written information about the time scales for treatment at initial visits would be helpful to patients. This was echoed by those women who felt the need for a written care plan, outlining the likely process of care. The failure to clearly explain the reasons why tests are needed or why the pace of investigations cannot always be increased, results in frustration and distress for patients who may see this as an unnecessary delay in receiving help. This was felt very keenly by those older patients who saw time running out for them.

Some 20% of participants expressed a desire for more sensitivity on the part of healthcare professionals treating infertility patients, especially when treatment is unsuccessful and some of the women spoke of the painful and unpleasant nature of the treatment process, especially injections and side effects of drugs.

Around 20% of participants were able to express some positive aspects of their experience. For some (successful) couples it was having the opportunity to have a child, for a small number of others it was the support from clinic staff, especially nurses. A small number mentioned a positive impact on their relationship with their partner or the fact that they felt stronger as a person as a result of having to face up to their fertility problem.

### **3. RECOMMENDATIONS**

The needs and concerns articulated by infertile participants in this study arise for many who experience infertility, irrespective of ethnicity. A consideration of ethnic difference should not obscure commonalities between groups. As Atkin (2004) has argued, “not every problem or difficulty a person encounters as they attempt to gain access to appropriate service delivery can be attributed to their ethnic background” (p.15). The issues which are of concern to South Asians are not dramatically different to those which the literature identifies as concerning many white infertility service users. Nevertheless, differences of culture, language and religion are also often important though not always in a unitary way. Specific cultural norms and values, language and communication needs, and the structural location of some minority ethnic communities in British society, give rise to specific areas of need which, this research suggests, are not always adequately met by existing service provision.

#### **3.1 Infertility service provision**

- The Department of Health should ensure the full implementation of the NICE Clinical Guideline on infertility treatment at the earliest opportunity to ensure fair and equal access to NHS infertility treatment for all couples regardless of where they live.
- Further research is needed to explore the issue of access to ‘inter-ethnic’ gamete donation and the guidance of the HFEA on this issue should be clarified.

#### **3.2. Data availability and monitoring**

- All relevant authorities should ensure that suitable and sensitive ethnic monitoring is in place and that regular analysis of data occurs. This would provide information on ethnic patterns of infertility incidence and prevalence, treatment outcomes and uptake of services.
- The HFEA should ensure that ethnicity data is available for all monitored treatments.

#### **3.3 ‘Social marketing’ of infertility treatment**

- The HFEA and other interested agencies should consider engaging with key opinion formers and other partners in minority ethnic communities to increase understanding of infertility and infertility treatment and to reassure people about confidentiality. Approaches could be made through religious centres (Mosques, Gurdwaras, Mandirs) and community centres and should utilise bilingual community workers.
- Information should also be made available via local Asian radio and Asian television networks

#### **3.4 Provision of information**

- Clinics should ensure that all patients receive appropriate written information about infertility and treatment at various stages of the treatment process.

- Clinics could conduct or commission their own research to investigate what information patients would find useful and in what form they would prefer to receive this.
- Clinics should consider providing patients with written individualised treatment plans.
- GPs and clinics should consider the use of patient-held record cards with dates and results of all tests as a means of avoiding unnecessary delays and costs of duplication of tests.
- Information about infertility and treatment should be made available in languages other than English. To avoid unnecessary expense, much of this could be provided by a central resource. The HFEA Guide to Infertility, for example, could be available in booklet form and on their Internet website in the main South Asian languages. This could be accessed by patients directly, and/or by clinics for distribution to non English speaking patients.
- Clinics should collaborate with each other and possibly with pharmaceutical companies to provide information on treatment protocols in minority languages.
- The needs of patients who do not read in their preferred language should be addressed and material made available in audio and video format.
- Service users and others from minority ethnic communities should be closely involved in the production of translated materials.
- The planned development of the NHS Online central depository of health promotion material could include the provision of translated material relevant to infertility. The planned extension of NHS Direct could also facilitate the provision of translated information and interpretation.

### **3.5 Interpreting services**

- There is a clear need for improved interpretation services in most NHS Trusts. However, improving interpretation services needs to happen alongside measures to increase the confidence of users in the effectiveness, cultural sensitivity and confidentiality of this service.
- It may be more practical for clinics and preferable for patients to use telephone-based interpretation services (such as Language Line) on some occasions.
- Clinics should consider making use of an official interpretation service a mandatory component of at least some consultations where one partner does not speak English, to enable shared decision-making, implement patient-centred care and ensure informed consent.
- Clinics should ensure that all staff receive training in the use of interpretation provision, including remote access services.

### **3.6 Emotional support**

- Steps need to be taken to increase awareness of support counselling and the confidential nature of this service. Efforts should be made to ensure that counselling is culturally sensitive.
- Further research to investigate the reasons for the low up-take of counselling generally should be considered.

- Clinics should consider other ways in which the emotional needs of patients might be met outside of formal counselling.
- Clinics should provide patients with contact details of infertility support groups and helplines.
- Infertility campaigning and support groups should consider ways in which they might appeal more directly to users from minority ethnic communities, including producing publicity with material and imagery that is 'inclusive'.

### **3.7 Professional Education**

- Health professionals should be provided with educational opportunities to explore ethnic diversity and the influence of ethnicity on health and healthcare. This may be through specific training programmes in PCTs and Acute Trusts (which should involve individuals from minority ethnic communities) and/or by accessing online training materials. It is understood that a planned new Specialist Library in the National electronic Library for Health (NeLH) may be able to offer access to such material.

## **4 RESOURCES FROM THE PROJECT**

This research project has included the production of:

**4.1.** *Trying for a Baby: information about fertility problems* - a basic information resource in Punjabi, Gujarati, Bengali, Urdu and English. This is available in booklet and audio format on CD.

**4.2.** *South Asian Communities and Infertility: a resource for health care professionals* - a resource for use by professionals working in the field of infertility

Copies of the above can be obtained from Nicky Hudson: [nhudson@dmu.ac.uk](mailto:nhudson@dmu.ac.uk), 0116 207 8766. Health and Life Sciences, De Montfort University, Leicester LE1 9BH.

The full report can also be obtained from Nicky Hudson at the above contact details.

## 5 REFERENCES

Acheson (1998) *Independent Inquiry into Inequalities Health Report*. London: The Stationery Office Ltd.

Ali, N. Neal, R. & Atkin, K. (2003) *Communication between GPs and South Asian Patients: final report to Northern and Yorkshire Regional Health Authority*. Leeds: Centre for Research in Primary Care.

Anionwu, E. & Atkin, K. (2001) *The Politics of Sickle Cell and Thalassaemia*. Buckingham: Open University Press

Arora, R. and Husband, C. (1995) *The Language Needs Assessment Project, Bradford*: The Race Relations Research Unit, University of Bradford: The Bradford Community Health Trust.

Aspinall, P. (2000) 'The new 2001 census question set on cultural characteristics: is it useful for the monitoring of the health status of people from ethnic groups in Britain?' *Ethnicity & Health* 5 (1): 33-40

Atkin, K. (2004) 'Institutional racism, policy and practice' in S. Ali & K. Atkin *Primary Healthcare and South Asian Populations. Meeting the Challenges* Abingdon: Radcliffe Medical Press Ltd pp 9-20

Atkin, K. Ahmad, WIU. & Anionwu, E. (1998) 'Screening and counselling for sickle cell disorders and thalassaemia: the experience of parents and health professionals' *Social Science and Medicine* 47 (11):1639-51

Atkinson, M. Clark, M. Clay, D. Johnson, M. Owen, D. and Szczepura, A. (2001) *Systematic review of ethnicity and health service access for London*, Warwick: University of Warwick.

Audit Commission (1994) *What seems to be the matter: Communication between hospitals and patients*. Audit Commission report. HMSO.

Beishon, S. Modood, T. & Virdee, S. (1998) *Ethnic Minority Families* London: Policy Studies Institute

Bhakta, P. Katbamna, S. & Parker, G. (2000) 'South Asian Carers' experiences of primary health care teams', in Ahmad, WIU (ed) *Ethnicity, Disability and Chronic Illness*. Buckingham: Open University Press

Bharadwaj, A. (2003) 'Why adoption is not an option in India: the visibility of infertility, the secrecy of donor insemination, and other cultural complexities' *Social Science and Medicine* (56): 1867-1880

Bhatia, J C (1978) Ideal number and sex preference of children in India. *Journal of Family Welfare* 24: 3-16.

- Bhatti, L. Fikree, FF. & Khan, A. (1999) 'The quest of infertile women in squatter settlements of Karachi, Pakistan: a qualitative study' *Social Science and Medicine* 49
- Biljan MM, Taylor CT, Gosden CM, Jones SV, Malone CG, Kingsland CR. (1995) 'How acute is the acute shortage of oocyte donors in the UK? Results of a British National Survey', *British Journal of Obstetrics and Gynaecology*, 102:746-7
- Blyth, E. & Hunt, J. (1994) 'A history of infertility counselling in the United Kingdom', in S Jennings (ed) *Infertility Counselling*. Oxford: Blackwell
- Blyth, E. Martin, N. & Potter C. (2003) 'Assisted human reproduction: contemporary policy and practice in the UK' in D Singer & M Hunter, (eds) *Assisted Human Reproduction* London: Whurr Publishers.
- Blyth, E. (1999). 'The Social Work Role in Assisted Conception.' *British Journal of Social Workers* 29: 727-740.
- Boivin, J. Scanlan, LC. et al. (1999). 'Why are infertile patients not using psychosocial counselling?' *Human Reproduction* 14(5): 1384-91
- Bradby, H (2001) 'Communication, Interpretation and Translation' in L. Culley & S. Dyson (eds.) *Ethnicity and Nursing Practice*. Basingstoke: Palgrave pp 129-148
- Bradby, H. (2002) 'Translating culture and language: a research note on multilingual settings', *Sociology of Health and Illness* 24 (6): 842-855
- Census (2001) National Statistics Online accessed online at <http://www.statistics.gov.uk/census2001/> on 28/05/03
- Chamba, R. and Ahmad, W.I.U. (2000) 'Language, communication and information: the needs of parents caring for a severely disabled child' in Ahmad, W.I.U. (ed) *Ethnicity, Disability and Caring*. Race and Health Series. Buckingham: Open University Press.
- Cohen, S. Arber, S. & Smaje, C. (1998) *Primary Health Care Services for Children from Minority Ethnic Groups* Guildford: Department of Sociology, University of Surrey
- Cook, R. Golombok, S. Bish, A Murray, C (1995) 'Keeping secrets: a controlled study of parental attitudes towards telling in donor insemination families' *American Journal of Orthopsychiatry* 65: 549-559.
- Cramond J (1998). 'Counselling needs of patients receiving treatment with gamete donation.' *Journal of Community & Applied Social Psychology* 8: 313-321.
- Culley, L. (2000) 'Working with diversity: beyond the factfile' in Davies, C. Finlay, L. and Bullman, A. (eds) *Changing Practice in Health and Social Care* London: Sage/ Open University Press pp.131-42

Culley, L. & Dyson, S. (eds.) (2001) *Ethnicity and Nursing Practice*. Basingstoke: Palgrave

Culley, L. Rapport, F. Katbamna, S. Johnson, M. & Hudson, N. (2004) *A Study of the Provision of Infertility Services to South Asian Communities*, Final Report prepared for NHS Executive Policy and Practice Research and Development Programme. De Montfort University, Leicester.

Culley, L & Ruane, S A. (1997) 'Game of chance: rationing infertility services in the NHS' British Sociological Association, Medical Sociology Conference, York, September 1997

Denny, E (1994) 'Liberation or oppression? Radical feminism and in vitro fertilization' *Sociology of Health and Illness*, 16 (1)

Department of Health (2000) *The NHS Plan: A Plan for Investment, A Plan for Reform* London: HMSO

DeSantis, L & Tugarriza D N (2000) 'The concept of theme as used in qualitative nursing research'. *Western Journal of Nursing Research* 23(3): 351-372.

Ebden, P. Bhatt, A. Carey, OJ. & Harrison, B. (1988) 'The bilingual consultation' *Lancet* 1 (8581): 347

Elderkin-Thompson, V. Silver, RC. & Waitzkin, H. (2001) 'When nurses double as interpreters: a study of Spanish speaking patients in a US primary care setting' *Social Science and Medicine* 52: 1343-1358

Erens, B, Primatesta, P & Prior, G (2001) *Health Survey for England. The Health of Minority Ethnic Groups 1999*. Volume 1. London: The Stationary Office

Gerrish, K. (1997) 'Preparation of nurses to meet the needs of an ethnically diverse society: educational implications' *Nurse Education Today* 17 (5): 359-65

Gerrish, K. Husband, C. & Mackenzie, J. (1996) *Nursing for a Multi-ethnic Society* Buckingham: Open University Press

Gillespie, R (1999) 'Voluntary childlessness in the United Kingdom' *Reproductive Health Matters*, 7 (13), May

Goffman, E. (1963) *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall

Golombok, S. Brewaeys, MT. Giavazzi, D. Guerra, D. MacCallumm, F. Rust, J. (2002) 'The European Study of Assisted Reproduction Families; the transition to adolescence' *Human Reproduction* 17: 830-840.

Golombok, S; Cook, R; Bish, A; Murray, C (1995) 'Families created by the new reproductive technologies: quality of parenting and social and emotional development of the children' *Child Development*; 66 (2):285-98



- Golombok, S; MacCallum, F; Goodman, E (2001) 'The 'test-tube' generation: parent-child relationships and the psychological well-being of in vitro fertilization children at adolescence' *Child Development*; 72 (2): 599-608
- Golombok, Susan; MacCallum, Fiona (2003) 'Practitioner review: outcomes for parents and children following non-traditional conception: what do clinicians need to know?' *Journal of Child Psychology and Psychiatry and Allied Disciplines*; 44 (3): 303-315
- Goodwin, R. Adatua, K. Sinhal, H. Cramer, D. Ellis, P. (1997) *Social support and marital well-being in an Asian community* York: York Publishing Services
- Greil, A (1991) *Not Yet Pregnant: Infertile couples in contemporary America*. Rutgers University Press, New Brunswick
- Greil, AL. (1997) 'Infertility and psychological distress: a critical review of the literature' *Social Science and Medicine*, 45 (11): 1679-1704
- Haffner, L. (1992) 'Translation is not enough – interpreting in a medical setting' *West Journal of Medicine* 157: 255-9
- Haimes, E (1993) 'Issues of gender in gamete donation' *Social Science and Medicine*; 36 (1): 85-93
- Hawthorne, K. (1994) 'Accessibility and use of health care services in the British Asian community', *Family Practice*, 11, 4:453-459.
- Helman, C. (2000) *Culture, Health and Illness* 4<sup>th</sup> ed. Oxford: Butterworth-Heinemann
- Henley, A. (1991) *Caring for Everyone* Cambridge: National Extension College
- Henley, A. & Schott, J. (1999) *Culture, Religion and Patient Care in a Multi-Ethnic Society. A handbook for professionals*. London: Age Concern
- Hennink, M Cooper P & Diamond I (1998) 'Asian women's use of family planning services' *The British Journal of Family Planning* 24: 43-52.
- HFEA (2002) 'Sex selection: choice and responsibility in human reproduction' Consultation paper available online at <http://www.hfea.gov.uk>
- HFEA (2004) *Code of Practice, Sixth edition* accessed online at <http://www.hfea.gov.uk> on 3/3/04
- Hornberger, JC. Gibson, CD. Wood, W. Dequeldre, C. Corso, I. Palla, B. and Bloch, D. (1996) 'Eliminating language barriers for non-English speaking patients' *Medical Care* 34(8): 845-56

- Imeson, M & McMurray, A (1996) 'Couples' experience of infertility: a phenomenological study' *Journal of Advanced Nursing*, no.24
- Inhorn, M (1996) *Infertility and Patriarchy. The Cultural Politics of Gender and Family Life in Egypt*. Philadelphia: University of Pennsylvania Press
- Inhorn, MC (2002) 'The "local" confronts the "global": Infertile bodies and New Reproductive Technologies in Egypt' in Inhorn, MC & Van Balen, F. (eds) *Infertility around the Globe. New thinking on Childlessness, Gender and Reproductive Technologies*. California: University of California Press: 263-297
- Inhorn, M. (2003) 'Global infertility and the globalisation of new reproductive technologies: illustrations from Egypt' *Social Science and Medicine* (56): 1837-1851
- Inhorn, MC & Van Balen, F. (2002) (eds) *Infertility around the Globe. New thinking on Childlessness, Gender and Reproductive Technologies*. California: University of California Press
- Johnson MRD (1999) 'Communication in health care: a review of some key issues' *Nursing Times Research* 4,1: 18-30, 1999).
- Katbamna, S. (2000) *'Race' and Childbirth*. Buckingham: Open University Press
- Kerr, J. Brown, C. & Balen, A.H. (1999) 'The experiences of couples who have had infertility treatment in the United Kingdom: results of a survey performed in 1997' *Human Reproduction* 14 (4): 934-938
- Khan D (1999) *Diversity in the NHS. Promoting Service Equality in Bradford*. Bradford Hospitals NHS Trust.
- Letherby, G. (1999) 'Other than mother and mothers as others: the experience of motherhood and non-motherhood in relation to 'infertility' and 'involuntary childlessness'' *Women's Studies International Forum*, 22 (3): 359-372
- Letherby, G. (2002) 'Childless and bereft?: Stereotypes and realities in relation to 'voluntary' and 'involuntary' childlessness and womanhood', *Sociological Inquiry*, 72 (1): 7-20
- Malin, M. (2003) 'Good, Bad and Troublesome. Infertility Physicians' perceptions of Women Patients' *The European Journal of Women's Studies* 10 (3):301-319
- Malin M, Hemmink E, et al. (2001). 'What do women want? Women's experiences of infertility treatment' *Social Science and Medicine* 53(1): 123-33.
- Miall, C (1994) 'Community constructs of involuntary childless ness: sympathy, stigma and social support' *The Canadian Review of Sociology and Anthropology*, 31 (4)

Modood, T., Berthoud, R., Lakey, J., Nazroo, J., Smith, P., Virdee, S. and Belshon, S. (1997) *Ethnic Minorities in Britain: Diversity and Disadvantage*. London: Policy Studies Institute

Monach J. H. (1994) *Childless: No Choice: The Experience of Involuntary Childlessness*. Routledge, London, 1993.

National Institute for Clinical Excellence (NICE) (2004) *Fertility: Assessment and Treatment for people with fertility problems*. Clinical Guideline, Developed by National Collaborating Centre for Women's and Children's Health February 2004. Accessed at: <http://www.nice.org.uk> on 2/3/04

Nazroo, J.Y. (1997) *The Health of Ethnic Minorities*. London: Policy Studies Institute

Netto, G. Gaag, S. Thanki, M. Bondi, L. Munro, M. (2001) *A suitable space: Improving counselling services for Asian people* Joseph Rowntree Foundation: Policy Press

Pandey, SK Hart, JJ and Tiwary, S. (2003) 'Women's health and the internet: understanding emerging trends and implications' *Social Science & Medicine* 56 (1): 179–191

Pfeffer, N & Woollett, A (1983) *The Experience of Infertility*. London: Virago.

Phelan M, Parkman S. (1995) 'How to work with an interpreter' *BMJ* 311: 555-557.

Platt, L (2002) *Parallel Lives?* London: Child Poverty Action Group

Pointon T. (1996) 'Telephone interpreting service is available' *BMJ* 1996; 312: 53.

Reissman, CK. (2000) 'Stigma and everyday practices. Childless women in South India', *Gender & Society*, 14 (1): 111-135

Remennick, Larissa (2000) 'Childlessness in the land of imperative motherhood: Stigma and coping among infertile Israeli women' *Sex Roles*, 43 (11/12): 821-841

Rhodes P. & Nocon A. (2003) 'A problem of communication? Diabetes care among Bangladeshi people in Bradford' *Health & Social Care in the Community*. 11(1): 45-54

Rhodes, P. Nocon, A. & Wright, J. (2003) 'Access to diabetes services: the experiences of Bangladeshi people in Bradford, UK' *Ethnicity and Health* 8 (3): 171-188

Richards, J (2003) 'Ethical Issues – the major faiths: a personal view' in D Singer & M Hunter, (eds) *Assisted Human Reproduction* London: Whurr Publishers

Robinson, M (2001) *Communication and Health in a Multi-ethnic Society*. Bristol: Policy Press.

Rosen, R. Florin, D. & Dixon, J. (2001) *Access to Health Care – Taking Forward the Findings from the Scoping Exercise* London: National Co-ordinating Centre for NHS Service Delivery and Organisation, Research & Development

Sandelowski, M. (1993) *With Child in Mind. Studies of the Personal Encounter with Infertility*. USA: University of Pennsylvania Press.

Serrano, A.C. (1989) 'Language barriers in paediatric care' *Clinical Paediatrics*, April, 193-194

Shepperd, S; Charnock, D; Gann, B (1999) Helping patients access high quality health information *British Medical Journal* 319 (7212) 18 Sep, p.764-6

Souter, V.L. Hopton, J.L. Penney, G.C. Templeton, A.A, (2002) 'Survey of psychological health in women with infertility' *Journal of Psychosomatic Obstetrics and Gynecology* 23 (1): 41-50

Souter, VL; Penney, G; Hopton, JL & Templeton, AA. (1998) 'Patient satisfaction with the management of infertility' *Human Reproduction*, 13 (7): 1831-1836

Steinberg, DL. (1997) 'A most selective practice. The eugenic logics of IVF' *Women's Studies International Forum* 20 (1): 33-48

Strathern, M. (1992) *Reproducing the Future: Anthropology Kinship and the New Reproductive Technologies*. Manchester: Manchester University Press

Street, R. (1991) 'Physicians' Communication and Parents' Evaluations of Paediatric Consultations,' *Medical Care*, 29 (11): 1146-1152

Szczepura, A., Clark. M., Johnson, M., and Owen, D. (1998) Assessment of the costs of the NHS arising from the need for interpreter, advocacy and translation services: Report to the NHS Executive; Technical Advisory Group

Thornton, H (2001) 'Information and involvement' *Health Expectations* 4 (1): 71-4

Tuffnell, D. Nuttall, K. Raistrick, J. & Jackson, T. (1994) 'Use of translated written material to communicate with non-English speaking patients' *British Medical Journal* 309:992

Ulrich, M. & Weatherall, A. (2000) 'Motherhood and infertility: viewing motherhood through the lens of infertility', *Feminism and Psychology*, 10 (3): 323-336

Unisa, S. (1999) 'Childlessness in Andhra Pradesh, India: treatment-seeking and consequences' *Reproductive Health Matters*, 7 (13), May

Van Balen, F & Inhorn, M. (2002) 'Interpreting infertility: a view from the Social Sciences', in Inhorn, M. and van Balen, F. (eds) *Infertility around the Globe. New thinking on Childlessness, Gender and Reproductive Technologies*. California: University of California Press (pp3-32)

Van den Akker, O (2002) *The Complete Guide to Infertility*. London: Free Association Books

Wasser, SK. Sewall, S. Soules, MR. (1993) 'Psychosocial stress as a cause for infertility' *Fertility and Sterility* 59, 685-689

Whiteford, LM. & Gonzalez, L (1994) 'Stigma: the hidden burden of infertility' *Social Science and Medicine*, 40 (1): 27-36

Williams, D Irving, J (1998) 'Counselling is not assessment' *Journal of Fertility Counselling* 5(1):13-15.

Winkvist, A. & Zareen Aktar, H. (2000) "'God should give daughters to rich families only': attitudes towards childbearing among low-income women in Punjab Pakistan' *Social Science and Medicine*, 51: 73-81

Woollett A (1991). 'Having children: accounts of childless women and women with reproductive problems'. In *Motherhood: Meanings, Practices and Ideologies*. A Phoenix, A Woollett and E Lloyd. London, Sage Publications.