

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



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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

- 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

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 & Woollett 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 & Woollett 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

Table 3: Interview participants by sex and ethnicity

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

In the communities studied here, the social

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

b e l e c - families (not having a male child) reinforced by leaving a bequest to the South

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 famrelybse2.4(i)-6.8123(r)0.2s7 Twence o25 0 TDrronalence

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

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.

key informant

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

would be relatively well informed, but the younger women did not express this feeling and argued that much more information was

were known about. There was little objection to the use of IVF

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 take

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

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

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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 helpfu

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 consulta

These findings confirm those of previous studies that have identified a need for more information and explanation for patients.

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 w iormiscussi fursesusingccwoid ab

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.

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

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.

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

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, t o t h e 1 0 4

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

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 taken for investigations and treatment would be helpful.

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
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- 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 website in the UK.

and these could be processed by a patient (5TJ18.4730 TD0.00043Tc0.23637Tw(rd) T3

distribution in English (0.419 0 TD0.0005 Tc00.0021 Tw(dh speaking patient)s).

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