

Infertility in British South Asian
Communities: Negotiating the
Community and the Clinic

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Abstract

Whilst there is research evidence on the consequences of involuntary childlessness in majority ethnic communities in the UK and other more developed societies, and also a growing literature on the experiences of infertile women in less well-resourced countries, there is a dearth of research exploring the potential impact of ethnicity and culture on the experience of infertility within Western societies. To begin to address this lacuna, this thesis was designed to explore the social meanings of infertility in British South Asian communities, and the infertility experiences of individual South Asian women.

The study used a qualitative, interpretive approach, and employed a multiple method design. The first phase of the study consisted of 13 single gender focus groups with a total of 87 participants of Indian, Pakistani and Bangladeshi ethnic origin, which explored public perceptions of involuntary childlessness and attitudes towards infertility treatments. The second phase of the study included in-depth interviews with 15 individuals of South Asian ethnic origin who had experience of infertility.

Central to the findings in this study, is the importance of the social context in which infertile lives are enacted. Using conceptual insights from the work of Pierre Bourdieu and Erving Goffman, the thesis investigates the ways in which infertile individuals negotiate two principal social spaces which shape and structure the individual experience of infertility: the community and the clinic. The concepts of habitus, field, capital and stigma are employed to understand this experience.

The focus group research revealed that British South Asian communities are characterised by a strong pro-natalist discourse. Involuntary childlessness is thus highly visible and highly stigmatised. Focus group participants reported that childless couples were subject to considerable social surveillance within family and community contexts, and women in particular were seen to carry the responsibility for infertility. Community understandings of reproductive technologies were ambivalent and complex, with evidence of generational and religious differences in the focus groups.

The interviews with infertile individuals revealed a concern about disclosure of infertility and the stigma that it would attract, confirming the significant role that community perceptions play in the lives of childless couples. The interviews also revealed that, as in other communities, the experience of infertility is one which is characterised as a major suspension of life course expectations, that gives rise to emotional distress and feelings of disruption and loss of control, particularly for women. Twelve of the fifteen interview participants in this study had used reproductive technologies in order to try to achieve a pregnancy. The infertility treatment process was experienced as an emotional, practical and financial struggle, and the participants were required to enact agency in a number of ways in order to negotiate both the clinic context and the actors within it.

The thesis argues that the infertility experience is shaped by an individual's habitus. Furthermore, different elements of the habitus are mediated by one another and each can become salient at different times and in different contexts. In this study, aspects of ethnic identity and culture are revealed as often highly significant for the experience of infertility and infertility treatment. However, it is argued that ethnicity can be de-centred by other elements of the habitus, specifically in this case, gender and/or religion. The

importance of economic capital is also highlighted, especially in accessing infertility treatment, since the possession of such capital allows individuals the opportunity to circumvent regulatory restrictions and the scarcity of treatment provision within the NHS. Therefore, the study suggests that ethnicity alone should not be seen as an essential and immutable facet of identity, which inevitably determines the infertility experience of minority (or majority) ethnic group members.

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Table of contents

Chapter One: Introduction	1
Introduction	1
<i>Infertility: definitions, prevalence and causes</i>	2
<i>Diagnosis and treatment</i>	3
<i>Regulation and access</i>	4
<i>The social construction of 'infertility'</i>	6
<i>British South Asian communities</i>	11
<i>Migration</i>	12
<i>Socio-economic position and employment</i>	13
<i>Households, family structure and marriage</i>	14
<i>South Asian communities, health and health care</i>	17
<i>Justification for the study</i>	20
<i>The structure of this thesis</i>	22
Chapter Two: Conceptualising 'race' and ethnicity in research	25
Introduction	25
<i>The origins of ideas about 'race'</i>	26
<i>Racialisation and racism</i>	27
<i>Ethnicity & culture</i>	29
<i>Positionality and the de-centring of ethnicity</i>	33
<i>Combining structure and agency in ethnicity research: utilising the work of Pierre Bourdieu</i>	35
<i>The approach used in this thesis</i>	39
<i>The conceptualisation of race and ethnicity in research</i>	40
<i>Implications for the research interaction: debates about ethnic matching</i>	45
Chapter Three: Discursive constructions of 'infertility' within social science	51
Introduction	51
<i>Infertility as 'distress': psychological studies</i>	52
<i>Infertility as 'disruption'</i>	53
<i>Infertility as 'difference' and stigma</i>	58
<i>Infertility as 'disease'</i>	65
<i>Infertility treatment</i>	66
<i>Infertility and ethnicity in the West</i>	79
Conclusions.....	86
Chapter Four: Methodology	89
Introduction	89
Methodology	89
<i>Study design & data collection methods</i>	92
<i>Study design</i>	92
Ethical issues.....	111

<i>Sensitivity of the topic</i>	112
<i>Reciprocity</i>	114
<i>Transcription & analysis</i>	115
<i>Transcription</i>	115
<i>Analytical method</i>	116
<i>Reliability & validity</i>	120
<i>Credibility</i>	121
<i>Transferability</i>	122
<i>Dependability</i>	123
<i>Confirmability</i>	123
<i>Limitations of the study</i>	124
<i>Interview sample constitution</i>	124
<i>Categorising and operationalising ethnicity & socio-economic status</i>	124
<i>Summary</i>	126
Chapter Five: Public perceptions of infertility in South Asian communities- the moral context	127
<i>Introduction</i>	127
<i>The significance of childbearing</i>	128
<i>Pro-natalism</i>	128
<i>The importance of children</i>	130
<i>Infertility as a source of social anxiety</i>	132
<i>Social surveillance of married couples</i>	132
<i>Gendered infertility</i>	135
<i>Remarriage</i>	139
<i>Public perceptions of ARTs</i>	140
<i>Seeking treatment</i>	140
<i>Understanding IVF</i>	142
<i>The role of religion</i>	146
<i>Conception by donor: involving a third party</i>	147
<i>Summary</i>	151
Chapter Six: Experiencing infertility	153
<i>Introduction</i>	153
<i>Disrupted Biographies</i>	154
<i>Child desire and the importance of parenthood</i>	154
<i>'Social' parenthood and adoption</i>	157
<i>The importance of pregnancy</i>	161
<i>Other women's pregnancies</i>	163
<i>Life-course disruption</i>	166
<i>Lack of control</i>	168
<i>Part two: Negotiating the moral context</i>	171
<i>Experiencing pressure</i>	171
<i>Remarriage/marriage prospects</i>	176
<i>Positive relationships with in-laws</i>	179

<i>Summary</i>	180
Chapter Seven: Negotiating technology- seeking a solution	183
<i>Introduction</i>	183
<i>Engaging with 'expertise'</i>	184
<i>Getting access to treatment</i>	184
<i>An 'unexplained' diagnosis</i>	185
<i>Having faith in the experts</i>	187
<i>Questioning expertise</i>	188
<i>Negative treatment experiences</i>	191
<i>Religious constraints and ARTs</i>	192
<i>Having faith in religion</i>	194
<i>Negotiating technology</i>	195
<i>The emotional impact of using ARTs</i>	195
<i>Physical experiences of treatment</i>	200
<i>Feeling out of control</i>	202
<i>Practicalities: accommodating ARTs in everyday life</i>	203
<i>Going abroad for treatment</i>	206
<i>Using donor eggs and sperm: the significance of biological relatedness</i>	208
<i>Disclosing the use of ARTs</i>	214
<i>Tentative futures: achieving normality?</i>	221
<i>Deciding to end treatment</i>	221
<i>When the doctors give up</i>	223
<i>Continuing to feel infertile</i>	224
<i>Summary</i>	226
Chapter Eight: Exploring the relationship between ethnicity and infertility	227
<i>Introduction</i>	227
<i>Habitus: exploring the relevance for infertility & subjectivity</i>	228
<i>Gender</i>	229
<i>Ethnicity: the significance of 'descent and culture communities'</i>	236
<i>Religion</i>	240
<i>The significance of field for the infertility experience: the community and the clinic</i>	243
<i>Community as field</i>	244
<i>Infertility in the community field</i>	246
<i>Engaging with ARTs: the clinic as field</i>	260
<i>Economic capital</i>	272
<i>Conclusions: Infertility as habitus?</i>	276
Chapter Nine: Reflections on the research process	281
<i>Introduction</i>	281
<i>Framing infertility as a 'problem'</i>	282
<i>The role of identity in the research process</i>	283
<i>Research participation as therapeutic?</i>	288

<i>Summary</i>	289
Chapter Ten: Conclusions	291
<i>Introduction</i>	291
<i>Habitus: the significance for infertility and ethnicity</i>	291
<i>Fields and capital</i>	294
<i>Ethnic 'matching' in research</i>	296
<i>Suggestions for future research</i>	297
Reference List	299
Appendix One: The ASFERT study and its relationship to this thesis	325
Appendix Two: Copy of ethical approval letter	327
Appendix Three: Breakdown of focus group participants by gender, age, ethnicity and religion	329
Appendix Four: Focus group question schedule	331
Appendix Five: Focus group demographic questionnaire	335
Appendix Six: Recruitment advertisement	337
Appendix Seven: Interview participant information sheet	339
Appendix Eight: Interview consent form	341
Appendix Nine: Interview topic guide	343
Appendix Ten: Interview demographic questionnaire	347
Appendix Eleven: Pen portraits of interview participants	349
Appendix Twelve: NS-SEC classes and collapsed categories	355
Appendix Thirteen: Interview participants' partners' socio-economic status	357
Appendix Fourteen: N7 coding framework with the tree node expanded	359
Appendix Fifteen: Section of a node from N7	361
Appendix Sixteen: Focus group code book	363
Appendix Seventeen: Glossary of terms	367

List of tables and figures

Figure 1: Causes of infertility.....	Page 3
Table 1: Gender of focus group participants.....	Page 98
Table 2: Ethnic origin of focus group participants.....	Page 98
Table 3: Religion of focus group participants.....	Page 98
Table 4: Age of focus group participants.....	Page 99
Table 5: Demographic profile of interview participants.....	Page 107
Figure 2: Diagnostic categories of infertility.....	Page 110
Figure 3: Number of children per participant.....	Page 111
Figure 4: Data analysis process.....	Page 117
Figure 5: Gender, ethnicity and religion as habitus.....	Page 229
Figure 6: The community field and the struggle over stigma and capital.....	Page 254
Figure 7: The clinic field.....	Page 273

Chapter One: Introduction

Introduction

The inability to conceive a child is described as both personally and socially damaging and can be devastating for an individual. Coupled with this is the fact that in many socio-cultural contexts, an involuntary lack of children tends to be perceived as a failing or deficiency, which is particularly visible and highly stigmatised (Inhorn & van Balen 2002). This study is about the way in which infertility is experienced at the personal and social level in South Asian communities. Its focus is on the way in which individuals attempt to resolve this life crisis within the context of complex and situational family and community connections.

This introductory chapter provides the reader with the context in which this study was conceptualised. It constructs the research question by introducing the reader to a number of key academic debates concerning the contested concepts of 'infertility' and 'ethnicity', and in doing so maps the focus and scope of the rest of the thesis. The chapter begins with an overview of the typical infertility experience, describing the definitions, prevalence, causes, diagnosis and treatment of infertility. This is followed by a discussion of the prevailing perception in the West of infertility as a medical condition amenable to medical intervention, in contrast to the meanings it may have in alternative historical and cultural milieu¹. The chapter then presents the reader with a description of the communities selected for inclusion in the study, including demographic data about groups from which the participants

¹ The problematic definition and use of the terms 'West' and 'Western' is acknowledged. However, existing literature in this field has previously made a distinction between western and non-western contexts in relation to infertility, particularly in relation to its treatment (Inhorn & van Balen 2002). These terms are therefore used here to describe Europe, North America, Canada, Australia and New Zealand whilst accepting the contested nature of this categorisation.

are drawn. This section also includes a discussion and problematisation of the importance of the concept of 'ethnicity' in understanding health related experiences, such as infertility. Finally, the chapter presents the justifications for carrying out this research and the aims of the study.

Infertility: definitions, prevalence and causes

In the UK, the National Institute for Health and Clinical Excellence (NICE) defines infertility as 'failure to conceive after regular unprotected sexual intercourse for 2 years in the absence of known reproductive pathology' (NICE 2004: 9). Recent estimates in the UK based on this definition suggest that approximately one in seven couples will at some time experience difficulty in achieving a pregnancy (HFEA 2008a). This represents a potentially large number of individuals in the UK who will at some time suffer the distress associated with infertility. Those who have never achieved a pregnancy are described as having 'primary' infertility and couples who have already had a previous pregnancy or have a child are described as having 'secondary' infertility (van den Akker 2002).

The causes of infertility are categorised according to a range of possible problems that may lie with either the male partner, the female partner, both or neither partners. The Human Fertilisation and Embryology Authority (HFEA) collects data on these causes (Figure 1) and classifies these as attributable to: male factor problems (32.5%) and female factors including: tubal damage (15.3%); ovulatory problems (8.4%); endometriosis (2.9%) and a small number of conditions affecting the uterus (0.4%). Five percent of women experience a combination of factors, and in 10.8% of couples there is a combination of both male and female factors. In a large proportion of cases (23.1%) there is no identifiable cause (HFEA 2008b).

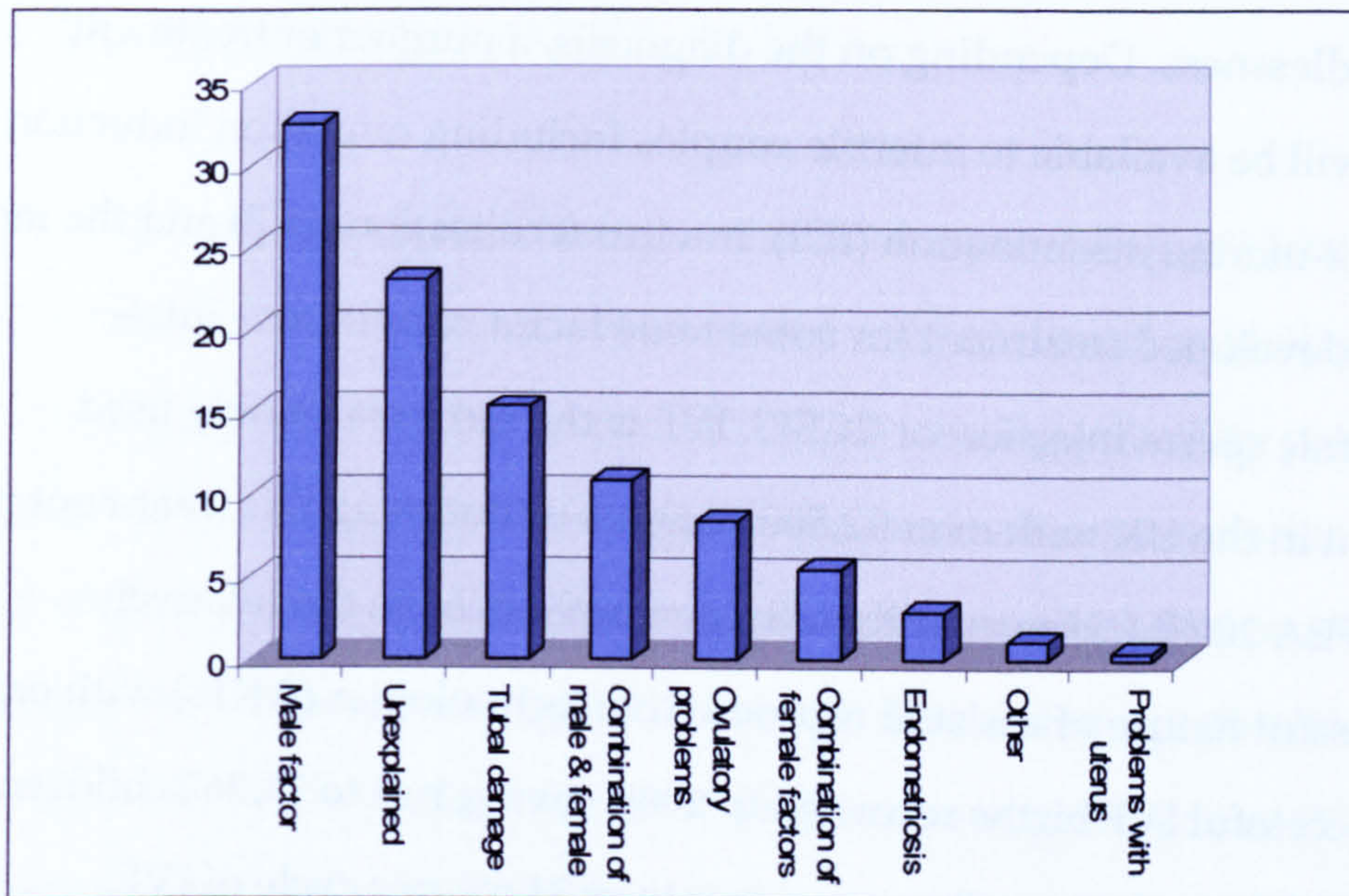


Figure 1: Causes of infertility

Diagnosis and treatment

When a couple have been trying unsuccessfully to conceive, the first source of advice and information is often their GP (van den Akker 2002). The GP may run a number of diagnostic tests in order to establish causality (as defined in Figure 1). Some GPs may refer patients directly to the gynaecology department in the local hospital at this stage. If the couple are presenting for investigation together, a number of tests will be carried out with each partner. For the male partner a semen analysis is carried out in order to check motility and mobility as well as the number of healthy sperm in the sample. For the female partner tests may include those relating to ovulation, such as blood hormone level tests, as well as more invasive tests such as the laparoscopic investigation, which allows an examination of the peritoneal cavity including the fallopian tubes (van den Akker 2002).

A typical infertility 'journey' may therefore involve a period of trying to become pregnant 'naturally', followed by a period of testing of one or both

partners, which may or may not result in a medical diagnosis of the cause of their childlessness. Depending on the diagnosis, a number of treatment options will be available to infertile couples including ovulation induction (OI), intra-uterine insemination (IUI), in vitro fertilisation (IVF) and the more recently developed treatment for some male factor conditions - intra-cytoplasmic sperm injection or 'ICSI'². IVF is the most commonly used treatment in the UK with over 32,500 patients undergoing this treatment per year (HFEA 2008b). However these large numbers belie the relatively unsuccessful nature of assisted reproductive technologies (ARTs) with only 9,058 successful IVF births recorded in 2005, giving rise to 11,262 children (HFEA 2008b) and an average success rate of 21.6% per cycle of IVF. However, success is variable with some individual clinics achieving higher rates of success. The length of time a couple will remain in treatment is highly variable and can be determined by a number of factors including whether or not they become pregnant, their financial resources, their willingness and ability to continue, as well as the willingness of their clinician to continue to treat them (Peddie et al 2005). Since the success rates of ARTs are relatively low, the experience of infertility treatment is overwhelmingly therefore one of failure and disappointment (Throsby 2004).

Regulation and access

In the UK, ARTs are regulated by the HFEA which was set up in 1990 to safeguard all individuals undergoing licensed fertility treatments. Only clinics licensed by the HFEA can carry out treatments such as IUI, IVF and ICSI, and can store gametes or embryos. The HFEA code of practice for infertility clinics insists upon strict monitoring of staff, facilities, storage material, treatments,

² A full description of these treatments is included in the glossary on page 367.

patient information, counselling, consent procedures and costs (van den Akker 2002, HFEA 2007).

In 2004, NICE, the independent body in the UK for providing guidance on health promotion and clinical practice, issued a set of clinical guidelines which were intended to offer direction to clinics treating infertility patients within the NHS (NICE 2004). These guidelines made recommendations on all aspects of the treatment of infertility, including the proposal that provision for three cycles of IVF for women aged between 23-39 years of age should be made within the NHS. At the time of writing however, provision of IVF treatment within England and Wales varies regionally, with a number of Primary Care Trusts (PCTs) failing to implement the NICE guidelines (Bionews 2007). In some areas, PCTs have implemented more restrictive eligibility criteria than those proposed by NICE, such as a more restrictive age range or the existence of children from a previous relationship (Bionews 2007). This means that a number of individuals who would otherwise be suitable candidates for infertility treatment are either forced into the private sector, where they may pay on average between £4,000-8,000 per IVF cycle, placed on long waiting lists in the NHS, or are effectively denied access to treatment altogether. As a reflection of this situation, approximately 75 % of infertility treatment currently carried out in the UK is funded by patients themselves (HFEA 2008b).

For those couples who have good local provision in the NHS, or are able to pay for their own treatment, their pursuit of a successful pregnancy will almost certainly lead them into the medical treatment sphere. For those who do not get to this stage, either because they are not able, or do not wish to access ARTs, they may nevertheless find themselves medically defined as infertile, by their GP or gynaecologist. It is argued that this is due to the fact

that infertility is increasingly constructed as a medical problem, requiring medical intervention (Becker & Nachtigall 1992). A majority of (often otherwise healthy) men and women will therefore find themselves under the jurisdiction of the medical establishment when facing childlessness. In turn, this can be seen to medicalize their experience of infertility and this, amongst other social constructions of infertility, will be discussed within the following section.

The social construction of 'infertility'

Sandelowski & de Lacey (2002) argue that 'infertility' was effectively invented (in the discursive sense) following the birth of Louise Brown in 1978, and since that time scholars from a number of disciplines have used it to their own ends (2002:34). They suggest that infertility is both a material and linguistic entity; in that it exists at the real or experiential level as well as holding a range of symbolic meanings. This has implications both for those researching infertility as well those experiencing it. A society's approach to solving infertility may differ therefore, according to the specific social and historical context. For example, existing research tells us that presently in the West, the experiences of individuals and couples who are unable to achieve a pregnancy often follow a similar trajectory to that described above (Greil 1991, Monach 1993, Franklin 1997, Letherby 1999, 2001, Becker 2000, Throsby 2004, Thompson 2005). The specificity of the setting will affect both the ways in which infertility is perceived, as well as the range of solutions which are available to deal with it. The same geographical setting is also open to historical change, so that prior to the development of ARTs in the West, one solution to involuntary childlessness was adoption, either through formal or informal means (Greil 1991). Adoption is still pursued by childless couples in the UK. However, in more recent years this route is often only taken when

medical treatment fails (Throsby 2004, Spar 2006). This, it has been argued, demonstrates how biological parenthood is valorised over other means of becoming a parent, and how medical technologies are implicit in this valorisation (Becker & Nachtigall 1992).

Alternative non-medical solutions also exist in other social and cultural settings. For example, in Egypt, India, Pakistan and Vietnam, the taking of a second wife has been reported as a potential solution for childless men, highlighting in these contexts, the importance of patrilineage in family constitution (Inhorn 1996, Bhatti et al. 1999, Unisa 1999, Pashigian 2002). In some countries including India, Pakistan and Mozambique, there can be a religious or spiritual understanding of infertility and therefore a corresponding resolution is sought, often by visiting a spiritual healer (Neff 1994, Bhatti et al. 1999, Gerrits 2002). Interestingly, in a number of African countries, there is evidence of a more proactive approach to understandings of, and solutions to, infertility than is reported elsewhere. A small number of studies note that in these contexts women (who tend to bear the responsibility for fertility across the globe), spend time proving or enhancing their fertility before or very shortly after marriage. In research from Mozambique, Gerrits (2002) describes how childlessness is seen as something to be avoided, and how initiation rites and pregnancy rituals therefore include teaching men and women how to improve their chances of childbearing. In another study in Africa, this time in Chad, Lori Leonard found that women were thought to be born with a fixed number of children, which were described as existing 'in the stomach' or 'on the back' (2002:205). Injuries to these areas were therefore taken very seriously, since they were considered to damage a woman's 'children' and hence her childbearing capabilities (2002a & b).

Understandings of infertility and the significance given to childbearing across the world, illustrate the importance of kinship and family continuity.

However it is the cultural *particularity* of infertility stories, which can offer us insights into its socially constructed nature. Several authors working in this field alert us to the fact that the social shaping of infertility is at play in all contexts and this includes those in the West, as much as those in non-Western countries. In particular these authors have described the way in which infertility is shaped by the medical model (Greil 1991, Becker & Nachtigall 1992, Sandelowski & de Lacey 2002, van Balen & Inhorn 2002). Greil suggests that in the West, infertility has come to be defined as a medical problem, resulting from the assemblage of a number of factors. These, he argues, include: the medicalisation of reproduction and women's bodies more generally, medical advances in the field of infertility, the demand for services (which he suggests has always existed), changes in demography such as increasing delays in childbearing, particularly amongst middle class men and women, and the media presentation of ARTs as a 'miracle' cure for infertility (1991). Others have also highlighted the influence of the media in this process (Franklin 1997), and the general perception in the West that most aspects of fertility are within the control of the individual (woman) (Earle & Letherby 2002, 2007). It is therefore to some degree an inevitability in the West, that childless couples are compelled to seek a medical explanation and corresponding solution for their involuntary childlessness (Greil 1991: 15).

Social scientists have been critical of this development, a development which is gradually expanding to include the medicalisation of infertility in countries where it has not historically been considered the jurisdiction of medical practitioners (Leonard 2002b, Inhorn 2003b). These criticisms are based on the perceived negative implications of medicalisation for childless individuals. Given the highly invasive nature of many diagnostic tests and medical

treatments, feminists in particular, have argued that the medical model presents an assault on women's bodies and autonomy (Corea 1987, Stanworth 1987, Spallone 1989, Pfeffer 1993, Foster 1995). Another concern is that despite its claims, medicine has only been partially successful in 'solving' infertility (Becker 2000, Sandelowski & de Lacey 2002). The HFEA statistics which report that almost a quarter of those seeking treatment in the UK have 'unexplained' infertility, highlights the gap in knowledge about its etiology. Equally, the figure of over 75% of couples who fail with IVF each year highlights the relative failure of the medical solution (HFEA 2008b). It is also possible that the construction of infertility as a disease amenable to medical help implies that couples are compelled to engage with medical treatments, whose use they may otherwise not consider (Sandelowski 1991, Becker & Nachtigall 1992).

A medical definition may also conflict with childless individuals' own experiences. For example, for some couples the recommended period of one year of trying for a baby may be considered too long. For others, the lack of children of a specific gender within the family may constitute a form of infertility which is not included in the medical definition (Pashigian 2002). There are of course, some advantages to a medical definition of infertility. Deploying the category of 'disease' means that involuntarily childless couples become 'patients' and are able (in theory at least) to relinquish the blame of infertility and instead make claims to treatment (Sandelowski & de Lacey 2002). This is not always successful, however. Despite the cultural hegemony of the medical model in this instance, infertility is not always perceived as a disease in the public sphere, especially in relation to rationing within the NHS (Bowling 1996, Sandelowski & de Lacey 2002).

The social, psychological and material implications of the medicalisation of infertility for the men, and especially the women who use ARTs, have been well documented particularly in the American and British contexts (Greil 1991, Becker & Nachtigall 1992, Franklin 1997, Sandelowski & de Lacey 2002, van Balen & Inhorn 2002, Earle & Letherby 2002, 2007, Throsby 2004).

However, what is consistently absent from these accounts are the voices of men and women from minority ethnic groups. Given the importance of the social and cultural context on the meanings given to infertility as described above, few studies include a diverse sample, focusing overwhelmingly on the experiences of white, middle class couples (Greil 1997). This thesis aims to address this imbalance by focusing on the experiences of members of British South Asian communities; the largest minority ethnic category in the UK (a further justification for the selection of this group for inclusion in this study is outlined below). This thesis will therefore explore the ways in which diverse sectors of British society have experienced the medical solution to infertility, which has so far been neglected in commentary on this topic.

The concept of infertility as a socio-culturally constructed experience implies that wider social perceptions of infertility must be taken into account. The social context of infertility is highly significant in shaping individual experiences. A small number of authors have drawn our attention to the need for a consideration of the perceptions of 'public' groups in contributing to the social shaping of infertility (Monach 1993, Miall 1994, Letherby 1999, Edwards 2002). However, there is a corresponding absence of the ways in which members of 'publics' and the wider kinship networks in which people are enmeshed, perceive infertility. As such, much of the research about infertility in the UK to date has also failed to fully explore the impact of the *social context* on infertile couples, instead focusing on the sphere of medical treatment only. Little is known, therefore, about how infertile couples and the treatments that

they use are viewed by their peers and kinship groups and about how infertility is socially constructed and negotiated in diverse cultural settings. This thesis aims to advance the current knowledge in this area by providing an account of how 'lay' members of South Asian communities (who are not necessarily themselves infertile), perceive infertility, infertile couples, and medical treatments for infertility.

The concerns with the medically defined category of infertility as outlined above, are taken in to account when using the term in the rest of this thesis. However, it is this term which is used throughout to describe those who have received a medical diagnosis for their inability to conceive. Since a number of participants in this study had been successful in achieving parenthood by the time they took part in an interview, 'involuntary childlessness' is an inadequate definition. However, the majority of them remained 'infertile' in that they were unable to conceive further children without medical assistance. The use of the term here recognises the socially constructed nature of this medical category, and its inadequacy in describing other forms of involuntary childlessness (Letherby 2002:277).

The next section of this chapter provides an overview of the demographic profile of South Asian communities in the UK including data on migration, socio-economic position and employment, households, family structures and marriage. It also provides a discussion of the health patterns of minority ethnic groups and how these have been explained by social scientists.

British South Asian communities

The term 'South Asian' here refers to members of those communities whose ancestral routes can be traced to the Indian subcontinent, i.e. India, Pakistan

or Bangladesh with this definition also including East African Asians. Figures from the 2001 Census suggest that the South Asian communities make up almost 2.1 million people in England & Wales. This includes 1.05 million people who classified themselves as 'Indian', 747,000 as 'Pakistani' and 283,000 as 'Bangladeshi'. Thirty percent of the Indian category is made up of first generation migrants and their descendents who came to the UK from East Africa (Peach 2006). Despite amendments to the way in which the question on ethnicity was solicited in 2001, a comparison with figures from the 1991 census show that there have been increases in each of the South Asian categories, giving a total increase from 1991 of 40%. Half of the South Asian population were born in the UK, meaning that the growth in population has resulted primarily from natural increases rather than immigration (Peach 2006).

In religious terms, the Pakistani and Bangladeshi groups are relatively religiously homogenous, with a large majority (92%) describing themselves as Muslim (686,000 Pakistani Muslims and 261,000 Bangladeshi Muslims). The Indian group is more heterogeneous, with 45% (471,000) describing themselves as Hindu, 29% (307,000) as Sikh and 13% (137,000) as Muslim (Census 2001).

Migration

Despite the recent growth of these communities in Britain, their presence is not a recent phenomenon; Visram (1986) reports that South Asian migration to Britain began in the 17th Century. However, two more recent periods of immigration have come to define the ethnic composition of Britain today. The first, beginning in the early 1950s, was as a response to labour shortages after the Second World War. The second period of immigration, taking place during the 1970s and 1980s, saw people from Bangladesh and East Africa

settle in Britain as a result of changing political circumstances in those countries (Smaje, 1995, Ali, N. 2006, Brah 2006, Peach 2006). South Asian groups are therefore distinctive in both their reasons for migration as well as the areas in Asia and Africa from which they migrated. It has been suggested that the patterning of South Asian migration to the UK from the sub-continent was impacted by the partition of India in 1947, with the Punjab, the Gujarat and Sylhet all affected. As a result, British South Asian communities tend to be overwhelmingly drawn from these areas (Ali, N. 2006, Peach 2006). East African Asians are effectively 'twice migrants'; first migrating to British colonies in countries such as Uganda, Kenya, Tanzania and Malawi from the Gujarat region of India often as indentured labourers, and coming to the UK in the 1970s following their expulsion from those countries (Brah 2006, Peach 2006).

Socio-economic position and employment

In terms of their location in British society since arrival, South Asian communities have fared very differently (including in health status, see below). Broadly speaking the Gujarati Indian group (including East African Asians) has been the most successful; achieving relative prosperity and affluence, followed closely by the Punjabi Indian group which has also been successful in the degree of socio-economic accomplishment achieved in the UK. This is in contrast to the Pakistani and the Bangladeshi groups who have achieved relatively poor rates of success since arriving in Britain (Platt 2002, Ballard 2003, Nazroo 2006, Peach 2006). The socio-economic context from which people migrate has a bearing on these trajectories, with differences between those originating from areas of long-standing agricultural success (such as the Punjab and Gujarat) compared to those groups migrating from less economically developed areas (Sylhet) (Ballard 2003). Many of those

migrating from East Africa had come to hold middle class positions in Africa as doctors, lawyers, civil servants and entrepreneurs and therefore migrated with a number of skills and social, if not financial, capital (Ali, N. 2006, Peach 2002).

Amongst all ethnic groups, including white categories, Indian men are most likely to be employed in professional positions, and Pakistani and Bangladeshi men least likely (Nazroo 2006, Peach 2006). Pakistani and Bangladeshi women are least likely to be employed outside the home with 29% and 25% of women in these categories respectively having a paid role, compared to 57% of Indian women and 60% of the total female population (Peach 2006). The numbers of Pakistani and Bangladeshi women entering the labour force is increasing however, and this trend may be a reflection of the growing numbers of women from these groups accessing and succeeding in higher education (Dale et al. 2002). However, Pakistani and Bangladeshi men and women still have the lowest levels of qualifications when compared with other minority ethnic groups, and experience higher rates of unemployment (Peach 2006) as well as greater levels of poverty and deprivation than other groups (Platt 2002).

Households, family structure and marriage

As a whole, South Asian communities are younger when compared with the total population; having a greater proportion of children and young people under the age of 16 years, as well as a larger number of men and women in the 16-34 age group (Census 2001). These figures demonstrate the higher numbers of families with dependent children in South Asian communities as well as a large proportion of men and women who would fall into the childbearing age bracket. In addition, there are fewer South Asian people in

the over 65 year old category. Findings from the Fourth Survey of Ethnic Minorities in Britain reflected some of these differences, highlighting larger family sizes amongst some South Asian groups (Modood et al. 1997).

Pakistani and Bangladeshi groups for example, had the largest families, 33% of Pakistani families and 42 % of Bangladeshi families had four or more children, whilst Indian and East African Asian families tended to be smaller in size (Modood et al. 1997). Findings from research have also reported childbearing to be considered the norm for married couples in South Asian communities (Katbamna 2000, Culley et al. 2004).

In terms of household structure there are differences within the South Asian category, predominantly between Indians and African Asians, and Pakistani and Bangladeshi groups. Beishon et al. (1998) report that the former hold the view that married children should set up home on their own, but should remain within close proximity to their parents should they be needed. The latter, however, were more likely to consider extended households to be the norm. For reasons of 'privacy and autonomy' a small number of Pakistani and Bangladeshi respondents felt that it was better to have parents nearby as opposed to within the household (1998:62). Figures from the 2001 census reflect these trends, with Bangladeshi households containing on average 4.5 people, Pakistani households 4.1 people and Indian households 3.3 people. These are higher than for the national average of 2.4 people per household and this is in part due to multi-generational households as well as higher numbers of children in Pakistani and Bangladeshi households in particular. However, it is important to note that the extended family, which was once the norm for South Asian families, is declining in the British context (Ahmad 1996). Factors such as immigration legislation, lack of suitable housing, and changing attitudes to household and family formation may be contributing to this change.

When comparing patterns of marriage, a number of authors have highlighted changing trends in this area (Beishon et al. 1998, Bradby 1999, Bhopal 2000, Ahmad 2006). These changes are largely due to a decline in formally, parentally arranged marriages amongst some groups. East African Asians and Indians for example tend to favour a 'negotiated' form of arranged marriage in which the couple themselves, as well as their parents can be involved, whereas Pakistani and Bangladeshi families are more likely to engage in more traditional arranged marriages (Beishon et al. 1998). Marriage per se is considered the norm in most South Asian groups, with lower rates of divorce, co-habitation and separation when compared with other ethnic groups. Amongst families with dependent children, 91% of Indians, 89% of Bangladeshis and 85% of Pakistanis were headed by married couples, whereas this is true of 77% of white families and 46% of Caribbean families (Peach 2006).

This overview of the demographic characteristics of British South Asian communities highlights the diverse way in which these communities have migrated to and settled in the UK. In particular it demonstrates the *structural* differences between the Indian and East African Asian categories and the Pakistani and Bangladeshi communities. The simple categorisation of people and communities by 'ethnic' group is problematised in the context of this data (Nazroo 1997), and these debates will be considered in more detail in the next chapter. The diverse nature of groups officially categorised as South Asian has implications for the health experiences of members of these communities and this is discussed in more detail below.

South Asian communities, health and health care

It is widely acknowledged that there is a relationship between ethnic group membership and a person's health status and experiences (Smaje 1995, Nazroo 1997, Acheson 1998, Sproston & Mindell 2006). The demographic data presented above show the demographic differentiation within the broad 'South Asian' category. This pattern is reflected in the data on morbidity and mortality, and therefore demonstrates some of the problems with treating the 'South Asian' group as a homogenous category (Nazroo 2006). A more nuanced reading of the data on ethnic health differences, allows us to see that particular minority groups have worse self-reported health than others. Self-reported rates of ill-health are markedly different amongst the South Asian groups, with the Pakistani and Bangladeshi groups consistently faring worse than the Indian, as well as other ethnic groups (Nazroo 1997, 2006, Sproston & Mindell 2006).

Explanations for such differences in health status amongst minority ethnic groups in the UK have taken a number of forms, suggesting that the disparity may be explained with reference to one or a combination of factors, including those related to: socio-economic status; processes of migration; racism; cultural factors or biology (Smith et al. 2000). The causes of differential rates of morbidity and mortality amongst ethnic groups are highly contested and a number of authors have reminded us of the complex interplay of factors impacting on a person's health status (Smaje 1995). In particular, the need to avoid overly simplistic explanations which focus uncritically on the impact of one causal factor has been argued (Culley et al. 2006). For example, a number of studies into the health experiences of minority groups have tended towards *cultural* explanations, focusing on and problematising difference in cultural practices and lifestyles between minority and majority groups as the cause of

ill-health (Ahmad 1996). Nazroo highlights the problematic nature of genetic and cultural explanations when he suggests:

'...explanatory factors are rarely assessed with any accuracy and the search for clues regarding aetiology is typically done with a focus on the *assumed* genetic and cultural characteristics of individuals within the ethnic group of greater risk. Consequently explanations tend to fall to unmeasured genetic and cultural factors based on stereotypes because such meanings are easily imposed onto ethnic categorisations' (Nazroo 1998:155).

The need for a theoretical shift away from such approaches has been highlighted, with authors arguing for an exploration of cultural difference within the broader social, political and economic context (Nazroo 1997, Atkin 2006). This thesis therefore attempts to avoid the 'culturalist' approach to understanding health experiences (Ahmad 1996, Culley 2006). Instead it attempts to locate experiences within the broader socio-structural context, without negating the potential influences of culture on health beliefs and behaviours (Kelleher 1996).

Nazroo (1997) has demonstrated the value of a structural interpretation of health inequalities as they impact upon different groups. He has argued that there have been a number of problems with simple explanations for ethnic patterning, including those which have attempted to attribute differences to crude or inappropriate measures of social class (for example see Marmot et al. 1984, Nazroo 1998). Structural explanations should therefore include an acknowledgement of socio-economic status, *as well as* lifetime patterns of deprivation, racism and ecological effects on health, for example (Karlsen 2007; the problematic nature of standard measures of social class in relation to ethnic groups more generally is considered further in Chapter Four). The need for a clear definition of ethnicity is also imperative in any measure of its impact on health, and this is discussed further in the next chapter.

Studies have also drawn our attention to the need to be aware of disparities in *access* to health care services, which may compound these inequalities (Acheson 1998, Smith et al. 2000, Atkinson et al. 2001, Atkin 2004, Ali & Atkin 2004, Szczepura 2005). Such research illustrates how inequalities in access to and delivery of services to minority populations, such as those caused by poor communication support (Bradby 2002), may exacerbate rates of ill health (Ali & Atkin 2004, Atkin 2004). However, some writers have pointed out that access to services may be influenced less by ethnicity, than structural factors such as general education levels and socio-economic status, including employment outside of the home (Hennink et al 1998, Rhodes et al 2003). Good quality, empirical research about the specific operation of such barriers however, is at best inconsistent (Smith et al. 2000, Goddard & Smith 2001, Aspinall & Jacobson 2004, Szczepura et al. 2005).

In a significant contribution to the understanding of structural factors in access to health care, Atkin (2004) draws our attention to the operation of 'institutional racism' in disadvantaging some groups within the British healthcare system. He argues that the ways in which healthcare services are organised, often to the disadvantage of minority ethnic groups, needs to be considered when attempting to address inequality. A lack of appropriate provision, such as the absence of effective interpreting support, or cultural misunderstandings amongst healthcare providers about the make up of South Asian families, are both examples of institutional racism offered by Atkin (2004). However he is also clear about the accompanying need for a more reflexive understanding of 'ethnicity', which allows for the consideration of *similarity* as well as *difference* in understanding health experiences. As he argues, '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' (2004: 15). The challenge for Atkin is in knowing when ethnicity makes a difference and when it does not. This thesis attempts to contribute to understandings about the difference that ethnic identity might make (as well as a number of other facets of identity) in the experience of infertility and infertility treatment in the UK.

Justification for the study

This brief overview demonstrates the importance of the interplay of a number of social, cultural, economic and political factors which combine to locate British South Asian communities in a unique social space. In particular it demonstrates the importance of these factors for a range of health experiences³, and this includes infertility. However, at present in the UK there are no data which report differences in infertility prevalence according to *ethnic group*. This is a possible reflection of the general history of poor ethnic monitoring in the health service in the UK (Johnson 2001). Projected figures from the HFEA, based on the 2001 census data for 18 – 45 year olds suggest that approximately 136,000 individuals of Indian, Pakistani and Bangladeshi ethnic origin could be experiencing problems in conceiving (HFEA 2006a). Research from India also suggests a similar rate of infertility to the UK at between 10% (Katiyar 1993) and 15% (Zargar et al. 1997), but comparison with the UK is limited given the very different make up of Indian society when compared to the UK.

Given the norm of having larger families, the almost universal propensity for marriage, and the larger proportion of individuals of childbearing age within South Asian communities, it could be suggested that infertility is likely to

³ A full review of the literature on ethnicity and health is not possible here, however the debates about ethnicity, which are of central concern in this thesis are discussed in the next chapter.

impact significantly on childless couples from these communities. Differently constructed perceptions of infertility, which are influenced by diverse socio-cultural contexts, have also been demonstrated in this introduction. However, to date, there has been a limited focus on experiences of infertility with minority ethnic communities in the West (Greil 1997, Culley et al. 2004), despite the potentially large number of individuals from minority communities who may be affected (HFEA 2006a), and the evidence that ethnicity impacts on health. For some, this absence is representative of the racist perception that black and minority women have too many babies (Roberts 1997, Katbamna 2000) and that infertility is therefore largely the concern of white, middle class women; further evidence of its socially constructed nature. This study aims to redress this imbalance, and to explore the experiences of women from the largest minority ethnic category in the UK.

This thesis therefore aims to provide an advance in knowledge in understanding the relationship between ethnicity and infertility, with a focus on both the individual experiences of infertility, as well as the 'community' or 'public' understandings of infertility and its treatment. It is designed in this way in recognition of the importance of how infertility is socially constructed. Crucially for childless couples, the views of others (family members, the wider community and society) are central to their experiences, especially in pronatalist contexts where childbearing is an expected and central element of adult life (Miall 1994).

The following aims were thus established:

- To explore the social constructions of infertility and assisted conception among South Asian communities in the UK
- To examine the experiences of women from South Asian communities who have used reproductive technologies.

The first phase of this study used focus groups to access a range of public groups in South Asian communities to discuss their views on this issue. In the second phase, individuals with a personal history of involuntary childlessness and experience with assisted conception were recruited to take part in in-depth interviews to discuss the impact of infertility on their lives. In particular, these interviews highlight how they have 'negotiated' these public and community discourses whilst attempting to resolve their infertility through medical means. A consideration of the impact of the identities of the researcher and the participants, especially their ethnicities, on research interactions was also an important focus of this study.

The structure of this thesis

This thesis is organised into ten chapters including this one. Chapters Two and Three present the academic debates on 'ethnicity' and 'infertility', respectively. Chapter Two is a conceptual chapter which discusses the ways in which ethnicity has been defined in the literature, ultimately providing an account of how it is defined in this thesis. It seeks to challenge the ontological notion of ethnicity and to explore the ways in which ethnic categories are reproduced and constructed in empirical research. This chapter also discusses current debates about the matching of researchers and participants in ethnic terms. Chapter Three presents a discussion of the ways in which infertility has

been constructed as a category within different bodies of academic writing. This chapter represents an attempt to explore a range of conceptual and substantive debates about infertility, and to further theoretically situate the research questions raised in this thesis. Chapter Four includes a discussion of the methodological approach of the study, including the demographic profile of the participants. Chapters Five, Six and Seven present new empirical data collected as part of this thesis. Chapter Five presents data collected from a series of focus groups conducted with 'lay' members of British South Asian communities, not themselves experiencing infertility. This chapter describes the ways in which infertility and its treatment is understood at the community level. Chapters Six and Seven present findings from in-depth interviews with infertile individuals. These two chapters describe the experiences of those who have experienced infertility and their attempts to overcome it. Chapter Eight of the thesis draws together the findings and discusses them in relation to theoretical insights from Bourdieu and Goffman and a number of sociological studies, which are reviewed in Chapter Three. This chapter presents the original contribution to knowledge proposed in this thesis and aims to show how the experience of infertility in South Asian communities can be explored using the concepts of habitus, field, capital and stigma. Chapter Nine presents my reflections on having carried out this study, including an extensive commentary on the dilemmas involved in researching across 'difference'. The final chapter, Chapter Ten, presents the conclusions to the research and suggestions for further research in this field.

Chapter Two: Conceptualising 'race' and ethnicity in research

Introduction

As suggested in Chapter One, the notion of 'ethnic' identity cannot be taken for granted. This chapter therefore, is designed to problematise the ontological foundations of 'ethnic/racial' categories and as such it should be understood as a conceptual chapter, rather than as a traditional review of the literature. Since this thesis is concerned to understand the experiences of a group of participants who are identified collectively as a minority in ethnic, cultural and religious terms in the UK, it is necessary to deconstruct the process by which this identification takes place and is reproduced in research. This chapter will offer a critical exploration of how concepts of 'race' and 'ethnicity'⁴ are reproduced both at the societal level as well as within the context of research practice, and will highlight what Gunaratnam (2003) refers to as the 'tensions' which face researchers in this respect. It considers how ethnicity has been conceptualised by those working in the field, and will discuss and develop the approach taken to theorising ethnicity and culture in this thesis. It will lay the basis for suggesting a theoretical shift in understanding ethnicity in relation to infertility, which is discussed and developed further in Chapter Eight. The chapter begins with a brief outline of the concepts of race, racialisation, and racism before proceeding to discuss the use of concepts of ethnicity in social science research.

⁴ It is acknowledged that the terms 'race' and 'ethnicity' are contested concepts. However, in order to aide the flow of the text, and following Phillips (2007), scare quotes are not used every time these terms are present in the thesis.

The origins of ideas about 'race'

'Race' and 'ethnicity' are terms widely used in social science and professional discourse, as well as in popular, everyday language. However, their significance remains an area of contention for social scientists and researchers and the debate around their use continues (Aspinall 2001, Bradby 2003, Nayak 2006). The term race, used to describe and differentiate groups of people based on perceived physical differences, which somehow relate to biological or genetic differences (Barkan 1992), is now scientifically discredited and no longer carries any theoretical weight, at least within the social sciences (Fenton 1999, Carter, 2007). Ironically, at a time when more than ever is known about the human genome, it is becoming increasingly difficult to understand the exact implications of such knowledge. In fact, increased knowledge about genes has somewhat muddied the water in race science terms. Scientists have (unwittingly or otherwise) reinvigorated old race categories in their quest to understand human variation and in particular its relationship to disease (Tutton 2007). This creates further complexity for social scientists, who are again called upon to deconstruct such configurations and identify the socially constructed nature of such a racialised search for difference.

The scientific discrediting of the notion of a biological concept of race and the corresponding critique from sociologists of race as a political and cultural construction, has not however, prevented the use of the term in popular language and in social discourse (especially in the USA). Instead it has been retained and is often used interchangeably with the term 'ethnicity' to refer in some sense to what Fenton refers to as 'descent and culture communities' (2003: 13-24). Fenton argues that race and ethnicity as well as the concept of nation, share a core idea about descent or ancestry in an attempt to categorise

groups of people. Van den Berghe argues that race has become nothing more than 'a special marker of ethnicity' (1981: 240 in Jenkins 1997:48), at least in the popular imagination, whereby physical features remain a visible test of common ancestry and therefore of difference. Importantly therefore, race as a social construct continues to hold weight, both in the public consciousness as well as in some academic writing. The process whereby biological or physical characteristics are used in order to define and categorise social groupings is referred to as *racialisation* (Miles 1989).

Racialisation and racism

The power to identify and define others in racial terms, especially when the effects are potentially inequitable, is significant. As suggested above, Miles argues that the idea of race still exists even in the absence of supporting scientific or political discourse. In explaining the enduring nature of this categorisation he suggests: 'the concept of racialisation therefore refers to the historical emergence of the idea of 'race' and to its subsequent reproduction and application' (1989: 76). Ideas about groups of people identified by their belonging to a specific ethnic group is compounded by and constituted through a process of racialisation. Collectives of peoples with shared migratory and ancestral histories, as well as shared languages, and in some cases religions, are 'racialised'; a process which is built on historical discourses of biological race. Imbalanced power relations between minority groups (often those who have migrated, such as the South Asian diaspora in the UK) and the majority population, are also implicit in this process of racialisation – or marking as other and racial. It is significant to note that this process draws on physical markers of difference, skin colour in particular, and as a result 'white' minority groups such as the Irish, can be eventually subsumed into the homogenous White category in the UK and effectively

made invisible. Processes of racialisation have tended to relate to 'minoritised others' and an increasing number of authors have commented on the popular and academic silence around the issue of whiteness as an unmarked, unnamed ethnic category. Dyer (1997) suggests that as long as whiteness remains un-deconstructed, differentials of power remain unchallenged. He suggests of the unmarked category:

'There is no more powerful position than that of being just human. The claim to power is the claim to speak for the commonality. Raced people can't do that – they can only speak for their race' (p.2).

The marking of some groups as racially 'other' has fed into the process of racism (Miles 1993). The less favourable treatment of groups based on physical, cultural and perceived ethnic differences has continued, both in the public sphere as well as in institutional settings (Atkin 2004, Puwar 2004). The theorisation of institutional racism in the British police force by the MacPherson Report (1999), and later by others in relation to health care (Ali & Atkin 2004, Atkin 2004), has argued for an understanding of racism which transcends individual prejudice and which can be found at the heart of a number of institutional structures. Racialisation then, allows an understanding of the identification of some groups as other. In doing so it draws on, and perpetuates the idea of race as a biological construct that persists in some theorising of ethnicity (see Bhopal and Donaldson 1998). In using the concept of ethnicity in place of race, many writers have been careful to point out that social constructionist perspectives can fall into the essentialist trap just as easily as those who use race in biological terms. As Pfeffer suggests: 'essentialism can be social as well as biological' (Pfeffer 1998).

Ethnicity & culture

As already suggested, some sociologists have argued for the need to retain a concept of ethnicity, because it relates to a social process or socially constructed categorisation. The development of ideas about ethnicity as a social process allows for a less essentialist reading of the idea of identity (Jenkins 1997, Fenton 1999, 2003, Culley 2006). It is suggested that although a social construction, the concept of ethnicity has real, material effects for people's lives. An important effect is the way in which it is used by individuals to identify one another as belonging to a particular ethnic group (Fenton 2003). In turn, this has explanatory value in understanding how these groups then inter-relate with one another - so-called 'race relations' - and for the effects of racism (Miles 1989).

Fenton (1999, 2003), following the work of anthropologists such as Barth (1969) and Nagel (1994), argues that we should understand ethnicity as a social process, in that ethnic groups are not fixed categories, since ancestry, culture and language are subject to adaptation and contestation. Instead, the moving boundaries and identities associated with ethnicity should be seen as an *element* of social relationships, rather than being what defines them. Social scientists have argued, therefore, that ethnic identification in essentialist terms is undesirable, both socially and analytically, and that ethnicity should be understood as culturally and historically contingent and, as such, as variable and negotiable. Fenton's use of the notion of 'descent and culture' communities (1999, 2003) is valuable when exploring the way in which ethnic identity is constituted, and is employed within this thesis as an operational definition of ethnicity. He suggests that the term 'descent and culture communities' is the starting point for understanding ethnicity rather than a definition (2003). He argues that the aim of social scientists should be to

highlight the social construction of these communities, saying that: 'People or peoples do not just possess cultures or share ancestry; *they elaborate these into the idea of a community founded on these attributes*' (2003:3). Ethnicity is therefore a 'lived' social process and the ways in which ideas of descent and culture communities are elaborated by individuals in the context of infertility is discussed in Chapter Eight.

'Culture' therefore, is an element of a person's ethnic identity (Fenton 2003). It remains however, a contested concept and there has been much discussion of its constitution and 'effect' on beliefs, values and lifestyles, particularly in relation to health (as described in the previous chapter). Although culture and ethnicity are closely related concepts, they do not map onto one another neatly; sharing an ethnic group with someone does not imply a shared culture and vice versa (Hillier & Kelleher 1996: 3, Fenton 2003:20-22).

Fenton, along with a number of other authors (Ahmad 1996, Kelleher 1996) has been critical of a simplistic notion of culture when describing ethnicity and ethnic identities. The categorisation of groups based on ideas about distinctive cultural practices and traditions should be avoided, since this leads to an essentialist view of fixed cultural groups which are in some concrete way tied in with the ethnicity of the group's members. Members of these groups are then identified as such by virtue of their perceived cultural essence, which is often also linked to common sense ideas about visible signifiers such as skin colour or dress; a position which many writers seek to avoid (Ahmad 1996, Brah 1996, Kelleher 1996, Ramji 2003, Ahmad 2006). Culture is therefore a highly fluid construct and is open to change; especially through social actors. It is therefore one which guides and influences people's lives but does not determine them (Kelleher 1996). As Kelleher suggests, people are not:

'...cultural dopes'...who live unproblematically by simply following the taken-for-granted rules of their culture, but actively play a part in the construction of their ethnicity by trying to reconcile and integrate the sometimes conflicting structures of relevance' (1996:77).

The task for researchers is therefore not to be able to predict how people will behave according to some set of guiding cultural norms, but to adopt a more critical approach to the understanding of culture, one which is informed by an awareness that people 'are using their cultural resources to address their current problems' (Kelleher 1996:82). In this vein, Ahmad calls for a reappropriation of 'a much more politicised and contextual notion of 'culture'' (Ahmad 1996: 215).

A growing number of scholars have contested the notion of culture as it relates to South Asian women in particular (Brah 1996, Bradby 1999, Purewal 2003, Puwar & Raghuram 2003, Ramji 2003, 2007, Ahmad 2006). This body of literature has been critical, both of the ways in which white feminist notions of patriarchy have been uncritically applied to South Asian families (Ahmad 2006), as well as the perception of South Asian women as sites of oppression and unquestioning bearers of traditional culture (Brah 1996, Purewal 2003, Ramji 2003, Ahmad 2006). These writers have linked culturalist perceptions of South Asian women to the colonial project, which simultaneously essentialised culture and pathologised South Asian families.

Along with others (Kelleher 1996, Ahmad 1996), these authors have been critical of static notions of culture. Instead they have questioned the use of cultural concepts such as *izzat* (honour) and *sharam* (shame) in relation to South Asian women, which they argue are poorly defined to begin with (Ahmad 2006). In addition, these authors suggest that these concepts vary in the way they are employed in the British context, ignoring differences of

caste, kinship, class, education and family practices. It is argued that few authors have attempted to expand these concepts in order to include female centred notions of honour, instead viewing honour as essentially 'male', whilst female relatives are seen as its carriers (Brah 1996, Ramji 2003, Ahmad 2006).

The tendency of researchers to focus on providing a cultural explanation for apparently 'exotic' cultural practices, such as arranged marriages, has been criticised (Ahmad 2006). Ahmad (2006), has critiqued the work of Kalwant Bhopal (1999, 2000) for example, for her problematic categorisation of South Asian women as either 'traditional' or 'educated', and the impact this has on their marriage choices. Ahmad (2006), suggests that women have a great deal more agency than is acknowledged in these accounts of culture. South Asian women, it is argued in this literature, have agency and are 'innovators and originators of new cultural forms' (Ramji 2003: 230). These processes of agency and innovation can be seen to be linked to wider processes of social change, occurring both for women more generally, as well as within South Asian communities specifically. Ahmad (2006) also points out the emergence of new cultural forms such as Asian speed dating and online dating agencies for example, targeted at South Asian men and women, which she suggests are evidence of a more active South Asian femininity than has previously been identified in the research literature. Access to resources for women clearly has a role to play in enabling a woman to enact agency, and this will therefore, as we saw in chapter one, vary between and within communities. Agency in shaping ethnic identity may also be linked to the accumulation of other types of resources, such as social class and religion (Ramji 2007). The need to resist the singular significance of ethnicity and culture has been demonstrated by those whose work can be described as working to 'de-centre' ethnicity, and

the contribution of this body of work to understanding a 'lived' ethnic identity is described next.

Positionality and the de-centring of ethnicity

In an understanding of ethnicity that explores its relationship and co-existence with a number of other social signifiers, Floya Anthias (2002a) argues that the concept of identity is of 'limited heuristic value'. Rather, she suggests that it may be more useful to use the idea of 'narratives of location and positionality' in understanding how individuals make sense of their place in the social order. Using data from research with young British people of Greek Cypriot background, she describes how the narratives that these young people articulate are an enactment or form of social action. She sees this as operating to construct 'subject positionalities' and rejects the idea of a fixed essence or identity (such as ethnicity). The concept of positionality allows a discussion of the ways in which other social signifiers, such as gender, social class and age, impact on and mediate ethnicity – therefore *de-centering* ethnicity as the most significant identifier in any given context (Anthias 2002a & b).

The concept of positionality is inherently anti-essentialist, as it allows a shift in focus away from the traditional idea of class or ethnic identity or essence, but instead allows the inclusion of different attributes which are potentially diverse and shifting. This development, which has been related to the linguistic turn in the social sciences, places an emphasis, not on identity politics, but rather on the construction of discourse and narrative (Wade 2002). Therefore, in this model, the process whereby an individual comes to be positioned is fluid and unpredictable and is discursively produced. In this way, other constructions of social difference, such as gender, can be accommodated into the 'identification' or social 'location', since it is argued,

they too are socially and culturally contingent (Hall 1992). Hall is interested in how identities become hybridized, and therefore, that it is no longer of use to talk about ethnicity as a fixed signifier of individual or group identity.

Instead, what is significant are the ways in which new and complex forms of identity are negotiated by individuals. However, this post-structuralist model has been criticised for its failure to sufficiently acknowledge the impact of material factors upon the ability of individuals and groups to locate themselves (Wade 2002). In considering the postmodern perspective, Rattansi (2000) suggests 'identities have to be regarded as having relative stabilities as well as instabilities' (p123).

Therefore, whilst positionality is a useful theoretical tool in the advancement of an anti-essentialist reading of ethnicity, it is less useful for allowing an interpretation of the significance of structure in this process. Jenkins (1997), for example, suggests that to say that ethnic identity is changeable, is not to say that it will always be or has to be contingent. He describes the ways in which ethnicity can be transactional as the following: through processes of *internal definition*, in that actors signal to in- or out- group members a self definition, or that processes of *external definition* take place in which one person or group defines the other(s) (1997:53). He suggests it is unlikely that external definition is an individual act, as it can only occur within active social relationships, and that the capacity to define is dependent upon the power or authority to do so, which are also 'necessarily embedded within active social relationships' (1997: 53). Structure, power and authority are implicit in this process, since only those with the influence to identify and categorise others are able to do so.

External processes are clearly important in understanding the construction and maintenance of ethnic identities. The conceptual challenge for researchers

working with ethnicity is to incorporate understandings of both ethnicity as identity or subjectivity (along with a number of other signifiers), as well as ethnicity as structure. The next section draws on the work of Pierre Bourdieu to consider these debates and in doing so presents the approach taken to understanding ethnic identity in this thesis.

Combining structure and agency in ethnicity research: utilising the work of Pierre Bourdieu

As described in chapter one, a number of writers have drawn our attention to the need to recognise the structural factors implicated in an understanding of ethnic identity (Nazroo 1997, Karlson & Nazroo 2002, Culley 2006). Culley suggests 'ethnicity is not merely symbolic; it is also materially constituted in structures of power and wealth' (p148). The work of James Nazroo and colleagues has been central to the recognition of the importance of structural factors which relate to the experience of ethnicity, especially in relation to health. Nazroo proposes that the structural positioning of some ethnic groups in the UK cannot be ignored when understanding the impact of ethnicity in shaping identity, since some ethnic groups tend to predominate in lower socio-economic groups in the UK (such as Bangladeshi and Pakistani communities for example) (Nazroo 1997, Platt 2002). Karlson & Nazroo (2002) acknowledge the importance of agency in the generation of ethnic identity, suggesting that ethnicity is important for understanding processes of self and other identification, but suggest that it is ethnicity as *structure* which impacts on a person's experience of health.

A number of authors, including Karlson and Nazroo (2002), have attempted to combine structural and individual elements in theorising how ethnic identity is lived, by drawing on the work of Pierre Bourdieu (Smaje 1997, May

1999, Culley 2006, Lynam et al. 2007). It is argued by these authors, that life choices are made within certain social constraints, a phenomenon which Bourdieu refers to as 'habitus' (1977). It is this theory which has been drawn on by researchers working on ethnicity, in order to facilitate a better understanding of the processes involved in the production and reproduction of (ethnic) identities. Although not specifically concerned with ethnicity, Bourdieu's work allows a conceptualisation of how identities and subjectivities are created and sustained. As with the work of Anthias and others, Bourdieu presents an understanding of subjectivity which is anti-essentialist, and which permits inclusion of the role of a range of dynamic social signifiers in understanding individual identities. However, Bourdieu's work constitutes a parting with more relativist debates about 'positionality', since it allows an in-depth consideration of the role of structure in identity formation and action. His concept of habitus is designed to allow a reading devoid of essentialising and determinist processes. For Bourdieu, what people do (agency) reinforces and reproduces identities, or in his terms the 'habitus', which he describes as:

'an acquired system of generative schemes objectively adjusted to the particular conditions in which it is constituted, the habitus engenders all the thoughts, all the perceptions, and all the actions consistent with those conditions' (1977:95).

The habitus is in turn related to the available structural resources on which an individual has to draw in making choices and creating subjectivities. For Bourdieu, the social structures that we encounter unconsciously shape our lives in significant ways. Importantly, this is not a determinist relationship, but rather one in which individuals have agency and purpose, and thus in turn shape the social terrain in which they move. Therefore, individuals will operate strategically, but within the constraints of a particular habitus (May 1999: 29). However, the strategies to which Bourdieu refers are not 'rational

choices', but are sets of dispositions which arise from an internalised 'practical sense' of how to behave and react in any given situation (Swartz 1997).

Bourdieu's theory of habitus includes an exploration of two related concepts: 'field' and 'capital', which are central to understanding the ways in which the habitus is enacted by individual actors. Bourdieu refers to the social terrain, or more specifically, the social spaces and contexts in which social life takes place as field. A field is a distinct social space, which he defines as a 'structured configuration of positions' (Bourdieu & Wacquant 1992). Fields impose guidelines for behaviour and regulations on those who enter them, and are also characterised by 'struggles' in which individuals battle over the distribution of capital (see below). A field is also defined as an historical constellation which has developed a certain degree of autonomy, in that it is able to uphold its own criteria of value and judgement (Bourdieu & Wacquant 1992:99, see also Wacquant 2006). 'Home' fields draw on, and support habitus, whilst unfamiliar fields may challenge the habitus and require change to the usual way of being (Lynam et al. 2007).

The third concept from Bourdieu's work which has implications for the production of identity, is capital, which can be social, material, cultural and symbolic. Bourdieu suggests that forms of capital can be acquired, exchanged and transformed into other forms of capital (1986). Capital is a resource drawn upon to gain entry to fields and to navigate and make sense of the social world. He articulates this relationship as:

[(habitus) (capital)] + field = practice (Bourdieu 1984: 101)

Bourdieu's work, therefore, allows an exploration of the ways in which individuals use forms of capital in negotiating different fields and for

constructing and reconstructing their habitus accordingly. Importantly, the habitus is 'shared by people subjected to similar experiences even as each person has a unique individual variant of the common matrix' (Wacquant 2006:6-7). This sharing allows an analysis of the patterning of the ways that different dispositions and practices are shaped by ethnicity, culture, religion, gender and so on.

Bourdieu's work allows us to see how culture and 'ethnicity' (as elements of habitus) have enduring qualities but are also capable of transformation (May 1999). As Wacquant suggests, habitus is a principle of both '*social continuity and discontinuity*' (2006: 7 italics in original) in that it allows us to examine the stability of social identities, as well as allowing a reading of the ways in which they can change over time and space. May (1999), drawing on Bourdieu to provide an understanding of ethnicity, suggests that habitus is a form of collective history, which normalises particular practices. However, he is also clear to point out, as does Wacquant, that the collective habitus is open to change, even if the transformation may at times be slow (May 1999:29). May also points out that the individual and collective habitus of dominant groups are constituted as cultural capital, that is recognised as 'socially valuable and normalised' (1999:30), whereas the habitus of subordinate groups (such as that of minority communities) is not. This, he says, 'helps to explain the normalization and valorization of whiteness' (1999: 30). In providing this theorisation, Bourdieu's work allows an understanding of how some groups are marginalised in their access to new fields and how some forms of capital are given more value than others.

However, other authors have been critical of Bourdieu. For example, Richard Jenkins (2002), suggests that despite Bourdieu's claims for avoiding dualisms, habitus is in fact a form of structuralism. He argues that this is because

Bourdieu claims that habitus provides an ultimately 'true' explanation for behaviour, in spite of the agency of individuals (2002: 93). Because of this, habitus can be seen as determining actions, precisely what Bourdieu is attempting to overcome. In addition, Jenkins suggests that some of Bourdieu's ontological categories – such as fields and the institutions within them – are ambiguous. These criticisms of Bourdieu will be addressed more fully in the application of his theory in chapter eight.

In defence of Bourdieu, May suggests (as does Jenkins), that 'habitus' should be used as a method, rather than a theory, that is, a way of thinking about structure and agency, which is actually Bourdieu's preferred approach for empirical researchers (May 1999). May therefore suggests the use of habitus as a method to 'think about' ethnicity.

The approach used in this thesis

This thesis uses habitus and its related concepts of field and capital as a tool to think about ethnicity and infertility. In particular, it focuses on the negotiation of ethnic identities and how these impact (or do not) upon infertility experiences. Within this use of habitus, ethnicity (as a facet of the habitus) is operationalised using Fenton's 'descent and culture communities'. However, this thesis also aims to demonstrate how ethnic identities are mediated and destabilised by other identities within the habitus, such as religion and gender, and may also be actively negotiated by individuals (as argued by Bourdieu, as well as Brah 1996, Ahmad 2006). In particular, it will explore the ways in which women actively negotiate their place and identities within descent and culture communities. In doing so, this thesis will explore how ethnic identity is mediated by other social signifiers. The theoretical value of

field and capital are also explored in this thesis in relation to the infertility experience.

Up to this point, this chapter has described some of the ways in which ethnicity has been theorised in the social sciences. Operationalising such an unstable set of ideas is complex and often contradictory (Bradby 2003). The ways in which researchers grapple with the use of these and related terms in practice has been discussed widely in the literature and is presented next.

The conceptualisation of race and ethnicity in research

A number of writers have questioned the sense in continuing to rely on social categorisations which have been shown to have no validity (Gilroy 2001 in Nayak 2006). Nayak (2006), highlights the contradictions found in social constructionism work on race, which see writers continue to use racial categories. Although categories relating to race and ethnicity have been found to be flawed, writers continue to use them in order to make sense of, and order their research. A body of literature has developed which addresses this apparent contradiction and offers some suggestions for a resolution to this complex dilemma.

As described earlier, the use of racial terminology in scientific research is well documented and has continued despite the discrediting of such terms by the scientific community themselves. This demonstrates the persistence of the social and political nature of these concepts. As previously suggested, increasing work in the area of genomics has in fact reinvigorated old race categories, and lent weight once again to the idea that humans are categorizable by virtue of genetic groupings. Carter (2007) suggests that 'genomics dissolves race categories (by undermining the link between somatic

appearance and group) only to reconstitute them at a deeper level (by suggesting that our most significant connections to other human beings lie in our genes). Race categories thus re-appear as a new truth about human identity' (p554).

These new 'truths' about human identity are perpetuated in research contexts, both scientific and social, ultimately leading to their reinforcement. Even where their use is contested, the lack of a viable alternative, coupled with a desire to understand their 'real' social effects, means that their use is sustained. However, importantly, and especially in relation to science, Ellison & Rees Jones (2002) suggest that basing scientific research protocols on problematic definitions of aspects of social identities (such as race) leads to flawed research findings. 'Unfortunately, the continuing use of social identities classified as discrete categorical variables in genetic research often contributes to deterministic views of social processes... and unleashes knowledge capable of re-creating these anew' (Ellison & Rees Jones 2002: 276).

A key element in the process of definition in research practice is the language which is used to describe groups. Bradby (2003) argues that the use of terms related to ethnicity are often left undefined, and are therefore not operationalised. She cites one study in which it was found that explicit definition of racial/ethnic categories was only found in 8% of the papers sampled (Ahdied & Hahn 1996 cited in Bradby 2003: 7). This raises the question of what is being studied when researchers do not operationalise concepts. She argues that due to the historical shaping of the language of race, (what she refers to as the 'historical burden of classifications'), even when the language is eschewed, the historical context cannot be ignored. Therefore she asks whether ethnicity can be conceptualised in such a way that is meaningful and flexible, but that avoids the reification of difference.

Examples of the poor operationalisation of ethnicity in research can be found in the medical literature on infertility, such as studies by Schmid et al (2004), Mahmud et al. (1995), Lashen et al. (1999). All three of these studies use inappropriate and confused categorisations of both 'white' women and 'ethnic' women in research about infertility and assisted conception. The term 'Caucasian', which is used in these studies of clinical outcomes, is often employed in scientific research more generally and has historically referred to populations originating from the Caucasus region of Europe/Asia (Tutton 2007). Bhopal and Donaldson make the point that some populations originating in Asia would therefore be considered Caucasian (1998:1304). The authors of the three comparative studies provide poor operationalisations of the racial/ethnic categories they are drawing on in order to compare the research subjects (White, Caucasian, Indian, Muslim). This leads to ambiguous findings on what exactly they are comparing, particularly in relation to 'success' with IVF (Mahmud et al. 1995, Lashen et al. 1999). The findings of these studies are discussed in chapter three.

Much of the concern over the use of inappropriate, or poorly theorised racial and ethnic categories has related to racialised minority categories. However, problematic use of the category of whiteness in research has also recently been highlighted. Tutton (2007), reporting a study which was designed to explore the use of race and ethnicity in applied population genetics, describes how leading genetics researchers in the UK conceptualise whiteness when designing studies. He found that in many cases scientists recruited what they saw as ethnically homogeneous samples in an attempt to avoid confounding their results through the introduction of genetic variation into the sample. The strategies used by the scientists had the effect of reifying the category of white/Caucasian in genetic terms. However, further probing revealed that the

classification used by researchers to include or exclude participants on the basis of ethnicity were somewhat problematic. Genetic analyses revealed that this category was in fact not as genetically homogenous as the scientists had first thought, a problem which was compounded by the reliance on self-assigned ethnicity data. Tutton, illustrates how the ethnic categorisation of study participants and the use of categories were often taken for granted and unproblematised by the genetics researchers in his study. The use of whiteness and related homogeneous categories in health research has also been raised by Bhopal & Donaldson (1998). They suggest that not only is terminology used in need of deconstruction, but also that in particular, related debates have bypassed the term 'white'. They suggest that the use of the term in research and in the census 'encourages the division of society by skin colour, reinforcing racial stereotyping, and hides a remarkable heterogeneity of cultures' (p1304).

The problematic use of racial/ethnic categories is not restricted to scientific study. Social science research has also continued to deploy such categories despite the acknowledged problems with their use. In particular, ethnographic methods, with their origins in colonial anthropology, have come under scrutiny, increasingly from within a more reflexive anthropology. Alexander (2006), suggests that ethnography has been criticised for perpetuating a 'zoological' and culturalist approach to minority ethnic groups, studying 'exotic' cultures as if they were fixed and unchanging. As such, and as part of a more reflexive and deconstructionist approach, anthropological methods are increasingly used to explore Western settings, including scientific institutions and practices themselves (see Thompson 2005, Outram & Ellison 2005, Tutton 2007). Developments from a collection of authors working within race/ethnicity research have encouraged a more reflexive thinking around the use of such categorisations (Bhopal &

Donaldson 1998, Aspinall 2001, Ellison & Rees Jones 2002, Atkin 2003, Bradby 2003, Gunaratnam 2003, Outram & Ellison 2005, Nayak 2006, Carter 2007, Tutton 2007). The message from this body of work is that there is a need to be mindful of the implications of the use of race/ethnic groupings both at the methodological and epistemological levels.

In a key text which refers to these discussions, Gunaratnam (2003) argues that researchers need to work against essentialism, whilst recognising the need to work with and against racial and ethnic categories in pragmatic ways. She suggests that essentialism can construct racialised effects and impact upon the ontological or experiential. Gunaratnam is therefore concerned to work through these tensions and to discover ways in which researchers can work with inadequate racial and ethnic categories, whilst avoiding the further reification of these categories. Gunaratnam suggests that whilst there must be:

‘temporary moments of closure in the defining of racial and ethnic categories in order to do research, these points of closure must also be opened up again in the process of doing research and in analysis’ (2003: 38).

Others have also acknowledged the dilemma this presents for empirical research (Aspinall 2001, Bradby 2003: 6, Nayak 2006: 424). Offering some useful and practical advice for researchers in this respect, Aspinall (2001) suggests that the type of categorisation used by researchers should relate to the nature of the research being carried out. So for example, collecting data on ethnic origin in terms of ancestry, may not be as insightful in some cases as gaining an understanding of a person’s perceived group identity as it relates to their current and self-assigned group memberships. The implications for this advice in terms of the methods used in this thesis are discussed in chapter four.

Not only does this evidence about the problematic categorisation of ethnicity have implications for the theorisations employed in research, but as highlighted by Gunaratnam (2003), it also has further methodological implications for the research interaction. The significance of these debates for how research interactions are carried out in practice is discussed below.

Implications for the research interaction: debates about ethnic matching

Debates about the socially constructed nature of ethnicity, and the meanings of categories relating to it in research, are by now well rehearsed. These discussions have had an impact on the practical dilemmas facing researchers who work with such categories. The suggestion that the research relationship is a socially constructed one, impacted upon and constructed through potentially competing forms of identification or subjectivity (such as ethnicity), is one example. The debate here has most often been carried out in terms of the way in which individual researchers and participants are 'matched' for ethnic identity (see Gunaratnam 2003). That is, whether the interviewer and participant are perceived to be of the same race or ethnic group and the impact that this has on the research findings. This issue is particularly pertinent in the context of this thesis, since as a white British woman (with an Irish family heritage), I am positioned differently in race/ethnicity terms from the participants in this study, who whilst also British, identify themselves as coming from ethnic groups originating in India, Pakistan and Bangladesh. In terms of the ethnic matching debate, this particular constellation of identities has significance, and the relevance of our particular habituses is discussed further in chapter nine.

The influence of feminist writing on questions of difference in the research relationship is significant for understanding debates about ethnic matching.

Writers such as Ann Oakley (1981) and Stanley & Wise (1993) first drew attention to the significance of identity within the research interaction. They highlighted the importance of woman-centred research, in which the emphasis was on women interviewing and empathising with other women, as it was argued, only they could. The recognition that the identities of the researcher and participant and the attendant power relationships were significant, had an impact on understandings of how research is carried out in practice. However, this position was later criticised by post-colonial feminists who felt that white, mainstream feminism had failed to recognise other forms of difference, and that white women are not and cannot be experts on all women (see Mohanty, Russo & Torres 1991). There was a call to recognise that race/ethnicity could be as significant as gender for understanding experience. Recognition of the power dynamics in research, made in this feminist writing, was crucial to the development of debates in this area; it was no longer taken for granted that the research interaction itself was a neutral space for data 'collection'.

Early writings in the field of ethnicity suggested that the impact of the researcher's ethnicity was crucial to the success of the research interaction, and that 'white' interviewers carrying out research with 'black' respondents would have a particular (negative) biased outcome, especially if the research topic itself related to 'racial' issues (Schuman & Converse 1971, Campbell 1981, see also Gunaratnam 2003). The proposal was that respondents would be less truthful if the interviewer was of a different ethnicity to themselves. However, more recent work in this area casts doubt on previous understandings of the impact of race and ethnicity in the research process. Ultimately, a call for increased reflexivity by researchers, including a questioning of their own positionality and the power dynamics in the research process, has been made (Ali, S. 2006).

In her research with South Asian women, Bhopal (1995) echoes the fears of the post-colonial feminists and asks whether white, middle class researchers can, and should be able to carry out research with individuals from minority ethnic communities. She suggests that in her own research, her 'insider' status as a South Asian woman allowed her access to participants that she would not otherwise have achieved, and also that women felt more comfortable talking to her as a result of such commonality. Bhopal argues that it is the perception of shared experiences, which facilitates research between those matched for ethnicity, as well as their common ethnic identity. It is thus suggested by those for whom the matching of individuals is a desirable methodological tool, that there are benefits to be gained in terms of the validity or 'authenticity' of the research accounts produced via such a device. It is argued that similarities between those engaged in research may engender a deeper understanding and may also displace traditional power relations between interviewer and interviewee, creating an alternative methodological and epistemological position (Collins 1990).

Berg (1999), also suggests using ethnically matched research assistants as a way of ensuring 'rapport' and therefore access to the study population. This she suggests, aids recruitment to research, but she goes on to acknowledge that the high response rate in her study could be attributable to the 'highly educated profile of the participants' (p241) who were very proud to be associated with what they saw as a prestigious university-sponsored piece of research. Secondly, acknowledges Berg, the women were recruited in the main from churches and community based organisations, which fostered a sense of community spirit and therefore the women were likely to be supportive of research which advanced the needs of their particular

community. This suggests that the reasons for participation in research, are at least more complex than a simple explanation in race/ethnicity terms.

In opposition to the ethnic matching position, several authors have questioned the notion of matching the researcher and participants (Edwards 1990, Phoenix 2001, Gunaratnam 2003, Culley et al. 2007). Rhodes (1994), has argued that excluding white researchers from research with 'black' people suggests that 'black'ness connotes homogeneity or an 'artificial harmony' (p556). To suggest that research can only take place between individuals and groups matched by ethnicity is to ignore other formations of difference that may be present and may be differently perceived and differently valued by individuals and groups. Furthermore, claims about authenticity provided by this approach suggest an essential notion of truth that is based in a realist ontological position, and which can be uncovered by rigorous social research. It also maintains that certain accounts are more genuine than others, since they are congruent with the 'truth' (Rhodes 1994). Given the earlier discussion in this chapter on the complexities surrounding notions of race/ethnicity, the suggestion that this, or indeed any other signifier, transcends all other formations of difference is problematic. The suggestion that 'black' individuals should be solely responsible for accessing 'black' respondents in research is therefore a problematic one. Aspinall (2001), suggests that ethnic matching of researchers 'reproduces a racist taxonomy' (p840). Rather, it is important to see how ethnicity is continually adapted, contested, resisted or reinforced within the research arena. In relation to the research interaction, Nayak suggests that:

'race is something that we 'do' rather than who we are, it is a performance that can only ever give illusion to the reality it purports. Significantly, there is no racial subject that prefigures ethnographic interaction' (Nayak 2006: 426).

Therefore it should not be assumed, that white scholars cannot carry out research with minority ethnic communities, or that they cannot access 'authentic' accounts, or indeed that black researchers cannot carry out research with white participants. Instead, white researchers should be aware of white privilege, should seek to challenge its effect on research, and should subject research to processes of reflexivity (Andersen 1993).

The work of these writers, and the suggestion that race/ethnicity as it relates to the research process is complex and shifting, can be aligned philosophically both with the work of post-modern writers who have contributed to the idea of a de-centred subject as described earlier (Foucault 1980, Hall 1992, Anthias 2002a & b), as well as with Bourdieu's theorisation of the habitus (1977).

Race/ethnicity is not the only, or even the most significant, category to which people relate themselves in any social situation. For example, gender can at times be more significant (Culley et al. 2007). It is therefore simplistic to imagine that a person can ever be wholly an 'insider' or an 'outsider' in any given social setting, since the boundaries and markers of membership are shifting, and at times are more flexible than at others (Coleman 2007).

Membership of a particular group or community is also mediated by a number of other social signifiers, including gender, religion, social class, age and social mobility, and these factors are certainly identifiable in the context of the data collection for this thesis. Therefore to presume that I, as a 'white' person, was classed solely as an 'outsider' based on my perceived ethnicity, would be highly problematic since the relationships that I fostered with the research participants in this study were not contingent on this categorisation alone (see Chapter Nine).

The need for flexibility and reflexivity in research is significant, and is perhaps hidden when the research that is being carried out does not cut across perceived racial/ethnic groupings, or gender (Oakley 1981). The need for the researcher to comment on the impact that their identity has on the interaction will often not be seen – especially when the researcher and participants are 'white' and their ethnicity is therefore left unmarked and unproblematised. Exploring and deconstructing our perceptions about the nature of race/ethnicity in research allows us to better understand what it is that is being studied and why.

This chapter has provided an overview of the debates surrounding the deployment of race and ethnicity in research. It has problematised the notion of race in particular and has provided an alternative in the form of a reflexive understanding of the related concepts of ethnicity and culture. Importantly, it has described the theoretical approach to be taken in understanding ethnicity in this thesis. The ongoing dilemmas facing researchers in this context are complex, and present ambiguities and contradictions which are not easily overcome. In recognition of these debates, and in line with the anti-essentialist position taken in this thesis, an additional objective of this study is therefore the exploration of the impact of subjectivities, including my own, on the research process. While these debates have been outlined here, the specific implications for this empirical study in particular, are discussed in more detail in Chapter Nine.

Chapter Three: Discursive constructions of 'infertility' within social science

Introduction

Chapter One demonstrated the distressing impact that infertility has on a person, leading those who experience it to seek its resolution. The introductory chapter also presented evidence to suggest that infertility (as with other health statuses), is socially and culturally specific. It is from this theoretical starting point that this chapter discusses the related bodies of academic literature. The aim of this chapter is to contextualise the present study within existing academic and theoretical debates in this field, and to develop a number of research questions, which are presented at the end of the chapter.⁵

Following Sandelowski & de Lacey (2002) in their reading of the discursive construction of infertility in academic writing, the first part of the chapter discusses the ways in which 'infertility' has been re/presented in a number of bodies of literature. The discursive categories 'distress', 'disruption', 'difference/stigma' and 'disease' are used to organise the literature. First, infertility as 'distress', as located within the sizeable psychological literature on the topic, is discussed briefly⁶. This is followed by a consideration of the bodies of literature (from within sociology and anthropology), which describe infertility as 'disruption', and infertility as 'difference/stigma', each being explored in turn. The construction of infertility as 'disease' is then discussed briefly, and this is followed by a discussion of the related body of literature on infertility treatments in the West. The final section of the chapter includes an

⁵ This chapter is therefore not a 'systematic' review of the literature. The process used in the selection of studies was guided by a need to conceptualise and frame the developing research, and was therefore conducted in an iterative manner.

⁶ Since the focus of this thesis is not on the psychological implications of infertility, this literature is not central to this chapter.

overview of the current state of knowledge on the relationship between infertility and ethnicity.

Infertility as 'distress': psychological studies

In this body of literature, infertility is identified as a major cause of emotional distress for those affected, especially women (Greil 1997). Numerous studies suggest that feelings of grief and despair are commonly associated with infertility (Lukse 1985, Olshansky 1987, Domar et al. 1992, Newton et al. 1999). Authors contributing to this body of research have explored the specific impact of infertility on relationships and marital functioning (Shaw et al. 1988, Benazon et al. 1992), as well as attempting to measure the 'coping' strategies amongst childless men and women (Stanton & et al. 1992, Souter et al. 2002). In recent years, psychologists have also been increasingly interested in the affect that accessing assisted reproductive technologies (ARTs) has on childless men and women (Newton et al. 1992, Morrow et al. 1995, Lukse 1999, Hjelmstedt et al. 1999, Domar 2004), finding this experience to be highly unsettling for those who undergo it. This body of research tends to construct those who experience infertility as psychologically impaired in some way, often suggesting that they are in need of counselling and psychological intervention (Morrow et al. 1995). As Sandelowski & de Lacey suggest, the psychological literature depicts infertile individuals as variously '(dis)stressed, depressed, anxious, hostile and ineffective copers' (2002: 38).

These studies offer some insight into psychologically conceptualised aspects of the experience, such as distress. However, the authors draw overwhelmingly on quantitative methodology, offering little insight into the meanings that men and women give to their experiences of emotional

distress. As such, in setting out to measure responses through the use of fixed response scales and questionnaires (Domar et al. 1992), these authors have simultaneously tended to represent the experience of infertility as a fixed, culturally universal phenomenon. Psychological studies have also tended to have a focus on the individual or the couple (Golombok 1992, Greil 1997), and have neglected to take into account the wider family and kin networks in their analyses. Authors such as Arthur Greil (1997) and Sandelowski & de Lacey (2002) have argued that, in general, the psychological literature on the experience of infertility fails to take into account the social construction of infertility. Greil argues that 'if one does not conceptualise infertility as being socially constructed, one might not stop to think that different groups might construct it differently' (p. 1693). This thesis has a wider focus on the social meanings and construction of infertility and there is therefore insufficient space to include a fuller discussion of the contribution of psychology here. The rest of this chapter considers contributions from sociology, anthropology and feminism.

Infertility as 'disruption'

Infertility has been described by a number of authors, as a chaotic life event over which an individual has little control and one which can bring about disruption and devastation to a person or couple's lives (Greil 1991, Becker 1994, 1997, 2000, Franklin 1997, Tjørnhøj-Thomsen 2005, Friese, Becker & Nachtigall 2006, Allan 2007, Earle & Letherby 2007). Studies with involuntarily childless couples demonstrate that seeking resolution, i.e. attempting to overcome infertility and become a parent, becomes a primary goal in many social contexts (Greil 1991, 1997, 2002, Franklin 1997, Becker 1999, 2000, Reissman 2000, Inhorn 2002, Throsby 2004, Allan 2007). In her work on infertility as a form of biographical disruption, Becker describes how

life interruptions, such as the inability to conceive at the expected and desired time, create chaos in an individual's life trajectory (Becker 1994, 1997, 2000). Becker's work describes the disparity between infertile couples' experiences and the moral cultural discourses which establish 'normal' life trajectories. She argues that the 'life course' is a powerful collective symbol, especially in the West, where the conceptualisation of continuity is linear (1994, 1997). She suggests:

'In all societies, the course of life is structured by expectations about each phase of life, and meaning is assigned to specific life events and the roles that accompany them. When expectations about the course of life are not met, people experience inner chaos and disruption. Such disruptions represent loss of the future' (Becker 2000: 4).

Much of the writing on infertility as disruption has followed Becker's lead, suggesting that infertility impacts upon the gendered life-course expectations of women in particular. As Earle & Letherby (2007) suggest, reproduction is marked by a series of biological events, which women are expected, and themselves expect, to enter into. It is argued that this can lead to a breakdown in gender identity (Thompson 2005), leading to an ambiguous status for childless individuals who have not fulfilled their status as adults, parents and especially as mothers.

Some authors have suggested that this feeling of disruption, and the ensuing chaos, is a result of culturally manufactured notions of linearity and progression. Earle & Letherby (2007) suggest that '...women enter into the process of conception with socially defined expectations' (p246). They argue that the idea that women have control over their fertility is in fact an illusion, which is bound up with social and medical discourses of choice and control (see also Greil 2002, Clarke et al. 2006). The fact that women regularly employ strategies to 'control' their fertility, such as taking the contraceptive pill, adds

to the illusion that they ultimately have power over their reproductive fate. Rather, suggest Earle and Letherby, the socially structured nature of time establishes culturally specific expectations against which people then judge their own progression (2007).

This body of literature suggests that biographical disruption occurs when there is a disparity between how things are and how they are supposed to be (Becker 1997, Tjørnhøj-Thomsen 2005). The work that individuals have to undertake in order to restore a sense of equilibrium to their lives can be seen both in the treatments that they pursue and also in the emotional work that they engage in, in order to normalise their experiences (Becker 1997, Thomson 2005). This process of disruption is clearly gendered for these authors. The metaphor of the ticking biological clock is representative of a woman's maternal 'drive', one which we are told by science, has a limited time in which to be fulfilled. The idea that a woman has a bounded period in which to fulfil her reproductive potential has become a strong discourse in recent years; fuelled by the growing regime of knowledge related to the sphere of fertility and reproductive medicine (Friese et al. 2006, Earle & Letherby 2007).

Sarah Franklin (1997) also discusses infertility in terms of its disruptive effect on the assumed life trajectory. She describes these disruptions as 'gaps' which create a sense of failure, of deviation from the norm, of the future being on hold and of missing out on the physical experience of pregnancy (p143). In common with several other authors writing in this field, Franklin uses the concept of liminality, albeit briefly, in the course of her study of women who use IVF. Liminality is a concept which allows the exploration of the status of being 'between' identities; it represents a state of uncertainty in which one's social identity is displaced or lost, often temporarily. According to Lupton, to be liminal is to be that which is '...uncertain, confusing and blurs the ordering

of binary oppositions' (1999: 131). Franklin, and others, in using this term describe women as being 'in limbo', a metaphor also used by women in Becker's study (1997, 2000), both in terms of their lives and in terms of pursuing treatment when there is no tangible diagnosis (p154). Relative to the volume of work that now exists about the infertility experience, little application of the theory of liminality appears to have been made in this field.

A small number of authors have however, directly deployed the concept of liminality (Becker 1997, 2000, Tjørnhøj-Thomsen 2005, Allan 2007), and others have loosely drawn on the idea in their work (Greil 1991, Franklin 1997) to understand the experience of involuntary childless couples. In her work with childless couples, Helen Allan (2007) describes the way in which infertility is considered a liminal experience. Allan suggests that medicalisation and the seeking of a biomedical solution does not necessarily resolve this liminality, but rather can engender further uncertainty and ambiguity which compounds the liminal status. She argues that, in terms of infertility treatment in the UK, liminality is tolerated in the clinic setting, but that treatment itself is also a cause of further uncertainty, since technological solutions to infertility have low success rates, despite the faith that patients invest in them. Even when a live birth is achieved, Allan argues, infertility remains part of the woman's identity (Allan 2007). The *continued* disruption caused by infertility has been investigated by a small number of authors working in this field (Sandelowski et al. 1992, Wirtberg et al. 2007, Redshaw et al 2007). These studies from the US, Sweden and the UK respectively, suggest that infertility is not a time-bound experience nor is it a 'crisis' which is of significance only to women of childbearing age. Instead these authors suggest that for both those who achieve pregnancy (Sandelowski et al. 1992, Redshaw et al. 2007) as well those who do not (Wirtberg et al. 2007), the experience of infertility is one which for some women, remains central to their identities. This was especially the case

for the childless women in research by Wirtberg and colleagues, who reported going on to experience 'grandchildlessness' later in life.

This body of research constructs infertility as a 'disruption', or in some cases a period of limbo, within an individual's expected life trajectory. It exposes the ways in which cultural constructions of a sequential and ordered life course, which is within the control of the individual, predominate in Western contexts. It provides a valuable reminder of the ways in which women are uniquely impacted by this discourse, especially in relation to conception, pregnancy and motherhood. The methods of data collection used by these authors are also informative; the majority of these authors employed qualitative methods, such as in-depth interviews (Becker 1997, 2000, Franklin 1997, Tjørnhøj-Thomsen 2005, Allan 2007), or letter writing (Earle & Letherby 2007). These methods allow a deeper understanding of the meanings that people take from this disruption than is possible with other methodological approaches. There are however, a number of limitations to this body of work. The studies reviewed here have been carried out overwhelmingly in Western countries and almost exclusively with middle class, white, heterosexual women. The disruption caused by infertility has not therefore been explored in relation to women with diverse ethnic identities in the West. It could be argued therefore, that this has the effect of constructing white, middle class women as those whose life courses are most heavily impacted by an inability to conceive. The discourse of disruption is one which is bound up with the related discourse of control, suggesting that these concepts only apply to white, middle class women who are (at least perceived to be) ultimately in control of their reproductive lives.

In addition to these criticisms, the *continued* disruption caused by infertility has also been largely ignored in this body of work. Instead authors have

focused their work on the infertility 'crisis', resulting in a lack of focus on the lives of women who are not able to resolve their infertility in the longer term.

Infertility as 'difference' and stigma

In the West, the focus has tended to be on women's (and to a lesser degree on men's) experiences of infertility as distressing, disruptive and chaotic. As previously described, these approaches situate infertility as a socially and psychologically constructed experience which impacts on the individual or on the couple. Less attention has been paid in the West, to the ways in which infertility can cause disruption to a woman's place within wider relationships and kinship networks. Much of the research which situates infertility as distress or disruption highlights the social significance of infertility, but has seldomly explored the impact of infertility as 'stigma'. There are a small number of exceptions; Whiteford & Gonzalez (1995), Greil (1991) and Miall (1986, 1989, 1994) for example, write about the stigma of infertility for North American women and illustrate how stigma associated with infertility rests on the sense of having broken a group norm. Women experience 'spoiled identity' in the sense that the role which identifies them as valuable is not fulfilled (Whiteford & Gonzalez 1995). However, Greil (1991) points out that infertility in the North American context can be concealed as a 'secret' stigma, since the possibility of remaining voluntarily childless in this context allows couples to effectively hide their infertility from others.

Letherby (1999) also contributes to this understanding of infertility as 'difference' and suggests that childless women come to be identified as outside of conventional womanhood. She argues that the dominance of mothering discourses leads some groups of women to become 'other' by the absence of them taking part in conventional parenting roles, and the lack of alternatives to this dominant expectation (Letherby 2002). She also suggests

that this aspect of difference between women (whether they are mothers or non-mothers) should become central to feminist analyses of women's lives (Letherby 2002, Letherby 1999).

Infertility as a moral concern however, has perhaps been most thoroughly theorised in a global perspective. Anthropological studies have demonstrated that in pro-natalist countries in particular, where children are valued symbolically, culturally and economically, childlessness often creates serious problems for women (and men) (Inhorn & van Balen 2002). Many studies (Miall 1986, Whiteford & Gonzalez 1995, Reissman 2000, Reminnick 2000) have drawn on the conceptual framework of stigma as theorised by Goffman (1963) in explaining how women in particular experience the social consequences of infertility. Women tend to be blamed for the inability to conceive and produce children, with the stigma of such blame often causing isolation, violence or abandonment (Unisa 1999). This often has significant consequences for kinship and family if women are victimised and in some cases rejected by their husband and his family. For example, one study from Bangladesh found that infertile women are reported as at risk from social and familial displacement, through the process of stigmatisation (Papreen et al 2000).

The experience of stigma among childless women in South India has been explored in detail by Reissman (2000), who demonstrates how the visibility and surveillance of female infertility is central to the stigmatising process. Poor women in Reissman's study found village life a difficult context in which to hide problems with fertility, whereas more affluent, urban couples were to some extent shielded from intrusive questioning by virtue of their private, often nuclear households. Infertility is the 'master status' for village women and Reissman argues that social class mediates stigma. She suggests

'Social class matters immeasurably: Village women living in or near poverty have more limited opportunities to avoid surveillance of infertility than advantaged women do, and judgements about infertility may be harsher in less-educated families and communities compared to affluent ones' (2000: 131).

This indicates that relative affluence, household type and level of education may account for differences in women's ability to resist the master status applied to them, and their ability to resist the label of 'other'.

This body of research suggests that visibility of a woman's infertility, made apparent by her childlessness, is central to the process of stigmatisation. In India, the use of donated gametes in fertility treatment is reported as acceptable as long as this fact is not disclosed publicly (Bharadwaj 2003). Couples in this study wanted the 'visibility' of their fertility to be displayed through the birth of a child and as such would favour donation over adoption in their quest for a child. Bharadwaj suggests that 'Kinship structures are resilient enough to contain such violations only when they are *invisible*' (2003:79, emphasis in original). Similarly for this reason, research in the UK by Culley et al. with British South Asian couples, demonstrates that couples work hard to keep their infertility 'secret' from other family members, in order to avoid being labelled as infertile (Culley et al. 2004)⁷.

Reissman describes the complex ways in which women can at times resist stigma, and how a woman's socio-economic status impacts on her ability to employ resistance strategies (2000). Remennick (2000) has also drawn on the concept of stigma in explaining the experience of infertility, this time from the

⁷ I was the Research Fellow on this study and a statement of my involvement in this research is included as Appendix One. This study is reviewed in more detail later in this chapter.

perspective of Jewish Israeli women. In a country with a strong pro-natalist ideology, she suggests that the stigma of childlessness is more difficult to resist and 'most devastating for the less educated women without career or other non-familial aspirations' (2000: 821). She also argues that few women actually 'resist' stigma, since to do this they would need to reject the dominant cultural norms, which generate their stigmatised position. Rather Remennick argues that women engaged in practices of 'strategic avoidance' and 'defensive thinking', which allowed them to maintain a position within the dominant discourse on compulsory motherhood. Remennick (as well as Reissman) found that it was only educated middle class women 'who dared to challenge the motherhood mandate' (p.838).

Infertility as difference which is threatening to social stability, is a common finding of cross-cultural studies of the childless (Inhorn & van Balen 2002). Infertility is perceived, in different ways in different cultures, as a threat to women's identity, status and economic security, to lineage continuity, and to family and community harmony (Inhorn 1994, Widge 2005). Pearce (1999) demonstrates how childlessness is a group concern for the Yoruba of Nigeria, since it is seen as a threat to group immortality and prosperity. Therefore new brides are watched very closely and any problems become a public concern. This research illustrates the way in which 'different subsets of women have distinctive reproductive interests, and patriarchal values and interests are often wielded by one subset of women over another' (p.73). A similar finding is presented in the work of Anjali Widge who suggests that childless women are perceived as 'failures' in the Indian context, and that for this reason they are willing users of ARTs as it offers them 'hope and helps them negotiate their position in the patriarchal family' (2005: 231).

Marcia Inhorn, in her extensive ethnographic accounts of infertility and the use of ARTs in the Middle East, describes how ARTs have been globalised and that this has resulted in them being co-opted into 'local moral worlds' (Kleinman 1995 cited in Inhorn 2006:429). As a result, the decision-making of infertile couples, especially with regards to the use of technology in attempting to achieve conception, is a highly moral enterprise. Inhorn points out that not only is it women who bear the brunt of the stigma associated with reproductive 'failings' but that it is other women who are implicit in the policing of female relatives' and neighbours' fertility (1994). She suggests: 'because infertile women are widely perceived as incomplete, they are, at best, the subjects of pity and at worst the objects of fear' (1994: 209). As with the women in Reissman's Indian study, the women in Inhorn's research experienced a constant need for the management of information about their fertility, in an attempt to resist stigma.

The consequences of social perceptions of infertility for individuals are clearly qualitatively different for women and men, and this is also the finding in studies from African countries. Leonard (2002a) explored how for the Sara of Southern Chad, childbearing for women is central, so much so that childless women (those who have never been pregnant) are referred to as *Kuja* (not the same as women who have had miscarriages, or have had children die). This almost constitutes a third gender category, since these women are considered to be inferior in status to fertile women. Leonard reports the 'struggle to prove one's womanhood and to avoid being labelled *kuja*' (p.104) She also suggests that childless women 'spend their reproductive years "doing research", first to prove that they have children, and then to ensure that they will be able to give birth to them' (p.105). Similarly, Pearce (1999) reports how historically infertile women in Nigeria were considered to be morally inferior,

and that problems with infertility were considered to be due to immoral behaviour. Infertile women were referred to as *agon* from the verb *gon*, which means to despise. However, Pearce reports that new ideas from Western medicine, which accompanied colonisation, have influenced thinking on infertility and have led to new 'configurations in which the old and the new have blended' (p.73). In these cultural configurations, infertile women are considered to be dangerous, since they constitute both a physical, social and moral threat to group norms.

The significance of children is also important in understanding the social construction of infertility as difference/stigma and a small number of studies suggest that there is an added pressure for women in some cultural contexts to produce a male child (Winkvist & Akhtar 2000). Inhorn and van Balen (2002) highlight three main reasons for having children: 'social security desires', 'social power desires' and 'social perpetuity desires' (p8-9). Male children can be considered necessary to secure a woman's otherwise unstable position in the familial hierarchy, ensuring that the lineage of the family is maintained. Recent findings from India highlight this trend; approximating that half a million female foetuses are aborted in India each year (Jha 2006). Studies from India and Pakistan highlight the economic burden that girls are seen to represent, especially in contexts where dowries are the norm (Winkvist & Akhtar 2000, Sheth 2006). By contrast, boys are viewed as holding an economic advantage, giving parents support in their old age (Winkvist & Akhtar 2000, Sheth 2006). These examples demonstrate the possibility that in some settings, not only the absence of children, but specifically the absence of male children can be considered problematic.

These international studies highlight how infertility can have social consequences, particularly for women. They also alert us to the fact that infertility can be a highly stigmatised position, particularly in pronatalist contexts. The perceptions of one's peers, and the affect of those perceptions on infertile individuals, are demonstrated in this literature. These facets of the experience are often absent from the infertility discourse in the West, and they present a reminder to researchers of the need to explore the social context in which infertility is lived.

This body of research has limitations, however. These studies tend to be concentrated overseas, and are often conducted by social anthropologists from Western countries who are concerned to explore cultural mores around reproduction and infertility. The resulting literature has the capacity to represent women as what Sandelowski & de Lacey (2002: 41) refer to as 'cultural dupes'. This literature effectively represents women as 'other' twice; once in relation to their experiences with family and other fertile women, and once in the literature by providing a contrast with the experiences of women in the West. This is compounded by the fact that, with the exception of a small number of studies where it is made explicit (Reissman 2000), there is little sense from this literature of the impact of women's agency in shaping their own lives. The methodological approach of ethnographers has been criticised in this respect with Alexander (2006) referring to it as 'zoological'. As argued in chapter two, the application of Western feminist concepts, such as patriarchy, to diverse cultural settings is problematic (Ahmad 2006). Finally, excluding a small number of studies (Whitford & Gonzalez 1995), few authors have developed a full theorisation of the role of stigma in understanding infertility in the West. The representation of infertility as 'difference' and

'stigma' in the literature, therefore fails to recognise the potential *similarities* of experience across the globe.

Infertility as 'disease'

The preceding sections of this chapter have explored the ways in which infertility is discursively constructed in the academic literature as 'distress', 'disruption' and 'difference'/stigma. In this final part of the discussion of infertility, those studies which have represented it as a 'disease' are considered. However, it is important to highlight the fact that the studies which have constructed infertility in this way have also often included a corresponding focus on its resolution with ARTs. As such, this section will briefly re-introduce these debates about disease (which were discussed in chapter one), and will then go on to discuss the body of literature which is concerned with infertility *treatment* specifically, in the next part of the chapter.

As was noted earlier, several authors have discussed the ways in which infertility has come to be seen as a 'disease' requiring treatment within the medical sphere (Greil 1991, Becker & Nachtigall 1992, Franklin 1997, van Balen & Inhorn 2002, Sandelowski & de Lacey 2002, Earle & Letherby 2002, 2007, Throsby 2004). These studies demonstrate that the proliferation of the disease discourse, almost exclusively in the West, has an impact on couples who feel 'compelled' to engage with ARTs as a result (Miall 1984, Sandelowski 1991). Sandelowski & de Lacey (2002) suggest:

'Post-1978 infertility is a product of the technology that has made it possible even to think about circumventing virtually any obstacle to procreation, including advancing age' (2002:35)

New diagnostic techniques and treatments therefore allow childless couples to lay claim to the category 'infertility' and correspondingly become identified

as 'patients' in many, but not all, cases. Research with those who choose not to seek treatment for infertility is conspicuous by its absence (Greil 1997). The next section in this chapter discusses the literature that has focused on and been critical of the various technological innovations developed to treat the infertile body.

Infertility treatment

In the Western context in particular (but increasingly also in the rest of the world), biomedical solutions to infertility such as IVF are routinely employed to offer couples a solution to the disruption of infertility (Becker 2000, Becker & Nachtigall 1992). The promise of continuity, in the form of genetically related offspring, is one of the ARTs' most attractive characteristics (Becker 2000). The ability to overcome childlessness and escape the disruption caused by infertility is an offer that few are able to resist. As Becker suggests: 'technologies embody cultural ideologies, such as the ideology of continuity, that tend to reinforce their use' (2000: 239). The technologies themselves are constituted through cultures of progress and as such are imbued with promissory potential, which their users come to embody. Thus seeking out a means to procreate in this way becomes more culturally acceptable even when, it is argued, the knowledge that biomedicine has to offer is at best an incomplete project (Franklin 1997).

The marking off of the 'problem' of infertility as a medical concern, has drawn considerable discussion and critique from social scientists. This collection of writings from within sociology, feminism and anthropology has consistently problematised the development of ARTs. Not only is it criticised for valorising biological parenthood (Miall 1989), but it has also been pointed out that biomedical knowledge about infertility and the means to overcome it is in fact relatively limited. As Tjørnhøj-Thomsen (2005) suggests: 'the

biomedical world is uncertain and its knowledge incomplete...there is no unequivocal connection between biomedicine's striving towards more knowledge and its ability to explain' (p89). The experience of those who use ARTs has therefore been characterised by uncertainty; ultimately with no guarantee of any form of success (Throsby 2004, Allan 2007, Peters et al. 2007). The fact that there are no definitive medical answers to the 'problem' of infertility, with IVF having only an average 25% success rate, means that possible treatment options are endless (Cussins 1998: 76, Tjørnhøj-Thomsen 2005: 81). Tjørnhøj-Thomsen suggests that the lack of a clear reason why treatment cycles fail means that there is always space for trying a new combination of drugs or a different procedure, offering endless opportunities for the hope of a pregnancy. She suggests that this makes it almost impossible to exhaust all options (Tjørnhøj-Thomsen 2005, see also Sandelowski 1991).

The treatment experience is one which is often marked by failure in some respect (Throsby 2004, Peters et al. 2007). Many couples experience failure during the process, even if ultimately they achieve a 'take home baby'. In a relatively rare study of the experience of failure specifically, Throsby suggests that this can be devastating, particularly for women as she argues: 'While failure tends to attach itself to the woman, treatment success attaches itself to the process and its providers' (p59). For Throsby, not only are the women to blame if the treatment fails, but they are awarded no credit if the treatment is a success. She suggests that the discourse used compounds this inequity, for example the term 'IVF baby' effectively removes the parents from the process and instead centralises the technology. Throsby (2004) argues that when ARTs fail they foreground the very inability to conceive that they set out to overcome, highlighting their 'un-naturalness'. This makes it more difficult for couples to re-establish a sense of normality in their lives, normality which Becker suggests is 'precarious at best' (Becker 2000: 240). As already

suggested, even pregnancy and parenthood themselves are not always the solution they would appear to be (Sandelowski 1992, Redshaw et al. 2007). Sandelowski & Pollock (1986) found that some infertile women still identify themselves as infertile even when they get pregnant; they experience a confusion of identity caused by their marginal position and find it difficult to 'relinquish the rituals of infertility' (cited in Sandelowski et al 1992: 283). In a more recent study, Redshaw et al. (2007) found that 'successful' women remained psychologically 'marked' by the experience of accessing ARTs. These women reported continuing to carry the 'burden of resentment and regret' that they needed to use infertility treatment to achieve pregnancy (2007: 303).

Feminist responses: ARTs as oppressive technologies

One of the earliest and perhaps most well documented responses to the use of assisted reproductive technologies was developed by writers from within the 'radical feminist' school of thought (Crowe, 1985, Corea 1985, 1987, Klein 1989, Klein & Rowland 1989). Such authors argued that ARTs, as a medical technology, are part of the wider patriarchal project to control women and their bodies. It was argued that as long as men (male scientists and clinicians) control these technologies, they will not be used to empower women but to consolidate male power (Crowe, 1985, Corea 1985, 1987, Klein 1989). In her critique of ARTs, Klein writes: 'technologies don't work, but we are led to believe they do; they are anti-woman; they are dangerous and dehumanizing in their theory and application' (1989:279). Such arguments have been located within the second wave feminist movement whose members alerted us to related concerns about the technologization of childbirth and women's reproductive bodies more generally (Thompson 2005, see Kitzinger 1978, Oakley 1993), as well as to the ways in which these technologies in particular valorised motherhood (Crowe 1985, Corea 1985). Fears about the

experimental nature of ARTs, particular in the early days of their use were also common (Klein & Rowland 1989).

Thompson (2005) suggests that this first feminist phase of writing on ARTs eventually paved the way for a more morally ambivalent theorising about the nature of these technologies and their implications for women, science, infertility and kinship. In particular, space for exploring the lived experiences of childless couples and their experience of using ARTs was eventually created in the research sphere. In this vein, Denny (1994) has been critical of the early writing of radical feminists who, she argues, failed to legitimate women's experiences through their overly theoretical approach to ARTs. Denny argues that much of this work failed to examine the views of women who experience ARTs, and that this is to the detriment of the radical feminist position. Work which tended to take into account broader social complexities and relationships and the cultural setting in which women's experiences of reproduction and motherhood are situated was later developed (see Franklin, 1997, Greil 1991, 2002, Becker, 2000, Letherby 2002).

The work of the feminist writer Jana Sawicki (1991) is interesting in its positioning of the debate about ARTs, power and women. Sawicki draws on Foucauldian theory and in doing so she breaks with other feminist theorists (particularly the radical feminists) as she argues that assisted reproductive technologies are not representative of a longstanding male desire to control women's bodies. Rather she suggests that as part of the historical project of biopower, these techniques have emerged from within sites of contestation and micro-practices. She suggests that there has been 'client resistance' to many practices in medicine and sees this as a result of the diffuse nature of power. Sawicki does agree that the medical profession has had control, but argues that this has had to be won. In this way power is seen as productive -

'as these medical disciplines isolate specific types of abnormality or deviancy, they construct new forms of healthy and responsible motherhood' (p. 84). In a similar vein, Greil (1991, 2002) also suggests that infertile women are not passive but rather that they are able to 'work the system' to get what they want. He suggests that 'they are problem solvers, operating creatively within a system they do not control' (2002: 103).

These authors (Sawicki 1991, Greil 2002) are illustrative of a more post-modern approach to understanding the nature of power in the role and application of technology and the ways in which users of technology are able to affect agency in this interaction. Sawicki (1991) in particular, has been critical of the radical feminist approach to ARTs, which she suggests has been too pessimistic, moralistic and one-dimensional (p 70). However, Sawicki's work is not based on empirical research and there are few examples of studies of power in relation to individual treatment experiences in the research literature. So, whilst early feminist writers had 'power' as central to their concerns about the developments of ARTs, but did little to advance our understanding of individual experiences, later work on the *treatment* of infertility has tended to focus on the patient experience in terms of issues such as 'satisfaction' whilst ignoring the impact of power relations in this process.

'Satisfaction' studies: infertile individuals as consumers of infertility treatments

Whilst they do little to advance understandings of the medicalisation of infertility, quantitative studies of patient satisfaction with infertility treatment, give us some insight into how treatment practices impact on their users. In questionnaire research from Finland, Malin et al. (2001) found that only 45% of the 344 women in their study were actually satisfied with the care that they had received, which was strongly associated with a negative treatment outcome; which either did not result in a pregnancy or involved

poor care. The authors also suggest that women may feel obliged to be compliant and grateful for the care they receive and may want to hide their anxiety and stress in order to present themselves as ideal patients (p131). Malin et al. suggest that this can be explained by reference to the uncertainty of the treatment. They suggest that 'in uncertain medical treatment like infertility care, there tends to be more tension between doctor and patient than in less uncertain medical treatment' (p130). In an Australian study, Hammarberg et al (2001) also found that feelings of satisfaction was related to success; for those women who were unsuccessful, questionnaire responses were much more critical of the care that they had received. In an earlier study based in Scotland, Souter et al. (1998) found that although the majority of patients (87%) reported an overall satisfaction with their care, they were less happy with specific aspects of the treatment such as counselling provision and treatment planning.

These findings give a somewhat inconclusive picture of the feelings of infertility patients about their treatment experiences in a limited number of countries. The use of quantitative methods further limits their use, since little sense is gained about the meanings that the participants gave to their experiences. Findings from a small number of qualitative studies help to add a more nuanced, in-depth understanding of satisfaction with the treatment experience. Tjørnhøj-Thomsen (2005) for example, drawing on qualitative research with Danish patients, suggests that the clinician comes to be in a kin-like relationship with prospective parents and that the clinic staff are remembered with warmth and gratitude by the patients. Other qualitative studies find negative feelings towards practitioners. Greil (2002) suggests that the patients he interviewed (twenty-two white, middle class women) were very critical of doctors who they felt ignored the 'human' side of their treatment (p110). Patients feeling that they had been treated as less than a

person or as 'just a number' is highlighted in both qualitative studies (Throsby 2004, Redshaw 2007) and quantitative studies (Malin et al. 2001). In a rare piece of research in the UK, which explores the views of women who have been successful with ARTs, Redshaw et al. (2007) used a postal questionnaire to collect qualitative data from a sub-sample of 230 women included in the Millennium Cohort Study, and who had reported that they had used ARTs to conceive. The study authors found that there were still critical patient views expressed by women, a finding which supports those from the quantitative studies. The authors suggest that women who experience higher levels of distress should be followed up at a later date, whether they are successful or not.

Very few of the studies mentioned above are carried out with ethnically diverse samples. In one isolated qualitative study, British South Asian couples were asked to comment on the treatment they had received when accessing infertility services in the NHS (Culley et al. 2004, Culley, Hudson, Rapport, Katbamna & Johnson 2006). The authors found that whilst the majority of participants were satisfied overall with the way that they felt they had been treated by staff, a small minority had particular difficulties in relation to language needs and sensitivity of staff. This study demonstrated that the concerns of infertility patients were similar to those expressed by white patients in other studies, emphasising a lack of information and little emotional support. For those who had lower proficiency in English the lack of appropriate communication support was a major issue.

There is a somewhat ambivalent picture over whether success in ARTs equals satisfaction in these studies, and more research is needed, particularly in the UK. These studies suggest that there may still be concerns amongst patients whether they are 'successful' or not and that this cannot be used as an

accurate measure of their feelings about ARTs. The invasive character of ARTs into what is or should be considered as a 'natural' reproductive process is unsettling for some and this unease is difficult to relinquish (Sandelowski et al. 1992, Redshaw et al. 2007). However, since much of the research described above is of a quantitative nature and is carried out with women soon after treatment ends, it is difficult to ascertain what the implications of infertility treatment might be in the longer term. In addition, studies about the relative levels of satisfaction that patients experience, tend to be rather atheoretical, and fail to explore relationships to the technologies that they are using and to issues of power and agency in the treatment process.

Revealing kinship & nature: the view of ARTs from Anthropology

Authors from within the discipline of anthropology have contributed significantly to the debate about ARTs, particularly the ways in which ARTs come to be incorporated into understandings of how human beings are connected to one another through biology and kinship (Strathern 1992, Franklin 1997). Kinship as a theoretical and social category has been used historically by anthropologists as a tool to explore concepts and ideas about what it means to be socially and biologically 'related'. These authors are interested in the 'social construction of natural facts' (Strathern 1992).

Anthropologists have provided particular insight into these connections by using ARTs as theoretical 'lens' through which to view human relationships and understandings about nature (Edwards 1999). There have been two broad strands to this work in empirical terms. The first strand includes a collection of authors carrying out ethnographic work with those actively engaged with ARTs as patients and providers. The work of Sarah Franklin and Charis Thompson is particularly important to highlight in this respect. A second strand of this work includes ethnographic research with 'lay' members of a

range of 'publics' who are not themselves using ARTs, but who are asked to comment on their use by others. These strands are discussed, in turn, next.

Sarah Franklin (1997) carried out qualitative, ethnographic research with couples undergoing IVF treatment to explore how 'natural' and 'biological' facts are culturally and historically contingent. Franklin (1997) suggests, through her use of the term 'embodied progress', that the women undergoing IVF in her study represent the desire to become 'a conduit of both 'natural' and scientific continuity' (p.197). She suggests that through this process of embodying progress, what were previously considered to be the natural, biological facts of life, become destabilised and de-naturalised. Ultimately she is concerned with the way in which conception is technologised but also with how it becomes culturally reconceptualised.

In her study of the infertility clinic setting, Thompson (2001) demonstrates how identities are naturalised and how people are 'doing kinship' through the use of ARTs. In one example, she reports how an African American woman considering using donated eggs from a friend or sister, described this as 'something we've been doing all along' (2001: 182). When asked what she meant by this, the woman described how within African American communities it was not uncommon for women to 'mother' or 'second mother' her sister's, daughter's or friend's children. The process of donation was renaturalised by reference to a pre-existing social phenomenon. It is through pre-established systems of parenting that, in this case, the narrativisation of a new and perhaps even 'deviant' form of parenting, to use Thompson's phrase, becomes legitimised.

In a similar vein, Becker (2000) argues that it is the men and women who use ARTs who are themselves implicit in their 'naturalization' (p239). She argues

that they “absorb the experience into their bodily knowledge” and that in doing so they are “remaking nature, as they understand it...they are creating a cultural shift in how people think about what is natural” (Becker 2000: 239). Throsby’s work also draws on the concept of naturalization, or in her terminology ‘normalisation’ (2004) (although she is not an anthropologist herself, her work draws on anthropological concepts and is useful for understanding how patients perceive what is ‘natural’). She suggests that one of the most important findings from her study was the need of the participants to ‘naturalise’ the technological aspects of IVF, often in attempts to play down their use. However, she also points out that the high-tech nature of IVF was simultaneously retained by the participants as a discourse which illustrated the fact that they had gone to great lengths to conceive (2004:78). Throsby suggests that there is a tension between nature and technology and that this needs constant management by users of the technology. She suggests that this occurs through ‘a subtle reworking of the categories themselves’ (2004:79), which in turn exposes their normative constructedness (Throsby 2004). For example, her participants were keen to distance themselves from technologies such as cloning in order to demonstrate how their engagement with science was morally and technologically uncomplicated (p61). Some have argued that this process of working to make ARTs appear natural is bound up with a need for ‘authenticity’ in the reproductive process (Tjørnhøj-Thomsen 2005). Tjørnhøj-Thomsen suggests that this is particularly pertinent in the case of treatment involving donor gametes or when couples decide to adopt; she suggests: ‘they have to work hard to redefine meanings of ‘real’ and ‘own’. (p79)

The anthropological literature on kinship and ARTs is helpful in illuminating the constructed nature of ‘biological’ human relationships. It is also a productive theoretical reference point for those who wish to explore the

shifting boundaries between nature and technology. However, some authors have been critical of the ways in which these 'kinship studies' have conceptualised culture (Kahn 2000). The term 'Euro-American' is employed by anthropologists when describing the 'dominant' cultural system in the West (Schneider 1980, Strathern 1992, Franklin 1997). This concept is represented as a homogeneous entity, a consistent system. The assumption is that Euro-American (Northern American or Northern European) notions of conception and kinship represent a set of distinctive and coherent cultural constructs. As already discussed in Chapter Two, 'culture' is a contingent and fluid category, receptive to change and adaptation (Ahmad 1996). The model employed in these anthropological studies is problematic in this sense, particularly in the case of European and American minority ethnic groups. This model of culture does not allow space for the expression of minority constructions of kinship, nor for the inclusion of a more 'hybrid' conceptualisation of culture. Acknowledging that culture is a contested and flexible entity is therefore significant when exploring how it is constructed. The second 'strand' of anthropological research on ARTs is discussed in the next section.

Public perceptions of ARTs

The concept of infertility as a socio-culturally constructed experience implies that wider social perceptions of infertility must be taken into account. The perceptions and understandings that 'publics' (Edwards 2002) have about infertility will influence how childless individuals or couples are perceived and will affect the interaction that takes place between them (Miall 1994). However, literature which has a focus on 'public' or 'lay' perceptions of infertility and its treatment is seriously lacking in the UK context. Few studies have surveyed the public on this matter, except to ascertain views on a specific issue, such as donor anonymity (Fishburn Hedges 2004), or in the

context of healthcare rationing priorities (Bowling 1996). One international survey of public perceptions, which included data from the UK, found low levels of awareness about infertility generally although the majority of respondents reported having heard of IVF (Adashi et al. 2000). These studies also tend to draw heavily on a quantitative approach, and there is a corresponding absence of ethnographic data in this regard. One exception to this is a small body of anthropological literature which has focused on the public perceptions of those who use ARTs in order to overcome their infertility (Edwards et al. 1999).

In *Technologies of Procreation*, a collection of essays that explore kinship and assisted conception (Edwards et al. 1999), the authors describe how individuals draw upon the matrix of kin relations and idioms of kinship in order to describe and discuss the implications of the new reproductive technologies. In two of these essays, ethnographic studies were conducted in England, with members of the public who were not themselves users of ARTs. Edwards (1999) describes how 'certain dangers preoccupy people when they explore the implications of assisted conception' (p82). She suggests that these perceived dangers are linked to the commonly held anxieties about the power of science, and that the participants drew on their existing expertise in the field of kin relations to make assessments about ARTs, even where their knowledge about specific techniques might be limited. Common fears expressed by participants in Edwards' study were related to the psychological effects on children and families, biological risks of 'in-breeding', and potential problems with the creation of 'novel' or non-conventional relationships. In the second of these papers, Hirsch (1999) reports that the informants in his study were also concerned with the limits of such developments and where such limits would lie, again implying disquiet with the power of science, as well as

a concern about the consumerist nature of ARTs. He also suggests that through everyday articulations of kinship, participants were engaging in the regulation of 'biological foundations' of relationships. As in Edwards' study, participants were concerned about 'in-breeding' through anonymous donation; an unwelcome incident which would transcend natural kinship structures.

This small body of mainly anthropological research is based on limited sample sizes. It is insightful in offering an insight into some of the possible concerns that lay members of the public might have about ARTs, however the criticisms presented above in relation to the use of 'Euro-American' kinship culture, also remain valid in relation to the anthropological studies presented here (Edwards 1999, Hirst 1999). This research is also limited in scope and little of this research has been carried out with minority communities in the UK.

In comparison to these anthropological studies of the early 1990s, media discourses on ARTs (an additional form of 'public' discourse) have been generally positive, with scientists and practitioners often valorised as the 'saviours' of infertile couples (Franklin 1997). Indeed, Franklin argues that the idea that ARTs represent scientific progress and a medical cure for infertility has become a powerful discourse surrounding the development of assisted reproduction. The media have played a central role in creating and perpetuating the scientific discourse of progress in relation to ARTs; they are presented as offering a 'helping hand' to nature and as such have contributed to some degree to the renaturalisation of medically assisted conception (Franklin 1997, Hadfield et al. 2007, Peters et al 2007). More recently however, with the emergence of debates about human-animal hybrid embryos, stem

cell research and 'designer babies', a more ambivalent tone of reporting can be noted (Highfield 2008), possibly suggesting an anxiety about the limits of ARTs, as was expressed by participants in Hirst's study (1999).

Infertility and ethnicity in the West

The preceding sections of this chapter have presented an overview of the literature on infertility and its treatment. However, despite the relative increase in studies which explore the lived experience of childless people, authors have noted the sustained absence of research with ethnically diverse samples (Greil 1997, Franklin 1997, Ceballo 1999, Becker 2000, Culley, Hudson, Rapport, Katbamna & Johnson 2006). This section discusses the small body of research which specifically explores the relationship between ethnicity and infertility.

There are a number of studies from around the globe (Inhorn & van Balen 2002) which show infertility to be culturally situated, but very little exploration of cultural diversity has taken place in relation to infertility within Western contexts. In a review of infertility studies, Greil (1997) was critical of the homogeneous composition of the groups who have taken part in such research, since they have tended to be middle class, white, usually female, treatment seekers. As Ceballo suggests:

'...infertility evokes a social script of well-to-do, white couples... this master narrative ignores and therefore silences the voices of women who do not fit within its domain' (Ceballo 1999: 16).

Dorothy Roberts suggests that such a marginalisation represents a 'devaluation of *black* reproduction' (1997:246 emphasis in original). As such, little is known about how diverse social groups in the UK experience involuntary childlessness and its treatment. This is despite the fact that

research from other cultures, albeit in an international context, suggests that the cultural context has a major impact on the experience of infertility and its treatment.

A handful of published studies have included participants from minority ethnic communities in Western contexts. These include studies with 'Muslim' women in Austria (Schmid et al 2004), 'Latinos' in America (Becker et al. 2006), African American women in America (Ceballo 1999), 'black' patients in America (Green et al. 2001), 'Asian American', 'Latino', 'African American', and 'Native American' couples in America (Szkupinski Quiroga 2007), 'Arab American' men in America (Inhorn & Fakhri 2006), 'Hispanics' in America (Feinberg et al. 2007), Turkish migrants in the Netherlands (van Rooij, van Balen & Hermans 2007), two clinical studies with 'Indian' patients in the UK (Mahmud et al. 1995, Lashen et al. 1999), and two published studies about the social context of infertility and ARTs in British South Asian communities (Culley, Hudson, Rapport, Katbamna & Johnson 2006, Culley & Hudson forthcoming 2009). A collection of studies also include discussion of a number of 'ethnic' groups in relation to access to services in the US (King & Harrington Meyer, 1997, Stephen & Chandra 2000, Jain & Hornstein 2005, Jain 2006).

Much of this research has been carried out in the US and has focused on 'access' to treatment services. In particular, this small body of work highlights the importance of economic inequality, which has characterised 'race relations' in the U.S (King & Harrington Meyer, 1997, Roberts 1997, Stephen & Chandra 2000, Green et al. 2001, Jain & Hornstein 2005, Becker et al. 2006, Inhorn & Fakhri 2006, Jain 2006, Feinberg et al. 2007). A number of these studies highlight a higher level of utilisation of infertility treatment services by 'Caucasian' women, and also by women who tend to have higher levels of

education and income (Stephen & Chandra 2000, Jain & Hornstein, 2005, Jain, 2006, Feinberg et al. 2007). Stephen and Chandra (2000) suggest however, that apparent 'racial' differences in service use cease to exist when factors such as marital status, income and private health insurance coverage are taken into account, demonstrating the importance of socio-economic factors for successful access.

In attempting to explain these differences in utilisation rates, Inhorn & Fakhri (2006) highlight the 'reproductive hierarchy' which exists in America, in which minority groups are more likely to experience poverty and racism, and are therefore less likely to gain access to high quality reproductive health care. For example, a study by Green et al. (2001) indicates that black patients were much less likely than white patients to have health care insurance. In their study with Latino men and women in the U.S., Becker et al. (2006) also highlighted the fact that in most research with minority populations (as well as in the public sphere more generally), the presumption is that fertility rates are high and hence there is no problem with infertility. In fact some have suggested that the perception is that minority families produce *too many* children (Ceballos 1999, Katbamna 2000), a situation which Roberts suggests is actually the reverse, with women from minority groups actually experiencing higher rates of infertility than white women (1997: 252). This presumption about minority women as 'over producers' is clearly problematic and may indicate why so little research exists in this field. Importantly, Becker et al suggest that although there are differences between the Latino community (whom, the authors point out are from predominantly low-income groups), and the majority white population, there are also similarities in the experience which affect all childless couples, regardless of ethnicity. Writing about 'race and the new reproduction' in America, Dorothy Roberts (1997), suggests that public images of ARTs are predominately those pertaining to their use by

white couples. She suggests that more often than not 'race', is only highlighted in problematic cases, such as those high profile stories of 'mix-ups' in the clinic, resulting in mixed-race children, or black children being born to the 'wrong' parents. A similar argument can be made in the UK, where equivalent cases have received intense media interest (BBC News 2003, also see Szkupinski Quiroga 2007), against a backdrop of no reporting on infertility stories about minority couples. Empirical research from America confirms fears about miscegenation in the clinical context (Szkupinski Quiroga 2007). The author discusses in particular, the ways in which ARTs privilege 'white' kinship patterns and fears about racial 'mixing'. This study is unique in the way in which it explores clinicians' perceptions of racial boundaries, particularly in relation to the purity of 'whiteness', and how they operate in subtle ways to exclude the 'mixing' of particular types of gametes in the clinic setting.

Studies into 'race', ethnicity and infertility vary widely in their approach to this subject, both methodologically and conceptually. In addition to the research on access, a number of 'comparative' clinical studies have attempted to compare the outcomes of women from different ethnic or racial categories. As described in chapter two, studies by Schmid et al (2004), Mahmud et al (1995) and Lashen et al (1999), each attempts to compare a sample of 'minority' women with a sample of 'indigenous' women (referred to as 'Caucasian'). Schmid et al (2004) explored rates of polycystic ovarian syndrome (PCOS) between Muslim women and Austrian women, reporting no significant difference between the two. They do, however, go on to discuss the perceived cultural and religious differences in approaches to infertility, with the Muslim women reported as being under more familial and community pressure to conceive than the Austrian women. In the UK clinical studies (Mahmud et al. 1995, Lashen et al. 1999), the authors report conflicting

findings. Mahmud et al. report differences in success rates for IVF, that they attribute to 'racial' differences, between the Indian and white women.

However, there are important problems with this study: the categorisation of the Indian women is problematic; they were in fact later described as of 'Asian' origin, coming from India, as well as Pakistan and Bangladesh. There are also discrepancies between the two sample groups, such as length of time trying to conceive. The second study by Lashen et al. also compares two groups of women by attempting to categorise them according to ethnicity or race. However this second study showed no difference in treatment outcome.

As discussed in chapter two, these studies suffer from poor operationalisation of ethnicity, and are based on the premise that observed differences in infertility prevalence or response to treatment can be accredited to some 'racial' attribute. However, poor use of ethnic categorisations is not restricted to the clinical studies. The research by Green et al. (2001) for example, uses the categories 'black' and 'white' to describe the participants, which is clearly problematic in terms of providing a nuanced understanding of the role of ethnic origin in access to healthcare.

As already mentioned, until recently no qualitative empirical study existed in the UK which addressed the issues of infertility and ethnicity. Two published studies carried out with South Asian communities in the UK (Culley, Hudson, Rapport, Katbamna & Johnson 2006, Culley and Hudson forthcoming 2009) have highlighted the need for an increased public engagement with diverse communities around the use and implications of ARTs. These studies demonstrate that the experience of childlessness can vary according to particular cultural mores around childbearing and motherhood. For example, in the first of these studies, which explored access to treatment in the NHS, the authors found that South Asian couples may be under more pressure

from the family and wider community to conceive than their white contemporaries (Culley et al. 2004, Culley, Hudson, Rapport, Katbamna & Johnson 2006). In addition, there may be factors which make accessing treatment more difficult for minority ethnic patients, especially within the NHS, such as a lack of interpreters, a dearth of appropriate information in minority languages, and a lack of cultural sensitivity and understanding from healthcare professionals (Culley et al. 2004, Culley, Hudson, Rapport, Katbamna & Johnson 2006).

In a second study, views about one particular aspect of infertility treatment, that of using third party gametes, was explored with British South Asian communities (Culley, Hudson, Rapport, Johnson & Bharadwaj 2006). In this study members of the general public were invited to identify and discuss important issues via a series of vignettes in which South Asian couples were described using donor gametes. The findings from this study demonstrate that the use of donor material is highly complex and contingent and that there is a distinction between the acceptability of donor eggs and donor sperm, with donor eggs being considered to be a less threatening solution to overcoming infertility than sperm, a finding that has been reflected in other research and commentary (Haimes 1993, Franklin 1997). The use and donation of gametes was also found to be religiously contingent in this study, with Muslim participants suggesting that there would be prohibition around the use of third party genetic material in Islam (Culley, Hudson, Rapport, Johnson & Bharadwaj 2006).

Childlessness is considered to be a serious transgression of normative practice in British South Asian communities, where expectations about childbearing for married adults are prominent (Culley et al. 2004). The cultural significance of childbearing is also cited by the authors of a study carried out with Turkish

migrants in the Netherlands (van Rooij et al. 2007). In this study, the experiences of Dutch, Turkish, and migrant Turkish couples living in the Netherlands were compared using structured questionnaires. The authors found that migrant Turkish couples had similar levels of emotional distress to the Turkish couples, and in both cases this was higher than for those from the 'host' Dutch community. The authors suggest that this might be linked to similarities in the meanings of childbearing and infertility amongst the Turkish couples and the Turkish migrants. For example, the authors indicate that children and childbearing is highly valued in Turkish culture and that there is a corresponding 'pressure' on couples to have a child.

A small sub-category of papers within this literature has explored the impact of religion in relation to the experience of infertility (Richards 2003, Dutney 2007, Latifnejad Roudsari et al 2007). However these articles are based on a review of religious doctrine and do little to advance knowledge of the 'lived' experience of religion (Inhorn 2005).

This small collection of studies suggests that the experience of infertility may be culturally contingent, and that the socio-cultural location in which the infertility experience takes place, needs to be fully acknowledged. The moral context in which couples find themselves during their infertility is therefore crucial to an understanding of that experience, as are the perceptions of significant others, as well as the social construction of what it means to be infertile in different communities (Miall 1994). Ethnic group membership clearly has a role to play in how infertility is experienced, but the research literature to date in this area is inadequate, particularly in the UK context, and research that provides a more sophisticated understanding of the interplay of ethnic, cultural and socio-economic factors is required.

Conclusions

This chapter has mapped some of the key research findings in relation to infertility. It has explored the ways in which infertility is presented in the literature as 'distress', 'disruption', 'difference/stigma' and 'disease'. Infertility has been shown to disrupt the perceived and expected life course, causing distress and turmoil. Powerful pronatalist discourses about motherhood, genetic continuity and bodily control compound this experience, rendering those who cannot not conceive 'naturally' and within some specified timeline, different, or even deviant. Biomedical solutions to infertility have come to dominate the experience, with ARTs readily offered to women as a way to 'fix' their dysfunctional bodies. Its treatment through the use of ARTs has also been heavily criticised by social scientists from within psychology, sociology, anthropology and feminism. The development of ARTs has been opposed for its objectification of women and its attempt to control their bodies and the procreative process. It has also been suggested that biomedicine, rather than being an all-powerful and all knowing institution, is in fact an incomplete and uncertain regime of knowledge. It is argued that it is this uncertainty which makes the treatment process a highly emotional and anxious experience for couples.

This chapter has shown that anthropologists have clearly demonstrated the relevance of culture to an understanding of infertility and infertility treatment, yet little work has been carried out with 'minority' groups within Western, developed nations. Most significantly, this chapter highlights an important gap in current literature, which has thus far failed to fully explore British minority ethnic women's narratives on infertility and assisted conception. There is an obvious opportunity for exploring the different ways in which diverse 'local moral worlds' (including amongst the ethnic majority

population) impact on people's experiences of childlessness. This thesis attempts to address some of those gaps and offer insight in to a small number of individual moral worlds.

The literature presented in this chapter, together with the debates highlighted in Chapters One and Two, raise a number of central research questions to be addressed throughout the rest of this thesis, and which contribute to the overall aims of the study as presented in Chapter One. These are:

- Are discourses of infertility as 'disruption' meaningful for women from minority ethnic communities?
- Are concerns about the 'stigma' caused by infertility present in the UK (i.e. Western) context?
- What is the impact of ethnicity and culture on the infertility experience?
- What are the experiences of medical treatment, especially in relation to 'agency' amongst minority ethnic women?
- How are the views and perceptions of 'lay' members of the public important in shaping experiences?

The next chapter describes the methodological approach employed in this thesis in order to answer these research questions.

Chapter Four: Methodology

Introduction

The dominant construction of infertility in the West is that of a medical problem affecting white middle class couples (Greil 2002). As demonstrated in the previous chapters, there has been a corresponding absence of research on how infertility is experienced within minority ethnic communities in Western countries. In chapter three, a number of research questions were developed, which correspond to these absences in the existing academic literature on infertility. This study was devised in order to address this lacuna in the knowledge of infertility experiences, and to attempt to provide substantive answers to these questions.

This chapter describes the methodology and design of the study; providing a justification for the particular approach taken and the methods employed. The demographic profile of the participants is presented in this chapter, as well as the strategy used to recruit people to the study. The data analysis method, questions of 'validity' and 'reliability', and the limitations of the study are also discussed.

Methodology

This research is located within the sociological tradition and follows a qualitative approach (Silverman 1997). The qualitative approach allows the researcher to have contact with everyday situations placing the emphasis on the lived experience, allowing researchers to 'get beyond initial conceptions and to generate or revise conceptual frameworks' (Miles & Huberman 1994:1). This methodological position is adopted in contrast to studies, some of which

were reviewed in chapter three, which have used a quantitative approach to the study of infertility (Domar et al. 1992, Golombok 1992). The qualitative approach allows participants to give full and lengthy accounts of their experiences and views of the subject under investigation. In this way, the meanings and interpretations that individuals bring to social phenomenon can be explored by researchers (Bryman 2004).

As with much qualitative research, an interpretivist epistemological position informs the design of the study (Williams 2000). Data are viewed not necessarily as an accurate representation of events, but rather as a means to understand how sense is made of the experience of infertility and the use of ARTs. Following Williams, 'interpretivism' is used to refer to:

'those strategies in sociology which interpret the meanings and actions of actors according to their own subjective frame of reference' (2000: 210).

By adopting an interpretivist approach to understanding the social world, the focus of this study is on the ways in which infertility as an experience comes to be defined in the context of British South Asian communities. In order to address the research questions raised at the end of the previous chapter, this study includes data collection with those who have experienced infertility, as well as with 'lay' members of the community, in order to explore differing perspectives on the topic.

In attempting to understand everyday meanings and interpretations and how they relate to broader social structures and categories (ethnicity, culture and gender) the methodological approach in this thesis is also informed by the work of Pierre Bourdieu (1977, 1979, 1984, 1986, 1990a&b, 1993, Bourdieu & Wacquant 1992). Chapter two described the conceptual and theoretical use of

Bourdieu's work within this thesis in relation to ethnicity and subjectivity. Bourdieu's work is also significant in epistemological terms, being described by commentators as 'good to think with' (Jenkins 2002:61). Bourdieu's usefulness for informing epistemological and methodological thinking comes from his theoretical shift away from the search for rules and structures in his earlier work (Bourdieu 1990a, Jenkins 2002). This earlier ethnographic work with the Kabyle peasantry in Algiers (Bourdieu 1979), led him to a critique of structuralism which would eventually lead to the development of his theoretical position on 'habitus' (i.e. his attempt to bridge agency and structure) (Bourdieu 1990a). However, this theoretical shift also led him to question the attempt by social scientists, anthropologists in particular, to search for rules in order to predict future behaviours and social practices (Bourdieu 1990a, Jenkins 2002).

With his theoretical shift from a concern with 'rules' to a concern with 'strategies', came an epistemological change in his thinking, which led to an interest in how individuals employ agency in engaging with their social environments. It is this element of Bourdieu's epistemological and theoretical position, which is adopted in the methodological approach in this thesis. However, this theoretical shift also resulted in his development of a critique of what social scientists *do* when they search for these rules, and his resulting call for researchers to 'objectify objectification' in their empirical work (Bourdieu 1990b). This aspect of his epistemological thinking is discussed in more detail in chapter nine in terms of a reflexive research practice.

An interpretivist methodological position, informed by Bourdieu, is therefore employed in order to explore the ways in which individuals work to shape, resist and reconstitute their social contexts. Interpretivism is adopted in the thesis to understand the role of agency in particular, in shaping habitus. The

aim is to explore the subjective experiences and social constructions of individuals and groups of individuals in relation to infertility. However, for Bourdieu, an overemphasis on subjectivity in research is undesirable since this leads to an undersocialised view of social action (Bourdieu 1977). This view of knowledge must therefore be corrected by 'recourse to structural indicators' (Swartz 1997: 57). The complexity of this position lies in the attempt to simultaneously hold together the dualism of structure and agency, objectivism and subjectivism in an epistemological perspective. Engaging with Bourdieu's related theoretical concepts of field and capital, however allows an exploration of agency whilst accounting for the impact of broader social structures. This theoretical triad allows one to 'think relationally' (Bourdieu & Wacquant 1992:96), and this is especially true of the use of the concept of field. Of fields, Schwartz (1997) suggests: 'interactions among actors within fields are shaped by their relative location in the hierarchy of positions' (p120). It is these wider relations and structures of meaning which are also of interest in this thesis. Importantly the approach used here is to explore the impact of structure and agency (through the concepts of habitus, field and capital) from the *perspective of the social actors themselves*.

Study design & data collection methods

Study design

This thesis was designed to provide data on both the social context of infertility in South Asian communities as well as exploring the experience of individual South Asian women⁸. Therefore two methods of data collection were employed in order to gain access to these two different types of data. In the first phase of the study (carried out between March – December 2002), 13

⁸ As was suggested in the preceding chapters, the focus of this thesis is on the woman's experience of infertility, rather than the couple, or the man, and this element of the study is discussed in more detail below

focus groups were carried out with members of South Asian communities in the UK. These focus groups were designed to access public or community perceptions of what it means to be childless and to use ARTs in South Asian communities⁹. In the second phase of the study (carried out between September 2005 and November 2006), 15 individuals were recruited to take part in interviews about their own experiences of infertility. The two data sets were analysed separately in the first instance, after which a simultaneous thematic analysis of both data sets was conducted, in order to compare the accounts of the individuals with the accounts from the community-based discussions. The design of the study and the methods used are discussed in detail next, alongside a detailed breakdown and discussion of the study participants from each phase of the study. Ethical approval for the entire study was given by the Faculty of Health & Life Sciences' Human Research Ethics Committee at De Montfort University (Appendix Two).

Phase one: focus groups

The use of focus groups to elicit 'community' perceptions has been increasing over recent years and using them in this way allows researchers to tap into collective views, or to access perceptions on more contentious topics where one-to-one interviews would be inhibitive. The advantages of using focus groups to access community perceptions is now well documented (Sim 1998, Cunningham-Burley et al. 1999, Kitzinger & Barbour 1999, Waterton & Wynne 1999, Bates 2005). This method is also useful when there is some consensus and meaning about the existence of a community or shared public voice, as can be argued in the case of some minority ethnic groups in the UK (Dignan et al. 1990, Chapple 1998, Twinn 1998, Fallon & Brown 2002, Atkin & Chattoo 2007). However, it is important to acknowledge that the views in a

⁹ The focus group data was collected as part of an earlier NHS-funded study for which I was the Research Fellow. My input in to this project is described in Appendix One.

focus group only represents the views of a 'sub-set' of those in the wider community (Chui & Knight, 1999), and that particular perspectives are 'developed and defined interactively' in the focus group setting (Waterton & Wynne, 1999). Waterton & Wynne, in assessing the benefits of using the method in this context, argue that 'such interactions are not just a neutral medium through which intrinsic preferences and values are expressed, but are themselves a substantive part of the *formation* of values and attitudes' (1999:136). That is to say, that it is the actual interaction between participants, and how this contributes to the construction of ideas and opinions in the group setting that is of value, as opposed to using the focus group to access multiple participants (Kitzinger 1994). These methodological and practical challenges are accentuated when the study involves accessing groups who speak a variety of languages which are different from those spoken by the research team (Maynard-Tucker 2000, Espositio 2001, Culley, Hudson & Rapport 2007). Using focus groups in this context requires careful planning, as well as the consideration of additional resources.

Focus groups in this study were used in order to generate discussion amongst members of the communities involved in the study about 'public' perceptions of childlessness and the use of ARTs. These focus groups were designed not to include those with specific experiences of reproductive technology (i.e. patients), but included ordinary members of the public, recruited via community contacts (a detailed discussion of recruitment strategy is included below). This method was chosen to allow an exploration of the wider construction of infertility within public groups¹⁰. Few studies on infertility in the West have taken into account the social context in which a childless

¹⁰ Focus group participants were not therefore, recruited on the basis of their own fertility histories, nor was the purpose of these groups to elicit information about personal experiences of infertility. It was acknowledged however, that this would not preclude those with fertility problems from agreeing to take part in a group discussion, whether or not they chose to disclose this information.

couple is embedded, despite the fact that it has been noted that this context can prove to be an additional stressor or source of support (Miall 1994).

Focus group recruitment

The focus groups for this study were designed to be exploratory and to provide a 'cross section' of views into possibly diverse ways in which fertility, infertility and its treatment is perceived within and between different South Asian communities in the UK. This approach can be described as dimensional sampling (Cohen & Manion, 1989). The intention was not therefore to represent the proportion of each ethnic or religious group within the general population. The aim was to include women as well as men, younger people as well as older people, and representation from across four main South Asian communities: Indian Gujarati Hindu, Indian Punjabi Sikh, Bangladeshi Muslim and Pakistani Muslim (Katbamna et al. 2004).

Recruitment of the focus groups took place in a number of ways. Several community based organisations (e.g women's centres and faith-based organisations) were approached and asked if they would be willing to take part in the research and specifically, to find groups who might be willing to take part in a group discussion; nine groups were recruited in this way. In addition, four groups (two with men and two with women), were recruited and conducted by one of the facilitators working on the earlier study¹¹.

Recruiting male groups was particularly challenging, as there were fewer occasions when men would be meeting as a group and the topic of infertility was perceived as being a 'woman's issue'. However, four male focus groups were successfully conducted, although this took longer than had been initially planned. With the women, existing groups such as keep fit classes and mother

¹¹ A team of community facilitators worked on the earlier NHS-funded study; carrying out a number of the focus groups included in this study in languages other than English. See Appendix One.

and toddler groups were accessed and groups who were already familiar to one another were purposely sought in order to facilitate discussion (Culley, Hudson & Rapport 2007). Word of mouth and personal contacts were extremely important in successful recruitment, as was the co-operation of a number of 'gate-keepers'.

Conducting the focus groups

As already highlighted, the focus groups formed part of an earlier NHS-funded study (Appendix One). As a result of the collaboration with community facilitators in this study, eight of the group discussions were conducted by the facilitators in a South Asian language and subsequently transcribed into English. The facilitators were also able to provide extra culturally specific information in relation to the data that they had transcribed (for example, offering explanations of relevant customs or practices in relation to childbearing). Five of the groups were carried out in English; three were facilitated by myself and the principal investigator for the NHS-study; one by me with a female facilitator and one conducted solely by a male facilitator.

Consent for the focus groups was taken verbally by the facilitator at the beginning of the group and information about participation and the wider aims of the study were also given by the facilitator verbally in each group. The focus group discussions lasted between 45 and 90 minutes and took place in a variety of settings according to the requirements of the members: four took place in community centres, three groups took place in two centres specifically aimed at South Asian women, three were carried out in places of worship, two in University premises and one in a restaurant. In each case, the participants were already known to one another and, in a number of these, were already meeting for other purposes. For example, the groups who were already meeting (n=6) included a mums and tots group, three social women's

groups, a men's sports group, and an older women's keep fit group. The other groups (n= 7) came together specifically for the purposes of the study, but were already known to one another on a friendship or social basis.

Participants were not offered any payment for attending the focus groups, but in each case refreshments were provided. A detailed overview of the participants is given below and a breakdown of this information is included as Appendix Three. The focus group question schedule was semi-structured in design, allowing direction of the discussion by the facilitators, whilst also allowing the participants scope to raise issues which they wanted to discuss. The discussions covered: the importance of childbearing and children; causes of infertility; treatment seeking for infertility; and alternative solutions to childlessness. The topic guide was tailored according to the gender of the groups and the male version is included as Appendix Four.

The focus group participants

In total, thirteen focus groups were conducted with 87 participants. The groups were relatively homogeneous in terms of ethnicity, religion and age, although there was some diversity within the groups. Since the groups were made up of individuals already known to one another, or who were meeting for other purposes, any internal heterogeneity was not necessarily considered to be problematic. They consisted of 9 groups with women (n=61) and 4 groups with men (n=26). Demographic data was collected from the group members using the questionnaire attached as Appendix Five¹².

¹² Since these groups were not constituted on the basis of the fertility status of the participants, this data was not collected.

Gender	No.	%
Female	61	70
Male	26	30

Table 1: Gender of focus group participants

Ethnicity & religion

The ethnic (Indian, Pakistani and Bangladeshi) and religious (Muslim, Sikh Hindu, and Jain) census categories that were used to define the sample population were found to have an empirical reality for people in shaping their identities (Katbamna et al. 2004); these categories were represented in the groups as follows:

Ethnic origin	No.	%
Indian	46	53
Bangladeshi	29	33
Pakistani	12	14

Table 2: Ethnic origin of focus group participants

Religion	No.	%
Muslim	42	48
Sikh	25	29
Hindu	19	22
Jain	1	1

Table 3: Religion of focus group participants

Age

Accessing the views of older as well as younger individuals was considered to be important, but it was felt that having a generational mix in the groups might inhibit discussion, given conventions of deferring to older people in many South Asian communities. It was therefore intended at the outset that focus groups would include members who were of similar age to one another.

However, the age of the focus group members is marked by some diversity. The younger 16-24 year olds and the older 60+ year old groups tended to be most homogenous in terms of age. However there was a greater variety of ages represented in a number of the groups that included those between the ages of 25-59 years. The overall breakdown is as follows:

Age	No.	%
16-24 years	10	11.5
25-34 years	17	20
35-44	10	11.5
45-59	18	21
60+ years	32	36

Table 4: Age of focus group participants

Language

In addition to ethnicity, religion and age, language and migration history were also significant in defining community boundaries. Therefore the Indian group was divided by religion and language into Gujarati-speaking Hindu people and Punjabi-speaking Sikh people. The Bangladeshi groups were more homogenous in terms of ethnicity, religion and language, with all members describing themselves as Muslim and speaking Sylheti (a dialect of Bengali).

The focus groups were carried out in a number of different languages and as described above, the community facilitators were able to conduct the groups in the languages spoken by the group members (as opposed to having live translation of the discussion). Five groups were carried out in English (groups 1, 3, 5, 9 & 10), four groups were carried out in Sylheti (groups 2, 8, 11, & 13), two in Punjabi (groups 7 & 12), one in Urdu (group 6) and one in Gujarati (group 4).

Phase two: in-depth, semi-structured interviews

In semi-structured interviews, the role of the researcher becomes one of guide, allowing the participant to tell their story in their own words and at their own pace. This approach allows for flexibility in the data collection and enables a rich level of data to be achieved (Bryman 2004). Drawing on an interpretivist position, in-depth interviews were therefore used in order to explore the meanings that people give to their experiences (Smith, Jarman & Osborn 1999, Williams 2000). The purpose of this method is therefore not necessarily to simply attempt to record what happened to an individual, but rather to understand what it meant to that individual, and how people come to reconstitute the account by drawing on a variety of cultural and linguistic resources (Miller 2000, Throsby 2004).

Interviews allow for a re-telling of experiences which are otherwise inaccessible to the researcher (Bryman 2004). They afford the individual the space to direct the conversation in a way that is acceptable to them (Mason 2002). Interviews are also well suited for the collection of data which may be considered of a sensitive or private nature (Kvale 1996). Significantly, the accounts that participants give in the interview setting are seen as being part of a process of 'narrative re-telling' in which individuals shape and actively 'account for biographical disruption' in their lives (Reissman 1990:1196). Through individual accounts we can come to achieve insight into the dominant practices and meanings that individuals construct in relation to particular life events.

Interviews have been used by a number of authors working in the field of infertility (Greil 1991, Inhorn 1994, Franklin 1997, Letherby 1999, Becker 2000, Reissman 2000, Daniluk 2001, Throsby 2004, Thompson 2005), demonstrating their value in accessing the stories of the involuntary childless in a range of

social settings. The interviews in this study were designed to access the subjective experiences of South Asian women.

Interview recruitment

In the preliminary stages of the development of the study, it was intended that both women and men would be included. However, it soon became clear that recruiting men to discuss this issue would be difficult. In the first few interviews with women, I inquired as to whether the participants' partner would be willing to be interviewed. However, in each case, the women suggested that he was 'too busy' or was happy for his wife to be interviewed on behalf of the couple. Nor did I receive any early inquiries from men about the study on the basis of the online and poster advertising (Appendix Six). Therefore, given the difficulties with recruitment generally, the decision was made to focus my efforts on recruiting female participants.

This decision paved the way for a focus within the study on the gendered experience of infertility and the invasive nature of ARTs for women in particular, which has been demonstrated by other authors (Greil 2002). A focus on women's experiences allowed an exploration of ARTs as 'women's work' (Franklin 1997:113). In addition, the focus group data and wider research suggests that in pronatalist contexts women are most likely to come under pressure from others when experiencing an inability to conceive (Inhorn 1994, 1996, Reissman 2000, Culley et al. 2004, Throsby 2004). Maintaining the homogeneity of the sample in these terms would therefore allow an exploration of the role of gender in shaping the infertility experience, although problems raised by systematically excluding men from research on infertility are acknowledged (Greil 1997).

It was also decided that due to the exploratory nature of the research and the lack of resources available for interpreters, participants would only be invited to take part in English¹³. However, none of the individuals who subsequently contacted me to take part in the interviews needed an interpreter. It is acknowledged that by carrying out the data collection in this way, that access was effectively denied for non-English speakers.

The sample for this study was therefore not designed to be random. The participants were recruited to the study on the basis of their fertility histories, gender, ethnicity and language – forming a non-probability, purposive sample (Bryman 2004). Participants were recruited on a self-selecting basis and as such, also represent to some degree an ‘opportunistic’ sample (Bryman 2004), as they were the participants who were available to me during the recruitment period. Since the sample was selected in this way, there was no way to ensure that the sample was representative of the wider South Asian population in the UK (also see note below about generalizability of qualitative research). Details of the eventual demographic characteristics of the interview participants are given at the end of this section.

The interview participants for this study were recruited via a number of routes (Sixsmith et al. 2003). Two private treatment clinics consented to assist with recruitment. However, access via this route was limited and the majority of participants were instead recruited via personal contacts and by advertising the study on a number of websites. Accessing patients from the clinics was difficult for a number of reasons. First, since the study was being carried out on a part time basis, it was difficult to maintain regular contact

¹³ The interviews carried out for this thesis are distinct from those included in the earlier NHS study (Appendix One), and represent a divergence in terms of the focus of the two studies. The interpreters used in the first phase of the study were employed as part of the NHS funded study and were therefore not available for the interviews carried out in this thesis.

with the clinic staff and to encourage the recruitment of patients. The nursing and reception staff in the participating clinics agreed to approach appropriate patients (female, undergoing some form of ART treatment and belonging to a South Asian ethnic group) on my behalf. If they were willing to take part they were provided with further information about the study and an appointment was made for the interview. This was of limited success since staff in the fertility clinic are, like many clinical staff, often very busy and recruiting patients to an external study is clearly not always an immediate priority. It is not possible to know exactly how many couples or individuals in the two clinics were invited to participate in the study on this basis, however, I would estimate this number to be relatively small (perhaps less than 15 in total), since recruitment of patients by staff appeared only to take place when prompted by phone calls, emails and personal visits. Recruitment through infertility clinics was therefore carried out very much on an 'ad-hoc' basis and as a result only one participant was recruited in this way. Marcia Inhorn (2004) suggests that infertility clinics act as gatekeepers to social science research. She describes this as the 'politics of patronage'. This relative failure in recruitment terms may be partially explained by the 'politics of patronage', since I was not an insider in the clinical context and the relationships I had with the clinic staff were intermittent and superficial. Although I would not agree with Inhorn that my presence in the clinic was 'unwelcome', I would suggest that it presented something of a nuisance to the staff.

This unsuccessful recruitment strategy led me to simultaneously seek alternative sources of participants. Given the potentially sensitive nature of the topic, locating participants was a difficult and lengthy process. Finding the resulting participants took over a year and was the result of pursuing several different avenues. Personal contacts built up over the course of carrying out the earlier phase of the study were invaluable in recruiting

interview participants; a total of nine participants were recruited in this way. An email was sent to all my research contacts asking them if they could recommend anyone who would be willing to take part. Personal recommendations about the research were therefore significant and all of those approached on my behalf agreed to take part; giving this method a 100% response rate. Two of the women recruited in this way had contacted infertility support organisations who had informed them about my research; they then made contact with me independently.

A further five individuals were recruited via the internet. An advert describing the research (Appendix Six) was posted on three websites and three discussion forum pages, inviting people to contact me about the research. One of these five individuals was male, Ramesh, who wanted to volunteer himself and his wife to the study. He was very keen to share his views as part of the research and as such presented me with a dilemma, since I had decided to focus on the female experience. After consideration I decided to include him in the study, as I felt it would be unethical to invite his wife to take part and not him, since he was so keen to be included (I had also of course, advertised for male participants at the outset). Added to this was the fact that Ramesh and his wife Gita had a distinctive experience from the majority of the other participants in that they had travelled overseas for treatment and were also in the process of attempting to conceive with donor gametes. This was a very important interview in terms of the uniqueness of their story and as such it adds to knowledge on this topic that would have not have been achieved had this couple been omitted from the study. Ramesh and Gita were interviewed together¹⁴.

¹⁴ Joint interviewing has been effectively utilised in a number of studies with infertile couples (Greil 1991, Franklin 1997, Daniluk 2001, Throsby 2004, Culley et al. 2004). Authors who have used this method highlight the benefits including: accessing shared narratives and experiences, the stimulation of

In addition to these methods of recruitment, posters and flyers about the research were distributed to a number of local community based centres (Appendix Six). An advert was also placed in the newsletters of two infertility support organisations. No inquiries about the study were made on the basis of these forms of advertising, which may suggest the inadequacy of this type of recruitment method in some communities (Sixsmith et al. 2003).

Conducting the interviews

Disseminating information about the study via the internet meant that the interviewees were drawn from across the UK. All of the interviews were carried out by me in English and were conducted in a number of settings; this was in most cases the person's home. On agreeing to take part, the participants were offered a choice of where they would like to be interviewed. Twelve individuals chose their own home, two asked to meet away from their home for concerns about the confidentiality of the interview from other family members (these were therefore conducted in interview rooms in local libraries), and one person travelled to meet me at the University.

Participants were either given or sent an information sheet about the study before agreeing to take part (Appendix Seven). On agreeing to participate, they were asked to sign a consent form (Appendix Eight) and were informed that they were free to withdraw from the study at any point. At the end of the interview, this point was re-iterated and I ensured that they knew how to contact me if they had any queries about the research, or if they should wish to withdraw. Interviews lasted between 30 and 90 minutes and were tape

one another's memories, observation of interactions between the dyad, and comfort for the participants (O'Rourke & Germino 2000, Morris 2001).

recorded, except in two cases (in one case this was at the request of the participant, and in another case due to a failure of the recording equipment).

The question schedule followed in the interviews was developed using data from the focus groups, as well as from the literature and is attached as Appendix Nine. It covered the following broad themes: importance of parenthood and starting a family, ideas about ART before treatment, discovering a problem, treatment experiences, and community/family views. At the beginning of the interview, the participant was asked to tell me their story in their own words, and I then picked up specific topics and themes using the semi-structured interview guide in order to focus and direct the interview. The focus of the interview was therefore directed by me, but the participants were able to raise additional issues spontaneously. The interviews were transcribed verbatim and the analysis process is described below.

The interview participants

A total of fourteen in-depth interviews were carried out with fifteen participants; this included thirteen individual interviews with women and one with a married couple (Gita and Ramesh). The questionnaire, which was used to elicit biographical details from the participants, is attached as Appendix Ten. Pen portraits of the individual in terms of their reproductive history and treatment experience are included as Appendix Eleven. However, this data has not been combined with data on ethnic group, religion and age to ensure the anonymity of the participants (Throsby 2004). In addition, pseudonyms have been used throughout. The data on gender, ethnicity, religion, age, place of birth and socio-economic status has been presented together in one table instead of being broken down and presented by each of these variables. This has been done in order to illustrate the particular

'habitus' of each of the participants, and to show how each of these facets is defined in relation with others when impacting on identity.

Gender	Age	Ethnic group	Place of birth	Religion	Socio-economic status
F	35-44	Indian	UK	Sikh	Professional & managerial
F	25-34	Bangladeshi	UK	Muslim	Professional & managerial
F	25-34	Bangladeshi	Bangladesh	Muslim	Routine & manual
F	35-44	Indian	UK	Sikh	Intermediate
F	35-44	Indian	Kenya (East Africa)	Muslim	Routine & manual
F	35-44	Indian	UK	Hindu	Intermediate
F	35-44	Indian	India	Christian	Professional & managerial
F	35-44	Indian	Uganda (East Africa)	Hindu	Intermediate
F	25-34	Indian	India	Hindu	Professional & managerial
F	25-34	Indian	UK	Hindu	Professional & managerial
F	45-59	Indian	Uganda (East Africa)	Hindu	Intermediate
F	35-44	Indian	Kenya (East Africa)	Hindu	Full time student
F	35-44	Indian	India	Hindu	Routine & manual
M	35-44	Indian	Kenya (East Africa)	Hindu	Intermediate
F	25-34	Pakistani	Pakistan	Muslim	Unemployed

Table 5: Demographic profile of interview participants

Ethnicity, religion and place of birth

Twelve of the participants (11 women, 1 man) described their ethnic group as 'Indian' (80%), two as 'Bangladeshi' (13%) and one as 'Pakistani' (7%). Eight participants (7 women, 1 man) described themselves as Hindu (53%), four as

Muslim (27%), two as Sikh (13%) and one as Christian (7%). Five were born in the UK, five were born in South Asia and five were born in East African countries. As described in chapter one, members of South Asian communities who migrated to the UK from East Africa are distinctive in both their patterns and reasons for migration, as well as their higher levels of education, socio-economic status and prosperity in the UK (Ballard 2003).

Age

The modal average age of the participants was 35-44 years (60%, n=9), which may reflect the fact that many of the participants had completed treatment, or had spent a significant number of years already trying for a child or seeking treatment. Of the six remaining participants, five were included in the 25-34 year category (33%) and only one who was older, falling into the 45-59 year bracket (7%).

Socio-economic status

This data was collected by asking participants to record their own and their partner's occupation. The limitations in attempting to collect data on socio-economic status in this way are recognised, since it does not include data on other factors such as standard of living (Chandola 2001), and occupation is a poor proxy for socio-economic status in minority ethnic groups (Nazroo 1997). As Karlsen & Nazroo suggest: 'conventional measures of socioeconomic position may actually serve to conceal the socioeconomic disadvantage experienced by ethnic minority groups, rather than expose it' (2002: 2-3). The resulting classes described above are devised from the 'National Statistics Socio-economic Classification' (NS-SEC) (ONS 2008) and have been collapsed into three broad groups, based on the original eight classes listed in the NS-SEC classifications (see Appendix Twelve). Five participants were classified in the highest three analytic classes (33%), five in

the intermediate classes (33%), three in the lower classes (20%), one as unemployed (7%) and one as a full time student (7%). The data collected on the partner's occupation is included as Appendix Thirteen. Unlike the majority of research with users of ARTs (Throsby 2004, Franklin 1997), the sample is more evenly balanced in terms the socio-economic status of the participants, with over 50% of the sample being drawn from intermediate and lower occupational groups. This pattern reflects the tendency for some minority ethnic groups to be over represented in lower socio-economic groups (Karlsen & Nazroo 2002).

Diagnosis

Fourteen of the fifteen participants in the study had received a diagnosis for their infertility (Figure 2). When compared to the national statistics on causal/diagnostic categories, this sample has a larger proportion of female factors, such as endometriosis and ovulatory problems, which might be expected when recruiting women to talk about their experiences. However, this over representation of cases of female infertility may also be due to the additional stigma associated with talking about male infertility (Becker 2000, Inhorn 2003b). The category 'ovulatory problems' includes two women with premature ovarian failure and two participants (Gita and Ramesh) who are seeking treatment due to Gita's age-related infertility. The large number of cases of 'unexplained' infertility (47% of this sample compared to 23% of all infertility cases) might also be due to the perceived social acceptability of discussing infertility which is apparently not either partners' 'fault'.

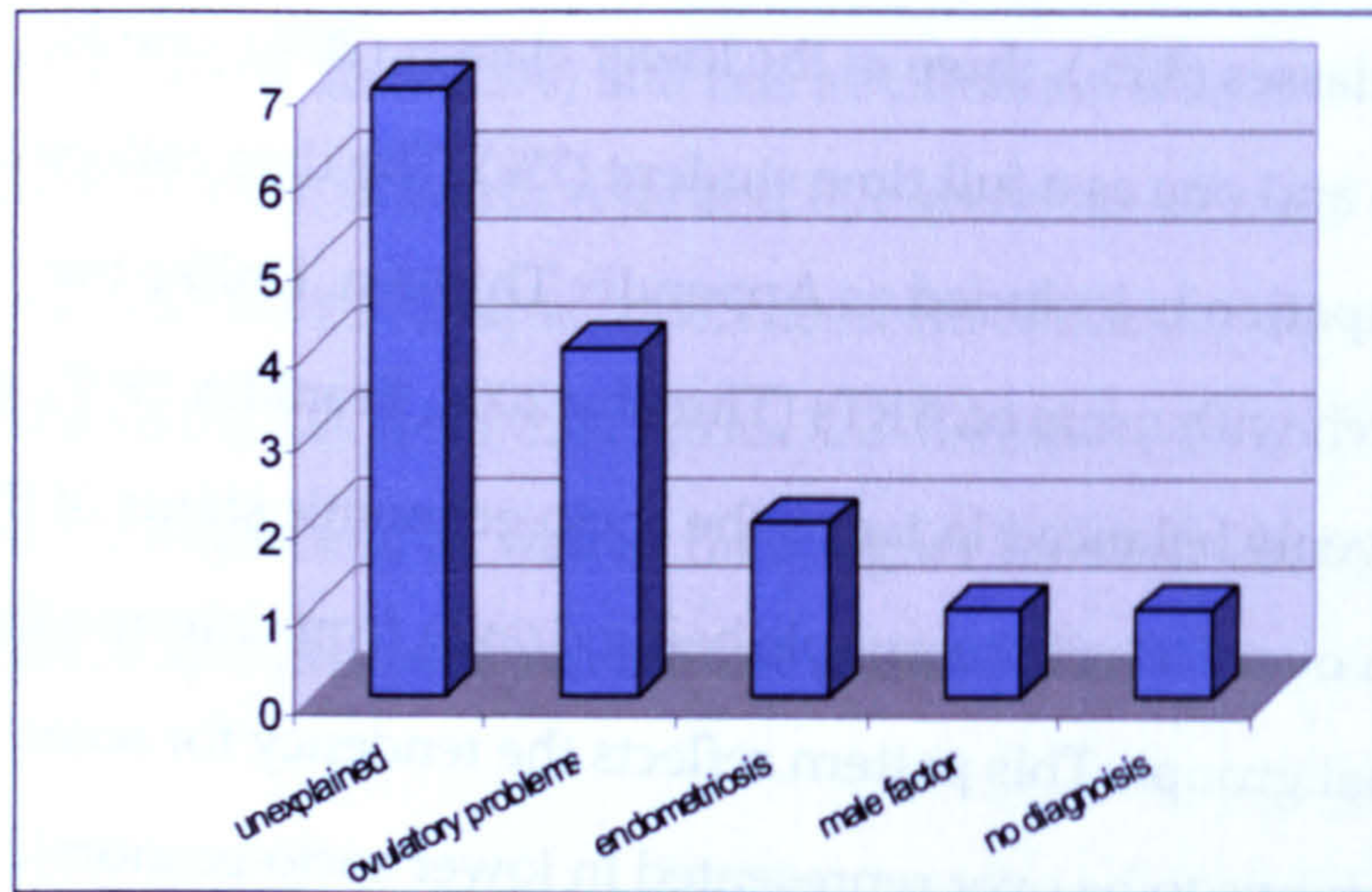


Figure 2: Diagnostic categories of infertility

Fertility status

Not all the participants in this study were childless (Figure 3); nine of the participants had at least one child. Two women (13%) had two children (in both cases they had one child conceived with ART; in one of these cases the woman had then gone on to conceive a second child naturally, and in the other case she had fostered a child before conceiving through ART); both of these women had stopped trying to conceive any further children. Seven participants (47% of the sample) had one child; three of these had an existing child conceived naturally (this includes the couple) and four had one child who was conceived using ARTs. The remaining six participants (40%) had no children. Five of these women had never been pregnant and one had suffered two miscarriages prior to beginning treatment.

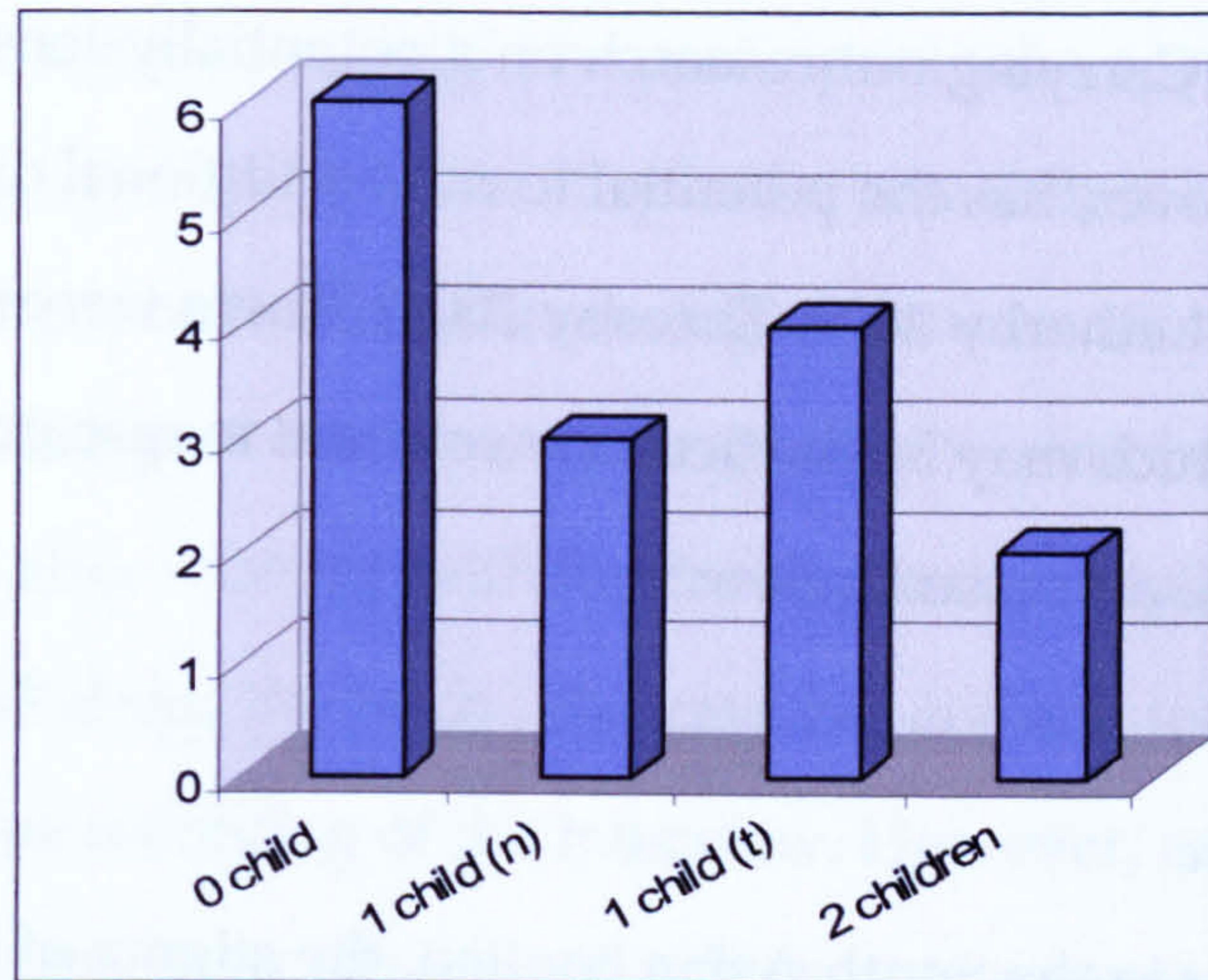


Figure 3: Number of children per participant

Treatments

Twelve of the fifteen participants (80%) had tried some form of treatment for their infertility. Eleven (73% of the sample) had used IVF (three of these participants also reported having had IUI treatment prior to beginning IVF), one participant (7%) had only used IUI, and three participants (20%) had not used any treatment at the time of interview. Of the three who had not used any treatment, one had not yet received a diagnosis for their inability to conceive (Bhavna) and two had experienced premature ovarian failure. One of these women was not planning to use ARTs and one was actively seeking an egg donor at the time of the interview. Of the twelve participants who had used some form of ART, eleven of them had paid for some or all of their treatment. The only exception was Rita, who had received all of her treatment for free (since she was one of the early IVF 'pioneer' patients).

Ethical issues

Social science research can raise a number of ethical dilemmas for researchers (Mason 2002, Bryman 2004). Some of the ethical considerations in this study were perhaps similar to those which would face researchers working in other

areas of social science. Carrying out research on a potentially sensitive topic such as infertility however, has the potential to raise additional dilemmas for researchers (Lee 1993, Letherby 2000, Throsby 2004). There were therefore issues in this study, which may be particularly relevant to research about infertility and these are discussed below.

Sensitivity of the topic

Evidence suggests that in the South Asian context, the stigma of infertility can be extreme and is often considered to be a 'taboo' subject (Neff 1994).

Findings from a number of studies in the West also suggest that infertility can be a difficult topic to discuss with others (Greil 1991, Franklin 1997, Throsby 2004). There is also now a well documented acknowledgment of the potential sensitivity of a number of research topics (see Lee 1993). Therefore, at the outset of the study there was concern that there would be a reluctance to discuss such a topic in the public setting of the focus group. However, this research highlights how what constitutes a 'sensitive' topic is context specific. Although infertility can be highly sensitive, particularly for those experiencing it, this is not always the case and researchers should be wary of universal claims about the contentious status of infertility as a topic. In the focus groups in this study there was little sense that discussing infertility in this way was problematic. Farquhar (1999) has written about how the notion of what constitutes a 'sensitive' topic in research is contextual and fluid, is socially constructed and constantly changing. This certainly seemed to be the case in this research. In the focus groups, the participants were known to one another and this may have facilitated the openness of the discussion.

Ensuring the matching of focus group members broadly by age and gender also appeared to ease the flow of communication.

In the interviews, there was only one participant who appeared to be uneasy about discussing the topic of infertility in the research context. In this case, the interviewee had contacted me after seeing my information on the internet and volunteered to take part in the study. I travelled to visit her in her home a week later, and after chatting with her for approximately half an hour about her situation and about the study, she gave her consent to take part. She also agreed to the tape recording of the interview. However, once the tape recorder was switched on she seemed reluctant to answer my questions. Knowing that people can often be self conscious about being recorded at the beginning of interviews, I continued to ask gentle introductory questions. However, it soon became apparent through her hesitance that she was reluctant to speak 'on record' and I asked if she would prefer me to take notes, to which she agreed. This interview was the shortest in the sample, lasting only thirty minutes in comparison to the other interviews which were all at least an hour long. The relatively brief nature of this interview can partly be explained by the fact that this participant had only recently been referred by her GP for diagnostic tests, and she seemed in her responses to my questions, unwilling to 'tempt fate' by speculating too much on her situation or on whether she might use infertility treatments in the future. It may therefore have been that the topic was 'sensitive' in this case, because her's was still a precarious and unknown situation with an outcome yet to be decided. There may have been other reasons for her reluctance to comment on some issues, or she may simply have offered all the information she was prepared to offer on the topic. As with the other interviewees, I confirmed her consent again at the end of the interview and left my contact details (telephone, address and email) in case she changed her mind about participation. Since she did not contact me to withdraw from the study, her responses are included. However, it is important to point out the partial view that this participant's account represents, due to the length of the interview

and the absence of a voice recording, when compared to the other interviews in the sample.

The topic guides for both the focus groups (Appendix Four) and the interviews (Appendix Nine) were also designed to take account of the sensitivity of the topic, by introducing relatively neutral topics before progressing onto potentially sensitive questions (Wellings et al. 2000). In addition to this the focus groups did not directly elicit personal perceptions. Instead, participants were asked to provide an account of what they thought the 'community' response to a range of issues would be. This strategy was also used as a means to permit discussion of potentially difficult topics such as gamete donation. However, many members of the groups did also contribute their own personal perceptions on the topics raised, and the data presented from the groups in the next chapter is a combination of both these types of accounts.

Dealing with sensitive topics in interviews, and the emotions that this can raise, has been well documented (Lee 1993, Birch & Miller 2000, Lalor et al. 2006). It was anticipated that the research interviews could be distressing to take part in, both for the participants as well as for the researcher. As such, before the interview, contact details for support groups offering counselling were prepared for any participant who requested them. In addition, the participants were told that they could stop the interview at any time if they wished to do so. Confidential 'debriefing' sessions were available with my supervisor if needed, after particularly difficult interviews (Lalor et al. 2006).

Reciprocity

The concept of 'reciprocity' in research is a consideration of the extent to which research relationships can and should be two-way (Egharevba 2001,

Culley et al. 2007). However, few authors give consideration to this aspect of research relationships. At the outset of this study it was felt that in order for the research to be ethical and in some way reciprocal, information-giving should be a priority and as such the focus group facilitators were given training on infertility and its treatment (as well as research methods training) in order to be able to answer any factual questions that the focus group participants may have. Since it was not part of the study design to actively recruit childless individuals in this first stage, it was envisaged that general members of the public may not necessarily have much knowledge about infertility and its treatment. A number of requests were made by focus group participants for further information and these were fulfilled where possible¹⁵. It was also envisaged that some interview participants may request information about access to treatment, types of treatment, clinics etc. and therefore I was prepared to be as helpful as I could in this respect.

The interviews also raised a series of additional and, perhaps less expected, 'ethical' issues, which I have written about in the section on 'reflections' on the research process in chapter nine.

Transcription & analysis

Transcription

The focus groups were either transcribed directly from the English, or in the case of the groups in South Asian languages, were translated and transcribed by the person who conducted the group. The focus group facilitators were called on during the data analysis stage of the NHS study to ensure that the overall meaning of the discussion in the groups was captured, rather than

¹⁵ As part of the NHS-funded study, feedback sessions were organised in some of the community settings as well as a leaflet and CD in South Asian languages being produced for use by community organisations as well as infertility clinics (see Culley et al. 2004).

providing a literal translation of words and concepts (Esposito 2001). Literal translations can be problematic and this can have implications for analysis (Esposito 2001, Bradby 2002).

Twelve of the interviews were transcribed verbatim from the tape recordings, and in two cases (Padma and Bhavna), notes were taken during the interview instead of a tape recording. As such, verbatim quotations from these two individuals appear less frequently in the data chapters.

Analytical method

In order to understand the common and divergent themes within the data collected for this study, the data sets were analysed using an inductive, thematic approach, employing a matrix-table design, which allowed the data to be managed and analysed systematically (Miles & Huberman 1994). This method allows a case-by-case comparison, whilst allowing the researcher to develop an overall analysis of each respondent's (or groups') comments. Ritchie and Spencer (1994) have used this approach, which they refer to as the 'framework' approach. They identify several steps involved in this type of data analysis: *familiarisation; identifying a thematic framework; indexing; charting; and mapping and interpretation* (Ritchie & Spencer 1994). An adapted version of Ritchie and Spencer's model is employed in this study (see Figure 4). In addition, the software package N7 was used to assist the management of this process in analysing the interview data.

The analysis process

Figure 4. shows the process of data analysis used for both data sets. The two data sets were initially analysed separately using this analytical method and were then compared in order to develop the themes which are presented in the data chapters. Despite the overlap of a number of themes within the focus

group and interview data, the decision was made to maintain the separation between the data sets within this thesis (chapters five, six and seven) in order to preserve their distinctive standpoints.

In the case of the individual interviews, the tape recordings represent the first stage in the analysis process. The interviews were then coded in N7 and a description of this process is included below. Since a number of the focus groups were carried out in languages other than English, the completed transcriptions (in Microsoft word and paper format) were used as the primary source of data during the analysis process. The focus groups were analysed using a similar method on paper and this process of analysis is also described below.

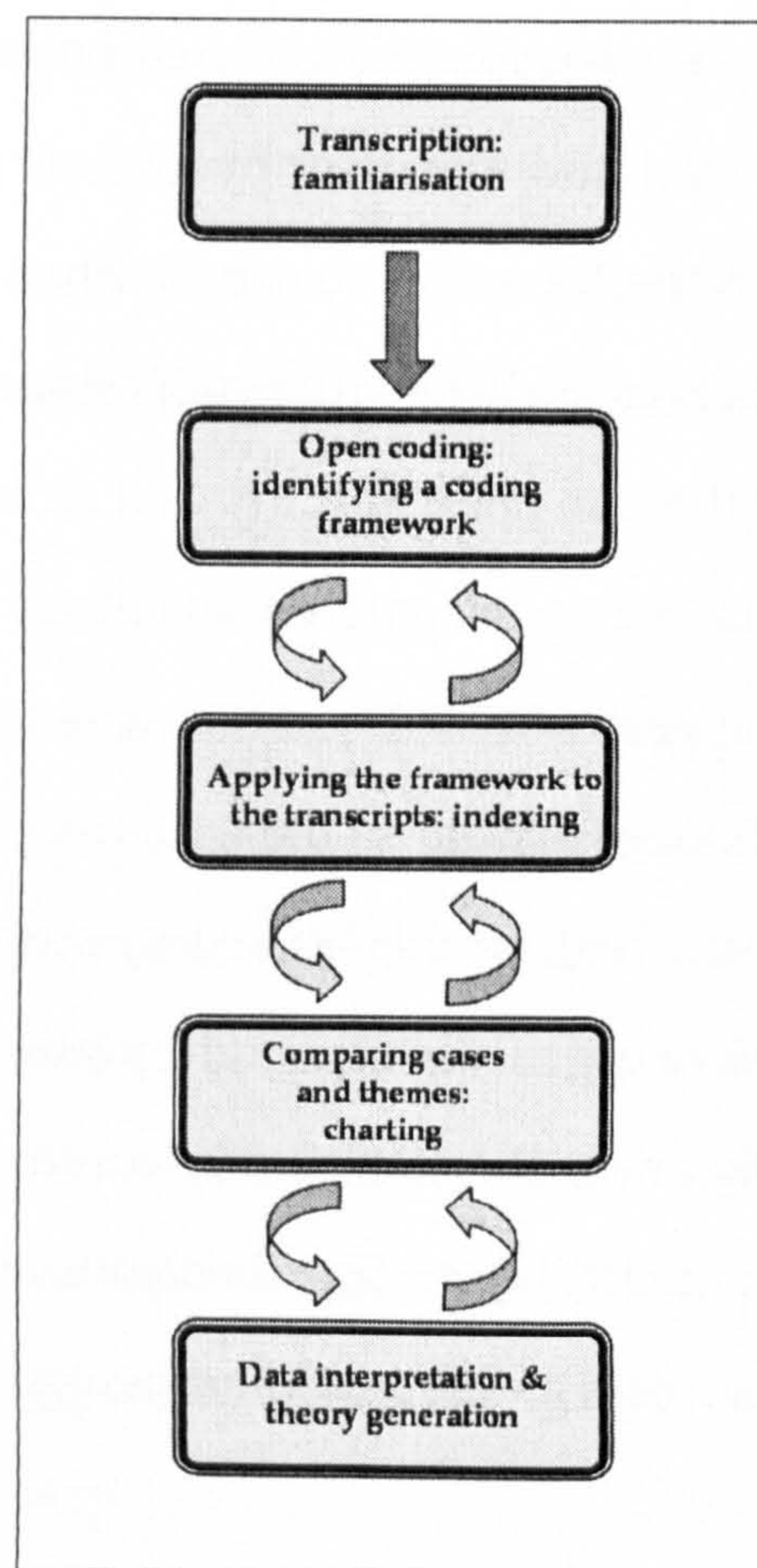


Figure 4: Data analysis process

Interview analysis

The tapes were listened to a number of times in the process of 'familiarisation'. Notes were made at this stage and ideas about themes and emerging similarities and differences were recorded. In addition, an overview of each participants' overall 'story' was constructed, which served as a kind of extended pen portrait of the individual to allow me to keep in mind the person's individual biography whilst I was analysing and breaking down the data into thematic segments (Radley & Billig 1996). A process of 'open coding' (Glaser & Strauss 1967), which Ritchie & Spencer (1994) refer to as 'identifying a coding framework' then took place in which emergent themes were recorded more systematically. This coding framework was built up gradually by reading and re-reading the transcripts, and first noting down on paper important themes and words, and then later by grouping and refining these categories into 'nodes'¹⁶ in the N7 software programme. An example of the resulting code framework is included as Appendix Fourteen. The appendix shows the breakdown of the tree node 'fertility and childbearing' from the interview data in N7. This tree node contains seventeen individual nodes (coding units). This screen grab of N7 also shows an example of the frequency with which this group of nodes appear in the data (references) and in how many of the transcripts (sources). At this 'indexing' stage of the data analysis (see diagram), the data were organised into eight preliminary 'tree' or parent nodes: fertility and childbearing; the community context; experiencing infertility; engaging with medical expertise; decisions about treatment; experiencing treatment; success and failure; and being interviewed (see Appendix Fourteen).

¹⁶ In N7 a 'node' is the basic unit of coding; these nodes are organised into broader categories or 'tree nodes'.

In stage four of this process, what Ritchie and Spencer refer to as 'charting', the individual nodes, of which there were 152 in total, were exported into individual documents in Microsoft Word, using the export function in N7. An example of part of one of these exported nodes is included as Appendix Fifteen. This shows the first page of the node 'unexplained infertility', which belongs to the tree node 'engaging with medical expertise'. These nodes were printed out onto paper, and the paper versions were then compared and re-organised as part of the charting process. The grouping of cases (participants) within these thematic categories allowed a comparison to be made of how different people addressed the same themes (see Appendix Fifteen). At this stage, the nodes as they appeared in N7 were re-grouped under the headings which now constitute the structure of chapters six and seven (and in the case of the focus groups, chapter five). In some cases, these nodes are amalgamated with other nodes to make the headings which appear in these chapters. For example in chapter six, the heading 'social parenting and adoption' includes the node 'adoption' with the node 'parenting other people's children'.

Stage five in Ritchie and Spencer's model, data interpretation, is extended here to include the process of theory generation (see Figure 4), since it was at this stage that the development of the theoretical ideas for chapter eight of the thesis were produced. There is also some overlap with stage four in that some re-organisation of the overarching themes, which now appear as headings throughout chapters six and seven took place. The arrows in the diagram also demonstrate the iterative process involved in this analysis, with most of the stages having some overlap.

Focus group data analysis

The focus group data, which had already been collected for the NHS project, were subjected to a second and distinct analysis for use in this thesis. The process followed similar stages to that described for the interviews. However, for the focus groups, this process was carried out using hard copies of the transcripts which were coded by hand. The indexing stage was completed on paper and in Microsoft Word and the resulting code book is attached as Appendix Sixteen. The decision to follow this procedure was made for practical reasons; there were fewer data to manage from the focus groups since they covered fewer topics than the interviews; and the process of entering data into N7 can be very time consuming. In addition, a considerable degree of familiarity with the material had previously been reached, given my involvement with the collection and analysis of this data in the NHS study. The same principle of organising the data into broad overarching themes was applied to the focus group data. Therefore, in chapter five (for example), the heading 'importance of having children' includes the sub-themes of 'economic reasons', 'social reasons' 'religious reasons' and 'emotional reasons'.

Reliability & validity

There has been a long standing debate within the social sciences about the application of concepts of reliability and validity within qualitative research (Seale & Silverman 1997). Whilst some have suggested ways in which these concepts can effectively be transferred to the qualitative setting (Mason 2002), others have argued for a modification of them when used by qualitative researchers (Lincoln & Guba 1985). Standard definitions of these terms relate to the way in which research can be said to have 'consistency' or 'repeatability' and is therefore 'reliable', or that it can be said to achieve

results which are in some way a representative or accurate version of the truth and is therefore 'valid' (Dyson & Brown 2006). The unease amongst qualitative researchers about the use of these concepts relates to the way in which they represent a realist ontological position, which suggests that there is a real world which exists 'out there', the job of the social scientist being to accurately measure it.

Since this study follows an interpretivist epistemology, wishing to explore the categories of meaning of the social actors themselves, the application of reliability and validity are inadequate means of assessing the quality and robustness of the research process and outcomes. Instead following Lincoln & Guba (1985), and others who have advocated their approach (Bryman 2004, Koch 2006), a number of methods were employed in this study in order to enhance the rigour and 'trustworthiness' of the findings (Lincoln & Guba 1985). Lincoln & Guba (1985) suggest that trustworthiness is composed of four elements: credibility; transferability; dependability; and confirmability. These concepts and the ways in which they have been applied in this study are discussed below.

Credibility

This concept relates most closely to the idea that research has internal validity; that is that there is coherence between the data that is collected and the subsequent development of theory. Within this study, credibility was established through the collection of data via a number of different sources; a process that is also referred to as triangulation. Dyson & Brown describe this process as follows:

'If different people, different angles and different kinds of investigations of the field of enquiry point in the same direction, then we can be more confident about the findings' (2006: 173).

In this study, focus groups and interviews were carried out in order to access multiple perspectives on the issue of infertility. This methodological strategy allowed corroboration between a number of different accounts, and in the case of the focus groups in particular, permitted the inclusion of a number of different 'voices' on the topic, that would have been excluded had this study only included those experiencing infertility. In addition to this, a sample of the emerging coding and interpretation of the data was checked by two of my supervisors to ensure consistency of my coding techniques. This allowed the emerging relationship between the data and the theoretical inferences to be checked for credibility.

Transferability

This concept relates most closely to that of external validity; that is the idea that research findings can be generalised to other social settings. This has historically been problematic for qualitative researchers due to the use of small samples in many studies (Bryman 2004). However, Guba & Lincoln suggest that since qualitative research produces 'thick description' of social phenomena, this provides a sound basis on which others can make a judgement about its transferability to other social contexts. Other authors have suggested that the nature of qualitative research findings means that researchers are making *theoretical inferences*, rather than the empirical generalisations associated with a positivist approach (Williams 2000). Williams (2000) refers to these inferences as *moderatum* generalisations. The use of both 'thick description' (Geertz 1973, Guba & Lincoln 1985), and 'modertum generalisations' in this study therefore aim to enhance the

transferability of the research findings and may allow others to infer from this research to other instances of the same phenomena.

Dependability

Guba & Lincoln (1985) use the concept of dependability to address the concern with 'reliability' in research processes. However, rather than a concern with replication, dependability instead proposes that researchers produce an 'audit trail' in order that peers may establish that proper procedures have been followed and that the inferences made about the research can be justified. The reporting of this study within this thesis and its appendices, as well as in the records maintained about the research processes (consent procedures, notebooks, transcripts, and computer aided data analysis files) allows an 'accountability' of its findings, and therefore a measure of its dependability.

Confirmability

This final element of trustworthiness relates to the neutrality of the researcher's position when conducting the research. As Bryman (2004) suggests, it is the degree to which the researcher can be said to have 'acted in good faith' (p276). On this basis, Seale & Silverman (1997) advocate the analysis of 'deviant cases' in qualitative research in order that findings are used faithfully and not in order to support the existing theoretical or political position of the researcher. Guba and Lincoln (1985) suggest that the confirmability of a study should be an objective of the audit process, and in terms of the doctoral qualification, could be argued to be part of the work of the *viva voce* exam in which the decisions made by the candidate are scrutinised by the examination team.

Limitations of the study

Interview sample constitution

Since this study was designed to be qualitative and exploratory the sample was not intended to be large scale. However, the opportunistic sampling method for the interviews meant that there was no way of controlling the number of volunteers from each of the ethnic and religious groups, in the way that was possible for the focus group recruitment. In fact, the ethnic and religious identities of the interviewees are perhaps to some degree a reflection of by whom they were recruited (in the case of local contacts) and this may account for the small numbers of Pakistani participants in the study overall, since there is not a sizeable Pakistani community in the study location.

However, this does not explain the lack of response via the internet for this particular group. This lack of response could be due to smaller numbers of Pakistani couples accessing infertility treatment. However, since there is no information about the utilisation of services by ethnicity in the UK, conclusions on this are hard to infer. This does, however, have implications for this research, since there is less 'voice' from members of this ethnic group in this study.

Categorising and operationalising ethnicity & socio-economic status

McKenzie & Crowcroft (1996 in Aspinall 2001: 846) suggest that descriptive data on ethnicity should cover a range of information including ethnicity, country/area of birth and religion, all of which I have used in this study.

Writers also highlight the importance of data on socio-economic status when discussing ethnicity (Karlsen & Nazroo 1997, Nazroo 1997, Aspinall 2001). As Aspinall suggests: 'The means of measurement should be related to the purpose of the research' (Aspinall 2001: 853), and since the study was

designed to explore a range of subjectivities, data on each of these factors was collected. However, this process was not always straight forward.

As already discussed, standard measures of socio-economic status can conceal differences between individuals from different ethnic groups (Nazroo 1997). Operationalising socio-economic status was therefore difficult and although I was aware that this data was significant for understanding the experiences of the participants, it was only towards the end of the study that the reality of working with the data that I had collected became more complex. This was further complicated due to the fact that some of the data was missing for people's partners and where it was available it was difficult to know how to combine this in some way to give an overall picture of the couple's socio-economic status. Therefore only the data collected from the interview participants themselves is used in the thesis, but it must be acknowledged that this is problematic since some of them had partners who were from considerably lower or higher socio-economic groups, demonstrating further the problems with this measure of socio-economic status (Nazroo 1997, Karlsen & Nazroo 2002).

Following Gunaratnam (2003), in a temporary 'closing down' of the meaning of ethnicity, the interview participants' ethnic origin was collected via the questionnaires attached as appendices five and ten. The classification 'South Asian' was defined in this study by membership of one of the census categories that constitute the category, 'Asian' or 'Asian British'. The four sub-categories: Indian; Pakistani; Bangladeshi or other Asian were used in this study to collect the data on ethnic group membership. However although these groupings did on the whole make sense for those completing them, a small number of participants offered extra information in the 'other' ethnic group box, such as 'East African' to acknowledge their migratory histories.

This suggests that the categories for ethnic group offered were perhaps not as accurate or flexible as people would have preferred, even though 'place of birth' data was also requested on the form. This finding reflects the importance of the use of self-assigned ethnicity data in research (Bradby 2003). One participant raised this with me before the interview as she felt that the category 'Indian' was not an accurate reflection of the way in which she identified herself (having Indian 'heritage' but having migrated from East Africa to the UK as a young woman). I have chosen to present the data together in Table 5 in this chapter, so that these multiple identifiers can be seen in context with one another. However, in hindsight, this is something I could have pursued further in the interviews, had there been time, and this could have potentially given a more nuanced understanding of the ways in which people identify themselves according to ethnic, religious, national and regional categories (Aspinall 2001, Bradby 2003).

Summary

This chapter has considered a number of issues in relation to the research process, and has presented the reader with a description of how the data were collected and analysed. Further reflections on this process are included as a separate chapter towards the end of the thesis. In the next three chapters the data collected through these processes are presented. They are discussed chronologically according to how they were conducted; the focus group analysis in chapter five and the interview analysis in chapters six and seven.

Chapter Five: Public perceptions of infertility in South Asian communities- the moral context

Introduction

Infertility is perceived in many communities as a 'sensitive' topic, one which is highly personal, and at the same time, socially relevant. In addition, and significantly in the context of this thesis, the views that public groups have about infertility and its treatment will potentially have an impact upon childless couples. The implication that infertility is seen as a social problem means that childless couples will be perceived in a particular way and this chapter describes the ways in which this happened in this specific socio-cultural context. This chapter presents data from the 13 focus group discussions described in chapter four, which are also designed to give context to the data presented from the interview participants in the next two chapters.

The continuous presence of information and debate in the public domain around the use of ARTs, and in particular, their regulation means that there are few people who do not have some knowledge and perspective to offer on this topic. Indeed, the focus group participants entered into lively and complex debate about the social benefits and risks of using ARTs in order to overcome the crisis of infertility. However, what these group discussions illustrate is that the debates about infertility and solutions, such as those offered by ARTs, have entered into diverse social contexts in varied ways, and that a range of social identifiers such as gender, religion, age and socio-economic status have mediated this process. The majority of the group participants had no personal experience of involuntary childlessness.

However, many had heard stories, or had relatives who had experienced infertility and these narratives are presented here¹⁷.

This chapter presents the findings from the focus groups in three parts. Part one: *The significance of childbearing*, describes the way in which childbearing and parenting were seen as crucial in South Asian communities and how voluntary childlessness was therefore, by definition, not considered an option, especially for married couples. The absence of children was therefore considered to be highly problematic, and the participants' discussion of infertility as an issue for social concern, is presented in part two: *Infertility as a source of social anxiety*. Participants' perceptions of the use of ARTs are discussed in part three: *Public perceptions of ARTs*. This last part also discusses the ways in which lay narratives around ARTs were articulated within a discourse of social change and scientific progress, literally the desire (or not, in some examples) to 'move with the times'. As described in the previous chapter, the themes presented here represent clusters of thematic codes identified in the preliminary analysis. These clusters have been organised into broader categories of meaning for presentation here.

The significance of childbearing

Pro-natalism

The focus group discussions revealed strongly pro-natalist discourses. The importance of children was a strong theme in all the groups. Men and women, older and younger participants, and all of the faith groups saw parenthood as the natural and desired consequence of marriage, as children were seen as highly valued in South Asian cultures. As a result, a lack of

¹⁷ Quotations from the focus group participants are used throughout this chapter and the descriptive labels used describe the focus group constitution, rather than the individual participant. See Appendix Three for a detailed breakdown of the focus groups.

children is highly socially visible, and it was suggested in the focus groups that couples without children would be under considerable pressure from the wider community, their own families and friends, to explain the lack of children:

Everywhere you go, everyone is talking about it, say you had just got married and another woman was talking to you, the first question that she would ask would be 'when are you going to have a family?' She wouldn't have got over the honeymoon yet.

(FG1 younger Indian Hindu women)

Upon marriage, wanting to have a family was seen as a natural and normal progression of adulthood. Not only was this in terms of family and community expectations, but also in individual terms. It was felt that this was something that was intrinsic to humanity; the need to procreate:

I do not know of any couple who do not want any children. In our culture, every couple after marriage, as far as I know, wants kids in their life. Every one wants kids.

(FG13 Bangladeshi Muslim men)

The 'taken-for-granted' nature of marriage, as a precursor to childbearing, can also be seen in this comment. It was also mentioned that this need for childbearing was perhaps gendered. Women, it was felt, were much more likely than men to feel the need to have a child:

Women crave for motherhood. Men have less craving for having children.

(FG4 older Indian women)

This was felt, by a small number of younger women, to put unwelcome pressure on them before they were ready to consider their future marriage and childbearing plans:

I don't want to have kids. I do, but I feel that I've been put in that role already.

(FG1 younger Indian Hindu women)

The importance of children

In this context of pronatalism, which was discussed in all the groups, the participants made explicit the importance of children in the family, and the central role that they played in the wider kinship network. Children were important for sealing a marriage:

The man marries the woman to have children, that's the whole reason.

(FG1 younger Indian Hindu women)

This comment also shows how children were seen as important in the continuation of the 'clan' (as it was expressed by the men in focus group twelve); as well as for the benefits they would bring to their parents as they grew older. Having someone to care for them in their later years was seen as especially significant for the older focus group members. Children were also seen as important in terms of the religious rites that they might be called upon to administer for a dying parent. Perhaps most commonly, children were cited as a means to 'carry on the family name'. Significantly, when the discussions turned to the importance of children, mention was made of the specific importance of male children. Again some of the older focus group members felt that this was particularly important, since there were certain roles that could only be fulfilled by male offspring (such as some death rites):

There is a need of a girl a daughter, but everyone wants a son, there is a need of a son in every family, do you understand, everyone wants a son.

(FG2 older Bangladeshi Muslim women)

One reason for the need for a male child, discussed in several of the groups, was the fact that traditionally, on marriage, a girl will go to her husband's family and is no longer considered to be a member of her natal family. As is illustrated in the following quotation, a girl is considered to go to her 'new home', and is therefore considered to be a 'temporary' member of her natal family:

Having boys is a little different. I suppose it's like this ... girls get married and go to their new homes and boys look after their parents.

(FG7 older Indian Sikh women)

As a result, it was highlighted that women felt under some pressure from the family and wider community to have male children. It was described how the birth of a baby boy was a cause for celebration, whereas this was not the case when a couple had a baby girl. There was, however, some resistance to this idea in the focus groups. It was pointed out that this is a tradition that is changing:

I think things are changing though. Families are becoming smaller now.

(FG1 younger Indian Hindu women)

It was also spontaneously pointed out by several women that the benefits of having male children were sometimes oversold, and that daughters could be more actively involved in caring for elderly parents:

A lot of families are saying that their sons are not doing anything for their parents, only daughters are caring for them.

(FG7 older Indian Sikh women)

Although there was a consensus that male children were still seen as important amongst the wider community, this tradition appears to be changing, particularly amongst younger participants, who were keen to resist what they saw as traditional views and to highlight how many attitudes were changing in relation to childbearing.

Infertility as a source of social anxiety

As discussed above, children were seen as a highly important element in the conjugal relationship, not purely for the couple, but for the potential grandparents and other significant relatives. In addition, the absence of children in a marriage was a cause for social interest more widely, and the focus group participants discussed how there would be questioning of a couple who appeared not to be having children.

Social surveillance of married couples

The presence of children in a marriage confirmed to the outside world that all was 'as it should be' with a couple, and served to quell rumours and gossip that either a couple were 'not getting on' (i.e. they must not be having sex), or that they were having problems in conceiving:

It reflects on your relationship with your partner ... (laughter). So if you are having children, yeh that's OK, you're sleeping with your husband, everything is OK and your marital, you know, life is fine. I think it does reflect that.

(FG10 younger Pakistani and Indian women)

Speculation around when, and if, a newly married couple would start a family was perceived as a source of social concern and, in many examples, as a source of anxiety for other family members and for the wider community:

If we haven't popped out a baby within a year of marriage, that's it, there's something wrong with you, or you're not getting on with your husband (group laughter).

(FG10 younger Pakistani and Indian women)

At the talk of sex, laughter in both of these examples perhaps highlights the uncomfortably public nature of this aspect of married life. It was described in all of the focus groups that there would be some level of concern about a couple who did not have children. This was described as manifesting in questioning from others about their plans to have a child:

Oh yes, there's always talk 'aren't you gonna have a baby?' Giving hints, 'when will I become a grandparent?', if the in-laws are still alive kind of thing, but oh yes, there is always talk.

(FG5 younger Indian Sikh women)

Participants described how a lot of this 'talk' about childless couples may take place at family gatherings such as weddings, where it was common place for acquaintances to inquire whether a newly married couple were planning to have a child, and where a couple's childbearing, or lack of it, would be entirely visible. The following quotation illustrates how sometimes the talk

about a couple could become more hurtful, with a couple being made to feel different or deficient by what they are missing out on:

They say that in our community, don't they, how beautiful the bride is or groom is so handsome? Especially to people who haven't got any children – to hurt them, get them upset.

(FG5 younger Indian Sikh women)

This quotation draws on the significance of the ritual of marriage for parents, to highlight what a childless couple would be missing out on later in life. Whilst there was a lot of discussion about interest in whether a couple were planning a family, there was also simultaneously a recognition amongst all of the focus groups, younger and older, that there is increasingly a delay in childbearing, with younger couples now choosing to stay in education, follow a career or buy and decorate a house before planning to have a child:

It also depends on the couple, such as their careers, their jobs, what their prospects are, if both mother and father are working, then a child isn't really a suitable thing straight away.

(FG9 younger Indian Hindu men)

This blurred the boundaries between voluntary and involuntary childlessness, and was a means by which a childless couple could delay the questions and intrusions into their personal situation. However, it was pointed out that this was only ever a temporary situation, since eventually it would become obvious that there was some 'problem':

In the beginning it would be a secret, but after some years everyone would automatically see that she couldn't have children.

(FG1 younger Indian Hindu women)

Again, this young woman draws on the discourse of the 'visibility' of infertility, to highlight the problematic nature of an absence of children. There was very little discussion in any of the groups about the possibility of remaining childless voluntarily. Only two groups highlighted this, and only one young Pakistani female participant discussed this option as a choice that a couple or individual would make. In all other discussions it appeared to be taken for granted that a married couple would plan to have a family at some point:

A *They wouldn't think that she wouldn't want kids, because the natural thing is for women to want kids.*

Facilitator *So they would never consider that it might be a choice not to have a child?*

A *No, never.*

B *That would never enter into it.*

(FG1 younger Indian Hindu women)

The use of the word 'natural' here, in describing fertility decision-making is of note, further emphasising the ways in which motherhood was expressed as mandatory.

Gendered infertility

As already highlighted in many of the examples given above, the female partner would most often be the spouse who was questioned, and with whom the focus of attention would lie. The group discussions revealed the gendered nature of the anxiety around infertility, with many participants pointing out that it would always involve 'blaming' the female partner, or more specifically, presuming that there was something physically wrong with her:

It would be seen as the woman's problem by the community.

(FG2 older Bangladeshi Muslim women)

In the Asian community, they blame the women, they do not bother to understand whose problem it is.

(FG13 Bangladeshi Muslim men)

Several participants pointed out that most of the questioning of a woman about infertility would come from her in-laws, especially her mother-in-law, and sometimes her sisters-in-law. This illustrates how, not only are women blamed for infertility, but that the 'policing' of newly married women is also a gendered process, with other women most likely to be amongst those expressing concern at a lack of children within their family:

The mother-in-law would be nagging at the woman and saying 'why don't you have any children?'

(FG1 younger Indian Hindu women)

A woman's in-laws were therefore seen as central in the role of surveillance. One of the participants in a focus group with older Bangladeshi Muslim women suggested that, yes, she herself as a mother-in-law would be concerned about this:

Yes, if my daughter-in-law wasn't having a child I would think she's got a problem.

(FG2 older Bangladeshi Muslim women)

Again, there was some dispute as to whether this was still the case, and there were differences between groups and between individuals. One participant from another group of older women, this time Indian women, felt that this was something that would have happened in the past, but that was now not so prevalent:

In the old days there could have been a lot of quarrels in the household, the daughter-in-law would have faced a lot of hassle as well. She would be called names like 'barren'.

(FG4 older Indian Hindu women)

Despite the discussion of social change, infertility was perceived in the groups as being highly stigmatising, with many examples given of how childless women in particular could be socially stigmatised. These included gossip, taunts and in more extreme cases, social ostracism. Stigma was often articulated in terms of the exclusion of women from social events, and also in the treatment by members of the family and wider community:

First of all, if someone is getting married they do different cultural customs, such as to put oil on the head or put henna on the hands. They say 'she is infertile, do not let her go near the bride, do not let her put henna or oil on the bride, she is infertile'.

(FG6 older Pakistani Muslim women)

I heard that in our country, people tease someone without children by calling them atkura [a slang expression in a local Bangladeshi dialect]. For example, people will say, 'You are just an atkura, why are you talking?' People get deeply hurt by being called this, it is a swear word in Bangladesh.

(FG11 Bangladeshi Muslim men)

Examples such as the one above were more likely to be given by older participants when describing the context in South Asia or in the past. Younger participants were keen to point out that there was more understanding of infertility, and more support for couples now than in the past. As part of this increased understanding, there were interesting discussions in the focus groups about the status and role of men in a couple's childlessness. There was a significant amount of talk in the groups about the fact that it was now commonly known that men too can be 'at fault' when it comes to conception.

Therefore, despite the significant impact that the gendering of infertility clearly seems to have on women in this context, men did not completely escape the stigmatising effects of childlessness. If it were known that a man was experiencing problems with his fertility, there would be social consequences for him:

People do laugh at this kind of man and they will really put him down, then he loses all the respect in the society when he can't even produce a child; what kind of respect do you think he would have in the society?

(FG12 Indian Sikh men)

One of the younger male participants also contemplated the impact that this would have on the man:

It is like, it is literally like an insult to your manhood; like your manhood is in many cultures is taken as a measure of your ability to bear children so you would feel like, incomplete is the word.

(FG9 younger Indian Hindu men)

However, it was also reported that people would be less likely to apportion 'blame' to the male partner, perhaps being more sympathetic in this case:

Nobody says anything about that, people don't say much to the male.

(FG2 older Bangladeshi Muslim women)

Perhaps most significant to emerge from the discussions of male factor infertility was the fact that in most cases this would not come to light, and even where it was the male partner who was 'to blame', this would be concealed and the woman would instead take public responsibility for the lack of children. In the following two examples, this went as far as suggesting that the man would remarry in order to have children, even where it might be known or suspected that it was male factor infertility. The suggestion that it could be the male partner in some cases was unthinkable:

And I think, even if it's a man's doing, not able to conceive, it's always a woman's fault... It'll never be his fault, he could get married three times and still not have kids, they'll just expect that its her fault. There's something up with her, never with him.

(FG5 younger Indian Sikh women)

There's a gentleman I know who's been married three times, and each time he has not had any children, and each time he got married it was, his mother was always saying, 'oh lets try the next one'... And with each of the three wives, he hasn't actually got any children, so, a lot of the people are saying, 'oh there must be something wrong with him, it can't be the women'. So I mean, it does get attention, but like you say, not as much as the women do who are infertile or having problems conceiving.

(FG10 younger Pakistani and Indian women)

Remarriage

The examples above highlight the issue of remarriage. This was something that was raised in almost all of the groups, the possibility that a couple could get divorced, or more likely in some communities, that a man could take a second wife in order to have a child. Again, this option met with some resistance in the groups, especially from the younger participants who felt it was an outdated and morally dubious practice. Nevertheless, there were many anecdotes and examples in the groups of how this might happen, and the pressure that men might come under to either divorce their wives or to take a second wife in order to have a child. This was particularly the case in the Muslim groups, since polygamy is permitted in Islam, but was also mentioned in one of the groups with men of Sikh faith:

Sometimes it's like that, that if a girl, a woman doesn't have a child, then we tend to go for the second marriage.

(FG12 older Indian Sikh men)

A small number of participants felt that the woman also had a role to play in her husband finding a second wife; that she should give her permission for

him to remarry in order to have a child. The following comment shows how this is still considered to be the responsibility of the woman:

Some wives would say to her husband, ' I cannot give you any family, it is best you go and remarry'.

(FG8 younger Bangladeshi Muslim women)

However, some of the participants, the younger women especially, felt that this was an outdated practice, and one which was open to abuse by men:

A *In Muslim law, in the Qur'an, it says that a man is, in Islam it does say that a man is allowed four wives, and you know...*

B *They manipulate that.*

A *They do use that, they use that.*

(FG10 younger Pakistani and Indian women)

Remarriage was described as one way that has been used (within specific religious, historical and cultural contexts) in order to overcome childlessness. The focus group participants also discussed how they thought ARTs were perceived within South Asian communities, and the associated pros and cons of using such treatments, and is discussed in the next section.

Public perceptions of ARTs

Seeking treatment

Many focus group members commented that a young couple (as they were inevitably imagined) experiencing infertility, would 'know what to do' in relation to seeking medical help. There was little resistance to the idea that science or specifically biomedicine was a major source of information and treatment in the context of infertility, and many participants expressed the view that this was another area of health amenable to medical intervention. There was a vague recognition from many that this would involve going to

see a GP and perhaps would at least initially, involve diagnostic testing of one or both partners:

Nowadays the educated couples go for a medical check up and they know through that who is at fault.

(FG 4 older Indian Hindu women)

There was little divergence in terms of the groups' responses to this issue, even where 'alternatives' to medical treatment, such as remarriage were suggested. Some of the older groups were in fact more adamant that although they themselves didn't know what the procedure would be, the younger generation would have no hesitation in seeking medical assistance. This appears to suggest that there is a generational difference in lay knowledge about ARTs. However, there was also ambivalence for some individuals around whether people indeed did have information about where to go for help:

Even though they probably can get treatment and get it all sorted out, they don't realise that it's all out there for them

(FG1 younger Indian Hindu women)

There was also the suggestion that this was such a crucial and intrinsic need, that they would try anywhere or anybody who could help them in their quest for a child, whether this be medical or religious experts:

If they had problems, they would probably go to their parents, or to the religious leaders, or the doctors, they would go to every door, everywhere, and open out their hands, they would try anything. Just keeping it and looking up to Allah.

(FG2 older Bangladeshi Muslim women)

I think that they would do as much as they could until they had a child, because they would probably think that they hadn't done enough to have one.

(FG1 younger Indian Hindu women)

These comments draw strongly on discourses of pro-natalism and the *need* to have a child. Although there was some difference of opinion about who a couple would seek help from first, it was acknowledged that at some point in their journey they would seek medical guidance. It was also pointed out by a small number, that seeking help would almost inevitably be instigated by the female partner, presumably since, as we have seen, infertility was considered to be a 'woman's problem':

It would always be a woman's responsibility to go for a check up.

(FG4 older Indian Hindu women)

When discussing infertility treatment, the participants considered how technologies, such as IVF, were illustrative of the ways in which society is in a state of social change. Therefore, the meanings that people gave to ARTs were complex and highly socially contingent, and demonstrate the fluid and diverse ways in which the moral context of infertility can operate.

Understanding IVF

In vitro fertilisation, or 'test tube baby' as it was often referred to, was the most commonly mentioned technique when groups were asked if they had heard of any medical treatments for infertility. This was a familiar treatment for most, although there was a general lack of technical knowledge about how this treatment was carried out in practice or whether it was available via the NHS. There appeared to be little resistance to the use of IVF, and perhaps even a sense that this technology had been 'routinised'. When discussing growing community knowledge about medical treatments, many of the participants mentioned the role of the media (TV, film and newspapers) in

this process of bringing about social change. Despite its apparent acceptance, there was also a recognition that this was only a very recent development within science:

- A *My daughter's sister-in-law had two girls by the test tube method; nowadays that is available*
- B *It was not available in our time*
- C *You could still try! (Laughter)*

(FG4 older Indian Hindu women)

This last comment also appears to suggest the perception that, to some extent, science is able to bypass natural obstacles to pregnancy, such as older age (as these were a group of older women i.e. over 45). This reflects current public discourses around older mothers, in the light of highly publicised cases of older women using IVF to achieve pregnancy.

The public recognition, and apparent naturalisation of IVF, may be related to its common use within marriage, that is, that it does not ordinarily require a couple to 'transgress' the conjugal relationship by the use of donated gametes:

- A *Is it the actual sperm and the egg, and they actually fertilise it don't they?*

Facilitator: *Yeah, that's right*

- B *They put it back in, yeah... so it is the man's baby?*

(FG3 younger Indian women)

This comment reflects the general unease associated with the possibility of donor material being used in IVF. There appeared to be a more complex understanding of treatment that involves gamete donation, which will be discussed later.

Younger participants, especially those from Hindu and Sikh faiths, were more likely to discuss ARTs in terms of social and scientific progress. That is not to

say that there was not anxiety in these groups about forms of assisted conception, but that these participants were more likely to articulate a discourse of progress, and of faith in scientific technologies. The discussion of reproductive technologies was used to mobilise a discourse of social change, and to express a readiness to engage with what were perceived as modern or 'high-tech' practices; literally a desire to 'move with the times'. Partly, it appears, this was in an attempt to challenge what they saw as the traditional thinking of older family and community members. As this young, male, Indian participant suggests:

Its like the viewpoint that you have as well. We'll look at everything very scientifically, whereas they'll look at it from their life experiences and the way they were brought up...more culturally, more religiously, so say like the cloning of sheep, they might think of it as interfering with nature and messing with God, whereas we just think, 'wow that's amazing being able to clone something, what's gonna happen next?'

(FG 9 younger Indian Hindu men)

And, as this Indian woman suggests when talking about the technology used in the Diane Blood case (where she won the right to use her deceased husband's sperm):

It's amazing what science can do: a dead man's sperm, keeping a dead man's sperm alive, so she could have his children.

(FG5 younger Indian Sikh women)

Lay narratives around ARTs were therefore articulated within a discourse of social change and scientific progress. These were discussed in relation to the changing nature of South Asian communities and were strongly linked to wider processes of social change, in particular, what people saw as the 'intellectualisation' and 'westernisation' of South Asian communities:

... people are turning more westernised now. We're brought up here, we think westernised, whereas our families don't think like that because they were

brought up in Asia and in other countries, so there's a lack of communication over there, where over here we speak, we ask more questions, we find out more, we're aware of more things nowadays than before.

(FG 3 younger Indian women)

Other participants also discussed the role that education had to play in the increase in understanding about infertility:

At one time we could not even talk about the subject. Everyone had to obey the elderly of the family, so they suffered. Also the ignorance and the lack of knowledge were also responsible for the suffering. Education has made people aware of things.

(FG4 older Indian Hindu women)

It also depends very much on how educated you are, cos pretty much now we're all educated ... but back in South Asia, where a lot of people are illiterate, they can't read or write, then they don't understand it as far as we do.

(FG9 younger Indian Hindu men)

In some cases, this was expressed as a 'relief from suffering', especially for women who have traditionally carried the burden of infertility:

We have come forward now to accept treatment and do not let wives suffer now.

(FG4 older Indian Hindu women)

For some of the older groups, this was expressed as a sense of resignation and resistance, and a need to maintain a faith in religion over scientific solutions to infertility. This was particularly the case amongst the older Muslim participants:

Now they trust in science, this era belongs to science. We do not talk about this scientific time, we trust in Allah, we expect from him and he is the one who gives and who keeps giving you understanding.

(FG6 older Pakistani Muslim women)

One young male participant summarises the findings from the groups when he suggests that:

Well at the end of the day there are going to be risks and rewards whether it be IVF, adoption, surrogacy,, there are going to be risks, and rewards as well.

(FG9 younger Indian Hindu men)

The role of religion

The religious identities of the participants were central in understanding the ways in which social location shaped understandings of ARTs. This was significant for specific groups and was further highlighted in terms of the age of the participants. For example, religious discourse was much more likely to be present in the groups with older participants (i.e. those over 60 years):

But it's not in your control. It's all in God's hands and you should just accept it.

(FG7 older Indian Sikh women)

In addition, all participants who identified themselves as Muslim were more likely to discuss the relationship between understandings of science and ARTs, and religion. These groups were more likely to express the view that conception is only possible with God's intervention, regardless of the use of any treatment:

Everyone says 'if God hasn't given to them pray to Allah and be patient', then God will give, and that is it... they would not say anything else.

(FG8 younger Bangladeshi Muslim women)

There was a complex interaction between what people perceived as the role of medical treatment and the role of religion in achieving pregnancy. There was a clear view that both were implicated, especially for the older focus group members and the Muslim participants. However, there was ambivalence around how this would operate:

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

(FG 2 Bangladeshi Muslim women)

Religion may be particularly important in times of moral anxiety and uncertainty, such as the crisis of infertility. This may also be the case when people are uncertain in discussing topics which may be considered to be 'publicly' sensitive. In this way, religion was also central to a number of the discussions in which participants specifically considered the option of gamete donation.

Conception by donor: involving a third party

The use of treatments which may involve a third party donor elicited anxiety and suspicion in the discussions. This led people to suggest that the use of fertility treatment (even where it may be treatment using a couple's own gametes), would be concealed. There would be gossip about a couple who used ARTs, which was indicative of a fear that the resulting child may not be biologically related to either or both of its parents:

We would probably talk behind them, say that it is not theirs, or his child, its from a treatment.

(FG 8 younger Bangladeshi Muslim female)

These discussions related to a mistrust in fertility treatment, that the resulting child is not 'authentic', that they are not 'of their parents'. It was reported that there was speculation around this issue, if it were known, that a couple were having fertility treatment:

I know somebody who had that [IVF] and my mother-in-law was saying 'well, is he the father, is it his, is it his?' ... after she became pregnant she kept saying 'oh, is it his baby, you know, how does it all work?'

(FG 3 younger Indian women)

This was the main concern amongst the participants in their response to the medical treatment of infertility. Treatment *per se* was acceptable, but not if it transgressed biological and conjugal boundaries. Almost unanimously, the focus group participants felt that using donated gametes would not be socially, culturally, and in many cases religiously acceptable. People reported having knowledge of the availability of treatment using donated eggs and sperm, but felt that this option was not likely to be readily used by South Asian couples. For some, there was a recognition that donated gametes *are* used in overcoming infertility, but that this would almost certainly not be revealed to the wider family or community:

I think even if it did go ahead, it wouldn't be like announced, or it wouldn't be said.

(FG 3 younger Indian women)

Test-tube is not considered as a bad thing. Egg or sperm donation is not accepted. Even for test-tube baby, if they know that someone else has donated the sperm, then people don't normally like it, but often the couples don't tell others about it.

(FG7 older Indian Sikh women)

This concern about disclosure was perhaps related to the finding that there may be social consequences for a couple of whom it was known had used this treatment, and potentially for a child who was conceived in this way:

If someone finds out about this nobody will marry that child, because this child is not his/her father's, the Nikah (Islamic marriage contract) is not proved so nobody will propose to that child when it grows older.

(FG6 older Pakistani Muslim women)

This was particularly problematic for the Muslim participants, since in Islam a child has a right to know his or her father, and this was seen to have particular social consequences for the child in later life. However, this was not to say that egg donation was permitted; receiving gametes from either an egg donor or a sperm donation was considered to be *haram* or forbidden:

That's not allowed. If Allah doesn't give it, then why should we do it?

(FG2 older Bangladeshi Muslim women)

It is the same if the man gives the woman the sperm, or if the woman gives the egg, it's not allowed, it's not in the religion. Why is there a marriage? The community would not allow this at all.... It doesn't matter if it's a man or a woman, it's not allowed.

(FG2 older Bangladeshi Muslim women)

Any intrusion into the conjugal relationship in the process of conception, either with donor sperm or donor eggs, was seen as contentious for the Muslim participants. This was tied to the fact that for a number of participants, both male and female, sperm donation was equivalent to adultery and as such was perceived as highly morally dubious:

I find it disgusting when a wife has to use some one else's sperm; it is like making love with another man.

(FG13 Bangladeshi Muslim men)

This view was not specific to the Muslim participants, however; a small number of the female participants in other groups also expressed this view in religious terms:

I'm quite a, personally, I would be ashamed to do this, because I can't face my God then, its like I'm cheating, you know, I just can't, I wouldn't, uugh, no way (laughter) ... it wouldn't be my husband's child, and I feel horrible, even my stomach feels horrible to think having someone's [sperm]

(FG5 younger Indian Sikh women)

Adultery was even more of a cause for anxiety when the groups discussed the possibility of having a donor from within the family. It was reported that because of the fact that a woman joins her husband's family on marriage, her brother-in-law was considered to be her own brother, and as such, having him as a sperm donor was considered to be highly complex and potentially disruptive.

Finally, where it was considered that a couple may use donor gametes, the importance of finding the 'correct' donor was also thought to be of great significance when choosing the ethnicity or religion of that person:

God knows whom the egg belongs to, whether it is a Sikh's or white persons'. The lady who would use this method would not be in peace with herself.

(FG6 older Indian Sikh women)

Meaning-making around ARTs, as represented by participants in this study, appears to be in a state of transition. Social change within South Asian communities was central to many discussions, with (especially younger) participants expressing the view that there is a move towards acceptance of

ARTs. However, as pointed out by a young Pakistani Muslim woman in focus group ten, this situation as she saw it may be slow to change whilst there are more 'traditional' views present amongst the powerful older generation.

Summary

This chapter has presented the data from the thirteen focus group discussions. A great deal of consensus was articulated in these groups about the ways in which childless couples are perceived. Strong discourses of pronatalism mean that childlessness is highly problematic, and participants in all of the groups commented that couples would be under pressure to prove their fertility within marriage. However, what is also clear from these discussions is that South Asian communities appear to be in a state of transition, with more fluidity and ambivalence present in the accounts of younger participants. This was most apparent in the comments about ARTs. In many discussions, social signifiers other than ethnic identity were significant. In particular, age, gender and religion play important roles in the ways people construct their perceptions of new technologies. This was especially the case when participants discussed tradition, religion and ideas about social progress, with generational differences becoming pronounced in these exchanges.

Following Marcia Inhorn (2006), I have referred here to this arena as the 'moral context', in order to suggest that it is in some way a representation of collective perceptions, norms and values that may be held within a 'community'. However, it is important to highlight the problematic notion of the concept of community, particularly in relation to the identification of a bounded and stable set of views of any given phenomenon (Alleyne 2002). The responses given in the focus groups were specific to this set of participants, at a particular point in time, and it would therefore be mistaken

to view them as an essential 'South Asian' standpoint on this topic. Furthermore, the public setting of the focus groups may also have inhibited some responses, whilst simultaneously eliciting other, more publicly acceptable comments from the participants. For example, it is difficult to know whether the view expressed in a number of groups that IVF using a couple's own gametes was socially acceptable, was indeed always so clear cut. In the individual interviews, a number of infertile women felt reluctant to disclose the use of IVF within the community which might suggest that technologies such as IVF are less readily accepted within South Asian communities than was expressed in the focus groups. The diverse, fluid and changing perceptions, suggested by the focus group data, means that the moral context with which couples may be faced, may be unstable and therefore difficult for couples to assess. This will be discussed further in chapter eight.

Data collected about the 'moral context' in which infertile lives are lived out, was also collected within the individual interviews, in order to explore how infertile women themselves felt that they were perceived by members of the community and kinship networks¹⁸. The next chapter discusses the ways in which the individual interview participants negotiated this context and how their childlessness affected their relations with others.

¹⁸ It is important to highlight that the focus group participants were not necessarily the family and community members of the individuals who took part in the interviews. There is therefore no direct or tangible relationship between the experiences of the two samples in the study. Instead, the two data sets should be seen as indicative of the views of these two groups, rather than (as with other forms of qualitative data) being a definitive viewpoint on these issues.

Chapter Six: Experiencing infertility

Introduction

This is the first of two chapters which present the in-depth interview data. It describes the experience of being infertile, as it was represented by the participants, and is divided into two parts: *'Disrupted Biographies'* and *'Negotiating the moral context'*. The first part discusses the expectations and hopes that the respondents held in relation to conception and parenthood, and how these are disrupted by the process of becoming an infertile person. Part two focuses on the complex, socially-situated and often marginal experience of being childless and the meanings that this has for South Asian couples' lives. The subsequent and final data chapter discusses the participants' journeys through the treatment process and describes their stories of disappointment and achievement in seeking resolution to their problem.

The chapters present data from the interview in a broadly chronological order, according to the typical narration of events. However, it is important to recognise that infertility and assisted conception are not experienced in an uncomplicated, linear fashion, but that this is a life crisis characterised by disorder, chaos and distress. As such, any re-ordering of events is a necessary tool of mediation, used both by the participants and the author in their re-telling of these infertility stories. Pseudonyms are used throughout these chapters to ensure anonymity.

At the time of interview, all of the participants had sought medical advice about their inability to conceive. Nine out of the fifteen participants had

children at the time of interview (which includes the couple)¹⁹. Therefore, in many cases the narratives are a retrospective account of experiences which happened some time in the past.

Disrupted Biographies

Child desire and the importance of parenthood

Participants expressed a strong desire when discussing the need to conceive and experience parenthood. This desire was tied to socio-cultural expectations surrounding adult conjugal relationships, but was equally expressed as an innate longing that could not be ignored. In the process of describing their fertility stories, the participants explained how the desire for a child was often overwhelming and had been (and for some, still was) all encompassing:

But I didn't think through at all. I just wanted this treatment and I just wanted this baby. I didn't care where the money came from, I didn't care what my husband was going through. You know. All I was obsessed was, was baby. And how I'm gonna get this baby.

(Aisha)

The imagining of a future that did not include children was painful, and the women described how their hopes for pregnancy and motherhood were tied into their future life plans. For both Anjali and Samina the need for a child was related to the need to create a 'normal' marriage and a 'normal' family structure:

...that's like, you know, the whole point, see, my idea of getting married and having a house, and having all the wonderful things in life is, erm a child just finishes it off and you do it for that child.

(Anjali)

¹⁹ As discussed in Chapter Four, this was due to the fact that some interviewees had now completed their infertility journey and some were seeking treatment in order to have further children. See Appendix Eleven for 'pen portraits' of the participants.

...I think that's why people want children and they can have their lives happily, so, that's why I want, I say, no we want, we want baby now, we need baby in this house, then, then we can forget about everything, we can live our life happily.

(Samina)

Later, Samina also describes how she sees being childless as having an impact on her very existence and describes the need for normality in her life, which she sees a child as bringing:

This is not life, you know, how, how many years I can live like this? Not all my life, if it's, I want to live a normal life, like, okay, having baby, okay, look after them, that's it.

(Samina)

Not yet having achieved a pregnancy, and living with the longing for a family, meant that the participants often described their experiences in vividly emotional ways. However, for Nadia, the impact of child desire on her life was not purely emotional, but had very practical implications. She described how her work was an important distraction for her from constantly thinking about the need to be pregnant. She also described how everyday activities, such as going shopping, could cause her distress:

...when you go shopping, right, you see the little kiddies' clothes, right, I'm not kidding, look at that cute thing and things like that, I do, honestly, I used to buy stuff, I did, honestly, it was mad. I used to buy stuff, and I thought what for?

(Nadia)

In describing their desire for a child, a small number of women mentioned that success in starting a family had been somewhat of an expectation. The idea that she would not be able to conceive had not occurred to Safiya:

I took it for granted it was gonna happen. Didn't, didn't even occur to me that I couldn't have kids, ever. You know.

(Safiya)

Disruption to the expected process of achieving pregnancy resulted in a change to the participants' perceptions of natural conception (which will be discussed in more detail later in this chapter), and led them to question the idea that conception and pregnancy were easily achievable goals. For the women in this study, there was a view that they should be able to control their fertility, and indeed that that was what other 'normal' women were able to do. They expressed frustration at friends and family members who, it was perceived, were able to control their fertility and achieve pregnancy when the time was right for them.

...his cousin... they were saying, oh well, it's the right time, I thought it's maybe the right time for you but not everybody can say oh, I can have my baby today.

(Safiya)

Several participants explicitly referred to the importance of motherhood when discussing the need for a child. Although it was acknowledged that involuntary childlessness was a difficult experience for both partners, ultimately, this was seen as a gendered phenomenon, which was more problematic for the female. Childbearing and parenthood were perceived by many of the women as being essential to womanhood:

I'm like, my only purpose in my life is just, you know, be a mother and that's it.

(Samina)

There's a need there, and there's a, how empty it feels not to have that....And being a mother now, you know, it, it is everything to me, it's the whole world to me.

(Safiya)

In addition, for a woman, childlessness was considered as negatively impacting on her status within the family and community, particularly given

the social pressure on women to bear children in South Asian communities. Motherhood gives women a role within wider social networks, which can only be entered into once fertility has been proven. This point is reflected on by Samina, when she discusses the time when she discovered a problem with her fertility, and the impact that this had on her family members:

the ovary was twisted and they had to remove the ovary as well so they said oh, I, because the cyst was very big so they had to remove it ... my whole family was crying, all, because she said after that day was very less chance for having a baby

(Samina)

Safiya also discusses the impact that eventually achieving motherhood has had on her relationships and acceptance within the family and wider community:

Before I was the bad girl that couldn't get involved in any of the conversations... 'cause they all had kids, they all did kid things and I didn't, I was not a part of that, I am the career girl. Now I'm part of it and they ask advice and they, you know, and I can get involved a little bit more so I'm kind of like more accepted.

(Safiya)

However, the stigma of the once, infertile-self was not entirely or easily erased once motherhood had been achieved, a point to which the discussion will return later in this chapter.

'Social' parenthood and adoption

For all participants, the importance and centrality of parenthood to adult identity was paramount. Achieving biological parenthood is seen to fulfil personal goals as well as allowing couples, and specifically women, to enter into the nexus of ordinary adult roles and relationships. The disruption that

infertility brings to expectations about reproduction, therefore meant that for some participants consideration of alternative ways to become a parent were necessary. Having a parenting role, even if this wasn't a relationship with genetic offspring, or even to have a child living within the household, was regarded as important and several women mentioned the significance of such social parenting. To a certain degree for participants, social parenting carried with it a validation of one's skills as a parent and worth as a person. As such, a small number of women drew on this experience in the course of the interview to demonstrate their caring and mothering capabilities. Aisha and Nadia mentioned having adopted children overseas in South Asia, to whose education and upbringing they contributed financially:

And what I did, I adopted a child in India, sort of I pay for his er education and all that and from a poor family so that's my other baby, obviously he can't, he doesn't live with me but I support him, that way. And, I'm in the process to adopt another baby girl in Tanzania.

(Aisha)

Several women mentioned the fact that they had very special relationships with nieces and nephews, and that these children were often closer to them than they were to their own parents. For Rita, this had been a very positive experience which had helped her emotionally:

I used to change the nappies as if they were my own. But, they were very, all of them, were very close, they didn't want to go back home. If I used to look after them, if I got them home, they never wanted to go back home. They were very, very close to me... so I felt good as well, you know, and relaxed. Yeah, that was good.

(Rita)

For Charanjit, who had experienced the menopause prematurely at the age of 35, the experience of caring for her nieces as babies had given her some

insight into being a mother and, she felt, had gone a small way to helping her cope with having never achieved biological parenthood:

And plus, that's another thing that helped me a little bit, maybe, is when they were babies, I looked after them, so I've got to see that aspect.

(Charanjit)

Aisha's experience was unique, in that she had been called upon early in her married life to informally foster a close family member whose own mother had died when she was a small child. Aisha had gone on to experience twelve years of medically defined infertility, although socially, she has been a parent for the past nineteen years. Reflecting on her experiences as a social parent, alongside her knowledge of delayed natural childbearing and parenting, she said:

and now, looking back, I'm thinking that things happen for a reason. Obviously, I couldn't have a baby but I had to look after this little person who needed a mum. If, I had a, I mean, if I went through a normal pregnancy and all that, I don't know. I couldn't have been a better mum to her. You know?

(Aisha)

Despite the foregrounding in the interviews of informal and often familial, social parenting roles, formal adoption or fostering was consistently considered as a second best option to genetic parenthood. However most of the participants reported having considered it at some point. One or two women told how they would definitely consider adding to their families by adopting a child, but that this idea met with resistance from their partners:

it's something (husband's) just not interested in and can't make him be interested. I wouldn't, I wouldn't expect him to change his opinion on that, but it's something I would do, just like that. If tomorrow somebody gave me, say, yeah, I'd take that child and baby, oh, I don't care, you know, I would take that child, I would be its mum.

(Safiya)

Yeah. He doesn't want to adopt. Full stop.

(Nadia)

Official adoption was considered as an option by some of the participants, particularly the adoption of a child from overseas from what were considered to be poor countries. However, thinking about the implications of adopting a child from outside the family brought with it dilemmas about how that child would be received by relatives, what the social impact would be on the couple, and also, as Aisha mentions, what the origins of that child would be:

Another thing is that adopting a baby from, you know, it's a very big, big issue in our culture, it is. It's okay, you can adopt a baby from a family, that's all right. But you can't bring another child from, you know, somewhere else, you don't know, you know, these people. You don't know, you don't know nothing about that. It's, it's so complicated. You know.

(Aisha)

But I think with us, you see, it's more our, you know, culture, our families and you know, we're afraid more of that, than just us. What they would feel... You know, so I think if, so I think people, I think the adoption would be the thing that would really not sort of fit.

(Ramesh)

A distinction was made between official routes of adoption (through social services or from overseas countries) and informal, unofficial adoption, which may take place within families. This form of adoption is akin to non-genetic surrogacy, with a childless woman's sister-in-law relinquishing children to her. In this way, patrilineage is maintained, since a South Asian woman is considered to join her husband's family on marriage. Therefore the connection to the male line is maintained through the brother relationship in processes of informal, familial adoption.

Aisha was the only participant who described having any personal experience of this phenomenon, as her mother-in-law had arranged for her to adopt her brother-in-law's child without her knowledge:

And then, what happened in between, she, obviously, my brother-in-law then they had, they were having, my sister-in-law, they were having babies so she sort of arranged from behalf of us for my brother-in-law to sort of, so that we can adopt a, you know, their child and we didn't know anything.

(Aisha)

This caused a breakdown in family relations, as this was not a solution that Aisha and her husband desired or instigated. Sita also described frustration at the interference and suggestions of friends and family to adopt a child when, for her, this was very much a last resort:

I had friends saying to me, well, some people aren't meant to have children, you just gotta accept it, it was very, erm I was getting options thrown at me that I didn't want. I had friends saying, 'Oh well, have you considered adoption?' And, I think, for me, adoption was the last stage.

(Sita)

For many participants, the importance of the physical experience of pregnancy and the biological relationship to a child may account for their reluctance to consider adoption, at least until all options for achieving pregnancy had been exhausted.

The importance of pregnancy

The centrality of pregnancy to becoming a mother, and the longing for the embodied experience of childbearing, was clearly expressed by the participants. The desire for the experience of pregnancy was clear in the accounts, and the women also described the pain and anguish that accompanies everyday contact with other women's pregnant bodies.

Pregnancy, as the physical and symbolic image of motherhood and fertility, was something that the women were keen to experience personally, as Safiya explains in this quotation:

...it's the whole idea of being pregnant as well, you know, I wanted to be pregnant, I really wanted to feel what other women felt, I wanted to be big, you know, [laughs] I wanted to be sick, I wanted all of that, yeah.

(Safiya)

The idea of morning sickness and a large 'bump', side-effects of pregnancy which may once have been not so desirable to Safiya, became truly miraculous when this was finally achieved. These were experiences considered to be something that men could not appreciate or be a part of, due to the disembodied nature of fatherhood. The disconnection of a man's role in child-bearing is compounded in infertility treatment (especially IVF), which is highlighted in Anjali's quotation, and which further demonstrates why women are considered to have more at stake in achieving pregnancy:

We just feel more because we wanna be pregnant, we wanna have that baby. They're not pregnant, they don't get pregnant, they won't have the feelings [laughter] or anything like that... We go through everything, they have one thing they have to do in a pot and that's it, you know, end of! [Laughter].

(Anjali)

The feelings about pregnancy, and significance given to the physical experience of it, were clear in the interviews. This was also the case when the discussion turned to egg donation, which was a treatment option which had been considered, or was currently being pursued by Charanjit, Nadia, Gita and Ramesh, and Samina. The importance of pregnancy for women (and their partners), using eggs donated by another woman, was apparent, and this particular issue will be discussed in the next chapter.

Other women's pregnancies

Considerable emphasis was placed on how other people's pregnancies impacted on the participants' day-to-day coping with infertility. Since pregnancy was such an important and visible part of reproductive success, other women's pregnancies, and the birth of new babies within the family, were difficult. Not being able to get pregnant was made all the more difficult by the fact that everyone else seemed to be pregnant:

And my sister, when I was having the first miscarriage, my sister-in-law was having a baby then. And that was really, really, that really got to me and now, even I'm thinking, God, I hope this happens [pregnancy], cos my sister-in-law, my brother's wife, older brother's wife, she's pregnant...everybody around you, you, is pregnant, my sister's, my brother-in-law, his wife's pregnant, my sister's sister-in-law, she's pregnant...

(Asma)

...the family were, from his side, they were having babies, my sister-in-law and that, and my sisters, they started having babies and wherever I went, all I could see was babies everywhere. And, and I think I did, I did find it very, very difficult, obviously, I got depressed.

(Aisha)

For the women, pregnancy was a visible signifier of what they were unable to achieve. Being faced with pregnant women in the hospital, whilst attending for IVF scan appointments in the maternity ward, was traumatic for Rita:

I can remember one time that I used to be, they did the scans in the maternity ward, and we were sitting there, and there were other babies coming in and out like, I thought, you know, from the labour ward and I sat there and I thought, you know, this baby's never gonna come...and I came out and I saw this baby go by and I burst out and I thought, you know, that's it.

(Rita)

For the following participants, it wasn't just the fact that other women could get pregnant, but it was their perceived attitude to childbearing that the

women found difficult. The ease, and for some, the irresponsibility with which it appeared that some women approach pregnancy, was a concern for the participants. Discourses of irresponsible and undeserving mothers were drawn on in these instances, for example, the 'over producer' and the 'teenage mum':

...It's really hard, you know, when people don't even want the baby and it happens to them and that's really hard, hard for me and it, and then you see lots of people oh have got so many children, they can't even cope with them and they still got, they're still conceiving, that really triggers me off, it does.

(Asma)

But it's just that, you know what I don't understand, right, how, you get all these young girls, right, with so many babies and that, right, and there's people who really, really want a baby, they can't have it.

(Nadia)

As well as those women who had unwanted pregnancies and chose to terminate:

You know, if it's meant to happen, why does it not happen to you, why does it happen to like, women who don't want kids and then have them aborted?

(Jasmin)

The lack of pregnancy was particularly marked around family occasions, such as the birth of a new baby. This event often brought home the difference between a woman and her relatives, in what was often a female-dominated celebration:

But it is, like, when you see their children, right, and you think, 'Oh God', you know, 'I'm the only one who's not, who hasn't got any'.

(Nadia)

The experience was a painful one, in which Jasmin felt she could not, and did not want to participate:

I'm thinking, you don't know what I'm going through, you know, it's a whole, like pain of it all and you're thinking, 'you don't know what it's like', you know, for them to take me, to some- to meet somebody who's had a baby and it's like oh my god, you know? You know, what do I do, so I just like grit my teeth and bear.

(Jasmin)

Two of the participants also mentioned that culturally, the birth of a new baby singled them out as deviant in their lack of children. Where this experience was reported, it was often accompanied with negative feelings, which left the women feeling isolated and stigmatised:

...when somebody's expecting or something like that, and they, they would not sort of come towards you, they think you might be jinx on them...I just keep my distance, but like when somebody's pregnant or something like that, it's, if somebody has a baby or something like that, if they invite me, then I'll go, if not, I'll not go, I, no, honestly, I'll not go, if I don't get an invitation, I would not go. And, there's some people, right, who won't even let you hold the baby!

(Nadia)

...you know, like, if it's a baby's, sort of what you call christening, if this lady, somebody didn't have a baby, she's not involved in these kind of things, it's, it's, you know, all those issues and maybe that's why you don't, I didn't realise, you know, but I did isolate myself. And just being around the babies was most difficult thing for me... the hardest thing ever.

(Aisha)

The distress that new births held for women appears to be in conflict with the fact (as discussed earlier) that it was often these very nieces and nephews who later provided opportunities for social parenting roles; roles which were represented as important for a woman's feelings of self-worth and in her capacity as a non-mother. These experiences demonstrate that involuntary

childlessness is an ambivalent state psychologically, socially and culturally. Socially important occasions, such as the as the birth of a new baby, were times at which the participants' marginal status was heightened. In many cases, the women, despite being in emotional distress, were in fact very happy for the new mother.

Life-course disruption

Perhaps most significantly, the pregnancies and birth events of female relatives acted as a temporal marker which served to remind women of the biographical disruption that infertility presents. For childless women, seeing others enter and pass through such events was difficult. A number of participants mentioned that the pregnancies of younger relatives, such as younger sisters or nieces, were particularly problematic, since they were a real reminder that their 'turn' had passed:

And then, when they've had the babies, they still have go to see the baby and all that, well, 'it's your turn now', you know, to have the baby, but you know, in the back of your mind you think you know, I know it's our turn, but I would have had it a long time back, if we, if it was our choice, you know, but there's nothing you can do about it, but we couldn't tell them.

(Rita)

For others, the disruption that infertility brought to their careers was also an issue. Notwithstanding the day-to-day disruption that infertility treatment brings (which will be discussed in the next chapter), not being able to plan in advance, or to know whether childbearing would be an option for the future, was stressful. Padma felt that she had not been able to progress in her career because of all the disruption to her work caused by having treatments. She also hadn't been able to make decisions related to her future career choices because of the continuing uncertainty.

The feeling that one's life became focused solely on the need to have a child and was, in effect, placed on hold, was a commonly expressed one:

It was all, my whole life revolved around that, just that one thing. I don't know, I don't know, thinking back, I didn't have any other life, you know
(Aisha)

Samina expresses this in terms of the passing calendar years:

...every year I think maybe this year I will be pregnant. In two thousand six when this start, I say, oh, this, I will be pregnant and now it's going, [laughs] this, two thousand seven is coming!

(Samina)

Narinder, also mentioned the issue of how the length of time she had been trying to complete her family had been disruptive, and did not fit in with the plans that she had imagined for herself:

oh I think, oh it never happens, you know, ... I also look at the time factor as well, that I've been trying for nearly nine years now and (child)'s just turned five and that could have been my second child and I could have been over and done with, you know, by the time I was thirty and I'm thirty five now this year and think, at thirty, my family would have been complete and, you know, so would have got on with it, really, with life and so held us back.

(Narinder)

This was not just an issue for the women. Ramesh, as the one male participant, also commented that he and his wife needed to try to complete their family before time ran out:

I mean, we will try, yeah, exactly so we thought, you know, 'cause time is ticking on as well, you know, for us and, you know, so, before it's too late really. Before for, it's, at least we can say we've tried but mm, yeah.

(Ramesh)

These findings begin to demonstrate the ways in which the status of being an involuntarily childless person represents a divergence from normative

biographical events, and represents a state in which life is 'on hold'. There were other ways in which infertility disrupted normative life expectations for the participants; the perception that they were in control of their lives was also displaced by this experience.

Lack of control

The participants described the way in which being infertile gave them a sense of helplessness, as this meant that they were no longer in control of their bodies or their biological destinies:

It's not as, you know, it's, it's, it's not my choice, not having children, you know, I'm lumbered with it 'cause I can't have it.

(Nadia)

...not being in control as well, you know, it does feel like that. With being able to achieve all the goals we set for ourselves and not, not being able to do this.

(Narinder)

For Safiya, who had suffered from endometriosis for many years, the issue of having control over her own fertility, and therefore having control of her life, was central to her story. The fact that she felt precariously balanced between being healthy and needing medical intervention was a difficult issue that she was acutely aware of. So, although she had achieved success, in that she had had one child through IVF treatment, her condition meant that her erratic menstrual cycle continued to control her fertility identity:

I'm in control of my life, the things that I can deal with, the day to day things, that, my work, my daughter, what we eat, those kind of things. But I'm not in control of my body and what happens there, still. And I'm, I know that at any point, somebody could say, right, you need to come in and have an operation now. Or you need to have this and then, and I'd be out of control, I'll lose that. But, my periods are so bad at the moment, they control me. So everything works round just, to everything that I do.

(Safiya)

A lack of control over her fertility led Jasmin to feel 'useless' and 'disabled':

I felt a bit useless like in a way, why does it happen to me, you know, I must be, there must be something wrong with me, I did feel like, oh there's something wrong with me, I did feel like a bit of a like, not like, I felt like, not like disabled in a way, I felt, God, you know, it's beyond my control now, you know.

(Jasmin)

Charanjit's story was one of loss, in which she had experienced the menopause prematurely, before she had the chance to get married, or to even try to conceive a child. She felt that any hope she had for childbearing had been taken away by something (premature ovarian failure) out of her control:

You know I had a lot of, I had a lot of hope in my life. But no, I'm gonna do it, or whatever, but something out of my control wrecked me.

(Charanjit)

Having the chance for controlling her own fertility taken away was deeply traumatic for Charanjit. The idea that she had lost something that others take for granted was apparent:

And that is the deepest loss that I've felt, that I can never have that sort of bond. I mean, don't get me wrong, people are bonded in [laughs] and don't care about people and their mother or whatever, but the thing is they have that thing, connection, still.

(Charanjit)

The loss of a connection with a child, which could never be replaced or treated, was something that Charanjit had to deal with for the rest of her life. Losing control of one's own fertility lead to a questioning of the whole process of natural conception, and to the idea that anyone could achieve the status of mother through nature alone. As in the earlier discussion about other women's pregnancies, the perception that anyone could make an active

decision to enter into the process of childbearing was amazing to both Narinder and Jasmin:

I just think, how do people normally get pregnant, how do they do it? ...It's a miracle. It really amazes me.

(Narinder)

You do, you do feel like oh God, you know, it's the most natural thing that can happen to you and you know, it's amazing what, how it happens and like, the baby inside you and you're thinking, why does it not happen? ... You know, it does, it makes you feel a bit like, mm, you know, there must be something definitely wrong with me, but, then over the, and like, over the past few months, maybe I felt, well, it's not, it's not the most natural thing that could happen to everybody, you know, it's not, it's not natural for everybody as it is, and it's not as easy for everyone.

(Jasmin)

This process of becoming an infertile person led Jasmin to question whether it was even realistic to consider that there was such a thing as natural conception, since it was so difficult for some people to achieve.

The above comments demonstrate how the participants presented themselves as existing outside of normal processes of decision making about fertility. Usual perceptions of oneself as being in control were lost, as infertility disrupted the participants' imagined biological destinies. The participants explained how this process did not take place in a moral vacuum. On the contrary, whilst dealing with the trauma of lost fertility, the participants were also faced with the response of the family and community to their childlessness.

Part two: Negotiating the moral context

As illustrated in the previous chapter, infertility is an arena of social anxiety within South Asian communities, and as such, childless couples, particularly women, come under close, public scrutiny. The local moral context, in which the participants often found themselves, was considered to be highly stressful and emotionally fraught. Being socially marginalised, due to their lack of children, either now or in the past, was central to several participants' stories, and the participants often expressed resentment when relaying stories about how they had been treated by relatives and social acquaintances. The absence of children, at a time when it was deemed biologically and morally appropriate to produce them, placed women in a problematic social space.

Experiencing pressure

As already discussed, particular social events, for example the births of new babies, were problematic for infertile women, both in that they were a traumatic reminder of childlessness, but also that in some cases infertile women were perceived to be 'bad luck'. Community responses such as these meant that for some women, social interactions became difficult and strained. The participants described the social anxiety that they came into contact with, often in terms of questioning at family gatherings, as pressure. Even good-willed questioning was hard to deal with, and women often withdrew from social life in order to avoid constantly having to field questions about their fertility:

But, I think the most, I think the most stressful thing, I don't think it's stressful going through the IVF or IUI, I think it's the pressure that the community put on you.

(Jasmin)

Many participants described the ways in which they would explain away their childlessness, by saying that they weren't yet ready for children:

They used to ask me why, you know, what's taking you so long and why do you want, why don't you want any kids just yet and things like that, but like we two have different explanations for different people, you know...So, whatever came into our minds, we used to say sometimes we used to get fed up, you know, didn't know what to answer.

(Rita)

As Jasmin points out however, this approach is not without problems, as they worried that they were tempting fate:

And it's awful to say because you feel like you're dicing with death then, don't you, thinking well, if you keep saying it, it's not gonna happen, but you're thinking that's the only way to shut people up.

(Jasmin)

Charanjit reports how she felt that she was made to feel different, or somehow less of a person, by those around her by virtue of her childlessness:

What I find, certain things, I sometimes think people think less of me, around me, that I've not got anybody or got married or had kids.

(Charanjit)

For the participants, this arena of social and moral anxiety surrounding infertility led them to withdraw from social life (to varying degrees). For some, the constant questioning and pressure that they endured meant that they stopped attending social events like weddings and the births of new babies in order to avoid such questions:

I did isolate from the whole sort of community as well, because of the questions.

(Aisha)

In Aisha's case she also avoided particular members of her family (in this case her mother-in-law) who were particularly difficult to deal with. Often, a

woman's story involved less than supportive in-laws (n= nine) who had therefore not been told of the treatment that the couple were undergoing. This was especially problematic if a couple lived with, or in close proximity to, those family members. Padma reported that she had been living with her in-laws who have been 'very nosey' and had asked lots of questions about why they were childless. Padma and her husband therefore decided to move out of his family's house and to delay treatment by two years, until there was physical space between them, at which time she felt she could cope with the treatment without constant questions. Samina also felt more able to deal with their childlessness away from the intrusion of her in-laws who were abroad in Pakistan:

...here I'm okay because if, if I live in Pakistan, it will be very hard for me. Because I have to live like, with my in-laws and every time, like, lots of family, friends and they all the time, whenever somebody see you, 'oh, any good news?' Anything, and, then, it's really hard for me if I lived there, so I'm really, really pleased I'm living here, like, nobody can ask to me every time.
(Samina)

Jasmin also told of how she was in constant contact with her in-laws, in whom she felt unable to confide and from whom she had to be on constant guard in case she let anything about the treatment 'slip out'. She felt it would be easier if they were not in such close proximity:

It's quite stressful itself, you're thinking 'oh god', you know, 'I wish I was somewhere else where they can't get to me'. Where, you know, they don't know who I am or...

(Jasmin)

In Sita's case, her sister-in-law (her husband's brother's wife) had experienced problems in conceiving and had been treated poorly by the husband's family. This led Sita to decide to disclose the nature of her childlessness as being male

factor infertility, in order to diffuse the possibility of her also being stigmatised by her in-laws:

I remember my mother-in-law feeling quite annoyed that I'd told them that it was the husband's, that it was her son's, not fault, but it was associated to something with him. And she didn't like it.

(Sita)

Sita goes on in her interview to describe how, although her mother-in-law was unhappy that she had disclosed this information in both families, it did change the situation and meant that she did not face the scrutiny she might otherwise have done:

As far as pressure to have children is concerned, I don't think they gave pressure because as soon as they found out it was a problem associated with their son, rather than me, all that changed things a little bit.

(Sita)

Other participants were ambivalent about whether disclosing the fact of infertility would help them to negotiate the moral context. Sita's situation was unique amongst the participants, since she and her husband had had a clear diagnosis of male factor infertility. This made it virtually impossible for her to be held responsible for the lack of children. Other women (even those with a diagnosis of 'unexplained infertility') were less able to resist the blame that they felt was put upon them, or would be if their situation were revealed. As Jasmin describes, disclosure may give her in-laws a legitimate reason to apply more pressure, whereas continuing to keep quiet and offer alternative explanations, gives her some space in which to resist their pressure:

...you want to tell people why you're moody and why you're this and that and it's quite hard not to. And it's like, shall I tell her because I'm like this and then I think, no, because I do get a lot of pressure from my in-laws.

(Jasmin)

In an interesting reversal of the marginal state that Aisha found herself whilst she was childless, when she had conceived her son, she felt overwhelmed and resentful of the attention that she then received:

... all these years that I didn't have any attention, from nobody, all this time, I isolated from everyone, from the friends, ...when people started finding out that I'm pregnant, all the attention and I, I, I didn't like that attention, I just, I don't know, I felt really resentful. I felt resentful, I felt that, you know, like, when I really, really needed the help and support, I didn't get and suddenly, you know you get this, I didn't like it.

(Aisha)

Some women chose disclosure as a mechanism to resist the stigma that they felt childless women were subjected to. As Nadia suggests, there was only so much that could be dealt with before the only option was to 'lash out':

I do lash out, I do have my moments, you know, I'm like that, I can take it, take it, take it and then you know, like, once in a while I do, you know, lose my head... You know, I tell them exactly what I think about them...then people respect you for it. 'Cause you, you're saying to them, what you think of them, I do. 'Cause I don't care, end of the day, right, who the hell they are?

(Nadia)

However, disclosure of the fact of infertility was usually a highly selective process, and the women reported only having told trusted family members, or friends who were not part of the family. In the cases of women who had conceived a child through the use of assisted conception, the process of disclosure was again used to resist stigma and to challenge established community views, and will be discussed in more detail in the next chapter. For those women who remained marginalised by their infertility however, disclosure appeared to be less of an option.

Remarriage/marriage prospects

For some, the social pressure from in-laws and other family members went much further (as described in the findings from the focus group discussions), sometimes as far as having to face the prospect of their husband taking another wife, or initiating divorce proceedings. This potential situation was faced by two participants. Aisha described how her mother-in-law constantly reminded her how lucky she was that they hadn't gotten rid of her:

So, another thing what I found really difficult as well, obviously, my mother-in-law, ... she would come to see me and she would go on and on and on about, you know, about how I can't have children and all that,' oh, we're a really good family that you're still here, if, if it was somebody, if it was another family, they would have get, got married their son, you know, so that he could have children'.

(Aisha)

Nadia was very upset when recalling an incident in which her sister-in-law suggested that her husband take a second wife in order for him to have children:

And his brother's wife...she said to my husband, right, that was when, when Eid day, that's our Christmas, you know, Muslim Eid, we went round there 'cause we normally tend to spend Eid day with in-laws and that, and we were all sitting down and she said to my husband, right, that were really hurtful, honestly, I will never forget that day...[getting upset]...She says to him, 'come on, I'll get you married off'.

(Nadia)

Nadia found this incident very traumatic as fears about the implications of her childlessness were realised. It led to a breakdown in relationships with her sister-in-law. As discussed in the previous chapter, in Islam, infertility is viewed as a justifiable religious reason for a man to either take a second wife, or as a reason for him to divorce his wife and remarry.

The fear of marital breakdown due to infertility was also reported by Samina, whose parents were concerned that her fertility problems, caused by the removal of one of her ovaries at an early age, would cause her husband to consider divorce (although he knew of her condition when they were married):

... inside my parents are worried about this... they didn't say to me, but I know what they are thinking, they know, maybe, tomorrow after few years, my husband will be fed up and say, 'oh, look, they, this girl can't give me family' and like this, 'so maybe I can give her divorce' or something like this, so my parents are worried about this.

(Samina)

Samina's story is interesting in this respect, since her marriage to a man, who would have been ordinarily considered an unsuitable partner, was permitted by virtue of her impaired fertility. Samina had met her future husband at university in Pakistan, and because he was not a family member, she knew that her parents would not permit their marriage. However, at the age of 21, Samina had to have one of her ovaries removed in an emergency operation, which meant that her marriage prospects (through the expected means of parentally arranged marriage to a family member, in her case) were now severely limited, as she explains:

So, it's really hard especially like in our culture, like, if something happen, if even you know, the minor operation happen with girl then people don't get married to that type of girl and especially, because the main reason the different families like having babies and if woman can't be pregnant and this, then they say, 'oh, there's no point to do marriage with that girl' and like this. So my parents was worried over that, what's going to happen with me.

(Samina)

However, after her operation, once it became apparent that her potential for childbearing was drastically reduced, Samina's future husband approached her parents to ask whether they might now consider allowing Samina to

marry him, even though he wasn't considered a suitable candidate, coming from outside of the family:

You know, he was from different background, like family and caste and everything was different and mine it was different. So, and like, in our family, we don't do, especially the girls marriage outside the family. So it was really hard for my parents, they said, 'no, we can't do it'.

(Samina)

Eventually, and somewhat reluctantly, her parents agreed, and Samina married her husband and came to live in the UK. Infertility had an impact on her marriage prospects that is unique amongst this group of participants, firstly because it meant that her infertility was known about before marriage, and secondly, it therefore facilitated her choice of marriage partner.

A second participant, Charanjit, also described how her marriage prospects had been affected by her infertility, but in a less favourable way than Samina. Charanjit experienced the menopause prematurely, before she was married, and has since given up hope of ever meeting a partner.

...this thing has shattered me. Tell you one thing it has done, it's really put my confidence low, where fellas are concerned. Now I don't even look at them in the same way. And I think to myself, I mean, this might be a funny thing to say, but I think to myself, 'what do they want with me and what do I want with them?'

(Charanjit)

For Charanjit, the main purpose of marriage was to have children, and since pregnancy and childbearing were not (easily or genetically at least) now options, she had resigned herself to remaining single. Charanjit's situation was further marked out from the other participants' accounts in that, by virtue of her single status, she had effectively experienced her infertility alone and had had little support from her parents or other family members.

In contrast to this, some of the participants reported that they had received a lot of support from their partners, without which they would have found coping very difficult:

...he's very supportive...even, because he knew all this problem before marriage.

(Samina)

Erm, yeah Nicky, he was a pillar, that's the only way I can describe it.

(Sita)

I count myself as lucky, really lucky actually, Nicky, because look at my husband he's really like supportive with everything and everything, he knows how much I've been through.

(Asma)

Positive relationships with in-laws

For some women, family support extended from their partner to siblings and parents, or in some cases, a woman's in-laws. In contrast to the experiences of those women who had a negative response from their in-laws, Nadia and Asma both reported that their parents-in-law had been supportive throughout the experience (although in Nadia's case her sister-in-law had assumed this role). In both cases, a faith in 'God's will' was central to their (the mother and father-in-law's) perception that childlessness was not the fault of an individual. This helped to relieve the pressure on these women:

They have been really helpful. Cos my mother and father-in-law, they said, they believe in Allah and they said 'whatever happens, Allah knows best', he goes, 'it's not like he doesn't help you, if Allah says you, you know, it will happen, it will happen'.

(Asma)

...my mother-in-law, she passed away last December and she was wonderful, honestly...Anyway, my mother in law says to me, honestly, she says to me, you know, like, when she was in hospital, she says to me, now, because she

knew she was dying anyway, and she says to me, 'when I go up there, I'll have a word with him' [laughs].

(Nadia)

These final comments demonstrate that the experience of infertility is not universal and fixed, but can be fluid and contextual. Some participants had experienced very difficult encounters, for example, in Nadia's case being told by her sister-in-law that she would get her brother (Nadia's husband) 'married off'. Yet these were countered at different times by more positive experiences of emotional support, often from individuals who it was presumed would not usually be thought of as supportive in these situations (for example, the mother-in-law). For those who had received support from partners and relatives, they were keen to acknowledge this important source of help in an otherwise traumatic, isolating and marginalising experience.

Summary

This chapter has demonstrated that infertility is an experience marked by disruption, emotional trauma and social marginality. The women reported many shared experiences, such as the pain at not being able to achieve something which others appear to do naturally, the feelings of isolation and a lack of control. For some women, the significance of relationships with family members (especially mother-in-laws and sister-in-laws) can be seen in the ways they figure in the narratives. Attempting to mediate these relationships, as well as negotiate the moral context of the community setting, can clearly be identified. What the women did in order to avoid negative comments and questions from others, such as avoiding family gatherings, and engaging in social parenting, are interesting in how they shape the women's perceptions of themselves as infertile individuals. The practices which they employed in this respect will be discussed later in this thesis.

There are differences in this life-cycle disruption which are clearly mediated by a woman's social location and particular point in the journey. The focus of the next chapter is the participants' experiences of a particular stage in their journeys: that of the biomedical treatment process. The majority of the participants had received a substantial amount of technological intervention in their quests to solve their childlessness, and the accounts of this process are discussed in the next chapter.

Chapter Seven: Negotiating technology- seeking a solution

Introduction

This chapter presents the participants' accounts of accessing and negotiating assisted reproductive technologies (ARTs) within the clinical setting. Infertility is increasingly considered as a legitimate site of biomedical intervention, and as such, the participants had all at some point sought advice from those with biomedical expertise for a solution to their childlessness. However, there is a great diversity of experience amongst these participants, in terms of their use of technological solutions to childlessness. Some participants had experienced, or were still experiencing, complex and prolonged periods of treatment, including several attempts at conception with IVF (one of the more invasive techniques). However, some participants had not yet had any treatment, but were facing the complicated dilemmas associated with using ARTs. Bhavna, Charanjit and Samina belonged to this latter category, and as such, their stories were dominated by a series of hopes and anxieties about the promissory potential of ARTs. The other twelve participants had received varying levels of treatment, ranging from one or two to multiple cycles of IUI and/or IVF/ICSI, carried out over several years (as many as nine years in Rita's case). Therefore, at the time of the interview, each of the participants were at different points in their fertility journey, and had a range of experiences from which to draw when narrating their 'quest for conception' (Inhorn 1994, see pen portraits).

The chapter is divided into three parts, and begins with a discussion of the ways in which the participants felt compelled to engage with biomedical expertise in attempting to become pregnant. On different occasions,

knowledge, and its related experts, were both deferred to and challenged by the participants. Both medical and religious expertise were discussed by the participants, and both of these types of data are presented here. Religious expertise is included in this chapter, as it is entwined with participants' experiences of using ARTs, and is classified as a further form of knowledge about dealing with infertility. The subsequent section, *'Negotiating Technology'*, describes the physical, emotional, and social implications of using ARTs, and living with the real intrusion and disruption that their presence represents in many of these accounts. The final section, *Tentative Futures* (to borrow the terminology from Franklin 1997, which is in turn borrowed from Barbara Katz Rothman 1993), discusses the hopes that these women have for achieving, what they perceive as normality in reproductive terms. The futures that they describe, however, are often ambiguous, and the discussions of them remain punctuated by anxiety and uncertainty.

Engaging with 'expertise'

Getting access to treatment

In deciding to use ARTs when trying to conceive, the participants were very quickly required to understand and engage with a complex set of scientific discourses and practices. This happened at varying paces, and with a variety of accommodating or resistant responses. For most participants, being given the opportunity of assistance in trying to conceive was an ambivalent experience; at the same time optimistic and daunting. Receiving a biomedical diagnosis of infertility was often the first stage in a long process of gaining access to the sphere of infertility expertise. However, as Sita describes, this information, and entry into this sphere, is an often unexpected, and almost always a traumatic experience, even if the couple already feel that there may be 'something wrong':

Complete shock. Complete and utter shock. I knew something was wrong, because we had been trying for nearly six, seven months, and I have regular periods, always come on time, I've never had a problem or anything that I would associate as a problem. So I knew that something was wrong, but just didn't know what it was.

(Sita)

Having a diagnosis, or in some cases prior to getting a diagnosis, several participants described their efforts in getting access to the sphere of infertility expertise. Most described frustration at the long waiting times for appointments, and between test results, especially within the NHS. This factor drove many to seek treatment in the private sector, a point to which the discussion will return. Anjali, describes how she was prepared for the fact that she might initially be denied access to the medical sphere, and therefore went to her GP ready to employ strategies which would enable her access:

So after six months, I went to the doctor's, and I told them that we'd been trying for a lot longer...cos, otherwise, I know the way the system works. [laughs] They'd tell me to go away and try again and try again, so they referred me pretty much straightaway.

(Anjali)

Once the participants had managed to get access to the biomedical sphere, they were, in most cases, given a number of tests in order to try to determine the cause of their infertility.

An 'unexplained' diagnosis

In eight of the accounts presented here, the couples had received a diagnosis of 'unexplained' infertility, where there was no discernable physical cause for the lack of conception. For Asma, Jasmin and Anjali, this diagnosis gave them some comfort in the fact that, as it was often expressed, there was nothing wrong with either partner. To some degree, this removed the responsibility or

burden of blame since there was no explanation available, even within the biomedical sphere:

There's nothing wrong with me, that's what my husband said, 'Asma, there's nothing wrong with you'. There's nothing wrong with me.

(Asma)

But there's nothing wrong with us, we're just coming into the unknown bracket.

(Jasmin)

However, in some of the other accounts, the lack of a firm diagnosis or reason for not being able to get pregnant was troubling. It had been expected that entering into this domain of expertise would give some reassurance that whatever was wrong could be fixed. Instead, Narinder and Nadia were both left feeling uneasy with the lack of explanation for what was happening to them, and questioning what was really meant by unexplained infertility:

I had so much faith in the medical profession in a way. You go for any op, you think, yes, it's gonna cure you, it's gonna work, so it's a similar feeling, yeah, you know, it's going to work, 'cause there's nothing wrong there. But then now, I look back, I think unexplained, it means they haven't found anything, there still could be something wrong, it's just different way of thinking.

(Narinder)

At one point in her account, Nadia describes trying to take comfort in this diagnosis: *'I said to myself, there's nothing wrong with me'*, but then immediately goes on to point out the reality of her situation: *'but there is, there is something wrong, I can't get pregnant [laughs]'*. This quotation highlights the ambiguous status that a diagnosis of unexplained infertility can confer on people.

Having faith in the experts

Relinquishing control over the reproductive process to the experts was raised in several of the participants' accounts. In order to do this, a certain amount of faith was needed to believe that the doctors knew best, that they could be trusted to make the correct decisions, and that a positive outcome could be achieved in the form of a pregnancy. Some had faith in the individual clinicians, but were sceptical about the treatment itself, whilst others had concerns about whether the medical treatment protocols were appropriate, and whether the clinicians and nurses were carrying out the treatment in the correct way. The amount of faith the participants invested in both the treatment and the experts was contingent on the point at which they were at in the treatment process, and how many failures or successes they had experienced. Having faith that the treatment protocols would result in a much desired for pregnancy, meant following all the advice that was given, as Aisha suggests:

Whatever they told me I just did without asking questions, I just went through and back of my mind, all I wanted was a baby. It was, it was a difficult journey, it was very, very difficult.

(Aisha)

Having faith in the experts was also important to two more participants, Nadia and Jasmin, although there is clear ambivalence in their accounts about how much they thought the individual clinicians could control such an unpredictable process. As Nadia suggests, although she has a good doctor, she thinks there is 'not much he could have done' when the IVF treatment failed for her:

I was really positive, in a sense because... I read so many articles about him in the paper and everything before I went in the treatment, and I thought, 'God, I've got myself a really, you know, a good doctor there', because that's how I

felt, but at the end of it, it wasn't working for me, there's not much he could have done as well.

(Nadia)

In many cases, the women reported having started out on the treatment journey with a lot of hope; Asma describes it as being an exciting prospect:

The first time I did the IVF, I had hope, I had a lot of hope, really, really, a lot of hope, it's like, oh yeah, I see these things on the TV, and everything, so, they should happen, it happens to anybody and everybody, that's what I thought, but I didn't realise, it's not everybody gets pregnant by IVF.

(Asma)

In many cases, the women followed a similar emotional trajectory in which they described initially being very positive about the prospect of using ARTs, especially when they had experienced childlessness for a lengthy period of time, followed by feelings of ambivalence and disappointment. As the women experienced failed cycles of treatment, they began to lose hope that it would succeed. This process of losing hope may have helped the women to protect themselves emotionally; having less hope and faith invested in the treatment could make the subsequent failures easier to deal with. Both Narinder and Aisha felt that they had been 'naïve' to have invested so much in the treatment, which had left them feeling disillusioned:

Naïve. I was very naïve. I was, thought it was going to work. Never had any doubts, never thought it wasn't going to work.

(Narinder)

Questioning expertise

Despite the fact that a certain amount of trust and hope was invested in the treatment regimes and the practitioners, especially at the outset, many of the participants described a developing scepticism of this sphere of expertise. Conflicting advice given by practitioners was compared to information from

other sources, such as family members, friends, or from the internet. In a small number of cases, this led the participants to question who was right, and to wonder which information was correct. For some, advice was given which didn't seem to make any practical sense or have any impact on the success of the treatment. As Nadia describes:

It's like, when they told me I had to lose weight and I said to them, 'why didn't you tell me that from the beginning?' And they said 'well, we didn't think that was the problem'. And they said, 'it's not the problem, but we would prefer you to lose a bit of weight', so I did, but then nothing happened.

(Nadia)

Jasmin questioned whether the advice about relaxing after IUI treatment was correct. Two other women (Asma and Sita) also described concern over the vulnerable state that they felt they were in after IUI or embryo transfer. For Jasmin, she would have perhaps liked more reassurance about how long was long enough to rest after the procedure:

You don't know how long you're supposed to be relaxing. You're thinking, I know they're good swimmers but [laughter] are you supposed to be there an hour? ...Just sleeping it off or what? [laughter] You know ... Cos like, fifteen, twenty minutes later, like, you're up and you're thinking, should it be like this? I don't know.

(Jasmin)

Sita described how she had a side effect of back pain after every attempt at IUI, which was dismissed by the clinic. She concluded that there was something different about her experience, even if she couldn't have this confirmed by the clinic. Her reasoning that the pain was in some way significant was further reaffirmed for her when, on the one occasion she didn't experience the pain, she was actually successful with the treatment:

I had a very severe back pain after the operations, which the staff at [the clinic] couldn't explain or justify, they said 'well, nobody goes through those

pains' but I did. And I felt very alone there as well because I was going through severe pains, I couldn't walk, it was painful to walk but nobody could explain what it was and why it was happening. The only thing I do remember, it didn't happen when I conceived.

(Sita)

A lack of satisfactory explanation from clinicians when she was seeking to understand why her IVF treatment continued to fail, was also highlighted by Narinder. She reiterates that, since a certain amount of trust is implied in the doctor-patient relationship, their explanations will be accepted. She also suggests that the lack of improvement in success rates is questionable:

*Every other field, you see improvements and you look at them [success rates] on the internet, some of the success is so poor. Why do they carry on?
[laughter]*

(Narinder)

One participant felt that she had been offered an explanation by the experts for her particular experience, which later, on reflection, she felt had been inappropriate. Safiya was the only participant who reported feeling that she had been treated differently because of her ethnicity, and had been subjected to the stereotype of an Asian woman:

And, I can remember, when I had my first internal and the first doctor that saw me wrote a report, and the nurse read it to me and she said it was probably because of a cultural reason. And it's probably because of your culture, you're very shy and you don't like people to, I was thinking, 'well, I don't suppose many women like a man that they don't know put a finger inside of them, and probe around. But okay, but maybe it's got something to do with culture, but now, like years on, I'm thinking, well no, actually, it was nothing to do with my culture...

(Safiya)

Safiya's comments also highlight how she had felt a certain level of dissatisfaction in the way that she was treated in this respect. Safiya was the

only person in the sample to report feeling discriminated against in ethnic or cultural terms. Almost half of the participants (n=7) had concerns about the level of service that they had received in other respects.

Negative treatment experiences

Narinder reported that she felt she had received particularly poor service from a well known clinic which had a good reputation:

what I couldn't cope with was the very, very poor service...really, really, really, really poor.

(Narinder)

This poor service was described as a lack of sensitivity from staff, difficulty communicating with the clinic, mistakes with charges, and confusion over treatment regimes. For Nadia and Sita, this poor service was manifested through the feeling that they had been treated 'like a number':

To them, I was just a number, not a person, not a human being, you know, I was just a number.

(Nadia)

Negative emotional experiences in the clinic were also linked to the experience of treatment failure. After experiencing her first failed treatment (IUI), Sita remembered asking for information about success rates:

When I wanted statistics as to how many people actually got pregnant, they said to me, 'oh, well, in some cases, it's not successful until the sixth attempt'. And I thought, 'oh God, I can't even bear to imagine going through this procedure six times'.

(Sita)

Similarly, Safiya now feels that she could not go through the feelings associated with failure again after having gone through eight unsuccessful treatment cycles before being successful on her ninth attempt:

I went through this battle. And I won. I won that battle and I don't want to be that person again. I don't want to go back to being that loser in a way, of being miserable and, because that one time that you go for IVF and it fails, I want to do it again and I want to do it again and I, it'll be like a personal little war of mine that I have to win.

(Safiya)

For Aisha, being unsuccessful wasn't purely a failed cycle:

Each time, you know, when the treatment didn't work, I sort of grieved for, I had this imaginary baby inside me, and then it didn't work and I did grieve for a very long time, until, I don't know how long I grieved, but I did, and it took me very long time to get over it and, and then start again.

(Aisha)

Religion, and its associated discourses was a second sphere of expertise (as well as biomedicine), that was frequently drawn on in the participants' narratives in understanding their infertility. When seeking solutions for childlessness, religion was at different times, and for different individuals and couples, either a source of support and knowledge, a source of ambivalence or dilemma, and for some it operated as constraint.

Religious constraints and ARTs

For the Muslim participants (n=4), it was significant whether a particular solution to infertility was permissible in Islam. For the participants who identified with other religions (Hinduism and Sikhism) (n=11), there was little discussion of whether a particular treatment was religiously acceptable (although religious teachings were significant in other ways – see below).

Asma and Safiya (both Muslim women) had both experienced IVF treatment, and had been required to face the challenge that what they were doing was religiously, and therefore morally, dubious:

I been through it and I know, it's not against our religion, I mean, if you have somebody else's sperm, then it is... against our religion, otherwise, it's fine. Then otherwise my husband wouldn't have allowed me to do it at all. If it was somebody else's sperm, he wouldn't have allowed me to do it.

(Asma)

For Asma, the fact that her husband (a practicing Muslim) would not have allowed her to have treatment using donor sperm was highly significant, demonstrating that the way individuals draw on religious expertise is indeed lived. It is unclear whether, had she needed this treatment, and her husband had been willing, she would then have gone ahead with the use of donor sperm.

Both Safiya and Samina discuss the way in which the community discourse surrounding religious prohibition operates in Muslim communities, both in the UK (Safiya) and in Pakistan (Samina). Samina discusses how a child born to a Muslim couple using donor sperm would be socially ostracised, and uses the comparison of a child born outside of the conjugal relationship to illustrate her point:

Yeah, it's like the same if woman in our country, if any girl has child without marriage, yeah, if she have boyfriend or something like this, and then, people say, 'oh this child, this child is haram'. And, people don't want to keep this child and sometimes you know, if, just when they are born or they, they throw them away or something like this...

(Samina)

This discourse of religious constraint has led Samina to the decision not to disclose her intended use of donor eggs. Although donor eggs are perceived to be less risky than donor sperm, their use is nonetheless problematic for childless couples (see later).

Safiya has disclosed her use of IVF, and although she did not use donor gametes she has still faced accusations from community members that the treatment she has used was religiously unacceptable, and that she should rely on God's intervention, something she disagrees with:

They don't understand it, so a lot of people said it was against the religion, a lot of people said it was something we shouldn't have done, you know, even now, they don't really understand ...so a lot of ignorant people still seem to think that, you know, it's in the hands of God, you know, [laughs] and things like that and if I, if I did something, I don't know, like go to Mecca, I'd get pregnant, you know, they still seem to think, it's like, as easy as that.

(Safiya)

Having faith in religion

As well as being a source of dilemma and moral regulation, for some individuals, religion and religious faith were also positive sources of support. Anjali points out that religion is often a comfort or solution that people seek in an hour of need:

The thing is, I think everybody, every single human being in this world, if they've got a problem, the first thing that they think about is God. If they're happy and they don't have a problem, they don't think about God.

(Anjali)

Nadia and Sita also describe how their faith helped them through their experiences of infertility. For Nadia it was the help to see that there is 'more to life', for Sita it was the strength to get through the treatment:

Since I been to Hajj, right, it's made me, I mean in general, I am a pretty strong person, you know but since I been to Hajj, right, then I think there's more to life.

(Nadia)

...our inner strength, it just came from nowhere, well, actually, it came from God but, it was there, it was just there, you know, how they say when you're at your most vulnerable, you will find a strength and it will carry you.

(Sita)

Finding the strength to carry on was a common theme in the accounts, especially in relation to the treatment process, which was in general felt to be stressful and traumatic. Most participants felt that faith in the medical profession was needed to get through this experience; some also felt that faith in their religious beliefs was the key.

The next part of this chapter describes the participants' accounts of negotiating assisted reproductive technologies. Twelve participants had already used either IUI or IVF treatment, or in most cases, a combination of both. Their accounts of the emotional, physical and practical implications of ARTs are described. For the remaining three participants who had not tried ARTs (Samina, Charanjit and Bhavna), this discussion centred on the potential that ARTs have in providing a pregnancy.

Negotiating technology

The emotional impact of using ARTs

The emotional impact of using ARTs was discussed by all participants. Coupled with the emotional loss of finding that they couldn't conceive naturally, the participants described how they experienced a range of emotions when going through treatment. Two of the women mentioned the 'rollercoaster' of infertility treatment; a metaphor commonly used in popular discourse to describe the highs and lows of the process. Many of the participants talked about how they had found it hard to come to terms with

the fact that this was happening to them, and six of the women specifically posed this as a rhetorical question in the interviews:

You feel as if, why me? What have I done wrong?

(Rita)

Where's the justice there? Because what did I ever do to have to suffer so much just to have a child, just for that one child?

(Safiya)

Although Samina also questioned why this should be happening to her, she was reflective, and concluded that although this was a negative experience, if she had have been fertile she would not have been able to marry her husband:

When you are very sad you think 'oh why only me', those thoughts. I say all my friends are okay, everybody is okay, but why this happen with me? But sometimes I feel okay because I think, if I don't have this problem, maybe I couldn't marry with my husband.

(Samina)

In describing the different emotions and feelings that they had about their need for biomedical intervention, all of the participants reported some level of anxiety about the prospect of treatment, or about its implications. Most were anxious when they discovered they would need to use ARTs, and the subsequent levels of anxiety fluctuated as treatment went on. Safiya describes the fear and uncertainty she feels, five years on from treatment, at the prospect of having any further procedures to treat her endometriosis:

I don't think I've progressed much further, because, to this day, if anything, it's got worse, because I, I believe I have a fear now of going and having anything done down below. And, if I'm really honest, it really scares me. And I've been through all of that and I know I've survived it and I know it's not that bad but the whole, the whole thing has just kind of like gone into this big ball and I don't feel I can cope with it.

(Safiya)

Similarly for Nadia, she had expected to be less anxious as treatment went on, but instead found that future cycles of treatment were more emotionally problematic:

It was really scary the first time, you know, when I went first time, right, I was so scared, but the funny thing is you think, when you go next time, it's gonna be a bit easier for you; no, it wasn't, it was harder.

(Nadia)

The concern and worry about future treatment may have been related to negative experiences in earlier cycles. For example, for Anjali, her fear of needles was compounded by the knowledge that they were painful, causing her more anxiety in the build up to her next round of treatment:

The only worry I had was having these injections, and that is my main concern again, when I have the treatment done, having these injections, 'cause I hate injections and they are painful.

(Anjali)

For Nadia and Narinder, the worry was also about the potential future effects of the treatment on their health. Both women mentioned concern over the possibility that the drugs used in IVF treatment were linked to cancer:

And they said to me that the drugs that I'm having, they said, there's no proof of it, but it could cause cancer, and that used to worry me. It really did.

(Nadia)

At the time of interview, Padma was in the process of using embryos frozen from her first cycle of IVF two years previously. She described how she was worried about the quality of the embryos remaining, since as she understood it they would have already used the 'best ones' in her previous cycle. She was also concerned that she would not hear until just before she was due to have the embryos transferred if any of them that had been chosen for thawing had survived the process. Jasmin and Narinder also expressed anxiety about their

embryos, but for different reasons to Padma. Their concerns were related to the possibility that a mistake might have occurred at the clinic, which meant that the embryos being used were not actually theirs (as in the high profile cases in the UK and elsewhere of clinic 'mix-ups', see chapter three):

I know they're using your own embryos but there's always that chance something can go wrong, can't they? And you're thinking, God, I don't want to end up with like a blonde baby or something [laughter] and think oh my God what's happened 'ere?!

(Jasmin)

Finally, Samina expressed her anxiety about IVF treatment in slightly different terms than the other participants. For Samina, who had lost one ovary at age 21 and who had since experienced the menopause, thus losing the use of her remaining ovary, IVF (with donor eggs) represented an option she had to take as quickly as possible before any further problems with her fertility arose. She was anxious to find a donor and go ahead with the treatment as soon as possible:

I don't want to waste, you know, lose this chance, I can have baby inside my body and I'm worried about my uterus, if my uterus will be bad and anything happen then it will be very hard for me, then I can't survive and I think I lose the chance and I waste my time, so I don't want to waste my time.

(Samina)

Three of the women (Safiya, Rita and Aisha) talked about their treatment experience as an emotional (and physical) 'struggle' or 'battle' that they had endured, and had come out of the other side successfully (in that they had all achieved pregnancy). These three women had all undertaken multiple cycles of IVF treatment over many years, and were not currently in the process of treatment; neither did they intend to have any further treatment. Having emerged from the other side of clinical experience, they were able to reflect on what they saw as their 'achievement', a narrative that was not, or did not

appear to be available to those who were either still having treatment, or who had never been successful:

I went through this battle. And I won. I won that battle and I don't want to be that person again, I don't want to go back to being that loser.

(Safiya)

Aisha reiterates that it takes a strong person to be able to come through such a struggle. A third of the participants mentioned the need to be strong in order to get through the treatment experience:

I'm very, very, very strong-minded person. If I put my mind to something, I go and achieve that, maybe that's why I've gone through this many years of, you know, rollercoaster, and in the end, I sort of achieved, you know, I was lucky enough to get through, but I'm a fighter, I don't give up very easily.

(Aisha)

Part of the reason that participants felt the need to be strong, and that it was a battle that they were engaged in, was that it 'took over' their lives, at least for the time when they were actively going through treatment:

I just feel like, well this is my life now, IVF. [Laughs]

(Jasmin)

Although many of the participants expressed strong emotional responses to the extreme physical procedures they were enduring (which are discussed in more detail below), a large proportion of them (n=8) were somewhat emotionally ambivalent about the treatment. The promissory potential of IVF gave the participants a reason to remain hopeful, whilst at the same time, the emotional and physical demands which were placed on them, coupled with the reality of relatively low success rates, meant that the participants often felt conflicting emotions about it:

I'm so grateful for the doctors, the nurses, their intelligence and all the science that goes into it, I'm ever so grateful. At the same time, I do feel that I went through hell and I'll never forget that.

(Safiya)

Sometimes I laugh about It, sometimes I cry about it, you know, it's one of them things, isn't it?

(Nadia)

Physical experiences of treatment

The invasiveness of the treatments involved in many ARTs, especially on the part of the female partner, was mentioned by ten out of the twelve participants who had undergone treatment. Having to learn to administer drugs by injection, or trusting their husband to do it, was a concern for a number of women, especially those like Anjali, who were afraid of needles. However, Safiya, who had undergone lots of painful examinations (due to her endometriosis) and several cycles of treatment, found the injections one of the more liberating aspects of IVF:

I would say the injections were the best part of it because at least you've got some kind of like, experience out of it, something that you know you can do.

(Safiya)

For many participants, treatments were found to be intrusive, uncomfortable and unpleasant. Sita describes her discomfort with the procedures involved in IUI:

You have to go through procedures that aren't really dignified and things that you don't really want to do, and I felt very uncomfortable with that anyway, because you didn't have one particular doctor that would see you, so even on the day of the operation, you could be seen by whoever was there [laughs].

(Sita)

Asma, a practising Muslim, found timing the medications around Ramadan, during which she was having a cycle of treatment, very difficult. This caused

arguments with her husband, as he felt she should be fasting, whereas she had prioritised the treatment on the advice of her clinicians:

I couldn't fast, my husband had a bit of argument with me that 'oh you should have fasted' but I spoke to the nurse and the consultant and he said no, I can't fast... Cos I had to eat in between as well, and I had to do the injections early in the morning which was about eight o'clock, and my husband say, 'why don't you do it around five?' but I did ask the nurse and she said 'that's too early'.

(Asma)

Seven of the women described specific physical effects of the treatment, including bloating, tiredness, hot sweats, mood swings and back pain. In one case, Padma described how she had experienced every single side effect listed on the side of the box containing the drugs. As a result, she reported feeling very low and asked herself: 'why am I doing this?' Two of the women who had conceived using IVF treatment, described having had a severe rash during their pregnancies, which was at times more distressing and uncomfortable than the treatment itself. Rita was told that it could be related to the IVF treatment she had received:

I came out in a heat rash, I was itchy all on my body, but they say to me that I've got too much body heat which could be with the treatment that I'd gone through.

(Rita)

In addition, five of the women commented that it was they, as the female partner, who bore the brunt of the intrusive nature of the procedures involved in ART treatments. It was felt that the man had a minimal role to play in decision making about treatments:

All the way through the decision was mine. I did all the research, I had to go through all the treatment... he just went along with it and supported me really.

(Anjali)

This also applied to the physical procedures:

We go through everything, they have one thing they have to do in a pot and that's it, you know, end of! [laughter]

(Anjali)

Feeling out of control

Experiencing bodily distress in relation to the treatment, both before and after pregnancy, was a concern for the participants. It was a sign that the treatment process was having an effect on them and their natural bodily rhythms, over which they had little or no control. A third of the participants described how they felt that it was the experts, and not them, who were in control of the treatment processes; in most cases this left them feeling inadequate:

Nothing's in your hands. They're in control. I used to get given a sheet of paper with all the dates on it and it was from the date that I started my period, and then everything that I had to do from basically that month to the point of when we can have sex, you know, and everything was timetabled... you're not in control of your life. They deal with everything. From start to finish.

(Safiya)

Aisha reported feeling the same way, but felt that going for private treatment gave her back some control. This came from the fact that she was paying for treatment, and therefore she had some rights over what happened to her, rights that she hadn't had in the NHS:

I tried to be very positive but it was quite difficult, quite a lot of time, the control was taken out of my hands...another thing I felt was because I was paying for this treatment, I could buy this service, I could arrange time when it suited me, but, while in NHS, that was taken anyway. I didn't have a choice, so in that sense, going private, I had some control.

(Aisha)

In particular, three of the participants felt that it was their sex lives that had become 'controlled' by the treatment regime:

...everything was timetabled and I can remember going in for scans and then the specialist guy pulling out the probe and then saying, 'right, you have to have intercourse tonight, you have to'... [laughter] it just made it so clinical.

(Safiya)

Practicalities: accommodating ARTs in everyday life

The emotional and physical aspects of the treatment were felt to be, at times, overwhelming, with some of the participants feeling that their lives were dominated by treatment regimes and hospital appointments. However, for the majority of participants who had been through more than one cycle of treatment (Narinder, Gita & Ramesh, Aisha, Anjali, Sita, Padma, Jasmin, Asma, Safiya), they described how the intensity of the experience varied depending where they were in the treatment journey. Whilst people were in the midst of treatment, it often dominated their day-to-day lives. However, between cycles of treatment, some relative semblance of normality could be achieved when other aspects of life such as work or family commitments provided respite from treatment issues. As Narinder explains:

when it's over, the cycle, it's just sort of such a relief in a way, there's no, not taking over my life any more.

(Narinder)

For those who were faced with the decision to go back and try for further treatment, either because they had been initially unsuccessful, or because they wanted a second child, when and how treatment would fit in was of crucial concern. This was especially of concern to those who had prior experience of treatment, as they were well aware of the disruption that being in treatment could bring. For Anjali, finding the time to fit treatment in, especially with a small child, was an issue:

To be honest, my lifestyle is just so busy, I haven't got time to think about it and I should, but I just haven't got time, you know, we're just really busy.

(Anjali)

Making preparations for beginning treatment was also mentioned by Gita and Sita. For Gita, getting time off work was difficult (she was planning to go for an extended trip to India for treatment), especially since this was the second such trip she had been on. Sita had a more pressing ultimatum, in that the clinic which was storing her husband's (surgically extracted) sperm sample had written to tell them that, due to regulations around the length of storage of gametes, they needed to use the sample or risk having it destroyed:

It's either now or never, if you don't do it now, they said, you'll never have a chance again. Which sort of puts you under quite a lot of pressure.

(Sita)

For Sita and her partner, this was stressful, as she reported needing to get her 'life sorted out' before they could plan for the last attempt at treatment.

Accommodating infertility treatment wasn't just a practical and emotional juggling act, but was also a financial stress for most of the participants. Of the twelve participants who had used some form of ART, eleven of them had paid for some or all of their treatment. The only exception was Rita, who had received all of her treatment for free (since she was one of the early IVF pioneer patients). All eleven participants felt that there were implications caused by the financial pressure placed on them through having to pay for treatment. Aisha reflects on what else she could have used the money spent on IVF for:

Over thirty thousand...A lot of money, I could have bought another house...I could have gone on holidays.

(Aisha)

Safiya and Sita expressed concern that the financial burden for treating infertility is, in the main, placed on the couples. Safiya was resentful that she paid for multiple cycles of IVF herself, and due to the fact that she was successful and now has a child, this renders her ineligible for any treatment on the NHS:

And they won't, they won't give me any free tries because I've had a child. The fact that I funded all of that by myself doesn't seem to have any kind of bearing on it.

(Safiya)

Concerns about the sensitivity of clinic staff, as described previously, were also seen as related to the fact that ultimately the relationship was a business one, and that this had an impact on how they were treated:

It was cold, hard cash, yeah, and they wanted it there and then.

(Ramesh)

All they're interested in is money, right, before you walk through the door, right, all they want is your money.

(Nadia)

Asma, however, who was relatively early on in her treatment compared to some of the other participants, felt differently. She reflected that the money was being used for a good cause:

I know that at least I've tried. And even the money ... it is going to good cause, so you might as well.

(Asma)

Financial concerns were amongst the reasons that people chose to go for treatment outside of the UK, and three of the participants (Anjali, and the only couple in the sample, Gita and Ramesh) had sought treatment from clinics overseas in their quest to become parents, partly for this reason:

I don't know what prompted us to look abroad, I think actually, I know what it was, money. Simple, right? [laughter]

(Ramesh)

Going abroad for treatment

The decision to go abroad for treatment at a foreign clinic was one which four participants had considered and subsequently ruled out (Jasmin, Samina, Nadia and Padma), with Anjali, Gita and Ramesh being the only participants to have taken this step. The primary motivation in both of these cases was the quest for, what they perceived to be greater success rates, with other factors such as the cost of treatment, and the ability to combine the trip with a 'break' (Anjali) or to see family (in Gita and Ramesh's case). Feeling comfortable with the surroundings was important in both cases, and all participants had travelled to India (where they all travelled for treatment) many times before and therefore felt at home.

Anjali felt that the regulations around embryo transfer in the UK were restrictive, and therefore going to a clinic in India provided her with more choice and higher chances of success:

Here, there's a lot of restrictions, there's a lot of rules that you have to go by and you can't have more than two embryos put back, unless you're over a certain age and trying for so, so many years, whereas in India, there's no rules, they just go ahead and do it.

(Anjali)

In fact, failure at a British clinic was what ultimately prompted Anjali's decision to go to India:

Right, forget this, it's not working here, I'm gonna go off to India and try there cos, yeah, there's so many stories you hear, they all come back and there's always good news, so, thought I'd try it, luckily, it did work

(Anjali)

In both cases, Anjali, and Gita and Ramesh, had been persuaded to try an Indian clinic on the basis of 'success stories' that they had seen in the media, or by word of mouth from family members (both had been encouraged by their mother's – Anjali's and Ramesh's – to try India). In Gita and Ramesh's case, they had also met a woman who recommended a clinic in India where she had had successful treatment herself, as Ramesh points out:

It's testimonials, I guess, that's what sells it, really, isn't it?

(Ramesh)

They also described how they initially had concerns about travelling for treatment, especially in relation to the standards and hygiene of foreign clinics:

My main concern was to make sure that the clinic was really clean and I could stay there and survive in the shower or [laughter] in the operation room and things like that.

(Anjali)

Although in both cases they were relatively happy with the standard of care they received, Gita and Ramesh found the experience difficult as they were separated from their daughter who stayed with relatives in the UK whilst they were away. The participants who had considered going abroad, expressed a number of fears and concerns which had ultimately led them not to choose this as an option:

But over here, if something goes wrong, you can sue, you know, left, right and centre, who you gonna sue over there?

(Nadia)

Padma also expressed concern that the doctors abroad would not know her and that therefore, she wouldn't be able to trust them. Jasmin had considered

going abroad as a way to save money, but had discovered that although treatment is cheaper in some countries, there are lots of other costs involved:

India, was, like, half the price, but obviously you've got your travel, because you'd have to be there for weeks.

(Jasmin)

Another reason that couples are deciding to pursue treatment overseas is the shortage of donor gametes in the UK. In Gita and Ramesh's case, this wasn't why they had initially decided to go to India for treatment, but they have since found themselves in this situation (due to Gita's age), which means they will now need an egg donor. They have decided to use a donor from an Indian clinic. The use of donor gametes was directly relevant in four of the cases in this study (Nadia, Gita & Ramesh, Samina and Charanjit). It was an issue commented on by many of the other participants, and is described next.

Using donor eggs and sperm: the significance of biological relatedness

Some of the participants who were not themselves using donated gametes, had, at the very least, considered the option. For Narinder and Charanjit, this was definitely not an option (even in Charanjit's case where it was her only chance of pregnancy), since they felt that there were children who needed to be adopted, and this would have been a more acceptable option than to conceive a child using donated gametes:

I would rather give them a chance than bring another child into the world who's, you know, not genetically mine anyway.

(Narinder)

I think that adoption is better than doing that [egg donation] because at least you're giving somebody a home and, I think, I'd look at the child and think, 'that's not mine'.

(Charanjit)

However, this wasn't the case in all the participants' accounts. As described in chapter six, the physical experience of pregnancy was considered to be of great importance for a woman and therefore, for others in this position, they were more likely to consider this than adoption. This was the case for the women actually faced with this dilemma (Nadia, Gita and Samina) as well as those who discussed the 'hypothetical' use of donor eggs (Anjali). Initially for Nadia, the excitement of being pregnant was a key factor:

I was all for it, I was, honestly, I thought, 'oh God', you know, 'I'll be pregnant', you know, I'll be carrying it, everything.

(Nadia)

However, on being told that there were 'no Asian donors', Nadia decided not to pursue this treatment (the issue of finding a suitable donor is discussed later in this chapter). For Gita and Ramesh, and for Samina, the importance of pregnancy was also crucial, especially since there would be no genetic link with any resulting offspring:

Ramesh: I mean, I suppose when it all happens, I think, you know, when it's in there [Gita's body].

Gita: Yeah. Then you feel it's mine.

Pregnancy was also important for Samina and her husband, it gave her a connection and a bond with the child that continued after birth:

Mothers love their children, because during pregnancy, they kept in their tummy nine month and then after, everything they do, that's why they, they love the child so it will be same with me.

(Samina)

This was seen as preferable to adoption because, in this case, the child will be genetically related to her husband. She also confirms that her husband is of

the view that gestation confers relatedness with the mother, regardless of a genetic link:

If I have chance, I don't want to adopt because, of course, my husband can get a child, of course, it will be totally belongs to him, and with me as well because my husband say, 'oh, I don't mind, if any childs come out from you, it means it's yours'.

(Samina)

Anjali discussed several hypothetical possibilities of treatments that she had considered (although she had already had success using her own gametes), all of which ensured that there would be what she saw as some connection to her or her husband. Using a surrogate with their own embryos would be a possibility for her, as would the use of donor eggs. However, Anjali did not wish to consider using donor sperm (if this had been a necessity in her case):

I don't think I could deal with somebody else's sperm, because if I get pregnant, that means it would be mine and this other person's, not my husband's, so I'm worried there might not be a connection, so it would have to be him.

(Anjali)

Breaking the connection with the male partner was also of concern for Samina, although she expresses her unease in religious terms:

I can't go for this because I know it's like, totally different, like, its father is different, your family is different so, then I think it's illegal.

(Samina)

Here Samina is referring to the fact that donation from a third party is *haram* (illegal) in Islam. Although she and her partner are currently looking for an egg donor, she feels that egg donation is not *haram* in the same way that sperm donation is, although she struggles to articulate this difference:

If you have to take a sperm from anybody, then I think it's illegal, because when you take a sperms from anybody then it means, it means like, okay, like if you take the egg donor, yeah, okay, the father is same and the mother is, mother is same because she bond that child, that's why. But, if sperm donation, like the father, you know, the, your partner have nothing to do with child, no relation, and mother has and, like, you know, it's a different father.

(Samina)

Her explanation demonstrates that although both types of donation are forbidden in Islam, Samina feels, as did Anjali, that sperm donation is in some way tangibly different from egg donation. Gestation appears to be the important factor in conferring a link with the mother onto the child, which is not available in the case of sperm donation. This was especially expressed by Samina, Gita and Ramesh, perhaps since it is they who have made the decision to go ahead and use donor eggs, a decision which the other participants had not had to fully contemplate.

At the time of the interview, both Samina, and Gita and Ramesh, were actively looking for an egg donor. Samina was searching for a donor in the UK, after being told by the clinic that she was attending that there were no Asian donors. She and her husband had decided that they were happy to use a white donor. However, the clinic were not willing to carry out this request. They were told that they could bring their own donor (i.e. not an existing clinic donor, and who was either white or Asian) in order to have treatment. In Gita and Ramesh's case, they were planning to return to India for a second attempt at IVF, this time using an egg donor. They had been asked to provide photographs to the clinic, which would then be used to 'match' them to a donor. Donor selection was therefore central to both these participants' accounts. In both cases, some level of physical resemblance was crucial for the couples in order that the child would fit in and would not look out of place. This was reported as being due to the fact that the couples were not planning

to tell anyone about their use of donor gametes. As Ramesh explains, they would want the child to appear to be 'theirs':

There has to be some resemblance. You know what I mean, otherwise it would look like an adoption and, I mean, that's something we'd never do.

(Ramesh)

However, there was recognition in both cases that this was out of their control and that the child may not look like them, despite their best efforts. It was reasoned that this was something which often happened in families that were genetically related anyway, and therefore could be explained away later on:

We see a lot of families and two or three kids but, you know, one doesn't look or two don't look or, [laughter]...

(Ramesh)

I think it's okay, [laughter] this is okay because lots of children, they don't look like their parents, their features, their face, everything is different.

(Samina)

The laughter in both of these examples seems to be significant. As they talk about the possibility of conceiving children who are not genetically connected to one parent, laughter is used to dissipate the anxiety of the situation. Although Ramesh and Gita had been asked for information about their physical appearance in order to match them with a donor, Ramesh was sceptical about whether or not this would result in the clinic finding a suitable donor. He was concerned that they might request certain criteria for a donor which would not be fulfilled by the clinic. However, having treatment in India assured them that the clinic would at least be using eggs from an Indian donor. In Samina's case however, the shortage of eggs in the UK, especially from South Asian donors, had led her to consider using eggs from a white donor. This was primarily led by her desire to have treatment as quickly as possible, as her fertility had deteriorated quickly over the past four years

since having her first ovary removed in Pakistan. She was now fearful that something would happen with her uterus, which would prevent her from achieving a pregnancy before she had chance to find a donor:

We asked to the doctor, we are prepared to take English donor. Because I want to have IVF as soon as possible because I don't want if something bad happen again, with my uterus, I don't want to lose this chance.

(Samina)

In contemplating the appearance of a child that resulted from the use of eggs from a white donor, Samina reasoned that in mixed relationships more generally, the child often 'looked Asian', and therefore this wouldn't be a problem:

Lots of families, or couples, if the guy is Asian and the girl is English and when they have baby, it looks like Asian, yeah? So that's why we thought, okay, it's, it doesn't matter, if it looks Asian, it's will, it won't be a problem, nobody will know.

(Samina)

Nadia also contemplated the possibility of using eggs from a white donor: '*as long as they've got dark hair and dark eyes, yeah, but can you imagine me having a baby with blonde hair?*' She reported that this had not been offered to her at the time of her treatment. Instead she was placed on a waiting list (where she had apparently remained for the past few years) for an elusive Asian donor.

The view that using a suitable white donor (i.e. dark eyes, hair, skin), which was a definite possibility in Samina's view (and perhaps may also have been for Nadia), appears to be at odds with clinical practice in these cases. In Samina's case, the clinic told her that they were not willing to use a white donor for her treatment. Instead, it was suggested that she went away and found her own donor – either a sister or a cousin – who was willing to act as a donor. However, the use of a family or known donor was considered as

problematic by Samina, and also for Gita and Ramesh, but for slightly different reasons. For Gita and Ramesh, they did not want the donor to have any further involvement in the child's life, and would prefer not to tell the child the nature of its conception. With a family member knowing about the donation, this would cause them to worry that this information would be leaked:

Gita: Yeah, I think, really we'd rather go to somebody we don't know.

Ramesh: Because we'll always have that over our heads.

In Samina's case, she and her husband were also worried that the information would be leaked, but because the use of third party donation was *haram* in Islam, and there would be implications for the child if this became known:

We can't ask in our family because, if we ask there because, according to our religion, it's illegal and that's why we don't tell to our family and we don't ask to them because we know it won't be good for baby.

(Samina)

This comment shows the way in which Samina's perception of what is acceptable differs from the official religious view of gamete donation. In relation to family donation, Samina also pointed out that her sister is younger than she is and is unmarried, without children of her own, and so therefore would not be considered as a suitable donor (as clinics prefer donors to be women who have had children of their own).

Disclosing the use of ARTs

As illustrated in the previous section, the issue of people finding out about the use of infertility treatments was of great concern to many of the participants, especially those who were planning to use donor gametes. In the same way that people attempted to conceal the fact of infertility from those

who it was felt could not be trusted (as discussed in the previous chapter), so too the participants limited who they shared information about their treatment with. It was felt that to some degree, other people must guess that a couple were having problems conceiving (due to the lack of a child), nevertheless all of the participants had been selective when deciding to share this information. Only one participant, Safiya, reported having been completely open about her use of IVF. The other eleven participants who had used, were currently using, or about to begin using ARTs had disclosed this information to varying degrees.

One common pattern of disclosure was that a woman confided in her own natal family, most often her mother, sisters and other close female relatives, but the couple had not disclosed the information to the male partner's family. This was the case for five of the women in the study:

They've been fine, it's not a big issue, like, with certain families, it is. Erm but with mine, it's not really, it's just normal... They don't know on his side, I never told them, because I feel as though, I only want to tell the people I want to tell. If, erm as far as I'm concerned, they don't have no interest [laughter] in knowing.

(Anjali)

Although it wasn't explicit in the accounts, a lack of disclosure to a woman's in-laws may be related to the underlying fear of implications for that relationship, which as we saw in the last chapter, can potentially have drastic consequences, such as divorce.

I don't know how they, his family would have reacted.

(Rita)

However, where the women had a good relationship with their in-laws, some had chosen to tell both sets of parents or select relatives on both sides of the

family (n=5). For two of these five women, Nadia and Asma, their mother-in-laws in particular had been very supportive.

The remaining two participants (Samina and Jasmin) had only decided to tell acquaintances or friends who were in no way connected to their families. Since Samina was actively trying to find an egg donor, it was necessary for her to talk to people about her infertility, but as already described, she had decided not to try to recruit a donor from within her own family. Jasmin had decided not to tell anyone within her family for fears about the information leaking to others. In some cases, telling others was for purely practical reasons. As Nadia points out, if something were to 'happen to her' she would want her mother to know:

I only told my mother because like, I thought, you know, if something happens, you know, I want her to know about it.

(Nadia)

However, for a small number of participants, disclosure about treatment was used as a tool to resist and challenge what were seen as more traditional views amongst the South Asian community. Both Safiya and Anjali described how they had disclosed, or planned to disclose in the future, the way in which they conceived their children. For Safiya, this was related to her view that having her daughter after so many failed attempts at treatment was a huge achievement, of which she was very proud:

If somebody says 'oh, she's lovely' I'll say, 'she's an IVF baby', and I've always been proud of that. One, because in our community they don't like it. Because it's something they don't like to discuss. I've even been told...by people in [my husband's] family not to advertise that she is an IVF baby. And because of that, I refuse to do it, I'm proud of the fact that I can't have children but she is what, can come out of, just trying and sheer will-power and, and I'm so proud of her.

(Safiya)

Anjali also saw what she had been through as 'a miracle', and felt that she had a duty to talk openly about her experiences in order to help others in the same situation:

To be honest, I don't care if the whole world knows that I've had IVF treatment and stuff. But being Asian, the community is just messed up and it's my husband who doesn't want people to know and stuff like that, but me, I'm happy. [Laughs] I'm not bothered, 'cause it's a miracle. You know? And I'll be helping other people that are too scared to come out and talk.

(Anjali)

However, despite the varying degrees of disclosure, almost all of the participants who had been through some form of treatment had experienced the stress associated with 'managing' the information about their treatment. For those who had not told any family members, such as Jasmin, the day-to-day practicalities of concealing treatment (syringes, infertility magazines) was at times demanding and traumatic.

You know, it's like, you always have to be in that one step ahead of them, and it's quite stressful itself.

(Jasmin)

Rita also talked about the excuses that she had had to come up with in order to stop people asking questions. She had told people that she was anaemic in order to explain the medication and the unusual hospital appointments:

You couldn't tell why you were going to the hospital and they were wondering, sometimes you have to go for injection on Saturday and they wonder why I have to go for injection on Saturday, you know, and when I used to go to, like a family wedding, I used to get changed very quickly and I used to rush to the hospital, come back, get changed and get into the public again.

(Rita)

However, for Padma and Jasmin, the hospital itself was considered to be a risky space, where it was felt they could quite easily be seen by someone who knew them and would want to know why they were there. Padma described an incident where she had been in the clinic for a procedure for which she had required some sedation, and so was feeling 'very groggy' and was being 'held up' by her husband. They bumped into her aunt and cousin who wanted to know what they were doing at the hospital. Padma reports that she had to think very quickly, and told them that they were there visiting a friend who had just had a baby. For Jasmin, the possibility of bumping into her mother-in-law at the hospital held a very real risk of unwanted disclosure about why she was there:

My mother-in-law being my mother-in-law, she knows the hospital inside out [laughter] and she'll probably ask questions, I know the people in hospital probably won't say anything but it's like she will find out, if there's a means, she will find out.

(Jasmin)

As discussed in the previous section, the issue of disclosure was perhaps particularly pertinent for those couples who were using donor gametes. For Samina, there was a concern that there would be implications for how the child would be accepted by the family if it were known that she had used donor eggs:

Then in future, if we will have a child you know, they will feel some gap... 'oh God this is not belongs to me'.

(Samina)

The participants discussed their plans to tell their child about the nature of their conception. For six participants, this was a real and current situation, in that they had all had a child conceived using ARTs and were faced, or had in the past been faced, with the decision to tell them. Three of the six had already told their child about the way in which they were conceived (Rita,

Aisha and Safiya). For them, they had explained by telling the child that they were very 'special' because of the way they had been conceived, and how much they had been wanted:

He knows that he's a special baby, he knows that Mummy had to go through a lot before he was born, he knows that.

(Aisha)

The remaining three reported planning to tell the child in the future, but felt that, at present, they were too young to understand. There was a substantial amount of discussion about the best time to tell a child. For Narinder, telling her young daughter now was risky due to her age, as she might inadvertently disclose this information to others:

*I will tell her when she, she's old enough to understand, yeah, I would, but she's, at this age, if I was to tell, she would go round telling everybody.
[Laughter].*

(Narinder)

In a slightly different approach to some of the other participants, Sita wanted to make sure that her child knew that she was 'normal', and not different to anyone else:

I want her to think that she's normal, and just as everybody else, but she was just brought about in the world in a very different way.

(Sita)

Sita felt that this would be made easier in years to come because of the increasing use of ARTs, which meant that there would be an increasing amount of children conceived in this way, and therefore, it would eventually become the norm.

For the participants who were currently still trying for a child (n=5), whether or not they planned to tell the child was dependant upon the treatment they

were using. For those planning to use donor eggs, they were very ambivalent about the prospect of telling the child. Ramesh felt that he and his wife didn't want to tell the child, but that this view may change:

Only time sort of will tell, but I'm not sure whether we'd want to.

(Ramesh)

Samina did think that she would tell the child, but planned to do this much later on. Her consultant had raised the issue of using a white donor with her, and it being of increased importance that she told the child about his or her origins:

I don't want to tell child, okay, when they grow up, twenty years old and then I can tell them because maybe in future, sometimes, you have problem like this, ...because sometimes the English people and the Asian people have different genes because that's why they looks different from each other so I think it will be important for my child like, like he should know, and maybe then I will tell them, when he or she will be twenty years old, something like that.

(Samina)

The prospect of telling a child about its origins was a decision that was still a long way off in some of the participant's journeys, especially for those who had yet to achieve a successful pregnancy. Thinking about the future, and what it held for the participants, was often a difficult experience, with all of them feeling that their situation was yet to be fully resolved. Even for those who already had a child, the prospect of having further treatment, or the prospect of ending treatment once and for all, was contentious. All of these participants described a tentative future, one which held, in various ways, uncertain and ambiguous potential.

Tentative futures: achieving normality?

Deciding to end treatment

In a variety of ways, all of the participants in this study described how they felt that their lives had been severely disrupted by infertility. For all of them, there was a level at which this disruption had yet to be resolved, even for those who had become parents, and decided not to have any further treatment.

Deciding whether or not to continue with treatment, was a decision that many of the participants had faced at some time. However, deciding to end treatment altogether had only been discussed by six participants. Like so many other elements of this experience, making decisions about ending treatment was closely related to the point at which the couple had reached in the treatment process. Therefore, for those people who had only just begun treatment, or had not started any treatment, this had not yet become an important issue. However, for those who had gone through multiple, and often costly treatment cycles, deciding to end treatment was a difficult but unavoidable crossroads.

Ending treatment was often related to the emotional, physical and financial impact that using ARTs entails. Three of the women (Aisha, Safiya and Rita) had made the decision that 'enough was enough', and they would not be having any further treatment. Of these three, Rita was the only one who had reached some level of resolution, as she had gone on to have a second child naturally and felt that her family was now complete. However, Aisha and Safiya both described unresolved emotions about their experiences and reported how they would have liked to have a further child. Having a sibling was a strong reason to continue treatment, and was mentioned by five of the

participants in total. In some cases, the participants' existing children had started to ask why they didn't have a brother or sister:

I think those sort of things can break your heart... If you decide you're only going to have one, I think that's easier to cope with, but if you always wanted perhaps a couple, then, it's a bit harder as well.

(Narinder)

Aisha had actually returned to treatment to try for another child when her son was a few years old, but the pressure of the additional procedures had subsequently led her to decide to bring this to an end:

Within three years we decided to have another IVF [laughter]. We wanted a brother or sister ...and we went through that again. I must have been mad, honestly [laughter]. ...So, obviously mentally and physically, I was very tired. Very, very tired. And the day I decided that this is it, this is it, you know, I haven't regretted that day.

(Aisha)

Safiya was prevented from trying for a second child by the prohibitive cost (she was not eligible for treatment on the NHS, despite having funded nine cycles of IVF herself), and the physical and emotional trauma of going through more treatment. Despite the emotional costs involved in ending treatment before fulfilling all of one's hopes for a family, this decision marked a point at which they were at least no longer beholden to the medical sphere of expertise; a change after which, to some degree, they could feel 'normal'. A degree of normality was highly significant for people, especially when they had at times experienced feeling abnormal, inadequate and marginal. Nevertheless, for some, ending treatment did represent giving up hope, something which they hadn't wanted to do.

The 'need to have tried', was one which was mentioned by five of the participants. This was tied into decisions about future treatment and to any

possible future resolution; if you had given it 'your best shot', you couldn't ask for more from yourself:

I'm gonna have three more attempts, that's it. Can't do any more than that.

(Sita)

Time is ticking on as well, you know, for us, and before it's too late really...at least we can say we've tried.

(Ramesh)

Sometimes, I think, was it really all worth going through all that, then I think oh, if I would have a baby then it would have been worth it, then you know, if you don't try then you won't know, will you?

(Nadia)

When the doctors give up

Deciding to end treatment, or thinking about the point when making the decision to stop would come, was difficult for people to deal with. However, perhaps even more difficult was when the medical professionals decided that treatment was not working and should be stopped. This happened to three of the women (Rita, Aisha and Safiya) and they described these fateful moments with great emotion; the thought that the medical experts themselves had given up was very distressing:

They said 'we've tried everything, we've tried different dosages, we'd done, what we could do, and I think this is the end', and I came out and I saw this baby go by and I burst out and I thought, you know, that's it.

(Rita)

And then one day he told me that, 'do you believe in God?' And he said, 'If I were you I would, you know, pray and meditate, because that's the only way you've got now'.

(Aisha)

Safiya had a similar experience, when one day she was called in to the clinic by her consultant and told that there was no point in continuing with treatment, as it wasn't going to work. However, as had Rita, Safiya persuaded the consultant to continue and not to give up:

So, I can remember saying to him 'there is no way on this earth that you can let me down because you are the only person in this world that can help me, you or God'... So I said to him, 'as long as I'm paying you and as long as I am willing to go through the IVF, you have to continue'. And he said, 'Fine, I'll continue and we can keep doing it but I just want you to know that I don't think it'll ever happen'. And I can remember being so distraught, but coming out of there thinking, well, what do I do? If this guy's given up on me, I've got no hope. I've lost it and I felt so, so lost and empty that day, and I can remember crying all the way home.

(Safiya)

Continuing to feel infertile

The feeling of being an infertile person was one which did not fully dissipate on entry to the world of parenthood. Talking about their experiences was a vivid reminder of what they had been through, both Safiya and Aisha both describe in detail how the experience of infertility never goes away:

I mean, the one thing you don't forget is the feeling of being, kind of, an infertile person, you don't forget that and that pain never goes away. And, and just because you have a child, the fact that you've got a child and you can be a mother and love somebody is amazing, but you never forget, you don't forget the pain.

(Safiya)

For Aisha, talking about her experiences in the interview made her realise that she still had a lot of unresolved emotions related to her infertility:

And sort of like, just, you know, talking about it has brought all the emotions back and I thought I've gone through that, I've you know, I've put this in a sort of an envelope and I've posted it, you know? [laughter] But it's still there.

(Aisha)

Safiya talked at length about the way in which infertility continued to be a part of her life. One reason was that she was still suffering from endometriosis, which meant that in very fundamental health terms, she was still 'suffering'. She described how the condition impacted on her everyday life. On the other hand, not being actively involved in any kind of medical treatment, either for her endometriosis or to overcome infertility through IVF, was a welcome relief, and allowed her some normality. However, she recognised that this was a temporary state, and that at some point this would need to be addressed:

It's like, it's almost like I'm pretending at the moment to be a healthy person, not be one of these people that need to go to doctors all the time and it's been so nice. And it's just been nice to just live my life and I just don't want to go back to having to juggle everything around, doctors appointments and people prodding me and probing.

(Safiya)

She also discussed how having had her child didn't mean that she no longer identified herself as an infertile person. For her, the association with others who can't have children was stronger than her association with her friends who have been able to conceive:

And I still identify with people who can't have children, I still have a lot of friends, not Bengali, a lot of white friends, who, you know, can't have children...I still feel as if I'm one of them and not one of them. Although...it's accepted with the children crowd that I can't have children. It makes me, I feel more to do with that other crowd that, you know, haven't got involved yet.

(Safiya)

Although the number of participants who were in the position of having ended treatment, and who were now trying to move forward with their lives was relatively small (n=3), their testimonies illustrate how their infertility had a profound and ongoing effect on them. The identity of being infertile was

difficult to disassociate from. Even when people were carrying on in their everyday lives and treatment was long behind them, the feelings and emotions associated with infertility were very evident.

Summary

This chapter has presented the participants' narratives on the treatment process. In doing so, it has highlighted the ways in which this group of participants negotiated with biomedical experts, as well as drawing on religious expertise in order to assist them in their goal of parenthood. Negotiating technologies, such as IVF, demonstrate how this is a journey which is characterised by feelings of anxiety and a lack of control, since experiences of ARTs are more often marked by failure than not. The significance of information control is also apparent in this data; deciding who to tell about infertility treatment was central to a number of the stories in this thesis. Finally, this chapter has shown how the status of being an infertile individual is one which is not easily relinquished.

The next chapter aims to draw together the findings from both the focus groups and the interviews, and discusses them in relation to sociological theory and the research literature on the infertility experience.

Chapter Eight: Exploring the relationship between ethnicity and infertility

Introduction

The aims of this study were to explore the social constructions of infertility and assisted conception in South Asian communities, and the experiences of South Asian women who have used ARTs. To demonstrate how these aims have been fulfilled, this chapter uses theoretical insights from Bourdieu and Goffman, in order to highlight how structure and agency impact on the individual as they seek resolution from the personal crisis of infertility.

The chapter is organised theoretically, using key concepts (habitus, capital and field) from the work of Bourdieu to structure the discussion. The first section on habitus, highlights how a range of social identifiers were key in shaping the practice of being a childless person. This section draws primarily on the interview data, and where appropriate, the focus group data, to illustrate how gender, ethnicity and religion are significant elements of the habitus for understanding this experience. The following section on field explores how two significant social spaces are central to the experience of infertility – the community and the clinic. This section draws on both data sets to illustrate the importance of social context. It also uses Goffman's conceptualisation of stigma to illuminate particular strategies and practices in relation to infertility, which characterise these fields. Finally, the section on capital explores in particular how economic capital is central to this process, particularly in relation to accessing treatment.

Habitus: exploring the relevance for infertility & subjectivity

Much of the writing about infertility, particularly from within the psychological model, has tended to focus on the ways individuals cope with childlessness. Even those writing from a sociological perspective, have paid little attention to the diverse ways in which infertility is culturally configured, especially in Western contexts. Where the reporting of experience is socially differentiated, the focus has tended to be on the ways in which infertility is gendered, with scant discussion of how these gendered experiences are mediated by culture, ethnicity, religion, socio-economic status and what I have termed 'the moral context'. In this section, I will explore the relevance of Bourdieu's concept of habitus for understanding the ways in which a range of subject positions intersect to shape experiences. As discussed in chapter two, the concept of habitus allows an exploration of the ways in which both structure and agency work to shape individual identities; it provides a bridge between objectivism and constructivism (Haimes 2003). Bourdieu's concept of habitus allows an exploration of the ways in which individuals work as agents and strategists within existing social structures. These social structures are in turn shaped by the habitus (see Figure 5).

Importantly, as highlighted in chapter two, the individual habitus has shared elements with others who are subject to similar experiences (May 1999, Wacquant 2006:6-7). As Bourdieu suggests, 'the habitus... produces individual and *collective* practices' (1977:82 my emphasis), such as those expressed in terms of gender or ethnic group membership. This section therefore describes the impact of different elements of the habitus on the individual experiences of infertility for the interview participants in this study. Drawing on the ways these elements present a pattern in the data, gender, ethnicity and religion in particular, are explored in order to better

understand how these are simultaneously shaped by and shape individual experiences (Figure 5). These social signifiers are highlighted, as they were the elements of the habitus which had most relevance for the participants in the study.

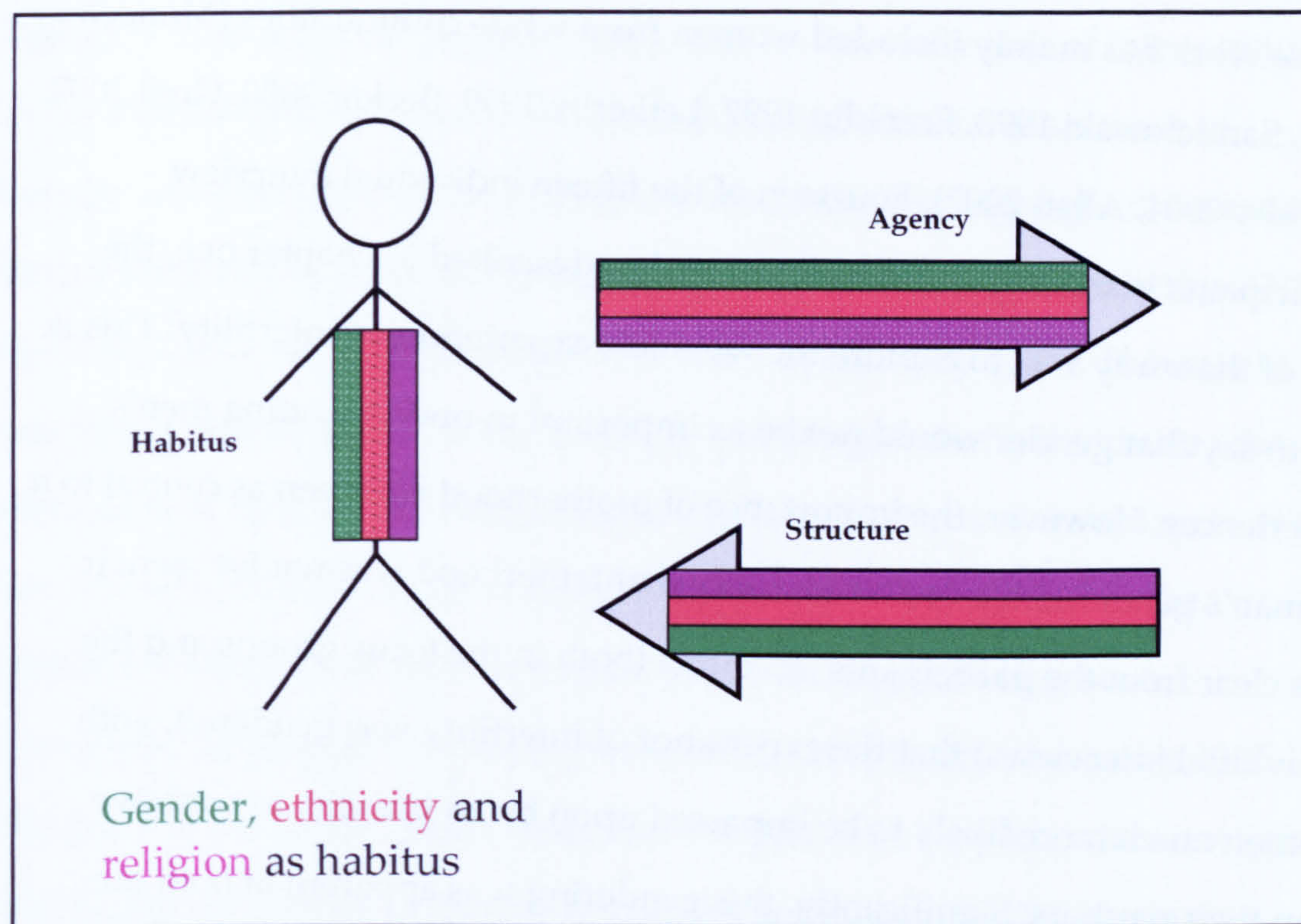


Figure 5: Gender, ethnicity and religion as habitus

Gender

Gender as a form of shared habitus has not received notable attention in the existing literature. However, in one paper, Lois McNay (1999), describes how a Bourdieusian reading of gender can be used to explore relations between men and women, as well as between women and dominant representations of femininity (1999: 104). This, she suggests, allows for a reading of women's negotiation of autonomy within a framework of male domination. How individual women negotiate their place in the gender order can therefore be understood within this theoretical framework. Given this understanding of gender identity as a form of collective and subordinated habitus (whilst

allowing for agency and individual differences), an explanation of the collective female experience of infertility can be proposed.

The role that gender played in shaping the experience for the women in this study was significant, and in this way confirms the findings of other authors whose work has mainly included women from white communities (Monach 1993, Sandelowski 1993, Franklin 1997, Letherby 1999, Becker 2000, Greil 2002, Throsby 2004, Allan 2007). Fourteen of the fifteen individual interview participants in this study were female and as described in chapter one, the aim of the study was to explore the woman's experiences of infertility. This is not to say that gender would not be as important in understanding men's experiences. However, the importance of motherhood was seen as central to a woman's gendered life course in a way that fatherhood was not for men. It was clear from the participants' accounts (both in the focus groups and the individual interviews) that the experience of infertility was gendered, with women much more likely to be impacted upon by an inability to conceive than their partners. Significantly, this gendering was apparent at both the individual and the social level; the women themselves reported this, as did the focus group participants. The cultural ideal of transition to motherhood for adult women is clearly a pervasive one, both in Western contexts (Maher & Saugeres 2007), as well as other socio-cultural settings (Ram & Jolly 1998). The public discourses around infertility further confirm the view that the experience of infertility is gendered. It was widely reported in the focus groups, for example, that childlessness is more difficult for women than it is for men, with women tending to take more of the blame for infertility in the social sphere, even in the case of male factor infertility. The data from this study support this evidence and demonstrate how the desire to become a mother is dependent upon both individual needs as well as wider cultural and community expectations.

Disruption to the gendered life course

As discussed in Chapter Three, the work of a number of authors, suggests that the life course is perceived, at least in Western cultures, as linear and progressive, and as such any interruption to this imagined trajectory is often experienced as traumatic and unsettling (Becker, 1994, 1997, 2000, Exley & Letherby 2001, Earle & Letherby 2007). This is especially true of interruptions to the reproductive life course in which powerful cultural discourses of lineage and continuity tend to dominate, and therefore highlight divergence from the normal cultural progression to parenthood (Exley & Letherby 2001, Letherby 2002, Becker 1994, 1997, 2000, Earle & Letherby 2007). The data in this thesis confirm these earlier findings, and suggest that individuals who discover that they are infertile, experience acute *biographical disruption* to their lives for which they seek resolution. This process is highlighted in the literature as gendered, with women in particular experiencing acute disruption in reproductive terms (Friese et al. 2006, Earle & Letherby 2007). The participants in this study described the pain that they felt when not being able to conceive either naturally or, later for some, with ARTs. Having children was perceived as the natural and inevitable consequence of marriage within South Asian kinship networks, particularly for women, and this was the case both for the interviewees as well as for the focus group participants, who collectively expressed the importance of procreation for the stability of female adult identity. Becoming a mother was seen as a rite of passage, which was both important for the individuals themselves as well as for the successful placing of them by others within the community context. The uncertainty of a future with no children in it was troubling for the participants in this study, as well as for members of their wider kinship networks, demonstrating the communal and individual expectations for women in South Asian communities.

For all of the interview participants in this study, the disruption caused by their inability to conceive meant that they felt at times that their lives were literally 'on hold'. Unexpected and involuntary childlessness meant that life plans could not proceed as expected, and that as a result, the future that they had anticipated for themselves was thrown into chaos. This experience of being 'in limbo' (Becker 1997) has been a common finding in the research literature on infertility with white women (Becker 1997, 2000, Franklin 1997, Tjørnhøj-Thomsen 2005, Allan 2007). For the women in this study, the disruption to their lives caused by infertility effected a change to their expected life trajectory. However, so far any discussion in the available literature has been limited to a consideration of the concept of 'disruption'. I would argue that the idea of a disruption is insufficient in explaining the ways in which this impacted on the participants' gender identity. The emotional trauma that they felt at being denied what they saw as the same reproductive choices as other women, was highly significant. I therefore propose that the impact of a disruption such as infertility to the gendered life course is accompanied by a period of biographical *liminality*, in which one feels that life is on hold. This theorisation relates to the way in which the concept of liminality has already been used in the research literature; that is in the way in which it impacts existentially on the individual. The concept of biographical disruption is therefore renamed as biographical liminality in this thesis, in recognition of the extended state of 'being in between'. The impact of this state of limbo for the habitus is discussed at the end of this chapter.

This state of biographical liminality was marked by the pregnancies and birth events of female relatives, which acted as a moral and temporal marker to remind the women of what they were missing. As Earle & Letherby (2007) suggest, reproduction is marked by a series of biological events, which women are expected, and they themselves expect, to enter into. The embodied

nature of fertility and childbearing for women meant that the absence of the physicality of pregnancy was a particular concern, again in a way that it was not for men. Not only did other people's pregnant bodies highlight the absence of conception that they were experiencing, but the social event of the birth of a new baby brought with it an additional upset. The feeling that they were being left behind, whilst other couples got on with completing their families, made dealing with births in the family very difficult. These examples served to highlight how infertility left these women feeling a lack of control over their futures, especially in terms of making any firm life plans. This feeling of a lack of control extended to the infertility treatment process, and meant that it was not easy to imagine their lives beyond the immediate present. The data from this study highlight the significance of the concept of 'disruption' in understanding how women from South Asian ethnic groups experience infertility. As suggested in Chapter Three, the conceptualisation of disruption in the existing literature is inadequate, in that it has tended to focus on the experiences of white women in this respect. It is further problematised in this study as an insufficient theorisation of the experience, one which is enhanced with the use of the concept of biographical liminality.

Practicing motherhood

It is widely agreed that, in pronatalist societies, status for an adult woman is conferred through becoming a mother (Phoenix et al. 1991, Maher & Saugeres 2007), and as such, a number of the participants in this study described how they had adopted parenting roles which to some extent fulfilled this desire and social need to become a 'real' woman. The practice of social parenting as described in Chapter Six, was particularly significant in this respect. The women used this practice of parenting to produce themselves (at least in the interviews) as mothers. Enacting the nurturing role of mother through practices, such as caring for nieces and nephews and 'adopting' overseas

children, allowed the women to express these elements of their gender identity, thus proving themselves as 'deserving' of the role of motherhood. This reflects the findings from research with childless women, who also reported engaging in the care of nieces, nephews and friends' children (Throsby 2004, Wirtberg et al. 2007). The concept of habitus is particularly useful here since it demonstrates how cultural practices are significant for individual subjectivities (Bourdieu 1977). In this case, the playing out of mothering practices simultaneously draws on and reinforces wider cultural norms of South Asian femininity, highlighting the fact that agency does not necessarily always need to be resistant (Szkupinski Quiroga 2007). This illustrates how even apparently marginal narratives are drawn from within the dominant field itself (Reminnick 2000). Throsby (2004) describes such a practice as 'meeting the motherhood criteria' (2004:177) and in doing so, women are 'laying claim to the normatively determined aspects of motherhood' (2004:171).

Although these practices were commonplace and held value for the women who described them, they were not a substitute for the role of pregnancy, childbirth and biological motherhood, which held shared symbolic capital in South Asian communities (Inhorn & van Balen 2002). The overriding need for having one's own children demonstrates the valorisation of biological motherhood for adult gender identity, a finding which supports the conclusions of research with women of a range of ethnic and national identities (Inhorn 1994, 1996, Cabello 1999, Letherby 1999, Becker 2000, Reissman 2000, Remenick 2000, Greil 2002).

Gendering of the treatment experience

The focus on women is further compounded within the medical sphere, with the woman's body being the focus of testing and treatment. In Chapter Seven

the individual participants described how the focus on the woman often presented a disjuncture between the experiences of her and of her husband. This was particularly significant in the case of Aisha, who described the impact on her marriage as a result. She felt that, to a certain degree, this experience was one that she had gone through alone, and save for providing the sample and helping to fund the treatment, her husband had not gone through any of the same experiences she had. The embodied nature of the treatment process, in which the woman is the one who is enacting the treatment through attendance at the clinic, being scanned, having injections etc., further compounds the gendered nature of this experience. Data from the focus groups confirm this finding, with many female participants pointing out that it would be the woman's responsibility to seek treatment if a couple were having problems conceiving.

The finding that the infertility experience is shaped by gender, suggests that perhaps it can to some degree be described as an experience with commonalities for women across all ethnic groups in the UK (and in ways that are different than for men), since for all main ethnic communities in the UK, the role of mother appears to be salient for adult female gender identity. As infertility disrupts gender identity in such a profound way, it could be argued that infertility becomes incorporated into the habitus of childless women, and implies to some degree that the infertility experience has generalising elements regardless of ethnicity, religion, social class, age and nationality (although perhaps not regardless of culture, to the extent that small world counter-cultures to the motherhood mandate exist within UK society, such as those which might be articulated within some feminist analyses; for example see Gillespie 1999). The idea of infertility as a form of habitus is discussed at the end of this chapter.

Ethnicity: the significance of 'descent and culture communities'

As described in Chapter Two, Fenton refers to the tangibility of ethnicity as something 'out there', despite its socially constructed nature. In wanting to articulate what the 'something out there' is, he describes ethnicity as being about the elaboration of a shared ancestry into communal relationships and it is this definition of ethnicity which is used in this thesis (2003: 3). A shared sense of values and belonging were clearly expressed to me throughout the fieldwork, for example, several people talked about the importance of South Asian 'culture' in understanding the experience of individuals. However, Fenton warns of treating 'descent' and 'culture' with equal significance when understanding ethnicity and this was certainly true in this study. As was seen in Chapter Four, some of the participants questioned the use of ethnic categorisation used in the study, clearly seeing themselves as members of distinct ethnic or 'descent' communities, which I had not used, such as those who had originated in East Africa. However, the concept of British South Asian *culture* appeared to be something material that impacted on the lives of individual members, and to which they related. However, following the work of Bourdieu (1990a) as well as others (Ahmad 1996, Brah 1996, Kelleher 1996, Ahmad 2006) the approach used here is to explore how culture is fluid and lived rather than static and proscriptive.

In both the focus groups and in the individual interviews, participants described how reproduction and parenthood were viewed through a cultural lens. This shaped the ways in which certain practices were viewed as permitted or acceptable. Equally, those practices that were disapproved of were also shaped by culture. However, the impact of culture, or a shared moral framework, was mediated by a number of other factors within the individual habitus, gender, as we have seen, as well as religion and the

impact of economic and social capital which will also be discussed in this chapter.

The perception of ethnicity as something 'out there' which was exerting influence, and was reproduced through practices, was confirmed in this study. The focus group data offer a particularly novel insight in this respect, in that a collective voice was often used for expressing and representing an 'imagined' moral and bounded community (Anderson 1991, Atkin & Chattoo 2007), in which specific practices are tolerable. As Anderson suggests, 'Communities are to be distinguished, not by their falsity/genuineness, but by the style in which they are imagined' (Anderson 1991:6). There was a clear consensus, for example, on the issue of parenthood, with little possibility for married couples to choose not to have children. The focus groups also voiced the opinion that pressure on women to produce male children was a source of cultural constraint in reproductive terms. Stories about the negative, or less enthusiastic, reactions of family members to the birth of a baby girl were common amongst all the focus groups in this study, illustrating how cultural practices shape people's experiences. However, as was discussed in Chapter Five, representing a coherent and definitive community view on these issues is problematic.

In many South Asian families, a daughter effectively moves in to the family (and sometimes household) of her new husband upon marriage (Bradby 1999), a point that was also made by a group of older Sikh women (focus group six). It was therefore pointed out that infertility can serve to restrict the potential for a woman to find a suitable marriage partner, which was evidenced in the case of Charanjit, who had not married on account of experiencing premature ovarian failure. The impact of infertility on women who have yet to marry is therefore critical, as this information can curtail their

chances for marriage and independence from their own parents (Charanjit was living with her parents at the time of interview). However, this can also lead to new marriage strategies, or new ways of defining adult femininity. Charanjit had, for example, established herself in a career and played an active role in the lives of her young nieces; she does however remain unmarried and sees no possibility of marriage because of her infertility.

In another example, Samina highlights the importance of community perceptions of female gender identity in her narrative in terms of marriage prospects. She describes in Chapter Six how, on hearing about her fertility problems, her 'whole family was crying', with the recognition that impaired fertility would considerably reduce her chances of finding a suitable husband. Samina, however, used this situation to her advantage, and renegotiated marriage to someone who became an acceptable partner in light of her identity as an infertile woman. Far from being a negative consequence, Samina was able to actively negotiate a positive outcome in this context, and this finding demonstrates the importance of agency in negotiating apparently fixed rules about marriage (Bourdieu 1990a, Ahmad 2006).

The significance of marriage for South Asian women has been highlighted by a number of authors (Bradby 1999, Fenton 1999, Ahmad 2006), and marriage was clearly articulated as mandatory in the focus group discussions.

However, these processes can be fluid and open to negotiation as Ahmad (2006) demonstrates in her discussion of arranged marriages. This thesis supports the idea that the specific shaping of femininity in South Asian communities is potentially open to negotiation. Infertility is presented in the public domain as a threat to a woman's marriage prospects, but this does not necessarily imply a closing off of the option of marriage for infertile women, as was the case with Samina. Infertility will also affect a married woman's

position in the family, in a way that it did not for men, and the impact of this is discussed later in this chapter. These examples illustrate the complex ways in which gender and ethnicity are intertwined within the habitus.

In addition, the function of divorce and remarriage as a solution to the problem of childlessness was also mentioned in the focus groups, further demonstrating the operation of culture in relation to this issue. Of course, this is not to say that this solution might not be used in other cultural settings, such as in white majority cultures. However, there were also clear levels of resistance to some aspects of this moral framework, particularly from the younger members of the focus groups, and this is discussed in more detail later in this chapter.

One practice that exemplifies the importance of the shared moral framework is that of gamete donation. As will be elaborated below, there were clear religious reasons to disapprove of gamete donation, especially in Islam. However, there was also a view that gamete donation was *culturally* unacceptable and therefore, that even if someone decided to use this treatment, they would not disclose this to others (as seen in the cases of Samina, and Gita and Ramesh). In another example from the data, Charanjit had decided not to take the option of donated eggs, although this was something she had contemplated. This decision was clearly impacted on by the cultural mores around single parenthood within South Asian communities; for Charanjit, exploring options of motherhood outside of marriage was something she could not consider. As Bharadwaj (2003) argues, it is the invisibility of gamete donation that makes it an attractive option to some, when compared with other solutions such as adoption. However, without the pre-requisite of a husband, her inability to conceive would be highly visible, and would render her doubly deviant. The cultural imperatives

of marriage and procreation within British South Asian communities mean that Charanjit's obvious fertility problem negatively affects her marriage prospects *as well* her plans for parenthood.

The significance of ethnic identity was most commonly raised in this thesis in relation to the impact of culture and community, and this has also been demonstrated in research with minority communities in the Netherlands (van Rooij et al. 2007). Few of the interview participants talked explicitly about ethnicity in relation to their own internalised subjectivities. In this respect, the impact of ethnicity on the infertility experience is highly complex and is mediated by a number of other factors, including gender, and, as will be discussed below, religion. However, the relational and structural elements of ethnic identity were clearly of importance in negotiating infertile identities in the public sphere. In a small number of cases, this was also experienced as racism within the clinical field, and this is discussed below.

Religion

This study illustrates how, as one element of culture, religious frameworks impact upon habitus and how participants draw on these frameworks in a variety of ways to inform their understandings of procreation and the use of ARTs. In particular, the significance of Islam for shaping the experiences of some South Asian couples was highlighted. The focus group and interview data with participants who described themselves as 'Muslim', supported the view that religion can impact on the experience of infertility (Inhorn 2003a, 2006). Marcia Inhorn describes how religion can operate as an 'arena of constraint' when couples decide to use ARTs (2003a), thus demonstrating the constraining role of particular elements of habitus. Significantly, the participants who described themselves as Hindu, Sikh or Christian, did not highlight religion as an important constraint in this respect. Instead a number

of these interview participants highlighted how religion was a source of comfort and support during this experience. These data illustrate, however, that even within constraints, individuals draw on particular cultural resources and enact agency in order to suit their specific needs. In this study, Samina, Safiya, Asma and Nadia all identified themselves as Muslim, and had all met with some level of resistance about whether or not IVF was religiously acceptable, often from within the family. Despite this, all four women had used IVF, and all had disclosed this fact to select third parties within the family or wider community.

IVF using a married couple's own gametes *is* considered acceptable within Islam (Clarke 2006, Inhorn 2006), but it is still a matter of contention in the public sphere. Several of the focus group members expressed concern about the use of ARTs, and whether or not they would be considered religiously acceptable within Islam (Chapter Five), demonstrating that religion is lived, and that the local moral worlds that individuals inhabit are as important in shaping lives as any formal ruling (Birke and Whitworth 1998, Inhorn 2003a). Samina and Nadia described how they were considering the use of donor eggs, and Samina was actively pursuing this option, by looking for a willing donor at the time of the interview. Given that Samina and Nadia were Muslim, it may have been expected that they would reject the option of donor gametes. However, this study highlights the centrality of becoming a parent, and for some this goal is sought despite any concerns they might have about the use of third party genetic material. Samina offers a complex explanation for her views about the use of donor eggs over the use of donor sperm, which she justifies by drawing on Islamic discourses of adultery. She suggests that it is only donor sperm which is problematic, since it severs the child's relationship with the father. In treatment that uses donor eggs, this relationship is maintained and, in addition, the mother/child bond is

conferred through gestation and childbirth, a finding which confirms other research on this topic (Culley & Hudson forthcoming 2009). In discussing egg donation, Samina works hard to re-negotiate what it means to have her own child (Tjørnhøj-Thomsen 2005). In discussing ARTs and how they naturalise the desires of infertile couples, Goslinga-Roy (2000) suggests that ARTs exclusively privilege one narrative at the expense of others, hence in the case of egg donation, the narrative of genetic fatherhood and embodied motherhood is privileged (see also Culley & Hudson forthcoming 2009). This view was also expressed in the focus group discussions (Chapter Five), with egg donation being perceived as marginally more acceptable than the use of donor sperm by community members, perhaps further clarifying for couples that this form of treatment is more socially acceptable.

These findings illustrate the importance of culturally located knowledges, and how they are informed by, and mutually inform a person's habitus. They highlight how religion is lived and how people interpret religious doctrine in the light of complex life decisions (Ramji 2007, Atkin et al. 2008). In Bourdieu's conceptualisation, Samina's example demonstrates the effects of agency on habitus, and how she has reinterpreted Islamic teachings around adultery and fatherhood, in order to make sense of the new form of motherhood practice with which she is about to engage.

The impact of descent and culture communities for understanding habitus is clear in this study, and supports the suggestion of a number of authors including May (1999), Culley (2006), Lynam et al (2007), that identities are created through a person's habitus. In particular, some of the complex ways in which facets of the habitus are entwined have been demonstrated in the first part of this chapter. However, understanding the social context in which ethnicities are lived, further advances the application of this theory.

Bourdieu's notion of the 'field' (1977), is helpful in this respect, and is one of the reasons why his work is 'good to think with' (Jenkins 2002) when theorising ethnicity. Fields are important in understanding the relational character of habitus, in that they permit an understanding of the social terrain and the actors within it (Swartz 1997). In this way, the spaces or fields in which people move are significant for their life experiences. In the context of South Asian communities, the centrality of the concept of community was clear, and whether or not it was 'imagined' (Anderson 1991), had a bearing on the lives narrated in the focus groups, as well as in the individual interviews. The next section explores the ways in which elements of 'culture' and ethnic identity were played out in community settings, or fields.

The significance of field for the infertility experience: the community and the clinic

Bourdieu suggests that a field is a distinct social space, a 'network, or configuration of objective relations between positions' (Bourdieu & Wacquant 1992: 97). Within any given field, these positions may be occupied by agents or institutions, and represent the broader social terrain in which individuals act out their lives. For Bourdieu, the fact that similar fields in different national and cultural settings are distinct, is due to the impact of human agency on their structures (1977, 1993). Thus, whilst the habitus shapes practice from within, the field structures agency and practice from without (Wacquant 2006). Writing on the field of 'cultural' production, i.e. that of art and literature, Bourdieu describes the concept of field as follows:

'The...field is a field of forces, but it is also a field of struggles tending to transform or conserve this field of forces. The network of objective relations between positions subtends and orients the strategies which the occupants of the different positions implement in their struggles to defend or improve their positions' (1993: 30).

Bourdieu clarifies the three characteristics of a field which enable an application of the concept in this thesis (Bourdieu & Wacquant 1992:99). He suggests that a field is a 'structured configuration of positions'; imposing norms and regulations on those who enter it. It is also a 'field of struggles', in which individuals battle over the distribution of capital. Finally, he suggests it is an historical constellation which has developed a certain degree of 'autonomy' in that it is able to uphold its own criteria of value and judgement (see also Wacquant 2006). Importantly then, the field is not an equal terrain for actors; engaging in the field requires individuals to adopt strategies and to deploy capital in an attempt to negotiate their own positioning vis-à-vis other actors and institutions.

In this study, I would like to propose that there were two highly significant fields in which interactions and practices were played out. The community, the social, familial and cultural spaces in which the participants lived out their lives as childless individuals, and the 'clinic', which here represents the sphere of biomedicine and infertility practice, and was the arena in which they became patients. The first to be explored in this section is the community field, and in particular, this discussion draws on the work of Goffman (1963) in exploring specifically how stigma is used within this field to mark those who are visibly childless, and how individuals develop strategies to resist stigma. This is followed by an examination of the strategies which are deployed by couples in the clinic field, and how they carve out and claim positions for themselves within the context of biomedical expertise.

Community as field

Using the definition given above, the community context can be seen as a field for the participants in this study. The community context was highly

significant as a structured space, both physically and culturally, in which certain behaviours, norms and mores exist to regulate the identities of individuals. In this respect, social spaces were of key concern for the focus groups and individual participants, in which ethnic identities were simultaneously played out and shaped. For example, a number of women noted that physical places of worship, such as the Gurdwara (Narinder) or the temple (Jasmin), could be risky in terms of the possibilities for questions and gossip. This echoes the work of Bradby (1999), who reports the significance of such social spaces as being those in which honour judgements are made, especially about women. Significant social events, such as weddings and the births of babies were also highly contentious cultural spaces, in which the issue of childlessness became difficult to manage. Individual agents in this cultural field were important, such as the mother-in-law, a role which again is discussed further below. Following Bourdieu's second element of field, I would argue that the community represents a field of struggle for childless couples, especially women. The concept of stigma is especially insightful in understanding this particular struggle, and the work of Goffman is used here, to explore this particular characteristic of the community field in relation to infertility. Finally, the community is an historical constellation with a degree of autonomy. South Asian communities have been present in the UK for decades, with a significant presence since the 1960s and '70s (Ballard 1994). During this time they have developed in particular ways in different geographic locations, and it can be argued, have evolved with a degree of autonomy in relation to the majority culture. However, there has always been fluidity, contestation and shifting boundaries of where communities begin and end (Ballard 1994, Ahmad 1996, Kelleher 1996, Fenton 1999, 2005). The struggle over the boundaries of fields is for Bourdieu, a central characteristic of what renders them significant (Bourdieu & Wacquant 1992). Evidence from this thesis also suggests that this field may be undergoing transformation. The

implications for this aspect of the theory are considered, especially in relation to childless individuals and their struggle over positioning in the community field. As Wacquant suggests:

‘those who occupy the dominant positions in a field tend to pursue strategies of conservation... while those relegated to subordinate locations are more liable to deploy strategies of subversion’ (2006:8).

Infertility in the community field

The findings from this thesis suggest that childlessness for a married couple is perceived as a social problem, which locates them in an uneasy and uncategorisable cultural space in the community. All the participants in the study, both in the interviews and the focus groups, discussed how infertility was perceived as a matter of interest for other members of the family or wider community. As such, gossip was mentioned as one way in which anxieties about married couples and their reproductive futures was expressed in the field. As a result, location in kinship networks is threatened, and a loss of status takes place (Link & Phelan 2001), including the possibility of a threat to a woman’s marital status, as was the case with Nadia, Aisha and Samina (Chapter Six). For women in South Asian communities, childbearing is seen to bring with it special status within the family, especially if there are male children (Katbamna 2000). An inability to conceive is, therefore, potentially detrimental to a woman’s position within the family. Due to this couples go to great lengths not to be identified as infertile, but rather in transition between marriage and parenting. As in other studies of infertility, in discussing the consequences of infertility we can see the significance of the concept of stigma for understanding this experience (Goffman 1963). Once a couple are known to be infertile, the likelihood of becoming stigmatised is considerable (Reissman 2000).

Stigma

Goffman suggests that stigma is used to refer to 'an attribute that is deeply discrediting' (1963: 13). For Goffman, a stigmatised individual is one whom is considered to be 'a less desirable kind' and 'is reduced in our minds from a whole and usual person to a tainted, discounted one' (p12). Stigma impacts on an individual's life chances and their relationships with others are indelibly marked by this impediment. Goffman (1963) briefly refers to what he describes as 'sterility' as falling into this category, however he does not elaborate fully on the consequences of this particular form of stigma. As discussed in Chapter Three, a number of studies have since explored the relevance of the theory of stigma to the experience of infertility, finding that this is a common experience for childless individuals across cultural contexts (Miall 1986, Greil 1991, Neff 1994, Whiteford & Gonzalez 1995, Unisa 1999, Reissman 2000, Remennick 2000, Donkor & Sandall 2007). However, this concept has seen limited application to research on infertility in the UK context. Following Donkor & Sandall, who draw on the work of Link & Phelan (2001) in their analysis of stigma, I suggest that this needs to be explored further to understand in particular the roles of power and agency in this process, elements of the process which, I would argue, are not fully explored in Goffman's original theorisation. Analysing stigma from the perspective of individual agents, also allows an understanding of Bourdieu's conceptualisation of the struggles which are played out in specific fields, and in doing so highlights the novelty of bringing together the concepts of field and stigma.

Discredited and discreditable individuals

Goffman describes the way in which stigma can cause a person to be either *discredited* or *discreditable*, depending on whether or not the stigma is immediately perceivable. In the case of a discredited person, the stigma is

known about and perceived by others, in the case of the discreditable, the stigma is not necessarily known about, but the possibility of the stigma being revealed is present (1963:14). In the case of infertility, both of these are possible. However, childless couples are more likely to belong to the second category, in which their infertility is not immediately perceptible to others. This is possible for a variety of reasons, and as argued by Goffman, is highly contingent on the success of a variety of techniques of what he calls 'information control'. Infertility, therefore, is only visible to others if the lack of children carries on for too long and becomes problematised. The narratives of all of the interviewees illustrate the social pressure that they felt put under to have children, even when it was not apparent to others that they were having problems conceiving. The lack of children in a marriage was evidence enough for people to intrude with questions and comments about when a couple may decide to have a child, an experience which is common to women of childbearing age in a range of social fields, not just South Asian communities (Throsby 2004). As in Throsby's study, the individuals that I spoke to were acutely aware of the need to manage the visibility of their infertility, particularly their use of ARTs from others. Eventually a lack of children would arouse suspicion, and a couple (if they were having problems conceiving) would be required to engage in a variety of techniques to manage the visibility of their infertility (discussed next) and resist becoming a discredited person or couple.

Passing and covering

In relation to concealing a stigma such as infertility, Goffman uses the term 'passing' to suggest that 'because of the great rewards in being considered normal, almost all individuals who are in a position to pass will do so on some occasion' (1963:95). He describes a number of strategies that individuals may employ in order to pass as normal, or to avoid the implications of stigma.

First he suggests that an individual may *conceal* signs that are considered to be symbols of stigma (p114). In this study, this strategy was mentioned by three of the participants, Jasmin, Padma and Rita. Both Jasmin and Rita discussed the problems with having to conceal needles and fertility drugs from others. In particular, Jasmin talked at length about how she had to be careful to conceal anything related to her treatment from family members, in particular her in-laws, including letters from the hospital and magazines from an infertility support group. Rita gave an example where she had been required to take her nasal spray to a wedding and had to go into the toilet to administer the drugs in secret. Another example of a symbol of stigma was a childless individual's presence at the hospital. Both Padma and Jasmin talked about their fears of being caught at the hospital; something which had actually happened to Padma, and she described how she had reacted by lying to a family member about her reasons for being at the hospital (Chapter Seven). The constant fear of being exposed, either at the hospital, or with syringes and other treatment paraphernalia, was stressful for those who had chosen not to disclose, as was echoed by Throsby's participants (Throsby 2004).

A second strategy of passing, according to Goffman, is to present signs of stigma as signs of another attribute which is a less significant stigma (p117). In the case of this study, some of the participants described how they would take on another attribute, that of 'delayed childbearing', in order to resist the infertility stigma. Delayed parenting is increasingly acceptable for newly married couples in South Asian communities, and so the participants described how they would use this to deflect stigma in social circles. For example, as Rita describes in Chapter Six, telling people that they weren't yet ready for children, and thus adopting a less stigmatised condition, was one way to avoid stigma. This can only ever be a temporary solution though, and

as Jasmin suggests, this strategy is a difficult one, and as with other forms of passing, ultimately causes anxiety for the couple (Goffman 1963: 109). The availability of this strategy to deflect stigma, is evidence of the shifting expectations around childbearing for some young women within South Asian communities (Brah 1996, Ahmad 2006).

A third strategy is the selective disclosure of stigma. As Goffman suggests, keeping the secret from the larger group and telling only a minority of people, is one way in which to handle the risks. In this way, the smaller group can be relied upon to help keep the secret (p117). This was perhaps the most common strategy used in this study, at least the one which was reported most frequently. Disclosure decisions were highly significant and complex, in which the implications of telling others could be considerable. As such, the women and their partners had been highly selective about to whom they disclosed this information. Only one participant, Safiya, had decided to be completely open about this fact (a separate strategy which is discussed below). However, this was considered as a risky approach, since the likelihood for attracting negative reactions and potential stigma was high. As such, most of the participants went to great lengths to conceal their treatment. Five of the participants described how they felt unable to disclose this information to their in-laws in particular. Mothers in-law and sisters in-law especially, were avoided in these cases, since it would be they who were seen to be most likely to interfere. This fear was borne out in the reality of some of the cases, where a woman's female in-laws did know about the infertility, and used this against her in a variety of ways. Aisha, Sita, Nadia, Rita and Safiya all reported feeling that they had been treated negatively by their in-laws as a result of their infertility, and in most cases this negativity came from female family members. In the most extreme cases, Aisha and Nadia had been

threatened with divorce by their mother in-law and sister in-law respectively (Chapter Six).

These examples illustrate how power operates in relation to stigma and marginality in South Asian cultures (Link & Phelan 2001, Donkor & Sandall 2007). As a woman who has proved her childbearing capabilities, the mother-in-law, in South Asian family contexts, can be a powerful individual, especially in relation to other, younger female relatives (Bhopal 1998). In this respect, the mother-in-law role holds symbolic capital within the community field. In these examples, specific women have power over other women, especially in relation to their reproductive behaviour, a finding which Goffman fails to explore adequately in relation to stigma. This finding can also be explained with reference to Bourdieu's theorisation, as the field is defined as an arena of struggle over positioning (1993) (see Figure 6). Even when the women concerned had relative independence and autonomy in other areas of their lives, for example in their education and career choices, decisions and practices related to producing children were areas in which mother in-laws appeared to have some jurisdiction. Few of the women in this study directly challenged this authority. As in the research by Larissa Remennick (2000), instead of directly challenging stigma, the most likely course of action for women in this study was to ensure the invisibility of their infertility for as long as possible. This was not easy, and Padma, Samina and Jasmin all noted the difficulties in avoiding their in-laws when living in close proximity to them. This had caused Padma to adopt new ways of dealing with these relationships, and she and her partner had moved out of the family home, away from her in-laws, in order that she could more effectively manage the information about her treatment. This distancing of oneself from others as a means to avoid stigma, is the fourth strategy described by Goffman (1963: 122). This strategy was also used around family celebrations,

whereby women would withdraw from aspects of social life in order to pass. For most, this was as pragmatic as wanting to avoid intrusive questions about their private reproductive lives. However, in remaining at the margins of family and community life in this way, their status as other was further reinforced (Letherby 1999).

In a small number of cases, disclosure was used to the opposite effect, in order to win the woman some distance from the stigma of the couples' infertility. In an example of this, Sita described how she disclosed her husband's male factor infertility to her in-laws as a means to avoid the implications that she felt would ensue, as it had done for another member of the family who had experienced similar problems (Chapter Six). Although her mother-in-law was annoyed at this revelation in the family, it had the desired affect, and meant that Sita was not forced to deal with the stigma of the couples' childlessness. Sita was able to use disclosure as means to resist the labelling power of her mother in-law. This form of selective disclosure was only possible because of the nature of the infertility in this case, and was not mentioned as a strategy by the other women in the study.

The final passing strategy described by Goffman differs from the others, and is a reversal of the concept. In this strategy he describes how total disclosure can be used in order to deal with stigma, he suggests, 'thereby radically transforming his situation from that of an individual with information to manage to that of an individual with uneasy social situations to manage' (p123). Two participants, Anjali and Safiya, talked about the ways in which they used public disclosure as a means to challenge prevailing cultural norms around fertility and childbearing within the community field (Chapter Seven). In these examples, the women talked about how they wished to educate people about how, for some couples, ARTs were the only means by which

they might have a child. However, even for these women the decision had not been easy, and although Anjali had been open with many people, this did not include her husband's family. Like a number of the participants in this study, both of these women had a particular habitus, they were independent and educated, and both were middle class and had very supportive husbands, giving them increased social and economic capital, which may have allowed them to feel able to make such a choice, one which might not be so easy for women with fewer cultural resources (Ramji 2007). As suggested by Wacquant (2006), those in subordinate positions (childless women) are required to attempt to subvert the field, in order to gain a better position for themselves, whilst those in superior positions i.e. some mother-in-laws and other family members, may attempt to maintain the status quo.

As with power relations, Goffman is relatively silent on the issue of agency as it relates to stigma. Others have discussed the role of agency in their work on infertility, and the ability for women to resist stigma, (Reissman 2000, Remennick 2000) and the role of agency in negotiating fertility treatment, in particular, is discussed later in this chapter. Agency is, of course, also crucial in understanding Bourdieu's conceptualisation of habitus, for the ways in which individuals are central in shaping the social and moral terrain, and therefore for rejecting the 'culturalist' position (Ahmad 1996, Brah 1996). I would like to expand on this by considering Rayna Rapp's concept of the 'moral pioneer' (2000). She suggests that women who make decisions in relation to new technologies do so in a way that helps to shape the social terrain surrounding the acceptability of such technologies. Therefore, although a set of choices are made in the realm of the private, these have simultaneous consequences and implications for the social sphere (see Figure 6). In the case of Anjali and Safiya, it could be argued that they were acting in the role of 'moral pioneer'; openly challenging what they saw to be the

unnecessarily negative and outdated treatment of infertile women who chose to use ARTs. Rapp points out that this role can also be assumed by the unwitting. For women who had not chosen to disclose their treatment more widely, such as Narinder, her choices may have also had an impact on shaping the moral context. Through the grapevine, people in her wider family and social network had found out about her situation. Although she herself had not made the decision to share this information, the facts had made their way into the public arena through other routes (Chapter Seven).

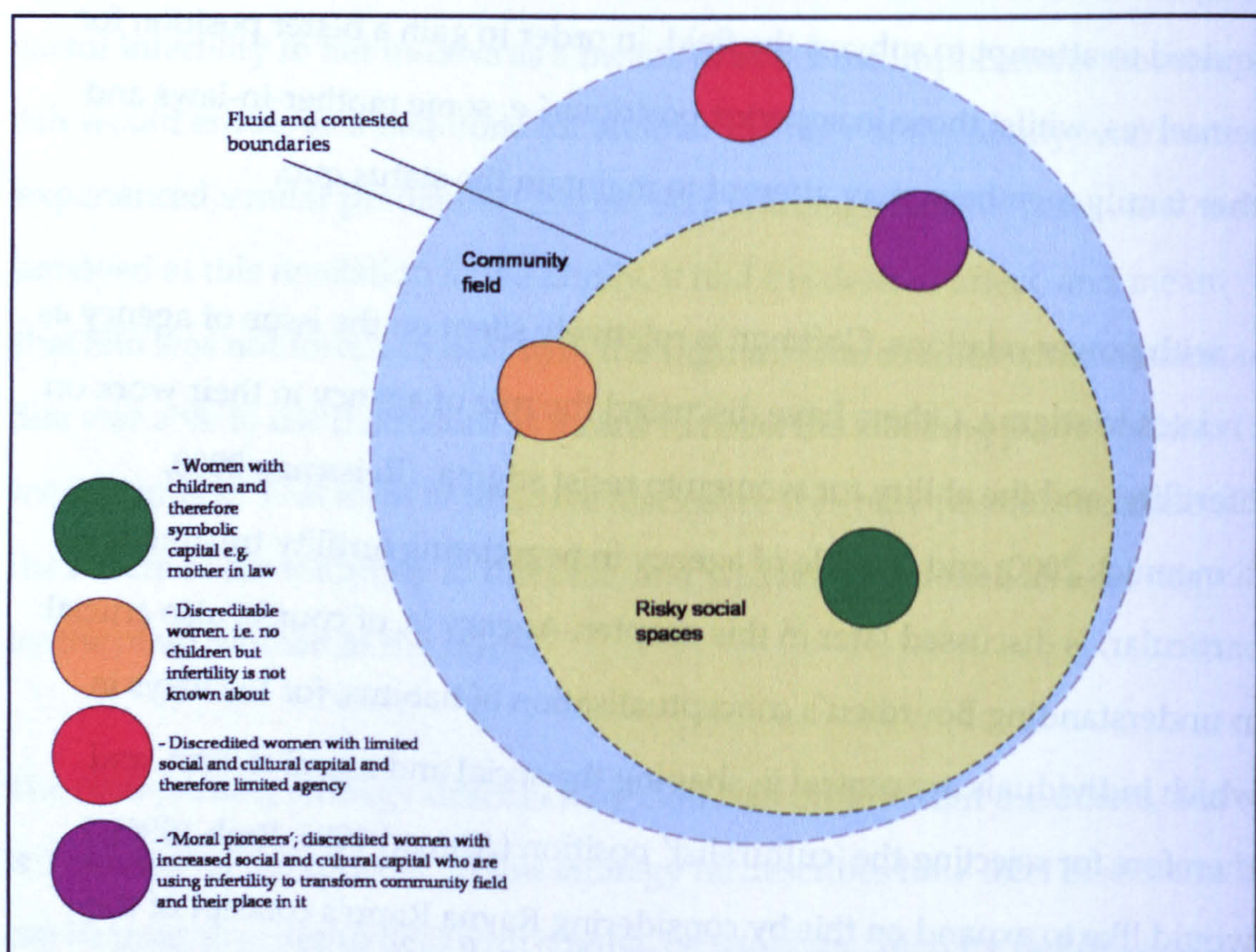


Figure 6: The community field and the struggle over stigma and capital

Finally, Goffman's use of the concept of 'covering' is significant in this study. Covering relates to those about which the stigma is known, yet who employ strategies to reduce the obtrusiveness of the stigma. Goffman describes this as a strategy to 'ease matters for those in the know' (p126). An example here was

reported by Narinder, Samina and Safiya. They described how they had decided not to tell people too much about the treatment that they were using. So for example, if they were undergoing a cycle of treatment, they would not necessarily share this information with family members who knew about their infertility. It could be argued, however, that this was employed as much to protect themselves from having to repeatedly discuss potential failure, as it was to reduce the 'obtrusiveness' of the stigma for others.

For a number of women in this study, developing strategies to avoid disclosure about their infertility was central to avoiding stigma. However, escaping stigma does not mean to say that they will not experience biographical liminality; even if they are able to pass as normal, the suspension of their own expectations for parenthood will cause them anxiety. In addition, during the period that they are married and without children, they remain socially problematic within the community due to shared expectations around childbearing, even when allowing for a period of marital adjustment. The only possibility a couple has to avoid becoming discredited individuals, is to avoid disclosure and to overcome their infertility in a reasonably short space of time, and in a way that does not attract suspicion.

If information about infertility is disclosed, then there is a likelihood that they will become stigmatised, which further impacts on their marginal status. This is a complex trajectory, mediated by the specific social context of each family and the particular power relations within it. What is clear from this study is that the dominant discourse of motherhood in particular, is difficult to circumvent, and as such, any resistance from individuals tends to take place within the dominant field rather than outside of it. For example, it was generally agreed in this study that voluntary childlessness was not an option for South Asian women.

Shifting perceptions of infertility in the field

The cultural field, which relates to the places in which a person's habitus is played out and shaped, is clearly significant in understanding the experience of infertility in British South Asian communities. Women enacted a range of strategies to avoid this field, specifically to escape the risk of being stigmatized, or to mediate its negotiation in order to resist stigma. For those women who were actively attempting to educate others about infertility, it could be argued that in their role as moral pioneer they were shaping the moral landscape on this issue, and by doing so were working to transform this particular field. In this respect, habitus is influenced by tradition, religion, language and culture, but is also open to challenge and transformation (McNay 1999). It could be argued that these women and their partners, especially those who had disclosed their use of treatment, were in the process of transforming what constitutes normative reproduction in British South Asian communities through their use of ARTs. In addition to this, shifting expectations around the acceptability of delayed childbearing in South Asian communities, particularly for women who want to seek an education or a career, means that opportunities for infertile women to pass are increased. This may imply that discourses of motherhood, at least in terms of delaying, are undergoing transformation in some sections of South Asian communities (Gillespie 2001).

However, as Rapp points out, the position of moral pioneer is neither a comfortable nor a safe place to be, particularly for the unwitting. Although, ARTs do appear to have some support amongst public groups, they remain problematic in their ability to disrupt kinship relations in new and novel ways (Edwards et al. 1999, Edwards 2004). Throsby (2004), suggests that although at one level ARTs appear to shore up family values, they also represent an unsettling ability to generate new structures and to fracture existing

categories, such as a mother and father; what Rosemary Gillespie refers to as a 'postmodern model of reproduction' (2001: 147). Therefore the needs of the individual using ARTs are finely balanced with what the public perceives as important (Hirsch 1999), and this may be particularly pertinent in communities which have close kinship networks and strong pronatalist discourses. In this context then, disclosure is risky, even for those making the choice to disclose, since the moral context is ambivalent and unstable. As illustrated in Chapter Five, members of the community expressed suspicion about what was involved in procedures such as IVF, despite the wish to present a general public acceptance of ARTs within the focus groups. As the women in focus group three expressed, there would be questions over whether or not a couple may have used third party gametes in order to conceive, which as we have seen, was viewed as culturally and for some religiously unacceptable. Disclosure of the use of ARTs in this context is therefore doubly risky. Although they offer the potential for re-classification as 'normal' in offering the chance to become a parent, they are themselves unstable. They blur the boundaries of nature and technology, presenting a hybrid form of reproduction that is not fully re-categorised in the public domain. Therefore for some, they become further evidence of one's marginal status, not fully offering the status of natural parenthood. It could be argued that ARTs represent one way in which childless couples are attempting to shape the contours of the community field, and therefore to gain a better position for themselves within it. The technologies are utilised in order to have children, which are of symbolic value in South Asian communities, and therefore to secure their position as adult members of kinship and community networks.

This process of 'normalisation' (Throsby 2004, Thompson 2005) of the use of ARTs can be seen in the focus group data. The participants, especially the

younger men and women, were keen to point out that they, as the next generation of British Asians, were fully embracing modernity, and as such the use of ARTs was not necessarily problematic for them. Younger participants, especially those from Hindu and Sikh faiths, were more likely to discuss ARTs in terms of social and scientific progress (Chapter Five, see also Sarah Franklin 1997 on how this process is embodied by IVF patients). That is not to say that there was not anxiety in these groups about forms of assisted conception, but that these participants were more likely to articulate a discourse of progress and of faith in scientific technologies. The discussion of reproductive technologies was used to mobilise a discourse of social change, and to express a readiness to engage with what were perceived as modern or high-tech practices, partly, it appears, in an attempt to challenge what they saw as the traditional thinking of older family and community members. Lay narratives around ARTs were therefore articulated within a discourse of social change and scientific progress. As the young men in focus group nine suggested, 'we just think wow that's amazing ...what's gonna happen next?' In the focus groups, these changes were discussed in relation to the changing nature of South Asian communities, and were strongly linked to wider processes of social change, in particular, what people saw as the 'intellectualisation' and 'westernisation' of South Asian communities. However, it is difficult to know, for example, if the views presented in the focus group context would be borne out in reality.

Meaning-making around ARTs, as represented by participants in this study, appears to be in a state of transition. Social change within South Asian communities was central to many discussions, especially with younger focus group participants who expressed the view that there is a move towards acceptance of infertility and ARTs. This may have important implications for the ways in which women and men from South Asian communities represent

themselves as involuntarily childless and as treatment-seekers. There is therefore some tentative evidence that the community field, whilst highly significant, is under transformation, and is not static (Bourdieu & Wacquant 1992). These findings add further credence to the rejection of a culturalist approach to understanding the mores and behaviours of ethnic groups. The related concepts of habitus and field, allow an exploration of the ways in which individuals define themselves relationally and interactively, and this approach permits an understanding of the role of agency in this process. Presenting a fixed South Asian response to this issue is therefore neither useful nor possible.

This section has attempted to bring together the concepts of 'stigma' (Goffman 1963) and 'field' (Bourdieu 1993), in order to understand some aspects of the experiences of these participants. Incorporating the work of these authors into one theoretical framework, allows more effective utilisation of the concepts of field and stigma than is possible when they are applied in isolation. These concepts are complementary, allowing the demonstration of stigmatizing effects of infertility in the community context and the strategies that the women enact in an attempt to win back power over the situation. These findings also illustrate the importance of the construction of infertility as 'difference' or stigma (as was raised in Chapter Three) in Western contexts. In addition they highlight the significance of 'lay' perspectives of infertility for infertile couples. In the next section, consideration is given to a different but equally important field, where struggles over agency and power are also apparent.

Engaging with ARTs: the clinic as field

I would like to argue that the 'infertility clinic' (as a generic term to represent the arena in which treatment is played out) represents an important and central field that childless couples are required to navigate. Again, Bourdieu's theorisation is useful in clarifying how the clinic represents a field. First, that it is a structured space of positions; in this example, patients, practitioners, technologies and regulation were all significant positions. Secondly it is an arena of struggle in which strategies are needed to negotiate the obstacles, institutions and agents in pursuit of the ultimate goal of a baby. Finally, it has a degree of autonomy; the field of assisted reproduction has developed as a specialism within reproductive medicine. It is also an historical constellation with its own systems, rules and regulations with which those entering into it must engage (Gillespie 2001). This section is organised in order to reflect the structuring of this particular field and the participants' engagement in it. In particular, the focus is on the ways in which the clinic represents a 'battlefield' (Bourdieu & Wacquant 1992, Wacquant 2006), in which resources are deployed in order to survive, and ultimately to improve one's position in the field. To represent the institutions that the participants, as patients and agents encountered, the findings are organised under the headings: 'infertility experts'; 'technologies'; and 'regulation'. The conceptualisation of the treatment process as an 'obstacle course' is one common to other research findings (Franklin 1997, Redshaw et al. 2007).

The interview participants in this study were at varying stages of the infertility journey, with some having not yet embarked upon the treatment process. Yet for all of the participants, the possibility of resolving their childlessness through the use of ARTs was central to their stories. In line with findings from other research (Greil 1991), a feeling of shock on hearing that there may be a need for the use of ARTs, was common amongst the

participants, with the general assumption, as discussed earlier, that once a pregnancy was planned for it would happen at the desired time. Expertise about infertility and its treatment, was generally not something the participants described as having before being faced with the news about their own fertility. Very quickly they needed to become experts in their own right, in order to understand the field that they were about to enter into. Since this was not an area in which the participants in this study (or those in other studies, see Franklin 1997, Throsby 2004) held any expertise, they were obliged to seek expert advice from other sources. Since biomedicine offers a solution in this case, all participants who had sought a solution had done so within the biomedical field.

Infertility experts

In the context of this field, the goal of a 'take home baby' is one that is shared by the couples entering treatment and the physicians treating them. However, the power balance over achieving this goal is unequal, and correspondingly, a number of participants felt that they were not necessarily in control of the field in this respect (Sawicki 1991). The participants highlight how control over the procedures, and how the treatment was mapped out within the field, was firmly in the hands of the clinicians. Having entered into the medical field hoping to regain control of their infertility, the treatment process further reduced their feelings of being in charge of what happened in their lives.

Relinquishing control over their lives, and following advice that they did not understand or sometimes agree with (as in Nadia's case of being told to lose weight) was problematic. For a number of the women in this study, this feeling of a lack of control led to them questioning the advice and information that they were given by practitioners (Malin et al. 2001, Redshaw et al. 2007). As has been found in earlier studies, the participants expressed dissatisfaction

with the process, and with clinic staff, particularly when the treatment had been unsuccessful (Hammarberg et al. 2001). Dissatisfaction with what was seen as the incomplete knowledge surrounding ARTs was discussed in the interviews. Sita, Jasmin, Nadia, and Narinder all expressed concern with the explanations and advice that they had been offered by the experts. Narinder describes how the explanation for failure was often unsatisfactory, as in the example she gives when she is told that, 'it could just be the cycle', therefore implying the need to try again with another cycle. This aspect of the clinic field highlights the relative power held by practitioners in their relation to patients, it is they who have the resources with which it is possible (allowing for success rates of the treatment) for a childless couple to get pregnant. This finding supports the existing literature on patient satisfaction (Redshaw et al 2007). However, for many participants their frustrations lie in being unable to affect the situation themselves and instead being totally reliant on this treatment.

Another area of struggle related to the ways in which they felt they had been treated as patients. Seven out of the twelve participants who had had treatment, described specific negative experiences in relation to clinic staff. Most common was the feeling that they had been treated 'as a number', whilst attending the clinic, and this further impacted on their discomfort whilst inhabiting the clinic field, a process that Redshaw et al. (2007) describe as 'depersonalisation'. Feeling that the staff were not sympathetic enough to their individual situations and needs was common, and supports the findings from other research (Malin et al. 2001, Culley et al. 2004, Throsby 2004, Redshaw et al 2007).

One participant in this study, Safiya, commented on the way in which she was treated within the clinic in relation to her ethnic identity as an Asian

woman. She describes how she felt she had been subjected to stereotyping by clinic staff, based on her perceived ethnic and cultural identity. In terms of Bourdieu's theory, it could be argued that in this healthcare context, as in others, 'whiteness' holds a symbolic value which is not afforded those who are visibly 'other' (Roberts 1997, Atkin 2004). Nirmal Puwar (2004) has argued that women and racialised minorities represent bodies 'out of place' in this respect. She argues that the historical embeddedness of whiteness and masculinity in a number of institutions in British society, means that minority ethnic women in particular, represent 'space invaders' in these institutions. The negative categorisation of patients by infertility clinicians and nursing staff according to their perceived ethnic identity, was found to be the case by Culley, Hudson, Rapport, Katbamna and Johnson (2006), who suggest that a number of their participants felt that they had been stereotyped because of their ethnicity in the infertility clinic setting. This also reflects other research findings (Bowler 1993). It could be argued therefore, that perceived ethnicity has an impact on the ability to navigate this particular field.

Jana Sawicki (1991), drawing on Foucauldian theory, suggests that in order to overcome anxiety and the sense of loss of control experienced in this field, women who use ARTs enact power in ways which allow them to regain some control over the situation. In this way, women are able to negotiate treatment and win back some autonomy in a situation in which they are open to objectification. Greil (1991) also suggests that often the treatment process is a negotiation, with women acting as 'active strategists' and 'fertility contractors' (1991: 77-88). Malin et al. (2001), use a similar concept of 'assertive consumer' in explaining findings in the Finnish context. This proposition, that women are strategists carving out their own treatment programmes and plans of care, is an important one for understanding the micro-politics of this particular medical encounter (Greil 1991, 2002), and supports Bourdieu's

conceptualisation of struggle in this context. As the participants in this study illustrate, agency, choice and power in the medical encounter are often elusive and, as Safiya describes in Chapter Seven, this process is often experienced as a 'battle', a metaphor which is clearly in keeping with Bourdieu's theorisation of field (Bourdieu 1993). The strategies which these particular participants employed in order to regain power over the situation, were related to 'choice', and as such were located within a consumer model. These strategies are discussed in more detail below.

Technologies

Since infertility presents a chaotic experience in which couples feel great anxiety and a loss of control over their lives, engaging with ARTs offers a way of regaining some level of control. As Becker (2000) argues, choosing to resist the identity of an infertile person and deciding to overcome this through the use of biomedical solutions, is one way in which the couples in this study engaged with treatment. However, once compelled to use ARTs, the dominant experience reported by these participants was one of anxiety and ambivalence. ARTs simultaneously embodied hope and fear, and entering into each treatment cycle was inevitably fraught with anxiety.

A major theme to emerge from this study in relation to the treatment experience, is that the amount of faith that the individuals had in the technologies related to the point at which they were in the process. At the outset of the treatment journey (for those who had undergone treatment), feelings of excitement at the possible 'goal' of a pregnancy were common. Although the prospect of infertility treatment, especially IVF, was daunting for the participants, it was also a reason to look forward, a reason to be hopeful. A lot of investment in IVF, both financial and emotional, was made and a couple's hopes of becoming a parent were bound up with the

expectations that biomedicine offers (Peters et al. 2007). Even where advice was given in consultations about the likely success rates (which are limited, at approximately 25% per cycle), this was overshadowed by the hope and promise that these technological solutions embodied for the couples. In her work on pre-natal screening, Rayna Rapp suggests that the technological and expert intervention involved in problematic reproduction (in this case a pregnancy potentially affected with a genetic condition), confers a specialness on that experience, even if a woman was going to lose the baby (2000: 232). It could be argued that in the case of infertility, the associated technological intervention presents a promising opportunity, where, at the least, it appears that something positive is happening even if treatment is ultimately not successful. It could therefore be argued that IVF becomes a substitute for the excitement and ritual of pregnancy itself.

However, faith in the efficacy of ARTs appeared to decline the longer women stayed in treatment, with two of the women reporting having felt 'naïve' to have invested so much faith in the treatment at the beginning. Experiencing failure was clearly related to a growing disillusionment with the expertise offered by biomedicine. With each failed cycle, concern increased over whether the treatment would work. This finding supports the findings of Malin et al., who suggest that the uncertainty engendered by the treatment, has an effect on relations between staff and patients (2001: 130). Nevertheless, this did not deter people from continuing with treatment. Three of the women I spoke to, Aisha, Safiya and Rita, had undergone multiple cycles of treatment including IUI and IVF over many years. For these women, biomedical expertise offered the only option for a pregnancy and although the overriding experience during this time was failure, they felt compelled to try. This compulsion to continue is related to what Sandelowski calls the 'never enough' of conceptive technology (Sandelowski 1991), in that there is always

some new combination of treatment or drugs that can be tried. Both Narinder and Rita illustrate this view in their interviews, with Rita describing how she felt like a 'guinea pig' after multiple attempts, at a time when IVF was still relatively experimental. Ambivalence about negotiations with biomedicine was the marker of many of the stories told to me in this study. Although ARTs did not effectively deliver what they so persuasively offered, it was difficult for the women to end their treatment journeys, until all avenues had been exhausted. As Throsby suggests, when IVF fails it foregrounds the very inability to conceive that it set out to resolve (2004).

Perhaps due to the fact that the participants expressed declining faith in ARTs, with each cycle of unsuccessful treatment they reported feeling increasingly anxious. In this respect, Helen Allan (2007) suggests that the clinic is a place in which the liminality of infertile women is tolerated. To some degree, these findings support this idea and, in addition in this study, the clinic was a place in which stigma was escaped. However, what the women with whom I spoke add to this, is an understanding of the ways in which the clinic field can also be a source of further anxiety. The longer treatment continued unsuccessfully, the more difficult they found the process of engaging with the technology. This caused further emotional distress, with the treatment itself reported as being a source of disruption, ambivalence and anxiety. Specific concerns about the injections, about risks to their health, about success rates and about 'mix ups' in the clinic were also raised in the interviews, further highlighting the anxiety that was caused by ARTs.

Seeking treatment to overcome infertility was represented in the interviews as something that needed to be tried. As Franklin suggests, 'having to try' is expressed as an inevitable obligation that couples feel in their quest for a child (1997: 168). This is related to the findings in Becker's research, in which she

argues that couples (in the American context) consume ARTs because they have the potential to produce them as parents. She suggests, 'Technologies derive from, and are created by cultural priorities' (2000:11), and that in using these technologies people are taking power into their own hands and resisting ideas that are undesirable, or impossible to live out. The data in this thesis support the view that, although traumatised and heavily impacted emotionally, financially and practically by ARTs, women are compelled to undertake treatment in order to attain desired identities (Becker 2000, Sawicki 1991). In Bourdieu's terms, they enter into struggles within this field in order to gain a better position for themselves i.e. that of 'mother' or parent.

Greil's ideas about how individuals carve out meaningful experiences for themselves as users of ARTs, illustrates how they are not simply oppressive technologies, as argued by a number of feminist authors (Corea 1987, Klein & Rowland 1989, Klein 1989). In the 1970s and 1980s, conceptive technologies such as IVF were pathologised by feminist writings, which ultimately saw the women who used them as passive victims or unwitting dupes. This understanding of the technologies has been criticised (Denny 1994), and a more nuanced insight into how women (and men) use these treatments can now be found (Greil 1991, 2002, Franklin 1997, Becker 2000, Throsby 2004 Thompson 2005). This is not to say, however, that ARTs are not problematic, or that control over them has been successfully won by their users.

Regulation

As an aspect of the clinic field, the regulation of ARTs, both within the NHS and the private sphere, was viewed as limiting for a number of participants who felt that they were restrained when attempting to access regulated treatment. For these participants, as with other users of ARTs, the ultimate signifier of success was a pregnancy which resulted in a baby (Peters et al.

2007). Therefore, decisions about treatment were made in order to maximise chances of success. Most often these decisions related to *where* a couple would access treatment. The political and economic situation in the UK in particular, means that infertility treatment is at best only partially funded by the NHS. This means that choosing to go private is often done so out of necessity, and only by those who are financially able to do so. Therefore, for a number of the participants, they had decided to go private in order to circumvent waiting lists and get access to treatment as soon as possible. In addition, where treatment was subject to limited funding on the NHS (giving access to one or two cycles at most), the cost of paying for treatment immediately outweighed the benefit of waiting for free treatment. A number of participants had also attempted treatment in different clinics, seeking out those with better success rates.

For Anjali, and Gita and Ramesh, this process involved choosing to have treatment abroad. In both cases, the decision was made to go to India, and this decision was partly based on perceptions of higher success rates in Indian clinics. This was due to the fact that in India, treatment is not regulated by a central body as it is in the UK (Widge 2005). Therefore, clinics have more freedom to determine treatment protocols and practitioners have more discretion in this respect. For the participants, this related to the number of embryos a clinic was prepared to transfer to the female partner in each cycle of treatment. Anjali makes this point in Chapter Seven, from her perspective the fact that four embryos were transferred, gave her a much higher chance of success. In the case of Gita and Ramesh, their second trip to India for treatment was partly motivated by the need for donor gametes, given the shortage of donors from minority ethnic groups in the UK (see below, HFEA 2006b). By travelling to an Indian clinic they could be assured of having a donor who was matched by ethnicity.

Debates about the phenomenon of so-called 'reproductive tourism' (Knoppers & LeBrius 1991), have begun to filter into popular and academic spheres, although little research has actually been conducted into the experiences of those who seek treatment overseas. On the one hand, reproductive tourism has been described as an expression of 'moral autonomy' (Pennings 2004), with users of ARTs exercising their right to choose to use technologies which are not legally or financially supported within their own country. However, a number of other authors have become troubled by the development of a globalised market for ARTs, and the impact that it has on users, donors and potential offspring (Blyth & Farrand 2005, Spar 2006, Sandel 2007). Since there has been no empirical work carried out with those who travel abroad for treatment, it is difficult to know whether the views of those in this study are similar to others who choose this option. However, they do further confirm Greil's suggestion that women (and their partners) become 'fertility contractors' in planning how, when and where they will have treatment (1991). What is clear in understanding the decision-making process in relation to the biomedical field is that, in attempting to regain control over their lives, these women and their partners are negotiating a complex web of personal, cultural, economic, political and biomedical factors. This further highlights how even when couples make decisions about their own treatment as a means of winning back some control within the field, they do so within particular constraints (Bourdieu 1993, Bourdieu & Wacquant 1992).

As mentioned earlier, the issue of the shortage of donors from minority groups was significant for those participants who needed to use donor gametes (Gita & Ramesh, Samina and Nadia). Until very recently, the HFEA guidelines on this issue stated that:

'...treatment centres are expected to strive as far as possible to match the physical characteristics and ethnic background of the donor to those of the infertile partner, ... unless there are good reasons for departing from this procedure' and that '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 2003: 32-3)²⁰.

However, this guidance does appear to give clinicians some discretion – in the determination of what 'good' or 'compelling' reasons are. The current shortage of donors from minority ethnic communities in the UK could perhaps be construed as a reason for offering treatment with eggs from a white donor. This was not the case in reality however, with Samina actively looking for her own donor (of either 'Asian' or 'white' ethnicity) at the time of interview. This was due to the fact that her clinician would not consider treating her with an existing white donor, but would allow her to recruit her own donor of any ethnic group (including from a white woman). The exact reasons for this decision were unclear to Samina, but appear to relate to fears about 'miscegenation' (Szkupinski Quiroga 2007). The fact that her clinician was unwilling to offer Samina the use of an existing donor's white eggs seem to suggest that this use of officially located donor gametes (i.e. belonging to the clinic) was inappropriate, whereas if Samina brought her own donor, the clinic was, to a degree relinquished of the responsibilities involved in the matching process (Szkupinski Quiroga 2007). These findings reinforce those made by Szkupinski Quiroga (2007) in her research with couples from a number of minority ethnic groups in the US. She suggests that through the decisions made by infertility clinicians in matching donors and recipients by 'race', the boundaries of racial categories are perpetuated through subtle means.

²⁰ In January 2008 new clinical guidelines were issued by the HFEA (HFEA 2007), which now make no specific reference to the matching of donors and recipients in these terms. How this will impact on the decision-making of individual clinics in this respect is unclear at the time of writing.

A number of authors have discussed the inconspicuous ways in which a range of 'deserving' and 'undeserving' women, including those from minority ethnic groups, lesbian women and single women, are given access to ARTs (Roberts 1997, Steinberg 1997, Saffron 2002, Malin 2003, Woodward & Norton 2006, Szkupinski Quiroga 2007). These findings also suggest the operation of institutional racism in the infertility treatment arena, in that, systems of governance within licensed clinics can work to the detriment of racialised minorities (Atkin 2004, Purwar 2004). Negotiating regulation in respect of matching donor gametes and recipients had therefore led Gita and Ramesh, and Samina to take drastic steps to attempt to facilitate access to treatment. Having one's own gametes to use in the treatment process could be described as a form of reproductive capital, in that this permits at least partial entry into the infertility field (see Figure 7 below).

These findings about choice and control, illustrate how women employ agency in shaping both their experiences, but also the field in which they are having this experience (Ramji 2007). In resisting some of the control exerted over them, they are attempting to win back some power from the medical experts and are active agents in negotiating the treatment terrain. Perhaps the most significant factor in the ability to exercise agency in this study was that of economic capital. For those who could afford financially to try different clinics in the private sector and overseas, as well as having multiple cycles of treatment, the experience was different from those who had to wait several years on an NHS waiting list, with only limited chances for success. Being able to employ such strategies, meant that the outcomes between agents in the field could be significantly different, depending on the resources at their disposal (Bourdieu 1977). This is discussed in more detail below.

Economic capital

For Bourdieu, the resources that individual agents have to draw on in order to negotiate the field are highly significant (1986). As described in Chapter Two, different types of capital are implicated in the struggle for positioning in any given field. This is further reinforced by those writers who have argued for a consideration of socio-economic positioning in relation to understandings of ethnicity and health (Nazroo 1997, Karlsen & Nazroo 2002). However, as described in Chapter Four, traditional measurements can be problematic for assessing the socio-economic status of members of minority ethnic groups (Nazroo, 1997, Karlsen & Nazroo 2002). In this study, the concept of 'economic capital' is employed in order to attempt to understand the ways in which access to resources configured the infertility treatment terrain for individuals and couples. Bourdieu suggests that forms of capital can be acquired, exchanged and transformed into other forms of capital (1986). In the case of ARTs, I would argue that the couples in this study were attempting to transform their *economic capital* into *symbolic capital*, in the form of a pregnancy. The women in this study (and their partners) were drawn from a range of occupational groups, as described in Chapter Four, which tell us something about levels of income and also about social class membership. Using this data on socio-economic status, as well as the narratives of the individuals, it is possible to tentatively explore the importance of economic capital in understanding this experience.

Economic capital appeared to be significant in two ways in this study: in accessing treatment and in patterns of disclosure. First, in terms of access to treatment, a number of women in the study described having gone private as a way of exercising control over the process. This choice, however, was often an enforced one in the light of lengthy waiting times in the NHS, and their wish to start treatment as soon as possible. For Aisha, who reported that

having made this decision, paying for her treatment gave her some rights over the experience, which she would not have had in the NHS system (see Figure 7). In this respect, couples could exercise some discretion over when and where to have their treatment.

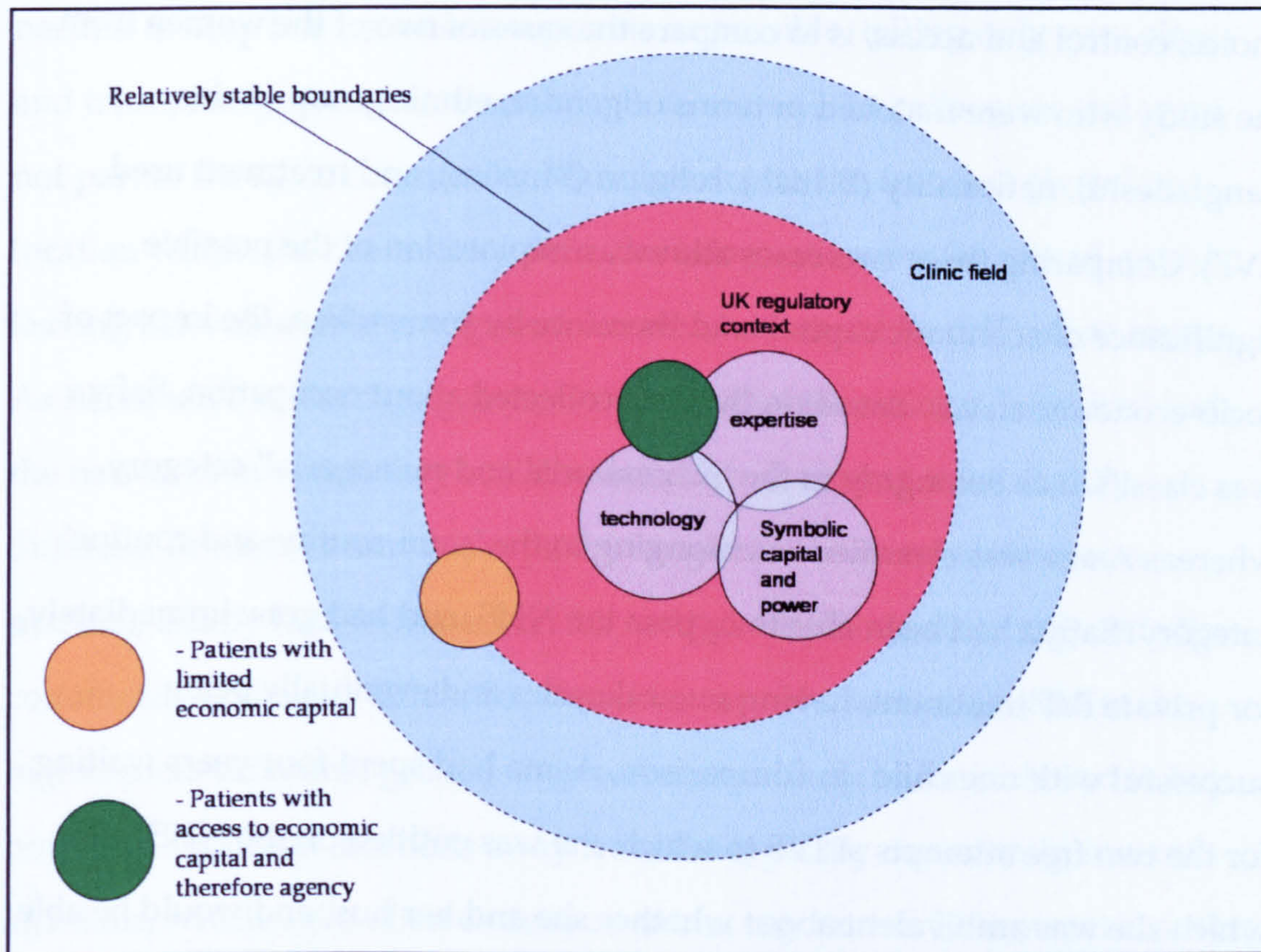


Figure 7: The clinic field.

However, using their consumer power, or in Bourdieu's lexicon their economic capital, in order to facilitate choice, did not sit easily with many of the participants. Eleven of the twelve participants who had used ARTs had been required to pay for some or all of their treatment, and all of those who had, felt that this had caused financial hardship. In addition, Safiya, Ramesh and Nadia, all expressed distaste at the ways in which infertility treatment had become a commercial transaction, and how clinics represent spaces of commerce, with Nadia describing how she was asked if she had paid whilst being wheeled down to theatre. This reflects the findings from other research

in which the commercial element of ARTs are problematised (Hirsch 1999, Spar 2006).

A good example of the difference that economic capital made in terms of choice, control and access, is to compare the cases of two of the women from the study who were matched in terms of gender, ethnic group (Asian Bangladeshi), nationality (British), religion (Muslim), and treatment used (IVF). Comparing these two cases allows an exploration of the possible significance of economic capital, and therefore by some token, the impact of socio-economic status. Based on the data collected about occupation, Safiya was classified as belonging to the 'professional and managerial' category, whereas Asma was classified as belonging to the 'semi-routine and routine' category. Safiya had been able to bypass the NHS, and had gone immediately for private IVF treatment, having several cycles and eventually being successful with one child. In comparison, Asma had spent four years waiting for the two free attempts at IVF to which she was entitled on the NHS, after which she was ambivalent about whether she and her husband would be able to find the resources to continue treatment.

Economic capital also appeared to be of significance in a more nuanced respect than simply facilitating the payment of cash for treatment. Reissman (2000), in her research with childless women in India, argues that professional urban women were much more able to resist the stigmatising affects of infertility than were 'poor village women'. The data from this study is perhaps more nuanced than was the case with the women Reissman interviewed. None of the women in this study could be described as poor, but some clearly had more economic and social capital than others. Interestingly, in terms of Reissman's view that it is those with increased social and economic resources who can best resist stigma, the disclosure choices of the

two cases described above are worth comment. Safiya, who lived in an affluent suburban area, had chosen to use her story to challenge what she saw as the outdated views of others, fully disclosing this and challenging the stigmatising effects of disclosure head on. On the other hand, Asma had needed to keep her treatment as private as possible, telling only very close and trusted acquaintances, some of whom were work colleagues and were not part of the same community. This was due to the fear that given her location within the community field, the information would spread quickly, leaving her vulnerable to stigma, from which it would be difficult to escape. As Reissman's research suggests, the spaces that the women inhabited and the networks in which they socialised and lived, tended to be slightly different. Levels of economic capital (using socio-economic status as a marker), clearly had an impact on the ability of individuals to negotiate the community and clinic fields. For those women who were classified in the higher socio-economic groups, they were more likely to have chosen to buy houses in suburban locations away from the typically community-centred locations, which were often close to an urban city centre. This meant that they were physically separated from the community, and this was important in deploying strategies to resist stigma. The second group of women were more likely to live in the heart of the community, often in urban city locations, and were therefore perhaps more vulnerable to gossip and stigma, as in the case of Asma; she had to work hard to avoid unwanted disclosure in the community. Therefore, having the economic resources to move away from the traditional community settings could be seen as an indirect benefit of increased economic capital.

The ability to make choices about treatment, as illustrated in the example of Safiya, and as was described by other middle class women in the study, highlights the importance of socio-economic status (see Figure 7). In very real

ways, having limited resources has a clear impact on women's experiences. Research from the American context, as described in Chapter Three, highlights the importance of social class and economic status for understanding infertility (Roberts 1997, Becker et al. 2006, Inhorn & Fakhri 2006). These authors suggest that for poor or non-white women, infertility can be conceptualised as 'suffering' and 'adversity', with little opportunity to resolve their situation through the use of ARTs. The data in the present study suggest that for British South Asian women, the picture is more complex than this. There does however, appear to be a socio-economic dimension to this experience, which interacts with other factors in shaping how women's (and men's) lives have the potential to be disrupted by infertility. I would also argue that economic capital, or to put it simply, the ability to pay, clearly marks out a divergence of experience for couples who have, and those who have not got, this ability. Being able to pay implies that private treatment can be sought, giving the couple much more chance to overcome their infertility in a shorter space of time, thus possibly avoiding stigma. Since child-bearing and children are symbolically and socially valued in South Asian communities (as in other pronatalist contexts), in successful IVF, economic capital (money) is transformed into symbolic capital (pregnancies and babies). The significance of social class and economic capital for the infertility experience amongst a range of ethnic groups is a finding which needs further investigation.

Conclusions: Infertility as habitus?

A person's individual location in a complex nexus of relationships, networks and sources of capital are central to understanding the infertility experience. In Bourdieu's theorisation, understanding how elements of an individual habitus locates a person in relation to others, is significant for understanding

their ability to negotiate the social terrain. In this respect, Bourdieu's work is insightful for understanding and explaining the infertility experience, not just in South Asian communities, or just for women, but for other groups in society. In developing the work of Bourdieu and thus providing an original contribution to the knowledge in this area, this chapter has disaggregated specific elements of the habitus in order to explore the ways in which they impact on the individual, as well as to demonstrate their shared character.

It represents an original understanding of the negotiation of ethnic identities in relation to a specific experience, that of infertility. Habitus helps us to understand the ways in which individual lives are shaped by both structural and subjective forces, and how together, these form the practice of being a specific individual. This theorisation aids an analysis of subjectivity which is not essentialised. Too often writing about health related experiences such as infertility are focussed on some solitary social signifier (gender, social class, ethnicity) and the use of habitus allows an exploration of how these elements combine and interact to shape individual lives. In this thesis, specific components of the habitus were explored and appeared to be significant, but this is not to suggest that there were not others.

Bourdieu's related concepts of field and capital also help to illustrate how individuals become engaged in struggles in their everyday lives, and how specific resources are central to these struggles. In particular, these concepts allow a contextualised and relational analysis of agency. In understanding the different public domains in which infertile identities are enacted, Goffman's conceptualisation of stigma is valuable. The process in which individuals were placed in a marginal social space by others was central to understanding these narratives. All of the participants, both in the individual interviews and the focus groups, spoke of the ways in which childlessness presented a social

problem. Even where there was sympathy for couples, the absence of children presented an uneasy status, especially for women. In this study, the economic capital that couples held was clearly an important part of this experience and facilitated the negotiation of both the community and clinic fields. Crucially I have argued that in attempting to have a baby using ARTs, these women were transforming economic capital into symbolic capital.

I would like to add to this theorisation and propose that infertility can be added to those facets of the habitus which are significant in shaping subjectivity. For the individual participants in this study, particularly those whose experiences had spanned many years and many attempts at treatment, infertility had become ingrained into their being. It was an experience that they had come to deal with, but that shaped their lives and their perceptions of themselves. Even when they had achieved their goal of having a child, the identity of an infertile person remained with them and they felt that this was something which would remain with them, albeit to a lesser degree, for years to come.

In common with findings from other research, the experience of infertility and identity as an infertile woman, is one which individuals retain, regardless of whether there is a pregnancy or not (Throsby 2004, Peddie et al. 2005, Allan 2007, Redshaw et al. 2007, Wirtberg et al. 2007). Relinquishing the infertile identity is not an easy process, especially where there has been the use of ARTs; which women have reported feeling 'marked' by (Redshaw et al 2007). As Sandelowski et al. (1992) suggest, the women in their study 'had permitted infertility to become central to their lives and the essence of who they believed themselves to be' (p294). Similarly, it has been argued that the infertility experience becomes dominant and alters a person's subjectivity (Jones & Hunter 1996). As such, it could be argued that infertility is incorporated in to

the individual habitus and shapes aspects of their lives as mothers or non-mothers (Letherby 1999). Further analysis of this finding is not permitted here, since the women were not necessarily asked to comment in detail on their feelings about this aspect of their experience and many of the women were still actively undergoing treatment for their infertility. This is a finding that warrants further research.

The next chapter discusses my reflections on the process of carrying out this study. The final chapter presents the conclusions to the study, and suggestions for further research in this field.

Chapter Nine: Reflections on the research process

Introduction

As discussed in Chapter Four, this study is informed by Bourdieu's epistemological position, whereby he attempts to find a 'middle way' through subjectivism and objectivism (Jenkins 2002). Rather than rejecting these positions his aim is to work *with* these categories, retaining the benefits of both and enabling an understanding of internal frameworks of meaning and external social structures. In order to do this, Bourdieu suggests that social scientists should step back and scrutinise the 'view from above' that their epistemological gaze imposes. He refers to this process as the 'objectification of objectification' (1990a), and suggests that it should involve an awareness of one's own position as a social agent and the distortion that this can have on the process of objectification. Speaking of the sociologist or anthropologist, Bourdieu suggests that when attempting to analyse and explain the social world:

'...what he describes as mythical thought is, quite frequently, nothing other than the practical logic that we apply in three out of four of our own actions' (Bourdieu 1990b:66).

That is to say, sociologists must apply the epistemological project to their own actions and frames of reference, as much as to those of their participants. This position is particularly useful when working with ethnicity and culture, since it accommodates a rejection of the culturalist approach, and encourages researchers to explore the familiar as well as the 'exotic' in research interactions.

In attempting to objectify the processes of objectification in this thesis, this short chapter represents an attempt to engage in a process of 'reflexivity'

(Bourdieu & Wacquant 1992, Adamson & Donovan 2002, Abbas 2006). It provides some reflections on the research process and in doing so exposes what impact my individual and 'professional' (researcher) habitus had on the research interactions. It presents a discussion of: the particular framing of the research topic within this thesis; the 'matching' of the identities of researcher and participants in this study; and finally the chapter questions whether research can be said to be 'therapeutic' for the participants.

Framing infertility as a 'problem'

In their interviews with infertile couples, Jones & Hunter (1996) highlight the fact that infertility is not a problem all of the time. There are points in which people's lives are dominated by the experience, and others in which it wanes and becomes less significant. However, the narratives presented in this thesis construct infertility as a continual and unrelenting assault on one's sense of self. For some participants, this seemed to be reflected in their current realities, for example, those who had recently gone through treatment and faced the everyday intrusion on their lives told it as such. However, for others, it could have been that it was less significant. For example, those who had long since completed treatment, (although still considering themselves marked by the process), had perhaps been able to return to some sense of normality, with jobs and childcare taking a central role.

I did not ask the participants to reflect on how infertility differently affected their lives from day to day, instead focusing on factors such as the intricacies of treatment, relationships, and feelings. This tended to frame the interactions in a particular way, with an inherent problematising of infertility. There are no accurate data on how infertility was viewed in this regard, only my sense of how it impacted on them. However, given the open-ended nature of the

interviews, and the fact that none of the participants chose to offer any comment on this, perhaps it could be assumed that the participants had constructed this experience as problematic in the same way that I had.

The role of identity in the research process

Those authors who advocate matching researchers and participants have suggested that this strategy promotes harmony and rapport in the research interaction and authenticity in the resulting accounts (Bhopal 1995, Berg 1999). Chapter Two of this thesis questioned the epistemological assumptions underlying this argument, arguing instead that research interactions are carried out amidst a range of complex social signifiers (Gunaratnam 2003, Culley et al. 2007). During this study there were a number of empirical examples of why matching for ethnicity may be problematic and these are presented here.

Whilst conducting the focus groups, it became clear that a number of social signifiers were of importance in shaping the relationship between researcher and participant. For example, in one focus group (focus group 10) with younger Indian and Pakistani women, the person who had convened the group (and who was also taking part in the discussion) requested that the facilitator be another South Asian woman. This was arranged, with a female facilitator of Pakistani heritage conducting this particular group in English. I also attended the discussion in my role as co-facilitator, to observe, take notes and assist where needed. As the discussion got under way there were several occasions where the younger women directed their comments and responses towards me, effectively excluding the older South Asian facilitator. This was particularly apparent when the discussion turned to issues of accessing higher education and juggling expectations about education, work and family

life. It appeared that in these instances, my similar age to them (26 at the time of this focus group) was more important in enabling the discussion of shared moments of experience, than the ethnic origin and potential shared culture of the older facilitator (who was in her late forties).

There was an instance in another group where the shared gender identity of the researcher and participants became more relevant to the process of data collection than ethnic identity (focus group four). In a number of instances the women in the group stopped the discussion and translated what was being said into English, so that myself and the other English speaking researcher could be included in jokes that were being made about men during the group discussion. This sharing of gender worked to unsettle notions of difference, which operated at the linguistic level (since this group was conducted mainly in Gujarati) and at the ethnic level, since the participants and facilitator were 'Indian' and the researchers co-facilitating the group were 'white'. This finding suggests that ethnicity is perhaps not the only, nor the most significant social identifier at play in constructing the research interaction, neither is it necessarily stable within research encounters. Most importantly the diversity of social and cultural difference within the groups in this study demonstrates the unpredictability and complexity of dynamics within research interactions (Archer 2002).

As with the focus groups, elements of identities other than ethnicity appeared to enable and shape the research interaction in the individual interviews.

Given the sensitive nature of the topic, developing a rapport with the participants was clearly of importance, but this did not appear to be impinged by my not sharing a South Asian cultural heritage. In most cases, rapport was engendered through the numerous phone calls and emails I exchanged with the participants in order to organise the interview, or afterwards when

requests for information were often made of me. Developing a relationship with the participants was also an integral part of the interview process, particularly since in most cases I was invited to people's homes to carry out the interview. Ultimately, the research interaction is a human one (Lalor et al. 2006) and as such listening with empathy, developing trust and sensitively facilitating the sharing of experience, are skills required by the researcher, regardless of who they are.

In most cases, I felt that a shared gender identity may have assisted with the process of developing rapport with the participants, which may not have been possible had I been male. This finding is, at first glance, supportive of feminist claims for the sharing of gender experiences in research (Stanley & Wise 1993). However, I would also argue that, as in the case of ethnic identity, gender is mediated by other factors. For example, studying in higher education, appeared to be a salient experience shared with a number of the participants, as did age, with some of the participants being close in age to me (29/30 at the time of the interviews). Conversations before and after the interviews often therefore turned to work life, home life and studies, and as such, it was these interactions and shared experiences that were important in developing rapport.

This is not to say that ethnic identity has no impact on the research process. Instead, I would suggest that it has an impact on how the research is shaped but does not necessarily add *authenticity* if matching takes place (Rhodes 1994, Nayak 2006). It could be argued that my ethnicity and perceived status (by some) as an 'outsider' to South Asian culture facilitated recruitment to the study, adding an extra layer of separation (and therefore confidentiality) between myself and the participants. This may have been particularly pertinent given the topic of infertility. Had I been a member of a South Asian

community, as suggested in the work of Bhopal (1995), this might have actually limited the number of people willing to speak to me. In this respect being perceived as an outsider could be construed in a positive light. In a further example of this, a number of the participants described at length the significance of religious or cultural traditions (such as those which might take place when a male child is born), which they may not have described for someone who was considered to be a cultural 'insider'. Expectations about what existing knowledge researchers already hold of the social context, therefore, can inhibit or facilitate discussion. In the case of this study, there was a great deal of elaboration on the part of the participants and willingness to speak to me, an apparent outsider. It could be argued that this willingness to speak, was precisely due to my status as stranger. This cannot, of course, ever be known for sure. However, what is clear is that the insider/outsider dichotomy is disturbed by the findings from this study. Recognising the importance of shifting and multiple identities is therefore crucial in understanding the research relationship (Gunaratnam 2003). Simple notions of matching, based on essentialised understandings of ethnic identity and belonging, are therefore flawed and do little to assist the reflexive process (Adamson & Donovan 2002).

A final reflection on the significance of identity, access, and insider/outsider status, is on the issue of reproductive history. Many writers working in the field of infertility, have described their own experiences with infertility and ARTs. In many cases, a personal history of involuntary childlessness has been the catalyst for their work in this field (Letherby 2000, Becker 2000, Thompson 2005). This is not an experience I have shared with those authors or with the participants in this study, although I have no children. There were two instances in which my reproductive identity became significant in the course

of the data collection. In addition, a number of participants asked if I had children and my reflections on these incidents are included below.

A number of participants were interested to know more about me, and in the course of the discussions we had before and after the interviews asked if I had children. I offered the information that I did not, and also that I was not married, which for some seemed to make sense, if I was not married then I would not have yet chosen to have children. Because of my age at the time of the interviews (29/30), I imagine that this did not appear to be problematic. Had I been notably older, the fact that I did not have children may have perhaps led people to ask, or at least possibly presume, that this was because I *could not* have them. One of the participants, however, probed further in our discussion before the interview and asked what had led me to be interested in this area of research. The notes I made after this interview read:

I thought, perhaps, she had wanted to know if I had personal experience of infertility, so although she didn't ask directly, I offered this information. I don't recall any of the others asking me this.

In this example, my perception of this interaction was that she wanted to know if I had experience of infertility; of course I could have misinterpreted this question. If I had this experience, sharing this information would have no doubt had an impact on the interviews, and this facet of our identities could have become the most salient in shaping the research; this is of course hypothetical. Since few people asked, it was difficult to know how I was perceived in this respect. Had I myself been a parent, I felt that this might have been a difficult piece of information to convey, given the topic of research and the status of the women I was speaking to as infertile.

In a second incident, I was interviewing a young woman who was relaying an account about her current search for an egg donor. She asked me at the end of the interview if I knew anyone who would consider acting as an egg donor for her. Since she was looking for a donor of any ethnic group, I thought for a moment that she might ask me to volunteer. Of course she didn't, but I was momentarily aware of the possibility that I could have, in theory, acted as an egg donor for her and this was an uncomfortable feeling. Again, this was my perception of the situation and entirely a result of the impact of my identity and reading of the situation.

Research participation as therapeutic?

Processes of ethical review in research require that the researcher takes account of any harm which might come to a participant in the course of the study (BSA 2002). However, rarely do researchers report on the possible *benefits* to participants in participating in research (Peddie et al. 2006).

Participants in this study appeared to volunteer themselves for a variety of reasons, including altruism towards people in a similar situation to themselves, as well it seems, as a need to talk to someone about their experience. Both of these findings echo those of Peddie et al. (2006), whose participants had all ended treatment, and were seeking a sense of closure. A small number of the participants discussed the impact that taking part in this research had had on them. For example, four of the participants became upset during the course of the interview, at which point I asked them if they were all right and if they would prefer to halt the interview. In Safiya's case, she responded as follows:

No, it's fine, don't worry, it's good; because I probably needed to do that. It's something I've been thinking about a lot, but not actually having the place to voice it.

Charanjit reflected on how surprised she was at how easy it had been to talk in the interview:

It's strange, isn't it, because I can't speak to anybody about this.

Finally, for Aisha, although the interview had been difficult, she resolved that it had helped her to realise that she had not dealt with her emotions about her previous infertility treatment:

And still, now, when I'm talking about things, you know, it just takes me where I was before, so I think somehow I feel that I haven't dealt with this, these emotions, and I find it difficult to, still, today, I find that difficult to deal with.

Peddie et al. (2006), conclude that for some participants, research can often be experienced as therapeutic, which was echoed in this study. Again, in hindsight, it would have been useful to have asked participants to reflect on this issue in a more systematic manner during, or at the end of the interviews. This process also places a considerable burden on the researcher, who is often party to traumatic and troubling life stories (Birch & Miller 2000). In this study, supervisory support therefore became important to the debriefing process after conducting interviews which were particularly difficult. This should be a consideration for others who conduct post-graduate research in this area, and training offered to novice interviewers (Birch & Miller 2000).

Summary

This chapter has attempted to highlight some of the intricacies of negotiating research interactions, and how individual identities, whether as researcher or participant, come to have a bearing on how research narratives are made. Following Bourdieu (1990a), these reflections allow a distancing from the research process and a questioning of the particular frame of reference that I, as a researcher bring to this study. The positioning of the researcher by the

participants, and their perception of the process, are clearly important in this shaping of the data. It is important to recognise that research interactions are inherently human and therefore, they are subject to the same fluidity, performativity and spontaneity as other, non-research interactions are. The next chapter presents the conclusions to this thesis.

Chapter Ten: Conclusions

Introduction

The aims of this study were to explore the social constructions of infertility and assisted conception among South Asian communities in the UK, and to examine the experiences of women from those communities who have used reproductive technologies. Using theoretical conceptualisations from the work of Pierre Bourdieu and Erving Goffman, this thesis has investigated the salient features of this experience from both a personal and a public perspective. The findings from this study suggest that the private experience of infertility is one which is characterised as a major suspension of life course expectations, and attempts to overcome it by biomedical means figure heavily in the accounts presented here. The social context in which infertile lives are enacted is also highly significant, even when childless couples do not choose to share this information with others. Two principal social spaces, the community and the clinic, and the social agents within them, are therefore important in the ways that they shape and structure the individual experience of infertility. This chapter presents a summary of these findings, and in doing so presents the original contribution to knowledge made in this thesis.

Habitus: the significance for infertility and ethnicity

The use of Bourdieu's conceptual framework of habitus allows insight into the inter-play of a number social signifiers in shaping the experience of infertility. Importantly, the findings from this study identify how these elements of the habitus are mediated by one another, and how each can become salient at different times and in different contexts. Gender, ethnicity and religion were each at specific points important in contributing to the experience of infertility, but a clear marking off of these individual elements

of the habitus is difficult. The theoretical appeal of the concept of habitus is precisely its scope for allowing an understanding of the co-productive nature of these (and other) social signifiers. As Atkin (2004) argues, ethnicity is not always the most critical of these signifiers, but there are clearly times when it does matter. This thesis suggests that it is perhaps at the structural level that ethnicity has the capacity to matter most in the case of infertility (Karlsen & Nazroo 2002). The impact of structures of meaning at the community level, particularly those in relation to marriage and procreation, were heavily implicated in individual experiences in this study. However, even at the structural level, it is difficult and unwise to disaggregate the impact of ethnicity from the structural impact of gender, and for some groups, religion, especially in relation to procreation. The impact of ethnicity as structure was also apparent within the clinic; the potential presence of institutional racism here is tentatively demonstrated as evidence of the symbolic and material marginalisation of minority ethnicities within the clinical context. Ethnicity as subjectivity or agency was perhaps less apparent in this study. The work of a number of post-colonial feminist authors adds theoretical weight to the concept of habitus, in understanding how ethnicity, when it is present, is intersected by other subjectivities, such as gender and religion (Brah 1996, Puwar 2004, Ramji 2007). Therefore, this study highlights how ethnicity and culture are significant for the infertility experience, but that at times they are de-centred and become less salient.

The role of gender in the experience was also highly mediated. Although there were clearly aspects of the experience which were gendered, and therefore might apply to women from other ethnic groups, such as the emotional difficulty at the births of new babies, this experience was also shaped by specific cultural structures around the risky and inauspicious status of infertile women at such events. However, the *subjective* gender

experience was highly salient in this study, and the idea that infertility presents a period of biographical liminality may represent evidence of the shared gender experience of infertility across ethnic groups. Women in this study, as in other research, discussed the way in which infertility represented an affront to their femininity and their expectations for adult womanhood. In this respect, this thesis tentatively suggests that infertility also becomes part of the habitus, and that this shapes women's future identities, whether they become mothers or not. Importantly, this study finds that discourses of disruption are meaningful in understanding South Asian women's experiences of infertility.

In Chapter Two, Jenkins' critique of habitus as implicitly structuralist was presented. I would argue that whilst there is a *danger* that habitus can result in a structuralist interpretation of experiences, adopting Bourdieu's approach of objectifying objectification allows the researcher to step back from the analysis, and in doing so to account for both their own agency, as well as the agency of their participants. Adopting an interpretivist position specifically allows an exploration of agency and subjectivity, whilst the importance of structural explanations is retained in the analytical moment. Working with Bourdieu at the epistemological *and* theoretical level, allows one to avoid the dangers of sliding into subjectivism or objectivism. In addition, I would argue that adopting Bourdieu's theoretical triad of habitus, field and capital further widens the scope of the researcher to explore both structure and agency. The concept of field in particular, is insightful in allowing an exploration of the relational aspects of subjectivity and agency. It allows a theorising of 'struggle' which brings in other actors and institutions, and further adds to the understanding of subjectivity.

Fields and capital

Jenkins (2002) has been critical of Bourdieu's use of the concept of field for being too ambiguous. However, the concept of field is perhaps what makes the most novel use of Bourdieu's work in this thesis. It allows an appreciation of how social spaces and other social agents can be highly significant in the infertility experience. Rather than its fluid nature being a disadvantage, I would argue that this is an advantage, as it permits an application to a number of contexts and is useful to think with, especially in spatial and relational terms. Within the community field, the struggle to resist the marking of one's self as a discredited individual was a key feature. The use of Goffman's theory of stigma is central in this analysis, and this thesis illustrates how each theory is advanced through their mutual combination. Stigma theory has traditionally lacked an analysis of the role of agency, and when combined with Bourdieu and with the work of writers such as Brah (1996), illustrates how women attempt to resist stigma in novel ways, and enables a rejection of the culturalist approach. Similarly, the concept of field (in this context) is improved and advanced by use of stigma theory in order to illustrate the specific characteristics of the shared social and community spaces that infertile South Asian women may inhabit or avoid. Stigma is clearly of importance in understanding infertility in the UK context. The studies reviewed in Chapter Three of this thesis, suggest that infertile couples are stigmatised and othered in a range of contexts, and this study adds to and advances existing evidence in this area.

The importance of social constructions of infertility and ARTs are also clear in the analysis of community as field. The perceptions of community members are embedded in the individual stories of childlessness in this thesis. These perceptions are of considerable relevance for shaping the individual

experiences of infertile men and women. However, these perceptions are not fixed and stable, but are themselves undergoing resistance and transformation, particularly amongst younger community members.

The use of field to explore the clinical space in this study was also of conceptual value, and adds to the current understanding of the infertility treatment experience. Negotiating this field was expressed as a struggle for the participants, as they sought to access the treatments they wanted and the outcome they desired – a ‘take home baby’. The notion of ‘struggle’ is central to Bourdieu’s work, and is a fitting analogy for what the participants in this study described. Experts, technologies and regulation are defined as key positions characterising this field, which couples are regularly required to negotiate. The agency of infertility patients in this respect is also an important finding, demonstrating that they are not simply passive consumers of ARTs. They enacted agency in order to achieve success, often by using a number of technologies in a number of different clinics. In some cases this resulted in patients travelling overseas for treatment.

Economic capital was a crucial resource in accessing ARTs. Without the financial resources to move between clinics, and in some cases to circumvent regulatory restrictions (such as those restricting multiple embryo transfer) by travelling outside of the UK, a couples’ options were limited. Waiting for treatment on the NHS (if it was available locally) was the only option for those with limited resources. Although economic capital is only a partial proxy for socio-economic status, it provides tentative evidence of the impact of this form of structure on the infertility experience. It highlights how for those with higher socio-economic status, access to resources permits more

choice, both in treatment terms, as well as in the ways in which stigma can be mediated.

Ethnic 'matching' in research

The findings from this study highlight the importance of a number of social signifiers for shaping the research interaction. Differently configured ethnic identities between the researcher and the participants did have a role in shaping the interviews in this study, but did not appear to have a necessarily negative impact on the research interaction or resulting data, as has been reported in other studies. Instead, being seen as an outsider, in some respects, could have a positive role in facilitating access and engendering feelings of confidentiality. Age, gender, education, employment status, and reproductive history all played a role in shaping the relationship with the participants in this study. 'Matching' researchers and participants by reference to an essentialised understanding of ethnic (or any other) identity is therefore flawed and a more nuanced approach to this interaction should be undertaken by social science researchers.

This thesis draws together a number of complex and highly contested concepts. Understanding the infertility experience, particularly as it relates to ethnicity, gender, agency and structure is not a straightforward task. These chapters have presented the experiences of these social actors, myself included, at a particular point in time and space. These experiences have been used in order to advance thinking and knowledge in this field and, it is hoped, to offer guidance and inspiration for further research to be carried out in this area.

Suggestions for future research

- It is clear that gendered expectations about the importance of motherhood are central to an understanding of the infertility experience. However, parenthood is also significant for normative masculinity (Webb & Daniluk 1999, Becker 2000), particularly genetic connectedness (Culley & Hudson forthcoming 2009). There is a need for further research on how cultural and social expectations for fatherhood impact on the experiences of infertile men from minority ethnic communities.
- This study included only a small sample from British Pakistani communities (both in the focus groups and the interviews) and there is little published research with Pakistani communities on the issue of infertility. Given the costly nature of infertility treatments, and the socio-economic positioning of Pakistani communities in the UK, further research specifically with this community should be carried out. Research about infertility with a wider range of minority communities (such as African, Caribbean and Irish communities) would also add to the limited knowledge base in this field.
- The complicated and messy nature of attempting to elicit community perceptions in qualitative research is confirmed in this study. Yet at the same time, the wider social context was seen as an important field for those experiencing infertility. Research which attempts to explore the complexity and multi-faceted nature of perceptions of what constitutes the community is needed, specifically, a multi-sited investigation of the ways in which meanings of community relate to individual subjectivities.
- The issue of 'informal' adoption and fostering within South Asian communities was raised spontaneously in this study by participants in

both the focus groups and individual interviews. This suggests that alternative, non-medical solutions to infertility may exist, although there has been no empirical research on this issue in the UK. Further investigation into whether or not informal adoption within families is practiced within the UK is therefore required.

- The concept of habitus is often referred to by authors wishing to highlight the complexity of ethnic identity, and its intersection with other social signifiers. This thesis has begun to explore the use of this concept for understanding ethnicity, structure and agency. However, a practical application of habitus in other realms of (ethnicity) research remains relatively undeveloped. Further work to advance the theoretical utility of habitus is therefore required.
- The significance of economic capital for the infertility experience is highlighted in this study, and there is a dearth of research with individuals from lower socio-economic groups. Further research which specifically explores the impact of this factor on couples' access to ARTs would therefore be informative.
- This study finds that couples who are restricted from accessing infertility treatment in the UK, due to financial or regulatory issues, may feel compelled to seek treatment overseas. To date there has been no empirical research with those who make this decision. However, a number of commentators have expressed concern about this trend (Blyth & Farrand 2005). Research which explores the motivations of those who travel abroad for infertility treatment is therefore required.

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Appendix One: The ASFERT study and its relationship to this thesis

In 2002, I was recruited as a Junior Research Fellow to work on the study: *Informing Policy and Practice: A study of the provision of infertility services to South Asian communities* (ASFERT) at De Montfort University. The study was funded by the former Trent Region of the NHS, ran for 2 years and was led by Prof. Lorraine Culley. My role on the project team of four other academics, was to facilitate the day to day running of the project, including the organisation of all data collection and analysis. The first phase of the study included data collected via fourteen focus groups, and it is a re-analysis of thirteen of these groups that is included as part of this thesis (one of the groups carried out in the ASFERT study was not recorded and therefore very little data was available for secondary analysis).

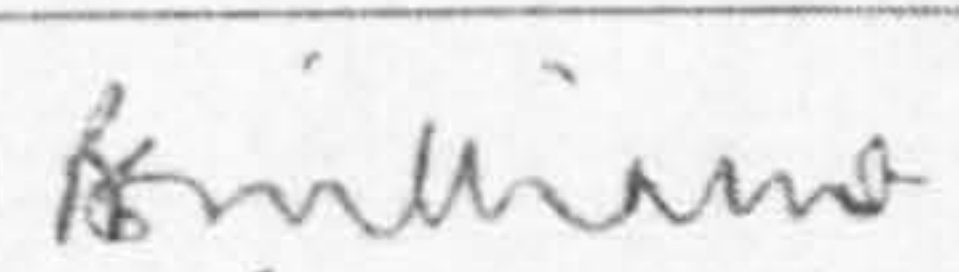
The focus groups presented in this thesis were thus generated with the involvement of several people. The focus group guide was produced as a result of collaboration between the members of the research team, and I was centrally involved in devising this tool. I was also the facilitator or co-facilitator of all but one of the focus groups, and was centrally involved in the initial analysis of the data for the purposes of the ASFERT project. In order to include speakers of languages other than English in the focus groups, several bi-lingual community facilitators were recruited to the study. Eight of the focus groups were carried out in languages other than English. For these groups, my role was to co-ordinate the group, ensure the smooth running of the event, observe the groups taking place, take field notes and consult/debrief with the facilitator immediately after the discussion had taken place.

Early on in the study (June 2002), I enrolled as a PhD candidate at De Montfort University on a part-time basis. The PI for the NHS study, Prof. Culley, was my first supervisor. It was decided at this time by the project team and my supervisory team, that the data from the focus groups could be used within this thesis following a further and distinct analysis of the data related to the themes of the PhD study. The empirical data collected in the interviews for this thesis are entirely new, generated from different interviews than those carried out with men and women in the ASFERT study. The subsequent theoretical and conceptual developments derived from both data sets are distinct from the NHS-funded study, and represent independent research. The ASFERT study received ethical approval from the then De Montfort University, Faculty of Health and Community Studies Research Ethics Committee (ref: project 108).

Appendix Two: Copy of ethical approval letter



Faculty of Health and Community Studies
 Human Research Ethics Committee

CHAIR'S ACTION RESPONSE TO APPLICANT	
Name of Applicant:	Nicky Hudson
Title of research:	PhD " An Exploratory study examining the social construction of assisted conception among South Asian Communities in the UK
Decision of the Ethics Committee:	
Approval given by Chair's Action	<input checked="" type="checkbox"/>
Interim approval given subject to the conditions below	<input type="checkbox"/>
Approval withheld (see notes below)	<input type="checkbox"/>
Approval not required (see notes below)	<input type="checkbox"/>
<p>Note to applicants: Spelling, grammar and syntax are not reviewed or commented upon by the Ethics Committee.</p>	
Comments:	
Signature:  Vice Chair of the Human Research Ethics Committee	Date: Wednesday, 30 April 2003

Ethical approval ref no.: 412.

Appendix Three: Breakdown of focus group participants by gender, age, ethnicity and religion.

Group	No. of members		Gender of group members		Age of group members					Ethnicity of group members			Religion of group members			
	MALE	FEMALE	16-24	25-34	35-44	45-59	60+	Bangla- deshi	Indian	Paki- stani	Hindu	Muslim	Sikh	Jain		
1	-	3	3	-	-	-	-	-	3	-	3	-	-	-		
2	-	10	-	1	-	7	2	10	-	-	-	10	-	-		
3	-	6	-	6	-	-	-	-	6	-	3	1	2	-		
4	-	10	-	-	-	3	7	-	10	-	9	-	1	-		
5	-	7	-	2	4	1	-	-	7	-	-	-	7	-		
6	-	9	-	-	-	3	6	-	-	9	-	9	-	-		
7	-	6	-	-	-	-	6	-	6	-	-	-	6	-		
8	-	6	-	4	2	-	-	6	-	-	-	6	-	-		
9	4	-	4	-	-	-	-	-	4	-	3	-	-	1		
10	-	4	3	-	1	-	-	-	1	3	1	3	-	-		
11	7	-	-	1	1	3	2	7	-	-	-	7	-	-		
12	9	-	-	-	-	-	9	-	9	-	-	-	9	-		
13	6	-	-	3	2	1	-	6	-	-	-	6	-	-		
Total	26	61	10	17	10	18	32	29	46	12	19	42	25	1		

Appendix Four: Focus group question schedule

Introduction:

Firstly, I'd like to welcome you all to the group and thank you for agreeing to speak to us.

Currently very little is known about the experience of people from the South Asian communities who are having difficulty having children. The aim of the study is to hear about the views of your community about the importance of having children and what the community might feel about people who cannot have children or who need help in having a baby. At the end of our study we will be producing some information about infertility and how people can get help with this problem, for individuals from your community to use.

Before we begin I would like to remind you that whatever you say here will be kept confidential. I hope that you will feel free to express your views. Your names and personal details will not be mentioned in any report.

I am using a tape recorder to record our conversation because it is difficult for me to write down everything you say. This will also enable me to give you my full attention and listen to what you have to say. Please try to speak one at a time so that I can follow what is being said.

1. First of all we would like to talk to you about families and children.

In your community how important is it to have children?

Probe: Can you tell us about some of the reasons people have for wanting children?

Is it important if families have a boy or a girl?

2. How soon after marriage would a couple expect or hope to have a child?

Probe: How soon would you expect your daughter-in-law/sister-in-law to conceive after marriage?

3. What have you heard people say about people or couples who do not have children?

Probe: Can you think of any examples where a woman or couple might be treated differently if they didn't have children (probe: weddings birth of new baby)

4. If a woman was having difficulty getting pregnant, what might she see as the cause of the problem?

Probe: medical problems with her or husband

Would there be a religious aspect?

Is it more likely to be seen as a woman's problem or a man's problem?

5. Do you know of any causes of infertility?

6. How might a woman who was having problems getting pregnant be treated by: her husband; her family; her husband's family and the community?

Probe: issue of divorce, additional wives

7. If it was known that a man was unable to father a child, how would the community regard him?

8. In your view, who would the couple be likely to discuss the problem with?

Probe: family member, who?

Keep secret

Religious leader

GP

Other

9. In one of the other groups that we have spoken to, people had mentioned that there have been problems when going to their GP with this difficulty. Have you heard of anyone having problems with their GP?

We would now like to talk about treatments for people who are having problems having children.

10. Have you heard of any treatments for infertility?

Probe: women/ men

Do you know if treatment is available on the NHS?

11. Do you know of any traditional remedies or foods used for this problem?

Probe: alternative therapies

12. Do you know of any special religious prayers or other activities that people might do?

Some women can get pregnant using eggs donated from another woman.

13. How would this be seen by the community?

Probe: family

Anonymous donor

Some women can get pregnant using sperm donated from another man.

14. How would this be seen by the community?

Probe: family

Anonymous donor

15. How do you think a child who was conceived using infertility treatment would be seen by the community?

Probe: how would other family members view them?

16. How does the community view adoption?

Probe: formal/informal

17. How does the community view surrogacy?

Closing Questions:

18. Summary – have we missed anything/ is there anything you would like to add?

19. Finally, as an outcome of the research, we are going to be developing an information pack for people who might want to find out more about infertility and the treatments available. As we begin this project, do you have any advice for us?

Fill in short questionnaire.

Appendix Five: Focus group demographic questionnaire

It would be very useful if you could provide the following information. Any answers you give will be in the strictest confidence and all information will remain anonymous.

1. What is your gender?

Male

Female

2. How old are you?

16 – 24

25 – 34

35 – 44

45 – 59

60 or over

3. What is your ethnic origin?

Bangladeshi

Pakistani

Indian

Other (please specify)

4. What is your religion?

Hindu

Sikh

Muslim

Other (please specify)

5. Which languages do you speak?

Bengali

Hindi

English

Punjabi

Gujarati

Urdu

Other(s) (please specify)



Trying for a Baby?



A researcher from De Montfort University Leicester would like to speak to both women and men from South Asian (Indian, Pakistani, Bangladeshi) communities who may be experiencing difficulty having a child. I am interested in talking to people who are having or have had treatment for infertility, about their experiences.

If you would be willing to help with this research or would like more information please contact:

Nicky Hudson on (0116) 2078766 or email to nhudson@dmu.ac.uk

All discussions will be completely confidential and no one will be identified in the research. The discussion will be carried out at a time and place convenient to you.

If you know of anyone who may be interested in taking part in this study, please pass this information to them.

Thank you for reading this poster.

Appendix Seven: Interview participant information sheet



Information Sheet

Study title: South Asian communities and Assisted Reproduction

Researcher: Miss Nicky Hudson

What is the study about?

There have been many studies of people from the majority population of the UK who have experienced assisted conception, but there is little information about the experiences of those from South Asian communities. The research aims to create a better understanding of south Asian patients' experiences of reproductive technologies. The results will be used to provide an increased understanding of the experience of assisted reproduction and an exploration of issues related to the use of fertility treatments for British South Asian communities.

Who is involved in the study?

The study is being carried out by a researcher from the Faculty of Health and Life Sciences at De Montfort University, Leicester.

Do I have to take part?

No, the study is entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

If you consent to taking part in the study, the researcher will contact you to make an appointment to meet and speak to you. The researcher would like about 60 minutes of your time, to ask you some questions about your

experiences. The researcher will tape record your interview if this is acceptable, in order to help them make an accurate record of your comments. The interview can take place at a time and place convenient to you.

What happens to the information?

All information you give is entirely confidential. No one will be able to identify you from the study. The tape recordings are transcribed and all comments analysed together to give a full picture of your experiences, and those of others like you. The data is kept in a locked office at the University and only the researcher can see it. At the end of the study all original material will be destroyed.

What will happen to the results of the study?

The results will be made available following the completion of the study in 2007/8. A summary of the research will be produced and you will be able to receive a copy of this if you wish from the researcher. No one will be identified in any publication or report.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential.

Who has reviewed the study?

The study has been scientifically reviewed by De Montfort University, Human Research Ethics Committee. It is supervised by Dr Lorraine Culley and Dr Sally Ruane at De Montfort University.

Contact for further information

If you would like any further information about the study or need to ask any questions please contact Nicky Hudson on (0116) 2078766 or email: nhudson@dmu.ac.uk. If you have any questions or concerns about this study, you should discuss them with the researcher leading the study or the study supervisor on 0116 257 7753 or email lac@dmu.ac.uk

Thank you for taking the time to read this information sheet.

Appendix Eight: Interview consent form



CONSENT FORM

Title of Study:

South Asian Communities and Assisted Conception

Name of Researchers:

Please circle
your response

Ms. Nicky Hudson

1. I agree to take part in the above study YES/NO

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason YES/NO

3. I agree to the audio-taping of the interview and I understand that I will not be identified and that the tapes will be destroyed at the end of the project YES/NO

Name of interviewee

Date

Signature

Witness to consent
(i.e. researcher/family member/friend)

Date

Signature

Appendix Nine: Interview topic guide

Before starting a family/trying to get pregnant

What did you imagine would happen when you decided to start a family?

Had you every considered that you might not conceive a child straight away?

How important was it for you to have children?

What did parenthood mean to you?

Was this influenced in anyway by family/friends/ community?

Have you ever felt pressure to have children?

Had you ever heard of anyone/know of anyone who could not have children?

Ideas about ARTs before discovering a problem

Had you heard of treatments for infertility?

Where from – media/friends/family etc.?

What did you think about/ know about their use?

Was this influenced by other factors? Religion?

Was this influenced by other people? Who?

Discovering a problem

How did you feel when you discovered you may have a problem with conceiving?

Did your ideas about becoming a parent change?

In what way?

How did you feel when you were told you would need to use medical treatments in order to conceive?

Did this affect your ideas about fertility/conception?

What did you think would happen?

Engaging with ARTs

Were your ideas about medical treatment correct?

How have your perceptions about NRTs changed?

Who/what has influenced your perceptions/attitudes?

Has your situation changed your views of medical treatments/NRTs?

In what way?

What do you think about treatments now?

How does this compare with what you thought before you discovered a problem?

Did your view of yourself change?

What about the doctors? Have your views of them changed?

Is it important that you have a good relationship with the staff?

Do you have any concerns about using these treatments?

What are the positive and negative aspects of using NRTs?

How did you feel when it didn't work?

How did the staff treat you when it didn't work?

Would you disclose/ have you told anyone else about the use of NRTs?

If not why not?

If yes, what was their reaction?

What about telling the child?

If you had to explain the need to use the treatment to an elderly relative, what would you say?

Donating embryos?

Do you think the experience is different for men and women?

How did you feel about yourself as a woman?

Community views

How do you think ARTs are viewed by the wider community?

How do you think a child conceived using ARTs would be viewed by the community?

What do you think knowledge levels about ARTs are in the community?

Has this changed? How?

How can this change in the future?

Do you feel that you have been treated differently because you don't have children?

Do you think people would treat you differently if they knew you had used NRTs?

Biological relatedness

Is it important to be biologically related to any child conceived?

Why/how?

Would you consider using donated gametes?

If this was the only option to have a child, would you take it?

Why?

How would a child conceived using donated gametes be viewed/treated by the community?

How would you be viewed?

What about family continuity?

Closing questions

How would you feel if you could not have a child?

Would there be any consequences?

How would you feel?

How would you be treated?

Do you think infertility/using ARTs changes your ideas about conception/parenthood?

How? In what way?

Appendix Ten: Interview demographic questionnaire

It would be very useful if you could provide the following information. Any answers you give will be in the strictest confidence and all information will remain anonymous.

1. How old are you?

16 - 24 25 -34 35 - 44
45 - 59 60 or over

2. What is your gender?

Female Male

4. What is your ethnic origin?

Indian Bangladeshi
Pakistani Other (please specify) _____

5. What is your religion?

Hindu Sikh
Muslim Other (please specify) _____

6. Which languages do you speak?

Bengali Hindi
English Punjabi
Gujarati Urdu

Other(s) (please specify) _____

8. What is your occupation? _____

9. Your partner's occupation? _____

10. Place of birth? _____

Appendix Eleven: Pen portraits of interview participants

Narinder

Narinder is married with one child conceived through her first attempt at IVF. She has since had multiple cycles of private IVF treatment in order to have a second child, but has been unsuccessful. At the time of the interview she was planning to have one last attempt at IVF and then to end to treatment. She has unexplained infertility. She is a middle class woman who does not live or socialise within the wider community. She has not disclosed any information about her infertility outside of the immediate family.

Safiya

Safiya is a middle class woman, who is married with one child conceived through IVF. Safiya had multiple cycles of IVF to overcome infertility which was caused by endometriosis. She would like to have a second child but the cost of further treatment is prohibitive. She has close relations with family and the community and has disclosed the fact that she has used IVF widely (although she has had a negative response from some in relation to this). She still suffers from severe endometriosis but has not given up hope that she may have another child.

Asma

Asma had previously had two cycles of NHS-funded treatment which failed, and she remains childless. She has secondary infertility, and had two miscarriages prior to beginning treatment. She has made the fact of her unexplained infertility known to family and friends, but not the fact that she

is using IVF treatment, which she has disclosed only to a small number of people. Asma lives, socialises and works within the community.

Charanjit

Charanjit is single and lives with her parents. She experienced the menopause prematurely at age 35 and this has had a huge impact on her life. She has never married, partly due to her infertility and partly due to her experiences of attempted arranged marriages earlier in her life. She has considered using donated eggs or adopting a child, but feels that these are still very much last resort options, for which she is not ready. She has not disclosed this information to many people outside her immediate family. She is now in her late thirties.

Nadia

Nadia has previously had six cycles of unsuccessful IVF treatment, which were self-funded. Although initially treated for unexplained infertility, due to her age (now in her mid-forties) she has now been advised that in order to conceive she will need to use donor eggs. She has accepted this decision, and remains on the waiting list for an Asian donor. She has not given up hope of becoming a parent, but realises that as time goes on her chances decline. She has disclosed information about her infertility fairly widely. She has had some negative treatment, especially from her husband's family, in relation to her infertility.

Jasmin

Jasmin has unexplained infertility and has previously tried private IUI treatment four times, each of which was unsuccessful. At the time of the interview she had tried IVF once within the NHS, which was unsuccessful. She and her husband had chosen not to disclose any information about their

inability to conceive to family members. Not telling members of her husband's family (who live close by and are in constant contact) was proving stressful. She has been married for seven years and trying for a baby for two years, although she and her husband tell people that they are 'not ready' for children. She works full time and the treatment was having an impact on her working life.

Bhavna

Bhavna is married and has secondary infertility; already having one child. She is having problems in conceiving a second child and has been referred to the local hospital for diagnostic tests. She was apprehensive about the prospect of infertility treatment, but hopeful that there would be a solution for her. She was in the very early stages of treatment-seeking at the time of interview and had not yet received a diagnosis for her infertility.

Padma

Padma had recently moved house, away from her in-laws, with whom she and her husband had been living. She has had a diagnosis of endometriosis and has had one cycle of IVF, which was self-funded, whilst living with her husband's family. She was currently undergoing a frozen embryo cycle, after a break of two years in treatment. She wanted to move away from her in-laws before continuing with treatment, since they do not know about their use of IVF. As a result, they ask lots of questions about why she and her husband don't have any children, which she finds stressful.

Sita

Sita and her husband had a diagnosis of male factor infertility and had been advised to go for private surgical treatment by their NHS consultant. She and her husband had disclosed their treatment-seeking to both of their families.

Sita felt that this was important that her in-laws especially knew that she wasn't responsible for their childlessness. Sita now has a child who was conceived after receiving IUI treatment, with her husband's sperm. They need to use the remaining vials of sperm before the storage deadline expires, and this will represent their last and only attempt to conceive a second child.

Anjali

Anjali is married and started to try for a baby as soon as she got married. She had an unexplained diagnosis and had unsuccessful IUI treatment within the NHS. Due to long waiting times, she subsequently decided to opt for private IVF treatment. Her second cycle of IVF resulted in a pregnancy, which ended in an early miscarriage. At that time, and as a result of failure in the UK, she decided to go to India for treatment, where she conceived her child. She intends to travel back to India in the near future to have further treatment for a sibling.

Rita

Rita went through nine years of infertility treatment in order to conceive her first child, who is now a teenager. Rita was one of the early IVF success stories and helped her clinic to secure a license to carry out IVF. She has since conceived a second child without the use of assisted conception treatment.

Aisha

Aisha began trying for a baby nineteen years ago and after twelve years was eventually successful with IVF treatment. Prior to learning about her unexplained infertility, she had fostered a close family member, a young child, who had lost their own mother. She estimates that she had ten cycles of IUI (some of which were failed IVF cycles) and four cycles of IVF. The years

of continuous treatment have had an impact on her emotionally and physically and have affected her marriage.

Gita and Ramesh

Gita and Ramesh have secondary infertility; they already have one child who was conceived naturally eleven years ago. They waited before trying for a second child and subsequently had problems conceiving. They were not eligible for treatment on the NHS and so decided to go to India for treatment as it was cheaper than having private treatment in the UK. A first attempt with IVF failed, and they are now planning to back to India a second time to have treatment, this time using donor eggs, since Gita is now over 35 years old.

Samina

Samina is married, in her mid-twenties and has premature ovarian failure. She has been told that she needs donor eggs in order to conceive. She is aware that there is a shortage of suitable Asian donors and is therefore happy to use either an Asian or a white donor. The clinic that they are currently attending, however, will not allow them to use an existing white donor. She and her husband are therefore currently attempting to recruit their own donor of either ethnicity. Their families and friends do not know that they are planning to use donor eggs, only that they are having IVF treatment.

Appendix Twelve: NS-SEC classes and collapsed categories

Original eight classes	Collapsed three classes
1 Higher managerial and professional occupations	1 Managerial and professional occupations
1.1 Large employers and higher managerial occupations	
1.2 Higher professional occupations	
2 Lower managerial and professional occupations	
3 Intermediate occupations	2 Intermediate occupations
4 Small employers and own account workers	
5 Lower supervisory and technical occupations	3 Routine and manual occupations
6 Semi-routine occupations	
7 Routine occupations	
8 Never worked and long-term unemployed	Never worked and long-term unemployed

Adapted from ONS NS-SEC Classes and collapses:

http://www.statistics.gov.uk/methods_quality/ns_sec/class_collapse.asp

Appendix Thirteen: Interview participants' partners' socio-economic status

Interviewee		Partner
F	Professional & managerial	Professional & managerial
F	Professional & managerial	Professional & managerial
F	Routine & manual	Routine & manual
F	Intermediate	N/A
F	Routine & manual	Missing data
F	Intermediate	Professional & managerial
F	Professional & managerial	Routine & manual
F	Intermediate	Professional & managerial
F	Professional & managerial	Intermediate
F	Professional & managerial	Professional & managerial
F	Intermediate	Intermediate
F	Full time student	Professional & managerial
F	Routine & manual	Intermediate
M	Intermediate	Routine & manual
F	Unemployed	Intermediate

Appendix Fourteen: N7 coding framework with the tree node expanded

Name	Sources	References	Created	Modified
Being interviewed	0	0	09/03/2007 13:49	09/03/2007 13:49
Decisions about treatment	0	0	09/03/2007 13:22	09/03/2007 13:22
Engaging with medical expertise	0	0	09/03/2007 13:11	09/03/2007 13:11
Experience of infertility	0	0	09/03/2007 12:58	09/03/2007 12:58
Experiencing treatment	0	0	09/03/2007 13:34	09/03/2007 13:34
Fertility & childbearing	0	0	09/03/2007 12:07	09/03/2007 12:07
Adoption	12	31	14/03/2007 19:07	23/03/2007 16:42
Age	2	6	09/03/2007 12:10	18/03/2007 17:24
Becoming an expert	2	2	09/03/2007 12:57	15/03/2007 11:09
Biological relatedness	7	11	09/03/2007 12:47	23/03/2007 16:42
changing perceptions of natural conception	3	4	09/03/2007 12:09	22/03/2007 20:09
Child death	6	13	09/03/2007 12:08	23/03/2007 17:38
Deciding to have a child	4	9	09/03/2007 12:08	23/03/2007 13:00
Getting periods	1	1	09/03/2007 12:10	15/03/2007 16:06
Importance of motherhood	4	8	09/03/2007 12:48	23/03/2007 17:38
Importance of parenthood	7	16	09/03/2007 12:47	23/03/2007 17:38
IVF children as special	1	1	09/03/2007 12:57	15/03/2007 09:50
Lack of control	5	9	09/03/2007 12:09	23/03/2007 12:39
Mandated parenthood	5	5	09/03/2007 12:06	23/03/2007 17:21
Other people's pregnancies	8	25	09/03/2007 12:47	23/03/2007 12:10
Parenting other people's children	6	12	09/03/2007 12:47	23/03/2007 12:52
Parenting skills	4	12	09/03/2007 12:57	23/03/2007 12:54
questioning of natural conception	4	7	09/03/2007 12:09	23/03/2007 11:04
Time passing	5	11	09/03/2007 12:10	23/03/2007 17:33
Success & failure	0	0	09/03/2007 13:30	09/03/2007 13:30
The Community context	0	0	09/03/2007 13:05	09/03/2007 13:05

Appendix Fifteen: Section of a node from N7

Name: **Unexplained infertility**

<Documents\Interviews\PhD 1> - § 1 reference coded [0.62% Coverage]

Reference 1 - 0.62% Coverage

¶233: I had so much faith in the, in the medical profession in a way, they're like, you go for any op, you think, yes, it's gonna cure you, it's gonna work, so it's a similar feeling, yeah, you know, it's going to work, cos there's nothing wrong there and, but then now, I look back, I think unexplained, it means they haven't found anything, there still could be something wrong, it's just different way of thinking.

¶234:

<Documents\Interviews\PhD 10> - § 2 references coded [1.04% Coverage]

Reference 1 - 0.39% Coverage

¶195: I didn't really have any problem, erm the doctors here said well, there isn't a problem, we just don't know why you're not getting pregnant.

¶196:

¶197: I Yeah. Unexplained.

¶198:

¶199: R But they say that sometimes you just need a baby to kickstart your whole system again, and then it might work. But erm...

¶200:

Reference 2 - 0.65% Coverage

¶375: I'd be like, Well, why isn't it happening for us, there's no problem, so why is it not happening? and that was the biggest problem. If I had a reason, I could say, Well this is the reason, that's why it's not happening, but then when I went to see Dr M, he was like, Well, you're better off not having a reason than having a reason?

¶376:

¶377: I Yeah. [laughs]

¶378:

¶379: R Cos that reason could be hard to solve. So, I thought about it, and I thought, yeah, it's true, what am I worried about but...

¶380:

¶381:

<Documents\Interviews\PhD 11> - § 1 reference coded [0.42% Coverage]

Reference 1 - 0.42% Coverage

¶373:

¶374: R Yeah, it is. Well, people say that why, you know, either you had the one or the second one you have to go for an IVF as well. But with me, you know, I think this is, this is the reason why we say that we could be that we were totally stressed out.

¶375:

¶376: I Yeah. Yeah.

¶377:

¶378: R There was nothing wrong with either of, because when they did the test on me, there was nothing wrong.

Appendix Sixteen: Focus group code book

Tree or parent nodes

Importance of having children	IC
Importance of having male children	IMC
Understandings about infertility	UI
Consequences of infertility - couples	CIC
Consequences of infertility/childlessness – men	CIM
Consequences of infertility/childlessness – women	CIW
Support offered to childless couples/individuals	SOC
Attitudes towards seeking help	AH
Attitudes towards treatment options	AT

Sub-themes

Importance of having children	IC
Religious reasons	IC-rel
Cultural reasons	IC-cult
Economic reasons	IC-ec
Emotional reasons	IC-em
Social reasons	IC-soc
Importance of having male children	IMC
Religious reasons	IMC-rel
Cultural reasons	IMC-cult
Economic reasons	IMC-ec
Emotional reasons	IMC-em
Social reasons	IMC-soc
Reaction to birth of daughters	IMC-daughter
Understandings about infertility	UI
Beliefs about causes of infertility	UI-bel/inf
- Religious	UI-bel/inf/rel
- Cultural	UI-bel/inf/cult
- Behavioural	UI-bel/inf/behav
- Medical/biological	UI-bel/inf/bio
Knowledge about causes of female infertility	UI-kn/fem/inf
Knowledge about causes of male infertility	UI-kn/male/inf

Consequences of infertility - couples

Pity of
Hidden
Gossip about
Taunting of
Stigma of
Sadness
Treatment by inlaws
Treatment by community

CIC
CIC-pity
CIC-hid
CIC-goss
CIC-taunt
CIC-stigma
CIC-sad
CIC-treat/inlaws
CIC-treat/com

Consequences of infertility/childlessness – men

Pity of
Hidden
Gossip about
Shame of
Taunting of
Withdrawal of inheritance
Pressure to take second wife
Pressure to divorce wife
Treatment by community

CIM
CIM-pity
CIM-hid
CIM-goss
CIM-shame
CIM-taunt
CIM-inherit
CIM-sec/wife
CIM-div/wife
CIM-treat/com

Consequences of infertility/childlessness –women

Guilt, feeling of
Pity for
Stigma of
Blame for
Blame for, by herself
Blame for, by family
Blame for, by community
Blame for her own infertility
Blame for her husband's infertility
Gossip about
Taunting of
Sadness
Ostracism from social occasions
Divorce
Remarriage
Remarriage of husband
Treatment by husband
Treatment by in-laws
Treatment by own family
Treatment by community
Relationship with additional wives

CIW
CIW-guilt
CIW-pity
CIW-stigma
CIW-blame
CIW-blame/her
CIW-blame/fam
CIW-blame/com
CIW-blame/own/inf
CIW-blame/husb/inf
CIW-goss
CIW-taunt
CIW-sad
CIW-ostr
CIW-div
CIW-remarr
CIW-remarr/husb
CIW-treat/husb
CIW-treat/inlaws
CIW-treat/own/fam
CIW-treat/com
CIW-relat/add/wives

Relationship with children from additional marriages	CIW-relat/add/child
Mental health	CIW-mental/health
Support offered to childless couples/individuals	SOC
From community	SOC-com
- about treatment	SOC-com/treat
- about practitioners	SOC-com/pract
From family	SOC-fam
- about treatment	SOC-fam/treat
- about practitioners	SOC-fam/pract
- about adoption	SOC-fam/adopt
- offers of children to adopt	SOC-fam/offers/adopt
Attitudes towards seeking help	AH
As a woman's responsibility	AH-wom/resp
As a man's responsibility	AH-man/resp
Knowledge about getting help	AH-kn/help
Lack of knowledge about getting help	AH-lack/kn/help
Influence of family	AH-infl/fam
Influence of community	AH-infl/com
Stereotyping	AH-stereo
Embarrassment	AH-emb
Shyness	AH-shy
Suspicion/mistrust	AH-susp
Fate/destiny	AH-fate
Cost (financial)	AH-cost
Fear	AH-fear
Language	AH-lang
Attitudes towards treatment options	AT
<i>Medical</i>	AT-med
Knowledge of medical treatments	AT-med/kn
Beliefs about medical treatments	AT-med/bel
Use of medical treatments	AT-med/use
Finance	AT-med/finance
Mistrust of medical treatments	AT-med/mistrust
Attitudes of family to medical treatments	AT-med/att/fam
Attitudes of community to medical treatments	AT-med/att/com
Acceptability of IVF	AT-med/accept/IVF
Knowledge of IVF	AT-med/kn/IVF
Beliefs about IVF	AT-med/bel/IVF
Acceptability of use of donated eggs	AT-med/accept/don/eggs
Knowledge about use of donated eggs	AT-med/kn/don/eggs

Beliefs about use of donated eggs	AT-med/bel/don/eggs
Use of anonymous egg donor	AT-med/anon/don/eggs
Use of known egg donor	AT-med/known/don/eggs
Implications of use of donated eggs	AT-med/impl/don/eggs
Acceptability of use of donated sperm	AT-med/accept/don/sperm
Knowledge about use of donated sperm	AT-med/kn/don/sperm
Beliefs about use of donated sperm	AT-med/bel/don/sperm
Use of anonymous sperm donor	AT-med/anon/don/sperm
Use of known sperm donor	AT-med/known/don/sperm
Implications of use of donated sperm	AT-med/impl/don/sperm
Attitudes towards child conceived through ART	AT-med/att/child/ART
Treatment of child conceived through ART	AT-med/treat/child/ART
Acceptance of child conceived through ART	AT-med/accept/child/ART
Attitude to child conceived through donated eggs/sperm	AT-med/att/child/donation

Access to information about infertility

Need for - education	ACI-need/educ
- support	ACI-need/support
- counselling	ACI-need/counsel
- information	ACI-need/info
Options when treatment is unsuccessful	ACI-opt/unsucc/treat
Mistrust of information in Asian newspapers	ACI-mistrust/As/news
Lack of knowledge among older generation	ACI-lack/kn/older/gen
Knowledge in younger generation	ACI-kn/youn/gen
Type of information	ACI-type/info
- leaflets	ACI-type/info/leaflets
- radio	ACI-type/info/radio
- TV	ACI-type/info/TV
- film	ACI-type/info/film
- self help groups	ACI-type/info/selfhelp

Appendix Seventeen: Glossary of terms

- **Adoption**
Taking a child into an existing family, usually (but not always) accompanied by legal proceeding that creates a parent-child relation between persons not related by blood.
- **Allah**
The Arabic word for God.
- **ART**
Assisted reproductive technology(ies). A collective term for specialist infertility treatments in which gametes are manipulated outside of the body. The aim of these treatments is the improved chance of pregnancy.
- **Cycle**
One complete attempt with a treatment e.g. a cycle of IVF.
- **Donor**
Person providing their gametes (eggs or sperm) for use by another person or couple.
- **Embryo**
The term for a fertilised egg at up to 8 weeks development.
- **Embryo transfer (ET)**
The transfer of one or more embryos to the uterus.
- **Endometriosis**
A condition in which endometrial tissue (that which usually lines the womb) is found outside of the womb.
- **Fostering**
The provision of parental care and nurture to children not related through legal or blood ties.
- **Gamete**
The female egg or male sperm.

- **Hajj**
A sacred pilgrimage to the holy city of Mecca, required of Muslims who are able, and can afford to go, at least once in their lifetime (see Mecca).
- **Haram**
or Haraam; that which is forbidden in Islamic law.
- **Intracytoplasmic sperm injection (ICSI)** a technique in which an individual sperm is injected directly into a single egg. The procedure is then very similar to that followed in conventional IVF.
- **Intrauterine insemination (IUI) or artificial insemination (AI)** a technique in which a sample of prepared sperm is inserted into the cervix or uterus of a woman. The procedure is carried out using a fine tube and is often accompanied by ovarian stimulation in order to increase the chances of pregnancy.
IUI or AI with donor sperm (DI) is often used when there are problems with the male partner's sperm or if there is a risk that he may pass on an inherited disease.
- **In vitro fertilisation (IVF)** a technique in which fertilisation takes place outside of the body in a petri dish. IVF can be carried out using the eggs from the female partner, which are then fertilised using her partner's sperm, or by using donor sperm. Donor eggs can also be used, fertilised with either the male partner's sperm or donated sperm, meaning that a resulting child can be genetically related to both partners, just the female, just the male, or neither partners.
- **Mecca**
A holy Islamic city in Saudi Arabia to which Muslims are expected to make a pilgrimage (see Hajj).
- **Miscarriage**
The spontaneous loss of a foetus before 24 weeks.
- **Nikah**
An Islamic marriage contract.
- **Polycystic ovarian syndrome**
A hormonal problem in which multiple cysts form on the ovaries. Symptoms include infertility, absent or infrequent periods, acne, obesity and hirsutism.

- **Premature menopause/premature ovarian failure**
Menopause starting at a much earlier age than is considered usual.
- **Qur'an**
The central religious text of Islam.
- **Unexplained infertility**
A term for infertility where there is no obvious medical cause.