

THE EXPERIENCE OF CANCER-RELATED FERTILITY IMPAIRMENT AMONG PEOPLE OF SOUTH ASIAN AND WHITE ORIGIN

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EXECUTIVE SUMMARY

1 Introduction

- 1.1 This report summarises the findings of a two year qualitative study funded by CRUK (C8351/A9005), which began on 1st April 2008. The aims of the study included understanding the social and emotional impact of threats to fertility in a multi-cultural context, while examining how this relates to the wider impact of cancer itself. The study specifically identifies similarities and differences in experiences of people within an ethnically diverse population and explores the extent to which these may be mediated by culture, religion or gender. The study then goes on, by offering various recommendations, to develop strategies for planning accessible and appropriate services (planning, commissioning and delivering health and social care).

2 How we did the research

- 2.1 We spoke to people whose fertility was, or may have been, affected following cancer treatment, and health and social care professionals from a diverse range of backgrounds, involved in their care.
- 2.2 We talked to 47 men and women from White (n=26) and South Asian (n=21) backgrounds, aged between 18-40 years old who had different types of cancer. We asked about their experiences of the long term (social and emotional) impacts of treatment and any specific issues related to fertility that they might have encountered. We were especially interested in how people made decisions about their treatment and how they felt about any potential impact these decisions had on their fertility. We also asked them about the kind of information and support they received from health and social care professionals and the role of family and friends in dealing with their illness.
- 2.3 In addition, we spoke to various professionals involved in cancer and fertility services, in three groups (n=17) and individually (n=16) across three fieldwork sites. This helped us explore their views on taking care of younger people

affected by cancer and how they respond to patients from minority ethnic backgrounds. It also enabled us to understand how services work.

3 The views of health and social care professionals

- 3.1 Professionals have to navigate many tensions in offering support to those who experience fertility problems following a diagnosis of cancer. Much of these tensions reflect dealing with uncertainty, which includes uncertainty about disease progression as well as potential effect on fertility. Professionals also raised tensions arising from the need to prioritise treatment of the cancer, while keeping options open regarding fertility. More generally, uncertainty could sometimes explain the re-active strategy adapted by those professionals who waited for individuals to raise questions before responding to them.
- 3.1 A lack of confidence among professionals, inappropriate service contexts and a feeling that they needed to offer hope, often militated against a more pro-active approach. Professionals to their credit have insight in to this. They were equally aware of the tension around facilitating choice, sometimes feeling the need to get the patient to come around to their point of view, especially when discussing cancer treatments. Professionals also relied on their own personal experience and ethical values when faced with, what they perceived as, dilemmas surrounding gamete preservation, parenting and posthumous use of gametes. To this extent it was difficult to determine the extent to which their advice was informed by an evidence base.
- 3.2 Compared to professionals' concern to get across the general struggles they faced in offering care to those with fertility problems following a diagnosis of cancer, ethnicity was often introduced as an aside. Gender, for example, was seen as a far important consideration, as was life course. When ethnicity was discussed it was often in terms of generalised assumptions, informed by a sense of homogenous communities, in addition to a strong sense of minorities being the 'other'. When probed, many of the difficulties faced by patients, which professionals attributed to 'culture' occurred irrespective of ethnicity. Professionals could interpret similar responses very differently according to the

cultural and ethnic background of the patient. This mediates many of the themes identified in the previous paragraph. It is also perhaps why some professionals felt ill-equipped to respond to the needs of a multi-cultural society and why certain contradictions emerge in how they respond to ethnic and cultural diversity.

4 The views of those who had undergone cancer treatment in negotiating potential threats to fertility

- 4.1 Those undergoing cancer treatment faced many dilemmas, when assessing the impact of such treatment on their fertility. In the first instance it is difficult to disentangle the experience of having cancer from the long-term consequences that treatment might have on a person's fertility. People generally accepted treatment should take priority, but sometimes felt let down by professionals, who they felt should have been more willing to discuss solutions to potential fertility problems, alongside outlining their treatment options.
- 4.2 As people learned to live with cancer, fertility issues came much more to the fore and our participants struggled with various dilemmas as they attempted to negotiate the consequences of potential difficulties with fertility. Gender was an important variable in mediating this experience.
- 4.3 Most participants felt that they had received efficient and timely medical care. However, a few felt their GPs had not taken the severity of their complaints seriously. This might have been due to their young age.
- 4.4 The potential risk to fertility caused by a particular cancer treatment is usually discussed during initial consultations on diagnosis and treatment. Doctors, however, cannot be certain about risks to fertility and are not able to give definite answers. Some patients, especially those who might have problems with fertility later in life, find it hard to understand why the clinicians may not have provided them with more definite answers.
- 4.5 Facing a risk to fertility is different for men and women. Most men were able to preserve a sample of sperm, irrespective of their ethnic or religious

background, contrary to the assumptions of some professionals about religious proscriptions for certain groups, especially Muslims.

- 4.6 In contrast, many women did not have a great deal of choice when it came to preserving eggs, embryos or ovarian tissue. This was the consequence of technical complexities and time involved (four to six weeks), which would have delayed treatment. Women who might face problems in conceiving naturally felt that they had not been given enough information or opportunity to discuss the matter with a specialist.
- 4.7 Preservation of gametes (sperm, eggs, embryos) generates many inter-personal and ethical issues. Younger people, in particular are forced to reckon with profound issues such as the meaning of procreation and kinship as well as death well ahead of when they might be otherwise do so. The process of consent for preservation can also involve a redefinition of what might have been, up to now, transitory relationships to one with a commitment to raising children together.
- 4.8 Most men and women felt that unless raised by them, fertility had not been discussed during follow up consultations. Some of the participants would have liked health care professionals to treat the issue of fertility as one of the priorities within follow up care, given its significance to them as an individual.
- 4.9 The experiences of participants within each ethnic group were marked by age, gender, severity of illness and socio-economic background. Faith, for those who believed in a religion, irrespective of majority or minority ethnic background, provided a framework for engaging with illness and options related to potential infertility. However, participants' engagements with religious beliefs and practices reflected a need to seek guidance for making the 'right moral choices' rather than a fixed response to a code of conduct. Similarly, reflections on kinship and blood relationships represented another important cultural issue for individuals, in weighing up their options across ethnic groups represented in our sample.
- 4.10 The accounts of our participants provided little support for some of the cultural generalisations used by professionals. Their situations reflected far more

complexity and subtlety, which in turn reflected the practical, social and moral dilemmas raised by the various options available to them as they sought to reconcile potential infertility, with their broader need to make sense of their lives. There was, for example, little evidence of pro-natalist views being any more prevalent among people of South Asian origin than any other ethnic group. Nor could a 'culture of silence' be associated with any particular ethnic grouping in relation to the use of reproductive technologies. Participants across ethnic groups treated the issue as a 'private' domain to be shared with close members of family and friends. To that extent, there were many generic and shared experiences associated with having cancer, negotiating treatments, and facing a potential risk to fertility, irrespective of ethnic origin. However, the relationship between the individual and a 'community' operates differently for some people of South Asian origin (not all), who might face a greater degree of moral policing within a kinship/religious community of which their family is a part.

5 Conclusions

- 5.1 As suggested in the introduction, our research cut across the fields of cancer, ethnicity and infertility. At a methodological level, we aimed at destabilising the notion of ethnicity by using a comparative method to analyse the biographical context within which treatment-related threats to fertility are experienced and negotiated. This was felt to be more helpful in understanding the lives of people than un-contextualised descriptive engagement, while also providing the basis for more constructive policy and practice solutions.
- 5.2 Our research offered a specific glimpse of the archaic stereotypes of 'Asian' families being secretive, deceitful, male dominated, and governed by prescriptive norms laid down by religion and culture, held by some of the professional participants in our study. Their views remind us yet again of the challenges of achieving the goals of 'cultural competence' alongside 'patient centred care' within a multi-ethnic society. Understanding and engaging with ethnic diversity and reflexivity should be seen as integral parts of the training

of health and social care professionals, rather than as an ad hoc 'competence' they can achieve at the end of a brief training session

6 Recommendations

- 6.1 There is a particular need for better co-ordination and communication between primary and secondary care following treatment. This would improve continuity of care, and offer better signposting for a range of support and advice not included in routine care
- 6.2 There is also a need for better communication, when talking about the risk to fertility following treatment and more openness about the possible options and their likely outcomes. It is especially important to avoid partial or rushed advice when discussing options for preservation of gametes with women, particularly when such discussions might raise unrealistic hopes.
- 6.3 All patients, but especially women, should be offered an opportunity to consult a specialist in reproductive medicine before starting treatment. This would enable patients to understand the process of preservation of eggs and embryos as well as the chances of a live birth following such treatments.
- 6.4 It is important to incorporate discussions of fertility in long term follow up care especially for those who might be facing difficulties.
- 6.5 The needs of cancer patients and their families during diagnosis and following treatment are multi-faceted, complex and responsive to context. Commissioning strategies need to reflect this, alongside the multi-disciplinary nature of care, which involves inter and intra-agency collaboration including across the spectrum of health, social care and the third sector
- 6.6 Professionals need to have greater confidence in responding to situations without relying on 'fact-files' or generalisations about cultural practices of minority ethnic groups.

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CHAPTER ONE: INTRODUCTION

This report summarises the findings of a two year qualitative study funded by CRUK (C8351/A9005), which began on 1st April 2008. The aims of the study were to: understand the social and emotional impact of fertility impairment and examine how this matches the wider impact of cancer itself. In doing so, the study would identify similarities and differences within the population and explore the extent these may be mediated by culture, religion or ethnicity. It would also develop strategies for accessible and appropriate services (planning and delivering health and social care). In meeting these aims, we spoke to people whose fertility was, or may have been, affected following cancer treatment and health and social care professionals from a diverse range of backgrounds, involved in their care.

Before turning to the findings, this chapter introduces the literature relevant to understanding policy and practice on the long term impact of cancer and treatments related to cancer; and the specific negotiation of threats to fertility in relation to ethnicity. Exploring the literature was an important aim of the original proposal. The next chapter outlines our aims and objectives and methods. This included reflecting on the research process and analyses underpinning the study and specifically highlighting some of the challenges of engaging with 'ethnicity' within the context of healthcare. This sets the scene for chapters three and four, which begins to present the main empirical findings generated by our study. Chapter three explores the general perspectives of various health and social care professionals working across different disciplines at three fieldwork sites serving significant 'South Asian' populations. Chapter four provides a bird's eye view of the complex experiential world of white and South Asian participants who have faced a diagnosis of cancer and in particular, explores how they negotiate threats to fertility caused by cancer treatment in relation to various aspects of their identity, including gender, socio-economic background and ethnicity. Chapter five discusses the contributions of the research within the context of policy and practice and concludes by presenting some recommendations that we hope will be useful for professionals as well as policy makers.

SETTING THE SCENE AND REVIEWING THE LITERATURE

Cancer and Fertility

Cancer affects every third person in the UK and is often perceived as the 'disease of the old'. Whilst 65 per cent of cancer diagnoses affect older people above 65 years of age, some cancers can have a significant impact on the lives of younger adults diagnosed in their childhood or teens as well as adult years. On a positive note, survival rates are improving across the age span and people are 'living with and beyond cancer'. This, however, poses further challenges - at individual and social levels - of dealing with the long term impact of cancer treatment (Eiser, 1998; Zebrack and Zeltzer, 2003), including residual levels of chronic conditions and disability among people surviving cancer (National Cancer Survivorship initiative, 2008:3). For a minority, cancer survival comes with irreversible loss of fertility at an unexpectedly younger age, caused by the treatment, if not the condition itself.

At a policy level, The National Cancer Survivorship Initiative - a collaboration between the Department of Health (DH) and the Macmillan Cancer Relief - is an attempt at addressing the need for appropriate support and service provision to address these broad issues. As a follow up to the aims of the Cancer Reform Strategy (DH, 2007) to improve the experiences of patients, the collaboration is meant to: 'consider a range of approaches to survivorship care and how these can be best tailored to meet individual patient's needs' (National Cancer Initiative, First Newsletter, 2008:1). However, neither the Reform Strategy nor the First Newsletter of the Survivorship Initiative mentions the probable long term impact of living with infertility caused by treatment. The emphasis in long term follow up clinics seems to be on surveillance, early detection of recurrence and late effects of treatment, such as, lymph-oedema, secondary cancers and cardiac problems (see recent BMJ Editorial, Meriel and Levitt, 2009). While various models of long term follow up services encompassing psychological support and financial/work/benefits advice have been established across

the UK (see DH, 2007: 80-81), consultations in clinics are often rushed and little is known of to what extent, if at all, concerns and issues related to fertility are addressed.

A number of studies within the field of psycho-social oncology (and social work) suggest that treatment-related disruption to fertility can cause long term distress (Grinyer, 2009); impinging on recovery and well being (Schover, Brey and Lichtin et al., 2002; Zebrack and Chesler, 2001). An earlier study carried out by one of this report's authors suggest that the impact of such disruption can affect the quality of life of teenage children during and after the acute phase of treatment (Crawshaw et al., 2009; Crawshaw and Sloper, 2010). However, quality of life is an elusive term defined and measured differently depending on disciplinary background and (quantitative or qualitative) methods used. Studies within psycho-oncology often reflect a biomedical model of disease and deficit models of coping. Coping, for example, becomes seen as an individual strategy, rather than one that is realised with a broader social context. However, there is a smaller field focusing on the process of psycho-spiritual 'thriving' as part of the reconstitution of self and relationships following the traumatic experience of cancer in childhood (for a review see Parry and Chesler, 2005).

Schover (2005) in an overview of the literature on motivation for parenthood in younger adults who have survived cancer (such as leukaemia, testicular cancer and Hodgkin's disease) outlined some interesting and contrary themes. In two of the quantitative surveys covering younger survivors aged between 14 and 40 years, 76 percent of participants who were childless, contemplated having a child in the future and a majority felt that the experience of having cancer had enhanced the value of parenthood and family ties. Only a small minority (6 and 13 percent in the first and second surveys, respectively) felt that having had cancer impacted negatively on their desire to have a child. However, a significant percentage of participants in both the surveys (38 percent and 31 percent respectively) had concerns that their children might be at increased risk of developing cancer.

The association of womanhood with motherhood - which cuts across cultures - can mean perceptions of infertility can be seen as largely a woman's issue (Throsby, 2004; Inhorn and Balen, 2002; Letherby, 1999). It is, therefore, hardly surprising that younger women might find loss of their fertility as painful (or harder) than the diagnosis of cancer (see Surbone and Petrek, 1997; Dow, 1994; Partridge et al., 2004). A number of qualitative studies carried out in the US and Australia look at the experiences of younger women who have survived breast cancer, their access to information and concerns about pregnancy, and use of new/assisted reproductive techniques (NRTs) or adoption (see, for example, Dunn and Steginga, 2009; Thewes et al., 2003; Siegel et al., 1999). Uncertainty about their ability to have children as well as their experience of premature menopause can become more salient themes following treatment, once the crisis and shock of diagnosis have abated (see Ganz, 2001); signifying a change in their information needs over time (Thewes et al., 2003: 506; Avis et al., 2004). Fertility might be a significant issue for some women at the time of diagnosis too, irrespective of their age or whether they already have children. This leads Thewes et al., (2003: 508) to conclude that some younger women: 'who have a strong desire to become pregnant at diagnosis may be prepared to trade off some survival benefits for preservation of their fertility'. Interestingly, some of the women in their study noticed a disparity between their own priorities and the attitudes of their oncologists. Following this, Adams (2007) reflects on the current emphasis within policy on greater patient choice and user involvement in decision making (Department of Health, 2001; 2003; 2006: 24) and its limitations in practice within the context of women undergoing treatment for breast cancer. One 46 year old participant in Adam's study wanted to take six months off before starting Tamoxifen, in order to try and conceive, a decision that clashed with her treatment plan. She was referred for cognitive behavioural therapy (CBT) to help her address the emotional issues and 'realise' the consequences in case she deteriorated and left her family bereaved. This suggests her choice was deemed 'irrational' within the context of treatment choices.

In contrast with the complexity of the clinical procedure and timing in offering preservation of embryos, eggs or ovarian tissue to women (relatively recent

technological developments as compared to use of retrieved sperm) and poorer success rates, the technically easier option for men to store sperm before starting treatment is a more standard practice (for a concise review see Hart, 2008). This has generated interest in how men relate to the threat of infertility caused by treatment and their experiences of 'sperm banking' (Achille et al., 2006; Schover et al., 2002; Bahadur, 2000; see also Green et al., 2003 for 'psychosocial' impact of potential infertility on younger men treated as children). The option of 'sperm-banking' can be seen as prioritising their potential infertility and making it more visible; in contrast with the situation of women (and this is contrary to the visibility and medicalisation of women's bodies within the field of infertility outside the context of cancer, as noted below).

Suffice to say, attempts at so called 'fertility preservation' in men and women raise a whole series of ethical issues related to the consent process including potential posthumous use, disposal of unused samples of gametes or embryos, as well as alternate routes to parenting with or without the use of assisted conception techniques. Wider social attitudes to cancer as a potentially terminal illness have not fully shifted and are sometimes reflected in the ethical issues raised by health and social care professionals regarding whether or not someone with a diagnosis of cancer should become a parent, have access to NRTs and adoption or fostering. There is a small body of research that suggests that adoption is more acceptable to cancer survivors than gamete donation (Schover et al., 1999; Schover et al., 2002); but it is an area that needs further research. Despite anecdotal evidence from the US on the prejudices and bureaucratic hurdles faced by cancer survivors in adopting (<http://groups.yahoo.com/group/adoption-after-cancer>), both national and international adoptions do take place. This observation is, however, contradicted by the social science literature, which highlights a preference for, in addition to social pressures, that often culminate in some pretence at a genetic link to a child among people using gamete donations (van den Akker, 2006; 1995, Bharadwaj, 2003; Gottlieb, et al., 2000).

Two concerns underpin the ethical debates concerning parenthood and cancer survivors: one concerning potential health risks related to treatment and mutations of the cancer and the specific harmful effects of pregnancy for women with breast or gynaecological cancers; and the second related to concerns about the 'welfare of the child' arising from uncertainty about remission and survival and the possibility of premature death (Towner and Loewy, 2002; Robertson, 2005). As suggested by some ethicists, concerns about the welfare of the child and a shortened lifespan of a parent suffering from cancer cannot be sufficient grounds for denying cancer survivors the opportunity for help in reproducing (Robertson, 2005); a view also endorsed by the American Society for Reproductive Medicine (2005). In contrast, the UK Human Fertilisation and Embryology Authority (HFEA) Code of Practice (2009: Guidance Note 8), requires that the welfare of any child born as a result of treatment, including the needs for supportive parenting, be taken into account before agreeing to treat.

As reiterated by Schover (2005: 2), infertility caused by treatment (or the cancer itself) may not be the only impediment to parenthood following cancer. Treatment can have serious career, financial and social implications for finding a partner and developing intimate relationships, especially given the uncertainties caused by the likelihood of recurrence or a second malignancy, depression or disability, or simply the costs of using fertility treatments. Sharing this experience with family and friends or potential partners and then deciding whether and when to have one's fertility status tested can be an emotionally difficult process (Langeveld et al., 2003; Parry, 2003; Thaler-Demers, 2001; Rauck, Green et al., 1999). Equally, the nature of an existing relationship might determine why some people decide not to tell or postpone discussing the subject with a potential partner, in anticipation of the stress it might cause (see Zebrack et al., 2004: 693). This might have particular implications for some people of South Asian origin, for whom marriage and having children as normative goals assume a specific 'social visibility' (Culley and Hudson, 2009), although this might be just as relevant to all irrespective of ethnicity. Very little research explores the relationship between the long term emotional and social implications of cancer treatment and infertility within

the context of ethnicity, even though the relation between fertility and ethnicity has been explored within the context of other chronic conditions (Atkin et al., 2006).

The role of service support

At a policy level, improved information and communication, and access to appropriate services, especially clinical nurse specialists (CNSs), are recognised as being central to improving patient experience, participation in decision making and choice surrounding cancer care (Department of Health, 2007, Chapter five). Efforts are being made at developing national patient information pathways, to be tailored to individual needs (Chapter five: 74). Access to information on financial support, benefits, and rights under the Disability Discrimination Act is expected to be integral to this pathway. It is well known that despite these rights and entitlements, nearly 75 percent of cancer patients never receive any information on financial support (National Audit Office Report, 2005). The role of the Clinical Nurse Specialist (CNS) encompassing clinical, emotional, informational, family based and individualised support embodies the goal of improving continuity of care within a multi-disciplinary team approach.

In practice, access to information on cancer and potential impact of treatment on issues of fertility varies across adult and paediatric services (see for example, Mitchell et al., 2005; Foster, 2002). Lack of appropriate information often contributes to poor access to services (Achille et al., 2006; Duffy et al., 2005; Schover et al., 2002; Zebrack and Chesler, 2001) and might cause unnecessary anxiety for some or lack of necessary precautions for others (Oosterhuis et al., 2007; Zebrack et al., 2004; Partridge et al., 2004). The importance of direct involvement of cancer patients in discussions and decisions related to treatment is highlighted in both policy and empirical research (Young et al., 2003; Jenkins et al., 2005). However, the pace and complexity of the process of passing on and making sense of information surrounding significant treatment decisions that potentially affect fertility must vary with age and individual circumstances (Green et al., 2003). As far as minority ethnic communities are concerned, research involving older adults suggests that lack of access to English as

well as professional attitudes to minority ethnic communities can seriously affect access to appropriate information and services (Chattoo et al., 2002; Karim and Bailey, 2000). However, it remains to be seen whether younger cancer survivors within these communities, especially those who were born in the UK, speak good English, or have lived and worked here long enough to understand the service system, have similar experiences; and to what extent ethnicity, gender or socio-economic position mediate their cancer experiences (see Atkin, 2009).

Clearly, within the context of treatment related threats to fertility, lack of access to appropriate information and services can have significant impact on choices related to life course in the long term, especially in younger women and men yet to contemplate 'settling down' or parenthood. NICE Guidelines (2005) for services for children and young people with cancer recommend that the potential impact of treatment on fertility and appropriate preservation options should be discussed. This is extended to all age groups in the NICE Guidelines on fertility assessment and treatment (2004) and the Royal College of Physicians, Radiologists and Obstetricians and Gynaecologists' guidance on the management of the effects of cancer on reproductive functions (2007). However none of these adopted the specific recommendation by the British Fertility Society's (2003) strategy for childhood cancer survivors that it should be addressed specifically in long term medical and psycho-social follow up services. Research suggests that the presence of stored gametes can alleviate stress for men by leaving an option for reproduction open in later life (Crawshaw et al., 2008; Saito et al., 2005). However, this option is still not available to all, especially a majority of women, while some young men still find the process leading to storage unsatisfactory and receive little psychological support about what it entails (Chapple et al., 2007). It has also been suggested that some men are reluctant to go along the preservation route on religious grounds (Tomlinson and Pacey, 2002; Oogle et al., 2008). However, while ethnicity, infertility and reproduction have been studied from social science perspectives, as discussed later, the potential relationship between dimensions of ethnicity and treatment related threats to fertility has not been analysed so far.

Health and social care professionals in the UK have voiced concerns about variable practices and issues related to fertility for people undergoing cancer treatment, largely focusing on the experiences of adolescent males (Bahadur et al., 2001; Glaser et al., 2004; Green and Crawshaw, 2006). There is some evidence that professionals, across disciplinary boundaries, lack the confidence or knowledge in handling issues related to fertility and sexuality or might not consider it important; implying that patients might, at places, not have access to appropriate information and services (Nagel and Neal, 2008; Quinn et al., 2008; Vadarampil et al., 2007). This might be further compounded for patients from minority ethnic backgrounds, since there is considerable evidence suggesting that health and social care agencies struggle to offer accessible and appropriate care, either ignoring or misrepresenting their needs (Chattoo et al., 2003; Atkin, 2004; Culley and Hudson, 2009). There is increasing awareness of the need to develop innovative ways of addressing ethnicity and diversity at various levels of service provision within both statutory and voluntary care sectors. This will be increasingly significant within the context of the changing profile of the British population where the demographic boundaries of minority and majority communities are rapidly changing in certain parts of England (such as Leicester) and an increasing number of children are born and brought up within families of mixed ethnic origins and plural identities. Our previous and in some ways old fashioned ways of conceptualising ethnicity may no longer be relevant. Ethnicity is but one aspect of a person's identity and its meaning remains contingent (Atkin, 2009). We, therefore, need to reconceptualise the analytical role of ethnicity within these diverse healthcare settings before appropriate and inclusive strategies can be developed or put into practice. We shall elaborate on the implications of this issue in the next chapter, when we turn to the research process.

The complex conflation between ethnicity and socio-economic position on incidence of chronic conditions and health outcomes is increasingly being recognised within research informing policy and practice (see Nazroo, 2003, Bhopal, 2004; Karlsen and Nazroo, 2002; Department of Health, 2007). Chapter six of the Cancer Reform Strategy, 2007 emphasises the need to reduce inequalities and recognises how, at times, it is hard

to distinguish between inequalities in access or outcomes due to socio-economic deprivation and those related to ethnicity. At the same time, gender and age might mark significant differences within, but similarities across ethnic groups when dealing with treatment related disruption to fertility and reproduction (Atkin et al., 2006). It is important to highlight contexts within which particular dimensions of ethnicity make a difference and those where other factors cutting across ethnic groups might be at play. We find more analytical insight into these interconnections in the wider social science literature on infertility and reproduction even though, as we shall see, the specific context of cancer makes a crucial difference to how these threats to fertility are experienced and negotiated.

Cancer, infertility and ethnicity: social science perspectives

Theoretically, we draw on two sets of writings (largely sociology and anthropology) to help us analyse the findings within a social science context: literature to date that has been considered separately from the more bio-medical and health service research orientated literature, which in itself creates analytical problems when we come to make sense of infertility. The first set of writings relate to the notion of 'biographical disruption' (Bury, 1982) that the diagnosis and treatment of cancer can cause, and reconstitution of self through narrative techniques (Williams, 1984; 2000). At one level, the physical *consequences* of symptoms, impending treatment or impairment that can cause disruptions in every day routine. At another, the *significance* of these at a more symbolic level for one's identity, reflecting wider cultural values associated with cancer, gendered notions of body, disability and, possibly, childlessness. Exley and Letherby (2001) have used this framework specifically to look at the disruption to life course and emotion work in narratives of men and women facing cancer as a terminal illness, where infertility is associated with stigma, loss and grief and where biographical reconstitution is associated with strengthening but also breakdown of marital relationships/partnerships. We know little about the biographical reconstitution of self for those who experience cancer in childhood or adolescence (Drew, 2003), and implications for social relationships posed by the prospect of

childlessness. Even though this literature focuses on the level of individual embodied experience, the structural factors of gender, age, ethnicity and socio-economic position, and the symbolic values, provide potential linkage with wider cultural scripts underpinning these experiences (see Seale, 1998; Chattoo and Ahmad, 2008).

The second set of writings is represented by a rich body of literature on cultural constructions and medicalisation of 'childlessness' and its association with 'infertility' as a medical condition that can be treated with the help of NRTs (Sandelowski and de Lacey, 2002; Sandelowski, 1993; Franklin, 1998; Greil, 1997). Taking a medical model of infertility as a disease that can be 'treated' (if not cured), the infertile are represented as patients. The possibility of technological/medical interventions to address a biological problem is located and enforced within a liberal (consumerist) view of giving women and men increasing 'reproductive choice' (see Calnan, 2007).

There is an important analogy between the fields of cancer and infertility as epitomised in Frank's notion of a 'remission society' (1995) where survivors inhabit the inter-space between the worlds of the healthy and (potentially) sick. Infertility, in contrast to notions of 'sterility' or 'breenness' (irreversible physical conditions), connotes a medically and socially liminal (transgressing/cross-cutting two domains) space wherein a person lingers between being in-fertile and overcoming (medically 'treating') a physical/biological difficulty in having a child (Sandelowski and de Lacey, 2002: 34-35). Once medicalised, infertility is often represented and experienced as an 'invisible' chronic illness, associated with the stigma of childlessness, the need to keep trying, or the feeling of a 'failed/ damaged' (embodied) self. As in the case of cancer and chronic conditions, infertility thus results in a 'biographical disruption' (see Bury, 1982; Becker, 1994) that can only be reconstituted, healed through narrative (a story with a beginning, middle and an end that reconstitutes the ruptured self). As reiterated by Sandelowski and de Lacey (2002:43): 'in the narrative- illness model, the infertile ... protagonists encountering the greatest obstacle of their lives and seeking to resolve the contradictions of their culture (eg., concerning who can be a legitimate

patient, who can be a legitimate parent, and the utility and morality of conceptive technology) with courage and even daring’.

Riessman (2002a) has challenged the view that infertility, by definition, threatens the gendered identity of women as potential mothers and results in biographical disruption that needs narrative repair. In doing so, she questions the underlying psychological theories of adult identity as a universal trajectory unfolding in time, premised on continuity. She analyses how a group of older women in South India find alternate ways of resisting dominant, gendered constructions of infertility, thus providing contrasting meanings of fertility reconstituted within the context of their social relationships over the life course. Hence, Sandelowski and de Lacey (2002) conclude that, ‘infertility’ is a culturally specific, western construct that mirrors the social norms and values. This is how NRT/ARTs come to represent a ‘barometer’ of debates on gender, subjectivity as well as cultural change. To this extent medical interventions become embodied within a dynamic and contingent social context.

It is important to mention that feminist writings bring the experience and agency of women into the centre of this discourse (Farquhar, 1996; Sandelowski, 1993; Franklin, 1997; Ragone, 1997; Lewin, 1997; Throsby 2004). However, most writings within the field marginalise the presence of men as (fertile or infertile) partners, sequestering their anxieties, emotions, experiences and physical discomfort related to infertility and the use of NRTs (Inhorn et al., 2009). It has been observed that infertility in men continues to be associated with greater stigma and secrecy in most cultures due to its close association with impotency and emasculation and notions of descent and legacy (Haimes, 1993; Inhorn, 2004; Simpson, 2004; Bharadwaj, 2003). The use of intracytoplasmic sperm injection (ICSI) has created a new experiential space for men and an option for couples who might otherwise have had to consider donor insemination (DI). As suggested earlier, the easier access to preservation techniques within the context of potential threat to fertility caused by cancer treatment makes men’s bodies and subjectivities more susceptible to greater medical and psychological surveillance.

Popular and academic discourses on infertility also represent infertile people as 'socially handicapped', while infertility is defined as a 'social disability' since it results in stigma and a 'spoiled identity' (Greil, 1991) and more broadly reflects the pro-natalist assumptions of the wider society (Culley and Hudson, 2009). Hence, infertile couples should be seen to need social support with adoption or help coming to terms with being childfree rather than technological-medical interventions to help them 'overcome' infertility. The psychological framework, in contrast, defines infertility as a psychological problem, where behaviour and emotional responses to treatment, its success or failure are the foci of intervention. Here, the infertile person is deemed in need of specialist fertility counselling and psychological therapies to help them understand and modify their emotions, feelings and behaviour (see Hunt and Meerabeau, 1993) in order to cope with different stages and types of treatment and its outcome, including eventual parenting or adoption (see Greil, 1997). A new team of experts define infertile women/couples as psychologically distressed, depressed and needing emotional support; any serious consequences of these emotions remain unknown. This has led clinicians and academics to question whether such emotions are more a product of this discourse on emotions rather than the needs of 'patients' themselves (see Boivin, 1997).

Given our focus and the scope of this report, we are unable to engage with a third and theoretically more sophisticated field of literature within new kinship studies. On the one hand, the use of NRTs destabilises the relationship between nature and culture underpinning kinship in the Euro-American cultures. On the other, it reasserts the primacy of biogenetic kinship by introducing new, quasi-biological forms of parenting, kinship and relatedness resulting in 'strategic naturalisation' of gamete donors and surrogates (for a summary of the field, see Inhorn and Birenbaum-Carmeli, 2008: 181). Adoption/fostering become relegated to the last resort, where once it was perceived as the 'natural solution' to infertility in both Western and non-Western cultures until the 1980s (see Bharadwaj, 2003; Becker, 2000; Carsten, 2000). Apart from these historical shifts within a culture across time, there are bound to be differences related to religion,

age, sexuality and socio-economic position in acceptance or resistance to these new technologies at a point of time (see for example van den Akker 2006). Purewal and Akker (2006) note that both white and South Asian women who follow a religion are less likely to donate eggs. However, religious responses to the use of NRTs also vary, as we know from the liberal Jewish interpretation of the use of NRTs (subsidised by state) in Israel (Inhorn and Birenbaum-Carmeli, 2008:184). In contrast, third party gamete donation and surrogacy are religiously proscribed within (majority) Sunni Islam, and despite minority Shia decrees issued in Iran and Lebanon legitimising the use of third party donation within the context of temporary (*mutta*) marriages, people still do not consider it to be acceptable in practice (Inhorn, 2006). Similarly, despite the proscription of NRTs by the Vatican and legislation against their use in some Catholic countries (Ireland, Italy, Costa Rica), NRTs are widely used in most Catholic countries (Raspberry, 2009). Hence, the influence of faith (and culture) is far from straightforward, with individuals actively and creatively engaging with their beliefs and values when making decisions.

Nonetheless and despite this complexity, a comparative perspective is useful in understanding the similarities and differences across different ethnic and religious groups. For example, a shortage of gamete donors among minority ethnic communities in the UK (HFEA, 2006) cannot simply be attributed to religion or culture, since there is evidence of different motivations for sperm and egg donors and recipients within the same culture. Literature suggests similar needs and concerns of people seeking infertility treatment, irrespective of ethnicity (Culley and Hudson, 2009; Culley et al., 2006). Yet an analytical focus on 'ethnicity' and 'ethnic monitoring' (Culley et al., 2006), paradoxically, reinforces notions about South Asian and other minority ethnic communities being constituted as the 'distant other', having different and *specific* needs and experiences by positioning them *a priori* as being a 'racialised community'. This is partly a reflection of the fact that ethnicity is a difficult concept to operationalise and whilst we know that it connotes country of origin, religion, culture, linguistic and nationalistic affiliations, studies often fail to identify the specific context used within analysis (Bradby, 2003). Ethnicity is a process of identification and works

only within the context of marking boundaries between groups, for purposes of inclusion and exclusion, that shift with political and social context; hence a potent euphemism for racism in the past or 'racialised minority' or 'cultural racism' in the present (see Blaut, 1992). 'White' refers broadly to a national 'majority' that is assumed to be a non-problematic, homogenous category, without reference to minorities (such as Irish, Polish, Jewish and, recent immigrants from Eastern Europe) within culture or religion, the focus being largely on life-style and individual choice. In contrast, 'South Asian' is a heterogeneous category that denotes four countries of origin within the Indian sub-continent (though Sri Lanka is often excluded, as in our research), regional, linguistic and religious affiliations as well as different histories of migration and settlement. To that extent, we are using dissimilar units of analysis. Meaningful comparison must draw on analytical categories that are specific to the context of analysis and can be operationalised (in terms of content), so that we can explain the similarities and differences across ethnic groups without taking recourse to a priori positioning of the subject within a 'racialised'/immigrant community, forever fighting the ghost of the postcolonial world (Ahmad and Bradby, 2007). This is not to contest the centrality and contribution of these frameworks in explaining racism, discrimination and processes of marginalisation but encourages a reflection on their contingent nature. This, as we shall see, poses us particular problems when justifying our sampling strategy

CONCLUSION

Providing a contextual literature review was an important aim of the research. Not only did it have an important analytical importance in setting the scene, it helped us refine our aims and objectives, develop the questions we needed to ask our participants and offered a broader empirical, policy and theoretical context in which to locate our findings. The literature itself offers some valuable insights in to the experience of those facing (in)fertility problems following a diagnosis of cancer, particularly highlighting differences between the experience of men and women; a struggle to understand the potential implications of infertility among affected

individuals and care professionals; and the more general problems of accessing appropriate provision. A gulf, however, appears between the more descriptive orientated research - often located within the broad discipline of health services research – and the more subtle and nuanced social science literature. One of our concerns is to bridge this gulf and, in doing so, offer a more sophisticated view of how ethnicity and culture mediate the experience of those whose fertility might be affected following cancer treatment.

CHAPTER TWO: DOING THE RESEARCH

In this chapter, we outline our aims, objectives and methods, in addition to describing the research process and analyses underpinning the study. We will also focus on some of the challenges of operationalising ethnicity within the context of research related to health and healthcare.

AIMS AND OBJECTIVES

As alluded to earlier, the aims and objectives of this study sit nested across two main fields of enquiry: negotiations of threats to fertility caused by treatment related to cancer; and issues of ethnicity, identity and access to appropriate services within the context of infertility. Our study is informed by different academic disciplines (medical sociology, social policy and social work) and aimed to look at the long term social and emotional impact of cancer on adults (18-40 years of age) who might have been diagnosed with cancer in childhood, teens or early adult life. For pragmatic and analytical reasons we chose to focus on those of 'South Asian' origin and offer their experience as a case study of a minority ethnic population that is known to be diverse in terms of religious, linguistic and regional affiliations within the subcontinent and yet shares certain common cultural features of family, kinship and caring practices (Ahmad, 1996: 51-72; Chattoo and Ahmad, 2008). Paradoxically, despite being the most researched minority ethnic population within healthcare research, the myths and racialised perceptions of difference still inform certain areas of professional practice (Anionwu and Atkin, 2001, Bhui et al., 2004; Cully et al., 2006). It is also important to note that, often, dominant voices within local communities competing for resources and appropriate support reinforce these wider perceptions of homogenous communities premised on religious and cultural difference. We will return to this.

As we have seen, the main aims of this qualitative study were to:

- understand the social and emotional impact of actual or potential cancer-related threat to fertility for younger adults (18-40 years) of South Asian and White

origins in the peak age groups for forming adult relationships and becoming parents, and their support networks ;

- explore how far threats and uncertainty related to fertility is experienced and negotiated within the specific context of surviving cancer;
- examine decision making processes including those associated with fertility preservation, fertility testing, fertility treatments or other routes to parenthood;
- identify similarities and differences in experiences across the ethnic groups in the sample, specifying where these are mediated by culture, religion, ethnicity, gender or socio-economic background; and
- summarise key messages for accessible and appropriate services for those responsible for planning, commissioning and delivering health and social care.

In meeting these aims, we collected two sets of data across three fieldwork sites:

1. A purposively selected sample of health and social care professionals representing different disciplines and services involved in caring for people with cancer, using focus group discussions and in-depth interviews (see Tables 1 and 2 for sample details)
2. A theoretically selected sample of people who had undergone treatment for cancer with potential implications for issues of fertility, using in-depth interviews (see Table 3 for details).

The research was approved by the MREC (07/H1307/181) and the R&D departments of each of the relevant Trusts involved in supporting fieldwork (see Appendix A).

FIELDWORK WITH HEALTH AND SOCIAL CARE PROFESSIONALS

As way of enabling the reader to contextualise and make sense of our findings, we offer a brief account of the service system in all three of our fieldwork sites. At each site, we established contact with paediatric/teenage and young adult (TYA) as well as adult services. All the cancer services dealing with children and young people ran 'late effects' services (including nurse-led clinics in Sites One (S1) and Three (S3), one of

which also offered telephone consultations) but these were not provided routinely for those diagnosed as adults. Cryopreservation services were provided by the NHS in all sites (hence free of charge). In two (S2 and S3), these were provided to both men and women through a single service; at S1, sperm banking was provided by a separate Andrology Service. Two of the sites (S1 and S2) ran a multi-disciplinary service specifically for women considering cryopreservation before starting treatment; one had been in existence for some time and the other had recently been established. Both included infertility counsellors who offered ongoing contact to women during their cancer treatment and beyond, free of charge. One site (S3) ran a joint oncology-reproductive medicine out-patient clinic (including doctors and nurses) for those treated for childhood or teenage cancer. NHS fertility analysis and fertility treatment services with both NHS and private provision were available at all three sites. Psycho-social services were provided either by the local authority (e.g. social workers¹) or NHS (psychologists; infertility counsellors; activity co-ordinators; youth support workers²) or privately (infertility counsellors in private clinics).

Focus group discussions

Our intention had been to run four focus groups and conduct ten individual interviews across the three sites after we had completed the interviews with individuals affected by cancer. However, given the pragmatics and unforeseen delays in recruiting, we considered it prudent to bring focus group discussions forward. This also had the methodological advantage of providing important contextual information that helped us focus the interviews with individuals affected by cancer.

Following a discussion with Advisory Group members (for membership see Appendix B), our CRUK liaison officer and collaborators, we decided to conduct three (rather

¹ Funding for some posts was from charities, although the local authority employed the staff.

² Similarly although funding for some posts was from charities, staff were employed by the NHS.

than four) focus groups (one at each site,) for reasons explained below; and increase the number of interviews from 10 to 16. We anticipated that the additional six interviews would provide us more insight into professional attitudes and practices, contextualised within a particular disciplinary background, than a fourth group discussion across disciplines and services.

A range of health professionals and scientists for both focus groups and individual interviews were drawn from adult and paediatric/TYA cancer services and fertility services in each site (S1, S2 and S3), together with two social workers, a psychologist, a third sector community-based oncology Equality and Diversity Officer and a member of the local primary care trust (PCT) with commissioning responsibilities for cancer services (see Tables 1 and 2). A total of seventeen people participated in the focus groups and sixteen in individual interviews. Out of the 33 professionals, six were from a minority ethnic background (including Indian and Pakistani origin), and six from white minorities (such as Polish, Hungarian and Irish).

Once participants were identified, formal letters of invitation, information sheets, consent forms and topic guides were sent in advance of the discussion (see Appendix C). Written consent was sought by the researcher/s prior to the start of each group discussion/interview. Interviews and focus groups were digitally recorded (with permission). Detailed field notes were also written. Participants were offered a transcript of the discussion/interview on request.

We followed a purposive sampling strategy in order to include different combinations of professionals in each group, while also trying to reflect the 'realities' of practice in each fieldwork site. We aimed for staff at S1 from adult oncology, andrology, reproductive medicine and psycho-social services; at S2 from reproductive medicine, psycho-social services and liaison adult oncology nursing staff; at S3 from TYA services, psycho-social services, reproductive medicine and adult oncology. However, the logistics of finding appropriate representatives and bringing together professionals from different disciplines and services, especially those working at different

geographical sites, proved time consuming and frustrating. If nothing else, this provided useful information about the operational difficulties faced by the staff when trying to liaise effectively across services and sites to develop shared protocols and practices aiming at policy goals of multi-disciplinary work.

Ideally, we would have liked to have 8-10 professionals in each group, scheduled to run for 60- 90 minutes. At S1, all those from the reproductive medicine service failed to attend because of last minute work pressures, resulting in a delayed start as well as a discussion that lacked the range of disciplinary and service specific inputs intended. At S2, one member left early on, saying that he would return but never did. At S3, two members arrived late and two had to leave early, restricting the range of the discussion. It also proved difficult to maintain the intended distinction between adult and TYA Services in sampling across groups: some of those whom we understood to be from adult oncology services in fact worked with younger people and those from reproductive medicine services frequently drew on their experience with both age groups in the discussion. This, however, did not undermine the quality of the discussion and despite the logistical difficulties, participants found the discussion helpful.

Table 1: Breakdown of participants taking part in the three focus groups (n= 17)

Site one	Site two	Site three
Social Worker Assisted Conception Unit; (ACU) Counsellor; Clinical Nurse Specialist (breast cancer); Clinical Nurse Specialist (lymphoma). <i>None of the staff invited from the ACU were able to attend due to operational difficulties.</i>	ACU Nurse Specialist (special interest in oncology); ACU Matron; ACU Embryologist; ACU Nurse; ACU Counsellor; ACU Registrar; Clinical Nurse Specialist (Gynaecology/Oncology).	Youth Support Co- ordinator (covering ages 18-25 years old); Activities Co-ordinator (covering age ranges 13 to 18 years old); Clinical Nurse Specialist (lymphoma); Clinical Nurse Specialist (lymphoma and myeloma); Consultant Oncologist (breast cancer); ACU Embryologist.

Individual interviews

The focus group discussions provided a range of perspectives from different disciplines and services and enabled the researchers to see where participants suggested shared beliefs and experiences and where there was divergence. Against this backdrop, the one-to-one interviews provided the opportunity to explore in greater detail specific areas of practice as well as individual responses within the context of a particular disciplinary background. In doing so, we were able to develop themes introduced during focus group discussions. Table 2 provides a breakdown of those we interviewed.

Table 2: Breakdown of Professional Interviews (n = 16)

Site one	Site two	Site three
Clinical Nurse Specialist (Young Oncology Unit); Clinical Nurse Specialist, Liaison (Late effects, Young Oncology Unit); Social Worker; ACU Counsellor; ACU Andrologist; ACU Embryologist.	Third sector organisation, (equality and diversity officer); Consultant Haematologist; ACU Consultant in Reproductive Medicine; ACU Sister.	Oncology Registrar (paediatrics and young adults); Clinical Nurse Specialist (germ cell/brain); Clinical Nurse Specialist, Late Effects (paediatrics, teenage and young adults); PCT cancer lead; Clinical Psychologist; ACU, Reproductive Medicine Consultant.

Analysis

A separate analysis of the professionals' data set to that performed by SC for contextual background to the individuals' interviews was undertaken by MC, using the main themes from the Topic Guides (see Appendix C). The aim was not to seek generalisations about a discipline or service but to seek an in-depth understanding of how key professionals engaged with the themes and issues raised by the topic guide. The aim was to help us understand the context of service provision. Responses were contextualised, where appropriate, within discipline, role, setting and reference to experience of fertility matters with non-cancer as well as cancer patients/clients. Since

the ethnic background of the professionals was not a focus of our enquiry, this was not explored systematically or in detail. However, we explored the ethnic and/or religious background of individual professionals where it seemed relevant.

FIELDWORK WITH PEOPLE AFFECTED BY CANCER TREATMENT

For the second data-set, we had aimed for a sample of 60 participants: 20 of 'white' and 40 of 'South Asian' origin, allowing for internal diversity within the white and South Asian groups (defined for our purpose, as people who identified themselves as being of Indian, Pakistani and Bangladeshi origin). One of the advantages of recruiting participants from three different geographical locations was the potential diversity in socio-cultural backgrounds, although none of the participants identified themselves as gay or lesbian (which may well reflect how professionals helping us, interpreted the eligibility criteria). While this diversity is challenging in terms of analysis, it helps destabilise the notion of ethnic groups as stable and bounded entities. Besides our commitment to recruiting an ethnically and culturally diverse sample, our more specific eligibility criteria were:

- Men and women aged 18 to 40;
- Diagnosis of sarcoma, lymphoma, testicular cancer or breast cancer;
- Diagnosed at any age;
- Preferably childless at diagnosis;
- Aware that there is a risk to their fertility, regardless of the level of risk;
- Not in any major treatment phase at the time of being approached; and
- Reasonable chance of five year survival.

Before describing our approach to recruitment and our relationship with fieldwork sites, some general points about the difference between our intended sample and actual sample need to be made. First, we had to extend the upper age of potential participants from 35 to 40 years old, due to problems with recruitment. After talking to our collaborators we realised that raising the age of recruitment could considerably widen the pool of potential participants, without undermining the aims of the study.

The Medical Research Ethics Committee regarded our request as a major amendment and after requesting evidence justifying our request, granted the amendment (see Appendix A). Second, we struggled to recruit an equal number of men (n=29) and women (n=18), in addition to a more equitable gender distribution among our 'South Asian' sample. This is despite extending our time for sample recruitment by four months (though we recruited four South Asian women during this time). As we shall see, our sample was dominated by people who identified themselves as Pakistani-Muslim, although some diversity in terms of ethnic and religious identification was achieved. Having reviewed the sample characteristics in detail and a round of preliminary analysis, we felt our sample did give us sufficient diversity to meet the aims of the study and enable us to explore the extent to which ethnicity (and culture) mediates the experience of those whose fertility was, or may have been, affected by cancer treatments.

Given the time constraints of recruiting from long term follow up clinics (which might only see people every 6 to 12 months or more), while maintaining our inclusion criteria, we stopped recruiting once we had interviewed 47 participants. We would ideally have liked to include a few more women of South Asian origin but given the pragmatic issues with recruitment faced by some of the teams, we were unable to do so. Given the smaller population living in the UK, we were lucky to have a man of Bangladeshi origin in the sample. We were aware of local community support groups in S2 with a significant 'Bangladeshi' population although governance issues precluded us from approaching participants through this or other alternate routes.

Participants in the study were recruited with the help of our collaborating teams at the three sites, through an adult and a paediatric/TYA long term follow up service at each. However, for variable and complex reasons, recruitment through the paediatric/TYA services was not as good as we had expected. One of these teams was able to recruit two people and the other two only one person each. (One of the latter teams started approaching patients quite late in the study since they had earlier lost the support of the research nurse designated to help us). Further, a majority of these patients have

only one appointment a year and we might have missed a number of patients otherwise eligible to take part. One of the teams (S3) were in the middle of recruiting for a large trial at the time of our own study and the research nurse felt it was not ethical to invite patients to take part in two studies at the same time. (There are issues here about conflating all credible research with a 'trial' that is in itself problematic) Other reasons might be that people in long term follow up clinics do not feel the same involvement and motivation to participate in research. However, this might be offset by the fact that this group of people would have moved on in life and might feel more at ease talking about difficult issues related to treatment, including fertility. Our current and previous experience of researching sensitive subjects suggests that successful recruitment across ethnic groups depends a lot on first contact and the process of explaining the study to the participants, rather than simply handing out information packs. The reasons why people might not take part can be varied and related to particular circumstances. Of those who participated in our research, a majority felt that they wanted to 'give something back'. Some had taken part in similar qualitative studies, suggesting that those who are inclined to take part will do so irrespective of their ethnic background or the 'sensitivity' of the research topic.

Each site and service were provided with an information pack to pass on to eligible 'patients'³ containing: letter of invitation to take part in the research, a brochure summarising the aims and what to expect if people wanted to take part, an 'agreement to contact' form and a self addressed envelope to be sent to us by those willing to take part. Each team was also provided with a generic reminder letter to be sent to those who had accepted an information pack (see Appendix D). Each team was also requested to fill in a recruitment diary with anonymised information on number of patients approached and their responses, to be collected periodically. However, given the number of professionals involved and different approaches used, it was difficult to get this feedback and collate information in a meaningful way. Written consent was

³ When talking about recruitment we refer to people affected by cancer treatment as patients. In exploring their experiences, we refer to them as participants.

sought from the participants at the time of the interview, and they were given the choice of informing their GP about their participation through a letter provided by the team.

Each team decided to use a slightly different approach to recruiting participants which fitted best with their notion of ethical practice (see Appendix E; letter explaining the recruitment process to collaborating teams). At S1, the research nurse within the adult service took the initiative of introducing the study to all eligible patients and handing out the information packs to those interested. We recruited nine participants in this way, while one man changed his mind since he lived away and wanted the interview to take place at his next appointment, nearly a year later (which we were unable to do). At S1, the paediatric consultant also introduced the study to some patients and passed on the packs to eligible patients at a long term follow up clinic. We interviewed two participants recruited via this route.

At S2, the adult oncologist felt it more appropriate to write a personal letter introducing the research to eligible patients, in order to give them 'some space' when decide whether they wanted further information or not. Twelve patients agreed to take part in the study using this approach although only 11 were interviewed since we were unable to contact one of the women. The paediatric/TYA service at this site started approaching patients towards the end of the recruitment phase, through direct contact by a consultant, at an out-patient clinic. This is when we were only looking for women of South Asian origin (see below). We interviewed one woman approached by the team.

At S3, within one joint adult/TYA service, two designated research/ specialist nurses identified the eligible patients, approached them and introduced the study. Those willing to find out more were introduced to the researcher (SC) in person (she attended clinics which were thought to include eligible patients) and she explained the study in greater detail and passed on the information packs. This was by far the most successful recruitment method. Out of those approached by this team, 30 patients

were willing to consider participating and 23 were interviewed; of the seven that were not interviewed: two agreed to take part then changed their mind (reasons unspecified); two rescheduled the interview more than three times and were 'lost': one had moved house recently and found the timing was not right: and two women of South Asian origin who had considered taking part changed their mind since their circumstances changed as they faced the prospect of further treatment. As for the paediatric/TYA team at S3, a research nurse approached eligible participants attending clinics and handed out information packs to those who were interested. Only two participants responded using this method; one (white man) declined to take part (reason unspecified) and the other (South Asian man) was interviewed.

At the end of the first year of recruitment, the process was reviewed. The teams were requested to approach only women of South Asian origin, either through letter (as at S2) or at their next follow up clinic visit. We recruited four women through this process, two of whom were interviewed while the other two were cancelled due to a change in circumstances. Table Three provides the break-down of our interviews with people affected by cancer treatment.

Table 3: Background of those affected by cancer treatment

Self-reported ethnic/religious background of participants		Men	Women	Total
Indian Hindu:	2	16	5	21
Indian Sikh:	4			
(2 non-practicing)				
Indian Muslim:	2			
Mauritian, Indian-Muslim	1			
Pakistani Muslim:	11			
Bangladeshi Muslim	1			
Irish/other Catholic:	5	13	13	26
Greek Orthodox:	1			
White British/Protestant	7			
African-Portuguese/Catholic	1			
Turkish/non practicing				
Muslim	1			
No religion	11			
Total	47	29	18	47

As shown in Table 3, we interviewed 47 participants from the three sites including 29 men (13 white and 16 of South Asian origin) and 18 women (12 white, 1 Portuguese-African and 5 of South Asian origin). A majority of participants of South Asian origin were either born here or brought here as children and had lived here most of their lives, with the exception of one woman of Indian heritage who was born and brought up in Africa, two men who moved to the UK within the last ten years following marriage and a young man from who was awaiting a decision on his citizenship (he had lived here for nearly ten years). One of the white women was born and brought up in Cyprus, another in Czechoslovakia, while a third defined herself as white- British though her father was from the Middle East and a fourth was of Turkish-Cyprus origin from a non-practicing Muslim family.

This account supports our cautious approach to defining ethnicity, especially with regard to the 'white' sample which demonstrated considerable diversity and the importance of taking into account religion as well as country of origin. For Irish-Catholics, for example, the relationship between national and religious identity, can be fundamental to a person's sense of identity. For people of South Asian origin, on the other hand, ethnic identity is often marked by religious as well as linguistic background (Atkin and Chattoo, 2007). Our analysis reflects this complexity by using the same analytical concepts to understand the significance of ethnicity across the white and South Asian sample, to highlight the contexts within which different aspects of ethnicity might be meaningful in a participant's life or experience of healthcare.

Men are over-represented in the sample since testicular cancer was one of the inclusion criteria. Even though we included breast cancer (on advice of the MREC panel) we did not expect to find many eligible women within the age range, especially since we were able to develop only one collaborative link with a breast cancer team (S3). As we have seen, we requested a change to the original protocol to raise the upper age limit of eligibility from 35 to 40 years old. This helped the overall participation given that we were approaching people with a reasonable chance of five year survival. The over-representation of men, in a way, provides us an analytical vantage point in representing their experiences and in particular addressing some of the concerns and issues raised by the health and social care professionals in the focus group discussions and interviews (often related to 'South Asian' men of Muslim faith).

Making sense of ethnicity

Logistically, it is difficult to negotiate access to participants, when the researchers do not have direct contact and are dependent on the good will of a clinical team who may or may not understand the complexity of the project or find time to explain the research to eligible patients in appropriate detail. Finding equal number of 'South Asian' women was one of the main challenges, even though recruiting 'South Asian'

men had not been difficult. This relates largely to the inclusion criteria and the fact that we are looking at a much smaller patient population on the whole. From previous experience of KA and SC and other research teams, recruiting women from South Asian communities is not an issue. What is important is that both white and South Asian participants reflect a range of religious backgrounds which is significant for analysis, both in terms of how ethnicity and religion are interpreted by researchers and the participants themselves. Some of the participants of Indian and white backgrounds said that they did not follow any religion, even though they had clearly inherited some of the religious values as part of an extended family values. Similarly, one of the healthcare professionals who said she was Christian by faith realised how some of her beliefs on the use of IVF and 'left over' embryos were part of her Catholic school upbringing.

Further, given the different methods of approaching participants, we interviewed five women who were strictly speaking either from a white minority or/and of mixed ethnic backgrounds (as explained above) including one woman of African-Portuguese origin whose mother was black-African. Except for one white woman whose father was Middle Eastern in origin; the links with country of origin through culture and kinship were strong and made salient in different ways within the context of cancer and/or childlessness. One of the women of Indian-Muslim heritage was born and brought up in Africa, and highlighted continuities as well as discontinuities in her identity as an 'Asian' based on culture (such as dress and food, as well as religious values). These unintended inclusions have added a layer of complexity to how we conceptualise and use ethnicity and notions of citizenship in research related to health especially within the context of increasing number of people immigrating/ living and working in the UK from within the European Union. For example, one of the participants who defined herself as white-British was born in Cyprus, came here to work, is married to an Englishman and has dual citizenship. She has had her treatment across both countries.

The concept of ethnicity is destabilised when we consider citizenship as a marker of ethnicity and the continued connections that people with dual or multiple citizenship might/might not hold with their country of origin through kinship, religion and de-territorialised notions of nationality. The stark contrast between invisible white minorities and hyper-textualised ethnic minorities is not new. For example, people of Irish origin in the sample defined themselves as 'white British' and unless specifically asked about their religion and 'Irish blood' may not have disclosed this link, given that it appeared not central to their identity (just as being Indian, Sikh or Muslim was not significant for all South Asian participants). This is a reminder of how we can sometimes impose ethnic categorisations which may or may not have any meaning for the people we classify. Even though a significant majority of South Asian participants were born here, some of them felt stronger links with India/Pakistan as still being 'home' than others who perceived themselves as 'British' and had minimal or no kin, emotional or religious ties in the subcontinent. Similarly, participants who had immigrated from within the EU and held dual citizenship maintained strong ties with their culture and country of origin, though were less visible to professionals as belonging to a white minority population (in contrast to visibility of African-Caribbean and South Asian patients, signifying the logic of race as been associated with 'colour of skin'). Two potential participants of South Asian origin challenged our focus on ethnicity as being divisive since they claimed, 'We are all British'. One of them declined the invitation to take part in the research as he did not support the 'ethnicity PR agenda' focusing on difference.

The argument of equality premised on common citizenship might signal a change within certain contexts of health, especially within cancer care that has a longer history of engagement with users from minority ethnic communities, especially highlighting the experiences of younger people who know the system and their rights. Theoretically, it can also be argued that recent policy responses to tackling 'extremism' culminating in wider Islamophobia might prompt individuals to resist being labelled as belonging to a particular minority ethnic community. However, the experiences of the participants in our study do not support this view. None of the participants

(except one mentioned below) suggested that they had been treated differently because of their colour, ethnic origin, dress or religion. One of the Muslim participants, who had started wearing a head scarf (*hijab*) following her treatment, remarked that she was pleasantly surprised that her concerns about a probable change in the attitude of staff at the hospital were ill founded. Only one (Sikh) participant of Indian origin who was a British citizen but had moved to England (following his marriage) a few years previously, suggested that he could not help but notice how he was treated differently from others (white) people. He chose to be interviewed in Hindi, although he said communicating in English was not a problem for him. Language, as we know, may not have been the only reason why he felt marginalised, though it often compromises the quality of communication and trust in the system (as we learnt from the experience of the woman of Czech origin). He seemed to be leading an isolated life, supported only by a small network of friends. Another participant of Pakistani origin provided a contrasting picture, emphasising the role of social capital in achieving the benefits of citizenship. He too had moved to the UK within the last ten years, following his marriage, but was well integrated into a work and kinship network through his in-laws and a wider circle of friends. Two other participants, who felt and appeared to be living on the edge of the system, had one thing in common: both faced long term consequences of unemployment and poverty related to a life interrupted by cancer. One was a white man of (Irish origin) who, for various reasons, was completely lost to the broader health care system and unable to register with a GP since he did not have valid documents proving his identity. The other was a man of South Asian origin who was waiting to hear a decision on his citizenship status, having lived in the UK for nearly ten years. At the time of the interview, he survived on £35 in vouchers a week, unable to work and with a severe disability caused by surgery for sarcoma in his leg.

The inclusion of some of the participants of mixed origin in our sample (identified by name as belonging to a certain ethnic group by the professionals), reflects the wider process of attribution of ethnicity by others, which is intrinsically related to ethnicity as a process of identification, inclusion and exclusion.

Age and diagnosis

Out of the 47 participants, 24 had a diagnosis of lymphoma (both Hodgkin's disease and non-Hodgkin's disease), 17 had testicular cancer, five had sarcoma and one had breast cancer. Some of these differences in diagnoses will be salient when presenting our analysis, reminding us of the materiality of the disease as well as the metaphoric connotations associated with gender and embodiment. The youngest participant was 21 and the oldest 40 years old. Thirty out of the 47 were between 26 and 35 years old, 11 between 18 and 25 years old and the remaining five between 36 and 40 years of age. The participant with the longest time since diagnosis (22 years) was in his mid 30s. Time since diagnosis is significant in terms of salient issues and life course choices made by some of the older participants, but also in terms of development of particular services and the kind of support that participants had received: an important factor affecting the experience of treatment for some. We have accounted for these differences in our analysis although they are not an explicit focus of our discussion.

Socio-economic and family background

Using the standard income categories, there was a good spread of income and socio-economic background (defined in terms of educational and employment status) across the sample (Table 4). Five participants had no regular income (either because they were a student or/and on sickness benefits); eight had annual income below £15,000; a majority, 17 had annual income between £15,000-£25,000; three between £25,000-£35,000; and 13 had an annual income over £35,000 (one participant did not wish to disclose his income).

Table 4: Breakdown of annual income

Income	Total	'White'	'South-Asian'
No regular income/ receiving benefits	5	3	3
Less than £ 15K	8	3	4
Between £15-25K	17	9	8
Between £25K	3	3	0
Over £35K	13	8	5
Not disclosed	1	0	1
Total	47	26	21

Out of the 47 participants, 26 (14 white and 12 South Asian) were married/had a partner, while one man (of Pakistani origin) had undergone his *nikkah* (nuptial contract ceremony) and was waiting for his partner to join him from Pakistan. Out of these 26, 14 (six white and eight South Asian) had one or more children and 12 (eight white and four South Asian) had none (including those who had not yet tried, were trying or believed they could not have children). Only one out of the remaining 21 participants in the sample - who was white and divorced - had children though they were not living with him.

The living arrangements across the sample were diverse and reflected the age and the importance of family relationships (including parents and siblings but also grandparents, uncles and aunts) in supporting the individuals through various phases of their illness. Hence, four of the white participants who were students or working at the time of diagnosis had moved back with their parents during the course of treatment. One of them eventually bought a house close to her parents, who continued to be her main source of practical and emotional support, especially since she was dealing with serious long term complications of treatment.

Out of the 21 participants who were not married/ did not have a partner, nine (three white and six South Asian) lived with parent/s and siblings or in some form of an extended household, including two men (of Indian origin) who lived with a widowed mother. Three (white) participants lived in shared accommodation and nine lived

alone. Of those who lived alone, six were 'white' (including two who were divorced) and three 'South Asian' (including one divorced). Only two of the South Asian couples (both Pakistani origin) lived as part of an extended family including parent/s and (unmarried) siblings (one did not have any children of their own and one were recently married); while a third couple (also of Pakistani origin) who had children lived with (husband's) parents, and a fourth couple (of Mauritian-Indian origin) lived with their children and (wife's) parents. This overall picture is different and more diverse from the dominant professional view of a majority of South Asian-Pakistani families living as large extended families (see Atkin and Chatoo, 2007).

Out of the 12 participants/couples who did not have children, at least three women (one South Asian) and two men (one South Asian) knew with some certainty that they would not be able to have children of their own; while one woman (white) was determined to resist the label of having 'ovarian failure'. One of these couples was pursuing donor insemination, and another was reconciling to the idea of having treatment (ICSI) in future. Of those not in a relationship at the time, two South Asian men (one person of Indian and one of Pakistani origin) believed that they would not be able to have children, reacting to the prospect in a contrasting manner, as explained later (see chapter four)

Of those who had children, only one (white) man had used donor insemination (DI) to have his children, while one woman had been able to preserve embryos prior to starting treatment and one woman had gone through egg preservation (but both had eventually conceived naturally following their cancer treatment). None of the participants/couples of South Asian origin without children had tried NRTs although one had contemplated egg donation before deciding to remain 'childfree'.

Conducting the interviews

We used a guide, informed by specific topics, to facilitate 'guided conversations' (Fielding, 1993: 144). We wanted to cover similar ground with our interviewees, to

ensure we could compare responses, while at the same time creating an environment enabling them to reflect on their specific experiences. The subjects we intended to cover in the interview were informed by our aims and objectives, discussion with health and social care professionals, in addition to our initial literature review. These subjects informed the basis of a topic guide (see Appendix D).

Interviews explored biographical details as a way of building rapport and contextualising subsequent discussion. We then went on to discuss how the individual made sense of their diagnosis and treatment, their understanding of the potential risk of infertility and any attempts they had made towards 'fertility preservation'. Revisiting the uncertainty regarding fertility and decision making about fertility analysis and or/ having children were also discussed. Finally, we invited our participants to offer key messages for the health and social care professionals. Under each subject heading, we included a series of detailed probes, to ensure focus.

All interviews were digitally recorded and transcribed verbatim with prior consent, except two: one conducted in Hindi (SC transcribed a summary since it was brief), and the other where a young woman (of Pakistani origin) did not give permission to record the interview (SC took notes for her during the interview). A majority of the interviews (38), including those with 'South Asian' participants, were carried out by SC (in anticipation that some of the interviews would be conducted in Urdu and Hindi) and nine by MC. SC analysed this data set as a whole, supported by KA and MC with contextual background provided by the interviews and focus group discussions with the health and social care professionals.

A majority (31) of the participants across ethnic groups were happy for the interview to take place at their home, while 16 preferred to be interviewed at the hospital or elsewhere. Three participants (including two men of Pakistani origin) were keen for their spouses to sit in on the interview and these were particularly interesting as

differences in opinion between the spouses unfolded as both the partners engaged with the idea of what would be acceptable alternate routes to parenting.

Reflecting on the process of interviewing, the research team realised that the language of the topic guide reinforced the wider pro-natalist assumptions of the broader society in which they worked, especially when discussing alternate routes to parenting. Those who had not thought seriously about being a parent, for example, might have felt that they were being 'judged'. Sensitivity to this dynamic had to be balanced against the need to probe sensibly and yet ethically, especially when faced with subtle ethical issues posed by particular biographical circumstances of an individual. For example, one of the participants was pregnant at the time of the interview and raising questions about whether she had concerns about passing on the condition to her unborn baby seemed insensitive and inappropriate. Similarly, one of the young men who had not thought about the possibility of fertility analysis before the interview said that the process prompted him to think that he should have a fertility test to 'get the issue out of the way' before he embarked on a new relationship he was considering. Another man who had never heard about such a test felt that the healthcare professionals should have offered him the choice.

Finally, intrinsically tied to the method of interviewing is the process of interpreting and locating 'narrative truth' within an interview: how to respond to obvious inconsistencies that are often central rather than incidental to a particular narrative, especially since the interviewer might have learnt more technical details about a subject than the participant. For example, one of the participants was not sure whether she was diagnosed with Hodgkin's or non-Hodgkin's lymphoma: a distinction that is clinically significant. Another participant narrated the 'miracle birth' of her first baby following a stem cell transplant (a rare occurrence that would normally make medical news). For us, to verify (from the outside) whether she actually had a transplant or whether her reconstruction of events was right misses the point; particularly since this is what the respondent believed. Finally – and more generally – how do these subtleties of listening and interpreting get incorporated or lost (edited) in the process

of analysing and writing (Riessman, 2002b), leaving aside the negotiation of multi-disciplinary perspectives within a team? These are issues that had to be carefully negotiated throughout the entire research process.

Analysing the material

Analysis involved, in the first stage, picking on the main themes covered in the interviews across the entire data set. The main themes were pre-empted by the use of a topic guide focusing on the following issues, which provided us with our initial analytical framework:

- Making sense of diagnosis and treatment;
- Making sense of potential impact (risk) of treatment on fertility;
- Understanding the process of 'fertility preservation' (largely related to men);
- Revisiting the uncertainty regarding fertility, decisions about fertility analysis (finding out) or/ and having children;
- Contemplating alternate ways of dealing with the situation; and
- Drawing out messages for the health and social care professionals

At a second level, detailed summaries were constructed for each interview (except for two already mentioned above). The interview notes and parts of the transcript highlighting the themes were analysed within the context of particular biographical features (such as gender, age, occupation/income, religion, ethnicity/country of origin) and significant relationships underpinning the experience of cancer, treatment and its long term consequences. In doing so, the aim was to move away from the essentialising framework of ethnicity - as underpinning the experiences of participants from South Asian communities - by using a comparative method focusing on differences within as well as similarities across ethnic groups. Our point was not to privilege ethnicity in explaining a person's experience, but rather to locate ethnicity within the broader context of a person's life. In turning our attention to biographical disruption and uncertainty related to fertility as analytical concepts, we see how gender, religion and culture are interpreted and negotiated by individuals within the

context of relationships central to their interpretation and experience of illness and treatment-related threats to fertility across ethnic groups.

Our broader biographical approach also explains why we present the material the way we do. Wherever possible, we provide as much contextual information about our participants we can. This is also why there are times when we present detailed case studies of individuals' lives as a way of capturing the complexity of their experience. Our intent is to move away from disembodied descriptive accounts, which give little sense of how a person's experience of illness and healthcare relate to their personal circumstances.

Finally, it is important to bear in mind that we do not intend to lay claims to generalisations for a whole religious or cultural community based on the 'representativeness' of the sample. On the contrary, the diversity within the sample - central to our approach to analysis and conclusions - reiterates the limitations of the use of ethnicity as an unspecified analytical concept in research related to health and social care. Further, any claims to generalisations and broader conclusions are premised on theoretical inferences drawn from the inter-space between the wider social science literature and what might broadly be defined as the psychosocial oncology literature. Interestingly, this process of creating a dialogue across the two has involved a critical analysis of our own ideas that were very much steeped in the language, concepts and assumptions derived from the medical model of treatment related 'fertility impairment', 'preservation' and a rationalist model of 'information' and 'choice'. Given the diversity on various scores detailed above, it is not possible to capture the whole breadth and the depth of the analysis within this report. We will, therefore, present detailed summaries cutting across the main themes capturing this diversity within the dataset. We will also provide linkages with some of the salient findings from the professional interviews and focus groups to highlight their significance.

CONCLUSION

This chapter outlined our methodological approach and in particular some of the practical difficulties we had to negotiate in recruiting our sample, in addition to the broader analytical problems of making sense of ethnic difference, cancer diagnosis and responses to (in)fertility when presenting our findings. Ethnicity is an especially problematic idea to reflect in sampling and analytical strategies. Understanding this is at the heart of our account. Our next two chapters explore this further and present the details of our empirical findings.

CHAPTER THREE: THE VIEWS OF HEALTH AND SOCIAL CARE PROFESSIONALS

Living with cancer and the consequences of treatment involves making complex and far from easy decisions. Health and social care professionals have an important role in supporting people and their families. In presenting the perceptions and experiences of health and social care professionals on the social and emotional impact of fertility matters from diagnosis onwards we aim to provide insights into how and why they negotiate issues and decisions with those affected. In doing so, we draw on focus group material alongside that from individual interviews, providing details of the specific discipline of individual professionals where necessary for contextual understanding but otherwise conflating disciplines by sector (oncology or fertility) and broad category (health – nurses, doctors; scientific - embryologist, andrologist; or psycho-social – social workers, psychologists, counsellors; activity co-ordinators and youth support workers). This is to guard against the danger of over-claiming disciplinary significance from such small numbers while at the same time acknowledging that some categorisation can be helpful. (Our own methodology reflected similar tensions – see above). We are presenting this analysis descriptively in this chapter and considering its themes in more depth in our analysis of the interviews with individual ‘patients’. This is to ensure that our policy and practice recommendations not only capture the experience of those individuals but are also grounded in the realities of service delivery and informed by understanding of professional behaviour. The chapter ends with a more general discussion of professional perception of South Asian patients as a way of making sense of professional practice, which returns us to a key aim of our work.

PROFESSIONALS' PERCEPTIONS OF THE SOCIAL AND EMOTIONAL IMPACT OF POTENTIAL INFERTILITY

While many professionals were aware that the cancer-related threat to fertility could provoke serious concerns, a range of mediating factors were identified including the threat from the cancer and treatment itself (including later relapses and second cancers), age, life stage, gender, ethnicity, socio-economic circumstances and whether or not the person's family was complete. To this extent professionals did attempt to contextualise the experience of the people they saw. For example, one psycho-social, community based oncology professional, working in a socially deprived area found the impact of both cancer and threatened fertility diluted for those coping with multiple social problems. Where longer term financial difficulties arose as result of having cancer, some found that this heightened the impact of fertility concerns given the restricted availability of NHS fertility treatments. Where impact was thought mediated by age and life course, it was considered to be heightened among childless women nearing the end of their childbearing years (of which more later) but diluted among younger people for whom other issues appeared more relevant to current identity and lifestyle, such as disruption to education and relationships, body changes and so on. Nevertheless several professionals had experience of younger people not using contraception because they believed themselves infertile, perhaps contributing to a recent run in one area of young women getting pregnant soon after treatment.

There were some reports of gender differences in the younger age group, with males being more concerned with sexual performance and a virile self identity than fertility (i.e. linked but not overtly). One oncology health professional talked at some length of recent work with two young male adults concerned about their general lack of interest/passion, unlike prior to having cancer. Another found older males expressed similar concerns about libido/performance rather than fertility. In contrast, body image concerns appeared more likely to cut across gender and some considered these affect the management of romantic relationships more than fertility, especially among younger people:

Body image is a huge thing as well with some of the young people, and certainly children that I've known who've ended up with ileostomies or colostomies or, amputees or whatever, lots of scars, scars left from Hickman lines, etc, have, have had difficulties in their marriages and their relationships, and it's all down to their own fears of their body image.
(Oncology health professional)

Many thought females of all ages were more affected than males by fertility (as opposed to sexuality), suggesting that it was more central to their gendered identity and hence the social context of their lives. This oncology health professional, in this case working with younger adults, remarked:

The whole issue of, this is who I am, this is, this is my, what make me a woman, this is sort of, and, and this inability to conceive, being robbed of that, you know, causing huge problems in their life. Not being able to, not being able to visit friends' houses, for example, who've got children and, and avoiding, avoiding you know going out, for example, in the car at school, school closing times, not being able to speak to young people and children and, and actively avoiding children. (Oncology health professional)

This was considered by some to be made worse among minority ethnic populations which were perceived to have more rigid gender roles (of which more later). However, one of the psycho-social oncology professionals had come to revise his views, prompted by his own research that indicated male identity included a strong desire for fatherhood even if this was less visible to professionals. Indeed in one focus group discussion (S2), members explored why their identification of, and service response to, the emotional needs of females considering cryopreservation had not prompted them until that stage to consider those of males more fully.

Beliefs were strong amongst both cancer and fertility professionals that fertility was valued especially highly within South Asian communities as a result of marriage being more universally practised than in 'white' communities and higher expectations that children should follow. Many talked of a South Asian 'culture of silence' around fertility matters with individuals keeping them confidential even from their immediate families and any children conceived later with the use of donated gametes:

I've certainly had a number who don't want their families to know anything about them if they're going for fertility assessment. So that was something that they'd decided they wanted to do, but it was very much their decision rather than their family's decision. Whereas with the British girls, you know, tended to find that, or, or, and males, that they didn't mind the families being involved...So that's certainly been something that's different, they seem to want more confidentiality when it comes to involving the, the families.
(Fertility professional)

Some fertility professionals spoke of South Asian men in particular asking for letters to do with sperm banking to be marked 'confidential' or sent to an alternative address. Whether such perceptions actually reflect the realities of practice, however, is something we return to.

Nonetheless, ethnicity-based explanations recurred across a range of fertility-associated experiences. One oncology health professional thought that lack of libido combined with premature menopause contributed to the failure of some relationships/marriages, especially where the marriage had been arranged and the husband had little or no prior knowledge of these possible side-effects because of, in her view, the Asian 'culture of silence':

I do feel that sometimes, because it might not have been shared about their past problems in, in the Asian area as it might have been in, in, in other cultures, that perhaps they're not as sympathetic, the men that they marry, as such. I've seen equal, equally as many marriages fall apart, I'm sure, in that. But I do wonder if the, the empathy isn't there because they haven't, they haven't known. A lot of our [white] girls that marry, that maybe their relationship would have fallen apart anyway, but their boyfriends might have been someone who was in class with them and knew about their past diagnosis.
(Oncology health professional)

However, difficulties in talking openly about fertility concerns within existing personal relationships were reported by others as common irrespective of ethnicity, leading to patients sometimes finding it easier to talk openly with professionals without their partners present. Elsewhere, professionals reported it not unusual for relationships to

break down from the stresses of the cancer experience itself, sometimes made worse when this appeared to signal the end of possible parenthood and hence not unique to South Asian couples.

Several spoke of their perception that the social context of arranged marriage negotiations (seen as a family and/or community based matter) heightened the impact. Some professionals had experience of, or perhaps more importantly had 'heard of', South Asian parents trying to veto fertility being discussed with their child, asking for related medical information without their child's knowledge and/or encouraging or discouraging fertility testing:

Usually at the arranged marriage stage, because they don't want the new family to be aware that there might be an infertility problem. So we've certainly had that before, that this is a taboo subject, we are not to talk about it because it might scupper their chances of a good match.

However, one oncology health professional who initially reported greater protectiveness and difficulty in 'letting go' among Asian parents, decided on reflection that this was probably more a feature of the intensity of a shared cancer experience than specific to this particular ethnic group. Assumed explanations, however, influence professionals' handling of situations, including their management of parental/family involvement (Taylor and White 2000). The belief in the patient's right to their own information and the desirability of unaccompanied consultations, led some to raise the subject without seeking prior parental permission, regardless of ethnicity while others remained cautious.

Ethnicity related comments were not restricted to the South Asian population. Other minority ethnic groups were also identified as especially valuing fertility, including African Caribbean women and Black Africans. Some saw the interplay between ethnicity and socio-economic circumstances as lowering the impact of fertility matters: for example in one service with a high Black African population of whom many were immigrants, living alone and/or with AIDS related cancer. While South Asian patients

were seen as wishing to retain privacy around fertility matters from their own family or wider community, another ethnic group, orthodox Jews, were seen as wanting to deal with them *within* their communities rather than with professionals:

They keep themselves to themselves...they get the support from their own community, they're a very, very close community, and if you ask them they say, no we're getting support from our community.

Finally a few suggested that the impact was mediated by religious or personal beliefs in 'God's will' or 'fate', with such views being more associated with minority ethnic populations rather than the wider population. Again, as we shall see in the next chapter, the situation is more complex than this. More generally, ethnicity related comments were often made as broad brush statements/generalisations that implied homogeneity but when probed, related to what were often assumed to be religious practices (which are also not homogenous of course), for example within Islam. No ethnicity based explanations were offered for behaviours/reactions among the majority 'white' population.

Where professionals took a reflective approach to their interventions in which they considered its impact on them and/or their impact on the encounter (Schon 2003), gender-awareness featured more strongly than any other factor, though sometimes this was combined with ethnicity. One oncology health professional speculated that his gender (male) combined with his ethnicity ('white') may explain why the only 'group' by whom he has never been approached in relation to fertility matters are female Asians. He himself felt constraints around gender but had tried to address them through undertaking further communication skills training and raising his self awareness, all of which he felt had paid off with all but this one group. For another, a fertility scientist, the combination of gender (female) and ethnicity (white) presented barriers, in her view, for some Asian males and led to them trying to circumvent her:

Some [South Asian men] can be more difficult...Quite demanding when, when they want things done or they're, we've had a couple of the men that have not wanted to speak to women or have dealings with women...We do have a

couple of male embryologists, but if you're dealing with it, you're dealing with it and, that can cause quite a few difficulties, because they will keep phoning until they get to speak to [a man]. (fertility scientist)

Another female, this time an oncology health professional, was concerned that her gender and ethnicity presented barriers in relation to South Asian males seeking fertility testing that were not so apparent to her when dealing with 'white' males.

Health professional: One thing I have picked up that there is definitely a sensitivity about, semen analysis discussions, with the South Asian men, and I, one of my difficulties is knowing about the cultural issues that affect that...Because it's sort of like, is it right to talk to them about this, and I, I always ask their permission first, you know "I would like to talk to you about this, is that OK?" But it's sort of knowing, are they just saying that 'cos they've known me for a long time and, and yes they feel comfortable with me, or is there a cultural thing where they actually shouldn't really be talking about...

Interviewer: May be a gender thing that...?

Health professional: Yes, might be a gender thing, male to female. So I'm not sure. I always approach it quite carefully and sensitively, but I don't know for certain. And each one I approach, you know, I sort of, I always think I'm going to offend somebody and, you know, and fortunately I don't, or I don't appear to have...but that's always in my mind, that I don't want to offend anybody.

However other professionals who felt that being female sometimes inhibited male patients when initially discussing sperm banking or related matters reported that such barriers were fairly readily dealt with by being warm, friendly and unembarrassed. One of the psycho-social oncology professionals challenged the commonly held view that having a same gender professional would be better if discussing sexual function. He argued that it was more important to offer choice, alongside confidentiality and a private space; in other words not assuming that shared characteristics such as ethnic/gender/age difference/ religious background matter but neither assuming that they do not. He was aware that some professionals were inhibited from saying anything for fear of getting it 'wrong':

In many areas I like to almost parade my ignorance. So I would say "I, I'm not familiar with your religion, I imagine that this has something, this affects the

decisions you're taking, could you explain it to me?"...But, but again this puts, that puts quite an onus on an individual in a difficult circumstance to educate me so then I can help them help appreciate their decision...perhaps just in the same way as a, a man talking to a man or a woman talking to a woman, we've got certain understandings between each other we don't have to go through before we start or whatever, whereas perhaps the idea of, of having a counsellor who is a member of the same faith community or at least knowledgeable. (Psycho-social professional)

For some, the research process provided an opportunity to think aloud about their existing practice, including this oncology health professional who started out by expressing the view that ethnic difference was insignificant: claiming a 'colour blind' approach:

I treat everybody as an individual and, and I'm aware of their religious issues, but, not issues, that's the wrong word...I don't treat the Muslim families any differently to how I treat the white population. I suppose my question from this [research study] is that I hope to get an answer as to whether I'm wrong in that, and that's probably quite important to me now, because the questions you asked me, and certainly thinking through it, makes me question do I need to be dealing with them in a different way. (Oncology health professional)

For one of the oncology psychosocial professionals, there were doubts as to whether 'white' professionals, especially counsellors, would ever be able to understand the cultural context of ethnically diverse communities sufficiently to provide effective services:

If they need counselling, you know, most counsellors are white and sometimes, I do, when I speak to them I can relate why it, that doesn't fit in with the culture competency, you know. So we need some counselling from other communities, you see, we need to recruit that, because they have to understand the culture where they are coming from. (Oncology psychosocial professional)

As we shall see, the accounts of individuals affected by fertility matters contradict some of the assumptions by which professionals operated. Presenting them here is important not only for viewing them alongside individuals' accounts but also for

considering how to encourage culturally competent and reflective practice through learning how to challenge own and others' existing assumptions and ideas (Moon, 2004). We pick this up again towards the end of this chapter.

To understand professional concerns and practices further we need to locate the discussion more specifically in the treatments/interventions available. This also gives more substance to the professionals' decision-making processes, the realities of their practice and the kind of priorities by which they operate. As we shall see, considerations of ethnic diversity do not necessarily dominate their decision making. The themes professionals have to engage with are more generic.

Offering gamete(s) cryopreservation

The impact of fertility matters at diagnosis or alongside recommendations of treatments carrying a high sterilising risk were seen as strongly influenced by the availability of, or decision-making about, gamete(s) storage. There was strong support for patients to be told of the possibility of fertility damage (though examples of when this failed to happen occurred) but professionals had more mixed views about whether cryopreservation should be offered automatically, especially for females. One focus group (S1) – the only one not to include a doctor - highlighted the role played by specialist and liaison nurses in prompting reluctant doctors to raise fertility matters, often drawing on the support of each other, the authority that came with their specialist role and/or the NICE Guidelines. However where cancer treatment needed to start without delay, or where the prognosis was poor, there was some support for professional discretion about offering storage services to either gender. Where prognosis was poor, some believed that the person should be 'left in peace'; others were influenced by personal views about the morality of someone with terminal illness becoming a parent either before or after their death. Nevertheless for some, support remained intact for discussing fertility even if storage was not offered in order to lay the groundwork for later discussions. One oncology health professional sought to

routinely debrief any males not offered sperm banking but it was unclear how widespread such practice was elsewhere and/or with females.

According to professional accounts, some patients appeared so preoccupied with the diagnosis/treatment or so embarrassed by or disinterested in fertility (especially younger males) that engaging them in fertility discussions was difficult. Parents or partners were usually invited into such consultations as this was believed to help patients to retain information and think through associated decisions. However parents of younger males in particular were sometimes found to be a hindrance through (apparently) seeking to impose their own wishes (either for or against sperm banking). This led some to routinely try and see such patients on their own as well.

Some fertility professionals found it distressing to deal with young males who were very ill or seemingly pressured by parents or other professionals and wondered if the service sometimes did more harm than good. This linked, for some, to concerns as to whether fully informed consent was possible in such circumstances:

I think some of them...have a very ambivalent attitude, some of them are very interested in fertility, some of them are just going through the motions, some of them are just far too ill to understand what, what they're being pushed through and there have been times when people have been sent here through...having just been on a high dependency unit and been extremely ill, and that really raised the issues about informed consent.

Distress could also arise in oncology circles from a very different patient reaction: there were examples – though only of females, albeit of differing ethnicities and ages - for whom remaining fertile was so important that they refused cancer treatment (at least initially):

It's difficult when, when young people are saying that their fertility's, so, is, is almost more important than their, their actual being or actual life.

Sometimes this was resolved by speedy access to a specialist fertility centre able to provide both medical information and access to counselling; sometimes by oncology

professionals 'staying with' the individual emotionally and giving them time to come round to the idea:

But you have to allow people time to get used to the idea, how can anybody be, 'cos people are quite startled, they don't expect that, they don't expect it to be so absolute, because nobody has high dose treatment without previously having ordinary chemotherapy, and they're used to the possibility being associated with ordinary chemotherapy. But when it comes to high dose treatment it's not a possibility it's a certainty, and that is so much, people find that much more difficult than the possibility. (Oncology professional)

Sometimes, however, such reactions remained intact and caused tensions within the multi-disciplinary team. In one case involving a South Asian young woman, the oncology specialist nurse supported her right to refuse treatment (the refusal, in her view, being for a combination of well thought-out reasons), while others (especially doctors) apparently saw her refusal as primarily on religious grounds and continued to pressure her to change her mind. We return to this case in the next chapter to discuss the influence of the assumed conflation of ethnicity and religion on this situation, although this time it is from the viewpoint of the patient.

General concerns articulated by professionals about female gamete(s) cryopreservation included that it involved:

- Delaying the start of cancer treatment far longer than for males;
- Introducing medication into the body that is not required to treat the cancer itself;
- The potential for the vaginally invasive procedures themselves to be distressing (especially for younger women who had not been sexually active); and
- The potential to raise false hopes as fertility treatments using stored eggs or embryos carry low success rates.

Given its additional complexity, few females used cryopreservation when offered. This led some professionals to question the wisdom of women being 'encouraged or allowed' to delay entry into treatment. For others, affording the opportunity for

women to decide for themselves was seen as easing distress as 'at least they can say that they've tried', perhaps ameliorating in part the distress that might come later because of the lack of the 'buffer' of stored gamete(s) against the threat of fertility damage.

The complexity was also perceived to have greater repercussions on female relationships than those of males. According to professionals, females often had to manage their partners' reactions as well as their own to the possibility of delayed entry to cancer treatment and the couple had to consider whether each partner was ready to commit to potential future parenthood together and hence whether to store embryos rather than eggs. This was true of longer term relationships as well as those catapulted into making long term commitments, as explained by one of the fertility health professionals:

A lady I saw today, her relationship over the last few weeks or months just hasn't been going very well and now she's got to this point where she needs to have fertility preservation...But given their relationship, she's finding it very difficult that, you know, if she freezes embryos and then further down the line, three or four years away, if he decided to withdraw consent.
(Fertility health professional)

Where the professional remit was to help those affected to think through the implications of the 'facts' in order to arrive at a decision – for example infertility counselling - the decision about whether they should be accompanied was more likely to rest with the woman than the professional. Some women opted to come alone:

She wanted to come and talk and she didn't bring her partner in, which was interesting...not because he was not caring, he just felt she needed to be on her own...she decided not to go ahead [with fertility preservation]. But it was quite valuable I felt that she could just, you know, look at the pros and cons of everything with me and say what she felt and say what she felt about her partner, which she couldn't have done there, you know what I mean?...And in a strange way he was being caring and saying you have this to yourself. I think he felt that she would not speak if he was there absolutely openly and honestly about what she felt, and it didn't go anywhere past this room.

Whether the use of gamete(s) storage meets with family or community and/or religious disapproval was another area about which professionals could feel ill-equipped to deal. For example, two South Asian females were reported as not telling their families that they were freezing their eggs as they were unsure of their reactions (and this was seen as ethnicity related). This was seen to leave these women without a family support network. However, parents, especially mothers or those with only one child were sometimes found to be as 'traumatised' as their son/daughter, regardless of ethnicity. This too could affect adversely the level of family support available:

So I have had some parents who have been very distressed about, about their, their, you know, their son or daughter's loss, you know. But, you know, when you talk to them, it, it's been about their own loss as well, you know, about the fact that, you know, I'll, I'll, I'll never hold a, my grandchild, you know, particularly if people, single, single parent, single children and stuff like that, you know. This, this whole issue about, you know, having, you know, having that child to carry on, yeah.

A small number of oncology professionals had experience of Muslim males saying they were reluctant to bank sperm because of religious prohibition on masturbation while larger numbers *assumed* this might sometimes be the case; with the latter presumably influencing their reactions to, or expectations of, Muslim men. Further, drawing on experience with both cancer and non-cancer populations, some fertility health professionals and scientists similarly reported that South Asians were less likely than 'white' men to masturbate successfully (and speculated that this was because they had less experience). To overcome these 'problems', one oncology health professional had involved a 'sympathetic' Imam for one young man and another had on a few occasions been able to explain successfully that such prohibitions did not apply in medically sanctioned situations. Another, while respectful of the reason, remarked on the incongruity to him of the patient of having a group of elders influencing decisions about one's future. However, religious disapproval of masturbation in these circumstances was scarcely mentioned by our affected individuals (see next chapter) and nor is it a specific feature of the literature which, in any case describes considerable diversity among Muslim males on the matter. Professional assumptions, therefore,

might be ill-founded and indeed one fertility professional explicitly stated that no such difficulties occurred in her clinic and that any difficulties would be readily overcome by the heightened desire of South Asians to retain a route to fatherhood. Others reported that problems with successful masturbation were not restricted to Muslims, perhaps suggesting this to be a broader problem where faith might be used to mask more general difficulties among males. For example, some working in an area which served a large proportion of Black-Africans reported them more likely than 'Asians' to experience difficulties; and in this case there no accompanying explanations informed by religious prohibition or masturbatory inexperience.

Explaining and discussing risks

There were differences in how professionals went about explaining or discussing risks to fertility. While it was mainly consultants that broke the news initially, other professionals also discussed risks and/or their implications and had a role in facilitating decisions about storage, taking consents, discussing fertility analysis or fertility treatments. Some professionals preferred to use less absolute language on the basis that very few in either the cancer or non-cancer population can be told with any certainty that they are *infertile*. Indeed some actively pointed out that patients may have had impaired fertility prior to diagnosis, with the aim of reducing its association with cancer alone. However two consultants had shifted away from 'softer' language as they felt it to be less effective in conveying seriousness, especially when the risk of damage was high. One, a fertility specialist explained how he was now quite blunt:

I usually tell them, tell it as it is, to be honest. I usually say "You'll become prematurely menopause and you'll have no period, you'll have all the symptoms of menopause, with hot flushes, with all these things"...I'm very blunt on that, I have to admit. I think they need to know. It's not that you, you need to make it easy and whatever, if they know already they have cancer they need to know the whole story. This is what I say to them, and I'm, I'm, I am very direct in these situations, I have to admit. But I try to make it, not in, in a way very confrontational or whatever, it's just to, to let them know that this is reality. (Fertility specialist)

The other, an oncologist now used phrases such as 'it is definitely going to make it impossible for you to have children' when prescribing 'high risk' treatments in contrast to using phrases such as: '[gamete(s) storage is a]...a little back up plan for if things don't go to plan, and if your, if your fertility doesn't return' when the threat was low. She also felt it important, based on her experience, to make reference proactively to the fact that damage to fertility did not automatically affect sexual performance:

I would stress for all of them, men and women, that it does not mean that for a man that he will be impotent, I say it quite plainly...And equally I say to women that they will be able to make love normally, that they will be able to have orgasms normally, that it does not influence their sexual function or feeling, it's just simply the fact that they may not have periods returning and that we will just have to wait and see what happens. (Oncologist)

However, one fertility specialist was critical of trying to quantify risk when discussing *cryopreservation* with females: she saw this as misleading and considered it more important at this stage for them to understand the complexity (and hence implications) of using storage services *and* later fertility treatments – including their success rates, costs, regulatory matters:

It is...not a quantifiable risk because even oncologists can't quantify it so we [fertility specialists] can't quantify it. It is a qualitative assessment...we have to talk through about how, what the, what problems could be after storage, about how it might be used...giving them figures is, is, is just misleading them. The, the, the worst side of information is wrong information...[women need to understand] the impact of storing...delaying chemotherapy by several weeks...potentially increasing the risk of progression in the process, not, not just the time delay, but because that requires stimulation of hormones...The risk of never being able to use the eggs, the risk of acquiring ICSI afterwards, the risk of having, you know, waited for five years. risk of recurrence...the potential risk of the act of storage leading to progression of disease and worsening of prognosis without any guarantee for success, a reasonable guarantee for success, 'cos success rates are very poor as well. (Fertility specialist)

As we shall see later, she used blunter language when discussing fertility treatments. However another oncologist chose not to refer directly to fertility at all with females at diagnosis but instead explained how menstrual periods might be affected, leaving it to

the patient to make the connection. We explore this further, from the patient viewpoint in the next chapter. How one intends to communicate and how the communication is received are not always the same, with one example of bluntness reported by a fertility psychosocial professional to have been especially distressing for the patient:

The urologist looked at the woman and said “Well he’s never going to be able to have children so you might as well have a one night stand”.
(Fertility psychosocial professional)

Communication could also be affected where English was not the patient’s first language (a common experience for many professionals working across different sectors of health and social care but one increasingly irrelevant when younger people, who speak English as their first language, are concerned). There was widespread awareness of the need to avoid using family members as interpreters, particularly given the sensitivities and technical complexities of the subject area. Professionals were also concerned as to whether the information was being conveyed in full and accurate manner. Accessing a formal interpreting service, however, was not always straightforward. A fertility scientist, for example, reported that referrals for cryopreservation did not always specify the need for an interpreter, and he then had to balance the stress of delaying the intervention against the risks of using a family member. There were also experiences where language barriers arose for other reasons: a patient and supporter having low levels of formal education, being very young or otherwise struggling to understand or engage with what was being conveyed. This, according to professionals, led to some patients not fully grasping the implications of any decision until much later. In other words, there were different facets to issues of communication, meaning and understanding that extended beyond the use of English.

Referral processes for cryopreservation

Most professionals felt cryopreservation referral processes worked well. Some concerns, however, did emerge. Sometimes it was believed that patients were not

referred early enough for fertility advice in the cancer pre-treatment stage, especially from adult oncology and/or secondary care centres; or not until after chemotherapy had already started; or having already been taken off the Pill (making storage procedures lengthier or impossible). All these problems occurred despite their contradiction of the NICE Guidelines (2004, 2005) and the Royal Colleges' recommendations (2007) (see the background literature). One fertility specialist cited the example of a woman who was referred for fertility advice three months after her diagnosis of cancer. Another described how a woman referred herself because her oncologist refused to discuss fertility. There appeared to be mixed practices about whether patients were informed explicitly about risks to their survival if they took time out for banking. Fertility staff felt this sometimes put them in a difficult situation. Some reported referrals that contained ambiguous or unclear information. Attention to details such as whether the patient was in a wheelchair or otherwise physically restricted, or had reduced mental capacity and so on could be poor. In addition, variability was reported in how well younger males in particular were prepared for the sperm banking process. One fertility scientist gave the example of a young man who was so nervous that it was unclear whether the pot even contained a complete ejaculate as he ran out of the clinic before anyone could talk to him.

Unlike perhaps the majority of reproductive medicine interventions, there is only a small window in which to intervene and fertility staff had concerns about their ability to become attuned to cancer patients and carve out sufficient reflective space for them. For those in oncology, professionals were more likely to feel deskilled because of their self-perceived inadequate knowledge base about fertility matters. Where referral processes were seen to work well, this involved several disciplines within as well as across health and social care sectors. The complementarity of accessing each others' specialist knowledge and providing a shared space in which to discuss issues was acknowledged by professionals.

Treatment effects

Professionals had little to say about fertility-related impact during cancer treatment. Commonly, they believed most patients put it out of - or to the back of - their minds in the immediacy of treatment regimes. That said, some professionals were proactive in discussing contraception at this stage, though usually as a discrete subject aimed at reducing health risks from STIs and unplanned pregnancies rather than linked explicitly to fertility, sexual performance or emotional and social wellbeing.

In the longer term and according to professionals, the most frequent triggers for fertility being raised by patients were when adult relationships became permanent; parenthood was considered actively; or peers were 'settling down'. Patients' most common concern was to acquire greater certainty about whether damage had occurred (we return later to the specific area of fertility analysis). However other professionals, especially those with a self-professed interest in the area, also reported patient concern to be triggered by anxiety or distress. One oncology health professional found fertility was the only side effect about which people, especially women, cried in 'Late Effects' clinics. Some patients were reported as saying that coping with fertility damage or its threat (and hence uncertainty) was worse than having had cancer; a few wished as a result that they had not survived. This is why some professionals located the impact of infertility within a wider context that evoked feelings of lowered self worth; feeling 'stuck' in their lives; and fearing that potential partners would see them as 'damaged goods':

Feelings of self-worth, feelings of depression, perhaps the feeling that, I don't know, my life's been spoiled by cancer, these, these sort of like, like the, these are the things that I keep going back to and I can't get moving with my life or something like that...a lot of the conversations I have in, in my sort of clinic room are with young people who feel precisely that they look around at their peer groups and I'm not doing as well in work, I'm on my own, I'm not, I've not got a steady girlfriend or boyfriend, I'm not sure...there is still an unspoken standard that people feel they've not met perhaps.

Professionals were aware how individuals entering new personal relationships had to decide whether, when and how to disclose fertility-related information, which was sometimes made difficult by them not knowing themselves whether damage had occurred. One psycho-social oncology professional was concerned that early disclosure could distort the 'natural' progression of relationships by prompting discussion about views on parenthood, way ahead of when this would otherwise take place otherwise. However, one of the psycho-social fertility professionals seeing couples at the stage of coming forward for fertility treatment found them perhaps more resilient than those from the non-cancer population.

Where cryopreservation had not been an option, the fears expressed by oncology professionals that this might prove distressing in the long term were confirmed by, for example, the experience of one of the fertility health professionals who reported patients' anger at this cancer legacy:

I have had some of these other 'if only' conversations with, that, that, you know...somebody should have, somebody could, could have just allowed me to..... So, so that's one of the several injustices that people feel about, you know, why me. (Fertility health professional)

Dealing with uncertainty as a professional or patient is, of course, a central aspect of the cancer experience and ran through many professional accounts. With regard to fertility, the uncertainty was on different levels: whether fertility was affected at all; if so whether it would return and stay or return and then reduce (eg: as with premature menopause); whether growing scientific knowledge would raise fertility treatment success rates. For some patients, this was thought to contribute to uncertainty around identity, sexual activity and 'romantic' relationships whereas others appeared less concerned. Professionals too could find their own confidence affected:

I think there are some people who, who have an attitude of 'well what will be will be' and some people who, who think about it a lot and it then becomes an issue through uncertainty and then it becomes very hard to deal with.

This does not mean that such features were common to all patients: professionals' stories suggest, while some patients appear deeply affected, others appeared less so or, at the least, less willing/able to engage in discussion:

They either want to talk about it a lot or they just don't want to talk about it at all, it tends to be one or the other...it's completely variable and I have never been able to predict how people will react when it's brought up. For some it's something they don't even think about, they don't think it's either relevant or they just don't want to know, and others it's something they thought about and probably didn't need to worry about and then for others, you know, they do need to worry about it and may not have done or the other way round. But I do think out of all the late effects fertility is perhaps, they certainly worry about it more than they would others.

So what contributed to professionals' decisions about whether or not to be proactive in raising the subject of fertility? Some saw it as good practice to be proactive. For example, one oncology nurse in young peoples' services made a conscious effort to raise fertility in private during treatment to ensure the patient understood what had been said previously or, sometimes, to raise it for the first time. He felt affirmed in his approach as some patients returned to discuss it again later. However, when it came to long term follow up clinics, he and another in a similar role found barriers to raising fertility among the myriad of other treatment side effects to check on, their general busy-ness and lack of private space:

It's just not high in that horizon, if you will. It's not that I particularly think about it and make a conscious decision not to talk about it, it's, it's more circumstantial really, busy clinic, there's often no private spaces, patients can quite, quite often even, even, you know, the, the older patients, the thirty year olds and stuff, they still come in with their parents and sometimes, you know, it's just, it's, it's a difficult thing.

Participants at two of the focus groups discussions concluded that recent improvements in awareness and practice at diagnosis were a long way off being matched during treatment or longer term follow up services.

In contrast, another participant was highly committed to fertility being raised proactively at each 'stage' of professional intervention: diagnosis, end of treatment, long term follow up clinic. This helped ensure that patients felt 'permission' to discuss it if they wished. Unlike the professionals above, her experience was that the 'late effects' setting lent itself well to raising fertility issues. She also found patients themselves raised it regularly. Some professionals only reversed their usual reactive approach if they 'guessed' that an individual was sexually active or in a 'serious' relationship but she questioned the wisdom of this as it may prove too late, inappropriate or may miss any hidden anxiety or distress on the part of their patient:

Every time they came through then I would give them that opening really to talk about it and, so broach it in such a way as, you know, right, well that, at this point now I'm going to talk through your possible late effects of your treatment and one of those is fertility, your ability to have children or not. We don't know, you know, how, whether you are, have got that ability unless you have an assessment that is available to you at any point in time. And then I would go through that assessment with them, what's involved in that. So yes, I bring it up every time and really just in as much depth as they want...And, and when you're looking at young people and children growing up, their understanding changes from year on year. So one year it'll go right over their head and the next year they might sort of say, well what's, what's fertility, you know, or, and ask some questions, and then the next year they might be really interested and asking.

An unfolding discussion in one of the focus groups considered that it was those professionals who saw fertility as having the potential to trigger feelings of loss that were more likely to tune in to, and facilitate expression of, patients' distress. One such oncology health professional found that raising it proactively led also to her sometimes being able to reassure patients; it was not always 'bad news' that she needed to be conveyed:

I had one patient who came through who'd had straightforward leukaemia treatment who should have had no risk to her fertility who said "I always thought that it would potentially affect my fertility and I'm, I'm just wondering if it would." And that was nice to just be able to say "No, you should be absolutely fine."...I think that's just as important as saying to patients that potentially you might have effects, to reassure those that won't, because

sometimes what you imagine to have happened to you is a lot worse than what did if you're a child and you don't remember. (Oncology health professional)

Some oncology health professionals felt enabled to be proactive by having access either to a jointly run oncology-reproductive medicine outpatient clinic, a reproductive medicine service or a psycho-social service in which they felt confident. Conversely, the lack of psycho-social services in particular was thought to sometimes heighten professionals' tendency to offer mechanistic responses that shut down discussion.

Decisions about being proactive in raising fertility were not driven only by organisational context or personal style. Sometimes they were influenced by whether the professional saw fertility matters as falling within their remit or sphere of knowledge. For example one psycho-social oncology professional saw them as primarily a medical matter and hence the province of doctors or nurses. Sometimes being reactive reflected hierarchies within a discipline. As a more junior doctor, one oncology professional considered that she could only be proactive at diagnosis or during treatment with her consultant's agreement, but held more authority to be so in the long term follow up clinic, aided not only by its inclusion in its protocols but also its (local) culture. Elsewhere, the decision to be reactive appeared located more in the professionals' views that it was inappropriate to raise because it could 'open a can of worms', cause distress or embarrassment to the patient or be seen as irrelevant and time wasting by them. An oncology health professional believed that patients with pressing concerns would raise them anyway, as was her experience on other subjects: 'You have to rely on patients bringing up issues that they're concerned about'. Other professionals, however, felt patients sometimes lacked the confidence to raise concerns about fertility. Nonetheless, those professionals who leaned toward reactive approaches did express some uncertainty about their approach. One wondered aloud whether she should raise it more and another said that such a shift was being discussed within the wider team in relation to sexual activity and relationships (matters which could be seen as linked):

I think there are issues around whether or not they believe it's OK to have sex or whether or not. I think, I think there is probably an assumption on nursing and medical staff that they're too ill to be bothered in some respects, but they're not and, and one, one of the patients asked me the other day, one of the patient's partners had asked me if it was OK for them to kiss, not, just from the germ perspective.

In balancing the need to be proactive, against the default position of reactive engagement, some professionals felt constrained in discussing 'late stage effects' by the presence of parents, partners or others. As referred to earlier, there was a common view that younger people should be encouraged to attend consultations on their own when they reached adulthood. One service had made a policy decision to this effect. It was considered easier on both the professional and patients to then raise the subjects of sex and fertility. In another clinic, this extended to making sure that there were a minimum number of professionals present when the doctor planned to raise these issues. This included excluding students and junior members of staff.

Whether fertility was raised by professionals or patients, the challenge of treading a tightrope between being frank and enabling patients to retain some hope, as highlighted earlier, remained present and similar divergences in professional behaviours prevailed. One explained how she as an oncology doctor tried to convey seriousness in her language (where damage was likely) without making definite statements:

I'd say there's no absolute, because I don't think there ever is...I do always say that, that it's not, the, the vast majority of people who've had treatment like yourself would be unable to conceive, although there are no absolutes...we would say the, it's extremely likely that you will be unable to conceive or almost impossible, you know, there would be that kind of language, 'cos there isn't an absolute.

Even among those taking referrals to discuss fertility treatment, differences in approach were also evident. One psycho-social fertility professional argued that: 'in most fertility cases there's always a window of hope' whereas the fertility consultant

who challenged the use of quantified risks for storage discussions, considered it important not to 'beat about the bush' when discussing fertility treatments:

It is not difficult to communicate, we have to be, you know, my, this is something, this is why we don't kind of beat about the bush, we actually give information straight on, face on, and people are generally prepared anyway. If they've not had period for nine months or are, are having tests they psychologically are aware that there is a possibility that they might be found to have no ovarian function left, for instance. (Psycho-social fertility professional)

Attitudes to fertility analysis

South Asian patients' requests for fertility analysis were seen by professionals as sometimes being triggered by proposed marriage negotiations. Other motivations across ethnic groups were noted too, including educational attainment and social upbringing of patients, coping styles or social changes such as preparing for parenthood. One oncology health professional found that some patients came forward early in 'romantic' relationships prompted by anxieties about whether to proceed without knowing their fertility status; often for the sake of their boyfriend/girlfriend rather than their own. Another, a fertility scientist, believed that some men sought testing as an indicator of how well their cancer recovery was going rather than as a predictor of future fertility:

Some of them aren't actually thinking of going for [a pregnancy], this is, some of them haven't even got partners at that stage...but I think some of them just, it's almost a stage in healing that, you know, if, if they'd been cleared, if they'd been given the all clear or whatever for the, for, for the cancer, then getting their fertility back is another, one of those stages. (Fertility scientist)

As elsewhere, there were differing views about whether or not to be proactive in providing information about fertility analysis and whether it should be included in any protocols. Sometimes this appeared influenced by professionals' views about the potential for a negative result to do more harm than good (echoes of earlier concerns about offering cryopreservation); sometimes by concerns that tests conducted too 'early' could either cause unnecessary distress if negative given that function might

return later or raise false expectations in females if positive because they may later undergo a premature menopause. Some oncology health professionals were concerned that negative results (including the way they were presented) could impact adversely on emotional or sexual well being:

If you're going to be burdened with 'I'm not fertile', you know, is that going to help an eighteen year old boy? Is it going to lead to more promiscuity? Is it going to lead to depressions? (Oncology health professional)

Delaying analysis was also seen as holding the potential for easing entry into new personal relationships:

You're not taking away all that hope, and sometimes that's easier to approach a girlfriend or boyfriend with and to say, you know, well I, I did have cancer in my childhood and there's a possibility I might have, I might struggle to have a family but I don't know, rather than saying, well I had childhood, childhood cancer and I definitely can't have children.

However the same oncology health professional also believed it good practice to ensure that patients knew fertility analysis was available, providing it was offered sensitively so the person could bypass it if they wished. Another oncology health professional, who was especially interested in female fertility, had similar views providing that the female was 'old enough', that they understood the implications of coming off the Pill (if applicable) and that they understood that being tested would only indicate their present 'state' and tell them little about future fertility. Nonetheless, this professional hoped, having raised it, to then dissuade many patients to pursue it further. However she also speculated that she went into fertility analysis a lot more thoroughly than did many of her colleagues whom she considered referred on too readily. Other professionals also raised the importance of professional support being available as part of decision making, acknowledging that replacing uncertainty with certainty (or different types and levels of uncertainty) was not necessarily beneficial. At the fertility clinic end, there were indeed examples of professionals seeing referrals as 'tasks to be acted' on rather than as opportunities for further discussion.

There appeared some agreement of circumstances in which professionals did not consider it desirable to raise fertility analysis. Where, for example, the patient had developmental delay or had entered palliative care. There were also references (as elsewhere) to the potential for the request to come more from parents or partners rather than the person themselves. Professionals felt this had to be guarded against.

Gender was seen as affecting the way that results were managed. The absence of stored gametes (more often the case for women) seemed to heighten the impact of a negative result, be that anger or regret. Some found men less likely than women to show emotional distress. While one female oncology professional thought this reflected the fact that women lost the chance of pregnancy as well as parenthood, one of the males, a fertility scientist, thought that men were more likely to expect the worst, especially if they were cancer survivors:

I might be saying more about myself than I am about the, the male gender, it might just be me...But no, I think it's across the board that, that, I think men are a more either pragmatic or, or pessimistic than, than women. (Fertility scientist)

This same professional spoke of the challenge of giving bad news, especially from tests carried out over time that showed no improvement. His approach was to try and convey the seriousness by inference. He considered this more beneficial for the patient:

Giving bad news is always difficult whatever...But, but the longer term ones, I mean I suppose if, the more they attend, the, I suppose the more resigned they are to not regain their fertility...we never say, we, we never say never 'cos, because, well...it's not, not good for the patient...I don't think we've ever done that.

Fertility scientist

PREPARATION FOR, ROUTE TO, AND TIMING OF PARENTHOOD

In keeping with earlier findings, there was evidence here of the interplay of professional and personal views about 'appropriate' approaches to the timing of parenthood, the 'right' to parenthood and the acceptability of different routes influencing approaches. This reflected in part the diversity of experience among professionals. Areas that could be seen as ethically challenging, such as posthumous donation and providing fertility treatment to someone terminally ill were rarely identified formally as such by professionals; a feature found among experienced professionals in other ethically challenging areas (Banks 2005). When talking about how they formulated their views about appropriate professional behaviours, professionals were more likely to draw on personal experiences for their benchmark than research evidence, policy guidelines or more formal ethical machinery. Managing the boundary between personal views, perceptions of professional obligations and the rights and wishes of the patient – and what comprised informed consent – sometimes posed strains.

One of the adult oncologists expressed personal feelings of unease about someone embarking on a pregnancy when they were unlikely to live to raise the child, although she could see that notwithstanding medical advice about critical time-frames for risks from relapse, cancer-treatment related toxicity and so on, the desire (from the patient or their partner) to ensure that part of themselves was left behind if they were to die could feel compelling:

A lot of the time people say, well even if I'm not cured my partner and I wish to have a child now and even if I die then at least there is something of me left behind on this earth... [or] they have a partner who says, 'oh but that's, that's, I don't care about that, I just want to have your child, I want to have the opportunity to have that child' [even if you die]. (Adult oncologist)

In contrast, the personal views of one of the fertility scientists led to her feeling comfortable about assisting such patients to conceive through fertility treatments:

You never know what's round the corner for anybody or anything and they're in no different situation to anybody else. They're not necessarily more likely to have cancer than anybody else coming through. (Fertility scientist)

In the first case, the oncologist concluded that there was both a 'right' and an 'obligation' on professionals to raise the ethical dilemmas with anyone considering parenthood (or already pregnant) while the fertility scientist, who set store by research evidence in some other aspects of her work, did not appear to be influenced by evidence that many cancer patients are at greater risk of second cancers than the general population.

The interplay of personal and professional views also appeared to influence whether to be proactive in advising females at risk of premature menopause not to delay childbearing. While some saw a clear professional obligation to share such information to aid life planning, others were more hesitant, echoing earlier concerns of taking away hope and/or heightening burdens and drawing on what they themselves might want in such circumstances:

It seems to affect some more than others and saying to them, yes, you may have an effect on your fertility, you may have had an effect on your fertility from your treatment, if you can have your children early in life that would be best. I mean what a thing to say to someone, I mean that's so hard to plan. I didn't get married till I was thirty and you don't want to just marry someone to have children, do you, or, you know. Yeah, it's not an easy thing to give someone as a burden really to say, have your children early or you might not have any.

Professional rather than personal views seemed more dominant where a pregnancy was already underway. For example the adult oncologist cited earlier saw her primary duty as being towards her patient (and their partner if they had one) rather than an unborn child and another oncology health professional whose religious views led her to consider abortion to be wrong in all other circumstances could override those beliefs where she considered that a pregnancy put a cancer patient's physical well-being at risk.

In any conflict of views between professional and patient, as with the earlier situation of patients refusing treatment, professionals found that time for reflection and use of absolute or blunt language (such as 'if you go ahead, you might die') was usually, but not always, enough to effect a change of mind. Two situations were cited where women had gone ahead with a pregnancy against medical advice and died. Interestingly, one oncology doctor who firmly supported patient choice realised in the interview that this had never been tested in reality as her patients had always come round to taking her advice about avoiding pregnancy.

Using alternative routes to parenthood

Once patients enter assisted conception units, the regulatory system under the Human Fertilisation and Embryology Acts of 1990 and 2008, states it is the treating doctor that makes the final decision as to whether treatment can go ahead, taking into account among other things the welfare of any child that might be conceived or affected. They may ask for advice from an Ethics Committee (where available) or a multi-disciplinary group set up to discuss such matters. All patients must by law be offered counselling prior to treatment but take-up is not compulsory. One other key contextual change is that the majority of UK fertility treatments are carried out in the private sector and a few professionals considered that the views of the 'paying customer' should carry more weight.

There was limited experience, especially among oncology professionals, of working directly with cancer patients using stored or donated gamete(s) but there was more experience of, and speculation about, the negative impact of the prospect of paying for fertility treatments. However, there was little support for their patients to be treated differently to non-cancer patients; rather there was support for more NHS provision available to all who faced fertility problems. However one fertility scientist handled the thawing of stored embryos of cancer patients differently because they were so 'precious':

Anybody coming through IVF, it's very precious, their eggs, sperm, and embryos are very precious but I think maybe more so when you know that is your, that's your infinite number that you've got and once that's gone it's gone. So we, we do treat them differently when it comes to sort of thawing policies to the general population, because they are much more precious...we would only thaw out the number of embryos that would actually be going back. So it may be that you're actually transferring slightly poorer quality embryos, but it's to try and sort of make sure you maximise every single one you've got frozen.
(Fertility scientist)

While some saw it as important to provide information about alternative routes to parenthood such as gamete(s) donation, surrogacy and adoption early in the cancer journey, others only did so if asked by the patient: 'Fertility we do but not fostering'. There was some awareness of the additional challenges of using donated gamete(s) across both individual interviews and focus groups.

Professionals' views (drawn from work with cancer and non-cancer populations) of the responses of many South Asian patients to certain aspects of fertility treatments raised their concerns: including those attributed to what they saw as a 'culture of silence' and religious disapproval of sperm donation (see above). The only two specific reports of relationship problems arising from cancer patients (both men) failing to tell their spouses about their fertility difficulties were both from the South Asian community. In one, the wife found out and returned to India on the grounds that she should have been told before the marriage. In the other, the wife was undergoing fertility investigations in ignorance of the man's situation and the professionals insisted that she was told. It is difficult to say, however, whether such instances actually reflected ethnic and cultural differences, as discussed earlier, rather than the challenges of knowing how and when to disclose, as found elsewhere (see Crawshaw and Sloper 2006).

With reference to non-disclosure in relation to sperm donation, one fertility psycho-social professional was concerned about instances of Muslim Asian men asking for their brother's sperm to be used, without their female partner being aware. Such

requests were refused in her clinic, particularly since she felt they were driven, in her view, by cultural or religious views and perhaps, the 'culture of silence':

A lot of [Muslim Asians] say they cannot have sperm unless they're married to the person who produced the sperm, so really sperm donation is out. So we have had couples coming through who bring in a brother but then they don't want their wife to know the, and we will not do it then. Because if the sperm donor's their brother and they're not telling their wife, we will not do it, because it compromises everybody, know what I mean, and there's a lie, we're colluding with sort of lies and so, so that. (Fertility psycho-social professional)

It is important to note that such remarks were often based on odd examples and it is not possible for us to speculate how often such instances actually occurred in practice. Assumptions about the disapproval of donor insemination within South Asian communities and the shortage of Asian sperm donors created another contentious practice for professionals, namely the possible use of 'white' donor sperm by Asian couples. One fertility scientist appeared content to provide this service on the grounds that prospective parents were 'given a lot of counselling' so that, in her view, neither the resulting child nor the wife would be 'rejected'; the key risk, in her view. However another fertility scientist was more uneasy about it and was especially concerned about the potential of South Asian couples to request 'Caucasian' sperm in preference to 'Asian' sperm so as to have a 'fairer skinned child'. Again, how real this was in practice is difficult to tell, particularly since it is not mentioned in the broader literature. The next chapter explores this from our participants' point of view, which generally suggests such assumptions or fears may be exaggerated.

Professional views might also reflect their own insecurities/ambivalence about their role in creating a family where there are both ethnic and genetic differences. This raises complex issues. For some, taking a 'supply' only perspective offers a seemingly straightforward solution: in the absence of 'South Asian' donors, 'white' donors seem acceptable (though interesting points arise as to what constitutes 'ethnic similarity', particularly given the homogeneity of terms such as 'South Asian' and 'white' - see above). For those charged with ensuring that prospective recipients are 'fully

informed' about the implications of their decisions and/or that the welfare of any children conceived or affected are considered, the relative paucity of any evidence base leaves them drawing on presumptions as to what constitutes good practice, evoking important parallels with the early days of trans-racial adoptions.

Some professionals believed that Asian women were especially vulnerable when considering alternative routes to parenthood. While professionals generally understood the use of donated eggs not to be prohibited on religious grounds, shortages of South Asian women coming forward to donate eggs were thought linked to disapproval of such practices within Asian communities with little prospect of change (explanations for shortages of 'white' egg donors were not ethnicity based). One fertility psycho-social professional went on to talk of the additional impact for Pakistani women whom she found especially likely to have poor education and live in poverty. Working in an NHS facility, she saw those who could not afford to take alternative routes such as overseas treatment, where both the supply of donated gamete(s) and the potential for privacy/secrecy was greater. She reported another 'unique' consequence for Pakistani women: that some husbands arranged to take a second wife. The literature, however, suggests this is extremely rare and such comments perhaps reflect the concerns of professionals or fears of some women rather than the actual practices of the communities they serve. This is beginning to be a re-occurring theme in our account and one we explicitly address at the end of this chapter. There were also reports, although again drawing primarily from fertility professionals' experience with the *non*-cancer population that South Asian prospective parents were especially unwilling to inform any donor-conceived children about their origins (something now strongly endorsed by the HFEA). A number said that while they found it difficult to support refusing to treat such patients, they also felt that agreeing to treat went against (for some) their professional and/or personal beliefs and (for all) regulatory requirements. Again it is difficult to say how common such practices are. Although one study into public perceptions of gamete donation in British South Asian communities found that disclosure was considered 'risky' given a general disapproval of third party reproduction, there was also support for a child's

'right' to know (Culley and Hudson 2006). Secrecy about donor conceived children has equally been an issue in the wider-white population, even though a change in cultural attitudes is on the way (see Crawshaw 2008). This provides another example of generalised cultural assumptions informing practice.

Parenthood planning during palliative treatment or posthumously

Professionals were especially likely to find challenging, any plans for parenthood during palliative treatment or posthumously. Their views appeared informed by a diverse range of approaches: belief that 'patient choice' should be paramount once good quality information had been provided; belief that parenthood was a private matter; personal reflections on what they would do themselves if faced with a similar situation; feelings of compassion towards those affected; or moral stances about forming families in such circumstances. One of those influenced by what she might do herself stated that she would never stand in the way of anyone choosing this route to parenthood even though as an oncologist she could exert influence on access to fertility treatment:

I think it, if I was dying and I wanted to have a child and I had someone who I knew was going to look after them I think that that's perfectly reasonable actually so long, it may be a bit selfish in a way to want to leave somebody behind, but I don't think that's my decision as a doctor to not allow them the opportunity. I think that so long as they had appropriate guidance and counselling in the right settings, and a partner who was able and willing to bring up a child then no I don't think I'd personally want to stand in their way.
(Oncologist)

Another, a fertility health professional, had experience of a man dying a few days before his wife was due to start fertility treatment using his stored sperm. The clinic responded by providing the woman with counselling and convening a case conference of fertility professionals (medical, nursing, scientific and counselling) to make recommendations to the treating doctor. They accepted the wish of the woman to go ahead with treatment because 'she felt like that was the only thing that was going to

actually get her through'. The professional felt the decision was further affirmed by the apparently therapeutic value for the man in his dying days of being taught how to give his wife the hormonal injections – a contrast to her providing him with nursing care – and his excitement at the prospect of a pregnancy. There were, however, no references in this example to the needs of the child to be conceived.

Another fertility professional – a doctor – said that she would refuse to treat a woman receiving palliative care (or who had a poor prognosis) because of what she perceived to be both the risk to the patient and risk to the child of losing their parent. She considered it ethically wrong, regardless of the strength of the prospective parents' wishes and any therapeutic value to them: 'People can jump off the cliff but you don't have to walk with them to the top of the cliff'. Nonetheless, later in the interview, she recalled treating a couple where the man was terminally ill. In this case she had been satisfied from their contact with the infertility counsellor that substitute father figures such as uncles would be available to the resulting child, raising the question as to whether the gender of the person dying may have influenced her decision.

Posthumous donation also raised mixed views among professionals, although experiences were restricted primarily to fertility professionals. There were some who saw it as the surviving partner's 'right to choose', including the oncologist who was earlier reported as feeling a professional obligation to advise her cancer patients to delay or avoid conception if they were at risk of relapse or with a limited lifespan. She now took a more 'hands off' approach:

I really don't think it's for me to get involved in that, that's between them and the person who died, or if they didn't discuss it between them and their conscience if that's right, but I, I don't have any right to tell them what to do, it's none of my business. (Oncologist)

The fertility doctor who expressed apparently contradictory views about treating someone that was dying also appeared less equivocal about posthumous treatment but again stressed the importance of a 'welfare of the child' assessment by others.

Some professionals felt better able to cope with any personal misgivings if the person concerned had undergone counselling to explore the implications:

I suppose you have some ethical issues when you've got, patients will come through using sperm from a, you know, a partner that's deceased, and obviously they're then being born into a family without a father already. But I think a lot of, to get to that point they've been through an awful lot anyway and an awful lot of counselling. I don't think it's an easy decision for a patient to make before they come through to do that. I don't, I don't feel I go against anything ethically working actually within in the field.

Another professional saw counselling more as a filter, 'wheedling out' unsuitable potential parents, but also felt affirmed in going ahead with interventions if people had been through this process. In other words, the contribution of counselling to the complementarity of multi-disciplinary working appeared to offer the potential to lower other professionals' moral or emotional uncertainty, giving them reassurance.

One fertility psychosocial professional found it less easy to resolve, illustrated by her reference to a case where a woman in a new intimate relationship, requested treatment using her dead partner's sperm:

I think I have, have had slight concerns when sperm has been stored and it's, then they've found another partner and then the partner seems to say, oh you can use the, you know, your deceased partner's sperm. And that I think, I have worried about that, and they seem to be having a full relationship, full intimate relationship with a new partner and then suddenly she's going to use the sperm of this, you know, that has caused me concern...Because I think, I think she's not worked out the relationship, is in a way not letting go of the dead deceased partner before starting another relationship and then what's it going to do to the relationship in front of me. Do you know what I mean?...It's not, I'm not going to stop it, do you know what I mean?...but I think it's something I would say to them "I will discuss this with the clinician" and we've discussed it more.
(Fertility psychosocial professional)

She went on to discuss the complexity that she perceived in people's relationship to their own stored gamete(s) or that of their deceased partner, including when they

appeared to put their 'head in the sand' rather than decide whether to proceed with treatment or allow their own or their deceased partners' sperm or embryos to perish. The explanation for lack of decision-making was seen somewhat differently by one of the fertility doctors who located it as arising not from emotional ambiguities but instead from a wider UK cultural context in which people failed to act responsibly in their dealings with health professionals and health matters:

A lot of the public don't take responsibility for their actions, don't take so much interest, particularly within the UK, they are kind of brought up where medical profession's been, kind of had a parental attitude for, to them and still have to grow up and learn to, you know, be independent. People are not responsible...in terms of responding to letters, in terms of keeping us informed of change of address...it's the whole process of where, you know, irresponsibly people store and walk away.

As we shall see, the next chapter suggests that while patients might share professional concerns, their emphasis is realised within a different context and reflects a different set of priorities and concerns.

MANAGING INTERDISCIPLINARY RELATIONSHIPS

Support for the importance of having staff of different disciplines in both oncology and reproductive medicine with a keen interest in cancer-related fertility matters and a pride in associated service developments has already been mentioned. Not only were such staff seen to put in additional time and effort but they were also seen as 'champions' within their own service and supportive to their colleagues, especially in the case of specialist nurses. Even with the most carefully thought out inter-departmental/agency systems, there was still a perceived need for individuals in key posts with the 'right' sort of approach: knowledgeable, interested in cancer and fertility, friendly and determined. However, while there were examples where the complementary nature of specialist tasks was both clear and facilitated job satisfaction - for example when dealing with a woman's request for cryopreservation services - there were also occasions where the presence of specialisations appeared to lower the

confidence of others to 'stay' with the patient long enough to see whether it was specialist knowledge that they required or whether the 'here and now' contact with them would suffice.

Where tensions were identified in inter-disciplinary relationships, these arose mainly from nurses in both cancer and fertility settings having to 'manage' their medical colleagues, especially in situations that called for sensitive handling. Counsellors also gave examples of managing the consequences for their clients of occasional poor professional practices of other disciplines. While acknowledging that people probably found it easier to talk to nurses than doctors because they had more time, were female (usually), were more likely to be in their posts for longer and hence able to build up more familiarity with patients, professionals were equally aware nurses were seen as less of an authority figure, one oncology doctor also thought that 'patients listen [more] to what the doctor says'

The value of flexible relationships and boundaries between services that could respond to particular patient needs was also identified. One oncology psycho-social professional found it an advantage to be seen as an integral part of the oncology service insofar as it made him appear more accessible and acceptable. However when it came to matters of sexuality, his 'outsider' status proved more helpful in that it offered the heightened confidentiality that he considered appropriate to such a potentially sensitive matter:

Particularly on any sexual matters, some sense of clarity about confidentiality, who gets to know this information and so forth...I think that's [being a peripheral service] quite helpful in that trying to have a place for a private conversation on an active hospital ward is very, very difficult, and the privacy of these conversations I think is important, physically and psychologically.
(Oncology psycho-social professional)

A professional working in one of the other more 'arms length' services – a community-based oncology information and support centre – had similar views about the value of

distance but found occasional tensions when 'inside' NHS staff appeared to feel threatened:

There are sometimes issues when the CNSs will say, well they, I have been asked, 'why did they come to you, you know, I provided that information'. I didn't ask them to come to me, they've come to me on their own accord and there must have been a reason why they've come to me.

Getting different disciplines together in one meeting space proved difficult *within* services and was largely absent *across* services even within secondary/tertiary settings let alone including primary care. Psycho-social professionals in both oncology and fertility services (separately) ran occasional psycho-social discussion sessions (although it was unclear how far this was true in adult oncology services). Such sessions were infrequently attended by doctors. Multi-disciplinary team (MDT) meetings – which were largely case-based – also tended to draw only from one service but more reliably included all disciplines.

Not surprisingly, some of the identified difficulties in inter-agency communications reflected the dominance of cancer-related needs in the early stages following diagnosis (also see above). However there appeared to be better ongoing contact between fertility services and paediatric and teenage/young adult services than with adult oncology services, especially those in secondary care centres. Experiences were also more variable between primary care and elsewhere with suggestions for improvement including the need for better protocols and improved patient information from the specialist services back to the primary care team.

PROFESSIONAL PERCEPTIONS OF SOUTH ASIAN PATIENTS:

EXPLORING THE TYRANNY OF FAMILY AND CULTURE

We end our account with a more general reflection on how professionals conceptualise 'South Asian' culture. We have identified some of the difficulties faced by professionals in making sense of ethnicity and cultural diversity and how some, in

particular, felt they lacked knowledge, insight and understandings. Many assumptions also appear in operation and the extent to which these reflected either actual professional practice or the behaviours of patients/families could be questioned. Before leaving our discussion of professional experiences, we summarise some of the main tensions. We will then pick up these tensions when discussing the views of those who have potential problems with infertility, following cancer treatment.

As mentioned earlier, there was a good representation of professionals from non-‘white’ as well as ‘white’ minority ethnic backgrounds. This in itself, however, did not predict the kinds of responses we had from the professionals. In addition, while some professionals across the board engaged with the issue of cultural, ethnic and religious diversity in highly reflective ways, others only provided generalisations (see above). What is interesting is that those who set out to provide examples about the peculiar attitudes and practices of patients and families from South Asian backgrounds, when (and if) prompted, often provided similar examples from ‘white’ families. The leap from an individual case or family scenario to culture, ethnicity or religion is interesting as is the disappearance of such explanations in discussions about ‘white’ patients and families. Notions of homogenous communities were also at times reinforced by professionals representing these communities. This is not to deny that some professionals did evoke the notion of culture while talking about ‘white’ patients, especially in relation to gendered notions of impact of fertility on identity; reinforcing the wider cultural perceptions of womanhood being tied in with motherhood.

Five inter-related themes identified across individual interviews and focus groups across the three sites provide a glimpse of the generalisations and contradictions at play. First, reified notions of culture and religion were perceived by some professionals as *determining* men’s ability to ‘produce a sperm sample’. As we have seen, South Asian, especially Muslim, men are perceived to have greater difficulty in banking a sample, due to religious proscription against masturbation. It was also assumed that a lack of experience leads to poor success rates and that, often, they have to be accompanied by their wives. However, some professionals acknowledged that

‘white’ patients could also want their partner to accompany them or have difficulties in producing a sample.

Second, the archetypal ‘Asian couple’ are perceived as acting in response to pressures of a pro-natalist culture, rather than as individuals desiring and interpreting notions of an ideal family. Some professionals drew on beliefs that South Asian women, in particular, must keep producing children until they have sons, resulting in large families. This raises the possibility for professionals that women might be forced to undergo fertility treatments, even if they have sons, to carry on having more children or even under pressure to produce a daughter. One of the fertility nurses taking part in a focus group discussion referred to one of the couples she was seeing, who already had two sons and the woman ‘was made’ to undergo IVF: ‘just because she hadn’t ‘fallen pregnant for a couple of years’. Apparently, the mother would force her son to divorce his wife if it did not work and she did not get her granddaughter.

A third set of assumptions focused on how ‘Asian’ parents of younger patients tend to be over protective and insist on sitting in on consultations which can be difficult in terms of focusing on the patient’s needs and discussions on fertility, sexuality and issues of body image. As we have seen, however, this can be a general problem. On probing, professionals recalled similar examples of white parents wanting to continue to sit in on consultations which led them to reconsider whether such actions reflected changes in parent-child relationships associated with the shared cancer experience rather than culture.

Fourth, some professionals assumed that ‘Asian’ patients tended to be secretive in sharing information about storing gamete(s), fertility analysis or undergoing fertility treatment with members of their families including their own partners. As suggested earlier, a perception of a ‘culture of silence’ was raised several times in our professionals’ accounts. When probed, professionals accepted that ‘white’ patients/couples did not like to tell everybody in their family network about these issues and information was shared selectively, given notions of emotional proximity and privacy.

The desire for privacy, privileged within the wider 'white' culture tended to be interpreted as *secrecy* within the context of patients of South Asian origin.

Finally, the process of finding a marriage partner in South Asian groups was perceived as a standardised family decision, excluding notions of individual choice and romantic love. Strain or breakdown of conjugal relationships due to infertility of a partner in the case of 'Asian' families and (Asian) men being less supportive of women having trouble in conceiving is attributed to culture. However, once more and when probed, examples of white partners breaking off relationships in a similar situation also surfaced in professional accounts (see above). For example, one of the professionals mentioned the case of a white man whose fertility was affected by treatment related to cancer, though he had a child from a previous relationship. He broke off a long term relationship with his partner under pressure since she was very keen on having a child using donor insemination. Neither her desire to have a child nor his inability to 'get his head round' donor insemination were attributed to pro-natalism or 'culture'. However, in another circumstance, an 'Asian' man refusing to let his wife use preserved embryos from a previous relationship was easily attributed to both personal and cultural reasons. In contrast, 'white' couples whose conjugal relationships and romantic notions of love come under strain due to issues of childlessness in the long term are attributed only to personal factors rather than culture. This as we have seen was an important and general concern of many professionals.

In summary, different professionals work within different explanatory frameworks in dealing with ethnic and cultural diversity. While some generalised for a whole ethnic group based on one incident taken out of context, others recognised that professionals often focused too much on the religious/cultural background of patients from minority ethnic communities, not recognising the role of other influences or individual choice. For example, the accounts of professionals suggest notions of fatalism underpinning the attitudes and health related behaviour of people from South Asian families still endure, with some professionals having little insight into the complexity of sets of beliefs that might provide legitimacy for an individual decision or life situation.

Despite anecdotal references to South Asian patients refusing treatment or parents preventing their children from having any discussion about fertility that might jeopardise their chances of an arranged marriage, there seemed little to substantiate inferences that such behaviours were widespread. The reflective account of one adult oncologist, who engaged with diversity more critically, illustrates this. In her long career as an oncologist, she remembered only three cases where a patient refused to have treatment. The first was a young Bangladeshi woman who initially refused treatment since she was concerned about her fertility but then agreed to having chemotherapy following a relapse, which made her see herself as seriously ill. Even though she was not able to have children, she went on to be happily married, defying the contradictory perceptions of an 'Asian' infertile daughter/wife'. The second was the case of a Muslim man who was seriously ill and believed that this was Allah's will. He, therefore, declined more treatment. The oncologist went out of her way in search of an *imam* within the local community to learn more on the issue. The young man's conversation with the *imam* convinced him that refusing treatment (under the circumstances) was contrary to the teachings of mainstream Islam (being Allah's property, it is a duty to preserve life). The third was the example of a Catholic woman facing a similar situation who believed that she did not need to go through further treatment and wanted to go home. Such examples serve to underline the complexity of individual responses, while also reminding us that sensitive, culturally appropriate practice is possible.

CONCLUSION

Chapter three presented the accounts of health and social care professionals, combining material from focus group discussions and individual interviews. We have deliberately located our analysis in the process of service delivery, so as to reflect the realities of practice, as faced by health and social care professionals and to reflect how 'ethnicity' is negotiated within it. Professionals have to navigate many tensions in offering support to those who experience fertility problems following a diagnosis of

cancer. Much of these tensions reflect dealing with uncertainty, which includes uncertainty about disease progression as well as potential effect on fertility. Professionals also raised tensions arising from the need to prioritise treatment of the cancer, while keeping options open regarding fertility. More generally, uncertainty could sometimes explain the re-active strategy adapted by those professionals who waited for individuals to raise questions before responding to them. A lack of confidence among professionals, inappropriate service contexts and a feeling that they needed to offer hope, often militated against a more pro-active approach. Professionals to their credit have insight in to this. They were equally aware of the tension around facilitating choice, sometimes feeling the need to get the patient to come around to their point of view, especially when discussing cancer treatments. Professionals also relied on their own personal experience and sense of morality, when presenting fertility options. To this extent it was difficult to determine the extent to which their advice was informed by evidence based guidance.

Compared to professionals' concern to get across the general struggles they faced in offering care to those with fertility problems following a diagnosis of cancer, ethnicity was often introduced as an aside. Gender, for example, was seen as a far important consideration, as was life course. When ethnicity was discussed it was often in terms of generalised assumptions, informed by a sense of homogenous communities, in addition to a strong sense of minorities being the 'other'. When probed, many of the difficulties faced by patients, which professionals attributed to 'culture' occurred irrespective of ethnicity. Professionals could interpret similar responses very differently according to the cultural and ethnic background of the patient. This mediates many of the themes identified in the previous paragraph. It is also perhaps why, some professionals felt ill-equipped to respond to the needs of a multi-cultural society and why certain contradictions emerge in how they respond to ethnic and cultural diversity. The next chapter picks up on some of these tensions highlighted in our analysis of professional accounts, by focusing on the experiences of participants affected by treatment related to cancer.

CHAPTER FOUR: THE ACCOUNTS OF PARTICIPANTS WHO HAD UNDERGONE CANCER TREATMENT AND HOW THEY NEGOTIATED POTENTIAL THREATS TO FERTILITY

We now turn to the material and the experiential domains of cancer and treatment-related threats to fertility, by exploring the lives of those directly affected. This analysis reflects some of the tensions outlined in the previous chapters, although as we shall see individual accounts reflect different priorities to those outlined by health and social care professionals. Our first section provides a glimpse of how treatment related to cancer pre-empts biographical disruption by making fertility an uncertain domain in the lives of the participants. We then explain the gendered nature of these threats and so called choices related to 'fertility preservation' including the ethical or religious dilemmas it might pose, before moving on to how participants use different explanatory frameworks to engage with the dialectics of uncertainty and hope. Finally, we look at the different scenarios of the long term impact of treatment, especially where the uncertainty has been resolved - one way or the other - and how participants engage with the possibility of using NRTs to help them have a child, with a specific reflection on the role of gender, religion and culture in making sense of these engagements.

BIOGRAPHICAL DISRUPTION, TREATMENT AND THREATS TO FERTILITY: CHOICES CONSTRAINED BY GENDER AND TECHNOLOGY

The contributions of social scientists to our understanding of socio-cultural underpinnings of living with and beyond cancer remind us of the liminality of the concepts of recovery and remission (Sontag, 1991; Frank, 1995; Stacey, 1997). In Frank's 'remission society', everybody lives with what Sontag (1991) describes as two 'passports': one to the world of sickness, the other to well-being. There is no return to life prior to having cancer, partly due to the symbolic associations of cancer with pain, death and dying (Seale, 1998), and partly due to the materiality of the condition itself, including the symptoms, side effects of often painful treatments, irreversible loss of

function (such as fertility) or body part. In many ways, the interpretation and negotiation of potential threat of childlessness by participants in our study is foregrounded by their individual experience of cancer.

This is why treatment related to cancer pre-empts a biographical disruption (potential childlessness) that may or may not happen, given the uncertainty about potential impact of treatment on fertility for men as well as women. As noted in the previous chapter, some oncology professionals are very careful in emphasising that while there is a certain (high or low) risk to fertility with a particular high/low dose chemotherapy or radiation to certain parts of the body, they can never be certain about individual outcome and more generally, struggling with uncertainty is a defining feature of their role, as it is with other professionals. To recap and as noted by one of the specialist nurses taking part in a focus group discussion:

Also the other problems are that we never, you know, there are a percentage of patients who will still have their fertility after they have had chemotherapy. And it is very difficult to get across to the patients because you don't really know who's going to be lucky and who isn't. (specialist nurse, Oncology)

Further, one of the oncology professionals, in response to how she explained the risk of infertility to her younger patients with breast cancer, replied that they always take a social history to find out whether a patient is in a relationship and has children (see previous chapter). She remarked how she and her colleagues had to be cautious in response to specific questions raised by patients, since they do not have a definite answer. A majority of our participants who had undergone chemotherapy or a combination of chemotherapy, surgery/radiotherapy said they were told about potential impact of treatment on fertility as part of the discussion on treatment and its side effects.

Only one woman did not recall what or whether she had been told about the issue of fertility, even though she was in her late teens at the time of treatment. She remarked, however, that it was likely she had blocked out details from her memory particularly

since she remember being 'very upset' on hearing her diagnosis. Her mother had to console and persuade her to undergo treatment. Her mother (interviewed on the participant's invitation) recalled that the doctors had mentioned threats to fertility. In fact, it was the grandmother who had emphasised the need to discuss whether it was possible to freeze eggs or embryos. It seemed that the doctors had suggested that given her age (and kind of treatment) her fertility should not be affected.

Apart from the severity of the condition and type of diagnosis, treatment associated with cancer (chemotherapy and radiotherapy/ surgery) brings teenagers and young adults face-to-face with profound questions of life, procreation, and death, and potential 'forced choices' or 'non- choices' as suggested by Franklin (1998:108) within the context of both preservation of gametes (often 'sperm banking', a more appropriate term than 'preservation') as well as future reproductive technologies. A majority of men in our sample had been given the option of sperm banking. At one end of the spectrum we had three ('white') participants who were diagnosed and treated during childhood and did not have the option of sperm banking. One of them, now in his late twenties, was only eight years old when diagnosed with lymphoma. He said that even though he always knew that his fertility might be at risk (through follow up sessions with his oncologist), he was not able to make much sense of it until he was 20 and met his now partner. Their relationship had been clouded by this issue for a while. He had hoped that they might be able to retrieve some 'sperm cells' until he had a fertility test a couple of years ago that suggested otherwise. Despite knowing for years that it was a possibility, he still felt devastated by the news.

The second participant, now in his mid thirties and from an Irish-Catholic background was in his pre-teens when diagnosed with testicular cancer. He had a traumatic time dealing with his delayed physical maturity, sexuality and potential threat to fertility and felt that his whole teenage years were dominated by a fear and inability to form stable relationships. Like others in his situation, he felt strongly that even though you finish treatment and survive, apart from the fear of recurrence, the scars of the treatment remain with you forever. These scars are both real and symbolic and

especially marked for those whose 'fidelity of the body' (cf. Kleinman, 1988) in relation to fertility is questioned and remains uncertain for a prolonged period of time. Even though he had been offered psychological support and counselling later on, he had refused since he believed that it was meant for 'people who are weak', until he realised that apart from spiritual help from the priest, he needed professional help. Towards the end of his interview, he suggested that professionals need to present counselling in a more positive manner, as something that might help them deal with issues in future, even if young people did not feel the need for such help in the present. Interestingly, even though his teenage years were overtaken by fears about his sexuality and fertility, he did not know for certain whether or not he would be able to have children. He had been actively discouraged by his previous oncologist from having a fertility test and advised to wait until he was in a stable relationship. This apparent recognition of the social context of fertility by the oncology professional is especially interesting (see previous chapter), since they may have reasonably anticipated their advice would leave open a window of hope open, a potentially important discursive strategy in resisting a narrative closure (Giddens, 1991): although such professional responses could also, of course, reflect a defensive strategy designed to minimise the difficulties they face when trying to raise potentially contentious and emotive subjects. Our participants, for their part wanted both hope and a definite answer which, of course, generates obvious tensions, particularly since the need for one over the other, can change over time and circumstance.

The third participant, again in their mid thirties, was 16 when diagnosed with Hodgkin's lymphoma. He had not been told about the potential impact of treatment on fertility or given the option to store a sample. He believed that his parents had colluded with the professionals and prevented such a discussion from ever taking place. He had been quite upset, especially since he had been denied an opportunity to bank sperm. This is interesting since he was in his mid teens at the time of diagnosis and the only participant whose (well educated) parents, he believed, had intervened in this manner.

At the other end of the spectrum were a majority of men who were advised and had 'chosen' the option of sperm banking irrespective of age, religious or ethnic background, being single or in a relationship. This challenges the assumptions reflected by professionals in our sample about the difficulties faced by South Asians/Muslim men in 'producing' a sample due to religious taboos on masturbation or lack of experience. As expected, while men across the board agreed that the process of giving a sample was embarrassing, they did not narrate horror stories (as suggested in some of the literature and accounts of our professionals), although a preference for men rather than women nurses would have made it easier for some. Most men seemed to have reconciled to the need to store a sample and went along with the instructions as a clinical procedure, overcoming the awkwardness of the act by redefining it as part of the treatment process. Most felt that the staff at the fertility unit explained things to them and helped them fill in the consent form, though some felt that it was assumed that they knew 'what they had to do'.

One of the participants, however, felt so humiliated by the whole process that he left without giving a sample. It needs to be borne in mind that his experience dated back nearly ten years, when sperm banking services for cancer patients and links between oncology and fertility services were less well developed. Moreover, this participant had generally had a bad experience during his hospital stay and lack of access to appropriate support thereafter, reflecting complex features of a life lived on the edge of unemployment and poverty perpetuated by the long term social and emotional consequences of treatment related to cancer. While his oncologist wrote him a supportive letter to help him find social housing, he relied entirely on the emotional and practical support from his partner and mother. The couple had a young child at the time of his diagnosis, lived an hour's bus journey away from the hospital and they did not have support from social work, hospital or primary care services. To make things worse, once he moved house, he was lost to follow up care at the hospital. The following summary of the joint interview with his partner provides a glimpse of their story.

Algar, who was in his late twenties, grew up in a large family, raised by a Catholic mum, after his parents had separated. Despite not being to church 'in years', he still regarded himself as part of his mother's supportive Catholic community and has aunts and cousins who live in Ireland. He always wanted children and a big family since everybody he knew had large families. He was until recently, unemployed following his illness and lives in a rundown council estate. He has a son and his partner is a Muslim of North African origin. He was diagnosed with Hodgkin's lymphoma in his early twenties and was treated on an adult ward where everybody was more than 20 years older than him. He had been told that the high dose treatment he would receive would 'most certainly' affect his fertility. This was a shock to him even though he already had a child. Against this backdrop, he felt that the whole experience of trying to bank a sample was humiliating. He recalled how he faced a group of nurses who were inappropriately 'chatty' (he felt in an attempt to cover their own awkwardness) and least helpful when he was still in a state of shock at his diagnosis and not being able to have any more children. His partner recalled how unprofessional they had been:

Partner: It was just the way they came across. They were laughing while talking to [him] about it and obviously it's a very sensitive topic anyway. They were laughing a lot, weren't they? Making a joke about it, saying if you need a hand...and laughing.

Algar: And then I was sent into a cupboard with their boxes of stock and I was just stood there, oh sod this and we just left...That was humiliating for me. I thought no, I ain't doing this.

(He did not complain since he did not want to talk about it with them as he was upset by it. He felt there should have had a man there, someone who could empathise with his situation.)

Algar: Yes. That would have made it a lot easier and a lot less awkward. Because when she was talking to me I felt so awkward to even ask questions if I didn't understand things.

Nobody had raised the issue of fertility again, except the nurse they met at the time of chemotherapy. Algar regretted that he wasn't able to bank a sample and achieve his dream of having a large family. It affected his confidence in himself and following his treatment was depressed and according to his partner, would not go out or meet friends.

Dilemmas of preservation: religion, culture, gender

Four of the participants of South Asian (two Pakistani and two Indian) origin had not been able to bank a sample. The two of Pakistani origin were Muslim, the third (Indian origin) said that he did not follow any religion, though he was from a liberal Muslim family and believed in God, and the fourth was from a Sikh family (Indian origin) though he himself did not follow any religion. None of these four provided a religious explanation for not banking a sample. Each had been seriously ill and in severe pain around the time of diagnosis and had gone through a particularly difficult time due to advanced disease before and after treatment.

One of the Muslim men of Pakistani origin said that he was offered but declined sperm banking since they had two daughters and did not intend having any more children. This is not to deny the social and symbolic significance of having sons within South Asian communities (across both the religious and ethnic divide), especially given a normative expectation that sons will care for ageing parents, while daughters' obligations are towards their parents-in-law. Nonetheless, it illustrates the problems of adapting cultural stereotypes and the complexity of incorporating ethnicity in practice. Retrospectively, the two Muslim participants reiterated that there were no religious injunctions against banking a sample within the context of treatment related threat to fertility, especially since it was intended to be used by the men/couple themselves (a therapeutic cause, rather than for erotic pleasure). One, for example, said that he didn't need to consult a scholar since he was a devout Muslim and knew right from wrong. One of them explained that, within the therapeutic context, the status of the act (masturbation) is proximate to *coitus interruptus*, where the sperm is stored for later, personal use.

Interestingly, while storing a sample did not come across as a contested issue, the use of stored gametes involving a technological procedure (usually IVF or ICSI) was a different issue, where some Muslim men felt they would need religious advice from a

learned person or a *maulvi* (a religious scholar who can interpret textual and customary sources of personal law). This is in sharp contrast to perspectives of Muslim participants on use of donor insemination (DI) which was considered a *gunnah* or *haram*, a transgression or breach of the conjugal relationship involving another man's biogenetic material and symbolising sexual contact by contiguity. During interviews we were provided with elaborate explanations regarding how the notion of *nasal* (lineage and descent) was central to identity within Islam, and the significance of knowing your parentage in order to avoid incestuous relationships.

Needless to say, not all Muslim participants engaged with the religious implications of these options in a consensual manner, often reflecting inconsistencies and dilemmas that are hard to reconcile at an abstract level of hypothetical situations; a theme well covered in the wider literature (see for example, Daniels and Haimes, 1998). One, for example, was not comfortable about the whole process of freezing sperm and having a 'frozen baby' on religious grounds. He and his wife (recalled from a shopping trip to join us towards the end of the interview) had a subtle disagreement on what is allowed/not allowed in Islam within the context of use of NRTs. They had a young daughter when he was diagnosed and another a year after finishing treatment. With hindsight, he said that he went along with the option to freeze sperm, despite his reservations, since his wife was keen on having more children (hoping for a son). Religion was important to him, but within this context he would acknowledge his wife's desire. He was happy to have two daughters and felt that they should withdraw consent for storage. His wife, however, was not ready to make that move given the uncertainty about his illness. They both said that they would be happy to donate the sample to anybody in need (or for research): a position that seems, at one level, contrary to the logic of third party donation and norms of conjugality within Islam. Whether this couple would have used the frozen sperm if they had not been able to have another child naturally, despite their (ethical/religious) reservations remains a moot question.

The moral boundaries of the use of NRTs will be negotiated differently by individual couples within any religious or cultural group, depending on personal circumstances and interpretations of a religious framework as an ethical guide for actions (see Atkin et al. 2008 for a similar discussion around faith and termination). Further, a gendered response to sperm and egg donation cuts across cultures, as noted in the background, although for some these explanations can come to have particular religious moorings. Naheed a Muslim woman of Indian origin, in her late twenties, said that she was not sure about the status of sperm donation and if faced with the prospect, would have consulted a *maulvi*. However, she also mentioned that her sister (who was married) had offered her eggs at a stage when it seemed likely that she may not be able to have children of her own (following treatment for Lymphoma when she was in her early twenties, although she eventually married and had a baby). While such offers within the close family reassert a feminine bond across ethnic groups, like other women, Naheed realised the complexity (and messiness) in family relationships such an exchange could involve. Participants across the board also recognised that when faced with a 'real choice', their answers to a hypothetical situation might change. We explore this further, when we later in this chapter discuss women's' experiences on the (lack of) options related to preservation and the potential impact this might have on their lives and relationships.

The dialectic between uncertainty and hope: a testing ground for relationships

The dialectic between uncertainty and hope is central to our participants' narratives, contrary to the insistence of some of the participants that they would much rather know for definite whether or not they were fertile; a tension already familiar to us. This dialectic hinges on both analytical (medical) and experiential explanations (see Webster, 2002: 106) mediating the meaning of risk within the context of significant relationships. Gender plays a significant role in these negotiations, given the materiality of women's body and menstrual history and often the intertwining of notions of fertility and sexuality for men. As recognised by some of the professionals,

uncertainty leaves a window of hope open, and this can be a significant discursive strategy for dealing with the aftermath of diagnosis and treatment, and moving towards the (perceived) five year mile stone of survival/remission on the part of professionals and our participants.

In exploring this dialect further, we present four case studies, which reflect the complexities of people's lives. They illustrate how people re-interpret threats to fertility and options within the context of significant relationships, while gendered and individual interpretations informing expectations of an intimate/conjugal relationship mark differences within a culture, sometimes resulting in strain or breakdown of relationships or in extreme cases, pre-empting an inability to develop serious relationships. This, however, is not inevitable, and many of our participants who faced uncertainty regarding their ability to have children, were able to form and continue intimate relationships, leaning on different cultural scripts to deal with the uncertain (religious, medical, philosophical).

Indeed, having a more definite (medical) answer may not be convincing or acceptable to some participants, irrespective of their desire to know. Ron, in his late twenties, who was engaged to someone he knew prior to his diagnosis four years ago and who had banked several samples prior to treatment, had gone back for a fertility test, even though his initial test was negative. He hoped that things might change, since he had been told that it might be a while before things 'get back to normal' following treatment. George, in his mid twenties, who was not in a relationship, had decided to undergo a fertility test since he had been told by professionals that it was likely that his fertility might be affected. Even though his test was positive, he said that he would have another test when in a 'serious relationship', just to make sure, before he withdrew consent for storage. For others, having banked a sample is only partial consolation in the face of other disruptions that might follow treatment. Javed's story illustrates this.

Javed, was in his early thirties, from Gujarat in Pakistan. He was diagnosed with a sarcoma in his early twenties and underwent surgery, chemotherapy and radiotherapy. Treatment had left him severely disabled, in chronic pain, sexually impotent and, not surprisingly, clinically depressed. He had stored a sample before starting chemotherapy and radiotherapy, even though he was told that the chances of his fertility being affected were low. However, given his concerns about his sexual function, he had a fertility test. This had been negative and came as a shock. He had given up on the thought of pursuing a prospective match (a cousin in Pakistan) and lost hope of ever finding a partner; not knowing how to disclose his problems if he ever met someone. The sample that he had banked was of little consolation to him, since it was not only his fertility but also sexuality and manhood that were compromised. He had heard friends who had difficulty having children remark:

The women will say this to you (generic), 'you aren't able to make babies. You can't give me babies ...you are no man any more'. No point saving one's life, if the life that is left is like that of an animal. (Javed)

It is important to mention that men – irrespective of ethnicity - who already have children from a previous relationship, might still bank a sample, recognising that having children might be significant for a future partner. However, others use the uncertainty about their ability to have children as a testing ground for relationships to see whether it is strong enough to last for its own sake rather than for the sake of procreating (reinstating the romantic notion of love and a modernist notion of conjugality freed from the traditional role of procreation). In an extreme case, Rahul, now in his mid-thirties who was of Indian origin from a Sikh family (although he followed a form of spiritualism rather than Sikhism), broke up with his (Punjabi) girl friend as a consequence of different expectations about their relationship. He had been diagnosed with testicular cancer over ten years ago and had stored a sample before treatment but was told that his sperm count was low and would need medical help with having children:

After I had the treatment, I think it must have been just a few months afterwards, I met up with somebody and we were going to pursue in order to get married and then I was completely honest with her about my low sperm count. So she had second thoughts and she wanted to meet the doctor and have a discussion. (Rahul)

However, his partner wanted him to undergo a test. He was upset by this pre-condition and broke up with her, recognising that both his sexuality and (sub) fertility were at stake. He did not want to marry someone just to father children, although he very much would like to have children. In fact, he was so upset by the incident that he withdrew consent for storage and asked for the sample to be destroyed (an act of emotional outburst rather than a logical conclusion of the relationship itself). As he reflected:

Yes, and the thing I was bearing in mind was, the girl who turned me down. And I thought I'll meet somebody (for) whom this is not a really big issue, as in having children. (Rahul)

It is interesting to note the similarities in Rahul's position with how Adam reflected on his previous relationship. Adam, a 'white' man in his early thirties, was diagnosed with non-Hodgkin's Lymphoma two years ago, while living with his previous girl friend. He had banked a sample, naming her on the consent form as someone entitled to use the sample posthumously in case of his death. Though Adam was keen on banking a sample and had clearly contemplated having children in future, he was not ready for fatherhood. His girl friend, however, was more anxious about the future and keen to have a child soon after treatment. This resulted in Adam having a fertility test only six months following treatment, which was negative, causing a lot of angst and a premature internet search for information related to fertility treatment. His girl friend's anxiety about his probable death, and desire to have a child to remind her of him, brought Adam face to face with his own mortality; something he had not openly acknowledged (despite giving consent for posthumous use) and resulted in an eventual break-up.

Charandeep, a man in his late thirties, of Indian origin worked in a factory prior to his illness. He had spent most of his life in and out of hospitals, recovering from surgeries and treatments ever since he was diagnosed with testicular cancer, over 15 years ago. The cancer had now spread. Charandeep had a biopsy (and a fertility test), when first diagnosed and was told he had 'no sperm count'. This in itself was not an issue for him since he was never keen on having children anyway. He was more concerned about never being able to get back to work or develop a relationship. While his mother, brothers, uncles and aunts never put any pressure on him to marry, his friends had suggested that he should marry and adopt a child. Considering he did not want to have children, though he would have liked to have a partner, he concentrated his energy on developing a pragmatic and self-reliant attitude of a 'survivor'. As he very poignantly concluded, 'It has been all over me. Every time it comes back, I have to have more treatment'. In many ways, he defies the professional perceptions of an 'Asian family' wherein 'arranged marriage' and desire for children is taken so much for granted.

In contrast, although with some similarities, Anne was a white woman, Christian (CoE) by faith, in her early thirties whose early life, education and career had been interrupted by a series of difficult events and decisions related to a diagnosis of lymphoma when she was a teenager. This included recurrence and the long term impact of various treatments including stem cell transplant. Anne had developed a good relationship with her oncologist, feeling she had an 'insiders' knowledge of her disease. Around the time of her first recurrence a gynaecologist had explained the high risk to her fertility (at diagnosis, there had been no discussion) and her increased chances of going through a premature menopause. There was a possibility of 'removing and freezing an ovary', though she was told that the technology to use it to have babies was not available at the time. She had to reckon with the possibility of facing menopause and osteoporosis, while still being in her late teens. Anne and her parents had to make a quick decision about preservation of ovarian tissue route, given the concerns of the haematologists about delaying treatment. She decided against preservation, given a mix of complex issues:

So it was a very difficult juggling choice of OK, well I may die anyway. And we knew that. So did it matter if I couldn't have kids? So there was this sort of, a lot of underlying things intermingling with one another and I could have done with probably a week to get my head around it, and maybe ask her the questions. (Anne)

Anne was in a relationship at the time, although she felt it was not strong enough for her to discuss her dilemma with her boyfriend:

I was (in a relationship) but he [was] off as soon as the cancer turned up. He couldn't deal with it; it wasn't a long term one as such.

A year after her stem cell transplant, Anne suffered menopausal symptoms and had to take hormone replacement therapy (HRT). The implications of not being able to have children made more sense to her, once she had a discussion with the gynaecologist about egg donation and other options:

I wasn't in a relationship but there's still that, the implications of me realising actually if I do find someone then I'm going to have a huge thing to tell them and when do you do that, do you do it straight off, do you do it when you're sure the relationship's going somewhere. I didn't know, and how the hell do you do it? How do you tell someone?

Anne specifically mentioned later how she didn't go out much and was wary of men and physical relationships:

I think 'cos I was, you know, wary of blokes I suppose, knowing that there might be problems...'cos I get, you think well if I go to a physical one then at some point he's going to talk about children. You know, how do you turn round and say to someone, 'Well, actually I can't have children', and it could wreck everything.

Now her close friends were marrying and having children, she felt subtle social pressure to settle down:

“Oh, you know, when are you going to have children?” And you sort of think, well I’m not, you know.

Anne had even contemplated egg donation, something that brought her some hope:

And then I sort of had a vague bit of hope ‘cos my cousin has always said that she’d, she had a long conversation with her husband and has always said that she would give me some of her eggs if it came to the stage where I needed IVF.

At the same time, her hesitancy in forming intimate relationships and the desire to have children was further complicated by the doctors trying to discourage her covertly, she felt, against the idea of having children:

But I think, also I think with my long-term health I probably won’t ever have children, I have been told it’s probably not a good idea by the doctors here...I’ve got a lot of health issues and they wouldn’t obviously want any of that being passed on, they don’t know whether it could be passed on.

She was explicitly asked whether it was ethically right for her doctor to make that suggestion or decision for her:

If it damages me to the point I’d be in a wheelchair then yes, and I’d much rather know and have an honest opinion on it. It’s still my decision but I think you have to know the facts, and I’d much rather they were honest with me....

Under those circumstances, she would consider adoption.

Dilemmas thrown up by the process of consent: culture and the meaning of quasi conjugal relationships

The process of consent surrounding preservation of sperm, eggs and embryos locates the potential biographical disruption of infertility within wider cultural scripts of pro-natalism, appropriate parenthood and ‘best interests of the child’ on the one hand, and death and rights of (potentially) terminally ill individuals to have children on the other,

even though posthumous use of gametes with prior consent is accepted in law. As we have seen in the previous chapter, professionals engaged with these dilemmas at different levels. Apart from participants having to contemplate their own death within the context of procreation (rather than simply a result of cancer), this also leads to questioning the nature of partnerships/conjugal relationships leaning on individuals' engagements with various cultural scripts.

At the same time, in contemplating 'choices' related to preservation and possible use of NRTs, these engagements also reconstitute notions of romantic love, conjugality, commitment and reciprocity, while often testing the strength of a relationship in the face of adversity. We had a glimpse of these issues in some of the previous case studies. The complexity of changing consent if or when one of the partners leaves highlights some of these tensions further. It is hardly surprising to note that while some relationships endure, others break down under the stress: an outcome negotiated individually in relation to, rather than determined by, a particular set of cultural codes or 'pro-natalist values' underpinning a particular ethnic or religious group. Some of these tensions were as we have seen recognised by professionals and are best captured in one of the focus group discussions, leading one of the nurses to remark:

Sometimes I will sit in a consultation and the boy friend or husband (of a woman undergoing cancer treatment)...and they will say, 'Oh don't worry about it, I'm not interested in babies. Honestly, I just want you to be ok'. And, you know, inside you are thinking, 'Oh, just go and speak to somebody' ...that is a personal (choice). But then it is amazing in the long term when you follow these patients...for four/five years and they've split up...But it's not because the service (preservation/ACU) hasn't been available to them, it's not because it hasn't been addressed (the issue of potential infertility)...I find really hard to sometimes address. Because, you know, you don't want to shed doubt on people's relationship. You don't want to look judgemental and you don't want to pass on your opinion (or force the 'fertility agenda' on women). (Oncology Nurse Specialist taking part in a focus group discussion)

The dilemma posed by the prospect of preservation and consent for the other partner is well summarised by one of the fertility counsellors in her interview:

And what's interesting, I think, the partner, the person who hasn't got cancer, is in a real predicament actually because, you know, they may not be wanting to have children, they may not, you know, be thinking this is a long term relationship and now they're forced to think about something, this hugely mature thing. (Fertility counsellor)

This is not the space to argue whether this 'lack of commitment' in adult/sexual relationships can be construed as part of the wider culture, rather than individual choice. What is important for our discussion, however, is to recognise how a threat to fertility can cause strain on this romantic ideal of love (not premised on a notion of conjugality tied to procreation), leading to a breakdown of relationships. On one hand, the wider values within the majority white culture assume a fluidity of adult/sexual partnerships that can be easily dissolved without commitments of a traditional marriage. On the other hand, and perhaps paradoxically, the process of preservation of gametes and consent (i.e. nominating who can use the gametes in case the individual dies or is mentally incompetent) brings to surface an assumption about 'settling down' and having children together, hence assuming that the relationship will endure. Mark's story provides a good example of these tensions.

Mark, now in his mid thirties was diagnosed with testicular cancer ten years ago. He 'designated' his girl friend on the consent form without consulting her, though he told her about it later, thus transforming the relationship into a quasi-conjugal bond. He thought it would be nice to have a part of him living if he were to die, assuming that she would still want to have his child, posthumously. This is perhaps an extreme case of a man contemplating and transforming his own 'bad death' into a 'good death' through posthumous procreation (Simpson, 2001, p111). It also brings to the surface arguments related to statutory references concerning the 'welfare of the child' which underpin the HFEA guidelines, prompting some professionals in our study (especially within reproductive medicine) to have reservations about such cases of posthumous use. However, Mark's relationship was under strain following the illness and he and his girlfriend broke up. Mark eventually married someone else and changed the consent in favour of his wife.

Not only does the process of consent create transitory conjugal relationships which, in some cases, might continue to have a presence despite a break- up (as in case of divorce). For example, going back to Adam's story (introduced earlier), even though they had parted, he was still fond of his ex-girl friend and had not changed his consent, especially since his new relationship was 'nothing too serious'.

Given the complexity of the consent process when banking a sample, and the varying circumstances of individual participants, it is not surprising that a majority (of men) did not remember the details, having received help from the nurses in filling and signing the form. Shahrukh was the only participant who, despite being seriously ill and in severe pain, had tried but was not able to bank a sample. However, he still had to go through the process of consent and think about his life and relationship with his girl friend at the time. At that stage in life, he did not think 'relationships are forever' and had obviously not thought about settling down or having children with her. The consent process and questions asked by the nurses helping him fill in the form led him to evaluate the relationship. He finally decided that his mother was the best custodian in case he did not live, since he trusted her values and judgement completely:

But it's not something that's a formal agreement between me and her (the girl friend). So what is the, what are the ramifications of giving her this power? What if she never does use it? You know, what if she doesn't think of it as being very important? And, to be honest with you, anything to do with my future life, in this point in my life, being single, etc, I just give that control to my mum, without a question. It doesn't even deserve thought. (Shahrukh)

That was not a difficult decision to make and he did not discuss it with his mother. We reserve our judgement about the boundaries between choice and culture in the above response, especially since Shahrukh who was born and brought up in England, considered himself to be part South Indian and part British. Even though his perceptions of conjugal relationships had changed over time, he did not want certainty about his fertility (confirmed by a test) to become part of what he perceived as a 'prenuptial agreement', premised on a possible breach.

Women's experience of disrupted fertility: negotiating competing discourses on choice

Despite the emotional and symbolic messiness of the process leading to preservation of sperm, a majority of men are able to exercise a 'choice', recognised as a 'back-up' in case their fertility is disrupted by treatment. A majority of women, in contrast, do not have the choice and, in fact, might feel that they have been 'robbed' of a potential choice. As suggested in the background, the wider cultural discourses on infertility reconstitute women as active agents of choice and control over their 'reproductive fate' (see Giddens, 1991), assuming access to (competing sources of) information and technology to do so (Calnan, 2007). However, we also noted that gender and technology, rather than religion or culture, restrict choices that women might have when preserving eggs or embryos, especially if they wish not to jeopardise the pace of their treatment schedule.⁴ Further, since preserving embryos have a better success rate of having a live baby than preserving eggs or ovarian tissue, the choice is further limited for women who are not in a stable relationship at the time of treatment. This was not a salient issue for some who had not thought about having children or had made a choice to be without children. For others, however, irrespective of age and being or not being in a relationship, these concerns marked a major rupture that could not be easily healed. Some of the women felt that the initial discussion about the impact of treatment on fertility, coming at a difficult time, was rushed and that while they understood the concerns of the doctors to avoid delays in treatment, they would have liked some time, even a day or two, to think the issue through, and discuss it with close family/ partner/ spouse and weigh the options with a fertility specialist. To a large extent, the kind of diagnosis, site, spread and progression of the cancer itself determined the pace of treatment and nature of discussions surrounding preservation for women. This partially explains why two of the women with different diagnoses,

⁴ Preservation of ovarian tissue is not yet a common practice in the UK and licences from the Human Tissue Authority are further restricted as a result of the European Union Tissues and Cells Directives 2004, introduced in 2006.

treated around the same time, had completely different experiences regarding the advice on threats to fertility and preservation options.

It is important to note that all four women who had been offered an option to freeze eggs/ovarian tissue/embryos were treated at the same treatment centre. However, two of the younger women, who were in their early and mid teens, when first given the option of preserving eggs, were eventually not able to do so. Of the other two, who were older and in stable relationships, one was able to preserve her eggs and the other embryos. Susie was 19 and at University when she was diagnosed with Hodgkin's lymphoma that had spread to her lungs. She had been given advice on preservation at the time of diagnosis and had discussed the possibility of freezing embryos with her boy friend. Both had prepared themselves emotionally for a huge commitment at a relatively young age. She, however, decided to move back with her parents to have her treatment and was transferred to a specialist treatment centre in another city where her oncologist advised her to start with the treatment straight away. Transferring to another treatment centre was felt to have wasted valuable time and explains why Susie felt cheated out of preservation. Retrospectively, she appreciated the need to get on with the treatment to save her life. Like some of the other participants, lymphoma was a gentle euphemism that dulled the blow of the diagnosis, meaning she had initially under-estimated the seriousness of her illness.

At the first hospital, they were very good at providing Susie with 'loads and loads of information', talking her through the side effects of chemotherapy and fertility in detail and explaining the difference between success rates of freezing eggs and embryos. She said that fertility 'was a massive issue for me':

Because I really, really want children, it's one of the things I've always I can't wait to be a mum. So when I found out that it could affect my fertility it really did panic me. And (first hospital) talked about how I could freeze eggs and stuff, and I was only nineteen and obviously like having children then wasn't something that, you know (would have normally thought about).
(Susie)

She discussed the possibility of freezing embryos with her then boyfriend:

So I like, I went to (boy friend) and had this like big conversation with him at nineteen that *I shouldn't have really had to have about*, and he was dead good and said "Yeah, of course you can". But obviously then I was moved to (the other hospital) and...it was like out of the question. I was gutted because (first hospital) had said, you know "We'll be able to do this before you start your treatment" but then (second hospital) kind of [said no] (her emphasis, Susie)

Given what we know about wider cultural assumptions about womanhood and motherhood, those who were keen on having children felt devastated by the prospect of treatment robbing them of that chance. This was often exacerbated by the pace of consultations within which fertility was initially discussed and then not mentioned during follow up discussions, unless raised by the women themselves or the doctors in relation to periods/contraception. However, the manner in which information related to uncertainty surrounding risk to fertility was conveyed by the professionals and interpreted by the women was enmeshed in a set of complex emotional, interpersonal and physical factors (such as the history of cancer and menstruation). Often the expectations about 'choice' were located in the interpretation of experiences of significant others (family and friends) as well as popular representations of cancer and infertility, as the following case studies show.

Mary, who was in her mid thirties and in a stable relationship, was diagnosed with breast cancer, three years ago. She had surgery, chemotherapy as well as radiotherapy. Mary was upset that the oncologist was dismissive of her concerns about fertility, not even knowing whether she had children or not and rushed her through treatment; though like Susie she recognised the significance of starting treatment without delays. In response to her queries, the possibility of freezing eggs was mentioned but she was also told that results were uncertain, leaving her with the feeling that even though her treatment had been 'brilliant and quick', the focus on cancer and treatment was at the price of brushing concerns about fertility aside. Retrospectively, Mary knew from her friend's experience (who had insisted on a referral to a fertility specialist before treatment) that, in reality, there were not any 'options' but would have felt better if

someone had discussed the issue and given her some time to come to terms with what might happen. Further, the idea of 'freezing eggs' was reinforced from popular culture; a story that serves as a pervasive reminder of 'choice' and ability to control one's reproductive destiny:

It's funny because when you talk to your friends, and they say, 'Did you hear about Kylie Minogue'? or somebody else, they always go, 'Oh! Did you get your eggs frozen?' And you're like, 'Er, no I didn't actually. It wasn't an option'. And maybe if you get treated privately it's different, I don't know. (Mary)

Even though Mary's menstrual cycle seemed to be normal, she had been advised to avoid pregnancy until she completed five years of taking Tamoxifen. She was unsure about the impact of Tamoxifen on ovarian function (given what she had learnt from accessing information on the internet). Mary was also aware that by the time she finished the treatment, she would be in her late thirties and her partner in his mid forties. She was reluctant, however, to ask specific questions of her doctors:

Sometimes, I think, you don't want to hear an answer, so you don't ask a question for that reason, maybe. I think maybe now I've just resigned myself – who knows what's going to happen. It's more important that the cancer's not going to come back, isn't it? And if I'm able to have children then that's just a bonus. So I don't ask them, I just think well let's just wait. (Mary)

Living with premature 'ovarian failure': another biographical disjuncture

As suggested earlier, uncertainty leaves hope and can be central to discursive strategies for living with long term impact of threats to fertility and, at the same time, for subverting the biographical disruptions and narrative closures implied by the language of medicine. In the case of women, there is no definitive fertility test, though some women mentioned an ovarian function test (which they said was available in online shops). Professionals, for their part, were often equally reluctant to use terms such as 'infertile'. A nurse specialist explained:

I think, from sitting in some medical consultations, I can see where confusion does occur. You know, things like, 'You have ovarian failure'...'Your ovaries are likely not to function'...But they don't mention the word 'baby' or 'conception' or any of those things. But then I see my role...as, kind of, demystifying that bit and put it into context for the patient. (Oncology nurse specialist)

We shall now see how, a clearer message from a fertility specialist can, in fact, be potentially threatening; and how some women might subvert the attempts and authority of clinicians at imposing a narrative closure introduced by the notion of 'premature ovarian failure'. Following Good (1994: 119), we assume that hope is central to the subjunctive mood underpinning these narratives, allowing the story to have multiple endings.

Earlier, we had a glimpse of the impact premature ovarian failure had on Anne's life and her ability to develop relationships in the long term. She was one of four participants (three 'white' and one of Indian origin) who experienced symptoms of premature menopause. Each engaged with the signs of imminent infertility differently. Given the fear of her lymphoma returning, Anne seemed to have accepted her premature menopause as a trade off against survival, focusing on regaining some of her independence in life. Her approach was in contrast with that of Angie.

Angie was in her early twenties, whose education was disrupted, when she was diagnosed with lymphoma. The diagnosis also resulted in a break-up of her relationship. Her story reflects how a definite answer from a specialist marks a biographical disruption, even though it was not unexpected within the context of treatment. She felt that the oncologists had not told her what they *knew* about potential fertility problems and she had been *denied* information and the opportunity to ask questions and seek options, even though she had been offered a consultation with a fertility specialist before she started her chemotherapy. At the same time, her hope hinged on their lack of certainty about individual outcomes:

And as far as my fertility was concerned, that was discussed but I was told that the chances of it being affected were slim with this chemotherapy and it was more important to them to get my chemotherapy started than it was to do anything else. And I was also informed, I feel now, possibly, misinformed (her emphasis) but informed that it was far easier to freeze embryos than it was to freeze eggs and it wasn't worth going down that route. (Angie)

Initially, since Angie felt the risk to her fertility was low, she went along with the treatment without seeking an alternate, specialist opinion to discuss possible options of freezing eggs; a decision she later regretted. Events took an unexpected turn and she had a quick relapse leading to two more rounds of chemotherapy before a stem cell transplant. It is interesting that Angie did not seem to focus on the seriousness of her illness in her account, largely because she was so upset that the possible impact on fertility was never raised again after the initial discussion, despite her changing circumstances and need for further chemotherapy. The following excerpt from the transcript highlights her sense of shock at hearing a definite diagnosis of premature menopause:

When I had my transplant, they gave me a pill to stop it (periods) and then after that I just never had another period. I brought it up at every appointment I had. 'Oh, I've not had a period, I've not had a period yet'. And the doctor I saw every time just said, 'We hope it will come back. We'll wait and see'...So it ended up being a year basically. I turned round to the doctor and I said, 'Look, I've not had a period for a year and I'm worried about it!' And this was the first doctor that had sort of sat up and (did something about it). So then I had blood tests and that's when I got referred to the endocrinology unit and that's when it finally all started to be a little bit addressed...So I went to see an endocrinologist and that was a horrible experience, because they were just very matter of fact and *very blunt about it* (her emphasis). Well, that's a little unfair. One doctor in particular...the consultant was very matter of fact and very serious about it. However, I think because I got so upset, his registrar...after he'd left the room, attempted to go through things a bit better with me, which was much better. (Angie)

While trying to come to terms with this, Angie wondered why the doctors could not have sorted 'something out before it happened'. She felt the oncologists were perhaps not giving her a definite answer, using hope and uncertainty as a rhetorical device to

make her feel better. Yet, when the endocrinologist was serious and blunt, she was upset at his lack of empathy:

I do understand that my fertility wasn't the priority of a single doctor in the hospital. Their priority obviously is getting me better, is fair enough. But I just always felt that as a young woman, someone maybe should have recognized that and been able to talk me through at least over a longer period of day, rather than being dropped on me like a bombshell. Because I was always told, even when I was going through my stem cell transplant, it was still there's a chance that...It was never, '*there's a high chance*' (her emphasis)...people were probably trying to make me feel better... They never said, we hope it will come back, but it might not, you know. And they know that they're just probably trying to say the right thing, but really it's the wrong thing, because then when it's dropped on you, it's a big shock. (Angie)

The endocrinologist suggested that Angie could come back, when she was ready to try for children and they would see whether she had any remaining ovarian follicles that could be stimulated, while also discussing other treatment options. She was disappointed that there was no follow up plan or offer of emotional support to help deal with the transitional period, while she came to terms with her new reproductive status of 'premature ovarian failure'. Angie continued to have many unanswered questions and felt that having a conversation with a specialist nurse or being directed to any web based chat groups might have helped deal with the shock. Left to fend for herself, she found random information on the internet of uncertain validity. A friend suggested a support group for women in her situation. However, the information on their website related to generic issues of premature menopause, which she was not able to identify with.

For Angie, the biographical disruption caused by premature menopause altered her sense of priorities. On the one hand she had to reconcile the idea of going through premature menopause while on the other hand, she found it emotionally draining to think about the possibility of getting pregnant, and whether it would be a good or bad thing. Apparently conflicting sets of advice led her to believe that 'you can never be certain'. She considered having children to be the 'most natural thing in the world' for women to do:

You don't feel like a proper person. It's the most natural thing in the world and I can't do it. It's really awful, because obviously ... I do know that it's not my fault, but part of me starts thinking, 'Why didn't I put more onus on it in the beginning. Why didn't I push them on it?' Because it's not blaming yourself for it, like obviously it's not my fault; you have thoughts that you're not, like I say, you're not a real woman or whatever...I just really want to have children. And I really want them to be my children and what a failure you are. (Angie)

For others the onset of premature menopause was part of a different moral economy of self wherein having children was not central to a woman's identity, though the idea of going on HRT remained a shock since it transcended the boundary between generations and notions of an ageing self. The following summary of an interview with a British woman of Indian origin defies all the professionals' assumptions and stereotypes of the 'Asian family' both in terms of her life style and the choice to remain 'childfree'. Nimeeta was in her early thirties. Her parents had immigrated from Indian Punjab but had never been prescriptive about religion and culture. Her kin network was spread across continents with few distant relatives still living in the Punjab. She lived with her partner (who was white) of ten years, in an upper middle class suburb. They were a career-oriented couple who liked their freedom of not being tied down with children and led a lifestyle shared by some of their friends, her brother and partner's sister. Nimeeta was in her early twenties when she was diagnosed with cancer and had to undergo surgery and chemotherapy. Fertility was one of the first things the doctors had discussed with her:

Interviewer: And was there any discussion at all about potential impact on issues of, you know, having children in the future or...?

That was the first thing they did talk to me about, having the chemo, because one of the chemotherapy drugs would have made me infertile and, at that time, I think I was more concerned about just getting through it and getting through the other end. So, really, I just didn't think about having children, it weren't the first priority. (Nimeeta)

Nimeeta's periods stopped during the first cycle of chemotherapy and she felt her they would not recur. However, she thought her menopausal symptoms were part of the side effects of treatment rather than premature menopause:

I remember talking about HRT and I remember that being quite shocking to me (laughs) I remember that, and I didn't realise at the time what was happening to me. Obviously I was having menopausal symptoms and I just thought it was all because of the chemo (laughs) and just feeling rather run down with it all.
(Nimeeta)

She was referred to a gynaecologist who suggested HRT. She specifically asked the consultant whether her periods might return in future:

SC: So do you think, even at that point, you might have still hoped that probably it'll all change and come back to some kind of normalcy or...?

Nimeeta: No, I didn't, no. I just knew at that point, because, you know, my doctor had made it quite clear to me that I wouldn't. So I was pretty sure, no... I didn't have any mood swings and I didn't have any of the symptoms, except for hot flushes, and that's why I think it took me by surprise to have HRT, cos I thought, 'I don't need HRT! I'm all right (laughter) and when I did have HRT and they talked about, actually it's for the long-term because of your bones and weaknesses occurring in your bones that you need to take it now. I thought right, I do need to have this (laughs) the benefits outweigh anything else, so.

One of the main issues raised by the women is that initial discussions about the potential impact of treatments on fertility take place within a broader consultation prior to starting treating the cancer. As we have seen, this is an issue that finds various forms of expression in the accounts of women. Women felt there was too much complex information about the treatment regimen and its various side effects and very little time to understand the relationship between treatment and fertility. Most women would have preferred more time to reflect on the issue, seek advice from a specialist and explore the possibility of options for preservation. Moreover, advice on continued use of an oral contraceptive masks the unfolding of 'disrupted reproduction', particularly since women might think that they are being provided contradictory advice.

ACCESSING NON-MEDICAL SUPPORT

While a large proportion of care for participants (and hence our analysis so far) related to diagnosis, treatment and long term follow up, access and provision of social care was equally or more important for some. On the whole, younger women and men who were treated within a specialist teenage and young adult service (TYA) reported better non-medical and social support. The TYA service involved younger people (16-25 years) in various social activities, camping trips, workshops and conferences, providing access to information on specific kinds of cancers and related treatment. The young people had opportunities to make friends and socialise with others who were, or had been, in a similar situation to theirs. Susie (introduced earlier), for example, was very enthusiastic about the fun she had with her group at the hospital:

I went to a function at, with the (TYA) unit and it was just for young people and they had loads of people from all around the world, specialists come and talk to us and give seminars and this guy that was a fertility specialist came and talked to us and made me feel better. (Susie)

Another participant, Pam found the sarcoma group meetings organised by the TYA service very helpful. She met others who had completed their treatment and were now feeling better, helping her 'look ahead', at a time when she was struggling to regain her physical mobility and financial independence. She met another woman (now a close friend) who had designed a website and a blog which Pam found helpful to read:

Well she just writes down what she's been doing and how she feels and it's just nice to read, you know, someone else who's going through it and to relate to them. She was a bit ahead of me, because she didn't go on the trial, so when I had the extra drugs, she'd like finished. Because I had like an extra two months – so it was nice to look at her then and see her hair growing back and her saying, oh I've been out for a meal today and things like that. (Pam)

Pam was especially pleased to have an opportunity to go on a discounted holiday with some friends from the group. These friendships were particularly important since Pam, like other participants, had lost some of her previous good friends who did not know how to deal with her diagnosis of cancer during treatment.

Some of the participants had received significant help with benefits and housing, at a time when they needed it most and two had received a grant towards domestic bills from a national charity. However, participants whose working lives had been interrupted significantly and quite early in life too, suggested that more could be done to support people in seeking employment. Some of the worst affected seemed to experience particular struggles in getting social and psychological support. Asif (Pakistani origin in his late 20s), for example, was diagnosed with cancer, eight years ago. Even though he received excellent medical care and in his own words was 'brought back from the dead', he commented on the lack of social and financial support once he was discharged after a prolonged hospitalisation. His family and friends supported him emotionally during his illness but once he left the hospital, he had no qualifications or experience to find a new job. Eventually he left home, married and was homeless for a little while, without any financial support from the extended family, until he and his partner approached the local authority, to seek help with housing.

Where participants did receive emotional and social support from professionals, this was usually informal and from specialist nurses within oncology. For example, one participant, Wasim, emphasised the significance of emotional support for people who might have a young family and need to have a positive outlook. The person he found most helpful, apart from the oncologist who was a 'top guy', was the specialist nurse who visited him every day while he was on the ward. He remembered how she cancelled a previously arranged meeting to see him, when she heard that he had been readmitted to hospital. He remarked on how she was 'somebody you can trust your feelings with':

Doctors only give you more like a bang on answer. Right, that is what has happened. Obviously they save your life...But someone like [specialist nurse] who's got time to come and sit down with you, talk to you, you can express your feelings and you can open your heart to that person, look, that's what's happening to me. It's not that she helped me with money or anything, no. The

way she talked to me and the way she dealt with the whole situation...That's what you need more in hospital'. (Wasim)

Four men in our sample said they had a history of mental health issues. While one had developed a good rapport with his psychiatrist, another realised that the psychologist he had been referred to by his GP did not 'have a clue' about the trauma caused by his diagnosis and his particular concerns about recurrence, death and the threat of hospitalisation. He had recently undergone a divorce and separation from his two children. He felt the psychologist was trying to push him to recognise issues that he was not ready for. Similarly, another of our participants who was struggling with similar fears of recurrence and death, following several painful hospitalisations, felt that the psychologist he was referred to simply expected him to 'get back to normal'. He was not ready for that. Eventually, he saw a psychiatrist who he found was more helpful in addressing his fears. At times, individuals and their partners were looking for specific advice or information rather than a 'talking therapy'. John and his partner, for example, were going through a difficult process of choosing a sperm donor and expected 'a bit of advice rather than a talking session' from the counsellor.

John, was in his late twenties and had been diagnosed with lymphoma when he was eight. Three years ago he had found out that he would not be able to have children naturally. He and his partner had been referred to an NHS fertility centre where they had undergone various counselling sessions to arrive at a decision regarding using his father as a potential sperm donor (an issue we will return to):

Yeah, we've seen a counsellor twice I think now. We saw one near the beginning really when we'd just first going to (fertility Centre), which we didn't really find over helpful. At the time we hadn't delved into it in terms of the effect on people and the different options and, I think we were just wanting some advice...We found it more helpful the next time we went and we saw the nurse and she gave us more information about it, so, whereas the first session with the counsellor she, obviously she, she wouldn't really comment, do you know what I mean? She was just getting us to talk about things. But we'd already done a lot of that and just felt that we didn't really get anything from it. (John)

John talked about how information and support are helpful only when you know what kinds of answers you are looking for. Some participants suggested access to net-based information, chat groups and 'blogs' could be a useful substitute for face-to-face support groups, allowing them more of a 'private space' for communication. However, seeking information and support is often a shared process in which partners and close family are involved. Often, participants did not want 'too much information' and let significant others sift 'unsafe information' (see also Schou and Hewison, 1999). Information needs could also change over time and according to context. This makes any singular policy about the best way to communicate information difficult and suggests the need for a flexible approach where individuals are given the option to choose a method best suited to them, allowing for opportunities to discuss particular concerns and needs for support as they arise.

ENGAGING WITH THE IDEA OF USING NEW REPRODUCTIVE TECHNOLOGIES: THE INTER-SPACE BETWEEN CULTURE, RELIGION AND ETHNICITY

We have provided an overview of how perceptions of threats related to fertility within the life of an individual are interpreted and negotiated within a web of social relationships, mediated by different cultural scripts including ones provided by medicine. We shall now turn to how negotiations of boundaries related to the use of NRTs engage more specifically with notions of culture (such as gender, generation, kinship and conjugality) and religion; an inter-space where ethnicity often makes a surreptitious entry. Before we come to that, we want to pause briefly and highlight two areas of professional practice regulating the use of NRTs, especially since these reflect the *boundaries* of wider shifts in dominant cultural (and ethical) values underpinning new forms of kinship, conjugality and parenting.

The first relates to how professionals working within assisted conception units can make judgements about what they might consider ethical/unethical choice, apart from what the law states. Our previous chapter illustrates some of the tensions faced by

professionals in this respect. For example, despite the legal acceptance of posthumous use of gametes stored with appropriate consent, health professionals make judgements about individual cases that appear to go beyond the statutory requirement to consider the 'welfare of any child conceived or affected'. In chapter three, we also noted how policy and professional representations can sometimes reconstitute the South Asian (and other ethnic minority) patients as passive blueprints of culture and religion (also see Culley et al., 2004). People from South Asian cultures are perceived to desire too many children and, hence, victimise the childless, and perpetuate a 'culture of secrecy' surrounding fertility treatments. Interestingly, a decision not to undergo fertility treatment or preservation or a demand for a white/Asian donor are equally perceived as reflecting constraints of culture/religion rather than choices negotiated by individuals within a particular cultural context, informed by a particular biography.

This takes us back to the cultural underpinnings of how decisions about the use of NRTs are negotiated by our participants across the different ethnic groups included in our study. Let us return to Nimeeta who did not see her ethnicity (Indian- Sikh origin) as being significant to her British identity and the life choices she had made. Nimeeta described how she been raised in a 'liberal' family and did not remember ever having gone to a Gurudwara (Sikh temple). She had never suffered the pressures of moral policing by the 'family'/ community. It is interesting, however, how her ethnic background (skin colour/race) was raised by professionals, against this backdrop of a modernist cultural script premised on choice and self reflexivity, once the couple faced a probable option of egg donation. This was partly related to an assumption about ethnic matching introduced by the gynaecologist. As we have seen, Nimeeta knew that chemotherapy was likely to affect her fertility and was later told she was undergoing premature ovarian failure. Her gynaecologist had a discussion with her and her partner asking whether they wanted to have children and outlining alternate routes to parenthood if they did:

Right, the options that she gave me were (finding) egg donor, which could have been from anyone from my background that, you know, similar background as me or my, you know, a family member, like a sibling, who could have provided that egg ... for me, if they wished to. That was one route. The other route she talked about was adoption...So...they were the two main options that were, you know, discussed. However, at that point, I didn't want to (laughs) raise a family and I still don't, so.... (Nimeeta)

Nimeeta had been asked by the consultant, if having a family was important for her partner and she replied it was not an issue for him. Having children had never been a part of their life plan. During her consultation with the gynaecologist, they were offered the choice of putting their names on a waiting list for egg donation. They were put off by a three year waiting time and decided against it. If her partner had been keen, Nimeeta would have gone down that route. The issue of what kind of donor they might have looked for was discussed. She would not have considered receiving eggs from her sisters or someone close to her (as suggested by the gynaecologist) nor would her partner, since both felt it 'messed up' relationships. However, he would have liked the egg donor to be from a similar *background* to hers so that the child looked like her. She herself would have preferred someone who looked *a bit like* her as well.

Apart from time required to find a matched egg donor, Nimeeta did not feel well enough to shoulder the responsibility of wanting children at the time. If they had ever wanted to raise children, adoption would have been their ideal option. When asked to explain whether there had been any pressure within the family or kin network to have children/provide grandchildren, she replied that her parents knew that she did not particularly want children and it was never an issue. Her family wanted her to get well. She believed that her generation was able to exercise choice.

SC: So are you defying all the stereotypes of, of the Indian family where everybody's wanting to get married and have kids, sort of?

Nimeeta: I don't think that was really an issue with us, 'cos we're all British born, and I think for our generation it's not been an issue at all in terms of how we live, you know. Mum and dad never put any pressure on us and we were allowed to just get on with what we needed to get with in life, and we have.

It is perhaps important to mention that is difficult to know how representative Nimeeta's experience. She might represent a minority of a people of Indian-Sikh origin, born and brought up here, who do not have to negotiate a religious or cultural code about how they lead their lives, who they marry or whether and when they have children (see also Culley and Hudson, 2009). For other participants religion was more central to their illness experience and how they dealt with adversity in general, including 'disrupted fertility'.

Muneer, a Muslim man of Mirpuri-Pakistani origin, in his mid thirties, came to England as a child. He had been part -self employed since his illness and had tried to adopt a more spiritual way of life, doing a lot of voluntary work within the community. He lived in a small, semi-detached house with his wife, mother and other members of his extended family. Muneer was diagnosed as having testicular cancer at 27 years old. However, going through treatment posed a very different set of issues for him since he already knew he had a low sperm count prior to his diagnosis. Banking, therefore, was not an option for him. Muneer and his wife had been married for a long time and had no children of their own. He seemed reconciled to the fact that they would not have any children, especially given his belief that third party/ sperm donation was not permissible within Islam. He was asked what helped him come to terms with the situation. He replied:

I am a very religious person in that sense and I have my beliefs, do you understand. And they're more important than anything else. And we have a belief that it is God that creates you and everything that happens to you, be it good or bad, it's with the will of God, and if that's what he chooses for you, it's best for you. And I have that belief and so it didn't really bother me. It was never a problem with me. (Muneer)

Despite his strong faith, the couple had sought medical treatment and both of them had undergone various investigations. This was within the dominant Islamic framework within which fertility treatment occurring in the context of a conjugal relationship is allowed. The only option they had considered was adoption or fostering, which they felt was encouraged within Islam. They interpreted fostering

broadly too and said they were happy to pay for maintenance of a child who lived with an adopted home. The situation about not having children was easy to accept as Muneer felt he had already had sufficient parenting experience. He was close to his nephews and nieces and actively helped his mother bring up his younger siblings too, following the departure of his father.

Muneer was asked whether he or his wife had faced any social pressure regarding having children and sons in particular. As we can see from his response, various distinctions emerge about culture, the role of religion, as well as different interpretations between generations:

Muneer: Not here. I mean we've been here since early 50s. My grandfather came in 1951. So we've adopted the Western sort of thinking, although we are very Islamic culture and try to keep, but everybody minds their own business kind of thing, but back home they don't. They seem to think that other people's affairs are more important than their own. So when we went there as a family, and we stayed there nearly a year a few years back. Eight months or nine months...She had people talking to her. They think they're sympathetic, but it's their culture. I think that was the only time when she felt that maybe she was the problem.

SC: What about the significance of having children, having sons of your own, within Islam. Did you think it was very important?

Muneer: I don't think it's, I think that's more of culture than Islam. If you look at the Prophet Mohammed (peace be upon him) he had no sons. The children he had, died. So it's not an Islamic thing. And other (religious figures) people did not even marry.

Muneer's acceptance of his childlessness is closely related to his role of shared parenting within the extended family and more importantly, his strong faith that provides a teleological explanation for adversity as an *azmaish* (test of faith and endurance). For him and his wife, donor insemination was not an option since he considered it *haram* (forbidden/unlawful), although he knew that others within his community would compromise their faith to use a donor.

Finally, as mentioned in the background, the symbolic proximity of sperm donation to a physical (inter-sexual) relationship makes it a more complex issue than egg donation and one that does not transcend the gender boundary. We might recall how one

participant - a Muslim by faith - had contemplated egg donation from her sister without worrying about any religious implications it might have. The point we wish to make here is that, rather than providing an overarching normative framework that predefines the choices individuals make, religious values and norms have to be interpreted by individuals within a biographical context, and often against competing sources of validity (see also Atkin et al., 2008). The following excerpt from Mark's narrative illustrates this at one level.

Mark (introduced earlier) and his wife, were Catholic by faith. Given the issues with his sub-fertility and the prospect of needing medical help, he himself did not think such an option transgressed his religious beliefs. However, he was quite upset by the remarks made by the Pope against the use of NRTs. He discussed the issue with his parents and was assured by them that it was a matter of personal faith and belief rather than the authority of the Pope:

Recently I've read a couple of articles in the paper, it's just wound me up, about the Pope and what he's been saying about certain things, including assisted conception, and the people who do that are sort of completely wrong and immoral. And I think that has sort of shook my faith quite a lot, to be honest with you. And I know it shouldn't really because the overall meaning behind being a Catholic is not listening just to the Pope but, then again, that's the person that's leading, not leading, well, I suppose giving guidance, leading the thought of the Catholic church. So yes, I suppose it has affected it [the idea of using NRTs] slightly but I've talked to my dad...and my mum about that and they are Catholics, quite strong Catholics, and they've said the same thing that it's about your faith and not necessarily what one person says about it. (Mark)

As highlighted by John (Catholic by faith, introduced earlier) within the context of choosing a semen donor and use of NRTs, individuals seek comfort from faith in legitimising difficult moral decisions rather than seeking *solutions* prescribed by religion:

I might pray about it and, and, but I, I don't really sort of rely on religion to give me an answer or to solve the issue. But I, I guess you pray and sort of hope that you'll make the right decision and, and, you know, get some kind of guidance maybe or, and that things will just work out OK. (John)

John added that even though he and his partner had briefly discussed the idea of talking with their priest, what he said would not dictate their decision.

Religion, despite being a contested site of beliefs and practices, also provides a language to explain and experience illness and its aftermath as adversity (suffering) that has a purpose or a meaning, thus helping to reassert a moral self despite the disruption caused by cancer. We have already seen, how for some of our Muslim participants, cancer was seen as a test of faith and endurance. Mathew was in his early thirties and like John grew up in a traditional Catholic family and was proud of his Irish heritage. His parish priest was like a family friend with whom he could talk easily. While he was having treatment, a lot of people within the parish sent him prayers and held a mass. He took a lot of strength from that, even though he was only twelve:

It's actually...given me a lot more humility and appreciation and realise just how lucky you are, regardless of what's wrong. (Mathew)

Mathew felt that despite his speculative moves to break away from the traditional Irish norms of adulthood, he still wanted to follow the ideal of 'getting married, settling down and having a family'. As he later poignantly summed up, 'Everyone has a cross to bear and I have had mine'. Interestingly, despite his fears of being 'robbed of his manhood' and fertility that, he believed, resulted in a few difficult relationships, he did not know whether he was fertile or not. Mathew had finally met a partner that he wanted to 'settle down with' and they had discussed the possibility of sperm donation. Despite his Catholic upbringing, his faith did not preclude him from considering sperm donation from his brother as one of the possible options, in the hope that the child might pass off as his own. His girlfriend, however, did not seem to approve of the idea. Mathew attempted a resolution by defining sperm donation as a clinical intervention, as reflected in the following excerpt:

Mathew: No she said, no, that would be weird. She said, oh no, no, we'll have a stranger. It's your brother. We can't allow that to happen. And I said, it's a medical thing, it doesn't matter.

SC: Do you consider that to be a very medical thing rather than it doesn't have any implications for the relationship between you and your girlfriend?

Mathew: Well no, it's injected. For me, it's a clinical thing being able to have a child. I can see past that, it's nothing. I'm not asking her to go to bed with him. It's a case of just being inseminated. I don't know. It's a big question. I'm not sure. I don't know (his emphasis).

Given the complexity of the moral maze within which third party donation and donor insemination are located, Mathew felt that adoption would be a more virtuous act:

In many ways I'd be more proud adopting, because I don't know anybody around my friends that have adopted. And I would feel like I was doing more than them...And I think that they'd think it was fantastic as well. So I think that everyone would embrace it. So in many ways it's quite exciting, the thought of giving the chance to a child that hasn't got that benefit. (Mathew)

Hence, while the medicalisation of childlessness creates choice by bringing couples/individuals face to face with the use of NRTs with complex social reverberations, the boundaries of choice are mediated by culture/religion. At the same time, we had a glimpse of how individuals from different cultural or religious backgrounds use alternate explanations to maintain their moral credibility of self.

CONCLUSION

This chapter presented a synopsis of the views of participants who had experienced the long term physical, emotional and social consequences of living with cancer. We looked, more specifically, at how participants from different South Asian and white ethnic backgrounds negotiated potential threats to fertility caused by treatment/s related to cancer, and the dilemmas they faced in engaging with the various options available to them in relation to use of NRTs. Clearly, it is difficult to disentangle the (emotional and social) impact of having cancer from that related to potential threats to fertility caused by treatment/s. While the (emotional and social) impact of facing potential issues associated with (in)fertility are located within wider cultural meanings

associated with gender and parenthood, participants negotiated these meanings within a specific biographical context. The range of negotiations within each ethnic group and similarities across reflect the complexity of the notion of ethnicity as an operational category. We need to disaggregate it conceptually (into race, culture, religion, language, nationality, region and so on) and specify the context within which individuals locate their experiences of illness and healthcare.

This is not to deny the significance of the concept of ethnicity, in defining boundaries of inclusion and exclusion between groups; marking insiders (host) from outsiders (immigrants). As noted in the previous chapter, some of the stereotypes about ‘Asian’ culture, religion and gender relations still persist in the perceptions of some health and social care professionals. The accounts of the participants affected by cancer, however, provided little support for these generalisations for various obvious reasons. There was, for example, little evidence of pro-natalist views or a ‘culture of silence’ being peculiar to participants of South Asian origin. There were generic and shared experiences associated with having cancer, negotiating treatments and facing a potential risk to fertility that cut across ethnic groups. At one level, the relationship between the individual and the religious/cultural community might seem different for some South Asian participants as compared to their white counterparts. This, however, does not determine their decisions related to health and treatment that are negotiated differently by individuals within a particular biographical context. We tried to highlight the how the internal diversity of South Asian communities (as of white community) reflects a complex relationship between the dimensions of culture, religion language and particular histories of migration. Hence, individuals within any cultural/religious community engage with particular values and practices (that might be shared at a collective level) within a particular biographical context. Hence, culture/ religion provide a framework for values and actions rather than a static set of rules that predetermines how individuals might think or make decisions about their health and treatment.

CHAPTER FIVE: CONCLUSIONS, DISCUSSION AND RECOMMENDATIONS

Having outlined our findings from our interviews and focus group discussions with professionals and those individuals whose fertility was potentially affected following treatment for cancer, we now discuss the implications of our research for policy and practice. In keeping with our original aims and objectives, we will make recommendations that we hope will be useful in addressing gaps and improving services.

As suggested in the introduction, our research cut across the fields of cancer, ethnicity and infertility. At a methodological level, we aimed at destabilising the notion of ethnicity by using a comparative method to analyse the biographical context within which treatment-related threats to fertility are experienced and negotiated. This was felt to be more helpful in understanding the lives of people than un-contextualised descriptive engagement, while also providing the basis for more constructive policy and practice solutions. A focus on materiality of the disease, gender, culture, religion as well as socio-economic background within each group, helped us operationalise ethnicity as an analytical concept without pre-empting its content, allowing for meaningful comparisons within and across ethnic groups. This method, we argue, is an important step towards de-essentialising 'ethnicity' and bringing it within the mainstream theoretical discussions on health, particularly since we need to understand better the health and social care needs of an increasingly diverse society with changing notions of citizenship.

Theoretically, the embodied experience of a particular type of cancer and *uncertainty* of risk (potential threat) to fertility shared across experiential and clinical domains presents our research as a specific case-study in itself. And one that has less in common with the wider field of ethnicity and infertility or 'marginalised reproductivities', especially given the context of living with cancer and its particular symbolic overload of a terminal condition. At the same time, choices related to fertility

‘preservation’ and potential use of NRTs are located and *negotiated* within wider cultural and/or religious notions of gender, conjugality and kinship rather than being pre-defined for a particular ethnic or religious group *per se*.

Our findings are in sharp contrast to those from a previous study on living with cancer, carried out by one of the authors, where a majority of participants were older (Chattoo et al., 2002) and recruited using similar methods across three fieldwork sites. This sample was far more critical of health care provision than those we interviewed in our present study. We believe that the reasons explaining the overall positive experiences of ‘South Asian’ participants within oncology and related services may reflect the history of developments within cancer care in the past decade. Cancer care in the UK is a privileged area of healthcare that is relatively well funded, with a long history of engagement with issues of holistic care (including involving the family) on the one hand and community and voluntary sector involvement in service provision on the other. The role of the hospice and palliative care movement, often called ‘deluxe care’, has been central to these developments (Chattoo and Atkin, 2009). In addition, developments in the paediatric and TYA services within the NHS have addressed some of the important issues regarding long term follow up of people diagnosed in early childhood or teens. As a case study, our research suggests that generic developments in a specialised and well funded area of healthcare - sensitive to the potential needs of an ethnically diverse population - and involvement of user groups in developing and delivering services across the NHS and voluntary sectors of care have the potential to improve the overall quality and equity of service provision for everybody. Equally, leadership within teams and partnership across teams can be crucial to how well policy guidelines are implemented in practice.

Our findings also seem to contrast with a major study within the field of ethnicity and infertility where a third of participants and their spouses had issues with language and communication (Culley et al., 2006). It is likely that if we had interviewed spouses/partners, we might have come across a slightly different picture, especially within some of the South Asian families. It is also possible that if we had interviewed more

women from South Asian backgrounds, whose fertility *had been* affected by treatment, we might have captured a different picture of negotiation of infertility in relation to their extended family and 'community'. However, the differences in the experiences of the five women within our sample suggest the importance of looking at the socio-economic background and histories of migration; thus highlighting the limitations of a 'community' approach. Another advantage of our sampling method, given the diversity within it, was that we had some participants whose fertility had been affected but who had decided not to pursue the route of NRTs. This group is often missed in the studies on ethnicity and infertility and in the broader literature on (in)fertility. Further, although some people of South Asian backgrounds experience greater moral policing by their kinship and religious community, individuals lean on different frameworks to explain and redefine their infertility within the context of a life threatening illness (also see Riessman, 2002a, on negotiation of infertility by older women in India).

Within this context of a potentially life threatening illness, the threats to fertility are interpreted and negotiated differently, even though the consequences of childlessness are the same and located in wider cultural scripts. Importantly, a majority of the participants who did not have or had never tried to have children were still dealing with uncertainty. Hence, it is quite likely that some of the South Asian participants would face similar cultural stereotypes once they stepped into the world of assisted conception/reproductive medicine to those described by Culley et al. (2004; 2006). We had a glimpse of the archaic stereotypes of 'Asian' families being secretive, deceitful, male dominated, and governed by prescriptive norms laid down by religion and culture, held by some of the professional participants in our study. Their views remind us yet again of the challenges of achieving the goals of 'cultural competence' alongside 'patient centred care' within a multi-ethnic society. Understanding and engaging with ethnic diversity and reflexivity should be seen as integral parts of the training of health and social care professionals, rather than as an ad hoc 'competence' they can achieve at the end of a brief training session (see Atkin and Chattoo, 2007).

IMPLICATIONS FOR POLICY AND PRACTICE

Following on from above, we shall now outline the policy and practice implications of our research by first highlighting the salient issues related to service provision raised by both professionals and patients. Apart from the main themes covered in the report, we specifically asked participants in both samples about any particular issues they would like us to highlight from their own experience. This section, therefore, includes some generic issues that we have not discussed so far (Chapters three and four). This will be followed by a specific set of recommendations which, we hope, will stimulate more discussion in this important area of policy and practice, as outlined by the Survivorship Initiative.

Salient issues within Primary Care

- The experience of some of the younger patients who had experienced ‘delays’ in diagnosis suggests that, at times, GPs may not suspect malignancy in younger patients despite severity of symptoms.
- Communication and continuity of care across primary and secondary care, during and following treatment, can be a major issue for some patients who live a distance from their treatment centres. Better collaboration and phone contact between GPs and oncologists can save patients a trip to the hospital for minor advice. This is a generic issue to do with the relatively marginal role of primary care in dealing with ‘specialist’ care of people with long standing illnesses.
- Lack of communication between primary and secondary care, once a referral has been made to a community service, can be another issue affecting continuity of care. Patients can, at times, feel that they are dealing with separate, disconnected services that do not speak to each other.

Salient issues within secondary and tertiary care

- The potential risk to fertility caused by a particular treatment regimen is usually discussed during initial consultations on diagnosis and treatment, at a time when patient and family members are taking in a lot of complex information. While oncologists are obviously best qualified to explain the side-effects of treatment and potential risk to fertility, patients often find it hard to disentangle the general 'side effects' of treatment and the significance of the 'risk' to fertility (that cannot be quantified). Hence, some patients (especially women) feel that they were not provided clear, expert advice on risk to fertility or options related to preservation. Offering an opportunity to discuss the matter with a specialist before starting treatment can address this issue, given that only a small proportion of patients and largely women might take up this offer.
- Given the time pressures of starting treatment, patients often do not have the an opportunity to 'ask the right questions' that might, retrospectively, help them come to terms with eventual loss of fertility or deal with the complexity of issues surrounding preservation. A majority of women, in particular, do not have a real 'choice' regarding preservation of eggs/embryos or ovarian tissue. Offering a separate consultation, at this stage, with a specialist in reproductive medicine can help clarify details about the risk to fertility and the implications of cryopreservation. Patients and their families or partners will then have an opportunity to raise questions and probe possible options related to preservation and of seeing a specialist counsellor, if they so wish.
- Often the issue of fertility is not discussed in follow-up consultations as a matter of routine, unless raised by patients. Professionals working within oncology are aware of this. However, uncertainty about the impact of treatment at an individual level and pragmatic issues of time constraints in busy follow up clinics often preclude an open discussion about issues of fertility.
- While most oncologists implicitly raise the issue of fertility when asking women whether their periods have resumed, women may not necessarily

interpret this as relating to return of fertility. Since disruption of periods during or following chemotherapy is expected, women can perceive the signs of premature ovarian failure as a temporary/ reversible 'side effect' of treatment. Routinely offering a follow up appointment, once treatment is over, for men and women, perhaps at a joint oncology-reproductive medicine clinic, such as that run at one of our sites for paediatric/TYA patients, would go some way towards addressing this gap, as would the use of more explicit language to discuss the link between menstrual cycles and fertility.

- Given the complex interplay between uncertainty about fertility following treatment and a three to five year mile-stone for achieving remission, advice on contraception and avoiding pregnancy during this time sends conflicting messages to patients and their partners about their fertility. Similarly, younger women experiencing premature ovarian failure find it emotionally more challenging when they are prescribed HRT and still advised to follow contraception. Such conflicting messages can leave a 'window of hope' open, raising expectations and making it harder for some to reconcile to their new status of being 'infertile'. Oncologists need to discuss the issue more explicitly in consultations following treatment, using non-technical language, so that patients can understand the logic behind such conflicting advice and their emotional concerns addressed.
- The role of parents and close family in providing emotional and physical support to younger adults with cancer cannot be over-emphasised, though their presence can, at times, feel inappropriate to professionals or patients themselves within the context of discussions about physical maturity, sexual activity, fertility and contraception. Some professionals struggle to accommodate the emotional needs of parents who sit in on consultations of their adult children since they feel that it conflicts with their 'duty of care' towards the patient - premised on a notion of an autonomous patient. This issue can become even more salient within the context of families of South Asian origin due to the assumptions professionals that have about their family culture being patriarchal, oppressive and intrusive.

Salient issues with providing psycho-social support

- Offering financial advice, especially regarding welfare benefits, irrespective of prognosis, would, according to patients, be especially valued, especially if such advice was available on an ongoing basis. Advice regarding continuing education, retraining, employment or housing also needs to be an integral part of support following treatment (including fertility). Often the long term physical and psychological side effects of treatment are exacerbated by loss of work or educational opportunities since employers and educational institutions may not recognise the non-visible signs of illness or its physical aftermath beyond treatment.
- For individuals facing difficult emotional issues related to treatment, a referral to a generic psycho-social professional, such as a counsellor or a clinical psychologist (rather than one with some knowledge of the field of cancer and infertility) can, sometimes, be counterproductive, given the complex combination of issues that individuals face when coming to terms with their diagnosis or its aftermath.
- Given the symbolic meaning associated with cancer as a diagnostic term, the link between treatment and infertility can add to the stigma faced by younger people, especially given the risk is often unknown. While public debate on survivorship needs to engage with potential risk to fertility and sexuality posed treatment, we need to exercise caution in how the message is conveyed so that we are not adding another layer of stigma associated with a diagnosis of cancer.
- Face to face and on-line support groups can be a useful source of support and information for younger men and women surviving cancer, who draw strength from sharing common experiences related to a specific condition, 'mile stones' of recovery and making new friends. However, such support is not always available or offered at the appropriate time and might, in fact, not be acceptable to some who are trying to avoid 'unsafe information'. For example, some women undergoing premature menopause due to treatment may not identify

with a generic support group for women facing premature menopause and/or infertility. Hence, such support must be offered within the context of specific issues faced by an individual.

Commissioning

- There seems a broad consensus among our participants, both professionals and patients, about the 'fairness' of cancer patients facing infertility being given the same treatment as others within the NHS. Funding for fertility analysis and treatment, however, varies across Strategic Health Authorities. Further, long waiting lists for fertility treatment coupled with the need to follow medical advice on achieving a three to five year milestone associated with remission, can compound the distressful situation for patients whose fertility has been affected by treatment.
- The needs of cancer patients and their families during diagnosis and following treatment are multi-faceted, complex and responsive to context. Commissioning strategies need to reflect this, alongside the multi-disciplinary nature of care, which involves inter and intra-agency collaboration including across the spectrum of health, social care and the third sector.

RECOMMENDATIONS

A. General policy and practice

1. Better co-ordination and communication between primary and secondary/tertiary care during and following the treatment phase would help improve continuity of care. Correspondence between primary and specialist care should include the information currently available about the individual's fertility, the ways in which further information and non-medical support can be accessed by the patients and their families.
2. Better communication about potential risk to fertility and realistic options for preservation and outcomes of fertility treatment can be achieved by offering a

consultation with a fertility specialist before starting treatment. This will ensure that individuals who have specific concerns, especially women, have the opportunity of asking questions and having their concerns addressed.

3. Ongoing and active engagement with issues of fertility by professionals, during and after completion of treatment by patients, especially in long term follow up services, would help resolve some of the salient issues summarised above, as would access to specialist psycho-social professionals who can help individuals deal with a difficult situation.
4. There is a need for better implementation of national guidelines for teenage/ young adult as well as adult patients, so that patients are well informed about the potentially sterilising impact of particular treatment regimens before starting treatment; and are offered cryopreservation and/or the opportunity to discuss the issue further with a specialist(see also Section B). Adherence to guidelines should be routinely audited and the findings of such audits incorporated into practice.
5. In addition, future national guidelines must recommend that medical and psycho-social professionals actively probe physical and emotional issues surrounding fertility as part of routine long term care, while being sensitive to the personal circumstances of individual patients. As a model of good practice followed at one of the participating Sites, every patient attending a long term follow up clinic is requested to fill in a pre-appointment questionnaire that included a section allowing them to identify which long term side effects including fertility and psycho-social issues that they wanted to discuss. This helped the patients as well as professionals to identify and address the important issues at a stage that felt right and could also facilitate appropriate referrals for psycho-social support within or outside the remit of the follow up service.
6. Given the disciplinary differences in priorities between Oncologists and specialists in Reproductive Medicine, joint training in areas of mutual interest to facilitate multi-disciplinary team work, and better communication that draws on best practice will greatly benefit patients. For example, sharing clinical details about males referred for sperm banking who are severely ill or otherwise physically restricted; providing information about prognosis and likely impact of treatment

on fertility (assuming these have been transmitted to the patient), or specific needs of patients who might require an interpreter and so on. Another area that would benefit from better communication between oncology departments and reproductive medicine/fertility centres (including storage services) concerns sharing follow up details of patients such as changes of address or, in particular, where a patient has died (which was already in place at some of our sites). This would help avoid inappropriate follow-up letters being sent out and minimise the risk of distressing close relatives.

7. Patient and professional accounts suggest there is a role for a designated professional with an interest and remit in fertility-related aspects of cancer (or cancer-related aspects of fertility) who could follow up individuals at each stage of their cancer journey, act as co-ordinator of referrals to fertility preservation or fertility analysis and more generally engage individuals in discussions about reproductive health matters, including identification of psycho-social issues. Such an individual would also be helpful in negotiating storage costs, where such funding is not provided by default within the NHS.
8. Written information about face-to-face and on-line support groups and sources of reliable information to do with fertility matters should be available at diagnosis and afterwards, at regular intervals.
9. Incorporating advice on financial assistance/welfare benefits into the pre-discharge and follow up routine, irrespective of the prognosis or severity of illness for all patients would be helpful. Equally, advice and support on continuing education/retraining, employment and housing can be central to improving people's quality of life, particularly those whose education and/or training has been severely disrupted by the diagnosis of cancer early in life. Shortages of social workers, and in particular specialist social workers, have been identified across children's and adults' services. Hence, closer working between health, social care and the third sector is needed to prevent socio-economically or psychologically vulnerable individuals from falling outside the net of social care. This recommendation fits particularly well with the specific aims of the Cancer Reform Strategy (2007), the goals of the DOH/Macmillan Survivorship Initiative (2009), in

addition to the recent Marmot Commission Report on tackling inequalities in health.

10. There is currently no service that collects national data on cancer-related fertility matters which could inform policy, commissioning and practice, such as, the number of people who are offered cryopreservation, the number or store gametes or embryos, and the number who return to have treatment using stored gametes/embryos following treatment for cancer. The HFEA does not collect data about long term storage for males as no 'treatment' (i.e. medical intervention), is involved and although this is collected when females access long term storage of their eggs or embryos since the process involves 'treatment', this information is not identified in a data set separate to that for non cancer patients. In addition, the HFEA regulates long term storage services but does not routinely collate national information on its inspections. There should be further debate on the appropriateness of collecting such data and which body should undertake this task, especially given the Government's announcement of the disbanding of the HFEA
11. As attention to this area is growing so is the need for inter-disciplinary spaces across health and social care and outside of the operational arena in which to discuss policy and practice. Consideration should be given to such forums being 'officially' encouraged and supported, perhaps by Cancer Networks.

B. Fertility preservation

1. As referred to at A4, better implementation of national guidelines is required. In addition, discussions and actions on fertility matters should be documented in the patients' files, not least as this would ensure that those working with the patient at a later stage know what has already been discussed and what action taken.
2. Referrals associated with fertility preservation, containing clear, unambiguous information should be made as soon after diagnosis as possible, even when cancer treatment is not scheduled to start for some time.
3. Avoiding partial or rushed advice on *options* for preservation of gametes for women, embedded in a wider consultation on the potential side effects of treatment

would be especially appreciated by patients and help avoid raising hopes that cannot be realised or unrealistic expectations about the possibility of preservation and success rates of treatment.

4. All patients - but especially women - would appreciate being offered an opportunity and choice to consult a specialist in reproductive medicine before starting treatment. This specialist could help explain the process of gamete preservation in addition to the success rates associated with using cryopreserved gametes. Access to (in) fertility counselling would also be of benefit at this time. Such discussions may also help individuals start to accommodate any potential or eventual loss of fertility.
5. Improving communication between patients who have stored gametes and services offering storage facilities is an issue that would benefit from the adoption of national minimum standards drawn up by the relevant professional bodies (in addition to matters raised at A6). The frequency of patient communication is left currently to the discretion of the storage centre as is the minimum information that should be conveyed in such correspondence. We believe that the content should include reference to the long term storage conditions (including any costs to the patient), the right to vary consent and how to do so and the processes by which fertility testing can be sought, including the availability of medical advice and implications counselling. See also A6.
6. Simplifying the process of consent should be considered within the context of people undergoing treatment. A more simplified process would help ensure patients have sufficient time to read and understand the various sections of the HFEA form, especially since (in contrast with individuals using the form for fertility treatment) these patients may never have thought about the complexity of potential ethical issues involved. Some Centres require a second set of consent forms to be filled in so as to comply with ethical requirements of the individual Trust, increasing the chances of patients not having the time or space to engage with the consent process.
7. Fertility preservation (and fertility analysis) should be considered as a service in its own right, given that it has therapeutic potential beyond whether or not it leads to

the use of fertility treatments. While the focus of assisted conception treatments is to lead to a pregnancy, it is not the focus of fertility preservation and fertility analysis services. Eligibility criteria and provision should reflect this difference.

8. More research into the longer term effects of having access to information and counselling for females about fertility preservation would also be valuable.

C. Access to fertility analysis and fertility treatments

1. Presentation and discussion of results of fertility analysis is an issue that needs some attention, given the emotional and symbolic significance of the outcome and the need to avoid conflicting information being communicated. As such information can have a lasting impact on how someone faces the prospect of infertility, referrals to discuss fertility analysis also need to include counselling services as routine.
2. Systems should be in place to ensure that all patients are advised of the availability of fertility analysis services regardless of whether they have gametes in store.

D. Long term follow up

1. Protocols at long term clinics should include routine checks as to whether the patient wishes to discuss anything relating to physical, psychological and social components of fertility matters. Referrals should be made to other services, including psycho-social services, if needs cannot be met within the long term clinic (also see recommendations A4, A8)
2. Regular affirmation of the role of nurse specialists - including their role as a bridge between services *and* as champions within services - would be helpful.

E. Professional practices

1. Professional explanations of risk should make it clear at each stage that it is *one's ability to have children naturally* that is being exposed to threat. The use of

euphemisms runs the risk of misunderstanding or confusion among patients and their family. A more careful use of language is, therefore, required.

2. Professionals need to draw boundaries between personal beliefs and disciplinary frameworks when dealing with ethically challenging situations. Greater understanding of professional ethical frameworks (i.e. rather than ethical processes and protocols), as well as the use of reflective supervision can facilitate this process. Sharing good practice through access to regular inter-disciplinary and inter-agency discussion forums is crucial to building the required pool of knowledge.
3. Although there are times when specialist subject knowledge is called for, there are also times when professionals need to feel more confident at 'staying with' someone rather than 'referring on' – waiting until it is clear whether the discussion in the here and now may meet the person's needs sufficiently well.
4. Where onward referral does take place, it is important to track whether it has been successful and if not, why not. It is not unusual for patients to be 'lost' during such transitions, especially when being referred on to psycho-social support.
5. Professionals need to have greater confidence in responding to situations, without relying on 'fact-files' or responses informed by generalisations about cultural practices of minority ethnic groups. Engaging with cultural, religious and ethnic diversity and challenging stereotypes is an important step forward and helps empower professionals to raise meaningful questions within the context of providing care to an ethnically diverse population. This begins to provide them with the cultural repertoire to engage with diversity and difference, which of course evokes themes much broader than ethnicity.
6. Rather than making yet more recommendations for attention to 'cultural competence', attention is given instead to the idea of the 'reflective/reflexive practitioner' who considers what is 'familiar in the unique and unique in the familiar' when working with a diverse range of patients and their families. And who is equally aware through reflective processes that they may impact on the patient and the patient on them and that such interaction forms part of the 'knowledge' informing practices of care.

DISSEMINATION

This final chapter offered an overview of our findings and their implications for policy and practice. However, we are acutely aware of the tension between providing recommendations and their practical application. To address this issue, we have used different forms of engagement and dissemination. This includes summaries, aimed at those affected by cancer treatments and their families, in addition to professionals, commissioners and policy makers (see Appendix F, which provides a detailed overview of our dissemination activities). These summaries are in the process of being widely distributed to a broad range of individuals and groups.

We have also led workshops at our three fieldwork sites. These workshops enabled professionals to engage with our findings and reflect on their implications for practice. To ensure our findings reached a wider audience, we also organised a national conference, bringing together various stakeholders (including patients and their families), to discuss the broader issues of cancer survivorship in a multi ethnic, diverse society. Details about the conference, including copies of presentations of workshops, in addition to the summaries associated with this project can be found at: <http://www.york.ac.uk/healthsciences/research-information/conference-cancer-survivorship/>

In the current climate of ‘evidence-based practice’, we were equally aware of the need to present our findings to wider academic and practice audiences. We have, therefore, presented and shared our research at various national and international conferences. We are also in the process of drafting peer-reviewed papers, which reflect the multi-disciplinary nature of our work.

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Appendix A

Ethical approval letter 2007



National Research Ethics Service

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04 December 2007

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Dear Dr. Karl

Full title of study: The experience of cancer-related fertility impairment
among people of South Asian and White origin
REC reference number: 07/H1307/181

Thank you for your letter of 26 November 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by Dr Catherine Coyle & Dr Vera Neumann, Committee members.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		21 September 2007
Investigator CV	Karl Atkin	21 September 2007

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority.
The National Research Ethics Service (NRES) represents the NHS Directorate within
the National Patient Safety Agency and Research Ethics Committees in England.

Protocol	V1	01 September 2007
Covering Letter		21 September 2007
Letter from Sponsor		20 September 2007
Peer Review		05 February 2007
Interview Schedules/Topic Guides	V1	01 September 2007
Interview Schedules/Topic Guides	Topic guide for Focus Groups with Professionals V1 Nov 07	
Interview Schedules/Topic Guides	Topic guide for interviews with professionals, V1 Nov 07	
Letter of invitation to participant	V1 (Initial Letter)	01 September 2007
Letter of invitation to participant	Reminder, V2 Oct 07	
GP/Consultant Information Sheets	Letter to consultants/clinical team	
GP/Consultant Information Sheets	V1	01 September 2007
Participant Information Sheet	V1	01 September 2007
Participant Information Sheet: For Professional Interviews	1, Nov 07	
Participant Information Sheet for Staff (Focus Groups)	1, Nov 07	
Participant Consent Form: Patients	2, Nov 07	
Participant Consent Form: Professionals	2, Nov 07	
Response to Request for Further Information		26 November 2007
Biographical Details	2, Nov 07	
Collaborator Letter	Galina Vekova	13 October 2006
Collaborator Letter	A Z S Rohatiner	22 November 2006
Collaborator Letter	John Radford	14 November 2006
Collaborator Letter	Bernadette Gleimian	09 November 2006
Collaborator Letter	Adam Glaser	13 November 2006
Collaborator Letter	Dan Stark	20 October 2006
Response to Funder / Grant Letter	Karl Aikin	10 July 2007
Funder / Grant Letter	Gender Research UK	26 June 2007
Cert of Employers' Liability Insurance		
Eligibility and Recruitment	V1 2007	

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from <http://www.rdforum.nhs.uk/rdforum.htm>.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2004) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

Here you will find links to the following

- a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.
- b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencesgroup@nationalres.org.uk.

07/H1307/181

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Laura Sawluk
REC Co-ordinator
On Behalf of
Mr Jon Silcock
Chair

Email: laura.sawluk@leedsth.nhs.uk

Enclosures: Standard Approval conditions

Copy to: Professor Mark Whyte,
Area 3, 1st Floor
Seaborn Rowntree Building
University of York
York


Central Office for Research Ethics Committees
(COREC)

**RESEARCH IN HUMAN SUBJECTS OTHER THAN CLINICAL TRIALS OF
INVESTIGATIONAL MEDICINAL PRODUCTS**

Standard conditions of approval by Research Ethics Committees

1. Further communications with the Research Ethics Committee
 - 1.1 Further communications during the research with the Research Ethics Committee that gave the favourable ethical opinion (hereafter referred to in this document as "the Committee") are the personal responsibility of the Chief Investigator.
2. Commencement of the research
 - 2.1 it is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.
 - 2.2 In the case of research requiring site-specific assessment (SSA) the research may not commence at any site until the Committee has notified the Chief Investigator that the favourable ethical opinion is extended to the site.
 - 2.3 The research may not commence at any NHS site until the local Principal Investigator (PI) or research collaborator has obtained research governance approval from the relevant NHS care organisation.
 - 2.4 Should the research not commence within 12 months, the Chief Investigator should give a written explanation for the delay. It is open to the Committee to allow a further period of 12 months within which the research must commence.
 - 2.5 Should the research not commence within 24 months, the favourable opinion will be suspended and the application would need to be re-submitted for ethical review.
3. Duration of ethical approval
 - 3.1 The favourable opinion for the research generally applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Committee should be notified.
4. Progress reports
 - 4.1 Research Ethics Committees are required to keep a favourable opinion under review in the light of progress reports and any developments in the study. The Chief

SCRs version 3.0 dated June 2006
SLA02 Approval conditions (research other than CTIMs)

Investigator should submit a progress report to the Committee 12 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

- 4.2 Progress reports should be in the format prescribed by COREC and published on the website (see <http://www.corec.org.uk/applicants/apply/progress.htm>)

- 4.3 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss the progress of the research.

5. Amendments

- 5.1 If it is proposed to make a substantial amendment to the research, the Chief Investigator should submit a notice of amendment to the Committee.

- 5.2 A substantial amendment is any amendment to the terms of the application for ethical review, or to the protocol or other supporting documentation approved by the Committee, that is likely to affect to a significant degree:

- (a) the safety or physical or mental integrity of the trial participants
- (b) the scientific value of the trial
- (c) the conduct or management of the trial.

- 5.3 Notices of amendment should be in the format prescribed by COREC and published on the website, and should be personally signed by the Chief Investigator.

- 5.4 A substantial amendment should not be implemented until a favourable ethical opinion has been given by the Committee, unless the changes to the research are urgent safety measures (see section 7). The Committee is required to give an opinion within 35 days of the date of receiving a valid notice of amendment.

- 5.5 Amendments that are not substantial amendments ("minor amendments") may be made at any time and do not need to be notified to the Committee.

6. Changes to sites (studies requiring site-specific assessment only)

- 6.1 Where it is proposed to include a new site in the research, there is no requirement to submit a notice of amendment form to the Committee. Part C of the application form together with the local Principal Investigator's CV should be submitted to the relevant LREC for site-specific assessment (SSA).

- 6.2 Similarly, where it is proposed to make important changes in the management of a site (in particular, the appointment of a new PI), a notice of amendment form is not required. A revised Part C for the site (together with the CV for the new PI if applicable) should be submitted to the relevant LREC for SSA.

- 6.3 The relevant LREC will notify the Committee whether there is any objection to the new site or Principal Investigator. The Committee will notify the Chief Investigator of its opinion within 35 days of receipt of the valid application for SSA.

Ethical Approval letter 2008



National Research Ethics Service Leeds (West) Research Ethics Committee

A/B Floor, Old Site
Leeds General Infirmary
Great George Street
Leeds
LS1 3EX

Tel: 0113 3926788
Fax: 0113 3922863

18 December 2008

Dr Karl Atkin
Senior Lecturer in ethnicity and health
Department of Health Sciences
2nd Floor, Seebohm Rowntree Building
Heslington, York
YO10 5DD

Dear Dr Atkin

Study title: The experience of cancer-related fertility impairment
among people of South Asian and White origin
REC reference: 07/H1307/181
Amendment number: 3.1
Amendment date: 13 November 2008

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 18 December 2008.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Advisory Board Members	1	13 November 2008
Notice of Substantial Amendment (non-CTIMPs)	3.1	13 November 2008

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority
*The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England*

Appendix B – Advisory board members

Dr. Mushtaq Ahmed

Principal Genetic Counsellor

Mr. Shafiur Rahman

Patient representative

Dr. Bernadette Brennan

Consultant Paediatric Oncologist

Professor Ama Rohatiner

Consultant Adult Oncologist

Professor Lorraine Cully

Professor of Social Science and Health

Mr. Dan Savage

Patient representative

Dr. Adam Glaser

Consultant Paediatric and Adolescent
Oncologist

Professor Bob Simpson

Professor in Anthropology

Ms. Caroline Hamer

Research nurse, lymphoma team

Dr. Dan Stark

Senior Lecturer in Cancer Medicine and
Hon. Consultant in Medical Oncology

Ms. Kim Hardwick

Senior Cancer Information Nurse

Dr. Mathew Tomlinson

Consultant Scientist

Dr. Claire Moynihan

Researcher

Dr. Jeremy Whelan

Consultant Paediatric Oncologist

Professor John Radford

Consultant Adult Oncologist

Ms. Anne Wilson

Social worker

Appendix C: Health and social care professionals

Information sheet for professional focus groups

THE UNIVERSITY of York

Relevant Trust logo

Experiences of cancer-related fertility matters among people of White and South Asian origin

Information Sheet for health and social care professionals taking part in a focus group

The purpose of this leaflet is to outline the above study and explain what will happen if you decide to take part in a focus group.

What is the project about?

We want to learn more from the experiences of adults aged 18 to 40 who have been through cancer treatments which may affect their fertility. We have already conducted approximately sixty, one to one interviews with them. We were interested to know more about what it is like to cope with fertility concerns, both at the time of being told and afterwards and what issues, if any, these raise for the individual within the context of their social relationships. We want to find out what has helped them and what did not. A full protocol is available from the research team.

We also want to find out what it is like for professionals to provide support to this group of patients and whether you face any particular issues in providing appropriate support to people from South Asian backgrounds. We would especially like to seek your views on current gaps in services and priorities for future developments.

Learning from their and your experiences, we hope to suggest ways in which the services are developed to provide more appropriate support to people of different ethnic and social backgrounds.

The study will involve participants (professionals and patients) from the Paediatric and Adult Oncology Units at St James University Hospital, Leeds; Christie Hospital, Manchester, Royal Manchester Children's Hospital; University College, London; and Barts Hospital, London.

Altogether, it will take us two years to complete the research. You will be sent a summary of our work, when we have finished it.

The main aims of the study are to:

- understand the social and emotional impact of actual or potential cancer-related fertility impairment on South Asian and White patients in the peak age groups for forming adult relationships and becoming parents, and their support networks ;
- examine decision making processes including those associated with fertility preservation, fertility testing, fertility treatments or other routes to parenthood;
- identify similarities and differences within the study population specifying where these are mediated by culture, religion or ethnicity; and
- suggest strategies for accessible and appropriate services of use to those responsible for planning, commissioning and delivering health and social care.

Who is doing the study and how is it funded?

The study is being conducted by a research team based at the University of York and is funded by Cancer Research UK (Ref: C8351/A9005).

Why do you want me to help?

We are keen for you to help us to identify any similarities or differences that you might have experienced (or are aware of) in working with people faced with cancer-related fertility matters when aged between 18 and 40 years (even if diagnosed when younger). We would especially like to know how you think gender, ethnicity or socio-economic background might mediate a person's experience and access to relevant services. We would also like you to help us try and identify what knowledge, skills and resources you think are needed to provide a good quality, appropriate service to them. Finally, we would like to discuss ways of developing the services further.

What would I have to do?

We are running focus groups of up to an hour and a half with staff drawn from a range of disciplines within paediatric and adult oncology units, assisted conception and associated support services. We would like to invite you to take part in a focus group discussion on issues outlined above.

Do I have to take part?

You do not have to take part. If you decide not to take part, you do not have to give a reason. If you do decide to take part and later change your mind, you can withdraw at any time.

If you agree to take part, we will ask your permission to record the session so that we can transcribe it afterwards. This transcript will only be available to the research team and will be destroyed when the project is finished.

What will happen to the information?

All information will be treated in confidence. No names or identifying information will be used in any reports of the study.

What do I do next?

If you are willing to take part in a focus group please complete the enclosed form and send it to us in the envelope provided, or contact us directly. Our contact details are provided below.

Further Information

If you are interested and you would like further information on the study, please contact:

Sangeeta Chattoo
Dept of Health Sciences
University of York
Heslington
York
YO10 5DD
Tel: 01904 321327
Email: sc543@york.ac.uk

Marilyn Crawshaw
Dept of Social Policy & Social Work
University of York
Heslington
York
YO10 5DD
01904 321254
mac7@york.ac.uk

Karl Atkin
Dept of Health Sciences
University of York
Heslington
York
YO10 5DD
01904 321355
ka512@york.ac.uk

Information Sheet for Professionals focus groups, Nov 2007

Revised Topic Guide for focus groups with professionals

19/02/09

In this focus group discussion we want to cover the following broad themes. We are aware that some of these might be more relevant to some of you than others.

1. Long term impact of cancer treatment and access to follow up service
2. Practical aspects of discussing and addressing fertility related issues – preservation, fertility analysis and introducing assisted conception techniques
3. Ethical and cultural issues
4. Interdisciplinary links and communication between departments and services, and networks across statutory and voluntary sectors of health and social care
5. examples of good practice, main strengths of your service (issues of equity)
6. addressing gaps and policy support

1. Long term impact of cancer and access to service

1.1 From your own disciplinary perspective, what are the significant long term implications of treatment related to cancer for people diagnosed in their teens or early adulthood?

- How good is the psychological and social support for younger people affected by cancer treatment?
- Does a diagnosis of cancer affect access to fertility support in positive and negative ways?

(Please provide some examples or scenarios covering the range of issues and services your average patient might encounter)

1.2 How important do you think is the issue of **potential threat to fertility** for your younger patients?

- Who is the most appropriate professional to first introduce the subject of disruption to fertility to a younger patient?
- How do you explain the potential impact of treatment on fertility to your patients
- How often is this issue raised again following treatment (early and late follow up)?
- Have you noticed any differences in how younger men and women respond to this news?
- Do South Asian patients respond differently? Please give some examples
- Do you face any difficulties in raising the subject of potential disruption to fertility with younger patients?

1.3 Issues related to fertility preservation

- How do you explain the options of fertility preservation to your patients? (men and women)
- What kinds of ethical or religious issues do you think your patients face in relation to options related to preservation?
- How well do you think your average patient understands the different parts of the consent form to give informed consent?
 - How do you conceive these – similar to tissue samples or potential life?
 - Do you have any ethical concerns about how gametes are stored and for how long?
 - Or what happens to unused samples? What do you think should be done with unused samples?

1.4 How do you decide whether or not to discuss contraception with your patients?

- What kind of related information do you routinely provide your patients
- Do you think patients follow your advice about delaying having children?

1.5 Issues related to fertility analysis

- How do you decide on the appropriate time and place to raise the issue of fertility analysis?
- Do you think it is a good idea for people to have a test?
- Do you think men and women both would ideally like to have a fertility test?
- Why do you think some people may not wish to have a test?
- Who, in your experience, is less likely to go in for a fertility test and why?

3. Support with alternate routes to parenting

- What kinds of option to alternate routes to conception/ parenting are you able to suggest to your patients?
- How do you decide on who should be offered what?
- Under what circumstances within the context of a life limiting condition would you have ethical concerns about somebody's desire to be a parent? Why?

4. Inter-disciplinary communication within and outside NHS

- How well does inter-departmental communication work to provide adequate support to people with fertility preservation, testing and assisted conception technologies?
- Who attends the team meetings – examples of MDTs.
- Examples of what works well across departments
- Examples of what works across sectors of care
- Examples of weak links – where are the gaps?
- Addressing issues of diversity and equity (gender, sexual orientation and ethnicity)
- What needs to change to address some of the current gaps identified (level of policy, commissioning or roles within teams?)

Experiences of cancer-related fertility matters among people of White and South Asian origin

Information Sheet for health and social care professionals taking part in an interview

The purpose of this leaflet is to outline the above study and explain what will happen if you decide to take part in an interview.

What is the project about?

We want to learn more from the experiences of adults aged 18 to 40 who have been through cancer treatments which may affect their fertility. We have already conducted approximately sixty, one to one interviews with them. We were interested to know more about what it is like to cope with fertility concerns, both at the time of being told and afterwards and what issues, if any, these raise for the individual within the context of their social relationships. We want to find out what has helped them and what did not. A full protocol is available from the research team.

We also want to find out what it is like for professionals to provide support to this group of patients and whether you face any particular issues in providing appropriate support to people from South Asian backgrounds. We would especially like to seek your views on current gaps in services and priorities for future developments.

Learning from their and your experiences, we hope to suggest ways in which the services are developed to provide more appropriate support to people of different ethnic and social backgrounds.

The study will involve participants (professionals and patients) from the Paediatric and Adult Oncology Units at St James University Hospital, Leeds; Christie Hospital, Manchester, Royal Manchester Children's Hospital; University College, London; and Barts Hospital, London.

Altogether, it will take us two years to complete the research. You will be sent a summary of our work, when we have finished it.

The main aims of the study are to:

- understand the social and emotional impact of actual or potential cancer-related fertility impairment on South Asian and White patients in the peak age groups for forming adult relationships and becoming parents, and their support networks ;
- examine decision making processes including those associated with fertility preservation, fertility testing, fertility treatments or other routes to parenthood;
- identify similarities and differences within the study population specifying where these are mediated by culture, religion or ethnicity; and
- suggest strategies for accessible and appropriate services of use to those responsible for planning, commissioning and delivering health and social care.

Revised topic guide interviews with professionals

10/03/09

1. Long term impact of cancer treatment and access to follow up service
2. Discussing and addressing fertility related issues
3. Identifying and addressing ethical and cultural issues
4. Interdisciplinary links and communication between departments and services, and networks across statutory and voluntary sectors of health and social care
5. examples of good practice, main strengths of your service (issues of equity)
6. addressing gaps and policy support

1. Long term impact of cancer treatment and access to service

1.2 From your own disciplinary perspective, what are the significant long term implications of treatment related to cancer for people diagnosed in their teens or early adulthood?

- How good is the psychological and social support for younger people affected by cancer treatment?
- Does a diagnosis of cancer affect access to fertility support? In what way?
- Do you think people whose fertility has been affected by treatment should have preferential access to assisted conception services and related support?

1.2 How important do you think is the issue of **potential threat to fertility** for your younger patients?

- How do you explain the potential impact of treatment on fertility to your patients
- Who is the most appropriate professional to first introduce the subject of disruption to fertility to a younger patient?
- How often is this issue raised again during early and late follow up sessions?
- Have you noticed any differences in how men and women respond to this news?
- Do South Asian patients respond differently? Please give some examples
- Do you face any difficulties in raising the subject of potential disruption to fertility with younger patients?

1.3 Issues related to fertility preservation

- How do you explain the options of fertility preservation to your patients?
- What kinds of ethical or religious issues do you think your patients face in relation to options related to preservation?
- How well do you think your average patient understands the different parts of the consent form for gamete storage to give informed consent?
- Do you face any ethical issues about discussing the subject with younger patients

2 Follow-up services once treatment is over

- What kind of issues are covered during follow up visits once treatment is over?
- What kind of information do you routinely provide your patients about avoiding conception during and following treatment?
- How do you decide whether or not to discuss contraception with your patients?
 - Do you think patients follow your advice?

2.1 Issues related to fertility analysis

- How do you decide on the appropriate time to raise the issue of fertility analysis?
- Do you think it is a good idea for people to have a test?
- Do you think men and women both would ideally like to have a fertility test?
- Why do you think some people may not wish to have a test?
- Who, in your experience, is less likely to go in for a fertility test and why?

3. Support with alternate routes to parenting

- What kinds of options to alternate routes to conception/ parenting are you able to suggest patients whose fertility has been affected by treatment?
- How do you decide on who should be offered what?
- What kind of responses do you get to these options?
- Under what circumstances within the context of a life limiting condition would you have ethical concerns about somebody's desire to be a parent? Why?

4. Inter-disciplinary communication within and outside NHS

- How does your team operate in relation to other teams and services that you are in contact with in routine work?
- Do you have any MDT meetings – how do these work?
- Examples of what works well across departments and sectors of care (NHS and voluntary sectors)
- Examples of weak links – identifying areas where it is difficult to offer support
- Addressing issues of diversity and equity (gender, sexual orientation and ethnicity)
- What needs to change to address some of the current gaps identified (levels of policy, commissioning or roles)?

Consent form for professionals

THE UNIVERSITY *of York*

CONSENT FORM FOR PROFESSIONALS

Title of Project: **Experiences of cancer-related fertility concerns among people of South Asian and White origin**

Name of Researchers: Sangeeta Chattoo and Marilyn Crawshaw

Please initial box

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected ☐

3. I agree to take part in the above study. ☐

4. I agree to the interview/ focus group being tape recorded and transcribed ☐

_____ Name of Participant	_____ Date	_____ Signature
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_____ Name of Person taking consent	_____ Date	_____ Signature
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Professional consent form version2: October 2007

Appendix D

Information brochure for patients September 08

Are there any benefits?

The study may not be of direct benefit to you. It may benefit patients in the future by improving the standard of care.

What happens next?

If you would like to discuss the study with us further before deciding whether or not you would like to take part, then do please phone us or send an email (see below). You could also discuss it with your consultant or other professionals that you know before deciding.

If you want to take part, please return the enclosed form in the stamped addressed envelope provided. Alternatively, you can hand it back to the staff at the clinic where you attend and they will return it to us. We will then contact you to arrange a time to meet. **Thank you.**

Sangeeta Chattoo	Karl Atkin	Marilyn Crawshaw
Department of Health Sciences	Department of Health Sciences	Department of Social Policy & Social Work
University of York	University of York	University of York
Heslington	Heslington	Heslington
York	York	York
YO10 5DD	YO10 5DD	YO10 5DD
Tel: 01904 321327	Tel: 01904 321355	Tel: 01904 321254
E-mail addresses:		
scs42@york.ac.uk	kas42@york.ac.uk	mac7@york.ac.uk

This research study is funded by Cancer Research UK

N.B. If taking part in this study harms you there are no special compensation arrangements. If you are harmed as a result of someone's negligence you may have grounds for legal action. Regardless of this, if you have any other cause to complain about any aspect of your treatment during this study, the normal NHS complaints mechanisms are available.



THE UNIVERSITY of York

Experiences of cancer-related fertility matters among people of White and South Asian origin

Information for Patients

Some questions answered

Version: InfoBrochure July 2008

This information sheet is about a research project in which we are inviting you to take part. Your decision to take part is entirely voluntary. If you do not wish to take part, this will not affect the care provided to you in any way. If you agree to take part you can withdraw from the study at any time and do not have to give a reason.

Why are you asking me to take part in this study?

When you were told that you had cancer, you may also have been told that the treatment involved might affect your ability to have children in the future. We are interested to know more about what it has been like for you to cope with that, both when you were told and over the time since and what issues, if any, it has raised for you.

By talking to people like you, we hope to better understand some of your experiences so that services can address the informational needs of people in a similar situation.

What is the study about?

We want to learn more from people who have been through this experience about what it was like. We want to find out what helped you and what did not and whether any of this was affected in any way by your being White or South Asian.

Learning from your experience, we may be able to improve the ways in which professionals try to help others in the future. We will be talking to people in their late teens through to their mid 30s.

What will be involved if I agree to take part in the study?

If you agree to take part, we will ask you to talk to one of us for up to an hour. If you decide to join and later change your mind and want to withdraw, that is OK. We will do our best to meet any preferences that you have for the interview in terms of language or whether the researcher is male or female.

When and where will the interviews take place? Who will know what I say to you?

We can visit you at home or at the hospital or elsewhere at a day and time to suit you. Everything you say will be confidential, which means that we will not tell your family or partner (if you have one) or any staff at the Unit what you have said, unless you want us to. We will also take care that you cannot be identified in anything that we write or say about the results from the study. We will ask if you are willing for the interview to be tape-recorded and will explain how we will make sure that the tape is stored securely at the university and how long we will keep it before destroying it. You can have a copy of the transcript of the interview if you wish.

The study will meet any 'out of pocket' expenses, including travel expenses, that you incur in taking part in the interview.

Where is the study taking place, and for how long?

The study is with patients in West Yorkshire, the Manchester area and London. Altogether, it will take two years to complete.

What will happen to the information you gather?

We will write and provide you with a summary of what we found from the study. We will also feed back to all the hospitals that took part. We will write about it in journals, so that staff who treat people in your situation in the future can read about the findings of the research. No names will be mentioned in any of the reports and care will be taken that individuals cannot be identified in reports of the results of the study.

Are there any risks?

There are no physical risks associated with this study; however it may cause you to think about issues which may be difficult or distressing. If you have any worries or want to ask any questions, the medical, nursing or social work staff would be happy to spend time talking with you. If you want us to arrange that, we will do so.

Information letter September 2007

THE UNIVERSITY *of York*

Department of Health Sciences

Second Floor,
Area 4,
Seeborn Rowntree Building
Heslington
York YO10 5DD

Telephone (01904) 321716
Fax (01904) 321383

www.york.ac.uk/healthsciences

date

(Initial letter to patients)

Dear

Re: Experiences of cancer-related fertility concerns among people of South Asian and White origin

We are writing to invite you to take part in a research study about your experiences of being told that your cancer treatment might affect your ability to have children in the future, and how you have coped with that. By learning more from people who have been through this, we hope that services can get better in the future. The staff in the Unit through which you have been approached know about the study and support it. The study is funded by Cancer Research UK.

As everyone taking part in this study is aged 16 and over, it is only the permission of those taking part that is required. It is also up to you whether you decide to tell anyone else that you are taking part.

We are based at the University of York, but we can come and visit you wherever you prefer, and at whatever time of day suits you.

We are enclosing a leaflet which tells you more about the study. We are also happy to talk to you about it some more before you decide if you want to take part in the study – just phone any of us on the numbers at the back of the leaflet or email. You can also talk to any of the professionals that you are in contact with, including those at the hospital where you got this leaflet.

If you are interested in taking part, then please fill out the attached form and post it back to us in the freepost envelope provided or hand it back to the hospital staff and they will return it to us.

Thank you for considering taking part.

Yours sincerely

Sangeeta Chattoo, Marilyn Crawshaw and Karl Atkin
Information letter Sept2007

Reminder letter November 2007

THE UNIVERSITY *of York*

date

Dear

Re: Experiences of cancer-related fertility concerns among people of South Asian and White origin

You were recently invited to take part in the above study. If you have decided to take part, we are writing to remind you that you will need to return the form that you were given by the person who told you about the study. We are enclosing a spare copy and a freepost envelope. This letter is being sent out automatically on our behalf from the hospital as we know that these forms can sometimes go astray. We, of course, do not know your identity.

If you have already returned your form agreeing to take part, then please ignore this letter as we will be contacting you shortly to make the interview arrangements.

If you have decided not to take part, then we would like to thank you for considering taking part and assure that we will not be contacting you again.

With best wishes,

Yours sincerely,

Sangeeta Chattoo, Marilyn Crawshaw and Karl Atkin
Researchers

Reminder Letter November 2007



CONSENT FORM FOR PATIENTS

Title of Project: **Experiences of cancer-related fertility concerns among people of South Asian and White origin**
Name of Researchers: Sangeeta Chattoo, Marilyn Crawshaw and Karl Atkin

Please initial box

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree/ disagree to my GP being informed of my participation in the study ☐
4. I agree to take part in the above study. ☐
5. I agree to the interview being tape recorded and transcribed ☐

Name of Patient	Date	Signature
-----------------	------	-----------

Name of Person taking consent	Date	Signature
-------------------------------	------	-----------

Patient consent form: version 2, November 2007

GP letter

THE UNIVERSITY *of York*

Department of Health Sciences

Second Floor,
Area 4,
Seeborn Rowntree Building
Heslington
York YO10 5DD

Telephone (01904) 321716
Fax (01904) 321383

www.york.ac.uk/healthsciences

date

Dear Dr

**Re: Experiences of cancer-related fertility concerns among people of
South Asian and White origin**

I am writing to inform you that your patient, xxxxxxxxxxxxxx, has agreed to take part in a research project looking at the experiences of cancer-related fertility matters among people of White and South Asian origin. There are no implications for their treatment.

Yours faithfully,

Name
Researcher

GP Letter

Biography sheet November 2007

Biographical details:

Ref:

Personal Information:

Age now:..... Age at diagnosis:..... Difference (yrs and mths).....

Ethnicity:.....

Religion (if any):.....

Impairment/health condition (if any) prior to cancer diagnosis.....

Highest level of education to date-

Full time school ☐ Further education ☐

Higher education ☐

Professional qualification ☐

Current education/work situation

Full time school ☐ Further education ☐

Higher education ☐

In training ☐ In f/t. employment ☐

In p/t. employment ☐

On sickness/invalidity benefit ☐

Other ☐ (Please specify)

Living situation:

	<i>diagnosis:</i>	<i>current</i>
Living with one parent (specify)	<input type="checkbox"/>	<input type="checkbox"/>
Living with both parents:	<input type="checkbox"/>	<input type="checkbox"/>
Living with partner alone	<input type="checkbox"/>	<input type="checkbox"/>
Living with partner and children	N/A	<input type="checkbox"/> (specify no & ages of children.....)
Living with extended family	<input type="checkbox"/>	<input type="checkbox"/>
Living alone	<input type="checkbox"/>	<input type="checkbox"/>
Living in shared accommodation	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

Any other details:.....

Medical information:

Type of cancer:.....

Prior diagnosis (length of time):.....

Biography Sheet, Nov. 2007

Topic guide patients

The comparative experiences of fertility concerns following cancer treatment among South Asian and White populations

TOPIC GUIDE

This guide is an aide memoir for the interviewer. It details the topics to be covered in the interview and not the actual questions. Phrasing of the questions and the amount of detail to probe, will be determined by the responses of, and negotiation with, the interviewee. Attention to be paid throughout to ethnicity and gender as perceived variables affecting the experiences, although such variables will be explored in greater detail during analysis as the research team compare and contrast different interviews.

1. Experience of being told about impact of treatment on fertility at the time of diagnosis and starting treatment

- Memories of the process leading up to diagnosis, diagnosis itself and immediately afterwards? General response to diagnosis and main concerns at that time (contextual prompts; temporal prompts)
- Emotional experience; cognitive understanding of being told that treatment might affect fertility (prior knowledge; comprehension at the time and afterwards – memories of what was said and what it meant – any changes in understanding or recall since; anything that reinforced or diluted the impact, including ethnicity and gender)
- Prior experience if any of talking about fertility or sexual matters – (i) with professionals, (ii) partners (ii) family members (iii) peers (iv) others. Content and purpose of discussion. (Did person discuss different things with different people? Why?)
- Sort of help, information available at the time about fertility-related matters, people to talk to, if any?
- What made it worse; what made it easier? Did ethnicity or gender make any difference - or anything else?
- Who/what *could* have been helpful if available? Views on this influenced by ethnicity, gender or anything else?
- Use of written, internet or audio visual materials and so on, if any – actual or potential use at different stages
- Mapping of who was *actually* involved in relation to fertility and related aspects – what was helpful; what not (professional and partner/family/friends)

For those who used fertility preservation services

- What level of help, information, people to talk to were available in making the decision and acting on it; getting ready to go to the ACU – professional and partner/family/friends etc? Level of involvement of parents/carers/partners by professionals. (influence of ethnicity, gender and so on)

Some useful websites and organisations

British Infertility Counselling Association – www.bica.net - this is the only specialist infertility counselling association. All licensed assisted conception clinics have to provide a counselling service by law but some only provide a very limited free service and additional sessions have to be paid for. Some BICA members are also willing to see people privately and completely independently of any treatment. The website includes a list of counsellors and gives some indication of their charges

Cancerbackup – www.cancerbackup.org – perhaps the largest support organisation for people living with cancer. They produce a mass of written information in leaflets and through their website. They also have a telephone helpline both for information and to provide telephone support to people coping with any aspect of cancer

Daisy Network (formerly called Daisy Chain) – www.daisynetwork.org.uk – a support group for women that focuses on premature menopause (also known as Premature Ovarian Failure or POF) – that is a menopause before the age of 40. It also produces written information and has a useful website.

DC Network – www.dcnetwork.org - this is the largest self help support group for people considering using egg, sperm or embryo donation, or people who have already become parents through this route. They also offer support to donor conceived offspring. They believe in the importance of parents being open with their children about their origins. They produce lots of useful written information; have DVDs, a library; e-newsletters; and hold national meetings twice a year.

FertileHOPE – www.fertilehope.org – this is a website from the USA which includes specific sections about infertility following cancer.

Fertility friends – www.fertilityfriends.org – another website which aims to provide information and support to people coping with involuntary childlessness.

Human Fertilisation & Embryology Authority - www.hfea.gov.uk - this is the body that regulates all assisted conception treatments in the UK. Their website lists all licensed centres. They also publish free information leaflets and a free Patients Guide which suggests questions to ask when seeking treatment etc.

Infertility Network UK – www.infertilitynetworkuk.com – this is the largest support group for people coping with involuntary childlessness, many of whom may be going through assisted conception treatments. It has a helpline staffed by trained counsellors at certain times of the week; produces fact sheets and a newsletter, runs regional support groups, has tel numbers for people willing to talk to others about their experiences etc.

More to life – www.moretolife.co.uk – this is an initiative run through InfertilityNetwork UK to acknowledge the fact that some people will not be successful in becoming parents even though they wish to be. Has a helpline, website and local groups/contacts.

Pink Parents – www.pinkparents.org.uk – this is a support group for lesbian women who are already parents or for those who wish to be (including through assisted conception)

Appendix E: Letter explaining recruitment process to collaborating teams

Experiences of cancer-related fertility concerns among people of South Asian and White origin

Eligibility Criteria and Recruitment Process

As you know, we are looking to recruit approximately 40 (in total) males and females from the South Asian community and 20 (in total) from the White UK community in total for this study. Within the South Asian cohort, we aim to recruit:

- 15 people of Pakistani origin (likely to be Muslim)
- 15 people of Indian origin (likely to be Hindu or Sikh)
- 10 people of Bangladeshi origin (likely to be Muslim)

Each will be asked to agree to take part in a single interview in a location of their choosing, which should take approximately an hour to complete. We will ask their permission to tape record the interview. The usual rules of confidentiality will apply and interview transcripts will be coded with numbers known only to the research team. Participants will be offered a copy of their transcript, the summary of findings and a full copy of the final report.

We hope to recruit as diverse a group as possible into the study, reflecting differing background experiences around social class, sexuality, disability, living situation etc. We will provide language or signing interpreters as necessary, including any specialist communicators for any disabled participants who require this.

We will pay travel and subsistence expenses.

Eligibility criteria:

- (i) Males and females aged 18 to 40.
- (ii) Diagnosis of sarcoma, lymphoma, testicular cancer or breast cancer.
- (iii) Diagnosed at any age.
- (iv) Childless at diagnosis.
- (v) Aware that there is a risk to their fertility, regardless of the level of risk.
- (vi) Not in any major treatment phase at the time of being approached.
- (vii) Reasonable chance of five year survival if this milestone has not yet been achieved.

Recruitment process

Potential participants will be identified through the consultant, senior doctors and clinical/ specialist nursing staff in the unit. Participants will be approached by a senior doctor or a specialist/research nurse, usually at a routine face to face appointment. They will outline the focus of the study and explain what will be involved. Anyone interested will be provided with:

- Patient information letter.
- Information brochure.
- 'Agreement to contact' form.
- Freepost envelope.

The patient will be invited to return the 'agreement to contact' form to the researchers direct. On receipt, the researchers will liaise directly with the patient to answer any further queries and make the interview arrangements.

All those approached *and agreeing to consider participation*, will be sent the 'reminder' letter approximately 2-3 weeks after the initial approach. This will contain the following:

- Reminder letter.
- Patient information letter.
- Information brochure.
- 'Agreement to contact' form.
- Freepost envelope.

Recruitment diary

Each recruitment site will be asked to keep a record of approaches that have been made and the outcome. In order to avoid re-approaching people who have declined, their names will be noted by the clinical team but information anonymised before being passed on to the research team. This will *not* include the name of the patient, only their age, ethnicity, gender, month in which they were approached and response. Recruitment tables will be provided by the research team and collected every three months. The research team will give regular feedback to each site on take-up.

Formal consent will be obtained by the researcher prior to the interview starting (consent forms attached).

Informing GPs

Participants will be provided at the research interview with a letter to their GP that they can pass on if they wish. This letter will simply inform the GP that they have participated in the research.

Eligibility and recruitment Version 1, 2007

APPENDIX F:

ASSOCIATED DISSEMINATION ACTIVITIES

Title	Type of presentation and setting	Audience
Negotiating risk to fertility caused by (cancer) treatment: alternate engagements across the analytical and experiential registers (SC)	Presentation at annual Medical Sociology Conference (BSA), Manchester, September 2009	Academic (Social Science)
Sperm banking for teenagers: Messages from research' (MC)	Canadian Fertility and Andrology Society Annual Meeting, Montreal, November 2009 (Nurses Special Interest Group)	Nursing professionals
Young people managing fertility issues associated with cancer' (MC)	Canadian Fertility and Andrology Society Annual Meeting, Montreal, November 2009 (Counselling Special Interest Group)	Counselling professionals
Treatment related risk to fertility, ethnicity and identity: findings from a recent CRUK project (SC)	Seminar at the St James's Hospital, Oncology Department June 2010	Oncologists, nurses and other health and social care professionals working within the area of cancer and fertility
Treatment related risk to fertility, ethnicity and identity: findings from a recent CRUK project (MC)	Seminar at NowGen, St Mary's Hospital, Manchester May 2010	Doctors, nurses, scientists, social workers and counsellors working within the area of cancer and fertility
Treatment related risk to fertility, ethnicity and identity: findings from a recent CRUK project (SC)	Seminar presented as part of the Medical Oncology Education programme, Institute of Cancer and the CRUK Clinical Centre, St Bart's London June 2010	Oncologists, health care researchers, nurses
Managing the experience of cancer-related fertility matters: does ethnicity matter and what should be the professional response? (MC)	Workshop paper at 6 th International Conference on Health and Mental Health in Social Work, Dublin June 2010	Social Workers

The long term impact of cancer: negotiating threats to fertility and identity (SC); Recommendations (MC)	Paper presented at the national conference on Beyond 'Survivorship', Leeds July 2010	Health and social care professionals, academics
Female experiences of fertility and cancer – double jeopardy? (MC)	Evening seminar organised by Serono, Perth, Australia August 2010	Presentation to Oncologists, and other health and social care professionals working within the area of cancer and fertility
Female experiences of fertility and cancer – double jeopardy? (MC)	Seminar for nurses, Perth Australia August 2010	Nurses working primarily in fertility settings
Female fertility and cancer – who cares? (MC)	Seminar at Centre for Women's Health, Gender and Society, Melbourne School of Population Health University of Melbourne Australia August 2010	Academics from a range of disciplines
The moral maze of cancer related threats to fertility: Negotiating 'preservation', consent and choice (SC)	Paper to be presented at the BSA, Annual international conference at Durham September 2010	Academics (Social Science), health and social care professionals
Ethnicity and engaging with the use of reproductive technologies (SC)	Invited paper, ESRC workshop, Department of Anthropology, University of Durham December, 2010	Academics, health and social care professionals

CONFERENCE FLYER

Registration form

Please complete the following registration form and return it to Anne Burton at the Department of Health Sciences, University of York, Seebohm Rowntree Building, Area 4, Heslington, York YO10 5DD.

You can register online at: www.york.ac.uk/healthsciences/lookingbeyond.htm
If you require any further information, please email: survivorship@events.york.ac.uk

Name _____ Title _____

Work address _____

Daytime telephone number _____ Email _____

Particular dietary needs (please specify): _____

Any other needs you would like us to know about prior to the conference (please specify): _____

The conference venue does have access for people with mobility difficulties. There is also a loop system for people with hearing impairment.

The conference is free of charge, although an administration fee of £25 will be charged to those who do not give us sufficient notification of not being able to attend the conference.

Please indicate which workshop you would like to attend.

- ☐ Workshop one: Ethnicity and issues of fertility.
Professor Lorraine Culley and Dr Nicky Hudson, De Montfort University.
- ☐ Workshop two: Involving BME patients and other BME community members in the development of cancer services.
Rose Thompson, BME Cancer Communities.
- ☐ Workshop three: Dealing with policy, commissioning and strategic issues in developing services for teenagers and young adults.
Mr Sean Duffy, Medical Director, Yorkshire Cancer Network, Harrogate and District NHS Foundation Trust and Kim Fell, Network Director for North Trent Cancer Network.
- ☐ Workshop four: Reflecting on and negotiating issues of sensitive communication: working within ethnically diverse communities.
Dr Jane Boden, University of Hull and Infertility Counsellor, British Infertility Counselling Association.
- ☐ Workshop five: Service provision for BME cancer patients: responding to needs, desires and aspirations.
Professor Gurch Randhawa, University of Bedfordshire.

THE UNIVERSITY of York



Looking beyond cancer 'survivorship': meeting the needs of a diverse, multi-ethnic society

A one day national conference to present policy and practice debates about how best to meet the needs of childhood and adult cancer 'survivors' in a diverse, multi-ethnic society.



Wednesday 7th July 2010

**Venue: Thackray Medical Museum,
Beckett Street, Leeds, LS9 7LN.
10.30am to 4.30pm
Coffee and registration from 10.00am**



This will be a valuable day for practitioners from a range of disciplines, commissioners, voluntary organizations, researchers and those personally affected by cancer, to debate and develop workable solutions for providing appropriate and accessible care.

The event is free of charge. It is organised by the Department of Health Sciences and the Department of Social Policy and Social Work, University of York and is supported by Macmillan Cancer Support and the British Infertility Counselling Association (BICA).

Places are limited and will be allocated on a first come, first served basis. For further details, please contact survivorship@events.york.ac.uk Alternatively please www.york.ac.uk/healthsciences/lookingbeyond.htm

Who should attend?

- Health and social care professionals (including oncologists, fertility specialists, specialist nurses, social workers, counsellors), commissioners and representatives of voluntary and community organisations with an interest in offering and developing support for those living with cancer.
- Researchers interested in the long term psycho-social consequences of cancer and the problems in improving access to appropriate services for people from different ethnic backgrounds.
- Those personally affected by cancer and family carers, who would like to share their experiences and ideas with a view to improving access to services.



The programme includes:

The day will be chaired by **Professor Mark Johnson** (De Montfort University). Highlights of the morning session include:

- a key note address by **Professor Sir Mike Richards CBE** (National Cancer Director, Department of Health) on the recent policy initiatives on cancer survivorship;
- findings from a recently concluded CRUK funded qualitative research study for the University of York looking at the longer term impact of cancer on fertility and identity among younger adults (18-40 years) of White and South Asian backgrounds;
- findings drawing on the experience of the Macmillan Survivorship Research Group, School of Health Sciences, University of Southampton, on how to involve ethnic minority populations in research and service delivery;
- experiences of other research teams involved in collaborative work in developing services with and for people from minority ethnic communities.
- personal experiences of those directly affected by the long term impact of cancer.

The afternoon workshops provide an opportunity for a more open-ended exchange of ideas. Please indicate your choice on your booking form.

Workshop one: Ethnicity and issues of fertility (moderators: Professor Lorraine Culley and Dr Nicky Hudson, De Montfort University).

Workshop two: Involving BME patients and other BME community members in the development of cancer services (moderator: Rose Thompson, BME Cancer Communities).

Workshop three: Dealing with policy, commissioning and strategic issues in developing services for teenagers and young adults (moderator: Dr Sean Duffy, Medical Director, Yorkshire Cancer Network, Harrogate and District NHS Foundation Trust and Kim Fell, Network Director for North Trent Cancer Network).

Workshop four: Reflecting on and negotiating issues of sensitive communication: working within ethnically diverse communities (moderator: Dr Jane Boden, University of Hull and Infertility Counsellor, British Infertility Counselling Association).

Workshop five: Service provision for BME cancer patients: responding to needs, desires and aspirations (moderator: Professor Gursh Raudhawon, University of Bedfordshire).

Looking beyond cancer 'survivorship': meeting the needs of a diverse, multi-ethnic society



Programme

- | | |
|----------|---|
| 10.00 am | Coffee and registration |
| 10.30 am | Introduction by Chair, Professor Mark Johnson (De Montfort University) |
| 10.40 am | Key note address: Professor Sir Mike Richards CBE (National Cancer Director, Department of Health) |
| 11.10 am | The long-term impact of cancer: negotiating threats to fertility and identity Dr Sangeeta Chattoo and Dr Marilyn Crawshaw (University of York) |
| 12.00 pm | Break |
| 12.20 pm | Personal Voices by jimmyteens.tv |
| 12.35 pm | Involving patients from minority ethnic groups in service delivery and research Dr Deborah Fenlon (Macmillan Survivorship Research Group, School of Health Sciences, University of Southampton) |
| 1.05 pm | Lunch |
| 2.15 pm | Workshops - please choose a session from the options listed (left) |
| 3.15 pm | Break |
| 3.30 pm | Feedback from workshops and panel discussion |
| 4.30 pm | Close |

WEBSITE

<http://www.york.ac.uk/healthsciences/research-information/conference-cancer-survivorship/>



Health Sciences University

University | A to Z | Departments

Health Sciences » General research information » Looking beyond cancer 'survivorship'

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- Studying nursing
- Studying midwifery
- Foundation degree
- Undergraduate part-time study (CPD)
- Postgraduate study
- Research
- Our staff
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- Information for mentors
- Information for current students
- Information for staff
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Looking beyond cancer 'survivorship': meeting the needs of a diverse, multi-ethnic society

A one day national conference exploring policy and practice debates about how best to meet the needs of childhood and adult cancer 'survivors' in a diverse, multi-ethnic society was held at the Thackray Museum, Leeds on **Wednesday 7th July 2010**. The Department of Health Sciences and the Department of Social Policy and Social Work, University of York organized the event, which was supported by Macmillan Cancer Support (<http://www.macmillan.org.uk>) and the British Infertility Counselling Association (<http://www.bica.net/>)

This website contains presentations given at the conference and as way of context we provide a summary of the day.

The audience included health and social care practitioners and academics in addition to cancer survivors and their families. **Professor Mark Johnson** (DeMontfort University), one of the leading UK scholars on ethnicity and health, chaired the event. National Cancer Director, **Professor Sir Mike Richards**, CBE used the plenary address to outline the current policy priorities of the Department of Health.

Other keynote talks explored the long-term impact of cancer on fertility (**Dr Sangeeta Chattoo** and **Dr Marilyn Crawshaw**) and how best to involve patients from minority ethnic groups in service delivery (**Dr Deborah Fenlon**, University of Southampton). **Jimmyteens.tv** presented a documentary, especially prepared for the event, in which young people talked about living with cancer (<http://www.jimmyteens.tv/2010/07/13/beyond-cancer/>), while **Katherine Lee** spoke of own personal experiences of survivorship, following a diagnosis of cancer, nineteen years ago.

Afternoon workshops, offering more open discussion, focused on **fertility** (**Professor Lorraine Culley** and **Dr Nicky Hudson**, University of DeMontfort); user involvement in service delivery (**Rose Thompson**, BME Cancer Communities); commissioning (**Sean Duffy**, Yorkshire Cancer Network and **Kim Fell**, North Trent Cancer Network); communication (**Dr Jane Boden**, British Infertility Cancer Association); and responding to the needs of ethnic minority populations (**Professor Guruch Randhawa**, University of Bedfordshire).

The conference is one in a series of dissemination events associated with a CRUK (<http://www.cancerresearchuk.org/>) funded project - led by **Professor Karl Atkin** - exploring the experience of cancer related fertility in an ethnically diverse population. Summaries of this project will also be available on this website in September. For further information contact Karl Atkin (ka512@york.ac.uk).



Presentations

- [Boden Workshop \(MS PowerPoint@ 44kb\)](#)
- [Chattoo Presentation \(MS PowerPoint@ 290kb\)](#)
- [Crawshaw presentation \(MS PowerPoint@ 766kb\)](#)
- [Duffy Workshop \(MS PowerPoint@ 73kb\)](#)
- [Fell Workshop \(MS PowerPoint@ 2,387 kb\)](#)
- [Fenlon workshop \(MS PowerPoint@ 475kb\)](#)
- [Hudson and Culley Presentation \(MS PowerPoint@ 377kb\)](#)
- [Lee Presentation \(MS Word @ 1kb\)](#)
- [Richards Presentation \(MS PowerPoint@ 336kb\)](#)
- [Randhawa Workshop \(MS PowerPoint@ 108kb\)](#)
- [Thompson Presentation \(MS PowerPoint@ 4,245kb\)](#)

SUMMARY



Experiences of cancer-related fertility concerns among people of South Asian and White origin

Introduction

This is a summary of our research exploring the personal impact of cancer treatment on fertility, within the context of a **multi-cultural society**. We talked to 47 men and women from White (n=26) and South Asian (n=21) backgrounds, aged between 18 and 40 years old, who had different types of cancer. We also spoke to a few partners who were keen to be involved.

We asked about their experiences of the long term (social and emotional) impacts of treatment and any specific issues related to fertility that they might have encountered. We were especially interested in how people made decisions about their treatment and how they felt these decisions might impact on their fertility. We also asked them about the kind of information and support they received from health and social care professionals and the role played by family and friends.

In addition, we spoke to various professionals involved in cancer and fertility services, in groups and individually. This helped us explore their views on taking care of younger people affected by cancer and how they respond to patients from minority ethnic backgrounds. It also enabled us to understand how different services and sectors work in relation to each other

The main aims of our research were to compare the experiences of younger men and

women from different ethnic backgrounds; identify gaps in service provision; and make some recommendations to address these gaps. This summary offers highlights from our findings. To help illustrate some points, we have used quotations from the people we spoke to. These are in italics. If you would like more information, the full report can be downloaded from the web address listed at the end.

Being diagnosed and having treatment

Most participants felt that they had received efficient and timely medical care. However, a few believed their GPs had not taken the severity of their complaints seriously. This might have been due to their young age. One of our participants said that getting her GP to refer her for investigations was like 'squeezing blood out of a stone':

I went four times with such excruciating pain and I begged them, and they forwarded me. So I'd urge GPs to try and listen to their patients. I mean, we're not just saying it for the hell of it.

The potential risk to fertility caused by a particular cancer treatment is usually discussed during initial consultations about diagnosis. Doctors, however, cannot be certain about risks and are not able to give definite answers to individual patients. Some participants found it difficult to understand why they were not given more definite information. Others on the other hand found the uncertainty comforting, allowing 'a

window of hope to remain open' and the possibility that 'things might turn out all right'.

Professionals relied on ethnicity-based explanations when talking about South Asian or other minority groups. Inappropriate stereotypes could therefore emerge, leading to some professionals interpreting similar responses very differently according to the ethnic background of the patient.

Facing a risk to fertility is different for men and women. Most men were able to preserve a sample of sperm, irrespective of their ethnic or religious background; contrary to the assumptions of some professionals about religious proscriptions for certain groups, especially Muslims.

Most men were aware of the possibility of a 'fertility test' but did not necessarily want to have one until they were in a stable relationship or thinking of settling down and having children. Professionals working within oncology often supported this decision, recognising the importance of hope in helping people move on and deal with their illness.

Many women did not have a choice to preserve eggs, embryos or ovarian tissue. This was due to the technical difficulties of the procedures and the time involved (four to six weeks), which could potentially delay a start of treatment.

Retrospectively, women who faced problems in conceiving naturally felt that they had not been given enough information or opportunity to discuss the matter with a specialist. As observed by one of the participants:

I do understand that my fertility wasn't the priority of a single doctor in the hospital. Their priority obviously is getting me better. But I just

always felt that as a young woman, someone maybe should have recognised that and been able to talk me through at least over a longer period of day, rather than being dropped on me like a bombshell.

Preservation of gametes (sperm, eggs, embryos) throws up many personal and ethical issues. Younger people in particular are forced to reckon with profound issues such as the meaning of procreation, kinship and death.

The process of consent for preservation involves a redefinition of what might have been up until now, a transitory relationship to one with a commitment to raising children together.

Professionals are aware of the dynamics of the changing nature of interpersonal relationships. They, however, struggle to resolve various ethical issues about preserving and using gametes when someone is terminally ill, or not likely to survive and be able to use their own stored gametes.

Long term care and psychosocial support

Most men and women felt that, unless raised by them, fertility had not been discussed during follow-up consultations. Even when women were asked whether their periods had resumed, they often did not make the link with fertility, seeing it more as a general question about the temporary side effects of the treatment. Some would have liked health care professionals to be more explicit about the issue of fertility, following treatment.

Further, clinicians advise their patients to use contraception and avoid having children or conceiving for three to five years following treatment; a mile stone for achieving remission or cure. Such advice often sends conflicting messages to individuals about their fertility.

One woman who was prescribed hormonal treatment for premature menopause was still advised to use a contraceptive by the chemist, resulting in anxieties about getting pregnant, mixed with a ray of hope that she might still be able to have children.

In addition, waiting for three to five years following treatment may not fit easily with the life plan of many who wish to have a child.

Individuals often negotiate a 'safe period' for having children, with or without the approval of clinicians. Most couples, for example, wait for a year to let the effects of chemotherapy 'flush out' of their system. One couple had planned on having their second child around the time the husband was diagnosed. His wife remarked:

I've waited the year, in that sense, if his cancer did come back, there's nothing I can do about it. But we can't stop living our lives... And I said, well, I am not going to live my life thinking what if. If it does happen we will deal with it, if it doesn't we get on with it.

Even though the husband in the above case took recourse to his Muslim faith to help him deal with the dilemma, his belief in 'what will be will be' (fate) did not preclude him from preserving a sperm sample before starting treatment or undergoing a fertility test to find out whether or not he was fertile.

Participants across different ethnic groups who had a faith, took recourse to religion in helping them make a right moral choice, and seek meaning in hardship. Religious teachings did not necessarily predefine their actions related to treatment. As observed by a man of Catholic faith who was contemplating using a sperm donor and was upset by the Pope's views:

It's just wound me up, about the Pope and what he's been saying about assisted conception, and the people who do that are sort of completely wrong and immoral. And I think that has sort of shook my faith quite a lot.

Participants from different ethnic backgrounds faced different social and cultural pressures. These can be broadly defined as 'pronatalist', reinforcing a need to have children; for example, the idealised view of a large Irish family, or the traditional values held by some South Asian families about having sons.

However, the association of womanhood with motherhood cut across cultural backgrounds. And many men – irrespective of their ethnic origin – found the prospect of infertility threatening to their manhood. Similarly grandparents' desire to have grandchildren is found in all ethnic and cultural groupings.

Despite these wider pressures, the threat to fertility was interpreted and experienced differently, when considered alongside a serious illness such as cancer. The complexity of reflecting on the meaning of cancer, while coming to terms with the risk of being childless implicated a need for highly specialised and trained health and social care professionals who can provide appropriate support to people in different cultural (and religious) settings.

Referrals to a generic professional, such as a counsellor or clinical psychologist, can at times be counter-productive. One of our participants who visited a counsellor because she was struggling with the prospect of not being able to have children said:

I started to get a bit tearful and said, 'I'm really concerned that I won't be able to have children.' And she didn't address it at all, just kind of skipped it and finished the session, and I just thought, 'Well, actually if we're not going to

address the one issue I'm struggling with, I'm not going to (go back).

We found that support and advice about education and employment need to be a part of support for long term care. Often the long-term physical and psychological side effects of treatment are exacerbated by loss of work or educational opportunities. Employers and educational institutions may not recognise the non-visible signs of illness beyond treatment.

Participants whose education or employment had been disrupted following treatment, often struggled to find advice regarding benefits and financial help. It is important to offer financial advice regarding benefits irrespective of prognosis.

Recommendations

Patients of all ethnicities should be offered an opportunity to consult a specialist in reproductive medicine before starting cancer treatment. It is especially important to avoid partial or rushed advice when discussing options for preservation of gametes with women, given the additional complexity of such processes and potential outcomes. More openness about the possible options and their likely outcomes would also be appreciated by patients.

All patients, including those where the need for treatment is too urgent to allow cryopreservation options to be considered, should be offered an early opportunity to discuss fertility matters again once cancer treatment is underway.

It is important to incorporate discussions of fertility routinely in long term follow up care, taking care to use plain language and to involve specialist therapeutic/psycho-social support services as necessary.

Another useful strategy would be to incorporate advice on financial

assistance/benefits into the discharge and follow up routine, irrespective of the prognosis or severity of illness.

Better coordination and communication between primary and secondary/tertiary care during and following treatment, including in relation to fertility, would improve continuity of care and offer better signposting for a range of support and advice not included in routine care.

Professionals need to have greater confidence in responding to situations without relying on 'fact-files' or generalisations about the cultural practices of minority ethnic groups. Incorporating attention to reflective/reflexive processes in professional training and support is called for. Engaging with cultural, religious and ethnic diversity and challenging stereotypes is an important step forward and helps empower professionals to raise meaningful questions within the context of providing care to an ethnically diverse population.

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October 2010

This is a summary of a CRUK funded research project, 'The experience of cancer-related fertility impairment among people of South Asian and White Origin' (C8351/A9005). Other summaries (including one aimed at professionals) and information about the research, along with details from a conference organised to disseminate our findings can be found at <http://www.york.ac.uk/healthsciences/research-information/conference-cancer-survivorship/>.

For further information about the research please contact Karl Atkin (ka512@york.ac.uk)

**Experiences of cancer-related fertility concerns among
people of South Asian and White origin:
Summary for professionals**

Introduction

This is a summary of a qualitative research project that explored the personal impact of cancer treatment on fertility, within the context of a multi-cultural society.

Survival rates are improving, leaving increasing numbers living with the long term consequences of cancer treatments. Actual or potential fertility impairment can be one of those consequences and can, for some, affect recovery and well-being. Professionals, however, struggle to offer appropriate support.

We interviewed 47 men and women from White (n=26) and South Asian (n=21) backgrounds, aged between 18 and 40 years old, who had lymphoma, sarcoma, testicular or breast cancers. We were especially interested in how participants made decisions about their treatment in the light of its potential impact on their fertility, what kind of information and support they received over time from health and social care professionals and the role played by family and friends.

By recruiting a culturally diverse sample, we hoped to explore when ethnicity made a difference to people's experience and when it did not.

We also conducted focus group discussions and interviews with professionals involved in cancer and fertility services. These included doctors,

nurses, social workers, scientists, psychologists, counsellors, youth workers, commissioners and representatives from third sector organisations (n=33).

Our discussions with professionals helped us explore their views on taking care of people affected by cancer and, more specifically, their responses and experiences of offering care to patients from minority ethnic backgrounds. These conversations also enabled us to understand how different services and sectors work in relation to each other.

Diagnosis, treatment and follow-up

The potential risk to fertility caused by a particular cancer treatment is usually discussed during initial consultations about diagnosis. Doctors, however, cannot be certain about risks and are not able to give definite answers to individual patients.

Some patients found it difficult to understand why they were not given more definite information and were troubled. Others on the other hand found that the uncertainty afforded them hope.

Some professionals did not engage with the long term social and emotional consequences of infertility, seeing it instead as a physical state with little meaning beyond the capacity to reproduce. This led to missed opportunities for revisiting information,

discussing coping strategies and/or offering psycho-social interventions.

Referrals to generic rather than specialist therapeutic or other psycho-social services could on occasion prove counter productive. One of our participants who was struggling with the prospect of not being able to have children felt her concerns were not addressed, as the counsellor chose instead to focus on her experiences of having cancer.

What did the professionals see as key influences?

Overall, professionals saw **gender, age or life course** as having more influence on people's experiences than **ethnicity, culture or religion**. Those at the younger end, for example, were perceived to be less affected unless in 'serious' relationships or actively considering parenthood. Women undergoing treatment when close to menopause were seen as especially vulnerable to distress.

Women, in general, were thought to face a greater emotional burden when dealing with potential threats to fertility. Professionals explained this in three ways: motherhood was seen as an intrinsic part of their identity; the limited options for women to store gametes/embryos; and the potential for premature menopause. Some had known women (but no men) refusing cancer treatment as a result.

Oncologists emphasised the need to prioritise and start treatment. While appreciating professionals' concerns, some women we spoke to felt that they had not been given enough time or information at this stage. They would also have valued the opportunity to discuss their options of preservation with a specialist, even knowing their choices might be limited.

This would, they believe, have enhanced their present and future abilities to cope.

Professionals only called on **ethnicity-based explanations** when talking about South Asian or other minority groups, often assuming their homogeneity *and* conflating ethnicity, culture and religion. Inappropriate stereotypes could therefore emerge, leading to some professionals interpreting similar responses very differently according to the ethnic background of the patient.

While acknowledging that some professionals took a more nuanced view - engaging with the complexity of individuals' experiences in which religion, culture or ethnic origin *may* play their part - we provide a summary of the most common stereotypes.

Some professionals perceived 'South Asian' men as having particular difficulties with masturbation when banking sperm, because of assumed religious prohibitions within Islam. None of the Muslim men we interviewed supported this view. It was seen by them as a medical procedure related to a serious condition. Like other men interviewed - irrespective of ethnicity - it nevertheless generated unease and embarrassment.

While professionals recognised parents' desires to accompany their adult children to consultations, the involvement of South Asian parents/fathers was, at times, seen as controlling, intrusive and driven by concerns about 'arranged marriages', whereas that of 'white' parents was more often seen as reflecting their struggle to detach from the intensity of the shared cancer experience.

Similarly, some professionals associated South Asian cultures with a 'pronatalist bias' and strong patriarchal values and saw this as explaining relationship breakdown for couples facing fertility problems. In contrast, breakdown of 'white' couple relationships was seen to result from emotional strain.

Another tension occurred around the supposed 'culture of silence' which professionals identified exclusively with South Asian patients. Among our participants – again irrespective of ethnicity – not sharing fertility-related information beyond a close circle of friends and family reflected a wish for privacy.

This is not to deny that for some patients of South Asian origin, the relationship between self, close/extended family and wider community might operate differently. However, our research highlights more shared experiences of a serious illness and its repercussions than differences across ethnic groups.

What did patients see as key influences?

Not surprisingly, patients talked of the biographical disruption caused by cancer permeating many aspects of their lives and recovery. Uncertainty as to whether fertility had been damaged was a major issue for some and could add to, or supersede, uncertainties attached to the cancer experience alone. For others, it carried relatively little significance.

Gender influenced the emotional and physical consequences of potential infertility, especially within the context of options for preservation and its long term ramifications. However it was also clear that self worth, personal relationships and life planning of both women *and* men could be significantly affected.

Effects could be invisible to others and could differ across time and place, often related to changing life circumstances. This results in a need for different kinds of information and support at different times.

Culture and religion – irrespective of ethnic background – can provide shared frameworks for engaging with illness, treatment and its aftermath. For some who followed a religion, illness assumed meaning and purpose and religious teachings offered guidance. However, where guidance ran counter to personal inclinations – for example, in relation to assisted conception treatments – some patients accepted it, while others sought their own religious interpretation, sometimes in discussion with those close to them.

Religious values usually had enough flexibility to enable this. Professional generalisations about religious 'communities', therefore, need to be used with insight.

Finding a way forward for individuals also extended to negotiating 'cultural expectations' around fertility and reproduction according to gender, age, class and so on rather than ethnicity and religion alone.

Religion and culture are not the preserve of 'Asian' communities either. Professional accounts could also rely on cultural assumptions too. This is why some professionals found it hard to disentangle their personal value judgements (as part of their wider cultural frameworks) from professional assessments in addressing ethical dilemmas (also see below).

Consequently, the complexity of reflecting on the meaning of cancer, while coming to terms with the risk of being childless implicated a need for highly reflective and specialised trained health and social care professionals who can provide appropriate support to people in different cultural (and religious) settings.

Professional encounters with ethical dilemmas

Professionals in the field of oncology and reproductive medicine encounter various ethical issues. These include whether people receiving palliative care should be helped to become parents; posthumous use of stored gametes; and the use of gamete donation across the ethnic divide.

Professionals did not appear to draw much on research evidence or formal ethical decision-making frameworks. Instead, they tended to be influenced by personal beliefs and what they thought they might do if faced with a similar situation.

Sometimes professionals' moral or emotional uncertainties were lowered when specialist counsellors had been involved. They felt counselling 'wheeled out' 'unsuitable' people or otherwise led them to feel less morally responsible for the outcome of their own part in the intervention.

What needs to get better?

On the whole, professionals thought that they had got better at dealing with fertility matters at diagnosis and during treatment but believed they had a long way to go to match this standard when offering longer term follow-up.

Even so, some professionals guarded their right to exercise discretion in talking about

fertility *prior* to cancer treatment. Sometimes this was prompted by protectiveness about 'troubling' patients with such matters or by moral beliefs as to whether someone with a poor prognosis had a 'right' to parenthood. Following treatment, some considered it better to avoid offering fertility tests until a person was actively planning for parenthood, believing an earlier negative result could pose too great an emotional 'burden'.

Most patients felt that they had received efficient and timely care during diagnosis and treatment but felt that, unless raised by them, fertility had not been adequately discussed during follow-up contact.

Professionals, in turn, felt cautious about raising fertility matters during follow-up appointments for fear of causing distress, appearing intrusive, or in the words of one, opening a 'can of worms'. Some felt that time constraints within busy clinics made it difficult to deal properly with the matter; others feared 'getting it wrong', especially when the patient was younger or of a different ethnicity or gender from them.

Patients wanted professionals to use plainer language concerning risk to fertility without being blunt and to make clear what information and services might be available in the future. Women in particular did not always understand that questions about their menstrual cycle related to their reproductive capacity.

Patients and professionals alike recognised the need for improvements to psycho-social support, both through specialist therapeutic counselling and through specialist social work and related services.

Patients would have also liked more support and advice about benefits, education and employment and greater challenges to discrimination against cancer 'survivors'. Often the long-term physical and psychological side effects of treatment - including those to do with fertility - are exacerbated by loss of work or educational and training opportunities.

Facilitating culturally competent practice

Our research offered many examples of assumptions about 'Asian' families being governed by prescriptive norms laid down by religion and culture. These views remind us, yet again, of the challenges of achieving 'culturally competent care' alongside 'patient centred care' within a multi-ethnic society.

Understanding and engaging with ethnic diversity should be seen as integral to the general training of health and social care professionals, rather than as an *ad hoc* 'competence' to be achieved through brief training sessions. Nor is reliance on 'fact-files' about cultural practices of minority ethnic groups an appropriate response.

This study indicates the need for reflective practitioners able to consider what is 'familiar in the unique and unique in the familiar' when working with diverse ranges of patients and families.

Greater sensitivity to the subtleties with which individuals use cultural values and norms to give meaning to their experience is called for - not denying the importance of paying attention to social and cultural context but doing so *as patients see it*.

Professionals need support and training to extend such reflective processes into reflexivity - to understand how they themselves impact on their patient/client

and vice versa and to use that 'knowledge' to inform their interventions. Such processes will facilitate improved confidence when working in multi-cultural settings, without assuming there is one 'right' approach.

Engaging with cultural, religious and ethnic diversity and challenging stereotypes is an important step forward in enabling professionals to raise meaningful questions within the context of providing care in a multi-cultural society.

Recommendations

1. Patients of all ethnicities should be offered an opportunity to consult a specialist in reproductive medicine before starting cancer treatment. It is especially important to avoid partial or rushed advice when discussing options for preservation of gametes with women, given the additional complexity of such processes and potential outcomes.
2. All patients, including those where the need for treatment is too urgent to allow cryopreservation options to be considered, should be offered an early opportunity to discuss fertility matters again once cancer treatment is underway.
3. It is important to incorporate discussions of fertility routinely in long term follow-up, taking care to use plain language and to involve specialist therapeutic/psycho-social support services as necessary.
4. Another useful strategy would be to incorporate advice on financial assistance/benefits into the discharge

and follow-up routine, irrespective of the prognosis or severity of illness.

5. Better coordination and communication between primary and secondary/tertiary care during and following treatment, including in relation to fertility, would improve continuity of care.
6. Professionals need to have greater confidence in responding to situations without relying on 'fact-files' or generalisations about cultural practices of minority ethnic groups. Incorporating attention to reflective/reflexive processes in professional training and support is called for.

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October 2010

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