

**'SWIMMING AGAINST THE TIDE'**

**AN EXPLORATORY STUDY OF THE EXPERIENCES OF GROWING  
UP WITH FERTILITY CONCERNS FOLLOWING CANCER  
TREATMENT**

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## **ABSTRACT**

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This thesis considers the impact on growing up among young people diagnosed in their teens with cancer and told that fertility impairment may result. The exploratory study informed by grounded theory recruited seventeen males and twenty-one females (overall take-up 35 per cent). Single in-depth interviews were conducted in two age groups – 13 to 21; 21 and over. Five were parents. Findings were considered theoretically within lifespan approaches and resilience theory. Protective or risk factors were identified within the approach of participants or those around them - including professionals and services, family members, friends and romantic partners.

Reactions ranged from being little troubled to deep distress. Strength of desire to parent and the stigma of infertility heightened concerns as did feelings of having little control over fertility outcome. Concerns were eased – but not removed - with the provision of regular, unambiguous information, access to help with strategy building, presence of stored gametes, hope of retention of reproductive function, availability of confidantes including friends and romantic partners, positive experience of disclosure and achievement of parenthood. Across all spheres, fertility matters were raised less frequently than were other cancer matters by participants or those around them. This was only helpful when it reflected protective communication or low concern. The personal and social meaning of fertility matters, including fertile identity implications, appeared more influential than age and life stage and was dynamic across time and context. Gender too carried social as well as biological challenges, including around fertility analysis. Where return to 'normality' was prioritised, fertility concerns were marginalised but presented periodic threats. Although many reported gaining strength through having had cancer none did so in relation to fertility matters. For some, fertility concerns overtook those associated with cancer.

Preferred professional attributes and suggestions for service developments across disciplines and agencies were identified.

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## **DEDICATION**

This thesis is dedicated to my brother Geoffrey who, if he had lived, would have approved of me doing this work.

## **ACKNOWLEDGEMENTS**

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I would like to record my warmest thanks to the people that took part in this study. Their generosity and openness in talking about their experiences on such a sensitive matter was both remarkable and humbling. I hope that I have done justice to what they told me.

There are many colleagues to thank at the university. My supervisor, Mike Stein, provided support and guidance in good measure; his encouragement and attention to detail, especially on the last lap, were just what I needed. Jane Phythian and Sandra Williams undertook all the transcribing and Jane helped with numerous other aspects of putting together this thesis. Their interest and enthusiasm for the study itself and the personal support that they provided was second to none. Tricia Sloper worked with me on the wider study and was unstinting in sharing her wisdom, generosity and warmth. Many colleagues within the social work section and the wider university offered support and stimulation, reminding me of the richness that can come from places where ideas are valued.

Colleagues in the recruitment centres deserve particular mention, as do members of the Advisory Group for the study and others within the fields of cancer and fertility impairment. I was fortunate to engage in many thought provoking discussions and to learn a great deal from individuals with significant professional or personal experience. Friends too got drawn in. They offered support when I needed it and the opportunity to 'think aloud' with people whose views I knew would be worth listening to.

Finally, my family. My partner, Phil, my children Julia and Jonathan, Jonathan's partner Katy, and my wider family have been involved in a myriad of ways. They have encouraged, listened, inspired, supported, challenged, proof read, celebrated – in other words, they have 'been there' for me.

## **AUTHOR'S DECLARATION**

This thesis looks in depth at selected parts of an interview study that formed part of a wider study funded by The Candlelighters Trust. The wider study employed two researchers, Patricia Sloper and myself. I was lead researcher. I held primary responsibility for the study's design, analysis and write up; I conducted all the interviews. I met with Patricia at regular intervals throughout the lifetime of the wider study and she commented on the draft research report for the funders. Her involvement ceased at that point.

# CHAPTER ONE

## INTRODUCTION

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This study looks in depth at the experiences of young people who are diagnosed with cancer and told that this may result in their reproductive system becoming damaged. Being able to decide whether and when to have children is an unwritten expectation for most people growing up and little is known about what happens when this is threatened. Prior to diagnosis, many of those affected will have experienced references to reproduction being dominated by messages about safe sex and avoidance of sexually transmitted diseases and pregnancy. The threat from cancer and its treatment challenges prior presumptions of fertility and reproductive choice and throws up many unanswered questions for service providers. At what stage is concern with fertility impairment likely to manifest itself and how? Is it *only* a survivor issue or does it matter to those going through treatment as well? What is it like to manage this for those diagnosed once the physical transition to adulthood is underway? Does it affect their growing up? Does it only start to matter when they become adults, set up long term partnerships or decide they want to start a family? Are there issues that are unique to gender or anything else? What do these young people need to know about it, if anything, and when? Is it better to talk about it or not? How do families, friends, partners deal with it? How should professionals approach it and are there gaps in services that should be filled? These were just some of the questions that led to the formulation of this study.

Given the paucity of existing research, a study funded by The Candlelighters Trust with myself as lead researcher was designed to contribute to the emerging picture by learning more about the associated range of thoughts, feelings and experiences among those affected. It included qualitative interviews with survivors, focus groups with professionals and the production of written and web-based materials.

This thesis examines selected findings from the interview study that was conducted with thirty eight participants aged 16 to 30 years who had been diagnosed with cancer between ages 13<sup>1</sup> and 20 years.

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<sup>1</sup> This includes one participant who had been diagnosed initially at age 11 and re-diagnosed at age 13 at which point she was told that her fertility might be affected. When making reference to this individual, including in quotes, the age of 13 will be used in order to maintain her confidentiality.

Those sections of the wider study not reported here include:

- Parts of the interview study that focused on the time of diagnosis and the use of fertility preservation services.
- Production of a booklet called 'Relationships, sex and fertility – for young people affected by cancer'. This is now part of the library of Cancerbackup<sup>2</sup>, the leading national cancer patient information charity for patients, their families and professionals (Cancerbackup 2007).
- Provision of information for the web pages relating to sexuality and fertility for the Cancerbackup website 'click4tic – Teen info on cancer' ([www.click4tic.org.uk](http://www.click4tic.org.uk)).
- Focus groups with a range of different professionals – medical, scientific and psycho-social – that were run towards the end of the recruitment phase of interviewing with the aim of (i) seeking to capture professionals' thoughts and reactions to receiving preliminary findings from the interviews and (ii) enhancing the dissemination of those findings.

The study used two researchers, Patricia Sloper and myself. In keeping with my role as lead researcher, I held primary responsibility for the design, analysis and writing up of the interview study and focus groups, I conducted all the interviews and analysis and co-ran all the focus groups. I wrote the sections on relationships and non-medical alternative routes to parenthood for the written and web-based materials and held editorial responsibility for producing the text for the Cancerbackup booklet. I met with Patricia at regular intervals throughout the study's lifetime and she commented on the draft research report.

There was an Advisory Group for the whole study whose role was to:

- Offer an additional perspective on the research design and process.
- Provide a forum for informed discussion on issues emerging from the analysis.
- Assist with the dissemination and implementation of the findings.

Given the multi-disciplinary and multi-agency context for providing services in relation to cancer-related fertility, the advisory group's membership was drawn from medicine (paediatric oncology and reproductive medicine), nursing, reproductive science, social work and clinical psychology together with the person who had chaired the influential British Fertility Society multi-disciplinary working party that produced the report 'A Strategy for fertility services for

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<sup>2</sup> Formerly known as CancerBACUP

survivors of childhood cancer' (Multidisciplinary Working Group 2003). Each was a figure of some influence within their field (see Crawshaw and Sloper 2006). The need to take account of the regulatory framework for fertility preservation services led to a decision to include a representative from the Human Fertilisation and Embryology Authority. The key role of the voluntary sector was reflected in the appointment of a representative from the Teenage Cancer Trust. The researchers discussed the relative merits of establishing a separate user advisory group or incorporating their representation in the Advisory Group and decided on the latter. An adult male and adult female survivor of teenage cancer who both had an interest in fertility issues were therefore appointed.

### **How the thesis is organised**

This thesis starts with outlining the literature relevant to the experience of people who are diagnosed with cancer as teenagers or young adults and move towards and into adulthood knowing that their fertility may be affected (Chapter Two). Chapter Three sets out the methodological design of the interview study and explores the complexities and challenges of undertaking research on such a sensitive subject with a diverse age and gender group. Next, the thesis moves to reporting the findings. Chapter Four provides a profile of those that took part together with a summary of their experiences around the time of diagnosis. Chapter Five sets out the key theoretical frameworks that were drawn on when analysing the findings – lifespan approaches to human development and resilience theory – illustrated where possible with findings from the wider childhood and adolescent cancer literature. Chapters Six to Eleven consider key aspects of participants' experiences across time and context. These start by looking at the impact on self before considering the professional relationships that were encountered when managing cancer-related fertility matters. Chapters Eight to Ten look at how fertility aspects were handled within relationships with family members, friends and romantic partners. The reporting of findings is completed with the specific experience of those contemplating parenthood, be that through deciding whether or not to seek fertility testing, finding out about treatment and other options, or becoming a parent. At the end of each of these chapters, reflective theoretical discussions are set out which include some broad signposting to the literature reviewed in Chapters Two and Five. The final two chapters consider the implications of the findings for policy and practice before drawing overall conclusions.

## CHAPTER TWO

# A LITERATURE REVIEW ON FERTILITY MATTERS IN TEENAGE AND YOUNG ADULT CANCER

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### Background

'A literature review is a systematic, explicit and reproducible method for identifying, evaluating and interpreting the existing body of recorded work produced by researchers, scholars and practitioners' (Fink 1998:3)

I anticipated that there may be context specific matters to be aware of in the literature. However, my anticipation of a limited evidence base led me to not place any exclusion criteria by country, time, discipline or conceptual framework on my search. All had to be in English as I have no other language skills. I searched on databases including Social Care Online, MedLine, PsychLit, PsychInfo, Cochrane, CINAHL, British Nursing Index, and Embase using key search terms such as adolescence, teenage and young adult, cancer, late effects, fertility, infertility, fertility preservation, sperm banking, cancer and parenthood in different combinations. This identified relatively small numbers of references, including some that focussed on younger children or adults as well as, or instead of, teenagers. Next, I searched for psycho-social literature on the impact of cancer as a teenager or young adult. This located a wider literature, some of which included reference to sexuality and/or fertility within it. Searches, including through Google Scholar, for authors whose work had proved useful from retrieved literature identified some additional material. Finally, searches on individual journal databases were conducted.

Although there is professional and academic acknowledgement that the cancer experience during the teenage and young adult<sup>3</sup> years has some unique and complex aspects both medically and psycho-socially, the field of teenage and young adult cancer is small across all disciplines when compared to childhood or adult cancer (Craft 2003; Eiser *et al* 2004; Haase and Phillips 2004; Kelly *et al* 2003, 2004; Lewis 2005; Neville 2000, 2005; Whyte and Smith 1997). Additionally, understanding of any unique aspects of the profiles and progress of

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<sup>3</sup> There is no standard term used to describe cancer diagnosed during this life stage. Of common usage are adolescent cancer, teenage cancer and teenage and young adult (TYA) cancer.

cancer in this age group - including the range of cancer types, treatments, mortality and long term effects - is hampered by the lack of a dedicated national cancer registry, by the resulting potential duplication on adult and paediatric (up to age 15) data sets and/or by inconsistencies in record keeping across regions (Whiteson 2003). Recommendations to redress this were included in recent guidelines from the National Institute for Health and Clinical Excellence (NICE 2005).

Limited data about, and attention to, this group of patients have led to them being called the 'Lost Tribe' (Michelagnoli *et al* 2003) and to growing pressure to acknowledge their particular needs, including around psycho-social research (Albritton and Bleyer 2003; Birch 2005; Haasse and Phillips 2004; Hollis and Morgan, 2001; Whelan 2003; Whiteson 2003, 2005; Zebrack and Zeltzer 2003).

It is perhaps a reflection of the improved life expectancy of those diagnosed with cancer (although the rate of improvement is less for teenagers and young adults than other age groups) that increasing attention is now being paid to its long term effects, including fertility damage or uncertainty (Albritton and Bleyer 2003; Birch, 2005; Davies *et al* 2003; Eiser, 1998; Eiser *et al* 2000a; Wallace *et al* 2001). Media attention to cancer-related fertility issues is also growing. A number of high profile individuals including Kylie Minogue (pop singer) and Lance Armstrong (cyclist) have spoken of them publicly following their own cancer diagnoses. Reports of scientific advances and of babies being conceived using gamete stored for many years increasingly hit the headlines. A recent court case following a dispute between an estranged UK couple around 'ownership' of embryos created prior to the woman's (Natalie Evans) cancer treatment also received widespread coverage (Dyer 2007).

The early academic literature came almost exclusively from clinicians and scientists trying to improve understanding of the extent and nature of any physical reproductive damage. They continue to provide the bulk of writing and research. A small number of studies have focused on the psycho-social aspects but primarily on specific events such as sperm banking or the contemporary or future concerns of survivors. Some researchers report on fertility aspects within a wider study of the cancer experience. However, studies commonly draw on mixed samples of childhood and adolescent cancer patients/survivors with little or no attention to any age or life stage effects.

As the literature on body image, sexuality and the wider cancer experience may also aid understanding of fertility issues, this is reviewed in Chapter Five where I also set out the theoretical framework for the analysis of the study's findings.

Before turning to the clinical and psycho-social literature, I first outline the background policy context as it affects cancer-related fertility matters.

### **The policy context**

Fertility preservation and medical aspects of fertility have dominated any reference to fertility within relevant UK policy statements for this age group. The National Institute for Health and Clinical Excellence (NICE) guidance for improving outcomes in children and young people with cancer recommends that both genders should be made aware of fertility risks, have fertility raised at the late effects stage and be referred to specialist services where appropriate. It also recommends that males should be offered sperm banking (2005). The majority of children and young people are treated within the twenty two Childhood Cancer and Leukaemia Group (CCLG) (formerly the UK Children's Cancer Study Group (UKCCSG)) centres. As well as recommending sperm banking being made available at around diagnosis, the CCLG long term follow up guidelines (UK Children's Cancer Study Group Late Effects Group 2005) recommends the provision of fertility counselling services for males and females though does not specify whether medical or non-medical. The role of psycho-social services is not highlighted.

Professional bodies have also come out strongly in favour of sperm banking and of addressing fertility concerns with both genders. The multi-disciplinary working party report for the British Fertility Society (BFS) concluded that reproductive services for childhood and adolescent cancer survivors required greater standardisation as well as specific practice improvements (Multidisciplinary Working Group 2003). The BFS adopted its key recommendations including the need for greater involvement of psycho-social professionals (Anderson 2003). A joint working party of the Royal College of Physicians (RCP) and Royal College of Radiologists is currently drawing up guidance on the management of the effects of cancer treatment on reproductive function (for adults and young people). It is likely to incorporate many of the BFS proposals and to be 'co-badged' by the Royal College of Obstetricians and Gynaecologists (personal communication with RCP 11.7.2007).



Recommendations for a multi-disciplinary approach to service delivery and partnership working specifically with young people who are ill or in hospital are included in the National Service Framework for Children, Young People and Maternity Services (2004). The NSF also stresses the importance of home-based services for young people experiencing crises in relation to mental health (p81).

Regardless of the service context within which children and young people in England (and, in part, in Wales) receive help, the Children Act 2004 underpinned the introduction of an overarching national programme of change called Every Child Matters: Change for Children (2004). The aim is to bring about improvements across five outcomes – being healthy, staying safe, enjoying and achieving, making a positive contribution, and achieving economic well-being – through greater attention to such as prevention, multi-disciplinary and inter-agency service planning and delivery, and listening to service users. All services are required to take account of these measures.

### **Physical effects of cancer-related fertility impairment**

Knowledge of the physical impact of cancer and its treatment on fertility for those diagnosed in their teenage and young adult years continues to evolve. The lack of data sets on which information is recorded systematically and the relatively low number of relevant studies (as reported above) have led to lively debates about the robustness of the available research evidence, especially in relation to relative incidence of long term infertility among cancer survivors. Additionally, longer term measures are more likely to be based on numbers that become biological parents than on clinical evidence of physical damage as fertility analysis is not offered or recorded routinely. That said, there is some agreement that the extent of any fertility damage is thought to be affected variously by age at treatment (risk appears to increase with age), type of cancer, type of treatment (certain chemotherapeutic drugs appear more likely to cause fertility damage than others; total body irradiation appears to carry particularly high risks) and gender (males appear to be more affected than females) with rates of damage ranging from 'minimal' to almost one hundred per cent (Balen and Glaser 2006; Byrne 1999; Wallace and Brougham 2005). The situation will continue to change as treatments themselves are constantly changing and as information from larger and more robust studies become available. A recent review concluded:

**'The current or future fertility of an individual can be affected by cancer and its treatment either by a direct effect on the gonad or by affecting the endocrine**

support of gonadal function through a deleterious effect to another endocrine organ, such as the pituitary. Sadly, the precise effects in any one individual are often difficult to predict' (Pacey 2007 *in press*)

This brings its own challenges as those affected often have to cope with a level of uncertainty that may not be wholly resolved until they try to start a family (Reid 2000; Self 1999; Wallace and Walker 2001; Wallace *et al* 2001). Even those who use fertility preservation services (predominantly males) face uncertainty as cryopreserved samples do not always survive thawing. Fertility treatments themselves remain relatively unsuccessful for both genders (Green 1997; Pacey 2006, 2007; Picton 2006; Reid 2000). Eiser (1998) has argued that fertility matters may be one of the most difficult areas of medical information to impart, given their uncertainty.

Survivors may also have to cope with other effects of treatment on their endocrine and fertility systems including delayed pubertal growth, osteoporosis and premature menopause (Balen and Glaser 2006; Davies *et al* 2003; Pacey 2007). Among females who achieve a pregnancy, there is a heightened risk of obstetric complications including increased risks of miscarriage, premature labour, low birth-weight and complications associated with treatment-related cardiac conditions (Davies *et al* 2003; Byrne 1999).

### **Awareness of cancer-related infertility**

The sparse research into young people's pre-diagnosis knowledge of fertility impairment as a side effect of cancer treatment suggests that it comes as a surprise for most (Crawshaw 2006).

Many survivors do not recall being warned about fertility impairment during diagnosis or treatment (Clarke *et al* 2004; Green *et al* 2003; Schover *et al* 1999; Schover *et al* 2002a; Wasserman *et al* 1987). In a telephone interview study with 32 US mixed gender childhood cancer survivors aged 19-37 (those diagnosed in their teens were not identified separately) some could not recall being given any information or were unclear what they had been told, others had been told that their status was uncertain and some had been told that any risk was low but nevertheless remained uncertain (Zebrack *et al* 2004). Some were worrying about things that they did not necessarily need to worry about while others did not know enough to protect themselves from potential or dangerous threats to their health (p695). A UK questionnaire study found that less than half (41%) of respondents recalled discussing fertility

issues with professionals and among those that did not, half (50%) would have welcomed it (Clarke *et al* 2004).

The need for more information, including non-verbal information, for those affected has been identified by professionals (Canada and Schover 2005; Crawshaw *et al* 2004; Schover *et al* 2002a) and by young people themselves (Crawshaw 2006; Edge *et al* 2006; Mitchell *et al* 2006). Data collection from more than 300 young people living with teenage cancer and their supporters attending a UK Teenage Cancer Trust 'Find Your Sense of Tumour' conference in 2004 found that around two thirds had not received information or counselling about fertility issues though interest in them was very high (Shaw *et al* 2005). This matches more general findings about the value that young people with cancer place on being informed fully and directly about their disease and its treatment (Decker *et al* 2004; Hooker 2004; Mitchell *et al* 2006; Young *et al* 2003).

Explanations for the potential for a mismatch between professional timing of information sharing and young people's needs may be found in a recent large scale study of paediatric oncology professionals (not only doctors). It reported that they thought:

- information was more important during treatment than at diagnosis (post treatment information needs were not gathered);
- medical information was more important than psychological;
- information about fertility, sex and contraception (which were grouped together) was ranked of medium importance only.

(Bradlyn *et al* 2004).

## **Services around cancer-related fertility**

### ***Professional responses***

There is evidence of professional unease and uncertainty around fertility matters in relation to this patient group as well as growing support for fertility preservation to be made available in the light of advances in reproductive medicine (Bahadur *et al* 2001; Anderson 2003; Coulson *et al* 2001; Crawshaw *et al* 2004; Davies *et al* 2003; Reebals *et al* 2006; Schover 1999; Wallace and Walker 2001; Wallace and Brougham 2005; Wilford and Hunt 2003). Although doctors, scientists, nurses and social workers have been reported to be involved in fertility preservation services, only doctors and scientists are involved routinely. Two studies in North America suggested that professional practices and services varied widely (Glaser *et al* 2000; Schover *et al* 2002b). More recent UK studies indicated similar discrepancies here (Glaser *et*

al 2004; Shaw *et al* 2004; Wilford and Hunt 2003). One study found that nurses were reluctant to discuss fertility issues as they thought that this was the doctor's responsibility (Shaw *et al* 2004).

The perceived challenges fall into various themes including:

- The challenges of communicating with, and obtaining informed consent from, young people in shock, post diagnosis.
- The challenges of communicating with young males about masturbation.
- The moral issues associated with offering a service with no guaranteed success at a time when it is not essential for current treatment.
- The lack of research into the impact of sperm banking, particularly for those who are very young or very ill.
- The difficulties in developing and maintaining up to date knowledge and skills where referral rates are low.
- The challenges of knowing how and when to involve parents.

There is some evidence of clinician-initiated screening for fertility preservation services on the grounds of medical factors (such as poor prognosis or aggressive tumours) or social characteristics (gay men and those who are HIV positive) as well as barriers to services being associated with time, cost, parental refusal and the facilities themselves (Crawshaw 2006; Edge *et al* 2006; Schover *et al* 2002b; Shaw *et al* 2004). One US study suggested that professionals were more likely to offer sperm banking to those that brought the subject up themselves (Reebals *et al* 2006). A UK study reported that adolescents were sometimes denied access to sperm banking if there were no male professionals available or none of either gender willing to discuss it with younger patients (Shaw *et al* 2004). Although over ninety percent of oncologists in one US survey said that sperm banking *should* be offered to eligible patients, just under half (48%) rarely, if ever, did so. More than a third said that they would not raise it with teenagers unless they had spoken to parents first (Schover *et al* 2002b). This contrasted with the findings in a companion study which showed that that young males wanted to be told on their own and prior to their parent's involvement (Schover *et al* 2002a). A more recent qualitative study in Canada with young adults (aged 18 and over at diagnosis) and their professional carers again reported discrepancies in that professionals saw the patients' age, fear of survival, sexual orientation and culture as more significant influences on decision making than did the males themselves (Achille *et al* 2006).

Several papers have indicated the need for up to date knowledge and improved training for professionals across disciplines in handling fertility related matters at diagnosis, during acute treatment, during remission or through late effects services (Crawshaw *et al* 2004; Crawshaw and Hale 2005; Davies *et al* 2003; Edge *et al* 2006; Koepfel 1995; Reebals *et al* 2006; Schover 1999; Shaw *et al* 2004; Thaler-DeMers 2001; Wilford and Hunt 2003; Zebrack *et al* 2004). It has been argued that oncology nurses or social workers in particular should be trained to take on a greater role in addressing fertility issues with cancer patients (Canada and Schover 2005).

The case for professionals to take responsibility for raising the issues rather than waiting for patients to do so has been made (Albritton and Bleyer 2003; Heiney 1989; Kline 2006). In a wider paper on the unique service needs of adolescents with cancer, Whelan, an oncologist, argued that multi-disciplinary team members (including social workers):

'...must have an understanding of the interaction between adolescence and cancer, be familiar with the experience and implications of treatment, for instance with regard to fertility and other treatment 'costs', and work closely together, joined by an agreed philosophy of care alongside ward nurses and medical staff' (2003:2576).

### ***Young people's views***

The limited research with survivors of childhood, teenage or young adult cancer suggests strong cross gender support for the availability of fertility preservation, even though there are currently few facilities for females (Crawshaw *et al* 2003; Schover *et al* 1999; Schover *et al* 2002a; Cancerbackup 2005; Shaw *et al* 2005). It has been suggested that the use of such services among adults with non-cancer related fertility difficulties poses particular difficulties for certain Black and minority ethnic (BME) groups including the Muslim and Jewish communities (Culley and Hudson 2006; Tomlinson and Pacey 2003). However the studies reviewed here frequently reported under-representation of minority ethnic communities in their samples and religious belief was rarely stated. One study reported that there were no significant differences for ethnicity or religion (Schover *et al* 2002a).

No studies were found that reported specifically on young people's views about their longer term needs around fertility matters. Studies of its longer term *impact* are returned to below.

### ***Take up of fertility preservation services***

There has been some research, mainly quantitative, into the take-up of fertility preservation services. The US postal survey cited above (Schover *et al* 2002a) was of 201 males aged 14 to 40 at diagnosis (though only 2 were under 18). Less than two thirds (60%) recalled being *told* about the possibility of fertility impairment as a consequence of treatment, only half (51%) were *offered* sperm banking and less than a quarter (24%) accepted. This reinforced findings from an earlier mixed gender postal survey of 43 men and 89 women diagnosed before age 35 (16% of whom were aged 12 to 20 at diagnosis) that found similar numbers not banking sperm (Schover *et al* 1999).

More recent UK studies indicate similar low take up (Shaw *et al* 2004:153). One found that less than a third of all eligible adolescent males in one regional paediatric oncology centre had been offered sperm banking between 1997 and 2001 (Edge *et al* 2006). In its accompanying postal survey of 45 males aged 13 to 21 who *had* been offered the service, two thirds banked successfully with the remainder being younger, more anxious and reporting more difficulty in discussing the subject.

The professional/patient relationship itself may make some difference to outcome. Those who had the opportunity to discuss infertility with their oncologist in the Schover *et al* (2002a) study were more likely to take up the offer to bank *and* to have greater knowledge about this aspect of their treatment. Shared gender has elsewhere been found of less importance than encouragement, warmth, friendliness, lack of embarrassment and clarity of communication (Achille *et al* 2006; Crawshaw *et al* 2003).

There is mixed evidence for the influence of parental involvement. The young men in Edge *et al*'s (2006) study reported being embarrassed when parents accompanied them to the sperm bank though content with their presence when it was initially raised. This reinforced the findings of an earlier records-based study that found an increased risk of failing to produce a sample among those accompanied by a family member or professional (Bahadur *et al* 2002). However, qualitative studies with both teenagers (Crawshaw 2006) and adults (Achille *et al* 2006) suggest that parents and partners' presence can be supportive. It may be that the difference lies in the degree of choice open to the males concerned.

There is some evidence, albeit small scale, that failure by young men to bank sperm (either because it was not offered or because the offer was turned down) is a source of later regret

(Broome and Allegretti 2001; Crawshaw 2006; Marik 2004). Similar findings were reported in a questionnaire-based survey with 55 male adult cancer survivors (Saito *et al* 2005).

Conversely, the potential for positive impact has been shown. In a practice based account of adults' experiences, Pacey (an adult cancer survivor as well as a scientist in the field of assisted conception) identified his own motivation to bank as: 'something positive to do at an otherwise emotionally negative time' (Pacey 2003:327). He speculated that 'maybe simply knowing that their sperm is somewhere safe, irrespective of what decisions they may or may not make about fathering, is a psychological benefit to men' (p328). He went on to say that undertaking sperm banking may be rational (investment against risk) but may also be 'to avoid regretting it later'; it may be passive (because the doctor told me to do it) or it may represent the chance to wrest back some of the shifted 'locus of control' by squeezing some personal control out of a situation where control has gone (p328). The reason given for banking among teenage males in my earlier study was primarily the preservation of reproductive choice for adult life, though passive compliance with adults' wishes was also present. Later satisfaction from having banked sperm was high in all cases (Crawshaw 2006). Two recent studies with adult males have reported that although the take up of fertility preservation did not eliminate worries about infertility (which were substantial) the presence of cryopreserved sperm aided coping (Achille *et al* 2006; Saito *et al* 2005). No studies were identified that looked at female experiences.

This suggests that, if made aware, many young people (especially males) are prepared to safeguard their fertility through fertility preservation, even when this has to be done at diagnosis. They may benefit psychologically from doing so regardless of whether or not damage occurs.

### ***Services available over time***

Literature reviews point to the dearth of studies on professional interventions following the acute phase of cancer treatment (Eiser 1998; Whyte and Smith 1997). Even more peripheral attention is paid to later interventions around fertility matters.

Writing from the experience of running a late effects service for childhood and adolescent cancer survivors, Davies *et al* (2003) reported that patients rarely initiate sexual and fertility discussions '...but are relieved when given the opportunity to ask questions' (p12). During adolescence and adulthood, more than half had questions and these fell into three main categories:

- (1) *hypothetical questions* concerning future fertility - frequently arising well in advance of active contemplation of romantic relationships or parenthood.
- (2) *questions about access to, cost and types of fertility treatments* – sometimes accompanied by a request for a fertility test.
- (3) *hormone replacement difficulties* – compliance with such medication was worryingly low; questions also indicated that medication may affect sex drive and sexual function.

Given the pregnancy-related risks (as outlined earlier), the authors also stressed the importance of addressing fertility issues with females in advance of a pregnancy so that an obstetric management plan could be put into place.

Others have suggested that infertility should fall into the category of profound medical sequelae alongside bodily disfigurements and organ damage, prompting special interventions to 'stimulate the child into actively creating a new perspective and a realistic outlook on life' (Van Dongen-Melman 2000:28).

### **Involvement of parents over time**

There is limited evidence about parental involvement in fertility matters other than sperm banking. It has been suggested that while parents are more concerned at all stages with prognosis and prefer sexuality and reproduction issues not to be addressed, young people want information on personal bodily concerns including fertility (Whelan 2003; Whyte and Smith 1997). Elsewhere there are accounts of parents expressing their own concerns about fertility matters including the associated uncertainty (Mitchell *et al* 2006; Patterson *et al* 2004; Shaw *et al* 2004) as well as offering considerable support to children and young people struggling with the impact of fertility and/or sexuality (Grinyer 2002, 2007). One UK questionnaire-based study that surveyed children, teenagers and their parents found that all parties would have welcomed greater attention to fertility issues, including the opportunity for discussion (Clarke *et al* 2004). However, while parents thought that it was important for their children to have access to a professional of the same gender for such matters (p77), gender was not seen as important by the young people themselves (p86).

### **Impact of cancer-related fertility impairment on self**

As stated already, some studies report on fertility matters as one small part of wider findings. Potential infertility has been found to carry a significant impact following childhood and/or adolescent cancer that may increase as the threat to survival diminishes following the end of



treatment, including when infertility is not medically predicted (Lozowski 1993; Roberts *et al* 1998; Self 1999, 2006; Weigers *et al* 1998; Zebrack and Chesler 2001; Zebrack 2006). Blacklay *et al* (1998) found the need for information about fertility to be the second highest category (83%) in their survey of those attending a late effects service and concluded:

'...understanding the possible effects of chemotherapy on fertility may allow survivors to come to terms with their situation and limit the risk of emotional disappointment' (p341).

In her review of existing research, Schover (1999) concluded that the experience of being unable to achieve genetic parenthood as a result of cancer brings unique stresses:

'The most profound loss, though, is the loss of the dream of having one's own genetic child.....Cancer survivors may be told by health professionals, friends or family that they should be grateful to be alive. Their right to grieve over infertility may be questioned' (p55).

Thaler-DeMers' review of intimacy issues in the lives of (mainly adult) cancer survivors indicated that treatment decisions made early in the process can: '...impact the interpersonal relationships, sexuality and reproductive capacity of all survivors' (Thaler-DeMers 2001:260). In similar vein, Puukko *et al* (1997a) found that those who underwent bone marrow transplants were not only likely to report this to be a frightening experience in itself but that the resulting fertility damage appeared to contribute to inferior self-perception and feelings of deficiency.

In an in-depth qualitative study with parents of young adults with cancer (many of whom went into palliative care), sexual matters and fertility concerns - including religious and ethical aspects - emerged throughout treatment and afterwards. One parent described her son's reaction:

'Fertility was for George a bigger issue in the weeks after diagnosis than having the cancer diagnosis because I think he believed that he would survive the cancer diagnosis but he knew that he would almost certainly be rendered infertile through therapy' (Grinyer 2002:61).

This was replicated in the author's follow up study with young adults during and shortly after treatment. Sexuality and fertility concerns were sufficient to be reported as a key theme (Grinyer 2007).

In their self report questionnaire survey of 500 Dutch mixed gender childhood cancer survivors, Langeveld *et al* (2003) found that survivors were significantly more likely than the control group to worry about fertility. A recent UK postal survey of 45 teenagers found that ninety-three per cent said that they worried about the impact of their cancer and treatment on their fertility – the highest scoring area of concern (Cancerbackup 2005). Drawing on her campaigning work with the Teenage Cancer Trust, UK, Whiteson (2003) cited fertility as a significant issue for teenagers and young adults, involving 'ethical, psychological and social considerations' (p2691).

There are varying reports of gender differences in impact. Wasserman *et al* (1987) found in interviews that female survivors were more likely to report concerns about fertility than were males. In a later questionnaire based study of childhood cancer survivors and a control group, worries about recurrence and worries about fertility were the two most highly ranked concerns with females again more likely to worry than males; the researchers speculated that this reflected greater cultural pressure on women to have children (Weigers *et al* 1998). However other studies that looked for gender differences did not find them either in relation to impact or fears of transmission (Schover *et al* 1999; Langeveld *et al* 2003).

Only a small number of psycho-social studies have focused on fertility matters per se. In Zebrack *et al*'s (2004) study of survivors' understanding of fertility and its effect on sexual behaviour, participants reported a range of concerns (including about parenting, see below). Their beliefs stemmed from what they recalled (or had forgotten) from conversations with parents and/or professionals and from lack of information. This influenced their approaches to sexual behaviour and use of contraception. The researchers concluded that:

*'Understanding the sources of survivors' beliefs about fertility, as well as what they know and how much they know, is critical as behaviours are often based upon beliefs as well as upon verifiable knowledge.....some survivors possess or recall information about infertility risks, but this information may or may not be accurate, thereby resulting in undesired outcomes like unplanned pregnancy' (Zebrack et al 2004:695)[authors' italics].*

In a study that focused on the reactions of fifteen male childhood cancer survivors (age at diagnosis not specified) to receiving feedback as adults aged 19 to 32 about their probable fertility status, emotional responses varied over time (Green *et al* 2003). While some were tearful or depressed initially, a more common reaction was anger, resentment and irritation at not being better informed earlier. Some thought it was relatively unimportant. Follow up suggested that many were able to adapt rapidly to the information. Reactions only became more intense for a few who felt, for example, that their manhood had been compromised and that future partners might be deterred. Like Zebrack *et al* (2004), the researchers concluded that the key influence on impact was the personal meaning of infertility at an individual, social and cultural level:

'The particular value that patients (and their families and partners) placed on fertility and parenthood determined the level of distress with which each had to contend. In essence they were not really dealing with the same stressor at all' (Green *et al* 2003:148).

There was common agreement among participants about the '....importance of not restricting discussion of fertility risk and its implications to a one-off interview however felicitously timed' but that it should be returned to on a regular basis (Green *et al* 2003:147). A few would have liked access to a specialist fertility counselling service. This echoed findings from my earlier study on sperm banking which found strong support for professionals to be proactive in raising the subject on a regular basis (Crawshaw 2006).

### **Effect on romantic relationships**

Several studies have attempted to identify any differences in adult relationship patterns between childhood/teenage cancer survivors and their peers. A review of psycho-social aspects of infertility and decisions about reproduction in the late 1990s concluded that childhood cancer survivors experience increased anxiety about body image, dating and fertility and that this may contribute to lower numbers achieving long term relationships (Schover 1999). Several recent large scale studies have found survivors to have a lower than average rate for marriage/permanent relationships (Langeveld *et al* 2003; Rauck *et al* 1999; Stam *et al* 2005). There is some evidence that survivors are more likely to be dissatisfied with important relationships than are their peers and have greater fears that potential mates would reject them (Grinyer 2007; Thaler-DeMers 2001). A postal survey of 303 childhood cancer survivors aged 14 to 29 (age at diagnosis not specified) found that some survivors

were concerned about their ability to attract a life time partner as a result of their possible infertility (Zebrack and Chesler 2001). Another study reported that those who were childless reported greater difficulties in finding a mate than those who had children (Schover *et al* 2002a).

There is only limited data about patterns of disclosure of fertility status in romantic relationships. In Zebrack *et al*'s (2004) US study, less than half had discussed fertility with a partner and some experienced tension in the relationship as a result. Some had not told, or delayed telling, because of not being in 'serious enough' relationships; others had experienced, or feared, rejection. Some were married and had not told.

The literature around sexual activity within romantic relationships is included within the section on sexuality in Chapter Five.

### **Desire to be a parent and reproductive concerns**

There is some evidence to suggest that children and young people think about becoming parents from an early age and that most assume they will one day become parents (Fraser *et al* 2006). However, various studies have found that childhood cancer survivors are less likely to become biological parents than their peers (Langeveld *et al* 2003; Rauck *et al* 1999; Stam *et al* 2005).

All the teenage males in my earlier study had thought about being a father prior to becoming ill, albeit in differing detail (Crawshaw 2006). Similarly, a majority (76%) of survivors in Schover *et al*'s mixed gender and age study (1999) were interested in having children and very few (6%) reported a decreased desire for children. Most (80%) thought that their cancer experience would make them better parents and almost all (94%) felt healthy enough to make good parents. In a later postal survey, just over half wanted children in the future (perhaps reflecting the male-only sample and the higher upper age limit) rising to just over three quarters (77%) among those who were childless at diagnosis (Schover *et al* 2002a). Again, only a small number reported that cancer had decreased their desire to parent. While similar numbers to the earlier study (92%) saw themselves as healthy enough to be good fathers, two thirds (66%) wanted to be parents even if they died prematurely, a similar number worried about living to see their children grow up and nearly three quarters (73%) worried about leaving their partner to be a lone parent. Despite anxieties about survival, risks to their children's health (see below) and anxieties about the prospect of parenting post cancer, many

nevertheless felt that their experience of cancer increased the value that they placed on family closeness *and* would make them better parents.

Zebrack and Chesler (2001) found similar concerns in their large survey of childhood cancer survivors cited above:

'Concerns about their own children's risk for getting cancer...., getting another cancer .... and the ability to have children .... top the list of survivors' cancer specific worries' (p249).

In Zebrack *et al*'s (2004) later telephone interview study, some were parents, some were having difficulty conceiving and others had not (yet) tried. Most wanted children. Several were worried about their child getting cancer, including through transmission, even when there was evidence to the contrary. As with other studies cited, many found that their cancer experience made them think differently about parenthood and some felt more confident in their skills as existing or future parents. A number talked of parenthood making them feel 'normal', which they welcomed. Zebrack went on to interweave his own experience as a cancer survivor, adoptive parent, social worker and academic into a later account mirroring many of these findings (2006).

Schover *et al* (2002a) found that just over a quarter (26%) had discussed with a health professional whether their treatment might affect children conceived subsequently and less than half (43%) had discussed the likelihood of increased risk of genetic transmission. Nearly two thirds (62%) of those actively contemplating parenthood would have welcomed genetic counselling. No research was found that reported whether concern about such risks influenced *actual* decisions about entering parenthood '.....although some preliminary evidence suggests that genetic risk rarely deters infertile couples [*i.e. in the wider population – my italics*] from using assisted reproductive technology' (Schover 1999:56). However, increases in the numbers among the wider UK population seeking pre-conceptual genetic advice together with a recent decision by the UK Human Fertilisation and Embryology Authority (HFEA) to allow pre-implantation genetic diagnosis to detect certain late-onset cancers following its national consultation 'Choices and Boundaries' (HFEA, 2006) suggest a changing medical and social context.

## **Alternative routes to parenting**

There is little research about how differently, if at all, cancer survivors fare within, or how they themselves view, alternative routes to parenthood including adoption, donor conception, surrogacy and other fertility treatments. Schover (1999) suggested that US society looks more favourably on adoption than third party reproduction but speculated that the cancer experience can make decision-making more complex:

'On the one hand, a brush with mortality may increase the wish to have one's own biological children. On the other hand, concern about inherited cancer syndromes or about the impact of cancer treatment on offsprings' health may make donor gametes more attractive' (Schover 1999:57).

In one study, whilst twenty per cent of participants were having difficulty in conceiving, less than five per cent had sought fertility treatment (Schover *et al* 2002a). In the event of biological parenthood proving impossible, almost two thirds (61%) said that they would consider adoption but less than a quarter (23%) would consider donor insemination.

Zebrack *et al* (2004) found that although some had explored alternatives, primarily adoption, knowledge about them was patchy. Some males had stored sperm but not tried to use it or any other assisted conception (yet). Financial constraints over accessing assisted conception treatments appear to be a cause of concern (Achille *et al* 2006; Zebrack *et al* 2004). This is likely to apply in the UK where the bulk of services are located in the private health sector.

## **SUMMARY**

There is an overall dearth of research and writing specific to the experience of coping with cancer during the teenage and young adult years. Where fertility matters are addressed, they are typically reported within more widely focussed studies that include those diagnosed as children. The small number of studies with fertility as their primary focus have, to date, been restricted either to a specific aspect (for example sperm banking) or to the resulting concerns of survivors, particularly as adults. There have been calls for further studies and for attention to the quality, quantity, consistency and range of professional services and information at all stages. Survivors' concerns include whether they will be able to attract a romantic partner

and have children that are cancer-free. Survivors have been found to be less likely to be in permanent relationships and to have children.

No studies have been identified that seek to understand the experience of moving from adolescence through to adulthood in the knowledge that fertility may have been affected. Neither has any inter-relationship between fertility, sexuality and body image been studied.

Existing work suggests that there is growing awareness by professionals and others of the potential for concern about fertility within this group from diagnosis onwards. Childhood and adolescent cancer survivors themselves are increasingly vocal about fertility concerns as part of their overall experience. This is no doubt affected in part by raised awareness in the public arena about cancer-affected fertility and infertility in general.

With this in mind, I turn to describing and explaining the methodological approach to the study.

## **CHAPTER THREE**

### **METHODOLOGY**

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#### **Introduction**

In this chapter, I explore and explain the design of this study. In doing so, I interweave the formative influences on my decision-making with the experience of implementation and later reflection. A key challenge in any study is to arrive at a design that is 'fit for purpose', is rigorous and has clear rules, principles and procedures (Robson 2002). The researcher also needs to remain engaged in thoughtful appraisal of that design as the study unfolds. The dynamic nature of the researcher's relationship with their chosen methodology is a significant piece of the jigsaw that makes up the emerging picture of the subject under study.

#### **RESEARCH DESIGN**

##### ***Development of research questions***

The review of the literature in Chapter Two indicates that fertility impairment is emerging as a significant long term effect of having had cancer in childhood or the teenage and young adult years. No studies were identified that focussed on the lived experience of growing up with the knowledge that one's fertility may be impaired. Studies of the impact among adult survivors have been limited largely to participants' views of their present situation and their thoughts about associated future challenges.

In conducting studies in an under-researched area, decisions have to be made about where best to focus in order to contribute to early stage understanding, taking into account questions of design and feasibility. Concentrating on the experience for both genders of growing up following major treatment after a post pubertal diagnosis and with awareness that fertility may have been affected, had the merit of being bounded but not constrained. Including attention to the role of service providers added to the formulation of the following key research questions:



- Does a diagnosis of cancer in the teenage years which is accompanied by the information that the cancer or the treatment might impair fertility have an impact on the process of growing up? If so, what are the ways in which those involved are affected?
- Are there any aspects that appear to be related to gender?
- How far does the way in which services are currently provided help or hinder these experiences?

The next decision was to consider how best to get at this material - what approach to take; what size and age range of sample; how to recruit and from where; whether or not to include parents, partners, professionals or others.

### ***Qualitative or quantitative?***

The concept that I was starting with was as simple (and as complicated) as this: possible cancer-related fertility impairment might complicate the transition to adulthood. The dearth of existing research into the overall experiences of cancer patients and survivors during this life transition meant there was no data against which to 'measure' any differences for those also faced with possible fertility impairment. Generating hypotheses derived from professional experience to test for the probability of harm also had significant drawbacks. The previous chapter indicates that professionals feel uncomfortable and/or lacking in competence with this area of work. This may be influenced by their views about the relative significance of fertility for this service user group. Variables thus developed may therefore be inappropriate, inadequate or simplistic.

Quantitative designs restrict the collection of additional spontaneous data framed by participants themselves. Their focus on outcomes rather than process tells us little about unfolding lived experiences (Mason, 2002; Robson 2002). They are well suited to testing hypotheses, predicting outcomes of interventions or testing the influence of a range of specific variables across a selected population where there is sufficient existing data. Qualitative research is more appropriate where existing data is limited or where the intention is to understand human experience in depth (Morse 1998). In a commentary on the comparative uses of qualitative and quantitative methods in infertility research, Blyth (2005) concluded that the former '... can provide what is so often lacking in the RCT [randomised controlled trial], an insight into the world as experienced by its participants'. In their systematic review of 20 studies of the psychological effects of childhood cancer survival, Eiser *et al* (2000a) concluded that 'interview data can highlight problems not included on

questionnaires measures..... and can capture features of the experiences that standardised measures may not' (p456).

Qualitative research has the potential to drill down intensively into individual experience and allow participants to describe, interpret and report their own reality. The complexity of human experiences means that the question of *cause* of the phenomenon being studied - in this case the experience of fertility impairment during transition to adulthood - becomes redundant until the researcher can use the developing understanding of its meaning for those directly affected to attribute possible cause. Such an approach assumes that behaviour is purposive and expressive of deeper values and beliefs and that research participants can (and do) construct and categorise their knowledge about themselves and their experiences. As Janesick (1998) has said, the research design then serves as '...the foundation for the understanding of the participants' worlds and the meaning of the shared experience between the researcher and participants in a given social context' (p37). Peddie and van Teijlingen (2005) - researchers specialising in the field of adult infertility - have found such approaches well suited to this field arguing that:

'... the sensitive nature of qualitative research allows appropriate enquiry of sexual and/or fertility related issues.... qualitative enquiry allows study participants to express why they think and act the way they do and to describe the social and economic factors that influence their decisions' (p266).

The accounts that people give are, of course, dynamic and this too is acknowledged. Explanations of actions or experiences are not 'once and for all' but 'true' for the time and place within which they are conveyed. The qualitative researcher draws on context, diversity, nuance and process as valuable data rather than seeking to control for them. Qualitative designs thus facilitate the mapping of the range and commonality of experiences and attitudes across encounters, contexts and time together with their impact on identity and the ways in which any patterned forms of social actions and relationships are reproduced, or not, within a population (Grinyer and Thomas 2001). By using such an approach to access 'knowledge' of *personal* meanings, experiences and actions from within participants' *social* activities and *socially constituted* meanings – i.e. meanings that are presented by the individual from within their social and cultural relationships and context – I could start to get at what Mason (2002) has called:

'.... the texture and weave of everyday life, the understandings, experiences and imaginings of our research participants, the ways that social processes, institutions, discourses or relationships work, and the significance of the meanings that they generate' (p1).

Those taking part would therefore not be 'subjects' to be isolated and manipulated but people whose own reality would be sought using their own definitions of concepts and *their* interpretations rather than the interpretations of those involved in their care (including professionals, parents or partners) (Bearison 1991; Denscombe 2003; Haase and Phillips 2004; Wilkinson 2003; Woodgate 2001). As Everitt *et al* (1992) have argued 'Research which does not include the users' voice has the potential to disempower or silence users' (p109).

Grounded theory approaches are founded in the belief that people construct their own realities from the symbols around them and through interaction with others. The data have primacy with any theoretical understanding derived from them providing that they have been systematically gathered and analysed (Strauss and Corbin 1998). Grounded theory emphasises the systematic discovery of theory *from* data in order for it to remain grounded in observations of the social world rather than being generated in the abstract. Research questions, therefore, are not derived *from* theory but are developed in the hope of *generating* theory on which hypotheses can be developed in, or for, future study. Existing theory is not ignored but neither is it privileged in this inductive analysis process. Issues are emergent in that new questions arise during the research process itself requiring a design that is flexible enough to evolve, develop and unfold during data collection (Robson, 2002). This requires the researcher to move beyond handling data descriptively towards conceptual density. By generating theory about the ways that participants made their world 'solid' and created social facts as accomplishments or failings as they negotiated the transition to adulthood, a tentative map could be offered to future researchers, those responsible for developing and delivering services and those with direct experience. Contours could then be filled in and/or boundaries redrawn as understanding developed.

Having decided on the approach, I could start to build the design in more detail. I had already determined that I wanted to seek understanding of experiences across gender. I also needed to consider who to interview, how many and how often, together with where, when and how to recruit. While the interview design had to be finalised before I could finalise the sampling and recruitment strategies, the implications of each for the other made clear their interdependency. Additionally, aside from practical considerations of how best to use the time available to me

for data collection, I was not working in isolation. The collaborating consultant paediatric/adolescent oncologists from an earlier study had agreed to participate in this study and their views had to be taken into account. It is these aspects to which I now turn.

## **STUDY DESIGN**

Janesick (1998) has suggested that the key challenge in study design is to orchestrate the different parts in a way that encourages the researcher to remain centred when managing the multitude of ongoing decisions that threaten fragmentation. This was to be a multi-site study, using health professionals as recruiters and aiming to enlist participants of different genders and ages from as diverse backgrounds as possible. The need for a conductor was clear! This section looks in more detail at how I arrived at and implemented the decisions around the composition of the sample and my approach to interviewing.

### **The participants**

While professionals, parents, partners and others may play an important role in the transition to adulthood of young people diagnosed with cancer - and thus have valuable thoughts and experiences to contribute - I wanted to use the time available to prioritise and gather the experiences and views of those directly affected. Others would only be involved if this met the needs and wishes of the person being interviewed. Where this happened, my skill as researcher would be to ensure that the participant's voice still remained centre stage. I return later to a more detailed discussion about the interviewing challenges.

Where a potential participant was aged under 16 years, their parent/guardian was required to give written consent to his/her participation as a condition of the NHS Multi-centre Research Ethics Committee (MREC) that approved the study. They were not, however, required to attend the interview itself. For those aged 16 and over, I ensured that the recruitment process allowed participation without parental or partner knowledge if so desired.

Understanding of the role and experience of others on this aspect of the cancer experience is nevertheless an area that warrants future research attention.

### **Sampling strategy**

As outlined earlier, I considered that the research questions could be met by gathering the experiences of those who met the following criteria:

- diagnosed with cancer post-pubertally and below the age of 21;
- aware that their fertility may be affected.

Given the high demands of treatment both physically and emotionally and the fact that the focus of the study was not on treatment *per se*, it was agreed with the collaborating consultant paediatric/adolescent oncologists at each recruitment site (and subsequently approved by MREC) that individuals would not be approached during any major phase of treatment.

I decided to conduct single interviews with males and females, some not yet adult and some who were. Planned numbers were distributed evenly according to gender and age group. I discuss the reasons for this in more detail below.

- 10 females aged under 21.
- 10 males aged under 21.
- 10 females aged 21 to 30.
- 10 males aged 21 to 30.

The purpose of a sample design is to obtain a cohort most likely to provide the data from which to achieve the aims of the study. As the aim here was to develop understanding of a complex human process rather than to look for data that required an empirically representative sample, theoretical or purposive sampling was appropriate (Mason 2002:124-5). Theoretical sampling requires the identification and consideration of possible theoretical constructs that might aid data analysis in order to pay conscious attention to them. In this study, there were three such constructs:

- (i) That the transition to adulthood may affect, or be affected by, being diagnosed with cancer during this time and learning that fertility may be impaired as a result.
- (ii) That gender may influence such attitudes and experiences.
- (iii) That acquired fertility impairment may have emotional and social consequences for affected individuals.

This did not mean that I determined that transition to adulthood and gender *would* be important variables or that fertility impairment would *necessarily* present an emotional and social challenge but that I held out the possibility that they might be important. Whilst I anticipated that other theoretical propositions might arise from the data, age and gender,

together with a cancer diagnosis during transition to adulthood, were the areas that I drew on theoretically to inform the characteristics of the sample design.

I needed to remain alert to the possibility that my design could obscure unexpected characteristics of participants and/or lead to me looking only for data to support these constructs. One way of attending to this was to enquire regularly of those undertaking recruitment whether or not they were drawing on as diverse a recruitment pool as possible. This could include those at each end of the age spectrum, Black and minority ethnic patients and those with learning or physical impairments. Neither did I presuppose differences in the experiences of those who had a type of cancer where the quantified risk to fertility was relatively low. A criterion for inclusion was therefore only that those affected had been *told* of a risk to their fertility.

With any sampling design, queries arise from time to time and it proved useful to have thought carefully about sampling strategy at this early stage. For example, one centre later queried whether it was acceptable to include those who were now parents (it was); another wondered whether to approach someone who had been diagnosed as a much younger child and re-diagnosed as a teenager (it was not); another queried whether to approach someone who had been told about his potential infertility quite some time after diagnosis but still during his teenage years (it was).

### ***One gender or two?***

Research suggests that gender and gender relations may influence attitudes to sexuality and fertility among young people (Andrews 2006; Holland *et al* 2004; Lees 1993). In the cancer context, the experimental and physiologically complex process of oocyte preservation means that this service is rarely available to teenage females (Picton 2006) while access issues to sperm banking are rarely associated with scientific complexity (Pacey 2006). The implications of availability of fertility preservation services were therefore likely to be an area better understood by the inclusion of both genders. At the same time, some professionals had expressed concerns informally about telling young people of the potential for impaired fertility ahead of them becoming either sexually active or adult. Withholding such information might be more likely to occur where fertility preservation services were not offered at diagnosis and hence this was likely to affect females disproportionately.

The inclusion of both genders thus had the potential to add to understanding of the influence of gender.

## **Age spread**

The literature review suggested that attitudes to, and the salience of, sexuality and fertility matters may change with the attainment of adulthood. There are at least two ways of trying to capture whether this starts during the transition years:

- (i) A longitudinal design.
- (ii) The inclusion of participants at different stages of the transition.

Given that I was only undertaking single interviews, I decided to sample from two different age bands – one aged below 21 years (called 'teenagers' throughout this thesis) and one aged 21 years to 30 years (called 'adults'). By inviting both groups to reflect on their past experiences (retrospective exploration), current experiences (contemporary exploration) and anticipated experiences (future exploration), I hoped that understanding could be enhanced. Participants would, of course, have been diagnosed at different points in their transition and spent differing lengths of time in treatment. That too would provide additional data to be considered in the analysis.

A lower age limit of 13 was arrived at somewhat pragmatically. Although puberty as an indicator of physiological maturation usually starts between 9 and 15 years in males and between 8 and 13.5 years in girls (Balen and Glaser 2006), social aspects of growing up are associated more typically with becoming a teenager. Additionally none of the recruitment centres had yet offered fertility preservation to anyone younger than 13.

Of course it is not straightforward to determine when someone has attained adulthood. There are a variety of measures, many of which are context- and culture-bound. I chose to use age 21. Young people acquire a range of rights and duties from the age of 14, including legal majority at age 18, but the progress towards full physical and social adulthood is typically still underway until at least age 21. Additionally, a lower age divide would have excluded those diagnosed in their mid to late teens who were still in active treatment.

The upper age limit of 30 was arrived at in order to keep any historical differences to a minimum while still drawing on the experiences of those newly adult and in peak contemplative child-rearing age groups. Although the 'adult' group had made the transition to adulthood in a different historical time – albeit slightly - I considered that any drawbacks from this would be slight when set alongside the advantages of drawing on experience across an age span.

I would need to remain alert throughout the study to the danger of sliding into using statistical or probability logic and seeing someone as representative of a particular age group (or gender).

### **Sample size**

Mason (2002) suggests that sample size and range need to be sufficient to help the researcher understand the social process being studied and to:

'... generate data to explore processes, similarities and differences, to test and particular contexts, rather than to make statistical comparisons between the categories themselves within the range, and to infer causality on that basis' (p135).

The use of a mixed characteristic sample (age and gender) also meant that the numbers within each cohort needed to be sufficient to allow for considering the influence of age and gender as well as whole group analysis.

Morse (1998) advocates the sample size in studies using grounded theory being determined *during* data collection, using indices of saturation such as repetition of information obtained and confirmation of previously collected data. However, I was recruiting through NHS services and over a limited timespan. The former requires formal ethical and governance approval and the bodies responsible require indications of intended sample size. In the absence of information to suggest the need for different sizes within the sub-groups and drawing on my limited experience of finding a slowing of new themes coming through in my earlier study of seven teenage males and five sets of parents (albeit on one specific aspect – i.e. sperm banking), I elected to recruit equal numbers to each by age and gender and to opt for ten in each category.

In deciding sample size, I was also alert to feasibility. The numbers diagnosed and surviving treatment, or otherwise available for interview, were likely to be relatively small and depressed further by the sensitive subject matter. Additionally, recruitment of those off major treatment meant that they would be approached only at a routine follow up out-patient appointment which, in some cases, would be annual. Hence, I decided to enlist three regional paediatric oncology centres in the North of England as recruitment sites, having established that their diagnosis rates offered the potential to achieve the required numbers



within the agreed time frame. Their catchment areas were also within a maximum three hours travelling distance for me. I had existing contact with two centres through my earlier research and recruited a third without difficulty. As most treatment for childhood and teenage cancer is carried out in regional centres, their catchment areas are widespread both geographically and in terms of socio-economic class; two of the centres also had ethnically diverse populations.

Taking all these factors into account, I aimed to recruit up to 20 teenagers (10 females and 10 males) and 20 adults (10 females and 10 males).

### **The design of the interviews**

Given the exploratory nature of the study and its sensitive focus, it seemed appropriate to be cautious about participants' level of exposure to the interview process. I therefore decided against conducting multiple interviews (either over a short or an extended timescale) or focus groups. It also became clear from early discussions with the collaborating consultant paediatric/adolescent oncologists that they were only willing to recruit to the study if it used single interviews given that any risk associated with greater exposure could not be assessed.

I was reasonably confident that single interviews would yield rich data. Interviews are arguably one of the most powerful ways through which to try and understand and explain human experience. Woodgate (2001) has argued that such 'an organised social discourse' (p152) is likely to encourage the exploration of the social and personal contexts and meaning of the experiences being studied among child and adolescent cancer patients and survivors. Reinharz too has suggested that an interview: '...offers researchers access to people's ideas, thoughts and memories in their own words rather than in the words of the researcher' (1992:18). Exploration in depth – a conversation with a purpose – may be prompted when the interviewer probes but does not lead (Blackburn 2002).

In my earlier study in a similar field (i.e. sperm banking) - though only involving teenage males - my gender (female) and age (early 50s) did not appear to be an inhibitor and participants were generally articulate and reflective about their experiences (Crawshaw *et al* 2003; Crawshaw 2006). However, the appropriateness and feasibility of using interviews warranted fuller exploration before making a final decision. I drew on what have been called 'path dependencies' – i.e. a tendency for research in a particular area of work to use

particular approaches - though was aware of the possible limitations of comparison, given my mixed gender and age design.

Davies *et al* (1998 cited in Wilkinson 2003) found that ninety-five per cent of cancer patients taking part in qualitative studies reported positively on the experience. In a small number of cases, they yielded information which, with permission, was reported back to the clinical team and resulted in a change in the individual's care. In a paper reflecting on their qualitative study of women's experiences of leaving infertility treatment childless, Peddie *et al* (2006) reported that the interviews produced rich data as well as having unexpected therapeutic outcomes for some. An earlier review of research into fertility matters with adults found that, where there were discrepancies between questionnaire responses and interview data: '...many [participants] stated that often what they stated in the questionnaire *'wasn't what they meant'*' (Peddie and van Etijlingen 2005: my insertion; authors' italics). Similar discrepancies were found in two multi-method studies looking at adolescent females' attitudes towards sexuality and body image following a cancer diagnosis. This led the researchers to conclude that the participants would have been assessed as having much closer views to the control group without the findings from the interviews (Puukko *et al*, 1997a, 1997b, 1997c). Blackburn (2002), in her research about sex matters with adults who had spina bifida found that face to face interviews worked best as did Lees (1993) when talking to (mostly) teenage girls about sexuality and body issues. Eder and Fingerson (2002) concluded in their review of qualitative studies with teenagers that, although much research with this age group is most appropriately conducted within groups, more sensitive topics need different contexts such as individual interviews. Relevant studies included those that talked to both sexes about the impact of pubertal changes, and to teenage girls about their experiences and feelings of sexual desire, love, romance, sexuality and feminism. Zebrack *et al* (2004) used single telephone interviews and Green *et al* (2003) used single face to face interviews in their studies with adult male survivors looking at fertility issues and gathered rich data.

Nevertheless, there remained the potential for some participants to experience distress and/or to need follow up for other reasons as a result of participation. This needed to be addressed before moving ahead. I therefore arranged for follow-up multi-disciplinary services to be available in all three recruitment sites. These were for a range of possible needs including those around fertility testing, storage, sex, fertility and relationships and could be accessed by self referral as well as through me (see Clandinin and Connelly 1998). Their availability was made clear both verbally and in writing regardless of whether distress had

been apparent to offset the possibility that need was there even when not obvious. In the event, though some participants were distressed during interviews, none wanted me to arrange follow up with therapeutic services. Several asked me to report back to their professional carers that they had taken part (mainly their consultants); a smaller number asked me to do so in order to pave the way to a discussion at their next appointment. Some said that they would raise the subject themselves with a known professional of their choice.

Given the subject area, I also had to consider the possibility that some might disclose sexually abusive experiences or other poor practice within their personal or treatment spheres (Bell and Nutt 2002). I was confident that I could draw on my previous social work and research experience to manage the 'here and now' in the interviews. Both as good practice and as part of the MREC requirement, I also agreed that I would alert relevant bodies if abuse or poor clinical practice appeared present, informing the participants if I did so. In the event, this did not arise.

As with all matters that include ethical concerns, the need to keep these aspects under continual review was clear.

### ***Limitations of the interview design***

Having decided to go ahead with single interviews, it was next important to consider any limitations this would impose with a view to reducing these where possible and to consider any implications for analysis and theory generation.

Multiple interviews have the potential to capture variation in spoken views in the short term (from one day to the next) or longer term (over a period of months or years), to revisit factual information or views and explore the meaning of any changes and to increase understanding of the multiple complementary realities that may make up the experiences that one is trying to get at (see Woodgate for an interesting discussion of 'multiple realities' 2001). Puukko et al (1997c) have argued that it is difficult for any single method to capture the richness and complexity of human experience around cancer and Eder and Fingerson (2002) have suggested that researchers should spend at least a brief period of observation in a setting relevant to the subject of the study. For those particularly affected by the context within which an interview takes place, seeing them in more than one setting may enable both researcher and participant to understand better its influence on an interview.

One way of trying to reduce these limitations was to invite explicit exploration of how far a participant's state in the interview reflected their state at different times and in different settings. For example, questions such as 'On a scale of 0 to 10, how much do you think that this affected you at the time? And how much does this affect you today?' were designed to encourage comparative reflection across time and contexts. Questions such as 'Are you where you thought you might be at this age in terms of romantic relationships, thinking about parenthood and so on?' invited comparative speculation. If someone was either rather flat in affect or highly distressed, then I invited them to tell me how far their current mood reflected how they were at other times when thinking about cancer-related fertility matters. I checked regularly how far they felt that their reactions could be attributed to cancer-related fertility matters and how far to other triggers. Of course, any self-perceived differences or similarities in thoughts and behaviours across a range of settings and times do not necessarily carry any more 'truth' than any other verbalisation of experience. But they do carry the added weight of enabling the researcher to hear what the participants themselves are choosing to present rather than only occupying that space with the researcher's interpretation.

Spending time in the hospitals and sperm banks was straightforward to arrange. I set up visits to all the recruitment sites' in-patient and out-patient facilities. I also took photos of most of the physical spaces in case these proved useful in interviews (in fact, I never used them). These visits proved valuable not only for forging links with professional staff but also for being able to talk with some knowledge when participants shared experiences of particular settings.

Although Eder and Fingerson (2002) had concluded that individual interviews were better suited to research into sensitive issues (see above), I was nevertheless aware of the potential for the group setting to equalise the power dynamic (by dint of the researcher being outnumbered), to reduce the likelihood of data being 'contaminated' by a researcher-only interpretation and to enable peer based dialogues to develop in a dynamic exploration of the subject matter and its meaning (p193). Given that the peer context is increasingly the place where attitudes and ideas are overtly and covertly formulated and re-considered during adolescence, they suggest that access to this should form part of data gathering where possible. Woodgate (2001) too has argued for conducting research within the social space of younger participants (in this case, children rather than teenagers) in order to capture the complexity of their world and to experience the way that they act with each other differently to the way that they act with adults:

'Individuals live in interdependent systems in which meaning is shared, shaped and created through interaction' (Woodgate 2001:155).

However, this was problematic for this study. Access to participants was to be when they were off major phases of treatment and therefore not in a setting where they occupied group space with other cancer patients. Indeed, I did not know how far they shared this aspect of their cancer experience within that space as my earlier study on sperm banking (albeit very small numbers) suggested that teenage males did not discuss sperm banking, sexuality and fertility while on the ward. Additionally, that study suggested that knowledge of possible fertility impairment was not shared with members of their 'new' or 'rejoined' group spaces. Such factors led me to conclude that neither entering participants' group space nor seeking to create specific group space from which to gather data was feasible or appropriate.

Further reading confirmed this decision. Edwards *et al* (2003) in their study on fatigue with adolescent cancer patients (arguably a less sensitive subject) failed to recruit through out-patients to focus groups for 13 to 15 year olds and only got a thirty per cent (4) take up among 16 to 19 year old in-patients, all of whom were white and female. In another study with in-patients and out-patients (again on a less sensitive subject), focus groups did run although with smaller numbers than anticipated (3 in each) and themes were not developed to the extent that had been anticipated (Wilkinson, 2003).

The significance of group experience in the formation, maintenance or management of cancer-related fertility impairment experiences would therefore have to be addressed through asking participants to describe and reflect on its impact within the various group spaces that they inhabited rather than through gathering group-based reflections.

That said, an unexpected opportunity arose early in the life of the study to access a group space. A colleague (an andrologist) and myself were invited to present a paper and run a workshop on fertility matters at a residential 'Find your Sense of Tumour' conference run by the Teenage Cancer Trust for almost three hundred teenagers and young adults and their siblings and peer supporters. The experience was rich on many levels.

Aside from pragmatics, single in-depth interviews appeared to have much to offer in these early stages of developing a research-based understanding of a phenomenon, providing that I remained alert to their limitations as well as strengths. The methodological information gathered through this study would also be available for future researchers to help inform their

decisions. I return in more detail later to the ways in which I approached the interviews themselves.

Having determined the design, the next stage was to put this into operation. Once the relevant paperwork and processes were complete, I had to negotiate the demanding and lengthy process of obtaining NHS MREC (see Appendix A for approval letter) and NHS Research and Development approvals and then could move ahead.

## **Data gathering**

### ***Developing the information materials***

Information Brochures and accompanying letters were developed from those used in my study on sperm banking as they appeared to have worked well. I decided to provide one information brochure only to cover all age groups and both genders as:

- it was administratively less complex. This is an important consideration when (i) recruitment is being done by busy professionals whose sole task in this study was recruitment and (ii) the recruitment process is likely to be slow with potential participants being approached at routine medical appointments;
- it addressed the fact that information aimed at adults has the potential to assume too high a reading ability and that the comprehension required to understand the purpose of this study did not require abstract thinking so phrasing could be appropriate to all;
- the subject matter was common to both genders and there was no information or phrasing that was unique to either gender.

A brochure for parents was required only for those with children under 16 (as stipulated by the MREC). Again I was able to adapt the one used in the earlier study which parents had reported to be clear and understandable.

I obtained agreement for brochures to include both the university logo and that of the appropriate NHS Trust with the primary aim of making it clear to potential participants that the research was supported by the staff treating them. The brochure itself made it clear that their actual participation would remain confidential.

## ***Recruitment strategy***

The need to pay attention to staff involved in recruitment is vital and was done through face to face, telephone and email contact. However, some clinicians were willing to recruit even though I had not met them and it proved impractical to have direct contact with them all. I therefore had to rely on research nurses and other clinicians to brief them and provide relevant written materials. In the two sites where I had existing relationships, my contact proved much easier to maintain than with the third. They provided the bulk of the referrals and several of their participants asked for interviews to take place at the hospital. When this happened, I took the opportunity to pay informal visits to the staff that I knew and introduce myself to those that I had not yet met. Relationships were strengthened when I met them subsequently at relevant conferences and so on. The same relationships did not build with the third site and they went on to recruit markedly fewer participants.

Neither was it possible to know the extent to which any internal gate-keeping by clinicians in any of the sites took place. Lowering the potential for professional gate-keeping could only partly be achieved through providing information about, and engaging people in, the recruitment process. I anticipated that the greater the degree to which professionals in the centres considered the study to be worthwhile, the less gate-keeping that they might employ. One major driver was likely to be the potential for improved insights into the experiences of these young people to improve professionals' abilities to handle fertility matters. This would perhaps be the case where professionals found fertility an especially difficult area to handle or where it was a particular area of interest for them. Set against that could be fears that raising the subject of the study would prove too challenging in terms of time, knowledge or skills; fears of parental disapproval where younger people were being approached; concerns that those being approached would object; beliefs that such matters should not be raised proactively for research or any other purpose; or beliefs that the subject was only relevant to certain age groups, social classes and the like. Although the two centres that eventually produced the higher numbers both had staff with a particular interest in fertility, took up my offers to present interim findings and to run focus groups of professionals (the latter formed part of the wider study), the third centre did not.

With hindsight, I perhaps should have been more proactive and strategic in my contact with the third centre.

Although recruitment was not to involve the assisted conception unit staff directly, I felt it was important to keep them informed of developments as they provided some fertility-related services (such as sperm banking) from the point of diagnosis onwards and could receive referrals as a direct result of the research interviews. I anticipated that their engagement with the study's findings would also influence any service developments. Again, I had existing contact with two of the units and knew some staff in the third informally. I visited each site, left copies of written materials about the study and maintained periodic telephone and email contact. However, this too proved less successful with the third site and I discovered well into the study that some key staff had never had sight of the written materials and were unaware of the study's existence.

The research paediatric oncology nurses who would alert clinicians to potential participants on their outpatient lists and the clinicians themselves were provided with a written 'Eligibility Criteria' checklist and copies of recruitment documentation. Once underway, it became clear that the medical records did not always record whether or not fertility had ever been discussed. Ethical considerations meant that people could not be approached unless this was clear.

If the person being approached agreed to consider participation (for under 16s, only with their parents' permission), they were given an information brochure, an 'agreement to contact' form for them to complete and a stamped addressed envelope in which to return it direct to me. The research nurses sent a reminder letter, another stamped addressed envelope and information materials to all who had agreed to consider participation approximately 2-3 weeks later. This letter made it clear that the hospital staff did not know whether or not the person had already contacted me. In keeping with a confidential approach to recruitment, I therefore only became aware of participants' identity once they made direct contact with me.

### ***Use of recruitment diaries***

From the beginning, I provided the research nurses with a recruitment diary to complete and return every three months with the aim of:

- obtaining regular information about take-up rates;
- keeping the study to the forefront of those with responsibility for recruitment.

These proved very valuable. They allowed me to gather the numbers approached, encourage attention to diversity in the recruitment pool and track the take-up rates across all three sites and between the four different target groups. They also provided a way of



maintaining regular contact of a routine nature. Through this, I could give some feedback about the overall recruitment picture by setting out which groups were recruiting well and which not, encourage them to consider diversity where possible, offer preliminary information about the quality of data coming through and so on. In other words, I was hoping that this contact provided positive motivation as well as factual information. Of course I could not determine the reasons for any differences between sites simply by obtaining such figures but it provided additional information to contribute to the emerging picture. It also posed a challenge once it became clear that the third centre was approaching fewer than I had anticipated and that one of the other centres was achieving a much higher take up than the other. I wanted to try to understand what was going on in order to encourage better take up if possible. However, I also anticipated that any sharing of the figures across the centres could prove counter-productive if it triggered a competitive or defensive reaction. My compromise was to provide each individual centre with the figures for their centre alone together with a composite picture to all on two separate occasions during the recruitment phase.

### ***The unfolding recruitment challenge***

As indicated, there were recruitment challenges as the study unfolded. Despite thinking that the process was underway, it became clear that the procedures for identifying potential participants were not in place in all three centres by the time that I had hoped to start interviewing. This reminded me that I had responsibility for the study without authority to insist on recruitment action. Knowing the demands of operational activity - especially in a service such as this - and aware that I was dependent on their goodwill made me reluctant to apply pressure. This continued to be a feature throughout.

Once recruitment got underway, it was as slow as anticipated. The interview approach itself was working well across the genders and age ranges and was revealing a range of reactions to fertility matters. Nevertheless, as projected targets were not reached, I gave serious consideration to involving another centre even though that would involve additional time and expense and a request for variation in approval to NHS MREC and R&D approval – a daunting prospect.

At this stage, more teenagers were being recruited than adults and this came as somewhat of a surprise. Anecdotal feedback from the clinicians concerned shed little light on this. Some said that most patients expressed interest on being approached and others reported reluctance to speak to a 'stranger' because of the private nature of the subject. Although the

low take-up rate was important information in its own right, I had not set up a system for gathering information from those being approached - an opportunity missed.

At around this time, a teenager who had agreed to take part asked me whether he could provide his views in writing rather than through an interview. It was important to him to take part but he did not feel he could manage a face to face interview. This, he said, was both because of having limited time and because there were some aspects that he would find more difficult to put over in person. He asked me to provide some questions to guide his response as he was not sure he could produce something totally freehand. I agreed, adapted the topic guide accordingly (see Appendix B) and he duly returned his completed written comments. This was an interesting ethical dilemma. Here was someone who had a contribution to make but on his terms. To have refused his offer, or to have marginalised his contribution by accepting it and then not using it, neither felt ethical nor consistent with grounded theory approaches. Moreover, this situation opened up the possibility of addressing some of the recruitment difficulties.

In order to introduce written submissions as an alternative to interviews, I needed to get provisional agreement from the staff involved in recruiting. I also wondered whether the offer of telephone interviews might be worth considering as they too offer more anonymity and/or require less of a time commitment. The recruitment staff agreed to both suggestions. However I also wanted to maximise the numbers of face-to-face interviews so we agreed that recruiters would only offer the alternative approaches verbally if there appeared to be barriers to participation that might be thus addressed. For everyone else, I redrafted the reminder letter to include written reference to these alternative mediums. This would ensure consistency of methodology as far as possible without compromising the intention of this change, i.e. to facilitate involvement. I anticipated that this development might also provide some valuable methodological information around recruitment strategies. I went back to MREC and obtained approval (see Appendix A).

A further unexpected challenge presented itself as a result of the funders of the larger study asking me to write a short article about it for their newsletter. The article prompted several responses from people interested in sharing their experiences and who had been treated at one of the recruitment centres. Two met the eligibility criteria and four did not (because they were children when diagnosed and/or were outside the age limit). I checked with MREC and obtained their agreement to interview those who were eligible. In the event, both were now living hundreds of miles away and therefore opted for telephone interviews. Those who were

not eligible to take part were invited to complete written responses to be used as background for the study but not included in the formal analysis. I offered the choice of using the same format as the teenage male above or making a freehand response. All agreed and opted to use the provided format.

Finally, there were a small number of people who returned their 'agreement to contact' form but did not proceed to interview. In each case, I was able to make contact but they then failed to respond to telephone messages or letters suggesting possible appointment times. One young woman even completed part of a telephone interview (on her mobile phone in the open air) before saying that she had to be elsewhere. She then failed to respond to all efforts on my part to re-engage her (her interview was not included in the analysis). For one at least, the reason for non participation was worrying. His mother reported that he found it too upsetting to go ahead even though he (and she) had thought that it might be helpful to him to take part. In each case, I tried to balance any need they may have for further encouragement to get over any barrier standing in their way with any danger that ongoing invitations might feel like undue pressure.

Recruitment remained low for some time until a steady upturn (with no obvious trigger) led me to abandon consideration of the inclusion of an additional site and opt instead for an extension to the recruitment phase. Final numbers were only two short of the original target, though with some differences in distribution across the four categories. No more took up the option of a written response; four in total opted for telephone interviews.

### ***Developing the interview schedule***

Although I anticipated that the pattern of the interviews would be dictated in large part by the participants, I still needed to develop a topic guide (see Appendix C). The aim was to facilitate a well informed attentiveness and dialogue on my part and to maintain focus, if necessary, while at the same time enabling me to ask a small number of core questions of all. It was developed through:

- Trawling the literature to identify key areas.
- Informal dialogues with health and social care professionals in the field.

### ***Pilot interview***

Conducting a pilot interview(s) allows testing of the move from 'design to reality' (Robson 2002:383). I had recent experience of interviewing teenage males in the sperm banking

study but wanted to conduct a pilot interview with at least one female. Despite centres expressing confidence that they could recruit females for a pilot interview, they failed to approach anyone in the required timescale. I therefore made an indirect approach to a woman with Turner Syndrome that had occasionally attended a support group that I co-facilitate for people with fertility difficulties and she agreed. Although not a cancer survivor, the interview drew on similar enough experiences for it to prove helpful in 'testing' the approach.

### **Consent process**

It was agreed that I, as researcher, would take participants' consents, as the separation of this function from the initial approach to participate had a number of advantages:

- I was better able to ensure that recruits were fully informed about the study.
- It allowed a 'cooling off' period, reduced the potential for recruits to agree in order to 'please' their doctor, ensured their confidentiality and separated treatment from research involvement in a study where their existing professional supporters did not 'need to know'.

Written consents were usually taken immediately prior to the interview, making it clear that participants could still withdraw at that stage or later. When the use of telephone interviews or written responses was approved, it was agreed that written consents for these would be obtained either prior to interview, prior to the interview being transcribed or alongside written materials being submitted. The following key features of the consent taking were adhered to:

- *Statement of the purpose* of the research and my role within it.
- *Outline of the confidentiality 'rules'* making it clear that representation of their views in public documents would be anonymous and non-identifiable but offering choice as to whether they wanted me to inform professional or informal carers of their involvement and/or pass on any information. It became clear soon after recruitment began that one of the sites had assumed that I would provide them automatically with the names of all who took part and thought that this was an MREC requirement (it was not). It emerged that they had no experience of consents being completed by someone outside of the unit and this presented an interesting cultural challenge. After useful discussions, they agreed to waive their wish for identifying information. It would also have been

easy to fall into information exchanges with staff in all three sites who were often understandably curious to know who had taken part.

- *Explanation of the interview process* including likely length and content, making it clear they could stop the interview at any time without explanation and/or refuse to answer particular questions without it affecting their treatment in any way. Participants were also invited to ask me to phrase things more clearly if they did not understand anything that I said. I acknowledged explicitly the potentially sensitive and embarrassing focus of the study, saying that, for example, I would not ask them anything explicitly sexual but would be happy to discuss any areas that they themselves wished to raise. I also sought to make it clear that there were no right or wrong answers, experiences or views and that some would have a lot to say and others relatively little.
- *Choice around interview being recorded* – I anticipated that tape recording might cause anxiety given the sensitivity of the subject but this was not realised, with concerns centring more typically on the sound of one's voice when captured on tape. I return later to other issues associated with transcriptions.

My aim was to gauge the length of consent taking to ensure opportunity for questions, to establish rapport and to lower anxiety prior to moving into the interview itself – not always an easy balance to strike. Consent also needs to be ongoing (Mauthner *et al*, 2002). For example, where a participant appeared uncomfortable with any part of the interview, I had to remain alert to the possibility that they needed permission *not* to disclose rather than help to voice their thoughts or experiences. I also needed to be careful about whether or not permission was given to any material given once the tape-recorder was switched off and to not assume that everything said in the recorded parts of the interview itself was consented for. An ethical approach to research extends well beyond seeking formal consent. As Forbat and Henderson (2003) say '...a dialogue on ethics should be part of the ongoing process of research (p1457). I return to this later.

## ***The interviews***

### ***Interview style***

Qualitative research interviews need to be flexible enough to adapt to the participants' needs *and* maximise their control through them dictating their content, pace and length. Flick (2002) has advocated that:

'.....increased structuring is introduced only ..... to prevent the interviewer's frame of reference being imposed on the interviewee's viewpoints' (Flick 2002:75).

Schmidt (2004) has suggested that a flexible approach is especially important when the subject is a sensitive one. The interview itself can be used to 'think aloud' and to make sense of experiences, something that Morse (2002) has found to be particularly useful for those exploring their retrospective experience of serious illness.

This is not to deny the active participation of the interviewer in the process. Indeed, a looser structure can sometimes lead to the participant (and interviewer!) digressing or otherwise struggling to uncover the material. Part of the interviewer's skill is to keep the interview on track while not being unduly intrusive, controlling or otherwise inhibitive.

In similar vein, I needed to avoid using what are called 'known-answer' questions (Eder and Fingerson 2002:184) that can stimulate patterned responses, sometimes prompted by a desire to 'please':

'Consciously or unconsciously, respondents might give the sort of answers they believe that the interviewer wants to hear rather than saying what they truly believe' (Haralambos and Holborn 1995:842).

Initially I assumed that it would be empowering to encourage people to tell their own story in their own way rather than to ask pre-set questions. However, when setting up interviews over the phone (that first crucial contact for engagement) it became clear that the prospect of this, for some, had the opposite effect. As I became more sensitised to this possibility, I adapted what I said – that I would be guided by them: if they preferred to 'tell their story' their own way that was fine but if they preferred me to ask questions, at least at the beginning, then that was OK too. Although I might feel confident that I could facilitate them telling their story, *they* did not know that I could and it was their state that was the most important to address. Perhaps this is especially pertinent to consider when the subject matter is intimate. Unambiguous messages need to be offered and these may, paradoxically, be obscured by the offer only of an unstructured approach at the point of engagement.

In the interview itself, I asked people to start by telling me about events leading up to the diagnosis and/or when fertility was first mentioned. The aim was to orient myself to their

particular situation but also to start with the familiar – a story that they were likely to have recounted before in part and which had the *potential* to be less sensitive (recognising that, for some, it may be traumatic to revisit this story) and thus enable the interview relationship to become established. Let them get a feel for me and me for them before entering more tricky ground. In doing so, I was managing a range of participant responses – the garrulous; the quiet; the emotional; the detached. Some spoke at length from the beginning with little input from me while others were almost monosyllabic at first. It is at these times that I felt the value of my social work experience in informing my ability to establish dialogue across a range of ages (16 to 30), articulacy and life styles (unemployed youth to lawyer) and to ‘stay’ with difficult areas of feeling including silences, despair and tears – though aware of the need to remain alert to the boundaries of the researcher role. My contextual knowledge about infertility, sexuality and cancer also proved invaluable.

### ***Elaboration, clarification and probing***

As the interview progresses, the researcher needs to know when and how to clarify what has been said. In this study, sometimes this was due to the use of unfamiliar terms – either technical (usually treatment related) or colloquial – and sometimes it was due to a difficulty in hearing their words because of a strong regional accent or because their voices had become too soft. This had to be done with care so as not to interrupt the flow or prompt retreat. There were times, especially with those with strong regional accents, where I took the decision to lose data by remaining silent.

There were also times when familiar words were used differently by different people - for example, reference to a close friendship could mean quite different levels of intimacy. The potential for misunderstandings and misinterpretation required a particular alertness on my part. Regular use of paraphrasing and summarising as a way of seeking confirmation of understanding proved invaluable (Woodgate 2001). So did the reminder that the use of words can in itself be a valuable component in the discovery of a new discourse (Shaw 1999).

Bryman (2004), Shephard (2004) and others suggest that alongside the need to clarify comes the need to probe beneath surface appearances in order to seek more accurate understanding of experiences. I found this to be a particular challenge with regard to sexual matters and rarely found a comfortable and/or effective approach. No doubt this was a mixture of the participants' unease and my own and, perhaps, also reflected the complexity of disentangling reproductive and sexual matters. However, there is also an associated danger

of participants divulging more than they want to because of getting 'carried away' in a face to face interview – what Shaw (2003) has called the risk of 'unwitting disclosure'.

One of the challenges therefore was to decide how and when to pick up the threads of a narrative and invite deeper exploration. When someone offered a full and lengthy narrative (or even a very factual one, delivered fairly mechanically), should I then go back and work through it chronologically to tease out and explore the threads more fully? Or was it more appropriate to stay with the most recent areas, explore them and then work back, trying to link/connect the parts together in a meaningful way (i.e. meaningful to the participant) in order to encourage fuller reflections and details? This is the skill of keeping the narrative unfolding without imposing one's needs, wishes or preferred style as researcher. It also requires alertness to role. In this setting, I was present as a researcher not in a directly therapeutic role. I had to be careful not to invite the opening of issues that might remain unmet and distressing when the interview was over - not to become therapist instead of interviewer, even though I hoped my style would have a therapeutic effect.

This also opens up the question of reciprocity – although participation was altruistic in that no formal payment was involved, I was aware of the debates about what motivates people to take part in research as well as those about whether researchers should actively seek opportunities to 'pay back' (Eder and Fingerson 2002; Mauthner *et al* 2002; Peddie *et al* 2006; Ribbens and Edwards 2006). Some researchers working in sensitive fields have reported participants welcoming the opportunity to gain fresh insights through talking with an 'interested adult' who was not a family member or friend; others have reported participants achieving 'closure' on previously painful subjects (Morse 2002; Peddie *et al* 2006).

### ***Sharing experiences across interviews***

As the study progressed and patterns started to emerge, the question arose as to whether or not it was appropriate to share these patterns with those being interviewed subsequently (anonymously of course). For example, I decided to share the fact that some had become biological parents (sometimes in response to direct questions; sometimes to illustrate the fact that not everyone having cancer treatment becomes infertile). Several asked how far their experience matched that of others and I answered them, as well as using the opportunity to see how far this was an opening through which to elicit further dialogue. After I had produced a mid-study newsletter that included some preliminary findings, I offered this at the end of interviews and answered any questions arising. When sharing such information, I made it clear that the picture may change as the study progressed.



I reflected at length at the time and subsequently about sharing information in this way. Methodologists such as Mason (2002) and Morse (1998) have pointed to the dynamic nature of qualitative research. The researcher is urged to compare continually the emerging responses, interrogate them against existing theory and seek new and extended conceptual understandings. For study participants, involvement is time-limited and motivations may vary (Peddie *et al* 2006). The researcher can assume understanding neither of motivation nor of impact following involvement. Indeed it was salutary to hear the only participant who had taken part in research previously talk about his distress and irritation at 'recognising' himself in a category that the researchers ascribed to him in subsequent publications that he did not accept to reflect his own understanding of his reactions. I was aware of the danger of doing the same. As patterns emerged, it became clear that there was a common experience of silence around the subject of cancer-related fertility impairment. For some that was troubling, for others it was not. However it seemed to me that any refusal on my part to answer questions compounded that silence. While they were members of a 'community' of people living with cancer or surviving in its aftermath, participants had the opportunity to 'hear' through me, and with due attention to confidentiality, of others' experiences – thus acknowledging that they were also members of a different sort of community, the 'community of those taking part in the study'.

The provision of information was not only about what other participants had said. I also provided factual information during the interview if asked about, say, fertility treatments and invited questions at the end. I of course needed to be aware of keeping within my levels of competence when doing so and paying attention to the potential need for referral to follow up services.

As part of recognising that some participants may need breathing space in which to consider whether to go deeper into the subject or leave it at the level that they had dealt with it – and given that their engagement in the subject matter of the interview was likely to be dynamic not static - I offered participants the opportunity to contact me after the interview with any further thoughts and experiences or to take up the offer of referral to follow up services. I sought to lower barriers to this by leaving them with blank paper and a stamped addressed envelope for written comments; audio cassette, computer disc and jiffy bag for recorded comments; visiting card with telephone number (including mobile number for texting) and email address. I made it clear that these could be kept for their own use if they did not use them to contact me – a small recognition of their involvement.

At the end of the interview, I spent time engaging them in lighter conversation, monitoring their affect and so on. This was not to deny that they might revisit the feelings surrounding the interview and/or continue processing its impact but to ensure they were emotionally ready to move on to whatever they were doing next.

I sent a thank you letter the following day that included reference to the availability of follow up services (or confirming any arrangements we had made for me to arrange these) and to explain when to expect their transcript and the study's findings (if they requested copies).

### ***Reflexivity – a guarantee of anti-oppressive practice?***

Qualitative research is flawed if it concentrates on skill in eliciting information from informants to the exclusion of understanding the researchers' impact on the data and the impact of the data on them. The emphasis on 'objectivity' in interviewing as a way of increasing reliability in data collection was challenged initially by feminist researchers (Finch 1984; Letherby 2003; Maynard and Purvis 1994; Oakley 1981). There is now a plethora of mainstream writing about the necessity for interviewer/researcher reflexivity during qualitative data collection and analysis and the potential for reflexivity to offer a different context for developing knowledge (Bryman and Burgess 1994; Bryman 2004; Gubrium and Holstein 2002; Mason 2002).

My interest in the experience of living with cancer was in part fuelled by my personal experience as a 24 year old in the 1970s of my older brother Geoffrey (aged 27) being diagnosed with cancer and dying within weeks. Although I have no personal experience of infertility or of having acquired physical or cognitive impairment, I do have knowledge of them through close friends and family members. Professionally I was drawing on my social work experience with people of all ages (including teenagers and adults) coping with a range of issues associated with reproductive and sexual health (including infertility), acquired illness (including cancer) and physical impairment (congenital and acquired). Politically, I was drawing both on my work as an educator enabling social work students and practice teachers to develop anti-oppressive practice approaches and as an activist within the women's health movement and campaigns around assisted conception issues.

Given that any similarities in experience with participants around cancer and fertility were invisible, I needed to consider to what extent I would disclose any personal information in interviews as a way of humanising myself and lowering any barriers or enhancing what Janesick (1998) has called 'authentic communication' (p39). Drawing on transferable

experience from social work, I anticipated that some participants would want to 'know' whether or not I could understand the context from which, or about which, they were speaking – for example about cancer treatment or their home community - and that this might influence what they would in turn tell me. Here, relevant disclosure might enhance the connection, providing that it did not divert the focus away from the participant's story and that I remained alert to what Reinharz and Chase (2002) have called the difference between 'rapport' and 'intense bonding' (p229). This proved to be the case for example when knowing that I had shared in a sibling's cancer journey as a young adult opened deeper dialogues, in a small number of cases. For others, disclosure was useful in establishing rapport in the sometimes awkward beginning stages of interviews, perhaps made worse for some in knowing that dealing with sensitive material lay ahead. For instance, several participants were football supporters and brief social chat about the relative league positions of our respective football teams went down well. For all but one, this was their first encounter with the research process and some were unsure of its 'etiquette', including around personal matters. This needed to be considered against the backdrop of their cancer experience. In-patient experiences are invariably intense and can be lengthy. The extent to which patients come to know about their professional carers' personal lives can be unusual, making it more difficult for them to know what to expect in other professional encounters.

However, just as personal and professional experiences are no guarantee of an enhanced understanding of others' personal experiences, so too is reflexivity limited if it is not informed by an understanding of the influence of power relations on personal encounters and knowledge production. Using a social model of understanding of the barriers to full citizenship and employing this in data collection and analysis was central to my approach. It also provided an added dimension to my understanding of the extent to which the participants and I might feel comfortable or threatened as different areas were broached (or not).

There are 'rules' that we acquire through our own unique and socially constructed experience. These are all the more difficult to identify and deconstruct because of the route for their formulation and maintenance – 'our' world as the norm and 'the other' as different because it is measured against us (Thompson 2003; Tomlinson and Trew 2002). Such social and cultural processes may lead researchers to make inaccurate causal inferences even when *they* assume similarity with participants. The more 'dominant' the number of social groupings of which the individual holds membership, the more difficult is the process of self-awareness and deconstruction and the greater the danger of assuming understanding (Vernon 1999). Any socially 'dominant' (and hidden to myself) views that I held of adolescent development,

gender, disability, social class and so on had the potential to constrict my beliefs in, and distort my understandings of, participants' ability to construct and 'know' the meanings they ascribed to their actions, the actions of those around them and the events and experiences that they were navigating.

In the interview situation, each party enters into a conversation and starts to negotiate membership categories – gender, social class, age-related, sexuality and so on. Without a reflexive and anti-oppressive approach, the danger was heightened that I might construct my own interpretations and assumptions rather than getting closer to participants' voices (Woodgate, 2001; Bearison, 1991). I was going to conduct interviews about a potentially sensitive and intimate set of experiences. Thus, as well as the issues surrounding theoretical orientation and personal experience, there were the issues of my age (mid 50s), gender (female), physical status (non-disabled) and social class (acquired middle class) to consider. I would share sexual orientation and ethnicity with some and not with others. I anticipated that many would not share the same social status as I did. The younger group in particular would come low on the socially constructed age-graded power structure. However, to offset some of these potential barriers I am also a Northerner with working class roots and the broadness of my accent changes with the context in which I find myself; I had contemporary personal experience of engaging with teenagers and young adults of both genders as well as many years of doing so professionally; my age had the potential for me to be seen as asexual by some of those being interviewed; teenagers of both genders are more likely to talk to their mothers than their fathers about health, emotional or intimate matters (Brannen *et al* 1994); and both adult males and females are more likely to use adult females for intimate discussion (Monach 1993; Pengelly *et al* 1995).

Harnessing attention to reciprocity within a reflexive, anti-oppressive approach would, I hoped, lead to people coming out of interviews reasonably satisfied in terms of feeling that they had been listened to, understood and given adequate time to present their views and experiences and that I had been respectful.

I have outlined previously some aspects of the interview process that drew on anti-oppressive practice principles and the following adds to those:

- *Making speedy contact on receipt of 'agreement to contact' forms and offering a variety of interview dates (including some early ones) so that participants could themselves determine the speed of take up rather than experience potential anxiety*

or undue rumination while awaiting my response. This worked well, on the whole, though there were a small number for whom the speed of response appeared disconcerting, reminding me of the potential for some to continue to contemplate participation beyond expression of intent.

- *Offering choice of time (including weekends and evenings) and setting for the interview (home, hospital or elsewhere) and whether or not they were accompanied* in order to maximise confidence levels and/or lower any anxiety. The resulting choices suggested that there were indeed differences between participants about what might work best and I report on this in Chapter Four.
- *Offering transcripts and summaries of findings* – my partnership approach extended to offering summaries of the study's findings using accessible language (and alternative formats if required). All were offered a transcript of their interview at the beginning and end of the interview, together with some preparation for what to expect of it, possible impact from reading it (Poland 2002) and a likely timescale for it to be ready. If anyone turned the offer down, I made it clear that they could change their mind at a later date (one took this up several months later when changes in her situation prompted her to want to revisit what she had said and felt at interview). I also needed to be clear about my purpose in making the transcripts available. Although I anticipated that few would want to revise their transcripts and did not place any obligation on participants to engage in what has been called 'member checking' (Morse 1998), I was open to further dialogue if this was requested. In the event, transcripts were requested by more females than males and by more teenagers than adults - 7/9 teenage females; 3/7 teenage males; 4/12 adult females; no adult males – and two females sent me additional information several months later following changes in their personal situations.
- *Aiming for transparency at each stage of the process* right through to production of the research report (Gould 1999; Miles and Huberman 1994). For example, once the study was underway, I became aware of the length of time that early participants would be waiting for the study's results. As already referred to, I therefore produced a mid-study newsletter to keep them informed of progress.
- *Phrasing my questions or comments in social model terms* – for example using socially inclusive language that did not 'blame' the person for their experience and predominantly open questions and so on. In particular, I sought to be alert to particular social constructions that might inform my approach to the younger participants (Alderson 1999; Eder and Fingerson 2002; Woodgate 2001), to women (Letherby 2003; Maynard and Purvis 1994; Reinharz and Chase 2002) to men

(Moynihan 1999, 2002; Schwalbe and Wolkomir 2002) and to disabled people (Corker and French 1999; Olsen and Wates 2003; Priestley 2005).

## **Written records**

### ***Logging basic quantitative data***

Although this was a qualitative study, it was useful to build an emerging profile of participants according to key measurable characteristics. I constructed Excel spreadsheets to record quantitative data following each interview. Some information was gathered onto a 'biographical data sheet' that I had devised. This was completed at the end of each interview. It included age at diagnosis, age at interview, religion, position in family, number of siblings, living situation at time of diagnosis and at present day, current education/employment situation, highest educational level to date. Medical information included type of cancer; length of time between symptoms starting and diagnosis; any prior impairment. Other information was extracted from the interviews, including when told about fertility; whether choice was available about who present when told; length of time between being told and banking (if applicable); whether any choice was present about accompaniment to sperm bank (if applicable). These were completed within a day of the interview. It became clear during analysis that it would have been useful also to have included the length of time since major treatment was finished and the length of time spent in treatment as these details were sometimes not clear in the interviews themselves and I did not always remember to clarify them.

### ***Use of field notes***

Field notes contain a running description of the context of the interview. Just as with transcripts, they are partial accounts of encounters with research participants (Poland 2002:645). The act of recording (usually within a day) enabled me to process my thoughts and internal reflections on that particular interview but also to reflect on the cumulative experience of interviewing and the unfolding 'story'. As such they formed part of the data from which I could review my approach and the overall methodology. I used the field notes to put flesh onto the spoken narrative, record facts (for example, type of house, number of people present, time of day), capture my thoughts and experiences and give focussed attention to power dynamics and personal assumptions.

I have referred already to the use of a question asking participants to place their reactions on a '0 to 10 scale'. For these responses, I kept a separate running record in which I set down my recollections of the reasons given to accompany the rating together with my own observations of how close or divergent this was to what I had anticipated.

Field notes have another use. Some participants continued to talk about relevant matters both before and after the tape recorder was running. While this sometimes appeared to represent avoidance (for various reasons) of committing their thoughts to tape, it was also sometimes happenchance. Field notes could allow these conversations to inform my understanding of these experiences.

I checked through field notes before and after listening to the tape when checking the transcript - anything from a few weeks to, in a small number of cases, a few months after the interview - sometimes making additions. A further read through before and/or after doing the computer aided coding of interviews and during analysis confirmed their value.

### ***Transcripts***

I decided to tape record the interviews, with permission, in order to concentrate more fully on the interaction in the interview and to avoid interviewer bias in recording (Denscombe 2003:176-7). All participants agreed to being taped but one telephone interview failed to record. In accordance with departmental practice, I did a transcript myself, with any verbatim text that I could recall (fortunately I had taken written notes during the interview) within two hours of the interview. I contacted the individual concerned the same day and she agreed to 'check' my written account. Once this process was completed, the account was included in the final analysis.

Participants and transcripts were given a unique identifier that identified the category of the participant (teenage male (TM), adult female (AF) and so on) with a number, the list of which was then stored securely. Tapes were identified by this code and transcribed by one of two administrative staff in my workplace who were not only known to me but who had done the transcribing on the earlier sperm banking study so had some familiarity with the context of this present study. Poland (2002) has identified four key problems faced in transcription:

- knowing where to begin and end sentences
- knowing where participants are paraphrasing or mimicking others
- missing odd words or phrases in the process of winding and rewinding tapes

- mistaking words for similar sounding words

All were present in these transcripts, and some were particularly significant – for example ‘...there’s a *deviation* now’ instead of ‘*DVD* now’ and ‘Yeah, the *concept* thing’s very interesting’ instead of ‘*contraception*’ and ‘... for a lot of the *transparent* procedures...’ instead of ‘transplant’. Problems associated with conveying affect through a transcript make an important fifth category. Although I felt confident beforehand that I would understand the relevant transcribing conventions on which the transcribers and I had agreed, they quickly became elusive when reading the completed transcript, not least because a third party (in this case the transcriber) is necessarily limited in capturing nuance and emotion. When listening to the tapes again and revising the transcripts, I took the opportunity to develop new conventions for subsequent transcripts as well as making notes on the existing ones. The danger of distortion could never be overcome fully.

‘Listening again’ is no longer common practice in qualitative research but I found it invaluable. Apart from improving the accuracy of the transcript, the impact of listening again was very powerful, especially noticing what I had recalled immediately after the interview and what I ‘heard’ on the second time of listening. The spoken stories carried their own power and the feelings were, at times, very raw. Aside from the length and complexity of some interviews, these factors by themselves reminded me that I could not have remained present to all that was being said, verbally and non-verbally, in the interview itself.

This process was enhanced unexpectedly by the dialogues that developed with the transcribers. They were, of course, the only other people that heard the interviews in full and they engaged actively in considering the emerging picture. Given the subject matter, I tried to identify beforehand those interviews that might prove especially distressing to transcribe (including where participants had been distressed, shared difficult memories of treatment and its aftermath and where it became clear that someone was facing an uncertain future) and made myself available to debrief with them afterwards. I also alerted them to interviews that brought challenges of a different kind – for example, interviewing people with strong regional accents (even though I tried to repeat words or paraphrase more than usual in the interview with the transcribers in mind) and interviews in a hospital that had a particularly noisy door just outside the interview room that came through loud and clear on the tape!

The dialogues themselves were invaluable. Sometimes these centred on what we thought was going on for someone in an interview; sometimes the transcriber picked up that I



appeared less comfortable than usual at certain points and checked that out with me, prompting discussion; sometimes we shared views on what we thought the explanations might be for someone's reactions, especially in relation to the influence of professional style.

Poland (2002) reminds us of the importance of seeing the transcript as a partial account of an interview – the spoken word only and even then not wholly accurate - and therefore not over privileging it. There was perhaps a particular danger of allowing the many other aspects of interpersonal communication, including non-verbal communication, to become less visible when I moved into the coding stages. As Oakley (1981) has said 'Interviewing is rather like a marriage: everybody knows what it is, an awful lot of people do it, and yet behind each closed door there is a world of secrets' (p41).

In summary, transcripts, like interviews, are open to multiple alternative readings as well as re-interpretation with each fresh reading. The potential for contested meanings and divergent interpretations of what is being said does not stay in the interview room.

## **ANALYSIS**

Analysis in studies such as this begins from the inception of the study with the researcher continually comparing, reassessing and refining concepts as the fieldwork proceeds (Pyett 2003; Denscombe 2002). As I have already indicated, I had been appraising constantly the data and my part in it (its impact on me and vice versa) and reformulating my working thoughts through a variety of stimuli: the interviews themselves; reflections on them; conversations with transcribers, practitioners from different disciplines, other researchers in the field, PhD supervisor, colleagues and friends; and reading. In addition to field notes, I recorded 'thoughts' and bullet points of emerging issues and kept these in a separate folder in date order and returned to them on a regular basis. When I employed these back into the fieldwork, I recorded the impact of any changes and any new reflections. Throughout, I kept a reflective diary which enabled me to maintain a running, introspective account of my thoughts, feelings and actions as they twisted and turned and unfolded – reflecting on '...how our own social positioning and personal experiences bear on our research-related actions and interpretations' (Grinyer and Thomas 2001:166). All of this also, of course, enabled me to look for what Morse calls 'negative cases' which have the potential to enrich emerging models and explain variations and diverse patterns (Morse 1998).

As a study moves towards its end goal of reducing the data into a manageable model, then certain tasks assume greater prominence including:

- Breaking the data down inductively.
- Reconstructing them.
- Examining them for patterns and shapes.
- Summarising them.
- Representing what the researcher thinks they say.
- Communicating that to others.

It is the process of constant comparison that informs the sifting into themes, concepts or similar and the search for possible relationships between them that makes for the distinctiveness of this type of qualitative research. As the analysis unfolds, the researcher develops working models to explain the behaviour under study and identifies relationships that connect portions of the description with the explanations offered in their working models. Attempts to determine the significance of the various elements in the models and to verify these by checking through field notes, transcripts and so on culminate in the data being presented in narrative form, supported by empirical assertions and an accompanying interpretive commentary (Strauss and Corbin 1998).

The need for ongoing vigilance to the danger of theoretical and stereotypical bias is as important here as at any other stage of the research process. Analysis requires a different knowledge to that which participants have. The skill is to present the data in a way that reflects the range of experiences among participants at the same time as making it clear that the theoretical framework that accompanies it is the researcher's interpretation.

What is less clear is whether the more formal stages of this process should come after the completion of fieldwork or whether it should be ongoing throughout. Some writers, such as D'Cruz and Jones (2004), appear to suggest the latter:

'...qualitative data analysis is not a separate stage that comes after the data generation process. Instead it is an ongoing process that ought to be a feature of data generation as well as a stage that follows it' (D'Cruz and Jones 2004:150).

Bryman and Burgess similarly have said that the heart of good qualitative research is a 'constant interplay between data gathering and analysis' (1994:219). However the more I read, the less clear I became about what stage the formal coding and analysis stages should most appropriately get underway.

I was further constrained by a number of challenges of a different kind:

- As recruitment had been slower than anticipated, it was clear that I might need to extend it if I were to achieve my target. This would reduce the time available for coding and analysis if I were to leave it until fieldwork was complete.
- I had planned to use computer assisted qualitative data analysis software for the first time and was nervous about developing sufficient competence if coding was spread more thinly over an extended period.
- I had expected to construct a preliminary coding frame following a first read through of transcripts upon which to build as I worked through them in more depth. The less transcripts that were used for this, the less useful this might prove and the greater the likelihood of having to revisit transcripts several times for 're-coding'.
- I had planned to use a second researcher to read a selection of my coded transcripts to see how close or divergent our views were; this had been based on an assumption that most of the fieldwork would be completed by a particular time.

After a surge in uptake left me having to concentrate on fieldwork, the decision was made for me and I was able to move into coding with the majority of interviews completed – a useful compromise.

### **Coding**

Miles and Huberman (1994) have noted that qualitative data is often poorly structured and extremely bulky and this requires rigorous processes of data reduction and conclusion drawing.

Coding begins the process of categorising data ahead of grouping, clustering and interpreting them, with the codes acting as descriptors - retrieval and organisational devices that allow the range and frequency of categorised responses to be classified and identified for the whole cohort and for any sub groups (Huberman and Miles 1998). There are three phases to the coding process – 'open coding' to find the categories, 'axial coding' to interconnect them and 'selective coding' to establish final core categories (Bryman 2004:401-408; Robson 2002:492-497).

As planned, I read through all available transcripts and provided a cross section for the second researcher to look through, having reminded ourselves of the aims of the study. At this stage, we were looking at a low level of granularity for possible patterns, key events or themes that could come together in groups which were *either* like one another (e.g. coping strategies, responses of parents) *or* which referred to a particular point in the process (e.g. diagnosis, returning to school or work, fertility testing). We met and agreed a four page preliminary coding frame with a provisional hierarchy of dominant and subordinate codes. Although the use of a second researcher was helpful for enabling me to 'see the data through another's eyes', I was aware of its limitations. Transcripts do not necessarily convey the verbal nuances of the encounter and non-verbal communications are largely invisible, as already discussed (Poland 2002). Neither is coding value free, influenced as it is by the personal and social assumptions of the person coding. However, acknowledgement of this increases credibility (Shaw 2003) and the employment of a second researcher can lead to useful challenging of subjective assumptions providing that the dialogue is transparent, negotiable and comprehensible. Additionally, the final analysis in this study was to rest with me, reducing the room for unhelpful compromise or distortion that writers such as Morse (1998) and Poland (2002) have cited as a challenge to this practice.

In keeping with the need to guard against the coding frame becoming a restrictive oversimplified analytical tool with data increasingly fitted into derived generalisations (Denscombe 2003:281) - especially given that the study was using a grounded theory approach - I remained ready to identify and note new or revised themes that emerged as I moved into a more thorough coding phase.

### ***Use of computer assisted qualitative data analysis software – help or hindrance?***

I had decided to use a computer assisted qualitative analysis programme to aid analysis and, as AtlasTi is the only university supported qualitative analysis package, I set about learning to use it. AtlasTi lists on the screen the transcript that is being coded currently, a drop down box containing all the codes that are in use, a list of their respective text references, a list of all transcripts being worked with and a memo list – i.e. a very visual way of showing coding and its context. Once coding is underway, the researcher can use the programme to search for coding patterns (i) throughout all transcripts and (ii) using selected variables. This sounded straightforward enough – once I had learned how to use it!

Not knowing how to use a tool nor having access to support to enable one to experiment is very disabling. I attended a short two hour class on AtlasTi and completed the on-line tutorial.

Being familiar with analysis of the 'highlighters and scissors' variety, I knew the principles and could see how that translated to computerised coding. It was a different matter when I sat in front of the computer alone. The anxiety of doing something that would either prove impossible to undo or would end up being a waste of time was paralysing. Eventually I enlisted the advice of someone more experienced which proved highly beneficial, though I did not use some of its more sophisticated capabilities.

I decided to do the analysis in batches, taking one category at a time, and started with adult females as it was almost complete. I kept the preliminary coding frame on a board in front of me and allowed myself to become immersed in the transcripts. As I ascribed a code (including new ones), I labelled it with the participant's unique identifier. The 'picture' started to build with some sections of the transcript free of codes and others having sections that were multiply coded (though rarely exactly co-terminous). From time to time, I checked against the predetermined coding frame as a 'check' to my emerging analysis.

After analysing three scripts, I checked the coding frame more rigorously. I conflated some codes, renamed some and added the new ones that had already emerged. Strauss and Corbin (1998) suggest that codes can be reorganised through a process of constant comparison whereby each code is compared with others to see where there is similarity (and therefore the potential to conflate) or difference. This proved unexpectedly anxiety-provoking as I contemplated the possible need to keep revisiting transcripts previously coded and keep track of what was happening. Interestingly, the use of a computer programme engendered a deeper sense of being committed formally to a code than in my previous experience of manual analysis. Nevertheless, I also found myself producing a vast array of codes and was reminded of Robson's (2002) acknowledgement of the propensity to feel overwhelmed by the sheer volume of data that accumulates even when they are regularly processed and summarised. There was a clear need to remind myself of what I was looking for and to pay attention to 'listening' to the participants' voices to offset the threat that technology would become an end in itself. My pile of accompanying notes mounted but at least I was back on track.

### ***Interrogating the codes***

Having completed the coding stages, the analysis moves into a more intense phase of searching for substantive and possible connections and differences across the codes - what Dey has called '....regularities, variations and singularities in the data' (1993:47). In doing so, the opportunity to consider relationships between the variables and reflect more and more

intensely on emerging working theoretical models starts to uncover a set of generalisations that are truly grounded in the data (Grinyer and Thomas 2001).

It was clear, then, that the codes I had identified needed to be clustered in a coherent pattern. Some appeared within more than one of these clusters. I used three main areas to aid my developing analysis:

- *the story* - the participants' stories about the process of what happened to them – in this case, receiving a diagnosis, being told that fertility may be affected, moving towards adulthood in treatment and family/social spaces.
- *the impact* – the effect that possible (or actual) cancer-related fertility impairment had on them at different stages and in different contexts.
- *managing the experience* – how they coped and what helped or hindered that coping.

I found it more challenging than I had anticipated to find the patterns. When I reflected back on my memories of the interviews, I had a sense of certain clear patterns emerging but they seemed somewhat more elusive after coding. I was concerned that the reduction of the data had obscured them just as Denscombe (2003) and others have warned and the process once again felt stopped in its tracks. In particular, the distinctions between 'impact' and 'coping' were surprisingly indistinct and my preoccupation with process started to dominate again.

Going back to my written notes about the unfolding process of interviewing, re-reading field notes and taking time to explore my emerging conceptual understanding was the shift in energy and focus that I needed. What did I think was going on for the participants? Why? What seemed to make a difference, for whom and in what way? These were the questions that the coded data were inviting me to explore.

Slowly, I was able to see where I might conflate codes as patterns started to emerge. I felt confident enough with what was emerging to use the computer programme to cluster by age and then by gender and to print out the results. Now I could get out my highlighters and immerse myself again, but this time using familiar tools with data that were in manageable clusters. I looked for alternative explanations and interrogated the computed codes and print-outs again for factors such as length of time since treatment, family patterns, current state of health, occupation, romantic relationships and friendship patterns. I looked for negative evidence – the things that did *not* appear – including issues that participants seemed

unaware of, unaffected by; or took for granted (unconscious under-reporting); or aspects that they wanted to hide or more consciously under-report and I sought to understand them.

As Strauss and Corbin (1998) advocate, this is the stage where a conditional matrix can start to emerge with its outer rings containing those conditional features thought to be most distant to actions and interactions and its inner rings being those that bear most closely. All the conditions have relevance; it was my task to try and understand how and why they inter-related and which were internal or external to the process of growing up – the ‘systematic statements of plausible relationships’ (p169).

It was helpful to remain alert to interpretations *as expressed by the participants* and to consider these alongside my own emerging analysis. This is not about what participants were *actually* told or what *actually* happened, it is about their perception of it in retrospect. My task was to consider the experiences of all participants, to see how I could develop an analytic view to understand further the range of experiences. It is from this point onwards - the process of interpretation and presentation - that the work moves into the public arena. This is also when, arguably, there is the greatest potential to abuse one’s power as a researcher in that participants now had no control over the production or distribution of findings.

## **SUMMARY**

In this chapter I have outlined the process of arriving at the research questions and the study design, highlighting the dynamic nature of my relationship with the methodology. By providing a detailed conceptual justification and exploring the issues arising, I have sought to ‘model the model’. The lack of prior research and the sensitivity of the subject led me to conduct and analyse single in-depth interviews informed by grounded theory and paying attention to social and political contexts. A topic guide informed rather than structured the interviews. Recruitment using theoretical or purposive sampling was through three regional paediatric oncology centres; a small number of participants referred themselves. Recruitment challenges included variable take-up across the groups at different stages and variations in take-up between centres. Interviews were completed with males and females aged 16 to 30 years who were diagnosed post-pubertally and below the age of 21, aware that their fertility may be affected and off major treatment. The interviews produced rich data and required judgements about when and how to probe, clarify and/or share information (including from other interviews). Analysis using coding and constant comparison of the transcripts

(manually and using computer software) together with my field notes, notes of emerging themes and working models, reflective diary and discussions with the transcribers looked specifically for relationships by gender or age (under 21; 21 and over) as well as those generated from the data. Attention was paid to process and outcomes. The role of reciprocity in research and the relationship between reflexivity and anti-oppressive practice were also explored.

I turn next to the findings from the study, starting with a profile of those that took part and a summary of their experiences at around diagnosis.



## **CHAPTER FOUR**

### **PROFILE OF THE PARTICIPANTS AND THEIR EXPERIENCES AROUND DIAGNOSIS**

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This chapter provides information about the recruitment process throughout the study. As well as setting out a profile of participants, it also summarises their experiences around the time of diagnosis. This provides background information for the main findings, which follow in later chapters.

#### **Recruitment**

Thirty eight participants were recruited to the study between May 2004 and July 2006. The majority of those approached agreed to consider participation though, not surprisingly, not all followed it up. The reactions of some (though not all) individuals caused surprise to their professional carers by being more enthusiastic than anticipated, by being more distressed or by seeing the subject as too private to discuss in a research study. Three males and one female who agreed initially to participate withdrew prior to interview including one who started but did not complete a telephone interview. No information was available from this group about their reasons for not taking it further. Finally, as reported in Chapter Three, four adults approached the study independently to offer to participate and were not eligible. They provided written information about their experiences which was then used as background material.

When one looks at recruitment patterns according to recruitment site, there were variations in the numbers being approached and in the take-up rate. The overall take-up rate was reduced significantly by the low take up rate from one of the sites (see Table 1). I have discussed possible reasons for this in Chapter Three.

**Table 1: Numbers approached and interviewed by centre and year**

	2004	2005	2006	Total approached	Overall take up rate	Total No Recruited through the centre
Centre 1	29	7	0	36	50%	18
Centre 2	20	11	3	34	35%	12
Centre 3	11	13	2	26	12%	3

There were also variations over time according to age group<sup>4</sup>. In 2004, the take up rate among adults was low – indeed it was less than half the take up rate among teenagers even though equal numbers of adults and teenagers were approached. If recruitment had stopped at this stage, I would have been reporting difficulty in approaching adults (and indeed that was a major concern at that stage). By the end of 2005 (a full year of recruiting) that situation had reversed with the teenagers (and especially the teenage males in 2 out of the 3 centres) proving the most difficult to recruit and pulling the overall take up rate down. By the end of the recruitment phase, the overall take up rate by age and gender was as follows:

- Teenage males – 24%
- Teenage females – 36%
- Adult males – 40%
- Adult females – 40%
- Overall take up rate for teenagers – 29%
- Overall take up rate for adults – 40%
- Overall take up rate for females – 38%
- Overall take up rate for males – 31%
- **Overall take up rate – 35% (average percentage)**

Even with the take-up rate lowered by the inclusion of the figures from the third centre, these figures compare well with other research with this patient group, particularly males (Edwards *et al* 2003; Larcombe *et al* 2002; Schover *et al* 1999; Schover *et al* 2002a; Wilkinson 2003), but also with this age group more generally (National Service Framework 2004:75). The desire to discuss an area perceived to be of importance and/or recruitment through known professional carers may have helped.

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<sup>4</sup> As is the case throughout the thesis, I use the terms 'teenager' and 'adult' to describe the two age groups even though the former included some aged 20 at diagnosis.

## **Interviews**

Single interviews lasted between 1 and 3 hours. One teenage male, two teenage females, two adult males and one adult female chose to have their parent or partner present for some or all of the time. Over half the interviews were conducted in the family home (21: 55%), eleven (29%) were carried out in the hospital where they were treated, four (11%) were conducted over the telephone and one was conducted elsewhere. Only one participated in the study through a written submission. These variations reflected the choice of the participants.

## **Profile of participants**

Participants (38) had a range of diagnoses and these have been grouped as follows:

- 14 (37%) were from the sarcoma group
- 9 (24%) were from the lymphoma and Hodgkins group
- 6 (16%) were from the leukaemia group
- 5 (13%) were from the germ cell group
- 4 (11%) were from the brain group

The breakdown by age and gender of participants was as follows:

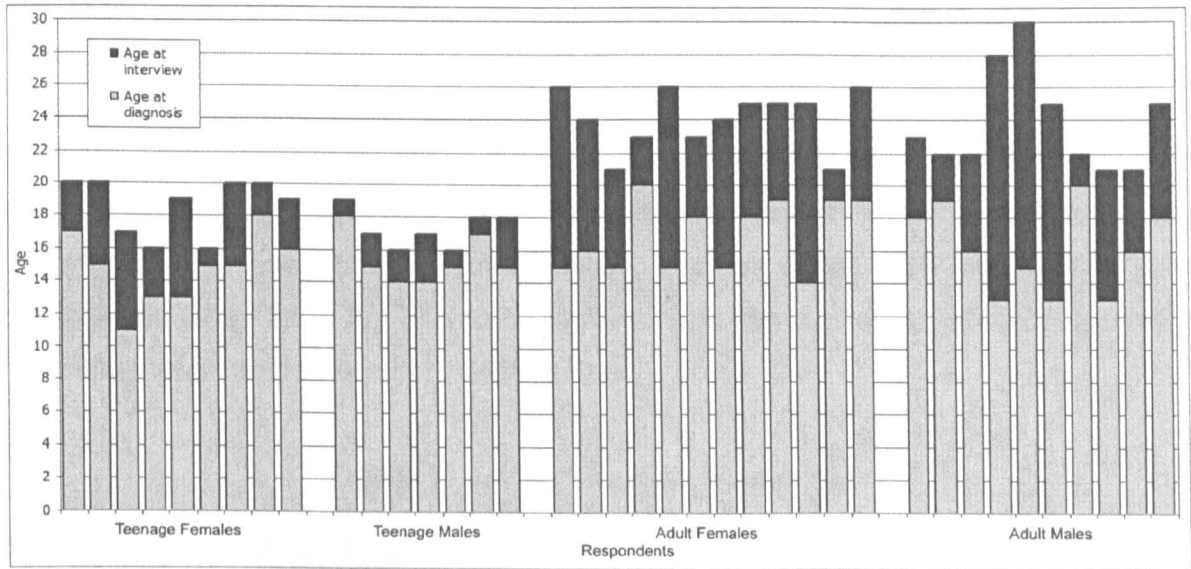
- 7 teenage males
- 9 teenage females
- 10 adult males
- 12 adult females

The overall age range at diagnosis was 13<sup>5</sup> to 20 years (median age: 15 years) and at interview was 16 to 30 years (median age: 21 years). The median age for teenagers was 15 years at diagnosis and 18 years at interview; for adults was 16 and 24 years; for females was 15 and 21 years; and for males was 15 and 21 years. The median length of time since diagnosis among teenagers was 3 years (range from 1 to 6 years) and amongst adults was 7 years (range from 2 to 15 years) (see Figure 1). When looked at by gender, the median length of time since diagnosis for females was 6 years (range from 1 to 11 years) and for males was 3 years (range 1 to 15 years) (see Figure 1).

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<sup>5</sup> See the earlier footnote – this includes one who was diagnosed originally at age 11

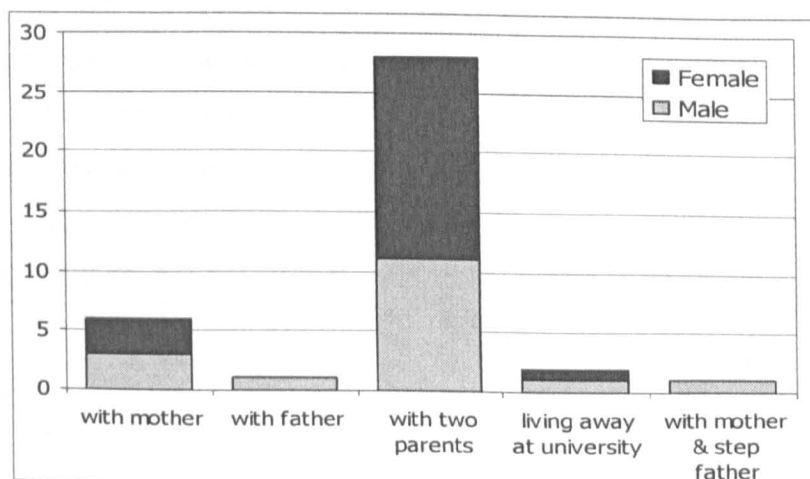
**Figure 1: Ages of participants at diagnosis and interview by group**



Thirty four of the participants were White British, one was Hindu Asian, one was Muslim Asian and two were of white Anglo-mainland European heritage. One had a prior heart condition and two had prior minor impairments. Two identified themselves at interview as lesbian, one of whom had identified herself as bi-sexual at diagnosis and the other as heterosexual.

At diagnosis, 28 (74%) were living in a two parent household and a further two (5%) were away at university but from a two parent household, seven (18%) were in households headed by a lone parent (6 female headed and one male headed), one lived with his mother and step father (see Figure 2).

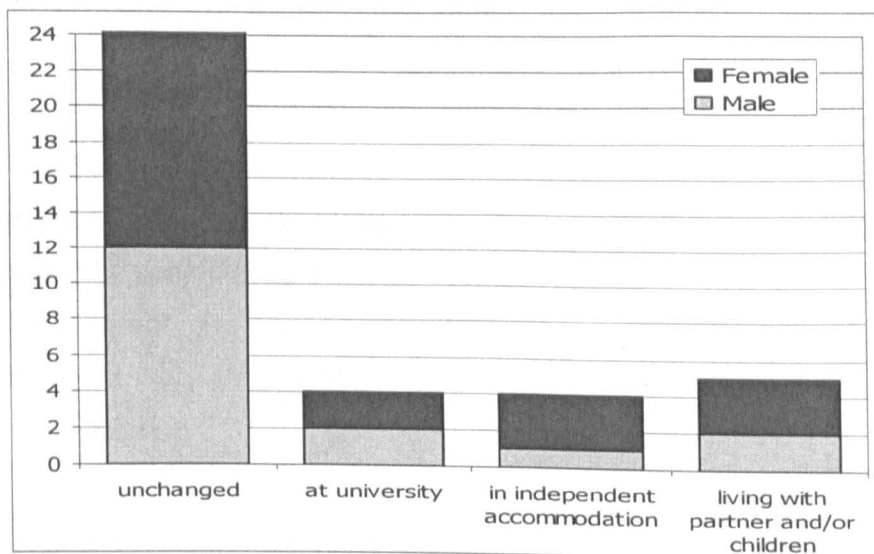
**Figure 2: Living situation at diagnosis**



Three were 'only' children, almost half (43%) were the oldest child in the family and just over a quarter (26%) were the youngest child. The majority (79%) had one or two siblings. Two had had new siblings born between diagnosis and research interview.

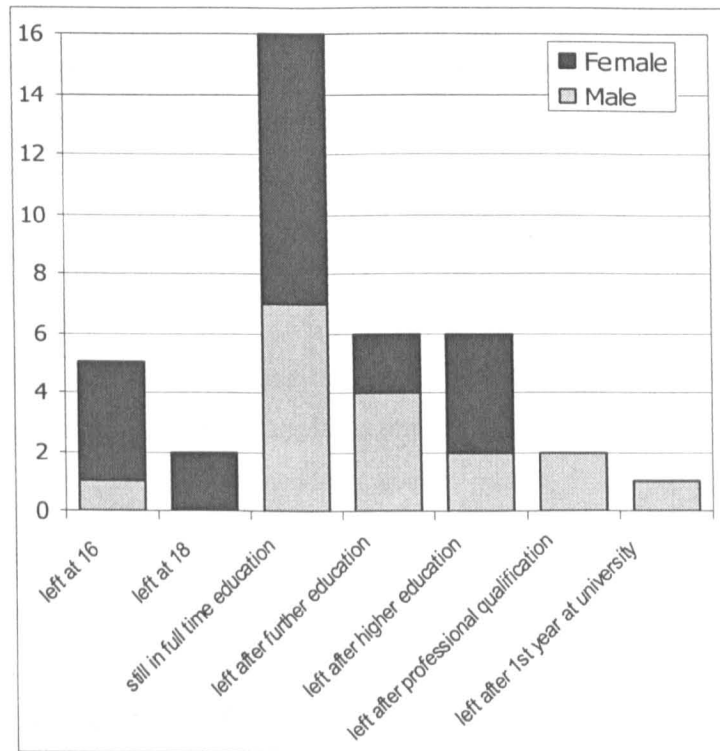
At the time of the interview, two thirds (66%) were still in the same living situation (though two had moved out and back again in the intervening period), four (11%) were away at university, four (11%) were in independent accommodation, and five (13%) were living with a partner and/or children (see Figure 3). Eleven (29%) described themselves as being in a permanent relationship though some were not living together.

**Figure 3: Living situation at interview**



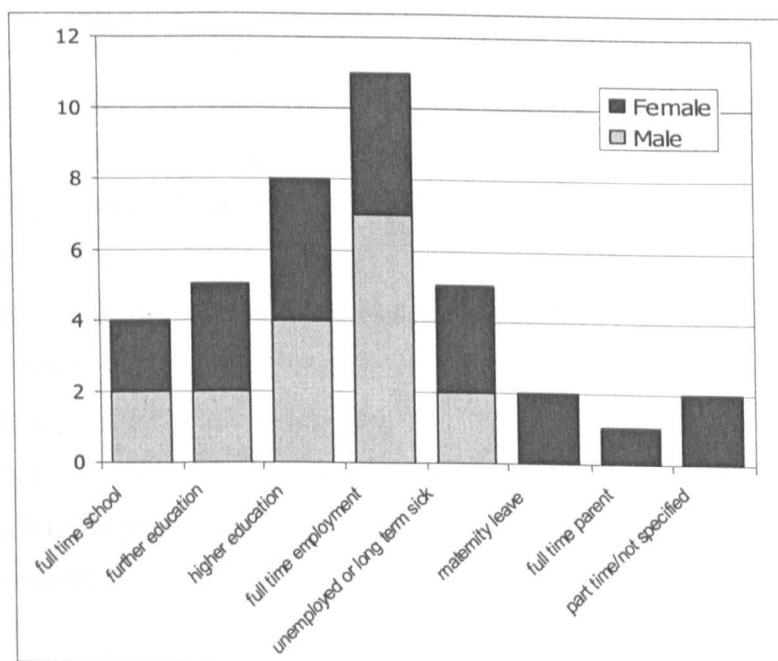
With regards to their educational profile at diagnosis, the majority were in full time education (including some in further or higher education), three (two females and one male) were in employment and one did not specify. The highest level of education obtained by the time of interview was as follows: the largest group (17) were still in secondary or tertiary education (45%); five (13%) had left education at age 16; two (5%) at age 18; six (16%) after completing further education courses; five (13%) after graduating from university; and two after completing post-graduate training. One was getting ready to return to university after taking some time out (see Figure 4).

**Figure 4: Highest level of education by time of interview**



In addition to those still in education at interview, eleven (29%) were in full time employment, five (13%) were either unemployed or long term sick, two (5%) were on maternity leave and one was a full time parent, one was working part time and one did not specify (see Figure 5). Those in employment were in a range of jobs from unskilled and semi skilled through to professional employment.

**Figure 5: Education and employment situation at interview**



Five of the sample had become parents between diagnosis and the time of the interviews (none were parents prior to diagnosis). One adult male, one adult female and one teenage female each had one child; one adult male had two children; one adult female had one child and was pregnant with another. Two of the mothers still lived in the family home. Fuller details of romantic relationships are covered in Chapter Ten.

### **Summary of Experiences around Diagnosis**

Within the wider study, discussions were held around the experience of receiving the cancer diagnosis, being told about possible threats to fertility from treatment, being invited to access fertility preservation services and undergoing sperm banking. Aspects that are pertinent as the backdrop to the findings discussed later are included below.

#### ***Leading up to diagnosis***

About a third of participants had moved to diagnosis within two weeks of developing symptoms and a further six did so within two months. However for almost a quarter, this process had taken up to six months. A similar number had been seeking medical advice about symptoms for longer including, in a few cases, over a year. Two females had referrals delayed because of apparently gendered assumptions about the cause of their symptoms – one young woman's GP insisted over several months that she was pregnant despite her making it clear that she was a virgin; another was told that her leg pains were the result of wearing high heels even though she explained that she only wore trainers.

At diagnosis, a number were at key stages of their education (moving schools, taking GCSEs; starting university) or social development (changing leisure pursuits, relationships).

#### ***Receiving the diagnosis and information relating to fertility matters***

By diagnosis, physical states ranged from relatively symptom free to severe incapacity. Many had strong memories of being given the diagnosis and for many it was unexpected. Most had their parents present. Some felt scared by the diagnosis while others said they scarcely understood the seriousness of the situation; some were more distressed by their parents' reactions than by the diagnosis itself. There were differences in whether or not the diagnosis generated fears of death.

The majority were told about the potential effect of treatment on their reproductive system at, or within a few days of, diagnosis and there were good levels of recall. As with the diagnosis, a range of reactions were reported ranging from lack of concern to significant distress. The same was true among parents. There was strong support for it to be raised at this stage.

In all cases where the threat to the reproductive organs came from the cancer itself, anxiety about infertility was present. For those for whom the threat was felt to be significant regardless of site, any assumption by professionals that it did not matter – for example because they were young - was also difficult to handle.

However, most reactions were less pronounced and, if anything, were a mixture of surprise and embarrassment especially among those males invited to bank their sperm. Many put this down to their difficulty in separating their lack of desire to have children at that age or life stage from their *potential* to want to parent when older. Looking back, most said that they had assumed that they would become parents one day but had given it little thought. They could therefore be described as passively pro-natalist. A small number remembered thinking that that their current lack of interest in parenting would never change.

Reactions were also tempered by the context of the volume and complexity of other information about treatment and side effects and the intensity of the situation - all of which were requiring to be managed.

Given all this, it is perhaps surprising that many in both genders remembered it in such detail.

### ***Understanding of information given***

There were generally good levels of understanding of fertility related information at around diagnosis. The overwhelming preference (as opposed to the experience) was for information to be 'broad brush' initially, with the opportunity to ask for more detail soon after being told and then at regular intervals.

### ***The experience of decision making about fertility preservation***

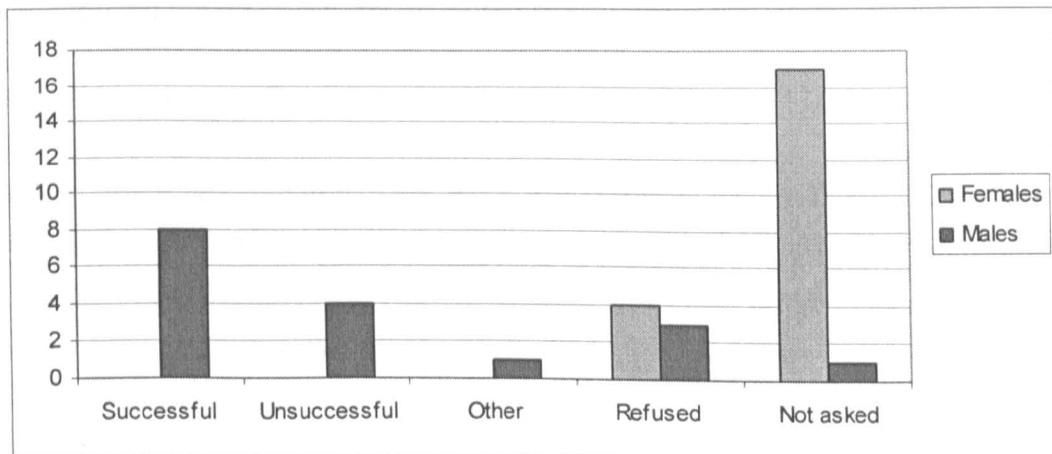
For those offered access to sperm or egg preservation, the focus shifted quickly to the decision making and/or process of procurement alongside getting ready for treatment. This affected disproportionately higher numbers of males. Both genders were supportive of being offered the choice regardless of whether or not they accepted or were successful.



Only three females remembered being given the opportunity to freeze their eggs, one was offered an ovary protection procedure and one underwent an ovary protection procedure but did not remember having to consent. All those given the choice (4) declined, primarily because it would involve a delay to treatment (see Figure 6).

All of the males except one (n=16) were invited to bank their sperm. Of these, three refused and one failed to have the service arranged, apparently because of his rapid physical deterioration. Of the three that refused, one did so on religious grounds and two primarily because they felt too young and embarrassed (ages 13 and 16). Twelve tried to bank (six (86%) 'teenagers' and six (67%) 'adults'). Eight were successful. Of the ones who failed to bank, three were already in treatment when they tried and the fourth was overlooked and then rushed through immediately prior to commencing chemotherapy (see Figure 6).

**Figure 6: Use of fertility preservation services by gender**



There was good evidence of adequately informed decision making among the males, including among those that felt themselves to be very young to be dealing with this. It was aided by clarity of information sharing, the manner and context within which it was shared and the involvement of parents (provided that the young person wanted their parents present). However, it was clear that the level and complexity of information required was not great. The decision was influenced primarily by the desire to secure future reproductive choice or, more passively, to conform to the expectations of the 'grown ups' (parents and/or professionals). While parental and family support, especially from mothers, enabled several to overcome their initial reluctance to contemplate banking, there were a small number where the presence of parents made the situation more difficult to manage.

### ***The banking process itself***

The process was eased when the service was well-organised throughout, when the young person exercised choice about being accompanied to the sperm bank and when arrangements ran smoothly. Many chose to take family members but some went with professionals (nurse, social worker) and some went alone. Participants had almost universal praise for the manner of professionals in paediatric oncology but their experiences were more mixed with sperm bank staff. Informality, friendliness and clarity of language were hallmarks of good professional practice as was direct communication with the young person rather than through parents. Some were distressed by consent questions about posthumous arrangements for semen disposal, current romantic relationships or plans for parenthood. A few felt that they were doing something 'smutty' or 'shameful' and allied with particular sorts of sexual practices. Most, however, approached it as part of the required process towards treatment and this helped.

Many had suggestions for improvement to the semen collection room and the overall process.

### ***The immediate impact at the time of trying and failing to bank sperm***

While all four males who failed to bank were supportive of having the opportunity, failure left them with additional feelings to manage – and with little help from either professional or informal carers. For example, one had the comfort of his step father waiting outside the room but could not remember anyone else raising it at the time (or since)

Two were offered containers to take away and use on the ward. Neither even tried. One felt too ill to try and the other, only 13 at the time, remembered setting his mind against it out of a mixture of embarrassment and realisation that he had so little privacy on the ward that he could be interrupted at any time.

### **SUMMARY**

The sample in this study was diverse according to educational levels and socio-economic groups (as far as this could be ascertained). Numbers from minority ethnic groups, those who were gay or lesbian or who had a prior impairment were small. Females were, on average, longer off diagnosis and were much less likely to have been offered access to fertility preservation services. The majority in both genders had been warned about the potential threat to fertility at around diagnosis. No females had stored their gametes but eight

males (21%) had done so out of the twelve that had tried. There were mixed reactions to the cancer diagnosis itself as well as to the information about potential fertility damage. Although most in the sample had assumed at diagnosis that they would become parents one day, for many this was a passive expectation rather than a strong and conscious desire at that stage.

I turn now to an explanation of the key theoretical models that I used in approaching the analysis of the findings.

## CHAPTER FIVE

# KEY CONCEPTS FOR UNDERSTANDING THE TRANSITION TO ADULTHOOD

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### Background

Conceptual understandings of the transition to adulthood are drawn from many stables and their depth and range have the propensity to overwhelm those seeking to enhance their understanding. Debates about their relative merits are lively. For example, developmental psychology 'stage' theories have been criticised as overly deterministic and paying limited attention to social context while critics of the 'sociology of childhood' camp express concerns about its inflexibility around taking account of psychological and individual processes (Dixon-Woods *et al* 2005). Challenges to the terminologies employed include that the use of 'adolescence' is inappropriate as teenagers and young adults draw on repertoires characteristic of childhood *and* adulthood as well as some that are unique; and that age groups should not be viewed only in relation to adulthood (Dixon-Woods *et al* 2005; Mayall 1998).

In seeking to understand the experiences coming through from the interviews, I needed to put workable boundaries around the theoretical and empirical sources that I might draw upon and these are presented in this chapter. I was guided by key concepts reflected in the study design and confirmed from the analysis, namely:

- Individuals are unique: while their experiences are located within, and therefore influenced by, their social context, the relationship between their personal and social circumstances needs to be considered across time and context if one is to understand their experiences.
- While broad themes emerge from qualitative data analysis, the resulting map of human experience that is drawn is complex and must remain open to revision.

This led me to literature addressing the dynamic nature of human experience and informed by attention to social context. However, while the transition to adulthood is time-limited, coping with cancer is not and can continue well beyond the stage at which someone is

deemed a 'survivor'. As Self (2005), a survivor of teenage cancer and a psychiatrist, reminds us:

'Adjustment involves a lifetime process of adapting to multiple psychosocial challenges. 'Adjustment' suggests a point of completion but survivorship may be more accurately viewed as a continuous transition' (p188).

These factors taken together drew me to examine theories and research using a lifespan approach.

It also became clear from the study that (i) some individuals appeared to fare better than others in their passage through treatment, the transition to adulthood and coping with possible or actual fertility impairment and (ii) some individuals appeared to gain strength through the adversity of the cancer experience. The concept of 'resilience' has proved a useful tool in other settings where young people have faced adversity so this too seemed a potentially fruitful source to aid understanding.

While work outside of these boundaries was not ignored – indeed I conducted broad sweeps of a range of literature – these foci enabled me to apply greater depth of conceptual reflection to the findings.

In order to ground the use of these concepts even more firmly, I needed to consider how they might be informed by literature from the wider cancer experience as well as the fertility-specific literature reviewed in Chapter Two. In this chapter, I draw on material from the mainstream literature on lifespan approaches and resilience together with relevant literature from the cancer field and consider the implications that these may carry in the context of this study. As with the earlier review, the usefulness of such literature is limited by its inclusion of children, the preponderance of studies completed during or soon after treatment and the lack of intervention studies. The two sources of literature (i.e. Chapter Two and this chapter) are then brought together when discussing the study's findings.

I start with summarising the key tasks and contemporary contexts associated with the transition years before looking specifically at lifespan approaches.

## **Developmental tasks associated with transition**

Although there may be social and cultural variations, there is broad agreement that the transition years provide a context of critical preparation or precursor for adulthood in which young people consolidate or amend existing skills and knowledge, acquire new ones and develop the identity with which they move into adulthood and adult relationships within and outside of their immediate network (Brannen and Nilsen 2002). By adulthood, desired attributes are said to include the ability to be self reflective, to employ enhanced abstract reasoning, to act competently, to have moral awareness, to be aware of the boundaries of individual self-determination posed by social and cultural structures and to incorporate all of these into relationships with others (Bee and Boyd 2003).

Traditional indicators are limited insofar as they reflect the prevailing dominant social and cultural norms (Morrow 1998). For example, moving out of the family home as a route to independence is a less appropriate measure in cultures where adult children can acquire independence while still remaining in the family home (Hussain *et al* 2002) or where physical impairment can complicate such a move in a society that privileges non-disabled peers (Hendey and Pascall 2002). Indeed, some have claimed that traditional social indicators are becoming too fragmented to be of relevance (Beck 1992; Giddens 1991).

A number of major UK research programmes from the 1980s onwards studied the transition years and found the emergence of 'extended transitions' across all social groups of young adults resulting from changes in the economic and social climate. Young people's education, employment and training profiles have altered as has the age at which they leave the family home permanently, attain economic independence and embark on parenthood (Brannen and Nilsen 2002; Bynner *et al* 2002; Catan 2004; Jones 2002; Morrow and Richards 1996). Gaps are widening on a number of personal, economic and social well-being measures between those with and those without good educational qualifications and supportive family and community backgrounds. Despite an appearance of greater choice, flexibility and individualisation, attendant risks of failure, insecurity and stress appear to be heightened and occur within more complex structures. As the transition years become more fluid, risky, and complex so too may they carry greater risk of social exclusion. Care-leavers, for example, are now expected to undertake their journey to adulthood far younger and in less time than their peers with resulting disadvantages in adulthood (Stein and Rees 2002).

There is also evidence of persisting disadvantage along traditional social structural lines including minority ethnic status (Haywood and Man an Ghail 2005; Margo *et al* 2006; Wright *et al* 2005), disability (Hendey and Pascall 2002; Morris 2002; Robinson and Stalker 1998) and gender (Henderson *et al* 2007; Skoe 1998). Age-related power relations appear fairly intact and Margo *et al* (2006) have talked of a 'growing obsession with the state of childhood and youth' (p1). 'Moral panic' about teenagers appears to shape both parents' and the wider community's view of them as troublesome and powerful (Stein and Rees 1999) and dangerously prone to treatment non-compliance when needing health care (Christie and Viner 2005). Adults appear more likely to lose their mask of patriarchal love and employ hierarchical power relations with this age group than younger ones, over-riding any prior (avowed) beliefs in young people's social competence (Alderson 1999; Hendry and Kloep 2002).

The reduced clarity surrounding structural oppression appears to have had some effect on how young people view their life chances. Although aspirations and the desire for autonomy and independence appear little changed, young people are reported as increasingly likely to attribute their lack of 'success' to 'frustrated agency' or personal failing than to structure and hence are more likely to see solutions as individualistic than collective (Catan 2004).

## **LIFESPAN APPROACHES**

### ***Key features***

Lifespan approaches employ biographical or life course perspectives to seek understanding of the interplay between an individual's immediate and extended social environment, their personal history and their expectations on their personal and social development (see for example Henderson *et al* 2007).

Hendry and Kloep (2002) have identified four main principles underlying an understanding of life processes:

1. Historical time and place are influential.
2. Impact of life events depends in part on when they occur in an individual's life.
3. Lives are linked inter-dependently.
4. Individuals make choices within these constraints – what is termed 'human agency'.

Development is seen to continue across the lifespan and result from meeting increasingly complex challenges, learning increasingly complex skills and adapting existing knowledge

and skills, though not necessarily in a synchronous process. Although facing challenges can drain an individual's resource 'pool', solving them can also fill it up. Challenges are identified as such by the individual and personal appraisal of its type – for example, good/bad; controllable/uncontrollable - shapes their response. Similar 'events' and hence challenges may be handled differently at different life stages, in different contexts and according to personal, social and cultural values and resources. Although avoidance of challenges can halt or slow development from time to time, this is only problematic where it is prompted by a depleted resource pool rather than contentment. The transition to adulthood is therefore seen to be affected by the macro-historical context, the micro-family unit and personal characteristics of those involved.

### ***Incorporating chronic health experiences within a lifespan approach***

Weekes (1995) looked at the experience of chronic ill-health during adolescence using a lifespan approach and usefully classified developmental influences as:

- (i) *normative age-graded* e.g. menarche; entering secondary school
- (ii) *normative history-graded* – biologic and environmental events that are experienced by a particular group at the same point in time, e.g. Gulf War, AIDS epidemic
- (iii) *non-normative* - environmental and biologic factors that do not occur as (i) and (ii) – e.g. onset of severe illness; moving to another part of the country.

The onset of cancer is, of course, a non-normative event. As such it may challenge not only the young person but also those around them in a professional and personal capacity. Social influences grounded in 'moral panic' may now have to compete with social imagery attached to young cancer patients such as 'brave fighter' and 'undeserving victim' – the adolescent 'in' trouble rather than causing trouble. The threat of fertility impairment is also a non-normative event but one for which there is no associated social imagery for those who are 'not yet adult'. For adults coping with non-cancer related fertility difficulties, the imagery is either pejorative or pitying – 'desperate', 'barren' and 'unfulfilled'.

### ***Lifespan approaches versus 'stage' development theories***

Weeke's categorisation does not carry the same deterministic properties found in so-called 'stage' development theories. There the focus is on linear progress through a series of developmental milestones, the achievement of which is thought to result primarily from psychological and cognitive maturation. Although physical changes from puberty through to



adulthood may lend themselves to the development of normative measures, such measures are less appropriate for non-physical changes (Alderson 1999). For example, young people of the same age behave differently (and have different expectations placed on them) across cultures within national boundaries and these differences become even more varied when one looks more globally (James and Prout 1997). Not only do lifespan approaches challenge the use of normative measures as flawed because of their limited attention to social and cultural context but they also point to the danger of such measures being used as if they were facts in 'cause and effect' discussions among professionals, policy makers, the media and the general public.

Within lifespan approaches, each age period is acknowledged as having its own developmental agenda but with continuous (cumulative) and discontinuous (innovative) developmental processes occurring throughout life, embedded in their larger historical and cultural contexts. Thus, while certain developmental aspects may be more likely to occur in discrete age groups, they are not unique to that age group (Bywaters 2007; Coleman 2002; Priestley 2005). At different parts of the lifespan, it is likely that the resources an individual possesses will be used differently – for example in early life they may be allocated mainly to functions associated with exploration and assimilation; in later life to maintaining or sustaining 'normal' levels in the face of contextual challenge or loss of function – but these too are not temporally or situationally fixed (Atkin *et al* 2006). As Grotevant and Cooper (1998) concluded:

'Development of identity is a lifelong process characterised by cycles of exploration and consolidation as well as experience of competence and vulnerability' (p6).

In other words, young people may face similar challenges from their cancer and associated fertility experiences but appraise and manage them differently from one individual to another, including across time and context. While certain strategies that appear to reflect life stage may be present, so may wider repertoires. Grinyer (2007) found a wide spectrum of experiences and attitudes alongside some that appeared life-stage specific in her study with teenagers and young adults.

### ***'Intended' identities and varying achievement of competencies***

Young people have been found to develop a range of identities for different contexts and to achieve varying levels of 'competence' across those identities, for example being good at

their part-time job while disaffected at school (Catan 2004; Henderson *et al* 2007). While these may have been shaped in part by human agency or what the researchers called personal 'invention', they also appeared to be shaped by the values of the young person's community:

'In inventing adult identities, young people drew on the resources of the family and community, whose values they could take on board or seek to move away from. Thus while social class was influential, the personally mediated values of particular families, localities and cultures were more directly implicated as the mechanisms whereby social class affects youth transitions' (Catan 2004:22).

Lifespan approaches thus acknowledge implicitly and explicitly that individuals' personal and social resource pools may differ (Catan 2004). For example, personal resources may be affected by earlier attachment experiences and social resources may be affected by membership of social group(s). Attitudes and life opportunities are seen as shaped by internal and external processes at affective, cognitive and social levels so consideration needs to be given to the relative influences of 'social structure' and 'human agency' in shaping identity and experience.

Young people managing cancer may 'invent' different identities (including adult identities) in different areas of their lives and achieve varying levels of competence across them. A series of interlinked studies with young people managing cancer in their teens (and their parents) found evidence of 'accelerated maturity' across many, but not all, aspects of development. This was thought to result from facing the challenges of existential life and death matters, treatment and the loss of more carefree times. However, delayed development in some areas led to the need to 'catch up' academically, in interpersonal relationships (including dating) and in career efforts. This sometimes stretched well into adulthood (Neville 1996, 1998, 2000, 2005). Fertility impairment may be found to contribute to delayed development and require those affected to invent identities to manage this during 'catch up' or beyond. This may be influenced by the personal, cultural and social values around fertility to which they are, and have been, exposed as well as the levels of personal and social capital available to them to aid coping.

## ***Extended transitions***

The impact of 'extended transitions' may also have particular implications for those managing cancer and fertility matters. For example, the impact of the benefits system, likelihood of moving back to the parental home if they had left and reduced employment opportunities together with the differential abilities across families to absorb the financial strain of treatment and its aftermath may delay moves towards economic and housing independence (Eiser 1998; Grinyer 2002, 2007; Jankovic et al 1999; Langeveld et al 2003; Roberts et al 1998; Self 2005; Sloper 1996). For example, Grinyer (2007) found that none of the young people in her qualitative study had the material or social resources to sustain themselves through the cancer experience.

The relative influences of social structure and human agency may be negotiated through tackling questions such as: 'Who am I? What sort of person do I want to be? What sort of lifestyle would I like? How far will I be able to make this happen? What might stop me or hold me back? What might help? How does my cancer experience affect this and how far does the possibility of fertility impairment do so?'

### ***Influences on identity development***

Lifespan approaches include attention to identity development during the transition years across the five key components of self concept:

- *Body image* – sensory awareness of the body's boundaries and internal body size and shape, sense of physical separateness, view of how we appear to others.
- *Personality traits* – loosely defined as a tendency to behave in a characteristic way across a range of situations influenced by a combination of 'nature' and 'nurture'.
- *Belief systems* – these influence perceptions of self and others and the world in general.
- *Self esteem* – an internal and internalised sense of own worth and competence which acts as a filter for experience; the evaluative aspect of self.
- *Self efficacy* – the extent to which we feel in control of our lives, including when faced with new situations; a sense of (internal) competence; control and understanding of own strengths and limitations.

In order to understand the potential for differences between and within individuals exposed to similar social and cultural influences, lifespan approaches suggest the need to be alert to what is called 'psychologic plasticity' (Weekes 1995). This represents the human capacity (variable rather than unlimited) to act as 'agents' in our own development by selecting, ignoring and modifying significant life events or life history influences. 'Psychologic plasticity' may thus sit alongside social and cultural forces in shaping 'invented' adulthoods, differing identities and variable competence between contexts.

While some argue that the onset of serious illness such as cancer during the transition years invariably has adverse consequences on subsequent development (Christie and Viner 2005; Kelly et al 2004; Whiteson 2003), others suggest that variations in responses and outcomes demonstrate this not to be the case (Parry 2003; Parry and Chesler 2005; Zebrack and Zeltzer 2003) and that young people '...are not at the mercy of the illness' (Weekes 2005:27). Psychologic plasticity might help explain such variations - for example, previously completed developmental tasks might be integrated and expressed in different forms through the use of psychologic plasticity; any regression in performing developmental tasks may contain transformative potential as well as indicating loss.

### ***Body changes***

Body changes are perhaps the most visible area of development in the transition years. There is some evidence of gender differences arising from the physical changes that start with puberty. Males appear likely to welcome puberty and associate it with gaining strength, freedom and status whereas females appear more ambivalent and associate it with reduction in freedom as a result of perceived increases in social-sexual dangers and a lower status female role (Christie and Viner 2005; Martin 1996 cited in Hendry and Kloep 2002; Tolman 2002). Ongoing development of body image becomes increasingly entwined with sexual and gender identities and affected by normative images including through role models such as pop stars and sports personalities, and portrayal of women and men as sex objects (Hendry and Kloep 2002; Sully and Walters 2002). Studies suggest this influences females more than males, though the gender gap appears to be narrowing (Chrissie and Viner 2005; Margo *et al* 2006). It has been argued that teenagers treated for cancer are particularly sensitive about their physical appearance (Hain 2005; Lewis 2005).

Cancer and its treatment can affect the body in three main ways during the transition years. Firstly they can have a temporary or permanent physical impact with wide ranging features.

Secondly, the body becomes the site for treatment and is therefore of 'shared' interest to professionals, family, friends and others. This alters any pre-diagnosis 'rules' about who is allowed legitimately to access it, when and how. Thirdly, the body becomes a heightened source of information for young people themselves about the progress of their cancer and treatment (Woodgate 2005).

Young people's relationship to their body may therefore change in ways over and above that to do with body image alone when they are coping with cancer-related fertility matters. Additional challenges may arise, depending on how well this meshes with the young person's relationship with their body either as a site for satisfaction (or otherwise) in relation to sexuality or as a measure of attainment of fertility.

### ***Sexuality***

Hormonal changes and increased sex drive combine with socialised behaviours to present developmental challenges through (for some) sexual experimentation, interest in romantic relationships and the need to incorporate these into social support systems (Andrews 2006; Keighley 2002). Discussions about sex and sexuality are more likely to take place with friends than with parents though remain limited in all arenas (Brannen *et al* 1994). Sexual and reproductive matters are thought to be among the most difficult for adolescents to seek medical attention over (Balen and Glaser 2006). Attention to romantic or sexual partners' suitability as parents is not thought to influence attraction until later, when the process aptly called 'mazing' comes into play (Sully and Waters 2002). Sully and Walters (2002) concluded that our sexual sense of ourselves relates to developmental processes, life experiences and individual differences and is closely linked to self regard.

However, sexuality is a contested and controversial area, perhaps especially during the transition years. The term is used variously to mean identity, choice of behaviour or sexual activity (Weeks 1985). Societal messages from the classroom outwards give it dominant attention during this life stage but typically equate it with heterosexual physical relationships and reflect a policy and professional preoccupation with the need to avoid pregnancy and sexually transmitted diseases (British Medical Association 2003; Health Select Committee 2003; Keighley 2002). The dominance of such conceptualisations of sexuality contribute to it being seen as polarised between either biologically determined (particularly associated with the male sex drive as a dominant biological force) or romantic 'have/hold' (particularly associated with female desires) with an assumption that sexual urges may be especially

difficult to control during the transition years (Dallos and Dallos 1997; Holland *et al* 2004; Lees 1993). The development of sexuality thus carries the potential to enhance or diminish self concept for all young people and can be:

'... a positive affirmation, or a distorted one. It can be the best choice for a person or a path that is determined by damage, power seeking or oppression' (Buckley and Head 2000:8).

Cancer and its treatment can affect sexual physical function though their impact on sexuality is less well understood. Physical cancer-related changes, including fatigue, may affect or distort sexual experimentation (Edwards *et al* 2003). This can be compounded by myths or fears such as that sex can trigger a relapse or cause cancer in sexual partners (Heiney 1989; Schover 1997). Such issues can be left unaddressed if professionals and significant others avoid raising them because of discomfort or lack of competence (Koeppel 1995; Schover 1997; Senanayake *et al* 2001; Shaw *et al* 2004; Thaler-DeMers 2001; Wilson and Williams 1988).

Puukko *et al*'s (1997b) research with female survivors of leukaemia found that their images of sexuality were more restrictive, including in their 'inner sexuality'. They speculated that it may be easier for females than males to appear to be developing normally as it is more socially acceptable as well as biologically possible for them to be passive sexual partners.

Cancer survivors of both genders appear to be more guarded or avoidant in their approaches to sexual relationships, more likely to delay intimate activity and less likely to initiate it (Fritz and Williams 1988; Kokkonen *et al* 1997; Mackie *et al* 2000; Ropponen *et al* 1990; Stam *et al* 2005; Whyte and Smith 1997). One 29 year old woman recently wrote: 'If I am really honest I am probably apprehensive of the whole relationship thing, using my body image as an excuse.... Sometimes when I'm out with friends who are all either married, engaged or have a long term partner, it brings it home and will get me down....' (Woods and Shearer 2005:163).

In each of these aspects, the presence of actual or potential cancer-related fertility impairment may have an influence. Among adults experiencing non-cancer-related fertility difficulties, risks to sexual well-being have been reported (Read 2004).

### ***Self esteem and self efficacy***

Attention to self esteem and self efficacy may prompt more intense introspection during the years leading to adulthood. This can be characterised by feelings of invincibility and beliefs that ideas and feelings are unique to them (which can be troubling or exciting), ('it might happen to others but not to me...'), that others (their 'imaginary audience') are as concerned with their thoughts and behaviours as young people themselves even though, paradoxically, no-one else can really understand them (Albritton and Bleyer 2003; Christie and Viner 2005). At the same time, the views of peers and friends appear to grow in importance as: 'significant others aid in the search for personal identity by providing information and feedback regarding specific behaviour and by serving as role models' (Weekes 1995:32).

Having cancer can lower self esteem, at least in the short term. While attention from others may be heightened during treatment and mediate its impact, attention to non-physical aspects may be more variable, as may the continuation of attention beyond treatment (Neville 1998; Nichols 1995; Woodgate 1999a, 2006). The impact on self esteem during treatment is thought to relate primarily to changed physical appearance and loss of lifestyle (Grinyer 2007; Faulkner et al 1995; Zebrack 2006). Given that fertility concerns have to date been reported more among longer term survivors than those in treatment (see Chapter Two) their effect on self esteem may become more evident in these later stages.

Having cancer can also make one feel less in control of one's life, be that in relation to the body, emotions, relationships, ability to 'make things happen' and future plans (Dixon-Woods et al 2005; Enskar et al 1996; Hinds et al 1992). While this may vary across time and context, some loss of control may continue to be experienced for many years, not least from fears of relapse or the emergence of residual effects (Self 2005, 2006; Zebrack 2006) including fertility impairment. Studies of adults facing non cancer-related fertility impairment have also identified feelings of loss of control to be a key threat to well-being (Throsby 2004; Verhaak et al 2005; Verhaak 2007).

### ***Social competencies***

Alongside development around self esteem and self efficacy, young people are developing social competencies. These draw on a growing range of skills and increasing abilities to arrive at sophisticated attributions for events and behaviours which take account of those in

their immediate spheres *and* the wider settings in which social values are defined. These have been defined as:

'..... possessing and using the ability to integrate thinking, feeling and behaviour to achieve social tasks and outcomes valued in the host context and culture' (Promoting Social Competence project (1999) cited in Daniels and Wassell 2002:89).

Social spaces and relationships occupied as a result of cancer pose threats but may also offer opportunities and challenges. While treatment may restrict opportunities to share social exploration with pre-diagnosis peers (Albritton and Bleyer 2003), time spent on the ward in contact with other patients, professionals and other adults or in post-treatment social and leisure spaces with such groups may offer new opportunities for developing social competencies (Kelly et al 2004; Morgan and Hubber 2004).

Moves by young people in the wider population towards taking more control of their lives are manifest in the health arena by growing numbers seeking medical advice without parents present. Confidentiality and access to the professional gender of choice become key influences on patterns of use (National Service Framework for Children, Young People and Maternity Services 2004).

For young people with cancer, this process may be accelerated. Not only do they have a greater volume of contact with health professionals but the culture within paediatric oncology circles places particular value on partnerships with patients (Bradlyn et al 2004; Hollis and Morgan 2001; Kelly et al 2003, 2004; Whelan 2003; Whiteson 2003). Issues around medical decision making and illness management can prove difficult and frightening for parents (Albritton and Bleyer 2003; Grinyer 2002, 2007; Whelan 2003). Given that independent decision making is a legal requirement in relation to fertility preservation matters, this may be one of the first areas where this has to be negotiated in the parent-child relationship.

### ***Relationships with peers and family members***

Leisure activities present further sites for general developmental challenges on all aspects of self concept. Previously accepted norms and belief systems may be reviewed as young people move away from adult-led activities towards more informal leisure pursuits with peers. Issues of trust, confidentiality and reciprocity may become increasingly salient as personal information and secrets are shared – a necessary risk to assess whether friendships and



social relationships are formed and/or survive. Although this applies across genders, girls seem to be more likely to share feelings with their friends and use them as aids to problem solving (Brannen *et al* 1994). Some young people may attempt acceptance into adult leisure settings or use other means to try and gain adult status, at least symbolically:

'In this way teenagers observe, rehearse and perform the skills and behaviours they perceive to be necessary for their absorption into the adult world' (Hendry and Kloep 2002:85)

Increased conflict with parent/s (and sometimes the local community and school community) around independence issues may occur during the transition years. However, the family (and, often, the communities of which the young person is part) still provides most with a 'safe base' and sense of belonging from which to explore and in which to experience interdependence. Families are likely to co-ordinate and/or provide ongoing emotional, economic, material, social, cultural resources for longer than before, given the increase in 'extended transitions' (Catan 2004). In reviewing the more psychologically oriented literature within a lifespan perspective, Grotevant and Cooper (1998) concluded that young people did well in terms of their identity development and sense of coherence when their families were able to encourage a sense of individuality *and* connectedness and this applied regardless of belief system (pp9-10).

There is increased potential during the transition years for conflict arising from differing interpretations of events and behaviours between parents and their children. In a study of young people, health and family life in the UK, parents viewed teenagers' behaviour more negatively than vice versa:

'... the idea of adolescence as a time of inevitable emotional turmoil is more widespread among parents than among young people. Young people do not perceive their emotionality as part of adolescent development; rather, they see it as a rational response to difficult events, such as .....unreasonable parental restrictiveness' (Brannen *et al* 1994:41)

The cancer experience has the potential to restrict leisure opportunities and the move towards using peers as the dominant reference group. Relationships with family members are likely to become closer, at least during treatment phases. At the same time, there can be a fall off in contact with friends as a result of physical constraints on visiting, difficulties in

seeing or being seen at such a time and reduction in shared interests (Eiser 1998; Enskar et al 1996; Nichols 1995) sometimes compensated for by the development of new friendships with peers with cancer. Lievesley's (2006) survey of social workers' views of the role of friends found that support from existing friends was variable after, as well as during, treatment and that new friendships carried the potential for distress given the frequency of relapses or death. Albritton and Bleyer (2003) expressed the challenges poignantly if a little stereotypically:

'Adolescent and young adult patients, who are developmentally dependent on peer group approval, often feel isolated from peers by their experience; the cancer patient's issues are illness and death, while their peers' are consumed by lipstick and homework' (p2594).

The desire to return to 'normal as defined by the peer group' following treatment can be hampered if existing friends have 'moved on' physically or otherwise or if the young person finds it difficult to re-enter their peer group for some other reason (Grinyer 2002, 2007). Negotiation of the effect of 'difference' on group membership is common in any peer/friendship group but where the difference arise from cancer and/or fertility impairment, negotiations may be more covert or individualised, especially given that the difference is unlikely to be socially valued within the group .

### ***Negotiating risk***

All young people can be seen within a lifespan approach as engaged in undertaking regular assessments of the risks and benefits arising from new and existing challenges as a way of adjusting their aspirations or intensifying their efforts. Where such assessments are viewed through an adults' lens, the dangers of risks may be seen instead of their opportunities. Young people's growing ability to recognise hypothetical risk combined with their self preoccupation or sense of invincibility may be seen by adults as compounding the dangers whereas within a young person's 'cost benefit analysis', risks remain as risks. For example, for young people drug taking may be about '*thrill seeking*'; initiation rites into a peer group may be '*audience controlled*' risk taking; not using contraception in order to experience sex may be '*irresponsible but worth it*' (Hendry and Kloep 2002). For the young person involved:

'..... testing the goodness of 'fit' between challenge and resources – learning what challenges one can accept in relation to the resources one had

– leads to learning how to assess whether one can cope with a challenge or not' (Hendry and Kloep 2002:86).

This is also true for those with cancer although some of the elements in their 'cost benefit analyses' may differ. Earlier research suggested that young cancer survivors may incline towards high risk behaviours (Hollen and Hobbie 1993). Although there has been little follow-up research, this nevertheless seems to have become part of folklore and thus may heighten adult fears. Young people with cancer are more likely to be 'treatment non-compliant' than children or adult cancer patients and this too is thought to be fuelled in part by risk taking (Albritton and Bleyer 2003; Morgan 2005). However as with non-affected young people, risk and danger may carry different connotations for young people than for adults and this may make it more difficult to achieve mutual understanding. For those who have been told that their fertility is at risk, it may be particularly important for adults to be alert to current understanding as it is the interpretation and meaning of information rather than information per se that is likely to influence any cost-benefit analysis.

### ***Decision-making, critical thinking and moral reasoning***

The need to be alert to how young people themselves perceive their experiences has led to critiques of traditional discourses around the development of abstract thinking and moral reasoning. Nevertheless, evidence suggests that young people in transition develop a stronger sense of purpose and future, increased capacity to act in a helpful, caring way to others without expectation of external rewards, understanding of unintentional and intentional harm, increased ability to see things from another's perspective, improved grasp of principles such as trust, loyalty and justice and the ability to think hypothetically. In addition, they are said to start to develop a language for feelings (both their own and others) and to think about feelings more contextually and with greater complexity.

Young people with cancer often find themselves thrown into situations where the distress faced by others is highly visible. During treatment, they are often required to share spaces with other children and young people, necessitating them taking account of others at a time when they are most likely to want to be self-centred. Decision-making about medical interventions, including fertility preservation and fertility testing, demands a level of critical thinking that may not have been required previously. Whether their coping abilities result from accelerated development, the emergence of latent capabilities or the use of existing abilities

is unclear. What is clear is that the experience of paediatric oncology nurses, among others, offers a challenge to a simple linear framework around the development of abstract thinking and moral reasoning:

'Our observations could provide evidence that although adolescents with cancer are in the process of 'defining self', they do so in consideration of others around them'

(Hinds 1997:1)

### ***Summary of lifespan approaches to the transition to adulthood***

In bringing together the need to pay attention to historical and contemporary context within a dynamic understanding of human development, lifespan approaches offer the potential to move beyond polarised debates in which young people's choices, decisions and actions are said to be influenced *either* by structural factors (i.e. beyond their control) *or* by determinist psychological forces. As such they offer theoretical explanations for the complex relationship between structure and human agency.

Lifespan approaches suggest that developmental changes derive from the interplay between personal, cultural and social systems and according to where they occur across the lifespan. They are therefore:

- *pluralistic* – emanating from the acquisition, maintenance, transformation and extinction of earlier behaviours. Some developmental tasks are age-graded and, once acquired, continue throughout life; some are unique to restricted age segments or developmental settings; some emerge as salient tasks later in life with little reference to earlier tasks and so on;
- *multi-linear* – changes in behaviour emerge at many points throughout the life cycle enabling individuals (within limits) to make changes in life style or to ameliorate perceived threats;
- *continuous/discontinuous* – some behaviours and processes will be maintained over time, others will be novel or altered.

Those managing cancer alongside growing up have to re-negotiate their identity and interaction with others (including family), manage their unfolding experiences in relation to treatment and its aftermath and integrate these alongside other developments in their lives (Smith et al 1991). This can remain true throughout what Self (2005) has called the lifelong acute, extended and permanent 'seasons of survival'. Work in the field of non cancer-related

fertility suggests that the need for re-negotiation and integration of the impact of fertility impairment on individuals and those around them is lifelong too (Blyth 2002; Bryan and Higgins 1995; Lorbach 2003; Wirtberg et al 2007).

In accord with the principles set out in Chapter Three, lifespan approaches lend themselves to encouraging understanding of the reality (or multiple realities) of the world *as experienced through the eyes of the person living it*. Unlike 'stage' theories, they have retained their conceptual rigour as life courses have become less standardised not only through 'extended transitions' but also, for example, through changes in 'mature' adult behaviours such as increased rates of divorce, return to study and 'gap' years. Lifespan approaches do not therefore support a dichotomy between adults as experienced, stable, protective, mature, wise, reliable and competent and non-adults as 'other' with its potential for the maintenance of hierarchical age-related power relationships (Alderson 1999:34). In conclusion, perhaps one only needs to consider how far as adults we measure up to the classic stage theory developmental adulthood milestone that Beckett (2002) sets out to see the attractiveness of a lifespan approach:

'The individual has developed a defined personality within a social reality which he or she understands; she has a secure sense of herself as a consistent person' (p118).

Having looked in some detail at a framework with which to consider human development, I was left with some questions about what happens when the challenges that arise pose deeper levels of threat and adversity than those that one might expect in the 'normal' life-course. In seeking further understanding of what might bolster or restrict young people's ability to cope with cancer-related fertility impairment in their transition years, I turned to the literature on resilience.

## **RESILIENCE THEORY**

### ***What is resilience and what does the research say about it?***

The term resilience has gained popularity in recent years, with perhaps the bulk of the work on it being undertaken in relation to children and young people who have been abused and/or who are in the 'looked after' system.

Work specific to resilience has considered both what enables some people to find fulfilment in their lives *despite* exposure to adversity and disadvantage and what enables some to develop resilience *as a result of* adverse experiences. In this context, adverse experiences are seen as those that go beyond what one might expect to encounter within the mainstream stresses and strains of growing up and hence beyond what the normative repertoire of coping skills might manage:

'Resilience refers to qualities which cushion a vulnerable child from the worst effects of adversity in whatever form it takes and which may help a child or young person to cope, survive and even thrive in the face of great hurt and disadvantage' (Gilligan 1997:12).

In doing so, it has identified what have been called 'risk' and 'protective' factors. As with lifespan approaches, resilience work has reported the importance of the interdependence of wider community, family and individual influences and resources for both internal and external worlds. This has been considered theoretically through ecological or systems frameworks (Bronfenbrenner 1989, cited in Daniels and Wassell 2002:9-10) as well as empirically (Fonagy *et al* 1994; Luthar *et al* 2000 cited in Stein 2006; Rutter *et al* 1998; Rutter 1999).

The recent theoretical development of a 'dual process' model of griefwork following bereavement in adulthood reflects the importance of a different sort of interdependence when coping with adversity (Stroebe *et al* 2001, 2003). This work challenged staged approaches to bereavement and the conceptualisation of coping as 'active/defensive' or 'emotion/problem focussed' and focussed instead on the promotion of resilience. The authors' research indicated that people employed a mixture of reactions across time and context that indicated a need to manage loss and restoration interdependently. Although gendered patterns were present, these were noted rather than given a value. Where any imbalance in addressing loss and restoration was sustained, recovery stalled. They concluded that professional interventions would be more effective if they focussed on enabling people to work on those areas that they found most difficult to manage but only insofar as this maintained the dual process recovery.

Woodgate (1999b) has suggested that discussions around risk and protective factors where adversity arises from cancer need to view coping strategies as a sub-construct of resilience rather than as interchangeable with it. This could facilitate a focus on their contribution to the

development, enhancement or maintenance of resilience, including in relation to fertility matters.

The theoretical and empirical work on resilience carries a hopeful message and fits well with strengths-based theories of intervention and with lifespan theories of understanding.

However, there have also been calls for tighter use of the term itself. A review of literature on resilience pertinent to young people reported that its interchangeable use in describing process, outcome or personality traits had hampered the development of robust research on resilience, its theoretical development and, implicitly, knowledge-informed practice (Olsson *et al* 2003:2):

'Resilience can be defined as an outcome characterised by particular patterns of functional behaviour despite risk. Alternatively resilience can be defined as a dynamic process of adaptation to a risk setting that involves interaction between a range of risk and protective factors from the individual to the social. Any theoretical account of resilience that does not discriminate between process and outcome may be prone to needless complexity' (Olsson *et al* 2003:2).

Various researchers have expressed similar concerns that too loose a use of the term could imply that it is, or can become, a permanent characteristic. This has led to a growing consensus that resilience should not be confused with invulnerability and that resistance to stress, or the ability to develop resilience, is relative rather than absolute and will vary over time and context (Howe 1998; Masten 2001; Rutter 1999; Schofield 2001). In keeping with this, it has been argued that it is misleading to refer to young people 'bouncing back' from threat or stress from cancer as this implies resilience is already present (Haase 2004; Woodgate 1999b). Similarly, it is important to remain alert to any features of resilience that appear especially relevant to fertility matters.

One example of how tighter use of the term could lead to the provision of clear messages for services providers was work done by Stein (2005) in relation to care leavers. He reviewed the research literature and developed typologies that identified process and outcome resilience factors at individual, family, substitute care and community levels. Together with studies across the wider field of work with young people, such approaches can improve understanding of those risks that may need to be lowered and those environments that may

need to be promoted in order for 'good-enough' emotional and social functioning to be achieved (for useful reviews see Daniels and Wassell 2002; Newman 2004; Newman and Blackburn 2002). Put descriptively, young people appear more likely to believe in themselves and their ability to have some control over their present and future lives if they:

- Have an easy 'disposition'.
- Are intelligent.
- Have a cohesive family.
- Have at least one parent or other close adult figure or mentor within the family, substitute care setting or elsewhere who is warm, supportive and emotionally available and who provide(s) good role models well into adulthood.
- Have a social network that is valued and which values them.

(Gilligan 1997; Jackson 2002; Rutter *et al* 1998 cited in Stein 2006; Olsson *et al* 2003; Schofield 2001).

### ***Family and social support***

The role of family has been looked at in general for children and young people managing a cancer experience. Families, especially mothers, have been found to be key sources of support though relationships with fathers are less well understood (Neville 1999, 2005; Quin, 2004; Ritchie 2001; Whyte and Smith 1997). There may be some gendered tendencies within parental coping approaches that reflect normative patterns of men being more emotionally distant and task-oriented (Dixon-Woods 2005; Mastroyannopoulou *et al* 1997; Reay *et al* 1998). Relationships with siblings can be supportive though there is also evidence of tension (Quin 2004; Roberts *et al* 1998; Sloper 2000; Van Dongen-Melman 2000). It is thought that families may also be better able to support their children when they themselves receive good levels of support (Clarke *et al* 2004; Dixon-Woods 2005; Grinyer 2002; Quin 2004) although there is evidence that parents can be unsure who to approach within the multi-disciplinary team or are hesitant to 'trouble' professionals, especially following the end of treatment (Crawshaw 2006; Sloper 1996).

Although increased parental involvement may coincide with some regression and loss of independence among young people (Hinds *et al* 1992; Self 2005) and may trigger earlier family dynamics, Woodgate (2006) noted the presence of interdependence between family members in her treatment-based study. While families provided the bulk of care, the young person was able to reciprocate this by 'being there' for their family at times and enjoyed the feelings of acting responsibly towards, and caringly about, others. Interdependence has



anyway been found to be more evident in some non-western cultures, regardless of the presence of cancer (Eiser et al 2002a). However interdependence, together with the ability to re-negotiate parent-child distances following cancer treatment, has the potential to be a protective factor (Smith et al 1991; Woodgate 2006). Interdependence appears less present when physical care similar to that provided to much younger children is involved, when treatments are lengthy and/or when relationships become dysfunctional (Eiser 1998; Grinyer 2002, 2007; Langeveld et al 2003). Where the opportunity for reciprocal care is blocked, risks may also be heightened not least as this may coincide with times when young people feel especially ill or incapacitated and when their condition or treatment causes distress that is beyond their control to alleviate.

Where protective communication takes place within families, this has been found to work well unless it is driven by avoidance and denial (Enskar et al 1996; Neville 1996, 2005; Weekes and Kagan 1995). The ability of family members to manage fertility aspects relative to cancer itself has not been studied. However, limited evidence suggests that mothers may be particularly helpful in associated decision-making, fathers may have greater potential to trigger difficulties (especially 'absent' fathers), communication may be more avoidant and there may be less interdependence (Crawshaw 2006; Grinyer 2007). Within the wider field of adult infertility, concerns about the loss of generativity and 'the family line' can affect all members of a family (Blyth and Landau 2004; Daniels 2004; McWhinnie 2001; Throsby 2004).

Wider social support systems have also been found to promote or enhance resilience (Nichols 1995) - providing that the young person views them positively (Neville 1998). Such systems might include professionals, friends and neighbours (Hinds et al 1999; Neville 1998; Patterson et al 2004; Woodgate 1999a) and provide either direct support or a route for 'coping by reference to others' – for example, where the young person feels valued by others or where they use others as a reference point for measuring progress, thinking what others would do in their situation and so on (Bauld et al 1998). Woodgate (2006) found that the importance of others 'being there' applied to mind and spirit every bit as much as to body and enabled young people to feel connected and part of the world, to gain or maintain self respect and self confidence and to feel cared for:

'It was through the act of 'being there' that adolescents experienced a sense of presence with the individual in the relationship and made the adolescent realise what was really important in life' (Woodgate 2006:126).

Following treatment, family and social support systems can act as a conduit back into 'normality' while responding to the need of the young person to feel special at times (Dixon-Woods 2005; Grinyer 2002, 2007; Weekes and Kagan 1995; Woodgate 2005). This period has been found to be challenging for young people and their families not only as a result of the loss of the support of, and intense health monitoring by, professionals but also because of the need to re-negotiate internal and external boundaries (Grinyer 2007; Haase and Rostad 1994; Kelly et al 2003, 2004; Quin 2004; Whyte and Smith 1997; Woodgate 2006). Where family and/or social support does not meet the young person's needs, the potential for risk is raised, especially where this continues over time (Zebrack et al 2002; Zebrack 2006). On all fronts, relapses and ongoing chronic health difficulties or impairments pose risks to well being and this is returned to later. Given that fertility impairment may only become apparent over time and that its impact may become more dominant as the threat from cancer recedes, it may come to be an additional item on this list.

### ***Friendships***

The presence of positive peer relationships and friendships appears to carry some significance in promoting or maintaining resilience, especially when this offers loyalty, commitment, genuineness, the opportunity to acquire and rehearse social skills and the potential for intimacy and fun (Hartup 1992; Olsson *et al* 2003; Schaffer 1996; Thompson 1995; Werner 1990). In their study of maltreated children, Bolger and Patterson (2003) found that when children had a reciprocal best friend, their self esteem tended to rise over time (and the converse was true). Triseliotis *et al* (1995) found that in spite of disruptive experiences, most 13-17 year olds in receipt of social work interventions identified friends as playing a key part in their lives (though they also found that social workers were not well informed about these networks).

The role of friends has received surprisingly little research attention despite the probability that changes in friendship patterns are likely to have risk or protective outcomes. Smith et al (1991) found that some young people felt stronger than their peers and had to educate them, be prepared to ditch them and take more initiative in awkward social situations. Morgan and Hubber (2004) have argued that specialist teenage units work better than children's or adults' wards in encouraging friends to maintain contact and get involved in unit activities both during treatment and afterwards and that this facilitates recovery.

However some survivors report feeling lonely (Eiser 1998) and some fear rejection (Faulkner et al 1995). Neville (1999, 2000) found that some felt set apart as cancer '...had changed their lives and made them see the world quite differently from those who did not have a life-threatening illness' (Neville 1999:254). A recent large scale study reinforced earlier study findings (Mackie et al 2000) in finding that survivors were less likely to have close friends and confidantes especially when they had low self esteem and residual health problems (Barrera et al 2005). As Shearer (Woods and Shearer 2005), a cancer survivor and amputee, has described: 'I have many friends and family but I can be in a crowded room and still feel alone' (p162).

Friends have also been cited as important sources of support providing that they listen and are emotionally available even if they cannot fully understand (Lievesley 2006; Mitchell et al 2006; Ritchie 2001). Indeed, the presence of close friendships appears to be experienced positively (Grinyer 2007; Kameny and Bearison 2002). Where friendships are made with peers who share the cancer experience, research suggests this carries more protective features than risks despite some professionals' fears to the contrary (Kelly et al 2004; Lievesley 2006; Mitchell et al 2006). Some young people would welcome professionals being more proactive in facilitating peer support (Clarke et al 2004). The experience of being 'all in the same boat' can allow new norms to be created that can challenge taboos around the social image of cancer and enhance coping strategies (Enskar et al 1996; Geehan 2003; Kelly et al 2004). Thus, where the pattern of such friendships reflects the young person's wishes and meets their needs, this seems to help and vice versa.

Sharing thoughts and feelings about fertility matters in any friendship setting may prove especially challenging (Crawshaw 2006).

### ***Education***

For those of school age, the school as a place, education as a process and educators as people all hold potential influence for good or ill (Daniel and Wassell 2002). A range of extra-curricular activities also have been found to promote the learning of competencies and emotional maturity (Newman 2004).

A recent review of the research into how children and young people aged 5 to 18 fare educationally following cancer found that most were willing to attend school, were not teased and were no more clingy or dependant on adults on the whole though were more likely to

have less energy and changeable moods than were healthy controls (Vance and Eiser 2002). However, while children and young people themselves were likely to report no significant differences with peers once back in school, some differences were identified by teachers and peers:

'While there is mixed evidence about whether children have significant behavioural problems in school, studies involving social behaviour and peer relationships generally conclude that children with cancer are more sensitive and isolated than peers, according to both peer and teacher report' (Vance and Eiser 2002:16).

Where there was significant absence from school during and after treatment (this was more likely to be true for adolescents) and where teachers lacked information about the child's potential and actual behavioural and psychological problems, the outcomes were poorer. Return to school was aided where the importance of a rapid return was stressed and where schools, including peers, were well prepared and sent relevant information in advance of re-entry. However, fertility matters are not included routinely in information provided to schools and the standard school sex education curriculum is underpinned by an assumption of fertility. Both factors may pose particular risks for those returning to education after cancer treatment.

### ***Self esteem, including body image***

With regard to self esteem in the wider population, the smaller the gap between what young people would like to be like (ideal self) and how they perceive themselves to be (perceived self) the lower the risk to well being. This can be affected positively by nurturing talents and interests that are valued within the 'ideal' self aspiration. Self aspirations appear to be influenced by global measures of self esteem and general self worth, including scholastic competence, athletic competence, social acceptance, physical appearance, behavioural conduct, presence of close friendships, romantic appeal and job competence (Daniels and Wassell 2002). It is not surprising therefore that a recent review of work on self-esteem concluded that there is a danger of oversimplifying what are in fact complex associations (Emler 2001).

Eiser et al's (2000a) systematic review concluded that, overall, young people's self esteem recovers well after cancer though a small number continue to have significant problems. Like

Emler (2001), they acknowledged the complexity of measuring and understanding it and this may go some way to explain previous conflicting findings.

Threats to the successful psychological integration of self may remain, even though outward appearances suggest that social desirability and 'normality' have been achieved. Body image may be a key factor. This was studied by the same team that identified difficulties in 'inner sexuality' and, as reported in some other self esteem and/or sexuality research, discrepancies were found between self reports and face to face interviews (Elkin et al 1997; Enskar et al 1996; Puukko et al 1997a, 1997c; Ropponen et al 1990). The researchers concluded that:

'Since body image is one of the central parts of a human's self-image and self perception, our results suggest that many survivors tend to continue to have difficulties in the integration of self following their illness' (Puukko et al 1997a:61).

This reinforced earlier findings suggesting that some survivors may have ongoing difficulties with body image and compensatory heightened traits of social desirability (Madan-Swain et al 1994; Fritz and Williams 1988). Elkin et al (1997) have also expressed caution about outward appearances of what they call 'illusory mental health' disguising deeper seated difficulties (p587).

Woodgate (2005) found young people appeared to do better when they used their body to monitor their way of 'being' in the world through talking about its 'feeling states and changes' rather than using medical jargon (p13). This was reinforced when professional and informal carers acted towards them and their bodies in affirmative ways. In similar vein, Zebrack et al (2001) concluded that the presence of long term medical or physical sequelae was less important than the meaning that survivors ascribe to their experience, their subjective understanding of it and their related outlook on themselves and their lives:

"The extent to which physical after effects interfere with life did not appear to be related to self-image and life outlook once we accounted for things that survivors worry about. Subjectively experienced worries, and not the objective existence of physical after-effects, are more powerful explanatory factors with regard to self-image and life outlook.....their meaning-making processes...may be more important than measures of physical status per se' (p253).

Elsewhere, those who employed both periodic cognitive re-living as well as selective forgetting appeared to manage well as this enabled them to revisit their experience and its meaning to them from time to time without appearing strange to family and friends or causing them distress (Nichols 1995).

As elsewhere, threats to well-being appear more likely among survivors who have relapses or whose physical or cognitive changes prove permanent or disfiguring (Eiser 1998; Eiser et al 2000a; Eiser et al 2004; Elkin et al 1997; Self 2005; Woods and Shearer 2005; Van Dongen-Melman 2000; Whyte and Smith 1997; Woodgate 2005). Threats also appear heightened among those who have discrepancies between hopes, expectations and reality and few strategies to manage these (Eiser et al 2004); who lack positive affirmation from those around them (Ritchie 2001); and who have raised somatic distress and low household incomes including through unemployment (Zebrack et al 2002). For those faring less well in the earlier stages, there is some evidence that this gets worse over time (Zebrack et al 2002).

There has been little work done on the impact of cancer-related fertility on self esteem but studies with adults facing non cancer-related fertility difficulties suggest that associated stigma and/or guilt are key threats and can carry gendered dimensions (Crawshaw 2003; Lee 1996; Letherby 1999; Lisle 1999; Mason 1993; Monach 1993; Throsby 2004). This may be compounded where significant others appear to hold similar views leading to the person feeling diminished in others' eyes as well as their own.

### ***Independence, interdependence and self efficacy***

Outcomes appear to be better when the young person's internal locus of control is high enough to minimise internalisation of any problems (Bolger and Patterson 2001); when they feel more engaged with making life choices than being 'done to' (Daniels and Wassell 2002); when they are able to reflect on both the strengths *and* difficulties in their situation and of those around them rather than only idealising, denigrating or dismissing the importance of any aspects of their situation (Schofield 2001) and when they can reframe adversities as beneficial as well as damaging (Gilligan 1997; Newman and Blackburn 2002).

The importance of achieving the right balance of independence and interdependence with family and peers has already been highlighted. During treatment in particular, young people are likely to have a high external locus of control because of the nature of the regimes (Zebrack 2006). However this may be ameliorated at all stages – and hence resilience

promoted – where treatment is in specialist units geared to this age group (Grinyer 2007; Hollis and Morgan 2001; Kelly et al 2004; Morgan 2005; Whelan 2003; Whiteson 2003); when the professionals involved are afforded high levels of trust (Ritchie 2001); where professionals offer choices where possible (Crawshaw 2006; Whelan 2003); where professional and informal carers encourage young people to talk about what makes them feel stronger (Blacklay et al 1998; Kameny and Bearison 2002) and where the young person and their family do not attribute undue personal blame to the onset of the cancer. Indeed, the meaning that the cancer has to the young person in their present and anticipated future has been found to influence self efficacy (Spinetta 2005; Zebrack and Chesler 2001). Although some work has suggested that females are more likely to create positive attributions and to have a more positive future outlook (Bauld et al 1998; Zebrack and Chesler 2001) there has been too little to yet report this with confidence.

### ***Uncertainty***

Both during treatment and afterwards, self efficacy can be either promoted or affected adversely by uncertainty. This led to the coining of the term 'Damocles Syndrome' in a seminal paper by Koocher and O'Malley (1981). Uncertainty can be prompted by the impact of cancer and treatment itself, the unpredictable course of either or both, fluctuations between acute and chronic phases, the likelihood of cure and/or relapse, perception of ability to cope, body changes and feelings of loss of control and so on (Van Dongen-Melman 2000; Neville 1998; Self 2005, 2006; Weekes 1995; Woodgate and Degner 2002). It is not always related to the level of risk that has been presented to those affected (Weigers et al 1998; Zebrack and Chesler 2001) and its impact appears to be affected by the level of threat that the uncertainty poses.

For those for whom the threat from uncertainty is high, the opportunity to acquire additional information (where this is available) and/or talk the issue(s) through with supporters, including those with 'credible authority', has been found to lower the threat while blocks to such avenues may heighten it further (Hooker 2004; Van Dongen-Melman et al 1986; Van Dongen-Melman 2000; Neville 1998; Young et al 2003). Where the continuation of uncertainty carries protective features - especially among those who prefer to live with uncertainty rather than hearing what they fear or otherwise prefer to delay knowing - information may heighten threat (Neville 2005; Woodgate and Degner 2002). For some, the provision of new information may in itself create uncertainty (Eiser et al 2000b; Woodgate and Degner 2002).

For whatever purpose it is offered, information needs to be available in a wide range of formats, to be offered more than once and to be made available directly to the young person (Earle et al 2005; Jankovic et al 1999; Kadan-Lottick et al 2002; Mitchell et al 2006). It should also be delivered with honesty (Kameny and Bearison 2002; Kelly et al 2004; Whelan 2003; Whyte and Smith 1997). However, more needs to be understood about how professionals decide what information to provide and when in order to reduce unhelpful professional behaviours (Eiser et al 2000b; Bradlyn et al 2004). Where information is limited, modified, extracted and/or discounted by young people themselves, this may also work well - providing that it represents a constructive strategy rather than a defensive one (Neville 1998; Weekes and Kagan 1995). Eiser (1998) has urged a cautious approach to providing information in certain circumstances, especially to those from minority ethnic cultures whose belief system leads them to believe that information might be damaging to their child. Managing the flow and impact of information is therefore a challenge for all concerned.

The presence of uncertainty in relation to fertility matters and the role of information in cancer-related fertility matters were identified in Chapter Two. Associated verbal discussions may be so infrequent as to make it difficult to determine their influence.

### ***Management of risk and challenge – strength through adversity?***

Resilience fits well with lifespan approaches in that they share a belief in the potentially constructive role of challenges. Emler's (2001) review on self esteem concluded that raised self esteem and development of resilience may result from the management of risk. Newman and Blackburn's (2002) review of international research on resilience found that exposure to challenging situations could provide opportunities to develop both problem-solving abilities and emotional coping skills. Schofield (2001) drew on lifespan approaches to explain the ability of some adults who grew up in foster care to engage in adaptive (and hence reparative) processes following exposure to damaging experiences:

'The relative nature of resilience can be understood further by considering the varying degree to which children have *adapted [author's italics]* to adverse and maltreating birth family environments in the past or *adapt [author's italics]* to their new [*family – author's word*] environment' (Schofield 2001:8).



There are also links between the resilience theory belief that 'turning points' can facilitate a break from a high risk situation, halt a downward spiral and trigger positive chain reactions (Rutter 1999; Schofield 2001) and the use of 'psychologic plasticity' and/or 'critical moments' within life-span approaches to explain a break away from a trajectory on which the young person appeared to be set (Catan 2004). All contain both personal and structural aspects:

'Similar critical moments could have different outcomes in different lives, giving rise to complex accounts in which personal and social resources were interwoven and often indistinguishable' (Catan 2004:22-23).

Although various studies have considered self concept to be at risk during a cancer experience during the transition years, there have also been reports of this leading to a gain in strength and self esteem among some (Eiser 1998; Grinyer 2007; Neville 1999, 2000; Parry 2003; Roberts et al 1998; Self 2006). Woodgate (2005) found that many in her study acknowledged that it had scarred them (some more than others) but reinforced its positives and said that they were now stronger and more mature, sensitive and caring to others. In a qualitative study with survivors aged 17 to 29 years looking at what might contribute to a process of thriving, Parry and Chesler (2005) concluded that 'negotiating one's place in the world or the meaning or purpose of life seemed inextricably linked to survivors' ability to find resolution within the meaning of their cancer' (p1065). They came to see their cancer experience as an opportunity rather than a threat both in terms of their own particular situation and on a more global level and this was both dynamic and '.....an active social process negotiated (and renegotiated) in a social setting, responsive to messages and reactions from significant others' (p1057). Those who thrived saw themselves as survivors not victims, having self-reliance and resilience, optimism (not necessarily in relation to their cancer), happiness and belief in their ability to deal with whatever life had to throw at them even though their experience also made them more aware of their vulnerability, the uncertainty of life and the inevitability of death. They were likely to hold a different perspective about what mattered most in life, to interpret events positively and/or to look for the good in events or people. For all, the opportunity to tell and re-tell their experiences with the disease and treatment over time helped them to make meaning of it. However the authors speculated that some may yet re-experience distress if future challenges - including infertility - proved too great (p1066).

Implicit in all of this is that adverse outcomes from challenging events are not a given. Events become adverse and hence threatening to existing well-being and future development when

they are experienced as such, either consciously or unconsciously, by the individual affected and, sometimes, by those of influence around them. Perceptions of threat are thought to be affected by any conscious or unconscious attribution that the individual makes to their cause, as already indicated – for example the different beliefs of ‘It’s all my fault’, ‘It’s all their fault’ or ‘It’s no-one’s fault’ can lead to very different outcomes. Although there may be times when the sense of threat and accompanying deterioration in coping in one sphere proves contagious across the board, this is not inevitably the case. Similarly, adaptive strategies for coping in one sphere may not prove universally effective (Gilligan 1997). As Schofield (2001) has said:

‘Events will have a different meaning to different individuals and the capacity to deal with stress will be influenced by the child’s appraisal of the situation. An understanding of the experience and actions of parents and children must take into account the meanings they attribute to events and to each other’ (p10).

This links with findings of the development of variable competence and differing identities cited in the section on lifespan approaches.

### ***Summary of work on resilience***

The work on resilience comes out of the experiences of people, especially children and young people, faced with experiences over and above those found in mainstream life-courses. Uniquely, it has sought to identify which factors within the individual, family and wider social context (including service provision) are more likely to enhance or maintain individual resilience and which carry particular risks. The importance of the interdependence of spheres of influence is highlighted as is the need for clarity about whether one is looking at personality trait, process or outcome. The need for clarity extends to perceptions of coping strategies; these are not interchangeable with resilience but its sub-construct. Resilience work also stresses the need to understand what leads to events being experienced as a threat to current and future well-being.

### **Additional aspects of managing the cancer experience**

There are two additional features of managing the cancer experience that point to risk and protective features that are implicit in certain of the previous sections but highlighted here.

## Hope

Implicit in discussions so far, especially those around uncertainty, runs the role of hope. This has been studied both directly and indirectly in children and young people managing a cancer experience, though restricted mainly to the treatment phases and illness self-management (Haase and Rostad 1994; Haase 2004; Hinds *et al* 1992, 1999; Ritchie 2001; Van Dongen-Melman *et al* 1986). Nevertheless, there are some findings which may be transferable to this study. Hinds and Martin (1988) found that hopefulness – which is different to wishing as it is more reality based - was a dynamic phenomenon comprising four sequential phases: from cognitive discomfort at around diagnosis (where personal survival activated efforts to achieve the more desired state of hopefulness) on to distraction (concentrating on neutral or positive thoughts and conditions) through to cognitive comfort (in higher spirits and able to consider the future) and leading to personal competence (where young people perceive themselves to be resilient, resourceful and adaptable in the face of serious health threats). Follow-up work suggested that young people's well-being was promoted where they were supported by others in their hopefulness (while recognising that this could change over time and according to context). This adds to findings that professionals that inspire hopefulness can bolster well being while high levels of distress in parents may engender hopelessness in their children (Kelly *et al* 2004; Ritchie 2001; Whyte and Smith 1997). Hopefulness appears more enduring when it is realistic (and this, of course, is a relative concept) and when the hoped-for object is defined with a degree of specificity (Hinds *et al* 1999). Little work has been done looking at the role of spiritual faith in relation to hope though what there is suggests that it can be important, though its protective qualities diminish with relapses or extended and complex treatments (Ritchie 2001) as does hope more generally.

Implicit in this is the conceptualisation of hopefulness/hopelessness as part of self perception rather than, or as well as, part of a process. Weekes (1995) considered that young people's self perception affected how well they managed and fell into two key types:

- (i) Seeing self as *vulnerable* – where the illness experience was seen as taxing and exceeding any opportunities to feel enough in control to feel good about oneself.
- (ii) Seeing self as *special* – hopeful; capable of transcending adversity; where the illness experience was seen as potentially or actually leading to self improvement.

This opens up the potential complexity of the relationship between hopefulness and hopelessness and carries echoes of the dual process model of handling loss and bereavement referred to earlier in the chapter. In other words, the two states may not be

polar opposites but may be interlinked – without attention to feelings of loss, feelings of restoration and hopefulness may also be curtailed.

### ***Communication patterns***

Communication patterns around cancer appear to fall into three main types: (i) guarded (ii) protective and (iii) open. Where they are guarded, these appear to reflect a heightened sense of threat by the young person and/or those around them. Protective communication patterns, on the other hand, appear to carry beneficial properties when used by young people *towards* others in order to protect others (rather than themselves) from distress as an act of reciprocity or when they are part of the rather pejorative sounding strategy of 'adaptive denial' (Enskar *et al* 1996; Neville 1996, 2005; Weekes and Kagan 1995). Adaptive denial includes concentrating on present-day oriented activities or present time tasks and/or employing future-oriented thinking that focuses on hypothetical events to look forward to, for example ending treatment, getting married.

### **SUMMARY**

This chapter has looked at two key concepts – lifespan approaches and resilience - that appear to be of particular use in looking at the experience of young people growing up with a cancer experience that carries the threat of fertility impairment. Lifespan approaches offer a framework of understanding in which each age period is seen as having its own developmental agenda while arguing that both continuous (cumulative) and discontinuous (innovative) developmental processes occur throughout life. Lifespan approaches are less deterministic than are so-called 'stage' theories, broader historical and cultural contexts are seen to be of more significance and the complexity of the relationship between structure and human agency is acknowledged. Participants in this study were not only dealing with the contemporary and complex non-normative experience of cancer and associated fertility matters but it was clear that this could continue well beyond the stage at which they felt themselves to have become adult. Resilience theory and research provides a framework for understanding how individuals manage adverse challenges (such as those associated with cancer) that are significantly outside their existing experience. They consider what traits, processes, attitudes and behaviours in individuals and those around them might promote, protect or maintain resilience and what might be sources of risk. In doing so, they take account of the interdependence of individual, family, community and social forces and the dynamic nature of life experiences over time and context. As such, they are especially helpful for informing policy and practice.

I now turn to the findings from the study. In each of Chapters Six to Eleven, the presentation of findings is followed by a discussion section which seeks to consider them against the literature and concepts reviewed in this chapter alongside those from Chapter Two.

## CHAPTER SIX

### THE IMPACT ON SELF OF CANCER-RELATED FERTILITY MATTERS

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The impact at diagnosis to the news of possible fertility impairment was summarised towards the end of Chapter Four. In this chapter, I bring up to date the impact on participants' sense of self, as distinct from their relationships with others. In doing so, I set out the overall impact of the cancer experience and the ways in which both strength of desire to parent and recovery appears to affect, and to have been affected (where it was) by, fertility matters. I also look at social identity influences in relation to ethnic and cultural norms, sexual orientation, gender and what I have called 'fertile identity'. Lifespan influences and possible risk and protective features in relation to resilience are given particular attention.

#### Background

it is not easy to separate impact from *either* coping strategies *or* those factors that appear to increase or reduce the impact. This reflects the lived reality. Hot on the heels of an impact comes adjustment and it is not always clear where the distinction lies. Often, participants located matters specific to fertility by describing and reflecting on their broader cancer experience. In many ways, it was artificial for them to try and effect a separation but we worked together on trying to tease them apart in the interviews. This posed similar challenges during analysis. Whereas there were some aspects that were fairly easily identified – for example, the predominance of the treatment experience during active treatment phases; the marked differences in the numbers of 'supporters' that were aware of fertility matters as against cancer - others were less obvious, such as the impact of body image on 'fertile identity' and vice versa. The relationship between sexual identity and fertile identity (and related activity) seemed particularly elusive.

Many participants were moving towards a life stage where reproductive decision-making might become more salient and some considered themselves to be there already. Participants had entered the cancer experience at different points along that continuum and brought a range of prior attitudes about themselves as prospective parents. While some had already incorporated a strong commitment to parenting into their self identity, others had

scarcely given it a thought. Many were involved in antecedent activity through getting ready for, or gaining experience in, romantic relationships. The dynamic forces of getting older and/or becoming adult, having romantic relationships, moving further away from treatment, managing changing information and advice about the level of risk to fertility, having peers becoming parents and so on had to be managed within a personal and social context in which cancer and fertility related concerns competed with other forces. However it was possible to look for statements that indicated the strength or otherwise of participants' desires or aspirations to become parents one day to see if that added more to the picture.

Not surprisingly then, cancer itself had a major impact on participants' lives. It disrupted school or work, separated them from friends and led to major disruptions for their nuclear family with parents often splitting their time not only between hospital, home and work but also between caring for their sick child and any other children. There were four key stages that participants talked about:

1. Leading up to diagnosis and the impact of diagnosis itself.
2. Impact of, and coping with, treatment.
3. The immediate post-treatment phase.
4. The longer term.

Some had only recently finished treatment so were glad simply to have got their central line out, have their hair growing back and be looking forward to getting back to 'normal' while others had completed treatment years previously. It was not unusual for those closer to treatment to talk at some length about their diagnosis and treatment though all talked about this to some degree.

What follows is an attempt to try and separate these intertwined forces as well as influences such as gender in order to start and answer the questions:

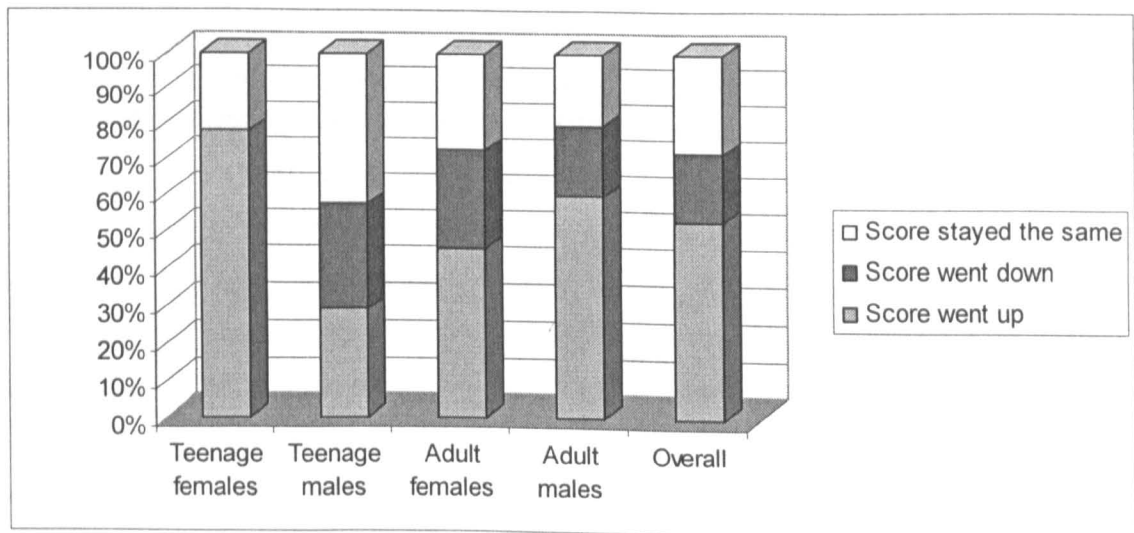
- What effect did the potential or actual fertility impairment appear to have on the individual over time and in different contexts?
- What did participants think informed this?

This starts with looking at numerical ratings of significance ahead of looking in depth at the qualitative data.

## Numerical ratings of significance over time

Data from the narrative of the interviews were the primary source for analysis. However, participants were also invited to give a score from 0 to 10 to the significance to them of facing possible fertility impairment at diagnosis and at the time of interview. The aim was to invite a numerical indication at these two points in time of any increase or reduction in threat experienced in order to augment verbal descriptions. This was not a validated tool of measurement and had the limitation of not recording any numerical variations in between (these were picked up instead through detailed analysis of verbal and non-verbal exchanges). Its usefulness was primarily as a different tool through which participants could indicate their experiences. It also proved to be a prompt for additional verbal discussion, including about how participants interpreted the question and arrived at their scoring. Figure 7 shows the data numerically and the accompanying text offers further description.

**Figure 7: Changes in significance ratings for fertility from diagnosis to interview**



Out of the 37 responses obtained (one of the adult females who was a parent was inadvertently not asked):

- ten (28%) kept the same score at each time interval (of which five scored it at 10 each time and two were very low);
- twenty (54%) increased their score;
- seven (19%) reduced it.

From within the four groups:



- *teenage females* showed the biggest changes with seven (78%) increasing their score, two (22%) keeping it the same (one at 10 and one who was a parent but with her family still incomplete at 5) and none reduced it.
- *teenage males* showed the least changes with two (29%) reducing their score slightly because of the reassurance of having stored sperm, three (43%) retaining a high score (including two who had banked and found that reassuring but not enough to change their score and one that had not banked) and two (29%) increasing it (neither had banked).
- Of the eleven *adult females* asked, three (27%) reduced their score, saying that they now felt slightly more able to cope with the consequences; three (27%) retained a high score; and five (45%), increased it (including a parent yet to complete her family).
- Of the *adult males*, two (20%) reduced their score (one because he had become a father and completed his family; the other because parenting had become less important to him); two (20%) retained the same low score; and six (60%), increased their scoring

In other words, the changes in ratings were more likely to be upwards, high scores were more likely to be retained than were low ones, entry to parenthood did not in itself lead to a reduction in scoring and neither did the presence of banked sperm. The only group that included members who reduced their score because they felt better able to cope with the consequences of possible impairment were adult females. Combining those who rated it high at each time point with those who increased their score, twenty five (68%) could be seen as rating fertility impairment as significant or increasingly significant. In contrast, only nine (24%) consistently rated it low or felt its importance to decrease over time.

The accompanying narratives gave some indication of the limited influence on scores of strong pre-diagnosis desire to parent. There were differences across the cohort in the presence, strength and consciousness of such desires. Adult numbers were fairly evenly divided between those who remembered being clear at diagnosis that they wanted children and those who had given it little thought. However the majority of the teenage males were in the former camp and the opposite was true for the teenage females. Among those who had given it little thought, most had assumed nevertheless that they would have children when they got older and might therefore be seen as passively pro-natalist. Very few had either not thought about parenting or had not wanted children. Findings explored below do so with this backdrop in mind.

## **IMPACT OF FERTILITY ON SELF**

The impact of cancer-related fertility on one's sense of self is of key importance to understand. Participants talked about it in different ways. For some, the impact on their global self esteem was their key focus – how they viewed themselves in terms of their self confidence, belief in themselves and ability to feel in control of their lives. However, identity comprises many different facets and these were also reflected. Some described the ways in which their social identity was affected, that is how they saw themselves and how others saw them in a social context. For some, this social identity was affected primarily by changes brought about through their cancer experience – for example residual physical impairments or ongoing health complications. The majority also talked of whether or not they saw themselves as fertile and to what degree – what I have called their 'fertile identity' – and what hopes and beliefs they had for themselves in relation to children. The relationship of their cancer experience and their perceived fertility to their sexual identity was also indicated by some. Underpinning these were the ways in which this was affected over time and between situations.

It is these different aspects that are now considered.

### **Global self esteem**

#### ***Overall impact***

A large number talked of having lost their self confidence during treatment and trying to pick up the threads of their lives afterwards. For some, it had not returned to previous levels even several years on whereas others reported fairly rapid recovery to previous levels. Many reported improved self esteem and self confidence. A small number felt that their cancer experience had little lasting impact on them.

There were differences between participants in the length of time that they had been dealing with cancer as well as the severity and complications of treatment. Nevertheless, surprisingly few across all four groups saw their treatment itself as having been unduly difficult even though their accounts made it clear that it had been very demanding in terms of time and frequency of infections and complications. This included some who were recently off treatment and therefore perhaps more likely to retain strong memories. A number counted themselves as having been fortunate compared to others and this included ones whose professional helpers had made it clear to them that their regime had been tough. Some

thought that it was harder for on-lookers (especially family members) than it was for them. However, all those who had undergone bone marrow or stem cell transplants or who had psychotic reactions reported that to be difficult to manage. With regard to this study, neither the length nor intensity nor complexity of treatment was cited as having a particularly significant effect on the impact of cancer-related fertility except where physical impairments or ongoing health problems were involved (see later).

Those closer to treatment were more likely to cite physical symptoms such as nausea, fatigue, infections and changes to their body image and associated physical attractiveness as impacting on their self esteem than fertility matters per se. For example, one talked about the impact of hair loss, acquiring scars in sensitive places and feeling unattractive.

..... it does take your confidence. I think in everything. Because at one point I got that stressed I started having anxiety attacks. .... it does take it out on you and people don't understand that. They only see you. They like see you 'oh, she's ill. She's got no hair' but they don't see the real side of what people feel like. They don't understand it..... I lost all confidence and the fact that my scar is like 'down there'. It is a very big problem [in relationships].

Teenage female 17:20<sup>6</sup>

Nevertheless, fertility concerns were present for a few of those close to treatment. One teenage male described how the undercurrent of fertility concerns combined with concerns about sexual attractiveness had the potential to rise to the surface from time to time during treatment itself and affect his sense of self:

When I looked at myself [after starting on steroids] I had put on loads of weight and everything like that, no hair and that. So you don't think about your sexuality and everything cos you lose all that, you think no-one will want to do it with me, or whatever like that. Make you feel like that. So it [sex and fertility] doesn't really cross your mind or anything at the time. And then it's just certain days, you know, when it does come back and hit you and everything like that.

Teenage male 18:19

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<sup>6</sup> In all quotes in this and subsequent chapters, I identify the participant according to their category (teenage female, adult male etc) together with their age at diagnosis followed by their age at interview. Thus, this quote was from a teenage female aged 17 at diagnosis and 20 at interview.

A number talked of the strangeness of the time following treatment. The immediacy of the treatment regime was replaced by a void until other activities could take its place. For some, this transition was fairly short but others were still struggling to feel that they had secured meaningful activities some considerable time later. In a few cases, sustainability of moving forward was a particular challenge and threatened their sense of emotional and social wellbeing, especially those with residual health problems. This time of transition was also when unprocessed thoughts and feelings about their experiences, including fertility matters, might come to the fore. One teenage male described how the return to his 'normal' context heightened his awareness of how his potential fertility impairment rather than his cancer experience made him feel different to his peers:

It's [fertility] hit me more since I've been out of hospital, you know when you're feeling back to normal and you're back in every day life, that's when it starts to, you know, you think to the future, you think what do you want to do in the future....

Teenage male 17:18

While some talked of feeling more or less back to their old selves at the time of the interview, others felt held back by the prospect of more treatments or fear of relapse as they knew how hard it would be to cope another time. Yet others felt that they were still a way off feeling stable and some were anxious that they might never attain 'full' recovery. Some identified fertility concerns as playing their part in holding back the recovery process and, for several, these had risen to particular prominence.

Across gender and age, there were some who referred to 'role models' - cancer survivors who had gone on to achieve parenthood. Such information came through different routes including via professionals, the media and social networks. For example, one of the males had been carrying distress since being told when younger that he was at ninety-eight per cent risk of being infertile. More recently, his consultant had told him of others who had undergone similar treatment and gone on to have children. He found that of comfort. Several had read media reports of a man who had gone on to use his sperm successfully twenty-one years after storage. A few had seen ex-patients coming onto to the ward with their children. None cited role models of cancer survivors who had coped successfully with remaining childless. However two talked of family members who had either undergone unsuccessful fertility treatment or who were otherwise living without children and now appeared to be

enjoying life. Another had an aunt who had an ovary removed (as she herself had) and went on to have children. All reported this as of some hope and comfort.

### ***Impact of second cancers***

At least four had to deal with second cancers and referred to the devastation that accompanied re-diagnosis and further treatment. For one, this happened while she was still in her early teens. She experienced lengthy, complex treatment, residual physical complications, deaths of many of her peers and severe disruption to family life. References to self esteem and identity were only present when describing her eventual return to school. For her, the 'freedom' gained by entry to a new peer group and educational context, combined with exit from treatment, afforded her the chance to develop an identity about which she felt, and has continued to feel, significantly more positive than her pre-cancer one:

I'm a very sort of outgoing person. But yeah that's how I've chosen to be. I recreated myself basically, 'cos I got my cancer when I went from junior school to secondary school, so I missed a year even, so when I came back in year eight I could be whoever I wanted to be, which was a lovely freedom, it really was so..... a lot of people say 'Oh, you had cancer! Oh my god. That must have been horrible'. But no, I do see it as a positive effect. I do say I wouldn't change having cancer.

Teenage female 13:17

The priorities in this 'new' life did not include parenthood. She reported feeling 'different' to most of her peers and did not share their everyday preoccupations with clothes, make-up, going out and boyfriends. Neither did she spend much time thinking a long way ahead and hence gave little thought to parenting except as a possible desired goal one day - especially as there had been times when she had not expected to make it this far:

Yeah, Mum is going sort of 'Either way, you might not have children' and I'm like sitting there 'I'm leaving home in a year, bigger problem' *laughter*.. .....I'm going to go travelling .... finish my A levels, last year, last year of school, scary. ....I lie in bed going...can't sleep...It's really exciting, I'm just glad to be here at the end of the day so....

Teenage female 13:17

For another, the second diagnosis came soon after the end of treatment in his mid teens. It knocked his confidence and led to a very demanding treatment regime which caused him to fear for his life at times. He was still having frequent check ups at the time of interview. Unlike the previous young woman, being able to have children was a very important matter for him and he had very clear ideas about the preferred sex and gender of his future family. Nevertheless his immediate priority was to rebuild his confidence. Like many others who had banked sperm, this was aided by the reassurance of having 'tadpoles' to use if necessary and this enabled him to keep some (but not all) of his fertility fears at bay:

So it's kind of like, that's the thing that I try to put in the back of my mind, about kids. Just like, when time comes for it, I'll try it and if it dun't work I've always got my tadpoles in hospital haven't I?!

Teenage male 15:18

The second diagnosis for the remaining two, both females, came at an age when they saw themselves as more grown up with one aged 18 and the other in her early twenties. Both found its impact was made worse by increased fears for their fertility. Although both had been aware of such a danger the first time round and both had held strong and conscious desires to be mothers since childhood, neither had felt threatened so seriously at that point. This was only partly because both had understood the earlier risk to be small. The younger one required further treatment to her reproductive organs with the attendant heightened risk; the other felt more aware of the threat even though there was nothing in the medical advice to say that it had increased. Both felt that this contributed to its negative impact on their sense of self:

And the second time around, I suppose I was older as well and I was thinking about, I was twenty-two, twenty three, so I was thinking about a family, having a family and things.....

Adult female 19:25

### **Impact of fertility concerns on recovery of global self esteem**

Participants appeared to manage the recovery process in different ways and, for some, this differed over time and context. This in turn appeared to affect and/or to be affected by fertility concerns. Responses were grouped around the following four themes:

- Where active recovery from cancer involved striving for 'normality'.
- Where active recovery from cancer was faltering.
- Where active recovery was affected by impairments or health matters.
- Where recovery from cancer appeared to have been achieved.

***Where active recovery from cancer involved striving for 'normality'***

These responses were drawn either from the teenage group, from those who had most recently finished treatment or from those for whom parenthood was not (yet) an important and/or immediate goal. The priority was to cope with the 'here and now', continuing for some the approach that had got them through the early stages after diagnosis:

But if the worst comes to the worst [and you're infertile], as long as you're alive and healthy, what's more important? There's always other ways of trying..... Cos it [fertility] is important but there are more important things than that [at the moment].

Teenage female 17:20

In the early stages after treatment, many focussed primarily on getting back into the trajectory that they might have been following but for the 'interruption' of the cancer experience. For those who felt '*in active recovery from cancer*', or remembered going through this stage, progress was measured typically by the extent to which they had achieved a return to 'normal for them'. In other words, the return to 'normality' was used as a milestone to be achieved and a way to cope with the impact of cancer and/or fertility concerns. Some did this by trying to 'forget' about the past and put it behind them:

So you started picking up the threads of your life again. I just wanted to get back to where I wa' before. I just wanted to forget it ever happened in a way and get back as what's classed as normal.

Adult male 16:22

Others revisited the past regularly (both prior to and during treatment) partly in order to keep processing what had gone on but also to measure progress towards 'normality'.

A number talked of the importance to their recovery of others treating them as 'normal' and/or of meeting people who did not know that they had cancer and therefore did not relate to them

in that identity. For some of those still in education, this was achieved more readily if they were able to return to the same school and, especially, the same year group. For others, a change of educational setting helped. None of those who had to drop a year group found this to be beneficial.

The attitudes of others appeared to be an important factor for some in building, or rebuilding, resilience:

I'm back to the person that they knew before, kind of, I'm still a little bit messed up in my head but I don't think you ever get over that really. Erm but I'm kind of back to normal, and new people that I meet and stuff they don't know about it. So they don't treat me any differently anyway.

Teenage male 15:18

One adult male remembered the importance of being treated as 'normal' by friends:

And, you know, it was difficult at first but then I've got good friends and they all treated me like normal, you know there was a danger that I would be treated as slightly special, erm, different and they didn't do that and because of that I soon got into, you know, 16, I was going down the pub and getting drunk and doing all the things that sixteen year old boys do. And then, you know, and it just sort of enabled me to put behind me many aspects of what happened ....

Adult male 13:28

'Normality' meant different things to different people given its contextual nature. Acting 'normally' was influenced, among other things, by age, gender and culture.

The significance of age appeared particularly fluid. For example, one twenty-one year old female explained her lack of preoccupation with fertility as being because she was still a 'child' herself whereas a twenty year old gave her age as the reason that she had become more preoccupied as she saw this as the time to start contemplating parenthood. A twenty-one year old female who was diagnosed at age fifteen reported that she had earlier been through some very difficult reactions to her probable infertility but now found it easier, even though she still got distressed at times, as she felt more mature:



But now I'm mature, I'm twenty-one, I'm an adult now, now it's just like, I'm much stronger to be able to deal with it, I mean if I'd spoke to you two years ago I wouldn't have been able to talk without crying.....

Adult female 15:21

A small number speculated that they were able to cope better with cancer-related fertility matters because they were older at diagnosis. One female who was nineteen at diagnosis (and twenty-one at interview) had been well travelled prior to diagnosis and felt that she had fitted a lot into her life. She thought that this contributed to her ability to feel more relaxed about coping with possible infertility (and she considered it highly likely that she was infertile) although she also talked at times of her strong desire to become a parent one day. However, this contrasted with some who were younger at diagnosis and thought that it would have been more difficult to handle if they had been older. This group also anticipated that it would become *more* of a problem for them as they got older and entered a stage in their lives when it was more 'normal' for them to think actively about parenthood.

Several in both genders had been very keen on sports before diagnosis. Indeed some thought that it might have been sporting injuries that led to them developing cancer. For most, if not all, their sense of self was very much caught up with their sporting identity and their recovery involved them having to develop an identity in which sport was less prominent. For example, two adult males had held promising rugby careers and this was an important part of their identity and lifestyle. One described the changes that cancer brought about for him:

I'd gone from being like first team rugby player to being, barely could walk or was really fat and could barely walk. And so I was just very angry at everything.... and then that [fertility] came along and it was something else to be angry at I think, something else to go and cry in my room about when I was younger.....It [cancer] never really hit me until afterwards, right. .... And all my rugby playing friends just made me think of that [*what he'd lost in terms of time and friends – my insert*] more I guess, so I just kind of lost touch with them all .... I was 'cancer boy' do you know what I mean? I was just the guy who turned up with no hair every so often and didn't have to wear a uniform and things, and I just didn't want to go back to that school.

Adult male 13:21

Like others with a sporting history, this young man had to work out a way of adapting and feeling good within a changed self identity. In the end, he opted to change schools, develop

new friendships and pursue academic studies. Although there were occasions when he remembered being highly distressed about his possible fertility impairment, his primary concern was to minimise the differences between himself and peers as part of re-entering 'normal life'. This resulted in him repressing his feelings about either cancer or fertility when they arose.

'Normality' could therefore become different after cancer and although this group were engaged in *active recovery of 'normality'*, some took a while to redefine what it now meant to them.

Physical appearance, making relationships and gaining sexual experience (or at least giving the appearance of doing) were cited as key aspects of being seen as 'normal' by both genders.

Two females praised their surgeons for taking care about resulting scars and assumed they had done so because of their youth and, by inference, their 'need' to retain 'normal' sexual attractiveness. For those whose reproductive organs had been at threat, efforts to retain as much of them as possible were also praised. Hope of retention of 'healthy and normal' fertility and sexuality, even if slight, appeared to act as a buffer against fertility concerns:

Had they taken everything out I think I'd have been a bit devastated now when I was thinking about it. Cos at least I know now there is a possibility and as long as there's a little bit of hope there then it's always got to be better than everything being gone and you not knowing. It'd be horrible. So I'm very grateful that they battled to save my fertility .....

Teenage female 18:20

For some of the males, the buffer of hope of achieving 'normal', i.e. biological, parenthood was provided through sperm banking. Those who had banked their sperm and had good quality samples (i.e. mainly the teenage males) reported limited preoccupation with the desire to be a parent on the whole, even where it was conscious and strong pre-diagnosis:

Well I've always wanted a family from when I was young. So it [sperm banking] was a natural thing cos I love me family and being with my family all the time. And having brothers and sisters I thought was the greatest thing. .... So hopefully I will be able to do it naturally but if not then, I'll

have to use the frozen sperm ..... before I knew [I could bank sperm] it [concern about fertility impairment] was like really, really high. ... I was really worried about that. .... but once they said I could bank sperm then it was really low and it was at the back of my mind and I was really calm about it after that. ...

Teenage male 18:19

Even for those who did think about it, the overwhelming expectation seemed to be that any impairment would be temporary *and* that the back-up of banked sperm offered additional guarantees:

.... well it kind of dun't matter really because it might be saying there when I go this time 'Oh no, you can't have kids in proper way'. But it dun't matter cos like maybe in like a few years down line stuff might reproduce again and stuff. So it dun't really matter. There's always that chance of hope in't there?

Teenage male 15:18

Moves towards recovery of self esteem sometimes included taking the plunge into romantic relationships, albeit with some trepidation. One teenage female identified her feminine identity as having taken a battering during treatment (she was mistaken for a boy on several occasions). For her and others, romantic relationships provided an important source of affirmation of their attractiveness. This appeared to encourage a down-play in attention to fertility by some because of its potential to adversely affect that process (see later in this section and in Chapter Ten).

Perceptions of 'normality' also appeared to influence contraceptive use for some. Even some who considered themselves to be infertile continued to use contraception because of long held family and cultural messages about 'responsible' sex. The more variable use of contraception by others indicated a more complex approach informed in part by notions of 'normality'.

One of the males who was sure that he was infertile continued to use condoms until meeting his long term partner, having become sexually active shortly after treatment ended in his mid teens. His long term partner was the only one with whom he had shared his status. While initially justifying his earlier use of contraception on the grounds of sexually transmitted diseases' (STD) avoidance, with probing he added other reasons including: to allay any

anxiety on the part of female partners that may arise from him not using contraception; and to appear to be fertile and thereby maintain his privacy including when:

....a couple of occasions the condom split, and I must admit at the time it went through my mind that I had nothing to worry about, and I didn't pass that information on to the woman.

Adult male 15:30

Another adult male who was also sure he was infertile had become sexually active shortly after the end of treatment in his mid teens and expected his girlfriend at the time to use contraception. This led to the apparent confirmation of his infertility (at that time) in a way that threatened to invade his privacy. Unbeknown to him, his girlfriend had stopped taking the pill in the hope of getting pregnant; when he found out and confronted her, she challenged him in return about his fertility and the relationship ended. He then started using condoms but said in the interview (even with probing) that this was to avoid STD transmission only. He continued not to tell partners about his possible infertility until he too entered a permanent relationship at which time he stopped using contraception. Like the adult male above, there were hints of ambivalence in his behaviour around contraceptive use in these different contexts. This included the present time as he said that he did not want children yet (if at all) and had not undergone fertility analysis.

Yet another male employed a different approach to contraceptive use but again driven by a desire to act 'normally'. He described how acting in 'peer group' character (in his case by not using condoms) overrode fertility concerns as he grew up – i.e. age, gender and culture all played their part:

Like me other mate, [.....], he's one of me other best mates and he was exactly the same. He was exactly the same. .... I was young wan't I? Every lad's the same..... I was like one of them - if it happens, it happens.

Adult male 13:25

**In summary**, this 'active recovery' group saw themselves as 'in recovery' rather than through it but held the expectation that recovery of self esteem would come in time. The desire to recover through a return to 'normality' appeared to take precedence. This was regardless of whether or not they considered their fertility likely to have been affected and whether or not they held strong desires for future parenthood. While the impact of fertility concerns was not missing completely, it appeared constrained. Such an approach may not have been

uniformly effective over time and across contexts in keeping thoughts and feelings about fertility matters at bay but it appeared to work for much of the time and had the potential to act as a buffer to fertility-related anxiety or distress.

There had not been any major shift in this group in the relative significance of cancer and fertility. Fertility concerns were not (yet) holding back progress towards recovery from cancer. Participants were likely to see fertility as primarily about the physical ability to reproduce rather than about self esteem and identity. In keeping with the approach of many to 'live life now', there was little preoccupation with whether or not they might achieve a pregnancy when they chose to try, even though a number recognised that this might change in the future:

Yeah, you cannot read that far ahead. You might not need to go into them things as well, so. I mean I don't, it seems like I've thought about lots of different things when I'm talking about [it in the research interview], but in actual reality I don't really think about these things that often. It's not something that really bothers us much..... it doesn't keep us awake at night at all. I don't think it would. It's maybe later on in life as I say, it would keep us awake thinking I really want a child .....

Adult female 19:21

There was also a strong sense that *they had no control over fertility* whereas their 'active recovery' from cancer was underpinned by the belief that it was possible to exercise agency over other aspects of their life. Perhaps this too encouraged concentration on such active coping strategies.

#### ***Where active recovery from cancer was faltering***

There was a small number for whom the potential impact on fertility was a source of concern from the early days and others where its significance relative to cancer had shifted over time. Additionally, some who appeared to be in *active recovery* were starting to struggle because of the impact of possible or actual fertility impairment. These were drawn from both genders and age groups (though were more likely to be adults) and included some with a strong and conscious pre-diagnosis desire to parent as well as some who were passively pro-natalist. Common features included:

- apparent high risk, or in a few cases knowledge, of being affected (which may have changed over time) together with strong or growing desire to be a parent, often from pre-diagnosis;
- uncertainty surrounding fertility impairment that was proving difficult to handle;
- not in a permanent relationship or in a permanent relationship but not yet with the children that they desired.

Parenthood for many in this group was an important part of their past, present and anticipated future sense of self even though not all were at a stage that they wished to become parents. Some of those not yet in permanent relationships considered that fertility matters had contributed to that. Several felt positive about other aspects of their lives and identities.

Some who held strong and conscious desires to parent pre-diagnosis reported that concerns arising from the threat to this desire came to the fore at regular intervals from diagnosis onwards:

Cos like family and things, it's like the key stage of life in't it? So it's like, one of things, definitely, it's one of most important things in life to me.

Teenage male 14:16

I don't see myself without them. I don't want to be just me. .... No I just think there would be nothing better than holding your own wee baby. I just, you know, just born and.... Nothing could be better than that.

Adult female 20:23

For one of the teenage males who had failed to bank sperm and who had a strong desire to have children one day, there were early indications of it being troubling for him. He talked of looking at small children around him and wondering whether he would ever have one of his own.

An adult male who had banked sperm but understood it to be of poor quality had a strong, longstanding desire to be a father. He reported that fertility concerns carried much higher significance for him over time than did cancer and had delayed his full social and emotional recovery from early on. If anything, this was getting worse for him and impacting increasingly on his self esteem.

I think more than anything it [fertility] was probably the most important thing that was said to us during the treatment. That's the one that's stuck in my mind and that's the one that.. you know. Cos I mean physically I'm perfectly well... Touch wood...Perfectly healthy now. But that's the one thing that you know, the lasting effect, that will have probably the biggest impact in my life ..... I accept the fact that I've had cancer cos that doesn't. I don't resent it in any way. That is just something that has happened, you know. But this [fertility] is the one thing that really, you know, you think why? Why, Why me? .... And there's no answer to it.....this [fertility] is the thing that is constantly, you know, there and thereabouts.

Adult male 18:21

For him and others in this group, attempts to regain a sense of 'normality' and/or agency in their lives were affected adversely by the undertow that came with feeling that, unlike recovery from cancer, fertility was beyond their control. Unlike the first group, they had strong reactions to this perceived lack of control. The significance of the fertility threat relative to cancer had shifted (for some quickly, for others more slowly) and was experienced as a threat to their sense of self as well as to their life style and life opportunities. In other words, they saw fertility as more than the physical ability to reproduce. The tentacles of cancer were coming from the unexpected source of cancer-related fertility impairment and its potential long term consequences and this appeared greater than fear of relapse. One said:

I never thought I'd die or anything like that. I always thought, I always knew I'd get better. But the thing is, like at the time you think, 'Right once this is all past me that's it, it's behind me'. But it's dragged on, other things have dragged on all this time and for the rest of my life really. And like changed my life in all these ways, you know. And that's not only cos of my brain tumour it's cos of the treatment I had to fix it, you know what I mean, so.. .... that's the thing, you think 'It's all behind me now, it's all behind me'. But it's not, it just haunts you, you know.....

Adult female 16:24

One female talked of the daily reminder that came for her through taking hormone replacement therapy in the daunting knowledge that this would be necessary for years. Another, who was eleven years post diagnosis, talked of infertility as '.. the only stumbling

block that I have yet to overcome... not a day goes by without me thinking how much I long for a child'.

Some located their increased preoccupation with fertility in the fact that career and life planning might be affected by parenthood plans:

You keep thinking about it in another course. And this time it changes. It's not 'Can I or can I not?'. This time it's 'If I did have a child, will this career benefit that?'. And you don't think about 'Will I make enough money for me to go out drinking?'. My thought pattern and process was 'Will I have enough money to support a child if I had one in the future?'. Which is quite a grown-up way of thinking about it. *Interviewer*: So at different stages as you've been moving through it, there's been different thoughts that you've been having to process?  
*Teenage Female*: Yeh. It's like the same question; you just think of it in a different way.

Teenage female 15:20

Others reported changes in the way that they thought about romantic relationships as they got older (or anticipated that they would). In other words, they were thinking increasingly about relationships as a route to parenthood rather than as an end in themselves and therefore were contemplating what possible fertility impairment meant for that process (see also Chapter Ten).

Some identified the uncertainty surrounding their fertility status as slowing recovery. Not knowing what they were dealing with and hence not being able to develop appropriate coping strategies were mentioned by several in both age groups and genders:

I'd just like to know like 'How will it come back? Will it come back in a year or will it come back in another 20 odd years?'. I'd like to know like, certain, like date or something like that. It's like a guessing game really, knowing when it will come back and everything, but.....

Teenage male 15:17

For a few, the lack of certainty around fertility status added to uncertainty about whether their future would be free from cancer and left them feeling even more insecure.



Females appeared more affected than males by uncertainty. Males, on the whole, were coping with uncertainty about when any temporarily impaired function would return (i.e. very few worried about permanent impairment) but presumably experienced the outward appearance of 'normal' function through ejaculation<sup>7</sup>. Females, however, faced uncertainty about whether any temporary impairment would recover *and* were more likely to have disruption to their 'normal' function through altered menstrual cycles. Many faced possible premature menopause, pregnancy-related complications or heightened chances of recurrence of their cancer if they were to conceive. Additionally, none of the females had the back up of stored gametes.

Even those females who reported aspects of their lives that provided important aids to coping (such as permanent relationships, as discussed in Chapter Ten), also recounted deep seated fears and anxieties arising from uncertainty that held back their ability to 'move on':

I would maybe consider doing things like that [fertility treatments] if I knew there was no hope whatsoever. But I would definitely rather have kids, a child of my own, erm.. *pause*. ....I don't really know if I can [get pregnant] or I can't at the moment. If I knew a definite answer I could maybe. .... I would be able to make a lot more decisions ..... I feel as if there's no end to it. .... you're thinking I'll just try, see if my periods'll regulate and in the glimmer of hope that I will fall so, but I could be waiting years still.

Adult female 18:23

Some of those facing premature menopause talked of the pressure of feeling that failure to find a permanent relationship early enough – or accommodate bringing forward relationship or parenthood plans - would jeopardise their chances of motherhood. There were also varying levels of understanding among females about premature menopause itself. For example, one teenager had already been through the menopause (even though it was not predicted medically) but remained very unclear about what it was.

.....one doctor said that what had happened, said it was a premature menopause, which I kind of latched on to. Alarm bells went off in my head and I thought 'my God if I don't take the pill, I'll turn into an old woman, what's going to happen to me'. But then another one, another doctor, called it, you know, premature egg failure. Even now I'm sat here, I don't know what it is, I

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<sup>7</sup> Only one male said that he was not ejaculating; although others did not mention ejaculation, it is likely that some at least would have done if they were experiencing difficulties.

don't know if it's the same thing, or whether when they say premature menopause, it's actually like the menopause my mother's going through.

Teenage female 13:19

One of those facing a premature menopause appeared to have been in 'active recovery' in the early years after treatment ended and had enjoyed a full social and romantic life. That had changed more recently and her 'active recovery' had faltered as the likelihood of fertility impairment appeared stronger.

Linked to premature menopause was the impact of the use of hormone replacement therapy (HRT). Only females talked of using HRT and, again, there was evidence of both factual uncertainty as well as of effect on recovery. One illustrated the confusion that some felt about the health implications of life-time use:

I take the [HRT] pill every day religiously, and every time I open the new box, there's always the leaflet with the graph about breast cancer and things, and I look at it and think 'I started taking that when I was about fourteen, fifteen and I'm going to be taking it until I'm nearly fifty', you know. No-one's ever said whether it puts me at any risk, it's never been brought up. And then I think to myself 'If there is a risk and I stop taking it what will happen to me then?'. I mean no one's said 'If you don't take the pill, this is what will happen'.

Teenage female 13:19

Another talked about the strain on her relationship with her fiancé of not being able to use the contraceptive pill, not knowing whether or not she was fertile (and fearing that this would never become clear), and being afraid of getting pregnant in case this triggered a relapse of her cancer. It also reinforced her feeling of being 'different' to her peers as, unlike most of her female friends, she could not use the contraceptive pill:

We still have to use protection even though I might not – there might be no chance that I can even get pregnant. .... I always worry about it. .... Even though there might never be a chance. What if I get pregnant by accident? It's like my worst fear. .... And if I come off these pills [HRT] and discover that my ovary doesn't work, I have to go back on the pills, I'd still have it in the back of my mind that there's a chance that I could get pregnant and I will never take it as being able to be positive that I'm

infertile. .... It's like I could sleep with [fiancé], I'd sleep with him without any protection and then I'd just worry for the next three months until there wasn't a bump growing that I was pregnant. I would just be obsessed with it.

Teenage female 18:20

A small number whose active recovery appeared to be in jeopardy were resentful of having had cancer either at the time or currently. A similarly small number felt that their personality had changed for the 'worse'. Their concerns about fertility impairment were part of their general disquiet and they could therefore be seen as struggling on both fronts. For example, one teenage male was still in the early stages of picking up his life again and reflected how much more difficult this was as a result of his worries about his fertility and his sexual performance being affected:

You feel like you're under a barrier and it's just awful. Sometimes you just really lose it. .... I never used to show.... like how upset I wa', I used to keep it inside and like in hospital I was trying to be calm and things but it just wan't, it were just awful. .... it's made me short tempered and I can't think properly some times, and I don't feel, I feel right weird now. I don't feel right and things. I think it's sort of messed my life up a bit, and the way I think about things. It's just, it's not really, but I try, I'm trying.. .... I think it's still quite a long time to go before I actually feel better.

Teenage male 14:16

As with the 'active recovery' group, there were also indicators of the importance of retaining hope of achieving biological parenthood. The emotional need to keep a window open that all may yet turn out well was clear even for those that believed intellectually that they were infertile. This was aided where significant others – parents, partners - voiced that hope as well:

So my Mum I think lives in hope that one day I'm going to ring her up and say 'Oh by the way Mum I'm pregnant'. And I suppose when she told me that, I clung on to that and always at the back of my mind is 'Well it might not be true, you know, they were wrong about the fact my fertility wouldn't be affected, they could just as easily be wrong about the fact that it has been affected'. But then, you know, I say to myself 'Don't be stupid', so....

Teenage female 13:19

**In summary**, those in this group were starting to find that their approach to recovery was being affected adversely by not being able to find a way of acting 'normally' or feeling 'normal' around fertility matters. These participants were more likely to see fertility as influencing self esteem, identity and relationships than as being (only) about the physical ability to reproduce. They were also more likely to be finding their apparent lack of control over fertility matters threatening to their well-being.

### ***Where active recovery was affected by impairments or health matters***

Several participants were dealing with residual impairments, ongoing close health monitoring or active investigations and treatments. For some, this appeared to affect, or be affected by, their self esteem, their return to mainstream activities and/or their approach to life planning, including parenthood. Some also talked about the ways in which this influenced the impact of fertility.

Physical and cognitive impairments and ongoing challenges were plentiful. More females were affected than males (ten females and five males, one of whom had two types of impairment) with the distribution by age being fairly even (seven teenagers and eight adults).

- Two had concentration difficulties, short term memory loss and some loss of cognitive function.
- Six had either artificial joints or limb amputations leading to some mobility impairments.
- Four continued to be monitored very closely and had a number of complications that had already required further interventions and were likely to require more yet.
- Two were left with significant hair loss.
- Two talked of having significantly low stamina several years on.

Many of the associated difficulties were tangible, visible and required active self management whereas very few knew with such clarity whether or not their fertility (which was invisible) had been affected.

For many, the contemporary threat posed by their physical condition and its impact was experienced as greater than the impact of possible infertility. For others, the two were intertwined. For example, one was coping with significant headaches and hair loss many years on. She reported that the visible effect of hair loss added to the invisible impact of

probable infertility to reinforce her sense of impaired attractiveness both physically and as a possible permanent romantic partner.

For some females, physical after-effects rather than concerns about fertility impairment impacted on their views about pregnancy and/or parenthood. One teenager who had a strong desire to become a parent in the future was anxious about getting pregnant as her ongoing health problems were associated with her menstrual cycle, her digestion and her bowels. Not only was she fearful of a physically difficult pregnancy but she also anticipated that she may become depressed:

I just worry now that if I was to have a child; it frightens me to get pregnant in case I take it the wrong way. Then rather than somebody who went through a nice pregnancy, I'd probably go through depression and all that. I can imagine it would take its toll, so. That's what frightens me.....

Teenage female 17:20

Two adult females had similar anxieties. For example, one had continuous pain, ongoing treatment, limited mobility and dexterity and was facing further medical interventions. She considered herself too disabled to contemplate becoming a parent in the foreseeable future as she was not able to live independently and needed a lot of practical and emotional support:

.....maybe if my situation were different, maybe it [fertility] would be more important, but at this moment in time all I want to do is try to get myself right. And be able to eat and drink again. ...

Adult female 18:25

Unlike some who felt ambivalent about the use of contraception (see earlier), she saw its availability as allowing her to enjoy a sex life. However for those whose physical complications were leading to a delay in being able to try actively to conceive, the use of contraception represented a double edged sword.

Another adult female had a part-amputated limb. She was not concerned about managing a pregnancy but had revised her earlier desire to have children as she felt that she could no longer be the sort of physically active parent that she admired and had previously expected to be (she was one of those referred to earlier who had held a strong sporting identity). She too was aware that she may need further medical interventions:

I think it may be unfair to bring up a child when I cannot run around with them and things like that. I mean I have thought that, I wouldn't want to stop a child from having a normal happy relationship with parents; I mean I know there are plenty of people who manage as good parents with disabilities. But when I was younger I saw myself as someone who would run around for the rest of their life doing all sorts of stuff ..... I don't know if it would be fair considering the raising that I've had and the running around, playing football with me brothers and everything, everything like that. .... there's potentially a lot of operations ahead in me life, if not a lot then there's going to be the loss of a leg at some point I would imagine. So it's, when I'm getting into a serious relationship, whoever this person in question, the bloke, that I find, they're gonna have to deal with a lot.....

Adult female 19:21

None of the males in this group expressed concerns about the impact of their physical condition on either coping with a partner's pregnancy or with becoming a parent. Each was more preoccupied with other matters including finding a job and managing academic work.

Some participants described the reality of struggling with the disabling effect of other people's reaction to their acquired physical impairments, especially where these were visible. One described the impact this had on their sense of self and attractiveness:

I do get paranoid, well like wi' this, wi' people, people looking and looking away. I don't mind like just out of curiosity. But it's them that carry on staring I can't do with..... Wi' that one I do get really offended by it....

Adult female 18:25

However, other participants felt they were making progress in coping with the impact of physical impairments and therefore felt more in control of this than they did of fertility impairment. Indeed, one felt that her popularity and hence her confidence grew as a result of becoming 'of interest' when she started going out socially without her false leg.

**In summary,** for some who were coping with residual physical impairments, the associated demands pushed away any fertility concerns in their immediate lives and in any contemplation of pregnancy and parenthood. None referred directly to physical impairments affecting their 'attractiveness' as a romantic partner but there was evidence of this when

combined with fertility impairment. As with the other groups, the extent to which participants felt that they had some control over managing their impairments was an important mediator of any adverse impact on self esteem. Where this was evident, it was more likely to be in relation to physical impairment than fertility impairment.

### ***Where recovery from cancer appeared to have been achieved***

It became clear that there were some who felt that they had, by and large, achieved a satisfactory recovery from their cancer experience, including fertility aspects. This included two adult males who reported that it had little ongoing impact in their lives. That is not to say that they never thought about their experience or that they considered it to have had no lasting impact, but rather that they did not need to expend emotional energy on dealing with it. They had both considered themselves to be infertile (though one has since gone on to be a father); one had had a negative fertility test. Each described their reactions to both cancer and fertility impairment as being located in their laid back personality, which both felt predated their cancer experience and was, if anything reinforced by it.

One of the adult females who had had a second cancer also felt that the cancer (and fertility) experience was now no longer holding her back. She had been through times when the impact of possible infertility had felt overwhelming and saw the surrounding uncertainty to have been a key influence at that time:

.... it was the uncertainty, it was the not knowing that if I was or if I wasn't [fertile]. Were me periods going to start again, was I infertile and.. it was the one thing that I possibly might not be able to do and it was the first thing that I might not be able to do since with everything I'd gone through and I didn't like it.....

Adult female 19:25

Despite the fact that she had a long standing wish to be a parent from before diagnosis and believed herself to be infertile, she had come to accommodate the latter. She felt that her survival (twice) had shifted her outlook on life. She was determined to 'live for the day' as a childfree woman ('I want to be me for a bit') in the belief that, if she were not able to have biological children eventually then she would feel comfortable and confident at adopting children. In other words, she had not changed her desire to be a parent but had delayed the time in her life when she wanted to fulfil that desire and had opened up other acceptable

scenarios through realising that parenthood per se was more important to her than biological parenthood.

As reported already, retention of hope of biological parenthood, no matter how slight, appeared to contribute to recovery from cancer. One adult male who felt himself by the interview to have 'recovered' from cancer had been devastated to be told when younger that he was infertile (even though he had not undergone testing). He felt strongly that he would have found it easier to cope if he had been told that it was highly likely but not one hundred percent certain – an approach that marked his more recent (and more helpful) medical consultations:

Factually, there's a possibility, it's not definite but there's a possibility that I will be infertile.....it's a high percentage, but then that's, you know, there's still a small percentage that I would be able to. So I'll sort of cling on that as long as I can until it becomes necessary. ....That's how I would probably have preferred to have heard it.....that someone said 'It's not definite, it's a possibility that you will have them but it's a strong probability that you won't' .... which is very, very different..

Adult male 13:28

Some of the others who felt recovery from cancer had been achieved continued to find fertility aspects difficult and draining. Many across all age groups and genders were positive about the cancer experience itself, including among those where active recovery was ongoing. Effects were described variously as having made them more resilient, outgoing, confident, compassionate or better people and/or that it had made them 'grow up'. Some talked about the personal strength that came out of the experience for them – including seeing themselves as someone who had coped with the major adversity of *cancer* and survived and could therefore face the future with confidence:

And I think I've got a lot more confidence since I've had cancer. It's a bit strange but every cloud has a silver lining.

Teenage male 18:19

I think that was the determination and the desire to achieve things that had come out of having cancer. The determination to, to make it happen.....And so in some ways, yes I'm glad I had cancer. You know it



sounds bizarre, a bizarre thing to say you know, it prepared me with a lot more worldly experiences than I probably would have got..erm, certainly a different view on life. And, er, it forced me to grow up.

Adult male 15:26

A move towards being more reflective as well as resilient was described by some. This included one adult female who had come to realise that life was not necessarily fair but now 'knew' that she could handle whatever was to come:

It's probably made me grow up as well, but not too much either, just grown up in a way that like you have to accept that you can't really get everything you want, but then that kind of makes you think well you can get through things and whatever you do want you have to work at it, I dunno, it's kind of made me grow up in a way, but like it's made me strong as well, so like if I have to cope with other things in my life, well I can get through that as well....

Adult female 15:21

There were, not surprisingly, variations in the intensity of preoccupation about fertility matters over time and context reflecting the potentially dynamic nature of the threat. For example, the adult male who had been told when younger that he was one hundred per cent infertile had not (yet) become a father and harboured a strong desire to do so. He talked of having been through peaks and troughs of coping for which he had drawn on a range of strategies. He saw his current calm state as resulting in part from emotional and social maturity but also from having had two serious relationships that survived disclosure of his probable infertility – i.e. he gained the knowledge that relationships (and he) might be able to cope with open discussion. Although more relaxed about it at the time of the interview, he did not underestimate the significance to him of fatherhood or deny the possibility that it would get worse again, especially as his peers were starting to have children:

I think that every stage of your life is different. I think now I'm in a stage where my career path is pretty much set, whereas I think I went away to school then I went away to university, and then I worked in a job, had a change of career, did a different degree and then down this path. And I think that each, you know at school the most important thing is, you know, making the team or whatever it is, or the school heartthrob, you've got different priorities. And then at university you've got your mates, you're out on the beer and having fun and then... but now ... and so at each stage you do have

different concerns and different things are important. And I think now I've got my house, I've got my job, it's a long term job, well it's a career path to head down, so I'm sort of set up in much of my life. The only thing that's really missing is a family, or not having a family now, but having the root of the family seat. And I think that's.. *pause*.. something that will become more and more of an issue.

Adult male 13:28

There were parallels with the experience of another adult male. He reported the threat to fertility as very low immediately prior to diagnosis, rising dramatically in importance once the danger was pointed out, reducing once his sperm was banked and then lingering until the unexpected arrival of a child in his early 20s eliminated the threat almost completely. He nevertheless opted for his partner to be sterilised rather than him once they decided that their family was complete.

None of those who made positive comments about cancer survival offered similarly positive comments about dealing with potential or actual fertility impairment. In contrast, a number referred to the stigma of fertility impairment making a difference to how they saw themselves or how they perceived that others might see them. Additionally, although there was some political awareness of the stigmatising and distorting influence of media portrayal around cancer, this too did not extend to (in)fertility. A number talked of the 'false' portrayal of cancer treatment that made its harshness more invisible than they thought it should be:

I had a problem with the hair loss, not for myself but the advert, the Cancer Research advert, when they had that little girl on and she's got hair. It really gets to us because there's not - when I've been on this ward there's not been one child that hasn't lost their hair. And I hate how they had that advert ... I think they should have it changed to the way it is because it's sugar coating it for people, and it shouldn't be.

Adult female 19:21

Others were angered at media coverage of childhood cancer patients as being 'poor angels', 'brave' or 'fighters' – i.e. worthy of sympathy through being seen as victims. The only references to media coverage of fertility matters were of 'positive' images of adults 'fighting' cancer and using fertility preservation services as part of that 'fight' (the pop star Kylie

Minogue) or of those who had 'overcome' their infertility through successful fertility treatment such as the man cited earlier who had successfully fathered a child using stored sperm.

Thus, some reported seeing themselves as 'damaged goods' when they talked of their feelings about infertility even when they felt good about themselves as cancer survivors:

I suppose it makes you feel a bit like you're [i.e. a possible boyfriend] not really getting a full package I suppose. I don't know what way to kind of describe it really. You feel a little bit like faulty goods I suppose; you're not quite how it should be, erm, you can't offer everything that maybe somebody else can.

Adult female 14:25

**In summary**, there were many participants who reported a later rise in self esteem and self efficacy resulting from their cancer experience. Some felt that, by and large, they had completed their recovery from cancer. None talked of raised self esteem or self efficacy arising from their experience of, or recovery from, fertility aspects. Regardless of whether or not they knew if they had suffered fertility impairment, many (but not all) had immediate and/or anticipated concerns. It was of note that politicised awareness of the impact of the public portrayal of cancer did not appear to extend to infertility even though there was awareness of its perceived stigma.

This leads into consideration of the way that identities can be constructed or influenced within the social world that we inhabit. Social constructions have an effect on the way that individuals see themselves, depending on the level of exposure to such influences and their and their carers' ability to accept or reject such influences and so on. The next section therefore looks further at some social influences on self esteem and identity in order to try and add further pieces to the developing jigsaw.

## **Social Identity**

### ***Ethnic and cultural norms***

Some participants were aware of how their views about the desirability of parenthood had been influenced by the wider social milieu and the accompanying internalisation of such messages:

Basically I can't see us without kids and stuff like that, so. It's just the way we've been brought up, just the way you are, it's just the way you feel inside.....

Teenage female 15:20

Others spoke of 'rules' or 'norms' about the age and/or circumstances in which they were expected to have children and the influence of this on managing cancer-related fertility matters:

But it seems that that would be the normal thing to do - get married, have house, have kids, have car, have a job, the normal nuclear family or whatever it is. But I just kind of assumed I would have children, but I never really thought that much of it. I thought I'll take it as it comes.

Adult female 19:21

Even for those who were not contemplating parenthood in the foreseeable future, some were worried that such 'social rules' might push them to leave it 'too late' especially if they were at risk of having a premature menopause:

His mam and dad only had him and his mam and dad brought him up in the best way that he loves to have children but he is not daft in the way that he wants children now, he wants them when he is 25. But that worries me. Would that be too late for me? That's the only thing that ever goes through me mind with what happened. Would I go through the changes a lot quicker than somebody normal or...? That's the only thing that worries me. What would be the appropriate age, you know, to do it, before worrying about whether it's gonna be took away, you know, completely, so....

Teenage female 17:20

For some others (all adults), expectations came from cultural and/or religious beliefs. Four participants came from families comprised wholly or partly of members of a non-White British culture. It was only these participants that made explicit reference to their ethnicity or culture in the interviews. One had an Anglo-mainland European heritage which incorporated a strong family culture and clear beliefs about patterns of child rearing and the importance of having children. However his parents appeared able to tolerate the possible non-realisation of those beliefs (after preliminary difficulties when he refused to bank sperm). They adapted

their approach and enabled their son to move through to adulthood without feeling affected adversely by his probable infertility. As he has since had children (to his parents' great delight) and at an earlier age than most of his peers, he can only speculate about whether or not the underlying cultural beliefs would have become more of an adverse influence on his well-being if he had continued childless for much longer (see also Chapter Eight).

The other with an Anglo-mainland European heritage felt that this was of significance in other family-related matters but not in fertility issues.

The two adults from an Asian background had both similarities and differences in their views. While both acknowledged the strong expectation in their communities that adults should marry and have children, both also felt that their probable inability to have children could be accommodated by themselves, their immediate families and some members of their communities. The female thought that the expectation to marry and have children was especially strong for women in her community. Both were prepared to consider having arranged marriages although the female thought that her possible fertility impairment was likely to prove a barrier to this. The male anticipated that his wife would come from within his extended family and that his cancer history would therefore not prove to be a barrier. He had not thought about the likely impact of his fertility impairment (and he had refused to bank his sperm on religious grounds). The female was concerned about the impact of her possible fertility impairment on any relationship as she felt that Asian males would, on the whole, find it difficult to cope with either a childless marriage or with using egg donation as a route to parenthood:

And a lot of Asian boys and young men and stuff, they're really old fashioned in the way they like 'If you can't give me any kids I don't really want anything to do with you'. It is kind of like that, a lot of Asian men are like 'I only want my kids, my blood'. So they wouldn't really accept other things and obviously you've got to take other things into consideration....

Adult female 15:21

Both drew on their shared religious beliefs (one was Hindu, one Muslim) to inform their approach to managing the impact on themselves. Each believed that children were a 'gift from God' and that they should be prepared to accept their fate as determined by this higher order:

... like we believe in fate, like our religion we believe in fate so, the gods write something for you already, so everything's already written out for you and obviously whatever you do does change that in a way. Like every decision we make kind of alters the course, but really everything in the future is written out for you because it's going to happen. So basically I can't change my fate, so if I wasn't meant to have kids I wasn't meant to have kids. It's just the way it happens isn't it?

Adult female 15:21

The female had found this difficult to accept when younger but was increasingly comforted by these beliefs as she got older (though was still not at the stage of entering a permanent relationship or coping with the onset of peers having children). The male also had significant physical after effects to cope with which reduced the importance to him of having children. While he had experience of other adults within his family and community being childless (though he did not know the reasons why) and appearing to be happy, the female did not. The presence of these 'role models' appeared helpful for the male.

### ***Sexual orientation***

Only two females identified themselves as lesbian at interview and none of the males said they were gay. One of the females had a partner and they had already discussed the fact that her partner may need to carry a pregnancy.

Both participants' sexual orientation had become clearer following their treatment so they had been negotiating that alongside everything else. One had a strong desire to parent *and* had believed that she would not be able to access fertility treatment as a lesbian. She had engaged in a series of heterosexual relationships in the hope of getting pregnant. It was not until she accepted that this was not going to prove successful *and* learned that treatments might be available for lesbians that she felt free to explore her sexual orientation.

### ***Gender***

There were fairly high numbers of participants in all four groups that referred to gender as a possible influence on their experience of coping with cancer-related fertility matters, though more females than males.

The majority of females and males talked of the importance of knowing from diagnosis onwards that their fertility may be affected, regardless of the degree of risk, level of incapacity and availability of fertility preservation. A number indicated the importance of being informed both as a source of empowerment and in order to start developing coping strategies. Several females cited the possible negative impact on themselves and their trust in professional carers if information was withheld, delivered later or discovered inadvertently:

I would wanna know regardless. I think there would be a lot of angry and upset girls if they weren't told from day one. That yes it's not a very nice thing to hear, and yes you've got a lot going through your mind at the time and the last thing you need is to be told is there's a chance you could be infertile at the end of it ... it's better than not being told ..... And I don't think it's fair, that yes it's a big thing for you to think about and stuff, but if the boys get told why don't the girls?

Adult female 19:25

This was true even for those who appeared withdrawn, but who were often absorbing much of what was said:

I just didn't want to know anything. But I think that's when they telled us that I couldn't have kids..... But like now I'm glad that they telled us then, cos I don't think I could have .. coped with it now, like getting told now, once everything's over. I'd rather get told at the start, even though like it's hard to take everything in when you first get diagnosed, like you just sit and think about everything, you know like you're glad you get told at the start rather than waiting and you're like 'why haven't you told us sooner?' you know, so..... but I am glad that she telt us in that way because it would have upset us more, cos not getting told, I just wouldn't like that.

Teenage female 15:16

There was unease among some females about the gender disparity in the availability of fertility preservation. This applied even when they understood that the explanation was biological and scientific rather than social – i.e. that it was not due to gender discrimination. Some would have liked an explanation at diagnosis about why egg freezing was not on offer to offset the potential distress of finding out about such services at a later date.

Even males who were unsuccessful at banking or who turned down the offer reported some associated well-being. Those who had banked successfully and whose samples were of good quality were likely to refer to the reassurance this afforded them as reported earlier. In contrast the small number of females who were offered the service and refused were more likely to report later periodic preoccupation with their decision.

Most males and females achieved generally good levels of understanding about fertility matters at around diagnosis (see Chapter Four). By interview, this had fallen to only about half feeling satisfied with the level of information and comprehension. This was especially true for females and appeared to relate in part to differences in the type and complexity of information required by them. Males appeared to have little need to understand how their body produced live sperm whereas females needed to understand how their menstrual cycle related to their reproductive system. Where this was not achieved, poor understanding of later formal and informal discussions and adverse impact appeared heightened:

... I think she [ACU consultant] just sort of like said, I think, my eggs are ovulating and things like that, so things are working but I'm having lots of problems with my periods, so I'm just bleeding constantly, I can bleed for like twelve weeks at a time. And have a couple of days break and bleed for another ten weeks. So from that point of view I don't think I would be able to have kids at the moment anyway, because of the bleeding, until that sorts itself out. But I couldn't really tell you anything else about my chances or anything cos I don't really know myself.

Adult female 18:23

A number of females saw their periods - either their return to 'normal' or their irregularity – as positive or negative indicators of their response to their cancer and its treatment rather than as indicators of fertility. A small number had not associated their menstrual cycle with their reproductive system at all. For example, one teenager only realised when looking back that questions asked of her at follow up appointments were about reproductive function and thought this should have been made clearer:

Every time I went they would always say, you know, 'how are your periods?', because apparently for a lot of girls, they stop during chemotherapy anyway, but mine never did. It was often commented on 'oh, you know that that's a good sign', and I always used to think that a good sign meant that the chemo was doing what it was meant to, instead of interrupting everything else.....



One adult male explored the impact on his sense of male self since becoming aware that he was probably infertile in his mid teens and growing through to adulthood. He reflected on the preferred status of males as fertile and virile (with the two often being entwined) and on the socially respected state of fatherhood. As a teenager, he considered his male identity to be less secure than when he got older. This was manifest through his fear that he would be 'found out' in his 'sub-masculine' state and labelled as lacking virility and sexual prowess. As he got older, he felt better able to incorporate a (male) parenting dimension as provider and protector to his male identity. He and others went on to consider how far the differences in reactions to cancer and to (in)fertility were gender based:

: .... it goes back to the virility thing I think, and the essence of manliness. I think if you start talking about fertility, that's a much more personal, because it's a much more personal topic, in some respects. Having cancer doesn't mean anything particularly to people. It's a disease, don't know much about it, don't know what part of your body it affected and if you start going into detail about body parts people are probably slightly less interested, not less interested but people aren't as concerned. It's a category whereas if you start talking about fertility, we're into the embarrassing subject erm of.. well, it's a very personal thing. I mean it is a very personal thing, and as soon as you start on about reproduction, fertility, manliness again, it's all awkward for everyone. And because a lot of guys do have hang ups about it, I think it makes them feel uncomfortable.

Adult male 13:28

Another adult male talked of maleness in a different way. He saw fertility analysis as holding the potential to enable him to find out if he was a 'real man'. Several females also talked of fertility impairment as threatening their sense of femaleness or womanliness with regard both to romantic relationships and motherhood:

.....like obviously women are, you know, they're made to have kids and...*sighs*. yeah, you, it's, I don't know, it's just odd, it's just odd. .... you almost feel like less of a woman or something,. *pause*. .... I can't really describe it...*pause*... .... You just don't feel like you're all there or something, do you know what I mean? Because you know, I don't know. Like

obviously I get periods and stuff but they're not real, they're fake do you know what I mean? And it's like I don't know, it's just odd I suppose.

Adult female 16:24

One adult female was surprised to learn that males were included in the study and that some had expressed distress as a result of potential infertility. She had assumed that only females would be so affected. She found it comforting to hear of this and said that it shifted her expectations of future relationships somewhat. One of the teenagers unpacked this a little further when she explored its impact on sex and relationships and speculated that males and females may both be affected but differently (though she still drew on gender stereotypes):

But I do think that women would feel totally unattractive that they couldn't have sex, or they'd lose confidence. And that it'd totally break their relationship and it would be worse the fact that they would probably end up fighting. And it would make the girl feel worse because she would think that it was all her fault why he was being the way he was. I think it would be a big problem. But I think it's the same for men as well. Because what would it be like for a man to say that he couldn't give you a child, you know what I mean. They'd see it worse because they'd think women always need children, you know.

Teenage female 17:20

Several females considered that males were less well able to cope with fertility difficulties than females but saw this as located primarily in their lower emotional literacy.

### **Fertile identity**

Some participants referred to *feeling or believing* themselves to be fertile or not. Findings were therefore analysed to see how far categorisation of what I have called 'fertile identity' might contribute to an understanding of how such views were formed or informed and how fertility impairment might be experienced.

Responses in which participants referred to whether or not they considered themselves to be fertile were categorised as follows:

- *Impaired* – where participants saw themselves as almost certainly infertile.

- *Uncertain* - where participants saw themselves primarily as unsure whether or not their fertility had been affected.
- *Fertile* - where participants saw themselves as almost certainly fertile.

Adult males were fairly evenly distributed across the categories (note that two of the three that had a 'fertile' identity were parents).

Only two of the twelve adult females appeared to hold a 'fertile' identity (both of whom were parents); the rest were evenly distributed between the other two groups.

Only two teenage females held an 'impaired' fertile identity with the bulk of the remainder appearing to feel 'uncertain' (including one who was a parent).

Only one teenage male appeared to see himself as having an 'impaired' fertile identity, two saw themselves as 'fertile' and the remainder were 'uncertain'.

There were no indications that any participants had seen themselves as holding an 'impaired' or 'uncertain' fertile identity prior to diagnosis. Neither did the level of pre-diagnosis desire to parent appear to indicate the category of fertile identity held at interview. Although factual knowledge seemed to affect, or be affected by, the impact experienced, this was not always in the way one might anticipate. For example, some participants had understood from their doctors that the threat to their fertility was low and yet thought that they were affected. For others, the opposite was true. For example, one young woman had been told that she was at high risk (75%) of infertility but thought that she might be one of the 'fortunate' few. Two others who had received new types of treatment with relatively unknown consequences for fertility assumed that they *would* be affected. One said that she had been told that she was at low risk and later said that she had been told that the level of risk was unknown. The same was true among some of the males. In other words, there were differences in the way that information about 'risk' was interpreted, especially that provided by professionals.

Many male and female participants lived with factual uncertainty about the impact of the cancer and treatment on their fertility from diagnosis onwards while others became more uncertain. Uncertainty appeared to have some effect on understanding and use of contraception, HRT and parenthood planning as well as on self esteem and recovery, as described above. It also appeared to affect fertile identity. Eight females (3 teenagers and 5 adults) were aware that they were at risk of a premature menopause; in some, but not all,

cases this augmented information that they had been given at around the time of diagnosis. All appeared to have incorporated this into their fertile identity in that they identified themselves either as having an 'impaired' or 'uncertain' fertile identity with none seeing themselves as 'fertile'.

Some participants of both genders had acquired new information to indicate a change to their apparent fertility status. The effect of new information worked both ways. Some who had previously thought that they were likely to have been affected were surprised to learn that this was not necessarily the case (including some who had found out by becoming parents) and vice versa.

A change to a 'fertile' fertile identity from either of the other two categories appeared more difficult to make than the other way round. For example, one adult female remained unconvinced that she was fertile despite medical advice and her body's functioning suggesting that she was:

... obviously my periods stopped when I was having me chemo, er, and for a long time they stopped afterwards, and it was a major concern and I spoke to [consultant paediatric oncologist] about it on a few occasions, cos I'd, I'd convinced myself I was infertile..... And it was two year before I had my first period. By this point I'd totally convinced myself that I was infertile ..... I still had it in my head that I was infertile. ....I was really happy when it [periods] started again. .... That doubt's still in me head that although yes my periods are going, you know that still doesn't mean, I might have always been infertile, so that I've still got that doubt in me head that I could still be infertile.

Adult female 19:25

Another female learnt through attendance at a conference that the risk to her fertility might not be as high as she assumed yet remained sure that she was infertile:

.... you automatically assume that with cancer you cannot have kids straight away. You just assume, you don't think that you can have them anymore. You think it's not right and, I mean it's proven wrong at the thing [meaning the conference]. I mean he did say that, but ...., to this day I still think I'll be one of the ones that cannot have it because of the way me body's reacted afterwards. It's took a long time for it to get back to normal and functioning

normal, or what is as normal as it can do without the limp and everything.....I've just always assumed that I won't be able to have them.

Adult female 19:21

That said, the presence of an 'impaired' or 'uncertain' fertile identity did not appear to trigger universal reactions and this adds to findings reported earlier around recovery. Many, but not all, holding an 'impaired' fertile identity indicated that this was a source of distress or preoccupation. Many reported using strategies to distance themselves from that identity in order to reduce stress. However a few reported little adverse reaction and offered various explanations. Some could contemplate alternative routes to forming a family so did not assume that parenthood was denied to them. Some had, as yet, a low desire to parent. Some considered other aspects of their lives to be more important.

The same was true amongst those with an apparently 'uncertain' fertile identity. Some who had adverse reactions felt that greater certainty one way or the other would ease matters. Others were fearful of this leading to confirmation of infertility and preferred to live with uncertainty. Those who reported little distress included some who saw fertility as of little immediate relevance and/or something that they could do little about, especially until the level of impairment became clearer:

I hardly think about it now.... I don't want to find out now if I am fertile because if I am not fertile it will plague me for the rest of my life..... I don't want to have the uncalled-for worry; it doesn't help me at all. If I am infertile and I find out now, it would mean years of upset looking at children whereas now I can enjoy life ...

Adult male 16:21

Those appearing to hold a 'fertile' fertile identity seemed the least likely to be distressed or preoccupied.

Thus, there appeared to be differences in the route through which participants arrived at their 'fertile identity' and the ways in which they dealt with any perceived threat to their emotional or social well being. This could not be explained by the presence of factual information alone.

## DISCUSSION<sup>8</sup>

These accounts bring alive the impact of managing a cancer experience during the transition years and reinforce the importance of taking a lifespan perspective to develop understanding of it. The distinctive experiences of those diagnosed at different stages on the journey to adulthood are intermingled with some that are common. Looking back from a distance – the longest being fifteen years - adds important insights into the unfolding challenges, as do participants' beliefs about the influences of gender, ethnicity and social norms. While there are clear resonances with the existing literature, the focus on fertility matters appears to have prompted responses that bring an additional dimension to understanding the impact of cancer and what might heighten or mediate it.

Although memories were often vivid, treatment itself was rarely seen as traumatic in hindsight, even among those most recently off treatment. Any trauma appeared to have been overtaken in large part by more positive feelings arising from knowing that they had been through a very demanding process and come through the other side – surviving treatment had the potential to become a 'badge of honour', as found elsewhere (see pages 88, 110). Many remembered comparing their own situation favourably to others and this seemed to help at the time and since: for example, some thought that it was worse for on-lookers or for patients who were younger or older. Such levels of reflection and awareness of others' situations were present across the age range. This suggests that the seeds of developing resilience from 'strength through adversity' and rising self esteem may be sown fairly early and that the use of comparative reflection may assist with this (see page 102) as well as the presence of hope and 'adaptive denial' (see pages 112-113). The concentration in existing research on experiences during or shortly after treatment (when greater trauma may indeed be more dominant) may mask these signs of recovery.

By analysing the findings in terms of recovery, a picture of where and how fertility matters might affect, or be affected by, recovery emerged. Other researchers have reported on the challenge of managing the transition out of treatment (see pages 102-103) and on young people's desires to return to 'normality', including the same educational context where applicable (see pages 104-5). Both were evident in this study. For a small number, the completion of the treatment regime appeared to trigger unprocessed thoughts and feelings about fertility. For the most part, however, participants used 'active recovery through striving

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<sup>8</sup> As indicated in Chapter One, the discussion sections at the end of the Chapters reporting findings will include some broad signposting to the literature reviewed in Chapters Two and Five.

for normality' to maximise similarities with peers and downplay differences while focussing primarily on present-day thinking (see pages 112-113). Some developed new or adapted identities to accommodate or take advantage of their changed situation, perhaps illustrating the use of psychologic plasticity, critical moments or turning points (see pages 88, 109-110). Embarking on romantic relationships was also a route for regaining 'normality', though often approached with trepidation. Approaches to the use of contraception reflected either the *use* of norms or the need to *appear* 'normal'. This sometimes overrode apparent risks posed by such patterns of use in relation to cancer (see pages 94-95). 'Normality' meant different things to different participants of course and was influenced variously by age, gender, ethnicity and culture of participants but also by the attitudes of those around them (see pages 86-87). Participants at the same chronological age placed 'normal' behaviours and expectations (including about fertility related matters) at very different points on a continuum. There was greater similarity around the self-assessed role of gender. Progress was measured against the yardstick of 'normality', aided where others reacted to them 'as if normal'. The price to be paid was the constraining of any fertility concerns.

Recovery was slowed or stalled for those who had relapses, second cancers, residual health problems or permanent impairments (of whom there were a number). The presence of fertility concerns carried the potential to make a difficult situation even worse where this increased feelings of hopelessness and lowered self esteem. For a smaller number, preoccupation with health matters lowered the impact of fertility concerns. This group are known to fare worse on psycho-social outcomes (see pages 103, 107, 112) but the impact of fertility has to date been little considered.

For a small number, the desire was to 'live life in the fast lane' with no apparent wish to re-engage with their past 'normality' and little indication that fertility concerns might slow them down.

For many, therefore, fertility matters were sidelined in these early stages and identified more with the physical ability to reproduce than with self esteem and identity. It was interesting to see how they were manifest and maintained during 'active recovery'. 'Hope' appeared to play a part in keeping concerns at bay, as has been shown in relation to non-fertility aspects (see pages 112-113). Males with banked sperm that they understood to be of good quality appeared reassured that this would enable them to achieve biological fatherhood if their fertility proved to be damaged. However most also appeared to believe that any damage would be temporary and this 'hope' also offered protection. For females and males who had

not used fertility preservation services and males whose sperm samples were of low quality, hope appeared more fragile. Although hope of retention of reproductive function was often still present, fears of permanent damage were held more frequently and the threat to achievement of biological parenthood was greater. Right across the cohort, there were some expressions of hope that fertility treatments would be successful if required. 'Hope' could also be bolstered by professionals and others and by knowledge of cancer survivors who had become parents or non cancer survivors who were involuntarily childless but appeared to enjoy life. Nevertheless, there was an underpinning sense that participants could employ little active agency around the outcome of fertility matters. This contrasted adversely with more active approaches to managing their cancer experience.

There were aspects of treatment itself that appeared to carry implications for managing fertility matters in the longer term. Many remembered treatment causing them to lose self confidence and to feel that they had little control over their lives and their bodies. The impact of temporary changes to body image echoed those found elsewhere (see pages 89, 105-107). For some, this included feeling less feminine or masculine or experiencing others responding to them as if they were. Similar feelings arose in relation to permanent changes, including some that might on the surface appear minor, such as scars in sensitive body parts or continuing hair loss. Some identified body changes as having an explicit effect on their confidence in actual or potential later romantic relationships. For others this was implicit. Earlier studies around body image and sexuality (see pages 90-91, 105-107) did not, on the whole, consider the possible contribution of fertility impairment to the development of such difficulties as diffuse body image or damaged inner sexuality. However some in this study talked about body changes in the context of both sexuality *and* fertility, suggesting that each carries an influence. Given earlier findings that inner concerns are not always apparent and may be downplayed by survivors themselves (see page 90-91; 106), the increased visibility of fertility concerns in this study suggest that attention to body image, sexuality and romantic relationships may be enhanced if the potential influence of this dimension is considered.

Regardless of approaches to recovery, the importance of fertility increased over time and in different contexts. Using a numerical scale of 0 to 10 measured at diagnosis and at interview, about half of all participants reported an increase. When combined with those who set it high throughout, the numbers rating it as of high importance at interview rose to more than two thirds. Becoming a parent, establishing a permanent romantic relationship or achieving status or satisfaction in other areas of life such as employment did not appear by themselves to lower its importance but new threats from relapse or treatment (including hormone



replacement therapy as well as cancer treatments), growing uncertainty or changes to the way that uncertainty was appraised may have done. Existing research suggests that uncertainty, including that arising from inadequate information, can bring particular challenges when it is experienced as threatening (see pages 15, 107-109). For example, the likelihood of a premature menopause brought uncertainties as those females affected faced a possible fore-shortened reproductive lifespan even if any temporary impairment was reversed. Many of both genders, but especially females, thought that more information at particular stages or greater clarity in the information provided would have mediated the impact as has been found true for cancer in general and fertility in particular (see pages 16, 21-22, 24, 107-109). However there was also evidence that the same information could be interpreted differently over time and context, as seen elsewhere (see page 16). Finally some preferred uncertainty to knowing whether damage had occurred though considered that this balance might shift in the future. This echoes previous findings with young adult males around cancer-related fertility (see pages 24-25).

Although uncertainty has been considered as an influence on self concept, the influence of uncertainty of fertility status has been little studied. In this study, all participants appeared to have considered themselves to be fertile prior to diagnosis but this did not remain the case. Changes to 'fertile identity' (using categories of 'impaired' 'uncertain' or 'fertile') seemed informed by more than a simple relationship to procreation. This may go some way to explaining differences in the meanings attached to similar experiences as well as building on earlier work around the 'meaning' of fertility (see page 24). Those in the 'fertile' category displayed least concern while impact was more varied in the other two groups. Where identities had shifted away from 'fertile', it was not always easy to shift back, even when medical information suggested this. However, where those who held 'uncertain' or 'infertile' identities also had a strong desire to parent from pre-diagnosis onwards and were not in a permanent relationship, reports of fertility concerns carrying a major impact were consistent.

While there were differences in the *strength* of conscious desire for future parenthood at diagnosis (and this was not age dependent), most participants had nevertheless expected to become parents one day, echoing findings from elsewhere (see pages 25-27). Parenthood therefore appeared to represent a 'normal' state of adulthood for many. The apparent lack of compensation from attainment of success in other areas of adult life may help to explain why some reported that 'active recovery' started to slow as fertility concerns came to the fore. Others reported that their recovery from cancer itself felt complete yet experienced growing distress from fertility matters. This is in keeping with lifespan approaches and research that

has found different rates of progress being achieved in different spheres of overall development among both cancer and non-cancer-affected groups of young people and of 'invented adulthoods' being employed to manage this (see pages 86-66). However, it also seemed that fertility was associated increasingly for study participants with their self esteem and identity rather than primarily to do with the physical ability to reproduce. While the same trend may be found for all young people as they get older, the 'difference' of having uncertain or impaired fertility seemed more difficult to manage as its meaning shifted. 'Hope' became more difficult to maintain, though where it was present it retained features similar to those in the 'active recovery' group. The stigmatised social imagery of infertility posed gender-specific as well as gender-neutral additional challenges to the development or sustainability of an acceptable personal and social identity. Increasing feelings of being unable to control this aspect of their lives when self efficacy in other spheres had become sources of satisfaction and pride added to the difficulties.

## **SUMMARY**

This chapter has focussed on the impact on participants' sense of self, as distinct from their relationships with others. It has considered this in relation to the overall impact of the cancer experience and the influences of strength of desire to parent, cancer recovery patterns and social identities. Participants' strength of desire to parent appeared undimmed by the possibility of fertility impairment, even when it was latent or low at diagnosis or during treatment. While the seeds of gaining 'strength through adversity' may have been present from early in the *cancer* experience and thrived as recovery proceeded, this did not extend to feelings about managing fertility concerns. Strategies based on re-entering 'normal' identities and activities were hampered by presumptions of fertility within peer spaces and sometimes became compromised over time. While the stigma of infertility was seen as heightening risks to well-being, perceptions of limited personal control over its outcome presented additional threats. Risks were lowered when the rewards of 'acting as normal' or 'living life in the fast lane' remained high, where residual health or impairment difficulties were dominant and where fertility was seen as primarily about physical reproduction rather than including stronger elements of self esteem and identity as well. Hope and uncertainty could carry risk or protective features. Some indications of an inter-relationship with body image, sexuality and romantic relationships were present as were influences of gender, ethnicity, culture and the type of fertile identity that participants held.

The next chapter turns its focus onto the role of professionals in this process.

## **CHAPTER SEVEN**

### **TELLING AND TALKING ABOUT CANCER-RELATED FERTILITY MATTERS WITH PROFESSIONALS**

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This chapter begins by looking at the professionals that participants made reference to in relation to fertility matters. It goes on to look at participants' actual and preferred patterns of communication with professionals over time and across contexts. This includes their views about who should raise fertility matters, when and how. The involvement of parents and partners is covered. Participants' views about which professional styles, attributes and actions helped or hindered their management of fertility matters are also considered, as are shortfalls in service provision.

#### **Medical professionals**

The largest single group with whom fertility matters were discussed were doctors and, in particular, consultant paediatric oncologists. However the context in which they were raised differed markedly according to gender. Most females recalled being asked at times about their menstrual cycle (though this was not always understood to be a query about reproductive function). No males remembered being asked about erectile function or whether they were ejaculating even though these are perhaps the nearest equivalent male reproductive system functions.

Many across all groups had not (yet) had fertility matters raised with them explicitly following diagnosis and treatment. For some, the first mention was when they were asked to take part in this study. Some, especially among the females, would have preferred it to have been broached sooner. This is not to say that it was unduly troubling for all of them, though this was the case for some. Only one (a male) said that he held a strong preference for the subject to be avoided as this suited his style of coping and general approach to life. He thought that having it raised might have proved at best irrelevant and at worst disturbing.

A number had experience of fertility matters being raised on a regular basis. Where this was clear, unambiguous and low key, it was seen as appropriate as it was then 'out in the open' should they themselves wish to pick up on it.

For a smaller number, fertility issues had been raised more proactively. For example, an adult female moved geographical areas after treatment and hence had follow up contact only at her current hospital. Her new consultant drew to her attention the fact that treatment might have damaged her fertility. Until then, the young woman had thought about it rarely as she had been told the risk was very low and that any problems would 'sort themselves out'. As time went by, the likelihood of damage became more apparent and this led her to raise it herself on many occasions.

A few of both genders raised the issue themselves, suggesting that they needed to discuss it earlier than their doctors thought appropriate. Three (two females and one male) were still teenagers when they requested a fertility analysis referral. One was motivated by curiosity and two by a 'need to know'. All three would have welcomed it being raised with them first. One was found to be infertile but did not have it raised with her again for many years, to her regret. An adult female raised it in her twenties once she and her husband decided they were to ready to start a family. Although she had been asked about her menstrual cycle previously, she had not discussed fertility matters per se and would have liked to have done so. A few participants had taken romantic partners along to a consultation to discuss matters such as contraception, risk of transmission to any children and so on. This was sometimes well ahead of any active planning for parenthood. Finally the mother of one teenage female had raised the subject with the consultant as she felt that it was an important area to address (though her daughter was relatively disinterested). Both mother and daughter felt that it had not been dealt with in sufficient detail, though this was compensated for by their own ability to handle it, as reported elsewhere.

### **Non-medical professionals**

Although the majority of the participants' comments referred to consultant paediatric oncologists, some also talked about the involvement of other professionals in the multi-disciplinary and inter-agency networks.

References to nurses were, on the whole, very positive but restricted predominantly to the broader cancer context and, in particular, the treatment stages. Although a few said that they had talked with ward nurses about fertility matters, a number saw this group as inappropriate for such discussions.

As well as ward staff, twelve participants referred to their contact with social workers, three with MacMillan nurses, three with counsellors, two with psychologists and one with an aromatherapist. Here again, fertility discussions were not widespread.

### ***Social workers***

Many who had social work contact did not see fertility as a subject that they would discuss with their social worker. This was especially the case where contact had been short term and centred primarily on financial and practical tasks. A few referred to the stigma of social work involvement presenting a barrier for them and/or their parents so that it was difficult, at least initially, to see them as sources of help rather than surveillance:

..... I normally associated social workers with people who were misbehaving a lot. *Laughs*. So to be given my own social worker was rather disturbing I suppose....

Adult male 15:30<sup>9</sup>

Even where contact was more intense, it did not necessarily include attention to fertility matters. In some cases, this appeared to be a missed opportunity. For example, one teenage male who had some residual cognitive impairment as well as fertility related difficulties would have welcomed professionals raising fertility issues with him. He included social workers as well as nurses and doctors as appropriate staff to do so.

There were a small number of participants whose relationship with their social worker was deeper and longer lasting and encompassed fertility issues. One teenage male remembered positively that his social worker had raised fertility issues from time to time and would welcome her doing so again. Similarly a teenage female remembered her social worker as being proactive in offering home based, long term 'counselling' (her words) in which fertility matters featured as well as other aspects of her cancer experience.

The parents of one female had not approved of social work involvement because of their stigmatised image. She had resorted to seeing her social worker initially at hospital and, on discharge, at home 'behind their backs'. This appeared to inform her willingness to make later use the counselling service when at university.

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<sup>9</sup> As previously, all quotes are identified by the category of the participant (teenage female, adult male etc) together with the age at diagnosis followed by the age at interview. Thus, this quote was from an adult male aged 15 at diagnosis and 30 at interview.

Some saw social work support as positive insofar as it aided the coping abilities of family members. One teenage female felt that her mother started to feel more at ease once the social worker was involved and this had a positive knock-on effect for her. This included the social worker's willingness to discuss fertility issues.

Some reflected on their social worker's ability to switch focus and adapt to changing needs. One teenage male who was troubled by fertility concerns reported that his social worker was key to helping him return to school and work and hence back onto the road of social and emotional recovery. An adult female reported similarly that it was her social worker that was instrumental in getting her back 'on track' after treatment had ended.

### ***MacMillan Nurses***

The three teenagers who singled out MacMillan nurses saw them as particularly helpful in facilitating emotional coping. A key feature appeared to be their ability to befriend and engage in discussions about 'normal' everyday matters:

.... if [Macmillan nurse] had known about it, I would have talked to [her] more, because she's more, I don't know, she's not like a nurse, she's more like your friend. She's like 'Hello darling, how are you this week?' And 'What have you done? Have you been shopping?' and she'll talk to you about everything so she like becomes your friend. And then she'd be the most likely person other than my doctor to talk to about it [fertility].

Teenage female 18:20

Only one remembered them raising fertility issues but all would have liked them to.

### ***Counsellors***

No-one in the study saw an infertility counsellor at any stage and few, if any, seemed to be aware of this service. However three participants, all adult and female, had used professional counselling services post treatment for non-fertility concerns. Two had used their university's student counselling service and found that helpful. The third, who had struggled massively with fertility issues, had received two separate bouts of specialist cancer-related counselling since ending treatment and was on the waiting list for more at the time of the interview. She reported that she had scarcely touched on fertility matters to date as they still felt so

overwhelming and scary. She was hoping that she would soon be able to use counselling to tackle this.

### ***Psychologists***

Only two (both adult females) reported seeing a psychologist. In each case, the contact was brief; the context did not appear to be related to fertility issues and they were not discussed. Both felt this was appropriate.

### ***Aromatherapist/Reflexologist***

One of the adult females was very positive about her contact with an aromatherapist during treatment during which she discussed fertility issues:

I've had an absolutely fantastic woman... who is an aroma therapist..... she does a lot of massage and Reiki and aromatherapy and stuff and is absolutely brilliant, they should have it everywhere. ... It sort of really helps. It's really, really good, makes you feel a lot better. And she could tell, like whenever they were doing reflexology she could tell that like I hadn't had periods in a while and stuff. It was really really good. Really good.

Adult female 20:23

### **Views about the ways in which fertility was discussed with professionals**

Some views were expressed about which professionals should raise fertility issues, in what way, how often and with what focus.

#### ***Should it be raised at all?***

There was general agreement across all four groups that professionals – especially doctors – should raise fertility matters regularly in order that young people knew that they could discuss it if they wished. This was true for those who had experienced it being raised in this way and those who had not; those who were troubled with fertility concerns and those who were not; those who thought that they might feel able to raise it themselves and those who might not:

I wouldn't really ask for them to bring it up, but if they did, I think it would help because talking about it now [in the research interview] has helped, cos I never really thought about it until I got asked to do the interview..... but like

talking about it, it's made us like, this study's like made us like think about it more and like how I'd feel. I've just like talked about it more with me friends so it has helped us.

Teenage female 15:16

### ***Who should raise it?***

If it were to be raised, all were happy for this to be done by doctors. Some were happy for it to be raised by nurses (especially MacMillan nurses) and social workers but others were not. Whilst relationships with consultant paediatric oncologists were generally close and characterised by high levels of warmth and trust, relationships appeared more variable with all other professional groups. This perhaps explains the less uniform support for other professionals to raise it. However it was not only the professional role that but also the nature of the professional-patient relationship and the particular focus of any query that informed the likelihood of dialogue proving helpful. This went some way to explaining what enabled some to raise and/or engage in discussion about fertility matters and others not.

Some talked of the importance of needing to feel secure enough in a relationship with a professional for fertility to be addressed. References to 'feeling comfortable' and 'having firm trust' and 'approachability' – especially with consultants – were frequent, including among those who had not yet discussed such matters. Even when discussions had taken place with one professional, this did not necessarily lead to the individual concerned feeling able or willing to discuss it with other professionals as well, whether holding the same role or not. For example, one teenage male had discussed it with his social worker but would have been alarmed if others (in this case he refers to nurses) had sought to raise it:

Depends how close you are really. [social worker] had mentioned it before and I don't mind discussing it with the likes of her cos we were very close as well. .... But if nurses had brought the subject up I would have just, er, faded away.

Teenage male 14:17

For others (in particular some males), the *opportunity* to talk and be taken seriously was more important than the existence of a close prior relationship. One adult male related how much he had welcomed it being raised by a doctor at a 'late effects clinic' appointment even though it was their first encounter because he warmed to his approach and apparent interest in fertility aspects:



.... the last doctor I saw - a new guy, brilliant guy, got on with him fine. And his face when we were talking about it just lit up and he went 'Brilliant'. .....he were really helpful actually, he were like 'If you ever need to talk about it, I'm always here, or there's a nurse here and we'll arrange everything for you.. you can come down and do it [fertility testing]'.

Adult male 16:22

Some of those who thought that they would not be able to discuss fertility matters with people that they did not know well nevertheless appeared able to talk at length and with some candour in the research interview. It was not clear how far this was related to the freedom of talking to a stranger in a single encounter ('the intimate stranger'), to an ability on their, or my, part to establish quickly a 'good enough' degree of trust and confidence, to the need to share or discharge thoughts and feelings generated in the preparation for the interview or to something else.

A few of the females hinted at feeling uncomfortable in discussing 'intimate' matters such as fertility with their male doctors. For example, a teenage female felt that she had a good relationship with her male consultant on other matters but found it difficult to talk with him about body functions and extended that to fertility. For this group, any need for information and discussion had not yet overridden their discomfort.

### ***When should it be raised?***

As reported in Chapter Four, there was overwhelming support across genders for fertility matters to be raised at around diagnosis regardless of level of potential threat, age, incapacity or availability of fertility preservation services. This was reinforced by the experience of the only male not to be told until several years after diagnosis. He remembered then being told with some insensitivity that he was definitely infertile. Coming as it did when he felt well on the way to becoming reintegrated into friendships and school, confident that the cancer was behind him and coping primarily with age-appropriate concerns about his virility (his words), he found his sexual and personal identity threatened by the information:

.... it was such a shock out of the blue, I mean it really was, and I think that that came as such a bombshell, erm yeah, its definitely cycles I think. Shortly after treatment, it's useful to know and I think you probably have a hard time

dealing with it, or I would have had a hard time dealing with it, just because of the nature of it, I've just finished everything, I don't want to deal with this. ....I should have been told earlier. I think whether I understood or not is irrelevant. .... If only to put the seed in my mind that that was something that I would have to deal with....

Adult male 13:28

There was support for it being raised again shortly after the first time in case there were immediate outstanding questions or concerns to be dealt with. Participants also felt that it should be raised at regular intervals thereafter in an unambiguous but low key way (as reported above), with the opportunity to go into it in more depth with the professional of one's choice according to personal preference. It was felt that this approach held the potential to lower anxiety and contribute to feelings of being more in control. Teenage males were the only group for whom the majority supported this in principle but where very few had as yet experienced any strong need for this for themselves.

There was more variation regarding the amount of information that participants wanted.

At around diagnosis, the majority felt that information levels about fertility matters were about right in volume and comprehensibility. A small number of females would have welcomed more information about the levels of risk involved and an explanation as to why egg freezing was not available. In relation to the latter, it was felt that it would have been better to know this from the beginning than to find out about such services later and wonder why they had not been offered. However at least one female found the absence of an offer of egg freezing to be a source of later comfort in that she interpreted it as meaning that she was at little or no risk.

While some across all four groups wanted fairly full information and/or discussion from soon after diagnosis, others preferred to wait. For some the trigger was contextual – for example a change in personal awareness about the implications of having impaired fertility, a move towards thinking actively about parenthood and so on – for others it was more to do with coping style. In other words, neither chronological age nor length of time off treatment appeared to be dominant influences per se.

While it is tempting to assume that treatment will push fertility concerns to the margins – and this was true for the majority in this study – there were a small number who needed to talk

and gain information during treatment. One teenage male raised some pressing fertility-related concerns with his consultant (with his mother's support) during treatment. The relief that he felt at being told there and then that his fear of passing on the cancer to any future children was unfounded was palpable:

I just said '[name of consultant] right I'm really concerned about this now cos like if I have a kid in a couple more year, in 15 years, if when me wife has the baby is our baby gonna have cancer or like when the baby gets to my certain age, at my time, is she, he or she, gonna have cancer like I did?' And he said 'No, no, no. It's nothing like that' or everything like that. I said 'Right. Good. That's another worry out of me mind and everything'.

Teenage male 15:17

Another teenage male found that worries about fertility started to crowd in during the latter stages of treatment and became very troubling soon afterwards. Unlike the young man above, he struggled to get his concerns taken seriously and recalled being told on more than one occasion that these were matters to be 'dealt with later'. He and others urged greater recognition to be paid to the fact that if the patient raises it then it means that it is important to them at that point in time and needs addressing.

Those who had the subject raised proactively soon after treatment ended spoke positively about this. For example, one teenage female remembered her consultant raising it regularly in a low key but clear manner once the acute phase of treatment was over (as well as from time to time during treatment) and felt that to be very important. She placed this within the context of the importance of feeling fully informed about potential risks even if she, like other young people in her view, was tempted sometimes to ignore things unless the doctors made her face up to them by (gentle) challenge.

Another female understood from early in her treatment that she was likely to have impaired fertility. She welcomed her consultant taking the initiative approximately a year after treatment of going through not only the functioning of her reproductive system but also the different scenarios that may lay ahead (including fertility treatment options that might be available). He had raised it briefly from time to time beforehand but this occasion felt right for her to go through it in more detail. They then returned to it from time to time until the stage several years later when she was ready to engage with it more vigorously within the context of a permanent relationship and decision to try for parenthood.

One teenage female had a similarly positive view of it being raised regularly even though she was neither sexually active nor contemplating parenthood. Questions about her periods were linked clearly to her fertility and emphasised by the offer of contraceptive advice. However it is a reflection on the underlying anxiety that possible fertility impairment can engender that she worried that the invitation to take part in the research was actually a subtle way of her consultant telling her that she was infertile:

[paediatric oncologist] said just, you know, 'If you have got a boyfriend and stuff, be really careful' and stuff like that, 'Obviously, cos you're only 16'.. *laughs*.. He said '...if you do things like that' but he said 'It looks quite good' he said, 'It's coming back'. But I were right happy then and then when he asked me to do this [study]. I thought 'is he trying to tell me something?'

Teenage female 13:16

Some linked their views on information flow directly to their coping styles including the way in which they liked to process matters. One teenage female thus found it useful to have information well in advance of taking any related actions:

I always like to know things in advance cos then it gives you a chance to think through them and to really think about what you want and really think about the consequences of every decision that I'm going to have to make to do with it. It's very good to have everything that I need to know now rather than be thinking 'Oh, next time I go to see [paediatric oncologist], is [...] going to tell me a bit more about this?'. I'd rather have everything dumped on me at one point and then I can ask questions about it as the time goes on as I want to think about each thing.

Teenage female 16:19

Others were aware that it suited them better to have less information and thought that any greater amounts might have caused them more distress:

If I'd been told a lot more than I had done I'd probably think about it more and it'll eat up inside. I'd probably... I don't know how I'd be. I think every day I might wake up and I'd be like doing things and thinking I can't have a baby.

Teenage female 15:20

Likewise, another female was pleased that she had been advised at diagnosis that her fertility might be affected but then not given any more detail until the picture became clearer. She felt this more cautious and gradual approach to information sharing enabled her to develop her coping strategies incrementally, especially as it became clear that she was highly likely to have been affected.

A teenage female illustrated the complexity of the challenge for professionals in getting this right when she reflected on her own individual context of recovery:

I think. I mean I was 15 when I was diagnosed.... I think the fact that they never told me after I had finished chemo was good. They never mentioned it afterwards again..... And then that gave me the time to recover, like have my treatment and give us time to recover after finishing treatment. I think maybes when your life seems to go back to normal and I say the word 'normal' very loosely, I think just to fit back into routine. Not one where you have to wake up, take tablets and waiting to take some tablets, some tablets just before your lunch. Maybes have an injection or whatever. That's, medical routine. That's what happens during treatment, perhaps even for a little while after. When I say you're back to normal life is when you are waking up in a morning and you phone your friends and you say 'Oh do you want to do something?'. Spontaneity routine. .... And I think that's the time when they should really bring it up because that's the time you're in the right frame of mind, you know. Perhaps not where your life is going but you know that you've got a life to live. .... That's the time they should bring it up. I think. .... 6 months to a year after you have finished treatment they should mention it. And I don't just mean 'Do you want to know about fertility?'. I think there should be something... maybe stick an extra 10 or 15 minutes on your appointment time just to go through what your options are..... and if they say 'No' then on the next appointment just mention it again just so that they know. And if after two or three times they say 'No, I don't want to know' then wait for them to come to you.

Teenage female 15:20

Some participants said that professionals needed to be prepared to raise the subject several times before the young person might feel able to engage.

This was, then, an unfolding process and meant that the impact of professional practices did not always become clear for some time. For example, one adult female whose consultant raised it routinely over several years found that this enabled her to raise it herself more recently after having seen a television programme that prompted some questions in her mind.

Some did not have the experience of information sharing practices that felt helpful. More than one pointed out that an external appearance of nonchalance on their part was not always an accurate representation of what was going on within. For those that knew that they wanted professional input, a proactive approach would have given them the permission to receive it:

I was trying to pluck up the courage to actually ask her. Because it had never been raised since and I don't know if it was because [consultant] felt awkward about raising it or, I'm not really sure, erm, but I just knew I had to ask. And I knew that I wasn't.. if I didn't ask I wasn't going to find out..... I felt so embarrassed asking her, I don't know why. I felt embarrassed and anxious, I felt worried, upset because I didn't know what she was going to say. And I think if it had ha' come throughout my treatment, and maybe when I'd just finished sort of, it wouldn't have been so bad. Because I'd have known rather than wait so long, and then have to ask

Adult female 18:23

A few reported that the subject had only been raised when professionals had realised that they were in a romantic relationship. For some that was acceptable; for others, the use of the presence of a relationship as a prompt meant it was too late.

Even among those who had not yet felt any particular need to discuss it, it had not felt intrusive if it had been raised or they anticipated that it would not have been.

Finally, the lack of involvement of psycho-social services was noticeable in these accounts. For example, an adult male who had fertility matters raised a few months off treatment found that it had a major impact on him. No follow-up information and support (professional and informal) services were offered beyond the contact with the consultant:

It was a few months later and she raised it and she talked through it and it. I mean it hit, it really hit hard..... probably more so than actually finding out I had cancer. I think that was the one thing that seemed to stick in my mind was that it was really, you know, against you..... I remember going down to the car and just sitting in the car and just breaking-down completely and... erm.. you know... It does.... I mean I think about it all the time and it's... It is difficult to come to terms with, you know,

Adult male 18:23

### ***How should professionals approach the involvement of parents and partners?***

The importance of professionals talking first and foremost to the young person, regardless of whether or not their parents or partners were present, was strongly advocated across all four groups. A number mentioned in particular the importance of receiving information at the same time, or ahead, of their parents:

I think it was good the way she just sort of told me instead of going round, like talking to my parents instead of speaking to me, and stuff like that. Where I think if she'd ha' told my parents that I couldn't conceive or, and not actually come to me, I think it'd have been worse than actually, cos I think you listen more to it like when a doctor or a consultant speaks to you so when she was saying it mightn't be a problem, well you think it's not going to be a problem, where if she'd have spoke to my parents I'd have been 'Well why didn't she speak to me, how come youse know and I don't', type of thing, I'd have been, thought they were hiding more things from me, where [consultant] spoke to me more than she did my parents, she made sure we were all there together, not taking my parents away and speaking to them.

Adult female 15:24

Being offered the choice about whether or not to have parents present, particularly in relation to fertility, was also seen as important to self esteem *and* for feeling a little more in control:

I remember [consultant] always used to say, 'Do you want me to talk to you separately or do you want your parents to come in?'. She was really professional about that, even though I was only fifteen she always asked me that, and that she always treated me like an adult, which is nice in a way, and she always used to come and say 'I want to tell you about this'. She never

used to go to my parents and tell them things without me. She used to tell me first and then my parents, that was really good. Yeah, it made you feel like an adult even though I wasn't actually an adult, I was fifteen, I still felt like I was being told things, and that's the main thing because you want to be told things, you want to be told everything really. Because you might think you're fifteen and you don't have to know that but I'd rather know so.

Adult female 15:21

However, a small number found that the focus could shift towards parents and away from them when fertility matters were involved and this was unhelpful. For example, one teenage female felt excluded when professionals got pulled in to talking with her mother rather than her:

I was sixteen at the time, and I kind of felt old enough to make the decisions for myself, and especially that kind of thing you know, the conversation was very much between [nurse] and my mother. And I mean they weren't doing it on purpose or anything, but I know [nurse] said she'd had to have an internal scan, and it was horrible and my mother said: 'Oh yes, I've had one before' and I felt like the child in the room.

Teenage female 13:19

The need for the choice to be offered without the parents present was identified by several participants. In other words, some found it difficult to exercise choice if their parents saw this as rejection, as illustrated by one teenage female:

.... the doctor used to ... say 'Is it OK if your Dad stays', and there were a couple of times when I plucked up enough courage to say well actually 'Yeah, would you leave' and my Dad used to go off the edge about it, and he used to get very angry and say that he cared about me and that didn't help. And that used to create problems by after a while I never used to ask him to leave, because I just didn't want all the extra trouble. So, yeh, the whole situation was a bit fraught..... I didn't feel as if I had an ally in the room almost. I felt as if I was completely on my own.

Teenage female 13:19



It worked well for some when the professional asked parents to leave the room, providing that the young person could then invite them back in if they wished:

.... if [consultant] like wants to talk to me summat, you know, personal, he'll say 'Do you mind going while me and [.....] have a chat'. I'm like 'Oh yeh, fine' and they'll go.

Teenage female 14:17

Some talked of the dilemma of wanting a parent present in order to help them remember what was being said but preferring them to be absent to enable them to talk with their doctor more freely. One teenage female found a compromise that worked for a while. She continued to have her mother accompany her and talked with her consultant about sex and fertility when they were 'behind the curtain' during examinations and hence in a more intimate space:

.... with my mam being in my appointments it was hard to talk to [consultant] about stuff like sexuality. And it was difficult to talk to her about something like that. We usually talk about anything like that when we're behind the curtain. Even though they could still hear it just means that they're not staring at me. It makes it easier to talk about anything.

Teenage female 18:20

As reported in Chapter Eight, increasing numbers opted to deal with professional contact on their own over time and others would have done so if the choice had been offered. An adult male said that he would have welcomed the chance to have his fertility tested two or three years previously but the presence of his mother in the consultations where it was raised inhibited him from engaging in any discussion, not least as it was accompanied by questions about his sexual activity. It was only when he started attending on his own that he felt able to move forward with this.

The involvement of partners in consultations appeared to present fewer barriers. Those who had taken partners along had instigated it themselves, usually within the context of wanting to discuss sex and fertility matters or to acquaint a new partner with the cancer treatment context, as referred to earlier. As such it appeared to have presented no concerns among those in this study as they felt in control of the involvement.

## Preferred Attributes of the professionals

### Age

The age of professionals seemed to matter little to those in this study. Only two females and one male expressed a preference for someone older in order to reduce embarrassment and increase confidence but even for these, this was not a strong preference.

### Gender

Participants were more likely to express a view about a professional's gender than their age but only in relation to doctors and nurses and then only a minority. All but one of those who expressed a view - one teenage male, five teenage females and three adult females - preferred female doctors (9:24%). Most, but not all, of these had a female consultant currently though a mix of genders for other professionals. Two adult males (2:5%) saw some advantages to having male professionals: one preferred having a male doctor when younger but now had no preference and one thought it might have been helpful to have had a male nurse when he returned from unsuccessfully trying to bank sperm (but had no preference over subsequent contact). However another male urged caution when matching male to male as he thought that males were inclined to be less honest with other males, especially over fertility related matters as '.... the male bravado kicks in a bit more'.

The preferences for having a female doctor were primarily to do with feeling more comfortable and/or less embarrassed at talking with a woman:

I'd rather have a female to have a male because, like, I dunno, it's just talking about that stuff with. .... plus like a woman is the same as you isn't she, so ..... Obviously like a male as a professional knows all about it, but I'd just rather have a female.

Teenage female 15:16

One adult female felt that female doctors were more intuitive and cited instances of that, even though with the backdrop of being satisfied on the whole with both genders:

Cos I mean he was good and he was nice and he was lovely, you know. He didn't say anything wrong, or you know. I think she just realised how much I was worried about it more than he did. And I think she sort of saw that, kind

of, that it was something that I really, really, really wanted and he....he did realise that I wanted it but sort of, I don't know, not to the same degree.

Adult female 20:23

One teenager identified what she *did not* want a male helper for (personal care) and what she *did* want a female for (discussion about intimate matters).

However, having the gender of one's choice in a professional was not a guarantee of a good experience as one female found in her contact with a female reproductive physician. A number did not find gender to be a major influence in helping or hindering the 'helping' relationship. For many, this comment from a teenage male summed up their views:

No, no, it doesn't bother me. Not at all. It's just like, it's yer doctor innit - he makes you better so it dun't matter who they are really.

Teenage female 13:16

### **Honesty**

Perhaps the strongest support was reserved for the importance of professionals being honest, sharing information clearly and approaching contact in a spirit of partnership. Even when the information being shared carried challenging implications, this was seen as preferable to being given false or unrealistic hope.

Such attributes were seen as important mediators of the impact of fertility issues and a boost to coping. This applied across all aspects of the cancer experience:

I like to be told straight as a dye and that's what she [consultant] does. She doesn't beat around the bush which is the way I like it, there's no point in stories, just come out and say it. .... and then if you're being totally honest there's less likelihood of, the patient may whoever, turn round and go 'I'm sorry, I don't understand'. If you come out and say it in laymen's terms from day one then... there's not going to be any misunderstanding at all.

Adult female 19:25

... everything was told straight down the line, like really clearly, but no beating about the bush... cos then there is no confusion about anything

Adult female 19:26

The partnership approach was signalled most clearly when professionals talked directly to the young person, acknowledging that they were the most important player in the room.

Where professionals themselves were uncertain or had incomplete knowledge, this could also prove challenging if understandable (though see the role of reassurance below).

Implicit in this was that professional honesty contributed significantly to the development of trust and confidence. It also appeared to contribute to participants feeling that they could ask for information as well as receive it – with the proviso that many said that asking questions about fertility was more difficult than about some other aspects of cancer and treatment.

### ***Approachability***

As already indicated, honesty appeared to be an important ingredient in approachability. There were also frequent references to the role of a calm, friendly and warm manner in lowering barriers and encouraging confidence. Some welcomed the use of humour, especially the males, though there were also notes of caution about this as it was experienced sometimes as inappropriate. A number talked of the importance of feeling that they could approach professionals outside of set appointment times if necessary. This extended to sharing good news about non-cancer matters as well as asking for health advice.

Important also were professionals who appeared to listen, take questions seriously, allow plenty of time and offer clear communication:

..... speaking like so you don't have to ask what that means, doing it on a level that you understand. Like instead of using like big medical terms, breaking it down so you can understand what's being said to you, instead of making you feel small because you don't understand what they're saying.

Adult female 15:24

Friendliness, however, needed to be carefully managed from both sides. One adult male valued the relationship that he had come to have as an adult with his consultant. It enabled him to explore his thoughts and feelings about how to approach addressing fertility issues in romantic relationships, for example. However participants also expressed the importance of knowing that boundaries were still in place within the professional friendship, ensuring sensitivity to inappropriate intrusion:

But I should say though that [.....] and other doctors and the nurses are all willing for you to go up and talk to them all the time. They're not guarded. You don't feel like you have to protect yourself from them or anything. They're more friends than doctors but you know that there's a line there and you don't cross the line.

Adult female 19:21

This was sometimes to do with confidentiality. Some welcomed the fact that their paths were unlikely to cross outside of the professional encounter or, if they did, that an appropriate distance would be maintained:

Cos it's not like I'm gonna meet them another four years down the line in the middle of the street or something and start talking about it [sperm banking and fertility] with crowds around.

Teenage male 15:17

However a small number also expressed concerns at not knowing how many of the professionals they encountered knew about the potential impact on their fertility and/or the fact that they had banked sperm. This left them feeling vulnerable either because of feeling embarrassed, or annoyed that staff may know something that they considered to be private, or fearful that staff may try to raise it with them at an inappropriate time.

### **Competence**

With regard to cancer matters, there was a general sense of confidence that health and social work professionals knew what they were doing. However this was not the same in relation to fertility. Several said that their professional helpers did not know enough about fertility matters. Sometimes, this was an assumption – for example that because their doctor was an oncologist, they would not know about gynaecology. Sometimes it was stated in the context of them being referred on for specialist medical help. In both scenarios, this was more likely to be presented as a fact than as a problem. The problem arose for those where more specialist help or information was not made available.

### ***Professional reassurance***

A similar but different set of comments was made about the reassurance gained from contact with professionals.

A number of participants reported feeling better able to cope with the impact of possible fertility impairment if they felt reassured by professional advice, information or manner (either early in the process or over time) about whatever aspect had the potential to trouble them. For some, the development of confidence in professional honesty around fertility matters led to the participant taking their lead from their consultant about whether or not they should feel concerned about it as illustrated below:

[consultant] usually tells me whether to worry or not to worry. So that's why I don't bring it up until I'm in with [consultant] cos [...]s the doctor after all.

Teenage female 18:20

The implications for those who had not experienced this or where professional reassurances turned out to be misplaced are clear. For example, a specialist nurse provided one young woman with a written sheet for use when explaining treatment side effects to school friends. It included the statement that her fertility would not be affected. She took that to be the case though, sadly, went through a premature menopause in her mid teens.

### **Difficult aspects of professional behaviour**

Some of the difficulties encountered are reported implicitly in the preceding section; some are drawn out more explicitly below.

#### ***Incorrect, contradictory or incomplete information sharing***

Some participants felt that they had received *either* mixed messages *or* incorrect information *or* incomplete information from doctors. This was more likely to reflect encounters from outside of paediatric oncology circles.

.....and I still didn't understand cos nothing had really been explained to me and I was like 'Yeah but I can still have kids ....?'. And it was like 'Yeah'. So I took that as yeah, so if he [surgeon] said to me 'Yeah' then and then erm I kept going in for my appointments to see [paediatric oncology consultant] and

it was then I realised that no, I couldn't have kids. ....I found out 'No' the possibilities were quite slight of me being able to have children, because obviously my periods had stopped. Like now I'm on hormone replacement, so erm because of that, obviously I realised myself no it's not just straight cut, that I can't have kids.

Adult female 15:21

Some females thought that this was a reflection of different cultures in other branches of medicine (females were more likely to have used medical services elsewhere). Having been used to very open and clear communication with paediatric oncology professionals, some reported finding information less clearly conveyed, consultations more rushed and atmospheres more formal elsewhere, including in reproductive medicine (though it is important to note that there were also some positive experiences). Some used paediatric oncology doctors to then help them translate what they had been 'told' elsewhere.

I didn't really have that relationship with the gynaecologist. It was obviously a man and I didn't feel at ease as much as I would with a woman. So I tended to shy away from questions I would have liked to have known. I sort of wanted to go in there, get my examination over with and come straight out. And anything I wanted to ask I asked [paediatric oncologist]..... cos I did find it hard to talk to the gynaecologist. And I suppose with the gynaecologist you're sort of in and out, you're just a patient. Whereas with [paediatric oncologist] you can sit down and it doesn't matter if I'm in there two hours. If there is owt worrying me [consultant oncologist]'ll take time and explain everything fully to me.

Adult female 18:23

Some felt that the information offered from elsewhere was not always realistic and/or offered false hope.

Parents too were reported to find such differences difficult, not least in their role as protectors/translators and so on.

A few reported having obtained information from elsewhere that led them to realise what they had not been told by their professional carers and thought they should have been. In particular, two teenagers 'learnt' through attendance at a Teenage Cancer Trust (TCT) 'Find

your Sense of Tumour' conference that not everyone with cancer becomes infertile while one was surprised to learn that others were more worried about fertility than she was:

And I learnt more at that fertility talk than what I did when I had the talk here. And they didn't mention that seventy percent of the people, I think more than seventy percent are perfectly fine to go on and have children. I mean he did say at the time, you know, most, a lot of people do still have children and they're fine with it and everything like that. But you think well maybe I'm not in that group and you automatically assume that with cancer you cannot have kids straight away. You just assume, you don't think that you can have them anymore. You think it's not right and, I mean it's proven wrong at the thing [meaning TCT conference]. I mean he did say that, but maybe there needs to be a bit more emphasis on it, I think because, erm, to this day I still think I'll be one of the ones that cannot have it because of the way me body's reacted afterwards.

Adult female 19:21

### ***Professional discomfort or insensitivity***

As reported above, professionals encountered outside the paediatric oncology services were experienced more frequently to be uncomfortable or insensitive about fertility issues. For example, some young women had experience of GPs and other health professionals assuming that their symptoms were pregnancy related prior to diagnosis, including some who were virgins (see Chapter Four). The strength of their distress from such memories was clear. This appeared to affect ongoing approaches to fertility matters, perhaps compounded when the site of their cancer was in or near reproductive organs:

And the fact that the doctor actually said ...I was crying and said 'Can't it be something else? I would know you know'. And he said 'No. I am pretty adamant you are six months pregnant'. So in a way if he hadn't ha' sent me for a scan, there wouldn't.... I wouldn't have been anywhere really would I? So it was terrible. Even one of the nurses said 'it's all in your head'. And I thought 'Who are you to say that?'. So... I've got a lot of issues....

Teenage female 17:20

And one of the males remembered with clarity the insensitivity of someone doing a scan



during treatment:

I think actually one of the more embarrassing comments was, I had this ultrasound scan and the man who was doing the ultrasound scan was saying something like "Oh can you move your friend [meaning penis] out of the way" and that's something that made me think 'Ooh no you shouldn't be talking like that. This is quite embarrassing for me, you know'. *Interviewer*: Because it makes it personal. *Adult Male*: Yeah, and I almost preferred it to be talked about in a scien..... *Interviewer*: Clinically. *Adult Male*: Yeah, clinically, so.

Adult male 20:22

Accounts of the contexts of information sharing in some 'outside' services also applied where participants referred to insensitive professional manner. In particular, there were references to lack of warmth, lack of clarity of explanation, tendency to be more formal, impersonal and rushed.

The fact that memories of such encounters remained for some considerable time afterwards is a reflection of the potential for lasting impact, albeit at differing levels. One of the most difficult encounters was that referred to already in which a young man was told that he was 'infertile' three years after diagnosis. Another was when a teenage female was asked a series of questions with her father present (not her choice) including about sexual activity, menstrual cycle and so on. The gynaecologist then went on to conduct a painful internal scan as she had not taken on board that the young woman was still a virgin:

The gynaecologist we saw was an absolute nightmare. She was an awful woman. She wasn't very kind of understanding, she was quite abrupt about everything..... she got quite kind of sharp with me, said that, you know kind of saying 'Come on, pull yourself together stop being such a child' ..... going to see that woman made everything ten times worse.

Teenage female 13:19

Whilst she was told later that her father's presence was 'allowed' because the professional concerned had assumed that he was her boyfriend (of concern in itself), she argued strongly that his presence was not appropriate and that neither would it have been acceptable for her boyfriend to be present without her permission.

### ***Continuity of professionals – coping with new professionals***

Not surprisingly, where people had had a change of significant professional helpers such as consultants, they did not like it. Coping with a new person was difficult and it took a while, if ever, to build up the new relationship:

I would much rather see the same consultant every time because there's a bond there. I think certainly so important, something, when something's so, you know, a life death situation that you're in, I think the bond that you have with certain consultants is... I'm very reluctant to leave one and meet a new one. I'm fine now I'm older, certainly as a younger, quite sensitive, you see someone for two years, then alternate and I met someone else and then gradually the first person disappeared, I met the second person.

Adult male 13:28

This extended to being referred on to other services. For example, one young woman said that her confidence in her consultant paediatric oncologist and her familiarity with hospital routines developed over a long time and did not ease her anxiety at encountering new staff and services:

Like when I get sent to different places I'm quite... I don't... I'm nervous. Like she [consultant] sends me for scans and stuff like that. I find I shake. I can't control the way I feel, so...

Teenage female 17:20

### **Unrequited needs for professional help**

The lack of psycho-social services for helping with fertility matters has already been referred to. Some wanted existing services such as social work and outreach nursing to be expanded and/or for staff within them to take a more active involvement in fertility issues. Others identified the need for new services. An adult female suggested the need for a specific professional available on the ward that anyone could go and talk to about fertility matters during treatment or when they returned for outpatient appointments. Another wanted a similar service but thought that it needed to be provided by someone independent of the treatment team in order to provide confidentiality or reduce embarrassment:

It could be, OK, like if you're someone from outside the doctors, like a different face, so you could sort of like tell someone else who you're not dealing with every day, things that you wouldn't like want people to know. Do you get what I'm trying to say? So you're not embarrassed or so you don't have to like look at that person all the time and think 'Oh I asked you that'. So I think it would be better if someone outside of the doctor/nurse role would be ideal.....

Adult female 18:23

While some saw a need for therapeutic services, others identified their primary needs as being for information-based services staffed by people who were both well informed and able to discuss the pros and cons of different courses of action. Several participants talked of unexplored and unshared worries and gaps in knowledge remaining unresolved:

..... there has been occasions when I think it would be good to talk about it because like I say, you know, the problem is if you feel angry about stuff then you've got no outlet and a lot of the time you are... I think it probably would help to talk through it more and see people and like rationalise it, you know.

Adult male 18:23

Another, this time a teenager, illustrated what it was like to be in the midst of needing someone to talk to. He had understood from diagnosis that he would definitely become infertile. He found that deeply troubling, especially as he had tried unsuccessfully to bank sperm, but did not feel able to ask for professional advice. When he returned to the sperm bank several months later to try to bank sperm again (again unsuccessfully), he plucked up courage to ask questions and gained some comfort in being told that infertility was not a foregone conclusion. By the time of the research interview several months later, he was very keen for further information and had still not felt able to raise it with his consultant, even though he got on very well with her in general. He has continued to have problems with erections which may well have contributed to his anxiety.

There were other barriers too. An adult female who appeared to have become troubled increasingly by her apparent infertility indicated a sense of ambivalence about whether or not professional help would make any difference – perhaps fuelled by a sense of hopelessness. She sighed a lot during the interview, got distressed from time to time and would undoubtedly have needed 'reaching out to' in order to receive help.

Some who were struggling emotionally were resistant to the idea of receiving help that was formally identified as therapeutic (such as counselling) seeing this as an indication of personal deficit or failure or only for those with 'problems'. Others thought that they might use counselling services in the future but, for now, preferred to find their own way through.

However some thought themselves that professionals could, and should, have been more proactive in providing help themselves or referring them to other services. One of those who had been for fertility analysis as a teenager felt strongly, with hindsight, that she should have had the opportunity for implications counselling. She had discussed it with her consultant and with the doctor at the assisted conception unit but felt that she should have been given the opportunity (or even been required) to attend counselling as well. She was found to be infertile.

Others too illustrated the complexity of seeking professional help when the subject matter was so sensitive. One teenage female who appeared to have little close contact with any professionals talked of her loneliness and her wish to be reached out to:

.... I don't know how they would go about it, you know, offering the opportunity to talk to someone, but I think it would have been helpful, cos sometimes, you do, I know I'm sat here now and I can't think of anybody I know who knows that they can't have children....

Teenage female 15:16

Two adult males would also have welcomed the offer of counselling – in their case to try and process the impact of possible infertility in general rather than to help with making a decision about analysis:

.... I think there's a lot of stuff that you can't discuss with parents and friends and that but I think you need to sometimes need to discuss with other people. You know, like a counsellor or something like that, I don't know. Just to get some things off your chest and talk about..... I think sometimes it does help just to talk about.

Adult male 16:22

There were also practical suggestions for improving accessibility. Some of those who would have welcomed more follow-up services said how difficult it would be if these were only available at the hospital where they were treated. For some, this would mean lengthy journeys and expenditure of time, money and, for those with physical difficulties, pain and effort:

It's hard to talk about anyway..... I just, I think if there was somewhere closer for me I would make more of an effort to sort of get things sorted out but I think just like I say having more people to talk to me about fertility would be a good idea.

Adult female 18:23

Those who had received follow up services at home, including counselling and support services had welcomed this.

Several referred to the internet as a source of fertility-related information, providing that it was accurate and comprehensible (and hence had professional input). One teenage male thought that internet-based information and support services (including chat rooms) offered an easier route through which to ask embarrassing questions and share problems:

I feel that's better cos then someone like may not be confident talking face to face with someone, so it's better like emailing, maybes, talking through letters.

Teenage male 14:17

At least one reported having considered ringing a cancer telephone help line for similar reasons. There were also references to information obtained through watching television programmes and documentaries.

There was general support for an increase in written information from professionals though with the plea for it to be attractive and age appropriate and for it to *accompany* verbal information rather than to replace it. However some participants said that they would be unlikely to make use of written material and others preferred the internet *alone*.

Making the information easy to access also means making it visible at the same time as discreet to gather. One young woman described having to memorise a website address that she had seen on a poster in a waiting area. One wonders how much that limited her ability to

engage fully in the consultation that followed. She explained the importance of being able to access printed information from the web to supplement verbal information that she received.

A few identified a need for written or internet-based information also to be available for parents and partners both for their own sake and to help their child or partner. Some thought face-to-face services needed to be made available for parents and partners too and that these too should be offered proactively,

....who does the partner go to if they have problems, maybe they don't want to discuss them in front of me because they may have issues that may be upsetting and they want to work through them but who wants to sit and say 'Actually I'm thinking of leaving you because xyz unless something happens'.

Adult male 13:28

## DISCUSSION

Young people going through cancer treatment come into contact with a range of professionals. They are encouraged to engage in discussion and decisions about their treatment and its progress in ways that most will not have experienced previously in professional encounters (see page 92-93, 96). In this study, relationships with professionals and the level of information provided exerted strong influences on participants' feelings of control, self worth, anxiety or confusion. Some felt that their own affect erected barriers to professionals at times and a small number took some 'blame' for not asking more questions. However, most participants placed greater responsibility on professionals than on themselves for ensuring effective contact. This contrasted with their views about relationships with non-professionals as subsequent chapters will show. It also emphasises the importance of professionals being alert to those features of their contact that might promote or maintain resilience and/or lower risk.

While there were many examples of effective relationships with professionals being achieved in relation to cancer matters in general - especially with multi-disciplinary paediatric oncology team members (including social workers) – these were scarce around cancer-related fertility matters. Professionals were less likely to 'reach out' at a frequency and in a style that participants would have welcomed. This led to missed opportunities to 'be there' in the same way that was achieved otherwise (see pages 101-2). Professionals' apparent difficulties in knowing when and how to handle fertility matters, or their avoidance of them, echoes and

extends existing research findings (see pages 17-18). On those occasions (including single encounters) when fertility matters were broached, professionals outside of paediatric oncology settings appeared to fare less well in ensuring that encounters were helpful than did those within. This adds weight to the importance of staff specialising in working with this age group and/or receiving specialised training and support (see pages 18).

Whether professionals were in specialist oncology services or not, there were consistent reports of what had proved helpful or otherwise in professional manner with relation to fertility matters. Participants were also able to anticipate what *might* be helpful. Taken together, these included:

- Professionals that can be relied on to be honest and say things straight but who are also friendly and approachable.
- Professionals that speak clearly, unambiguously and are not embarrassed by the subject.
- Professionals that can be trusted, be that in a first contact or over time.
- Professionals that make one feel safe, reassured and who offer hope (although not false hope).
- Professionals that acknowledge what one is going through and show compassion.
- Professionals that treat service users with respect and as 'primary partners' regardless of whether parents or others are present.
- Professionals that know what they are doing (i.e. competent) *or* who refer on to someone that knows more, if appropriate.

Given the finding in the previous chapter that young people might be more likely to think about 'fertility as reproduction' in the earlier stages of recovery, the use of doctors as the key professionals to raise it during these stages appeared to work well. Where it was raised directly, unambiguously and unobtrusively at regular intervals in the months and years after diagnosis, this was also well received in that it enabled participants either to go into it further or leave it to one side according to need. However, for those where its significance was wider at any stage or where the relationship with the professional was more important than the role – what Kelly *et al* (2004:855) have called 'the person within the professional' - the importance of all members of the multi-disciplinary network feeling confident about 'reaching out' or feeling able to respond was clear.

As well as discomfort or lack of confidence inhibiting professional responses, the findings here suggest that professional conceptualisation of 'fertility as reproduction' has the potential to compromise their ability to be attuned to individual young people. This could be reinforced by any hierarchical or developmental stage assumptions about what young people might understand/find important/be ready for. The lack of attention to the *individual and social meaning* that fertility might hold at different times and in different contexts may in turn obscure any links to broader issues of self esteem, self efficacy and belief systems (see pages 19, 86, 91-92, 105-110) or more specific issues such as body image, sexuality, romantic relationships and contraception. This might also go some way to explaining the paucity of information that was made available on fertility treatment options and the reduced clarity of understanding that some participants reported over time. The lack of psycho-social services in general and the lack of specialist services in particular both during and after treatment may also reinforce any tendency for professionals to adopt a medical model approach to fertility matters as this is then more likely to go unchallenged.

Where information and access to services (medical and psycho-social) were provided *at the right time and level*, participants reported feeling more in control of fertility aspects of their lives and more confident in general.

Finally, these findings indicate the need for greater gender awareness among professionals and in service patterns of delivery. Although there were some aspects of managing fertility issues that were common across gender, there were also clear differences arising from biological differences and from social context that were not always attended to as such.

## **SUMMARY**

This chapter has reported on participants' experiences of contact with professionals. Although doctors were the largest single group with whom fertility matters were covered, it was clear that other disciplines also had an appropriate actual or potential role. This was especially the case for those participants who saw fertility within a social and emotional context as well as a reproductive one. The importance of professionals being alert to the individual and social meaning of fertility for the young people came through strongly. This could be compromised where professional assumptions about its meaning were located within a medical model and/or a hierarchical, staged conceptualisation of human development. Participants' experiences, together with their suggestions for improved professional practices, indicated those professional attributes and behaviours that were likely to promote or maintain resilience



around fertility matters and those that posed risk to associated well-being. The importance of professionals being proactive in raising fertility matters, offering meaningful choices about parental involvement, being honest and clear in information sharing, being approachable, reassuring and respectful came through. It was also clear that there is a need for more psycho-social services in relation to fertility, perhaps building on existing social work and nursing services as well as bringing in dedicated, independent services.

I now turn to the experience of fertility matters being managed outside of the professional context and start with family members.

## **CHAPTER EIGHT**

### **THE IMPACT ON FAMILY RELATIONSHIPS OF CANCER-RELATED FERTILITY MATTERS**

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This chapter looks at participants' experiences within their families. It starts by looking at the impact on the family of the cancer experience as a whole, taking account of such influences as gender, ethnicity and culture where these were raised. This provides the background context within which fertility matters were managed. It then looks in particular at verbal communication patterns within families and with different family members. The possible reasons for, and impact of, 'open' and 'closed' communication styles are explored as are the meanings of independence and interdependence.

At the time of diagnosis, over three quarters (79%) of participants were living in a two parent family (including two who were away at university and then returned home for treatment), one was living with mother and step father and the remainder in lone parent families (all but one of which were female-headed). Almost two thirds (61%) were still in that situation at the time of interview, including a small number who had left home and returned in the meanwhile. Three were only children; most had two or three siblings and a small number had more. Just under half (45%) were the oldest child.

#### **Broad impact of the cancer experience on the family**

Practical impacts, especially during treatment, were numerous. When the young person was living in the family home, there were repercussions around alternative childcare for siblings, transport, parental employment patterns and finances. Some returned home or delayed planned departures. One family had to make childcare arrangements for younger siblings to enable the mother to stay with her daughter during treatment in her university city. Wider family members, friends and neighbours were drawn in frequently to provide support.

Some participants reported strengthening of relationships with parents whereas for a small number it deteriorated. Among the latter, two had pre-existing family tensions and one whose pre-diagnosis relationships were good found that they deteriorated during treatment and this has continued up to the present day.

Many participants talked of the importance of the help and support that their parent(s) gave them:

OK I was twenty, old enough to make decisions for myself but, you're at a very vulnerable stage, and you do like to have reassurance from people who know you and love you. And my parents were the absolute rock, in my experience you know. .... I think it's quite important for people to have their parents or loved ones near to them. I think it does make a huge difference.

Adult male 20:22<sup>10</sup>

I don't know what I would have done without my Mom being there she was. I mean I'm sure every parent's obviously there, but she was really there for me, every second of the way you know..... She was wonderful..... I couldn't have done it without her you know.

Adult female 16:24

Even where there were good relationships, the heightened presence of parents in their lives and/or the parental style of coping were not experienced as universally positive. Parents' needs occasionally, and unhelpfully, overshadowed their own. Sometimes parents read their child's needs inaccurately. Some participants did not welcome their parents' constant presence during hospital stays and felt that this inhibited them in making relationships with others. A few found their presence to be intrusive and running counter to their emerging sense of independence:

..... you're classing yourself as independent at that time, you're trying to get away from your parents as much as possible, to be out with your friends, and suddenly you can't go out with your friends, cos you're being wrapped up in cotton wool.....It's such a strange feeling the way you suddenly get treated, have to deal with things, have to look at the world.

Adult male 15:30

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<sup>10</sup> As previously, all quotes are identified by the category of the participant (teenage female, adult male etc) together with the age at diagnosis followed by the age at interview. Thus, this quote was from an adult male aged 20 at diagnosis and 22 at interview.

Where there were difficulties, these were often not easy to manage, sometimes because of not wanting to upset parents:

For some reason I remember, not resenting my parents because they didn't do anything wrong, they never, but just not wanting them there a lot of the time. I didn't want anybody there, but especially them, I don't know why. It upset me quite a lot after I'd finished my treatment because I was so horrible.

Adult male 13:21

The level of parental involvement was affected to a certain extent by the approach of professionals. As seen in Chapters Four and Seven, many felt that the professionals' approach was 'about right'. For the minority where it was not, it was always about parental involvement being too high. Across the board, parental involvement reduced over time and this was felt to be appropriate. Those who felt they were offered regular, meaningful choices about the nature and depth of involvement welcomed this as a way of enabling them to involve their parents at a level that felt right for them.

Some differences in reactions emerged between parents, often reflecting gendered family roles. Mothers were more likely to have practical and emotional involvement and fathers took more of a backseat. In some families, one member appeared to hold the role of 'worrier' leaving the others (including the participant) to feel more worry-free. Although this role was usually held by the mother, it occasionally fell to the father or grandmother. For one adult male, it passed from his parents to his wife after marriage. Sometimes different coping styles amongst family members emerged with, for example, one parent being more likely to be pessimistic or to show their feelings than the other and so on.

Although many talked warmly about their mothers, their approach rarely seemed to come as a surprise. Where fathers were mentioned, it was more likely to include an unexpected development. Two placed their changed relationships with fathers within a cultural as well as a cancer context. For example, one adult female had drawn closer to her father in what had been previously a fairly distant, culturally common father-daughter relationship:

Asian Dads are a bit more out of the circle so you don't really talk to them, that's not a bad thing, it doesn't mean he's a bad Dad, you just don't talk to them you know, but now it's like I'm so much closer to him, like I can talk to

him about anything, it's like my relationship's grown stronger, it's really nice now, it's like he's my best friend now, so it's really good...

Adult female 15:21

For another adult female, the experience heightened cultural differences between her and her father (he came from a very different European culture) and contributed to driving them further apart. Others reported increased distance that was not culturally informed. One young woman felt somewhat abandoned by her father as he had taken responsibility for caring for siblings during her treatment and saw less of her than did her mother. An adult male felt that his father's philosophy of 'grin and bear it' made him less sympathetic than his mother during treatment and this reinforced a pre-existing relationship distance.

Two females found themselves having more contact with estranged fathers during treatment. Only their fathers were car drivers and so provided transport – in both cases for lengthy journeys. In one case, this resulted in an easing of a previously distant relationship but, for the other, it proved difficult to manage particularly in relation to appointments around cancer-related fertility matters as shown in Chapter Seven.

Many talked of their concerns about the impact on their siblings. Two adult males said that their sisters (both younger) had developed longstanding difficulties that appeared to be related, at least in part, to the cancer experience and, possibly, fertility matters. Both males had become parents (unexpectedly for both) but neither sister had yet done so. This led them to wonder how far this had fuelled existing feelings of jealousy and generated resentment within their sisters towards parents who showed delight at being grandparents.

A number reported feeling closer to at least one sibling through the cancer experience but also in relation to fertility. A teenage male had talked through the decision about sperm banking with an older brother. An adult female had considered using her younger sisters as surrogates or egg donors if necessary and a teenage female had been offered eggs by her sister. Another female talked about the strength that she gained from being close to an older sister and talking at length with her over time about her feelings about her probable infertility, how to tell her boyfriend about this, and alternative routes to parenthood. Another teenage female drew strength and comfort when considering alternative routes to parenthood from her shared experiences with siblings of being adopted.

Another adult female 'shared' her sister's baby during treatment and re-diagnosis and felt that helped her to cope with the fertility aspects. A teenage female also talked of the pleasure that came from having a close relationship with her new baby brother.

In contrast, one adult female had a younger [childless] brother and regretted the shifts in their previous close relationship (forged through various shared family adversities) as he got older. This was made worse as she was finding it increasingly difficult to cope with a growing realisation that her residual physical difficulties may be permanent as might her fertility impairment *and* she had not yet been able to establish a permanent romantic relationship.

Others had never been particularly close to any of their siblings. For example, one adult female's sister had had mental health problems following her diagnosis and treatment which were still not fully resolved. The sister had gone on to have children and appeared insensitive to her sister's involuntary childlessness. One of the teenage females spoke of her older sisters [both with children] being supportive but considered both to have considerable personal difficulties and therefore relatively little to offer.

Some considered that the impact of the cancer experience on family members was greater than on themselves. A few became aware of parents turning to medication, for example, to help them through. Some thought it was worse for others having to look on whereas they themselves were focussed on managing, especially during active treatment:

..... I think they see the pain more, whereas I'm going through it, yes it's hard for me, but I know how I'm getting through it and all they see is me just lying there you know and it's not very nice seeing me attached to all the machines and having chemotherapy, losing my hair and all that.....

Adult female 15:21

This led to a number saying that one of the most difficult parts for them to manage was seeing the effect that the experience had on family members. They often felt guilty about the times when they themselves had 'taken it out' on them.

As time went by, some participants held fertility-related consultations without parents present. Some kept parents up to speed with such discussions and any developments while others chose actively to exclude them. For some this was prompted by the need for privacy within a

basically sound relationship. For others it reflected a poor prior relationship or the need to protect themselves from parents who found the subject difficult to deal with:

They don't even know that I'm going, that we're going to the fertility clinic. It's just, I don't have a relationship with my Mum and Dad that I feel is that great, and I've never been able to talk to them about personal things really, erm, partly because they're not very good, they are not very good about talking about personal things. I don't think they really know how to. But I think there's also a bit of a trusting issue, that I don't trust them not to tell other people, erm, so. And I also don't trust them to know me well enough, to know when not to talk to me about it, and when to stop asking questions. So I've just found it easier than not knowing.

Adult female 14:25

For some, it reflected the changes that came as romantic partners got involved.

There was evidence in some families of positive family adaptation to the cancer experience itself and of 'coming through and moving on' as the journey unfolded:

.....I think everyone's fine about it now you know, we still talk about it, when we were at the children's hospital and all that but it's more kind of like, we've got over it, it's more just like, 'ah yeah it was a bad part of life but we're over it now, so..... with my family it hasn't changed one bit, if anything it's made it stronger, because like we've gone through it, and like I feel I can tell anyone you know, talk to them about anything.....

Adult female 15:21

However, there was limited reference to the effect of fertility concerns on such recovery, perhaps reflecting the infrequent overt attention this attracted within many families. However, fertility concerns were an ongoing cause for distress for some. The adult male not told of his probable infertility until several years after diagnosis spoke about its particular impact on his family:

But my family, if you talk about it now, my family get quite emotional about it, more so than I do, I think, cos Mum's desperate to have grandkids. Erm and I think my Dad gets upset cos I think he sees or thinks that it must be upsetting

for me which it is, but I think he doesn't like to see me upset. And my sister's just very emotional and gets generally upset anyway .....

Adult male 13:28

There were illustrations of the potential for the wider kinship system to aid recovery. As well as finding the presence of infants within the nuclear family helpful, some participants found the same to be true where there were small children within the wider family network. Others found it helpful when extended family members shared the fertility experience, even though non-cancer related:

I found it easier to talk to my cousin cos she's, she hasn't had cancer but she's having fertility problems, so I think I found it easier to talk to her cos she's sort of going through the same thing as I have.....

Adult female 18:23

However, such contact also led to awareness that fertility treatments can be unsuccessful and that was a source of anxiety.

### **Parents becoming grand-parents – loss of a dream?**

Several participants talked explicitly and implicitly about the fact that cancer-related infertility might lead to them not being able to 'provide' grandchildren for their parents. Some were comforted where siblings had already produced children or were likely to do so. Others reported shared disappointment rather than feeling that they were letting parents down.

The impact of the potential loss of being a grandparent affected a small number of parents at diagnosis in ways that were obvious to the young person. One teenage male felt that he was handling the diagnosis alright until he was told that his fertility might be affected at which point he and his parents broke down:

I went in there to be strong, and I thought 'right, come on, I can do this'. And then once he said that, it might affect like the way you have kids and stuff, Jesus, that were like a gunshot that. Started bawling my eyes out and then my Mum started booing and then my Dad ..... he han't cried since he wa' seven and he was close to crying, but he didn't cry, he finds it hard to cry. But .. and that's the first time he ever put like his hand on my back and said



'it'll be alright [.....]' and pulled me into his arm. And like, he's not really like that, he's like a bit, doesn't show his feelings a reight lot. And he's done that quite a lot ever since.

Teenage male 15:18

One strongly pro-natalist father could not cope with his son refusing to bank sperm. This not only left the young man in tears for a day but also threatened to delay the start of treatment until the intervention of the paternal grandmother persuaded the father to stand aside. The young man did not speak with his parents about fertility matters again for many years – an approach driven by his parents but which he welcomed. It became clear how difficult this had been for his parents when he told them of his pending parenthood:

We told my mum and dad before we told anyone else. Me mum was working and she just screamed down the phone. Me dad thought I was lying. Well my mum thought, shut up, and then she screamed and then she were crying. Mum had to sit down and cry. *Partner*. And when they came to visit us in the hospital after we'd had [oldest child] they were in tears weren't they? 'Oh thank you thank you, we didn't think this day would ever come'..... *Adult Male* ... when they found she were pregnant I thought that was enough but when she was actually there [born]. Really grateful. You don't realise how much.. looking back.. I don't realise how, at the time, didn't realise how much me dad did for me.

Adult male 13:25

For most, however, the level of parental distress only became clear with hindsight. It was not always clear how much this reflected their concern for their child and how much the potential loss of being grandparents.

The only other direct report about grandparenthood came from the other adult male who had become a father. His parents had less positive reactions to the news of their son and partner's pregnancy which was unplanned and preceded the couple living together. Major tensions ensued before his partner intervened to remind them that they should be pleased that their son was still alive rather than worrying about whether the circumstances were good for him becoming a father:

Partner: I said 'Look you should be happy that (a) your son's here, because he could quite not easily be and you should be thanking your lucky stars that you're getting a grandchild, you know naturally, not through IVF,..... we're not having to adopt'. I think they'd set their mind to the fact that you would have to adopt, and I mean she got all upset and tearful and whatever, but it brought her round. And I said 'You know you should be thankful that he's here walking around, never mind sort of everything else *Adult Male* Yeah. I think that was the start of it. Then their attitude changed completely

Adult male 15:30

### **Telling and talking about fertility matters with family members over time**

The family is an important site for forming and maintaining communication styles as well as for forming and maintaining attitudes on subjects such as fertility and sexuality. The way in which communication about fertility was managed within families and between family members was therefore an area of keen interest.

A range of communication styles seemed to operate within families of origin. Some pre-dated the cancer experience and, if anything, were strengthened by it while others appeared to be different to their usual patterns. A few (but not many) had changed over time. However of particular interest here is that the communication patterns for cancer in general and fertility aspects in particular appeared to differ in some families but be fairly constant for others.

#### ***Open communication about fertility matters***

There were examples from all four groups of families of communication that was open enough about fertility related matters to satisfy the participant. This was more true for females than males and reflected in part the frequency with which mothers and daughters talked about menstrual cycles, including any post treatment difficulties. However, even though female participants referred to these conversations as examples of openness, it remained unclear how far each party saw them as being about fertility per se. Adult males were the least likely group to talk to parents or family members.

A number had either a prior close relationship with their parents and/or family members or one that enabled them to talk currently at a level and frequency that felt right for them regarding fertility matters:

We're quite a sort of close knit family so. It was really easy to talk to me mam and dad. We got on really well and they were supportive and there wasn't the sort of element of embarrassment that you might expect, having to tell your parents that kind of thing. So yeh it was OK I didn't have any problems with it and I still don't.

Teenage male 18:19

Some families seemed able to accommodate the 'new' need for such discussions by shifting some considerable way from previous patterns in which the subject was never raised or was restricted to, say, discussions between siblings.

Topics discussed included contraception, fears about the risk of transmitting cancer to any future children, fears of being infertile, and concerns about disclosing this information to prospective partners. Conversations were most likely to be with mothers.

In some close family networks, there appeared to be open communication strategies involving many family members. One adult female who had to cope with a second cancer and the strong likelihood of affected fertility (which she found very difficult to cope with at times) reported that her family's response of not ignoring or minimising it helped her through. Even though the male members' approach was more restrained, the fact that they took an interest was nevertheless very important to her:

I always go home and tell me Mam, and generally me sister just cos they're there, what's been said. Me brother'll text us to say how did your appointment go and I'll say 'Champion' and that's pretty much all. Not because he's not interested just because he's a bloke and that's what blokes do. Me Dad's the same when, I'll tell him how it's gone and stuff but I don't really get an opportunity to talk to him properly just cos he works so hard, erm, but then I don't know, me Mam probably tells him as well,.....I talked to me mates, I talked to me Mam, I talked to me sister and they all knew my opinion. And I suppose everyone did the right thing by not going 'Don't worry about it; you'll be fine'. They just kind of went 'Well you've got that opinion, and it's better to look on the black side and then be told the good news'...

Adult female 19:25

At least one parent was pro-active around fertility issues – perhaps because she got pregnant during her daughter's treatment and because one of her own siblings was coping with fertility difficulties. She was concerned to help her daughter develop appropriate coping strategies and did so from within what appeared to be a close mother-daughter relationship. This seemed to have worked well. Fertility was not deeply troubling for the young woman (though of course it may not have been even without her mother's intervention).

However an adult male remembered his parents each trying to raise fertility on at least one occasion but did not want to discuss it with them and pushed them away. Along with some other participants, he was of the view that it should be the young person that decided when it should be raised and by whom.

### ***More closed communication about fertility matters***

Not all participants found it easy (or appropriate) to talk openly with family members about the fertility aspects of the cancer experience and vice versa. Even the presence of close relationships did not necessarily mean the topic was discussed. For some, this was not troubling, including several who preferred to use outside relationships or to maintain silence. Others felt confident that they *could* discuss it within family relationships if they chose to but had not yet exercised that choice.

One teenage female who chose to avoid fertility-related discussions with her family members had got very close to them since diagnosis and had only completed treatment recently. She now wanted to resume moves towards independence that had been interrupted by treatment. This meant putting energy into re-establishing friendships and returning to discussing sex and fertility with them more than with her family. She, as with a few others, also felt that the subject was perhaps more manageable to discuss with friends as she wanted to protect her parents from further upset, including about fertility matters:

I spent lots of time with them [parents] when I was bad, and now I hardly spend time, well I do spend time with them but I'd rather be out with me friends. But like they know that, they know I like to be out with me friends, but because like I'm a teenager, it doesn't mean anything else ..... Sometimes, like, I do have an odd day like getting upset but I just like to keep it to myself you know. Rather than other people getting upset. Especially me Mam and Dad. I hate like crying in front of them or anything, cos I just don't like them getting upset, so..... I just feel that I would rather talk to someone

else because I don't like seeing me Mam and Dad upset, like. So I'd rather talk to someone else because it won't upset someone else you know. .... because they can go, after I've talked to them, they can like be there for us but they can also go back to their own house and just live life.

Teenage female 15:16

This was also true of another female who had chosen to restrict fertility discussions to those outside of her family (especially friends) saying: 'It's too serious for us [family] to talk about'. Although she felt that she could turn to family for support if she wished, in the meanwhile she kept them at bay by saying that she had little interest in children – an approach used by some others who nevertheless hoped to become parents one day.

One teenage male with a generally close relationship with his parents felt that fertility was not an appropriate topic to discuss as it did not fit their family style although he had welcomed his parents' involvement when undergoing sperm banking.

There were others with close relationships with at least one family member who found more closed communication around fertility to be troubling. One adult female had a longstanding close relationship with her mother. They became even closer through treatment. Towards the end, they shared the experience of cancer after her mother was also diagnosed with cancer. However fertility was never broached in the aftermath of treatment and she talked with some regret of keeping her mother and other family members at bay by affecting disinterest in, or avoiding discussions about, children (as with the female above). Similarly an adult male, this time from a lone parent family, who appeared close to his mother did not talk to her or anyone else about fertility even though it distressed him deeply. Both appeared to locate the reasons for their closed communication within themselves rather than their family's communication style.

Another female whose previously close relationship with her mother did not survive into her adult years regretted not being able to talk with her. This was especially upsetting as she had not felt able to talk with others either about the major impact that fertility impairment had on her. It was not clear where the barriers came from.

Some talked of the difficulties that arose in apparently sound relationships when parents (in these cases mothers) acted inappropriately around fertility matters, leading the participant to control communication by shutting it down. One teenage female was affected so adversely

by her mother's negativity about her future that she opted to talk more to a few close friends and her boyfriend about fertility issues. She also hoped that this would have the spin-off of protecting her mother though this was a secondary reason:

..... if someone else raises it then that starts me thinking about it and then. It's as long as it's out of my mind I'm not bothered about it. It's OK. And as long as I know that when I am ready to talk to someone, I can. It's OK but I don't like other people bringing it up as much, at all. Especially not my mam. It's harder to talk to my family than it is to talk to friends..... when I think about my fertility, I don't really want to talk to my mam about it .... she doesn't look at the positive side as much, whereas my boyfriend is the most optimistic person in the world and just says 'Well there's not going to be any problems, it's going be fine'. And that's what I want to hear when I'm away from the hospital, so....

Teenage female 18:20

For another teenage female, her mother's desire to talk with her about fertility caused a different set of problems. This mother appeared so preoccupied with making her daughter 'feel better' that she minimised the impact of (in)fertility with which her daughter was struggling. Other female members of her extended family used similarly insensitive approaches by downplaying the importance of motherhood and stressing the value of having a career, even though this was not the role model that they themselves offered:

I remember I would go back and I would tell my Mum what had been said because obviously she wasn't there, and I would say to her and she would obviously be upset that they'd said I wouldn't be able to have children, and she would say 'It's not the be all and end all you know, there are more important things in life'..... So we have this thing now, ... I just said 'I'll talk about it with whoever I need to talk about it when the time comes when I want to have children', so we just don't talk about it anymore. ....I know they're trying to make me feel better, but it just makes me feel angry..... my Mum says 'You shouldn't be angry about it, you can't blame the doctors, you should just be grateful for what they have done for you' and yet trying to explain that I'm not ungrateful, I'm really, really grateful, I just feel that I wasn't warned about it. .... I wasn't able to prepare for it and then when I was told, not enough was done.

Teenage female 13:19

For others, silence around or avoidance of the subject appeared to be more a reflection of a prior (or developing) distant or uneasy relationship with parents or family even where good levels of support around cancer were present.

One of the adult males who had failed to bank his sperm thought his previous relationship with his family had been 'good enough' even though his father in particular was very reserved. He chose not to confide in them (or anyone else) - even during one particularly strong reaction to his probable infertility following the birth of a baby to a family friend when he was in his mid teens - until meeting his long term partner. He speculated that this reflected his family's communication style as, like some others, the subject was never raised until he informed them of the research study at which point his mother urged caution about his participation:

I remember being quite resentful of my Dad's friend [who had a baby], and quite resentful of everyone for me not having given a [sperm] sample, and very like being angry about it, but that, I don't think it lasted very long, I had a few like silly crying sessions and stuff just on my own, I've never spoken to anyone about it and erm.. well I've probably spoken to my girlfriend about it actually.. but not my parents or anyone. It was just something that I had to let go, cos you can't really talk to your friends about it.

Adult male 13:21

One of the adult females who had never had a close relationship with her parents remarked that they asked her regularly about her physical state but never about her emotional well-being. That pattern had continued to present day although she had instead drawn closer to an older sister with whom she confided at length about fertility matters.

Finally, for a few, a previously distant relationship with family members improved through the cancer experience. One teenage female had envied a friend's close relationship with her mother but felt that her own had improved through the cancer experience, including being able to encompass fertility discussions.

## DISCUSSION

As one might expect, there were some common themes running through participants' accounts of the ways in which the broader cancer experience was experienced within families. These, together with experiences that were more divergent, provided the backdrop against which the impact and handling of fertility matters were explored. As in previous chapters, analysing the findings with a view to identifying those features within families that presented risks or promoted/maintained resilience proved valuable.

In keeping with existing research, participants talked of increased physical and emotional closeness with their parents - especially their mothers - through the treatment phases (see pages 101-103). The closeness with mothers was rarely recounted with surprise but any reported changes in relationships with fathers were more likely to be either unexpectedly positive or predictably negative. This adds to the sparse existing research about fathers. Relationships with siblings were often reported as a source of concern, especially where participants felt guilty at the effect of their illness and associated behaviour on them (see page 101). However the ways in which fertility matters were handled within, or otherwise affected, sibling relationships has not been reported before. In relation to this aspect, they were perhaps more likely to provide sources of comfort and problem solving. Older siblings in particular sometimes acted as confidantes, supporters and advisers on fertility matters as well as, or in addition to, parents.

Parents' roles in managing, translating and employing information with, or on behalf of, their children have been well documented. In this study, these roles extended for some to decision-making and other consultations around fertility matters at around diagnosis. However there was some indication of the need for relatively early shifts towards greater autonomy and privacy given the potential for parental presence to prove inhibiting when such sensitive issues are raised (see pages 20-22, 92-93, 96). For many, the level and style of parental involvement in fertility matters worked well, especially when professionals took the initiative to enable the young people to exercise choice more freely. Where it did not, tensions often pre-dated diagnosis and persisted through treatment and beyond.

As participants were off major phases of treatment at the time of the interview, all had experience of re-negotiating family relationships in their wake. For the most part, this did not present significant difficulties even though many were still living in the family home at interview (including some that had moved out and back again). It may be that the increase



in 'extended transitions' within the wider population of young adults (see pages 82, 86-87, 93) aided this as several indicated that others in their peer group were also still living at home.

Ongoing closeness within family relationships, including in extended family networks, proved satisfying for many as did positive affirmations of what each had done for the other through the cancer journey. This appeared to reflect interdependence through reciprocity rather than over-dependence (see pages 101-102, 107-109). Any strains in re-negotiating family relationships were likely to centre on fears about the future (including around fertility matters) and differences in the extent to which participants and their parents wanted to revisit the past cancer experience and/or talk about their current or future situation. This matches patterns that have been reported on other aspects of the cancer experience (see pages 106-107) although attention to fertility has rarely been reported previously. Where there was an absent parent (i.e. a parent who was still alive but not living in the family home; in this study these were all fathers), the potential for difficulties appeared greater. Absent fathers were sometimes involved in follow-up appointments that included fertility-related discussions. This presented difficulties where the young person did not feel in sufficient control of the situation.

The particular threat to the family life cycle from the potential loss of its next generation was evident in some cases but marked by relatively little open discussion. Indeed, patterns of communication around cancer-related fertility matters in general appeared to differ from those about wider cancer matters with the former being more closed.

Where closed patterns around fertility matters reflected participants' use of protective communication (see pages 102, 113) aimed at the avoidance of distress to parents or family members, this worked well. In these situations, professionals, friends or partners were sometimes used for support. Similarly, closed communication patterns worked well when the participant had not felt troubled by fertility concerns and hence had not felt the need to talk with family or anyone else. They also appeared satisfactory when any decision to talk to people outside rather than within the family was taken because this felt more appropriate or helpful. This is picked up further in subsequent chapters.

Where communication appeared to be more guarded (see page 113) than protective, this indicated a more worrying situation. Some participants had a deep-seated level of distress around fertility which they had difficulty in sharing with anyone. Some found their parent(s)'s reactions upsetting (even if well-intentioned) rather than comforting. For example, some felt that parents tried to dismiss or minimise their reactions. For others, the lack of sharing

appeared to stem from feelings of hopelessness about the ability of anyone else to understand, fear that they may not do, or, perhaps, fear that speaking aloud about it might make it even more 'real'. In some families that adopted closed communication, it was not clear whether family members were colluding in the silence, not aware of any unmet need or waiting for explicit 'permission' from the one affected.

Some families communicated openly about cancer-related fertility matters. This appeared either to reflect pre-existing patterns around sex and fertility discussions within the family or to have developed as a result of responding to the new concerns around fertility preservation, sex, contraception, romantic relationships and fear of transmission to any future children.

## **SUMMARY**

This chapter looked at the way in which the overall cancer experience was managed within families and then turned to specific experiences around fertility matters. Where participants felt in control of the level at which their parents and family members were involved externally and internally both in the past and in the present, this was experienced positively and appeared to promote resilience. Patterns of communication and support were less important to well-being than whether or not they met the needs of the young person. Thus, families who operated closed or fairly closed communication about fertility matters could prove as supportive for participants as could those who were more open. Where participants had alternative or supplementary sources of support available or where they were not troubled by fertility concerns, this too appeared to help. Of most concern were those who were troubled and not able to discuss their concerns within or outside their families. Reasons included poor pre-existing relationships, insensitive or inappropriate reactions by family members, lack of being 'reached out' to or feelings of hopelessness about the usefulness of sharing concerns. As well as whole family responses, those of individual family members contributed to positive or negative experiences. Reactions of fathers were more likely to come as a surprise than were those of mothers. Siblings were more likely to be sources of help than concern in relation to fertility matters.

I turn next to the findings of how friendships and similar relationships were negotiated.

## **CHAPTER NINE**

### **THE IMPACT ON FRIENDSHIPS OF CANCER-RELATED FERTILITY MATTERS**

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Friendships are key sites for discussing matters to do with sex and relationships as well as experimenting with, and getting ready for, entering such relationships. This chapter starts with exploring the impact of cancer and possible cancer-related fertility impairment on friendships and goes on to look at 'telling and talking' patterns within those relationships. Friendships across education, employment and social spheres are included. Responses are drawn from the wider context of the cancer experience as well as from specific references to the fertility matters.

#### **Impact of cancer and cancer-related fertility impairment on friendships**

There were perhaps three main themes that held true across both cancer and fertility matters though were not necessarily co-terminous for each:

- (i) A range of reactions amongst friends were reported – some withdrew while others remained steadfast.
- (ii) Reactions of the individual with cancer towards friends differed over time and context – some wanted their friends to be around throughout; others did not.
- (iii) Friendship patterns changed and/or had to be managed as circumstances changed – for example, re-entry to education or employment; moves to new educational or social settings; receipt of new medical information.

The reactions of friends were reported as both immediate and longer lasting. Some participants had good levels of support in general throughout their cancer journey and found that helpful. For a small number in the early days the presence of friends normalised, albeit briefly, a very abnormal time. This helped with managing the immediate impact. A small number found that their friendship circle grew initially but then fell back after diagnosis. A similar phenomenon was reported by some when they re-entered education. However others found that friends quickly dropped by the wayside once treatment was underway for various reasons, including difficulty in coping with illness, geographical distance from hospital and so

on. Sometimes the young person themselves did not want contact, especially during treatment, if they felt too ill, out of sorts or did not want to be seen in a changed physical or emotional state. There were times when infection control concerns interrupted contact. The resulting isolation could prove difficult to handle especially if having friends to play computer games or watch television with and so on was an important source of distraction, confidence building and 'normality'.

Some established new and important relationships with others with cancer. Sometimes these were fairly short-lived – especially where geographical distance made it difficult to maintain face to face contact or where one or other wanted to distance themselves from their shared cancer experience. For others, they were longer-standing important sources of enjoyment and support.

Even though many friendships fell away, some found that a core of prior close friends remained solid throughout treatment and beyond. Where this was the case, it often proved an important source to aid coping with both cancer and cancer-related fertility matters.

Some understood why friendships faltered, did not take it personally and were able to re-establish those relationships at a later stage, if they so wished:

..... they [friends] just found it really difficult and they didn't like it when I talked to them about it [cancer], they didn't like it when I said 'I feel absolutely shit today, I feel really, really down, I just don't want to see anybody, I just don't want to do this'. They didn't like it when I talked like that. They said to my other friends 'I don't want to talk about it with her cos I just don't want to' and they feel uncomfortable. ....but afterwards, now, they're OK about it cos it's not like the centre of everything anymore.....

Teenage female 15:20

For some of those whose primary motivation after treatment appeared to be returning to 'normality' – what I have called 'active recovery' in Chapter Six – re-entry to peer groups appeared more important than any feelings of resentment to those that had 'deserted' them.

Many of those still in education talked about the impact of the educational setting on friendships. Several faced decisions after treatment about whether to return to the same year group, which subjects to drop/retain and so on and felt apprehensive. Others had the

decisions made for them. A small number kept going to school throughout treatment. Most returned to their previous educational setting, either so that they could be back with friends or (less frequently) so that they could be in familiar surroundings with staff that would understand and support them. Where possible, they opted to return to the same year group and welcomed this even where it resulted in them studying for fewer subjects and/or needing additional teaching support. One teenage female was able to return to her year group and friends by having a mentor allocated and dropping some subjects. She used her friends extensively to support her on both cancer and fertility matters. However a teenage male in a similar situation was relieved when his special help ceased as it enabled him to feel less 'different' even though it also increased his academic struggles. He too discussed both cancer and fertility matters with friends but difficulties with the latter were leading him to be increasingly selective in what he disclosed and with whom.

Those that returned to a lower year group were more likely to report negatively on the experience. Some found it particularly difficult to establish new friendships; some talked of feeling different to those around them as a result of their cancer experience as well as age. For one male in particular this brought the added tension of having two friendship groups – one in school and one of older friends outside of school:

So when my hair grew back and I was back out nightclubbing and clubbing, the friends that I had at school were good friends for the canoeing, for football, for sports, and for schoolwork. And then on an evening I met other friends that I knew from work, part-time work, and that I knew from sixth form .....

Adult male 13:28

On reflection he also thought that he lacked the maturity or perspective to recognise the negative impact that the tales of his cancer experience or his desire to show off his potency-related prowess had on the school friends in particular:

..... they obviously didn't want to discuss things and you know part of my initial naive understanding of being infertile was not being able to get an erection. And, er, you know, that wasn't the case so, I was still able to, to have fun so to speak. And I suppose my wish at that time to point that out, be boisterous about it with friends was probably quite high.

Adult male 15:30

Among those who felt sure that their fertility had been affected were some who felt that this in itself erected a barrier with friends. A number looked forward to a time when they might have friends outside of the cancer circle that also faced fertility difficulties (only one had yet done so - a school friend had amenorrhoea and this led to supportive conversations until her periods returned and the subject was never re-opened). They anticipated that this might happen only as friends embarked on trying for parenthood. Some hoped that the common ground of shared fertility difficulties would then lower the barrier of not sharing the cancer and cancer-related fertility experience.

Others were less sympathetic to their existing friends' reactions. Some continued to feel angry, upset or resentful about them (or came to feel so), even some years on.

Finally, one adult talked of times when he feared that others may not want to have contact with him because he had had cancer – and this was hinted at less explicitly by a few others:

To have close contact with me, yes it worried me, because they wouldn't want to be associated with someone who has cancer or who's had cancer or that sort of thing..... All of a sudden you're something different and you're something that needs to be protected or put to one side or... and in some ways I aided that by trying to be different myself but I didn't want to be, erm, and so you.. .. Yes I did think that people avoided me because I had cancer

Adult male 15:30

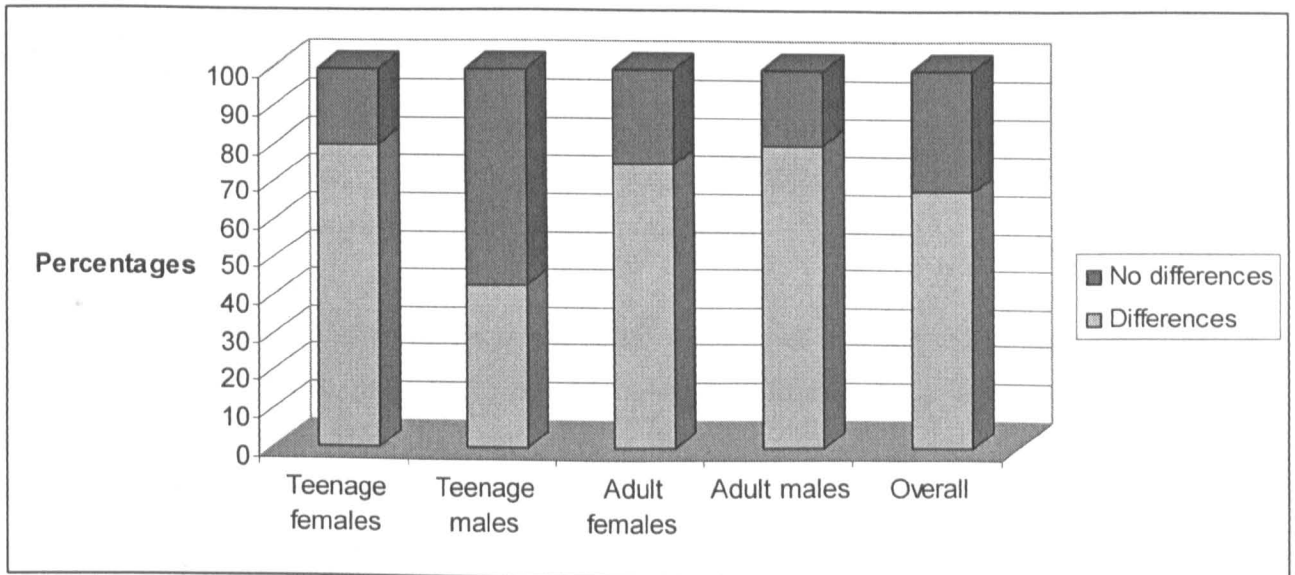
## **Telling and talking with friends and others**

### ***Overall patterns***

Different verbal communication patterns emerged around cancer to those around cancer-related fertility impairment. Participants divided into two broad groups (see Figure 8):

- (i) those who approached talking about their possible cancer-related fertility impairment with friends very differently than they did talking about cancer in volume or manner – 9 (75%) adult females, 6 (67%) teenage females, 8 (80%) adult males and 3 (43%) teenage males – i.e. 68% overall.
- (ii) those who were not aware of any particular differences in their approach to communication – 3 (25%) adult females, 3 (33%) teenage females, 2 (20%) adult males and 4 (57%) teenage males – i.e. 32% overall.

**Figure 8: Differences in verbal communication patterns with friends about cancer and cancer-related fertility**



Not surprisingly, the volume of conversations about cancer and about cancer-related fertility was markedly different. The majority in all except the teenage males group also reported different patterns of approaching ‘telling and talking’ with friends about cancer-related fertility than were present with cancer. While all were likely to be open and willing to talk about their cancer experience, this was far less true of fertility aspects – i.e. where a difference was reported, it related to more closed communication about the latter. Those who reported little difference in their approaches across both topics were more likely to be open than closed.

With regard to cancer and its treatment, those closer to treatment were still, on the whole, having fairly regular conversations about them. These were predominantly about the more commonly understood side effects such as hair loss, weight loss and nausea. Those further off treatment were less likely to have such conversations though most, but not all, were happy to do so if they came up. Those with visible side effects such as artificial limbs were likely to be asked about the cause of these at any stage. In all instances, conversations were a mixture of self instigated or ‘other’ instigated with most participants preferring the former (this is returned to below). Of course there were variations around this with some avoiding discussions at any stage, some trying to avoid them increasingly and some whose friends appeared to avoid the subjects.

Where cancer-related fertility issues were concerned, the picture was very different. The majority reported that these issues were discussed with only a small circle of friends, if at all.

This appeared to result from a mixture of participants' preferences and the frequency with which cancer-related fertility came up relative to cancer itself. The likelihood of fertility being discussed within only a small circle of close friends did not differ on the whole over time, according to self-assessed personality or according to the level of concern that the person affected was experiencing. For example, some of those that reported having a generally open personality adopted a more closed stance on fertility issues whereas others remained open across both areas. Overall, fertility discussions were more likely to take place with friends or romantic partners than with family members.

However, the communication balance appeared more even within the teenage males group. This does not, of course, mean that teenage males *are* more open. In this small group, it was also possible that the pattern reflected a more restricted categorisation of friends in that they appeared less likely to separate friendships into 'close' or not.

There was no apparent difference in communication patterns between males who banked sperm and those who did not, noting that proportionately more teenagers than adults banked sperm.

### ***Telling and talking patterns with opposite gender friends***

While most seemed to talk about cancer-related fertility matters with friends of the same gender only, some did so in mixed gender friendships as well. Two females had made use of male friendships to test out whether or not males could contemplate having a relationship with someone who was infertile:

..... they [boys] don't really realise it ... but I try and ask them loads, not loads, just little things like 'Do you want to have k...?' if it comes into the conversation, and they'll go 'Yeah I'm going to have loads of kids' you know, and you just see what the.. and usually it's really weird cos I always think girls always think about having kids but lads as well do, they always know, do you know what I mean?

Adult female 15:21

### ***Telling and talking in friendships specific to the education or employment context***

Another setting that affected communication patterns with friends was education and employment.



Although some participants *said* that they did not mind talking about fertility, the reality was that they found this difficult, on the whole. This included when faced with new situations. For example, an adult female who had been required to drop to a lower year at university and found it difficult to break into well-established friendship groups had not told anyone about her probable fertility impairment until the day of the research appointment when she disclosed to one friend.

For many who returned to their previous school, their illness had often been widely reported so there was no choice about the cancer experience remaining private. Some were happy about this with a small number relishing the high profile that it afforded them. Others worked hard at becoming 'one of the crowd' again. As the fertility aspect was less widely known, the option to retain privacy about this was available and many took it. For some, this was because they had not had a close prior friendship group and this continued; for others this represented a change in their use of close friends. However, one female had not had the option of privacy in the wider school context as another girl in the same school had cancer at around the same time and it became known that her fertility may have been affected. This led to her having to field questions. This proved stressful at times, though was helped by the fact that she understood herself unlikely to have been affected.

The small number that had chosen to change their educational setting were able to decide for themselves who to tell - both about their cancer history and about their potential cancer-related fertility difficulties. This appeared to work well. However those who were at a transition between educational contexts at around the time of treatment were less likely to report positively about the 'choice' this offered about how to handle their history.

Some found that the formal classroom space also had to be managed. This too affected relationships. A small number had chosen to talk and/or write about their cancer experience as part of classroom presentations. None included reference to fertility (including one who had banked sperm). One recalled a taught session on the reproductive system in which the teacher asked how many children everyone wanted. She described herself as a very open character and she opted to be honest in her response, with some regrets:

.... here I am doing health and social care. And I was sitting doing about reproductive organs and doing about the growth of children and the teacher asked 'Who here, how many children does everyone want?' and I went 'I'd be

lucky if I can have one. I just want the one'. And the whole class was dumb struck and I was like I shouldn't have said that, you know.

Teenage female 15:17

There were also work-related relationships to manage. One teenage female had a part-time job as a barmaid, where knowledge of her cancer and related fertility problems was widespread. Some of the [male] regulars joked with her using sexual innuendos about how they might help her overcome the latter. She found that worked well for her:

And then I had like all these blokes saying 'I could get you pregnant, you know'. It's like, 'whatever'.... I know it's a serious subject but I can't take it seriously. I mean I'm 20 year old. What's there to take seriously?

Teenage female 15:20

Others that had decided to be open with colleagues and friends in their workplace found this to be manageable, on the whole. Some reported positive hoped-for outcomes including, for a few, that their openness might avoid them having to go through the anxiety of deciding when to disclose in any future romantic relationships arising from the workplace (see Chapter Ten). However, others had opted to keep either the whole experience private or only to disclose about the cancer.

### ***Telling and talking to others with cancer***

Most in this study had not developed friendships with others who shared the cancer experience. This was for a variety of reasons including that they spent little time in hospital, they were too ill when on the ward or that social contact was inhibited – either by the constant presence of parents and family members or being in a side ward. Some made friendships that were not maintained as one or other wanted to move away from their shared history. A small number, especially among the teenagers, maintained longer lasting friendships and found that helpful. These had often been strengthened by shared attendance at events such as the Teenage Cancer Trust 'Find Your Sense of Tumour' conferences.

Where such friendships were established, there were varying experiences of fertility discussions. For many, it never came up as a topic; for others it did and was fairly intense; whereas for a third group it was raised but the conversations did not develop very far. As elsewhere, this was only a problem for those whose needs went unrequited. A small number speculated that such conversations might increase within existing or new such friendships as

more became aware that they had been affected or as they got older and found the issue more pressing.

### ***Managing conversations with friends about parenthood***

Some areas of discussion in friendship groups had the potential to carry particular challenges regardless of whether participants had disclosed to friends. Talking about parenthood plans was such an area though it was only mentioned directly by females.

Some found that friends could be hesitant to talk about children and/or motherhood once they knew that the participant might have fertility damage. One had started to take the initiative herself when this came up and encouraged her friends to talk openly as that is what she preferred.

Some females had friends who had become pregnant. This was the case for one adult female who was sure she was infertile and whose friends were aware of her situation. Her friend was finding the sex of the unborn baby difficult to come to terms with following a scan until she realised her good fortune relative to the participant. From that point onwards, she was able to 'share' her pregnancy and went on to involve the participant in the child's upbringing. Another spoke of having to put her own feelings of distress to one side when a close friend got pregnant in order to 'be there' for that friend.

However, a teenage female who had told only one friend found it increasingly difficult to cope with conversations in which tentative parenthood plans were shared. Not only did she report that they were happening more frequently (even though she was still in her teens) but she had also had confirmation since the end of treatment that she was indeed infertile:

.... people do go 'I want three children', or 'I want a boy first', and only the other day, I was laying on one of my flatmates' bed with her and we've got an old flat, very, very cold and we'd got hot water bottles up our jumpers to keep us warm. We're both lying on a bed and she said 'just see it in a few years time, this could be us but we're pregnant'. It was just a throwaway comment, and I laughed and said 'Oh yeah' And I just thought 'No that's not going to happen'..... That is one of the biggest, you've got your head saying 'Oh for God's sake, pull yourself together. Having children isn't the most important thing and a bloke is not going to run off screaming when you tell him'. But then you always have this fear that it will happen

As was the case with other aspects of their lives, those facing a premature menopause reported particular challenges. For some, conversations with friends prompted them to think about the speed of their biological clock. Some tried to be sensitive to friends' needs to talk aloud about their tentative life plans then dealt with their personal distress in private afterwards.

The fact that males did not refer to conversations about parenthood plans with friends did not mean that they did not think about parenthood as is clear from Chapter Six. However for males, especially when younger, it was conversations around virility that were more likely to be cited as posing challenges:

Yes, I think in your teens it's not about fathering a child I think. Well, it's not even, virility is not sort of like a subject of discussion but there's something, it crops up and I think that in teens people, particularly boys are nasty to each other.....we weren't nice to each other when we were younger. And you sort of.. it's an area of weakness... it goes back, I think virility, it's one of the most important things to men at a base level you know. I think it is one of the most fundamental things that goes through you as a boy ... I think at that age, sex talk all the time you know, and I think then at that age virility and potency and everything else .... no-one distinguishes between that and say sexual prowess ....

Adult male 13:28

### ***Conversations instigated by self or others***

Differences in verbal communication patterns between cancer and cancer-related fertility impairment were present regardless of whether these were instigated by participants or friends. Many, especially males, said that fertility was not a subject that friends brought up much, if at all, thus mirroring their experience with family members and professionals as seen earlier. Where it was raised, it appeared more likely to be driven by curiosity than concern for well-being. A number of females reported being asked, for example, about whether or not they had stored their eggs and/or what they intended to do with regard to the use of fertility treatments.

A small number of both males and females thought that friends or colleagues did not raise the subject (if they knew) but waited to be given the 'green light'. While most found such an approach to be helpful, a small number would have preferred their friends to raise it. One teenage male talked of his sense of relief when a friend raised it as a result of media coverage:

..... We were coming back from the [shopping] Centre one day and me mate had picked up this magazine from somewhere about cancer and whatever cos he was worried about me or whatever and he just read up. And he said ..... 'Is it true that it does affect your reproductive systems and things like that?'. ..... and I said well, this and that. And he's kept it quiet and everything like that. But it did help me saying that to me mate and everything. I could get it off me chest and everything. .... It did take a bit of confidence for me mate to actually come out and say that to me and everything. But it was good like to get it off me chest and everything like that. And I said I can still do it now but I don't know if they are swimming or whatever.

Teenage male 15:17

An approach employed by several males and a smaller number of females when talking about their cancer experience was to use humour. They often did so to detoxify difficult subjects such as hair loss, loss of stamina and others' tendency to imagine the worst. Only two – a teenage male and a teenage female – reported using fertility-related humour with friends. Both took a very open stance on fertility matters as well as cancer and reported feeling in control of their use of humour, i.e. it was to aid recovery rather than being used against them:

.. and the thing about the fertility sort of like, all me friends know, that that was a possibility so we make jokes about it all the time. It doesn't really bother us at all. It's quite easy to live with, so that's good.... I think there is an episode of 'Only Fools and Horses' where they call Trigger a jaffa cos he's seedless. Which seems to be the running joke at the minute. But half the time I instigate it so. I don't mind at all.

Teenage male 18:19

However, humour about sex and fertility within friendship circles more generally could be a source of discomfort or distress. This was especially so where the participant had not disclosed his situation, felt little or no control over the situation and where the humour itself drew on stereotypes:

..... I knew they [friends] weren't doing it to be upsetting but secretly I actually thought 'God, if they're making these jokes, you know, there's a possibility that I can't and this is what we all think of people that can't have them'. Then that sort of was quite difficult at 16, 17, erm, you know, and I was going out with my girlfriend at school then and I suddenly thought 'Oh my god, what happens if she finds out; she's probably gonna think..'. ..... although on the outside I was probably laughing, on the inside, I was actually quite upset. I think it just sort of brought it home that actually, that would mean I was different and having already been different cos of having no hair and being in a wheelchair, I just sort of - 'Not again. I could be doing without this'.

Adult male 13:28

For some this appeared underpinned by a feeling that infertility was a stigmatised state and this is returned to later. For others, it appeared more to reflect the seriousness with which they personally viewed both fertility impairment and its implications. Thus, one adult male who was struggling increasingly with his probable infertility said that he had used humour extensively when talking about cancer. However he had only ever talked to his parents and one close female friend about fertility matters. He said that he would never contemplate using jokes around this subject:

..... it [cancer] is something... I made a joke of it in a way. Even like when my hair were falling out and people were seeing us like. ..'Look don't use Wash and Go shampoo'. It's wicked but then I'd pull me hair out and people were going 'Oh, what's wrong'. 'Me hair's just falling out'. It's something in a way I've just always made a laugh and a joke about. Cos that's been the easiest way to me.... it's my way of getting through it. To me it's been and gone and no point in seeing the bad things about it..... I don't think that's [fertility] something that I've told anyone. I think that's something that's my own thing. Everything else is a laugh and a joke in a way because it's... but this .. isn't. This is serious. I mean obviously it's not a laugh and a joke

having cancer, but. I think that's [fertility] one of the special associations, that's not a laugh and a joke cos that's something that can affect your life.

Adult male 16:22

Some had the experience of being in a setting shared with friends when fertility had been introduced indirectly – usually through a television programme. One teenage female was watching a late night television documentary about childlessness with a friend at university and became upset. The disclosure that followed did not lead to either her or her friend returning to the subject afterwards, much to her regret:

I only told them cos we were sat watching the telly one night, and we'd been out and it was the early hours of the morning and it was some documentary about people who can't have children and I got upset about it, you know and if it hadn't been for that I probably wouldn't have told them. And even then it's never been brought up, it just gets shoved under the carpet, no one wants to discuss it.

Teenage female 13:19

An adult male was older when he disclosed to a male friend as a result of watching a television programme together. This had a better outcome. It came at a time (in his 20s) when he was starting to think seriously about taking a 'risk' and telling some close friends. He was able to build on that disclosure and tell others, though still with some caution, and saw it as a turning point for becoming more open and better able to cope.

### ***Changes over time***

Some adults described how conversations with close friends developed over time to accommodate the changes that came with growing up. In some cases this led to shared strategies for managing the participant's potential childlessness – for example through greater involvement in helping friends to rear their children (see above and similar examples within family relationships in Chapter Eight):

There's a very solid group of six of us including meself, and we've grown up together, I mean we've grown up in the same village, we've been together since we were little babies, a lot of us. ... They've always come in to see us and they've known what I've been going through the whole time.....

and I suppose I would be the Auntie to a lot of them [their children] because we're that close, no matter what.....

Adult female 19:21

However such references were often accompanied by the comment that others could never understand fully the impact of fertility impairment, no matter how sympathetic and supportive they might be. This sense of a difference lurking not far below the surface was voiced more often by adults, especially those without children:

.... you don't have or you're not aware of many of my friends being in a similar situation. ... a lot of my friends, although supportive, none of them really understand what I might have to go through, what I have gone through. Erm and I think...it's just so strange cos I do feel slightly, not isolated that's the wrong word, but out of my friends there's no one that's in that same position. I mean there might be, I guess, but generally speaking all the ones that weren't families seem to be having families and I think there will come a time if I'm the only person that isn't able.. certainly isn't able to on my own without some sort of treatment then I think I'll find that probably quite hard.

Adult male 13:28

For some, previous levels of distress appeared to have lessened over time leading to a lowered need to discuss the issue with friends.

### **Factors influencing the decision about who and what to tell**

There were some who said that they had never talked to friends because they felt no need to discuss the subject. This remained true across their other relationships, for example with family members. Among the remainder, there were various factors that appeared to affect decisions about which friends to tell and when.

#### ***The presence of supportive friends***

Among those that had a core of friends whose support had been relatively unwavering, most said that they had not even considered holding back on sharing this aspect of treatment regardless of age or gender. This appeared to provoke little anxiety, especially for those who



described themselves as having very open personalities, coming from close knit communities or where the existing culture of their friendship group was reported as being very open.

One such adult male found the support from existing and new close friends to be invaluable, especially that from other males:

And my housemates [at university] knew, as well, which was quite an important thing as well. Because I was close to them as well. They were boys; I don't know if that makes a difference. It probably does actually. .... In that they would have similar concerns if it happened to them. They could identify with it yeah. .... I talk about it quite openly with my friends, my new friends here [current situation] who never knew I had cancer, they all know.

Adult male 20:22

Where friends and colleagues had taken an interest *and* were able to handle the information that was shared, this too had a positive impact. For some who were more hesitant about sharing fertility-related information, evidence of friends' ability to handle cancer-related information encouraged disclosure of fertility aspects as well.

Positive experiences of disclosure encouraged some to carry on with being wholly open and/or to widen the circle that they told. For example, one teenager valued drawing from a range of friends in order to avoid any one individual feeling too overwhelmed. This led to her being open with relatively large numbers:

But like me friends in school, like I tell them like when I'm thinking about it and that and when I'm upset and everything. I tell me friend, I just talk about it and then it's over. And then I just have a good cry and then it's over and then it doesn't come back for a while so. ...

Teenage female 15:16

However a small number with close friends rarely, if ever, talked with them about fertility matters. Sometimes this was because it was not an area of particular importance or concern for them, sometimes it was because they found it too difficult a subject to raise or discuss, even though troubling.

### ***The impact of adverse reactions from friends and colleagues***

There appeared to be more divergence among participants with regard to the impact that adverse reactions by friends and colleagues had on disclosure patterns. A small number opted for being upfront regardless. Others were more likely to withdraw when the subject met with awkwardness, avoidance or inappropriate humour about cancer or fertility:

With my friends at home, they didn't handle me having cancer very well. They didn't have a clue what to say and it was .... I remember people in town actually crossing the street to avoid me so they didn't have to talk to me, erm, which is quite difficult, erm. Friends would avoid me cos they didn't know what to say, and I pretty much lost contact with most of my friends during the treatment. Erm, didn't really get any support from them. They couldn't handle it themselves I suppose. Erm, so I didn't speak to any friends at home about any of it [including fertility] really... .. I suppose from those experiences I just don't have friends that I talk to quite in depth about things.

Adult female 14:25

Resulting damaged links were not always re-established. This sometimes also affected participants' likelihood of telling others.

Where recovery from the cancer experience did not embrace a need to return to 'normality' (see Chapter Six), the lack of shared priorities with previous friends also seemed likely to lead to decisions not to discuss cancer-related fertility matters. However some were driven more by trying to temper what they said in order not to upset those around them. This too inhibited their willingness to share fertility matters.

### ***The need for self protection***

Some participants limited discussions about fertility or changed their approach in order to avoid getting hurt by others' lack of knowledge and/or potential insensitivity. This sometimes enabled them to feel more in control, mirroring for some their approach to verbal communication with family members:

Pretty much everyone that knows me knows what I've been through [with cancer]. ..... They don't know about my fertility side. .... But serious things like my fertility or like this other lump are only people that are really

close to me that I talk to. And it's only when I'm ready to talk, I don't bring it up very often. It's only if I'm thinking about it that day and it's bothered me for a few days that I'll talk to anyone about it. I try and keep it to myself quite a lot, so... I don't feel I could talk to just anyone about it. .... And like my fertility's nothing, no-one else's business. It's mine and my boyfriend and few close friends. And no-one else really needs to know about that, cos most of them aren't going to be there when it's going to be happening so. When it comes to that time I'll tell people then.

Teenage female 18:20

One teenage male who adjusted his approach to disclosure towards greater caution about fertility as well as cancer in romantic relationships (see Chapter Ten) made similar changes with friends after he found that female friends got upset and male friends were likely to joke about sperm banking – he found neither reaction helpful nor appropriate:

My mates just laugh and say 'Ah kid. Sperm like yours, that won't be damaged' and stuff like that. *laughs*. ....It's kind of funny but at the same time it's yeah, yeah it might be damaged actually.

Teenage male 15:18

Some participants said that they simply felt too embarrassed about fertility matters to discuss them with friends. This was reinforced where fertility issues in general were rarely, if ever, discussed within their friendship circles.

### ***The desire to be 'normal' and to avoid stigmatisation***

In keeping with the findings about apparent recovery styles reported in Chapter Six, a desire to be back as 'one of the crowd' appeared to influence decisions about if, when and how to discuss fertility matters. Some appeared better able to approach recovery *because* of having one or two friends that they could talk with openly about fertility matters. This left the majority of their emotional and social space available for what they saw as age-appropriate and 'normal' activities. However many had decided not to disclose such information at all, including some who were troubled by fertility issues and/or some who considered themselves highly likely to be infertile.

For a few, the desire to be 'normal' was expressed as a desire not to be seen as an object of pity. This too led to avoidance of fertility *or* cancer discussions:

I find it hard to talk about, I would rather, I don't want people feeling sorry for me because I've had cancer and because I might not be able to have children. I would rather them get to know me and then if I want to tell them afterwards I would tell them. But it's not an easy topic that I find to talk about, I would rather just forget about it. .... I find it easier to talk about the cancer than I do the fertility part, it's still a bit raw, erm but I do tend to not tell people until I feel they need to know. I wouldn't like to just say 'Oh I've had cancer'. Because I know they'd be thinking 'Oh I feel so sorry for her' and I don't want that. *Interviewer:* You don't want that, you just want to be treated for you. *Adult Female:* I just want to be normal yeah, cos I am normal.

Adult female 18:23

There was evidence as reported earlier in this chapter and elsewhere of the inhibiting influence of the stigma perceived to be attached to infertility in particular. For example, a teenage female explained her decision to refrain from discussing it with friends in such terms:

...although part of me didn't want to admit to it, and you know admit's maybe the wrong word, but I felt it kind of reflected on me almost and I suppose not telling people almost makes it not real. And so I mean I'm at University now, twenty next week, and even up here, I can't think, I think there's maybe one person who knows.

Teenage female 13:19

Even among those who felt more in control, the use of stereotypical humour had never come to be acceptable, as reported above. For example, one adult male who had come to feel able with maturity to engage in banter around his residual physical impairment – because he saw people as respecting his ability to cope with that impairment and did not feel threatened – never did so in relation to his probable infertility;

.... I can make a joke out of [cancer], people have fun, people have respect that I've come through it and have decided to still progress through school and career, and that's great and I like that.....And so I joke about it with friends and all my friends are so rude about me, anything offensive they generally are but all in good spirits and likewise you know, and it's just a bit of fun..... And likewise now if people make a joke, for example people make

jokes about calling me hop-a-long or cripp or whatever, you know - tasteless but... if someone made a joke about infertility ..... I think 'How to make someone feel small in one easy step'.

Adult male 13:28

### ***The influence of shared experiences***

The only participant who had experience of a friend having menstrual difficulties (though non cancer-related - see earlier) that led her to disclose her own situation did not experience this as positive given the friend's disengagement once her periods resumed.

Of those who had discussed fertility matters in friendships formed through the shared cancer experience, this had been triggered in a variety of ways. For some, it had 'just come up' in conversation on the ward; for others it was prompted after discharge when one friend had made reference to it and this opened it up for others to add their experience.

### ***The impact of getting older***

A few talked of having friends that were older and speculated that this may have influenced their ability to share fertility matters (though this was not true for all). Others felt that the passing of time had led to a shift in earlier influences on telling and talking. This was usually in the direction of gradual moves towards more openness as a source of increased support and away from the desire to appear 'normal' or finding fertility an inappropriate subject to discuss with friends. Even so, the daunting nature of telling someone for the first time never fully seemed to disappear. For some, the influences had shifted but had not yet led to changes in verbal interactions themselves. Turning wishes into actions proved difficult for some, as was reported across other relationships.

### ***The impact on disclosure of participation in the study***

Finally, for some participants, disclosure and/or discussions about fertility with non cancer as well as cancer friends were prompted by participation in the research study.

## **DISCUSSION**

Lifespan approaches indicate that relationships with friends and peers can be an important site for developing personal and social identity, providing support and offering influential messages about belief systems during the transition years (see pages 93-94). It is perhaps

not surprising therefore that all four groups in this study were more likely to discuss cancer-related fertility matters with friends than with family members. This has not been reported before. Relationships with friends and peers offered some complex but significant interactions that enhance understanding of risk and protective features around resilience.

It was a common experience for friendships to falter during treatment as has been found in other studies (see pages 103-104). By the time recovery was underway, re-entry to the friendship space was facilitated if participants had not taken this personally and/or where any negative feelings were subdued by the drive towards 'normality'. Those who were more preoccupied with feeling angry or sad about friends' earlier (or contemporary) reactions – perhaps, for some, reflecting lowered self esteem - appeared held back in finding a friendship space in which they felt comfortable and confident. This process was invariably found to be more challenging where existing friends had 'moved on' physically or otherwise, where participants were required to return to a different setting such as a lower year education group or where entry into employment proved elusive (see also pages 104-105).

Some patterns present in the previous two chapters were repeated here. However the apparent need to conform to friendship and peer norms was perhaps more evident and therefore appeared to pose more risk to well-being than did the drive to conform to, say, family norms.

There were differences in the level and extent to which discussions about cancer and cancer-related fertility matters took place. This included work-based relationships. Those that reported similar approaches to both were more likely to be open than closed. For some that reported differences, this reflected lower levels of concern about fertility matters and hence low support needs. However the majority of those that reported differences said that this arose from the need to be more cautious around fertility matters. They were also more likely to discuss them with close friends only, if at all, and/or less likely to have friends raise this topic with them. In other words, their needs around fertility matters were not necessarily being met fully. For some, this was a price worth paying in order to be an accepted member of a friendship or peer group (see page 95). This was especially the case for those in the 'active recovery' group (see Chapter Six). For those that did not discuss it because of anxiety about disclosure to friends or lack of hope that sharing would help, the lack of support was more likely to be a source of regret. This could contribute to feelings of heightened isolation and lowered self esteem. These participants were more likely to be in the group whose active recovery was faltering or where it was 'complete' with regard to cancer only. Although

loneliness, low self esteem and lowered rates of friendship have been reported before (see pages 103-104, 105-106), the risk from fertility concerns has not previously been identified.

Unlike in families, closed communication with friends appeared little influenced by protective motives. Neither was the ability of friendships to accommodate other aspects of the cancer experience necessarily an indicator of their ability to manage fertility issues. This appears to mirror the development of different levels of competence in different contexts among non cancer-affected young people (see page 86).

There were indications of the impact of the social context on disclosure decisions. The stigma attached to fertility impairment (see pages 84, 107) was reinforced by messages from the context inhabited by young people - for example the classroom or workplace - about the 'normality' and hence social desirability of being fertile (see pages 89-90). There were also gender and cultural differences to be negotiated. Females were more likely than males to report having to manage conversations about parenthood plans and actual pregnancies. While some in both genders used humour themselves (albeit rarely) to diffuse some difficult aspects of cancer, males were more likely to have negative experiences of being *exposed* to 'laddish' humour around virility/sexual prowess. This invariably took place in contexts where peers were unaware of their situation and served to reinforce their silence while compounding their sense of being 'other'. Even where friends were 'in the know', it was nevertheless often the person affected that had to take the lead, as found in other challenging post-treatment friendship contexts (see pages 103-104). Cultural and gendered messages were, as above, premised on an assumed (and socially preferred) state of fertility (see pages 84, 107). The resulting isolation came across. Several looked forward to a time when they might have friends (old and new) that also faced fertility difficulties thus opening up opportunities for mutual support. Finally there were several instances that illustrated the unpredictability with which fertility could rear its head and present challenges.

In contrast, there were also examples where friendships were an important source of support and/or a site for developing coping strategies. Although fertility discussions were restricted typically to same gender friendships, a few females had used conversations (often covertly) with male friends or work colleagues as a 'rehearsal' for anticipated contact with future boyfriends. Discussions within close friendships were found to be valuable, as has been found to be the case with other cancer-related matters (see pages 103-104). A few spoke warmly of times when friends had 'reached out' proactively on the subject. Others felt such relationships enabled them to feel a little more in control and less isolated, providing that

sharing happened at a time and in a manner that they preferred. As was the case with some family relationships, participation in the study prompted some to initiate discussions with, or disclosure to, friends and found this helpful.

There was mixed evidence of participants talking about fertility within friendships made through cancer. Where this had taken place - including as a response to participation in the study - it was an important site for sharing experiences and gaining support. However others felt some regret that they had not been able to broach the subject and wondered if there were ways in which this could have been encouraged by professionals. This matches findings from a more general study of cancer-affected young people's views (see page 104).

Some of these experiences were, of course, spread over time as well as context. Sometimes this reflected changes in their own, peers' or friends' circumstances and perceptions. This was especially the case where permanent partnerships and firmer plans for parenthood became more the norm. Some participants acquired new information or new uncertainties about their fertility. This too could affect the meaning that fertility held for them and hence the usefulness or otherwise of earlier approaches. A small number became more closed in order to protect themselves from the repeat of earlier unhelpful reactions while others became more open (or wished to be) when their need for support overrode previous influences. Moves towards openness were often accompanied by a sense of relief and satisfaction that both they and their friendships could survive disclosure. Even with greater openness, however, there were indications that any ensuing support was limited both by others' inability to understand fully despite being emotionally available and by the potential for differences in understanding to grow over time as life choices of friends, peers and colleagues were less likely to be constrained by fertility impairment. In other words, the sense of difference was often not far below the surface.

## **SUMMARY**

This chapter has looked at the ways in which cancer and related fertility matters affected, and were affected by, friendships across education, employment and social contexts and over time. It confirms the significant influence of the peer context for maintaining or re-establishing connectedness and hence healthy self concept for the young person managing cancer through the transition years. For some, the cost of achieving this was to pay reduced verbal and non-verbal attention to any fertility concerns. Any tendency towards caution in disclosure was also reinforced by gendered and cultural messages about the 'normality' of being fertile.



These increased risks to well-being, not least as fertility issues could intrude unpredictably into friendship and social spaces. Females were more likely to be faced with managing conversations about pregnancy and parenthood while males were more likely to be exposed to hurtful conversations about virility and sexual prowess. Maintaining low levels of attention to fertility proved more difficult where fertility concerns became more pressing. Where friendships could accommodate fertility matters – and this was usually close friendships - this seemed an important source of support, promoted resilience and sometimes resulted in the building of shared strategies. Fertility-related discussions were more likely to take place with friends than with family members.

## CHAPTER TEN

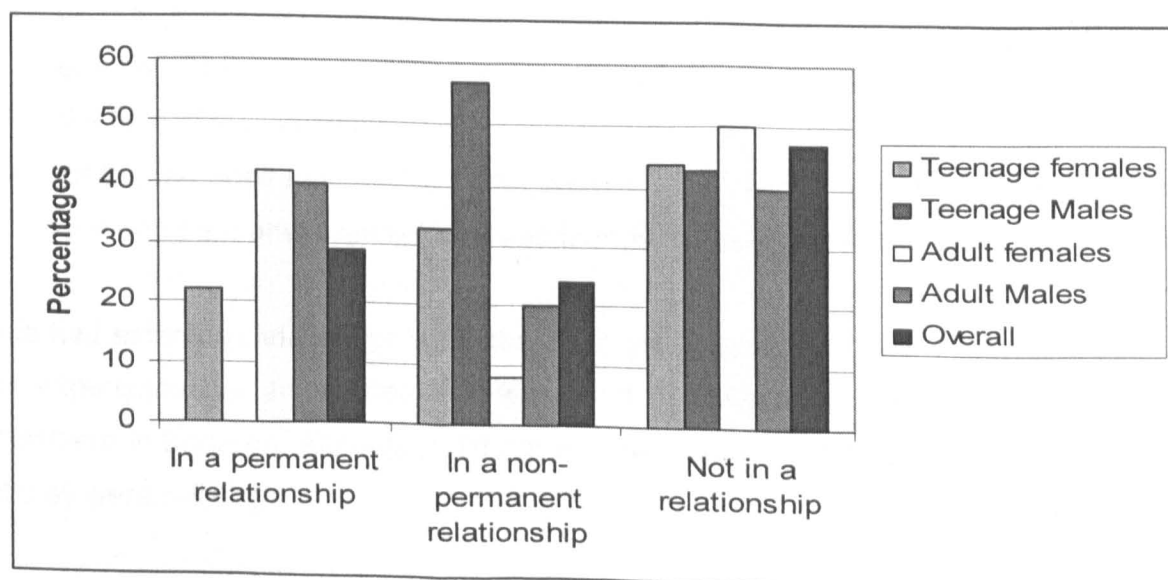
### THE IMPACT ON CURRENT AND FUTURE ROMANTIC RELATIONSHIPS OF CANCER-RELATED FERTILITY MATTERS

This chapter takes forward the developing understanding of how cancer-related fertility impacts on relationships, including 'telling and talking' patterns. I start with information about the levels and types of romantic experience within the cohort. Participants' thoughts and feelings about actual and potential romantic relationships are considered, separating out where possible the influences of cancer in general and fertility in particular. As in previous chapters, lifespan influences and factors that appear to have promoted or maintained resilience – or threatened it – are afforded particular attention.

#### Patterns of relationships

Given the qualitative approach to the study, I was looking to gather experiences, thoughts and feelings rather than frequency patterns. However, I have collated the 'romantic relationship' situation of participants at interview from references made in interviews in order to provide some background information to the qualitative analysis findings (see Figure 9).

Figure 9: Types of romantic relationships held at interview by age and gender



None had been in a permanent relationship at diagnosis but one relationship had survived to become permanent and they now have a child. All of the other romantic relationships from before diagnosis ended before treatment was completed or shortly after.

At interview, eleven (29%) participants were in a permanent relationship of whom two were teenage females, five were adult females and four were adult males. Only five (3 females and 2 males) were living with their partner. All five parents in the study saw themselves as being in a permanent relationship, three of whom were living with their partners. The remaining two (both female) were living in their parental home with their child.

At least nine (24%) were in a non-permanent relationship at interview including two teenage females, one adult female, four teenage males and two adult males. The majority of the remainder appeared to have had romantic relationships since diagnosis.

A small number had either never had a romantic relationship or had not had one since diagnosis. This was for a range of reasons, i.e. not simply because of age, cancer and/or fertility- related factors.

Put another way:

- Of the nine *teenage females*, two (22%) were in permanent relationships, three (33%) were in a non-permanent relationship and four (44%) were not in a relationship.
- Of the seven *teenage males*, none were in permanent relationship, four (57%) were in a non-permanent relationship and three (43%) were not in a relationship.
- Of the twelve *adult females* interviewed five (42%) were in permanent relationships, one was in a non-permanent relationship and six (50%) were not in a relationship at the time of the interview.
- Of the ten *adult males*, four (40%) were in a permanent relationship, two (20%) were in a non-permanent relationship and four (40%) were not in a relationship.

Some had entered relationships with little or no pre-diagnosis experience. Others had some prior experience but augmented that with a lot of subsequent experience. Others were somewhere in between. Although I did not ask the question directly, a number made it clear that they were still virgins.

## Impact on actual and anticipated subsequent relationships

Many said that they did not feel that cancer-related fertility matters had affected their potential or actual approach to romantic relationships except insofar as they had to decide whether and when to disclose relevant information. The reality appeared to be less clear cut.

Where a pre-existing relationship had ended, the reasons were primarily that the relationship could not withstand the strain of cancer and its treatment and/or that the couple grew apart (that is to say that it may have ended anyway). For small number, the fertility threat was present but not dominant:

He couldn't deal with this kind of thing [fertility]. It was hard because I was taking it out on him and when I was down... he couldn't relate to how I felt and because he was young he didn't understand, you know, 'oh she's not as bad as she makes out'. It was that kind of immaturity that just said it all, so. You know, boys are a lot younger than girls. So we'd split up in that time. It was me illness. I was on me own, which I couldn't have been with anybody cos I couldn't deal with it. I didn't want nobody to look at me. You know, it was a big thing. I couldn't let anybody see me without a hat and that was a deal for me.

Teenage female 17:20<sup>11</sup>

However some had experience of fertility matters affecting their approach to, and experience of, later relationships. For example, a small number of females and one male reported ex-partners being unable to contemplate the relationship moving forward because of fertility concerns. Here again, it was not clear whether this was the major reason for the relationship ending.

The adult female who identified at interview as lesbian (see Chapter Six) felt that fertility concerns had impacted massively on her approach to relationships. She had had unprotected sex in a large number of short-term relationships to 'test' her fertility (she had been through fertility analysis and been told that she was infertile). She had disclosed neither her motives nor her probable infertility and ended the relationships quickly when she failed to

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<sup>11</sup> As previously, all quotes are identified by the category of the participant (teenage female, adult male etc) together with the age at diagnosis followed by the age at interview. Thus, this quote was from a teenage female aged 17 at diagnosis and 20 at interview

get pregnant. By interview, she feared that she would never have a long term relationship as she could not contemplate making a partner childless.

One teenage female was aware that a fear of rejection got in the way of her responding to encounters that might lead to a relationship forming:

I think it does [have an effect], I always, you know if I'm out and a guy chats me up, for some reason alarm bells always go off. I don't know why that is and you know, Mum and Dad are divorced and he had an affair and left when I was about eight. So I think is it because of that, that I just don't trust blokes maybe, or is it because I don't want to get into a serious relationship, then have to explain that I can't have children - obviously not that I'm intending to get married yet, I'm only nineteen - and then for them to say 'Sorry not interested, I want to marry an incubator'. You know, I just, I don't know what it is but I do think it does affect, especially now, I'm getting older...

Teenage female 13:19

Neither did having casual relationships in the younger age group automatically remove the impact of such undercurrents (though it did for some). For example, one teenage male had not had a girlfriend for some time following treatment. At interview, he had been going out with someone for two months or so. She knew about his cancer but he was grappling with whether and when to tell her about the fertility aspects. In other words, this was an additional factor to accommodate. He did not feel that he could let the relationship unfold in the same way that it might have done if fertility issues were not present:

It's [fertility] always something in the back of me mind thinking everything. So it's hard and everything like that...

Teenage male 15:17

Fuller findings about disclosure are covered later.

For the relatively small number that talked specifically about their approach to sex, most said that the possibility of fertility impairment made little or no difference. This included ones who had had sexual relationships post diagnosis and those who were yet to have one. Where sexual activity had been said to be affected (only a small number) this was more likely to relate to the after-effects of treatment through:

- Having to learn how to cope with a prosthesis during sex.
- Having difficulty with erections.
- Coping with exposing scars that were 'embarrassing'.
- Having to abstain during recovery after surgery.
- Having to take more care with contraception than they thought they would need to otherwise.
- Feeling too tired and lacking in stamina to have sex at times.

As reported in Chapter Six, concerns among those currently in 'active recovery' and among some others looking back appeared more likely to result from the impact of temporary and permanent body changes - hair loss, changed body shape, scars - on physical/sexual attractiveness. As with the interplay between sexuality and fertility identities, it was difficult to disentangle where, if at all, body image concerns were shaped by fertility factors.

There were some who reported that other people's reactions to them as romantic partners had been, or might be, affected. For a few, this was in the context of their cancer history alone. One male had worried, at least initially, that girls only went out with him because they felt sorry for him. Conversely, another thought that girls were attracted to him either because of their curiosity or because they saw him as a 'super hero' for having survived treatment. For others, their worries incorporated the reactions engendered by their possible fertility impairment, including that this would make them less attractive as a partner.

There were some in all four groups that had concerns about the effect of possible cancer-related fertility difficulties on their ability to establish a permanent relationship. The depth to which this was troubling varied considerably – for some it had been a passing thought, for others it was more preoccupying.

The group who were almost universal in having concerns were females facing premature menopause. They reported an awareness of the ticking of their biological clock *and* the need to disclose this to a partner as impacting on the way that they thought about relationships in general and permanent relationships in particular. The same appeared to be true more generally among females and males who understood themselves highly likely to be infertile already. Sometimes, these concerns were manifest as worries about whether or not others might view them as a less attractive 'mate' if they could not have biological children together. Some also worried that partners might think they did not mind, only to realise later that they

did after all. For a small number – all female – concerns about attracting a partner were turned on their head. They wondered whether they themselves could fall in love with anyone who was attracted to someone unable to become a biological parent; or whether they could face the risk of hurting someone they loved who realised too late that they wanted children after all:

But you know how it is, I suppose if you meet someone and they love you for what you are they'll accept that I think, they should accept that. And really if I was in a relationship and if I felt it was going somewhere from the start I'd be honest with him and say 'This is the situation, look I can't help it, but would you be willing to stay with me and do you want to give it a go?'. And if they don't, that's fair enough. And I wouldn't ever blame them either cos if they accept it, I'd be able to last cos I'd never want to ruin their dreams you know, cos if they've always been set on having kids and I've told them and they're like 'Oh sorry', then that's fine, that's totally fine cos I'd rather be straight up and leave it so, it's better you know.

Adult female 15:21

Some were anticipating what they might need to be prepared for on entering a casual and/or permanent relationship and were starting to develop relevant strategies. A small number of females in both age groups had used their contact with male friends to 'rehearse' such strategies as reported in Chapter Nine. A few males in both age groups had started to prepare by gathering relevant information, contemplating fertility analysis and talking with others in order to be ready to help a future romantic partner:

I keep thinking well maybe I should go and do it [analysis] and get it out of the way. Because, you know, it's not something, like down the line, like I say, if you meet a girl and that and it might be best to deal with it myself now rather than two or three years down the line and then with it being more emotional at that time.

Adult male 18:23

Several of both genders identified the need to know about fertility treatment options for their own wellbeing *and* to help them prepare for relationships, including disclosure. This is returned to below.

A few of the adults reported that their patterns of relationships had changed over time. They linked this in part to fertility matters and the changing implications that they perceived these to have. In the aftermath of leaving treatment, they had enjoyed a series of relationships before romantic activity had slowed. Their main thoughts at interview were focussed on their ability to form and sustain longer lasting relationships in the light of fertility concerns. They considered that such an influence had only really come into play, at least consciously, as they got older and started to think longer term. For example, one adult male feared at age 16 that a girlfriend would find out and ridicule him; in his late teens he was more preoccupied with whether or not a girlfriend would want to be with someone long term who was infertile; in his mid 20s he talked with girlfriends more openly and with less fear of rejection; in his late 20s his fears were more present again but now focussed on pending loneliness if he did not find a permanent partner and potential lack of fulfilment if he did not become a biological father. An adult female said that her relationships had not been affected previously (of which she had had a number) but she was increasingly deeply troubled by her probable infertility. She had not had a relationship for quite some time.

Of those with limited romantic experience, a few still did not feel ready for relationships. Both Asian participants (one male and one female, both adults) said they would not enter non-permanent relationships for religious and cultural reasons. I have referred to this more fully in Chapter Six.

The aspect that was mentioned most frequently across all four groups in relation to both permanent and non-permanent relationships was disclosure – whether, when and how to tell. It is that aspect to which I now turn.

### **Telling and talking with a prospective or actual romantic partner**

#### ***Who had told a partner or thought about doing so?***

The need to decide when and how to tell a partner about fertility impairment rarely applies to adults facing non cancer-related fertility difficulties as these are more likely to become apparent within the relationship (though, of course, may then be carried on to any subsequent relationships). Numbers growing up with the knowledge of potential impaired fertility are restricted primarily to those with iatrogenic infertility.



Not surprisingly the most troubling aspect of relationships mentioned was disclosure, regardless of whether or not they had had relationships since cancer. Typical concerns included:

- Should one always tell a romantic partner that there is a possibility that fertility may be impaired and if so, when?
- Should one only tell a romantic partner if the risk is high and if so, when?
- Should one only tell a romantic partner once the relationship becomes permanent and if so, when?

In other words, there were very real dilemmas to be faced about the perceived rights, wrongs and risks around disclosure. These were tangled with thoughts about how to go about it. For some, this posed few dilemmas - especially those who took an open stance without appearing to experience prior anxiety - whereas the picture was very different for others.

Although only one participant had remained in the same romantic relationship since prior to diagnosis, several had known their boyfriend or girlfriend beforehand. In all these cases, the other knew about the cancer but very few were aware of the potential associated infertility. Some, especially as adults, established a relationship with someone whom they did not know during treatment but through later work or social circles before embarking on the relationship. For a few of these, cancer-related infertility had been discussed in these wider circles.

Acknowledging the dangers of generalising from small numbers, there were differences in this study according to permanency of the relationship. Of the eleven participants who were in a permanent relationship at interview (which included all five who were parents), all had disclosed, though in different ways and at different stages. For example, one did not do so until after she had started living with her partner but before they started trying for a family. However she had also been fairly confident that he knew through conversations shared more widely in their joint work base.

Of the nine participants in a non-permanent relationship, four had told their partner. Of these, one was a long standing relationship while the other three were more recent. Among the five that had not told, two relationships were fairly longstanding whilst the others were more recent. The five were drawn from both genders and all but one were adults.

There was a mixed picture with regard to other relationships. Some had never told a romantic partner (including some who had had a number of relationships), some had always told and others had told in some relationships but not others.

### ***Deciding whether and when to tell***

Making the decision about whether or when to disclose appeared to be influenced by a range of factors. For some, there was one dominant factor – for example a generalised belief in complete honesty in all relationships at all times (disclosure). For others, there were several factors that tipped the balance, though operating in different combinations for different participants. Being young *and* having had casual relationships only might lead to non-disclosure as might fear that disclosure would lead to rejection fuelled by stigma around infertility. Some felt that the decision was made for them when, for example, the information was made public in their social circle. Uncertainty about the full extent, if any, of fertility impairment was also an inhibiting influence as was the lack of information about treatment options and the resulting restricted ability to answer a partner's questions or concerns about alternative routes.

For those in all four groups who took a generally open stance in non-romantic relationships about both cancer and fertility matters, this extended typically to romantic relationships especially those which progressed beyond a very short duration. Disclosure appeared to be the least troubling for this group even though it contained some who considered themselves highly likely to be infertile. None had so far experienced rejection following disclosure. One adult female explained her reasoning thus:

Yeah, he knew from the beginning when we first - I mean, when we got together, you know, I told him. I thought I'm going to tell him straight from start, because if he finds out further down line, if he's like 'Oh why didn't you tell me?'. So I told him everything he needed to know at beginning, and to him that wan't important, it were just, it were me who he wanted, like he said 'I'd rather be wi' you than have kids, it's you that's important to me' so....

Adult female 18:25

At the other end of the spectrum was a group who had not yet told anyone. Several appeared troubled at the prospect. This included a number who were sure that they were infertile and realised that they would have to make that clear when disclosing. For this group as a whole, fear of rejection and stigmatisation appeared a significant influence:

I've had sort of one really serious relationship you know but erm.. but never to the stage where I've been like talking about having kids or anything like that, so. But that does stick, and like I say I've really thought about it the last couple of years. And like it does get on my mind and I think like if I meet somebody and want to get married, that's going to be an issue. I'm going to have to tell them 'Well I might not be able to have any kids'. And what's that going to do? Wreck my whole relationship? You think about things like that and just like how it's going to affect you, it'll affect you in so many different ways, so.....

Adult female 16:24

One adult male thought that he was approaching the time for disclosure in his current relationship as it was on the brink of becoming more serious. He was anxious that this would lead to rejection. This was compounded by the fact that he had been told that his stored sperm sample was of poor quality, had never had the subject raised again, had never felt able to raise it himself formally or informally and knew little about fertility treatment options (for example he was not aware of ICSI<sup>12</sup> procedures). He also felt at a loss as to how to approach disclosure but felt increasingly uncomfortable at withholding this information: '.... not lying to her but, you know, just not giving her the full picture'.

Another anxious adult male was sure that he was infertile and had not banked sperm. He had not told any girlfriends so far; indeed he had not had any long term relationships. He had been putting off going for fertility analysis and used the interview to think aloud about whether or not the 'need to tell' would be better managed if he was aware of his fertility status:

But then again, especially wi' girlfriends and that, it's like well always on the back of your mind. It's summat. Especially difficult subject to raise. Cos obviously you don't know how long you're gonna be or what. So, in a way it would be a good way to find out, then if I can have kids, it's not a subject I would have to raise. Then if it is one that I can't have kids then it's obviously then a difficult situation to raise again, especially if they don't know my past.

Adult male 16:22

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<sup>12</sup> ICSI (Intracytoplasmic Sperm Injection) is the name of a particular form of fertility treatment

Fear of rejection led some to arrive at a different solution. This group decided that it was better to 'get it over with' and tell a romantic partner very early in the relationship. In this way, the relationship would not proceed any further if the partner could not accommodate the information:

Well it wasn't really that difficult at the time, because I told him straight away. I didn't want to hide things from him..... knowing that if he did want children, cos obviously he might not get it from me, then he could make his own mind up of what he wanted to do. So I was a bit anxious that he might leave me or you know even though it was pretty much the first couple of days of dating, erm, but he just reassured me that it was me he wanted and obviously it would be nice to have kids together but if it doesn't happen it doesn't happen, and there's other ways of doing things, erm, so from there really..... it was like a huge weight lifted off my mind.

Adult female 18:23

A small number arrived at the same decision but explained it as coming from their need to protect their shaky self esteem. For example, one teenage female whose self esteem had been deeply affected from the cancer experience and who also thought that she was infertile explained her caution about entering a romantic relationship. She tried to protect herself by ensuring that her potential boyfriend was fully aware of her fertility situation before agreeing to embark on the relationship in an attempt to minimise the risk of rejection following a later disclosure:

You don't want to be hurt again, it's a different kind of hurt but you're still not going to put yourself out for it, if you know what I mean, and erm, I'm lucky I've got a lovely boyfriend and I've been seeing him for like a year and a bit now, over a year. But I did sit down and talk to him and just said 'I'm not going to be made a fool of, I've just got my self confidence back in myself, I've just got my self esteem back, I don't need it to be knocked down' I said.

Teenage female 15:20

However, some worried that disclosure in the early stages of a relationship could be misconstrued as suggesting that they saw the relationship as more serious than it was though were clear that they did not want to hide it either:

I'm single at the moment but if I'd suddenly announced to my ex-boyfriend, 'Oh by the way....', I think he'd have, he'd have run for the hills. I mean I'm obviously not wanting to have children just now but I don't want to be in a relationship and them not know that, because even though it doesn't make who I am, it is important, and I don't want the awkward situation where you talk about children and things and me shut down..

Teenage female 13:19

Even among those inclined towards later disclosure were some who talked of trying to gauge their romantic partner's likely reaction from early on. Floating the idea sometimes became an important part of deciding whether or not to remain together – as well as a source of comfort if this indicated that their partner might cope when the time came:

But like me boyfriend who I've been with for quite, like a couple of year, obviously I said to him 'What would it be like for you if I couldn't have children?', just in general conversation maybe. But with speaking to my boyfriend he is fine by that but he'd be willing to do anything he could, like treatment. Like the treatment that they do at the IVF treatment and stuff like that. So I said to him 'What would it be like if it took a lot of strain and stress just to get a child?'. And he is quite supportive. So it doesn't really worry me until we actually decided.

Teenage female 17:20

Others hoped that the need for disclosure would be avoided by discussing their situation within their wider social circles as a way of trying to ensure that future partners might get to know.

A small number thought that the decision was more likely to be made for them. An adult female with residual physical impairments (both visible and less visible) was still attending frequent checkups. She speculated that these factors meant that she could not avoid telling future boyfriends about her cancer history and that this may lead some to asking about her fertility:

I mean I wouldn't say at the start 'I may not be able to have kids' but I would say.. I mean they would know I'd had cancer because I'm still coming up for monthly checkups. So as soon as you tell somebody you've had cancer, then

if it was the other way round I would put two and two together and think they might not be able to have kids. And I mean I suppose it would come up in conversations anyway because you would say 'Oh, that kid's cute; oh yeh, I may not be able to have them, get over it' kind of thing.

Adult female 19:21

The presence of visible signs of treatment and/or hospital appointments or further treatment had indeed provided the trigger for disclosure for a few. However, unlike the prediction of the adult female above, partners had not always 'put two and two together' so control over timing remained with them.

One adult male had felt that he had little choice about disclosure when the sperm bank where his sample was stored informed him that it was moving sites and he was asked to decide whether or not to maintain storage. This proved stressful, not least as it was the first time that he had discussed the matter with anyone, let alone a girlfriend, since banking his sperm. As the relationship soon became permanent, he had not faced further disclosure decisions. Another, as discussed elsewhere (see Chapter Six), had been forced into disclosure as a teenager when his girlfriend demanded to know why she had not got pregnant after having unprotected sex for a year. He had chosen not to disclose in later relationships – but was more careful about the use of contraception – until he entered a permanent relationship. This time, the disclosure was planned.

Thus, there was some evidence that different stances were taken over time and/or as the perceived consequences of disclosure shifted. Whereas fear of rejection or being seen to be different may have tipped the balance towards non-disclosure at one stage, risks to well-being of not knowing whether disclosure was survivable either personally or within a relationship could become great enough to prompt openness at another. For example, one teenage male reversed his earlier approach of being open when he realised that it led to female friends and girlfriends feeling sorry for him.

### ***Managing the telling***

Many of those with experience of disclosure talked of how they went about this, often reflecting on the need for great sensitivity as well as the ability to handle their own anxiety. Many were aware that the information could prove difficult for a romantic partner to handle – even though they themselves might have learnt strategies for coping with emotionally laden information, partners were less likely to be experienced at this.

Two teenage females used their boyfriends' mothers as a conduit:

Well it were just, it just come up in conversation with his mum, cos his mum's known me since I were little cos she used to look after me. And obviously he were there and it just like come up like that and she helped me tell him in a way. .... and he were like 'Oh well that dun't bother me. It dun't make you no less of a person to me'. It's just like... he's been right good with things like that so. He's been right helpful.

Teenage female 13:16

Several remembered heightened anxiety in the run up to disclosure and intense details of the event itself. For example, the male prompted to disclose by the imminent move of the sperm bank recalled his feelings, sitting on a wall outside a pub on a frosty night:

I hadn't discussed it with anybody [at any time since banking sperm] ....nobody tried to mention it to me and so it was just something that was at the back of my mind constantly, niggling at me. And it wasn't until [girlfriend] and myself discussed it that, I don't know, it brought it to the front, and.... That was the first time and it was quite an emotional moment for me.

Adult male 15:30

A teenage female realised that the time had come in her increasingly serious relationship when faced with another operation. Like some others, she had already sown the seeds but still needed the prop of alcohol to tell her boyfriend about her cancer history. Even then, she held back from telling him about fertility until later:

....it was obvious that I'd had chemo ... cos I used to always say when I had long hair or when I was bald or make little jokes about when I was bald and there was photographs of me with like a skinhead virtually, just like no hair. So he sort of clicked that I'd had cancer and things and then I was forced into telling him cos I had to have another operation. .... After the operation I just got drunk and told him everything. .... I just told him everything I could remember on that day and it was just all a big, just blurt out of everything. And it wasn't about the fertility stuff at that point. I didn't bring that up with him until I realised how serious it was. And how important it was that he realised

that there was a possibility that he might never be able to have kids with me which I thought was a bigger issue than it was. Cos I thought that it would make a difference but it doesn't, to him. He just...he doesn't mind, he knows about it and he says that if we have to adopt, we have to adopt, and we'll think about it then.

Teenage female 18:20

Another planned the disclosure very carefully with the help of an older sister who also knew her boyfriend (he already knew her cancer history). She decided that it would be done better away from the town where they both lived in order to avoid him telling others in their mutual circle in a knee-jerk reaction. She instead undertook a lengthy journey to his university address. This was ahead of the relationship becoming serious. Her boyfriend (now her husband) wondered why she was telling him *and* he remembered few details of the actual event in their joint interview:

I was going up to stay with him, and kind of said that I had to tell him about this, and very nervous going up on the train, and I remember having to change trains part way up and nearly getting back on one in the wrong direction and turning round but ..... I didn't want to tell him over the phone. And I think I quite consciously didn't want to tell him when we were both at home as well. Erm, I think I was a little bit nervous of how he'd react. ... I didn't want everyone to know at that stage, didn't want friends to know I suppose, I suppose I was a little bit concerned that if I told him at home and he just.... *Interviewer*: He would tell others. *Adult Female*: Yeah,.. maybe. I suppose it was easier to tell him when it was just, when he was the only person that I knew there, I think. *Interviewer*: And what did it feel like once you'd told him? *Adult Female*: Erm. Really scary. Not knowing at all what he was thinking, erm. What he was going to think in the future. What he thought about me saying it to him then, cos like I say his initial reaction was 'What are you telling me for now?' kind of thing. 'It doesn't affect me' and ..... relieved as well though that he knew, and that I'd kind of got it over with, and kind of hoping I didn't have to tell anyone else in the future.. *laughs...*

Adult female 14:25



### **Consequences of disclosure**

Only one reported a relationship (not a permanent one) ending as a *direct* result of disclosure but she continued to believe openness to be the right approach for her. More often, the romantic partner took the news well and affirmed that the person disclosing was more important to them than whether or not they could have children. Regardless of whether the relationship continued, this experience appeared to reduce anxiety and/or boost self esteem, though the extent of this varied:

..... at the end of the day, the way I see it is if he wants to be with me he has all me packaging as well..... he was dead cool about it.

Adult female 19:25

One adult female referred to the comfort of knowing that, after disclosure, she and her partner were coping together with her probable infertility. Even so, she had what she called occasional 'wobbly' patches when her fears of rejection resurrected themselves:

I have kind of wobbly, wobbly periods where I start telling him 'You know, I understand if you want to go'. Erm, I think it's probably always there. It's something that I am quite aware of.....I don't know how I'd cope if I wasn't in a long term relationship to be quite honest erm, I mean it crossed my mind that if anything happened to [husband] or he did decide to go, I suppose, that that probably would be my chance of having my own family lost as well.

Adult female 19:21

Two adult males were faced with reactions of a different kind. In both cases, their female partners were delighted at the news as neither wanted children. However both adjusted their desires subsequently when it became clear that the men were in fact fertile. Both have gone on to have biological children within the relationship

Not all whose romantic partners reacted positively were so accepting of themselves. There were also variable patterns to the extent to which conversations returned to the subject over time. One adult female in a permanent relationship had told her partner early on, at which time he reassured her that she was enough with or without children (he also had children from a previous relationship). At interview, she reported being concerned increasingly about

the possibility of not being able to conceive. However she said that she rarely discussed this with her husband (or anyone else) even though she identified him as her key source of support and comfort in general:

..... I don't even really talk about it that much to my husband [...], not because I don't feel at ease talking to him, it's just not one of those things I like to talk about. I mean I don't keep him in the dark about anything but if the situation doesn't need to be brought up I won't bring it up.

Adult female 18:23

Ambivalence was also present. An adult male who had told his permanent partner and reported feeling at ease with his probable infertility said that they rarely discussed it but also talked of his partner contemplating what names they would give their children:

I mean sometimes like, she'll mention kids, like just joking, like 'Oh, we'll call our first kid whatever', not being serious, in the same way you'd joke about marriage or whatever, erm, but I always think, I don't know, yeh, it's definitely, it's definitely something we bypass quite well.

Adult male 13:21

## DISCUSSION

Attention has turned in this chapter to the impact of cancer-related fertility matters on romantic relationships, past, present and future. The greater caution in talking about these compared to the wider cancer experience found in previous chapters was repeated here. The non-normative challenges of cancer itself once again appeared complicated by the negative social imagery surrounding fertility impairment (see pages 84, 107) and by being 'out of sync' with peers. There were indications of what mediated or reinforced this – risk and protective features that contribute to the emerging picture around resilience.

Relationship experiences varied. Some had been in permanent relationships for some time while others had yet to have their first romantic experience. There was fluidity over time, across different situations and within different relationships. For example, some of the older group had enjoyed a number of post treatment relationships (mainly casual) but this had slowed or stopped more recently. Although many *said* that the threat of fertility damage was

not a major influence, discrepancies in accounts suggested that this did not present the full picture.

For most (but not all) of those closer to treatment, threats from fertility impairment appeared lower than those from body changes and/or sexual worries. I have discussed these more fully in Chapter Six. While fertility matters rarely seemed to cause the breakdown of romantic relationships, anxieties were common about disclosure (if, when and how) and about establishing and maintaining permanent relationships. This matches previous research findings (see page 25).

Disclosure concerns were present across both genders and both age groups. Only a small number had partners that knew of the fertility situation beforehand. Most of those with post diagnosis relationship experience had thought about disclosure from early on (and some had disclosed). For those not in relationships, disclosure was an anticipated concern. Unlike findings from large scale quantitative studies (see page 25), all in permanent relationships in this study had disclosed though one had not done so prior to them living together. The picture was more varied in non-permanent relationships.

The qualitative approach in this study enabled exploration of the influences on decision-making and this extends existing research. Where honesty was a strongly preferred feature in family relationships and friendships and/or where earlier disclosures had been relatively problem-free, early disclosure in romantic relationships was more likely. This appeared to generate relatively little anxiety about the process regardless of the perceived likelihood of fertility damage or whether the relationship looked likely to be permanent.

For others, the picture was more complex. Fear of rejection was present for many and appeared fuelled, at least in part, by the stigma of infertility. Some appeared to have internalised this and saw themselves as, for example, 'damaged goods' or 'not a real man'. Some who considered themselves likely to be affected had decided actively to withhold that information in order to reduce the risk to other desired outcomes - for example, appearing 'normal' (i.e. fertile) or achieving a pregnancy 'against the odds'. Others had not yet disclosed because they felt that this should be restricted to 'serious' relationships and might give the wrong message if done too early – perhaps reflecting personal or cultural views towards relationships (see pages 86-87). Where participants had little or no experience of raising it *with* others or having it raised *by* others, any tendency towards caution was reinforced. However some decided to disclose early in order to protect themselves from later hurt – in

other words if a boyfriend or girlfriend could not contemplate a childless relationship, it felt better to end the relationship before there had been too much emotional investment in it.

As with friendships, many participants felt that the initiative around handling this aspect rested with them, though they remained acutely aware of what little control they felt over their fertility.

Among those that had taken the plunge and told at least one romantic partner, the outcome was generally more positive than anticipated and led to feelings of relief and bolstered self esteem. In other words, the anticipation of disclosure appeared worse than the reality. Nevertheless, disclosure did not alleviate anxiety completely. Fear, albeit abated, could remain that the next time might have a worse outcome. There was also variation in the extent to which fertility continued to be an area for discussion following disclosure. Some were unhappy, implicitly or explicitly, with the extent of discussion even within permanent relationships. This was especially the case among those who were deeply distressed. Some took personal responsibility for this including some that said they presented outward nonchalance or disinterest in parenthood when in fact they wanted to be 'reached out' to – a recurring theme from previous chapters. Similarly, accounts of the comfort and reassurance gained through tackling the issues in a shared way following disclosure were sometimes tempered by references to ongoing loneliness and awareness that the empathy of others could only ever be partial. Such sentiments were not dissimilar to those mentioned in relation to close friendships in the previous chapter and to friendships and social support elsewhere (see pages 101-104).

Survivor concerns about establishing and maintaining permanent relationships and quantified lower than average rates of permanent relationships have been reported (see page 25). There were some interesting insights that came to the fore in this study to suggest that fertility concerns may carry some influence. Some participants were anxious about finding someone willing to enter a potentially childless relationship; others were concerned that their (in)fertility might be the cause of distress to a loved one who thought children were not important at one stage but then later changed their minds. Indeed a few had fears about whether existing permanent relationships would survive childlessness. A few wondered whether they themselves could be attracted to someone willing to contemplate a childless relationship.

An underpinning influence for both disclosure and the establishment of permanent relationships was uncertainty about fertility status. This echoes other aspects of cancer where uncertainty poses risks (see pages 108). Some who found it difficult to understand

and cope with such uncertainty felt that they needed more information about their status and/or about fertility treatments and other routes to parenthood in order to feel better prepared in and for romantic relationships. Several would have welcomed more professional help with developing relevant strategies. In keeping with this, some of the older ones had wondered whether to undergo fertility analysis and this is returned to in the next chapter. However, for others, uncertainty held protective features as has been found elsewhere (see pages 107-109), especially if it was feared that certainty might remove any hope of biological parenthood.

## **SUMMARY**

This chapter has focussed on the ways in which romantic relationships, whether actual or potential, were affected. Information about the levels and types of romantic experience among participants was identified as were lifespan influences and factors that appeared to influence the likelihood of resilience being promoted or maintained. The findings suggest that fertility matters can form an important challenge to be negotiated within romantic relationships. This can occur ahead of relationships being formed or at any stage afterwards, including within those that have become permanent. There were general concerns about whether having cancer and/or possible associated fertility damage might reduce their romantic attractiveness. Many also held specific fertility-related anxieties about disclosure and about their ability to form and maintain permanent relationships. This offers important new insights that might help explain the lower than average rates of permanent relationships found among childhood and teenage cancer survivors. Anxiety about disclosure in particular appeared to be eased where participants held strong beliefs in openness across all relationships, had 'survived' earlier disclosures and saw disclosure as of personal benefit in the relationship. Anxiety appeared raised where there was fear of rejection, internalisation of a stigmatised identity around fertility and no prior experience of disclosure. Disclosure did not necessarily lead to adequate levels of verbal and non-verbal support or remove fear of rejection. As in other situations, some participants would have welcomed being 'reached out' to more often by loved ones even if their outward appearances suggested otherwise. Some felt adversely affected by inadequate information and lack of strategies for their perceived role in supporting a partner following disclosure. Here again, such thoughts could be present well ahead of contemplation of permanent relationships.

The final chapter reporting findings looks at experiences around more active contemplation of parenthood.

## **CHAPTER ELEVEN**

### **THINKING ABOUT BECOMING OR BEING PARENTS**

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There have been references in previous chapters to aspects of participants' views in relation to parenthood. These have included variously: strength of desire to become biological parents at different stages before and during the cancer journey; patterns of 'telling and talking' with others about future parenting; and the relationship of fertile identity to the desire to parent. This chapter takes the story further. It starts by focusing on those participants who had contemplated taking (or had taken) active steps to find out through fertility analysis whether or not their reproductive system had been damaged (fertility status). Where participants had expressed thoughts and feelings about alternative routes to parenthood, these are analysed next. Finally, the experiences of those who were actively trying to get pregnant and who had already become parents are considered. As before, this has been undertaken within a lifespan approach, taking care to draw out any features that reinforce, contradict or add afresh to the growing picture around resilience.

A small number of females had become aware of fertility damage unexpectedly as a result of gynaecological rather than fertility investigations. Similarly a few had been on 'holiday' from hormone replacement therapy (HRT) for medical reasons rather than in order to determine fertility status. Those experiences have not been included here.

#### **Contemplation of active investigation of fertility status**

There were some gender differences as well as similarities in the ways in which the question of fertility testing was approached.

Four of the five teenage males and one of the adult males who had banked sperm anticipated being recalled routinely for fertility testing. Some had started receiving routine letters about renewal of storage, some of which contained a reminder that testing was available (but at the instigation of the patient rather than through a routine appointment). The adult male concerned had expected to be tested at a recent routine appointment and was disappointed to learn that it could only be done if he requested it specifically. None were experiencing particular anxieties about the thought of being tested though neither did any appear to believe that their fertility might have been permanently damaged. Nevertheless, there were

indications that they were preparing to protect themselves against a negative result. In particular, there was widespread reference to their understanding that any loss of function could take some time to reverse and that they may therefore receive several negative results ahead of a positive one. All thought that they would like to have children one day though the strength of desire varied.

There were a small number in this group who were preoccupied from time to time about whether it was better to know or not, especially in relation to handling romantic relationships (see also Chapter Ten):

.... it is one thing over the last couple of years that has started niggling me just thinking like, do I want to know, do I, don't I? Obviously I don't at the moment but it's like I want to know just in case if I can or I can't. .. And it's like...it's one of those things if I find out I can, brilliant, if I find that I can't, how is it gonna ... I don't know but it's like, just one of these things, do I, don't I?..... In a way yes, but in a way, if I can't, then where do I go from there. But then again, especially wi' girlfriends and that, it's like well always on the back of your mind. It's summat.... especially difficult subject to raise. Cos obviously you don't know how long you're gonna be or what. So, in a way it would be a good way to find out, then if I can have kids, it's not a subject I would have to raise. Then if it is one that I can't have kids then it's obviously then a difficult situation to raise again, especially if they don't know my past. So it's something always there in the back of your mind subconsciously that is niggling away. But, don't know.

Adult male 16:22<sup>13</sup>

No females and none of the males without stored sperm were expecting to be called routinely for fertility testing. Within this group, strength of desire to parent appeared to influence contemplation of testing for both genders as did age among females. The numbers of males in this group were too small to look for any age-related differences. Older participants were more likely to talk of the complexity of decision making and this included some with stored gametes (including one with poor quality stored samples). For many, the risks being weighed up were those from getting a negative result versus the uncertainty of not knowing. In other

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<sup>13</sup> As previously, all quotes are identified by the category of the participant (teenage female, adult male etc) together with the age at diagnosis followed by the age at interview. Thus, this quote was from an adult males aged 16 at diagnosis and 22 at interview

words, the decision was related less to active contemplation of parenthood than to managing the implications of uncertainty within their present context.

One adult male without stored sperm who had been told already that he was infertile (but had not been tested) had been grappling with whether or not to be tested for some time. To date, his fear of the removal of any remaining hope of biological fatherhood had won the day though he continued to revisit the decision, including in the research interview itself:

I think postponing dealing with something isn't denial, I think you're just putting it to a time when you can deal with it when you're at a stage that you feel you can deal with it. I don't think that's denial, that's postponing. I think denial is to always just say, you're wrong, you're wrong, you're wrong to the doctors. I mean I accept, I've always accepted what they say is a possibility, I think the denial comes when I say it's a definite, because I don't think anything is 100% definite, and I think there is always a chance, always a chance, even if it's nine hundred and ninety-nine percent certain there is a possibility and I would like to think I'd that possibility, although I know all the odds are stacked against me but, and I suppose that is the denial aspect is that I would be that .0001% but I don't know if that's denial, that's hope and optimism, isn't it.....if I didn't have the hope I'd get tested now .....

Adult male 13:28

Several adults saw their approach as affected by their gender. Two males worried whether getting a negative result would affect their sense of virility and male pride at a gut level even if they could cope intellectually. Another thought his maleness contributed to his tendency to avoid dealing with the issue. This latter passive approach carried echoes of those anticipating routine testing and the disappointment of the one when this did not materialise – i.e. that it might be easier if the decision was to opt out rather than to opt in.

## **UNDERGOING FERTILITY TESTING**

Four participants (one male and three females) had become aware of their fertility status as a result of pregnancies so are not included in this section.

By interview, ten participants had activated requests specifically for fertility testing. Two males and two females had completed fertility testing when in their teens or early 20s. Two



adult females were in the process of undergoing analysis; one adult female had started the process but suspended it indefinitely; and one adult female, one teenage male and one adult male had just been referred into the process. Hence the data for those who had formally requested analysis is limited.

### ***Those in the process of undergoing fertility testing***

One of the males at the start of the process appeared quite relaxed about finding out even though he had no banked sperm. He was in a permanent relationship and had not been using contraception for a long time. He saw testing as a route through which to tell his parents of his infertility without having to disclose his sexual activity. He was unsure whether or not he ever wanted children and was anyway prepared to consider adoption. The adult female at the same stage also said that she had few anxieties about the process even though she was unsure whether or not she had been affected, knew that she might face a premature menopause and knew that any damage was irreversible. She explained that her decision was driven by curiosity rather than any deep-seated 'need to know'. She thought she would be able to handle the result either way, not least as she had a fairly low desire to parent:

I thought it would be interesting to know the results. I suppose it could be quite depressing if they suddenly said 'Oh you've got four years', so in a way that might be better off not knowing. But I think I'd be quite interested to know anyway, so. I like the scientific way for that kind of side of it anyway.

Adult female 15:26

However there were indications of anxiety about the outcome for others. One teenage male who had no banked sperm held a strong desire to parent. He had requested a referral unsuccessfully on a number of earlier occasions. When one such request was 'suddenly' accepted, he appeared apprehensive, had limited support available and was aware of hiding behind nonchalance at times:

Well when you're walking around, even though I'm only eighteen, you see it like when you're at school or walking, you see little kids, it just makes you think you'd like to have that when you're older, then you start to wonder what if you can't, what if this happens or whatever, so. You can think about that as much as you want but you just need, you know, to get it sorted, and know what's going to happen and all that.

Teenage male 17:18

The adult female who had suspended the process had a strong desire to parent, was sure that she was infertile and had no permanent partner. She had found the investigations too stressful, had very limited informal support (only one close friend knew what was happening) and no non-medical professional support.

For these two, the desire to be tested appeared driven by a need to know ahead of active contemplation of parenthood but where parenthood was a strong feature of their preferred future identities.

There were similarities in the experiences of the two adult females undergoing investigations. Both had opted for fertility testing as a direct result of actively trying to start a family, having previously decided against. They were highly motivated to keep going but also apprehensive about finding out. One had kept postponing arranging her next appointment. Her situation was exacerbated by the presence of ongoing cancer-related symptoms of low stamina and heavy menstrual bleeding. The other was free of such symptoms *and* had engaged in regular discussions with her professional carers about different options, thoughts and feelings from soon after treatment ended in her mid teens. Even though she was finding the process stressful, this approach had worked well for her:

And initially it was something that I thought about and didn't want the tests. I wasn't... ready to have a family and I felt that it would be more difficult to know that I couldn't have children than it was to not know at that point. I think for every appointment after that it's one of the things that comes up and they talk to you about and I think in the first appointment [husband] came to, it came up again and we again at that point made the decision that it's something that we'd go to the clinic when we were, when we wanted to have a family, when we'd got to the stage when it was the right time

Adult female 14:25

Only one out of this group (a female) remembered being offered non-medical counselling or support.

### ***Those who had completed testing***

Neither of the males found it a difficult decision to make at the time. One had discussed it with his partner after being prompted by the sperm bank moving sites and possibly starting to

charge for storage (see Chapter Ten). He wanted children one day but his partner did not at that stage. This discussion came before their relationship had become permanent. The other male saw testing as routine. He said that he did not discuss it with anyone outside of health professionals. He had no strong desire for children at the time.

As with the males, the females' requests came from neither a symptom nor an adult relationship context. One female was motivated primarily by distress at the thought of being childless, a 'need to know' and an overheard conversation between doctors and nurses in which her fertility was being discussed. The other was motivated by curiosity with no attendant strong desire to parent:

I were just curious to whether I would be able to have kids or not so I went to assisted conception unit and they did some tests, and ... I think were it me left ovary? I don't think that were working, and me right one were working but it were smaller than it should be, a fair bit smaller. And I were told if I wanted to have kids then then were best time to try, but I wa' twenty and I wan't in a serious relationship or owt like that, so I wan't - time wan't right. .... So I was just being curious so I thought I'd find out.

Adult female 18:25

None remembered being offered or receiving non-medical counselling.

There were differences both in the impact of being tested and in retrospective views of the process. Two – one male and one female – found the results manageable at the time and since, even though both were told that their fertility appeared to have been damaged. Neither felt a strong desire to parent at the time and this remained true at the time of the interview. The male had no detectable sperm and said this was what he anticipated. He located his laid back reaction within his general approach to his cancer experience (and life) but also held the understanding that he may still start producing sperm at some future stage. The female also emerged from the process without any apparent trauma. She was found to have reduced ovarian reserve and hence lowered fertility and understood that this was irreversible. Now engaged, she is not contemplating parenthood though this is because of significant (and ongoing) cancer-related physical difficulties and treatment. Hence her views about her fertility since testing have remained similar, though for changed reasons.

The impact on the two remaining participants was stronger. As reported earlier, the male prompted to undergo analysis because of changes at the sperm bank found himself (unexpectedly) to be fertile. He was delighted, even more so when he and his partner later conceived. The remaining female was firmly of the view that the process should have been slowed down. She had pushed her consultant to refer her for testing soon after treatment ended, even though the consultant was reluctant and she was still only in her teens. She found the negative result devastating, saying: 'It's like my whole life was being taken away'. She received little help in coping either at the time or in the longer term. It was she that had engaged in multiple sexual relationships in an effort to get pregnant. Several years later, she continues to struggle and has undergone extensive counselling around her wider cancer experience though is only just trying to open up on fertility issues. At a recent check up, she raised the subject again and, for the first time, was referred on for factual information about treatment options, names of support groups and so on which she found very helpful.

Thus, while the process of giving results appeared to be unproblematic for this small group, the content and aftermath proved challenging for some. The pattern of the influence of strength of desire for a future identity and lifestyle that prioritised biological parenthood seen earlier was repeated in this group.

**In summary**, there were some gender differences with regard to fertility testing. Some females had become aware of fertility damage as a result of gynaecological investigations but no males had undergone urology investigations. None of the females and none of the males without stored sperm were either expecting to be called routinely for fertility testing or receiving letters that might contain routine reminders about the service. All but one of the males who had banked sperm anticipated being recalled routinely. Most of them had started receiving routine storage renewal letters, some of which reminded them of the testing service. Few appeared anxious at the prospect but most considered that any negative tests results would be reversed later. Older participants were more likely to talk of the complexity of decision making about fertility testing. Only one remembered being offered non-medical counselling or support.

## **ALTERNATIVE ROUTES TO PARENTHOOD**

Many had thought about becoming parents at some stage in the future, a number of whom had acquired knowledge of fertility treatment options and/or considered the possibility of using alternative routes to becoming parents.

## Understanding of fertility treatment options

It was interesting to see whether knowledge of fertility treatment options as a route to parenthood might have affected either the management of fertility matters over time or decision making about fertility testing. There appeared to be gendered differences around awareness of them.

Several participants, especially females, reported increased knowledge of fertility treatment options from that held at diagnosis. Females were also more likely to report being asked by female friends and others whether or not they had used fertility preservation services. Females also more often reported knowing others in their family or wider networks who were coping with fertility difficulties and/or who had had unsuccessful fertility treatment (eight females and two males). None reported knowing anyone that had successful treatment. This may reflect a gendered difference around awareness of assisted conception.

Media portrayal prompted some of both genders (and family and friends) to think about fertility matters. It offered a source of information and understanding about fertility preservation and treatment options and provided some with hope. In particular, there were references to the extensive coverage of the pop star Kylie Minogue who had been diagnosed with breast cancer and opted to freeze her eggs (especially among females) and the man who had become a biological father with sperm stored twenty one years previously (especially among males).

None in the study had yet used assisted conception treatments though the two adult females undergoing tests knew they may need to. Very few indicated knowledge of treatment success rates or of complications such as multiple births. Some males with stored sperm were unclear about what they had consented to and the number of treatment attempts that their samples might offer them. Several used the research interview to ask questions:

Like I know that I've got it in a jar or wherever it is now... I would like to know how they get it into the woman you know. Would they use like a needle or would they put her to sleep and do it some other way like that. So that maybe in time if it's still not come back, I could sit down to me wife or me girlfriend and say, explain, how they would do it so she wouldn't feel so nervous about it or things like that.

Teenage male 15:17

One adult male in particular was unaware of promising developments in treatment for male infertility, as referred to earlier in this chapter. New knowledge gained in the research interview cast a very different light on the likelihood of his relatively poor quality stored sperm samples being of use to him in achieving his desire to be a biological father. However, a small number were very clear, including about issues surrounding treatment using donated gametes.

Some females knew that, even if they were to conceive naturally, the pregnancy itself may not be straightforward.

Fertility treatments were also referred to in both age and gender groups as an important source of hope and comfort. It appeared less important, for some, to have *knowledge* about the treatments than it was to have *belief* in them (and other medical advances in reproductive medicine) as an alternative route to parenthood:

It is hope, isn't it .. they're forever testing new stuff. I think some of the stuff is amazing what they do these days. So I think as time goes on there is always hope somewhere. ....It's just amazing what they can do I think. I think it doesn't all have to be bad. Not in this day and age anyway.

Teenage female 17:20

**In summary**, there was relatively little knowledge about fertility treatment options across the cohort and a firm desire to know more. A number saw them as a source of hope for the future. Females were far more likely than males to be aware of others in their family or social networks that had been through fertility treatments and to have more knowledge about such treatments. Some in all four groups cited media coverage as a prompt for them to think about their own situation. None had yet accessed fertility treatments though two were starting down that path. Some of the males with stored sperm were very unclear about what they had consented to.

### **Range of alternatives considered**

There were gender differences in the extent to which alternative routes to parenthood had been considered in the light of possible fertility impairment.

A number of females spoke of the importance to their well-being of knowing that alternative routes might be available should they be infertile. Only one had not (yet) considered alternatives. All the adult females and about half the teenage females had thought about adoption as an alternative, albeit fairly fleetingly for some. Among those who also talked about fertility treatments, adoption was more likely to be mentioned first.

But it's like now right I can't have kids, but you can adopt, you can do loads of other things, like just because one option's closed, the others are all open, so it's like it's easy to dwell on that and say 'Oh I can't have kids, I can't do this, can't do that' but just because of that you can do other things. And another way it could be good is if you're adopting you're giving other kids a chance, you know, and that can be just rewarding in itself.

Adult female 15:21

All but one of the teenage females who did *not* mention adoption talked instead about fertility treatments, including egg donation and surrogacy.

In contrast, only half the adult males and two of the seven teenage males said they had considered alternatives. Even then, they were less likely to be specific about what these had been. Three adult males talked in rather vague terms about 'options' and one talked briefly about adoption but did not discuss this any further. Three males (two adult and one teenager) talked a little about donor insemination.

Only two females (one adult, one teenage) and two males (both adults) said specifically that they would consider remaining childless if they found themselves to be affected (this is disregarding those referred to the Chapter Six who thought it unlikely that they would contemplate parenthood because of residual physical impairments). One of those pursuing fertility treatments at the time of the interview thought that she might remain childless if unsuccessful.

### **How they had come to consider the alternatives**

Here again there were differences between the genders. Among the females who had thought about alternatives, this was more likely to result from thinking about it on their own or as a result of conversations with family, partners or friends than through professionals raising it. Some adult females referred to television as a source of information about adoption,

surrogacy or fertility treatments but none of the males did. Those males who had thought about alternatives rarely talked about the context for doing so. However one adult male recalled a female friend sharing her views on adoption with him, not knowing that he was probably infertile. She had expressed the view that people should adopt rather than become biological parents in order to provide much needed family homes. That had greatly influenced his thinking and helped him turn a negative into a positive:

She told me she would never have children cos there are so many children that need adopting, so many children that need looking after, and like that put me a whole new perspective on it, and I always thought since then that if I'm desperate to have a child then I can have a child, there's no stopping me having a child, it's just, you know..... *Interviewer*: So that gave you a different perspective on how you get to be a parent, it gave you an alternative. *Adult Male*: Definitely.

Adult male 13:21

A number of females across both age groups had received offers of egg donation or surrogacy from female relatives or friends. Some thought they could contemplate this option while others were firmly against the idea. One female had asked her sister if she would, in principle, act as her surrogate (she refused but the participant herself had had second thoughts about it by then). None of the males had received offers of sperm donation from family or friends nor had they sought them.

## **Influences on views about alternative routes**

### ***Influence of actual or prospective partner***

A few of the females but only one of the males talked about whether their decision would be influenced by their partner's views though for many this was hypothetical. Most concluded that it would and that they may modify or reverse their existing views as a result. However, one female said that it would be *her* decision alone, given the potentially greater implications that it would have for her.

Some participants drew on their *actual* experience of taking partners' views into account. Three females (one teenage, two adults) had partners that were willing to consider adoption and one had agreed to consider egg donation if need be (the other two did not refer to egg donation). Another reported some differences in views but these were resolved by an



unanticipated natural conception. One of the adult males had discussed alternatives in more than one relationship and was comforted by the fact that each time the partner was open to considering alternatives.

### ***Influence of sexual orientation***

Two female participants identified themselves as lesbian. As referred to previously, one had been working on the assumption that fertility treatments were not available to lesbians so had not allowed herself to consider alternative routes. Having recently learned that this was not the case, she had started to gather information and allow herself to explore her thoughts and feelings. The other had discussed with her partner (who attended the interview) the possibility that she would be the carrying mother if treatment were sought.

### ***Influence of the perceived importance of biological parenthood***

Many females and males expressed the belief that having one's own biological children was preferable to adopting or using gamete donation. Some thought it highly unlikely that they would ever go down the alternative route. This brought added stress to their ability to cope with potential fertility impairment:

I don't really like any of the other options is the other problem, I want my own child in the sense that I want it to be part of me that I've created.

Adult male 13:28

Of those that could contemplate alternatives, these were, on the whole, seen as second best:

And people say, oh you can adopt, I don't think it will ever be the same as having one of your own.

Adult female 20:23

As well as being mentioned ahead of fertility treatments, adoption appeared to be preferable to donor conception treatments *among those that made such a comparison* (that is to say that not all did so). For one female, the resulting biological connection between a future partner and the egg donor would, she thought, lead to her feeling as if he had 'slept' with the egg donor and that the child was 'theirs'. The only males (one adult and two teenagers) to talk about donor insemination (DI) voiced similar views but with additional concerns about impregnation. All three were against the idea, each citing their resistance as being because it

would involve the impregnation of their partner with another man's sperm as well as that their 'ownership' of the child might be in doubt:

I wouldn't really like that [DI], because it's like it's not your kid is it, it's like, it's still your wife's, but it's like another man's sperm in't it, it's a bit funny and like one day what if the kid wanted to see their real Dad. Then you'd feel like proper heartbroken. So I wouldn't like that. *Interviewer*: Yeah, yeah. ....But it doesn't feel like that with adoption? *Teenage Male*: No because like, it's not both of youse, it's not the woman and the man's, it's somebody else's all together. It would feel a lot better, for some reason. *Interviewer*: Yeah, yeah, that's understandable that, it's like both being in the same boat, instead of one of you.... *Teenage Male*: Yeah. And if you ever like split up, like she could say that she's the real Mum and you're not, and then you wouldn't be able to see that kid and things like that. If owt like that happened. *Interviewer*: Mmm, that's interesting. So you'd feel you might have less claim over..... *Teenage Male*: The child yeah.

Teenage male 14:16

However for one of the females undergoing investigations that might lead to fertility treatments, egg donation was preferable to adoption because of the biological connection *and* because it might relieve her feelings of guilt at not being able to 'give' her husband a child:

That yeh, we needed a bit of help to get going but then it would still be ours, I suppose, whereas fostering and adopting bring up a lot more other, a lot different issues that it's not your child it's somebody else's child and actually how we'd feel about that.....I think maybe from my point of view that, one thing that has always concerned me was that I might not be able to give [husband] his children, erm, and egg donation would still be [husband's] children, erm, so I think maybe I'd feel a little bit less guilty about that in a way..'

Adult female 14:25

There were hints of the potential fluidity of views among some others, with interviews sometimes used as an opportunity to 'think aloud' on this issue. One teenage male said earlier in the interview that he would only want a child if it were of his 'own flesh and blood'.

As we talked further, there were hints of his willingness to consider the lack of a blood tie provided that the children were 'young enough' to become attached to him. In doing so, he drew on his own positive experience of having a step father. This was similar to another teenage male who made his contemplation of adoption provisional on it being of a baby that could be 'moulded' to his way of being.

An adult male who held a strong desire to be a parent but thought it highly likely that he was infertile appeared to use the interview to *start* thinking about alternatives. He was clear that, in his view, biology was *not* the most important ingredient for fatherhood. This enabled him to realise the opportunities through alternative routes to parenthood:

I think you can be a biological father and not be someone's dad, you know..... personally I think the two things are completely different. Umm, I mean, you know, I haven't really considered like adoption or, you know, whatever at the moment. But, umm, it will be something that has to be brought, the subject'll have to be brought up eventually but. Not really, I mean, you know, obviously I'd like to have kids but, you know, I might have to explore other.....

Adult male 18:23

### ***Influence of views on social parenthood***

A few appeared less concerned with the primacy of the biological connection than with seeing parenthood as a desirable state in and of itself. Some females, for example, viewed adoption in this light and cited the need for existing children to be found loving parents:

I'd always had it in me head that if I was infertile that there are other ways to go. That just because I couldn't give birth to a child doesn't mean that I can't have children, and that's always been the way that I've been. That's just the kind of person I am. That you get crap thrown at you from one direction and you just bat it off and keep on going. Find a way out and there's always another option. Generally there's always another option.

Adult female 19:25

The only male participant who talked in any depth about adoption did so from a predominantly altruistic viewpoint but tinged with the sense that it offered him a fallback position if he decided in the fullness of time that he did want to become a parent (he was not

sure at the time of interview). A small number saw it as having the potential spin off of making the adopter feel good.

Others who did not appear in principle to be against the idea of adoption or fostering were nevertheless apprehensive because of the time that was involved in the process. They also worried that they might have to wait too long to get accepted or, in the case of fostering, that they might get too attached to the child.

Some of the females who had considered surrogacy and egg donation hypothetically appeared alert primarily to matters to do with financial costs, the invasive nature of treatments, the exposure of the surrogate or egg donor to hormonal regimes and the risk in the case of surrogacy of non-relinquishment. The only female reference to parenting a non-biological child other than that from one of those undergoing investigations came from a teenager who did not wish to contemplate her sisters' offers to help as she had misgivings about having children with their genes (see Chapter Eight).

In summary females were more likely than males to have thought about alternative routes to parenthood and were more likely to have had this subject raised with them. Females in both age groups had received, or invited, offers from family members to donate eggs or act as surrogates. Although reservations were expressed across genders and age groups about alternative routes to parenthood, these were more often about gamete donation than about adoption. Romantic partners' views were anticipated to be an influence though few had yet had experience of this. As with fertility testing, the issues around alternative routes to parenthood were considered by some well ahead of any active contemplation of parenthood.

Against this backdrop, the experiences of that sub section who were pursuing parenthood actively or already parents are now explored.

## **TRYING TO BECOME PARENTS**

Two adult females were trying actively to get pregnant at the time of the study of whom one was already a step mother (though her step children did not live with her and her partner).

One couple were due for a further appointment at the assisted conception unit (ACU) soon after the research interview. They had known since early in their relationship that the female was at risk of premature menopause. This had affected their life planning as a couple and

brought forward the age at which they wanted to start a family – though they had still thought about this carefully.

We kind of.... we decided that it's something that we would, we did want a family and that it's something that we would embark on quite early, probably earlier than we would have done otherwise. We got married in [...] and at our appointment previous to that we kind of said well once we are married we'll start trying to have a family, and we discussed that with [consultant oncologist] and he kind of said 'Yeh, that's a good idea'. And then we got married and kind of straight away started. I came off the pill and we started trying to have a family and we're still trying.. *Laughs*. A few months ago, we had our first appointment at the assisted conception unit, for the first sort of round of tests, and we've got our next appointment in [.....] to go and see what the results of those tests were to see where to go next really I suppose. That's it at the moment. We're just waiting and trying.

Adult female 14:25

Both were present throughout the interview at the woman's request and some differences emerged in their views of professionals' handling of 'their' potential infertility. While the husband felt that the paediatric oncology staff tended towards negativity over his wife's fertility status and preferred the more upbeat approach at the ACU, she preferred the former approach as she thought there was less possibility of 'false hope' being generated:

*Partner*:...from what I've heard of the consultants [paediatric oncologists], he only tells you the bad things; in a way, what more can they say really, they just leave you with a negative feeling. Like when I went, and you just start thinking that we're not going to have children. All the assisted conception stuff has been really positive hasn't it? [to AF] There's never been anything to say ... she's never been told that she's not going to have children, but you're probably thinking in your own mind that you're not. And there's no reason to think that is there? You've never been told that you're not going to be able to have kids? *Adult Female*: No I've never been told that definitely won't be able to, it's just.. . .always been it's more likely that I can't than I can. ... But they've never given us false hope. *Partner*: but there's never any evidence to that, sort of thing.. *Adult Female*: No, and it was one of those things that you just don't know until you start trying, really.

Adult female 14:24

This may relate to a number of factors – gender, the fact that the partner has not been through the cancer experience, preferred coping style and so on – but illustrates the challenges that can accompany integrating new and significant actors into these encounters.

There were indications of greater ambivalence for the other couple. The male partner had children from a previous relationship. The female was coping with unresolved treatment related complications and found it hard to show her feelings or talk about her difficulties in conceiving with anyone. This included those with whom she held otherwise close relationships. At the interview, she reported feeling 'stuck' and had been postponing moving on to the next stage.

## **BEING A PARENT**

None in the study had been parents prior to diagnosis though five had become biological parents since the end of their treatment. This included an adult male who now had one child; an adult male with two children; an adult female with one child; an adult female with one child and pregnant with another; and a teenage female with one child. Only two of these five parents (one male, one female) had planned their pregnancies and neither had needed fertility treatment. The adult female with one child was also a step mother but her step child did not live with her and her partner.

### ***Unplanned pregnancies***

All those with unplanned pregnancies were using contraception at the time of conception. Another couple (who were not living together at the time) had only started to use contraception after the male was tested and unexpectedly found to be fertile. The pregnancy followed undetected contraceptive failure a few months later. They had not resolved the fact that the male wanted children (though believed himself to be infertile) while his partner did not prior to conception. It was the announcement of the pregnancy that finally made him believe that he was not infertile and the couple subsequently set up home together:

And I was like 'Oh, so I'm not shooting blanks then, right, OK'. And that was just.... cos in some ways I still hadn't believed what they'd said, because.. I'd heard nothing for five, six years, I'd been for one little test, they'd suddenly

said 'Yes you're fertile, now start using contraception'. It was a... from having one view I suddenly had to take on another view and until that moment...

Adult male 15:30

One of the females had not sought medical advice for some time after developing symptoms fearing that they heralded a return of her cancer. When she finally plucked up courage to go (her first ever medical consultation without her mother) she told her boyfriend but not her mother, her intention being to protect her mother from the anticipated bad news. She then had to pluck up courage of a different sort to give them the unexpected news that she was well into a pregnancy.

The third participant had agreed with her partner that they wanted children, but the pregnancy was not planned and came at a difficult stage in their relationship. They were still together at the time of the interview and were hoping to move into shared accommodation before too long (she was still in the family home). However she had experienced bouts of depression following the cancer treatment and again after the birth of her baby and was still receiving treatment for this. Although she was generally positive about becoming a parent, these other aspects clearly took their toll.

### ***Planned pregnancies***

One of the couples who had a planned pregnancy had started out with little hope of success as the male was sure that he was infertile. Early in their relationship, neither had expected to want children at any stage. This had shifted for both of them even though none in their friendship group had become parents at that stage. Interviewed together at the male's request, they thought that their low expectation of success, their philosophy of 'if it happens, it happens' and their decision not to tell either set of parents may have helped them to cope with trying for the first pregnancy for approximately a year. They now have two children, with the second pregnancy coming soon after they started trying. The couple were taken aback at the strength of feeling that flowed from the male's parents on being told of the first pregnancy which suggested that they had retained strong desires to be grandparents throughout the time during which they too had believed him to be infertile (see Chapter Eight).

For the female whose pregnancy had been planned, the circumstances were a little different. She had entered a permanent relationship when still relatively young with someone who had a child from a previous relationship. They worked together and she assumed (but was not wholly sure) that he was aware of her possible infertility through conversations in the

workplace. They did not discuss their views on parenting prior to moving in together though she said that she was not aware of consciously avoiding telling him. It was some time later that her partner suggested 'out of the blue' that they try for a baby. She agreed, with little further thought or discussion. Despite thinking that it might take time for her to become pregnant, it happened almost straightaway:

I think we were just sat one day, and.. I think it was my partner who said, 'er, I think we should start trying for a child' and I just laughed. And he said 'No, I'm being serious'. So I said 'If you want', type of thing. So I came off my pill a couple of days later and then within just over two months I fell pregnant.. *laughs.* *Interviewer:* So that was a fairly straightforward decision to make was it in the end? *Adult Female:* Yeh. I think I always said I didn't want them but I felt comfortable in the relationship to actually have one when the time came. *Interviewer:* Yeh. So it was something about being in this relationship. *Adult Female:* Yeh.....I never thought it would be as quick as it would be, with having all the treatment and then being on the pill, I didn't think, I thought it would be a couple of year before I fell pregnant.

Adult female 15:24

All appeared positive about their parenting experiences and about their ability to parent.

### ***Reactions of prospective grandparents***

In all these cases, the prospective grandparents had to take on board that their child, whose fertility had previously been uncertain, was now going to become a parent. Their reactions are covered in Chapter Eight.

### ***Managing the pregnancy***

Several referred to the level of monitoring during pregnancy. One of the females who had become pregnant close to the end of treatment had been reassured greatly by scans that indicated that there were no obvious health problems. She welcomed being closely monitored even though this involved additional visits to a distant hospital. She had feared that the pregnancy might trigger a relapse and lead to difficult decisions about whether or not to continue with it. The attention to monitoring continued throughout her labour and again was a source of reassurance.



The other female was also monitored closely by the consultant and welcomed that. She did not voice fears about her own cancer being triggered. However, she had been off treatment longer and had already had the 'all clear'.

### ***Fear of hereditary transmission***

One of those trying to conceive did not appear to be too concerned about pregnancy triggering a relapse but was worried about possible transmission to the child. She had welcomed the reassurance from discussing this with her consultant paediatric oncologist – in this case before the conception. All the parents mentioned fear of transmission, including the two female partners, but not all had had the chance to discuss this at the stage that they would have preferred. One did not get the opportunity until she saw her paediatric oncologist at her routine check-up after the baby was born. It was not clear why this had not offered sooner:

I was scared to start with in case what I had, would be, [baby] would get type of thing with her, if she got like a tumour for her thingies but they said that it was a so many percentage, a one off type of thing, because there was only me and another little, at the time there was me and another child that had only ever heard of this cancer that we'd got.

Adult female 15:24

One of the adult males found that the fear of his child getting cancer grew, if anything, with the passing of time:

Yes I'm worried about it, and yes I'm constantly worried about it. I don't know why. I don't know what I'd do if I've passed it on to [son]. It's an upsetting thought. Erm..pause..In the back of my mind, you hear all sorts of different stories, I remember seeing one on the news or something that they'd just released that said that cancer was hereditary, and I immediately emailed it to [consultant] and said 'Have you read this rubbish? They've just announced that cancer's hereditary on the BBC news'. ..... Yeah, it's a constant thought in the back of my mind. It's not one that I like having .....

Adult male 15:30

With one couple, it was the non-cancer survivor who worried more about transmission (though this was in keeping with the man's laid back approach to life). They had sought

medical advice from her partner's paediatric oncologist and a genetics expert prior to conceiving and that helped – though her concerns nevertheless remained throughout the pregnancy, not least because the medical information available was limited.

Finally several among this group and the whole cohort speculated in more positive vein that their own experiences of having cancer would make them better equipped than their own parents were if their child were to have cancer.

## **DISCUSSION**

The key focus in this chapter has been the potential complexity of managing fertility matters in relation to parenthood desires. Five participants had become parents (all since the end of treatment and none with the assistance of fertility treatment), two were trying actively to become parents and a number had contemplated undergoing fertility analysis as a way of finding out more about their likelihood of becoming biological parents.

Gender differences emerged in relation to fertility analysis. No females and none of the males without banked sperm were expecting to be called routinely for fertility testing, unlike most of those with banked sperm. Given the shorter reproductive lifespan for all females, regardless of cancer-related risks, this suggests that fertility analysis services may be driven less by providing a service to cancer survivors than by the need to facilitate disposal of any cryopreserved samples that may not be needed.

Males awaiting recall did not express any particular anxiety about this providing they understood their banked sperm to be of good quality as:

- Many thought that they were anyway unlikely to be affected.
- Many thought that any damage detected at this stage would be temporary.
- Many saw their banked sperm as offering them an alternative route to biological parenthood should they need it.

Females were much more likely than males to discover their status as a result of investigations for other medical complications (no males in this study had done so). Most females were also aware that any damage to their eggs would be permanent and that any resumption of reproductive function after temporary impairment could be followed by a premature menopause (see also Chapter Six). The implications of undergoing planned fertility analysis were therefore very different according to gender and according to whether or

not sperm had been stored. This has not been reported before. Increasing age also appeared to influence whether or not decision-making about analysis was experienced as complex although this finding should be treated with some caution as fewer adult than teenage males had stored their sperm.

Risks to well-being associated with undergoing analysis appeared to be lower when the person seeking it:

- Was curious about their status rather than concerned.
- Had some confidence in their ability to cope whatever the outcome.
- Had a low desire to parent.
- Could contemplate alternative routes to parenthood.
- Felt that continuing uncertainty was more stressful than knowledge.

The absence of psycho-social services for aiding decision-making and coping around fertility analysis was noted by several participants.

The paucity of information about fertility treatment options has already been identified as limiting the management of fertility concerns more generally (see Chapters Seven and Ten). It also impacted on thoughts about treatment routes to parenthood. It was clear that attention to alternative routes could be needed well ahead of active contemplation of parenthood. This may require professionals to engage in early 'scaffolding' work as well as providing relevant, age-appropriate information. This has not been reported before.

Females were on the whole more articulate than males about alternative routes to parenthood, appeared to have thought about them more frequently and in greater depth and were more likely to have watched relevant television programmes. Females were also more likely to have the subject raised with them by others in their networks. For example, the lack of offers of sperm donation to the males contrasts with the numbers of females being offered donated eggs or surrogacy arrangements. In other words, females appeared more likely to be exposed to, engage in, and be influenced by such social and verbal discourses, perhaps reflecting gendered assumptions about parenthood at individual, cultural and social levels (see pages 57, 107).

Gamete donation appeared less attractive than adoption across both genders as has been reported previously (see pages 27-28) although this did not appear to reflect general disquiet about fertility treatments. Indeed some in both genders expressed a mixture of hope and

confidence in the ability of medical science to provide them with 'solutions' if necessary. The expression of concern about the lack of biological connection had some gendered aspects that may go some way to explaining the disquiet about gamete donation. For example, while males expressed disquiet about sperm donation in terms of their unease about another man's sperm entering their partner, females did not have the same unease about receiving another woman's egg into their body.

The response of romantic partners to alternative routes was seen as important though few had actual experience of this.

The numbers trying to become parents (two) or who were already parents (five) were small. One had brought forward significantly the timing of contemplating parenthood because of the likelihood of a premature menopause. Both those who were yet to conceive expressed feelings of guilt towards their partners. They appeared to carry the brunt of the emotional impact within the relationship. However the fertility literature suggests that such gendered divisions are common within couples experiencing non-cancer fertility difficulties (see pages 107). It is unclear how far these participants were influenced by being cancer survivors or by gender or both. Although it was proving stressful for both, one couple was more engaged in building strategies around the process and appeared a little less at the mercy of health professionals and medical science. However caution is necessary with such small numbers.

There were also indications across all seven participants of the challenges of integrating partners into the medical arena for participants so well versed in such contact, albeit in a different sector.

Among the parents, only two had planned their pregnancies. Some had believed themselves highly likely to be infertile beforehand so the early stages were taken up with adjusting to unexpected pregnancies, even if planned. Increased levels of pregnancy monitoring among the female survivors were welcomed for the reassurance this brought to fears that the pregnancy would trigger a relapse. There was also concern, including among non-affected females, about the risk of transmission of cancer to the unborn child as has been reported elsewhere (see pages 25-27). For a few, the opportunity to get information about this did not happen until after the birth although it would have been welcomed earlier.

One parent reported that the fear of his child getting cancer had been lower in the child's early years but had grown over time. Most commented that they thought that they would be

better equipped than their parents to cope with their child getting cancer as they would draw on their experience and on the strengths that had come with that experience. On the whole, all appeared to have adjusted well to being parents. Again these match findings from previous research (see pages 25-27).

## **SUMMARY**

This chapter has studied the thoughts and experiences of those participants who had contemplated parenthood more actively. This included those who had undergone, or were undergoing, planned fertility analysis, those who were trying actively to become parents and those who were already parents. Participants' views about alternative routes to parenthood were also considered. Anticipated and actual parenthood is, of course, a normative state attached (usually) to adulthood and of influence to those outside adulthood. For the participants in this study, the non-normative experiences gained through having cancer and living with the possibility of fertility damage appeared to carry some additional and complex influences. Gender differences were apparent on a number of fronts. No females were invited routinely for fertility analysis although a number were aware that their biology and lack of stored gametes arguably reduced their opportunities for achieving biological parenthood. Females were more likely than males to have thought about treatment routes to parenthood and to have had greater exposure to the associated issues. However both genders felt disadvantaged by inadequate levels of relevant information about fertility treatments (though hopeful about their success levels). Both also shared concerns about becoming a non-biological parent though for partly different reasons. Those who had become parents felt more resilient if they had access to prior genetic advice and if they or their partners were closely monitored during pregnancy. Although fears of transmission were present, as were fears of pregnancies triggering relapse, there were also universal expressions of confidence in their parenting skills and their abilities to withstand any future trauma.

This brings us to the end of the story reported through analysis. In pulling these accounts together with the literature through the reflective discussions at the end of each chapter, messages have started to come through. The next step is to shape these into their implications for policy and practice.

## CHAPTER TWELVE

### IMPLICATIONS FOR POLICY AND PRACTICE

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In this chapter, I will explore key messages for policy and service delivery contexts. I outlined the policy context in Chapter Two. In this chapter, I start by considering professional practices and service frameworks before pulling out key messages from the study's findings and their implications at both policy and service delivery levels. Attention to fertility matters associated with cancer does not fall within the remit of one particular discipline. The range of professionals within social care and health alone that are, or could be, involved include doctors, nurses, scientists, counsellors, psychologists and complementary health practitioners in addition to social workers. The implications for the range of such professionals and services including those whose remit is therapeutic in outcome (which includes social work, generally speaking) as well as those which are therapeutic in intent are considered at operational and policy levels. The influences of conceptualisations of fertility and of human development held by professionals and their impact on risk and protective factors around resilience are also taken into account.

#### **The service context**

There has been growing recognition of the importance of psycho-social services at each stage of the cancer journey (Eiser 1998), the need for more standardised levels of provision (Mitchell *et al* 2005) and calls for closer attention to the links between hospital-based and community services (Kelly *et al* 2003, 2004). As the literature reviewed in Chapters Two and Five indicated, services often fall short of meeting policy recommendations and guidelines. Jankovic *et al* (1999) said: 'Questions, uncertainties, worries and late problems can be dealt with effectively when psycho-social support is available and can make a dramatic difference to the quality of life of the individual family members' (p277). There is less agreement about, or attention to, the composition and delivery of psycho-social services and how these map onto health services and vice versa. Additionally, a recent review of psychosocial research reported that there are almost no pre- or post- treatment intervention studies (Last *et al* 2005). None have been identified that were specific to cancer-related fertility matters.

Involvement of social workers in the multi-disciplinary network has been supported by those outside as well as within social work (Albritton and Bleyer 2003; Arbuckle *et al* 2005; Grinyer

2007; Hollis and Morgan 2001; Jankovic *et al* 1999; Kazak 2001; Mitchell *et al* 2005; Quin 2004; Whelan 2003), by cancer survivors (Earle *et al* 2005; Mitchell *et al* 2006; Zebrack 2006) and by parents (Clarke *et al* 2004; Mitchell *et al* 2006; Sloper 1996). While social work services for those receiving treatment or immediate after-care are poorly resourced, they are especially limited for survivors. Given that survivors may be geographically mobile and given the trend towards health self-care, one study concluded that social workers should run or facilitate targeted 'one-shot' interventions such as workshops, conferences or survivor celebration events as well as providing more in-depth follow up for individuals (Zebrack and Chesler 2000). However the provision of social work services in UK paediatric and adolescent oncology is outside of the NHS (except for Northern Ireland where different arrangements apply) and funded largely through the voluntary sector (which brings a level of financial insecurity) even though staff may be employed directly by the local authority. As in other sectors of health-related social work, this, together with lack of acknowledgement of their expertise, can lead at times to social work services being left out of key operational and service development discussions within the dominant health arena (Quin and Clarke 2006). Equally, their specialist focus can marginalise them within mainstream social work services. This is complicated further by the fact that this service user group straddles children's and adults' local authority service sectors and that the care management models of service delivery that are dominant in both sectors arguably limit creative, user-centred practice.

While Eiser (1998) concluded that there was a need primarily for specialist psychological services and Mitchell *et al* (2005) reported the greatest shortfall to be in psychological therapies, others have argued for more general counselling services (Davies *et al* 2003) and/or for services that take a family-centred approach (Whyte and Smith 1997). Van Dongen-Melman (2000) suggested that it would be more appropriate for a range of services to be made available if different needs between individuals and amongst family members were to be met. She suggested that this should include a standard aftercare programme to provide information (including written) and support (including preparation for anticipated points of challenge) to family members as well as children/young people, professional facilitation of contact between those affected to increase peer support and more in-depth support.

Olsson *et al* (2003) concluded from their review of studies around resilience outside of a cancer context that there was a need for services that helped young people build skills and capacities to facilitate successful negotiation of high risk environments and reduce risk by removing or avoiding risky factors and processes (p9). While some cancer survivors want to

'forget it and move on' and have minimal contact with professionals, others welcome ongoing help with planning how to talk to others about their cancer history, residual emotional difficulties, 'survivor guilt' and staying positive. The same is true for many family members (Earle *et al* 2005).

Finally, Gilligan (1997) has argued that the underpinning principle for any professional intervention should be one that takes account of resilience:

'The challenge for those who seek to influence the child's well-being is to try to cultivate, carefully, as many protective factors as possible and to minimise the risk factors so that resilience can manifest itself' (p14)

### **Messages from this research study**

A number of participants made specific suggestions for improvements. The interviews themselves also provided rich data from which recommendations could be drawn. These fall into certain categories:

- Timing and context for raising fertility matters
- Professional approaches
- Involvement of parents
- Need for information
- Access to fertility preservation and fertility analysis services
- Follow up services post treatment
- Access to services in relation to planned parenthood

This study was not designed to consider whether age-specific services were more effective than those delivered from within broader age bands. However it was clear from the findings that it was important for professionals and services to be alert to the particular context of their service users' lives, of which being in the transition years was one.

### ***Timing and context in which fertility matters are, or might be, raised***

The importance across all ages and genders of being told at around diagnosis that fertility may be affected by the cancer or its treatment came across strongly for two main reasons. Firstly in order to reduce the risk of trust in their professionals being jeopardised through later



disclosure. Secondly in order to enable them to consider this side effect alongside others when developing strategies for managing their unfolding situation.

Study findings made it clear that the implications of fertility matters extended well beyond medical considerations alone and could therefore require a range of professional responses within and across disciplines. Although services were discussed most frequently in the context of contact with doctors, fertility matters were not seen as their exclusive preserve. The dominance of such references may reflect the paucity of existing psycho-social services and a lack of awareness or reluctance within other disciplines to engage in these issues. As suggested in Chapter Seven, medical model approaches to fertility matters and hierarchical, staged conceptualisations of human development may also carry the potential to restrict professional attunement to fertility concerns, regardless of discipline.

The finding that fertility matters may be pushed to the margins for those prioritising a 'return to normal' during active recovery (see Chapter Six) emphasises the need for professionals to remain alert to any brief or extended changes to this approach. Where recovery from the cancer experience appears to be going well, the potential for fertility matters to slow or distort it is clear and professional vigilance is again required. Where recovery from cancer appears to be largely achieved, professionals need to watch for signs of fertility concerns moving centre stage (if they do). Prompt professional attention at any stage – medical and psycho-social - may minimise disruption to the recovery process.

Some of those experiencing unease will not necessarily recognise fertility concerns to be a contributor. Professional experience indicates that the roots of distress can remain unclear, even to those experiencing it. This, together with the research findings around distorted 'inner sexuality' (Puukko *et al* 1997b) and inner mental health concerns (Elkin *et al* 1997) supports the importance of professionals considering fertility matters alongside other possible causes. This study suggests that risk may be heightened where an individual appears to hold a strong desire to become a biological parent one day, an 'impaired' or 'uncertain' fertile identity, a lack of good-enough professional or informal support and/or inadequate strategies to manage any gap between desires and reality. Professional encouragement of a 'dual process' approach to recovery that attends to issues of loss *and* restoration (see Chapter Four), as well as vigilance by professionals sensitised to the potential influence of fertility matters, could prove effective.

Findings relating to impact on self, family, friendships, romantic relationships and parenthood (Chapters Six, Eight, Nine, Ten and Eleven) indicate a range of contexts within which professional input has the potential to lower risk from fertility issues and promote or maintain resilience. There was support for in-patient and out-patient service developments around fertility matters including a dedicated ward-based staff member, an independent service (i.e. from outside of the 'known' team) and greater attention to the subject from social work and community/outreach nursing services. Such services would need to be advertised clearly.

Only a small number had used counselling services but none (yet) for fertility concerns. While some appeared to have therapeutic needs, meeting these through dedicated therapeutic services alone may prove too limited. Within assisted conception services, counselling has been found to be helpful in reducing negative affect (Boivin 1999; de Liz and Strauss 2005). However, voluntary take-up is small even though those affected say that they want such services to be available (Boivin *et al* 1999). A review of psycho-social interventions in infertility settings also found that those emphasising education and skills training were more effective in producing positive change across a range of outcomes than was counselling (Boivin 1999). In a study of young people coping with adversity in a different context (asylum seeking), the researchers concluded that therapeutic care needed to be woven into existing service provision (Kohli and Mather 2003). Many of those with deep-seated psychological distress – including some whose external affect was of disconnection, regression or politeness - could not engage with formal therapy. However practical support together with what has been called 'therapeutic witnessing' from professionals able to hold, contain and bear witness – in other words 'be there' – proved effective and recognised 'the balance that the young people need to strike between inner and outer worlds' (Kohli and Mather 2003:210). While additional dedicated therapeutic services around cancer-related fertility matters should form part of service provision, existing service provision may therefore also need to be responsive to individual therapeutic need through the following core features:

- Having one key professional – usually the consultant oncologist - raising fertility matters in the early phases of diagnosis and treatment with others involved according to the preference of the young person and with their knowledge.
- Having clear procedures for providing broad brush information initially with further questions or discussion invited shortly afterwards and then at regular intervals during treatment and follow-up. This to be done in a routine, unambiguous and low key way in order to facilitate take-up by those who wish to do so while not being unduly intrusive to others. While this should be a feature of medical consultations, it may also

be appropriate for other professional encounters, depending on the local service context – for example nurse-led late effects services.

- Having staff in all disciplines involved in treatment and beyond who have basic, up-to-date knowledge and awareness of fertility matters, are willing to discuss associated thoughts and feelings with those affected and have the authority to refer on to other services as appropriate.
- Having staff who are alert to the need to understand the meaning and implications that fertility matters hold for particular individuals, including whether or not they *believe* themselves to be fertile. As these are likely to be dynamic across time and context, individual staff and service procedures need to avoid making assumptions based on existing experience with the individual concerned. Likewise, generalising from wider experience with, or assumptions about, young people must be avoided.
- Promoting an atmosphere on the ward, outpatient settings or other contexts that encourages open and safe discussion of fertility matters with peers and challenges associated stigma.
- Providing verbal and non-verbal information, support and advice to individuals, family members, partners and other supporters, though with careful attention to maintaining confidentiality of details specific to the person affected. As well as meeting their own needs, this may also enhance supporters' ability to 'be there' for the young person.
- Where referral to therapeutic or other services is made, facilitating take-up of those services beyond the action of making the referral.

### ***Professional approaches***

The literature makes it clear that professionals across the disciplines within paediatric oncology circles are committed to taking a partnership approach to working with young people. There was evidence of that in this study. As has been found elsewhere, it was the quality of the relationships, even in single encounters, that were more likely to be commented on by participants than organisational frameworks (see Chapter Seven). Experience outside of paediatric oncology circles (which was wholly with health professionals) was more mixed in relation to both partnership working and manner. There were suggestions for improvements in approach as well as affirmations of what worked well and why.

Preferred professional approaches mirror some of the features of service provision above and could be grouped as follows:

### *Providing clear, understandable information*

- Using easy to understand verbal communications that are free of jargon, especially in medical consultations.
- Being honest and willing to offer opinions about a course of action while making it clear that the decision still rests with the person affected.
- Providing the opportunity to ask for clarification, to ask questions and to discuss implications or to have access to someone else able to do that.
- Checking out what the person affected has understood so far, including about predictions of risk of fertility damage and the interpretation they have made of that risk.

### *Being user-centred and affirmative*

- Acting respectfully towards them and maintained a user-centred focus, including in the presence of parents.
- Showing warmth, friendliness and an interest in the person affected.
- Being approachable, competent, compassionate and not embarrassed.
- Maximising the opportunities for those affected to make their own choices, no matter how small.
- Proactively affirming the 'value' of the young person in the here and now regardless of their fertile status.

### *Being pro-active but not intrusive*

- Managing the balance between raising fertility related matters proactively and not interrupting preferred styles of managing.
- Understanding that fertility concerns can arise ahead of any active contemplation of parenting and can attach to other aspects of one's life or identity.

### *Being non-judgemental*

- Not making assumptions about the views or reactions of the person affected; in particular being alert to hierarchical assumptions based on age, gender, ethnicity, culture, sexual orientation and so on.
- Modelling a social model approach to fertility impairment in which any feelings of shame or guilt are acknowledged and not trivialised alongside 'naming' the place of stigma in shaping such responses. Breaking down some of the stigma attached to fertility impairment by normalising fertility concerns, challenging stigma where it arises and developing shared strategies in much the same way as some of the taboos associated with cancer have been, and continue to be, challenged.

### *Being hopeful*

- Offering hope of some fertility being retained, even if limited, and demonstrating professional belief in the ability to have a good quality of life if childless or if parents through non-biological routes.

Professionals need to remain open to intervening at individual, family or couple level. They should also facilitate peer support at individual or group level and proactively address fertility matters within that. Although some of those affected will prefer to discuss fertility issues in more private settings, it should not be assumed that this remains true for all.

As referred to already, professionals need to be alert to the possibility that they will, on occasion, be able to identify where fertility concerns are contributing to a reaction more readily than will the individual concerned and/or those around them. The masking of causes of distress is not an unfamiliar feature for professionals. For example, an unexpectedly intense reaction to some other source of loss, stress or uncertainty may be fuelled in part by fertility concerns.

### *Involvement of parents, partners and others*

Although there was widespread affirmation of the important role that parents in particular played in helping young people cope with the cancer-related fertility experience, it was clear that some professionals were better able to manage the involvement of personal supporters than others.

In the early days around diagnosis, there was general acceptance among participants that it was difficult for professionals to offer choice about parental involvement in fertility matters (see Chapter Four). However, given that the absence of choice made the situation more difficult for a small number to handle, every opportunity should be taken to offer choice at all stages. Where this is not possible, steps can nevertheless be taken to minimise the chances of negative impact – for example offering the choice of accompaniment to the sperm bank beyond the parent(s)' hearing; not assuming that one parent is more or less appropriate than the other when fertility issues are raised; and making sure that any discussion is direct with the young person if the parents are in the room.

Although more choice about parental involvement was available as time went by, this was not always offered in a way that enabled participants to exercise it (see Chapter Seven). For

example, some participants were asked to decide in the presence of their parents and found it difficult to say no. Sometimes this was because they wanted to protect their parents from feeling rejected, sometimes it was because they anticipated that parental anger would follow. Where the professional asked the parents to leave and then asked the question - or asked the young person when their parents were otherwise absent - choice was experienced as more meaningful.

There were a few instances where professionals were drawn into discussing fertility matters with parents rather than participants and this was not seen as appropriate. However there is also a role for professionals to offer information and support to parents who are distressed about fertility matters. Indeed some participants would have felt some relief at such support being made available. While this may be offered by hospital-based staff during treatment phases, it is more likely to fall to home-based services such as social work or community nursing, especially following the end of treatment. The need to maintain confidentiality and hence to know what 'information' belongs to which family member is clear.

The involvement of partners appeared to be managed more easily (see Chapter Seven). This is perhaps because the young person themselves took an active role in preparing their partner and choosing the timing and content of the session. However, few professionals receive training in couples work and that skill shortage may need addressing through additional training and/or access to suitable casework supervision. Recognition that a partner will usually have had less time to process and accommodate any fertility concerns together with any gender differences (if a heterosexual couple) is likely to prove a central feature.

### ***Need for information***

There were indications of a need for more information about cancer-related fertility matters to be available for those affected, especially females, and for parents and/or partners (see Chapters Six, Eight, Ten and Eleven). Although there was acceptance that some uncertainty may result from incomplete information held by professionals, some participants experienced uncertainty because of ambiguous or otherwise unclear information.

While care needs to be taken to avoid information overload or disruption of preferred patterns of information use, the proactive and regular provision of clear information may lower risk and promote and maintain resilience. Those affected do not know necessarily what information might be useful. For example, information about fertility treatment options may be welcomed even if not requested specifically. Given the apparent complexity around understanding of

contraception, hormone replacement therapy, female reproductive system and premature menopause, these areas may warrant particular medical and psycho-social attention.

All participants welcomed the verbal provision of information. Some wanted information in a written or audio-visual format or via the internet in addition. Access to non face-to-face contact with a professional – for example through a help-line or via email – has the potential to make it easier for some to deal with embarrassing matters. In similar vein, if posters or leaflets are displayed, they need to be prominent enough to be seen but discrete enough to be picked up or noted (or available as well through more discrete routes).

Any written information needs to be easy to read and appropriate to the context in which it is being provided. For example, it is inappropriate to provide a young woman in her teens wanting to learn more about her options for future parenthood with leaflets on egg donation written for couples with non-cancer-related fertility difficulties seeking fertility treatment.

Any development of such materials should also always include multi-disciplinary input. Similarly, all members of the multi-disciplinary team should feel able to make such materials available to those affected and their supporters. It is likely to be helpful for there to be a regular sharing of experiences about such professional practices so that good practice can be built on.

Given that media attention to both cancer and fertility matters is extensive, the potential for this to lead to misinformation as well as distress means that it would be helpful if professionals were alert to current media-based issues. They should also check regularly with those affected whether they have questions or issues arising from such exposure.

### ***Access to fertility preservation and fertility analysis services***

Although it was only males that *used* fertility preservation services in this study, all those given a choice voiced strong support of this (see Chapter Four). This included participants who were very young, ill or incapacitated at the time, those who tried and failed and those who refused. These findings strengthen existing policy recommendations.

Many females recognised that fertility preservation is more complex for them than it is for males (see Chapter Six). Services for females are less well developed scientifically, in very limited supply and hence more likely to be geographically distant (Picton 2006). However firm consideration should be given either to making their availability known or to explaining at

around diagnosis why they are not on offer. This would fit with participants' preferences for professionals to be honest and give full information, even if broad brush, from the start.

For both genders, and especially females, professionals need to be alert to the possibility that decisions made at around diagnosis to refuse offers of fertility preservation might be ruminated on and cause later distress.

Suggestions about service provision around fertility analysis are more difficult to determine (see Chapter Eleven). It was clear that associated decision-making could be complex. Among those who had opted already for analysis, only those who were curious (rather than concerned) and had a fairly neutral view about parenthood appeared to find the process straightforward throughout, even when results indicated impairment. Among some of those with stored sperm, there were clear expectations that they would receive routine tests. Some had already started receiving a standard 'renewal of storage' letter from the sperm bank. The only one that had attended an appointment at which he expected to be tested was surprised to find that this was not in fact routine and involved a referral on. It might be important to consider whether such expectations are commonplace and what implications this carries. For those without stored gametes, none were receiving routine reminders of the availability of fertility testing. This discrepancy warrants attention. The lack of stored gametes or the presence of poor quality stored gametes also appeared to inhibit or complicate the desire to be tested, given the lack of 'back up' routes to biological parenthood. The complexity of decision making was experienced most strongly, but not exclusively, by the older age group. Additionally females were aware that any damage would be permanent immediately and might lead to a foreshortened reproductive lifespan. While males were aware that damage to their reproductive system might be permanent, they were inclined to expect any damage to be temporary, especially those with stored sperm. Professionals discussing the implications of testing need to keep these gender differences at the forefront of their thinking. Findings also suggest that some young people will welcome preliminary discussion of such issues well ahead of any formal referral to specialist services.

What is clear from this study is that fertility analysis requires more extensive and careful professional attention than is available at present. In particular, only one offer of non-medical counselling to aid decision-making and the building of strategies for managing the results appears to have been made even though several participants had been referred for testing. Neither was it clear how fully decision-making had been explored within existing professional relationships. At least one of those tested wished, with hindsight, that the process had been



slowed down and that counselling had been made available. Without access to such services, the potential for harm is heightened. The need to make help available to family members and partners as a further way of aiding those affected directly is also clear.

### ***Follow up services specific to post treatment***

As referred to above, there was strong support for fertility to be raised proactively at follow-up hospital appointments (including for long term follow up), in any ongoing contact with home-based services or through peer survivor groups. Identified needs were for more information, help with decision making or strategy building and for opportunities to process feelings therapeutically. This applied to family members and partners (and possibly friends) as well as individuals.

However all services should be alert to promoting a context in which the inter-connections between feeling good about self, lifestyle and ability to make choices about relationships and future planning are attended to. The scaffolding for this might draw on skills across the multi-disciplinary network and include help with:

- Education or employment.
- Attainment of security through having an adequate income and accommodation.
- Maintenance or formation of close friendships, especially given their heightened role around sex and fertility matters.
- Negotiation of family based relationships that promote interdependence.
- Attention to body image and inner sexuality.

Specific attention should be paid to alerting staff in schools to, and educating them about, fertility matters.

Services designed to be therapeutic in intent (such as counselling) as opposed to therapeutic in outcome (such as social work, medical, nursing) have a potential role at this stage as elsewhere. As suggested earlier, attention needs to be paid by staff referring between services to finding effective ways of facilitating take-up.

### ***Access to services in relation to planned parenthood***

Aside from fertility testing services, some participants welcomed the opportunity to discuss their active plans for parenthood with professionals. For some females, this might include seeking advice about their own likelihood of relapse if they were to get pregnant and any

potential for pregnancy-related complications. Across genders, it might involve seeking advice about transmission rates. Making such services clearly available prior to conception or during pregnancy has the potential to abate some anxiety. Similarly, recognising and acknowledging explicitly that fears do not necessarily disappear with the birth of an apparently healthy baby but may increase over the years may be helpful.

As already mentioned, a number of the participants in this study expressed the need for themselves, their partners and parents to have access to information about fertility treatment options together with the opportunity to discuss psycho-social as well as medical aspects of this route to parenthood. However all alternative routes to parenthood can throw up needs. Not surprisingly, understanding of contemporary adoption was also very limited, with a tendency for it to be seen somewhat simplistically as providing a needy child with a home. It was unclear how well informed were those health and social care professionals in the cancer arena to whom participants had ready access if they wished to discuss adoption. Although participants themselves were less likely to see adoption as a gap in their information needs, there remains the potential for any misinformation to adversely affect later coping if they came to realise that their strategies were ill founded. At the other end of the service provision in adoption agencies that may be approached by those seeking parenthood, the lack of an evidence base around cancer survivors' experiences of parenting, including adoptive parenting, to inform assessments of their suitability as adopters also has the potential to lead to poor experiences. Finally, those contemplating assisted conception treatments will have to manage the fact that the bulk of such treatments in the UK are only available through the private healthcare sector. Despite attempts over several years by such movements as the National Infertility Awareness Campaign to reduce so called 'post-code lotteries', provision within the NHS remains very limited (see <http://www.infertilitynetworkuk.com>). For those cancer survivors whose treatment has left them financially disadvantaged as a result of reduced employment prospects, permanent impairments and the like and/or whose sense of well-being is already low and/or who feel angry or bitter about their experiences, having the door effectively closed to this route to parenthood could add to their social and emotional disadvantage.

## **SUMMARY**

There are important messages here about the importance of the multi-disciplinary and inter-agency context for enhancing management of fertility matters by individuals and those in their support systems at all stages. Improvements require some increases in provision and some

changes to use of existing resources. All require professionals working in ways that maximise the adaptive capabilities of those managing the challenges of fertility concerns, facilitate the promotion or maintenance of resilience and lower risk to well-being. The provision of regular, good quality, clear information in a variety of formats is called for, providing that its content pays attention to psycho-social as well as medical matters and that it is provided sensitively. Professionals should raise, or respond to, fertility issues in an unambiguous and low key way, taking care to look for their individual meaning for those affected. As individuals will not necessarily have conscious awareness of any fertility-related distress, professionals should also be alert to possible hidden manifestations. Psycho-social input should not be identified solely with psychological therapy services. Staff within services whose primary remit may not be therapeutic provision (such as social work) may afford appropriate 'therapeutic witnessing' and help with problem-solving and strategy building. Preferred professional attributes are easier to specify than to provide. They include honesty, approachability, clarity, respectfulness, competence, compassion and hopefulness. The need to offer meaningful choices about parental involvement is clear. There is a need not only for training but also for supportive cultures within workplaces to encourage all of this. There is an underpinning need for policy and practice adherence to see fertility matters within their social as well as their medical context. If they are viewed within the narrow confines of the body as a reproductive system rather than as applying to social beings in their social context then the risk of needs being ignored, unmet or misunderstood is heightened.

Regardless of improvements in professional practices and service delivery, those obstacles that relate to the privatisation of assisted conception health care retain the potential to further disadvantage cancer survivors wishing to exercise the choice to become parents.

Policy and service developments have to date been hampered by limitations in the research evidence base. This exploratory study has not only produced rich data but has also indicated areas where further psycho-social research is needed. With regard to improving understanding of the meaning of fertility matters to young people in this context, further work on the relationship between social, sexual and fertile identities is called for. There is an urgent need for studies that look at experiences associated with the contemplation or process of fertility analysis. Improved understanding of decision-making processes around disclosure of fertility concerns to friends and romantic partners could prove helpful as could studies that look more closely at planning for parenthood, alternative routes to parenthood and parenting itself. A further gap is research that focuses more specifically on common and unique experiences across sexual orientation, ethnicity and disability.

No research has yet been undertaken into either the impact on parents themselves of coping with their child's possible cancer-related fertility impairment or on the parent-child relationship. The same is true of wider family members, friends and romantic partners.

There has been some research into professionals' experiences of managing fertility matters. Although limited, it may be sufficient to move towards conducting studies that evaluate different models of intervention around fertility matters, especially where these are multi-disciplinary and inter-agency.

## CHAPTER THIRTEEN

### CONCLUSIONS

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#### Background

This interview study set out to address the following research questions:

- Does a diagnosis of cancer in the teenage<sup>14</sup> years which is accompanied by the information that the cancer or the treatment might impair fertility have an impact on the process of growing up? And if so, what are the ways in which those involved are affected?
- Are there any aspects that appear to be related to gender?
- How far does the way in which services are provided currently help or hinder these experiences?

In doing so, in-depth single interviews were conducted that drew on participants' retrospective, contemporary and future explorations. Thirty eight individuals took part, all of whom had been diagnosed between ages 13 and 20 and were aware that there was a risk, no matter how small, that their fertility may have been affected. Of the thirty eight, twenty one were females (nine teenagers and twelve adults) and seventeen were males (seven teenagers and ten adults). The cohort was drawn from a range of backgrounds with regard to educational achievement, employment, family situation and ethnicity. While none had a prior major impairment, several were left with impairments following treatment.

Participants were recruited through three regional paediatric oncology centres in the North of England. Take up rates were the same for adult males and females (40%) though lower for teenage males (24%) than for teenage females (36%). Overall, slightly more females (38%) than males (31%) agreed to take part and rather more adults (40%) than teenagers (29%). Recruitment to studies involving face-to-face contact with teenagers (including those affected by cancer) and/or on sensitive subject areas is known to be difficult. These take-up rates were therefore encouraging. There is no data on reasons for refusal or on how far their experiences may have replicated or challenged the findings here. The aim to map a range of

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<sup>14</sup> As referred to previously. 'teenage' here is taken to cover those aged 13 to 20 years.

experiences was realised. Increasingly few new factors emerged in later interviews, suggesting that the sample size proved sufficient for the purposes intended. That said, there were only low numbers from minority ethnic groups, those with prior impairment and those who identified themselves as gay and lesbian. This presented particular limitations in interpreting any unique aspects of their responses.

The literature review did not identify any studies that focussed on the impact of cancer-related fertility matters following diagnosis during the transition years. However there were studies that reported on other aspects of fertility matters, such as sperm banking or the views of adult survivors, and these were reviewed. Studies that reported on fertility matters as part of a wider study with young people and/or that also drew on younger age groups were also included.

Findings were analysed with particular reference theoretically to lifespan approaches to human development and to the ways in which young people's experiences of themselves and those around them (including professionals) contributed to the development or maintenance of any resilience in relation to fertility matters. In keeping with this, risks to well-being were also identified.

### **Impact on self**

The strong mixed gender support expressed retrospectively for fertility side-effects to be raised and for fertility preservation services to be offered (especially for males) at around the time of diagnosis reinforces and extends existing research findings (Cancerbackup 2005; Crawshaw *et al* 2003; Schover *et al* 1999; Schover *et al* 2002a; Shaw *et al* 2005; Zebrack *et al* 2004). The adverse impact over time on males who were not offered or who refused sperm banking also reinforces existing practice- or research-based accounts (Achille *et al* 2006; Broome and Allegretti 2001; Crawshaw 2006; Marik 2004; Pacey 2003; Saito *et al* 2005). The finding that males who tried and failed – including some who were very ill at the time - were nevertheless positive about being afforded the opportunity adds to existing limited evidence (Crawshaw 2006). The support of females to be told of the risks at diagnosis and the greater likelihood that females who refused fertility preservation might ruminate on their decision subsequently has not been reported previously.

Reports of good levels of understanding and recall about fertility information at diagnosis are similar to those in an earlier study (Crawshaw 2006). This contrasts with other studies

showing limited recall of fertility-related information (Green *et al* 2003; Schover *et al* 1999; Schover *et al* 2003; Zebrack *et al* 2004). This suggests that limited recall may result more from not having been told than from having been told and then forgotten.

There were some gender differences in comprehension at diagnosis that appeared to affect later impact. For example, some females were unclear of the relationship between possible interruption to their menstrual cycle and fertility damage. Some females would have preferred to be told at diagnosis about why egg freezing was not available in order to avoid later distress on learning of such services. Following diagnosis, overall levels of comprehension decreased as did satisfaction with range, quality and quantity of available information. This heightened the threat from fertility concerns, especially around hormone replacement therapy, contraception, premature menopause and fertility treatment options. This challenges previous research which found no significant gender difference (Langeveld *et al* 2003; Schover *et al* 1999). Some had sought information from alternative sources and many wanted age-appropriate written, internet-based or audio-visual information to be available more readily and discreetly. This extends previous findings (Cancerbackup 2005; Crawshaw 2006; Zebrack *et al* 2004).

It was difficult to gauge how far incomplete or ambiguous information arose from sources such as personal coping mechanisms – or from professional attitudes, as reported in other studies (Koeppel 1995; Schover *et al* 2002b). Similar levels of factual information appeared at times to be 'heard' and to influence behaviours and reactions differently as was also found by Zebrack *et al* (2004). Where professionals provided regular, clear information and/or appeared to take a genuine interest in fertility matters, this was well received.

For most participants, fertility concerns were subdued during treatment. However, they wanted the subject to be raised regularly in a routine, low key and unambiguous way during treatment and afterwards such that further information or discussion could be sought as and when those concerned felt ready. This matches findings from earlier studies as well as those reporting the importance of ongoing information for well-being more generally (Crawshaw 2006; Green *et al* 2003; Hooker 2004; Van Dongen-Melman 2000; Young *et al* 2003).

Fertility matters had the potential in some cases to slow recovery. For some, they had remained of limited concern at any stage so far. Among those who had relapses, second cancers, residual health problems or physical impairments, some found the impact of fertility matters to be suppressed. Others found that fertility concerns increased feelings of

hopelessness or despair and caused further dips in self esteem. This extends the findings of other adverse outcomes for such groups (Eiser 1998; Eiser *et al* 2000a; Elkin *et al* 1997; Self 2005).

Overall, indications of recovery appeared from early in the cancer journey through the use of comparative reflection, 'hope' and 'adaptive denial'. The protective features of trying to get back to 'normal' have been reported elsewhere (Dixon-Woods *et al* 2005; Grinyer 2007; Weekes and Kagan 1995; Woodgate 2005, 2006). Most participants in this study appeared to use what I have called 'active recovery through striving for normality'. This entailed maximising similarities with peers, downplaying differences (including around fertility) and adapting pre-diagnosis personal and social identities where necessary. Preferred approaches to romantic relationships and the use of contraception reflected the importance of acting 'as if normal' even when this led to 'risky' behaviours. However, (in)fertility presented unpredictable and unwelcome challenges to this strategy, often made more difficult by the accompanying silence among professionals, family, friends and others together with its stigmatising image. Norms about sex and fertility could of course differ across contexts and over time as well as being contingent in part on age, gender, religious beliefs and so on. There was some evidence that conceptualisations of 'fertility as reproduction' was more prevalent during early post treatment stages before shifting (for some) to incorporate a more complex relationship between fertility and other features of personal and social identities. Finally some participants acquired new information which moved what I have termed 'fertile identity' along a continuum from 'fertile' through 'uncertain' to 'impaired'. Similar movement rarely occurred in the other direction even when the news suggested that damage was less likely than had been thought previously.

The cumulative stress of acting 'as if normal', 'catching up' with peers and/or the changing meaning of fertility matters for young people negotiating their way through the transition years and beyond may contribute to the rise in reported fertility concerns over time in this and other studies (Blacklay *et al* 1998; Gray *et al* 1992 cited in Weigers *et al* 1998; Lozowski, 1993; Neville 1998, 1999, 2000, 2005; Reid 2000; Roberts *et al* 1998; Schover *et al* 1999; Schover *et al* 2002a; Self 1999, 2006; Zebrack *et al* 2002). More than two thirds of participants reported fertility as of high importance at interview, including some who had become parents, established permanent relationships or achieved success in other areas of their lives. This also appeared to reflect findings with non cancer-affected young adults that of the achievement of differing levels of competence across personal and social roles and the use of 'invented adult identities' (Catan 2004; Henderson *et al* 2007).



Many participants reported positive outcomes and resilience - 'strength through adversity' - from their cancer experience. No similarities were reported from managing the adversity of potential or actual fertility damage. For some, the threat from fertility concerns had overtaken that from cancer. Although many had been confident of surviving cancer from early on, there was less confidence that fertility damage could be overcome. This was especially the case among females or among males without good quality banked sperm. Accounts of feeling 'different', having little control over the implications for their present and future and having limited professional, personal and social support were often more extensive than in accounts of the cancer experience. This may have been reinforced by the risks attached to holding a marginalised, stigmatised identity, as reported elsewhere (Haywood and Man an Ghail 2005; Henderson *et al* 2007; Hendey and Pascall 2002; Hussain *et al* 2002; Morris 2002; Robinson and Stalker 1998; Skoe 1998; Stein and Rees 2002).

The impact of fertility matters on recovery has not been reported before.

A running thread through the findings was the role of uncertainty. Factual uncertainty about the level of any fertility damage was sometimes handled differently between genders. Several females were facing a shorter reproductive lifespan through the possibility of a premature menopause (which was also uncertain in itself). This was a source of distress on many levels and, together with the lack of stored gametes, could bring its own imperative to life planning. Conversely, the presence of stored sperm was an important source of reassurance to males, providing that they were confident of its quality. Similar findings have been reported among adult male cancer survivors (Achille 2006; Saito 2005). Promotion of the retention of hope of reproductive function (but not false hope) by professional or informal carers - even where there appeared to be a strong likelihood of damage - was an important boost to coping. Although the impact of uncertainty has been studied more widely in cancer care, uncertainty around fertility matters has not been reported on before.

Finally, these findings reported on how far the risks arising from fertility concerns appeared to be linked to participants' strength of desire to parent. As one might expect, most had assumed prior to diagnosis that they would become parents in adulthood as has been found in the wider population (Fraser *et al* 2006). Not all held a strong and conscious desire to do so at that stage (and this was not age dependent). Many who held strong desires to parent appeared especially vulnerable. This was eased where participants appeared able to accommodate the idea of potential childlessness or the achievement of parenthood through

alternative routes such as adoption, perhaps through the use of psychologic plasticity (Weekes 1995).

### **Involvement of professionals**

Preferred professional attributes for handling fertility matters were similar at all stages and across all disciplines. They included honesty, approachability, clarity, respectfulness, competence and compassion. Participants wanted to be treated as partners and prioritised over their parents as found in the wider literature on this subject (Mitchell *et al* 2006; Whelan 2003; Young *et al* 2003). Participants valued professionals who were interested in fertility matters and who engendered hope (though not false hope), as reported above. Professionals from the paediatric oncology multi-disciplinary network were rated consistently highly by participants; the picture was more variable amongst those encountered in other settings. This reflects existing concerns as well as adding new information (Crawshaw 2006; Wilford and Hunt 2003).

Although consultant oncologists were consistently the preferred professionals for raising fertility matters, there was support for a wider range of professionals to take more initiative in 'reaching out'. However those professionals who adopted a medical model approach or saw human development in a hierarchical, staged framework were likely to see 'fertility as reproduction' only. Important opportunities may have been missed to tune into any individual concerns. Any links to broader issues of self esteem, self efficacy and belief systems or more specific issues such as body image, sexuality, romantic relationships and contraception may also have been obscured. Such approaches may reinforce any tendencies in young people to take personal 'blame' for their situation and seek individualistic solutions (Catan 2004). This has not been reported before but adds to the literature on professional unease with this area of work and could inform approaches to training (Koeppel 1995; Schover *et al* 2002b; Thaler DeMers 2001).

The lack of psycho-social attention to fertility concerns was marked. Named staff on the wards, the provision of an independent service and/or home based services drawing on social work and community/outreach nursing services (regionally based services being too costly in time and money to access) would have been welcomed. Given the low take-up of directly therapeutic services more generally, the need for all staff to develop confidence and competence in 'therapeutic witnessing' *and* to pay particular attention to facilitating take-up if

they make referrals is called for. This reinforces and extends earlier findings (Davies *et al* 2001; Eiser 1998; Mitchell *et al* 2005; Multidisciplinary Working Group 2003).

### **Involvement of family**

In keeping with existing research, there was evidence in this study of increased physical and emotional closeness between participants and family members, especially mothers (Neville 2005; Quin 2004; Ritchie 2001; Whyte and Smith 1997; Woodgate 2006). This appeared to include elements of interdependence as well as heightened dependence. Family members, including those directly affected, were reported as 'being there' for each other in relation to cancer and, to a lesser extent, fertility matters. This has been reported elsewhere in relation to cancer (Woodgate 2006) and more widely (Catan 2004).

Where any interdependence around fertility was reflected in protective communication on the part of participants, closed or fairly closed communication patterns appeared effective. In these cases, participants had *either* not felt troubled enough to talk with family members and felt confident that they could do so if this were to change *or* preferred to use other sources of support such as professionals, friends or romantic partners. Where families were more open in their attention to fertility-related discussions, this usually reflected either pre-diagnosis patterns or a change that had arisen through the need to deal with cancer-related challenges including fertility preservation, sex, contraception, romantic relationships and fear of transmission to an unborn child. In some families, the openness was more likely to be with siblings than parents. In all these cases, openness worked well.

Across the board, families were much less likely to talk about cancer-related fertility matters than cancer matters and that is not surprising. Where this arose from participants' fears of being upset by family members' reactions – so-called guarded communication – it was often a source of regret or anger. Similarly, it was troubling for those who wanted family members to 'reach out' to them. Both appeared to reflect difficulties for family members, especially parents, in meeting participants' needs. A few participants showed closed patterns of communication with their families and other relationships that appeared driven by a sense of hopelessness about the likelihood of openness proving helpful.

While a number of participants were saddened by the strain that their cancer experience had already imposed on their family, some also worried that they may add to this in the future by not being able to provide grandchildren. This was rarely discussed within families.

Thus, where participants felt in control of the level at which their parents and family members were involved in fertility matters in the past and in the present (including in relation to professional services), this was experienced positively. Where communication was restricted in order to avoid anticipated hurt or where it reflected a lack of confidence that it could help, this was of concern. This has not been reported elsewhere.

### **Involvement of friends**

Participants across all four groups were more likely to discuss cancer-related fertility matters with friends than with family members. They nevertheless reported different reactions towards, and from, friends around this area than were present with other cancer matters. In general, this took the form of being more cautious, more likely to be discussed with close friends only (if at all) and less likely to be raised by friends. This has not been reported before.

Some found fertility aspects particularly difficult to manage in their re-entry into the education-based or employment-based contexts. Classrooms or workplaces were likely to reinforce messages about the social desirability or 'normality' of parenthood and being fertile. A review of research looking at re-entry to education (Vance and Eiser 2002) did not report on this potential source of risk.

Discussions with close friends could prove helpful even if a sense of difference was retained, as has been found more generally in wider research around cancer (Geehan 2003; Enskar *et al* 1996; Grinyer 2007; Kelly *et al* 2004; Lievesley 2006; Ritchie 2001). For those that rarely or never talked with friends, this was only of concern where their primary motive was fear of rejection, fear of not being understood or fear of being beyond the help of friends. A small number would have welcomed being 'reached out to'. This extends previous findings about such influences and may add to understanding of loneliness, isolation or feeling 'different' among cancer survivors (Neville 1996, 1998, 2000, 2005).

The stigma attached to fertility impairment and the desire to be 'as if normal' appeared to influence decisions about disclosure either in the early stages or over time. This has not been reported before.

Closed approaches appeared more difficult to sustain over time. Whichever the need to achieve a return to 'normality' was dominant, limited attention to fertility matters could prove a

price worth paying even though unexpected threats still had to be managed. The strategy could start to falter when measures of 'normality' brought fertility matters to the fore, where the desire for 'normality' became less rewarding and/or where new information about the threat of fertility damage was acquired. Other changes over time included friends becoming less interested in cancer-related fertility matters or becoming more involved and supportive. Some females had been involved by friends in bringing up their children and/or had been promised such and found that helpful.

There were gender differences in the impact of fertility matters on friendships. Females were more likely to find themselves managing conversations about parenthood plans and actual pregnancies. Males were more likely to have to cope with 'laddish' jokes about virility and sexual prowess. This was made more stressful where friends were not aware of their possible fertility impairment. However, it could also prove demanding when others were 'in the know' when it was left to the person affected to take the initiative in diffusing difficult situations. This has been reported in relation to other awkward situations but not in relation to fertility matters (Smith *et al* 1991). A small number discussed fertility matters with opposite gender friends though the majority restricted it to same gender friendships. A few females had used discussions with male friends as a 'rehearsal' for anticipated discussions with boyfriends.

There was mixed evidence of participants talking about fertility within friendships made through cancer. Sometimes it had not come up at all whereas for a small number, it was an important site of shared experience. This matches the previous limited research base (Crawshaw 2006). None had yet had the experience of friends facing non-cancer related fertility difficulties but anticipated this with the hope for mutual support.

Although there is some research into the experience of friendships in the wider cancer experience, none was identified that looked at the influence of fertility matters. These findings extend understanding of those wider patterns and suggest areas that might pose risk as well as offer protection.

### **Involvement of actual and prospective romantic partners**

Some in the study were in permanent relationships but many were not; some had yet to gain experience in romantic relationships. Most of those closer to treatment were concerned primarily with the impact of body changes and sexual worries, as reported elsewhere (Hain 2005; Lewis 2005; Woodgate 2005). Although many said that the possibility of fertility impairment did not influence their approach to relationships, there were many examples of

how it had done so. Two main areas of concern were disclosure and the impact on establishing and maintaining permanent relationships.

Anticipated and actual concerns about disclosure – when and how to tell - were dominant in the study. They were often present from early in existing relationships as well as anticipated for future ones. This reflects earlier questionnaire-based research (Schover *et al* 1999; Zebrack *et al* 2004). Insights into the influences on patterns of disclosure add flesh to quantitative findings. Early disclosures reflected personal belief systems, family cultures or a desire to avoid later hurt. Except for those driven by the latter, little anxiety appeared to accompany disclosure. Fear of rejection, the stigma of (in)fertility (which some appeared to have internalised, particularly in this context), the desire to avoid jeopardising other hoped-for outcomes, the belief that disclosure should only come when a relationship became 'serious' and exposure to more general silence around cancer-related fertility matters all heightened concerns or delayed disclosure. Where disclosures had been made in these circumstances, anxiety was a strong feature.

Those who had gained experience of disclosure found the outcome to be more positive than anticipated in general. It engendered feelings of relief, improved self worth and, sometimes, provided comfort in the knowledge that any problem solving may now become a shared enterprise. However follow-up discussions were not always at a level that proved satisfying, including for some who were aware of affecting disinterest when in fact they wanted to be 'reached out to'. Mirroring experiences in non-romantic relationships where disclosure had taken place, some participants reported ongoing feelings of loneliness. Restricted communication appeared more likely to be guarded than protective. This may add understanding to Zebrack *et al*'s (2004) finding of tension in some relationships following disclosure. The desire for proactive attention by others matches that reported already across other relationship contexts.

Turning to concerns about the likelihood of establishing and maintaining permanent relationships, previous studies have indicated that such rates are below average for childhood and adolescent cancer survivors (Langeveld *et al* 2003; Rauck *et al* 1999; Schover 1999; Schover *et al* 2002a; Stam *et al* 2005; Thaler-Mers 2001; Zebrack *et al* 2004). However there has been little prior attention to the particular influence of fertility matters. This study's findings reveal a complex picture. Some expressed anxiety about finding anyone willing to enter a potentially childless relationship. Some feared that a partner may think that they

could cope and then realise later that they could not. A third group wondered whether they themselves could feel attracted to anyone willing to contemplate a childless relationship.

Experiences were not static but changed over time and context, including within different romantic relationships. For example, some of the older group who had enjoyed a number of post treatment relationships reported a drop off more recently.

As with friendships, the initiative for raising and managing fertility issues rested with the cancer survivor. It was poignant that this responsibility attached to a side effect of cancer typified by feelings of powerlessness. The latter were heightened where there was uncertainty about fertility status, poor levels of information about alternative routes to parenthood and lack of access to professional or other help with developing management strategies. Some had contemplated fertility analysis as part of this preparation and strategy building process and this is returned to in the next section.

### **Becoming and being a parent**

Only five in the study had become parents (all since the end of treatment, none with the assistance of fertility treatment and only two in a planned way). Two were trying actively to become parents and a number had contemplated undergoing fertility analysis.

Gender differences emerged with regard to fertility analysis – what for some was to be the first step on establishing the likelihood of achieving biological parenthood. The only participants that were expecting to be called for routine testing were males with banked sperm. Most in this position expressed little anxiety about testing. This coincided in general with not having plans to become parents for the foreseeable future, with a belief that damage was unlikely and with an expectation that any damage was reversible. Females in both age groups and males with poor quality or no stored sperm were more likely to talk about the complexity of such decision-making. Additionally, females were aware that any damage to their egg supply would be permanent and any temporary loss of reproductive function could be followed by a possible premature menopause. Among the small number in both genders that had undergone analysis, or were about to, the impact appeared lower when the motivation was curiosity rather than concern. Several would have welcomed access to psycho-social services but only was offered this.

A range of reactions, including ambivalence, was also found in a qualitative study of male childhood cancer survivors offered fertility analysis (Green *et al* 2003). This study extends understanding of the experience of contemplating fertility analysis ahead of it being raised directly by professionals. Risks to well-being appeared lowered where participants had good quality banked sperm, expected any damage to be reversible, were curious about their status rather than concerned, felt confident that they could cope whatever the outcome of analysis, had a low desire to parent, could contemplate alternative routes to parenthood or felt that continuing uncertainty was more stressful than knowledge.

There were also some gender differences in thoughts and experiences about alternative routes to parenthood. Females were, on the whole, more articulate about alternatives and had thought about them more frequently and in greater depth than had males. They also had the subject raised with them more often than did males and it was only females that had received offers of surrogacy or donated gametes. Both genders and age groups held reservations about non-biological parenthood, though more about gamete donation than adoption as has been reported elsewhere (Schover 1999; Schover *et al* 2002a). The response of romantic partners to alternative routes was seen as important though few had actual experience of this.

For the two trying to get pregnant, the strain was clear. The bulk of the emotional impact appeared to be carried by the participants, although this may be a reflection of their gender rather than their cancer experience (both were female) as found in the non-cancer fertility literature (Crawshaw 2003; Lee 1996; Letherby 1999; Lisle 1999; Monach 1993; Throsby 2004).

Among the parents, some had believed themselves to be infertile beforehand so had particular adjustments to make following conception. Increased levels of pregnancy monitoring among affected females were welcomed as a way of reducing fears of relapse. Others, including non-affected females, were concerned about the risk of transmission of cancer to the unborn child and this confirmed findings from elsewhere (Schover *et al* 1999; Schover *et al* 2002a; Zebrack and Chesler 2001; Zebrack *et al* 2004; Zebrack 2006). Although some had sought advice pre-conceptually, this did not appear to be widespread and professionals did not appear to be raising it proactively. This matches what had been found in an earlier US study (Schover *et al* 2002a). One parent reported that the fear of his child getting cancer had grown over time. Several commented that they would be better able to cope with their child getting cancer than their parents had because of their own experience



and resulting strengths. This too matches other findings (Self 2006; Zebrack *et al* 2004; Zebrack 2006). On the whole, all appeared to have adjusted well to being parents.

## SUMMARY

By focussing on cancer-related fertility matters within a lifespan approach and using resilience theory to identify risk and protective features, this study has brought some unique perspectives to understanding young people's cancer experience. They have been shown to throw up challenges at different times, in different contexts, in different levels of intensity and at different stages throughout the transition to adulthood and beyond.

Although certain themes emerged, it is important to acknowledge the limitations of this study. Numbers were small from minority ethnic groups, gays, lesbians and disabled people in particular. The study used only single interviews within one methodological approach. Recruitment was restricted to age groups no smaller than 13 to 20 years and 21 to 30 years. Neither were there restrictions by cancer type or treatment even though some are known to carry greater risks of fertility damage than others. The findings are therefore not generalisable but neither are they intended to be. Their validity lies in the extent to which they represent the experiences of those involved. The interpretation of these experiences rests with me and this too is open to challenge. What the findings are intended to provide is a prompt to consider the significance or otherwise of fertility matters to the cancer journey and to provide a backdrop against which to review current service provision, professional practice and individual experience.

Running through the accounts was the relative invisibility of fertility matters in contacts between participants and those around them – be they professionals, family members, friends or romantic partners. Survivors were coping alone with their thoughts, feelings and uncertainties for much of the time. Their access to help, including opportunities to have misinformation corrected, receive new or repeated information, have distress lowered or receive help to build strategies for managing current or anticipated future needs was limited. Where individuals felt little or no associated concern, this was not troubling. Similarly where individuals employed protective communication with those around them and had sufficient other support outlets, this appeared to work well. For others, the silence and the lack of support reinforced any tendency to feel that this aspect of their lives and identity was perhaps beyond help.

Young people moving through the transition years continue the process of engaging with their emerging identity as potential parents that may have started consciously or otherwise in childhood. This is regardless of whether or not they have made any firm decisions about parenthood as a personal goal. It is not necessarily halted by a cancer diagnosis; indeed it may even be strengthened for some. What is evident from this study is that young people diagnosed at this stage have to negotiate the implications of possible fertility damage for their personal and social identity development, membership of families, peers and friendship groups, adult status, romantic relationships and feelings of being an active agent in their lives. Not surprisingly, uncertainty about fertile status appeared to pose additional strains unless it provided a protective buffer to feared confirmation of permanent damage. Although some had the cushion of fertility preservation to draw on as a source of hope and reassurance, others had to look for alternative sources of hope of retaining reproductive choice. Where such hope was fragile – including where self-assessed fertile identity was uncertain or impaired – the likelihood of resilience being developed or maintained appeared jeopardised, especially when fragile hope combined with a strong desire to become a parent one day.

There are reports within the wider childhood and adolescent cancer literature of the importance in recovery of regaining 'normality'. However the perceived 'normality' and social desirability of parenthood is pervasive in social and cultural messages during the transition years and beyond and can be associated with potency and gendered identity. This appeared to contribute to the downplaying of fertility concerns in order for 'normality' to be harnessed as a recovery vehicle. Nevertheless, fertility matters could still rear their head unpredictably. Managing them could widen the emotional gap between what was shown to the outside world and what was felt on the inside.

While recovery of 'normality' seemed to be within the grasp of some in relation to cancer matters – indeed for many, cancer survival was accompanied by feeling good about having been exposed to adversity and 'coming through' – there was no equivalent sense of 'feel good' around managing fertility challenges. It was unclear whether 'recovery' was seen by anyone as encompassing anything other than a resumed ability to exercise reproductive choice. Additionally, there was a strong sense of limited personal control over the outcome with all the accompanying dangers of having a low inner locus of control (Self 2005, 2006; Zebrack 2006). The potential for feelings of hopelessness to develop was high. There was poignancy in the situation of those participants who found themselves having to take the driving seat in managing decisions about disclosure, handling awkward fertility-related

situations and protecting loved ones from associated hurt when they themselves felt so little in control.

Stigmatised images of (in)fertility exacerbated the situation and were reinforced by the surrounding silence. They may also contribute to the difficulty for some participants in shifting away from holding an 'impaired' or 'uncertain' fertile identity – and acting within that identity - even when they acquired information to suggest strongly that they were indeed fertile.

Finally restrictions were posed by others seeing 'fertility as reproduction' or otherwise making assumptions about what meaning it held to individuals. This limited opportunities for understanding either any interdependencies between fertility and sexuality, body changes, self esteem and so on or its influence on relationships with self, family members, friends, peers, romantic partners and children. This may also go some way to explaining the limited attention that was paid by professionals in particular to gendered experiences that arose not only from biological difference but also from the social context.

The opportunity to exercise reproductive choice about whether to enter the social state of parenthood is one that most young people expect to acquire as they move into adulthood. For young people diagnosed with cancer, that opportunity may be unexpectedly threatened and they can find themselves swimming against the tide in a society dominated by presumptions of fertility. When placed alongside the threat to life, this can become invisible. However, if life is for living, then it is of little surprise that it did not remain invisible for many of the teenagers and adults in this study. Perhaps it is time that those around them also make it more visible.

## APPENDIX A

# APPROVAL LETTERS FROM NATIONAL HEALTH SERVICE METROPOLITAN MULTI-CENTRE RESEARCH ETHICS COMMITTEE

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### *Metropolitan Multi-centre Research Ethics Committee*

Chair – Dr H M Biggs

15<sup>th</sup> August 03

Ms Marilyn Crawshaw  
Department of Social Policy and Social Work  
University of York  
Heslington  
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YO10 5DD

University Hospital Lewisham  
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Lewisham High Street  
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Tel: 020 8333 3367  
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E-mail: cheryle.curtis@uhl.nhs.uk

Dear Ms Crawshaw

**MREC03/11/066** please quote this number on all correspondence

#### **No Local Researcher**

#### **A qualitative study of the experience of teenagers and young adults when faced with possible or fertility impairment following cancer treatment**

The Chairperson of the Metropolitan MREC has considered the amendments submitted in response to the Committee's earlier review of your application on 4<sup>th</sup> July 03 as set out in our letter dated 15<sup>th</sup> July 03.

The Chairman, acting under delegated authority, is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you our approval on the understanding that you will follow the conditions of approval set down below. A record of the review undertaken by the MREC is contained in the attached MREC Response Form. The project must be started within three years of the date on which MREC approval is given.

While undertaking the review of your application the MREC noted the research involves the establishment of a new disease or patient database for research purposes / the use of an existing database collected for previous research or other purposes with no patient contact patient. For this reason you are not required to notify any LRECs when undertaking this research.

#### **LREC Involvement**

When undertaking the review of your project the MREC observed that there is limited patient contact involving the performance of technical procedures or additional data collection as described in the MREC approved protocol/initial contact by a local clinician for purposes of recruitment. It is felt that these tasks appear well within his/her routine professional competence and adequate facilities for such procedures are available as part of his/her normal professional practice.

For this reason you are asked to only inform the appropriate LREC of the project by sending a copy of this letter and also giving the name and contact details of the local clinician involved and what procedures will be undertaken by this person. If

(unusually) the LREC has any reason to doubt that the local clinician is competent to carry out the tasks required, it will inform the clinician and the MREC that gave ethical approval giving full reasons.

When such tasks are performed by centrally based researchers it should be assumed that the MREC has reviewed their competence to undertake the tasks and it is not necessary to inform the LREC of the contact details, but only that the research will take place.

You are not required to wait for confirmation from the LREC before starting your research.

#### **Local NHS Management**

The local clinician must inform his/her NHS organisation of their co-operation in the research project and the nature of their involvement. Care should be taken to ensure with the NHS organisation that local indemnity arrangements are adequate.

#### **Legal and Regulatory Requirements**

It remains your responsibility to ensure in the subsequent collection, storage or use of data or research sample you are not contravening the legal or regulatory requirements of any part of the UK in which the research material is collected, stored or used. If data is transferred outside the UK you should be aware of the requirements of the Data Protection Act 1998.

#### **ICH GCP Compliance**

The MRECs are fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and a Statement of Compliance were included on the computer disk containing the guidelines and application form and are available on request or on the Internet at [www.corec.org.uk](http://www.corec.org.uk)

Yours sincerely,

  
**DR HAZEL BIGGS**  
**CHAIR**  
**METROPOLITAN MREC**

Enclosures MREC Response Form 15<sup>th</sup> August 03

List of members present and members who submitted written comments.



## **Metropolitan Multi-centre Research Ethics Committee**

Ref: CPW/CR

13<sup>th</sup> August 2004

Ms Marilyn Crawshaw  
Department of Social Policy and Social Work  
University of York  
Heslington  
York  
YO10 5DD

University Hospital Lewisham  
Research & Development Centre  
Lewisham High Street  
London  
SE13 6LH

Tel: 020 8333 3367  
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E-mail: cheryle.curtis@uhl.nhs.uk

Dear Ms Crawshaw,

**Full title of study:** *A qualitative study of the experience of teenagers and young adults when faced with possible or actual fertility impairment following cancer treatment*

**REC reference number:** MREC 03/11/066  
**Protocol number:**

**Amendment number:** 1: 28<sup>th</sup> July 2004  
**Amendment date:** 28<sup>th</sup> July 2004

The above amendment was reviewed by the Sub-Committee of the Metropolitan Multi-Centre Research Ethics Committee at the meeting held on 10<sup>th</sup> August 2004.

### **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:

- Notice of Substantial Amendment dated 28<sup>th</sup> July 2004
- Candlelighters study / Reminder letter dated July 2004 from University of York

### **Site-specific issues**

It was noted as part of the review that the amendment has no implications for the suitability of local investigators, sites or facilities. You are not required to obtain any further site-specific assessment, and there is no need to inform Local Research Ethics Committees of the amendment.

### **Approval of host organisations**

Local principal investigators or research collaborators should notify their host organisations of this amendment and check whether it affects local management approval of the research.

SOPs version 1.0 dated February 2004  
SL28 Favourable opinion of amendment (multi-site)

*The Central Office for Research Ethics Committees is responsible for the operational management of Multi-centre Research Ethics Committees*

**Membership of the Committee**

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

**Statement of compliance (from 1 May 2004)**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**REC reference number: MREC 03/11/066 Please quote this number on all correspondence**

Yours sincerely,



**Mrs Clair Wright  
Acting Administrator**

*MD*

*Enclosures List of names and professions of members who were present at the meeting and those who submitted written comments*

## APPENDIX B

### FORMAT FOR WRITTEN RESPONSES

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NOTE: ACTUAL FORMS USED HAD BIGGER SPACES IN WHICH TO RESPOND

THE UNIVERSITY *of York*

**A Qualitative study of the experience of possible or actual fertility impairment  
following treatment for cancer**

Thank you for agreeing to take part in this study. Your experience and comments are very valuable to us. Please be assured that your responses will be treated with confidentiality; nothing that you write will be identifiable to you in any reports and publications that arise from the research.

*Firstly*, it would be useful if you could tell me a bit about your experience of becoming ill and being told that you had cancer. Whatever way you want to describe it is OK – for example, what were your symptoms, who did you go and see and when (in what year), who told you about the cancer and how long after you got symptoms was that?

Can you tell me about what it was like when someone told you that this might affect your ability to have children in the future? Can you remember who told you and what they told you, who else was there (did you have a choice about who was present when you were told), what do you remember about being told and how it felt? Could it have been done any better (and if so, how), or was it done well (and if so, what was good about the way it was done)? Was this all a complete surprise to you, or did you know anything about it beforehand?

If you are female, please go straight to page 5



***If you are a male***, I don't know whether or not you were offered the chance to bank any of your sperm. If you were, can you tell me anything about that – if you were offered the chance, did you accept or decline? What made you make the decision you did? Looking back, are you pleased with your decision or not? Was there anything that might have made the decision making any easier?

If you decided to bank your sperm, can you tell me about that? Did you go to another place to bank (and if so, where); did anyone come with you (and were you offered any choice about that); how well prepared were you for doing it – what was good about the way that you were prepared and what could have been better? What was good about the staff, the set-up, the room etc at the clinic/sperm bank and what could have been better?

Can you remember anything about the consent forms for storing your sperm and the way they were completed with you? Was it done well or could it have been done better?

Can you tick the people that you talked to about this at the time: (please tick or circle)

Consultant

Other doctors

Nurses

Social Worker

Counsellor

Lab people

Parent(s)

Brothers and sisters

Other family

Girl friend

Friends

Others (please say who)

Can you tell me if you've talked with anyone at all (professionals or others) since that time:  
(please tick or circle)

Consultant	Parent(s)
Other doctors	Brothers and sisters
Nurses	Other family
Social Worker	Girl friend
Counsellor	Friends
Lab people	Others (please say who)

If you have talked to someone, can you tell me a bit about that – was it OK or could it have been any better? If it was OK, what was good about it?

Can you tick the people that you talked to about possible infertility as a result of treatment at the time of diagnosis or during your treatment: (please tick as many as apply)

Consultant	<input type="checkbox"/>	Parent(s)	<input type="checkbox"/>
Other doctors	<input type="checkbox"/>	Brothers and sisters	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	Other family	<input type="checkbox"/>
Social Worker	<input type="checkbox"/>	Girlfriend/boyfriend	<input type="checkbox"/>
Counsellor	<input type="checkbox"/>	Friends	<input type="checkbox"/>
Lab people	<input type="checkbox"/>	Others (please say who)	

Can you tell me if you've talked with anyone at all (professionals or others) since that time:  
(please tick or circle)

Consultant	<input type="checkbox"/>	Parent(s)	<input type="checkbox"/>
Other doctors	<input type="checkbox"/>	Brothers and sisters	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	Other family	<input type="checkbox"/>
Social Worker	<input type="checkbox"/>	Girlfriend/boyfriend	<input type="checkbox"/>
Counsellor	<input type="checkbox"/>	Friends	<input type="checkbox"/>
Lab people	<input type="checkbox"/>	Others (please say who)	<input type="checkbox"/>

If you have talked to someone, can you tell me a bit about that – was it OK or could it have been any better? If it was OK, what was good about it?

Have there been any times when you would have liked to have someone to talk to about anything to do with sex or reproduction but didn't? If so, can you tell me a bit about it – what you would have liked to talk about, when, why, to whom etc – and what got in the way of you being able to talk to anyone, if anything?

Would you say that you had any experience of talking with other people about sex or reproduction before it was raised with you? (please tick as many as apply)

- No experience at all
- Talked with parents
- Talked with brothers or sisters
- Talked with girlfriend or boyfriend
- Talked with friends
- Had previously talked with professionals (eg doctor, nurse, teacher)
- Other

Thinking back to the time of your diagnosis and when you were told that your fertility might be affected, how important would you say this was to you on a scale of 0 to 10 at that time?(please circle one)

0 1 2 3 4 5 6 7 8 9 10  
not important very important

and how would you rate its importance to you today? *(please circle one)*:

0 1 2 3 4 5 6 7 8 9 10  
not important very important

Is it something that you have thought about a lot, occasionally or hardly at all over the time since you were told? What sorts of things do you think about; what causes you to think about it, if anything?

Thinking back to the sort of information that has been available to you about sex and reproduction from the beginning and right up to today, has the information available been about right or could it be improved and how? And for the future? For example, would it have been useful to have any written information, videos, access to websites about anything to do with sex and reproduction when you have cancer, or not?

Have you asked anyone for any information about your fertility since your treatment? For example, have you had your fertility checked yet? Do you know who to ask for any information that you might need in the future? Has anyone raised it directly with you and, if so, was that OK or would you prefer that they hadn't – and if no-one has raised it, do you wish that someone would do and, if so, who would you like to raise it with you?

**In summary:**

Can you tell me whether the possibility that cancer affected your ability to have children has affected you at all since you were told? Has it made any difference to the way that you think about yourself, to your existing relationships with your parents, brothers and sisters, family, friends? Has it affected the way that you think about having relationships at all?

Looking back, how do you feel now about the fact that you were given or not given the opportunity to use fertility preservation services?

Looking back, is there anything that could have been done better, by whom and when?

And what was done well, by whom and when?

Finally, can you think of up to two things or people or events that made it more difficult for you to cope with the possible effect on your ability to have children than it might have been otherwise?

1.

2.

And up to two things or people or events that made it easier for you to cope with the possible effect on your ability to have children than it might have been otherwise?

1.

2.

Many thanks for taking the time to complete this questionnaire. Please return it to me in the envelope provided. Please also free to make any additional comments that you wish to.

I'm happy to let you have a copy of the report that we do at the end of the study and the recommendations that we make for improving the services (though please note this is still a way off yet as we are only just in the early stages of this study).

Please tick here if you would like a copy:

We are also planning to develop some information materials and we are inviting anyone who is interested to comment on the design of these and perhaps come along to the hospital to help us with them

Please tick here if you would like to comment on them

Marilyn Crawshaw  
Dept of Social Policy & Social Work  
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Tel: 01904 321254. Email [mac7@york.ac.uk](mailto:mac7@york.ac.uk)

## APPENDIX C

### TOPIC GUIDE FOR INTERVIEWS (FULL STUDY)

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

- 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
- Emotional experience; cognitive understanding of being told that treatment might affect fertility
- Prior experience if any of talking about fertility or sexual matters – (i) with professionals, (ii) with family members (iii) with peers
- Sort of help, information, people to talk to, available, if any (about fertility & related matters)?
- What made it worse; what made it easier?
- Who/what *could* have been helpful if available?
- On a scale of 0-10, where would they place the importance to them of potential fertility impairment at this stage (for males, this means before banking, if applicable)?
- Mapping of who was *actually* involved in relation to fertility and related aspects – what was helpful; what not (professional and family/friends)
- Use of written materials or video, if any – actual or potential use at different stages
- *For those who used fertility preservation services* – level of help, information, people to talk to, in making the decision and acting on it; getting ready to go to the ACU –

professional and family/friends etc. Level of involvement of parents/carers/partners by professionals

- Who/what *could* have been helpful if available?

### **During the fertility preservation process**

**Note: This section only applies where services were accessed –banking or egg collection according to whether male/female (very few females are offered egg freezing)**

- Memories of the process of *getting to* the ACU
- Emotional experience; cognitive understanding
- Memories of the process of *being at* the ACU
- Emotional experience; cognitive understanding
- Sort of help, information, people to talk to, available, if any? Professional, family, girlfriend/boyfriend, friends etc
- What made it worse; what made it easier?
- Who/what *could* have been helpful if available?
- Level of involvement of parents/carers/partners by professionals
- Mapping of who was *actually* involved in relation to fertility and related aspects – what was helpful; what not (professional and family/partner/friends)
- Use of written materials or video, if any, to explain the process etc – actual or potential use at different stages
- Consent form - who completed it with them? Recall of the experience and reaction to it; level of understanding of it; understanding of whose decision it was, reference to Deceased Fathers Act (if appropriate) etc. And now. Memory of getting a copy and, if so, where it is now?



- 'Consent to disclosure' – memory and understanding of who else (among health professionals) would know what happened; memory of signing 'consent to disclosure'
- How well prepared for what happened at the ACU?
- Recall of HIV or other screening at this stage. If so, what impact if any, did this have?
- Knowledge of *where and how* the sperm is stored and does it matter whether they know or not?
- Payment for storage costs or fertility treatments - knowledge, expectations and so on about this

#### Afterwards – bringing it up to present day

- Memories of the impact of potential or actual fertility impairment up to present day (broken down into different periods of time, if applicable)
- Emotional experience; cognitive understanding
- Experience of forming and maintaining friendships post diagnosis; role of peers in discussing sexual and romantic relationship matters
- Experience of forming and maintaining sexual and 'romantic' sexual and 'romantic' relationships
- How far are any difficulties attributable to fertility impairment and how much to cancer
- Some professionals have expressed concerns that undertaking sperm banking at the time of diagnosis might lead to sexual and relationship problems in this area in the future. Any views on that?
- On a scale of 0-10, where do they place the importance of potential fertility impairment at this stage in their lives?

- For teenagers, where do they hope to be in terms of adult relationships, parenting etc by their mid to late 20's? And is this any different to what they *think* they would have wanted if they had not had cancer?
- Understanding of the practical and financial implications and processes of fertility testing, treatment etc
- Sort of help, information, people to talk to that was, is and might be available, if any (professional and family/partner/friends)
- Mapping of who has *actually* been involved in relation to fertility and related aspects
- Have they had their fertility checked? And if so, what motivated/triggered them to do so?
- Who/what *could* have been helpful if available, and when would they have preferred it? And what sort of involvement?
- Experience of decision making (if any) about having children, seeking assisted conception treatment etc; and experience of acting on that decision
- Use of written materials or video, if any – actual or potential use at different stages
- Raising of the subject by professionals and/or by parents/family members/friends/partners/others
- Specific offer of services related to the effect/s experienced
- *For those who used fertility preservation services only* - Annual Review of Storage letter

## Looking back (prompting review/summary of what they've said)

- Frequency of thinking about the fertility aspects of cancer treatment outcome – what triggers thoughts; what sort of thoughts?
- Anything about the *manner* of the professionals that helped or got in the way at the different stages of the process of coping?
- Did it matter whether they were:
  - Male or female
  - Near in age or not
  - Same ethnicity or not
  - Anything else
  - Did this differ over time or context?
- Did any of these matter more or less depending on what their job/role was?
- Looking back, did they feel that they knew and understood as much as they wanted to at each stage, including now?
- Looking back, how do they feel about the fact that they were given/not given the opportunity to use fertility preservation services?
- Looking back, do they think that any aspect of it has had an effect on them (i) at the time (ii) immediately afterwards (iii) in the intervening time (iv) now?
- How did they feel about the level of involvement that their parents, carers, partner had in the whole process, at each stage?
- Looking back, what, if anything, could have been done better, by whom and when?
- Looking back, what was done well, by whom and when?
- One or two things/people/events that made this whole process more difficult than it might have been otherwise? (*vulnerabilities*)

- One or two things/people/events that made this whole process more manageable than it might have been otherwise? (*buffers, protectors*)
- Any surprises for them?
- *For those who were offered fertility preservation services only* - how do they feel about the decision they made (whatever it was)?
- Looking back now, did anything particularly affect that decision?

### Messages

- What messages would they send to the professionals involved?
- What messages would they send to parents, partners involved?
- What messages would they send to the others about to go through all this?

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