

**A qualitative study of staff perceptions of men's experiences of
sperm banking**

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Word Count

Abstract	286
Literature Review (excluding references)	6172
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1	Part 1: Literature Review	1
1.1	Abstract	1
1.2	Introduction	2
1.2.1	Search Strategy	3
1.3	Reviewed Literature	3
1.3.1	Male Cancer	3
1.3.2	Infertility	9
1.3.3	Sperm Cryopreservation for Adult Male Cancer Patients	13
1.3.4	Sperm Banking Literature	14
1.4	Discussion	20
1.5	References for Literature Review	24
2	Part 2: Research Report	37
2.1	Abstract	37
2.2	Introduction	38
2.2.1	Aims of the Current Study	41
2.3	Methodology	42
2.3.1	Research Design	42
2.3.2	Ethical Approval	43
2.3.3	Researcher Characteristics	43
2.3.4	Centre X	44
2.3.5	Participants	44
2.3.6	Procedure	45
2.3.7	Memo-Writing	48
2.3.8	Theoretical Sampling	48
2.3.9	Enhancing Quality	49
2.4	Results	50
2.4.1	Core Category: Negotiating Threat	52
2.4.2	Area of Negotiation: The Threat and Impact of Existing Attitudes	55
2.4.3	Area of Negotiation: Knowing Enough	59
2.4.4	Area of Negotiation: Accessing and Using Supportive Relationships	65
2.4.5	Area of Negotiation: Coping and Defence	69
2.5	Discussion	71
2.5.1	Core Category: Negotiating Threat	72
2.5.2	The Proposed Process Model	73
2.5.3	Clinical Implications and Recommendations	75
2.5.4	Implications for Further Research	78
2.5.5	Critique and Limitations	79
2.6	Conclusion	81
2.7	References for Research Report	82
3	Part 3: Critical Appraisal	86
3.1	Introduction	86
3.2	Choice of Topic and Planning	86
3.3	Grounded Theory	86
3.4	Difficulties and a Change in Direction	88
3.5	Recruitment of Participants and Interviewing	89
3.6	Analysing the Data	89
3.7	Theoretical Saturation	90
3.8	Enhancing Quality	91
3.9	Write-Up	91

3.10	Supervision.....	92
3.11	Motivation.....	92
3.12	Professional Development	93
3.13	References for Critical Appraisal.....	95
4	Appendices.....	97
4.1	Appendix 1 – Initial Ethical Approval	97
4.2	Appendix 2 – Final Ethical Approval	100
4.3	Appendix 3 – Participant Information Sheet.....	102
4.4	Appendix 4 – Consent Form	105
4.5	Appendix 5 – Interview Schedule.....	106
4.6	Appendix 6 – Revised Interview Schedule	108
4.7	Appendix 7 – Example of Coding.....	111
4.8	Appendix 8 – Record of Category Development.....	112
4.9	Appendix 9 – Memo Example	113

List of Figures

Figure 1 The Core Category and Process Model of Areas of Negotiation 51

List of Tables

Table 1 Participant Characteristics 45

Abstract

In 2000 alone 134,272 men were newly with diagnosed with cancer in the UK. Treatments for neoplasms may result in sterility, and as such sperm cryopreservation is recommended for all men about to undergo treatment. Whilst research in the field of psycho-oncology is expanding the area of fertility preservation, and sperm banking in particular, has remained largely medically dominated.

This study begins by reviewing the existing literature on the psychological implications of sperm cryopreservation for the oncology patient. Whilst scanty, research is available from the paediatric population, however there is an absence of research focusing upon the adult male.

Interviews were undertaken with six healthcare professionals, four based within a reproductive medicine centre and two within oncology. Interviews focused upon exploring professional's perceptions of men's psychological experiences of sperm banking, and their perceived role in the process. The interview transcripts were analysed using Grounded Theory methodology, which also informed the data collection. A core category was developed termed 'negotiating threat'. This category details how sperm banking is used as a way of managing the threat generated by a diagnosis of cancer and possible infertility. A process model was also proposed containing four areas of negotiation, labelled: the threat and impact of existing attitudes, knowing enough, accessing and using supportive relationships, and coping and defence. Each area refers to a specific task encountered, and details how threat can also permeate sperm banking itself.

The limitations of the study are discussed. Clinical recommendations made include the provision and development of training for staff and the possible introduction of a support group for men. Further research is required into the direct experiences of men and also into the difficulties for staff in suspending normed beliefs and attitudes regarding fatherhood.

1 Part 1: Literature Review

1.1 Abstract

Background: Large numbers of men receive a diagnosis of cancer each year. A large proportion of these will require treatment that may leave them infertile or sub-fertile. In order to preserve reproductive potential men may opt to bank sperm prior to commencing treatment.

Aims: This article aims to review the literature examining the psychological implications of sperm cryopreservation for adult male oncology patients.

Method: A literature search of English language journals was conducted using the Medline, Embase, and Psycinfo databases.

Findings: There is an absence of research in this specific area. The research that is available has significant methodological limitations. Despite this the research suggests that that there are several areas of potential psychological interest.

Conclusion: Research into the psychological experiences of adult male oncology patients who opt to bank sperm is extremely limited. Further research into this area is necessary in order to develop services' potential to deliver a wholistic approach to health care.

1.2 Introduction

Cancer is the cause of 26 per cent of all deaths in the United Kingdom (Cancer Research UK, 2004). In 2000 alone there were more than 270,000 *new* cases diagnosed in the UK and it is estimated that around 1.2 million people in the UK are living with a diagnosis of cancer (Cancer Research UK, 2004). Whilst the incidence of many cancers is increasing (Cancer Research UK, 2004), in part due to an increasing ageing population, medical technology and knowledge also continues to develop, enhancing increased survival post-diagnosis (Meadows, 2002). Despite these advances, treatments to combat neoplasms engender numerous side effects. Amongst these infertility remains as one of the most common and distressing (Meadows, 2002). Given the known risks to the reproductive system sperm cryopreservation (banking) is now recommended for all adult male oncology patients (Royal College of Obstetricians and Gynaecologists, 2000).

Whilst research in the field of psycho-oncology is expanding (Baum, 2004; Temoshok, 2004; Brennan, 2001; Somerfield and Curbow, 1992) the area of fertility preservation, and sperm banking in particular, has remained largely medically dominated (Hallak *et al.*, 1998; Agarwal *et al.*, 1995). Little attention has been paid to the psycho-social aspects of a procedure that is recommended for all men when life-saving treatment may result in sterility. The aim of this review is to consider the psychological literature relating to sperm cryopreservation. It is hoped that by reviewing an evolving and to date neglected area, clinically relevant research opportunities will emerge.

1.2.1 Search Strategy

A literature search of English language journals was carried out using Medline, Embase and Psycinfo databases. The search strategy used the keywords: *sperm banking, psychological experiences, sperm cryopreservation, infertility and cancer.*

1.3 Reviewed Literature

This review is structured in three sections. The literature on male cancer is considered first followed by that on cancer-potentiated infertility. The emergent literature on sperm banking forms the third section. The emergent literature will then be discussed and the paper will conclude by offering suggestions for further research.

1.3.1 Male Cancer

1.3.1.1 Prevalence

In 2000 alone 134,272 men were newly with diagnosed with cancer in the UK, an increase of 2.8% from 1999 (Cancer Research UK, 2004). Of these most are diagnosed with prostate cancer, followed by lung and colorectal cancer. As cancer is primarily a disease of the older person this rise is, in part due to the effects of an ever-increasing ageing population. However, a number of cancers predominate in younger men. Whilst testicular cancer is comparatively rare it is the most common malignancy in men aged between 15-44 and approximately 2,000 new cases are diagnosed per annum (Cancer Research UK, 2004). Incidence rates for testicular cancer have more than doubled since the mid 1970s; however as testicular cancer is in most cases curable, mortality rates are low, currently standing at only 0.2 per 100,000.

Treatment for cancers may potentiate infertility or sub-fertility, compromising sperm quality and enhancing sterility. This may arise via chemotherapy, that is toxic to the reproductive system, or via surgery, that either damages neurological pathways for semen emission (Meistrich *et al.*, 1997; Schover, 1997) or removes the prostate and seminal vesicles (Palermo, 1995).

1.3.1.2 The Impact of Cancer

A diagnosis of cancer is a major life-changing and life-threatening event for most people (Edelman and Kidman, 1999). At, and subsequent to diagnosis, individuals will be confronted with various different challenges and stressors (Stiegelis *et al.*, 2003) and may continue to experience clinical symptoms of anxiety, depression, anger, apprehension and fear (Maguire and Faulkner, 1994).

Estimates of prevalence rates of psychological distress amongst this population vary. Several authors have reported moderate to high levels of psychological morbidity (Greer *et al.*, 1992; Zabora *et al.*, 1997; Schou and Hewison, 1999) and more recently Harter *et al.* (2001) estimated that 23.5% of individuals with cancer will develop a mental health problem. Schou and Hewison (1999) also postulate that it is possible that there is an under diagnosis of depression amongst this population, possibly due to confounding organic effects of the cancer. However, psychological morbidity is not static and longitudinal studies have indicated that it is fluid throughout the disease course, with the highest levels of distress, incorporating both anxiety and depression, observed prior to the first treatment session and decreasing as treatment progresses (Bye *et al.*, 1995 and Munro and Potter, 1996). Research indicates that treatment modality (radiotherapy and/or chemotherapy) does not appear to influence the degree of psychological morbidity (Lim *et*

al., 1995). However, in contrast Hughes (1987) reports a meta-review regarding adaptation to cancer in which half of patients report no symptoms of emotional distress, and many patients demonstrate an ability to cope with cancer and maintain general levels of pre-diagnosis functioning (Carpenter, 1997; Cella and Tross, 1986).

1.3.1.3 Coping with Cancer

The literature on coping is extensive. Many models have been proposed, some are stressor specific, for example, trauma (Kleber and Brom, 1992), whilst others provide an overarching theoretical framework of coping (Lazarus and Folkman, 1984). It is not possible to review the entire literature here and thus this discussion will focus upon two main areas. It has been argued by De Ridder (1997) that the most authoritative theoretical framework of coping is that offered by Lazarus and Folkman (1984), and thus this model will be examined in detail. The remaining models reviewed are those that offer illness, or cancer, as the given stressor, and thus the most relevant to this discussion. Whilst the adequacy of each model will be considered it is important to first consider some wider conceptual difficulties in the coping literature.

Given the vast array of coping models it has been argued that a fundamental and underlying problem exists with regards to the concept itself, with a lack of consensus amongst researchers as to its basic properties (De Ridder, 1997). De Ridder (1997) argues that it is necessary to elaborate on the actual dimensions of coping, thereby creating a framework for empirically studying such behaviour. A further difficulty associated with the coping concept refers to the assumption that coping is a conscious process and that people are able to retrieve and verbalise past coping efforts (De Ridder, 1997; Lazarus, 1991). Again, De Ridder (1997) argues that further attention needs to be paid to

examining the conditions in which valid and reliable data can be obtained. She argues that until the concept of coping has been clarified, enabling empirical study, models and assessments will remain methodologically flawed.

Lazarus and Folkman (1984) propose a cognitive theoretical model of coping and stress. They assert that an individual will make a primary appraisal regarding the likely impact the event will have on their life and a secondary appraisal regarding perceived options for coping with it. The event is then appraised as a threat, harm/ loss, challenge, or a combination of these. Coping strategies utilised are dependent on the appraisals that are made. For example, perceived high levels of control may lead to problem solving based coping whereas low levels may lead to emotional based coping such as avoidance. Whilst the model may offer a useful framework, criticisms levelled at theoretical models apply, such as its failure to provide an empirical basis for clinical interventions (Sommerfield *et al.*, 1999). In addition it has also been argued that the model does not actually function as a theory but rather as a frame of reference due to the fact that key concepts are poorly defined, for example, the lack of a specified time period for coping efforts (De Ridder, 1997). The model has also been criticised for neglecting the impact of personal and social resources that may shape the coping response (Moos and Schaefer, 1993). More specifically Lazarus (1993) also postulated that a person with cancer is confronted not by a single threat but by many diverse threats and therefore research into coping processes in cancer should be threat specific (e.g. sperm banking).

A further theoretical model of coping has been advanced by Moos and Schaefer (1993), who assert that a combination of personal factors and environmental factors, combine with the stressful experience to influence an individual's appraisal of the situation and

subsequent coping. Unlike the Lazarus and Folkman (1984) model the Moos and Schaefer model (1993) accounts for the impact of personal and social resources; however it remains largely conceptual and does not offer an empirical basis for clinical intervention (Somerfield *et al.*, 1999). In response to this limitation Somerfield *et al.* (1999) have evolved the Moos and Schaefer (1993) model to develop a threat-specific model regarding adaptation to somatic distress amongst cancer survivors. The authors argue that formulating problem-specific models, rather than an all-encompassing disease model may offer a better empirical basis for interventions regarding the given stressor. By isolating specific personal and event-related factors in existing research they developed a model containing a specific set of variables relevant to somatic distress. On the basis of these variables four areas of clinical intervention were then proposed. The suggested areas focused upon patient education regarding recurrence, in order to prevent the development of erroneous beliefs and to maintain a balance between inattentiveness to symptoms and preoccupation, management of family distress, and encouragement to professionals in the need to increase adherence to follow-up care. Whilst the model does offer possible clinical interventions regarding a cancer-specific stressor the authors acknowledge that the model is empirically untested.

Folkman and Greer (2000) aimed to integrate theory, research and practice to inform a therapeutic programme for individuals experiencing serious illness. It was hoped that such work would bridge the gap between conceptual models and clinical practice. Using the revised Lazarus and Folkman (1984) model (Folkman, 1997) the authors defined variables, as indicated by research, which contribute to psychological well being during serious illness. Dispositional variables defined included concepts such as hardiness (Kobasa, 1979) and internal locus of control (Rotter, 1966), situation variables included

self-efficacy (Bandura, 1982) and conceptualisation of hope (Snyder *et al.*, 1991), and coping processes included growth-related coping (Park and Cohen, 1993) and transformational coping (Aldwin, 1994) (see paper for exhaustive list). They argue that situational variables and coping processes are the most amenable to brief intervention work and thus suggested a therapeutic programme for psychological well being on this basis. However, the programme is empirically untested and therefore limited in its validity. The programme is also a general one aimed at serious illness and as already noted it may be more appropriate, given the multiple challenges facing an individual with cancer, for problem specific interventions such as that posited by Somerfield *et al.* (1999).

Brennan (2001) develops the popular view of adjustment to cancer as a coping process by considering the additional concept of personal transition. He proposes a social-cognitive transition model that, he argues, accounts for both negative and positive adjustments to cancer, a criticism he levels at solely social-cognitive models. Brennan argues that an individual's assumptive world, developed through learning in novel and predicted situations, is temporarily overwhelmed following a diagnosis of cancer. This is seen in the period immediately following diagnosis as disorientation. Three factors are suggested as combining to influence an individual's reaction to the event, cognitive models of the self and the world, social context and the reaction to information and experiences that are in conflict with the internal world. A period of stress follows where adjustment to the assumptive world takes place. This can be an emotionally distressing time as human information processing is biased to maintain high-level assumptions (Janoff-Bulman, 1992). Denial is therefore considered to be an adaptive process, unless continuing on a long-term basis when it may serve to prevent the absorption of new information. The degree of success of the adjustment of assumptions will determine an individual's

ultimate response to the cancer, be that positive or negative. Brennan considers some core assumptions and how they may be re-adjusted in light of a cancer diagnosis. He also suggests treatment options for instances involving a negative transition. Whilst offering a broad conceptualisation of normal adaptation to cancer Brennan's model is empirically untested and does not take into account the multiple challenges facing an individual with cancer.

1.3.2 Infertility

1.3.2.1 *The Impact of Infertility*

Infertility may represent multiple losses: control over one's life, genetic continuity, the opportunity of joint conception with a partner, and the opportunity to parent (Johnston, 1992). Given these multiple losses it is perhaps not surprising that infertility has been described as a 'life crisis', 'emotionally stressful', 'psychologically threatening' (Menning, 1975) and comparable to grief (Menning, 1980; Schover, 1999).

Primary infertility is deeply distressing for many couples and individuals (Connolly, *et al.*, 1992), and a number of studies have shown increased levels of depression, anxiety, guilt and frustration when compared with the general population (Bresnick, 1984; Keye, 1984; Pfeffer and Woollet, 1984). Methodological concerns, such as gender differences in self-disclosure and the type of distress displayed, have led to inconclusive evidence regarding the difference in distress experienced by infertile women in comparison to men (Berg & Mikesell, 1996). Whereas some studies have reported higher levels of depression, anxiety, distress and lowered self-esteem amongst women (Daniluk, 1998; Bernstien *et al.*, 1985; Newton *et al.*, 1990) other studies have reported comparable rates of depressive symptoms amongst men and women (Draye *et al.*, 1988; Berg *et al.*, 1991).

However, men and women have been found to *experience* infertility in different ways (Berg *et al.*, 1991).

A diagnosis of infertility appears to be profoundly threatening for men (Shapiro, 1988) and may trigger feelings of shame and deficiency as a complete, functioning man (Berg and Mikesell, 1996). Feelings of shame may arise from the compromising of reproductive and sexual potency (Bents, 1985): men may fear they will be viewed as sexually inadequate and be subsequently rejected by others due to perceived deficiencies in sexual and reproductive functioning (Berg and Mikesell, 1996). Mahlstedt (1985) also commented that when a man is sterile and unable to father a child he may feel that other people doubt his masculinity and manhood. Berg and Mikesell (1996) argue that universally held societal views of masculinity are dependent upon sexual virility and reproductive ability, and that a diagnosis of infertility can therefore have a negative impact upon a man's sense of self-esteem. When the fertility problem resides with the male partner a sense of personal responsibility is also felt (Berg *et al.*, 1991), accompanied by feelings of loss, stigma and lowered self-esteem (Nachtigall *et al.*, 1992). Irrespective of the diagnosis many men experience a sense of role failure (Kedem *et al.*, 1990). Men may also feel that they have lost the ability to carry on the family name, genetic lineage and the associated sense of immortality (Baran and Pannor, 1993).

Infertility amongst cancer survivors has been hypothesised as having an even more devastating impact, becoming an additional insult to the original diagnosis of cancer (Schover, 1997; 1999). Cancer survivors may simply be expected to be grateful to be alive (Schover, 1999). Cognitive dissonance may result, given that the very treatment that saves may also destroy many dreams of future parenthood and family life. Schover *et al.*

(2002a) studied male cancer patients, aged between 14-40 years of age at the time of diagnosis, and reported that approximately a quarter of the men were distressed about the risk to their fertility; a further third had worried about this at least a 'fair amount'.

Anxieties may be felt the most by those men who are childless at the time of receiving a diagnosis (Schover *et al.*, 2002a) and by those who have actively construed themselves in a future role as a father and family man (Green *et al.*, 2003). However Schover (1999) cautions against presuming that infertility affects only the childless, that secondary infertility may be equally as distressing.

1.3.2.2 Coping with Infertility

Research suggests that men and women differ in strategies used to alleviate and cope with the distress associated with infertility (Berg *et al.*, 1991; Mahlstedt, 1985; Harrison *et al.*, 1986). Women appear more likely to discuss and disclose the problem to a wider range of people and engage in information-seeking behaviours (Berg *et al.*, 1991). Men may find it hard to disclose infertility due to feelings of shame and inadequacy and in some instances the female partner assumes public responsibility for the male's infertility (Berger, 1980; Miall, 1986). In these instances men may be perceived by the woman as being unable to cope (Berg & Mikesell, 1996).

Connolly *et al.* (1992) investigated the impact of primary infertility on 130 couples attending an infertility clinic. Participants were assessed using a battery of psychological measures. They reported several factors that were found to help individuals cope with infertility. For men being in a stable and well adjusted marriage was found to help, and for both men and women being dispositionally less anxious and neurotic was also found to positively influence coping ability. However, this may be a reflection of the

characteristics of couples that seek help. The authors also found that as investigations progressed couples became less anxious, however one exception to this rule was noted. When the diagnosis of infertility had been attributed to the male they found that the anxiety levels in men rose. This led to the suggestion that primary male infertility may cause specific psychological difficulties. Whilst this study provides interesting information on infertility amongst couples it is limited in scope given that its results are not applicable to individuals that are not in relationships, who may experience and cope with infertility in different ways.

Green *et al.* (2003) investigated the experience of 15 young male cancer survivors who had received counselling regarding possible treatment-related fertility problems. A qualitative grounded theory (Strauss and Corbin, 1998) approach was utilised. One emergent theme concerned the coping style adopted, which partly accounted for the range of emotional reactions experienced by the young men. The range of coping styles adopted varied from not wishing to engage with the topic through to a willingness to disclose, discuss concerns, and consider alternative treatment options. The authors noted that the continuum of emotional processing coincided with coping style research into those living with cancer as either 'blunters' or 'monitors' (Miller *et al.*, 1996). It was also noted that whilst some of the coping styles used by participants were consistent with enduring coping styles, some of them were not. This would seem to suggest flexibility in coping style. Whilst employing techniques to increase the reliability and validity of the research, such as respondent validation, the authors acknowledge the lack of generalisability to other cultures, given that all 15 young men were white British nationals.

1.3.3 Sperm Cryopreservation for Adult Male Cancer Patients

The medical technology surrounding sperm banking for male cancer patients will be briefly reviewed before considering the emergent literature in this area.

1.3.3.1 Medical Provision for Fertility Preservation In Male Oncology Patients

Following a diagnosis of cancer that may result in sterility (either through the disease or associated treatment) men will be invited to consider sperm cryopreservation. Sperm cryopreservation refers to the process of freezing and storing the male reproductive cell. Men usually provide the sperm via masturbation, or more exceptionally via testicular biopsy or aspiration of the epididymis. This sperm is then frozen and preserved for future fertility treatment. Traditional fertility methods include intrauterine insemination and in vitro fertilisation, however both of these techniques require sperm to be of a reasonable quality. In 1992 a new fertility technique was developed, in vitro fertilization with intracytoplasmic sperm injection (IVF-ICSI). This technique increases the likelihood of successful treatment by reducing the number of live sperm cells necessary, this is especially important in men with cancer as many will already have poor quality sperm at the time of diagnosis (Agarwal *et al.*, 1995; Lass *et al.*, 1998; Naysmith *et al.*, 1998; Padron *et al.*, 1998). Whilst many cancers are aggressive and treatment will be urgently required, sufficient sperm for storage and IVF-ICSI can be obtained via only one or two ejaculates (Agarwal *et al.*, 1995).

Sperm banking is now recommended for all men about to undergo treatment for cancer throughout the UK and Europe (Foley *et al.*, 1996; Hallack *et al.*, 1998; Koeppel, 1995;

Lass *et al.*, 2001; Royal College of Obstetricians and Gynaecologists, 2000; Sweet *et al.*, 1996).

1.3.4 Sperm Banking Literature

In light of the new technological developments and the above recommendation several authors have begun to study sperm banking in greater depth, moving away from the medical and towards the psychosocial, considering experiences, decisions, and motivations. Evidence has emerged from studies of both adult and paediatric populations, however this is scanty.

1.3.4.1 *Adult Oncology*

Much of the initial understanding of the impact of sperm banking began with two American-based studies (Schover *et al.*, 2002a; 2002b). The authors consulted 201 male cancer patients, aged between 14-40 years of age at the time of diagnosis, via postal survey, about their knowledge, attitudes and experiences of cancer-related infertility and sperm banking. The questionnaire comprised 21-true/false items of knowledge about the two areas and multiple-choice questions aimed at assessing several other areas of personal experience. Response rate was low, with only 27% of the 904 men invited to take part replying. Respondents did not differ significantly in age, ethnicity or cancer site, however the sample was highly educated. It had been on average three years since the men had received the diagnosis. Half of the men in the sample were childless at the time of diagnosis.

Whilst 41% of respondents reported a definite wish for children in the future only 24% banked sperm. Whilst 60% of men recalled a health professional discussing fertility with them prior to commencing treatment, only 51% recalled that they had been given the option to bank sperm. Twenty percent of the sample cited a lack of information as the main reason for not banking sperm-information covaried positively with banking. Other reasons cited for not banking included not wanting a child and already having completed the family.

The authors concluded that oncology health care providers were not routinely offering men the opportunity to bank sperm. Whilst offering interesting information a key limitation to the utility of the study is the differences between UK and US health care systems, and the subsequent implications for health care provision. Methodologically too, Schover et al (2002a) acknowledge their low response rate, and that the sample was self-selecting, creating a possible bias towards those interested in fertility issues. The use of multiple-choice questions directed men to the authors' areas of interest, failing to access men's more self-defined subjective experiences of sperm banking. Whilst providing explanatory data the study does not illuminate any psychological processes involved in the sperm banking experience.

Schover et al (2002a) support their conclusion with the results from their parallel study (2002b), evaluating oncologists' attitudes and practices regarding sperm banking. Deploying postal surveys 418 oncology staff physicians were sampled from two cancer centres and 300 staff were sampled at random from 26 clinic sites. The response rate was again low at 24%. Multiple-choice questions and rating scales examined factors that may be influential in their decision to offer sperm banking, such as sexual orientation. Whilst

91% of respondents agreed that sperm banking should be offered to all men, 48% reported failing to introduce the topic. Oncologists cited a lack of time as a potential barrier to offering the service and were less likely to offer it to openly homosexual men, those with HIV-positive status, and those with a poor prognosis. Whilst offering limited insight into American practice the study is hampered by a low response rate and biased towards those physicians most interested in fertility services.

A further source of information on sperm banking experiences is found in the personal account of Pacey (2003). The author himself a professional who managed a regional sperm banking facility and who, when diagnosed with testicular cancer, proceeded to bank sperm. Pacey's account is a narrative review of his own experience. This obviously generates several limitations, the main one being its lack of generalisability. It may be more appropriate to consider it a case study. Pacey's account is also atheoretical, no attempt is made to link any of the experience to any underlying psychological processes. However, despite such limitations the account offers some stimulating thoughts and provides a deeply personal overview of the experience.

Pacey comments upon his experience by considering six different stages: the decision to bank, the referral process and appointments, consent and associated decisions, production of the sample, life after cancer, and starting a family. Pacey invites professionals to challenge some widely employed practices and consider the psychological aspects of sperm banking.

Based upon his professional experience Pacey argues that oncologists are selective in who they invite to bank sperm, believing it is those men who express a strong desire to have

children. Pacey invites this view to be challenged, alleging that men may have reasons other than fatherhood for wishing to bank sperm, such as taking positive action at a negative time and preserving masculinity. Prior to sperm banking the Human Fertilisation and Embryology Authority (HFEA) require that all men must stipulate what they would want to happen to their sample in the event of their death. If a man opts to leave his sample for a wife or partner to use he is also required to give his consent to his name being placed on the birth certificate. Pacey comments that many men are not ready to face such decisions at this time. In addition to this requirement the HFEA also enforce an annual audit, requiring professionals to contact clients on a yearly basis. Pacey questions the psychological implications of the timing of such contact, with the anniversary of a diagnosis being a sensitive time. Pacey further considers whether a reproductive medicine unit is the best place for men to produce a sample, hypothesising that it may raise anxiety further to be surrounded by couples with infertility problems. Motivations regarding the prolonged storage of sperm samples following a regaining of fertility are also questioned; suggesting that to allow the sample to be perished may represent a form of loss.

The account highlights several areas that may benefit from further study. What are the fundamental reasons that men bank sperm, and what are the attendant psychological processes? May it be that men are also preventing a psychological loss by banking sperm? However, due to the individual nature of the account it is not possible to answer such questions.

1.3.4.2 Paediatric Oncology

Despite fertility preservation services for young men expanding within the UK (Crawshaw *et al.*, 2003) the search again revealed a very limited literature, partial in focus. Crawshaw *et al.* (2003) carried out two qualitative investigations into this new area, one investigating staff perceptions and the other investigating the decision making process amongst adolescent minors.

The initial study, focusing upon staff perceptions, aimed to establish an understanding of the process and identify any concerns regarding current service delivery. Existing literature informed a topic guide and 22 professionals from three different centres were interviewed and audio taped. The audio taped interviews were analysed using 'selective transcription' (Fielding, 1993). This refers to the process of listening to the tapes and noting any processes or themes.

Attributes that staff felt it important to have when working in this area included a professional manner, honesty, clarity, a lack of embarrassment, and the ability to attune to the emotional state of young men. There was mixed opinion on the gender of the professional and on obtaining consent, with some staff finding it hard to ascertain whether the information had been properly understood. It was also commented that it was hard to discuss sensitive issues with young men when insufficient time had been spent establishing some level of rapport. A further area of concern was the potential for psychological harm should an individual be unable to produce a sample or that the sample produced contained no live sperm. Techniques used to cope with this included normalisation and exploding the myth regarding fertility and virility as one in the same.

As noted by Pacey (2003) staff also worried about the implications of young patients being asked to stipulate their wishes regarding the sample in the event of their death.

Methodologically the study is limited. No additional measures were taken to enhance reliability and validity, such as using an additional researcher to assess and validate emergent themes, or respondent validation. This may have led to researcher bias, attending only to information deemed relevant and thereby excluding a vast amount of data. Given that the themes were then used to inform a topic guide for the subsequent study of young men, the possibility of that interview schedule containing bias must also be noted.

Retrospective interviews were carried out with seven young men who were not currently undergoing intensive treatment. The sample was biased towards white British men although one Asian young man was also interviewed. All men had been offered the opportunity to store sperm and four had accepted the offer. The parents of five of the young men were also interviewed. Interviews were audio taped, transcribed, and then analysed using framework analysis (Ritchie & Spencer, 1994). Respondent validation was used in order to validate the researcher's analysis.

Several themes emerged from the analysis. Attributes desired in staff included kindness, an ability to use some humour when discussing the area, and to be thoughtful in the language used. Choice was considered important and although written information was considered valuable young men reported feeling ill-equipped to challenge any aspect of the process due to a lack of information. Many of the young men also reported feeling so shocked by the cancer diagnosis that any subsequent decisions were incredibly difficult to

make, some of the men chose to put sperm banking to the back of their mind in order to deal with high levels of stress. Few of the men recalled being warned that their sample may be of insufficient quality to store. Opinion remained divided over the preferred gender of the professional.

From the results of the two studies Crawshaw *et al.* (2003) proposed several recommendations for professionals working in the area, such as a need for further written information, training in psycho-social interventions, and the need to be proactive in raising the subjects of fertility and sexuality. The study is limited by the small sample size, a criticism noted by the authors, who are currently replicating the study in a larger cohort of young men and women. Whilst providing interesting qualitative data the study is not linked to any psychological models or processes and is essentially atheoretical.

Adolescent experiences of sperm banking have also been addressed by other researchers. Evidence from one case series suggests that many adolescent boys may reject sperm banking due to embarrassment or a belief that they will not become infertile (Cella and Najavatis, 1986). Research suggests that young men would prefer to be informed of the option of sperm banking alone (Crawshaw *et al.*, 2003) than with their parents due to embarrassment.

1.4 Discussion

The past five years has witnessed an emergence of literature concerned with the psychological aspects of sperm banking for cancer patients. This area, although intrinsically linked to a diagnosis of cancer has emerged as a research area within its own

right, an acknowledgement of the unique difficulties and challenges facing this population should they wish to preserve their reproductive potential.

The emerging literature certainly suggests that the area has been neglected at cost.

Research indicates that men may have complex reasons for opting to store sperm and an understanding of the attendant psychological processes would be beneficial (Pacey, 2003) given that research has also questioned current practice (Crawshaw *et al.*, 2003; Pacey, 2003; Schover *et al.*, 2000). Pacey (2003) also comments upon the emotional needs of staff involved in this area, that the traumatic nature of the work and its impact on staff has also been overlooked.

It is also important to consider that this area is not only of consequence to men and staff involved in the process but also to the National Health Service (NHS). If, as the literature would suggest, men are storing samples for reasons other than fertility, not returning for treatment and once regaining fertility refusing permission for samples to be perished, then sperm banks may be meeting needs other than that they are provided for, at high financial cost to the NHS.

Whilst the literature described above has provided some initial insight into this complex area it is lacking in several key areas. As reviewed earlier many models exist on adaptation to and coping with cancer, yet the sperm banking literature has not made reference to any of these as a way of understanding some of the emerging findings. There also exists a vast array of health and clinical psychology models concerning adaptation to health challenges. These include constructionist (Viney, 1990) and cognitive (Wells & Hackman, 1993) approaches from the clinical literature and from health psychology, The

Health Belief Model (Rosenstock, 1966; Becker, 1974; Sheeran & Abraham, 1996), the Theories of Reasoned Action (Fishbein & Ajzen, 1975) and Planned Behaviour (Ajzen & Madden, 1986), the 'Process of Change' Model (Prochaska, 1994) and Leventhal *et al.*'s (1982) self-regulation model. These models may all be able to help explain men's actions around this time. In addition to specific models, current research does not consider any over-arching psychological concepts, such as loss, control, isolation or bereavement. These concepts may all be underlying psychological processes present when sperm banking and therefore may be of utility in furthering current understanding of this area.

The existing literature, although limited, provides some interesting points of departure. Currently the literature favours the adolescent patient with proportionally more studies of this population. Pacey's account (2002) certainly suggests that further investigation of the adult patient is warranted. This may be commenced in several ways:

- A direct study of men's experiences: This would more than likely adopt a qualitative methodology, for example grounded theory (Strauss & Corbin, 1998) or Interpretative Phenomenological Analysis (Smith *et al.*, 1999), given that there is very little literature already available (Stern, 1980). Such methodologies are better suited to 'research that attempts to understand the meaning or nature of experience of persons with problems such as chronic illness...' (Strauss & Corbin, 1998, p. 11).
- It may also be beneficial to ascertain the views of staff, as initiated by Crawshaw *et al.* (2003). Ascertaining staff perceptions of the psychological experiences of men may provide an initial study that can then be developed into a direct study of men's experiences. It is also important to note that staff act as gatekeepers for sperm banking facilities and as such their views and perceptions shape service

delivery. There is also a literature on staff perceptions from other areas of health (e.g. Adcock *et al.* 2000). Again this study would benefit from a qualitative methodology.

- Despite the methodological flaws in Schover *et al.*'s (2002) study the relative reluctance of oncologists to offer sperm banking to eligible men is of concern. A similar survey in the UK to establish patterns of referral to sperm banking would provide specific data on UK referral patterns. This could be a relatively short audit exercise in the first instance, and then to supplement this further qualitative interviews could also be undertaken. It may be that an educational programme designed at raising professional's awareness of sperm banking would be beneficial.

Any further research should aim to address some of the limitations in the current research, by employing a sound methodological approach and incorporating some element of psychological theory and/or process.

Given that the area is currently in its infancy any one of the above research opportunities would be an appropriate place to begin further exploration. In order to provide a holistic approach to patient care research needs to progress further and aim to develop an evidence base regarding the psychological experiences and needs of men at this challenging time. When a diagnosis of cancer is made it may be easy for sperm banking to be overlooked in an, albeit understandable but nonetheless present, urgency to begin treatment. This may be at a psychological cost to men and a financial one to the NHS.

1.5 References for Literature Review

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2 Part 2: Research Report

2.1 Abstract

In 2000 alone 134,272 men were newly diagnosed with cancer in the UK. Treatments for neoplasms may result in sterility, and as such sperm cryopreservation is recommended for all men about to undergo treatment. Within the past five years research has begun to focus upon the psychological aspects of the sperm banking process and although limited, there are early suggestions that the process is complex for both patient and staff. Given the importance of staff in both gate-keeping and service delivery, the opinions and perceptions of staff are crucial in furthering current understanding of the sperm banking process. This study describes six interviews with health care professionals, four located within reproductive medicine and two within oncology. Interview transcripts were subsequently analysed using a grounded theory approach, which also informed data collection. A core category was developed, termed 'negotiating threat'. This category proposes that sperm banking is undertaken as a means of managing the threat generated by a diagnosis of cancer and possible infertility. A process model was also proposed comprising four areas of negotiation: the threat and impact of existing attitudes, knowing enough, accessing and using supportive relationships, and coping and defence. Each area details a specific task encountered, and details how threat can also permeate sperm banking itself. The results of this study are compared to the existing psychological literature in this area. The limitations of the study are discussed, including the small sample size. Clinical recommendations made include the development of staff training, the implementation of best practice in offering sperm banking to all men, and the possible introduction of a men's support group. Further research opportunities stimulated by the study include direct research with men and further research with the staff group.

2.2 Introduction

In 2000 alone 134,272 men were newly diagnosed with cancer in the UK, an increase of 2.8% from 1999 (Cancer Research UK, 2004). Cancer is primarily a disease of the older person and this rise is, in part, due to the effects of an ageing population. With life expectancy in the UK continuing to rise it is estimated that there will be an additional 100,000 cases of cancer by the year 2025 (Cancer Research UK, 2004). It is therefore of some reassurance that survival rates post-diagnosis are also increasing (Meadows, 2002), in part due to advances in medical technology. However, treatment to combat neoplasms engenders numerous side-effects with one of the most common and distressing being that of infertility (Meadows, 2002). Given the known risks to reproductive organs sperm cryopreservation is now recommended for all male oncology patients about to commence treatment (Royal College of Obstetricians and Gynaecologists, 2000).

Whilst numerous studies have been carried out examining the psychological effects of male cancers and consequent infertility (Berg & Mikesell, 1996; Connolly *et al.*, 1992; Sanden *et al.*, 2000) any focus upon sperm cryopreservation has remained largely medically dominated. In recent years however, researchers have begun to consider the sperm banking process in greater detail and initial explorations of the area have led to the belief that it is a complex and psychologically challenging task.

Research within the UK currently favours the adolescent patient, with proportionally more studies of this population. However despite this, research is limited and partial in focus. Crawshaw *et al.* (2003) carried out two qualitative investigations, one investigating staff perceptions and the other investigating the decision making process amongst adolescent minors. The study investigating staff perceptions revealed many areas in which

professionals felt unclear about best practice, such as the gender of the professional and the potential for psychological harm should young men be unable to produce a sample. However, the study is compromised by several methodological concerns. The reliability and validity of the study are constrained by the involvement of only one researcher in the data analysis, creating a potential for researcher bias. Respondent validation was not sought. The study investigating adolescent minors relied upon retrospective interviews with seven young men who were not currently undergoing intensive treatment. The sample was biased towards white British men although one Asian young man was also interviewed. The interviews were audio taped, transcribed, and analysed using framework analysis (Ritchie & Spencer, 1994). The results of the study revealed several areas of concern. Adolescents reported a marked difficulty in making decisions regarding sperm banking in light of receiving a diagnosis of cancer. A lack of information resulted in adolescents feeling unable to challenge any aspects of the sperm banking process and few patients recalled being warned of the possibility that their sample might be of insufficient quality to bank. Amongst the recommendations made by the authors were the need for healthcare professionals to receive training in psychosocial interventions, the need to be proactive in discussing fertility and sexuality, and the need for further written information. As acknowledged by Crawshaw *et al.* (2003) the study is limited in generalisability by a small sample size, biased towards the experiences of white British adolescents within one service. In order to address these concerns the study is currently being replicated with a larger sample size.

Research focusing upon the adult male is largely neglected within the UK, with much of the initial interest in, and preliminary understanding of, adult sperm banking in North America (Schover *et al.*, 2002a, 2002b). Schover *et al.* (2002a, 2002b) questioned adult

survivors of cancer about their knowledge and experience of sperm banking, and concluded that a proportion of men who wished to father children had not actually banked sperm at the time of diagnosis. This was attributed to health care professionals failing to offer sperm banking routinely, a conclusion supported by a parallel study questioning oncologists' practices and beliefs regarding the process. Despite reporting a belief that sperm banking should be offered to all patients, accounts of clinical practice indicated this was true in practice for only half of the sample. Such a discrepancy indicates that sperm banking may be a complex task not only for the men involved but also the professionals gate-keeping the service. Yet the research is not without limitations. Methodological concerns such as a low response rate limit utility, and differences between US and UK health care provision cannot be overlooked.

Pacey's (2002) narrative account is the only published UK work in this area. Pacey, a professional managing a sperm banking facility, questioned many of his beliefs about the area following his own diagnosis of cancer and experience of sperm banking. Whilst a subjective narrative account lacks generalisability Pacey notes several areas of interest. Like Schover *et al.* (2002a, 2002b) Pacey noted that oncologists are selective in whom they invite to bank sperm; that only those who express a strong desire to father children will receive the offer. From his own personal experience, and subsequent professional discussions Pacey questions different motivations for sperm banking, including the wish to do something positive at an otherwise negative time and the desire to preserve a part of oneself. Many aspects of the sperm banking process Pacey had accepted as a professional he now calls into doubt given his personal experience. These include the provision of counselling, the location of the service, the needs of staff, and the psychological

implications of difficult decisions and yearly audit. Pacey ends his account by calling for more research into the area.

The past five years had witnessed the development of a new area of interest, the psychological experiences and implications of sperm banking for the oncology patient. To date however research remains limited, especially within the UK adult population. Staff working within the facilities shape service delivery and staff within oncology act as gate-keepers to the service. Early indications from Pacey (2003) and Schover *et al.* (2002a, 2002b) suggest that the role of gate-keeper may be complex given the discrepancy in who is offered to bank sperm. In order to establish more wholistic models of service delivery the opinions and beliefs of staff working within this area are pivotal.

2.2.1 Aims of the Current Study

In order to contribute to the growing research within the area, this study aimed to focus upon service provision to the adult male oncology patient. Whilst work has been undertaken with staff in paediatric settings, to date an adult focus has been neglected. The beliefs of staff working within this area will inform future clinical delivery and may stimulate interventions for adult patients.

This study therefore aimed to explore staff perceptions of men's experiences of the sperm banking process and explore how staff might impact upon the process, through either roles assumed or beliefs held. Given the lack of existing research from which research questions could be hypothesised and tested a qualitative grounded theory approach was employed (Strauss & Corbin, 1998, Charmaz, 1995). Grounded theory research is particularly suited to new research areas where there is little existing knowledge.

Understanding within this area was facilitated by individual interviews, which were then analysed within a rigorous set of procedures in order to construct a theory, built upon and grounded in data. It is argued that such an approach is therefore more likely to represent reality and offer a meaningful guide to action (Strauss & Corbin, 1998).

2.3 Methodology

2.3.1 Research Design

Research questions that focus upon understanding individual experience in a relatively novel, and little explored area are particularly well suited to a qualitative methodology (Strauss & Corbin, 1998). As the understanding of sperm banking experiences is one such area a qualitative method was employed. Grounded Theory (Strauss & Corbin, 1998, Charmaz, 1995) was selected as it offers a rigorous set of analytic procedures in which large amounts of rich qualitative data (obtained via interviews) can be synthesised and understood. Systematic inductive procedures guide the research process, through obtaining, synthesizing, analysing and conceptualising the data in order to construct a theory which is grounded in, and built from the raw data (Charmaz, 1995). This is in contrast to other qualitative methods, for example Interpretative Phenomenological Analysis (Smith *et al.*, 1999), where theory development is not the overall aim. It is argued that this is therefore more likely to represent reality and offer insight, understanding and a meaningful guide to action (Strauss & Corbin, 1998). As the staff at Centre X hope to implement changes following the research this method was felt to be especially appropriate.

Grounded Theory has several distinguishing characteristics; these include the simultaneous collection and analysis of data, using the data to create analytic codes and categories as oppose to hypothesis testing, the development of theory to explain phenomena, the importance of memo-making where the researcher makes analytic notes to develop theory and theoretical sampling (Charmaz, 1995). These fundamental characteristics of grounded theory will be explored in greater depth as each task of the research process is described.

2.3.2 Ethical Approval

An application was made to the appropriate NHS Local Research Ethics Committee, using the standardised NHS Research Ethics Committee Application form. Ethical approval for the current study was obtained in March 2005 (see Appendices 1 and 2). An application was also made to the relevant NHS Trust Research and Development Department and approval was also obtained in March 2005. A contract for research was also obtained as the Trust in which the research was undertaken was not the principal researcher's employing trust.

2.3.3 Researcher Characteristics

When undertaking qualitative research in which the researcher is central to the way in which the data is constructed it is important to be explicit about any potential sources of bias (Charmaz, 1995; Strauss & Corbin; 1998). The researcher was aware that she was currently working and training within a large psychoanalytic institute and was focusing very much upon unconscious processes. This is a possible source of tension given that Grounded Theory analysis focuses upon the detail of what is said rather than interpretations. This possible source of bias was monitored in the reflective diary and

during supervision meetings. Whilst the researcher was immersed in psychoanalytic thought at the time of the research she considers herself to be more ‘constructionist’ in theoretical orientation, with particular interest in the work of Kelly (1955) and Personal Construct Theory.

2.3.4 Centre X

Centre X is a Reproductive Medicine Department located within a large City acute hospital. In addition to fertility treatment Centre X provides sperm banking facilities for men diagnosed with cancer. The centre accepts referrals of cancer patients from within a 20-mile radius. Further characteristics of Centre X have been omitted in order to ensure anonymity.

2.3.5 Participants

Five participants were initially recruited from Centre X and subsequently two further from the oncology departments responsible for the referral of patients for sperm banking. The participants all had direct involvement with oncology patients, at varying times during the sperm banking procedure. One participant (P5) was no longer working within the Centre but had been doing so at the conception of the research and was keen to contribute.

In Grounded Theory participants are recruited up until ‘theoretical saturation’ (Charmaz, 1995, Strauss & Corbin, 1998). This refers to the point at which no new data is gained from participants. Given the time constraints placed upon this research it is unlikely that theoretical saturation will be achieved.

Staff working in Centre X and referring departments were invited to attend a presentation and discussion of the proposed research into sperm banking. The researcher then

contacted potential participants via email if they had indicated interest, attaching a Participant Information Sheet (Appendix 3). The only inclusion criterion was that staff must have had experience of working with men during the sperm banking process. Willing participants were then contacted by telephone in order to negotiate appointments. Prior to commencing the interview participants were asked to review the Participant Information Sheet and sign a consent form (Appendix 4). Participants were also asked whether they had any further questions.

Table 1 Participant Characteristics

Participant Code	Profession	Age Band	Gender	Ethnicity	Years in Profession
P1	Head of Andrology	31-40	Female	White UK	11
P2	Trainee Andrologist	21-30	Male	Asian	Less than 1
P3	Counsellor	51-60	Female	White UK	10
P4	Nurse Specialist	41-50	Female	White UK	20
P5	Ex Head of Andrology	31-40	Female	White UK	15
P6	Consultant Clinical Oncologist	41-50	Male	White UK	22

2.3.6 Procedure

2.3.6.1 Design & Administration of Interview

A semi-structured interview schedule was designed as a facilitative tool to discussion and understanding participant's views and experiences (Appendix 5). The questions were open-ended in order to facilitate as rich a description as possible. The interview was

structured chronologically, from referral to and completion of sperm banking. Staff were asked their opinions on several areas and were asked to comment, from their observed experience, on what they perceived men's experiences to be and how men negotiated the process. A question regarding service improvement was also included. The interview schedule contained specific prompts should participants seek clarity about a question. As the interviews progressed specific areas of interest were added to the schedule and questions that yielded little data removed (Appendix 6).

Interviews lasted between 60 – 120 minutes and were audio taped. Following several interviews the researcher noted points of interest generated in a reflective journal.

2.3.6.2 Data Analysis

Data analysis commenced following the transcription of the first interview. This is in line with grounded theory techniques of constant comparison and theoretical sampling (Strauss & Corbin, 1998; Charmaz, 1995). Constant comparison refers to the task of continuously sorting and comparing elements of data throughout the research project. Theoretical sampling refers to the active sampling of new cases based on current analysis. New cases are selected for their potential to elaborate, confirm or disconfirm emerging concepts and aim to enhance the researcher's understanding of the area. This method is in contrast to Interpretative Phenomenological Analysis (Smith *et al*, 1999) where the interview schedule does not alter to reflect emerging themes.

Line & Focused Coding

Analysis of the transcribed data began with line by line coding of the text. The actions, meanings and events that were described by participants were assigned a code. The codes were kept close to the data and were as specific as possible; Charmaz (1995) argues that

by doing so processes will become more apparent. The codes were noted in the right-hand margin of the transcript.

Subsequent to line coding focused coding was commenced. Focused coding refers to the process of comparison between and within transcripts of frequently used line codes and raising them to a more conceptual and abstract level. Initial line codes with similar properties and characteristics were grouped together to form a focus code. Focused codes within the text were noted in the left-hand margin of the transcript. In order to ensure the specific text relating to the focus codes was not lost the researcher created a file card for each focus code, upon which the source of the code was noted (e.g. interview and line numbers). An example of both line and focused coding is available in the appendices (Appendix 7).

Category Development

The researcher then started to develop categories from the focus codes. Categories emerged when focus codes shared similar properties to one another or described an overarching process within the data. A record of category development was kept (see Appendix 8 for example). In raising categories properties and characteristics were explicated, the circumstances in which the process arose noted along with any factors that influenced its maintenance. A note was also kept of how categories appeared to be linked to one another.

Throughout the category development the process of constant comparison was employed (Strauss & Corbin, 1998). This process refers to the constant checking of emerging categories with the raw data and modifying them in response to this before re-checking again in light of any new data.

A core category was identified, which aims to be representative of the research as a whole. A core category should be a conceptual and have the analytic power to subsume all other categories (Strauss & Corbin, 1998).

2.3.7 Memo-Writing

Memo-writing helps the researcher to elaborate on the emerging properties and characteristics of categories. Each memo that was made consisted of the properties of that category, how it may be related to other categories and any identifiable gaps in the emerging data. An example of a memo can be found in the appendices (Appendix 9). Memo-writing helps to identify which categories are major and minor, and guides the shape and form of the emergent theory (Charmaz, 1995).

2.3.8 Theoretical Sampling

The active sampling of new data in order to elaborate on an emergent theory stems directly from memo-writing (Charmaz, 1995). Theory-driven sampling may refer to either the recruitment of a specific type of participant or the development of a new interview question to reflect an emergent theme. As the data were analysed an emergent category about 'language' emerged. In order to gain further information on this it was included as a specific area of interest in subsequent interviews (see Appendix 6) and directly questioned about if the participant did not initiate its discussion. Following analysis of the first three interviews a category regarding 'referrer assumptions' began to emerge. In order to explore this fully two participants (P4 and P5) involved in the referral of men to Centre X were theoretically sampled for.

2.3.9 Enhancing Quality

Trustworthiness, reflexivity and representation are three key concepts in enhancing quality in qualitative research (Merrick, 1999). Steps were taken throughout the research process to address these concerns.

Trustworthiness

Steps taken to enhance the trustworthiness of the study are based upon those recommended by Stiles (1993). In order to be explicit about any potential sources of bias the researcher has included a section on her own theoretical orientation. The researcher has also attended a Qualitative Research Group in order to seek peer supervision and discussion around emerging findings and process. There has been an intense and prolonged involvement with the data and grounded theory methods and the procedure has been described in detail. Examples of text will be provided in the results in order to ground higher-level abstractions in the data.

Reflexivity

The researcher is central to the construction of the data. Techniques were therefore employed to increase researcher reflexivity. A research journal was kept throughout the process (Lincoln & Guba, 1985) in order to reflect upon the researcher's relationship with the data. Attendance at the Qualitative Research group also provided an opportunity to reflect on, and critically evaluate the research experience.

Representation

Coherence and integration of the findings was enhanced by the use of a core category, from which the remaining data can be understood. Attendance at the research group and

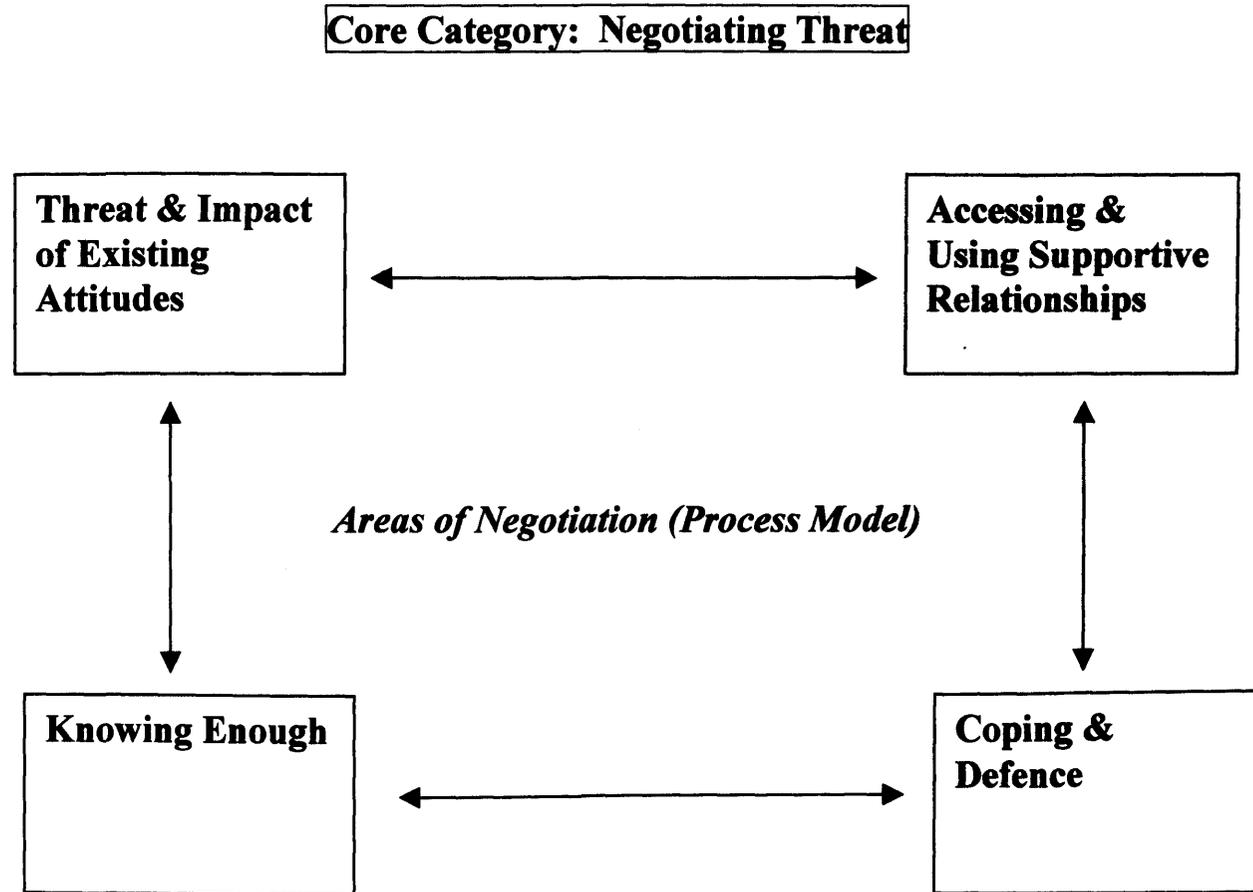
regular supervision meetings also offered the opportunity to explore the most appropriate means of representing the research.

2.4 Results

Following transcript analysis, as described in the methodology, a core category was developed and identified as a central phenomenon from which other lower order categories could be understood. The core category, termed ‘negotiating threat’, was perceived as central to participants’ perceptions of the sperm banking process and to the lower order categories, termed as key areas of negotiation. The four areas of negotiation form a proposed process model of the sperm banking experience. The process model represents men’s experiences as perceived by staff and also incorporates staff experiences and roles within the process. The model is illustrated in Figure 1. The areas of negotiation are represented and described discretely but do however contain areas of overlap and fluidity; this is to be expected given the complexity of human experience. The areas are also not presented sequentially as the process is not linear and each task may be being undertaken simultaneously with another.

Overview of Analysis Presentation The presentation of the results begins with a description of the core category, ‘Negotiating Threat’, and three lower order categories contained within it, ‘Threat to Lifecycle’, ‘Threat to Identity’, and ‘Managing Threat’. Following this each Area of Negotiation will be considered in turn. Initially each area will be defined and the lower order categories within it will then be described in order to explicate upon specific properties and characteristics.

Figure 1 The Core Category and Process Model of Areas of Negotiation



2.4.1 Core Category: Negotiating Threat

Threat emerged in many different forms throughout the interviews and the theme permeated and connected lower order categories. The notion of infertility and cancer as a potential source of threat was evident: *'it interrupts the natural order of things, you know, young men, you know, in their twenties or whatever, the natural life process is that they reproduce.'* (P3, 503-504.) The way in which sperm banking might be used to negotiate this threat also evident: *'it's an insurance policy, is what quite a lot of them say to me.'* (P1, 93-94.)

Whether a threat was initially appraised and subsequently negotiated by sperm banking was considered in relationship to a man's current life stage, experiences and attitudes. One variable within this being age. Participants observed that the level of threat appraised increased as a man progressed through his late twenties to thirties, when it then began to decrease around the age of 40. Attitudes towards fatherhood were also considered in relationship to age:

'[y]es and whether fatherhood is about sex or being part of a family. I think at 16 its one thing and at 35 it's another so, you know what I mean...yes it's very much about the association of sperm and where sperm sits in your psyche I suppose at that time of your life really.' (P5, 137-138)

Participants understood a decision not to bank sperm as reflecting either low level, or an absence of threat. The exact properties of the threat appraised were perceived as evident in a man's reason for banking sperm. The exact nature of the threat could be placed in one of three lower order categories: lifecycle and/or identity.

Threat to Lifecycle: Several of the proposed reasons that staff perceived men banked sperm appeared to be in response to a threatened lifecycle. The most apparent example of this being the direct threat that possible infertility would pose to their genetic ability to father a child: *'Primarily in reproductive age it's to maintain the opportunity to father, to pass on your genes if you like, to father a child of a biological...'* (P5, 421-422). There was consensus amongst all participants that the opportunity to father a biological child was the main reason that men opted to store. However, there was a sense in which the threat to the lifecycle extended further than this in relationship to a man's own life ending. One's own genetic survival, obtained through a biological child, was also an area under threat. By banking sperm it was perceived that a man could ensure his own genetic survival in the face of physical death by leaving the sperm for a partner to use. This was viewed as important for those men with very poor prognoses:

'well I think there's the future in which one survives and there's the future in which ones genetic material survives, erm, and there's one actual death, ones physical death and one's genetic death and maybe they are different, erm, so there's the idea of leaving, living on after one's death is a kind of future as well isn't it?' (P3, 227-231.)

Ultimately a threat to the life cycle also represented a wider threat to the survival of the species: *'if men can't fertilise women then, you know, they will die out because there's no genetic survival, but in large enough numbers the species would die out.'* (P3, 499-501.)

The threat was believed to extend beyond the patient himself and into the lifecycle of partners and parents. This was witnessed in the accounts of participants who either described meeting with men who claimed to be banking for their partner's sake, or, who had witnessed interactions where such threat was evident:

'his mum and his sister were both seriously haranging him about, you know...get on and do your sample, do your sample, we want that sample producing, we want to be able, you know, to have nephews and nieces, grandsons running around in five to ten years time.' (P1, 229-232.)

One participant (P5) also commented upon incidents she had heard about in America, where mothers had claimed a legal right to be grandmothers: *'there have been cases documented in the States and I don't know that it's happened here in terms of mother figures believing they have a right to grandmother status.'* (P5, 841-843.)

Whilst patients were confronting their own mortality, professionals were also hypothesised to be experiencing threat to their own lifecycle, in terms of resonance with patient's age, life stage and circumstances.

Threat to Identity The other source of threat expressed by participants was that to identity and thus preserving a part of themselves: *'then the other stuff is about maintaining wholeness I suppose, being, not losing that part of you that makes you an individual.'* (P5, 424-425.) A more specific threat perceived by participants was a threat to *male* identity, that even if a man had no wish to father children the ability to impregnate women was still central to a male identity:

'I think a threat to their sense of wholeness as well, as there is indeed with women, you know not feeling complete, you know, and I think reproduction is at the core of biological womanhood and manhood really.' (P3, 492-495)

By banking sperm it was perceived that men could preserve this facet of their identity. This was also offered as a possible explanation for the reason why some men, even upon regaining fertility or not wanting children, refuse permission for stored samples to be perished.

Managing Threat In addition to the specific nature of the perceived threat sperm banking was also seen as a more general response to a wholly negative and threatening time: *'that when somebody is going through this terrible time it's something that you know, can be achieved out of a very negative experience.'* (P4, 157-159.) Participants felt that implicit in the suggestion of banking sperm was a message of hope for the future, that men may feel by banking sperm there will be a future after cancer: *'if somebody suggested to them, you know lets freeze some sperm for you for the future then they're thinking 'OK so there is a future.' ...'* (P1, 95-97.)

2.4.2 Area of Negotiation: The Threat and Impact of Existing Attitudes

Definition of Area: This area reflects the way in which various attitudes may impact upon and influence men as they negotiate the process of banking sperm. More specifically certain attitudes were perceived as a potential hindrance to a man's experience and psychological well-being at this time. Individual, systemic and contextual attitudes were considered and three main areas emerged: assumptions regarding lifecycle norms, sperm banking as a sexual act, and patterns of disclosure. All participants expressed concern, albeit in varying degrees, over the impact of such attitudes, societal or individual, on men. The following lower order categories describe the exact properties and characteristics of this area in greater detail.

Assumptions Regarding Life Cycle Norms Participants appeared acutely aware of how professionals' personal beliefs regarding lifecycle norms could impinge upon a man's progression through the process. This was especially evident at the point of referral: *'I think it's just that they [consultants] make their own suppositions about who might need it and who might not.'* (P1, 37-38.) Participants recruited from Centre X all expressed similar opinions to this. These beliefs were thought to be a reflection of a wider set of societal norms concerning fatherhood. In order to examine these beliefs further participants 4 and 6 were recruited, both of whom are involved in the referral of men to Centre X. Both participants were aware and interested in thinking about their own personal beliefs and how they influenced the process, given that: *'[t]he problem is you're like the gatekeeper aren't you, the entry point to this process.'* (P6, 484-485.) The most influential factors determining referral were age and prognosis. Participants acknowledged that their own personal beliefs about age were likely to influence the referral process. Participant 6, a Consultant Clinical Oncologist, describes his patterns of referral and questions his own behaviour:

'I wouldn't as a rule offer it to the majority of men with prostate cancer because they're, because they're old are they? Or because I'd assume that they're past their child bearing years I suppose-rightly or wrongly, that's an assumption I make, that's a belief.' (P6, 20-23)

This was a view echoed by Participant 4, a Nurse Specialist, who described difficulty in accepting that her own values influenced how she felt about discussing sperm banking with certain age groups. Participants were aware of how such beliefs could potentially exclude certain patient groups from banking: *'you've made assumptions, the middle age*

senior executive in there but you've forgotten he's got a wife two decades younger than he is and who might want kids.' (P6, 283-285.) In addition to age, prognosis and health were also influential in the decision making process. Participant 4 described that the very ill received perhaps the least information about sperm banking, however Participant 6 stated that whilst they may only get one opportunity to bank, it was still very much discussed: *'they normally get one chance, because you normally get a day or two.'* P6, 82.) This was in contrast to those where the prognosis was poor, and the cancer was terminal. Participant 6 hypothesised that this may be as a result of his own discomfort in discussing sperm banking having just delivered a terminal prognosis to a patient: *'I think part of me says that they're going to think you're mad if you say 'do you want to do sperm banking?'* (P6, 170-172). It is important however, to acknowledge that whilst participants were aware of the possible implications of such attitudes, it was believed that the majority of men were given the opportunity to bank sperm.

Sperm Banking as a Sexual Act This area describes the relationship between sperm banking and attitudes regarding sexuality and masturbation. Explaining the apparent stigma associated with sperm banking Participant 5 considers the alternative, of women donating eggs and concludes that egg harvesting is not as stigmatised due to being achieved via a surgical procedure, as opposed to sperm banking and: *'the stigmatisation associated with a sexual act.'* (P5, 332.) It was felt that this link could make sperm banking potentially more difficult to talk about, and Participant 4 appeared to confirm this in part:

'I think there's an element of embarrassment on the part of the nursing staff, erm, you know, that can cloud the issue, it's not something that I feel

totally comfortable discussing, erm, but I think I'm getting better at it.'

(P4, 174-176)

Although this was not a view shared openly by other participants, perhaps not surprising given that 4 of the remaining 5 participants work within reproductive medicine, participants did feel that this view may be shared by the men themselves: *'a lot of them are very scared of even using the word sperm, mentioning that...of embarrassment around the whole process of sperm.'* (P1, 502-505.) It was also suggested that men might feel embarrassed that staff knew they would be masturbating.

Attitudes held by the individual, his family, friends, and wider social context towards masturbation were also seen as impacting upon progression through the process. Negative attitudes towards masturbation were seen to threaten a man's progression through the process whereas open attitudes were seen as facilitative:

'I'm just thinking about an individual that has been brought up to not have a stigma about masturbation or issues about sex may find it a lot easier than someone who has been brought up to believe that masturbation is bad or talking about it is bad. It depends on how sexuality and reproduction and stuff has been dealt with them as individuals I suppose'. (P5, 596-600)

In addition to attitudes held within the family in which the individual grew up, attitudes held by the family in which the individual was now living with were also considered important. For example Participant 1 reported the negative effect upon a man who witnessed his wife's disgust at the presence of pornographic material in the sample room. Specific religious and cultural views towards masturbation were also seen as potentially

threatening to a man's psychological well-being at this time. When individual beliefs conflicted with clinical necessity it was hypothesised that men would find sperm banking considerably more difficult: '*one [Asian] was mortified at the prospect of having to go.*' (P6, 207-208.) All of the participants felt that sperm banking would present additional challenges to those men where their cultural or religious beliefs prohibited masturbation or viewed it as sinful.

Disclosure: Limited and Inevitable If negative attitudes towards sperm banking and infertility surrounded an individual, disclosure was considered to be less likely. This was thought to be due to '*...fear of ridicule perhaps.*' (P3, 480.) However, disclosure was also viewed as somewhat inevitable amongst immediate family, partly due to the subject being almost always raised in their presence, although in some cases the next of kin was not always disclosed to and this was thought to be possibly reflective of information being shared on a '*need to know*' (P6, 370) basis only.

2.4.3 Area of Negotiation: Knowing Enough

Definition of Area This category encompasses knowledge, information, and learning about the sperm banking process and relates to both staff and patients. Included within this area is the patients' knowledge about the process, their associated information-seeking behaviours and participants' understanding of such behaviours. Staff factual knowledge about sperm banking and cancer, and the knowledge and abilities that staff feel they should possess in order to work with patients are also discussed. The third area within this category concerns the absence of knowledge relating to the overall process.

The Patient Information Spectrum

Participants described witnessing men engaging in several different information-seeking behaviours. Staff described men's behaviour on a spectrum, noting some men who amassed a vast amount of knowledge relating to the process and some who did not engage with any information. Participants believed this spectrum to be representative of health care provision as a whole.

Participant 1 summarises some of her experiences of the different behaviours men engage in:

'Some of them come with, armed with, questions, they've looked it up on the internet...some of them have obviously thought about it and talked to their partner and they've come with, you know, a few ideas...but a lot of them have not prepared themselves at all, erm... and I think that's just down to a whole range of things. Quite a few of the patients are still well enough to continue working...some of them it's denial, not wanting to find out anything about it beforehand... some of them are perhaps too ill and, I mean, we get the complete spectrum of patients being referred to us, some of them struggle to fill in the basic form... so it's probably just that they're not really the sort of person who would sit down and read two sides of A4 of information let alone look on the internet.' (P1, 427-450)

Participants expressed several ideas and explanations for the range of information-seeking behaviours witnessed in men. One such explanation being the view of information seeking as a coping response that could also be generalised to other areas of patient's lives. Staff believed that amongst those seeking information, positive effects in the form of reduced anxiety and an increased sense of empowerment and control may be evident: *'I think it's a way of getting more information that may then give them a clearer*

understanding, thereby possibly reducing their anxiety about it. ' (P4, 457-458.)

Alternative behaviours of not seeking information were also viewed as potentially positive. It was hypothesised that by not engaging in the information-seeking process patients could be maintaining denial and avoidance, which was viewed as an adaptive coping response. One participant believed that patients abdicating complete responsibility to doctors were regressing to a child like state that yearned to be '*looked after*' (P3, 640).

Whilst patients are provided with a patient information sheet prior to their first attendance at Centre X participants suggested it had limitations. Whilst some patients had engaged with the information sheet many had not and this was felt to be due to an inability to absorb any further information following a diagnosis of cancer.

Apprehension witnessed on the first visit to Centre X was partly attributed as due to a lack of knowledge of what to expect. Whilst information was considered to have a role in providing knowledge it was again felt to be limited in its utility when compared to lived experience:

'It is not something you can write down on a piece of paper. There are instructions now provided and some of them do have information sheets... but that wouldn't necessarily make you not feel awkward or make it any easier for the first visit. ' (P2, 156-160.)

Knowing the Basics This aspect of the area encompasses staff knowledge and their beliefs about potential areas of learning. All of the participants were extremely open about areas in which they felt lacking knowledge. A main area of concern raised was the

lack of knowledge amongst professionals outside of the Centre regarding sperm banking procedures, whether that be amongst General Practitioners or Oncology professionals:

'there is information that people over in oncology need to be able to give, knowledge that they need to have in order to prepare people more effectively for coming through the centre.' (P3, 860-862)

This was a common view shared by professionals working within Centre X. With this in mind they had recently organised a study day on fertility issues, incorporating sperm banking for the oncology patient. This study day appeared beneficial to staff with three participants commenting on its value and the learning opportunities it provided. The Nurse Specialist in lymphoma services described a sense that staff were less knowledgeable about sperm banking than other procedures attended by patients.

'And for most of things that our patients go for like scans, operations, tests we can give the patients quite a good idea, in some cases there's written literature, but again with sperm banking it's, you know, it's skirted around...' (P4, 367-369)

The Consultant Clinical Oncologist however did not share this view and described perhaps the ideal amount of knowledge to have, *'I wouldn't say I'm an expert but I know enough about it in advance of them getting to the centre'* (P6, 304-305). It was felt that staff in oncology needed to be in possession of the basic facts, such as alternatives to masturbation, in order to help men negotiate the process. However, it was also commented upon by one participant (P3) working in Centre X that the lack of knowledge was not only regarding sperm banking but regarding cancer, that professionals in the centre may benefit from a greater understanding of the investigative and diagnostic

processes involved in oncology. Similarly Participant 1 also described, with regret, that she had been unable to attend a seminar in oncology to facilitate talking with cancer patients, commenting that she found it incredibly difficult to use the word 'cancer' with patients.

Study days were felt to be crucial in raising professional's awareness and in challenging attitudes. Feelings of a lack of knowledge seemed to be linked to feelings of embarrassment, that the subject needed to be made more comfortable to talk about to allow learning to take place: *'the whole ethos has got to change so we are all comfortable and it is given priority.'* (P4, 264-265)

A further area of concern related to knowledge about a diagnosis of infertility. There was a sense amongst some of the participants that sperm banking was sometimes viewed as a cure, which it is not. Infertility is incurable and whilst it can sometimes be circumvented via artificial conception that should in no way diminish the devastating effects of a diagnosis.

What is Actually Going On? In addition to a lack of factual knowledge participants also reported a lack of knowledge regarding men's experiences of the process. Several participants made reference to previous research to suggest that there remained a great deal unknown about the process and questions regarding whether services are meeting men's needs. Participants hypothesised that many of men's needs at this time may not be being met:

'I'm sure we're not addressing it, we're not talking to them, we're not asking them how they feel, it's almost like a procedure, it's like the sperm

banking is 'right then if that's what you want to do that's what you've got to do' and that's it end of story and I think there must be a hell of a lot of work to really put this psychological and emotional needs of men on the agenda, on the priority.' (P4, 721-728)

Several specific areas where knowledge was thought to be lacking included the preferred gender of the professional, the impact of being unable to produce a sample, and sources of support. Participants were also conscious of men who are not offered the opportunity to store and that it was hard to establish whether these men would welcome the opportunity to do so:

'I think there may a gap in the market but without more research its difficult to know whether we just imagine older men would want to do it for themselves but they don't actually.' (P5, 24-26)

Gaining knowledge of men's experiences and of the sperm banking process seemed to be hindered by several factors. Staff at Centre X described minimal contact with men after they had banked their final sample. This lack of follow-up may prevent opportunities to engage in discussion with men about their experiences of the processes. A further hindrance appeared to be related to attitudes towards sperm banking as an uncomfortable subject to raise with men. It was felt that sperm banking needs to be more widely discussed amongst staff in order to facilitate conversations with patients about their experiences, removing the taboo associated with the subject. It was interesting to note that whilst difficulty in discussing the subject was felt at some level to prevent learning, that the same lack of knowledge was also viewed as an important factor in maintaining embarrassment and thus hindering discussion.

Participants expressed a need for further research, that the experience of men needed to be heard in order to establish whether hypothesised needs are real or not, whether men '*are really bothered about it*' (P4, 270). It was also considered important that service user involvement was sought prior to implementing any change.

2.4.4 Area of Negotiation: Accessing and Using Supportive Relationships

Definition of Area: This area refers to the way in which participants perceive men to access and use sources of support, from both within and outside the hospital environment. Encompassed within this area is the way in which gender differences appear to be influential in how participants conceptualise and understand men's support-seeking behaviours. A further issue considered is the sources of support that participants believe men do access and the associated threat to existing supportive relationships. Finally within this area, participants consider their own sources of support in working with this patient population.

Men are Do-ers, not Talkers All participants considered the influence of gender upon the source and type of support engaged with by men. Much of men's behaviour at the time cryopreservation was offered was understood to be a reflection of inherent gender differences and preferences. Men were observed to engage in fewer support-seeking behaviours than women in a comparable situation, such as talking to staff or counsellors about emotionality. This was a reflection not of emotional experience but of emotional expression: '*I don't necessarily think it's more emotional for women but men don't talk, wouldn't talk about it as much as women do with breast cancer, about their*

fertility.' (P6, 340-342.) It was considered that this might be in part due to expectations of male behaviour that men respond to:

'I think on an emotional level, we do tend to talk to our friends, our girlfriends, our mums, our relatives...I don't think it's that men aren't going through the same things as women, but because they are men, there is an expectation that they don't do that sort of thing.' (P4, 504-508)

The exact nature of the support accessed by men was also viewed as an artefact of gender differences, men were considered to be less open about difficulties and less inclined to discuss matters:

'Would they want to talk full stop...Maybe it's something to do with the male psyche anyway, they tend to be do-ers rather than talkers anyway.'
(P3, 550-552)

Participants questioned whether support accessed by men might be of a more practical, and hence less observable nature; watching football matches and seeking support through routine, as opposed to talking with friends or family at length. Participants also felt that men would be unlikely to access counselling services, since they might perceive it as a female provision. Whilst the lack of acceptance for support was partly attributed to gender differences, participants still believed that men should be offered the same supportive facilities as women.

Sources of Support and Threat Participants perceived that men were able to access sources of support from both within and outside the medical system. Within the medical system participants proposed that men would access the support that seemed the most

relevant to their situation, and at the time of sperm storage participants questioned whether men would view Centre X as a relevant source of support:

'... although they need support around that time their support is probably perhaps in their mind, rightly or wrongly, is not linked to the fact they're storing sperm, I'd say if they need support around that time it's much more around the fact that they're ill.' (P1, 703-707)

The exception to this was when the support was very much related to the production of a sample, or for factual information about the sperm banking process. However participants did acknowledge that some attachments may be made, although it was felt that these attachments were more likely to be in a service that was more familiar to them as: *'at the end of the day they don't know you they have no reason to open up to you.'* (P5, 307-308.)

Oncology patients were viewed as having little in common with other men in the Centre. It was hypothesised that they might feel isolated from the apparently healthy men within the centre. Participants noted that very few men accepted the offer of counselling, and although this may be related to gender as discussed previously, participants also questioned whether this was also because the service seemed irrelevant to their current situation.

The main source of support for men at this time was thought to be provided by partners or immediate family: *'[support] for going through the sperm banking procedure-it'll be their partner or family won't it, largely.'* (P6, 348-349.) However, potentially supportive relationships were also considered vulnerable to threat during this time. This was considered a result of two main factors. The first of these stemming from the pressure of having to discuss important relationship issues at a forced, unnatural time. Decisions

involving children and the permission to use sperm in the event of a man's death were considered to be potentially threatening:

'I wouldn't say it necessarily made people's relationships stronger...it could be... that it raises certain issues... where any couple may be at the early stages of their life and their relationship and then maybe his girlfriend or wife feel he would leave his sperm to her when it could be the case that he is not comfortable... and that maybe be an issue.' (P2, 643-651)

This threat extended to relationships with parents, who might also wish that their son leave his sperm to a partner in order that they may become grandparents. Whilst these conversations were felt to be critical in any relationship it was felt that this forced nature of them could threaten existing supportive relationships at this time. A further threat was felt to exist when needs of partners conflicted with those of men, for instance should a partner wished to discuss issues that a man did not:

'Which can cause tension as well you know because if somebody is trying to be understanding you know you can't imagine what somebody is going through but you've got the pressure from somebody who wants to do their best and try and help you and make life easier but you know you don't want to open up your feelings to them but you need to be able to do that to be able maybe to discuss it as well.' (P2, 704-709)

In order to avoid threatening existing relationships in such a manner Participant 6 questioned whether a man might decide not to bank sperm, anticipating the conflict that may arise.

Staff use of Peer Support Staff reported the almost exclusive use of peer support in coping with their work. Characteristically peer support was of an informal nature, *'[r]ather than it being a formal thing like we'll get you counselling or an off load session once every fortnight because I don't think that would work so well'* (P5, 1017-1019). This was viewed at the most helpful way of obtaining support, a *'listening ear'* (P1, 871) as opposed to formalised support that may be recorded on a personnel file and be viewed as evidence of not coping. The counsellor located within Centre X was seen as a particular source of support. Staff were also aware that support for technical information was available and indicated the sources of such information. Support across department was felt to be facilitated by familiarity; that it was easier to telephone with a query when both parties knew with whom they were talking.

2.4.5 Area of Negotiation: Coping and Defence

Definition of Area: This area concerns specific means of coping and defence. This was an area not detailed by all participants, but briefly commented upon by most. The use of humour as a possible means of distancing and coping with difficult situation and emotions was considered, in addition to the possible use of projection to cope. However, half of the participants did not speak of their own defence mechanisms.

Distancing the Self This concerns the use of certain techniques to remain at a distance from difficult situations and emotions. Men were believed to have more difficulty in coping with emotions than women and as such were observed to use possible strategies to

keep emotions at a distance. The main way in which men were observed to do this was by using humour, in order to avoid being overwhelmed by the enormity of the situation.

'...[M]aybe, you know, but err, maybe there's a need to make light of it as it's too much otherwise, a need at this initial stage to keep it there, at a distance, you know for fear of being overwhelmed by the enormity of it all...' (P3, 715-718)

Language was thought to be used in a similar way. Participant 4 describes 'innuendos' (P4, 214) between staff and patients as being a way of covering up embarrassment and coping with the situation, for both patients and staff. When asked whether such banter was helpful or not Participant 4 replied: *'Erm, is the banter helpful? [Long pause] I think it could be. At that particular time, even though it's skimming over what is really going on, it's easier to cope with.'* (P4, 247-249.) Included within this banter was the use of terms such as 'wank bank' (P4, 285), which men had been noted to use. Whilst these may be helpful for some men it could also be the case that some men find such terms pejorative:

'I mean I think, well think of the terminology around 'wank bank' it's a bit pejorative really, erm, or this could just be me, it's not a, it's an act that's erm, associated with erm, I don't know, well when you think about it it's what school boys do, or that sort of thing, the culture is, you think of the language, you know, 'jerk off', if someone, if you call someone a 'tosser'. It all has certain negative connotations around it...' (P3, 406-411)

An alternative means of distancing the self from distressing emotions was hypothesised by one participant only to be through projection: *'...maybe [men] have a pattern that is easier to project needs or to think of displaced needs, look at other people's needs rather than their own.'* (P3, 177-179.) This was understood as a way of engaging in necessary behaviour without having to confront painful realities; men could believe that they were banking sperm for their partner rather than themselves. This was hypothesised as being an unconscious process and possibly functioning to preserve *'...some sense of being intact, erm, erm, maybe some sense of still being able to something for someone else, so does it kind of, deny or disguise a sense of powerless[ness].'* (P3, 196-198.)

When discussing the challenges and difficulties faced by staff working with this population Participant 5 refers directly to defences and coping strategies:

'I think lack of training in terms of distancing yourself and your own personal feelings. And just dealing with, I think that the people in health care who deal with terminally and very sick ill people must develop a hardening to it' (P5, 701-703).

Some defence was thought to be helpful for staff when working with such an ill client group.

2.5 Discussion

The current study contributes to the growing literature investigating psychological aspects of the sperm banking procedure for oncology patients. In particular the study provides the first UK based research on staff working with adult male patients. The study also contributes to the literature on staff perceptions of psychological experiences within

healthcare (Adcock *et al.* 2000). The results of the study, their implications and limitations will now be discussed.

2.5.1 Core Category: Negotiating Threat

From the analysis it became apparent that participants understood men's decision to bank sperm as being a response to a perceived threat. Sperm banking was seen as a way of negotiating the perceived threat, thereby creating an 'insurance policy'. However, threat also permeated the sperm banking process itself in various forms. Attitudes held by the self, family, and professionals could threaten a man's progression through the process, as could a lack of knowledge, and difficult decisions could threaten the existence of supportive relationships. The use of defence mechanisms and coping strategies within the process were a way of negotiating the threat generated by sperm banking, amongst both staff and patients.

The initial sources of threat, to lifecycle and identity, can be further explored by considering the Kellian understanding of the term 'threat' (Kelly, 1955). George Kelly identified 'threat' as one of six main professional constructs. Professional constructs offers a system for understanding an individual's construing; that is the way in which they experience and make sense of the world around them. Kellian 'threat' refers to the awareness that an individual is facing comprehensive change to the most fundamental of constructs held, those regarding core-role and identity. When considering the presence of threat in this study it may be useful to hold in mind the Kellian definition of the term. A diagnosis of cancer and possible infertility can be understood as a major source of threat, given the number of core role constructs facing change, for example, healthy person to sick person, potential father to unable to father, employed to unemployed. By banking sperm men manage the threat to their core role, whether that be as a man, father, or both,

by creating an insurance policy. The existence of threat amongst close family and partners can similarly be understood. Professional constructs describe transition, and given that men are in a period of transition and change at this time it is likely that Kelly's other professional constructs would be relevant. One of these constructs is anxiety, which refers to the recognition that the events with which one is confronted lie outside of the range of convenience of existing construct systems. Given that a diagnosis of cancer and sperm banking are novel events, they can very much be understood as a source of Kellian anxiety. Aggression refers to the active elaboration of an individual's perceptual field, and may be witnessed in men as they explore alternative constructions of themselves in light of the events they are facing. Aggression is viewed as a forward move, and it may be that some men negotiate threat and anxiety via an aggressive decision to bank sperm.

The theory asserts that staff perceive men as having diverse motivations for banking sperm. Whilst the motivations may relate to either lifecycle, identity, or management of general threat, the diversity of reasons within each category supports Pacey's (2003) assertion that reasons for sperm banking may not always be related to the desire to father children. The results are also concordant with Berg and Mikesell's (1996) writing on male infertility, who propose that the *ability* to reproduce is central to the male identity and a loss of that ability may lead to low self-esteem and feelings of shame. This literature lends support for two of the possible categories of motivations regarding sperm banking identified in this study, lifecycle and identity.

2.5.2 The Proposed Process Model

The proposed process model consists of four areas of negotiation, with each of relevance to both staff and men. As with psychological models of bereavement (Parkes, 1970;

Bowlby, 1980; Worden, 1991; Sanders, 1999) the areas are not linear, and individuals may move in and out of different areas, or be negotiating more than one area at any given time. As with Worden's (1991) grief work it may be more accurate to consider each area of negotiation in the process model as a 'task for negotiation', implying that an individual can exert influence and control over each task. Each task of negotiation is also vulnerable to influence from external factors, for example the attitudes of staff and family.

The attitudes, beliefs, and to a degree practices, employed by the referring professionals in the study again support both Pacey's (2003) account and the American findings from Schover *et al.* (2002a, 2002b). Whilst believing that the majority of men were referred for sperm banking, professionals in the study acknowledged that they did not discuss sperm banking with certain patient groups. The patient groups with whom sperm banking is least likely to be discussed are older men and those with a terminal illness. Older patients are less likely to be offered sperm banking as referrers believe them to be past child rearing age. For those patients with a terminal illness referrers described a fear of how such patients would react to the offer, concerned that it would seem insensitive, irrelevant, and inappropriate. Participants were aware that holding such beliefs may exclude some men from banking, but believed that for the majority of men they had made the correct judgement. This highlights a potential area of difficulty for staff, the ability to suspend one's own beliefs and morals when faced with such patients.

Much of men's behaviour at this time was understood to be a coping response. This was especially true for the amount of information sought out and engaged with. The continuum of information-seeking behaviour observed by participants is similar to the pattern of coping noted by Green *et al.* (2003) in their study of young male cancer

survivors. The authors noted that the range of coping styles adopted varied, from not wishing to engage with the topic of possible infertility through to a willingness to disclose, discuss concerns, and consider alternative treatment options. The authors noted that such a continuum of emotional processing coincided with coping style research into those living with cancer as either 'blunters' or 'monitors' (Miller *et al.*, 1996). Green *et al.* (2003) did note that the particular coping response used was not necessarily consistent with enduring coping styles. In the current study however, participants very much understood men's coping styles to be reflective of enduring traits. By holding such beliefs this may, for example, lead to early signs of depression, e.g. social withdrawal and disengagement, being misinterpreted as an enduring coping style.

2.5.3 Clinical Implications and Recommendations

This research highlights the complexity of sperm banking, not only for patients but also the professionals involved. The results of the study suggest that service delivery could be enhanced in several key areas. The recommendations are based on the results of each area of negotiation, with the exclusion of coping and defence, and are targeted at the staff group. This section will conclude by considering ways in which clinical psychology services may be able to contribute to service delivery on the basis of this research

The Threat of Existing Attitudes & Beliefs The results from this area suggest that not all men receive the opportunity to bank sperm. It is not possible to say from this research however, whether judgements made by professionals involved in the referral of men are accurate. It remains unknown as to whether older and terminally ill men may wish to bank sperm. The only way to ascertain this would be to start asking men within the two groups. This is a potentially difficult area to negotiate, particularly within the

terminally ill patient group and support for referrers would be need to be established and outcomes monitored. Both participants P4 and P6 welcomed the opportunity to explore how their own beliefs about fatherhood impacted upon their professional practice and it may be that the existence of a forum to continue such discussions would be beneficial, although negotiating time to do so may be difficult. Given the apparent failure of professionals to implement best practice at all times, in accordance with the recommendation of the Royal College of Obstetricians and Gynaecologists (2000) that all male oncology patients about to commence treatment are offered the opportunity to store, this gap in referral patterns requires intervention.

Knowing Enough This category highlighted several clinical areas that may benefit from training. Several participants expressed a desire for more knowledge in order to aid them in their clinical work. Whilst participants were competent in their own clinical area there was a desire to know more about the alternative area; e.g. sperm banking or oncology. It was felt that a basic understanding would be sufficient and would ease discussions with men. Specifically staff at Centre X desired further knowledge of oncology diagnostic procedures and advice on how to communicate with cancer patients, and whilst the Consultant Oncologist felt that he knew the basics of sperm banking the Nurse Specialist felt that more study days would be useful. These would also serve to highlight sperm banking and may go some way to tackling the stigma and embarrassment associated with the act. Staff may be able to help men prepare for the experience by being better informed about the procedure themselves and by being able to provide written information to patients. Additionally staff would benefit from more research into the sperm banking process, which will be discussed in further detail shortly.

Accessing & Using Supportive Relationships The importance of staff support being both accessible and informal was highlighted and such provision should remain. One area discussed by two participants concerned the possibility of introducing a support group for men. It was felt that current support groups for men at Centre X would be inappropriate for this patient group as men may perceive those in attendance as having little in common with themselves, for example, cancer. The group should aim to include men that had already been through the process in order that they may share the experience with those preparing for it. Whether men would welcome such a support group remains unknown.

Implications for Clinical Psychology In addition to the above clinical implications the results of the study suggest that there may be several areas in which the involvement of clinical psychology services may be beneficial.

The results of the study do not suggest that men require any direct involvement from clinical psychology at this time, and indeed it may be harmful should this be introduced. However, there may be a role for clinical psychology in providing consultancy-based work. Given the established difficulties staff face when working with this client group, such as the tension between personal and professional views, a forum in which the impact of such issues could be considered further may be beneficial. A Clinical Psychologist would be ideally placed to facilitate such a group, given their external position to both departments. In addition to this a Clinical Psychologist could also provide assistance should any audit work be undertaken; for example, to enhance current knowledge regarding existing referral patterns.

Should staff seek to establish a support group for men it may be beneficial to consult with clinical psychology in order to obtain the direct services of a practitioner. Whilst it may not be necessary for a Clinical Psychologist to be directly involved in delivering or facilitating a group there may be a role for the provision of supervision services to those staff that do. It may be that staff would also benefit from some basic training on mental health issues, for example, the early signs of depression and normal responses to acute illness, and counselling skills. One participant in the study also hypothesised that should a support group become popular and well used, it may then help to facilitate direct research with men. Planning such research would also benefit from the involvement of clinical psychology services, with a particular emphasis on ethics, methodology, and data analysis.

In addition to the above recommendations regarding the involvement of clinical psychology services the following section detailing further research opportunities is also pertinent, given that Clinical Psychologists are skilled and trained in undertaking research.

2.5.4 Implications for Further Research

In addition to the clinical and service-related implications discussed above the study identifies several areas that would benefit from further empirical research.

In common with the work of Crawshaw *et al.* (2003) studies of staff perceptions can inform further studies into patient experience. Participants expressed a desire for research into actual patient experience and the results of this study suggest specific areas that would benefit from such exploration. A fundamental facet of this research may be the consideration of motivations for sperm banking, testing out the hypothesis within this study, that motivations reflect either a threat to lifecycle or identity, or an active attempt

to manage generalised threat at this time. In addition to this, areas for further research emerging from this study include the impact of sperm banking decisions upon existing relationships, the impact of being unable to produce a sample, the use of defence and coping mechanisms and the role and use of information. Any research investigating men's experiences would benefit from a similar qualitative methodology, in order to access subjective experience.

Whilst providing several points of departure for patient-based research, further investigation into the staff group may be beneficial. The current study suggests a possible conflict between personal and professional beliefs, especially in the referral of men. It would be interesting to explore how professionals manage this conflict within themselves and explore ways in which this conflict can be managed and acknowledged by services. This may benefit from a similar qualitative methodology.

In addition to providing further avenues for research this study would benefit from replication within several different services. This would help ascertain whether the findings are representative and generalisable to other services or reflect participants in this study only.

2.5.5 Critique and Limitations

Whilst providing a valuable contribution to the literature within an under-researched area the limitations of this study should be held in mind.

As with much qualitative research the primary limitation of this study is the small sample size. The small number of participants all worked within the same Acute Teaching

Hospital and were all interested in the research. This raises difficulties in generalising the research outside of this setting, given that the data represented is currently reflective of only one team's perceptions and needs. In addition to this, strict time constraints and a limited pool of participants meant that theoretical saturation might not have been achieved. However, the final two interviews failed to produce any new categories, with existing categories only being slightly altered in order to more accurately reflect the data.

Should the study be replicated in the future several measures could be taken to enhance its reliability. Such measures may include purposive sampling. An example of this being the active recruitment of additional professionals involved in the referral of men in order to examine referrer behaviour further. Given that only one participant was from an ethnic minority this group would also benefit from some direct sampling.

The current study would also be complemented by further research. Interviewing men directly about their experiences would provide a patient perspective to the study. In addition to this it may also be possible to triangulate any data obtained by interviewing family members about their experiences and perspectives regarding the sperm banking process. Given that the results of this study suggest that men from different cultural backgrounds may experience unique difficulties in sperm banking any further research should aim to recruit from multiple cultures in order to examine this further. Finally, considering a longitudinal design may also enhance the study. This would allow men's experiences and reflections to be monitored over a period of time, which may provide insight into how sperm banking is perceived over an extended time-span.

2.6 Conclusion

This study explored staff perceptions of male oncology patient's psychological experiences of sperm cryopreservation. The study also considered the role of staff in the process. Staff were recruited from Centre X, a large regional sperm banking facility, and the referring oncology department. The research utilised a grounded theory methodology and six individual interviews were analysed.

Grounded theory analysis revealed a core category that permeated the process, entitled 'negotiating threat'. Sperm banking was perceived as being undertaken in response to one or more sources of threat. Three main sources were identified: lifecycle, identity and generalised threat. Reasons for sperm banking were therefore understood as being potentially more complex than simply the desire to father children. Threat was also viewed as permeating the sperm banking process itself. A process model was proposed detailing areas, or tasks, for negotiation. Existing attitudes held by those involved in the process were considered as a potential threat, especially those held by referring professionals. The importance of knowing enough about the process was also considered. The difficulties in accessing, using and maintaining supportive relationships in the face of threat were discussed. Finally coping and defence mechanisms were explored as a response to the threat generated by the process.

Clinical implications discussed include the provision of training for staff in both oncology and sperm banking and the examination of patterns of referral. The possibility of introducing a support group for men was also discussed. Several areas for further research were discussed, including direct research with men. Whilst this preliminary study is limited by the small sample size it provides a valuable contribution to the existing literature investigating the complexities of sperm banking for the adult male oncology patient and associated staff.

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3 Part 3: Critical Appraisal

3.1 Introduction

Throughout the research process a diary was kept. This critical appraisal is based upon the diary and reflections upon completion of the research. It is important to be aware that the critical appraisal relates to the entire process of completing this research. Prior to completing the study on staff perceptions the initial aim had been to recruit men and explore their experiences. The critical appraisal thus begins with the initial study attempted and details the change in focus.

3.2 Choice of Topic and Planning

My choice of topic was initially pragmatic. Listening to tutors' and other trainees' horror stories about recruitment difficulties I was determined to try and avoid such problems. I was also keen to embark upon a piece of research that a service desired and would therefore be clinically relevant and not sit on the shelf gathering dust. The staff at Centre X had contacted a tutor to express a desire for some research investigating the psychological effects of sperm banking upon male oncology patients, and were willing to facilitate access to participants. As this coincided with my own needs I decided to pursue this.

3.3 Grounded Theory

As I researched my chosen topic I discovered very little existing literature investigating the psychological aspects of sperm banking for male oncology patients. As my initial literature review took place in late 2002 to early 2003 I did not find the work of

Crawshaw *et al.* (2003) until I revised my literature review in early 2005. There was a dearth of literature in this area and therefore qualitative methodology was appropriate (Charmaz, 1995). I also wanted to focus upon individual lived experience, again making qualitative methodology an appropriate choice (Strauss & Corbin, 1998). Grounded theory was largely a pragmatic choice, as experience, and thus supervision, in Grounded Theory research was stronger within the department than in Interpretative Phenomenological Analysis (Smith *et al.*, 1999) or Discourse Analysis.

Having made a decision to use Grounded Theory I began reading papers on the area. I also began attending a qualitative support group, facilitated by a tutor and attended by my peers. As I began to learn more about Grounded Theory I started to explore different epistemological positions. I was aware that qualitative researchers have a responsibility to make their epistemological position clear in order that research findings can be evaluated (Madill *et al.*, 2000) but found it very difficult to arrive at a position myself.

Prior to commencing the research I arrived at a somewhat tentative critical realist position (Madill *et al.*, 2000). A critical realist asserts that whilst a truth can be discovered there remains an inherent subjectivity in the production of knowledge, and that perception is influenced by individual beliefs and expectations. I rejected the other realist positions, naïve and scientific, as neither stance appeared to acknowledge the impact of subjectivity. The radical constructionist position however, challenges the notion that language can represent reality. I struggled to accept this position and was also aware that Grounded Theory is not normally undertaken from such a position, that Discourse Analysis would then be more appropriate. Madill *et al.* (2000) argue that Grounded Theory is most compatible with realist and contextualist positions, given that the words of participants are analysed rather than the way in which the conversation is constructed. It was interesting to note that as I progressed through the research and began interviews and analysis my

position strengthened as I witnessed the production of knowledge but could also see evidence of subjectivity in the process.

3.4 Difficulties and a Change in Direction

Having obtained ethical and research and development approval I organised a meeting with staff from Centre X, oncology, haematology and urology services. During the meeting professionals were made aware of the research and agreed to help in the recruitment of participants. Staff appeared interested and motivated to help and assured me that they foresaw no difficulties in recruitment. It was somewhat of a surprise that 4 months later I still had no participants. I continued to liaise with services who ensured me that they were doing all they could but that there had been a drop in the number of men being diagnosed with cancer and sperm banking. This was initially attributed to the onset of Christmas and New Year when men may not go to their G.P with problems. However, as time wore on things began to look bleak. A couple of men expressed interest and I was about to leave to interview one man when I received a call to say that his car had broken down and he was therefore not attending the Centre. Given the strict deadline I was working to it was decided that the research needed to change direction. Having discovered Crawshaw *et al.*'s (2003) paper investigating the views of staff working within a paediatric sperm banking facility it was decided that it would be valuable to examine the experiences and perceptions of staff working within adult services. After discussion with my academic supervisor, the Chief Investigator and staff at Centre X I began to amend the study.

This required notifying the ethics panel of a substantial amendment, which they took a full month to approve. Thankfully the research and development department did not require the amended study to be peer reviewed.

3.5 Recruitment of Participants and Interviewing

I finally began interviewing in April 2005. Recruitment of participants was relatively easy, I believe that some staff felt responsible for being unable to recruit men and were thus anxious to 'make up' for this. However, given that one member of staff I was keen to interview had been named as the original Chief Investigator I had to again approach ethics for permission to include her in the study. Interviewing for research purposes was very different from undertaking a clinical interview within a therapeutic environment and this took a while to adapt to. I was aware as I became more interested in the results of the study that I fell into the trap of asking more closed questions than I would have liked, and it was important to be aware of this tendency.

3.6 Analysing the Data

I opted to transcribe my own interviews, believing that it would help in becoming immersed in the data. Although transcribing the interviews was a lengthy process I believe that I gained from doing so as by listening to the words of participants several times over I was able to hold quotes in my head quite easily. I began open coding of the first transcript with a combination of trepidation and excitement. I was keen to start but also doubted my ability to do so. As may be expected when learning any new skill I became both more confident and competent the more transcripts I analysed.

I experimented with several ways of recording a paper trail, and eventually developed a file card system for each emerging category with a list of focus codes, stored upon the computer, attached to each. During the analysis I also kept a notebook in which I made

notes about emerging ideas and memos. The memos were extremely helpful when it came to writing up the research. It was interesting after having developed a model to see how significantly it differed from my early ideas. My early ideas were far more structured and procedural and I believe reflected my anxiety about undertaking grounded theory. Speaking with colleagues it became apparent that most people endured a period of severe anxiety, with feelings of being lost and stuck. I now believe that my overly structured ideas were in response to these feelings and that actually feelings of being lost and overwhelmed by the data are perfectly natural and may be a necessary part of the process.

The development of the core category and the process model was gradual, unlike other colleagues I did not have a 'eureka' moment, it seemed that everything slowly slotted into place. On completing the results section I noted with interest how the core category overlapped with my theoretical area of interest, personal construct theory. I was therefore anxious to establish that this had emerged from the data and not solely from my own interest. Looking back through the memos and notes, and by talking with colleagues I became convinced that it had emerged from the data but I recognise that as a researcher I am always going to bring some of my own interests to bear upon the results.

3.7 Theoretical Saturation

Theoretical saturation refers to the point at which the data fails to produce any significant new material (Strauss & Corbin, 1998). The initial interview analysed (P3) generated 22 categories, the fifth interview analysed failed to produce any new categories. One existing category was modified on the basis of the final interview analysed (P6). Due to a limited pool of participants and severe time constraints I was unable to recruit a further

participant as desired. The research reflects initial provisional findings, derived from careful and thorough analysis of the collected data.

3.8 Enhancing Quality

As discussed in section 2.2.9 many guidelines exist to enhance rigour and validity in qualitative research (Barbour, 2001; Elliot *et al.*, 1999; Merrick, 1999; Silverman, 2000).

I attempted to increase the rigour of my research by following such guidelines where possible and the steps I took are detailed in section 2.2.9. Respondent validation is often used in grounded theory to further increase validity. I considered seeking respondent validation but decided against doing so for a number of reasons. Seeking respondent validation would have placed further demands on participants' time and I was reluctant to do this (Barbour, 2001). I was also aware that in seeking respondent validation many individual and discrepant accounts may emerge, conflicting with the aim of analysis in providing an overview of the data (Mays & Pope, 2000).

3.9 Write-Up

The writing up of the thesis was a mixed experience. At times it was empowering and at other times frustrating when feeling unable to express my thoughts intelligibly on paper. Having moved away from the data at the end of the analysis towards a more conceptual and abstract level I felt the need to re-engage with the raw data when writing up the results.

Additional challenges included the change in thesis format that was introduced by the course. My cohort was the first to undertake this new format and the transition was difficult. Given that previous years had used the old style there were few examples from

which to draw upon. In addition there appeared to be, at times, confusion amongst the staff regarding the new format and this sometimes resulted in mixed and unclear messages being communicated in terms of structure and format. The lack of clarity around the new format heightened ever-present anxiety. Having recently completed the main body of the write-up I now believe the changes to be beneficial. I believe publishing work will be made easier and I believe that the stricter structure, and word count serves to improve my own writing style.

3.10 Supervision

Having accepted a clinical placement in London it was necessary to organise supervision meetings in advance. My supervisor also appeared sensitive to my geographical isolation and made herself available via telephone and email. I was able to attend a qualitative support group, consisting of peers and an experienced grounded theory researcher.

During the initial problems with ethics and research and development I found it frustrating not to have a field supervisor who was familiar with trust policy and who could have also assumed the role of Chief Investigator. I believe this would have significantly reduced both the amount of time spent trying to submit the project and my own feelings of anxiety and lack of control.

3.11 Motivation

My motivation throughout the research process is probably best compared to a roller coaster. At times my motivation was high, especially when I finally received ethical approval (in both instances!) and whilst conducting interviews. I generally left each interview feeling excited about the discussion and eager to begin transcription. My

motivation took a serious nosedive during January, February, and March 2005 when I was unable to recruit any men and needed to change studies. At this point I feared that the study would be meaningless and it was not until I began interviewing participants that I realised this fear was unfounded. During the write-up my motivation again wavered. Whilst enjoying clinical work it was frustrating at times, especially when clients did not attend appointments, to be away from my desk and the write-up. However, at times I also felt resentful towards the research as I spent weekend after weekend at my desk whilst friends were out enjoying the good weather.

3.12 Professional Development

In undertaking this research I believed I have developed my abilities in a number of different areas. My confidence to undertake research has increased and I believe I would now feel more competent in any other research I undertake. I have specifically gained knowledge and experience in Grounded Theory approaches and should I use the approach again I would do so feeling more confident and less daunted and anxious. By experiencing the whole research process I have become aware of several potential pitfalls that I would try and plan for in the future. My experience of obtaining ethics and R&D approval was traumatic, and I now appreciate how long the process can take. The importance of early submission and a working knowledge of the Trust appear to be hugely beneficial. The difficulties I had in obtaining a sample had not been anticipated and although the service desired me to wait longer due to a pressing deadline I was unable to and needed to change my approach. This tension, between the needs of the service and the requirements of the course, helped me recognise the needs and demands of multiple stakeholders. It also highlighted the difficulty of completing research in a limited, and relatively short, period of time.

Prior to undertaking the research I had very little knowledge of male cancer, male infertility and assisted conception. My knowledge in all of these areas has grown and I was amazed that when one participant based in oncology asked me for information about sperm banking procedures that I was able to supply the answer. Working closely with Centre X staff has enabled me to obtain an accurate picture of sperm banking facilities and several myths have been dispelled. I now believe that I appreciate the complexity associated with working within a reproductive medicine unit. Working with staff in an acute teaching hospital was extremely beneficial. I was surprised at how willing staff were to make time to talk with me and discuss psychological aspects of their work.

At several points during the research I felt discouraged, concerned that my study was going to be meaningless. I am now pleased with study, and believe that the results offer some interesting points of discussion and stimulate further research opportunities. Whilst acknowledging the limitations of the study, such as a small sample size, I believe that it makes a valuable contribution to the emerging literature in this neglected area.

3.13 References for Critical Appraisal

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Smith, J.A., Jarman, M. & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds). *Qualitative Health Psychology: Theories and methods*. London: Sage.

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4 Appendices

4.1 Appendix 1 – Initial Ethical Approval



26 October 2004

Miss
Leicestershire Partnership NHS Trust/
University of Leicester
Clinical Psychologist in Training
Clinical Psychology, University Of Leicester
104, Regent Road,
Leicester
LE1 7LT

Dear Miss

***Full title of study: The psychological experiences of men sperm banking, prior to undergoing fertility threatening treatment for cancer.
REC reference number: 04/Q2802/48
Protocol number: One***

Thank you for your letter of 15 October 2004, responding to the Committee's request for further information on the above research.

The Chairman has considered the further information on behalf of the Committee.

Confirmation of ethical opinion

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

The favourable opinion applies to the following research site:

Site:
Principal Investigator: Miss Kerry Howcroft

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully. If any of the content of this submission is subsequently changed to suit further R&D requirements then you are required to submit an amendment to protocol form to this Research Ethics Committee for final approval.

Approved documents

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

Document Type: Application
Version: Version 3
Dated: 11/10/2004
Date Received: 21/10/2004

Document Type: Investigator CV
Version:
Dated:
Date Received: 16/09/2004

Document Type: Investigator CV
Version: One
Dated: 29/06/2004
Date Received: 29/06/2004

Document Type: Protocol
Version: One
Dated: 17/04/2004
Date Received: 29/06/2004

Document Type: Covering Letter
Version: Clarification
Dated:
Date Received: 16/09/2004

Document Type: Copy of Questionnaire
Version: Version 2
Dated: 10/08/2004
Date Received: 16/09/2004

Document Type: GP/Consultant Information Sheets
Version: One
Dated: 17/04/2004
Date Received: 29/06/2004

Document Type: Participant Information Sheet
Version: Version 2
Dated: 10/08/2004
Date Received: 16/09/2004

Document Type: Participant Consent Form
Version: Version 2
Dated: 10/08/2004
Date Received: 16/09/2004

Document Type: Response to Request for Further Information
Version: Covering letter
Dated: 15/10/2004
Date Received: 21/10/2004

Document Type: Response to Request for Further Information
Version:
Dated:
Date Received: 20/09/2004

Document Type: Other
Version:
Dated: 23/06/2004
Date Received: 29/06/2004

Document Type: Other
Version: One
Dated: 29/06/2004
Date Received: 29/06/2004

Management approval

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant host organisation before commencing any research procedures. Where a substantive contract is not held with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Notification of other bodies

We shall notify the research sponsor,
that the study has a favourable ethical opinion.

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: 04/Q2802/48 Please quote this number on all correspondence

Yours sincerely,

Mrs Christine C Wright
Chairman

Enclosure *Standard approval conditions SL-AC2*
CC

4.2 Appendix 2 – Final Ethical Approval

SL32 Favourable opinion of amendment
Version 2, October 2004



06 April 2005

Dear Miss

04/Q2802/48 – Please quote this reference number in all communications

Investigating the Psychological Experiences of Men Banking Sperm, Prior to Fertility Threatening Cancer Treatment.

Amendment number: 3
Amendment date: 28 February 2005

The above amendment has been reviewed by the Executive Sub-Committee.

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:

Participant Information Sheet version 4 dated 05/04/2005.
Consent Form version 4 dated 05/04/2005.
Covering letter dated 28 February 2005.
Protocol including flow chart version 3 dated 22/02/2005
Notice of Substantial Amendment No 3 dated 22/02/2005
Staff Interview Schedule version 1 dated 22/02/2005

Membership of the Committee

The members of the Executive Sub-Committee who reviewed this amendment were:

Management approval

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

Statement of compliance

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.

04/Q2802/48

Please quote this number on all correspondence

Yours sincerely,

Committee Administrator

4.3 Appendix 3 – Participant Information Sheet

Note: This Patient Information Sheet was produced on letter headed paper, but for reasons of anonymity it has been reproduced on plain paper for this appendix.

Participant Information Sheet - Version: 4, Date: 05.04.2005

Staff Perceptions of the Psychological Experiences of Men Storing Sperm Prior to Undergoing Treatment for Cancer

You are being invited to take part in a research study. Before you decide whether you wish to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like to take part. Thank you for reading this.

What is the purpose of the study?

The study is investigating staff perceptions and beliefs about the psychosocial needs and experiences of men who are banking sperm before starting treatment for cancer. Very little is known about any psychosocial needs and experiences men may encounter during the sperm banking process. It is hoped that this research will help to begin to understand the possible experiences and needs men may have during the process and how well staff feel that these needs are currently being met. It is also hoped that the research will identify areas for further study and possible service improvement.

Why have I been chosen?

You have been asked to take part in the study as you are a professional involved in either offering, discussing or providing sperm banking facilities for men who are about to undertake fertility threatening treatment for cancer. It is therefore believed that you will have developed some beliefs around this area based upon your clinical experience.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw your consent at anytime and without giving a reason. A decision to withdraw at anytime, or not to take part, will not affect the conditions of your employment.

What will happen if I decide to take part?

If you decide to take part you will be asked about your perceptions and beliefs about the psychosocial needs and experiences of men who are banking sperm. This will be in the form of a one interview lasting approximately 45-60 minutes. The interview can take place in a location of your choosing, however a room is available for use at [Centre X]. The data will be analysed using a research method called Grounded Theory. Due to the nature of this method the researcher may contact you again to ask your opinion on emerging themes and concepts that arise as a result of the interviews. The reason for this is to validate the research by asking participants to comment on the interpretations that the researcher makes. If this does occur, the researcher will contact you during working hours.

Will taking part in this study be confidential?

We will ask for your permission to record the interview on audio tapes. These tapes will only be used by members of the research team for the purpose of this study. Copies will not be made and the tapes will be destroyed after they have been transcribed. Anonymous transcripts will be kept for 15 years in accordance with General Medical Council guidelines. Recording will be stopped immediately if requested.

We will comply with the Data Protection Act (1998). All identifying information will be removed from transcripts and you will be given an alternative identifier (e.g. a number). All data will be stored in a locked cupboard and any information on computers will be password protected. The only people to have access to this data will be the core research team, including individuals from xxxxx and the University of Leicester. xxxxx, Principle Investigator, is the designated owner of the data and is as such responsible for data storage and access.

What if I am harmed by the study?

If you are harmed by taking part in this study, there are no special compensation arrangements. If you are harmed due to someone's negligence then you may have grounds for legal action, but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study the normal NHS complaints mechanism is available to you.

How do I make a complaint?

If you wish to make a complaint this can be done by putting your concerns in writing and sending it to the Trust Complaints Department.

What will happen to the results of the research study?

The results of the study will be written up both for the purposes of doctoral research (Doctorate in Clinical Psychology, University of Leicester) and will also be submitted for publication to the Journal of Health Psychology. Your identity will be completely

anonymised. You will *not* be identifiable from any publication and you will be informed when the study is published.

Who is organising and funding the research?

The research forms part of the investigator's Doctorate in Clinical Psychology. The University of Leicester and Leicestershire Partnership NHS Trust will be funding the research costs. The research is sponsored (organised) by xxxxx.

Who has approved the study?

The study has been approved by xxxxx Ethics Research Committee.

How can I learn more?

By contacting xxxxx. My address is: xxxxx

Please leave a message for me and I will return your call as soon as possible.

4.4 Appendix 4 – Consent Form

Note: This was produced on letter headed paper, but for reasons of anonymity it has been reproduced on plain paper for this appendix

Consent Form

Version: 4, Date: 05.04.2005

Title of Project: Staff Perceptions of the Psychological Experiences of Men Storing Sperm Prior to Undergoing Treatment for Cancer

Name of Researcher: xxxxxxxxxxxx

**Please
Initial Box**

- | | | |
|----|---|--------------------------|
| 1. | I confirm that I have read and understand the Information sheet dated 05.04.2005 (version 4) for the above study and have had the opportunity to ask questions. | <input type="checkbox"/> |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, without my employment rights being affected. | <input type="checkbox"/> |
| 3. | I understand that psychological research is covered for mishaps in same way as other treatment within the NHS i.e. compensation is only available if negligence occurs. | <input type="checkbox"/> |
| 4. | I understand that all identifying information will be anonymised and my name will not be used in reports or held on computer. I understand that interviews will be audio taped and these tapes destroyed when the interview has been transcribed. I am aware that anonymous transcripts will be kept for 15 years in accordance with General Medical Council guidelines | <input type="checkbox"/> |
| 5. | I agree to take part in the above study | <input type="checkbox"/> |

Name of Participant	Date	Signature
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Name of Person taking consent	Date	Signature
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Name of Researcher	Date	Signature
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4.5 Appendix 5 – Interview Schedule

Original Interview Schedule

Interview Schedule: Staff perceptions on patient’s experiences of sperm banking prior to fertility threatening treatment for cancer

a. Referral and Subsequent Discussions

1. Who do you believe receives the invitation to bank sperm before commencing treatment?
Prompt: Do you believe it is offered to all men? What criteria or beliefs do you think may influence who receives a referral?
2. Can you tell me who first discusses sperm banking with men? How do you feel men respond to this conversation?
Prompt: some men may feel relieved that they can protect their fertility, but other men may find it shocking and distressing, do you believe they understand what is said?
3. What are your thoughts on how easy or difficult men find the decision about whether to bank or not?
4. Can you tell me some of the reasons you believe men may decide to bank their sperm?
Prompt: for some men it’s about preserving their fertility and the chance to father children, for others it’s about preserving masculinity.

b. The Sperm Banking Process

5. What are your views on sperm banking?
6. How do you believe men might feel on their first visit to CRM?
Prompt: nervous, hopeful, unsure
7. What do you believe are the main challenges facing staff when talking to men about sperm banking? And how are these managed?
Prompt: e.g. in the event of their death...
8. Do you believe that there may be, or have observed any, things that have helped or hindered men prior to producing a sample to store?
Prompt: the challenges, physical, emotional, mental or cultural.
9. How do you think men might prepare themselves for the experience?
10. How much do you think men find it helpful to talk with staff during this time, do you feel able to talk to men about the process?
Prompt: e.g. embarrassment
11. I was wondering what you believe men’s overall experiences of the sperm banking process may be?
Prompt: some men find the experience positive and uplifting at an otherwise negative time, however some men find it a distressing and negative experience.

c. Psychological State

12. Which thoughts or feelings do you believe may change after men have banked sperm? How do you think their outlook on life may have changed, if at all?
Prompt: Some men feel that they now have something to live for, for other men it doesn't really affect their view of the cancer. Consider the self/disease/relationships
13. How do you feel that being able to store their sperm affects men's emotions & moods?
Prompt: some men find it lifted their mood at an otherwise depressing time, and provided hope for the future.
14. Where do you believe men obtain support from during the process?
Prompt: family, friends, professionals, self.
15. How aware are you of the psychosocial needs of men at this time? And do you feel able to meet these needs?

d. Any Suggestions

16. How do you feel that the service could be enhanced to further meet men's psychological needs?
17. How well do you think that staff manage the challenges that arise from working with this particular patient group, now, and in the future when they may return to seek fertility assistance?

4.6 Appendix 6 – Revised Interview Schedule

Interview Schedule with Areas for Exploration after 2 Interviews

Interview Schedule: Staff perceptions on patient's experiences of sperm banking prior to fertility threatening treatment for cancer

a. Prior to attending CRM

1. Can you tell me a little bit about the characteristics of the men who are referred to CRM to bank sperm?

To cover: Consultant assumptions
 Value judgments

2. How do you believe men might react to the invitation to bank sperm?

To cover: Impact of life stage on response

3. What thoughts do you have on the decision making process men engage in, in order to make this decision?

To cover: *easy/difficult*
 Impact of life cycle
 Impact of family
 Whose decision is it anyway?
 Avoidance/delegation of decisions
 Who is talked to?
 Patterns of disclosure-what is this about?

4. Could you tell me some of the reasons you believe men opt to bank their sperm?

To cover: *insurance policy – do men believe they will need to use it-unrealistic optimism*
 Future
 Free
 What impacts on the reason they have-e.g. prognosis
 Family pressure to do it

b. The Sperm Banking Process

5. How do you believe men might feel on their first visit to CRM?

To cover: *apprehensive*
 Unfamiliarity
 Embarrassment

6. Do you believe that there may be, or have observed any, things that have helped or hindered men prior to producing a sample to store?

To cover:

- role of family*
- Role of partner*
- Anxiety*
- Geographical location/room*
- Uncertainty*
- Meaning of masturbation*
- Physical*
- Cultural*
- Level of investment in family*

7. How do you think men might prepare themselves for the experience?

To cover:

- informal & unintentional preparation through conversation*
- Preparing & coping through the active acquisition of knowledge*

8. How much do you think men find it helpful to talk with staff during this time, how much do they value conversation?

To cover: Perceived appropriateness of support & congruence with primary concern

- Discussion of active issues only not future issues*
- Discussion with partners etc.*
- Discussion with staff as an extension of being prepared & coping, an enduring coping mechanism?*
- The difficulty of the language – e.g. sperm*
- Gender bias*

9. What do you believe are the main challenges facing staff when talking to men about sperm banking? And how are these managed?

To cover:

- In event of death...*
- The use of humour & normalisation*
- The difficulties associated with words e.g. cancer*

10. I was wondering what you believe men's overall experiences of the sperm banking process may be?

To cover:

- Positive by the end*
- Relief*
- Views alter as process proceeds*
- As an act of necessity*

c. Psychological State

11. Which thoughts or feelings do you believe may change after men have banked sperm? How do you think their outlook on life may have changed, if at all?

*To cover: Outlook and effect on relationship
More optimistic, feel there may be a future
Forcing life issues
Tensions in family*

12. How do you feel that being able to store their sperm affects men's emotions & moods?

To cover: Positive experience despite initial being anxiety producing

13. Where do you believe men obtain support from during the process?

*To cover: family as a source of support & stress
Relationships
Staff & appropriateness of staff
Self
Attributions made about reason for support
Disclosure to family – explore it.
Gender biases?*

14. How aware are you of the psychosocial needs of men at this time? And do you feel able to meet these needs?

*To cover: Staff training
Are men aware of needs?*

15. How do you think staff manage the challenges of working with this client group, working with people that may be very ill or dying?

To cover: Staff support both technical & emotional

d) Service Development

16. How do you feel that the service could be enhanced to further meet men's psychological needs?

4.7 Appendix 7 – Example of Coding

Box 1 Example of Coding

Focused Coding		Line Coding
<p>198-206 Diverse attitudes towards SB</p> <p>198-200 For some decisive decision</p> <p>200-202 A group that find sperm banking a taboo subject</p> <p>205-206 Use of jokes, laughter & innuendo to disguise embarrassment in both staff & pts.</p>	<p>I think there may be people who want to do the sperm banking and that's it they're going to do it/, they feel they've had enough information and they are going to go off and do it/. I think there are others were it's a bit of a taboo subject/, erm, they're embarrassed to talk about it so they don't bring it up, so the/, and the other thing that I would say is that there another group/ who it's all a bit of a laugh, you know,/ there's kind of innuendos perhaps made between the staff and the/, 'oh I know where you're going, you're off over the way aren't you' /and there's kind of a sort of, kind of like, what am I trying to say, a joke about it, a bit of a laugh/, maybe to cover up embarrassment again on behalf of both possibly/.</p>	<p>198 those who want to do it do.</p> <p>199 provide enough information</p> <p>200 for some SB is a taboo subject <i>201 hypothesised feelings of embarrassment-can't talk about it</i></p> <p>202 alternative experiences</p> <p>202 a bit of a laugh 203 shared innuendo between staff & pts</p> <p>204 provides e.g.</p> <p>205 make jokes & laugh</p> <p>205-6 Jokes & laughs possibly cover up embarrassment for both staff & pts.</p>

4.8 Appendix 8 – Record of Category Development

Box 2 Extract from record of category development

1st Transcript Analysed (P3)

Disclosure is influenced by attitudes of self & others
Attitudes of consultants may influence referrals
All involved are vulnerable-parents, grandparents.
Acquisition of info vs. avoidance of info
Attitudes may generate anxiety
Act of genetic survival
Private things become public
Defence mechanisms to stay intact and disguise powerlessness
Language can help or hinder
Loss of biological manhood
Preserving a part of the self
A process of creating an 'insurance policy'
Difficulty in negotiating & providing support
Men are do-ers not talkers
Sperm banking helps envisage a future
Cancer & infertility threaten natural order
Infertility irreversible
Sperm banking can disrupt relationships
Resonance with staff's own lifecycle
Need for greater communication & knowledge between departments
Impact of life stage on decisions
Staff value peer support

2nd Transcript Analysed (P1)

Passivity in decision making
Uncertainty of source of support
Staff have difficulty in using words
Unfamiliar on first visit
Unable to absorb information.

4th Transcript Analysed

Assumptions made re. age & prognosis
SB as a taboo subject
Embarrassment associated with genital/sexual areas.
Difficult to suspend one's own beliefs
Health care professionals lack of knowledge

6th Transcript Analysed – No new categories, 1 changed.

Lack of knowledge changes to 'knowing enough'

4.9 Appendix 9 – Memo Example

Box 3 An extract from a developing memo

Knowledge about the Process

‘This area encompasses information, knowledge, and learning about the sperm banking process. This area appears to relate to both staff and men. Included in the area are patient’s knowledge about the process and their associated information seeking behaviours and how participants (staff) opt to understand and make sense of them. Participants witnessed men engaging in several different information-seeking behaviours. Men’s behaviour was viewed on a spectrum. For some men actively enquiring information about the process may help in creating a sense of control and empowerment, however, for others avoiding information may be a way of maintaining a distance from it. The difference is partly understood to be a reflection of enduring coping traits. Also included within this area is staff knowledge about not only the sperm banking process but also the diagnostic procedures for cancer. This includes the factual information participants feel is necessary to have in order to share with patients. An absence of knowledge is seen as having a detrimental effect on the patient, threatening their progression through the sperm banking process. Although it may be that participants need to ‘know enough’ in order to help men make the journey to the centre where the expertise is based. Lack of knowledge is partly attributed and intertwined with feelings of embarrassment and of sperm banking being a taboo subject...’