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**The Emotional and Interpersonal Aspects of Fertility Damage and/or
Premature Menopause from Cancer Treatments**

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**A thesis submitted in fulfilment of the requirements for the degree of
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ABSTRACT

This research constitutes the first New Zealand study to explore the emotional and interpersonal aspects of fertility damage and/or premature menopause from cancer treatments. Using a qualitative approach, the study provides an in-depth exploration and interpretation of how seventeen women, with varied cancer diagnoses, experienced these ongoing and life-changing effects of their cancer treatments, using the theory of chronic sorrow as the conceptual framework. This method enabled a deeper understanding than could be attained using a different approach. The theory of chronic sorrow provided an opportunity to recognize and explore aspects of these women's experiences that have not been explored previously in this group of cancer survivors. Data for the study were collected through semi-structured interviews with 17 New Zealand women. The data were analysed using general inductive analysis techniques.

For fourteen of the seventeen participants, the cancer diagnosis and treatment resulted in often significant disruptions to their lives, identities and intimate relationships, in response to which they struggled, to varying degrees, with ongoing emotional distress. In addition, the findings showed a notable increase in distress associated with engagement with processes such as fertility preservation, assisted reproductive technologies, adoption and surrogacy. The remaining three participants, however, described positive responses and personal growth, suggesting the possibility of such responses for other people in similar situations.

Further to this, health professionals did not adequately provide, allow or encourage discussions about issues related to fertility and premature menopause, which contributed to the difficulties and distress described by some participants. While the distress described in this study can be interpreted as a normal and understandable response to the losses and life disruptions these participants had experienced, this does not suggest that the amelioration of this distress should not be attended to by health professionals through appropriate screening, diagnostic and intervention activities. Despite the suggestion that the participants were objectively cancer-free, physically well and functioning normally, many continued to suffer considerably in the aftermath of cancer and its treatment.

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Dad, this is for you. I wish you were here to read it.

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CHAPTER ONE: INTRODUCTION

INTRODUCTION

The aim of this qualitative study was to ascertain and articulate the emotional and interpersonal aspects of fertility damage and/or premature menopause from cancer treatments, using the theory of chronic sorrow as the conceptual framework. This study was motivated by concerns raised by many patients throughout my clinical nursing career in oncology and palliative care. In the course of my clinical practice, a wide variety of patients and their partners expressed concern, distress or confusion related to the impact of cancer and its treatments on their fertility and sexuality. These concerns transcended gender, age, diagnosis, prognosis, sexual orientation, relationship and family status, ethnicity, and socio-economic situation. The level and extent of the distress these people described was frequently high, and the resulting suffering they experienced contributed significantly to the burden of cancer for themselves and their loved ones. This study offers the opportunity to gain a deeper understanding of these fundamentally challenging long-term effects of cancer and its treatment in response to the research question, ‘What are the emotional and interpersonal aspects of fertility damage and/or premature menopause from cancer treatments?’

This chapter describes the background and clinical context within which fertility damage and/or premature menopause from cancer treatments occur. This will be followed by a description of the structure of the thesis.

BACKGROUND

From the time of diagnosis until death people with cancer are now described as cancer survivors (Doyle, 2008; Dunn & Steginga, 2000; Marlow, Cartmill, Cieplucha, & Lowrie, 2003; S. Olshansky, 1962; Teel, 1991; Thewes, Butow, Girgis, & Pendlebury, 2004), and almost two-thirds of those diagnosed with invasive cancer will be alive five years from the time of diagnosis (Alfano & Rowland, 2006; Ganz, 2001; New Zealand Health Information Service, 2006, 2006a). This progressive increase in the number of patients surviving a diagnosis of cancer and its treatment can be attributed to more effective and less toxic treatments, earlier diagnoses, and better supportive care (Cancer Control Taskforce, 2005; M. E. Hewitt, Bamundo, Day, & Harvey, 2007).

As this number increases and the duration of survivorship extends, more attention from both the clinical and academic arenas is crucial. The quality of life enjoyed or endured by these survivors is increasingly and appropriately seen as a key outcome of cancer treatments. It is therefore vital that research into issues pertinent to people with cancer extends to the survivorship phase of the cancer continuum. As well as having a focus internationally (Centres for Disease Control & Lance Armstrong Foundation, 2004; Department of Health, MacMillan Cancer Support, & National Health Service Improvement, 2010; National Breast Cancer Centre and National Cancer Control Initiative, 2003; National Institute for Clinical Excellence, 2004), this concern has been expressed in New Zealand health policy in the Cancer Control Strategy and Action Plan (Cancer Control Taskforce, 2003, 2005), a principal purpose of which is to “reduce the incidence and impact of cancer” (2005, p.1).

Fertility damage and premature menopause from cancer treatments occur most commonly as a result of irreversible ovarian damage. There are differing estimates of the risk of permanent ovarian damage for pre-menopausal women undergoing cancer treatments, ranging from 20-80% (Gerber, Dieterich, Muller, & Reimer, 2008; S. J. Lee et al., 2006). Ovarian damage can result from all of the main treatments currently used in cancer care – surgery, chemotherapy, radiotherapy and bone marrow or stem cell transplantation.

Anecdotal evidence from my own clinical practice and that of other oncology nurses suggests that fertility and menopause issues are an important consideration for pre-menopausal women diagnosed with cancer, that the emotional impact of fertility damage and/or premature menopause may be considerable for some, and that these often go unreported and therefore unacknowledged. Accordingly, research into the emotional impact of cancer treatment-induced fertility damage and premature menopause is highly recommended (J. Carter et al., 2005; Duffy, Allen, & Clark, 2005; Partridge et al., 2004; Schover, 2005; Wenzel et al., 2005).

The following section describes the clinical context in which fertility damage and premature menopause from cancer treatments occur. This will include information related to the physiological basis of their occurrence, the current provision of fertility preservation measures and the physiological effects of premature menopause.

THE CLINICAL CONTEXT

The clinical term ‘premature (or acute) ovarian failure’ is generally used to describe the physiological process leading to fertility damage and premature menopause from chemotherapy and radiation therapy, and is therefore used in this discussion of the clinical context.

Cancer Treatments

Surgery

For pre-menopausal women diagnosed with gynaecologic and some other pelvic cancers, surgery has typically resulted in immediate and permanent loss of their reproductive potential, and often an abrupt transition to menopause. However, with greater understanding of both female fertility and cancer, increasingly specialized surgical techniques, and significant advances in measures to preserve female fertility, reproductive outcomes for many pre-menopausal women with a diagnosis of gynaecological cancer are improving (J. Carter et al., 2005; Rodriguez-Macias Wallberg, Keros, & Hovatta, 2009).

Chemotherapy

Due to the limited number, irreplaceable nature and decreasing quality of oocytes over time, rates of successful conception and pregnancy diminish rapidly from the age of 30 even without cancer treatments (Simon, Lee, Partridge, & Runowicz, 2005). Menopause is both the marker and the result of this reduction. Accordingly, the risk of premature ovarian failure from chemotherapy increases rapidly from the approximate age of 30

years. Although younger pre-menopausal women may continue to menstruate throughout treatment or resume menstruating after completion of treatment, it is highly likely that damage to the ovarian reserve will result in premature menopause (Partridge et al., 2007; Stroud et al., 2009).

Premature ovarian failure from chemotherapy is related to the chemotherapy agent, the dose and duration of the treatment, and the age of the woman at the time of the treatment. Women younger than 30-35 years of age are able to tolerate higher cumulative doses of gonado-toxic agents than older pre-menopausal women. The agents most frequently associated with premature ovarian failure are the alkylating agents, the most common of these being Cyclophosphamide. The use of combinations of different agents in 'regimes' may increase the potential for damage (Maltaris et al., 2007).

To put this risk into perspective, the majority of pre-menopausal women diagnosed with breast cancer receive chemotherapy to reduce their risk of cancer recurrence (Camp-Sorrell, 2009). One of the most common chemotherapy regimes used in this population is 'AC' (Adriamycin and Cyclophosphamide) with, or without, the addition of one of the newer Taxane agents. In a recent study, the risk of amenorrhea (indicating at least short-term ovarian damage) in women younger than 40 years with AC alone was 55%, and this rose to 64% with the addition of a Taxane. For women older than 40 years, the rate of amenorrhea with AC alone was 82%. Forty percent of younger women resumed menstruating within the months after treatment, but this was far less common in women aged older than 40 years (Tham et al., 2007). It is important to note, as mentioned above,

that resumption of menstruation does not imply the absence of ovarian damage (Partridge et al., 2007; Schover, 2008).

Radiation Therapy

The potential for premature ovarian failure from radiation treatment is related to the anatomical area being treated, the total dose of radiation given, and the age of the woman at the time of treatment. Women receiving external beam radiation treatment to an area including, or close to, the ovaries are at high risk of permanent ovarian failure (S. J. Lee et al., 2006; Rodriguez-Macias Wallberg et al., 2009). Women aged less than 40 years may develop premature ovarian failure at a total dose of 10-20 Gy, and this may occur at a total dose of just 6 Gy in women aged greater than 40 years (Maltaris et al., 2007; Salooja et al., 2001; Sklar, 2005).

In addition, radiation therapy to the brain can result in changes to fertility through disturbance to the hypothalamic-pituitary axis that acts as a feedback system for reproductive hormones. Further, pelvic radiation therapy can cause damage to uterine tissues which markedly increases the risk of miscarriage, intra-uterine growth retardation, and premature birth in subsequent pregnancies (Maltaris et al., 2007).

Bone Marrow/Stem Cell Transplantation

Bone marrow and stem cell transplantation are relatively recent developments in potentially curative cancer care. There are two phases to transplantation, with the initial destruction of the existing blood cells, using either high doses of chemotherapy or radiation therapy (conditioning), being followed by the infusion of the new stem cells or

bone marrow (transplantation). It is the conditioning phase of the transplant that can result in premature ovarian failure (M. Davis, 2006; Salooja et al., 2001).

Endocrine Therapy

The most common use of endocrine therapies in the treatment of cancer in women is in the management, and in some cases prevention, of estrogen-responsive breast cancers (Love & Lindsay, 2000). Endocrine therapies do not induce permanent menopause but women taking these must actively prevent pregnancy during the course of the therapy. These five or more years of pregnancy prevention may affect fertility due to the increase in the woman's age that occurs over this time (Partridge et al., 2004; Thewes, Meiser, Rickard, & Friedlander, 2003).

Fertility Preservation

There are a number of potentially useful fertility preservation techniques currently in use or under investigation, although there is great variability in both rates of success from, and access to, these services.

Embryo Cryopreservation

This is considered to be an established fertility preservation technique. Oocytes are harvested following ovarian stimulation with follicle-stimulating hormone. Ovarian stimulation commences on the first day of menstruation and continues for two weeks. Oocytes are then fertilised in vitro and the resulting embryos are cryopreserved until required. This requires the presence of a fertile and willing partner, or sperm donor, at the time of treatment.

Due to the two week ovarian stimulation period, delays in the commencement of cancer treatment are common with this technique. Oocytes can be harvested without ovarian stimulation but the number of resulting viable embryos is low. Agents such as Tamoxifen and Letrozole have been used with traditional ovarian stimulation to theoretically reduce the level of circulating estrogen for women with hormone-sensitive tumours, but there is not yet sufficient research to fully establish the safety of this. The success of embryo cryopreservation is influenced by the age of the mother and the number of embryos that were successfully cryopreserved (S. J. Lee et al., 2006; West et al., 2009).

Embryo cryopreservation is currently available in New Zealand as part of routine clinical practice. Government funding may be available depending on each District Health Board's funding criteria.

Oocyte Cryopreservation

The process of oocyte harvesting for oocyte cryopreservation is identical to that described above, with the same associated risks and considerations. The primary benefit of oocyte cryopreservation is the lack of a requirement for a partner or sperm donor at the time of treatment. A recently published study reported in excess of 900 live births worldwide, with no statistical indication of an increase in congenital anomalies (Noyes, Porcu, & Borini, 2009).

A new technique under investigation involves harvesting immature oocytes, and has the benefit of requiring neither the time nor ovarian stimulation required for the usual

harvesting of mature oocytes. Unfortunately, unfertilised oocytes are more prone to damage during the cryopreservation and subsequent thawing process, which reduces the success of this technique (S. J. Lee et al., 2006; West et al., 2009). An alternative procedure currently being investigated is the in vitro maturation of ovarian follicles prior to in vitro fertilisation and re-implantation (West et al., 2009).

Oocyte cryopreservation is available in New Zealand in some centres, but remains an experimental procedure and is not government funded.

Ovarian Tissue Cryopreservation

This technique is currently considered experimental, having been first performed in 2000, but has the benefit of requiring neither ovarian stimulation nor a partner or sperm donor. Usually, the entire cortex of one ovary is removed laparoscopically and cryopreserved, to be re-implanted surgically after the completion of cancer treatment. This re-implantation may be back into the pelvis, or subcutaneously elsewhere on the body, with the aim of restoring endocrine function. This restoration of function has so far been limited in length of effect, with three years being the maximum. Ovarian tissue cryopreservation is not recommended in women over the age of 40 due to low remaining numbers of primordial follicles. One issue of concern with this technique is the risk of transferring cancer cells back in to the body with the re-implanted ovarian tissue. There have been six live births reported after this still experimental technique (Von Wolff et al., 2009).

Ovarian tissue cryopreservation is available in New Zealand in some centres, but ethical approval for tissue thawing and re-implantation has not been granted. Ovarian tissue cryopreservation is not currently government funded in New Zealand.

Ovarian Transposition

Ovarian transposition involves surgically moving the ovary/ovaries to a position outside of a prospective pelvic irradiation field to protect them from the effect of radiation treatment. The transposed ovaries then receive only 5-10% of the radiation dose that they would have if left in position. The current success rate of this technique (as measured by the maintenance of short-term menstruation) is 50%, and is influenced by reduced blood flow to the transposed ovary, the effects of scatter radiation, the total dose of radiation given, and the impact of radiation on the non-transposed ovary (Maltaris et al., 2007).

Fertility Sparing Surgery

There are fertility-sparing surgical options for women with some gynaecologic or other pelvic cancers depending on the individual diagnosis and stage. For almost 50% of women with early stage cervical cancer, vaginal trachelectomy is an option that leaves the uterus intact allowing for possible pregnancy in the future (Plante, Renaud, Francois, & Roy, 2004). Some early and less aggressive ovarian cancers may be treated with fertility sparing surgery where the non-malignant ovary and sometimes the uterus are left intact. This can result in an increased risk of cancer recurrence but is still seen to be a viable option due to a lack of statistical impact on survival (Zanagnolo, Sartori, Trussardi,

Passinetti, & Maggino, 2005). Non-surgical treatments, such as hormonal therapy, have also been proposed for some early endometrial cancers (Gershenson, 2005).

Ovarian Suppression

Suppression of ovarian function during chemotherapy is an experimental technique and a contentious issue. Gonadotrophin-releasing hormone agonists/analogs or oral contraceptives are used to suppress ovulation with the theoretical aim of protecting ovarian tissue from the impact of chemotherapy by slowing cell division. A number of clinical trials are currently underway to further investigate the efficacy and safety of this technique. One recent review reported no evidence for the success of this technique (Oktay & Oktem, 2009), but another suggested that it has promise despite a lack of statistical data to support its efficacy (Blumenfeld & von Wolff, 2008).

Physiological Aspects of Premature Menopause

The onset of treatment-induced premature menopause is often acute, and the associated physiological symptoms may be more intense than those experienced with normal menopause (McCarthy, Rogers-Clark, & Batkin, 2009; McPhail & Smith, 2000; Rogers & Kristjanson, 2002; Schover, 2008). The most commonly reported physiological issues associated with menopause are vasomotor symptoms such as hot flushes, palpitations and night sweats. These may be experienced by up to 75% of women at some stage of menopause, with the later onset of vaginal dryness, lowered libido and urinary incontinence which may impact considerably on sexual function and overall quality of life (Absolom et al., 2008; Ganz, 2001a; Schover, 2008). Later effects on cardio-vascular function and bone density are also of concern (Ganz, 2001a).

Previous management of vasomotor and vaginal symptoms has primarily involved the use of hormone replacement therapy (Ganz, 2001a), but this is a controversial issue where breast or other oestrogen-sensitive cancers are concerned and has traditionally been contra-indicated (Ganz, 2001a; Schover, 2008). Alternative management strategies for vasomotor symptoms include the use of anti-depressant medications such as Venlafaxine, anti-epileptic/analgesic medications such as Gabapentin (Schover, 2008), and psychological therapies such as relaxation and stress-reduction (Schover, 2008; Tremblay, Sheeran, & Aranda, 2008). The management of sexual dysfunction related to menopausal symptoms may be more difficult, but studies indicate a measure of success from the use of vaginal moisturisers and/or lubricants, estrogen creams where this is considered safe, pelvic floor muscle relaxation training, and varied psycho-social interventions for women and/or couples (Schover, 2008).

THESIS STRUCTURE

The thesis will be structured as follows:

Chapter Two: Literature Review

This chapter reviews relevant literature from 1999-2010. In the first section, this chapter reviews relevant current literature pertaining to the emotional and interpersonal aspects of fertility damage and premature menopause related to cancer treatments. In the second section, an overview of issues related to fertility damage and premature menopause from cancer treatments is provided for the purpose of positioning the study in the wider context of cancer care.

Chapter Three: Conceptual Framework

This chapter introduces and describes the theory of chronic sorrow, which is the conceptual framework used for this study. This will include the early development of the concept of chronic sorrow, the development of a middle-range nursing theory from the concept, the use and further development of the theory in the clinical arena, discussions of the relationship of chronic sorrow to grief and depression, and a brief explanation of why this theory was used as the conceptual framework for this study.

Chapter Four: Methodology and Methods

This chapter describes the qualitative research methodology used in this study, focusing firstly on a discussion of the methodology and the rationale for using it. This will be followed by a description of the methods used in the study, and the ethical considerations in the study.

Chapters Five to Seven: Findings

There are three categories of findings in this study and these are presented in individual chapters. These categories are, respectively: 'Communication and Decision-Making in the Cancer Context', 'Loss and Disruption', and 'The Emotional Impact of Loss and Disruption'.

Chapter Eight: Discussion

This chapter discusses the key findings of the study in the context of relevant literature and the theory of chronic sorrow, and highlights the contribution of this study to existing research. It also sets out implications of the study findings for clinical practice and education.

Chapter Nine: Conclusion

This chapter provides a brief overall summary of the study followed by a description of the possible methodological strengths and limitations of the approach. This is followed by recommendations for practice, education and further research.

CONCLUSION

There are many ways in which cancer survivors may be negatively affected by cancer treatments, and it is imperative that both clinical and academic attention is paid to finding ways to ameliorate these effects. While a limited evidence base related to the emotional and psychosocial aspects of fertility damage and/or premature menopause from cancer treatments exists, there are many aspects of this that are poorly understood. This study will add to this evidence base through providing an in-depth exploration of these issues using the conceptual framework of the theory of chronic sorrow, and the research question, ‘What are the emotional and interpersonal aspects of fertility damage and/or premature menopause from cancer treatments?’

CHAPTER TWO: LITERATURE REVIEW

INTRODUCTION

The first section reviews relevant current literature pertaining to the emotional and interpersonal aspects of fertility damage and premature menopause related to cancer treatments. An extensive search of the literature was undertaken early in the research process, in which the following databases were searched for relevant nursing, medical and psychology literature from the years 1999-2007: Medline, CINAHL, Scopus, PsycINFO, and Embase. The search terms on which the search was based were: cancer, fertility, infertility, menopause, premature menopause, emotions. The search terms were used individually and then combined: cancer, fertility, infertility, menopause, premature menopause, emotions; then cancer AND fertility, cancer AND infertility, cancer AND menopause, cancer AND premature menopause; then (cancer and fertility) AND emotions, (cancer and infertility) AND emotions, (cancer and menopause) AND emotions, (cancer and premature menopause) AND emotions. The initial search when the term 'emotions' was included returned almost 500 articles (cancer, fertility, infertility, emotions = 224; cancer, menopause, premature menopause, emotions = 271). After removing duplicates, the abstracts of the articles were read, and the articles were retained if they were reports of research, syntheses of research or critical reviews of the literature that focused on the research question for this study. Due to the limited published literature specific to the research question, some articles addressing more general experiences of cancer were included if issues related to fertility and/or premature

menopause were specifically mentioned. In addition to the initial search, subsequent searches were made throughout the study, and articles were also found from the references sections of other articles.

The second section provides an overview of research related to cancer survivorship and ongoing quality of life; information, decision-making and support in the context of cancer; and the psycho-social aspects of infertility and premature menopause in the general population. This is for the purpose of positioning the study in the wider context of cancer care. The following nursing, medical and psychology databases were searched in response to needs for this additional contextual information that arose at times throughout the research process: Medline, CINAHL, Scopus, PsycINFO and Embase.

REVIEW OF RELEVANT LITERATURE

The Psycho-Social Impact of Fertility Damage from Cancer Treatments

There is limited published literature specific to the emotional and interpersonal aspects of fertility damage from cancer treatments. Because fertility issues were the prime focus of only five studies, a small number of studies addressing wider issues are included in this review on the basis that they included key findings related to fertility. Studies focussed on women with breast cancer are reviewed first, followed by studies including women with gynaecological cancers. The studies are firstly described in some detail to provide an insight into current knowledge, and then a concluding comment at the end of the section summarises the review and the strength and usefulness of this existing literature.

Fertility issues have been previously shown to be of considerable concern to, or even the primary concern of, younger women who have been diagnosed with breast cancer. A recently published systematic review of studies from 1988-2008 reporting fertility-related issues for younger women with breast cancer identified three themes: concerns regarding menstrual changes and potential infertility; attitudes to, and actual decisions made by women regarding pregnancy, breastfeeding and contraception; and fertility-related information needs (Peate, Meiser, Hickey, & Friedlander, 2009). This review included a total of twenty studies (nine quantitative, eight qualitative and three using mixed methods), involving over 2000 women, the majority of which were undertaken in the United States (US) or Australia. In their review, Peate et al. reported that fertility and menopause-related issues were of significant concern to the majority of younger women with breast cancer in the included studies, causing a high degree of distress for many. Further to this, issues related to potential pregnancy (both as a positive and negative possibility), breast-feeding, and contraception were shown to be an added concern. However, while the article reporting the review provides a detailed description of the search and article selection strategy, there is insufficient information to judge the quality of their methods for analysis.

As part of a qualitative study conducted in the United States (US) looking at decision-making about pregnancy in women who had previously had treatment for breast cancer, thirty-four participants answered a subset of open-ended questions regarding issues particularly related to being women of a young age with breast cancer (Siegel, Gluhoski, & Gorey, 1999). This group of women reported a number of issues, including the fear

that pregnancy may increase the likelihood of cancer recurrence. They were thus choosing to prevent potential pregnancy, and described this situation of impaired fertility or elective avoidance of pregnancy as a “profound loss” (p. 8), symbolic of the greater changes in their lives brought about by their diagnoses. They perceived that a basic right and function of being female had been violated. There was also mention of being unable to fulfil the dreams for parenthood held by a partner and the couple together, and a sense of the unfairness of having this most basic of human desires denied them. The participants identified as feeling different from their peers as a result of their breast cancer, and this was described as distressing. The grief and loss they experienced was increased by witnessing the reproductive activities of their peers. Breast cancer at a young age led to feelings of vulnerability, and potentially altered the participants’ future options. While the small number of participants in this study limits the generalisability of the findings, the study does contribute qualitative evidence to our understanding of women’s experiences of having cancer at a young age.

Also focusing on young women with breast cancer, McMahon (2002) interviewed nine Californian women who were diagnosed with breast cancer in their twenties. The aim of this study was to examine their experiences of breast cancer at a young age. The findings related to fertility were only part of the study, but issues related to fertility were reported to be of the highest level of concern for the participants. Some participants reported that their quality of life would be significantly reduced if they were unable to have children. As described by Siegel et al. (1999) above, the disruptions to their daily lives and their life plans and aspirations were distressing, however McMahon reported that this could

also be used in a positive manner to encourage or allow them to pursue experiences that they may otherwise have missed. Those who had continued menstruating after treatment described feeling pressured into having children quickly due to the threat of premature menopause. This potential loss of reproductive ability was described as devastating, and probably the most significant and feared side effect of their cancer treatments. McMahon reported that some participants described the possibility of being unable to have children as more difficult to manage than their cancer diagnoses. Once again, the small number of participants in this study limits the generalisability of the findings, yet this study adds important additional context and depth to the findings of Siegel et al. above.

Fertility issues were also shown to be a significant concern to younger women with breast cancer in a web-based survey conducted in the US (Partridge et al., 2004). The aim of the survey was to improve understanding of young women's attitudes to fertility and how this many influence their decision-making. The questionnaire, which was developed and piloted for the study, was completed by 657 women with a mean age at diagnosis of 32.9 years. The majority (90%) were European. The women were recruited from a web-based breast cancer advocacy group which the authors acknowledged may have resulted in selection, non-responder and/or recall bias. The findings showed that 57% of participants recalled being considerably concerned about the possibility of infertility at diagnosis, with this being significantly associated with a wish for children/more children ($P < .0001$), and 29% reported that this concern had influenced their treatment decisions. An interesting point identified in this study was that many women appeared to over-estimate their risk of going into menopause as a result of their treatment, which was concerning

when considering the influence of fertility issues on their decision-making about cancer treatments.

Finally, an Australian study looking at the fertility concerns, as against infertility concerns of young women with breast cancer examined issues pertaining to pregnancy, contraception and breast-feeding after breast cancer, as well as lost fertility, although the latter to a lesser degree (Connell, Patterson, & Newman, 2006). This longitudinal qualitative study involved thirteen women who were under 40 years of age at the time of their cancer diagnoses. The women were interviewed three times over a twelve to eighteen month period. The authors of this study reported that for some, issues regarding infertility became more of an issue as the study progressed. This was related to the participants' regrets that possible means of preserving fertility prior to treatment had not been utilized. As their post-treatment lives were returning to 'normal', issues like fertility assumed a greater level of importance. It is important to note here that being fertile where this was unexpected, and the associated issues of contraception and breast-feeding, were equally as distressing for some participants. Although infertility was not the primary focus of the study, the authors repeatedly noted that many participants' feelings regarding their fertility status changed over time but not necessarily towards a sense of resolution or acceptance. As mentioned previously, the findings of a small study such as this, while contributing valuable depth to our understanding of the impact of fertility issues related to breast cancer, cannot be generalised. This study adds, however to the growing number of studies in the field addressing the qualitative aspects of this

issue and is therefore useful, in conjunction with other studies, for advancing understanding and knowledge.

Other studies of young women with breast cancer have included data pertaining to fertility, but were not included specifically in this review as the fertility data was only a small part of the overall studies. The findings, however, showed the importance of fertility issues for the ongoing quality of life of affected women (Avis, Crawford, & Manuel, 2004; Coyne & Borbasi, 2006; Duffy et al., 2005; Dunn & Steginga, 2000; Thewes et al., 2004).

In addition to the studies described above that were focussed on women with breast cancer, four studies were also found pertaining to the emotional aspects of fertility damage associated with treatment for gynaecological cancers although, once again, not all were specific to this topic. The study by Wenzel et al. (2005) included women with lymphoma. First was a phenomenological qualitative study undertaken in the United States (US) and focused on the experiences of women diagnosed with ovarian cancer during their childbearing years (Schaefer, Ladd, Lammers, & Echenberg, 1999). For this study, five women who were recruited through the private practice of one of the authors participated in three or four interviews with a focus on, 'What is it like to be living with ovarian cancer?' Although not all of the study findings are pertinent to this review, the authors described a theme entitled "hysterectomy violating one's sense of being" (p. 233), which was related to infertility brought about through surgical treatment for ovarian cancer. The abrupt and sometimes unexpected removal of reproductive ability led to a

profound sense of loss, emptiness and meaninglessness for some participants, even up to ten years from the surgery. A second theme described loss of fertility as the “loss of a natural life process” (p. 242), causing a great deal of emotional distress. This was strongly associated with the desire to be able to choose whether or not to have children, and to have this acknowledged by health professionals. While this study only included five women, it provides a useful early insight into the experiences of women with gynaecological cancer diagnoses rather than only breast cancer.

Carter et al. (2005) assessed the emotional and sexual effects of cancer treatment-induced infertility in a cohort of 20 gynaecological cancer survivors who were one to five years post-diagnosis. The study was conducted in the US. The participants in this study were aged 27-49 years, and 80% were European (no details were given for the ethnicity of the remaining 20%). The participants completed a questionnaire that included the Centre for Epidemiologic Studies – Depression Scale, the Impact of Events Scale, the Modified Inventory of Traumatic Grief, the Female Sexual Function Index, and the Menopausal Symptom Checklist. They reported depression (40%), distress/significant depression (35%), grief specifically related to infertility (50%), and meaninglessness related to infertility (75%). Analysis of data from the open-ended questions showed that the impact of fertility damage related to cancer treatment was profound, with 50% of participants reporting a sense of being overwhelmed or devastated by their lost fertility in an ongoing manner. All of the participants reported some level of meaninglessness in their lives without the possibility of a genetically-related child, and a quarter of participants described this as ‘marked or overwhelming’. These participants also reported a lack of

purpose in their futures, and a sense of the loss of safety and security in their lives. Over one third stated that they found it hard to move on past the distress related to their enforced childlessness, and some reported feelings that parts of themselves had died along with their ability to reproduce. Just over a third of responses reflected a lessening of this distress over time but nearly two thirds described the worsening of these feelings of loss, regret, grief and anger. A minority described coming to some acceptance of their loss of fertility and were making future plans. The number of participants in this study was small for a quantitative study, and this was attributed by the authors to issues with the medical records data from which eligible women were approached. While this small number limits the generalisability of the findings from the study, it adds useful empirical evidence to inform future research into the effects of cancer treatment-related infertility.

Subsequent to this and employing a larger sample, another survey study also conducted in the US indicated that significant distress, ongoing menopausal symptoms and sexual dysfunction were found in the survivorship phase in women with fertility impairment from treatment for gynaecological cancers (J. Carter et al., 2010). (Because the full report of this study was not available at the time of this review, the abstract only was used, and was included due to the limited available literature.) The aim of this study was to assess and describe the emotional, sexual, and physical impacts of cancer-related infertility for survivors of gynecological cancers. The 88 participants ranged in age from 21 to 49 years and completed a self-report questionnaire which included measures of mood (Center for Epidemiologic Studies Depression Scale), distress (Impact of Event Scale), sexual function (Female Sexual Function Index), and menopause (Menopausal

Symptom Checklist). Clinically significant levels of distress in relation to loss of fertility or impaired fertility were reported by 77% of participants. The authors concluded that the emotional and physical impact of impaired or loss of fertility can be complex, lasting well into the survivorship phase. However, because only the abstract of this study was available, these findings cannot be judged in terms of reliability at this stage.

Finally, the relationship between reproductive concerns and quality of life was explored in a sample of survivors of lymphoma (n = 69), cervical cancer (n = 51) and gestational trophoblastic disease (n = 111) in the United States and the United Kingdom (Wenzel et al., 2005). As reported in other studies, the majority of participants were of European ethnicity. The participants were aged 17-45 and had been treated for cancer 5-10 years previously, and were recruited from cancer treatment centres. Initial contact was made through a letter inviting them to participate in the study. In this study, which included an unmatched control group, participants completed a 60-minute phone or mail questionnaire. The instrument included questions pertaining to general health, quality of life, social support, reproductive concerns and sexual functioning. The items related to reproductive concerns comprised a scale developed for the purposes of, and validated in, this study and attended to issues such as loss of control over one's reproductive future, varied emotional responses to the inability to have children, and feelings about self in relation to inability to have children. This study indicated that fertility damage as a result of cancer treatments can impact on women's quality of life, particularly those who desired children or more children. There were no significant differences between the three survivor groups for scores on the reproductive concerns items. This study was the

only one found that included women with cancer diagnoses other than breast and gynaecological cancers. This is important for our understanding of the experiences of a wider range of women in terms of reproductive concerns and quality of life after treatment for cancer.

In summary, although there is limited published research related to the emotional and interpersonal effects of fertility damage from cancer treatments, the findings of the studies reviewed here suggest that many young women view fertility damage as a feared and distressing potential long-term impact of cancer treatment. Only five studies specifically focussed on cancer treatment-induced fertility damage were found, and only one employed a qualitative approach. As a result, there is limited depth to current knowledge of this topic, with most studies describing the type and degree of emotional responses found without a deeper interpretation of this. Apart from the inclusion of women with lymphoma in one study (Wenzel et al., 2005), the others were specific to women with breast cancer or gynaecological cancers. This is likely to be because these are the most common types of cancer in pre-menopausal women, and women with breast cancer are more easily accessed for study participation through the existing extensive breast cancer support networks. Another concern, and a frequent issue in published English language studies, was the predominantly European ethnicity of the participants in all the studies. No studies involving New Zealand women were found.

The Psycho-Social Impact of Premature Menopause from Cancer Treatments

Although fertility damage is a considerable concern for many younger women with a cancer diagnosis, for some the spectre of premature menopause is the most feared potential outcome of life-saving cancer treatments. The physical, psychological and interpersonal implications of premature menopause can be significant, and are a particular challenge to normal life-stage functioning and expectations. In addition, there is evidence that the symptom experience of acute treatment-induced premature menopause can be considerably worse than that incurred in the normal process (McCarthy et al., 2009; McPhail & Smith, 2000; Rogers & Kristjanson, 2002), and that the onset of premature menopause can considerably impact on women's general quality of life (Ganz, Greendale, Petersen, Kahn, & Bower, 2003). This impact has been found to be both related to (Coyne & Borbasi, 2006), and unrelated to (Avis et al., 2004), the implications of premature menopause for fertility.

In an early Canadian study, premature menopause was not found to be singularly important in the context of the wider effects and ramifications of the cancer experience for women who had been treated for breast and gynaecological cancers (C. S. Davis, Zinkand, & Fitch, 2000). The aim of this qualitative study was to examine women's experiences of premature menopause and to document common issues or concerns. The study report is not clear as to where participants were recruited from, but the eight participants were at least six months post-treatment, and described at least six months of post-menopause with accompanying distressing symptoms. Data were collected through

semi-structured interviews. While the participants described mild to severe menopausal symptoms and a sense of loss related to menopause was apparent, the main finding in this study was that menopause was merely a contributor to, or a part of, the whole cancer experience, and that it was this whole experience that was difficult for many participants. While the findings of this study highlight some difficulties associated with ascertaining sources of distress in cancer survivors, the generalisability of the findings is limited by the small number of participants.

In contrast, a study conducted in the US reported that quality of life can be considerably impacted by the sexual repercussions of cancer treatment (Wilmoth, 2001). A premise of this study was that sexual difficulties after breast cancer treatment do not solely relate to body image changes resulting from breast surgery, but also to the impact of systemic adjuvant treatments such as chemotherapy or hormonal therapy. This is important for the relevance of this study for women with other cancer diagnoses. Wilmoth conducted semi-structured interviews with 18 European women and aged between 35 and 68 years, who had a diagnosis of breast cancer. The participants were six months to ten years post-treatment. Wilmoth described the primary sexual outcome of treatment for breast cancer as an “altered sexual self” (p. 280). This was influenced by two main categories: “losses” (p. 280), which included four sub-categories - missing parts, loss of bleeding, loss of sexual sensations and loss of womanhood; and “influencing pieces” (p. 283), which included two sub-categories - relationships and information control. Of particular interest, the cessation of menstruation was deeply associated with feelings of becoming old, and was an effect that the participants felt poorly prepared for, and very poorly

supported through. They described grieving processes associated with their perceptions of sudden aging and the loss of fertile potential. They found their senses of themselves as women significantly threatened by the onset of menopause and changes in their sexual functioning, and described this feeling as being less of a woman. The degree of influence that the participants were able to exert over 'information control' impacted on their general outcomes. This study, while limited by the small number of participants, provides important qualitative evidence of the impact of premature menopause from treatment for breast cancer that contributes to the limited number of studies in the field.

Likewise, the impact on sexual function of premature menopause from treatment for breast cancer was recently described as inhibiting and marginalizing, leading to feelings of being alienated from one's own body and normal ways of relating to others (Klaeson & Bertero, 2008). In this phenomenological study undertaken in Sweden, six women aged between 38 and 48 years were interviewed. There were three main categories of findings: "not recognizing oneself" (p. 188), "being in an existential vacuum" (p. 189), and "new strength in intimate relationships" (p. 190). The cessation of menstruation was viewed both positively, in terms of losing the inconvenient aspects of periods, and negatively, in terms of losing a monthly reminder of health, fertility and womanliness. The participants described feeling old, unattractive and unfeminine and losing their feelings for who they were as women and who they would be in the future. Their identities were challenged and changed, particularly their sexual identities. They reported a need to renegotiate their intimate relationships due to their altered sexual feelings and functioning. This was described in terms of a bird that had been "pinioned"

(p. 190) and was no longer able to fly. The participants also reported feeling that their concerns and experiences related to premature menopause were not recognized or attended to by health professionals. As this study included only six participants, the findings from it cannot be generalised. This study does, however, contribute to knowledge of women's experiences of premature menopause, particularly as the participants were from Sweden.

In a grounded theory study conducted in the US, 27 women with breast cancer who had experienced cancer treatment-induced premature menopause were interviewed (Knobf, 2001, 2002). These women reported an initial sense of confusion associated with ascertaining whether their treatment, or the onset of premature menopause, was responsible for their symptoms, and a notable lack of interest or discussion related to menopause from the health professionals involved in their care. In addition, the onset of premature menopause set them apart from their peers who were not menopausal, creating an additional layer of isolation and making them feel old. Some women also reported their concerns related to the future impact of premature menopause on cardio-vascular function and bone density. Knobf identified vulnerability as their primary psychological and social outcome. This was associated with uncertainty and a sense of lack of control over the future. This necessitated a balancing act between the need to avoid normal medical treatments for menopausal symptoms and long-term impacts due to the risk of cancer recurrence, and avoidance of the physical risks described above. Knobf described this process as "carrying on" (p. 11), the ongoing work of the participants to live with, and adjust to, the dual states of having cancer and living with premature menopause.

These findings were expanded on in a later report from the same study focusing on three types of responses from the participants: “making the best of it”, “struggling”, and “barely noticing” (Knobf, 2008, p. 388). The majority of participants demonstrated ‘making the best of it’, and these women generally felt better prepared, more in control, and better supported, and described less intrusive or better managed physical symptoms. Participants who ‘struggled’ to manage generally felt poorly prepared for, or informed of, the potential for premature menopause, felt less in control and less well supported, and described more intrusive or poorly managed physical symptoms. Those who ‘barely noticed’ were focused on survival, and were able to minimise issues related to their cancer diagnoses and treatments in the light of their successful treatments and positive futures. Knobf noted that a greater time distance from their treatments increased the likelihood of negative reports related to premature menopause as the participants’ focused increasingly on longer-term quality of life. While this qualitative study included only twenty-seven participants, Knobf developed a coherent and illuminating grounded theory of the experience of cancer treatment-induced premature menopause that contributes a considerable amount to knowledge in the field.

Finally, a study exploring the wider psychosocial problems of younger women with breast cancer in the US identified premature menopause as a significant aspect of these women’s experiences (Avis et al., 2004). For this survey, 220 women aged between 25 and 50 years (96% European) were recruited through cancer treatment centres and 204 completed all parts of the survey for analysis. Subscales from the Cancer Rehabilitation Evaluation System scale (CARES) were used for data collection. In addition, specific

inquiries about premature menopause and pregnancy were included, and open-ended questions were posed related to any other ways in which breast cancer had affected them. Quantitative data were analysed using descriptive analyses and multiple regression analyses. Data from the open-ended questions were analysed thematically. Premature menopause was found to be of a high level of concern from both quantitative and qualitative data and many areas of sexual dysfunction were reported. However, as demographic data pertaining to psychosocial factors that may have impacted on problem areas was not collected, these findings may be limited in terms of their generalisability.

As described in the above review of the literature related to fertility damage, the majority of the literature related to premature menopause from cancer treatments involves women with breast or gynaecological cancers only, although one Australian study included a variety of cancer diagnoses (McCarthy et al., 2009). While the physiological impact of premature menopause from cancer treatments was described in this study as 'hitting the wall' due to the sudden and intense changes associated with it, the data relating to the psycho-social impact of premature menopause are still being analysed and this has not been reported to date (A. McCarthy, personal communication, April 1st 2010).

In summary, as reported above for fertility, only a few published studies focussed on the emotional or psychosocial impact of premature menopause from cancer treatments were found. Those reviewed here suggest that premature menopause is often of significant concern to younger women. Further, this has a considerable impact on the lives of many women, and is particularly related to sexual functioning and identity. The generalisability

of four of these studies is limited by their small participant numbers and qualitative approach. These do, however, add important depth to the understanding of the topic. An area of concern, as with many areas of health research, is the extremely limited inclusion of women from ethnic minorities. More importantly, only one study included participants with diagnoses other than breast or gynaecological cancers and thus far, only findings pertaining to the physiological aspects of these women's experiences have been published (McCarthy et al., 2009).

Overall Summary

It is clear, from the above reviews of the published literature specifically addressing fertility damage and premature menopause from cancer treatments, that there is a need for further research into women's experiences of these long-term effects. It is also clear that such research should address certain areas in which existing studies are lacking or limited. Firstly, while qualitative studies are important for providing context, depth, breadth and detail to knowledge of the topic, and some valuable qualitative studies have been described above, the majority have been descriptive in nature. I believe that it is important to take this knowledge further through research that provides a deeper interpretation of women's experiences, acknowledges and builds on this existing knowledge, and uses an appropriate theoretical or conceptual framework to ground and guide the analysis. Secondly, it is crucial to include a wider range of participants in future research in this area in terms of ethnicity, sexual orientation and, importantly, cancer diagnosis. As the scope and quality of research in this area increases, it will become easier to elucidate the importance of this issue in the cancer experience. To this end, the current study will add to the growing depth and breadth of knowledge of this

topic through including a different participant population in terms of ethnicity, diagnosis and sexual orientation, and using the theory of chronic sorrow as the conceptual framework for the study.

OVERVIEW OF RELATED ISSUES

This section provides an overview of the literature related to the context in which fertility damage and premature menopause from cancer treatments occur. This is included to situate this study in the wider cancer survivorship research arena. Firstly, a brief review of literature related to fertility damage and premature menopause unrelated to cancer is provided. This is followed by an overview of research related to cancer survivorship, information and decision-making in the clinical environment, and survivorship care and support.

The Psycho-Social Impact of Infertility in the General Population

Infertility in western societies is a growing concern due to the rising average age at which women are having children, and the effect of this on their fertility. Accordingly, research into the experiences of women and couples experiencing infertility and/or infertility treatment is increasing.

One of the most commonly reported psychological outcomes of infertility in the general population is grief (Alesi, 2005; Cousineau & Domar, 2007; Johansson & Berg, 2005; Syme, 1997). In addition, increased levels of anxiety and depression are found in many people undergoing investigations or treatments for infertility (Cousineau & Domar, 2007; Lukse & Vacc, 1999). Sherrod (2004), in a review of psychological distress related to

infertility, described difficulties with mourning and expressing grief when nothing 'tangible' to others had been lost. This can lead to a sense of isolation, and perceptions that others are unsupportive and don't understand. In addition, some women have reported the presence of guilt related to past actions that they believe may have caused their fertility difficulties (Sherrod, 2004).

Other issues, such as those related to life stage and the inability to meet socially mandated expectations, including becoming parents, have been reported (Alesi, 2005; Cousineau & Domar, 2007; Sherrod, 2004). This may lead to a perception of isolation and separation from peers. Supporting this, a study looking at the impact of menopause after infertility reported the participants' feelings of finally being 'normal' and at the same life stage as their peers (E. Olshansky, 2005), although a recent study reported that reaching the 'grandparent' stage of life led to increased feelings of grief related to the acknowledgement of another level of loss related to infertility (Wirtberg, Moller, Hogstrom, Tronstad, & Lalos, 2007). The experience of infertility has been described as becoming a 'stranger' due to this effect of being in a different life and personal space from others (Exley & Letherby, 2001). Exley and Letherby also described the experience of infertility as a life disruption that has implications for the affected person's future and identity.

Involvement in assisted reproductive technologies has also been studied, and found to be variously a positive (Johansson & Berg, 2005), or a difficult and potentially negative (Allan, 2007; Lukse & Vacc, 1999) experience. There is very limited literature exploring

the psycho-social aspects of engagement with adoption or surrogacy from the perspective of the potential parents. A recent review of this literature suggested that surrogacy is often a final attempt to achieve parenthood after the failure of fertility treatments (Edelmann, 2004). Accordingly, Edelmann found contradictory reports of the psychological health of couples seeking surrogacy due to their previous, often lengthy involvement with fertility procedures and services. The literature acknowledges the difficulties associated with finding a suitable surrogate, and the resulting distress where arrangements fall through. Edelmann commented on the paucity of the literature on this issue despite increasing numbers of couples seeking parenthood this way. Another study sought to compare coping, quality of life and psychological symptoms between women engaged with assisted reproductive technologies, adoption and surrogacy (van den Akker, 2005). This quantitative study reported no significant differences between these groups, but recommended that attention be paid to coping and potential distress in these populations.

The Psycho-Social Impact of Premature Menopause in the General Population

There are a number of physiological reasons for the onset of premature menopause, of which treatment for cancer is only one. A brief review of the literature in this area suggests similarities with the range of psycho-social effects described above. A qualitative study focusing on the impact of premature menopause on a woman's sense of self found that its effect was noted in all aspects of 'self' (Pasquali, 2001). Physical changes and losses, changes to their identities with the transition from menstruating to being menopausal, and a sense of being disconnected due to being different, were

reported. The participants also, however, recognised the potential for positive transformations through the experience. Of interest here, those participants whose premature menopause was caused by cancer treatments viewed these changes less negatively than those who were menopausal due to treatments for benign conditions.

Perceptions of inhabiting different bodies after the onset of premature menopause were reported by the participants in another study as the loss of their previously known and recognisable bodies, and disruptions between their physical bodies and how these were experienced (Boughton, 2002). In addition, the participants in this phenomenological study identified as different from their peers, yet also different from other menopausal women. Thus they both belonged, and did not belong to, two different social groups, and felt a pull between both. These women also identified disruptions to their identities related to premature menopause and the implications of this for their fertility.

Emotional reactions such as shock, sadness, guilt, hopelessness, a realisation of loss, feeling abnormal, and identifying as damaged were described in a web-based study of women with premature menopause (Halliday & Boughton, 2009). The participants in this study described alterations to their self-concept in which they felt less attractive and healthy, with perceptions of having aged and lost their youth. These participants also identified the loneliness of being in different life-stages to those of their peers.

In summary, although a search of the published literature returned only a small number of studies focused on the emotional impact of premature menopause from cancer treatments,

it is clear from these that the impact may be considerable, and has significant implications for the future lives, relationships and identities of affected women. Studies exploring the experiences of women with premature menopause in the general population report similar findings. Once again, the vast majority of published studies related to cancer treatment-induced premature menopause involve women with breast, or to a lesser degree, gynaecological cancers.

Cancer Survivorship

A recently published concept analysis of cancer survivorship provided a useful and comprehensive understanding of this emerging and burgeoning health concern (Doyle, 2008). Doyle proposed that cancer survivorship commences at diagnosis and is an ongoing state associated with uncertainty. It is a life-changing experience with both positive and negative aspects, and has individual and universal features. The number and range of studies exploring the experiences of cancer survivors is rapidly increasing as the population of cancer survivors grows in number and their needs become more apparent. Recent reports suggest that although cancer survivors generally report good or excellent overall physical health, many also report ongoing physiological and psychological issues that continue to impact negatively on their lives (Alfano & Rowland, 2006; Andrykowski, Lykins, & Floyd, 2008; Bloom, Stewart, Chang, & Banks, 2004; Cancer Control Council of New Zealand, 2009; Centres for Disease Control & Lance Armstrong Foundation, 2004; Heading, Mallock, Sinclair, & Bishop, 2008). These findings may be more common in younger cancer survivors (Costanzo, Ryff, & Singer, 2009; Rosen,

Rodriguez-Wallberg, & Rosenzweig, 2009).¹ Evidence is emerging, however, of the potential for positive psychological and psychosocial outcomes from the cancer experience, as for other traumatic events (Bellizzi, 2004; Little, Paul, Jordens, & Sayers, 2002).

Of particular relevance for the current study are reports of the general psycho-social functioning and needs of cancer survivors, which are varied but often reflect the negative impact of the long-term sequelae of cancer treatments. The most commonly reported issues are fear of recurrence, the unrealistic expectations of others, fatigue, difficulties in resuming life or adjusting to new levels of functioning, sadness (Baker, Denniston, Smith, & West, 2005; Jefford et al., 2008; Steele & Fitch, 2008), concerns such as stress and adjustment, survival and personal growth (Beatty, Oxlad, Koczwara, & Wade, 2008), side effect management, the effect of cancer on self concept (Beatty et al., 2008; Jefford et al., 2008), benefit finding or maintaining optimism (Oxlad, Wade, Hallsworth, & Koczwara, 2008), and vulnerability (Bower et al., 2005). Many also report support needs related to information pertinent to their ongoing cancer journey (Jefford et al., 2008).

In addition, some patients develop clinical psychological problems such as depression, anxiety or post-traumatic stress disorder (Alfano & Rowland, 2006; Jim & Jacobsen, 2008). Post-traumatic stress disorder has been estimated as occurring in up to one third of people with a cancer diagnosis, and has been related largely to fears of cancer

¹ These issues will discussed throughout this review

recurrence and associated hyper-vigilance (Andrykowski et al., 2008; Jim & Jacobsen, 2008).

The Impact of a Cancer Diagnosis on Life and Identity

The impacts of serious or chronic illnesses on a person's life course and identity have long been acknowledged (Becker, 1997; Bury, 1982; Charmaz, 1983). Bury (1982) described this as 'biographical disruption', where the onset of chronic illness disrupts not just the expected life course of those affected, but also how they view themselves and believe that they are viewed by others. Likewise, this effect in people with a cancer diagnosis has been explored. An early study of identity changes in the context of cancer described a process of 'renegotiating identity' in response to the practical disruptions that the cancer induced (Mathieson & Henderikus, 1995). There was an acknowledgement here of an 'old' self and a 'new' self, and the requirement to work out where and how the cancer experience would fit into the person's life and future.

However, the majority of previous research into the effects of a cancer diagnosis on a person's identity has focused largely on women with breast or gynaecological cancers, or men with prostate cancer. In a meta-synthesis of studies looking at alterations to 'self' after a breast cancer diagnosis, Bertero and Wilmoth (2007) found that this impact has been widely attributed to the intimate nature of breast cancer surgery and the meaning of this for perceptions of womanhood and femininity, which in turn affects central aspects of 'self' and identity. Another focus of research in this area has been the adoption of a dominant cancer-specific identity, for instance, 'survivor', as a result of the cancer diagnosis (Deimling, Bowman, & Wagner, 2007; Park, Zlateva, & Blank, 2009).

Of particular interest for the current study, cancer survivorship has been shown to lead to identity changes by creating ‘discontinuity’ in a person’s sense of identity (Little et al., 2002). In this qualitative study undertaken in Australia, the authors interviewed thirteen cancer survivors aged 13-89, and three of their family members. They described three different experiences of discontinuity in this context. “Discontinuity of memory” (p. 172) was related to the biographical meaning of life as a whole, and changes to how meaning was ascribed to events in past, present and future contexts; “discontinuity of embodiment” (p. 173) was related to physical changes related to the cancer and its treatment; and “existential disruption” (p. 173) was related to uncertainty and bewilderment as a result of such a significant event.

The authors found that this discontinuity could be resolved in a number of ways. Firstly, through the use of “anchor points” (p. 173), which were strong values or beliefs that were able to withstand the disruption; “resumption” (p. 174), which reflected an adapted resumption of life; “incorporation” (p. 174), which involved using the cancer experience as a positive growth and life-change opportunity; and “imbuing extreme experience with meaning” (p. 174), which involved finding meaning in the experience of cancer. They also reported two less positive ways in which their participants sought resolution. “The importance of future memory” (p. 174) described a state of feeling regret for aspects of the past, but also for a less-than positive future; “alienation” (p. 175) described a state of social and communicative disruption. The authors commented that a positive ‘survivor’ identity is valued by society as a reflection of the person’s return to normal after the miraculous and hoped-for cure, and that less positive identities such as the latter two are

not such socially acceptable outcomes. They proposed that the “survivor’s dilemma” (p. 176) is about developing a new identity through, and accommodating, the cancer experience (Little et al., 2002).

Jefford et al. (2008), in a focus group study involving both cancer survivors and health professionals, also identified changes to self-identity as a problematic issue in cancer survivorship. This was particularly related to having a different outlook on, and attitude to, life, and changed priorities. Both groups identified similar issues for survivors, and noted the lack of sufficient information and support services for cancer survivors related to identity changes and the many other issues reported in the study.

Finally, just prior to the completion of the current study, an article applying the concept of biographical disruption to men living in the first year after a diagnosis of prostate cancer was published (Cayless, Forbat, Illingworth, Hubbard, & Kearney, 2010). The authors described the concept of biographical disruption as providing a way of understanding how people make sense of their experiences of serious or chronic illnesses within the contexts of their lives. This sense-making includes consideration of aspects of one’s life and self, and adaptation to the changing situation and new requirements. A diagnosis of prostate cancer was found to induce both biographical disruption and a sense of chaos, due to health-related uncertainty and ongoing physiological difficulties.

Psychological Adjustment to Cancer

Key to these discussions is consideration of the processes involved in adjustment to traumatic events. Traumatic events, such as a diagnosis of cancer, have been described as

creating chaos, and leading to a disrupted life in which there is a need to create meaning (Becker, 1997). Many authors have proposed that reactions to, and interpretations of, traumatic events are mediated by a number of person-specific factors that are unrelated to the particular event concerned. These include pre-existing personality features, beliefs about self, life and the world, personal history both general and relevant to the event, the life context in which the event occurred, and the intra-personal and inter-personal support systems available to the person. Andrykowski et al. (2008) described this as the dynamic interaction between the stress and burden imposed by the cancer, and the resources available to the affected person. These combine to influence the degree to which a potentially traumatic event will be interpreted as such by the person concerned. The process of adjustment or adaptation to such events is then mediated through assessing and potentially adapting beliefs about, and expectations of, life and self, and influenced by physiological changes over time (Andrykowski et al., 2008; Naus, Ishler, Parrott, & Kovacs, 2009).

There is also acknowledgement of the potential for positive outcomes or personal growth through the experience of cancer which occurs, as do negative outcomes, in response to the combination of factors described above (Bellizzi, 2004; Clemmens, Knafl, Lev, & McCorkle, 2008). This also involves a process of altering the meaning of the traumatic event so that it can fit with personal assumptions about life and the world (Jim & Jacobsen, 2008), or altering personal assumptions and goals to accommodate the event (Naus et al., 2009).

A recent study examined the experiences of men treated with hormone therapy for advanced prostate cancer (Navon & Morag, 2004). The authors described this experience as invoking “the inability to classify themselves into culturally available categories” (p. 2343) – their “continuous sense of self” was irrevocably altered (p. 2344), and they were left in a state of “recovery without wellbeing” (p. 2340). Although many aspects of the participants’ lives were regained following their recoveries from their treatments, many were not, leaving the participants still unable to reclassify themselves as they had been, or into new statuses or roles.

In summary, previous research suggests that cancer survivors may experience both positive and negative long-term outcomes related to their diagnosis and treatment. A cancer diagnosis has the potential to significantly challenge the affected person’s understandings and experiences of life and self, particularly where physiological impairments continue to impact on daily life.

Information and Decision-Making in the Clinical Environment

This section provides a brief overview of research in this area related to general communication in the cancer context in addition to fertility, menopause and sexuality, recognising that these issues are not generally discussed in isolation. Many studies have confirmed that the majority of people with cancer diagnoses wish to have as much information as possible about their diagnoses and treatments, particularly as these impact on treatment decision-making (Beckjord et al., 2008; N. J. Davies, Kinman, Thomas, & Bailey, 2008; Jenkins, Fallowfield, & Saul, 2001). In addition, the timing and delivery of

information has been shown to be important (Burns, Costello, Ryan-Woolley, & Davidson, 2007; Halkett, Short, & Kristjanson, 2009; McCaughan & McKenna, 2007), as have patient-related factors such as age, educational background, past experience, and ability to comprehend the information received (Adams, 2007; Hordern & Street, 2007a). Patient satisfaction with the information they receive has been shown to have implications for general quality of life after a cancer diagnosis (N. J. Davies et al., 2008; Wilmoth, 2001). It is important, however, to note that studies also show that both readiness for information, and the degree of information desired, should be assessed on an individual basis (Beaver & Booth, 2007).

There are varying reports of the inclusion, degree and usefulness of discussions specifically related to the impact of cancer and its treatment on fertility and sexuality, including menopause. A sense of a disparity between issues of importance to patients and health professionals was noted as a key issue by McMahon (2002) in her study, described in a previous section of this review. The participants in this study reported that their concerns about fertility were not addressed, and they felt that their most important questions were not answered. This impacted on their emotional adjustments to their diagnoses.

Partridge et al. (2004) performed a web-based survey in the US examining the fertility concerns of young women treated for early stage breast cancer. The majority (86%) of the participants reported knowing at the time of their diagnoses that adjuvant treatments may damage their fertility; 72% recalled discussions with their oncologists about this

issue. The authors reported that fertility issues were of a high level of concern for many of their participants, and, where discussed prior to the commencement of systemic treatments, had influenced the treatment decisions they had made.

In contrast to this study, Duffy, Allen and Clark (2005) reported that only 34% of participants in their study undertaken in the US recalled fertility discussions having taken place with health professionals, and 68% recalled discussions about menopause, although 98% recalled discussions of other side-effect related issues. Bloom et al. (2004) reported that 37% of breast cancer survivors described communication difficulties with health professionals, feeling that they were not listened to and that physicians seemed to be insensitive to psychological matters. This study was also undertaken in the US.

A qualitative study undertaken in Australia explored the information needs regarding issues of fertility and menopause, of younger women with breast cancer (Thewes et al., 2003). The 24 participants were up to five years post-diagnosis and reported feeling that available information was insufficient or non-existent, and sometimes difficult to access. They reported that their needs for information and discussions around fertility issues increased after the initial diagnosis phase, and were ongoing needs. Some expressed their senses of disparities between the importance of this issue to them versus the importance of the issue to the health care providers. There were also reports of inconsistent and incompatible information being given by different health care providers. Some participants felt that they were rushed into treatment decisions and not given the time or information needed to make informed choices where issues of fertility were concerned.

The authors recommended that information about fertility and menopause issues for young women with cancer be more readily available, be given by a designated health professional with expert knowledge of both oncology and fertility, and that this information and support be available in an ongoing manner. In this study, consultation with a fertility or menopause specialist was reported to be the preferred means of receiving information about these respective issues.

Another Australian study explored the phenomenon of decision-making for women with breast cancer (Halkett, Arbon, Scutter, & Borg, 2007). The authors reported five key themes: “being challenged”, “getting ready”, “surviving”, “sharing the challenge”, and “interrogating the future” (pp. 324-325). Of interest for the current study, the theme ‘getting ready’ described the processes by which the participants developed relationships with health professionals and other sources of support or guidance, gathered and assessed information, and prepared themselves for making informed treatment choices. Crucial aspects of success in this phase were information quality and availability, good relationships with key health professionals, and enough time to absorb the impact of their diagnoses and then gain an understanding of their situations and treatment options. In addition, the theme ‘surviving’ included the participants’ experiences of loss of control over their lives, futures and choices in response to their cancer diagnoses. They described feeling that their lack of knowledge and expertise required them to rely on the guidance of health professionals. This meant handing control over to others in the urgency of their situations. The limited time available for information and decision-making impacted on some participants’ abilities to make decisions that they were

comfortable with. Over time, and after the initial rush to surgery in the wake of their diagnoses, the participants were able to regain a degree of control over their future choices and decisions.

In a large qualitative study in Victoria, Australia, patient and health professional constructions of intimacy and sexuality in cancer and palliative care were explored (Hordern & Street, 2007a, 2007b). The findings of this study showed clearly that these two groups were widely mismatched in their understandings of intimacy and sexuality. The authors described the overall findings as “unmet needs” on the part of patients, and “mismatched expectations in the communication process” between the two groups (2007b, p.225). The findings suggested that the majority of patients desired open communication regarding sexuality regardless of age, diagnosis, partner status or sexual orientation, but that health professionals continued to construe sexuality in very limited terms. The findings indicated that health professionals expressed uncertainty and embarrassment in sexuality discussions, and privileged their own clinical concerns, assuming that patients’ priorities were the same as theirs - survival being the primary concern. This study also identified systemic constraints, such as lack of privacy and time that impacted on the possibility of open discussions.

The way in which information is communicated has also been shown to be important. As part of a larger study, the long-term menopause-related effects of cancer treatments were reported in another Australian study, previously described (McCarthy et al., 2009). Of note for this part of the discussion, some participants in this study were unaware that the

menstrual changes that they had been informed about actually implied permanent menopause. This indicated that either the information given, or the timing and manner of information provision, was inappropriate for their needs.

There is also a need to both improve and explore the provision of information regarding fertility, menopause and general sexuality throughout the cancer trajectory, as issues and needs related to these continue over time (J. Carter et al., 2005; Connell et al., 2006; Hammond et al., 2008; Knobf, 2008). Accordingly, a large survey study of women who had undergone haematopoietic stem cell transplantation while pre-menopausal, found that 38% had discussed fertility issues with health professionals subsequent to their transplants and 54% had discussed issues related to menopause (Nakayama et al., 2009). While the participants considered that fertility and menopause were of equal concern at the time of their diagnoses, they reported that issues related to menopause were increasingly important to them in the survivorship phase.

Ramfelt and Lutzen (2005), examining patient participation in cancer treatment decisions in Sweden, reported an overall theme of “compliant participation in serious decisions” (p. 147), consisting of complying with or without active participation. Complying with participation reflected open communication, self-confidence and feelings of competence. Complying without participation reflected feelings of powerlessness, distress, and being hurried. This was influenced by a multitude of factors, including the patient’s understanding of the situation, the information they had or were given, the meaning that the illness had for them, and other contextual factors. Both styles were seen to be ways of

maintaining a degree of control in an unusual and threatening situation. In concordance, another British study examining the decision-making preferences of people with colorectal cancer found that feeling informed and part of decision-making about potential treatments may be more important than the making of the final treatment decision (Beaver et al., 2005).

Two concepts, “communicative alienation” and “boundedness” (p. 1486), were proposed in an Australian study of people with cancer diagnoses (Little, Jordens, Paul, Montgomery, & Philipson, 1998). ‘Communicative alienation’ was described as being unable to fully share the cancer experience with others who had not themselves experienced it. This led to a sense of isolation, and sometimes a voluntary withdrawal from normal social relationships related to feeling misunderstood, a perception of being different, or desiring different sources of support from those sought prior to the diagnosis. ‘Boundedness’ was described as the uncomfortable knowledge of the presence of boundaries to time, space, personal resources and empowerment due to the cancer diagnosis. This was particularly noted in the diagnosis and treatment phase in which the participants felt contained physically by the limitations of their treatments and/or hospitalisation. They also described feeling contained cognitively by their lack of knowledge and expertise, and the shock associated with their diagnoses. This resulted in a state of “necessary compliance with the medical system” (p.1488) at this stage of their cancer trajectory (Little et al., 1998).

These concepts were further explored in a study of women with advanced ovarian cancer (K. Thompson, 2007). Thompson challenged the negative connotation of ‘boundedness’ described by Little et al. (1998), suggesting that a cancer diagnosis may lead to an increased sense of empowerment through a perceived need to employ advocacy within a system that was felt to be unresponsive and difficult to negotiate. Where a sense of ‘communicative alienation’ was present, Thompson related this to the inability of significant others to hear and understand rather than the person’s inability to articulate. This alienation could, therefore, be counteracted in communication with another who shared the same experiences, such as in a peer support group or support relationship. Thompson also suggested that the sense of alienation that people experienced was related to their experiences of communication with health professionals, as well as loved ones. This was an extension of the findings of Little et al. (1998) in which ‘communicative alienation’ was related to social relationships.

Finally, the first phase of results from the New Zealand Cancer Control Council-led Cancer Care Survey were reported in December 2009 (Cancer Control Council of New Zealand, 2009). This survey involved 2,221 participants who had received treatment at one of eight cancer centres in New Zealand over the previous twelve month period. Where information about treatments and decision-making were concerned, 57% of participants reported being given enough information to assist in their decision-making about treatments, 54% reported understanding this information, 62% reported that this information was given at the right time for them, 60% of participants reported being satisfied with their level of involvement in decision-making, 68% felt comfortable posing

questions to members of their healthcare teams, and 58% reported knowing who to pose questions to. Less than half of the participants reported that, if needed, they received enough information about the potential emotional effects of their diagnoses and treatments, and potential changes to their intimate relationships and sexuality.

Research into the Beliefs and Practices of Health Professionals

Studies focused on the knowledge, attitudes and practices of health professionals related to fertility, fertility preservation, and sexuality issues in cancer have been reported in recent years. Of note, level of knowledge, experience or preparation (Lavin & Hyde, 2006; E. R. Park et al., 2009; Quinn et al., 2007; Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002; Stead, Brown, Fallowfield, & Selby, 2003), beliefs about what is important to patients (Quinn et al., 2007), systemic variables such as time pressures and the availability and cost of fertility services (Quinn et al., 2007; Stead et al., 2003), and embarrassment or discomfort (Hordern & Street, 2007a; Lavin & Hyde, 2006; E. R. Park et al., 2009; Stead et al., 2003) have been reported as important influencing factors on the likelihood of health professionals raising these issues with patients.

Supporting this, a recent qualitative study looking at oncology nurses' knowledge, attitudes and practice related to fertility preservation reported that only half of their participants routinely discussed fertility preservation with patients (King et al., 2008). This was despite their reported beliefs that this was part of their role. The knowledge bases of the participants were variable, and they reported issues with time, privacy, their own comfort levels with the topic, concerns for ethical and financial issues, patient factors, and the prioritisation of survival over other issues.

In summary, many studies related to information, communication, and decision-making in the context of cancer have been reported. These indicate that there are ongoing issues in communication practices, information provision, and decision-making, particularly related to issues of fertility, menopause and sexuality that remain to be adequately addressed. Many of these issues relate to the communication skills and practices of health professionals, and the impact of the systems in which they practise.

Survivorship Care and Support

Clinical Follow-up Care

There is much debate about the current and future provision of quality care for cancer survivors. A growing body of research suggests that current ways of providing care to cancer survivors often fail to meet the non-physiological needs that patients describe as important (Absolom et al., 2009; Baravelli et al., 2009; Ganz, Casillas, & Hahn, 2008; M. E. Hewitt et al., 2007; Hordern & Street, 2007a; Lewis et al., 2009). Where current services are predominantly provided by hospital-based medical practitioners, there are suggestions that nurse-led care may be more appropriate and acceptable from both patient and service perspectives, although the evidence for this is equivocal (Lewis et al., 2009; Lydon, Beaver, Newbery, & Wray, 2009; McCabe & Jacobs, 2008).

Innovative styles of service provision are also being suggested and trialled, including the use of telephone support during and after treatment completion (Beaver et al., 2009; Ream, Richardson, Wiseman, Hughes, & Forbes, 2009) and the use of formalised survivorship care plans (Baravelli et al., 2009; M. E. Hewitt et al., 2007). In addition,

alternative ways of providing information pertinent to cancer survivorship are being explored (Karahalios et al., 2007).

Of note also is the need for age-appropriate information, care, treatment and support for younger adults (Zebrack, Mills, & Weitzman, 2007), and the development of a wider range of services that meet patients' needs and the needs of current and future fiscal constraints (Beaver et al., 2009). Anecdotal evidence suggests that some cancer centres are developing advanced nursing roles in areas related to fertility and sexuality in cancer care (Canada & Schover, 2005; Foy, 2008).

Psycho-Social Support

There are two basic phases of the cancer journey in which support may be required – through the diagnosis and treatment time, and in the ongoing survivorship phase. Within this, professional psychological support and peer support offer different yet complementary services.

Marlow et al. (2003), in an Australian study, developed an integrated model of psycho-social needs and support for women with breast cancer that included “knowing what to expect”, “being able to make choices and decisions”, “having an integrated support network”, and “being taken seriously throughout the cancer trajectory” (p. 326). This model was supported in the findings of another Australian study (Thewes et al., 2004), that suggested that breast cancer survivors, particularly those of younger age, report psychological, practical, physical and informational needs related to their diagnoses.

The recently reported initial findings of the New Zealand Cancer Care Survey (Cancer Control Council of New Zealand, 2009) suggest that the experiences of New Zealand cancer patients were generally very positive, with 98% of participants reporting their care as good, very good or excellent. Of interest for the current study, however, some aspects of care were rated as less satisfactory. Fifty-three percent of participants felt that their healthcare providers could have done more to assist them to manage their fear and anxiety by referring them to suitable services at the time of their diagnoses, and 36% in the survivorship phase.

In response to continuing poor outcomes for Māori in terms of rates of cancer diagnoses and survival, a study exploring the experiences of Māori with cancer and their whānau was recently reported (Walker, Signal, Russell, Smiler, & Tuhiwai-Ruru, 2008). The findings from this study indicate that increased governmental support for Māori healthcare providers, continuing focus on the cultural competence of health professionals, increased representation of Māori in the health professions and, of importance here, increased availability of patient navigation services for Māori, would help to mitigate the negative aspects of their engagement with the current cancer care systems in New Zealand.

Professional Psychological Support

Support for people with cancer comes in many guises, from therapeutic communication and the provision of information during consultations with members of the healthcare team, to the provision of specialist psychological care. This may be in the form of individual consultation or specific therapeutic group programmes (Cameron, Booth,

Schlatter, Ziginskas, & Harmon, 2007; Gunn, Meiser, Thewes, & Cairns, 2005). Although the support needs of some patients may be met during general consultations with members of the healthcare team, reports suggest that referral to specialist psychological services may be indicated for some patients at all stages of the cancer journey (Armes et al., 2009; C. Davis, Williams, Parle, Redman, & Turner, 2004; Steginga et al., 2008; Zebrack et al., 2007). In addition, some reports suggest increased needs for supportive care in younger women with cancer related to the unique challenges associated with their young age (Connell, Patterson, & Newman, 2006a). Some also report deficiencies in the provision of information about, and referral to, supportive care services (Redman, Turner, & Davis, 2003; Steginga et al., 2008; Walton, Reeve, Brown, & Farquhar, 2009).

Of particular relevance here, a recent New Zealand study reported the supportive care needs of women who had received treatment for gynaecological cancers (Walton et al., 2009). This qualitative study involved 23 women aged 27-79 with diagnoses of gynaecological cancers, who were recruited from a tertiary gynaecology service in Auckland. The main findings of relevance for the current study were related to the women's motivations for seeking support, and their assessments of how this care is provided. The participants were motivated by desires for information and reassurance, particularly during treatment decision-making, and a sense of being heard was important. Younger participants expressed their concerns at the lack of consideration, or even avoidance, of issues related to sexuality. Where organisation of care was concerned, although many described their positive experiences of the specialist services provided,

many also expressed disappointment at a lack of co-ordination or continuity of services, particularly involving psycho-social or off-site services. This was mainly noted at the end of the intensive treatment period.

In addition, a large prospective longitudinal survey of the supportive care needs of cancer patients in the UK was recently reported (Armes et al., 2009). The main study instrument employed was the Supportive Care Needs Survey, a validated instrument that assesses cancer patients' needs in five domains: psychological, health system and information, physical and daily activity, patient care and support, and sexuality. This instrument and other baseline surveys were completed at the end of treatment and six months later. The study involved 1,152 participants with varied cancer diagnoses. While most participants did not report unmet supportive care needs after completion of their cancer treatments, one third of participants reported five or more unmet needs in these domains at the end of their treatments, and 60% of these continued to report unmet needs after six months. Fear of recurrence, hormonal therapy, and experiencing a traumatic event subsequent to treatment completion were predictors of moderate to severe unmet needs at the six month assessment. Needs in the psychological domain and fear of recurrence were the most prevalent unmet needs at both assessments.

Peer Support

Peer support, in which people with similar experiences are brought together in some way to share and support each other, is a commonly sought source of support for people with cancer diagnoses. A number of Australian studies have explored the use of support groups, including a recent systematic review that reported a high level of patient

satisfaction with different types of peer support, but mixed results for psycho-social benefits (Hoey, Ieropoli, White, & Jefford, 2008). The authors identified five types of peer support: one on one face-to-face, one on one telephone support, group face-to-face, group telephone support and group internet support.

Butow et al. (2007) reported diverse involvement in and preference for peer support in a survey of 417 participants in 47 cancer support groups also in Australia. The participants generally preferred to meet with people with similar diagnoses, in groups with strong leadership, and with some level of endorsement from their healthcare teams. The opportunity to learn more about cancer was valued, and the level of emotional support was generally reported to be acceptable. Interestingly, 93% of participants felt that a poor prognosis should not be a reason for exclusion from peer groups. It was notable that peer support for people of different ethnic backgrounds was limited, particularly where English was not the primary language. The authors recommended that the provision of peer support be individually assessed based on the demographics and need of the group concerned, but that skilled joint leadership including both a health professional and a cancer survivor was optimal (Butow et al., 2007).

A number of studies have reported the lack of peer support that is specific to younger people (Connell et al., 2006a). Being unable to contact and communicate with women of a similar age may lead to feelings of isolation and difference because the issues and needs of older women are seen to be different, and often less relevant or helpful (Dunn & Steginga, 2000; Marlow et al., 2003). Thewes et al. (2004) also described this sense of

isolation and aloneness experienced by younger women with breast cancer. The participants in their study felt that existing peer support groups did not cater to their needs, as they wanted to ‘debrief’ with someone close to their own ages, with similar social circumstances and life stage concerns. Also, meeting with, or hearing of other young women with positive prognoses was important to these participants. Another finding in this study was that younger women wanted more ‘positive’ support, and saw themselves as healthy ‘survivors’ rather than in patient roles.

There is also some progress in examining and diversifying the ways in which peer support is offered to increase its availability. For example, a study reporting video-conferencing as a way of providing peer support to women in rural areas in the US suggested that this may be a useful and successful alternative way of reaching women (Collie et al., 2007). This has also been suggested in Australian research (Connell et al., 2006a).

Regarding access to information, the positive and potentially negative aspects of peer contact, information sharing, and support were reported in an American study involving 30 people who had previously undergone haematopoietic stem cell transplant (Rini et al., 2007). The findings of this study indicated that while positive results, such as being more prepared for treatment and being able to assess one’s own situation in comparison with others, were prominent, negative results such as receiving distressing or inappropriate information were reported, and may be a cause for concern.

In addition, a study examining the quality of information about breast cancer posted on the internet was recently reported (Ream, Blows, Scanlon, & Richardson, 2009). In this study information related to breast cancer that was posted on the internet by ten voluntary organisations in the UK was appraised. Concerns were raised as to the authorship and current relevance of the information provided by some sites. Recommendations were made as to the oversight of this information by those responsible for their posting, and for health professionals to be well informed about the quality, completeness, currency and accuracy of the sources of information to which they direct patients.

In summary, published studies demonstrate that there are many forms of support available to people with cancer, and innovative ways of providing both physiological follow-up and psycho-social support. Despite this, many patients report a lack of access to support that meets their needs throughout their cancer journeys. Once again, the majority of published studies were related to the experiences and needs of women with breast and gynaecological cancers.

CONCLUSION

This review of the literature has shown that there is a growing interest in the longer term psycho-social impact of cancer and its treatment. There is much evidence to suggest that this impact may be both considerable and wide-ranging for some cancer survivors. While there is limited literature specific to the emotional and interpersonal aspects of fertility damage and/or premature menopause from cancer treatments, existing studies suggest

that these long-term effects are often experienced as distressing, and have implications for ongoing quality of life. In addition, there is evidence that issues such as fertility and premature menopause continue to be neglected in treatment discussions and decision-making, and survivorship care.

It was concerning that the majority of the limited research specifically addressing fertility damage and premature menopause related to cancer treatments involved European women with breast or gynaecological cancers. In addition, due to the small number and primarily qualitative nature of previous research projects, the range of experiences accounted for in the literature is very limited. Therefore, building on the findings of the previous studies discussed in this review, the current study will provide a deeper understanding of the emotional and interpersonal impact of fertility damage and/or premature menopause from cancer treatments. This will include the experiences of women with diagnoses of breast, gynaecological and haematological cancers, and women of different ethnicity and sexual orientation.

This study will meet a number of needs identified in this literature review: firstly, it will address the issue of fertility damage and premature menopause from cancer treatments specifically rather than as one aspect of women's wider experiences of cancer; secondly, it will contribute to knowledge of the issue from the perspective of a wider range of women in terms of ethnicity, sexual orientation and cancer diagnosis; and thirdly, it will move beyond qualitative description to provide an interpretation of women's experiences,

building on existing knowledge and strengthened by the use of a defined and appropriate conceptual framework.

CHAPTER THREE: CONCEPTUAL FRAMEWORK

INTRODUCTION

This chapter discusses the concept of chronic sorrow and the middle-range nursing theory that has been developed from it. In contrast to other theoretical concepts, chronic sorrow has also been applied clinically as a diagnosis and was accepted by the North American Nursing Diagnosis Association (NANDA) as an official nursing diagnosis in 1998. The middle-range theory of chronic sorrow was initially developed by a consortium of nurse researchers and published in 1998 (Eakes, Burke, & Hainsworth, 1998), and has been extended by a small number of subsequent studies. The majority of the research literature related to chronic sorrow is focused on it as a diagnosis, contributing to the understanding of the concept of chronic sorrow and its application in the clinical context.

The chapter begins by describing the early development of the concept of chronic sorrow, followed by a description of the development of the middle-range theory of chronic sorrow that is the primary source of the conceptual framework used in this study. Following this, studies of the clinical application of the theory will be described, and the relationship of chronic sorrow to both grief and depression will be discussed. A brief explanation of why this theory has been used as the conceptual framework for this study will follow.

EARLY DEVELOPMENT OF THE CONCEPT

Chronic sorrow as a concept was first proposed by Olshansky (1962) with reference to the profound, pervasive sorrow experienced by parents of children with severe developmental disabilities. Olshansky, a rehabilitation specialist and counsellor, and his colleagues at an American child development service, identified symptoms such as ongoing sadness, grief, and guilt in the majority of the parents they worked with, regardless of the age of the child or the particular situation of the family. They also noted that these symptoms were variable in their intensity within and between people, but were chronic and pervasive (being persistent and having a wide-spread effect on those affected). Olshansky emphasised that the presence of ‘chronic sorrow’ in these families was a normal response to their situation and the many losses associated with it, and that this should be accepted as an understandable reaction to “a tragic fact” (1962, p.191).

Chronic sorrow as an alternative way to explain and understand the experience of loss was then largely ignored in research for two decades before being re-introduced in a small number of studies in the 1980’s (Copley & Bodensteiner, 1987; Damrosch & Perry, 1989; Fraley, 1986; Wikler, Wasow, & Hatfield, 1981). These studies confirmed chronic sorrow as a valid way to understand and explain people’s responses to loss situations, particularly parental responses to the birth of a disabled child. These also added considerably to the development of the concept of chronic sorrow.

Chronic sorrow as a concept continued to be applied in research throughout the 1990’s with a notable increase in studies undertaken by nurse researchers. During this time the

concept was applied to a greater range of patient populations, including adults with various chronic illnesses. Key studies from this period are described below.

An early analysis of the concept of chronic sorrow was undertaken by Teel (1991). Teel proposed that chronic sorrow occurs in response to events with life-long implications, and results in individuals experiencing “psychic pain and sadness” (p. 1316). She emphasised the importance of acknowledging that the interpretation of an event as loss-inducing is highly personal, and that the presence of chronic sorrow hinges on this interpretation, and on the perception of a ‘disparity’ between past and present/future caused by the loss. This disparity may be tangible, such as a lost relationship or physical ability, or symbolic, such as lost dreams or expectations. Teel differentiated chronic sorrow from the more common linear theories of bereavement on the grounds that loss with a component of ongoing disparity is different to temporally defined loss such as death, and requires a different understanding. Olshansky’s (1962) designation of chronic sorrow as a normal, rather than pathological, response to loss was reinforced. Teel’s analysis also confirmed periodicity (recurrence), variability (within and between those affected), and permanence as key aspects of chronic sorrow.

Further development of the concept was undertaken by ‘The Nursing Consortium for Research on Chronic Sorrow’ (NCRCS), which was formed in 1989. This group formally tested the concept of chronic sorrow, and undertook a number of studies in different patient populations. Some of these studies are described below. At this time, Burke (1989) developed the ‘Chronic Sorrow Questionnaire’, an instrument for the

assessment and diagnosis of chronic sorrow (Burke, 1989). This was used and developed further by the NCRCS in the course of their studies (Burke, Hainsworth, Eakes, & Lindgren, 1992; Eakes, 1993). Through their formal examination of the concept of chronic sorrow, the NCRCS confirmed that chronic sorrow occurs in response to an identifiable “antecedent loss event” (p. 35) that has a persistent impact on life (Lindgren, Burke, Hainsworth, & Eakes, 1992). They also confirmed that chronic sorrow involves a recurring, periodic sadness that is both permanent and progressive, and associated with the losses and disappointments of chronic illness or disability. Accordingly, they proposed four “critical attributes of chronic sorrow” (Lindgren et al., 1992):

1. A perception of sadness or sorrow over time in a situation that has no predictable end
2. Sadness or sorrow that is cyclic or recurrent
3. Sadness or sorrow that is triggered either internally or externally and brings to mind the person’s losses, disappointment, or fear
4. Sadness or sorrow that is progressive and can intensify even years after the initial sense of loss, disappointment, or fear (p.31)

They extended the original conceptualisation of chronic sorrow by proposing firstly, that it can be used diagnostically in patients themselves rather than in family caregivers alone, and secondly, that it is continually re-defined in new situations which stimulate or ‘trigger’ more sadness. Their analyses differentiated chronic sorrow from grief on the grounds that chronic sorrow involves a number of ongoing losses over time, and that resolution is therefore unlikely to be achievable. They also differentiated chronic sorrow from depression, but found that chronic sorrow can co-exist with both depression and grief (Lindgren et al., 1992). Clearly, however, chronic sorrow, depression and grief also frequently exist independently of each other. The NCRCS studies confirmed that

chronic sorrow is a normal response to significant loss (real or symbolic) and suggested that the person is tied to the ongoing loss due to constant reminders of the disparity that is the consequence of the loss. They further differentiated chronic sorrow from grief or depression, by stating that the person experiencing chronic sorrow is likely to be highly functioning and able to perform the ongoing activities of daily life (Burke et al., 1992).

One of the consortium members explored the concept of chronic sorrow as a means to understand the experience of living with cancer (Eakes, Burke, Hainsworth, & Lindgren, 1993). The participants in this study were aged from 38-76 years, and were three to fifteen years from the time of their cancer diagnoses; there were ten participants of both sexes, with a range of cancer diagnoses. The findings confirmed the presence of chronic sorrow in nine of the ten participants, who described the range of feelings they experienced at the time of their diagnoses, and the periodic recurrence of these feelings since. The emotional responses they described included sadness, denial, fear, depression and despair. The intensity of these recurrent feelings was described as varied, ranging from more intense than those experienced at the time of their diagnoses, to less intense, and fluctuating over the time since their diagnoses. Many factors were found to trigger a recurrence of these feelings, including “management crises” (p.1328). These were described as events directly related to the cancer or its treatment and ongoing management, reminders of the cancer arising from the diagnosis of, or death from cancer of someone else, other stressful life events, anniversaries related to the cancer, and the ongoing physical reminders of the cancer (Eakes, 1993).

The participants in this study also discussed coping strategies that they used and/or found successful (Eakes, 1993). Cognitive strategies such as positive thinking and trying to regain control were common, as were action-oriented strategies such as journaling, keeping busy and being informed. Less common were interpersonal activities such as talking with others, and emotional strategies such as crying. Of note, some participants described difficulties in discussing their diagnoses with their families, leading to a sense of isolation. In addition, although the participants generally reported positive relationships with health professionals, some stated that they were not given adequate time to assimilate their diagnoses before needing to make life-changing decisions, and that their needs for information and support were not always met.

The consortium also published a study examining the presence of chronic sorrow in people with a range of chronic illnesses, including five couples with infertility and ten people with a cancer diagnosis (Hainsworth, Eakes, & Burke, 1994). Of relevance for the current study, chronic sorrow was identified in 90% of the couples with infertility and 90% of the people with cancer. The most commonly reported emotional responses were sadness, guilt, anger, frustration and fear. A range of coping strategies were used by the participants in this study. 'Action' strategies, such as remaining involved in personal interests, keeping busy, and acting to regain control, were used by 80% of people with cancer and 50% of couples with infertility; 'cognitive' strategies, such as remaining positive, having a 'can-do' attitude, taking 'one day at a time', and acting to regain control, were used by 90% of people with cancer and 60% of couples with infertility; 'interpersonal' strategies, such as peer support or support from loved ones or health

professionals, were used by 50% of both groups; and 'emotional' strategies, such as venting feelings and praying, were used by 40% of people with cancer and 30% of those with infertility.

Researchers not associated with the NCRCs also contributed to the literature on the concept of chronic sorrow during this time. The concept was discussed in an article reviewing grief reactions as a response to 'loss of ability', including infertility (Hewson, 1997). Hewson supported the findings of Teel (1991) by differentiating between linear models of grief and chronic sorrow, stating that new crises related to the loss of ability require the person to undertake new "grief work" (p. 1129). This review also confirmed and expanded on Teel's (1991) findings that the experience and meaning of loss is mediated by the context of the loss, a personal appraisal of the situation, the implications of the loss, and the personal values, experiences and expectations of individuals. Further, the presence of chronic sorrow was found to be dependent on the perception of ongoing disparity related to the loss. This article also confirmed that people suffering from chronic sorrow are mostly able to function well, but that the sorrow recurs and the feelings may be as intense as the first time. Hewson (1997) suggested that 'episodic' would be a better word than 'chronic' to explain the temporal nature of the concept as the extreme sorrow is not constant. She proposed an alternative "Episodic Stress Response Model" (p. 1134), similar to the concept of chronic sorrow but arising out of stress and adaptation theory. This model emphasises that the many stressors associated with loss of ability result in different psychological responses, and thus require a range of management strategies.

THE DEVELOPMENT OF THE THEORY OF CHRONIC SORROW

The NCRCS undertook a number of qualitative studies involving 196 people during their concept analysis and theory development work, culminating in the development and validation of a middle-range theory of chronic sorrow (Eakes et al., 1998). These studies, some of which were described above, involved three distinct populations – people living with chronic or life-threatening illness (including cancer and infertility), people caring for loved ones with chronic or life-threatening illness, and bereaved people (Burke, Eakes, & Hainsworth, 1999; Eakes, 1993; Eakes, 1995; Eakes et al., 1993; Hainsworth, 1994; Hainsworth, Burke, Lindgren, & Eakes, 1993; Hainsworth, Busch, Eakes, & Burke, 1995; Hainsworth et al., 1994; Lindgren, 1996). The presence of chronic sorrow was confirmed in 86% of those with chronic or life-threatening illness, 82% of their family caregivers, and 97% of the bereaved population (Burke et al., 1999).

These studies corroborated much of the existing knowledge, described above, of the nature and course of chronic sorrow in response to a primary antecedent loss event. They determined that this significant loss may be a concrete or a symbolic loss, and that the way this is interpreted and experienced is highly individual and contextually-mediated. The pervasive, permanent and cyclic nature of chronic sorrow was also substantiated in these studies, as was the presence of chronic sorrow in both an individual suffering a loss, and their significant others (Eakes et al., 1998).

As a result of some of their findings, however, the NCRCS also challenged existing knowledge of chronic sorrow, and modified their own earlier statements in two key ways

(Eakes et al., 1998). Firstly, their research did not consistently confirm the progressivity of chronic sorrow (the potential of chronic sorrow to worsen over time), but did identify the potential for progressivity. Secondly, their research demonstrated the presence of chronic sorrow in people after a single, circumscribed loss event such as the death of a loved one, a circumstance that had previously been considered to be outside of the boundaries of chronic sorrow. This important finding led to their claim that it is the ongoing presence of “unresolved disparity” (p.181) produced by the loss that leads to chronic sorrow, not the loss event itself. It is this ongoing, life-changing disparity between the reality of the life situation and the desired and anticipated life situation that leads to the pervasive, permanent, periodic and potentially progressive cycle of chronic sorrow. The NCRCS thus re-defined chronic sorrow as “the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with ongoing disparity resulting from a loss experience” (Eakes et al., 1998, p. 180).

The NCRCS studies also added to the understanding of the nature and the importance of triggers, or “trigger events” (p. 181) in the continuation of the chronic sorrow cycle. The authors described trigger events as experiences, events or milestones that relate to or highlight the initial loss or resulting life disparity, and are therefore also individualised and contextual in nature. Trigger events reinforce the person’s loss and the resulting disparity, leading to an exacerbation of their emotional suffering (Eakes et al., 1998).

Finally, the NCRCS suggested “management methods” (p. 182) that could be used to reduce the emotional suffering associated with chronic sorrow (Eakes et al., 1998).

‘Internal management methods’ that they suggested included personal coping strategies employed by the individual. These are congruent with strategies used by people in many stressful situations, such as: action strategies (engaging in activities and interests, seeking information, accepting respite); cognitive strategies (positive thinking, taking ‘one day at a time’, and having a ‘can do’ attitude to life); and interpersonal strategies (meeting with others in a similar situation, talking with close friends or family, or health professionals); and other internal methods such as trusting in religious beliefs. ‘External management methods’ suggested were those employed by health professionals to assist people living with chronic sorrow. These involve, firstly, an awareness of the potential for chronic sorrow and an understanding of how chronic sorrow is experienced, then offering an empathic and caring presence, and providing appropriate and desired information.

The work of the NCRCS in confirming and developing knowledge of chronic sorrow resulted in their middle-range theory of chronic sorrow, illustrated diagrammatically below (Eakes et al., 1998):

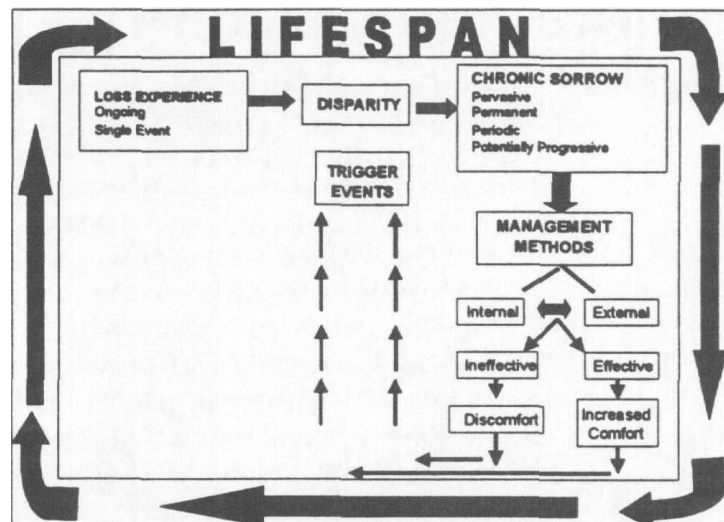


Figure 1. Theoretical Model of Chronic Sorrow (Eakes et al., 1998)

Following this early development of the middle-range theory of chronic sorrow (Eakes et al., 1998), the NCRCS continued to explore its application. In particular, they focused on the presence and impact of trigger events, or “milestones of chronic sorrow” (Burke et al., 1999, p. 377). These were found to be largely the same over the three populations that they studied (people living with chronic or life-threatening illness, people caring for loved ones with chronic or life-threatening illness, and bereaved people) but with differences in prevalence or importance. For those with chronic illnesses (including cancer and infertility) comparisons with norms (social, developmental and personal), ‘management crises’ and anniversaries of significant events were identified as the three principal triggers of exacerbations of distress.

The authors found that comparisons with social norms were induced by people or circumstances that reminded the affected person that they were different from their peers, reinforcing the disparity between self and others. Comparisons with developmental norms were related to the acknowledgement of the normal developmental milestones that individuals or families achieve, and the realization that these were no longer achievable. Comparisons with personal norms were induced by noting the differences, or disparity, between the past self and the present/future self and the associated abilities and options. Management crises were defined as occurring when symptoms of the chronic illness intensified, or complications arose, leading to temporary or permanent alterations to functioning; and anniversaries were defined as reminders of either positive or negative past experiences related to the current and ongoing situation (Burke et al., 1999). The authors reiterated that all of these trigger events or milestones serve to reinforce the

impact of the initial loss and resulting disparity. They emphasized again, however, that the majority of their participants managed to live well and meet the responsibilities of their new lives in between exacerbations of emotional distress, and some reported that they received benefits through new insights and relationships (Burke et al., 1999).

A small number of subsequent studies has contributed explicitly to the ongoing development of the theory of chronic sorrow and will be discussed here. Northington (2000) explored the experiences of caregivers of African-American children with sickle cell disease in order to develop “a substantive theory of chronic sorrow” in this population (p. 141). The participants’ experiences of chronic sorrow in this study were described as “dynamic, cyclic, variable in duration and intensity and not always predictable” (p.147). Northington (2000) concluded that the sorrow experienced by the participants at the time of their children’s diagnoses did not become chronic until it was re-experienced as time progressed. The diagnosis and associated practical life changes challenged the participants’ existing behavioural patterns, or ways of being and reacting, which required the seeking and development of new patterns to manage the disease and the associated disruptions to their daily lives. Northington described this as “doing what you have to and moving on” (p.149), a process of understanding that although they had no control over the disease or its outcome, they could control their own reactions and responses to it. Over time, these new ways of reacting and responding became the new ‘pattern’, allowing the participants to cope and make sense of their situations. Northington reported that in this way, the participants found themselves continually defining and redefining their notions of reality in response to the demands placed upon

them by their situations and the effects of triggered exacerbations of their emotional distress. The lifestyle and psychological alterations they made in response to the hardships associated with caring for a child with sickle cell disease then became normalised into their everyday lives as new patterns of living and being.

Northington (2000) concluded that through this cycle of internalisation and repatterning in response to an ongoing loss situation, chronic sorrow can result in personal growth. This was the key contribution made by Northington to the theory of chronic sorrow, expanding the understanding of internal management methods to encompass personal growth in addition to a reduction in the level of emotional suffering experienced.

Another study, comparing mothers of children with chronic illnesses to mothers of children with acute illnesses in an attempt to quantitatively validate the construct of chronic sorrow in this population, challenged the validity of chronic sorrow as a concept separate from grief (Dunning, 2000). This study was published as her doctoral dissertation. Dunning used a number of quantitative instruments for data collection including two visual analogue scales that were developed specifically for the study. Data were collected to measure fear, sadness, anger, frustration, helplessness, hopelessness and depression, aspects of chronic sorrow that were determined from the literature related to parents of children with chronic illnesses or intellectual disabilities. The study findings indicated no clear differences between the groups for the measured variables. Dunning argued that the construct of chronic sorrow, as defined by these variables, was not

validated in this population and may not, in fact, exist separately from wider understandings of grief.

Roos (2002) defined chronic sorrow as encompassing a set of grief responses related to the loss of some aspect of the self or a much-loved other, particularly in relation to those who care for loved ones with significant disabilities or chronic illnesses. She suggested that the presence of such loss results in the experience of “living loss” (p. 26), and requires ongoing renegotiations in life in response to the demands of the loss situation. Roos contended that chronic sorrow occurs only where the loss has an ongoing tangible impact on life, and therefore situations of bereavement would induce grief rather than chronic sorrow. The perception of disparity that is such an important feature of the theory of chronic sorrow (Eakes et al., 1998) was also a key consideration for Roos (2002) as she described the irreparable division between the affected person’s anticipated or expected life and the reality that they are living – a “painful discrepancy between what is perceived as reality and what continues to be dreamed of” (p. 26). Roos also supported previous findings that those affected by chronic sorrow are generally able to function according to the realities of their circumstances in between periods of exacerbation of chronic sorrow, and noted that where the loss is invisible (as in infertility) there may be the added grief of such a personal and encompassing loss being unacknowledged.

Roos proposed an alternative model of chronic sorrow that included five dimensions: the characteristics of the loss, the continuity of the loss, initial and ongoing grief responses, the discrepancy between that which was dreamed of and the reality of life, and the

continuing presence of the source of the loss (Roos, 2002). The key difference with Roos' model is the requirement for the ongoing and life-impacting presence of the "actual source or object of the loss" (p. 45), rather than the ongoing presence of 'disparity' related to the loss that was proposed by Eakes et al. (1998). Roos contended that chronic sorrow does not occur where loss is related to bereavement, for example, because although bereavement may result in persistent grief, it does not result in the ongoing crises and adaptations associated with chronic illness or disability.

Following on from this, Roos focused on the aftermath of the onset of chronic illnesses or disabilities (Roos & Neimeyer, 2007). Of note, Roos and Neimeyer expanded on the ways in which life events are interpreted as loss-inducing, and the influence of personal and contextual factors on this. They proposed that the meanings attached to particular aspects of life prior to the loss-inducing event mediate the post-event response, and that the presence and degree of distress the person experiences is related to this. They also described how traumatic loss can disrupt a person's understanding of self and the world. Expanding on Roos' previous work (2002), Roos and Neimeyer described how others may attribute blame to the person for aspects of the situation in which they find themselves, particularly where the loss and resulting disparity appear insignificant or are unseen. This may result in a decrease in the availability of social support, and an increase in the degree of distress the person experiences.

Hobdell (2004) examined chronic sorrow in parents of children with neural tube defects, seeking to clarify the dimensions of chronic sorrow and examine the relationship of

chronic sorrow to depression. Using an adapted version of the 'Chronic Sorrow Questionnaire' (Burke, 1989; Burke et al., 1992; Eakes, 1993), and a graph measure of the cyclical aspects of chronic sorrow, in addition to a validated measure of clinical depression, Hobdell surveyed 64 fathers and 68 mothers. The study findings supported existing understanding of chronic sorrow in three dimensions: types of emotional responses, cycling of emotions, and intensity of emotions, although Hobdell suggested that further investigation with more specific measures was indicated (Hobdell, 2004). The fourth dimension of progressivity was not examined because there was not an existing measure for this. The findings of this study suggested that depression may be associated with chronic sorrow although this association was 'modest'.

Kendall (2006) developed and tested the 'Kendall Chronic Sorrow Instrument' (KCSI), a quantitative instrument for the empirical assessment of chronic sorrow. This was reported in her doctoral dissertation. Kendall proposed a conceptual framework for chronic sorrow as a result of her review of the chronic sorrow literature, and after discussions with people affected by loss. Based on this, she recommended that the definition of chronic sorrow be extended to include feelings of invalidation, social isolation, being 'unheard', and being overwhelmed, exhausted or vulnerable. As a result, she suggested six domains that she considered to be key aspects of the experience of chronic sorrow: triggers, disparity, sadness, feelings of invalidation, being physically overwhelmed, and renormalisation (the return to normal functioning after an exacerbation of sorrow). The KCSI was based on these domains.

The KCSI (Kendall, 2006) was designed to assess for and measure chronic sorrow and was tested in a sample of 96 women who had identified as having experienced ongoing loss or losses of varied types. Two previously validated measures of depression (Centre for Epidemiology Studies – Depression Scale: CES-D) and general wellbeing (Global Wellbeing Scale: GWBS) were used in the validation and testing process. The KCSI was revised during this testing and validation process and the final version included eighteen items reflecting the key aspects of chronic sorrow. Kendall reported that the instrument also clearly differentiated chronic sorrow from depression, based on the statistical analyses she performed to test the KCSI, which included analysis of CES-D and GWBS scores. She further reported that chronic sorrow could exist in the presence or absence of both depression and wellbeing, as determined by these instruments. Kendall also proposed that although ‘grief’ and ‘chronic sorrow’ have many similarities, they are distinct entities, with chronic sorrow having particular relevance to the experience of ongoing loss. The development of the KCSI has contributed to the application of chronic sorrow in clinical practice and research. The key contribution of this study to the ongoing development of the theory of chronic sorrow, however, was Kendall’s suggestion that the current definition of chronic sorrow be extended to include a wider range of experiences.

Subsequently, Casale (2009) developed and tested a new quantitative instrument, the Casale-Roos Chronic Sorrow Inventory (CRCSI). This was reported in his doctoral dissertation. The aim was to test the CRCSI for the empirical assessment of chronic sorrow, and to investigate chronic sorrow as a diagnostic category separate from grief.

This instrument was based on Roos' (2002) conceptualisation of chronic sorrow as a 'living loss' (described above), rather than on the tenets of the theory of chronic sorrow described previously (Eakes et al., 1998). Casale administered the CRCSI and two additional validated instruments to three groups: the test group, which consisted of 66 infertile couples, and two control groups of couples who had experienced perinatal loss. The findings of this study suggested that chronic sorrow could not be empirically defined as separate from grief on the basis of the CRCSI, in the study population of infertile couples. The author acknowledged that the study findings suggested a construct more closely related to the conceptualisation of chronic sorrow proposed by Eakes et al. (1998) in their theory. Despite this, Casale contended that chronic sorrow remains, even theoretically, indistinct from grief and requires further empirical investigation (Casale, 2009).

A Swedish study investigating the experiences of people with multiple sclerosis was recently reported and included an examination of chronic sorrow and depression in this population (Isaksson & Ahlstrom, 2008; Isaksson, Gunnarsson, & Ahlstrom, 2007). The presence of chronic sorrow was related to different losses experienced by the participants. Of interest for the current study, these included the "loss of integrity and dignity", and the "loss of a healthy identity" (2007, p.320). The loss of integrity and dignity was related to feelings of diminished value and worth, and of being stigmatised by the physical manifestations of disease. The loss of a healthy identity was related to their taking on identities of being unwell and disabled, and was linked to forced changes to their sense of self, and their connections with their former selves (Isaksson et al., 2007). As also

described above by Roos and Neimeyer (2007), the participants reported the significant negative impact of “deficient affirmation” from family, friends and health professionals (2008, p.183). This involved the lack of acknowledgement of the impact of their illness, and the absence of suitable psychological, emotional, informational and practical supports, impacting on the effective management of their emotional distress.

Isaksson and Ahlstrom (2008) found that successful management of the participants’ emotional distress included patient-led measures such as distraction, positive thinking, sharing with others in similar situations, and a process of adjusting their expectations and requirements in response to their new situation. Acknowledgment from others of the potential impact of their diagnoses and the life disparities resulting from them, and the provision of empathic and supportive professional care were effective ‘external’ management methods. The authors noted the potential for personal growth for people with multiple sclerosis despite the many losses they experienced. The key contributions of this study to the development of the theory of chronic sorrow were this confirmation of the potential for personal growth through ‘effective management methods’, and recognition of the importance of ‘affirmation’ from family and friends.

CLINICAL APPLICATION OF THE THEORY

The majority of studies and articles related to chronic sorrow have applied the concept in its diagnostic form, exploring the presence or experience of chronic sorrow in different patient populations (Bettle & Latimer, 2009; K. L. Davis, 2006; Gordon, 2009; Hayes, 2001; Kearney & Griffin, 2001; Kerr, 2010; A. L. Lee, Strauss, Wittman, Jackson, &

Carstens, 2001; Lichtenstein, Laksa, & Clair, 2002; Melvin & Heater, 2004; Peljert, 2001; Schornaienchi, 2003). These have contributed to the understanding and application of the theory of chronic sorrow and how chronic sorrow is experienced. Literature of particular relevance for the current study is discussed below.

The findings of a recent study exploring the presence of chronic sorrow in the parents of children with Type 1 Diabetes (Bowes, Lowes, Warner, & Gregory, 2008) supported Kendall's (2006) recommendation that the definition of chronic sorrow be extended, as described above. The participants in this study reported feeling the lack of understanding of, and support for, the emotional and psychological impact of their children's illnesses, from the health professionals involved in their care. The authors suggested that the parents' appearance of 'coping' at outpatient clinic visits, the time limits imposed on outpatient visits, and the absence of easily available psychological services led to this perceived lack of understanding and support, and that this contributed to the parents' ongoing sorrow in response to their children's situations. This negative emotional impact persisted despite the participants' adaptation to the physical practicalities of their situations.

Another recent study reported losses in physical, emotional and social domains for people with disabling conditions (Ahlstrom, 2007). Of most relevance for the current discussion, a category entitled "loss of life imagined" (p.80) described the disparities the participants experienced between their past and present/future lives, and their imagined and real present/futures. These participants also described the loss of their identities,

which was related to perceived decreases in their productivity, attractiveness and worth (Ahlstrom, 2007).

Further to Northington's (2000) finding above regarding the cyclic resurgence of sorrow followed by internalisation and re-patterning of behaviours, chronic sorrow has been recently described as an adaptive response to loss, allowing joy and growth to live alongside sorrow and distress (Bowman, 2008). Bowman emphasised that loss and sorrow are a normal part of life and that chronic sorrow may therefore, in the absence of functional decline, be a normal state for many people in their work towards learning to live with loss. He commented that persistent sorrow in response to loss often goes unacknowledged or is pathologised, yet should be seen to be a normal response. Bowman also noted that having a significant loss go unacknowledged may worsen the impact, as described above by Roos (2002).

Finally, an overview and critique of the theory of chronic sorrow was reported by Schreier and Droes (2006). They found that the theory made intuitive sense and was widely recognised and utilised in nursing and other disciplines, including being accepted as a formal nursing diagnosis by NANDA in 1998. However, they argued that the theory fails to explain why not all those experiencing life-altering loss develop chronic sorrow. This concern was based on the fact that the studies from which the theory was developed provided no additional data about the participants who did not develop chronic sorrow. This issue has been partially addressed where the personal and contextual nature of the interpretation of loss was emphasised as an important aspect of chronic sorrow theory

(Eakes et al., 1998; Teel, 1991), but remains to be fully explored. Schreier and Drees also expressed concern that the theory does not explore the reported 'potential progressivity' of chronic sorrow enough, and queried whether the progression of chronic sorrow would result in a pathological outcome such as depression. They suggested that these issues, and further clarification of the methods of internal management, should be addressed (Schreier & Drees, 2006).

Relationship of Chronic Sorrow to Grief

A number of authors have considered the concept of chronic sorrow in relation to more commonly understood linear approaches to grief in response to loss. As described above, Teel (1991) associated chronic sorrow with ongoing loss, in contrast to the presence of grief in response to a single loss such as the death of a loved one. This was, however, disputed by the authors of the theory of chronic sorrow who reported the presence of chronic sorrow in bereaved people, related to ongoing disparity that they incurred in response to the loss of a loved one (Eakes et al., 1998). As has been shown throughout this discussion of chronic sorrow, the relationship between the concept of chronic sorrow and common understanding of grief continues to be controversial and open to debate. Two points are of note, however. Firstly, as diagnoses, both chronic sorrow and grief describe emotional and psychological responses to loss, and therefore could be viewed as closely related on a spectrum of responses to loss. Arguments as to whether chronic sorrow is distinct from grief or not are ongoing, as shown earlier in this chapter, but chronic sorrow is more commonly, although not exclusively, associated with loss that is not bereavement-related. The concept of chronic sorrow, therefore, provides a

framework for interpreting people's ongoing responses to loss, particularly where the loss is less clearly delineated than that associated with bereavement.

Secondly, and more importantly, there has also been recent discussion of 'complicated grief' or 'prolonged grief disorder', as distinct psychological diagnoses, and recognised pathological responses to loss (Bonanno, Neria, Mancini, & Coifman, 2007; Smith, Kalus, Russell, & Skinner, 2009). These differ from chronic sorrow in that functional decline is a feature of their presentation. This conflicts with a key tenet of the concept of chronic sorrow, which is its status as a normal response to ongoing loss and resulting life disparity (Eakes et al., 1998; S. Olshansky, 1962; Teel, 1991).

For the purposes of this study, the key point of difference between the concept of chronic sorrow and common understandings of grief, as consistently reported in a variety of populations, is the presence of ongoing life disparity resulting from the initial loss event, and the ability of trigger events to exacerbate the sorrow and distress that the person experiences. Accordingly, as suggested by the theory of chronic sorrow, some bereaved people could be regarded as suffering from 'chronic sorrow' rather than the usual linear understanding of 'grief', regardless of the type of loss experienced, or the time that has passed since the loss event. While more attention could be paid to further determining the usefulness of the concept of chronic sorrow for understanding the experiences of those that we would normally describe as 'grieving', and to delineating the relationship between chronic sorrow and grief both as concepts and diagnoses, that is not the focus of this study. Distinguishing chronic sorrow from complicated or prolonged grief, however,

on the grounds that those with chronic sorrow are not functionally affected by their distress, is important for understanding the use of the theory of chronic sorrow as the conceptual framework for this study.

Relationship of Chronic Sorrow to Depression

A number of authors have discussed the features of chronic sorrow that differentiate it from depression. The most important of these is the person's ability to continue with their normal activities of daily life despite their unchanging situation and recurrent sorrow. This sorrow is not disabling, although the level of distress fluctuates from time to time (Burke et al., 1992; Lindgren et al., 1992). Chronic sorrow as a diagnosis has, however, been reported to be a 'risk condition' for depression (Lindgren et al., 1992), although it is important to note that depression and chronic sorrow as diagnoses frequently exist independently of each other. Another study indicated a possible 'association' between chronic sorrow and depression in some populations (Hobdell, 2004). However, in contrast to this, and Kendall's (2006) finding that there are clear diagnostic distinctions between chronic sorrow and depression, Lichtenstein et al. (2002) found in their study of people who are HIV-positive that chronic sorrow and cyclical depression were conceptually alike. This suggests that there remains some controversy related to the relationship between the two, which requires further examination. The most important distinction between the two, however, is that depression is characterised by alterations in cognitive, emotional, behavioural and physical functioning (Hobdell, 2004), while the concept of chronic sorrow emphasises that those affected by 'chronic sorrow' continue to function normally despite the ongoing presence of loss and intermittent exacerbations of sorrow (Eakes et al., 1998; S. Olshansky, 1962; Teel, 1991). As

previously stated, while depression and chronic sorrow as diagnostic entities may co-exist, they also exist independently.

A call to maintain the diagnostic acceptability of non-pathological responses to loss such as chronic sorrow was the focus of a recently published epidemiological study (Wakefield, Schmitz, First, & Horwitz, 2007). In this study, the authors challenged current psychiatric practice that allows only loss related to bereavement to be considered a non-pathological reason for symptoms of sorrow and distress. They proposed that non-bereavement related losses can also induce such responses and should not be considered pathological or diagnosed as such. Essentially, the authors proposed that sadness is a normal response to a number of life situations and a normal life experience for many people, as described above (Bowman, 2008). Accordingly, the key attributes of the concept of chronic sorrow that mark its difference from depression are the presence of a discernible loss event and resulting life disparity, and the person's ability to continue with their normal activities of life despite the potential for exacerbations of sorrow over time.

RATIONALE FOR THE USE OF THE THEORY OF CHRONIC SORROW

My initial introduction to the theory of chronic sorrow was through a poster presentation at a qualitative research conference. The description of chronic sorrow in this presentation, although used in the clinical context of multiple sclerosis (Isaksson et al., 2007), struck me as an interesting perspective from which to explore people's experiences of cancer and other chronic illnesses. During my subsequent search for an

appropriate conceptual framework for this study, I found the theory of chronic sorrow described in the nursing literature. The theory describes a cycle of sorrow that occurs in response to life-changing loss, and is therefore an appropriate approach to understanding how such loss may be interpreted and experienced. After some reading and discussion, I determined that it was an appropriate and useful conceptual framework for this study.

Using the theory of chronic sorrow as the conceptual framework for this study has provided an opportunity to explore, in depth, the participants' experiences of the emotional and interpersonal aspects of fertility damage and/or premature menopause from their cancer treatments. The theory of chronic sorrow acknowledges the considerable emotional impact of life-changing loss, and provides a way of understanding how this affects people's lives in an ongoing manner. It also recognizes such responses as a normal and non-pathological way of responding.

CONCLUSION

This chapter has reviewed the development of the theory of chronic sorrow and the application of chronic sorrow as a clinical diagnosis for people who experience ongoing loss in response to a variety of situations. The key features of the theory of chronic sorrow are the presence of an antecedent loss event, a resulting life disparity, an emotional response of sorrow that is pervasive, permanent, periodic and potentially progressive, and the action of trigger events in exacerbating this emotional response. A range of management methods are often used to alleviate this emotional response.

The theory of chronic sorrow provides a unique framework for the exploration of the emotional and interpersonal aspects of fertility damage and/or premature menopause from cancer treatments. The following chapter will discuss the methodological approach to the study and the methods used.

CHAPTER FOUR: METHODOLOGY & METHODS

INTRODUCTION

This chapter discusses the research methodology used in this study and the methods used for data collection and analysis. The purpose of the study was to answer the research question, ‘What are the emotional and interpersonal aspects of fertility damage and/or premature menopause from cancer treatments?’ This research question was developed in response to many conversations with people in my clinical practice who had been affected by fertility damage or premature menopause from cancer treatments. Their experiences suggested that this was an area of great concern to many patients, and one that was potentially neglected in clinical practice and research. This study was undertaken to answer this clinically grounded research question, and with the aim of contributing to knowledge that will lead to improvements in the clinical care of women affected by fertility damage and premature menopause related to cancer treatments.

The chapter begins by discussing the research methodology. This is followed by a description of the methods used in the study, and finally a discussion of the ethical considerations in the study.

DISCUSSION OF RESEARCH METHODOLOGY

The aim of this study was to use a qualitative approach to determine the emotional and interpersonal aspects of fertility damage and premature menopause from the treatment of a range of different cancer diagnoses. As discussed in the previous chapter, the theory of chronic sorrow was used as the conceptual framework for the study, as it offers a useful way of understanding the experiences of women in this situation. This study builds on the findings from earlier related studies but both focuses more directly on, and delves more deeply into these participants' experiences of fertility damage and premature menopause related to cancer treatments, from the perspective of the theory of chronic sorrow (Geertz, 1973).

Justification of Methodological Approach

A basic tenet of research practice is that the research question should influence the choice of research methodology, whilst recognising that all aspects of research are influenced, whether implicitly or explicitly, by the ontological and epistemological positioning of the researcher (Chamberlain, 2000; Crotty, 1998; Gray, 2009; Strauss & Corbin, 1998; Streubert & Carpenter, 1995). The research question addressed in this study was of an exploratory nature, and was grounded in the personal and contextually-mediated experiences and interpretations of the participants. As such, a qualitative approach allowing for such exploration and interpretation was indicated (Fossey, Harvey, McDermott, & Davidson, 2002; Gray, 2009; Streubert & Carpenter, 1995). The epistemological background to this decision is the constructionist viewpoint expressed eloquently by Crotty as follows (1998, p. 42):

What is constructionism? It is the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context.

This definition suggests that the social meanings that we as human beings attribute to phenomena are constructed through interaction between phenomena and ourselves - they are co-constructed interpretations that are neither objective (in which meaning pre-existed in phenomena and was passively awaiting discovery) nor subjective (in which meaning was developed from within us as human beings and applied to phenomena) (Crotty, 1998; Fossey et al., 2002; Gray, 2009). This in turn suggests that there are many ways of understanding any phenomenon, and that, therefore, multiple and changeable iterations of 'reality' exist (Crotty, 1998; Fossey et al., 2002; Gray, 2009; Streubert & Carpenter, 1995). Accordingly, this study involved constructing meaning in partnership with the participants, just as they constructed the meanings of their experiences of fertility damage and/or premature menopause from cancer treatments through their own interactions with these experiences and their responses to them (Crotty, 1998; Fossey et al., 2002; Gray, 2009). The findings of this study, therefore, are a contextually and temporally situated construction of the participants' realities that contributes to the breadth and depth of other research findings (Crotty, 1998; Gray, 2009; Streubert & Carpenter, 1995).

It has previously been suggested that qualitative methodologies that are philosophically grounded in other disciplines may not be appropriate for answering some research questions arising from applied disciplines such as nursing (Caelli, Ray, & Mill, 2003; Sandelowski, 2000; Thorne, Kirkham, & MacDonald-Emes, 1997). Therefore, in recognition of the clinical focus of the research question, and after consideration of

different approaches to qualitative research I decided to pursue a generic qualitative approach (Caelli et al., 2003; Chamberlain, 2000; Cooper & Endacott, 2007; Sandelowski, 2000; Thorne et al., 1997). This approach was selected as a functional and applicable approach to answering a question with a clinical basis and application, one which allows for the flexible combining of research strategies from a variety of methodological approaches (Gray, 2009). While there is some controversy about the use of generic qualitative approaches in research, there is recognition that their use is increasing, particularly within applied disciplines such as nursing, medicine and health psychology (Caelli et al., 2003; Chamberlain, 2000; Cooper & Endacott, 2007; Sandelowski, 2000; Thorne et al., 1997). Much of the controversy seems to relate to a lack of transparency as to the approach that was used in a given study, a lack of congruity within the research process, or difficulty in assessing the quality of the research (Braun & Clarke, 2006; Caelli et al., 2003; Chamberlain, 2000; Cooper & Endacott, 2007; Sandelowski, 2000; D. R. Thomas, 2006). Accordingly, Caelli et al. (2003) suggest four key considerations that studies employing generic approaches must both consider and explicate, and these are addressed here in relation to the current study:

1. Theoretical Positioning

Caelli et al. (2003) associate this with the researcher's background and history, and the beliefs and presuppositions that have led to the particular inquiry. Although I have no personal experience of cancer, fertility problems or premature menopause, my clinical background in oncology and palliative care is perhaps indicative of a tendency to value and attend to the subjective and deeply personal aspects of peoples' experiences of ill health. This background has also conditioned me to take note of (or, conversely,

indicates a predisposition towards noting) situations in which loss and grief may be present. As stated previously, conversations with patients about the impact of fertility damage and premature menopause from their cancer treatments were a key motivation for this study. The degree to which women were affected by this was sometimes very high. This suggested to me that many women experienced fertility damage or premature menopause as a significant loss in their lives and suffered grief in response. In addition, my impression was that something was missing from these women's preparations for their cancer treatments despite the existence of previous research and clinical guidelines advising of the need to attend to such concerns as part of treatment discussions and survivorship care. Accordingly, I wanted to explore women's emotional responses to fertility damage and premature menopause from cancer treatments with a view to contributing to knowledge, clinical practice and the education of health professionals who practise in cancer care.

Crotty (1998) relates theoretical positioning or perspective to the philosophical stance taken by the researcher, which is influenced by the epistemological position taken, and in turn influences the methodological decisions made. As stated above, the epistemological position that was taken for this study was constructionism. The related theoretical perspective that this study was influenced by is interpretivism, which "looks for culturally derived and historically situated interpretations of the social life-world" (Crotty, 1998, p. 67). The construction of meaning, therefore, is seen to be an interactive process between people and phenomena, or people and other people, which results in contextually and temporally situated interpretations of the world in which they live and

their experiences associated with this (Crotty, 1998; Gray, 2009). Contributing to this, the conceptual framework for this study was the theory of chronic sorrow, which provided the conceptual underpinning of the study and guided the interpretation of the data. This resulted in a contextually and temporally situated interpretation of these participants' experiences from the perspective of the theory of chronic sorrow. This is discussed further in point four, below.

2. Congruence Between Methodology and Methods

Caelli et al. (2003) refer to the need to make clear the methodological and philosophical background to the study to allow assessment of the congruence between this and the research methods used. The methodological and philosophical backgrounds to this study have been addressed above, and the research methods employed in this study are described in detail below. The research methods allowed for the development of a study that forms a contextually and temporally situated interpretation of the constructed meaning of fertility damage and premature menopause from cancer treatments for the seventeen participants.

3. Strategies to Establish Rigour

The concept of rigour in qualitative research relates to the validity and reliability of the research (D. Davies & Dodd, 2002). There are three principal ways in which I sought to maintain rigour in this study. Firstly, through the processes discussed above which make my epistemological, theoretical and methodological perspectives explicit, and make clear the pre-suppositions and professional history that I bring into the research process. Secondly, in the 'research methods' section below, I clearly describe the methods used in

the study for data collection and analysis, and chapter three has explored the conceptual framework underpinning the study.

Thirdly, I sought to maintain rigour through external and internal processes that encouraged reflexivity. Reflexivity is a formal and informal process of the researcher critically reflecting on the research process and his/her own place in and influence on the process (particularly data analysis), and then making explicit the ways in which decisions within the research process were made, in order to privilege the participants' 'voice' in the interpretation of the data rather than the researcher's (D. Davies & Dodd, 2002; Gray, 2009; J. Hewitt, 2007; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Porter, 1998; Pyett, 2003). An important aspect of reflexivity in this study is my acknowledgement that my own professional experiences, personal experiences and pre-existing knowledge of the topic influenced each stage of the process, including my decision to embark on the study, the research question posed, and the methodological and conceptual approaches and actions undertaken. My pre-conception that the impact of fertility damage and premature menopause from cancer treatment is likely to be associated with loss and sorrow was clearly articulated above, and is demonstrated in my choice of the theory of chronic sorrow as the conceptual framework for the study. This pre-conception is grounded in clinical practice, previous research, and my knowledge of the experiences of women with infertility unrelated to cancer. In addition, my clinical experience suggested that many clinicians continue to neglect discussions related to fertility, menopause and sexuality both prior to cancer treatment and in the survivorship phase.

Reflexivity was attended to throughout the research process and specific examples will be described in the following sub-sections in this chapter. On a more general level, the research process was an iterative one in which the formulation of the research question, review of the literature, selection of chronic sorrow theory as the conceptual framework, sampling, data collection and data analysis formed an interactive system in which each aspect fed back into the development of the overall project (Fossey et al., 2002; Gray, 2009; Morse et al., 2002; Strauss & Corbin, 1998). In this way, the research process was emergent and responsive to the influencing factors associated with each stage of the research (Fossey et al., 2002; Strauss & Corbin, 1998). Each decision made from the outset of the study thus influenced the eventual findings of the study. Therefore, a study involving alternative epistemological, theoretical and methodological standpoints, conceptual framework or research methods or, importantly another researcher working with different participants, would likely result in a different, but equally valid interpretation of the topic (Crotty, 1998; Gray, 2009; Streubert & Carpenter, 1995).

In addition, throughout this process, I paid attention to my cognitive and emotional responses, particularly in relation to the emotional content of many of the interviews and emerging findings. Importantly, due to my previously stated pre-conceptions regarding loss and grief in relation to my topic, I became aware that I was preferentially focusing on and responding to such aspects in the participant interviews and data analysis. Although loss and distress were a significant factor in the data, I was slow to move beyond this to recognise the more positive points in the data – I became aware that I had been looking for signifiers of loss and distress and initially failed to note signifiers of

other things, or to look for alternative experiences or contrary findings (Gray, 2009; Morse et al., 2002). Further discussion of this occurs below, including finding ‘contrary findings’, and the contribution of this to the overall findings of the study.

In addition to these more internal reflexive activities and the processes described in the sections below, the following external actions were undertaken:

- Regular academic supervision with research supervisors throughout the project, particularly in relation to the study design, and the interpretation and analysis of the data at all stages
- Discussion of the methodology, theory, data collection, data analysis and emerging findings in group peer supervision (doctoral students within the department) on at least six occasions over the time of the study
- In-depth discussion of the methodology, theory, data, data analysis process and emerging findings in one-on-one peer supervision on numerous occasions
- Presentation of research findings at early and later stages of analysis at two international cancer nursing conferences, and two national multi-disciplinary psychosocial oncology conferences
- All 17 participants were sent a summary of the study findings at the completion of the study, as agreed at the time of their interviews, but no feedback was received

4. Analytic Lens for Data Analysis

Caelli et al. (2003) described this as relating to how the researcher ‘engages’ with the data. As described in detail in the previous chapter, the conceptual framework for this study was the theory of chronic sorrow, which consequently provided the analytic lens

for data analysis. Much discussion took place within academic and peer supervision sessions about the 'fit' of the theory of chronic sorrow with the research question, and the way in which the theory should be used or applied in the data analysis process. As described in the previous chapter, the theory was initially chosen as an applicable framework in consideration of the descriptions of loss and sorrow in relation to fertility damage from cancer treatment arising from my clinical practice and existing research. In addition to this, the theory was developed out of clinical practice and was therefore an appropriate approach to a study that was grounded in clinical practice and aiming to inform clinical practice. A complicating feature of the theory of chronic sorrow, however, was its additional application as a clinical nursing diagnosis. Due to my own inexperience with the use of theory in research, this initially presented a considerable challenge to my understanding of how to use the theory as the analytical lens through which I viewed and interpreted the data without implying that I was trying to diagnose the participants with the clinical diagnosis of 'chronic sorrow'. This was my greatest struggle throughout the study process.

Early in the data analysis stage I was concerned that the theory of chronic sorrow may not be the best approach and, after discussions with my academic supervisors, explored other potential theoretical approaches. As a result of this, the concept of liminality and related concepts arising from the liminality literature were used as alternative theoretical viewpoints for the analysis of some sections of data, where the theory of chronic sorrow was not able to provide the depth of understanding required. It became clear after further analysis and interpretation of the data, however, that the theory of chronic sorrow was a

sound and appropriate analytical lens for the interpretation of much of the data, and this was therefore confirmed as the conceptual framework for the study.

RESEARCH METHODS

This section explains the methods that were used in this study for sampling, data collection and data analysis.

Sampling

Sampling was purposive or purposeful. That is, potential participants were sought on the basis that they had experienced the emotional and interpersonal aspects of fertility damage and/or premature menopause as a result of cancer treatments (S. M. Carter & Little, 2007; Fossey et al., 2002; Gray, 2009; Streubert & Carpenter, 1995). In addition, a ‘maximum variation sample’ (Fossey et al., 2002; Gray, 2009) was sought, in terms of geographical area, services through which cancer treatments were accessed and, most importantly, cancer diagnosis.

For the specific purposes of this study, the criteria for eligible participants were women who:

- were aged 20-45 at the time of their diagnosis of cancer and primary cancer treatment (any cancer that required potentially fertility-damaging treatment)²
- believed they had sustained damage to their fertility from cancer treatment

² Although the study initially focused on fertility damage, premature menopause was added as a focus for the study during data collection, as described below

- were free of disease to the best of their knowledge
- were 6 months to 5 years from the completion of their primary treatment³

Potential participants were self-selected through response to advertisements⁴ and word-of-mouth, and the sampling technique of 'snowballing' was employed, in which participants were encouraged to disseminate information about the study to other eligible women with whom they were in contact (Fossey et al., 2002). While it may have been easier to seek ethical approval to directly contact women through the records of the local cancer treatment centre, Cancer Society division or breast cancer support groups, my desire to sample widely led to an eclectic approach. Accordingly, the study advertisement was placed in a breast cancer consumer magazine, on the national Leukaemia and Blood Foundation website, and on a national Cancer Society peer support internet bulletin board. In addition, I was invited to attend a consumer-led and focused breast cancer conference to distribute the advertisements (the advertisements were placed prominently on a table, and I was asked to speak briefly about the study at one of the concurrent sessions), and the advertisements were also made available through a number of breast cancer support groups. Further to this, I contacted medical, nursing and psychology colleagues in both public and private practice throughout the country, to advise them of the study and request that they make the advertisements available as appropriate; and finally, a colleague undertaking a related doctoral thesis in psychology with a

³ This range was subsequently considerably expanded due to difficulty in recruiting, and comments from many women that while the topic was very relevant to them, they were outside the prescribed age range

⁴ See Appendix 1

gynaecological oncology focus made my study advertisement available to her participants. Importantly, the study advertisement was worded carefully to avoid any suggestion of seeking only women who had been negatively affected by their experiences. The rationale for this was to encourage women with a range of experiences to respond, contributing to a 'maximum variation sample' (Fossey et al., 2002; Gray, 2009; Morse et al., 2002), and the success of this will be shown in the findings chapters.

During this stage, women who were chiefly concerned about premature menopause (rather than specifically fertility damage) responded to the study advertisements asking to participate in the study. This was despite the fertility-specific wording in the advertisement, and indicated to me and my academic supervisors that premature menopause was so closely linked to fertility damage for some women that this should be considered to be part of fertility damage in the study. Accordingly, the research question was altered to include premature menopause as an additional focus. This degree of flexibility and responsiveness, whilst challenging to a novice researcher such as myself, is a strength of qualitative research because it recognises the constructed and interpretive nature of meaning and knowledge (Fossey et al., 2002; Gray, 2009; Morse et al., 2002) – that while my 'meaning' of fertility damage was fertility-focused, the 'meaning' of fertility damage for some affected women was clearly far wider. It also provided for a broader sample of participants.

The final number of participants interviewed was seventeen. Of these, ten identified fertility damage as their primary concern and seven identified premature menopause as

their primary concern (three discussed concerns related to both). The participants were from throughout New Zealand, both urban and rural areas, and had received their cancer treatments through a range of public and private services throughout the country. While the majority of participants identified as European, three participants identified as Māori, the indigenous people of New Zealand, and three participants identified as lesbian. Diagnostically, ten participants had diagnoses of breast cancer, five had gynaecological cancers and three had haematological cancers (one participant had both breast and gynaecological cancer diagnoses). While the participation of more women identifying as Māori would have been welcomed, only three volunteered. As a result, and due to the small overall number of participants in the study, no comparative analyses of the experiences of those identifying as Māori or lesbian, or those with different cancer diagnoses were possible. In addition, there were no clear distinctions between the groups in terms of issue of greatest concern, or type or degree of emotional responses.

Data Collection

Data were collected through semi-structured interviews, although the initial interview question, asking the participants to ‘speak freely about their experiences’, was ‘non-directive’ (Gray, 2009). The interview as a data collection technique is frequently used in exploratory studies (Fossey et al., 2002; Gray, 2009; Polit, Beck, & Hungler, 2001), and is a reflection of the constructed nature of knowledge, in which knowledge is interactively constructed and transmitted using a jointly understood symbol system or ‘language’ (Crotty, 1998; D. Davies & Dodd, 2002). A semi-structured interview approach provided a focus for the interviews, allowing me, as the interviewer, to ‘probe’

for information on various aspects of the topic (Gray, 2009; J. Hewitt, 2007; Polit et al., 2001; Streubert & Carpenter, 1995).

Data collection began in March 2008 and was completed in December 2008. As stated above, data collection and early analysis occurred concurrently, allowing subsequent interviews to be responsive to issues or questions arising from analysis (Morse et al., 2002; Strauss & Corbin, 1998). The interviews were undertaken at a time and place agreed between the participant and myself and lasted 30-120 minutes. While the majority of interviews took place in the participants' homes, Carol's interview took place at her place of work, Anne's at a local hospital where she had been visiting a friend, and Susan's, at her request, in my motel room in the city that she lived in (her home was undergoing renovation and she was concerned about privacy). The interview schedule⁵ reflected the requirements of the research question, the focus of the conceptual framework, and knowledge gained from an early review of the literature (Strauss & Corbin, 1998; Thorne et al., 1997). This schedule firstly included going over the participant information sheet which had been previously posted or emailed to the participants,⁶ the signing of the consent form,⁷ and the collection of demographic data related to each participant's age, family situation, living situation and cancer diagnosis.

⁵ See Appendix 4

⁶ See Appendix 2

⁷ See Appendix 3

The interviews were audio-recorded with the participant's consent. During the initial stages of each interview, I was careful to attend to the building of rapport with the participant, building on conversations that had taken place during the setting up of the interview (D. Davies & Dodd, 2002; Gray, 2009; J. Hewitt, 2007). This process was greatly assisted by my extensive clinical experience. The research question was then restated and, as mentioned above, the participant was first invited to speak freely about her relevant experiences of the topic. A series of prompts were used to guide the interview as necessary and appropriate to allow for the collection of the full range of data that the research question indicated. In this way, the interview format allowed the participants to respond in a manner appropriate to their own understanding of the questions and experiences of the topic, yet I was able to elicit more information on certain issues or clarify areas of confusion where required.

Although I did not specifically ask for positive or negative experiences, all of the study-related information that the participants had been given was couched in neutral terms, and the initial open-ended interview question merely asked that the participant 'talk freely about her experiences'. With hindsight, however, a sentence in the participant information sheet may have intimated my above-mentioned bias towards expecting more negative experiences. The phrase, "...whether the possibility or certainty of fertility damage from cancer treatment has had an effect on you and your close relationships and, if so, what kind of effect that has been, and the strategies you have used or use to help you manage this", may have suggested that I anticipated negative responses that had required 'managing'. Despite this, as will be shown in the findings chapters, a range of

experiences, both anticipated and unexpected, positive and negative, were described by the participants.

Once I felt that I had gained sufficient data to answer the research questions the participant was invited to add any additional comments or information, and pose any questions or concerns arising from the interview process. Subsequent to this, the interview was completed with my offer to contact the participant the following day to assess for any emotional difficulties related to the interview process and topic. All of the participants denied being concerned about distress related to their participation, and none suggested that they required contacting after the interview. A number of participants expressed their appreciation of the opportunity to 'tell their story', and some indicated that the process of participation had been useful and beneficial to them. At times I also found the interviews distressing although, as described later in this chapter, this was more manageable due to my clinical background. Because of this, however, I needed to be aware that my own emotional responses may influence my interpretation of the data, or lead to a privileging of the 'voices' of the more distressed participants. This is discussed further in the next section.

Finally, I informed the participants that the study is likely to be completed in late 2010 and offered to provide the participants with a summary of the study. All participants accepted this offer. Data collection was stopped when no new ideas were being identified in the data (Morse et al., 2002; Strauss & Corbin, 1998).

Data Analysis

Because data collection and analysis occurred concurrently, the audio-recorded participant interviews were transcribed verbatim as each was completed. These were transcribed by me as a way of familiarising myself with the data, and to contribute to the maintenance of confidentiality. As mentioned above, analysis of the resulting data was undertaken using general inductive analysis techniques (Braun & Clarke, 2006; D. R. Thomas, 2003, 2006). This process has also been described as ‘constant comparative analysis’ (Thorne, 2000), or ‘thematic analysis’ (Braun & Clarke, 2006), and is used as a systematic way of identifying, describing, analysing and finally reporting the themes or categories that are found in qualitative data (Braun & Clarke, 2006; D. R. Thomas, 2003, 2006). This is an interactive process between the data and the researcher through which a constructed interpretation of the data can occur (Braun & Clarke, 2006; Gray, 2009; Morse et al., 2002; Strauss & Corbin, 1998).

The data analysis process drew on the theory of chronic sorrow as the conceptual framework for the overall study and the analytical lens for the analysis, existing literature, and my professional experience as sensitisers, comparators and interpretive guides to add to the rigour of the analytical process (Morse et al., 2002; Strauss & Corbin, 1998). The analysis drew out ideas that challenged my pre-conceptions and the findings from previous related studies. In addition, the theory of chronic sorrow was found to be not useful for the interpretation of some sections of the data. When this occurred, alternative ways of viewing the data and interpreting these emerging findings were sought. For example, although it initially appeared that the level of distress related

to fertility damage was particularly high, with a closer look at the data, it was clear that those with the highest levels of distress were generally those who were still engaged with processes such as assisted reproductive technologies, adoption or surrogacy. In response, the findings pertaining to this were analysed as a separate sub-category. Another example is the 'contrary case' findings, where participants described positive responses and personal growth. These contrary case findings were important as they demonstrated the ability of the sampling strategy, advertisement and interview schedule to draw out a range of different experiences and responses (Gray, 2009; Morse et al., 2002). These findings were also analysed as a separate sub-category.

Although the theory of chronic sorrow provided the conceptual framework for the study, a framework analysis was not the analytical process undertaken. The theory was used as an interpretive guide, or a 'lens' through which the data were to be viewed, and the perspective from which the study was undertaken, but the findings categories were inductively derived from the analysis of the data and only after these categories were identified and defined was the theory applied as an aid to interpretation (Braun & Clarke, 2006; Strauss & Corbin, 1998; Thorne, 2000). The analysis took place in a number of stages, some of which were revisited as the analysis progressed. These stages are described in detail below:

Stage One: In this stage, the audio-recorded interviews were transcribed verbatim by me, allowing me to familiarise myself with the data.

Stage Two: In this stage, the interview transcripts were initially uploaded into the QSR NVivo7 computer qualitative analysis software for the purposes of data management

(QSR International, 2006). Each transcript was then read through in its entirety to look for the main themes occurring in an 'overview' of the whole interview (Braun & Clarke, 2006; Strauss & Corbin, 1998; D. R. Thomas, 2003, 2006; Thorne, 2000). This resulted in the earliest categories for the study. Subsequent to this, the transcripts were read in detail and potentially important segments of the data were identified and assigned to these early categories, or new categories were developed to accommodate them (Braun & Clarke, 2006; Strauss & Corbin, 1998; D. R. Thomas, 2003, 2006; Thorne, 2000).

Stage Three: In this stage I printed out the transcripts to enable me to read each transcript in 'hard copy', to re-look at the main 'points' that could be identified in each. The earliest categories identified in stage one were confirmed as valid and I proceeded with the analysis. I then returned to the process of going through each transcript and 'coding' sections of data appropriately into these existing categories, or creating new ones as appropriate. Some data excerpts were coded into more than one category. Each category was, at this stage, comprised of a loose category title and a set of excerpts from the data (Braun & Clarke, 2006; Strauss & Corbin, 1998; D. R. Thomas, 2003, 2006; Thorne et al., 1997). After all of the data were coded and each category had been described there were a total of twenty categories. When this process was completed, each category was examined and I wrote a summary of the category based on the key point(s) from each excerpt of data. This was my first written 'interpretation' of the data.

Stage Four: In this stage, similar categories were combined as appropriate into higher level categories, resulting in ten categories, and then five (Braun & Clarke, 2006; Strauss & Corbin, 1998; D. R. Thomas, 2003, 2006). I initially intended to analyse the fertility and menopause data separately, but they proved too intimately linked, so a decision was

made to analyse the data as a whole but discuss the two issues separately where it was indicated by differences in the data. As the analysis of the data continued, the five categories were further combined, resulting in the final three categories, shown in the following table:

Early categories	Developing categories	Developing categories	Final categories
Difficult choices Moses and the red sea (communication and decision-making) Fertility most important	Difficult choices Moses and the red sea (communication and decision-making)	Choice and control	Communication and decision-making
Being different Issues relating to sexual orientation Feelings about self Quality of life Life out of own control Forced or unwelcome change of life options and plans or bodily status Loss of family longevity Unexpected grief and loss Unresolved issue affecting life and relationships Relationships	Being different Feelings about self Quality of life Relationships	Perception of self Multiple losses	Loss and disruption
Guilt Emotional rollercoaster All about support Utter devastation followed by slow recovery If life gives you lemons (positive responses) Loss Timing right	Emotional rollercoaster All to do with support If life gives you lemons (positive responses) Loss	Emotional responses Support findings	The emotional impact of change and loss

Table 2: Category Development

Over this time, I also changed from working in NVivo to working manually with the categories, because I found it a lot easier to work with printed pages of text than with text on a computer screen. Working in this way enabled me to physically move blocks of text

to position them differently, making it easier for me to see linkages in the data, and therefore continue with the data analysis.

Also in this period, as I began to use the theory of chronic sorrow as an additional ‘lens’ through which to view the data and developing analysis. After discussions with my academic supervisors, I also looked for an alternative theoretical or conceptual tool to use when the theory of chronic sorrow did not provide me with an appropriate lens for interpreting some aspects of the data. To do this, I went back to the literature and found that the concept of liminality had been previously used in studies related to cancer and infertility (Allan, 2007; Little et al., 1998; Navon & Morag, 2004; K. Thompson, 2007). After further reading, I decided that this would be a useful additional ‘lens’, and this was subsequently used in the analysis of some sections of data.

At times, a particularly emotive or strongly-worded example from the data would stand out, and I would be drawn to work with this piece of data, which would result in an exaggerated overall interpretation of the category or sub-category. I would ask myself, “Is this illustrative of all the data in this category? Or is this exceptional? If so, why? Is this the overall point of this category or ‘in contrast’?” Strauss and Corbin (1998) describe this questioning as being at the “heart” of the inductive analysis process (p. 22). This initial and uncertain interpretation was then tested by further examination of all of the data in the category, reference to the findings of other studies, and an examination of my role in constructing the developing interpretation (Chamberlain, 2000; Morse et al., 2002). If this more emotive or strong interpretation did not seem to ‘fit’ in the light of

such examination, the more emotive data extract was dealt with as a separate 'case' or category. For example, as described above, it was at this stage that I noted that the majority of the most distressing excerpts of data were from three particular participants and this data was subsequently formed into specific sub-categories so that the data could be analysed separately from the slightly different focus of the other data excerpts. This process is described by Morse et al. (2002) as 'thinking theoretically' (p. 13), moving between individual data excerpts, sub-categories and categories to confirm or challenge a particular point or the evolving analysis. This process requires 'responsiveness' in the investigator, the ability to be flexible, open to new or emerging ideas and open to challenges to existing ideas (p. 11). This is the 'constant comparative analysis' process previously described (Strauss & Corbin, 1998; Thorne, 2000).

Throughout the analysis, I wrote multiple 'notes' to myself recording questions, insights, concerns and suggestions. These 'notes', sometimes described as 'memos' (Strauss & Corbin, 1998), were often recorded after time spent away from the data and the analysis process – for example at night, or when out walking. This may reflect an 'over-closeness' to the data, periods in which my perspective was lost and I found that I couldn't 'see' anything anymore. I believe that while working full-time on the study was a privilege, being so focussed on the same project for such a period of time at times challenged my ability to maintain a productive distance between myself and the study. This is a previously recognised issue in qualitative research, particularly when researchers have a professional history in the research field, and during intense analysis of sometimes emotive data (Chamberlain, 2000; Strauss & Corbin, 1998). At all stages

of the analysis, and often in response to these notes, I 'queried' the emerging analysis, asking such questions as: "Does this fit? Does it fit the participants? What is different? What is similar? What is contradictory? What else could explain this?" I went back to the interview transcripts repeatedly, and also kept the participants and their 'stories' in my mind as a reflective reference against which to check the developing analysis.

Stage Five: In response to critique from two external sources, and after a break from the study of four months duration, I 'took another look' at the study findings and refined my analysis further. In this phase, I asked such questions as: "Does this interpretation ring true? What does it mean? Have I provided evidence for it? Have I considered other explanations? Are there contrary cases? Is the theory helpful? If not, what is? What else may help explain this? What does the literature say? Does anything else stand out here?" As a result of this further analysis, with the added perspective gained through spending time away from the study, and in response to the probing questions and concerns of these two external sources, I re-wrote the findings chapters. These now represent, I believe, a more refined, less emotive and far more clearly supported analysis and interpretation of the data. While the scope of the core findings has not changed, there has been a change of emphasis, and the language used to describe the findings has been moderated. In addition, I believe that I have more appropriately and subtly used the interpretive lens of the theory of chronic sorrow (or alternatives where appropriate), leading to an analysis that was viewed from this theoretical perspective, but not overpowered by the theory and its concepts.

ETHICAL CONSIDERATIONS

The primary ethical consideration in this study was related to the sensitive nature of the issues involved. In addition, as the study takes a partially retrospective view, there was the potential for participation in the study to initiate distress relating to something that can no longer be prevented or changed. This sensitivity meant that the participants were a vulnerable group, and particular attention needed to be paid to their emotional safety in the study, and the procedures related to their informed consent to participate.

It is now recognised that there is the potential for both positive and negative emotional or psychological outcomes of participation in qualitative research (McIlfatrick, Sullivan, & McKenna, 2006). It is crucial, therefore, that the researcher considers the likelihood of a negative outcome for the participants regardless of the potential positive outcomes for other stakeholders (LoBiondo-Wood & Haber, 1998; Polit et al., 2001; I. E. Thompson, Melia, Boyd, & Horsburgh, 2006). Conversely, an early 'negative' reaction to participation in a qualitative study may result in a long-term positive outcome related to the cathartic properties of 'telling one's story' and the benefits of having one's experiences and opinions validated. In addition, there may be an acknowledgement of the potential for a positive outcome for others in a similar situation as a result of the development and dissemination of the resulting new knowledge (McIlfatrick et al., 2006).

The information given to potential participants in this study prior to their consent to participate was clear as to the nature and intent of the study and their involvement in it.⁸ The possibility of emotional distress occurring as a result of participation was made explicit, and provision was made for participants to access suitable psychological support should they require this as a result of their participation in the study (I. E. Thompson et al., 2006). Having had many years of clinical nursing experience working with people with a diagnosis of cancer, I had a high degree of sensitivity to the experiences of the participants and endeavoured to provide a safe and supportive environment for their participation. A number of participants described positive emotional outcomes from their engagement in the interview process. While a number of participants were visibly distressed at times during their interviews, none accepted the offered psychological support at the time of their interviews or subsequent to them.

The second key ethical concern for this study was that of the anonymity of the participants and the associated confidentiality of the data arising from the interview process (LoBiondo-Wood & Haber, 1998; Polit et al., 2001; I. E. Thompson et al., 2006). The identity of the participants is known only to me as the primary researcher, and all of the interviews were performed by me, as was data transcription. The audio-recordings of the interviews were deleted after transcription. The interviews were given an alphabetical identifier related to the order in which they were undertaken. The participant consent forms were kept separately from the transcriptions and any other identifying documents, on University premises. The participants were also given a pseudonym to be

⁸ See Appendix 2

used in the reporting of the study findings, and any other potentially identifying information was changed (Polit et al., 2001).

The final consideration was negotiating the interface between 'nurse' and 'researcher' in the data collection process. The potential for conflict between the researcher's need to collect data and the nurse's imperative to be a therapeutic agent was acknowledged prior to data collection, and a means to manage this decided upon (McIlfatrick et al., 2006). Although it has been argued that the advanced communication skills employed by an expert practitioner may serve to increase the quality of the data (Strauss & Corbin, 1998), there is a risk that the nurse's engagement in research without the protection offered by the clinical role may result in a negative outcome for the nurse, and a decrease in the quality of the data collected (Kidd & Finlayson, 2006). It is also possible that a qualitative interview undertaken by a nurse who is proficient in nurse-patient communication, and who demonstrates the skills of active listening and empathy, may become a therapeutic encounter in itself (Leslie & McAllister, 2002). For my protection as the researcher, and to maintain the quality of the data, regular academic supervision was undertaken. Negotiating this role division was difficult at times during data collection due to the high degree of similarity between the interview discussions and the types of clinical discussions involved in my usual clinical role. I was identified as a nurse in the study advertisement, participant information sheet and consent form because the academic department within which I undertook the study was a 'School of Nursing', and my professional and academic qualifications clearly identify me as a nurse. In addition to this, I felt that identifying my background was important to the participants in

terms of their ability to make an informed decision about participating in the study. Clearly, it was not my intention to address issues other than those related to the study, but where a minority of participants raised issues or questions, I felt compelled to respond. When participants asked questions that I thus felt compelled to answer, this was done as an aside to the interview process, with recommendations as to where appropriate advice or support could be accessed, and in particular, the importance of taking such questions or concerns back to their own clinical team.

Ethics approval for this study was given by the University of Auckland Human Participants Ethics Committee (2007/263).⁹

CONCLUSION

This study was undertaken using a generic qualitative approach and employed general inductive analysis techniques to analyse the data. The theory of chronic sorrow provided the conceptual framework for the study and the predominant, but not only, analytical lens for data analysis. The analysis resulted in three categories of findings that are a constructed, temporally and contextually-mediated interpretation of the participants' responses to the research question, 'What are the emotional and interpersonal aspects of fertility damage and/or premature menopause from cancer treatments?'

⁹ See Appendix five

The following three chapters present the study findings in the three main findings categories: 'Communication and Decision-Making in the Cancer Context', 'Loss and Disruption', and 'The Emotional Impact of Loss and Disruption'.

CHAPTER FIVE: COMMUNICATION & DECISION- MAKING IN THE CANCER CONTEXT

INTRODUCTION

In this and the following two chapters the findings from the data analysis are presented and discussed using the theory of chronic sorrow as the conceptual framework. These chapters represent the three main categories of findings from this study. These are the participants' experiences related to 'Communication and Decision-Making in the Cancer Context', 'Loss and Disruption', and 'The Emotional Impact of Loss and Disruption'.

This chapter, reporting the study findings of the first category, is focused on the participants' experiences of communicating with health professionals and making decisions about treatment. The first short section is comprised of participant 'vignettes', short descriptive texts which introduce the seventeen women who were the participants in the study. Following this, there are two main sections, focused respectively on treatment discussions and decision-making, and some participants' feelings of not fitting the usual profile of patients in the cancer care environment. Each section or sub-section of findings includes illustrative examples of data with accompanying interpretive comments, followed by a more in-depth analysis of the section drawing on relevant literature and the theory of chronic sorrow.

The participants were invited in the interviews to talk about the initial information that they received about the possibility of fertility damage and/or premature menopause from their cancer treatments, and any information that they received subsequent to this. The data resulting from this are presented here.

PARTICIPANT VIGNETTES

Hannah:

Hannah was a 32-year old health professional at the time of her diagnosis of ovarian cancer, four years ago. She was single and had, until her diagnosis, not thought much about having children because of the difficulties associated with having children in same-sex relationships, and the fact that she still had some time in which to make such a decision. When she met with her surgeon to discuss her diagnosis and the radical surgical treatment that was recommended, she was extremely surprised to find that the prospect of immediately becoming infertile was devastating. This was particularly related to her Māori heritage and led to her feeling like a ‘full stop’ in the family line. Hannah declined the surgeon’s offer of a referral for fertility preservation advice because she felt that there was little likelihood of her successfully applying for a surrogate mother in the New Zealand environment, due to her sexual orientation. She did not want to decrease her chances of a positive surgical outcome while pursuing something that she felt would be a waste of time. Hannah was also affected by the sudden onset of premature menopause as a result of her surgery. These symptoms acted as a forceful reminder to her of her lost fertility.

Anne:

Anne was 37 when she was diagnosed with breast cancer, three years ago. She was in a new relationship, and she and her partner had not reached the stage of discussing having children in the future. Anne was unsure as to how her partner would manage her diagnosis and felt that she was ‘damaged goods’; she was thrilled when her partner said that he was staying around, and that he would support whatever treatment and fertility decisions she made. Anne met with a fertility specialist and commenced the process to harvest eggs and cryopreserve embryos so that she had the possibility of becoming a mother in the future. She was ambivalent about this, however, and eventually stopped the process because she was very frightened of the delay in her breast cancer treatment that this required. Anne remained unsure of both the decision to commence fertility preservation, and the decision to stop.

Ellen:

Ellen, a 43-year old Māori woman, received her diagnosis of breast cancer 3 years ago. Ellen has a 16-year old son from a previous relationship, but was single at the time of her diagnosis and at the time of her interview. Ellen had an oophrectomy as part of her cancer treatment, and while she was not concerned about her loss of fertility, she felt that had she not already had her son, this would have been devastating for her. She suffered from acute and disturbing menopausal symptoms, however, and found these difficult to manage at times. Ellen remained very positive through her experiences, using the phrase, 'If life gives you lemons, make lemonade!', to describe her outlook on life, cancer and premature menopause.

Robyn:

Robyn was 52 when she was diagnosed with breast cancer, 2 years ago. She had been married for nearly thirty years and has two adult children. A health professional, Robyn was surprised at the depth of her emotional response to the loss of her fertility and pre-menopausal status as a result of her cancer treatment. Although she had not wanted any more children, and was probably close to her natural menopause anyway, she was very attuned to her body and its natural cycles, and mourned the unnatural body changes that she went through. This also deeply affected her sexuality, something that she noted was a major issue for many women in a similar situation.

Debbie:

When diagnosed with uterine cancer at the age of 45, five years ago, Debbie was in a relatively new marriage with plans to start a family. The medical recommendation to have radical gynaecological surgery to manage her cancer was a devastating prospect, and Debbie was still deeply affected by her resulting infertility at the time of her interview. Her inability to have children significantly affected her husband and their relationship, and Debbie felt that he would be better to have left her so that he could have had children with someone else. Debbie and her husband were actively involved in adoption proceedings at the time of her interview, and this was having a major impact on their lives, choices, emotional and psychological health, and their relationship. Debbie was considering opting out of the adoption process for her own mental and physical health, and that of her husband.

Wendy:

Wendy was diagnosed with Non-Hodgkins Lymphoma at the age of 24, 14 years ago. She was in a relationship but did not consider this a serious or long-term one. Wendy was devastated when told that the treatment she required would likely make her infertile, and that there was not time to pursue fertility

preservation due to the acuity of her illness. She was particularly affected by her perception of her doctor's lack of understanding of the impact of this on her. Wendy's cancer treatment was successful, and because she did not need to have a bone marrow transplant, she did maintain a degree of fertility. She has since had a son through in vitro fertilization, with her new husband. The in vitro fertilization process was very difficult and traumatic for Wendy and she feels the burden of the 'difference' in this process versus the normal and natural processes of pregnancy and birth. Wendy also described her ambivalence about the prospect of having another child from the embryos that she and her husband have stored.

Meredith:

Meredith was diagnosed with breast cancer at the age of 46, a year ago. She is married with three children, the youngest aged 17. Meredith was particularly affected by the impact of premature menopause on her sense of self, her sexuality, and her relationship with her husband. She described how her loss of fertility and the onset of premature menopause left her feeling unattractive, undesirable and old, a different person to who she had been. Meredith was actively seeking to find new ways to contribute and be generative in her new post-cancer and post-menopausal life.

Carol:

Carol, a 44-year old health professional, was diagnosed with breast cancer at the age of 40. Carol is married with three children, the youngest aged 18. While Carol was not affected by the prospect of her lost fertility, she was very deeply affected by the impact of premature menopause on her body, her sexuality and her self-esteem. Carol described her perceptions of her early aging due to the onset of premature menopause and the effects of this on her feelings about herself and her life. She was concerned that these issues went unacknowledged and unrecognized by the majority of health professionals.

Susan:

Susan was initially diagnosed with breast cancer at the age of 36, and then with cervical cancer when she was 39, 2 years ago. Susan and her husband were living overseas when she was diagnosed with breast cancer, and had been discussing plans to start a family just prior to this. They were both devastated by the possible impact of her cancer treatment on her fertility, and this had a significant impact on their relationship. After a period of time, Susan moved home to be closer to her family, hoping that her husband would also come back to work on their relationship. Shortly after they reunited in NZ, and had decided to see whether they would be able to conceive, Susan was diagnosed with cervical cancer and radical gynaecologic surgery was recommended. Susan recalled the great difficulties she encountered in discussions with the surgeon about fertility-preserving surgery, because maintaining her fertility was

crucially important to her and her husband. This was an extremely traumatic time for Susan and she was still deeply emotionally affected by this at the time of her interview. Susan's fertility was spared, and she and her husband were pursuing gestational surrogacy. This was proving to be a difficult, draining and emotionally challenging process for them both.

Maryanne:

Maryanne was diagnosed with breast cancer six years ago, at the age of 43. She is married with three adult step-children. Maryanne was initially very surprised at her emotional reaction to the prospect of losing her fertility due to her cancer treatment, as she had thought that she was well accustomed to her earlier decision not to have children of her own. She felt that having the decision made for her through the need for treatment changed the way she felt about it. After her treatment, Maryanne was deeply affected by the impact of premature menopause on her sexuality and her sexual relationship with her husband. She described the impact of a cancer diagnosis and treatment as akin to 'a car wreck', and the expectation that people who have experienced this will get on with their lives without assistance as naïve and unacceptable. Although generally positive and proactive in her outlook on life, Maryanne continued to struggle with the ongoing effects of her cancer and its treatment and her own emotional reactions.

Leane:

Leane had been diagnosed with breast cancer six years ago, at the age of 44. She is married with three children aged 13, 11 and 7. Leane, an articulate, confident and highly qualified professional woman, contacted me for the study because she wanted to ensure that people who had experienced positive outcomes from cancer were represented in the study. Leane was an advocate of positive thinking, and described her choice to maintain a positive outlook from the very beginning of her cancer journey, and the importance of this for a positive clinical, as well as psychological, outcome. Leane was clear about the value of knowledge, assertiveness and confidence in approaching a diagnosis of cancer and navigating the cancer journey.

Dawn:

Dawn, who openly identifies as lesbian, was diagnosed with breast cancer at the age of 33, 7 years ago. She was single at the time, with a young son who had been conceived with the use of donor sperm in a previous relationship. Dawn was deeply affected by the impact of her cancer on her fertility as she had wanted a sibling for her son, but was advised to avoid pregnancy for five years after her diagnosis. During this time, she was found to carry the BRCA1 gene and was advised to have an oophorectomy to reduce her chance of developing a further breast or ovarian cancer in the future. Dawn had wanted to pursue fertility preservation to maintain the possibility of having another child, but felt

that difficulties in communicating the importance of this, and delays in hospital referral systems resulted in it being too late to do this successfully. Dawn remained very distressed by her inability to have another child at the time of her interview.

Sandra:

Sandra, a 40-year old Māori woman, was diagnosed with breast cancer a year ago. Sandra is married with two children aged 4 and 7. Although Sandra stated that she had not wanted any more children, and felt that the loss of her fertility was not an issue for her, she was greatly affected by the unnatural changes to her body and its functioning that were caused by her cancer treatment. Sandra was distressed that the monthly cycles that she had relied on, celebrated and seen as a positive sign of her health and vitality, were stopped by her treatment. She mourned the ‘normality’ of menstruation, and felt separate to, and different from, her peers.

Elizabeth:

Elizabeth was diagnosed with leukemia 19 years ago, at the age of 35. She was in a relationship at the time, but she and her partner did not have children. Elizabeth had always wanted a child, however, and was devastated to find that she would be infertile after her treatment. Initially, she felt that the fertility issue was almost ignored – recalling only a question as to whether she was using any contraception, and the advice that she did not have time to consider fertility preservation, had it even been available. Elizabeth recalled feeling relief that she did not have to make a decision to delay cancer treatment to pursue fertility preservation, as she felt that this would have been a very difficult one. Elizabeth, now single, described her great regret that she did not have children, and the sense of alone-ness that she feels through not having a child to carry on for her in the world. This feeling had been particularly apparent since the death of her mother.

Marie:

Marie was diagnosed with cervical cancer three years ago at the age of 39. She is in a long-term same-sex relationship, and she and her partner had made a mutual decision many years ago that they would not have children. Marie was very surprised at the great depth of her emotional reaction to the news that the treatment for her cancer would leave her infertile, and the discovery at this time that she did, in fact, want a child. This realization was devastating to her, and has caused great difficulties in her relationship, as her partner’s perspective has not changed. Marie was still very distressed about her lost fertility and resulting childlessness at the time of her interview, describing this as worse than the cancer itself. Marie also described her sense that her sexual orientation impacted on the way in which her treatment discussions were undertaken,

feeling that it was assumed that fertility would not be an issue for her, with only a token mention made of the issue of infertility.

Christine:

Christine was 27 when she was diagnosed with cervical cancer 23 years ago. She was newly married and living overseas at the time. Christine was initially deeply affected by her diagnosis and the loss of her fertility, describing herself as ‘a spayed bitch’ with nothing to offer any more. Christine’s relationship with her husband was irreparably damaged by her cancer and infertility, and Christine believes that this was because her husband was very much affected by it, yet was unable to talk with her about it at all. He became an alcoholic, and their marriage ended within a few years. After this, Christine suffered greatly in terms of emotional distress and low self esteem, believing that her infertility made her useless as a partner. Early relationships during this time reinforced this feeling, when men declined to continue in a relationship after she told them about her fertility status. Christine described herself as a very strong person, however, and told of how she harnessed her inner strength to overcome her emotional distress rebuild her life and her self-concept. She has subsequently married a man who didn’t want to have children.

Bridget:

Bridget was diagnosed with leukemia 2 years ago, at the age of 38. She is married with three children, aged 3, 6, and 12. Bridget and her husband had wanted to have another child prior to her diagnosis, and the impact of her treatment on her fertility and the ability to do this has been greatly distressing to both of them. She described her feeling that she has let her husband and her children down by not being able to bring another child into the family. Her treatment has also resulted in premature menopause, which has had a considerable impact on her sexuality and her relationship with her husband.

NEGOTIATING TREATMENT DISCUSSIONS AND DECISIONS

The first, and arguably most important, phase of the cancer journey is that in which the initial discussions regarding the cancer diagnosis and potential treatment occur. This is a vital opportunity for patients to gather information, discuss concerns and priorities, and begin to build a relationship with key members of the healthcare team. The participants in this study reported a variety of experiences in this stage of negotiating information, discussions and decisions. A minority reported very positive experiences of discussions

with key health professionals (usually, in the initial stages, a surgeon and/or oncologist) and attributed this to the particular health professionals concerned.

Finally, it was the registrar, and she approached [issues related to fertility] and talked about it and she really seemed to get it – Anne

Yes, I went through [private clinic] and he [surgeon] was absolutely fabulous, he was so good. You know, when you went to see him, you'd be the only person in the room, no matter who was with you, you were the only person in the room and he doesn't talk to anyone but you. And he goes through everything and he explains it clearly, he draws pictures, and they're really simple, clear pictures, he's fantastic – Ellen

However, the experiences described by a number of participants suggest that they were required to make too many life-changing decisions too quickly, and without adequate information or understanding. While these decisions may have appeared simple at the outset, the long-term ramifications of them seem to have needed a great deal more discussion and consideration than the majority of participants experienced. All of the participants, however, had undergone or were still undergoing recommended cancer treatments.

You know, 'You've got breast cancer, we're going to save your life! We're going to cut off your breast, we're going to give you things that are going to make you sick, we're going to put you into menopause, make you fat, even though you're determined to stay skinny, and then you get the bill for Herceptin!' And then they say, 'And it MIGHT save your life' – Robyn

I really felt in the whole process – at the start, that was my number one consideration, was preserving my fertility - ... that [fertility] was none of the doctors'... number one consideration whatsoever. And even though I always opened things with saying, 'This is my number one consideration', because they were a breast doctor or a plastic surgeon it wasn't on their radar – Dawn

So the fertility, sometimes, when you're actually newly diagnosed and going through treatment, you think, 'Oh, yeah, I'll deal with that'. But it's at the end of your treatment when you start thinking about it again. 'Oh, are my periods going to come back? What's going on here?' – Carol

Knowing what I know now, I would definitely want more information, more support, well, maybe more support, but I'd want to be given that choice. I really would want to be given that choice. Although, at the time, it didn't matter that the choice was taken away, the treatment had to be done, but, you know, if you can do something half way through your chemotherapy and find that you're still producing eggs, or still fertile, or however it works, do something about it – Wendy

These findings suggest, therefore, that the choice to commence potentially fertility damaging or menopause-inducing cancer treatments was difficult and distressing for some participants. They felt that members of their healthcare teams did not understand how crucially important fertility and menopause concerns were to them, and some perceived that these issues were considered to be trivial and unimportant in comparison to survival. This suggests the presence of covert boundaries around topics that were or were not acceptable and appropriate for discussions with health professionals regardless of the needs and preferences of the participants. Issues related to fertility, menopause and sexuality appeared to be neither acceptable nor appropriate topics for discussion.

We didn't see the fertility specialist until after I'd had my [breast] surgery. You know, the fertility thing was by-the-by, the surgery just had to be done, but I think it needs to be about someone's whole life, not just about life or death, it's about quality of life as well, and that actually sometimes that might just be more important to people, they might actually feel that life's not worth living if they aren't going to be able to have a chance to have children... Things like that need to be taken into account – Susan

I kind of think it's appalling that they [surgical team] didn't mention anything about that [fertility], but I could have followed up on it... Then when I saw the oncology doctors she just touched briefly on it. She didn't talk really about and I sort of got from her that it wasn't a subject that we talked about. It was more about surviving and about the chemo and how that was going to be - Anne

Fertility was very much a cursory mention at the end and I was kind of disappointed in that – Hannah

Because doctors are saving your life, people don't feel comfortable about talking to them about [things like sexuality, fertility], especially if the doctor is male, young, suit and tie – Robyn

The findings here suggest that many participants acknowledge that survival is the primary medical outcome of cancer treatment, and accept that their healthcare teams operated with their best interests as a priority. Many maintained, however, that their most important goal may not have been survival, and that this should have been taken into consideration to a greater degree.

I was offered an oophrectomy, and no one said, 'Oh, have you finished having your family yet?' You know, people are having their children later, and even if you've got one, you might want another one... They obviously have a task, and they want to get it done. But they actually just don't explain – and that's the thing, they don't...[necessarily ask for, or get, the things that are of real importance to the patient'] – Carol

Well, it upset me, because the choice was taken away, but now, knowing what I know, I would have liked to have had the opportunity to discuss this further, not just, 'Let's just worry about you now'. That's the only regret - Wendy

And it's like they had the script ...but all this information's coming at them – I was saying all this stuff, and they weren't hearing it - Dawn

She did ask, the specialist did ask. And I look at these specialist medical professionals as...kind of scientific. And so their minds are maybe a little less cluttered than mine. And she did as good a job as she probably thought she could have. But I think that there was definitely more needed. She just didn't know that – Marie

This difference in priorities remained a distressing and frustrating issue for Susan who reported feeling unheard, dismissed and ridiculed when trying to raise these matters with her surgeon.

So, anyway, we felt...and we always made it very clear to any health professionals that we were talking to, that fertility was actually a big issue for us – the whole fertility impact. But I kind of found that the surgeons usually kind of take the approach of, 'Well, we just want to get the cancer out basically and that's the most important thing – just be thankful that we'll do that, everything else is kind of trivial in comparison'... I just remember that the surgeon that I had...He still kind of makes jokes about me being a bit 'mad' or a bit 'loopy' because I basically...if there was any way that I could hold on to my uterus and have a chance of conceiving and carrying a pregnancy then I would, and I would get really upset if he was kind of saying anything otherwise. So he kind of, yeah, he didn't take that very kindly, he was, 'Shit, you've got cancer, surely you just want to get it out!' – Susan

For those with haematological cancers, life-saving treatments needed to commence immediately and fertility preservation measures were not considered possible. Wendy recalled being devastated when she was informed of the potential for the loss of her fertility, but she perceived that she was without options due to the acuity of her illness.

And at that time, that devastated me. I remember, I couldn't [have] cared less about having cancer, I was devastated at not being able to have a child...She [the haematologist] did say, 'You don't have time, you start doing chemotherapy tomorrow.' And I did, I started the next day, and I'd only just been told. It was like, 'What?' – Wendy

In contrast Elizabeth, who was also diagnosed with a haematological malignancy, recalled the relief she initially felt in the same situation. She acknowledged, however, the effects of fertility damage on her long-term quality of life.

Because at the time, you just sort of forget about all that, you just think, 'Oh God, my life's more important than anything else' – Elizabeth

Some participants reported that difficulties in negotiating the health system further affected the levels of control that they were able to exert over their decision-making processes. For example, the nature of the public referral and appointment system led to delays in consultation that denied Dawn the opportunity to pursue fertility preservation measures prior to cancer treatment.

But obviously if someone was going to die if they weren't seen [at oncology clinic], I'd rather they didn't die than I had a baby. But it's that stuff about who's making the decisions about what's important – Dawn

Susan and Leane were adamant that patients have a responsibility to themselves to be well-informed and to direct oncology appointments according to their priorities.

One thing I would say is...that you've got to be pretty switched on and well informed in order to get the most out of your consultant. They don't volunteer stuff, like you've got to pump them for information, you've got to know the right questions to ask, and in order to know the right questions to ask you've got to have done your own research - Susan

Well, I was a lawyer, so I went through this as well, but, as a client or a patient, you've got to be up to speed, and be discussing things on an equal level with the doctor and then you're in a position to make a choice – Leane

Others implied however, that this is an unrealistic expectation for many people experiencing the extreme emotions often associated with a new cancer diagnosis, and that they may neither think to, nor have the courage to, raise an issue if the healthcare team have not done so.

You don't ask the right questions at the beginning either, because you don't know what the questions [are], you don't know what the context is...they haven't hit you yet – Robyn

Some also suggested that the responsibility for discussing or even emphasising the risk of potentially life-changing long-term treatment effects rests with the healthcare team due to the above-mentioned vulnerability and distress experienced by people in this situation, and their understandable lack of knowledge.

At the time you're so scared anyway that you don't look for options, you just do what you're told – Christine

The doctors didn't make a big deal [about the risk to fertility], and I didn't think! Until later on – Elizabeth

If at the time they had really pushed the point home – these are the consequences of getting this surgery...I mean, the consequences are obvious, but because the time is such a shocked time, it is completely different from any other time. It turns everything onto sort of a freeze or a hold mode so you don't know what you're saying or doing, really, at the time. But at least if they had pushed the point a little bit more and made you a little bit more aware of what the consequences meant to you, then I would feel that it had been my decision. But I don't feel that. I didn't at all think about the consequences, not really. It would be better to have the same discussion again a week later when you've had time to get over the initial shock and think more about the consequences – Marie

The findings in this section indicate that the majority of participants perceived that the health professionals involved in their care lacked understanding of the degree to which issues other than survival were important to them. Further, some felt that health professionals were unwilling to even consider issues such as fertility and menopause as potentially important - that anything other than a cure simply didn't register with them as a valid issue. This implies a possible division between the two parties in which potential quantity and potential quality of life seemed unnecessarily opposed rather than discussed and negotiated in an open and equal manner.

These experiences suggest that the health professionals involved in the care of these participants 'missed the boat' in discussions around cancer treatments and their potential impact on fertility and wider sexuality. Ramfelt and Lutzen (2005), in exploring patient compliance with cancer treatments, found that where patients comply with treatment recommendations, this compliance may be represented by either end of what they described as an "activity-passivity construct" (p. 144). They found that compliance with treatment recommendations may occur with or without active patient participation. The most significant influences on this process were the relationship between the health professionals concerned and the patient, and the nature of the decision-making

environment. Considering the current environment in which services are provided in New Zealand, it is probable that systemic limitations such as short consultation times, pressure to make rapid treatment decisions, difficulties in accessing specialist fertility advice, and limited research into the needs of younger people with cancer added to these difficulties.

The decision-making experiences reported by the majority of participants in this study reflect “compliance without participation” (Ramfelt & Lutzen, 2005, p. 147) through a process in which they felt at best, vulnerable and unsure, and at worst, pressured and unheard. This is concerning because these participants were young, articulate women who, theoretically, should have had a better opportunity than many to achieve collaboration in treatment decision-making. The findings presented here, however, indicate that many felt that they had not done so, which is concerning from an ethical perspective. Because their healthcare teams inadequately addressed the wider implications of the treatments they received, the findings suggest that the participants’ autonomy and dignity were compromised. Therefore, their healthcare teams did not meet the requirements of the principle of autonomy, which is of equal importance as an ethical principle in healthcare (I. E. Thompson et al., 2006).

Employing the analytic lens of the theory of chronic sorrow to further develop this interpretation, a crucial aspect of the theory - the presence of an identifiable ‘antecedent loss event’ that leads to ongoing ‘disparity’ - is useful (Eakes et al., 1998; Lindgren et al., 1992; Roos, 2002). While the concept of chronic sorrow initially focused on the birth of

an intellectually disabled child as the antecedent event (S. Olshansky, 1962), this was subsequently extended to include the onset of chronic illness as a valid antecedent to the development of chronic sorrow (Eakes, 1993; Eakes et al., 1998; Lindgren et al., 1992; Teel, 1991). From the perspective of chronic sorrow theory, the cancer diagnosis and treatment could be characterised as an ‘antecedent loss event’ that resulted in a number of ongoing losses including fertility damage and/or premature menopause. Contributing to this were the participants’ often negative experiences of discussions and decision-making. The negative impact of poor communication, lack of support and unrealistic expectations on patients has been previously described in the chronic sorrow literature (Bowes et al., 2008; Isaksson & Ahlstrom, 2008; S. Olshansky, 1962; Roos, 2002; Roos & Neimeyer, 2007). Of particular relevance here, Eakes (1993) found, as was the case for these participants, that a lack of time to assimilate diagnostic and treatment information, and the perception of a lack of support from health professionals impacts negatively on treatment decision-making, and contributes to the development of chronic sorrow in people with a cancer diagnosis.

The anthropological concept of liminality is also useful for this interpretation. The concept that would come to be named ‘liminality’ was first described by Arnold van Gennep in 1909 in his ethnographical studies of significant life challenges or ‘rites of passage’ (van Gennep, 1960/1909). Van Gennep focused on rituals in which transition was a key element in the process of movement from one social state to another. He proposed a three part model of these transitional rituals: separation (from the former state), transition or threshold, and incorporation (into the new state). It was the central

stage of transition that van Gennep was most interested in and that was later developed into the new anthropological concept of liminality. Little et al. (1998) employed the concept of liminality as a descriptor for the cancer journey. They proposed the term 'communicative alienation' to express the loneliness of the cancer experience. Their interpretation was that the person with cancer is unable to fully share with others what it is like for them to live with cancer. Thompson (2007) extended this concept in two ways. Firstly, to say that this alienation is the result of the inability of the hearer to hear and comprehend, rather than the inability of the affected person to articulate their experience. Secondly, she recognised that communicative alienation can exist in the relationship between patients and health professionals.

The findings of this study suggest that although the participants were able to articulate their concerns and needs, they were not being heard by their healthcare teams. They felt that they could not communicate openly and equally with their healthcare teams, and this inhibited discussion of issues of significance to them, and therefore, their opportunities to make truly informed treatment decisions. Despite this, however, all of the participants reported that their treatment decisions would have been the same if open discussions around fertility and menopause had taken place, as described above. The difference would have been an increased ability to accept and assimilate the changes to their fertility and menopausal status and what this would mean for them, thus improving their long-term quality of life (N. J. Davies et al., 2008; Wilmoth, 2001). Health professionals did not consistently and adequately provide, allow or encourage discussions about issues important to these participants. This challenged many participants' abilities to make

good quality treatment decisions and decreased the level of support they received throughout their cancer journeys, contributing to the long-term negative impact of their cancer diagnoses and treatments.

THE CHALLENGE OF NOT FITTING THE ‘USUAL’ CANCER PATIENT PROFILE

Further to the more general findings above, the experiences described by some participants suggest that their relationships with health professionals and healthcare systems were complicated by factors specific to themselves. Some perceived that health professionals made implicit judgments based on their age, sexual orientation, relationship status or parenthood status, and based their level or inclusion of discussions about fertility, menopause or sexuality on this.

I was offered an oophrectomy, and no one said, ‘Oh, have you finished having your family yet?’ You know, people are having their children later, and even if you’ve got one, you might want another one. And when I said, ‘No! [to the oophrectomy]’, he said, ‘What’s your reason?’. I said, ‘I’m not ready to have this’ – Carol

I suppose there is probably attention paid especially to women who really were thinking about it [having children] or in love and wanting to have children...and this terrible thing happens. But so many people in different situations, either single, or in a gay relationship or whatever....Or, [there is] the assumption that because you have one child, you wouldn’t want another – Dawn

Some participants perceived that their young age at the time of their diagnoses meant that their care may have been compromised by the lack of available research and reliable information about younger people with cancer, and specifically about fertility/sexuality issues.

I was quite shocked at how little information there was... Yeah, I'm just kind of disappointed at the lack of attention paid to that side [sexuality and fertility] of things. Basically, when I go for my checkups with the gynae-oncologist, they ask about that kind of thing but then they can't really offer any assistance, and they've even admitted that they're kind of woefully inadequate in that respect – Susan

At the moment you've just got the basic script, and if you don't fit the basic script, it's, 'Oh, you don't fit, we don't know what to do with you!' - Dawn

In particular, Marie, who was one of three participants who identified as lesbian, reported feeling that the potential for fertility damage was not deemed to be such an issue when her treatment was being planned and discussed. She perceived that her sexuality may have had a negative effect on her health care and the options she was given.

I definitely feel now that she [the surgeon] could have made more of it [the infertility issue], yes. At the time I thought, 'Well, she brought it up, and I did say no'...But it was just the one question brought up on one occasion and dismissed very, very quickly. And I don't know whether it was my living situation, or my age, or I don't know, but that was all, that was the sum total of the discussion, and now I definitely do think that she should have made more of an effort to get me to think it through – Marie

Finally, a number of participants perceived that their added symptoms related to treatment-related premature menopause were a complicating factor at oncology appointments and challenged health professionals in an unfamiliar practice area. They remained a part of the oncology system for their ongoing assessments yet their most pressing symptoms, being related to the rapid onset of premature menopause, were neither recognized nor dealt with. For these participants, the end of cancer treatment and receiving positive prognoses seemed to be overshadowed by their ongoing issues with premature menopause and sexuality, and variations in health professionals' confidence or willingness to confront these issues.

They've saved your life, but you've still got your life to live afterwards, thinking, 'Yes, you have saved my life, but I've now got x, y and z happening to me because of my treatment. And I've got to live a life that's shortened because of it.' I guess I've got to learn to deal with it ...and oncologists don't know what to do [about] these things either, and they don't like to talk about them – Carol

But mostly I found that, I mean, you have to like drag stuff out of them sometimes, pump them for information, and they also...the shocking thing that I mentioned earlier is that they didn't have all the answers. I mean, I sort of thought, well, shit, that was kind of a basic question! And you don't actually know – not that that particular person didn't know, but that it hasn't been studied, there's nothing to tell us – Susan

One thing I have found hard is wanting to talk to someone about, you know, sex and libido and things with the chemo and radiation, but they just don't want to know which I find tricky – I think he's [the doctor] embarrassed about it – Anne

This feeling that they did not fit the usual profile of people with cancer led to perceptions, for some participants, that their ability to openly discuss their concerns with health professionals was affected and, likewise, their options and decisions. Because they were younger than the majority of women and people diagnosed with cancer, most of the participants felt that they presented a challenge to the ability of the health system to adequately meet their needs, as previously reported by McMahon (2002). This perception was increased for some due to their sexual orientation.

Following on from the previous section in which concern regarding some participants' autonomy was voiced, the findings here suggest additional neglect in relation to the principle of justice. Within this principle is the requirement that people are treated without discrimination (I. E. Thompson et al., 2006). There are many ways in which health professionals and the systems within which they work may discriminate against individual patients or patient groups, and the experiences of some participants are suggestive of inadvertent discrimination in terms of sexual orientation. This involved

individual health professionals and features of the healthcare system that potentially impacted on some participants' rights to receive just or fair care and consideration. In addition, many participants perceived the presence of wider discrimination related to their age in their individual engagement with healthcare teams, and in the limited availability of information relevant to their care as younger people with cancer.

Turning, once again, to the lens of the theory of chronic sorrow to help explain these findings, we find that little has been written in the chronic sorrow literature around issues of marginalisation and vulnerability, although Kendall (2006) proposed that the definition of chronic sorrow be extended to include feelings of invalidation and being unheard, social isolation and vulnerability. The findings in this section indicate that having cancer at a young age, and the resulting feelings of vulnerability and uncertainty, resulted in a loss, for some participants, of confidence in their own choices and decisions, and in the ability of the healthcare team to acknowledge and act on their preferences. Some participants perceived that their needs, preferences and decisions were less likely to be attended to because they presented in a manner, or as a person, that was different to the norm. They therefore felt vulnerable and fearful of being unheard, which impacted negatively on their overall experiences of treatment discussions and decision-making.

Little et al. (1998) described the concept of 'boundedness', which they defined as the limits perceived by the person with a new cancer diagnosis in terms of time, space and of interest here, empowerment. They defined empowerment as having autonomy and self-determination. The experiences of some participants in this study suggest that they felt

dis-empowered in their relationships with health professionals and the health system, particularly related to factors such as their age or sexual orientation. A diagnosis of cancer is frequently associated with a high level of distress, which decreases a person's ability to comprehend complex new information and assimilate this into coherent decisions (Andrykowski et al., 2008). Thus, many participants in this study found themselves in an unexpected, frightening and vulnerable position whilst making life-altering decisions about cancer treatments, with variable information to hand. They felt both alienated in communication with the healthcare team, and dis-empowered when communicating and making decisions.

CONCLUSION

Health professionals did not consistently provide, allow or encourage open discussion about issues related to fertility, menopause and sexuality, suggesting a division between the needs and expectations of the participants, and the expectations and practices of those involved in their care. As a result, many participants felt unsupported, unheard or vulnerable, and therefore experienced a degree of distress and/or difficulty when making decisions. This decreased the quality and assurance of the decisions they made, and increased the sense of alienation and distress experienced by some participants.

The next chapter reports the study findings related to the loss and disruption the participants experienced as a result of the cancer diagnoses and treatments.

CHAPTER SIX: LOSS & DISRUPTION

INTRODUCTION

This chapter, reporting the findings from the second category, is focused on the loss and disruption the participants described as a response to their cancer diagnoses. These were associated with their cancer diagnoses and treatments, and to a greater degree, with the onset of fertility damage and/or premature menopause.

There are three main sections, focused firstly, and to a lesser degree, on loss and disruption related to the cancer diagnosis and treatment, and then in greater detail, loss and disruption related to fertility damage, and premature menopause. The section focused on fertility damage includes sub-sections related to the impact of this on the participants' identities, the impact of engagement in processes to achieve parenthood, and the impact of fertility damage on partners and intimate relationships. The section focused on premature menopause also includes sub-sections related to the impact of this on their identities, and partners and intimate relationships. Each section or sub-section of findings includes illustrative examples of data with accompanying interpretive comments, followed by a more in-depth analysis of the section drawing on relevant literature and the theory of chronic sorrow.

The participants were asked to talk freely about possible fertility damage that resulted from their cancer treatments and how this may have affected them and their relationships.

As described in chapter four, the interview schedule was amended during data collection to include premature menopause in addition to fertility damage.

LOSS AND DISRUPTION RELATED TO THE CANCER

DIAGNOSIS AND TREATMENT

The findings in this section indicate that the negative consequences of many participants' cancer diagnoses and treatments were considerably greater than the majority had anticipated. They perceived that their lives were significantly and persistently changed by their cancer diagnoses and the ongoing impact of them. This presented a challenge to their previously held beliefs about, understandings of, and expectations for, their lives and themselves. Although they were objectively cancer-free, physically well and functioning normally, fourteen participants continued to subjectively struggle with the ongoing impact of their diagnoses and treatments.

You hear the word 'cancer' and you just think, 'Ok, let's just get on with it, let's get it out', and you don't actually realize until the end what they've actually done – Carol

Cancer treatment suddenly takes things away from you, no questions asked – Robyn

But there's this whole thing about we treat you and then you get on with your life... it's not just a case of taking pills and you go home. You've sent home a car wreck. And saying to you, 'At least you'll live now' is not enough – Maryanne

I just wanted to be normal, and I was until I was 24. And then it all changed. I didn't think it would change my world – Wendy

This was previously described by Navon and Morag (2004) as “recovery without wellbeing” (p. 2340), or achieving “adjustment without reconciliation” (p. 2342) after cancer treatment, resulting in the loss of a “continuous sense of self” (p. 2344). As

cancer survivors, the participants had passed through the acute phase of their illnesses, but did not return to the same lives that they had left (Doyle, 2008). Their experiences of cancer and its treatment negatively impacted on their ability to resume a seamless continuation of their lives. The continuity and coherence of their pre-cancer to post-cancer life stories was fundamentally disrupted as they experienced ongoing changes to their lives that marked their post-cancer state from their pre-cancer state.

Chronic sorrow theorists use the term ‘disparity’ to denote the often considerable life differences people experience as a result of significant loss or change. This difference marks a division between the person’s past and present/future (Teel, 1991), or between the reality of the person’s current and projected future life situation and that which they had previously anticipated or desired (Eakes et al., 1998). ‘Disparity’ implies difference, dissimilarity and lack of congruence between entities. Thus, the persistent physical and psychological difficulties that fourteen of the seventeen participants described could be understood as denoting a disruption, or interruption to their lives, which could be seen as such a ‘disparity’. The disruption that is revealed in the findings above resulted from the losses associated with their cancer diagnoses and treatments (Ahlstrom, 2007; Eakes et al., 1998; Hewson, 1997; Teel, 1991) and was demonstrated in the negative differences that they perceived between their pre-cancer and post-cancer lives. This overshadowed their physiological recoveries from treatment, yet remained largely unseen and unacknowledged by others. This disruption was fundamental, altering their understandings and experiences of their lives.

In addition to this, the participants described further difficulties related to the onset of fertility damage and/or premature menopause. These are presented and discussed in the remainder of this chapter.

LOSS AND DISRUPTION RELATED TO FERTILITY DAMAGE

The loss of any aspect of the ability to conceive, be pregnant with and give birth to a child due to their cancer treatments was, as suggested in this section, traumatic and difficult for a number of participants. This loss constituted additional and serious disruptions to some participants' dreams and plans, to their expectations of normal and uncomplicated lives. For some, this had centred on the probability of pregnancy and motherhood, but this disruption led to a vastly different foreseeable reality imposed by fertility damage. This loss was life-changing for some due to the high value that they placed on their fertility and the potential to conceive and bear a child or further children.

I really do wish that I'd had a child...These things affect you more long term than the cancer diagnosis itself – Marie

But it has been...there's a lot of grief associated with it for me, and even grief over not being able to fall pregnant, not being able to be pregnant – Susan

I don't know how you do that, how you work through the fact that you can't have kids – you don't, you know - Debbie

I thought it was a huge thing, at a young age. I was only 27. It was... a huge big thing to try to come to terms with at that age - Christine

Although Marie and Maryanne had not consciously planned or anticipated having children prior to their loss of fertility, the loss of this possibility was still difficult.

I don't know whether it's your older years, I don't know whether it's just the way things go, or maybe it hits some people younger, that they want a family. But for me it's happened this way around. That now, when I have everything, pretty much everything I want, I don't have the one thing that I really want...Well, it's a huge thing, isn't it, to have a child? And it's a big huge part of my life... that I won't ever have. And now there's no choice. That's really difficult – Marie

I did a creating health programme and there was one session in which we got quite [close] to grief, I mean we touched on grief a lot but in one session we sort of honed in on it. And that particular week...she had a picture of a tree, a bare tree, with twigs on it, and we had to write, we spent some time writing on it our griefs, things like our major griefs and all of the other griefs that came off that. And I actually realized that losing my fertility was actually a grief. It was like, 'that's gone' – Maryanne

Being around friends and family who were able to have children and live the lives that they had dreamed of and expected acted as ongoing reminders, to many participants, of their own losses. They were made aware that their childlessness could be lifelong, and that they would always have something 'missing'.

And friends falling pregnant at the moment, and [husband]'s sister has just had her first child, and stuff like that, and when I found out she was pregnant, I burst into tears, you know. And when I found out her daughter was born, I burst into tears again. And I didn't think I would. My first reaction was, even though I want to be happy for her, and I am happy for her, my first reaction was to just feel bloody sorry for myself because that's never going to happen [for me] - Susan

It's just there in the back of my mind just sitting there especially now when my friends are having their babies – Anne

And I realize that we're the only ones who won't have children to look after us... we've got no-one to cook lunch for us [when we're old] - Debbie

For some, the impact of fertility damage extended beyond their personal losses to affect how they viewed their place in the genetic continuum of their family tree and their sense of meaning in their lives.

I think children give your life some meaning; I think they would give you some, it sounds a bit corny, but, legacy, I suppose – this is what I've left behind and what I've contributed to the world – Marie

[There is] just a sense of being on my own...it was a dream I had, there was nothing negative about it, your outlook if you had, if you'd had a child - Elizabeth

The loss of their dreams of future parenthood and an ongoing genetic contribution to their family tree thus represented a significant challenge to the personal and extended life plans held by some participants. This was particularly distressing for Hannah, whose life story is deeply influenced by her Māori heritage. Hannah described herself as a 'full-stop' in her family line.

I felt a responsibility. The lack of fertility... in regards to disappointing my grandmother is hard...I know she wouldn't be disappointed in me but knowing [in mind] and making that connection [with heart]...they're different...My grandmother was the last female in her line...I'm hoping my brother will have a daughter. I was really looking forward to, not that I had decided that I really wanted children, but I really wanted to [produce a daughter for the line]' - Hannah

In contrast, Wendy stated that her deepest distress was most significantly related to the possibility that she would be unable to give her husband a child.

I never thought, 'Why am I even in this world?' or 'Why are they even bothering with me?' I never felt like that, I've never been that way inclined... No. The only real problem I had, the thoughts I had at that stage was that I ... couldn't give my husband a child – Wendy

And Christine reported that her sense of meaning in life was not affected by her infertility because her real commitment and meaning was related to her work with her horses, which were her lifelong love.

I know that I'm here not for people but for the horses. And I know that the knowledge that I'm getting is going back into the horses. My role in life is that, it's what I'm good at, it's my skill. So I don't worry about - I don't think that I was here to produce children to become scientists or rule over the world or anything like that, no. I never have done. What I leave behind is what I have done for the horses and for knowledge about the horses – Christine

An important aspect of these participants' experiences of fertility damage from cancer treatment is how these events were interpreted by them in the context of their lives. In his seminal work proposing chronic sorrow as a normal response to loss, Olshansky (1962) noted that variation in the development and degree of persistent emotional distress in response to loss was mediated by such basic factors as personality, ethnicity, beliefs, previous history and other person-specific variables. Later writers in the field supported this, emphasising that the interpretation of loss is an individually and contextually mediated process (Eakes et al., 1998; Roos & Neimeyer, 2007; Teel, 1991).

Further, many psychological theories have suggested that the variability of general responses to stressful or traumatic life events reflects the personal and situational context in which the affected person and traumatic event converge (Livneh & Parker, 2005; Naus et al., 2009). Roos and Neimeyer (2007) emphasised that the meanings attached to particular aspects of life or self influence the presence and degree of distress experienced in response to their loss, and Andrykowski (2008) described the dynamic interaction

between the stress and burden of cancer, and the resources available to the affected person.

Thus, the context in which many of these participants experienced fertility damage is important. Fertility and the potential for motherhood were highly meaningful to many participants prior to their diagnoses, and central to their understandings of how their lives would be shaped and lived out. The prospect or possibility of conceiving, being pregnant, giving birth and being a mother was part of who they were and was associated with every part of their lives. The findings here indicate that the loss of, or alterations to, this possibility impacted not just on the parts of their lives in which pregnancy and mothering were the focus, but potentially on their current and future lives as a whole. This created an additional and fundamental disruption between what they had anticipated or dreamed of, and their current and future reality.

Allan (2007) described this type of life disruption as the “existential chaos” (p. 132) of infertility unrelated to cancer, where the normal and expected progression of life is interrupted, leading to chaos, isolation and distress. The degree of emotional distress these participants experienced in response to this loss was, therefore, correspondingly high. Added to this was the implicit nature of their loss. The death of a child is a public and recognised event, but the loss of the potential for a child is not (Sherrod, 2004). Such invisible or less visible loss may be misunderstood, go unnoticed, or be minimised by others, adding to the suffering of those affected, and reducing the level of support they receive (Bowman, 2008; Roos, 2002; Roos & Neimeyer, 2007).

Viewed from the perspective of the theory of chronic sorrow, the cancer diagnosis and treatment could be seen, as mentioned in the previous chapter, as an ‘antecedent loss event’ that resulted in a number of losses, including the fertility damage described here. This in turn led to the development of painful life disruption (disparity). As many of these participants had anticipated that childbearing and parenting would be the focus of their future, the difference between this expectation and their new reality was huge. They were forced to acknowledge the often painful reality of all that they had lost as a result of the cancer and its treatment. They were also required to live with the resulting disruption between what they had anticipated for themselves and their lives, and the reality of what actually was and would be. The loss and disruption associated with the cancer diagnosis and treatments was therefore compounded by the onset of fertility damage, and these participants’ realisation that regardless of the success of their cancer treatments, their lives were irreparably altered.

In addition to this, fertility damage had a considerable impact on the way that many participants viewed themselves, and their ability to reconcile their pre-cancer selves with their post-cancer selves. This is discussed in the next section.

The Impact of Fertility Damage on Identity

Ongoing contact with siblings and peers who were reproducing and raising children, and the evidence of collective fertility constantly displayed in the general public domain resulted in a feeling, for some, of being different or even abnormal. The findings here suggest that some participants felt that they were lesser women because they were unable

to bear a child (at all, or without intervention), that they compared poorly with other women for whom fertility and fruitfulness appeared to be the effortless norm.

I did at the end of it feel like some sort of spayed bitch. You know, 'I'm a spayed bitch now, what have I got to offer anyone?' Which is stupid, and I realized later that it was stupid, but at the time you get locked into this kind of pity for yourself - Christine

... and I'm damaged goods – Anne

Christine reported that her infertility, which she was very open about with potential partners, impacted on these relationships and this, for a period of time, reinforced her perception of herself as 'a spayed bitch' with little to offer to a partnership.

Then when my marriage broke down and I went back on the 'dating' scene, if you like, I went out with this guy, and he was...we started off as good friends, and then we went out on a 'date', if you like, and we sat there, and I remember in this restaurant, and he was talking away about 'I can't wait to have children, it'll be really great and I'll love life with children!'. And I just sat there and I thought, and I sat there, and I said, 'Look, I can never have children, I can't have children, I've had a hysterectomy and I can't have children!'. And he said to me, 'Oh, okay, well, there's no point in us going out any more'. And that was such a blow, such a blow for me. I thought, 'I can't believe it! I can't believe it. I can't believe this has just happened to me!' - Christine

While many participants reported finding a degree of joy in being an aunty, a godparent or a friend to the children of their friends and siblings, this reinforced the conspicuous differences that existed between the lives that they had anticipated and desired for themselves, and the realities of their present and future lifestyles. This also appeared to be associated with a sense of the unfairness of these changes.

I'd look at everyone else around me, and all my friends were having children at the time and I just sort of hated them all, but also I was really happy for them. But I wanted to stamp my feet, and say, 'Why me?' – Wendy

It's like when I see a pregnant woman. I was at the airport today seeing someone off and there was a pregnant woman getting someone else to take a photo of her, so there's this gorgeous young woman with her beautiful bump, and it's like, 'That will never be me!' – Susan

Susan also described a sense of distance developing between her and her husband, and others who were parents.

By that stage, all of the people that we knew, our friends and so forth, even... the 'last-lap harrys' had started their families. Even the really late ones had started their families, so we really felt that we were left kind of high and dry while everyone else was getting on with it – Susan

Others talked of the inevitable enquiries as to if and when they were planning to have children, or more children, and how this invoked both distress and concern related to how much of their stories to tell.

Sometimes people say to me, 'Are you going to have any more children?' And I find it really hard to say that I can't – to actually say it is hard – Bridget

Then people and potential partners want to know whether or when I'm going to have another child, and assume that I have chosen to only have the one. And then I have to decide how much, if any, to tell - Dawn

Christine reported that her tale of cancer and childlessness left others uncomfortable and embarrassed, thus increasing her perception of herself as different and abnormal.

Sometimes people would say to me, 'Well, how come you and [husband] have never had any children?' And I'd say, 'Well, I can't have children'. And they'd be like, 'Oh, that's dreadful, No!' And I'd be like, 'Well, yes, but no, I'm fine, you know, I'm healthy, I'm alive'. See I'd look at that side of it. And they'd be, 'Oh, I'm so sorry, I should never have asked you that.' And I'd be like, 'No, it's fine, of course you should have asked me, it doesn't matter, I have to deal with it, it's part of the deal, we have to talk about it.' But they'd be, 'Ooh, I said the wrong thing to her!' They'd be far more embarrassed than me – Christine

For Marie, fertility was not an explicit theme in her pre-diagnosis identity, yet the sudden and unanticipated loss of this still meant that her existing understandings of self and worth were challenged.

On some level, [losing your fertility] makes you feel a little bit less of a woman, I think. When they talked ‘hysterectomy’, that was the initial thing that I had, the initial shock value was, ‘You can’t take all of my womanly bits!’ Even though I still have my ovaries, thankfully. I think that’s a good thing. But the other part, which was such a curse, was something that I really felt I didn’t want to lose. So that was the initial part, the initial shock, when you’re talking about feeling feminine – Marie

This feeling of being different to and even lesser than their peers and their former selves reflects previous research findings in the non-cancer infertility population describing infertility as a potentially stigmatizing disability (Allan, 2007; Cousineau & Domar, 2007; Whiteford & Gonzalez, 1995). Some participants in this study described their perceptions that people judged, and continue to judge their childlessness negatively. Further, the findings indicate that many judged themselves negatively and struggled to view themselves in a positive manner. Where the potential to conceive, be pregnant, give birth and be a mother was inherent to their perceptions of themselves as useful, desirable and valuable women, the loss of this resulted in considerable damage to their ability to see positive potential in themselves and their lives. It is of particular note here that Christine, who described identifying herself as ‘a spayed bitch’ earlier in her cancer journey, was able to positively reconceptualise herself and her situation over time.¹⁰

Because for me, it was more important that I actually had life. I had life and good health and that was far more important to me. And I was hanging on to that and there wasn’t anything else, so long as I’d got my life and I’d got good health, at the end of the day.. Ok, I can’t have children, but that’s not the end of the world either. And as long as I could hang on to that, I was fine. And having children is not the be all and end all of life - Christine

¹⁰ This is discussed in detail in Chapter 7

But such clear evidence of identity re-conceptualisation in the stories of the other participants was not found.

Chronic sorrow theorists have identified that the onset of chronic illness or disability can result in the loss of aspects of the self (Isaksson et al., 2007; Roos, 2002; Roos & Neimeyer, 2007), as have other authors (Becker, 1997; Bury, 1982; Charmaz, 1983). The impact of fertility damaging cancer treatments on women's perceptions of themselves has also been previously reported. Schaefer et al. (1999), for example, described the impact of a hysterectomy as "violating one's sense of being" (p. 233), and Siegel, Gluhoski and Gorey (1999) reported women's perceptions that a basic right and function of being female had been violated. Mathieson and Henderikus (1995) described a process of identity renegotiation in the aftermath of cancer, acknowledging that there may be an 'old' self and a 'new' self, between and within which a new identity would be negotiated, and Little et al. (2002) described 'discontinuity' of identity in cancer survivors. While it is not clear as to why only Christine's story suggests identity re-conceptualisation, this may be explained by her overall long-term approach to managing her cancer journey (Little et al., 2002),¹¹ or to the length of time that has passed since her cancer diagnosis. Alternatively, this difference may be explained by reference to the personal context in which each participant experienced cancer and its impact, and the particular meaning held by each participant in relation to fertility and motherhood (Andrykowski et al., 2008; Becker, 1997).

¹¹ As described in Chapter 7

Many participants' perceptions of being different to others and their former selves, therefore, constituted a disruption to their very selves resulting from their cancer diagnoses and treatments and the onset of fertility damage. Their resulting negative perceptions of themselves as both intra-personally and inter-personally different compounded their experiences of loss, disrupted the continuity and coherence of their identities, and added to the disruption to their lives.

In addition, these negative comparisons served to heighten some participants' emotional reactions to the losses and life disruptions they had incurred. From the perspective of the theory of chronic sorrow, such negative comparisons could be seen to act as 'trigger events' (Eakes et al., 1998) that reminded them of the considerable differences in their lives and themselves that resulted from the cancer and its treatment. In negatively comparing themselves with their peers (social norms), the expected life journey of women at their stage of life (developmental norms), and who they used to be and had expected to become (personal norms), the losses and disruptions that they lived with were reinforced, triggering periods of emotional distress, as identified by Eakes et al. (1998).

A small number of participants were, or had been, engaged in processes to achieve parenthood due to proven fertility damage from their cancer treatments. These participants experienced additional difficulties that are discussed in the next section.

The Impact of Engagement in Processes to Achieve Parenthood

The four participants who underwent (Anne), or were currently undergoing (Debbie, Wendy and Susan), processes such as fertility preservation, assisted reproductive technologies, adoption or surrogacy reported difficulties that were additional to those described above. Their reports of the processes, both physical and practical, that were involved in trying to achieve their dreams of becoming parents suggest that these were numerous, time-consuming and often invasive. Their initial choices to pursue parenthood through these processes were not easily made, although there were many positive aspects to these choices, particularly where the possibility of genetic parenthood remained.

We decided to go on with the physical side of the IVF [harvesting eggs] because, you know, we just weren't getting any younger... and it was actually a really positive experience. We had a bumper crop of eggs, 19 eggs, and we ended up with 11 embryos so it just felt like I was kind of doing the womanly thing even though it was induced by injections and all the rest of it. It was kind of the closest I would ever get to being pregnant - Susan

Anne was initially thrilled to find that fertility preservation, in the form of embryo cryopreservation, was an option for her, but after commencing the oocyte harvesting process, she reconsidered her decision and decided to stop.

But I started off, I did about a week of it at first and then I just freaked out. I just had this moment where I just thought 'What are you doing?' You know, 'You're injecting these hormones into your body big time and you don't know what the cancer's doing'. And I remembered the doctor – oncologist – saying, 'What's more important - children or survival?' – Anne

Wendy underwent in vitro fertilization after her cancer treatment but found this to be an unexpectedly challenging experience.

I had to do 2 rounds of IVF, and the first time, I did all the injections and IVF, I didn't even produce an egg and that's normally pretty weird. So that was pretty devastating, I thought, 'This is never going to happen'. But then the second time around, I managed to get six! I got six eggs and I have used three, no, I've used four, because they transferred a live one in and that failed. So I waited six months, I just said, 'No!'. I probably really hadn't been myself for about a year...the headspace was just gone and my husband was just looking at me as if I was this completely other person and I said, 'No'. I just took off for six months and drank, and partied and did whatever you do and then had a go and it worked. We had two transferred. One didn't survive the thaw, so we had 2 transferred in and one survived, and we got [son] – Wendy

Wendy and Debbie described experiencing a sense of alienation from family and friends who, although supportive, were unable to comprehend the emotional and practical requirements and effects of these processes.

My IVF treatment - I didn't tell anyone when I was going for the second time, I just couldn't do all the drama - Wendy

And I suppose that's one thing that we have trouble with, with our friends, as understanding as they can be. But some will say, 'Why can't you get them [adoptive children] quicker?' And we just say, 'There's a process.' There is a reason, and we understand the reason. But they still don't. [They] have no idea what it's like for us to live through it... It's not the same and nobody, except for [husband's] brother and sister-in-law who started to go through the adoption process because they couldn't conceive – they've got 2 children from IVF after 10 years of trying – they have some level of understanding. Other than that, no-one else we know has any idea of what it's like - Debbie

Compounding this, Debbie told of how things that could be considered normal changes such as a new job or a house move became subject to the projected effects this may have on their central goal of achieving parenthood.

If I want to change my job, if I want [husband] and I to stay or move house, or whatever, we have to think about those choices before we make them whereas other people would probably make them a lot quicker - Debbie

Wendy also described the need to make the processes through which she had gone known and accepted in anticipation of a successful outcome. She wanted to ensure a supportive and understanding environment for her son and any other children in the future. Acknowledging that these pathways to parenthood may be viewed negatively by others reinforced her feelings of being different, or even abnormal.

But if I'm in groups and stuff I'll make little jokes about it too. I went out for breakfast one morning, and I said, 'Oh, [son] was defrosted a year ago today!' And I was just sitting there with a big grin on my face, and eventually they all laughed. But at first it's like, 'Oh, she's talking about taboos!' But you've got to get it out there... But I make light of that because it's better for people to feel comfortable around you, and look at your child without thinking that they're weird. We will make him fully aware of all this when he's at an appropriate age...He needs to know where he came from...I want everyone else to be comfortable around me about it because, you know, why not? There's nothing abnormal about it and he's still made of exactly the same stuff – Wendy

In addition, Susan, who underwent fertility treatment to harvest eggs for cryopreservation, recalled not even being 'normal' in the world of infertility.

Even though they [had] dealt with women in my situation before, where they'd had a hysterectomy but they'd kept their ovaries, they never seemed to quite cotton on to the fact that I don't fit their programme of phoning up on the first day of my period! And I actually had to explain to a nurse, twice, 'No, I don't have periods because I've had a hysterectomy. That means I don't have periods!'...It was kind of another reminder that I didn't fit, that I wasn't normal, even among people with fertility problems, I wasn't. I seemed to be falling through the cracks because I was kind of different - Susan

When Susan and her husband then decided to pursue the option of engaging a gestational surrogate, they were fearful of being discriminated against by potential surrogates and the relevant ethics committee, because of her history of cancer.

[Husband] was worried that people would kind of think we were a bad risk. Because... if I'd had all these cancers could I get another one, and then I wouldn't be around to care for the child. But that does come up, I believe, with CYFS [Child, Youth and Family Services] and the ethics committees. If you've had a cancer history you've got to get letters from all your consultants explaining that your prognosis is good, yadda-yadda. So I guess it's a reasonable worry - Susan

It is interesting to note that Hannah and Dawn, who did not engage in processes to achieve parenthood, also reported concerns about potential discrimination in ethics processes, although theirs was related to their sexual orientation. This influenced Hannah's decision not to undergo fertility preservation prior to commencing her treatment.

Nowhere in New Zealand history has a surrogate mum ever been granted through the ethics board to a gay woman who is single – Hannah

I knew that to use a surrogate, you have to go for ethics committee approval and someone said that actually my situation was outside the guideline. I did look at the guidelines and that was actually correct. I can't remember, it was too complex – but it seems wrong to me to make a blanket, 'No', if you're going to use an ethics committee to make these decisions – why don't you let them look at it and make one - Dawn

Conversely, Wendy recalls that compared to her brother who was infertile for no known reason, she at least could focus her anger and grief on the cancer, knowing due to previously conceiving, that this was the cause of her infertility. Also, Wendy and her husband were accepted preferentially into their District Health Board in vitro fertilisation programme due to the fact that her infertility was directly related to her cancer treatment.

The findings here are suggestive of these participants' ambivalence at continuing with these processes. Similar to these participants, Allan (2007) found that women experiencing non-cancer related infertility became cast or trapped in a transitional, or liminal, space in which they were between social identities and therefore failed to fit into social or cultural categories. She found that engaging with fertility treatments increased the ambiguity and uncertainty that the women in her study experienced because the outcomes of treatment were unpredictable, and the periods of time in which they were engaged in treatments increased their sense of separation from normal life and other people. Navon and Morag (2004) also examined liminality, although related to the experiences of men treated with hormone therapy for advanced prostate cancer. They proposed that the experience of being cast into a liminal or transitional state resulted in individuals' 'inability to classify themselves into culturally available categories' (p. 2344). Navon and Morag suggested that the ever-growing distance between the positive effects of treatment and the de-classifying or liminalising negative effects of such treatments leaves the person 'trapped' between them.

The experiences of many of the participants in this study reflect a clear sense of isolation and uncertainty. The possibility of success, although small, kept them involved, yet they experienced constant doubt and ambivalence about these processes, and the impact of them on their lives. This affected their ability to engage with others and with their lives outside of these processes, increasing the practical and day-to-day disruptions to their lives. Throughout their involvement in these processes, they were unable to fully re-enter or re-engage with normal life, nor to identify fully as parent or non-parent. Interpreted in

this way, these findings suggest that these participants, particularly Debbie and Susan, were living in a liminal or transitional space, separated from normal life and those around them who were living normal lives.

Chronic sorrow theorists described a range of ‘management methods’, both ‘internal’ and ‘external’, aimed at reducing the emotional impact of loss and ‘disparity’, and thus disrupting the cycle of chronic sorrow (Eakes et al., 1998). ‘Internal management methods’ include coping strategies employed by the affected person and are comprised of actions to manage the stress and distress associated with their situation. Northington (2000) expanded on this, suggesting that people living with ongoing loss make deliberate changes to their lives and their ways of responding to the demands of their lives, in response to the loss and ‘disparity’ they have incurred. For these participants, engaging with processes to achieve parenthood could be seen as active and explicit attempts to ‘manage’ and change the unwanted new realities of their lives. Yet, conversely, this resulted in an intensification of the life disruption they had already experienced, and the distress associated with this. These processes and the practicalities of their involvement in them, could be interpreted therefore, as ‘trigger events’ - concrete or practical reminders of their cancer diagnoses and loss of fertility, and the fundamental changes that this has meant for their current and future lives (Burke et al., 1999; Eakes et al., 1998; Northington, 2000). This served to increase the level of distress experienced by the participants who were engaged in these processes, and suggests that there may be limits to the extent to which active management that attempts to ameliorate the impact of a loss

situation can be effective, particularly where such an attempt compounds the degree of disruption to one's life.

The Impact of Fertility Damage on Partners and Intimate Relationships

Many participants in this study described the effects of fertility damage on their relationships with partners and others. Some reported that the trauma involved with their fertility difficulties had altered their relationships irreparably, and some have required professional assistance to manage these changes. However, many also described the high level of support and commitment demonstrated by their partners.

My reaction when I first found out was to give [partner] the opportunity to go find someone else because we'd only been together for a year, and we're not married, not in sickness and in health, and I'm damaged goods. And he was like, 'What are you talking about?' That's just what my first reaction was. He's a good man, really good - Anne

I'm lucky he's a good husband, patient, hopefully he still will be in six months time! But, you know, I'm sure it must affect him. He'd like there to be a lot more intimacy. And the children thing, I know he'd love another one. But he'd rather I was here too. So he wouldn't put pressure on me that we try - Bridget

A number of participants, including Anne, as quoted just above, expressed previous or current plans to discontinue their relationships with their partners to give them an opportunity to achieve presumably problem-free genetic parenthood with another woman.

I do think I would have [left him], I know in my mind the type of person I am, I would have. But I also adore him so much, it would've been the hardest thing I'd ever have to do. It just would have destroyed me, and him. And I knew it would've. That's why he was like, 'Don't be stupid! You know, you're not doing that to me. I'm here for you, not for a baby, not for some possible child, something in the future' - Wendy

When I first got cancer, I did say to [husband], because we had to put off our wedding, and I had to give him the option and said to him, 'Look, I can understand if you want to move on, if you want to split up.' I really can, and I didn't feel that I could hold him to stay with me because things had changed and when we got together, we got together under these circumstances, and, not because I had cancer, things didn't change because of that, they changed because we couldn't have children. That's what I was referring to, and I, even up to a year afterwards, I was saying, '[Name] are you sure, because I can understand. Look, I can understand that, I can cope with being sad, but you actually still have a choice to still have kids and you have to really think about that.' And although I'd be sad, I'd understand, it would be sad for me, but I can understand, I can separate that. So I did give him that option, so many times, that eventually he said, 'That's actually sounding a bit sick, now, [Name].' But you know, things like that can, you have to sort of look at and consider – if one of you can still have children, you've got to look at that - Debbie

Christine described her belief that her infertility was the cause of the failure of her first marriage and a number of relationships since. She eventually married a man who had no expectations of having children. Christine felt that her inability to have children was considered a failing by her first husband's family, and reported that her husband was unable to ever discuss the issue with her, leading to a complete breakdown in the relationship.

I'd say to him, 'How do you feel, how do you really feel about this, about not having children?' And he'd just say, 'Oh fine! What will be, it's fine'. But... I knew that he wasn't really telling me the truth, that he just didn't want to talk about it. He didn't want to say, 'Well actually, yeah, I'm disappointed.' It was a hard thing to... take, but he wouldn't tell me how he really felt. You know, I would have much preferred if he'd said, 'Yeah, I'm really disappointed that, yeah, I would have loved to have children, I'm really disappointed'. And then he could have joined me in my grief and we could have grieved together - Christine

Marie, who is in a long-term same-sex relationship, described a growing distance between herself and her partner related to her newly awakened wish to have had children despite their previous joint decision that they did not want this.

My partner's position [on having a child] really hasn't changed. And even now when I talk about it, she sort of, just sort of shakes her head and gives me a confused sort of look, like, 'Well, you know we can't do that!' She just doesn't see that need in me, and she doesn't really understand it – Marie

Debbie described the huge emotional effect on her, her husband, and their relationship.

Even though I may have had the illness that caused me to become infertile it does also effect [husband] because he becomes infertile through me, which is hard

And there are times when [husband] turns to me and says, 'I'm having a really bad day today' and I'll go, 'Why, what's wrong?' And he'll say, 'I really want kids'... So it's not only you, your husband or partner goes through it too

We've become a bit unstuck as a unit...And now we look at each other and go, 'O God, who are you?'...And you know, we're both kind of angry, and sad...We've been too busy just trying to keep things together and move through things. Now, we're dealing with the pain and the loss and the anger, and about three months ago we decided, 'Well, we're committed to each other, but we need some help' - Debbie

These findings suggest that the impact of fertility damage on these participants' partners, and their relationships with their partners, was a significant additional source of concern and distress. The findings here appear to be a combination of some participants' distress at their partners' desire to become a parent, and their feelings of being responsible for their inability to do so within the relationship.¹² In addition to this, the premises on which their relationships were grounded had changed, altering the 'identity' of the relationship, in addition to the individual identities of each partner. This takes us back to

¹² This, and other sources of guilt described by the participants, will be discussed in the next chapter

the discussion of identity in the previous section, suggesting that they struggled with ‘old’ and ‘new’ identities in response to their experiences of cancer and its treatment. These struggles both impacted on, and were in response to, their relationships. The individual and relationship identities that existed pre-cancer were disrupted and this led, as described in these findings, to distress.

Such relationship identity distress has been examined in couples with infertility from causes other than cancer using a ‘relational turbulence model’ (Steuber & Solomon, 2008). This model describes how partners in a couple relationship can be led to question and be unsure of their position within the partnership during periods of transition, such as that presented by unexpected infertility. Thus, the experience of infertility may lead couples to question the strength, goals and future of their relationship, and then feel the need to renegotiate their relationship in response to such a major life transition. This helps interpret the findings in this section.

The theory of chronic sorrow, as described previously, is a cycle in which new loss, or the recognition of new ‘disparity’ related to the initial loss, feeds into and perpetuates the ongoing cycle of disruption and distress experienced by those affected (Eakes et al., 1998). These participants’ recognition of the negative impacts of their situations on their partners and their relationships clearly contributed to their distress. Both their partners’ distress and their feelings of responsibility for it could be seen, as also previously described, as ‘trigger events’, reminding them of what they had experienced and lost, and what this meant for them, their partners and their relationships in the long-term.

In the next section, the experiences of those participants who identified premature menopause as their greatest concern are presented and discussed.

LOSS AND DISRUPTION RELATED TO PREMATURE MENOPAUSE

The onset of treatment-induced premature menopause has also had a significant ongoing impact on the lives of many of the participants in this study. The findings here indicate that the sudden physiological and emotional changes they underwent, and their permanent nature, were experienced by these women as traumatic. They struggled with the unexpectedness of both the numerous physiologically negative effects of premature menopause, and their emotional and psychological responses to them.

I was quite proud that I was still having regular periods, and was still sexually active, and enjoying that side of my life, and not looking forward to when menopause hit. And so you go into chemo, and by the second cycle, that was it, no more periods, it's gone, never come back. And that was actually, that was quite hard – Robyn

In a way, because I didn't have children...I think it was the end of my girlhood. I sort of went from being this nubile young thing...because I didn't look my age, to being menopausal...and after you've been through everything, you and your partner are left struggling with the changes and I think probably... I don't think our marriage will split up over it but we've had to re-adjust our marriage hugely because of it – Maryanne

I suppose the basic thing is just that my periods... because I view my fertility and my periods and ovulation in one thing, and that did make me sad that that stopped because it's a huge part of me as a woman at this stage of life which is still a fertile stage - Sandra

These participants were not ready to surrender their age-appropriate pre-menopausal status. Regular menstruation had been the basic visible evidence that they had of their fertile potential and youthfulness, and when their monthly cycles ceased, the transition

from fertile to infertile, and pre-menopausal to menopausal was rapid, this was a surprisingly difficult experience for some participants.

That's [menopause] been harder than what I thought it was going to be. And it's because it takes – well, obviously my husband and I weren't planning on getting pregnant, but it's funny how much you hold onto that as a woman in this age. I've been quite surprised at that...so it has surprised me quite a bit, the fact that my own body's way of doing things was stopped, and it was forced, you know, rushed through the menopause – Robyn

I've always really loved having my periods, you know, I always really loved that fact that I got pregnant very easily. I did natural family planning so I know all about when I ovulate and I'm really in touch with my body. And that part of it made me really sad. When suddenly my period was like the enemy. And it never used to be, it was my friend before, it was this miracle that happened every month - Sandra

Well, fertility to me is creativity, and basically, I've had 3 beautiful children - gorgeous, I love them, our most beautiful present, and our most trying present. But I've done that, and I feel so lucky to have those beautiful children in my life...[but] I'm realizing now that a lot of my sexual feelings were tied up with the possibility of being fertile - Meredith

Sandra, who particularly celebrated and enjoyed the natural menstrual cycles of her body, described her distress at the monthly reminder she received not of her fertility, but to attend her health centre for her monthly Zoladex injection to ensure that she remained physiologically menopausal.

Yeah about periods... it was just a real change of mindset to go from ovulating and menstruating being really positive things, to being a really bad thing and I was taking drugs to stop something natural. So every 28 days instead of getting my period, something I celebrated, now I get my phone bleeping to remind me to go for my injection, which isn't pleasant. And because of how I feel about it and my periods, it's not 'just' an injection - Sandra

In contrast, Hannah and Maryanne acknowledged the positive impact of freedom from difficult periods, and for Hannah, pre-menstrual tension. This contrast is likely to be related to the ways in which the different participants experienced menstruation and the meaning of menstruation for them. This is evident in the words used by them, such as

‘celebrated’ and ‘friend’ (Sandra), or ‘noose’ (Hannah) and ‘bride of dracula’ (Maryanne).

I don’t have to have periods anymore. It’s such a noose around a woman’s neck. I don’t have the same emotional rollercoaster on a monthly basis, not to the same extreme – Hannah

At the time, I was having what my sister would describe as ‘bride of dracula’ periods – I was having some problems menstrually which were probably indicative of the fact that I was entering peri-menopause and so in fact the idea of going in to menopause was quite good – I thought ‘ok, we get rid of that’. There are silver linings to dark clouds. So when it happened, theoretically, everything in the garden was kind of rosy – Maryanne

The physical signs of early aging, however, became increasingly apparent and distressing over time for many participants.

You know, you end up getting chin hairs, and all that sort of stuff. Some of the things that I see in my mother, at an older age, I can see in myself, like sunspots – Carol

Your waist’s coming out here, your bum’s sagging a bit more, after the menopausal thing and your wrinkles are becoming more prominent, and, you’re just an older woman now. It’s hard. I don’t think you’re an object of desire any more. So that is kind of sad. You know, it’s a loss of something we’ve all had and there’s going to be grieving with that – Meredith

These findings indicate that the rapid and demanding physiological changes brought about by treatment-related premature menopause were perceived by many participants as abnormal and unnatural. This has been previously described as a disruption between women’s physical bodies and how their bodies are experienced (Boughton, 2002). The onset of premature menopause was an explicit demonstration of the power of cancer and its treatment to irreparably alter the most basic of bodily functions, affecting these participants’ experiences of their bodies, and challenging their confidence in the health and integrity of their bodies. While their bodies remained familiar although changing,

their new experiences of living within their bodies were unfamiliar. Isaksson et al. (2006) proposed the 'loss of a healthy identity' as a category of loss for people with multiple sclerosis. For some participants, their trust in their natural bodily processes, and their ability to protect and maintain their bodies and the natural cycles of their bodies, was compromised through premature menopause, and could be understood in terms of the 'loss of a healthy identity'. This loss constituted an unwelcome transition from being pre-menopausal, which these participants had associated with youth, nubility, sexuality, health and vitality, to being post-menopausal, which they associated with aging, loss of attractiveness and desirability, and decline. Accordingly, these obvious physiological changes were very practical and often distressing reminders of the changes these women had experienced.

Premature menopause was, for these participants, a significant loss that resulted from their cancer diagnoses and treatments, and led to practical, as well as symbolic, disruptions to their lives, and between their pre-cancer and post-cancer lives and selves. These were traumatic because they represented changes to how they physically experienced their bodies and their sense of health, vitality and generativity, and to how they viewed themselves and their lives in the light of these changes. Interestingly, only one participant mentioned concerns relating to the long-term physiological effects of premature menopause such as increased risk of heart disease and decreased bone density. Carol alluded to a potentially shortened life related to premature menopause, but her principal concern remained the more current personal and sexual impacts. This suggests that the focus for these participants, at the time of their interviews and as evidenced in the

content of their interviews, was situated around identity and sexuality. It is possible, however, that many participants were unaware of these increased risks, linking back to the findings of chapter five regarding communication and decision-making.

The Impact of Premature Menopause on Identity

Some participants also described the challenge of premature menopause to their identities, and the selves that they felt they presented to others. These findings indicate that this difference was reinforced during contact with peers who remained pre-menopausal, or with other post-menopausal women whose menopausal experience was not comparable.

Being called ‘menopausal’ instead of ‘pre-menopausal’ and having my friends whingeing and moaning about their periods – Sandra

That’s the end of that part of my life I’ve been living in since I hit puberty. So, there’s your childhood, there’s your fertile years, from age of about 14 to early 40s, or even early 50s in some cases, and then there’s the rest of your life. But you’re actually in a different space... It was like, that’s that, gone [periods and fertility]... I still feel that I regret losing that because it’s part of your identity as a woman. And the other thing is in fact that most people don’t realize it’s happened – Maryanne

You don’t realize the impact it has on you. As much as you think, ‘Oh, that’s bad!’ - I guess it’s what women go through when they have menopause - but that happens slowly. But when you have an operation, it’s like wham, bam, slap - Ellen

With the loss of fertile potential and the cessation of menstruation, some participants described their sense of being lesser women, because these outward demonstrations of their femininity were gone. These findings suggest that their identities as women were tested, and that they were required to reassess and reconsider who they were and where they fit in a society that judges women in terms of youthfulness, desirability and fertility.

They described feeling old and no longer desirable, 'sexy' or beautiful, which affected how they viewed themselves and their sexuality.

Yeah, I feel the loss of my womanhood, I feel that I've aged – you know, oh no, here's another wrinkle! And that's probably been quite hard for me. And you know, I've got a few scars now and that kind of affects your body image. You know, I always used to think before I had cancer that if I ever had breast cancer and needed a mastectomy that I would just have it chopped off and that would be it, but now that I've got some scarring and stuff, I understand how those women feel now, how they feel as a woman. Because you just feel ugly, I feel ugly, scarred and old - Bridget

It's to do with standing up and acknowledging how important being a woman is to you, and how much of that is invested in those parts of you – so your fertility, and your menstrual cycle, the reassurance of a monthly menstrual cycle – I'd never missed a period, you know, up to the time of my chemo, apart from when I was pregnant - Robyn

Losing my fertility has affected how I feel as a woman. I don't feel sexy anymore. I feel a lot older than 44 – Carol

And your beauty fades, just like that, and I just, you know, it's sad – Meredith

Although menopause is a natural part of the normal progression of a woman's life, the findings here suggest that premature menopause represented an unwelcome and unavoidable challenge to this norm with significant implications for some participants' identities. They found themselves in a vulnerable space where their fertility status and life stage were mismatched, as were their pre-cancer and post-cancer perceptions and expectations of themselves. This represented a further disruption to their 'continuous sense of self' (Navon & Morag, 2004). It was difficult for these women to understand who they now were in response to the loss of such intimate and defining characteristics. In making the transition from being women who were menstruating and fertile, to being menopausal or post-menopausal women, they found themselves unwillingly adopting different identities (Pasquali, 2001).

The onset of premature menopause could, therefore, be seen as an assault on the participants' dignity and the integrity of their identities, in addition to the losses associated with the physiological changes of menopause (Isaksson et al., 2007). Although Isaksson et al. associated this with people's social and work lives, in the context of the current study a loss of 'self-value' can clearly be related to the participants' perceptions of their lost value as desirable, sexual, fertile women. The loss of feelings of value in such a fundamental part of their lives and their identities impacted on their feelings about themselves over-all, and thus their sense of dignity and pride. Consequently, these findings indicate that they perceived specifically negative comparisons between their pre-cancer and post-cancer selves which were reinforced through the obvious physiological manifestations of menopause, and in comparison to their peers. These participants perceived that they now compared negatively to their peers, their developmental stage, and the people that they used to be and should still have been, in a similar manner to that described by those participants who identified fertility damage as their primary concern. They experienced intra-personal and inter-personal differences that were both distressing and unwelcome, and were unchangeable. These comparisons, as described in the section related to the impact of fertility damage on identity above, reinforced and compounded their experiences of disruption in response to their cancers and cancer treatments, and the losses, particularly premature menopause, associated with this. In this way the very personal life disruption they had incurred as a result of the cancer altered these participants' identities, which in turn induced further disruption to the continuity and coherence of their lives.

The impact of premature menopause on their intimate relationships was also considerable, and of significant concern for some participants. The findings related to this are reported below.

The Impact of Premature Menopause on Partners and Intimate Relationships

The majority of those who identified premature menopause as an issue were in long-term heterosexual relationships, and all described some level of distress related to the impact of changes to their sexuality on themselves, their partners and their relationships. Whereas normal menopause occurs as a process over a period of time, these women experienced it as rapid and traumatic. The findings here indicate that for a number of participants and their partners these effects were a surprisingly important and unanticipated complication.

We actually fell in lust... And that, in many respects, was one of the driving things in our marriage. So what I was ...interested in was...what was it going to do to my sexuality, and what it was going to do to that side of my marriage? – Maryanne

When you lose your periods, you don't just lose your fertility, you lose your interest in and ability to enjoy sex, to a large extent – that's a big one. That's a big issue. I can talk about that, because, you know, everything is dry and sore – there's no fun anymore – Robyn

I said that I'd gone on to the estrogen cream. [The oncology registrar said] 'Oh, you shouldn't be on it because you've got a hormone fuelled tumour'. 'Well, what do you want me to do,' I said, 'I'd like to actually have sex again once more in my life, you know.' - Ellen

These changes resulted in the loss of ease and fun in their sexual relationships, and a marked decline in their interest in, and frequency of, sexual contact. There was also great

sadness at the perceived loss of desirable bodies and youthful libidos available for their partners and their relationships at a life stage when these should still have been the norm.

But I suppose for me it's...some days I feel as if the whole losing fertility thing has aged me quite a bit, like the skin, and just, I don't know, kind of the woman thing, and loss of sexual desire, that's been a big thing, because, you know... I was always more interested when I ovulated, it was like, 'Watch out!' But I don't get that now, I'm just kind of on a [even keel] so that's different for me - Bridget

It's been very testing for my husband. I think that he's doing very well, really, but I can only see it from my perspective. I said to him...maybe it's not a good thing, but I said, 'You know, if you did have an affair with someone, I wouldn't be happy, but, you know, it does happen'. But he's never said that he's done anything like that, I don't know, you know, perhaps, it's difficult...I said to my husband the other day, 'I'm so sorry that I don't have a beautiful body for you anymore' - Meredith

You might hit what all our parents have been doing for years, but a lot sooner than you really want it - Maryanne

You know, it's skin, it's hair changes, vaginal problems, loss of interest in sex. I'm lucky, my husband's ok, but, if he wasn't, it would be really hard, you know. And I know quite a few women talk about that, saying that their husbands don't understand, and they demand sex, and that must be shocking - Robyn

The findings here clearly indicate that some participants experienced premature menopause as a great loss, reflective of the value they had placed on their pre-menopausal status, and what this meant for them as women and sexual partners. The related loss of previously valued and enjoyed ways of expressing their sexuality reinforced on a very personal level the extensive life-altering changes that they had undergone, and impacted on some participants' abilities to see themselves as valuable and valid partners. Klaeson and Bertero (2008) expressed this impact as like a bird that is 'pinioned' and unable to fly. This may be a useful way of viewing these findings. The onset of premature menopause altered, and suppressed or inhibited, some participants'

sexual desire, sexual function and, the findings suggest, their confidence in their status as sexual women and viable partners. The implication here is that these participants felt less secure as women and partners, and doubted their value in the wake of their changed menstrual status and physiological life-stage.

As described above in the section pertaining to the impact of fertility damage on some participants' intimate relationships, the findings suggest here that the impact of premature menopause altered the identities of some participants' relationships in addition to their individual identities. The 'relational turbulence model' discussed in that section is also useful to help understand the findings presented here (Steuber & Solomon, 2008). Premature menopause, particularly occurring in the rapid and traumatic fashion described, can easily be perceived as a transition that may impact on, and cause turbulence within, intimate relationships. The findings clearly suggest that this transition disrupted the ways in which some participants' sexual relationships were usually conducted, leading to feelings of insecurity and the need to adjust their relationships accordingly.

CONCLUSION

For the majority of participants, cancer and its treatment led to multiple losses, including fertility damage and premature menopause, resulting in fundamental and permanent disruptions to the continuity and coherence of their lives and identities. These disruptions between their pre-cancer and post-cancer lives and selves were evident despite their having objectively or medically physically recovered from their treatments, and re-entered their 'normal' lives. These disruptions to their lives and identities extended to

affect the identities of their partners and their relationships. In addition to this, ongoing engagement with processes to achieve parenthood markedly increased the disruptions to the lives of three participants.

The next chapter reports the study findings related to the emotional impact of the loss and disruption described here.

CHAPTER SEVEN: THE EMOTIONAL IMPACT OF LOSS & DISRUPTION

INTRODUCTION

This chapter, reporting the study findings of the third category, is focused on the participants' emotional responses to their cancer diagnoses and treatments, and the subsequent onset of fertility damage and/or premature menopause. There are four main sections, focused respectively on emotional distress, other emotional responses, positive responses, and the participants' use of support services. The section focused on emotional distress includes a sub-section related to engagement with processes to achieve parenthood. The section focused on other emotional responses includes sub-sections related to guilt and anger. The section focused on support services includes sub-sections related to professional support, peer support, and the possibility of a specific fertility/sexuality support service set within the oncology environment. Each section or sub-section of findings includes illustrative examples of data with accompanying interpretive comments, followed by a more in-depth analysis of the section drawing on relevant literature and the theory of chronic sorrow.

The data discussed in the first three sections were in response to the principal interview question described in the previous chapter. The data that resulted in the findings presented in the support section were in response to questions about the sources of

support used by the participants, and additional sources of support that they would have accessed had they been available.

EMOTIONAL DISTRESS

The theory of chronic sorrow uses the word ‘sorrow’ to depict people’s emotional responses to loss, although other descriptors have been used in the chronic sorrow literature. Of most relevance, Eakes (1993) described sadness, denial, fear, depression, detachment and despair in her study of people with a cancer diagnosis, and Hainsworth et al. (1994) reported sadness, guilt, anger, frustration and fear in their study of people with a range of chronic illnesses including cancer and infertility. The word ‘distress’ describes a broad emotional experience incorporating anxiety, sorrow, suffering, affliction and trouble, and has been described as the ‘sixth vital sign’ in oncology care (Bultz & Carson, 2006). With respect to this, and because it acknowledges the range of emotions described by the participants in this study, ‘emotional distress’ is used as a general descriptor for the findings in this section of the study.

All but one participant (Leane) described experiencing some degree of emotional distress as a result of their diagnoses and the various ways in which these impacted on their lives. Two participants (Ellen and Christine) recalled being distressed initially, but this was not ongoing.¹³ The findings here suggest, however, that the majority of participants experienced some level of emotional distress related to their cancers and the impact of

¹³ The positive experiences described by these three participants are discussed separately below

these, although the degree to which this was experienced fluctuated both within and between individual participants.

I feel sad that the cancer just takes over [and changes the course of life] ... there's no rhyme or reason to it [sadness]... [you] just have to go through it – Anne

We've been too busy just trying to keep things together and move through things. Now, we're dealing with the pain and the loss and the anger...so we keep going into a slump, so it's not so much that we go up, it's that we go further down – Debbie

I'd always thought of myself as having 'children' [rather than only one child] ... it is something that bothers me and it's not resolved – Dawn

[Husband]'s sister has just had her first child... and when I found out she was pregnant, I burst into tears, you know. And when I found out her daughter was born, I burst into tears again. And I didn't think I would. My first reaction was, even though I want to be happy for her, and I am happy for her, my first reaction was to just feel bloody sorry for myself because that's never going to happen [for me] - Susan

As shown in the quotes above, the level of emotional distress described by those participants who identified fertility damage as their primary concern was often high, but those who were most concerned with premature menopause also described emotional distress.

But there are heaps of problems [and] I know I am not the only [one] that's encountered [them]...The amount of pain involved with [the sexual effects of premature menopause] is just terrible...there's a whole lot of grief entailed in things that have changed - Maryanne

I've been surprised at how difficult [the sexual impact of premature menopause] is to cope with – Robyn

So that part of it made me really sad. It was like they'd really like me to not have my period again – Sandra

Despite this, however, the findings suggest that most of the participants continued to function effectively within their normal lives.

I wouldn't say that we have a poor quality of life. I'd say that on a day to day basis we're pretty content but I'd also say that it feels like there's a big hole and that we both feel unfulfilled – Susan

And it's just a sadness that I have. Always there, but not stopping me from living my life...[and] the sadness does [affect my quality of life] a little bit ... these things affect you more long term than the cancer diagnosis itself - Marie

But things just seem so normal now and I just sort of think, 'Well, that's the way my life is always going to be'. I'm always going to have something [the cancer and the ongoing effects of it] hanging over my head – Wendy

Some, who were distressed but not devastated by the impact of fertility damage or premature menopause, perceived that had their personal circumstances been different, their emotional responses would have been much more severe.

I guess I was lucky that I was the age I was, and I've had my son, so I was very lucky. Had it been 10 years earlier, it would have been a whole other story ... So I think I'm really, really lucky there and I feel for anybody who's younger who has to go there – Ellen

Well, I think I'm probably in a different category because I'd had my three children, so I'm not in the situation of not being able to have children because of it - Leane

But I was aware that if I was younger, and if I was wanting a baby, it would have been a bit of a blow. I was aware that there was a wider issue going on that didn't really affect me – Maryanne

But I suppose in some ways I did feel a little bit of a relief, I felt lucky that I had actually had my kids - Sandra

Research undertaken in the general population has reported distress related to the losses associated with infertility (Cousineau & Domar, 2007; Lukse & Vacc, 1999; Sherrod, 2004), and to a lesser degree, premature menopause (Halliday & Boughton, 2009). Similarly, previous studies of people with cancer have identified considerable distress in

women who have incurred fertility damage (J. Carter et al., 2010; J. Carter et al., 2005; McMahon, 2002; Peate et al., 2009; Schaefer et al., 1999; Siegel et al., 1999) and to a lesser degree, premature menopause (Klaeson & Bertero, 2008; Wilmoth, 2001), as a result of cancer treatment. Olshansky (1962) proposed that chronic sorrow should be seen as an understandable, non-pathological emotional response to life-changing loss. He suggested that an increased level of emotional comfort or a reduction of acute distress may be the only reasonable expectation for people whose loss is ongoing. Viewing distress that occurs in response to life-changing events as normal acknowledges that in many loss situations, such as those experienced by these participants, resolution and/or acceptance may not be achievable outcomes. Bowman (2008) described chronic sorrow as an ‘adaptive’ response to life-changing loss, agreeing with Olshansky that in the absence of functional decline, chronic sorrow may be a normal state for many people. Indeed, this absence of functional decline is a key point in chronic sorrow theory, differentiating chronic sorrow from pathological sadness, such as that seen in depression or complicated grief (Hewson, 1997; Northington, 2000; Roos, 2002; Teel, 1991). This is reflected in the theory of chronic sorrow, which describes a cycle of periodic triggered exacerbations of sorrow within the person’s normal life functioning, but allows for the constant presence of some degree of sadness related to the loss and ‘disparity’ that resulted from the ‘antecedent event’ (Eakes et al., 1998).

The findings reported here suggest that this cycle may be a useful way to understand the emotional distress described by the majority of participants in this study. Their cancer diagnoses and treatments resulted in a number of ongoing losses, including fertility

damage and/or premature menopause. This disrupted the continuity and coherence of their lives and identities, leading to the distress described here. Yet all of these participants appeared to be, or reported functioning normally in their day to day lives. A degree of emotional distress in cancer survivorship has been previously described as a normal response (Jefford et al., 2008), and the emotional distress described by fourteen of the participants could be viewed as a normal, or even adaptive, response to the life-changing impact of their cancer diagnoses (Bowman, 2008). Multiple and ongoing reminders of their diagnoses and the multiple losses associated with these, and the impact of these on their lives and themselves contributed significantly and practically to the continuation and occasional exacerbation of their distress. Because of this, their emotional distress showed no sign of permanently abating despite the passage of time and their apparent physiological recoveries from their treatments.

Distress Related to Engagement in Processes to Achieve Parenthood

The distress described above was particularly evident in the experiences of the three participants who were still engaged in processes such as assisted reproductive technologies, adoption or surrogacy at the time of their interviews. The findings here indicate that their ongoing distress may be related to the rigours associated with being engaged in such processes, and the persistence required to continue these processes to their completion, which they had not yet reached. Although, as stated in the previous chapter, engaging in these activities seemed at the outset to be a positive step towards their aims of achieving parenthood, the findings suggest that these processes and procedures were very traumatic and invasive, both physically and personally.

[The adoption process is] very, very long, and it's been one of the most traumatic experiences that we've gone through, and are still going through. No other way to put it - Debbie

But the surgeon, and my doctor [GP] both say that they're more concerned at how stressed I get, and I'm like, 'How am I supposed to be less stressed when I'm still trying to adopt?' It's actually quite difficult to get your stress under control, to find ways of dealing with your stress... But while that process stays open, it's a hard thing to move on from - Debbie

But then come January-February, we plucked up our courage and posted a message [on an online surrogacy message board] and agonized over it and argued over it ... then we didn't even have a nibble for like three weeks and we were just thrown into the depths of despair, we were feeling absolutely hopeless, and then somebody emailed us and said, you know, 'You sound like a nice couple', and wanting to kind of chat. And so we've been chatting with this potential surrogate down in Dunedin but we're taking it quite, kind of, cautiously and slowly, because, you know, from other peoples' experiences on that website they really emphasise not to rush into things, to make sure you know each other very well and you've kind of got everything ironed out - you know, all the kind of, what each other wants out of the relationship and what your views are on like abortion and all of that sort of stuff. So we've been taking it quite slowly and we've just heard recently she's having real big problems at the moment but she's still really keen to be a surrogate for us, so we don't quite know what that means but we're sort of expecting it to all fall apart and then having to start again. And because the rules are, through the ethics committee, that you have to have a close relationship and you have to have known the surrogate for at least ten months - if you're starting again with somebody new, it's a long process. Which is kind of disheartening - Susan

Although Wendy had successfully had her son through in vitro fertilisation from frozen embryos, she continued to be caught in the 'process' because she and her husband still had three frozen embryos stored, and she felt under intense pressure to follow through on having these embryos implanted and therefore, potentially, having another child.

It's really stressful on just driving, and money, and all that sort of stuff, and I'm taking time off work, and my husband's taking time off work...And so of course, I'm stuffed, I'm absolutely stuffed...And you know, they transferred the embryo in [the first time], and I remember thinking, 'I'm not ready for this! I'm absolutely stuffed!' I remember thinking, 'If I get pregnant, I don't know how I'm going to cope.' ... Emotionally, I was a wreck, things would just set me off and I would get really angry, and people would just look at me as if to say, 'Geez, what planet are you on?' ... So [now] I feel this sort of pressure that I need to do something about [the remaining three embryos] and I don't like it. I've spoken to my husband about it a lot and I don't like that, I've kind of, I have to know. I have to know if they're going to survive the thaw or not.

Honestly, I don't want another baby but I know if it came to it, I know if I got pregnant, I'm not going to - I'm going to go through with it. I'm just scared because I don't know if I'm going to be able to carry a baby full-term, and the problem that I have is a 2 ½ to 3 year-old to look after, is the baby going to, I don't even know if I'd cope – Wendy

Susan and Debbie acknowledged that their distress may not resolve, and may therefore remain a constant in their post-cancer lives.

I've still got this thing, this black cloud hanging over me, that won't go away no matter what I do...I can kind of make myself feel a bit better or a bit worse by doing various things, and on the whole, I'm pretty much ok but it is always there. And I kind of think, well, what would it take – is it just time, or is it having a baby, or, I don't know - will it just always be there from now on? ... There's still a lot of grief to work through and I think you know... it's not over yet, and if we do fail to have children...there'll be a whole lot more to work through and I really fear for that situation - Susan

I'm a pretty strong person when I need to be and I've found it difficult to move on so I hate to think how other people cope. We have no guideline. But I also wonder ...when do people get to that point where they go, 'Oh my God, I've had this cathartic experience and it happened to be cancer and now I'm living my life!' And I'm like, I'm waiting for that to happen and it would be cool, it wasn't just, 'Ok, I've had cancer and I managed to survive and I'm going to move on', I'm just thinking it's going to be,' Ok, I've had cancer, now I can't have kids, which is what I wanted...yeah'. It kind of stops that – Debbie

In addition, Susan was diagnosed with mild clinical depression in the year prior to her interview. She elected not to have treatment for this as she feared that this may interfere with her application for approval to engage a gestational surrogate.

I went to see [counselor] at the Cancer Society and she said, 'I think you're actually probably depressed and why don't you go and see your GP', which I did. And she gave me the one page depression score and said, 'Yeah, you're mildly clinically depressed, maybe you should consider anti-depressants'...but I decided that I didn't want to go down that route because I'm worried about how it would affect our application with CYFS. Although in this day and age you shouldn't be discriminated against for this, but if they're worried about your fitness as a mother because of the cancer history, well, I imagine they're going to be worried because of your mental health history and if you've got actual proof of mental health issues because of anti-depressants then, you know, so I decided that I wasn't...that I would try alternative therapies - Susan

Debbie described feeling that the only possible relief from the pressures of the adoption limbo, in which she and her husband felt trapped, lay in choosing to discontinue their quest for parenthood and moving on.

Because our loss isn't resolved yet. Resolution will be one of two things: Either we get the children - and... there may still be loss there after we get the children - or we say, 'No, we can't wait any longer and we need to carry on with our lives' – Debbie

As described in the previous section, the majority of the participants in this study struggled with ongoing distress related to the losses and disruptions associated with their cancer diagnoses and treatments. Susan, Debbie and Wendy described a greater level and persistence of this emotional distress related to their engagement with processes to achieve parenthood. Their engagement with these processes served to focus their attention on their loss of fertility and the impacts of this on their lives in very practical ways. The tenets of the theory of chronic sorrow lead to the suggestion that this involvement acted as an important 'trigger' to exacerbations of their emotional distress, holding them in very practical ways in the ongoing disruption to their lives. As previously described, the theory of chronic sorrow suggests that the use of 'management methods' may help people manage the emotional effects of loss through disrupting the cycle of recurring distress (Eakes et al., 1998; Northington, 2000). These participants' engagement in these processes to achieve parenthood were an active attempt to 'manage' their new realities, yet, as described in chapter six, they resulted in greater levels of distress and disruption. Even in the midst of this positive action towards achieving what they so desperately desired, they were compounding the distress they experienced. The

emotional impact described in the previous section was therefore significantly worsened by their involvement in processes towards achieving parenthood. While it is possible that the provision of appropriate psychological interventions may have ameliorated the negative effects of these processes, Debbie's experiences of the support offered through the adoption process suggest that this was not the case for her and her husband at the time of her interview. In addition, Debbie and Susan, as stated above, both reported their suspicions that even the success of their attempts to achieve parenthood may not necessarily resolve their distress. This was also described by Allan (2007) in her study of women with infertility from causes other than cancer. She suggested that even where conception and successful pregnancy through assisted reproductive technologies occurred, the woman's identity as 'infertile' remained persistent, as did the accompanying emotional suffering.

Living with infertility not related to cancer, and undergoing fertility treatment procedures, have been previously linked with disruption, uncertainty and vulnerability (Allan, 2007; Cousineau & Domar, 2007). Further, improved fertility preservation measures and assisted reproductive technologies, while enabling some infertile couples to achieve parenthood, can be difficult and traumatic experiences (Allan, 2007; Lukse & Vacc, 1999; van den Akker, 2005). Previous research has also shown that symptoms of depression are more common in women with infertility than in the general population (Cousineau & Domar, 2007; Lukse & Vacc, 1999). In addition, depression has been shown to co-exist with chronic sorrow, and the presence of chronic sorrow has been described as a 'risk condition' for the development of depression (Hobdell, 2004;

Lindgren et al., 1992). Susan's experience of depression reported above is illustrative of the extreme impact of fertility damage and her surrogacy journey, on her mental health.

OTHER EMOTIONAL RESPONSES

Guilt

In addition to the distress described above, Wendy and Susan expressed guilt related particularly to the onset of fertility damage. This guilt reflected feelings of shame or regret associated with their perceptions that they were in some way to blame for their situation. Although they acknowledged that they were not responsible for the development of their cancers, they assigned to themselves a degree of responsibility for their fertility damage due to issues relating to pre-cancer activities.

The reason why I know it was definitely...the cancer treatment that made me infertile is that I had had two terminations before. And that grated on my nerves, that pissed me off a lot because I thought, 'Well, I've blown it. I've blown my opportunity because I had these terminations when I was a teenager'. It was like, 'God, you know, am I being punished because I terminated two when I was a silly teenager?' – Wendy

The guilt of thinking, 'Well, why didn't we start earlier, we should have started earlier', because you just never know what's going to happen, you don't expect something like this to happen. You know, we just, we were kind of, we were pushing our luck, and we got unlucky – Susan

Many participants also expressed guilt at the considerable impact of their fertility damage and/or premature menopause on their partners.

I said to my husband the other day, 'I'm so sorry that I don't have a beautiful body for you anymore' – Meredith

I had somebody actually phone me up and abuse me – you know, 'It's your fault, you've ruined this man' – Christine

I still look at [husband] and think, 'You know, you really want kids!', but I know he's not going to go off and do that because he doesn't want to. So he's made a choice which is a really hard choice for him to make. I get upset about that every now and then, and I think, 'Oh my God, what am I doing to you?' – Debbie

While he doesn't blame me because it's not my fault that I got the cancers but it's because of me that he can't have kids. And so there's still, at some level, some resentment there, you know, and I'm very aware of that - Susan

In addition, some participants described guilt related to their inability to feel and honestly express joy at the reproductive successes of friends and family, seeing this as a failing in themselves. Some also described feelings of resentment towards other children because being in the presence of other people's children, or being witness to parenting as an observer, acted as painful reminders of their own childlessness, and triggered exacerbations of emotional distress.

It sounds horrible, but my best friend has two lovely girls and she's absolutely, oh, she's just, she's just so close to her girls...seeing that relationship does make it worse. And, I mean, a lot of my friends have had children and when I'm with them, or hear about them, or see that kind of relationship, yeah, there is regret – Marie

And I was even resenting my nephews and nieces because I was thinking, well, what's the point in being nice to them if I can't even have one of my own - Wendy

And if it's somebody close to you, you feel bad, you feel guilty for kind of resenting the fact that they've got a bump and you haven't and never will have, you know and you're supposed to just be happy for them which you desperately want to be and it's just a mix of grief at your own situation and sometimes that swamps the wanting to be happy for them - Susan

Susan described feeling guilt at seeking professional and peer support in survivorship while there were more recently diagnosed people who she felt should have preferential access to these supports.

Sometimes I feel hesitant even to go and see [counsellor] because...she must have so many more needy people who want to go and talk to her because they're...dealing with some very pressing, very serious issues, life and death issues...And here I am, 18 months later - Susan

Guilt is a frequently reported psychological response to infertility from any cause, particularly in relation to the perceived impact of past actions on the current situation (Sherrod, 2004), and has also been previously reported as a response in young women with fertility issues caused by cancer treatments (Siegel et al., 1999). Loscalzo and Clark (2007) argued that societal expectations and judgements provoke and support the development of feelings of guilt in women who are infertile, due to the perception that procreation is preferentially viewed in society and that responsibility for community fertility rests with women. This relates equally to the impact of premature menopause, reinforcing the meaning of fertile potential and procreation as definitive of femininity, womanliness and value in society.

Chronic sorrow theorists have also addressed the issue of guilt, although to a minor degree. Hainsworth et al. (1994) identified guilt as one of five emotional responses to a range of chronic illnesses, including cancer and infertility, and Roos (2002) commented that guilt can be a major complicating factor for people experiencing the negative impact of loss as it can affect mood, decision-making ability and resilience. For these

participants, guilt was an additional emotional response to the impact of their cancers on intimate aspects of themselves and their lives, and may have complicated or interfered with their ability to successfully manage this impact.

Anger

A small number of participants also described feeling anger in response to fertility damage. Anger can occur in situations that are seen to be threatening and out of a person's control, and a sense of being powerless to change unwanted life situations is reportedly the most common cause of anger in women, regardless of circumstances, ethnicity or age (S. P. Thomas, 2005). The findings here suggest that the cancer diagnosis, even prior to the onset of life-altering ongoing effects, was experienced by some participants as an injustice; the advent of fertility damage compounded this, adding 'insult to injury'.

I want to get off my chest a whole lot of stuff that I'm angry – 'Oh, my God, I'm going to grow old on my own!', I'm never going to experience what all these people experience - Debbie

I went through anger and bawled my eyes out and it was silly, it's really odd – emotionally, I was a wreck, things would just set me off and I would get really angry, and people would just look at me as if to say, 'Geez, what planet are you on?' – Wendy

Yeah. [It] pissed me off. About every 15-18 weeks I'd hit a major wall, and I just wanted to forget it and have a life again – Hannah

Hainsworth et al. (1994) identified anger as an emotional response to both cancer and infertility in a study of people with a range of chronic illnesses. In addition, a sense of injustice in response to the many losses that accompany a diagnosis of multiple sclerosis was described by Isaksson et al. (2007), and could help to explain these participants'

experiences of anger in response to cancer and its impact. Anger, as a result of the perceived injustice of receiving a cancer diagnosis at a young age, and the considerable impact of this on the lives of some participants, is therefore an understandable response.

In addition, as described in chapter five, many participants reported that their engagement with health services left them with perceptions of being unsupported and unheard, and therefore, disempowered. 'Boundedness', a concept arising from the literature pertaining to liminality and described previously, relates to the perception of limits to empowerment experienced by people with a cancer diagnosis (Little et al., 1998), and a sense of powerlessness is frequently associated with women's anger (S. P. Thomas, 2005). These findings suggest that some participants experienced anger in response to the injustice of their situations, and their sense of being powerless to change their circumstances or maintain their power in treatment discussions and decision-making, particularly as this had impacted on their fertility.

It is interesting to note here the conflicting attribution of personal accountability between the emotional responses of guilt and anger. As stated above, guilt is related to the attribution to the self of responsibility for the current negative situation, whereas anger relates to feelings of powerlessness and loss of personal control. This conflict reflects the complex nature of the emotional distress experienced by these participants in response to the fundamental life, and personal disruptions they reported.

Despite the many difficulties described by the majority of participants there were a small number who described positive responses and personal growth. These are discussed in the next section.

POSITIVE RESPONSES AND PERSONAL GROWTH

Three of the seventeen participants in this study described predominantly positive responses and personal growth as a result of their experiences of cancer. Ellen was open with her assertion that she was able to manage her loss of fertility because she already had a child prior to her diagnosis of cancer, but that had this not been the case, she would have been devastated. However, the onset of premature menopause was initially traumatic for her due to the impact on her sexuality, and the fact that medications that may have relieved these symptoms were contra-indicated. It seems that her ability to reframe this potentially negative life experience in a constructive manner transformed its long-term impact and outcome. Ellen described her cancer journey as a learning experience, and an unanticipated but important opportunity for personal growth despite the associated trauma and life change.

You know - if life gives you lemons, make lemonade! - Ellen

Christine, despite not having children, made a very deliberate choice to reclaim control of her life by altering the way she thought about herself and her situation. Although initially overwhelmed by the loss of her fertility and the subsequent break down of her marriage, she described quickly harnessing the strength of her own self belief to reclaim control of her cancer journey and personal future. The time between Christine's diagnosis and this study was the longest (23 years), but she was adamant that her decision to approach her

situation in a positive manner took place early in her cancer journey and was not the result of time diminishing the impact of it. Christine was able to recognize, however, that this level of personal strength may not be available to every person in such a situation.

Because I was a very strong person, and I am a strong person, and I was determined that I wasn't going to let it bring me down, I wasn't going to let it. Like it was hard for my marriage to break down and it was hard for me to pull myself together. But all of that comes into the whole thing... 'Ok, I can't have children, my marriage has broken down' - all these things were part of learning to love myself again. And I did go way, way, way down and I didn't like myself at all...But my whole...pulling myself together, my whole strength, that was all part of that as well. Realising that I couldn't have children, coming to terms with that was a huge big thing that I had to do and I had to come to terms with it, and 100% come to terms with it, not come half-half – Christine

Unlike the other participants, Leane did not describe experiencing a negative impact from her cancer diagnosis and the onset of premature menopause, although she did acknowledge that her life situation contributed to the lesser likelihood of a negative response.

I was very fortunate to have the 3 children, so I didn't feel it that way...um... you've got to go through menopause some time anyway - Leane

She was adamant, however, that personal growth occurred for her as a result of this potentially challenging life experience. She asserted that a person's perceptions of, and responses to, negative experiences can be transformed to positive ones through deliberate personal choice. Her choice was to take control of her cancer journey and seek personal growth through the experience, from the beginning.

I do have an incredibly positive attitude to life. You know, you get hot flushes: they keep you warm at night! - Leane

I'm a believer that there are a whole lot of things that life throws you as part of your fate and...I just see this as another part of the fabric of life. You've got a rich tapestry of life, and you're going to have to weave some black threads and some red ones and blue threads, and they're very hard at the time. But when you look back, that's what actually gives your life its colour. And there's no doubt that it is the difficult experiences you go through that make you progress the most in terms of your spirituality, your character, your personal development. And you look back, and if you just plod on, day to day, you don't actually make that development and those changes – Leane

Retaining or regaining control, and striving for a positive attitude seemed to give these three participants a sense of reclaiming their rights to navigate their own life courses, albeit different ones from those anticipated prior to their cancer diagnoses.

You know, some people, when they have cancer, they want everything to be the same again afterwards, but everything is NOT the same, you cannot expect everything to be the same again. But the taking control of your choices and your life is the most important thing, especially with something like cancer, or the fertility issues related to cancer. The more you get your head around it, and take control of it, you can see that there may be some positives around it. It's all about choices and deciding on the choices – Leane

In contrast, Susan and Debbie both commented on their inability, thus far, to find a positive outcome from their cancer and their experiences since.

I'm not one of these people who's glad that I've got it – and that's a shame really, because it hasn't changed my life, it hasn't made me appreciate life more, I don't wake up every morning and think, 'Thank goodness I'm alive!'. And it hasn't meant that I look after myself, well I do look after myself a little bit more health-wise, but I haven't radically changed my lifestyle or anything to get more out of each day - Susan

But I also wonder...when do people get to that point where they go, 'Oh my God, I've had this cathartic experience and it happened to be cancer and now I'm living my life!' And I'm like, I'm waiting for that to happen and it would be cool, it wasn't just, 'Ok, I've had cancer and I managed to survive and I'm going to move on' - Debbie

The experiences described in this section suggest that these three participants were able to choose (Leane), or transform (Ellen and Christine), their initial emotional responses to the impact of their diagnoses and treatments, preventing the development of persistent emotional distress. Leane was adamant that she chose and maintained a positive response to her cancer, and achieved personal growth through it, because that is how she always chooses to respond to difficult events in her life. She related this to taking control of the situation through being well informed and assertive in her relationships with health professionals, and actively creating positive thoughts and beliefs about her situation. The theory of chronic sorrow was therefore not helpful for interpreting Leane's experiences.

Ellen and Christine, while initially responding to their cancers and the impact of them with emotional distress - to a high degree for Christine - transformed this into personal growth through harnessing their personal strengths to overcome their distress, and making deliberate choices to view their situations in a positive light. They related this to the acknowledgement that while they could not change the physiological realities of their situations, they could alter the ways that they psychologically and emotionally responded to them. Although, from the perspective of the theory of chronic sorrow, their experiences of the life-changing impact of their cancer diagnoses and treatments could be understood in terms of an 'antecedent loss event' leading to multiple losses and resulting life 'disparities', when they acted to transform their emotional responses they prevented the development of the persistent recurring emotional distress described by the other participants. The theory of chronic sorrow, while helpful for understanding the initial

impact of their cancer diagnoses and treatments on their lives, does not help to interpret their transformed positive responses.

People react differently to traumatic events in their lives and these reactions can be influenced by factors that are not directly related to the event itself, as previously discussed. Such factors as personality, personal history, beliefs about self, life and the world, the context in which the event occurred, and the support systems available to the person interact with the event and its impact to create their response (Bellizzi, 2004; Livneh & Parker, 2005; Naus et al., 2009). Andrykowski et al. (2008) described a dynamic interaction between the stress and burden imposed by a traumatic event such as a cancer diagnosis, and the resources available to the person to manage this stress and burden. They stated that this interaction influences the degree to which a potentially traumatic event will be interpreted as such by the person concerned, and how they respond to it. Leane and Ellen acknowledged that the potentially negative impact of fertility damage for them was lessened because they had already had children, although Ellen described her experiences of the negative effects of premature menopause. Christine, however, described being initially devastated by her loss of fertility as a result of her cancer treatment, and spoke of how she struggled to manage the high level of emotional distress she experienced at the time.

These differences suggest that the stress and burden (the impact of the cancer and its treatment) initially imposed by the cancer was higher for Christine than for Leane and Ellen, yet all three described developing positive responses and personal growth.

Although the development of this positive response was temporally different for Leane in that she was able to choose a positive response at the start, the processes by which these responses occurred may be the same. Adjustment or adaptation to a traumatic event such as a cancer diagnosis occurs through two complementary processes. Firstly, through adjusting one's assumptions of, and expectations for, the present and the future to more closely align with the new reality imposed as a result of the traumatic event. Secondly, through adapting the meaning of the traumatic event and its impact to fit one's personal assumptions about life and the world (Andrykowski et al., 2008; Jim & Jacobsen, 2008; Naus et al., 2009; Teel, 1991). Through these processes, and the personal and other resources available to them, Leane, Ellen and Christine were able to influence the degree to which their cancers and the impact of these affected them emotionally, and respond, whether immediately or after a period of time, with positive responses and personal growth. This suggests that appropriate professional psychological input may be able to help others in similar situations to transform their experiences into manageable, or even positive ones, using similar tools to those used by these three participants.

USE OF SUPPORT SERVICES

In this section, the study findings pertaining to the support services that the participants had accessed, or would like to have had access to, are presented. These services were sought or used by some participants to help them to manage the emotional and psychological effects described in this chapter.

Professional Psychological Support and Information Services

A number of participants sought and received psychological support and/or information services such as those provided by nurses, psychologists and counsellors during their treatment for cancer, or subsequent to it. Some are still engaged with such support services. Support was and is accessed predominantly through the Cancer Society (a Non-Government Organisation), but also through their Breast Care Nurses or the oncology services that they attended. Some participants described positive experiences with these services and the support they received, particularly counselling and information services.

The first person we saw was [the counsellor]... we'd gone straight there after an appointment and we were completely freaked out and we just went straight into see [her] and she was fantastic. And she actually, she's good with blokes too because she's got sons she's got 3 boys or something so I think she can really relate to guys. And she was good because she had some really practical tips as well as more emotional things and I've kind of encouraged him to go and meet with her again but he doesn't want to - Susan

Yes, while I was having the treatment, I was in contact with the Cancer Society. I had everything – I used to go into the Cancer Society and ask 101 questions. I spent heaps of time. I was so in need of support. It was so good because I know that the doctors were busy up at the hospital and I just didn't want to follow them around. So I was up there [Cancer Society] all the time. And when I started IVF, I was just like, 'Cancer Society!' So they were the ones who were guiding me with my questions to go back to when I had my time with the oncologist or the IVF doctor – Anne

When I had my diagnosis, which was horrible, there was a woman, she came to my house... and talked [the information] through really slowly, and was someone who checked in, 'How you going?'... and all of that, and she was someone who I could have talked through those things with - Dawn

Others, however, found that some services or particular service providers did not meet their needs.

I did go to counselling for a little while, but it didn't really do anything for me. I just felt like I was going along and having a big moan about how awful my life was. Maybe it was that the counsellor was the wrong person for me. I'd rather...I don't see her very often, but earlier on she was involved with me - a Social Worker. She was fantastic. I just used to go along and tell her...she didn't do anything for me but I just felt that I could let it out. And the oncology nurses were good too - Bridget

I have gone to the Encore/YMCA programme which was just fantastic, and the Cancer Society - not as good. I think it's more of an illness focus there and that's not anyone's fault, it's just the way it is - Meredith

The breast care nurse...came up to see me on the third day, and the third day after a mastectomy is a bad day, I think for anyone having surgery, the third day is a bad day. And ...she came in and was just so, she was such a fast talker, she was so sort of flighty, and upbeat and, 'Oh there's this and that, and this and that', and I was like, I'd just had this mastectomy and axillary clearance and then she left, on my bed, on my legs, this big heavy folder of stuff, a big heavy thing, and I felt like I had just been inducted into 'the club', and I didn't want to be, I was really angry - Robyn

These findings suggest a perception amongst some participants that information, expertise and support related to issues of fertility, menopause and general sexuality was sparse and sometimes difficult to find or access.

[Surgeon] did offer us service of sorts... there was a psychologist who had rooms in the same building, and I went to see her [once] - Maryanne

When I got to the Cancer Society, I was looking for information on sex, and the emotional impacts of cancer and fertility and I'm sure the Cancer Society had one very small book, and I didn't find that very useful, and that was it. I was quite shocked at how little information there was....Yeah, I'm just kind of disappointed at the lack of attention paid to that side [sexuality and fertility] of things - Susan

The main thing was I was so surprised at the lack of research out there [about fertility damage] - Anne

You don't feel all that comfortable talking to the oncologist about your lack of sexual interest, and it's embarrassing - Bridget

I never kept in contact with anybody. It was just, I lived in [rural town] so I was just out of the zone. I would have had a lot more contact with the Cancer Society and perhaps their groups, and their counsellors and their fundraising and all that side of it. But I used to have treatment, get in the car and come home - Wendy

Debbie voiced concerns that if health professionals do not refer people to a particular service, that the service may be viewed by them as being inappropriate for their needs.

People need to take up support at different stages through their grieving process, and if they haven't got the information there they may not have the wherewithal to look up the phone book and go, 'Oh I'll ring the Cancer Society'. Because they might think, 'Am I allowed to?' The onus shouldn't be on the patient to do that – Debbie

In addition to her own support needs, Debbie also commented on the need for support for her husband.

But also, when saying that, what about spouses? That's the other part of that – where do they get to unleash their anger and sadness in a safe place, because often, it's anger – it's the woman that's infertile from cancer, or the other way, because obviously it can be the husband as well...I keep saying to [husband], 'You need to get out the boxing bag! You need to go for a bike-ride!' – Debbie

Debbie and Maryanne alluded to poor referral practices of health professionals and their difficulty in finding information about suitable professional support services for self-referral.

[Health professionals should be asking], 'Have we got the resources set up to assist?' Because, imagine those people that are out there who don't have any resources and don't know where to go? Honestly, I don't know how they cope. I mean, this is a horrible time for me - we've got a pretty good life here but I still feel miserable, you know? I'm thinking, 'Good grief, what about someone who doesn't have the supports that we have?' I just think people need to know that they can have, get something... But the information letting us know that we could access something like the Cancer Society, that we could still go there, was not there, wasn't easy to find... That is so frustrating that the message is not getting across clearly. It's left us without a load of support that could have been so useful, from the physio to everything really... It's that kind of stuff that probably would have been really helpful in retrospect. I might still use the service, but when I look back, I think, 'Oh, how disappointing!' We could really have used it – Debbie

But there's this whole thing about we treat you and then you get on with your life - Maryanne

Debbie's experiences, as reported in this section, suggest that she feels that her psychological well-being was neglected when suitable referrals for physical and psychological support were not made – that 'offering' a referral to a service was not sufficient, but 'recommending' that a referral be made may have made her feel more comfortable about accepting and accessing the service. While it is likely, due to the region in which Debbie lived, that appropriate services were available, the means and/or encouragement to access them were missing. This suggests that Debbie fell into an avoidable gap between her needs and the services that may have been appropriate and easily accessed means for meeting those needs.

The findings in this section reflect those of a number of previous studies, indicating that information services and to a greater degree, professional psychological support, are desired by many people dealing with cancer and its aftermath (Armes et al., 2009; C. Davis et al., 2004; Steginga et al., 2008; Zebrack et al., 2007). This need has also been noted to be potentially greater in younger women due to the unique and life-affecting challenges associated with such an experience (Connell et al., 2006a). The theory of chronic sorrow, as described previously, includes a range of internal and external methods for 'managing' the emotional impact of ongoing loss, such as that experienced by many of the participants in this study (Eakes et al., 1998; Isaksson & Ahlstrom, 2008). The external methods described in the theory relate to the types of interventions described here, although those that the theory recommends would arguably not meet the

needs that the findings of this study indicate may be outstanding. While the theory does recommend services such as those provided by health professionals, the primary role attributed to these in the theory is the provision of a therapeutic environment and relationship (Eakes et al., 1998; Isaksson & Ahlstrom, 2008). While this is clearly crucial to the success of any helping relationship, the experiences reported in this study indicate that for some, a far higher level of psychological care may be needed in order to assist them to manage, or even transform, their responses to their new and traumatic life situation. Roos (2002), however, does address the deeper psychological needs of people suffering from chronic sorrow, recommending the rigorous assessment of individual needs, and the planning of interventions including a range of psychological treatments and strategies as appropriate. Placed within the model of the theory of chronic sorrow, the hope would be that such assistance may result in a greater reduction in the number and depth of exacerbations of sorrow for the person concerned.

The findings in this section also reflect the difficulties that many participants experienced in accessing professional psychological support, and in judging whether available sources of such support were appropriate for them. These findings are similar to those of another recent New Zealand study in which concerns about referral practices and continuity of care at the end of intensive radiation therapy for gynaecological cancers, were voiced (Walton et al., 2009). In addition, in a large survey of New Zealanders who had received cancer treatment, it was found that 53% of participants felt that they should have been referred to suitable psycho-social support services at the time of their diagnoses, and 36% felt the same in the survivorship phase (Cancer Control Council of New Zealand, 2009).

This raises concerns about the ways in which the health professionals involved in these participants' care discussed sources of support and information (or did not discuss them), and the lack of clarity that some participants therefore felt about where, if anywhere, they could turn for support.

Peer Support

Peer support, provided by other people with a cancer diagnosis, was drawn on by the majority of participants, but as the findings below suggest, with varying success. Some participants found this a positive experience.

If you survive and get through your treatment, I think you need peer support, a support group, personally. I mean, there are people who don't want to know, but I think, for those who do want to be part of a group, that it's amazing. The support you get from your peers is very different from the support you get from health professionals and counsellors, because when you [the professional] haven't been there, you don't get it – Carol

I realize that people who have had cancer get a lot out of talking to other people who have gone through the same thing. Even now, if you meet people, like, I'll ask them questions directly whereas other people will hedge around - they don't want to say, but I'll ask. I know that that's what people want, people want honesty – How's it going? Tell me how you are really. I can see, there is a bond with people that have had cancer, they can relate to another person who has cancer more than someone who hasn't - Christine

I've also been involved with a group of people with cancer who dance, that is very healing for me - Meredith

For others, however, their experiences were less positive.

[The support group was] sort of self-facilitated. I think it was set up initially with a psychologist, and I think maybe, maybe if I'd got involved from the beginning I'd feel more comfortable with going. I've found it a bit heavy, a bit hard going, and maybe because there were quite a few new members that night, including myself, I just found it a bit overwhelming actually and I haven't been back. I think I would've preferred something less formal - Bridget

I've thought about this one a lot actually. I speak the same language as certain other breast cancer survivors, I just do.... I just notice that in my Dragon Boating team, where we've all had breast cancer, you'd think we'd all be sisters, we'd all be in the sisterhood, and we are, but then we're divided by the ones who've had chemo and the ones who didn't, and at the end of the day it comes down to, if you had chemo, your cancer was a bit worse. If you didn't have chemo, then you probably had a friggin' little lump removed. I have more in common with those women who went through chemo. So, in saying that, if I went into a support group that had men and women, all different cancers, I think I would work out very quickly who had breast cancer, and I'd have connections with them, but then I would also, I would feel that I would have connections with anyone who had had chemo. I feel like, when I meet people now, even if they'd had other cancers, but they've had chemo, I feel like we speak the same language. I wouldn't feel comfortable with guys in the group. I know that some people probably would, but I wouldn't - Sandra

It appears that the key determinant of successful peer support was meeting people with whom they 'click', and those with comparable life and cancer experiences, and future aims.

It's good to talk with people who are like-minded. It's very hard to relate to someone who is obviously completely and utterly in a different place. A lot of the concerns are different [for] a totally different generation. All the other women had [had] their children, so something that is the biggest issue for me is not even a consideration for them - Anne

I wouldn't feel that a group of older women was relevant to me. What would be most useful would be a broad band of ages then you wouldn't feel like an outsider, when you feel that way anyway. I don't think that the gender or diagnosis of the people in the group would matter to me - cancer's pretty levelling really, it wouldn't matter, you're all in the same boat, sink or swim, you just keep paddling - but it's much easier if you've got one on each side - Ellen

It's true that younger women want to meet with younger women because their needs are different from those of older women...When I was going along for my radiotherapy treatment, which I had in the UK, and I was surrounded by old people and I just felt so out of place, the odd one out. And I wouldn't have related to a support group that was dominated by older people - Susan

I met up with another young woman at the conference [Breast Cancer Consumer Conference]... who was from Wellington and we got talking about support for younger women and I can see that that could be a problem. Because I, within BCS, I feel like quite a young woman. Let's face it, I'm now in my late 40s but I was in my mid-40s when I was diagnosed. But even in comparison with 30-year olds, we're not in the same age band and God only knows where they get their support. There probably does need to be support for them but how, I don't know – Maryanne

Appropriate support was, however, difficult to find for some.

With the cervical cancer, I decided that I would find it [support] quite useful, and also, I wanted to find somebody who'd actually been through similar experiences to me. And there wasn't anybody in NZ. The Cancer Society, through CancerConnect put me in touch with 2 different women in Australia, one that had had cervical cancer and had a radical hysterectomy at a similar age, but she had children, so she was in a different situation. And then another one who had had breast cancer and it had affected her fertility I think because of the Tamoxifen or whatever. So I tried talking to them a few times but I didn't really connect with them, and I also found it really difficult for us to find a time to talk, and that kind of fell to the wayside which was ok, so I've just been going along to Connect. It meets once a month and I find that really good, although now the group's got really big and there's...when I first joined there was a lot of people in a similar [situations]. It was very female dominated for starters, and then it was mostly people who had finished their treatment and were kind of in a similar situation, piecing their lives back together. And so further down the track than I was, so I could get some tips and learn from their experiences. But now there's a lot more people who are kind of still in the middle of their treatment, they're having chemotherapy, some of them have got pretty poor prognoses, so then again, I'm kind of back to feeling like I've got no right to be here... Not everybody that gets cancer is necessarily somebody that you click with or a nice person. It [having cancer] has meant that I've met some people that I wouldn't have normally met or talked to about important stuff, you know, people who are way younger than me or way older than me - Susan

I kind of thought that maybe [the private breast clinic] could have organized something. They might have just looked on their books and went 'Ok, there's five of you', and we could contact each other and arrange to meet at a playground or a park or something, or the Cancer Society – Sandra

This was also a problem reported by Susan on behalf of her husband.

I encouraged him to join the support group for carers but it took quite a while for them to get the numbers to form one. And then when they did, it was really unfortunate because the group was really disparate because basically they were a groups of people who were caring for the terminally ill brain tumours or really in the late stages of cancer; things were just absolutely ghastly and they were just in floods of tears and totally distraught. They were dealing with different issues, a different ball game and then there were people like [husband] who were dealing with people who'd started their treatment, and their prognosis was good, who were trying to put their lives back together and while that was irrevocably altered, they were alive. So it didn't really work for him because they were - he found it too harrowing. He was thinking, 'Well, shit, what right have we got to be here, because our situation is bad, but it's nothing compared to them!' So that didn't work - Susan

The findings suggest that for some, the sharing of experiences and ongoing difficulties helped to normalise what was happening, and offered some ways of managing emerging issues. Some participants reported that one-on-one support with another person in a similar situation was the most useful, although others were unable to access this.

It would be neat to talk to somebody else who's got leukaemia, and it would be neat to talk to somebody else who's got the same kind, and someone my age -
Bridget

There were women who had been through this operation and were happy to talk to people...And that, I would say, is the most useful thing to have, names available of people who've been down that track, people to talk to. To talk to someone who has actually been down the track of doing what you've done, who can give you constructive advice. The whole cancer story for me is all about someone who can look you in the eye, and say, 'Look, this is what happens and this is the scenario' - Leane

Some also found their issues too personal to broach with someone that they didn't already know.

There is one woman in my Dragon Boat team who was diagnosed - I think she was 30, and she hadn't had children - and I would love to talk to her about why she hasn't had kids. You know, it might just be something where they were never going to have kids or decided not to have kids... But no, I sort of feel that it is kind of a taboo thing and I'd not want to bring it up unless I knew them really, really well... You know it's funny, I haven't had a conversation with a breast cancer survivor about fertility. There is that one person that I'd like to on my team but I just don't know that I want to go there with her - Sandra

But how do you talk to someone you don't know without being in an environment that's made conducive to having that conversation? I find that a bit odd to talk about something really personal unless it's in a [facilitated] group so you're there to talk about it - Debbie

Susan also described feeling that her issues were insignificant compared to others in their group, and she did not feel comfortable sharing them and seeking support for them.

There's a lot more people who are kind of still in the middle of their treatment, they're having chemotherapy, some of them have got pretty poor prognoses. So then again, I'm kind of back to feeling like I've got no right to be here - Susan

It is clear from the findings in this section that peer support, while often beneficial and sought after by many, can prove to be challenging. Previous studies have reported this desire of people with cancer to meet with others in similar situations (Butow et al., 2007; Hoey et al., 2008), particularly if the participants in the peer support situation are from similar life stages (Connell et al., 2006a; Dunn & Steginga, 2000; Marlow et al., 2003; Thewes et al., 2004). The experiences of some participants here, however, demonstrate the difficulties associated with finding appropriate and satisfactory peer support that meets their specific needs at any particular time. The concept of 'communicative alienation', which was introduced in chapter five, expresses these difficulties in finding

the right people to 'share' with, and finding the right words to use to share difficult or traumatic experiences (Little et al., 1998; K. Thompson, 2007). For some participants, peer support was able to meet this need, reducing the level of 'communicative alienation' they experienced. For others, however, having had a shared experience did not negate the influence of different personalities, personal style, and interpersonal communication on the success of their engagement with their peers. These findings indicate that some of this difficulty was associated with these participants' younger age where the majority of people with cancer were older. The concerns and needs of other women who were at a different stage of life were sometimes so different that a common ground was hard to find. The comparatively small numbers of younger women diagnosed with cancer made it difficult for many participants to find peers or groups that were of similar ages.

From the perspective of the theory of chronic sorrow, and following on from the discussion of 'external management methods' above, chronic sorrow theorists also suggested a range of 'internal management methods' that may be used to decrease the impact of life-changing loss (Burke et al., 1999; Eakes et al., 1998; Isaksson & Ahlstrom, 2008; Northington, 2000). These are personal coping strategies employed by people to assist their own coping. Such strategies include engaging in enjoyable and/or distracting activities and interests, seeking information, positive thinking, taking 'one day at a time', and meeting with others in a similar situation. Peer support has the potential to contribute to all of these strategies and more, offering significant opportunities for effective 'management' of some of the emotional and psychological effects of cancer, because the experiences are shared ones, and the effects are therefore more likely to be understood.

The findings here, however, reinforce the importance of ensuring ease of access to peer support, and attending to the acceptability and appropriateness of the type of peer support, and the experiences and life stages of the people involved.

Specific Fertility/Sexuality Support Service

Anecdotal evidence suggests that some cancer centres in the UK and the US are planning or offering specific fertility/sexuality support services, set within the oncology environment and provided by appropriately trained advanced nurses (Canada & Schover, 2005; Foy, 2008). When presented with this idea, the participants were unanimous in their positive responses.

But certainly they [women of child-bearing age] need a co-ordinator type person, someone to sit with them through the appointment, and probably another appointment and get them information even if it's hard to get – Dawn

I sure hope that [something like that service] does happen over here – Marie

It's definitely something that should be dealt with because it's huge! It's just like, 'Oh, my God, what else can go wrong?' – Maryanne

So that [the service] sounds like a really great set up to me – I can't imagine it being set up in NZ in the current environment, but I definitely think there needs to be more attention paid to the whole issue... to treating the whole person, their whole life - Susan

These findings suggest that a service providing such assistance with treatment decision making, and ongoing support and advice for the issues they face related to fertility damage and/or premature menopause would be welcome and useful.

I was always asking questions – 'Is this normal? What do you think of this?' And after a while, they told me about this education nurse, and I thought, 'What a brilliant idea! That makes so much sense.'...Women hear this, they suss it out, and then it's good for them to come back and have another session, an hour, where they can sit and go through it all again, and just ring whenever they've got a question - Robyn

Well, it [fertility damage] is certainly not talked about, I think it was mentioned once. And that's why it needs to change...If they don't make enough of it, you don't remember that they said it. Even like, a handout on fertility and menopause – 'This is what it could do to you, this is what you might experience, the symptoms, and this is where you can get some help and information'. Because they give you information on how to look after your mouth and things like that, but they don't give you anything on those more 'down the track' things – Bridget

I remember the doctor saying to me did I have any questions and he said that some people have 101 questions and some people just don't want to know, they just want to be told what to do... But I just had to keep having people remind me, 'You're getting the surgery now, you're getting the chemo now'. But having another person for the fertility thing, I think definitely a good idea. It would be overwhelming, it would be a huge day but it would make people start thinking. I hadn't thought of that thought process because I was in a new relationship ... and I wouldn't necessarily have thought about it, and if the doctor didn't mention it then it might not have been brought out, and that would have really pissed me off if I'd already started on the chemo and told 'Too late, too late' ... So yeah, I think that's a great idea. Sometimes patients feel that it's easier to talk to nurses because doctors are like, specialists, like my doctor was over from Australia doing some research and she was like, way up there, you know – Anne

The findings here reflect many participants' recognition, as described in chapter five, that they presented with some features that set them apart from other people with cancer. Due to their younger age, they required a far greater level of input into fertility and sexuality issues than could be provided by oncology specialists at the time when decisions were being made about possible treatments, but other sources of information or options for discussions were not readily available. A key component of this is the availability of one person or service that patients can approach for assistance and advice at key times, such as when treatment decisions are being discussed and made, but also in an ongoing capacity. Doyle (2008) described cancer survivors' feelings of being unsure of how to help themselves and powerless to affect change in the aftermath of their cancer diagnoses and treatments. The participants in this study identified this need for general survivorship support, and specific support for their needs as younger people and people for whom

fertility and sexuality were a key consideration and concern. This is an ongoing need that current services did not appear to adequately meet for the majority of participants. This need is a reflection of the depth and breadth of the disruption to their lives and selves that the participants experienced as a result of their cancer diagnoses, as discussed throughout this study.

CONCLUSION

For fourteen participants, the most frequently reported emotional response to the losses and disruptions associated with cancer and its treatment was emotional distress. The degree to which this emotional distress was experienced fluctuated within and between individual participants, yet showed no sign of permanently abating despite the passage of time and their status as ‘cancer survivors’, rather than people undergoing cancer treatment or with recurrent or advanced disease. This emotional distress, however, could be seen as a normal response to the losses and life disruptions associated with their cancer diagnoses, although this should be balanced against the suggestion that appropriate and skilled psychological care may have been, or could be of assistance. Although such appropriate professional psychological support and peer support may have helped them to manage their distress, this was not always available, acceptable, or easily accessed. In addition to this, the levels of distress described by the three participants who were still engaged in processes towards achieving parenthood were notably higher than for the other participants, suggesting a link between the ongoing practical disruptions to their lives that this engagement constituted, and the emotional distress that they reported.

The remaining three participants described positive responses and personal growth through their cancer diagnoses. They were able to adjust their assumptions of, and expectations for, their present and future lives to meet their new reality, and, in a complementary manner, adapt the meaning of their cancer diagnoses and the impact of them to fit their assumptions about life and the world. This has implications for the greater provision of, and easier access to, targeted psychological care for other women in a similar situation.

The following chapter discusses the overall study findings in the context of current knowledge and the theory of chronic sorrow. The implications of the study findings for clinical practice and education in cancer care will also be discussed.

CHAPTER EIGHT: DISCUSSION

INTRODUCTION

This study was undertaken in response to conversations with many people affected by fertility damage from cancer treatment in the course of my clinical practice. People of both sexes, varied diagnoses, different cultures and many different family and relationship situations described similar responses of surprise, grief and longing in relation to their lost opportunities to have children as a result of their cancer treatments. The level of distress they described and demonstrated was often high and some women were clearly deeply affected and traumatised by their experiences. Further, as described in chapter four, during the course of data collection it became clear that premature menopause was an equally important and distressing issue for younger women with cancer, and the research question was altered to include premature menopause as an additional focus for the study. In response, this study provides an in-depth understanding of how seventeen women with varied cancer diagnoses experienced the emotional and interpersonal aspects of fertility damage and/or premature menopause from cancer treatment.

This chapter begins by discussing the key findings from the study in the context of existing literature on the topic and the theory of chronic sorrow. A discussion of the contribution of the theory of chronic sorrow as the conceptual framework for the study will follow. This chapter will also explore the limitations of the theory, and ways in

which the theory could be further developed to give a fuller understanding of the experiences of people who encounter significant loss. Following this, implications of the findings for clinical practice and education in oncology care will be discussed.

KEY FINDINGS

The findings from this study suggest, firstly, that for fourteen of the seventeen participants, the cancer diagnosis and treatment resulted in often significant disruptions to their lives, identities and intimate relationships. In response to this, they struggled, to varying degrees, with ongoing emotional distress. The cancer and its treatment resulted in multiple losses, including fertility damage and/or premature menopause. This created a disruption between the participants' past lives and selves, and their present and future lives and selves, between their dreams and expectations for their lives and the reality of what their lives were and would be. The continuity of their lives and selves was fundamentally and permanently disrupted by the life-changing impact of their cancer diagnoses. Despite this, they were objectively and medically well and had returned to their normal lives, suggesting that these effects remained hidden and subjective, and may, therefore, be unlikely to be attended to by health professionals in the day-to-day healthcare environment. Of note, the continuing engagement of three participants with processes to achieve parenthood appeared to considerably increase both the practical life disruptions they experienced, and the level of emotional distress they described.

Secondly, three of the seventeen participants described positive responses and personal growth through their experiences of cancer and its treatment. This suggests that such

positive outcomes are not only possible, but may be encouraged through attention to screening for distress in oncology care, and responding to distress such as that described by the other fourteen participants with appropriate psychological care and intervention.

Thirdly, the findings indicate that a contributing factor to the difficulties that some participants experienced was a lack of consistency in the approach of health professionals to discussions about fertility, menopause and sexuality. In not adequately providing, allowing or encouraging such discussions, health professionals added to the distress described by some participants.

Previous studies have identified that cancer and its treatment can have a range of long-term effects that impact on physical and psychological function (Alfano & Rowland, 2006; Bloom et al., 2004; Cancer Control Council of New Zealand, 2009; Heading et al., 2008), particularly in younger women (Rosen et al., 2009). More specifically, studies have identified that traumatic experiences, such as cancer, can disrupt life and affect a person's identity (Cayless et al., 2010; Deimling et al., 2007; Little et al., 2002; Mathieson & Henderikus, 1995). The current study differs from these in a number of key ways.

Firstly, this study used a generic qualitative approach to elicit a deeper understanding of the emotional and interpersonal aspects of fertility damage and premature menopause from cancer treatment (Caelli et al., 2003; Chamberlain, 2000; Cooper & Endacott, 2007; Sandelowski, 2000; Thorne et al., 1997). This study builds on the findings of related

earlier studies, delving more deeply into these particular experiences (Geertz, 1973). In addition, in contrast to the majority of studies in this area, this study involves women with a range of cancer diagnoses.

Secondly, other studies of people with cancer and cancer survivors overtly or covertly imply the presence of ongoing physiological disability that disrupts life and identity in practical and visible ways, including a person's ability to fulfil their usual roles and activities (Cayless et al., 2010; Coyne & Borbasi, 2006; Little et al., 2002; Mathieson & Henderikus, 1995; McMahon, 2002; Siegel et al., 1999). This was not the case for this study. The participants were objectively well and functioning fully in their daily lives and did not report, nor demonstrate, ongoing disabling physiological effects. Previous studies have also linked issues with identity to how people take on a new identity directly related to the cancer such as 'survivor' or 'victim' (Deimling et al., 2007; Little et al., 2002; C. L. Park et al., 2009). Other studies have explored the specific impact of premature menopause on sexual identity but not overall identity (Klaeson & Bertero, 2008; Knobf, 2002, 2008; Wilmoth, 2001). For example, Wilmoth (2001) described an 'altered sexual self' after the diagnosis and treatment of breast cancer, although she acknowledged the importance of a person's sexual self image for their overall self image or identity. And Siegel et al. (1999) found that the diagnosis of breast cancer threatened young women's sense of invulnerability, requiring them to adjust their assumptions about themselves and the world. They also noted the impact of having breast cancer at a young age on a woman's identity as feminine, and this was related, in part, to fertility damage. In

contrast to these studies, the participants in this study described broad identity changes, particularly in relation to how they compared themselves to their peers and former selves.

Thirdly, the findings from this study indicate that even women who are objectively healthy and recovered from treatment may continue to experience difficulties in the aftermath of cancer and its treatment. Regardless of appearing physically well and recovered from their cancer treatments, the majority of the women in this study remained emotionally affected by their experiences, having to face up to the rest of their lives with altered identities, and life choices and experiences that are, for some, very different from what they had expected. Their cancer diagnoses and treatments and the resulting onset of fertility damage and/or premature menopause had a profound effect on who they are and what their lives will be. Many continued to struggle with ongoing distress related to this. While previous studies have identified such emotional distress in response to the losses associated with fertility damage and to a lesser degree, premature menopause from cancer treatment (J. Carter et al., 2010; J. Carter et al., 2005; McMahon, 2002; Schaefer et al., 1999; Siegel et al., 1999; Wilmoth, 2001), the current study also differs from these in a number of ways. The findings from this study indicate that the participants' cancer diagnoses and treatments resulted in a number of losses, including fertility damage and/or premature menopause which in turn, resulted in disruptions to the lives, identities and intimate relationships of fourteen participants, leading to ongoing, although varying, emotional distress. While losses were clearly an important part of this, the 'bigger picture' suggests that it was the major changes to their lives and themselves (of which these losses were a part) that led to their persistent distress. Therefore, the impact of

fertility damage and/or premature menopause from their cancer treatments included, but transcended, loss to encompass a far greater impact on the lives and identities of those affected.

Further, the degree of distress described by the three participants who were still engaged in processes such as fertility preservation, assisted reproductive technologies, adoption or surrogacy was considerably higher than that described by the other participants. Although pursuing parenthood through these means initially appeared to be a positive and proactive response to their fertility damage, the practical realities of their engagement intensified the disruption to their lives and as a result, the distress that they experienced. While the literature related to the psychological and emotional impact of engagement with assisted reproductive technologies in the general population acknowledges that these experiences are disruptive and emotionally demanding (Allan, 2007; Johansson & Berg, 2005), there is very limited literature pertaining to the experiences of couples engaged in adoption and surrogacy (Edelmann, 2004; van den Akker, 2005). The findings of this study indicate that the ongoing and practical disruptions to the lives of these three participants, and the cycling of hope and despair inherent in their engagement in these processes triggered their sometimes intense distress, despite the potential for their desired outcome of becoming parents. This was in addition to the existing life disruption and distress they incurred as a result of their cancers and the onset of fertility damage. While the theory of chronic sorrow suggests that the use of 'management methods' may ameliorate the emotional effects of loss through disrupting the cycle of recurring distress (Eakes et al., 1998; Northington, 2000), this was not the case for these three participants.

Their engagement in these processes to achieve parenthood could be viewed as an active and explicit attempt to ‘manage’ and change the unwanted new reality of their lives. Yet, conversely, this resulted in them experiencing more intense distress, suggesting that there were limits to the extent to which such pro-active ‘management’ was effective, particularly where this compounded the degree of practical life disruption they experienced.

Finally, a degree of emotional distress in cancer survivorship has been previously described as a normal response by both cancer survivors and health professionals (Jefford et al., 2008), and ongoing emotional distress in response to life-changing loss has been described as an appropriate response that indicates growth and adaptation (Bowman, 2008). Olshansky (1962) proposed that persistent recurring sorrow should be seen as a “natural and understandable response to a tragic fact” (p. 191), and ‘chronic sorrow’ has been previously identified as a normal response in couples with infertility and people with a cancer diagnosis (Hainsworth et al., 1994). The emotional distress described here could be viewed as a normal, understandable and non-pathological response to the participants’ experiences of the life-changing impact of cancer and its treatment. This ‘normalisation’ of distress, however, should not be taken to imply that positive outcomes from loss are not possible, nor lead to an assumption that appropriate and skilled psychological care and intervention may not ameliorate such distress, allowing those affected to develop positive responses and personal growth.

Such positive outcomes are the focus of the second key finding from this study. For three participants the cancer diagnosis offered positive opportunities for personal growth despite challenging the status quo of their pre-cancer lives and ways of being. For Ellen and Christine, this still required unexpected and often demanding changes in order to adapt to their altered lives and identities, as has been previously described (Jim & Jacobsen, 2008; Little et al., 2002; Naus et al., 2009). Although they reported the considerable initial impact of their cancer diagnoses and treatments on their lives and selves, they were able to transform their early responses of emotional distress into positive responses, preventing the development of the distress described by the majority of participants. Leane, however, attributed her positive response from the outset to a deliberate choice to transform negative experiences in all areas of her life into positive ones. In this way, Leane denied experiencing a negative impact from her cancer diagnosis. As stated above, the theory of chronic sorrow provided a conceptual framework to interpret Ellen's and Christine's initial experiences of the impact of their diagnoses but not the positive responses that they subsequently developed. These, and the positive experiences described by Leane, cannot be explained by the theory of chronic sorrow, but can be understood in terms of general adjustment and adaptation to traumatic events (Andrykowski et al., 2008; Bellizzi, 2004; Jim & Jacobsen, 2008; Little et al., 2002; Naus et al., 2009). Through this, these participants were able to adjust their expectations of themselves and their lives to positively accommodate the changes instigated by their cancer diagnoses, aligning their dreams and expectations with their new reality. Complementing this, they were able to adapt the meanings of their cancers and the impact of them to fit their personal assumptions about life and the world.

We turn now to the third key finding from this study, which suggests that the health professionals involved in the care of the majority of participants did not consistently or adequately provide, allow or encourage open discussions about issues related to fertility, menopause and sexuality. Although some participants were able to articulate their needs and concerns, many felt that these went unheard, unappreciated and unacknowledged by the health professionals with whom they were communicating. They perceived that health professionals, consciously or not, discounted their concerns, placed priority on the medical outcome of survival, and limited the range of acceptable topics for discussion at all stages of their cancer journeys.

Access to quality information, developing a good relationship with key members of the healthcare team, and having enough time to adequately consider the implications of treatment are crucial to successful decision-making (Halkett et al., 2007), and contribute to emotional adjustment to the diagnosis (McMahon, 2002). Yet many participants described poor access to, and availability of, information, unsatisfying encounters with health professionals, and rushed treatment decisions. Eakes (1993) found that a lack of time to assimilate information, and the perception of a lack of support from health professionals impacts negatively on treatment decision-making, and contributes to the development of chronic sorrow in people with a cancer diagnosis. And Knobf (2008) reported that women who were better informed about the potential for premature menopause related to cancer treatments appeared to manage far more successfully in terms of both physiological symptoms and psychological wellbeing than those who were less well informed. The importance of having appropriate and sufficient information has also been demonstrated related to general quality of life after cancer treatment (N. J.

Davies et al., 2008), for the maintenance of a positive sense of self (Bertero & Wilmoth, 2007), and for emotional adjustment to the cancer diagnosis (McMahon, 2002).

The evidence that the majority of people with cancer wish to be fully informed is unequivocal (Beckjord et al., 2008; N. J. Davies et al., 2008; Jenkins et al., 2001), yet it is clear that the experiences reported here do not reflect this level of information sharing. These findings are important, therefore, because they suggest that the manner in which the participants in this study communicated with health professionals and discussed their treatments may have impacted on their long-term psychological wellbeing through contributing to the distress they experienced in relation to their cancer diagnoses and treatment decisions.

CONTRIBUTION OF THE THEORY OF CHRONIC SORROW AS THE CONCEPTUAL FRAMEWORK FOR THE STUDY

This is the first study to explore the emotional impact of fertility damage and/or premature menopause from cancer treatment using the theory of chronic sorrow as the conceptual framework. This approach offered a unique perspective from which to explore these women's experiences, and helped to interpret the experiences of fourteen of the seventeen participants. Of the remaining three, the theory enabled the interpretation of Ellen's and Christine's initial experiences of the impact of their cancer diagnoses and treatments, but not their subsequent positive responses; the theory did not assist in explaining the experiences of Leane, who described choosing and maintaining a positive approach to her situation from the beginning.

The central tenets of the theory of chronic sorrow are the presence of an antecedent loss event, the recognition of disparity as a result of this, and persistent recurrent sorrow in response to this disparity. Contributing to this distress are trigger events that serve to remind the affected person of what they have lost. Finally, a range of management methods are suggested, with the aim of disrupting the chronic sorrow cycle. These central points provided a useful perspective from which to view many of the findings of this study.

Firstly, it was useful to understand the cancer diagnosis and treatment, and the contributory factor of difficult or disappointing interactions with health professionals, as akin to an antecedent loss event. This was temporally and physiologically appropriate. Secondly, the notion of 'disparity' was helpful for understanding the many areas of loss and disruption reported by the participants, both in terms of the practical disruptions to their lives, and the more personal disruptions to their own, their partner's and the relationship identities. Thirdly, the response of persistent recurrent sorrow that is central to the theory was helpful for viewing the emotional responses of many participants, particularly the 'normalisation' of these responses in many loss situations. This helped to explain the dichotomy between the participants' ability to function normally in their daily lives and appear to be fully recovered from their cancer treatments, and the life disruptions and emotional struggles that they concurrently experienced and described so vividly in the interviews.

Other findings in this study were usefully understood in terms of the trigger events that the theory describes, particularly as this relates to personal comparisons with self and others. This perspective was also useful for understanding the ongoing practical life disruption described by those participants engaged in processes to achieve parenthood. Finally, the management methods described in the theory of chronic sorrow provided some, although limited, interpretive guidance, for reasons that will be discussed in the following section.

LIMITATIONS OF THE THEORY OF CHRONIC SORROW

While, as described above, the theory of chronic sorrow provided a useful, insightful, practical and, I suggest, appropriate conceptual framework interpreting the data in this study, there were findings for which the theory was less useful, or not useful. Firstly, the findings related to communication and decision-making were more appropriately interpreted using concepts from the liminality literature and with reference to the basic ethical principles underlying the provision of healthcare. Secondly, the findings related to engagement in processes to achieve parenthood, although they can be understood in terms of trigger events and practical life disruption, were more usefully interpreted by reference to the concept of liminality. This helped to interpret these participants' sense of isolation and of being in a state of transition between their former lives and future lives, and between the identities of parent and non-parent.

Thirdly, the 'relationship turbulence model' (Steuber & Solomon, 2008) was used to assist in the interpretation of the findings related to disruption to the participants' intimate

relationship identities, where some participants felt the need to renegotiate the goals and future of their relationships in response to the major life changes they had experienced. And finally, the positive responses and personal growth described by three participants could not be understood in terms of the theory of chronic sorrow, other than the initial period described by Christine and, to a lesser degree, Ellen. Wider concepts of psychological adjustment to cancer were drawn on here, particularly related to the interaction between the level of stress and burden imposed on the participants by the cancer and its treatment, and the personal and situational resources available to them to manage this stress and burden. This lack of attention to the potential for positive outcomes is a considerable limitation of the theory of chronic sorrow (Eakes et al., 1998), as predominantly used in this, and previous studies. This limitation is clearly reflected in the very limited range and degree of ‘external management’ strategies suggested in the management methods section of the theory, and will be discussed further in the following section.

CONTRIBUTION TO THE ONGOING DEVELOPMENT OF THE THEORY OF CHRONIC SORROW

Firstly, the study findings clarify the relationship between the losses associated with an antecedent loss event and the disparity that results from this. Although the theory of chronic sorrow acknowledges that the loss experienced is ‘ongoing’, the theory implies a linear relationship between loss and disparity that was not supported in this study (Eakes et al., 1998; Isaksson & Ahlstrom, 2008). Rather, this study suggests that there are also losses associated with disparity, and that in this way, loss and disparity are ‘inter-

related’– recognition of new losses leads to new disparities, and new disparities lead to the recognition of new losses. The components of chronic sorrow – the antecedent loss event, the losses that result from this, disparities, trigger events, recurring emotional distress and management methods - are inextricably related in a less linear manner than has previously been suggested.

Secondly, the findings from this study suggest that the theory of chronic sorrow could be developed further to provide a fuller understanding of the emotional impact of chronic illnesses such as cancer. The theory uses the word ‘sorrow’ to describe people’s emotional responses to life-changing loss, which suggests a particular emotional state. The emotional responses the participants in this study experienced were more appropriately represented by the use of the word ‘distress’ as a descriptor, which describes a broader emotional experience including anxiety, sorrow, suffering, affliction and trouble (Dictionary.com, 2010). ‘Distress’ has recently been described as the ‘sixth vital sign’ in oncology care (Bultz & Carson, 2006), and the importance of recognizing a range of emotional responses to cancer has been previously reported (Andrykowski et al., 2008). Although such descriptors as sadness, grief, guilt (S. Olshansky, 1962), psychic pain (Teel, 1991), denial, fear, depression, despair (Eakes, 1993), sadness, guilt, anger, frustration and fear (Hainsworth et al., 1994), invalidation, social isolation, being unheard, overwhelmed, exhausted or vulnerable (Kendall, 2006), and anger, anxiety or frustration (Isaksson et al., 2007) have been used in the chronic sorrow literature, the earliest descriptor continues to be used preferentially and inaccurately expresses its applicability. The findings from this study, in addition to those quoted above, suggest

that the definition of chronic sorrow needs to be expanded to include this wider range of emotional responses. This would increase the utility and applicability of the theory for understanding and exploring people's experiences of chronic illnesses.

Finally, the findings of this study add to current understandings of the contribution of 'management methods' to ameliorating and limiting the cycle of distress associated with ongoing loss situations (Eakes et al., 1998; Northington, 2000). Engagement with processes such as fertility preservation, assisted reproductive technologies, adoption and surrogacy, were ostensibly a practical and active way to change or 'manage' an unacceptable and distressing situation. Unfortunately, these actually served to exacerbate the life disruption and resulting distress experienced by those participants who pursued these, regardless of the eventual outcomes. Northington (2000) suggested that lifestyle and psychological changes made in response to ongoing loss situations become normalised into everyday life, thus reducing the negative impact of the situation. This study suggests that there may be limits to the extent to which such changes can happen before they become disruptive themselves.

In addition to this, the positive responses and personal growth described by three participants, and interpreted using common concepts related to psychological adjustment to cancer and other stressful or traumatic experiences, challenge the very limited external management methods that the theory of chronic sorrow describes (Eakes et al., 1998). The possibility that skilled psychological intervention may have assisted other participants to achieve less negative emotional outcomes cannot be discounted. The

theory of chronic sorrow diminishes the opportunity for positive outcomes through attending only to the most basic of therapeutic communication techniques, although this is possibly due to the nursing rather than psychology focus and affiliation of the authors. Roos, however, a psychologist who has a focus on chronic sorrow (yet not directly related to the theory that was predominantly used in this study) has attended to this need (Roos, 2002). Roos' recommendations for assessment of, and psychological intervention for, people affected by chronic sorrow, and the findings reported in this study strongly suggest that the management methods suggested in the theory of chronic sorrow be reconsidered and extended.

IMPLICATIONS FOR CLINICAL PRACTICE AND EDUCATION IN CANCER CARE

The findings of this study have a number of implications for clinical practice and education in cancer care. Firstly, health professionals need to be aware of current research and practice guidelines that highlight their responsibility for, and influence on, patients' long-term health outcomes, both physiological and psychosocial. This is particularly important in relation to long-term effects of treatments, such as fertility damage and premature menopause. Despite evidence that fertility and other issues of sexuality need to be addressed in health professionals' cancer education, clinical practice and research (S. J. Lee et al., 2006; New Zealand Guidelines Group, 2009), it was clear from the findings of this study that either many New Zealand health professionals are unaware of this evidence or, for some reason, are not translating this evidence into their own clinical practice. This is strongly supported by the findings of a recent national

survey undertaken in New Zealand and described previously (Cancer Control Council of New Zealand, 2009).

There are three key influencing factors in the cancer information and decision-making arena, the first of which is the environment in which cancer treatment and follow-up consultations occur. Potential concerns here relate to lack of privacy, and time pressures placed on consultations (Hordern & Street, 2007a), the need for patients to make swift treatment decisions to allow for treatment scheduling, lack of personnel to specifically address fertility and sexuality concerns where clinicians are unable or unwilling to do so, variable availability of specialist fertility services (Quinn et al., 2007; Stead et al., 2003), variable availability of supportive care extending into the survivorship phase (Redman et al., 2003; Steginga et al., 2008), and the ongoing development of treatments without consideration of their wider implications (I. E. Thompson et al., 2006). All of these may impact on the ability of health professionals to provide ethically sound care in relation to communication, information and decision-making.

Secondly, most discussions at this early stage of the cancer journey are undertaken between the patient and either a surgeon or an oncologist, and it is clear from this and other studies that there is still a need for improvement despite clear care guidelines and much research indicating the need for changes to practice (S. J. Lee et al., 2006; National Breast Cancer Centre and National Cancer Control Initiative, 2003; National Institute for Clinical Excellence, 2004; New Zealand Guidelines Group, 2009; Scottish Intercollegiate Guidelines Network, 2005). It has been shown that personal discomfort (Hordern &

Street, 2007a; E. R. Park et al., 2009) and personal judgements of relevance (Quinn et al., 2007) are significant reasons why doctors fail to initiate, encourage or ensure these crucial discussions, in addition to lack of knowledge and confidence (Schover et al., 2002). Yet despite this evidence, increasingly available information, and the guidelines mentioned above, the findings from this study demonstrate that patients continue to be affected by poor communication, lack of relevant information, and inadequate referral practices, and therefore experience flawed decision-making processes (Cancer Control Council of New Zealand, 2009; Duffy et al., 2005; Halkett et al., 2007; McCarthy et al., 2009; Ramfelt & Lutzen, 2005; Thewes et al., 2003; Walton et al., 2009).

Fortunately, new ways to provide information and support the decision-making process are being suggested and trialled, such as audio or video recording of consultations, the use of computers and digital media for information provision, and decision-aids or question prompts (Canada & Schover, 2005; Hack, Pickles, Bultz, Ruether, & Degner, 2007; Schofield et al., 2008; Silvia, Ozanne, & Sepucha, 2008; Stacey, Samant, & Bennett, 2008; van der Meulen, Jansen, van Dulmen, Bensing, & van Weert, 2008).

Finally, nurses provide care at all stages of the cancer journey and are in a unique position to ensure that issues related to fertility, sexuality and menopause have been, or will be discussed before decisions are finalised and treatment commenced. It has been shown that nurses' involvement in providing information and decision-making may be influenced by their understanding of their roles, systemic issues, and their own levels of comfort with issues related to sexuality (King et al., 2008; Lavin & Hyde, 2006).

Unfortunately, it is clear from the findings from this study that nurses, also, inconsistently provided adequate care in this area, once again despite the evidence of its importance, and associated cancer nursing guidelines (Ministry of Health, 2009; Oncology Nursing Society, 2008; Royal College of Nursing, 2003; The National Cancer Nursing Education Project (EdCaN), 2008). Although nurses may have less direct contact with patients at the early decision-making stage, there is a role for nurses in advocating for improved services in relation to providing information and supportive care. Nurses are also particularly well situated to inform patients of appropriate and available support services and, more importantly, facilitate referral to such services with the patient's consent. Currently, as indicated in this study and others, nurses' referral practices are inconsistent and often inadequate (Redman et al., 2003; Steginga et al., 2008; Walton et al., 2009).

An important point here is that this inconsistent or inadequate attention to the needs of the participants suggests the neglect of fundamental ethical principles of care, notably that of autonomy (Beauchamp & Childress, 1994; I. E. Thompson et al., 2006). In addition to the conceivable distress and information overload inherent in these discussions, patients cannot be expected to 'know what they don't know'. In this respect, and in the light of the findings from this study and others, I suggest that it is the responsibility of health professionals to not only raise these issues before treatment decisions are made, but to ensure that patients have an understanding of the importance of these issues for their treatment considerations.

Autonomy is a key ethical principle in informed consent and an important part of this is a dual approach of disclosure and understanding – disclosure of information of potential importance to the patient on the part of health professionals, and understanding of this information and the implications of it for them on the part of patients (Beauchamp & Childress, 1994). For this to be achieved, health professionals need to be aware that what they consider important to patients may not be, and to take action to become cognisant of what is important to patients in order to address any unexpected issues.

Another implication for clinical practice arising from the findings from this study is that engaging in processes such as fertility preservation, assisted reproductive technologies, adoption or surrogacy significantly increases the level of life disruption and resulting distress experienced by women and their partners. There are many such medical technologies and other processes that offer answers to challenging life situations, yet can be viewed as a ‘double-edged sword’ in terms of the suffering they themselves induce. The availability of such technologies does not necessarily mean that they are the best or most beneficial option (I. E. Thompson et al., 2006), and this is an important consideration for health professionals providing information about, and referral to, these services. Just as it is crucial that women are informed of the availability of such services where it is indicated, the risks associated with such technologies and processes need to be made clear to facilitate informed decision-making (Beauchamp & Childress, 1994; I. E. Thompson et al., 2006). Further, as noted in the findings from this study, it is imperative that the need for appropriate psychological and practical support for couples engaged in such processes is recognised and acted on.

There are current recommendations that screening for psycho-social distress be included in regular cancer care throughout the cancer trajectory (Andrykowski et al., 2008). The participants in this study are women who are likely to be overlooked in clinical practice because they look ‘good’, have returned to work and have no obvious or disabling problems to consider. They are unlikely to be raising ongoing issues at medical appointments because they consider that the issues they are concerned about are not appropriate or acceptable for discussion in the clinical setting. They are unlikely to be asking for referrals to other services because either they don’t know of them, or don’t consider that their needs could or should be met by such services. The findings of this study, therefore, support these recommendations for screening for psycho-social distress, by demonstrating that fully-functioning and healthy-looking cancer survivors may still suffer undetected distress as a result of their cancer diagnoses and treatments. Because of the potentially hidden nature of such distress, informal consideration of patients’ psycho-social status may not be sufficient. If, as this study suggests, recurrent periods of distress may be a normal part of cancer survivorship for some, particularly in the presence of fertility damage and/or premature menopause, then such distress should be routinely assessed for, and appropriate information and support consistently provided.

Attention to the provision of, and pro-active referral to professional psychological support and peer support services is crucial to supporting and improving the psycho-social functioning of many cancer survivors and their significant others. Unfortunately, the findings of this study indicate that age-appropriate peer support services are not readily available for younger people with cancer in New Zealand. This is a well-

recognised issue internationally (Connell et al., 2006a; Dunn & Steginga, 2000; Marlow et al., 2003; Thewes et al., 2004), and innovative ways are being suggested and trialled to improve the provision of these and other peer support services (Collie et al., 2007; Hoey et al., 2008).

Further, the findings of this study suggest that due to the restraints imposed on surgeons and oncologists by time, and their limited expertise in issues related to fertility, menopause and sexuality, a realistic response to the needs of younger people with cancer may be the provision of a separate fertility/sexuality service set within cancer care. This service could be most appropriately provided by specialist oncology nurses (Canada & Schover, 2005; Foy, 2008). Such a service should be accessible throughout the cancer trajectory, offering information and psycho-social support, and referral to specialist services as required. It is also important that people at risk of fertility damage from cancer treatments have access to funded or affordable specialist fertility services in a timely manner.

Finally, both undergraduate and post-graduate health professional educators have a responsibility to provide accessible, current, evidence-based education incorporating both survivorship care and increased attention to the general psycho-social impact of cancer and its treatment. The findings from this study suggest that health professionals involved in the care of women with cancer continue to lack confidence and expertise in discussing issues related to fertility, sexuality and menopause. Therefore, such issues clearly need to be attended to in health professional education at all levels. In addition, such education

should address the fact that while cancer survivors may appear well, they may have ongoing physical and psychosocial needs that health professionals should be aware of and responsive to. Such issues could be attended to at both undergraduate and post-graduate levels in papers with a focus on cancer survivorship and/or the psychosocial aspects of living with cancer. Further, a multi-disciplinary approach to such education is appropriate, promoting knowledge of the underlying psychological and emotional responses to such diagnoses and treatments, and how positive outcomes and personal growth in those affected can be facilitated.

CONCLUSION

This study contributes to knowledge in the field of cancer survivorship in a number of ways. This is the first study undertaken with a group of New Zealand women to explore the emotional and interpersonal aspects of fertility damage and/or premature menopause from cancer treatments. The findings indicate many similarities with other studies in both the experiences of the participants, and the ways in which these issues continue to be inconsistently, and often inadequately addressed. However, in contrast to previous studies that have explored issues of fertility, sexuality and menopause in the context of cancer, the findings from this study indicate that for these women, the effects transcended the previously reported emotional responses of grief and loss to affect the core of how they viewed and experienced themselves and their lives. The use of the theory of chronic sorrow as the conceptual framework provided a unique perspective from which to explore these experiences and was supported by other concepts where this was appropriate. Importantly, this study involved women with a range of cancer diagnoses, which is in

contrast to the majority of published studies in this area which have focused on women with breast or, to a lesser degree, gynaecological cancers.

For fourteen of the seventeen participants, the cancer diagnosis and treatment resulted in often significant disruptions to their lives, identities and intimate relationships, in response to which they struggled, to varying degrees, with ongoing emotional distress. In addition, the findings demonstrated a significant increase in distress associated with engagement with processes such as fertility preservation, assisted reproductive technologies, adoption and surrogacy. The remaining three participants, however, described positive responses and personal growth, suggesting the possibility of such responses for other people in similar situations. Finally, health professionals did not adequately provide, allow or encourage discussions about issues related to fertility and premature menopause, contributing to the difficulties and distress described by some participants.

Although the participants in this study were objectively cancer-free, physically well and functioning normally, the majority continued to struggle to some degree with the ongoing impact of their cancer diagnoses and treatments. This suggests that even women who appear to be healthy, recovered and living full lives may suffer considerably in the aftermath of cancer and its treatment. It is crucial that this is recognized by health professionals, and that they attend to their role in ameliorating this distress by providing, or referring such women to, appropriate and sensitive support.

The findings of this study also contribute to the development of the theory of chronic sorrow. Firstly, by clarifying the inter-relationship between loss and disparity; secondly, by suggesting that the definition of chronic sorrow needs to be expanded to include a wider range of emotional responses; thirdly, by indicating that there may be limits to the extent to which personal changes aimed at ‘managing’ the distress associated with loss can be made before they become disruptive themselves, thus exacerbating the chronic sorrow cycle; and finally, by challenging the limited attention paid in the theory to the potential for psychological care and interventions to ameliorate distress and promote positive outcomes and personal growth.

CHAPTER NINE: CONCLUSION

This research constitutes the first New Zealand study to explore the emotional and interpersonal aspects of fertility damage and/or premature menopause from cancer treatments. The contribution of this study has been to provide an in-depth exploration and interpretation of how seventeen women, with varied cancer diagnoses, experienced these ongoing and life-changing effects of their cancer treatments, using the theory of chronic sorrow as the conceptual framework. The theory provided a unique perspective for this study, enabling me to recognize and explore aspects of these women's experiences that have not been explored previously. In addition, the use of a qualitative approach enabled me to explore the depth as well as the breadth of these experiences.

In contrast to other studies, this study found that the emotional and interpersonal effects of fertility damage and/or premature menopause from cancer treatment included, but transcended, loss. For fourteen of the seventeen participants, the cancer diagnosis and treatment resulted in often significant disruptions to their lives, their identities and their intimate relationships. In response, they struggled, to varying degrees, with ongoing emotional distress. They experienced a life-changing disruption between their pre-cancer and post-cancer lives and selves, fundamentally affecting how they viewed and experienced their lives, themselves and their intimate relationships. In addition, this study found that pursuing parenthood through such processes as fertility preservation, assisted reproductive technologies, adoption or surrogacy considerably worsened the life disruption and distress experienced by the three participants who were still engaged in

them. This finding contributes to the limited literature related to involvement in these processes in the general population. In contrast to this, three participants described positive responses and personal growth through their experiences of fertility damage and/or premature menopause from cancer treatments.

While the distress described in this study can be interpreted as a normal and understandable response to the losses and life disruptions these participants had experienced, this does not suggest that the amelioration of this distress should not be attended to by health professionals through appropriate screening, diagnostic and intervention activities. Despite being objectively cancer-free, physically well and functioning normally, many participants continued to suffer considerably in the aftermath of cancer and its treatment.

STRENGTHS AND LIMITATIONS OF THE STUDY

The strengths of this study relate firstly, to the use of the theory of chronic sorrow as the conceptual framework, and secondly, to the use of a qualitative approach to the study. As mentioned above, the theory of chronic sorrow provided a perspective that has not previously been utilized to explore such experiences in this population, and it has contributed to these findings in a number of key ways. First is the recognition of the relationship between the cancer diagnosis and treatment, the multiple losses resulting from this (including fertility damage and/or premature menopause), and the life-changing disruptions to the pre-cancer and post-cancer lives, selves and intimate relationships of the participants. Overall, these are inextricably related experiences constituting a

fundamental disruption to the participants' lives and selves, transcending the loss and grief noted in previous studies. Second, is the recognition that the emotional distress that many participants described occurred as a response to their many losses and resulting life disruptions, and the repeated reminders of these that occurred in their daily lives. Finally, is the recognition that this emotional distress may be a normal and understandable response to such life-changing events, yet conversely, the potential for positive outcomes from the same events must not be discounted. While the normalisation of distress in such situations should be recognized by health professionals, there is also a need to understand the important role that they have in ameliorating the intensity of such distress by providing, or referring to, sensitive and appropriate psychological support.

Using a qualitative approach allowed me to undertake a deep exploration of the research question. This study built on the findings of related earlier studies, but, as mentioned above, delved more deeply into these experiences to elicit a multi-faceted understanding of the emotional and interpersonal aspects of fertility damage and premature menopause resulting from the treatment of a range of different cancer diagnoses.

There are also some limitations to the study, most important of which is the tentative nature of the findings, which are contextually bound to the experiences of these participants and the interpretation undertaken in this study. Due to the purposeful sampling approach used, some of the women who participated in the study may have been more profoundly affected by their experiences than other women who did not participate. To balance this, however, three of the participants did report positive

outcomes, and the findings related to these women contributed significantly to the findings of the study. In addition, due to the methodological approach, the sample was not large and not representative, and therefore, the findings cannot be generalized to similarly affected cancer survivors. As mentioned above, however, this study provides a deep understanding of the participants' experiences that contributes to the limited but growing literature related to fertility damage and premature menopause from cancer treatments.

The use of the theory of chronic sorrow as the conceptual framework for the study clearly implies, as discussed in chapter four, that the study was undertaken from a certain perspective and with a certain set of assumptions based on clinical experience and existing literature. While this was a useful approach for this study, another approach would have provided a different framework for the study and lens for the analysis, and is likely to have resulted in different but complementary findings.

Finally, while it would have been both interesting and useful to explore the similarities and differences between different groups within this study – women with breast or gynaecological cancers vs. women with other cancers, Māori vs. non-Māori women, those identifying fertility as their greatest concern vs. those identifying premature menopause as their greatest concern, heterosexual vs. homosexual women, and those with children vs. those without children – this was not possible due to the small number of participants in the study. Although there were participants from all these groups the findings showed no clear differences between them, and as the clarification of such

similarities and differences was not the primary focus of this study, recruitment to gain a sufficient number of participants to adequately explore these was not undertaken.

RECOMMENDATIONS FOR PRACTICE, EDUCATION AND RESEARCH

In light of the overall findings from this study, and as addressed in the ‘implications for clinical practice and education in cancer care’ section, a number of recommendations are made for practice, education and research:

Practice –

- That health professionals become familiar with, and use, current best practice guidelines relating to information, communication and decision-making in cancer care, and psychosocial support of people with cancer
- That clinical teams ensure that issues related to fertility, sexuality and menopause have been or are discussed to the satisfaction of patients before treatment decisions are finalised and treatment commenced
- That health professionals act to become cognisant of what is important to patients during treatment decision-making discussions and address any issues that arise
- That nurses inform patients of appropriate and available support and information services and facilitate referral to such services with patients’ consent
- That women are informed of both the positive and potentially negative implications of pursuing such processes as fertility preservation, assisted reproductive technologies, adoption or surrogacy to assist in their decision-making related to these services

- That screening for psychosocial distress be implemented in cancer care
- That appropriate referral and intervention strategies are planned and provided to meet needs that may arise as a result of screening for distress

Education –

- That undergraduate and post-graduate educators ensure that health professionals are taught the skills and knowledge necessary to provide current, evidence-based cancer survivorship care
- That undergraduate and post-graduate education addresses the psycho-social impact of cancer and its treatment, particularly issues related to fertility, sexuality and menopause
- That education pertaining to the psycho-social aspects of cancer promotes awareness of, and responsiveness to, the less visible psycho-social needs of cancer survivors, acknowledging that while cancer survivors may appear well, they may have ongoing physical and psychosocial needs that need to be screened for and addressed
- That a multi-disciplinary approach to such education would be appropriate, acknowledging the multi-disciplinary nature of cancer care, and the varied needs of people living with cancer

Research –

- That longitudinal research to determine women's experiences of fertility damage and/or premature menopause from cancer treatments over a longer period of time be conducted, contributing to the planning of long-term supportive care services for the growing cancer survivor population

- That cohort studies be undertaken specifically to determine the similarities and differences related to fertility damage and/or premature menopause from cancer treatments between different groups of women, eg. women with breast/gynaecological cancers and women with other cancer diagnoses, European women and women from indigenous groups, and women with infertility related to cancer treatments and women with infertility related to other causes
- That research examining the effectiveness of currently used psychological interventions for ameliorating distress and promoting positive psychological outcomes in this population be undertaken, to progress knowledge from identifying those likely to be in need, to providing effective interventions to meet such need
- That research addresses the experiences of those who engage in such technologies as fertility preservation, assisted reproductive technologies, adoption or surrogacy to assist in the development of support specific to their needs and the needs of their significant others
- That following the development of post-graduate educational opportunities, as described above, the effectiveness of advanced nursing roles focussed on fertility and sexuality in cancer care be evaluated in terms of their impact on cancer patient outcomes

APPENDIX ONE: RECRUITMENT ADVERTISEMENT

YOU ARE INVITED TO PARTICIPATE



THE UNIVERSITY OF AUCKLAND
FACULTY OF MEDICAL AND
HEALTH SCIENCES

The University of Auckland

Private Bag 92019

Auckland

New Zealand,

85 Park Road, Grafton

www.health.auckland.ac.nz

Telephone: 9 373 7599

Facsimile: 9 367 7168

Email:

m.finlayson@auckland.ac.nz

My name is Sarah Hunter. I am a Registered Nurse and Doctoral Candidate in the School of Nursing at the University of Auckland. I am interested in talking to women about fertility damage from cancer treatment. This is for a research study for my doctoral degree.

I would like to interview 15-25 women who:

- had their first cancer treatment during their childbearing years
- are 6 months to 5 years from the end of their first treatment
- are free of cancer, to the best of their knowledge, and
- believe that their fertility has been damaged through their cancer treatment

The interview will take around 60-90 minutes at a time and place agreed between the participant and me.

If you are interested in being involved in this study, or know someone who might be, please contact me as follows:

Sarah Hunter RN MNurs(Hons) shun044@aucklanduni.ac.nz 027 264 3502

(In the event of a large number of interested women, participants will be selected from among the first 30 indications of interest.)

(University of Auckland Human Participant Ethics Committee ethical approval Reference 2007/263)

APPENDIX TWO: PARTICIPANT INFORMATION SHEET

SCHOOL OF NURSING



THE UNIVERSITY OF AUCKLAND
FACULTY OF MEDICAL AND
HEALTH SCIENCES

The University of Auckland
Private Bag 92019
Auckland
New Zealand,

85 Park Road, Grafton
www.health.auckland.ac.nz

Telephone: 64 9 373 7599 extn 88508
Facsimile: 64 9 367 7168
Email: m.finlayson@auckland.ac.nz

Project Title: Determining the emotional and interpersonal aspects of fertility damage from cancer treatment in pre-menopausal women.

Researcher: Sarah Hunter RN MNurs(Hons)
PhD Candidate, School of Nursing, Faculty of Medical and Health Sciences, University of Auckland.

To: Participants

You are invited to participate in this research that will be reported as my Doctoral thesis. Although you have indicated an interest in participating, the decision to participate or not is entirely yours. You will be free to withdraw from the research at any time, without explanation, and may request that your data be withdrawn up to 30.6.08.

This study is about living with fertility damage from cancer treatment from the emotional (that is, in yourself) and interpersonal (that is, in your significant relationships, such as spouse or partner) experiences of women who were diagnosed with cancer and had cancer treatment during their child-bearing years.

The types of things I would like to talk with you about are:

- whether the possibility or certainty of fertility damage from cancer treatment has had an effect on you and your close relationships and, if so, what kind of effect that has been and the strategies you have used or use to help you manage this;
- what sources of support and information you have had;
- the sources of support you could or would have used if they were available

To do this, I would like to interview 15-25 women, each interview taking about 60-90 minutes. The interviews will be face-to-face where possible, and the time and place will be arranged between each participant and me. Where a face-to-face interview is not possible, you will be offered a telephone interview. The interviews will be audio-recorded with your consent and the recording will be stopped at any time at your request. The recordings will be stored in a locked cupboard at the researcher's home and will be

destroyed when transcription is complete; the recorded data will be transcribed by me for the purposes of this research only. The transcripts will be destroyed, by shredding, when the research process is complete. Should you wish to see it, a summary of the findings of the study will be made available to you, and the full thesis will be available in the library of the University of Auckland.

All personal information will remain strictly confidential and participants will be identified only by a letter of the alphabet. The findings will be reported in a way that does not identify you as the source of the information.

Due to the emotional nature of this research topic, there is a possibility that you may feel some emotional distress related to talking about your experiences. If this happens, I will ensure that skilled and experienced counselling services are available to you at no cost to yourself. I will also, with your permission, contact you the day after our interview by phone to ensure that you are not distressed from your participation in the study.

Researcher name and contact details	Supervisor name and contact details	Head of Department name and contact details
Sarah Hunter C/o School of Nursing, Faculty of Medical and Health Sciences, University of Auckland., Private Bag 92-019, Auckland. Phone: 3737599 ext 88508	Associate Professor Mary Finlayson Ph. 3737599 ext 88508 m.finlayson@auckland.ac.nz	Associate Professor Judy Kilpatrick Ph. 3737599 ext 82897 j.kilpatrick@auckland.ac.nz

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON ...16/8/07..... for ...(3).....years.
Reference Number 2007...../...263...

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 extn. 8783

APPENDIX THREE: CONSENT FORM



THE UNIVERSITY OF AUCKLAND
FACULTY OF MEDICAL AND
HEALTH SCIENCES

SCHOOL OF NURSING

The University of Auckland

Private Bag 92019

Auckland

New Zealand,

This consent form will be held for a period of six years.

Project Title: Determining the emotional and interpersonal aspects of fertility damage from cancer treatment in pre-menopausal women.

85 Park Road, Grafton

www.health.auckland.ac.nz

Researcher Name: Sarah Hunter RN MNurs(Hons)

Telephone: 64 9 373 7599 extn 88508

I agree to take part in this research:

Facsimile: 64 9 367 7168

I have read the Participant Information Sheet, have understood it, and am prepared to take part in the research project named above.

Email: m.finlayson@auckland.ac.nz

I have had the opportunity to ask questions and have them answered.

I understand that I am free to withdraw myself at any time, and to withdraw any data pertaining to me up to 30.6.08.

I understand that, if I give permission for audio-recording of my interview, this permission can be withdrawn at any time.

I understand that the recorded interview will be transcribed by the researcher and will be destroyed after this has taken place. The written transcript will be destroyed by shredding at the end of the research process.

This consent form will be stored in a locked cupboard on University of Auckland property, separate to the data.

I understand that participation in this research may cause a degree of emotional distress and that access to skilled emotional/psychological support will be offered, at no cost to me.

I _____ accept / do not accept audio-recording of my interview.

I _____ consent to take part in this research.

Signature: _____ Date: _____

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS
ETHICS COMMITTEE ON ...16/8/07..... for ...(3).....years.
Reference Number ...2007../...263...”

APPENDIX FOUR: INTERVIEW SCHEDULE

Consent Form: Go over form and answer any questions, sign.

Demographic Data: ‘To start with, can I just ask some background questions about you – these will not be used with your name or any other identifying details?’

Age: now and when diagnosed	
Relationship status: now and when diagnosed	
Ethnicity	
? Number and age of children	
Area of residence: urban or rural	
Closest major cancer centre	
Occupation	

Cancer Diagnosis Data:

Type of cancer and any other details	
Time since completion of treatment	
Type(s) of treatment	

Interview:

‘As you are aware, the aim of this study is to talk about possible fertility damage from cancer treatment and how this may have affected you in your self and in your relationships. It would be great if you could just talk freely about this as long as you are comfortable.’

(Prompts: ‘Some women have mentioned (grief/loss; meaning and purpose of life; effects on partner; pattern over time; effect on quality of life) when talking about these experiences – does this fit with your experience?’)

Information stream: ‘Can you tell me more about the initial information you had about the possibility of fertility damage from your treatment?’

‘What about ongoing information?’

Support stream: ‘What sources of support have you used – tell me about this?’

‘What would you like to see in terms of care for women around this issue?’

‘Thanks so much ... Do you have any questions about what we have talked about? How has it been for you to talk about this at length? Could I call you tomorrow just to see that you are ok? I expect the study will be published in a couple of years. Would you like me to send you out a summary of the study then?’

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