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The experiences of cancer survivors as they transition from chemotherapy treatment to life after cancer

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The Experiences of Cancer Survivors as they Transition from Chemotherapy Treatment to Life after Cancer

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RN BSc (Hons)

This thesis is presented in partial fulfilment of the requirements of the degree of Masters by Nursing Research.

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Abstract

This study explored and described the experience of people with a diagnosis of cancer, as they transitioned from life as a chemotherapy patient to life after treatment as a cancer survivor. The purpose of this study was to ultimately improve the care of people as they transitioned into life after completion of chemotherapy treatment. There is minimal information related to this phase of the cancer trajectory, therefore this study was intentionally exploratory and descriptive.

To achieve the proposed outcome a two-phased approach was undertaken. In Phase One a qualitative approach was followed using Grounded Theory to the descriptive level of data analysis. The study was undertaken in a large tertiary hospital in Western Australia. The sample comprised of 14 cancer survivors who had completed chemotherapy treatment in the previous four to twelve weeks. Data was collected via semi structured telephone interviews. Descriptors of issues and experiences that arose in the first six months following completion of chemotherapy were elicited. Data was subsequently transcribed, coded and organised into themes of congruent relevance.

Cancer survivors were found to transition through two stages in the early weeks following completion of chemotherapy. When physical symptoms and emotional losses were all encompassing, the survivors displayed vulnerability due to the loss of the treatment environment and a range of challenging emotions. As the weeks passed and physical symptoms began to abate, the survivors began to display characteristics of resilience, self empowerment and information seeking strategies which both informed and protected the survivor. The domains that challenged the survivor throughout this transition period encompassed physical, social, psychological and spiritual issues.

In Phase Two of the study, key findings from Phase One were utilised to inform the adaptation of an existing quality of life tool, Quality of life – Cancer Survivor, which was identified following an extensive literature review. The adapted tool, Quality of Life – Chemotherapy Cancer Survivor, was assessed for clarity, content validity and apparent internal consistency by an expert panel of six oncology nurses who were employed within the same tertiary hospital setting. Feedback from this process was used to further amend the original tool. The researcher intends to pilot test the revised tool with cancer survivors in preparation for a larger scale population based study following this Masters study.

This study has provided an insight into the survivorship issues as people transition to life after chemotherapy and findings begin to fill a gap in understanding which has not previously be addressed in the available literature. Implications for future research and clinical practice including, gaps in survivor's knowledge and transition process issues, are provided.

Declaration

I certify that this thesis does not, to the best of my knowledge and belief:

i. incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education:

ii. contain any material previously published or written by another person except where due reference is made in the text of this thesis; or

iii. contain any defamatory material.

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Chapter One
Introduction

Cancer and survivorship were once considered contradictory terms. Advances in screening, diagnosing and treating cancers over the past 20 years have resulted in improved cancer survival rates. It has been estimated that more than 60% of all people diagnosed with cancer are alive five years after their initial diagnosis (Jefford et al., 2008). With a rising incidence in cancer diagnosis due to an ageing population and a rising survival rate from the initial cancer diagnosis, there is increasing cancer prevalence within the Australian community. Australian survival rates for cancer are high by world standards, in 2004 survivors of cancer represented 3.2% of the population (Australian Institute of Health and Welfare [AIHW], 2008).

The incidence of cancer continues to increase globally, and the prevalence of cancer in developed countries is increasing dramatically. Prevalence of cancer refers to the number of people who have previously received a cancer diagnosis and who are still alive at a given point in time, whereas incidence is the number of new cancers diagnosed in a specified period of time. Prevalence figures are therefore affected by both the incidence and survival. In Australia in 2010, cancer accounted for 19% of the total burden of disease (AIHW, 2010). Survival rates following a cancer diagnosis have improved to such an extent that cancer is now considered one of the top six chronic conditions in Australia (Australian Bureau of Statistics, 2011). Chronic diseases are illnesses that are prolonged in duration, do not often resolve spontaneously and are rarely cured completely (AIHW, 2002). This is a dramatic turn around for a condition that was once considered rapidly fatal; cancer remains one of the most feared illnesses within the general population despite increasingly successful outcomes, this fear sets it apart from other chronic conditions (Rassmussen & Elverdam, 2007; Tritter & Calnan, 2002).

The significant change in the cancer care trajectory has led to a new phase in the cancer care continuum widely known as “cancer survivorship”. The most commonly accepted definition is the one advocated by the National Coalition of Cancer Survivorship which is “the experience of living with, through and beyond a diagnosis of cancer” (Hewitt, Greenfield, & Stovall, 2006, p. 27). The continuum of cancer was once mostly linear beginning with diagnosis, moving on to treatment and then a limited remission, followed by recurrence and death within a short time frame or for the few

fortunate individuals the pathway became follow up monitoring and a confirmation of cure at the five year post diagnosis mark.

The current continuum of cancer is much more cyclical once the primary treatment is complete, for those who are considered cured there is now a long pathway of monitoring and managing long term side effects of treatment. There are now several episodes of recurrence of cancer for the individual which is managed by subsequent treatment and ongoing monitoring before eventual death. The timeline in this cycle may amount to many years.

Background

A diagnosis of cancer is one of the most feared health conditions within Western societies; the diagnosis brings with it stress, physical and psychological consequences, the stigma of cancer and segregation from significant others and the general population (Skillbeck & Payne, 2003; Stringer, 2008; Towers, 2007). Whilst coming to terms with the diagnosis, the person diagnosed with cancer also faces a multitude of decisions and challenges across a spectrum of physical, psychological and social domains. The challenges whilst undergoing acute cancer treatment are well researched and documented with the focus of effort concentrating on completing treatment and aiming for cure.

Despite ongoing fear and misunderstanding of cancer as a disease with a fatal outcome, substantial investments in cancer research have resulted in better outcomes for individuals diagnosed with cancer, with significant success in terms of improved survival rates (Hewitt, et al., 2006). There are a number of factors attributed to the trend of increased relative survival from cancer across the continuum of care. First the increased education of the population as a whole about the signs and symptoms of cancer; second the benefits of screening; and finally the importance of self examination have increased the awareness of prompt action in seeking advice. Primary care has made considerable improvements in the diagnosis of cancer and the follow up methods related to suspicious signs and symptoms of cancer. Further, service redesign has improved referral pathways and a led to more widespread availability of treatment. Advances in scientific knowledge and technology have led to more effective investigations and staging of disease and the addition of subspecialisation in cancer treatments have further increased the effectiveness of treatments (AIHW, 2008).

Surviving cancer has consequences that can change an individual's way of life considerably. The impact of cancer does not end after treatment; the 2008 "Health and

Wellbeing Survey" in the United Kingdom found that cancer survivors reported poorer health and well being than the general population (Department of Health, Macmillan Cancer Support, & NHS Improvement, 2010). As this is a relatively new phenomenon to health, research in this area continues to identify new issues which need addressing. Survivors of cancer have been strong advocates for the development of survivorship care, led largely by the National Coalition of Cancer Survivorship in the United States of America (USA).

There is now a growing body of published research addressing long-term survivorship issues. "Living beyond Cancer" (2004) reported there were 10 million cancer survivors in the USA, many of who were at the end of treatment and found themselves "in a world that is intimately familiar, yet forever changed" (Reuben, 2004, p. 5). There are as many research domains in cancer survivorship as there are in cancer treatments and symptom management. However, there is a great imbalance in the amount of research undertaken in these domains as shown in Figure 1. PubMed citations between 1992-2004 have almost doubled for adult cancer treatment research from 11,928 to 23,736, whilst citations for adult cancer survivorship research has almost trebled they are still relatively small numbers 132 to 374 during the same period (Aziz & Rowland, 2003). Since 2005 there has been an exponential rise in the research approaches to the domain of cancer survivorship with 57,041 citations available on the PubMed database in 2011.

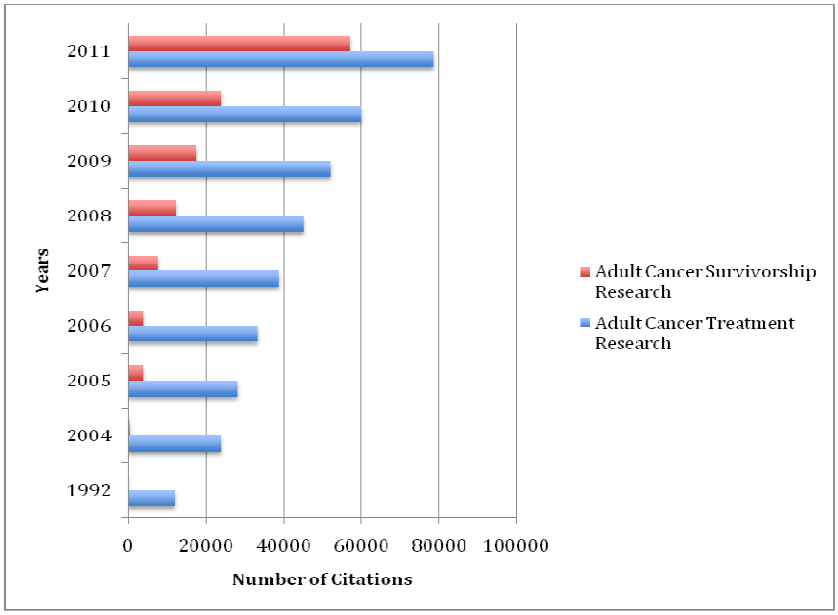

Figure 1. Illustration of the imbalance between adult cancer treatment and adult cancer survivorship PubMEd citations available on an annual basis between 1992 and 2011.

Of significance, times of transition during the cancer trajectory have been identified as being particularly stressful. It has been stated that many newly diagnosed cancer sufferers who have completed treatment, found the period of time to the first follow up visit to be an anxious period (Hewitt, et al., 2006; Morgan, 2009; O'Neill, 1975). During this time the individual and their family are confronted with a fear of recurrence and the prospect of having to deal with the physical and emotional pain (O'Neill, 1975). Mullen (1985), a clinician and a cancer survivor himself, postulated that:

> Survival, in fact, begins at the point of diagnosis, because that is the time when patients are forced to confront their own mortality and begin to make adjustments that will be part of their immediate, and to some extent, long term future (p. 270).

Mullen (1985) also described the survivorship journey according to three seasons: acute survival (beginning at diagnosis, dominated by interventions, fear and anxiety are constant elements); extended survival (begins when the patient goes into remission and undergoes periodic follow-up, psychologically dominated by fear of recurrence and a period of treatment-related physical limitations); permanent survival (commonly known as the time when a person is deemed to be "cured", although person is indelibly affected by longer-term effects on mental and physical health from the secondary effects of cancer treatment). This study focused on the under researched early extended survival season, specifically, the time from when a patient completes primary treatment.

Research Problem

The time following the completion of treatment has been acknowledged to be as challenging as the time spent undergoing treatment (Hewitt, et al., 2006; Leigh, 1992). Very little is known about the issues and challenges that individuals face as they transition from acute cancer treatment into the post treatment extended survival phase particularly in relation to chemotherapy. As more people survive cancer there is an identified need to increase evidence-based knowledge about the survivors' lived experiences (Carter, 1993; Ganz, Schag, Lee, Polinsky, & Tran, 1992). Specialist oncology nurses contribute significantly to information and education during treatment based on evidence, however preparing the individual for post treatment life is predominantly based on anecdotal evidence and previous patient feedback. There is a

lack of evidence based studies in this area and very little is known about the actual patient experiences as they transition into life after chemotherapy.

On completion of chemotherapy, patients are discharged home and experience a gap of four to eight weeks before their next hospital visit to begin the follow up or the surveillance part of their cancer journey. This time in particular has been identified as a time when cancer survivors may be left feeling abandoned and uncertain about their future care. Several authors consider the transition time from active treatment to post treatment care as a critical time for the survivors' long-term health (Cardy, 2006; Taylor, 2008).

Study Purpose

The purpose of this two-phase study was to further understand the specific needs of cancer survivors as they transition from chemotherapy into life after cancer, and, to develop a method by which these needs could be measured. This study was undertaken in two sequential phases.

Phase One: Qualitative.

The aim of this phase was to identify the key experiences of cancer patients on completion of chemotherapy as they transition to life after cancer treatment.

Objectives.

1. To explore and describe from the patient's perspective, the experience following the completion of chemotherapy.
2. To identify factors which improved or exacerbated this experience.
3. To identify the main themes relating to patient experiences of this transition from chemotherapy.

Phase Two: Quantitative.

The aim of this phase was to either develop a new research instrument or to modify an existing instrument which could be used to explore the needs of a large population of cancer survivors. Rather than develop a new instrument, the researcher modified an existing instrument for the Australian context: *Quality of Life – Cancer Survivors(QOL-CS).* This instrument was originally developed and validated by (Ferrell, Hassey Dow, & Grant, 1995). This tool was primarily chosen because the items were consistent with the majority of key themes identified in Phase One. The revised instrument Quality of

Life – Chemotherapy Cancer Survivors (QOL-CCS) was then reviewed by an expert panel to assess clarity, apparent internal consistent and content validity.

Questions.

1. To what extent are the items in the QOL-CCS clear?
2. To what extent do the domains in the QOL-CCS confirm internal consistency?
3. To what extent do the domains in the QOL-CCS confirm content validity?

Significance of the Study

In order to meet the needs of this growing population it is important to first recognise and understand those needs. This study provides an understanding of the needs of the 5000 cancer survivors who transition from chemotherapy to life after cancer in Western Australia each year. The number of survivors within this cohort is set to rise exponentially in the next 20 years as the successes of current treatment improvements and earlier diagnosis continue to be delivered in cancer care to a rising number of cancer patients. The increased number of cancer patients projected in Western Australia is connected to both an increasingly aging population and a rising population due to migration projections. The results of this study will contribute to improving the quality of education and information that is provided to patients as they complete chemotherapy. This study will highlight the physical, emotional, social and spiritual experiences that patient encounter during the immediate post treatment time period. No Australian studies were identified that focussed specifically on this transition of care in cancer patients following the completion of chemotherapy.

Definition of Terms

There is a great deal of international debate about when survivorship begins. This will be discussed in greater depth in the literature review chapter. The following terms surrounding survivorship are used throughout this thesis.

Cancer Survivor: An individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life (Hewitt, et al., 2006; Morgan, 2009)

Cancer Survivorship: The experience of living with, through and beyond a diagnosis of cancer (Clark et al., 1996)

Oncology Nurses: Nurses who have undertaken specialist training to work specifically with cancer patients throughout their patient journey.

Prevalence: Prevalence of cancer refers to the number of people who have previously received a cancer diagnosis and who are still alive at a given point in time.

Quality of Life: “an individual’s perception of their position in life in the context of culture and the value system in which they live and in relation to their goals, standards and concerns” (World Health Organisation, 2007).

Summary of the Chapter and Organisation of the Thesis

This initial chapter has provided the introduction, purpose, objectives, questions, background significance and definition of terms for the study. The relevant literature is discussed in Chapter Two, where the context of survivorship and current levels of knowledge are discussed. Chapter Three describes Phase One of this study, which was the qualitative methodology approach, alongside the ethical considerations associated with this research. Chapter Four presents the findings from Phase One. For clarity, the method and findings for Phase Two, a quantitative approach, is found in Chapter Five. In Chapter Six the findings are discussed in relation to current knowledge. The conclusion and recommendations are also found in this chapter.

Chapter Two: Literature Review

Introduction

This chapter presents an overview of the literature currently available, in relation to the survivorship experience for people with a diagnosis of cancer, as they transition from completion of active chemotherapy treatment to life after cancer. The topics addressed during this review are: development of a survivorship concept; current level of knowledge regarding survivorship experiences and research; context of survivorship following chemotherapy treatment for cancer; differences in survivorship experience related to tumour type; differences in individual experiences at different timelines; quality of life issues relating to survivorship and survivorship knowledge in the Australian context. Themes relating to the family experience have not been included in this literature review, except from the viewpoint of the person diagnosed with cancer. Further, given the differences in survivorship issues for children and adolescents, this literature review focused solely on adults diagnosed with cancer, as they comprised the target population for this study.

The literature review commenced with a search of the following databases: CINHAL, MEDLINE, ProQuest Nursing & Allied Health Source and PsycINFO. All years were included as this research domain is in its infancy and it was considered important to understand the context within which this research was grounded. The search terms used were:

- survivorship;
- cancer survivor;
- transitional survivorship;
- treatment end;
- end of chemotherapy treatment;
- research;
- quality of life.

The last search term “quality of life” was added following the realisation that quality of life in cancer survivors was a recurring theme when searching with the other search terms. The words cancer and oncology were used interchangeably with all search terms

to ensure all relevant information was captured. All additional appropriate references cited in relevant studies were also reviewed.

Development of Survivorship Concept

The concept of survivorship as a new and distinct phase of the cancer care continuum has been increasingly developed over the past two decades. Advances in technology and treatment have changed the trajectory of the illness to a chronic disease in many instances, and it is now estimated that 61% of those diagnosed with cancer will be alive in five years (Ferlay et al. 2010).

Macmillan Cancer Support in the United Kingdom (UK) have represented this new cancer continuum in the diagram below, representing both the stages and the directions which are now evident in the cancer journey.

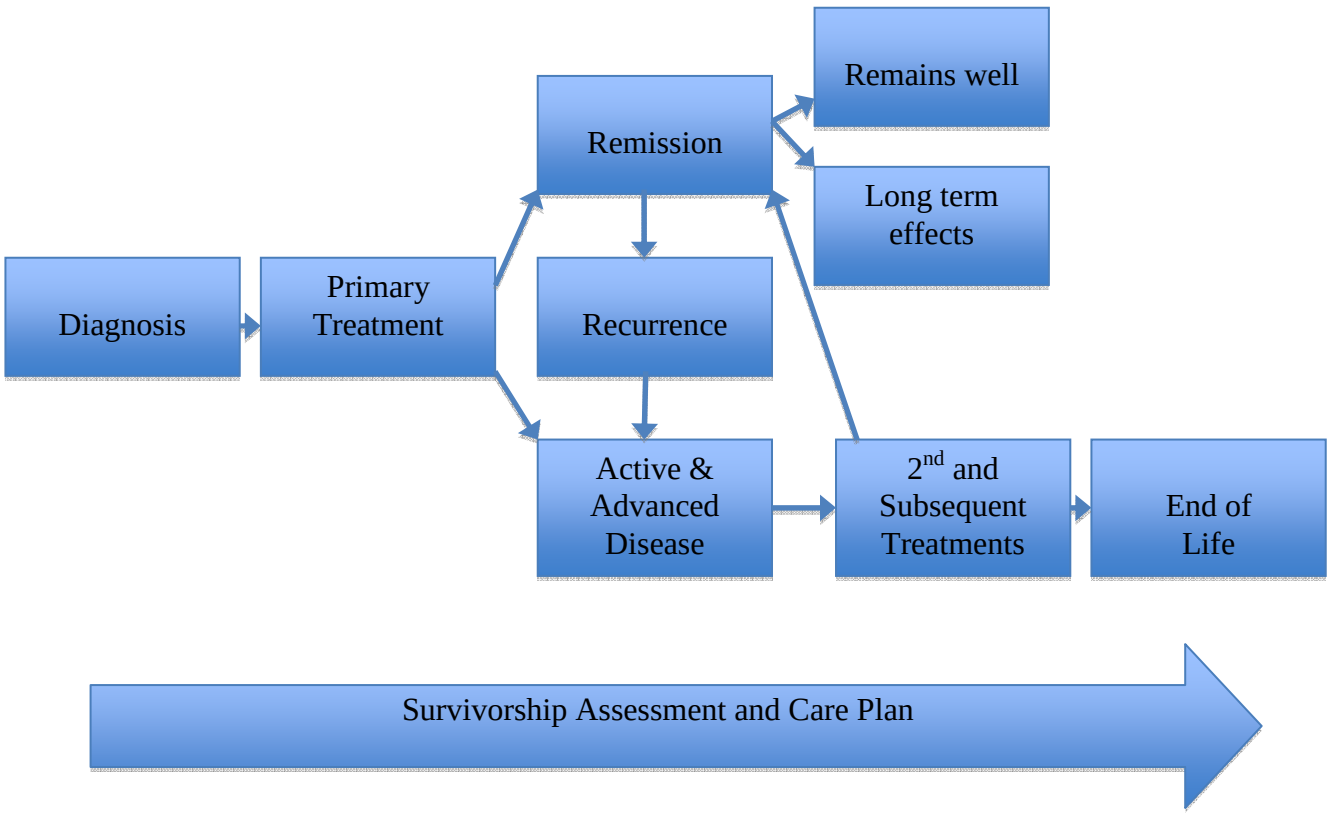

Figure 2. Survivorship Care Pathway -Illustration of the different phases of health or illness that a person with cancer may experience from diagnosis onwards. Reproduced from Vision and five key shifts by Department of Health, Macmillan Cancer Support, & NHS Improvement, 2010. The *National Cancer Survivorship Initiative Vision*, p. 23. Copyright 2010 by Crown. Reprinted with permission.

As the number of cancer survivors increased throughout the 1970s and 1980s, a cancer survivorship advocacy community emerged. As a result numerous physical, medical, psychosocial, economic and legal issues were identified as a legacy of having had a cancer diagnosis and treatment. In the USA in 1986, representatives of 20 organisations amalgamated to form the National Coalition of Cancer Survivorship (NCCS). This organisation evolved from a peer-support organization to what is now in 2012 a formidable advocacy group, which sets public policy priorities on behalf of people with cancer. The first goal of the NCCS was to change the perception and use of the term "cancer victims" to that of "cancer survivors" (Morgan, 2009). In 1996 the National Cancer Institute (NCI) created the Office of Cancer Survivorship (OCS) in recognition of the increasingly large number of individuals surviving cancer and their unique and understudied needs (Hewitt, et al., 2006).

The combined efforts of the NCCS have forged many new approaches to survivorship care and research. One of their leading policy documents "Lost in Transition" (2006) is used by health professionals internationally. The first recommendation of this policy is particularly pertinent to this study: "Health care providers, patient advocates and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care" (Hewitt, et al., 2006 p. 3). Historically, the concept of survivorship generally held by society was often associated with living through extraordinary life situations such as earthquakes, volcanic eruptions, floods, or evil wrong doings such as victims of violence or war (Breaden, 1997; Dow, 1990). Being associated with cancer holds a heavy social stigma as does being a holocaust survivor; many people may not want to be labelled as a survivor or thought of as different to anyone else (Markus, 2004). Whilst the true meaning of the words is simple, the connotations associated can be complex. The word *Survivor* is derived from the middle French word *survivre* to outlive, and from the Latin word *supervivere* to live more (Merriam-Webster, 2012).

Sontag (1978) articulated societal perceptions that *cancer = death* and people with cancer were *victims.* Other preferred terms for survivors include fighters, thrivers, champions, patients or simply individuals who have had a life threatening disease (Hewitt, et al., 2006; Reuben, 2004). It appears that society still holds Sontag's (1978) view. Previous studies identified that public attitudes towards cancer appear to be pessimistic and that cancer is perceived as contagious, a death sentence, threatening, a

dreaded condition and painful (Rendle, 1997). Corner (1988) summarised several studies regarding health care professionals and attitudes to cancer and concluded that most attitudes were negative. Whilst researchers continued confirming negative attitudes to cancer the improvements in treatments were gradually increasing the numbers of people surviving cancer.

A source of debate and consideration in this area of research has been the definitions that have been attached to the survivorship journey. This was particularly evident in earlier years when the starting point of survivorship was contentious. The range of views included: survivorship starting at the point of diagnosis; survivorship starting on completion of initial treatment; or survivorship starting when the person had lived five years beyond their diagnosis (Breaden, 1997; Reuben, 2004). In one of the seminal cancer survivorship papers Mullen (1985) suggested that "survivorship begins at the point of diagnosis, because this is the time when patients are forced to confront their own mortality and begin to make adjustments that will be a part of their immediate and long- term future" (p. 270).

The NCCS defined cancer survivorship as "the experience of living with, through and beyond a diagnosis of cancer" (Hewitt, et al., 2006) and further stated that "an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life" (p. 27). These latter definitions are by far the most accepted at present and are used throughout this thesis (Morgan, 2009; National Cancer Survivorship Initiative, 2010).

The NCCS purposefully chose the term survivorship at its inception in 1986, believing that it promoted empowerment in those with a diagnosis of cancer (Twombly, 2004). Since then it has been used extensively to promote the new stage in the cancer continuum, however, very little research has been undertaken to elicit the acceptability of the term survivor to those cancer patients to whom it refers. Hewitt et al. (2006) inferred the term survivorship was less palatable to the European community because of the holocaust associations; however in recent years the majority of publications from Europe widely use the survivorship terminology. Park, Zlateva and Blank (2009) undertook an interesting study in which they explored whether survivors in the first one to three years identified themselves as: a "survivor", a "victim", a "patient" or a "person with cancer". The most popular self-identity in this study was "survivor" for 83% of the cohort, and "person who has had cancer" for 81% of the cohort. Of note, the researchers concluded that each individual identity carried meaning for the individual that affected not only health behaviours, but also interactions with others. The

researchers postulated that survivors who self-identified with the "patient" label may have experienced reduced feelings of control and hope. These patients may continue to relinquish responsibility for their health to their health care team, thus maintaining the passive role. There was an association between self-identifying as survivors and having a better psychological well being. The findings from this study were congruent with other studies of long-term cancer survivors (Deimling, Bowman, & Wagner, 2007; Deimling, Kahana, & Schumacher, 1997; Park, et al., 2009).

Many researchers have identified the multi-dimensional nature of survivorship. It encompasses physical, psychosocial and economic sequelae of cancer diagnosis and its treatment, as well as issues related to health care delivery, access and follow up care among both paediatric and adult survivors of cancer (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; National Cancer Survivorship Initiative, 2010). The complex nature of survivorship issues and needs impact upon many aspects of care ranging from prevention, screening and rehabilitation through to end of life care (Morgan, 2009). Survivorship as a health care concept is still a relatively new phenomenon, despite or perhaps due to this, there remains a struggle to deliver one accepted definition of who is a survivor and when survivorship begins. What is accepted, however, is that survivors have many unique needs, which are at present not well understood.

Current Level of Knowledge Regarding Survivorship Experiences and Research

The goal of survivorship research is to understand and thereby reduce the adverse effects of a cancer diagnosis and treatment in order to optimize outcomes for cancer survivors and their families (Aziz & Rowland, 2003; Ganz, 2003). The focus of cancer care has traditionally been confined to diagnosis and treatment. Consequently, there has been a plethora of research in these two areas compared with survivorship. For example, by 2004 the imbalance in research cited in PubMed related to active cancer treatment (n=23,736) was enormous compared with the research relating to cancer survivorship (n=374) (Aziz & Rowland, 2003). Since 2005 there has been an exponential rise in research related to cancer survivorship with 57,041 citations available on the PubMed database in 2011. The inequity in research contributes to the survivorship conundrum. Whilst the concerted research effort into cancer treatments has resulted in great strides forward producing more cancer survivors, the lack of survivorship research has resulted in a widespread failure to recognise and address the psychosocial needs of cancer survivors because of a variety of barriers (Kaplan, 2008).

The approach to survivorship research has been fragmented as the isolated approaches of survivorship research have made oversight of the process difficult (Breaden, 1997). It is now increasingly understood that there are as many research domains in cancer survivorship as there are in cancer treatments. While the physical and emotional impact of cancer treatment in the acute period are well known, there is less understanding about the fact these effects can continue well beyond treatment (Hewitt, et al., 2006). Survivorship research has demonstrated there are significant longer term implications for the survivor as a result of the cancer diagnosis and its subsequent treatments; this has been referred to in several texts as the "price of survival" (Davies, 2009; Ganz,2002; Gotay & Muraoka, 1998; Hewitt, et al., 2006; Hewitt, Rowland, & Yancik, 2003).

Recently there has been a considerable increase in the amount of research undertaken to develop and test interventions to improve the survivorship experience. This work has included studies on the use and delivery of follow up care plans (Ganz & Hahn, 2008; Morgan, 2009) and screening tools (Holland & Reznik, 2005; Pigott, Pollard, Thomson, & Aranda, 2008). However, what appears to be lacking in this approach is a determination of the individual's unique lived experience of cancer treatment, that is, the follow up care needs as determined by patients' own perceptions (Adewuyi-Dalton, Zieland, Grunfeld, & Hall, 1998; Mullen, 1985; Schlairet, Heddon, & Griffis, 2010). A handful of researchers have explored the individual's experience of survivorship according to specific timeframes (Carter, 1993; Gotay & Muraoka, 1998), or following specific interventions (Emery et al., 2008; Galvao & Newton, 2005), or by tumour group (Baravelli et al., 2009; Brennan, Butow, & Spillane, 2008; Dizon, 2009). There is now growing evidence of unmet needs in the first year after treatment, with a 2009 study showing that one in four cancer survivors had at least five unmet physical or psychological needs (Hindle, 2010, Lobb, 2009).

The NCCS has clearly set the agenda for cancer survivorship research by directing that it should address the physical, psychosocial and economic domains of a cancer diagnosis and its treatments, whilst retaining the focus on the health and the life of the person with the cancer history. Intervention studies are needed that develop or test strategies to promote optimal health status in survivors of cancer, information on survivors of cancer who have previously been understudied, and research on the impact of cancer on the family (Hewitt, et al., 2006; Rowland, Aziz, Tesauro, & Feuer, 2001).

The importance of survivorship was demonstrated by the development of a committee by the Institute of Medicine of the National Academies in the USA. The role

of this committee was to investigate medical and psychosocial issues faced by cancer survivors and to make recommendations to improve their health care and quality of life. As previously discussed, the expert committee produced a pivotal report focusing on survivors of adult cancer during the phase of care that follows primary treatment, this report was entitled: “From Cancer Patient to Cancer Survivor: Lost in Transition” (Hewitt, et al., 2006). Findings were based on evidence from the research literature rather than indirectly from survivors. The report provides an excellent summation of what was known and understood in relation to survivorship in the USA until 2005 and concludes with ten recommendations, the first aiming to raise awareness of the needs of cancer survivors and establishing cancer survivorship as a distinct phase of cancer care. Understanding what cancer patients need to know and from whom they receive information during the course of their care is essential to ensuring quality care (Finney Rutten, Arora, Bakos, Aziz, & Rowland, 2005). The current study sought to contribute to this important body of knowledge by providing evidence to further raise the awareness of the unique needs of cancer survivors as they transition from completion of chemotherapy treatment into follow up care.

Context of Survivorship Following Chemotherapy Treatment for Cancer

The period following primary cancer treatment is recognised as under researched and therefore lacking in evidence based guidance for health care providers (Breaden, 1997; Hewitt, et al., 2006; Little & Sayers, 2004; Rassmussen & Elverdam, 2007). Cytotoxic chemotherapy is one of the main treatment modalities used to manage cancer; in Australia if optimal treatment rates are achieved 51% of those treated for cancer will receive chemotherapy (Blinman et al., 2012). Despite the significant number of people who receive chemotherapy there is a considerable lack of chemotherapy survivorship related research available, although there is a plethora of research related to chemotherapy delivery and treatment of side effects.

Several researchers have identified the mixed emotions of completing treatment. Elation on completing treatment is often coupled with anxiety of losing contact with the treatment team and fellow patients. Conversely, a desire never to see the treatment team again may exist. This suggests an association between somatic anxiety and substantial psychological distress (Allen, Savadatti, & Levy, 2009; Doyle, 2008). Survivors frequently and with intense language described feeling abandoned, pushed out or cast adrift by the health care system at the time of treatment completion (Allen, et al., 2009; Jefford, et al., 2008; Rancour, 2008).

Qualitative and quantitative studies have attempted to establish the issues faced by patients completing treatment for cancer; the following themes have emerged from the literature:

- Thoughts and fears about cancer including: fear of recurrence; anxiety about the future; isolation, fear of death and intrusive or avoidance thoughts about cancer.
- Physical and psychological consequences of treatment including: the possibility of early menopause; late or longer term effects such as fatigue.
- Returning to normal including: dealing with changes to identity; body image; returning to work; and uncertainty about health and effects of treatment.
- Sexuality and fertility including: decreased libido; erection and ejaculatory difficulties; reduced frequency of sexual intercourse; anxiety about future infertility; and decreased interest in having a child.
- Follow up including: ambivalence about discontinuing treatment; fear of future; follow up appointments; and longer term effects of treatment.
- Impact of cancer on family and friends.
- Financial implications including: a loss of income and assets during treatment and ongoing challenges obtaining insurances and mortgages.

(Department of Health, 2010; Hewitt, et al., 2006; Jefford, et al., 2008; Karahalios et al., 2007).

The physical impact of chemotherapy in the short term has been acknowledged in several papers that discuss the longevity of some side effects such as fatigue (Jefford et al., 2011; Speigel & Kato, 1996; Spiegel, Kraemer, & Bloom, 1989). It has also been identified the likelihood of post cancer disabilities were more than three times as likely if chemotherapy was a part of the treatment (Taylor et al., 2004). Available papers suggest there is a new balance to be found as a return to good health may not necessarily be a return to the normality of life before cancer (Dow, 1990). It would appear that survivorship has at least two stages: surviving the initial diagnosis and subsequently the aftermath of treatment (Leigh, 1992). The NCCS identified that many patients completed their primary treatment unaware of their heightened health risks, and lack of preparation to manage their future health care needs (Hewitt, et al., 2006).

Differences in Survivorship Experience Related to Tumour Type

The cancer sites with the highest frequency of survivors were recently described as: breast (22%), prostate (19%) colorectal (10%) and gynaecologic (9%) (Kaplan, 2008; Ries et al., 2004; Rowland, 2008). When contemplating the survivorship

experience in relation to the actual cancer diagnosis each tumour group will be unique in terms of needs, even those with the same cancer type and treatment regime will identify very different needs (Hewitt, et al., 2006; Hodgkinson, Butow, & Hunt, 2007; Jefford, Karahalios, Angle, Baravelli, & Akkerman, 2007; Jefford, et al., 2011). For example, Fox and Lyon (2006) argued that lung cancer patients may have a unique view of transition from completion of chemotherapy, as treatment related symptoms may exacerbate disease related symptoms and further contribute to poorer quality of life outcomes, as well as survivorship. For this reason the authors believe that specialized care must extend beyond the treatment phase. Hewitt et al. (2006) discussed long-term needs unique to specific tumours, showing there are wide ranges of physical and psychological side effects which are evident in the long term profile of cancer survivors. There is however no evidence to indicate when these side effects become evident or if they are burdensome during the immediate post treatment episodes.

Fox and Lyon (2006) found that survivors of lung cancer experienced distressing symptoms; specifically depression and fatigue, well into cancer survivorship and these clustered symptoms significantly influence quality of life. There are some distinctions to be found in the survivorship experience according to the initial cancer diagnosis. Taylor & Odey (2011) reported that colorectal cancer patients identified fewer physical symptoms or concerns than other cancer survivors. Jefford et al. (2011) however, identified a range of distressing, embarrassing and potentially life threatening complications to which colorectal cancer patients are susceptible. Breast cancer patients often experience physical side effects unique to their cancer treatment, which cause an early menopause. The post treatment effects of menopause can affect fatigue, quality of life and sleep. Success in treatment for ovarian cancer, once an almost fatal form of cancer, has now caused a psychological shift from preparing for death at diagnosis to preparing for life after cancer. Cochrane (2003) compared this to the phrase “health within illness” a concept commonly used in HIV/AIDS literature. Rassmussen & Elverdam (2007) claimed that regardless of the type or location of the cancer and the treatment received, cancer survivors have similar experiences in the process of surviving cancer. Jefford et al., (2008) identified common themes in their research with survivors across a range of tumour types, which appears to support Rassmussen & Elverdam’s (2007) claims. It would seem that survivors encounter a range of common experiences such as fatigue and a range of disease / treatment-specific experiences such as early menopause.

Differences in Individual's Experiences at Different Timelines.

For many of the 114,000 people diagnosed with cancer each year in Australia (AIHW, 2010), resuming the routines of work and family life after completing active treatment may be especially difficult. Anxiety over cancer recurrence may dominate at this time, and questions also arise about the next steps in the care continuum (Alfano & Rowland, 2006; Breaden, 1997; Jefford, et al., 2008). The transition from diagnosis and active treatment to survivorship is an understudied phase in the cancer trajectory (Hewitt, et al., 2006; Stanton et al., 2005). Research to date has shown the longer term picture of the journey many experience, the needs at time of transition onto this journey remain as yet only marginally explored.

The period prior to the first follow up visit is likely to be an anxious time when the individual and their family are confronted with the fear of recurrence and having to deal again with the physical and emotional pain (O'Neill, 1975). This highlights the importance of understanding patients' issues and concerns on completion of chemotherapy, to ensure that health care practitioners are aware of potential information needs. Personal accounts of having cancer by Armstrong (2001) and Carr (2004), have added to the literature by expressing their feelings of being powerless after completion of treatment and being unsure about what they were supposed to do to help themselves. Earlier studies have also identified these feelings (Breaden, 1997; Pelusi, 1997).

Transition at the end of treatment can be a traumatic time for patients; whilst they are finally leaving treatment behind they are also leaving what has become a safety net of health professional connection, no longer being required to attend clinic visits, hospital stays and even emergency attendances. Patients who look forward to the day they would complete the arduous demands of treatment are often surprised by the void (Hewitt, Barmundo, Day, & Harvey, 2007; Rancour, 2008). Well planned and coordinated care to facilitate transition from acute cancer treatment to life after cancer has been identified as critical; a deficit in this knowledge will increase risks for the survivor (Hewitt, et al., 2006).

Mullen (1985) developed a framework for the survivorship process, which entailed distinct phases that an individual moves through; he described this as the three "seasons" of survival in the survivorship journey:

- Acute Survival – beginning at diagnosis and dominated by diagnostics and therapeutic interventions – fear and anxiety are constant and important elements of this stage.

- Extended survival – this period is entered as the patient goes into watchful waiting with periodic examination. Psychologically this period is dominated with fear of recurrence and contains a period of physical limitations following the therapeutic interventions.
- Permanent survival – "cure", although the person that has got to this stage of the cancer experience is indelibly affected by it. Longer-term effects on health from secondary effects of cancer treatment may represent another area of risk (Mullen, 1985).

No specific timeframes exist for the stages described by Mullen and it has been suggested that not all patients experience all stages (Decker, Haase, & Bell, 2007; Morgan, 2009; Mullen, 1985).

A transition implies moving from one relatively stable state, with an experience of disorganization and upheaval during the process, toward another stable state (Boyle, 2006; Clarke-Steffen, 1993). Any transition implies the letting go of old relationships, forms, methods and roles, even if the nature of the transition is perceived as positive one (e.g. promotion, marriage or completing treatment for cancer); all transitions imply leaving the familiar and suggest a sense of loss or grief. Survivors can feel lost and confused by the sudden cessation of treatment. They may be pronounced "cancer free" or have "no evidence of disease" but rarely are they told they are cured (Rancour, 2008). Studies have revealed that periods of highest distress for women with breast cancer are associated with transition points in treatment (Kaplan, 2008). Comprehensive reviews of available literature report the period after completion of treatment brings its own unique, and in some cases, still poorly understood challenges. Whilst survivors are relieved to be ending treatment, many survivors report being unprepared to manage the long-term effects of cancer and its treatment. Survivors are articulating that being labelled disease free does not mean being free from disease (Alfano & Rowland, 2006; Hewitt, et al., 2006; Reuben, 2004).

As they transition to recovery survivors want to know: who will follow them; which symptoms to monitor; when to be alert to changes in health; what their "new normal" will be and how they can reduce their risk of recurrence and remain healthy (Alfano & Rowland, 2006; Hewitt, et al., 2007). Similarly, it has been demonstrated that survivors also want to know and understand their follow up plan; who will monitor their health and risks; and what they can do for themselves to adapt and prevent further recurrences (Rancour, 2008). Getting the balance of information correct is important; many survivors claimed to have been overwhelmed at the end of active treatment and

were given so much information about follow up care verbally they couldn't take it all in (Hewitt, et al., 2007).

It is evident the cancer experience changes the psyche of individuals as they move between roles of patient and survivor. When a person is diagnosed with cancer they become a patient, they also become a part of the community of practice that consists of specialist doctors, nurses and technicians who are mobilized to have an impact on the patient. As the person completes treatment they must change roles yet again, from being a patient to being a survivor, adjusting to limited contact with the health professional team and a requirement to assume the responsibility of self monitoring and to find a new equilibrium (Allen, 2009).

Quality of Life Issues Relating to Survivorship

The World Health Organisation (2007) defined quality of life as "an individual's perception of their position in life in the context of culture and the value system in which they live and in relation to their goals, standards and concerns" (p.1). Ferrans (2005) explains that quality of life has been conceptualized as normal functioning, social usefulness, general well being, ability to fulfil life's goals, and happiness and life satisfaction, this description is supported by several authors (Albaugh & Hacker, 2008; Wochna Loerzel, McNees, Powel, Su, & Meneses, 2008). The meaning of health and life itself can be altered following a diagnosis of cancer (Vachon, 2001). Cancer survivors report struggling to achieve a balance in their life's and a sense of wholeness and life purpose after a life altering experience (Ferrell, 2004). It is therefore evident that one's own perception of quality of life is determined in accordance with one's own values of normal, being culturally acceptable and usefulness. It includes the ability to set goals and have a purpose in life. Quality of life measures are now commonly found in many research papers and are widely used to determine how individuals assess their own general well being. However, there is a lack of consensus on a health related quality of life definition. Ganz (2000) labels the health effects of cancer and its treatments on perceived quality of life as "the price of survival" (p. 324).

Fatigue is a commonly described symptom considered to greatly impact on quality of life. Broeckel, Jacobsen, Balducci, Horton, & Lyman (2000) found that breast cancer survivors 3-36 months following adjuvant chemotherapy reported more fatigue than a comparison group with no history of cancer. Adjuvant chemotherapy indicates that the survivors have had chemotherapy in addition to another treatment to assist in amelioration or cure of the breast cancer. This USA quantitative study

compared results to two surveys between cancer survivors post chemotherapy and women who had never been diagnosed with cancer. Overall the cancer cohort scored lower in both surveys, and physical aspects were much more poorly scored than psychological aspects. Women who were older and married scored higher in psychological well being than the remainder of the group (Broeckel, Jacobsen, Balducci, Horton, & Lyman, 2000).

A third of breast cancer survivors have reported severe fatigue associated with higher levels of depression, pain and sleep disturbances (Bower et al., 2000). Bennett, Winter-Stone & Nail (2006) undertook a review of available literature relating to exercise intervention in cancer survivors and concluded that many cancer survivors reported a decline in their physical functioning, including basic body mobility and engagement in work and leisure activities, during cancer treatment and immediately afterwards related to fatigue. Their paper presented a conceptual model, which provides opportunities for further studies to increase an understanding of how exercise interventions may work for survivors.

A comprehensive conceptual model of quality of life in cancer survivors was developed by Ferrell, Hassey Dow, et al. (1995). This team recognised that whilst on active treatment the main focus of care had been physical and psychological well-being. Several months later the focus shifted to social and spiritual well-being, often with a change in direction around managing physical and psychological well-being, for example the late effects of fatigue or cognitive impairment whilst not life threatening are certainly life altering. There is a lack of agreement about what constitutes the dimensions of quality of life, however the domains in this model are consistent with the predominant view (Ferrell, Hassey Dow, et al., 1995; Spiker, 1990)

Based on this quality of life model, Ferrell, Dow et al., (1995) also developed and tested a quality of life instrument for longer term cancer survivors; the aim of this instrument was to measure the specific concerns of this group of survivors. The Quality of Life – Cancer Survivors tool (QOL-CS) is based upon a previous quality of life instrument developed by researchers at the City of Hope National Medical Centre (Ferrell, Dow, et al., 1995). The instrument has been widely used in cancer care and has been adapted for several different cancer populations across a range of ages, tumour types and languages, for example: Hispanic patients with cancer, (Juraz, Ferrell, & Borneman, 1998); breast cancer survivors (Ferrell et al., 1996) and ovarian cancer survivors (Ferrell, Smith, Juarez, & Melancon, 2003).

Short, Vasey, Joseph & Tunceli (2005) showed that 20% of cancer survivors have cancer related disabilities one to five years after diagnosis. Re-establishing oneself back into pre-cancer lifestyle norms may occur gradually during the course of active cancer therapy or abruptly following completion of treatment depending upon individual's requirements of hospitalization and recovery (Boyle, 2006). The positive aspects of cancer survivors' quality of life perception include a greater appreciation of life (Bush, Haberman, Donaldson, & Sullivan, 1995; Mellon, 2002), and a healthier lifestyle (Alfano & Rowland, 2006; Allen, et al., 2009; Mellon, 2002). Hoffman & Stoval (2006) showed that survivors who were informed about their options believe they have some personal control over decision-making generally have higher quality of life. Reported negative aspects of quality of life perception have included longer term side effects of cancer (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996), altered sexuality and self-image (Ganz et al., 1996) and economic problems (Ferrans, 2005). Control, aches and pains, uncertainty, satisfaction, future appearance and fatigue were the most consistent domains shown to affect perception of quality of life. Quality of life was also reported to be higher in those who had survived for longer than five years past diagnosis (Morgan, 2009).

Spirituality has been described as an important aspect of quality of life for patients with cancer; it encompasses not only religiosity but also other dimensions such as hopefulness, transcendence and purpose. Spirituality is linked to life meaning; previous literature has described the importance of spirituality as a component of deriving meaning from cancer (Ferrell et al., 2003). Roos & Powell (2005), both cancer survivors from Australia, eloquently discussed the journey from a person confronted with cancer to a patient and then back to an individual but changed. These changes occur along a continuum of meaning based on negotiation with information the person receives along the journey. In negotiating this process the person is dealing with issues of self, issues of meaning and issues of identity all of which link to the original quality of life definition from the World Health Organisation at the beginning of this section. It would appear that maintaining or restoring quality of life is vital to all cancer survivors.

Survivorship Knowledge in the Australian Context.

One of the few Australian studies in this domain and timeline is a qualitative study undertaken by Jefford et al. (2008), which looked at survivorship issues following treatment completion from the viewpoint of 22 survivors and 20 health care professionals. Through a process of focus groups, this study found that dealing with

fatigue, anxiety about cancer recurrence, others expecting you to be back to normal, having to create new expectations about physical ability, and anxiety about leaving the hospital system, were the most commonly reported. The participants ranged in length of survivorship from less than 12 months to over 10 years with over 75% of participants being over a year post treatment. The strength of the current study is that it focused solely on patients who had completed chemotherapy within three months.

There is a great deal of congruence between Jefford et al.'s (2008) findings and the quality of life research discussed previously in this section. This work has been instrumental in highlighting the issues of survivorship in the Australian context and has led to the development of the Australian Survivorship Centre based at Peter MacCallum Cancer Institute in Melbourne, Victoria. Jefford et al.'s (2008) findings have provided a broad platform on which more specific research can now add to the understanding of survivorship challenges in Australia. Jefford and his team continue to build upon this research with a series of interventions designed to address the unmet needs identified in the 2008 study. For example, developing and testing written information booklets (Jefford et al., 2007) and more recently, piloting nurse-led follow up support for patients with bowel cancer (Jefford et al., 2011).

Lobb et al. (2009) recently added to the Australian context with findings from a study undertaken in Western Australia with 66 survivors of haematological malignancies. Participants were surveyed using a structured quantitative instrument in order to establish their unmet needs on the completion of treatment. Findings were consistent with those identified earlier in this chapter as well as the work of the Jefford team (2008) as discussed above. Lobb et al.'s (2009) research began to explore the perception of strategies which may help to meet the unmet needs, for example, use of case managers. It was also reported that 59% (n=39) patients perceived it would have been helpful to speak to a professional at treatment completion about the experience of diagnosis and treatment, and making the transition from active treatment.

The current study builds upon the work by Jefford et al. (2008) and Lobb et al.'s (2009) work by specifically targeting individual survivors within the early transition phase, who had completed chemotherapy and providing them with the opportunity to openly discuss their needs through a semi structured interview process. An understanding of the concerns from the survivors' perspective allowed the researcher to develop items for an instrument that could be used clinically to determine specific needs at completion of chemotherapy treatment. It is anticipated that development of such an instrument would assist health professionals to provide care that is: tailored to an

individual's care needs; facilitates the delivery of appropriate information in a timely manner; and supports a smoother transition for patients as they leave the acute care setting.

Summary of Chapter Two

The increasing prevalence of cancer survivors in developed countries is a clear challenge to both clinicians and researchers alike. Whilst it is important to continue looking for cures and improvements in treatment experiences, it is now evident that research and care of cancer survivors is equally important. The literature review confirmed that cancer is an extreme experience that disrupts people's lives and sense of identity. For the previous months whilst undergoing treatment patients are forced to relinquish normal life, social roles and often work, in order to cope with the complex treatment requirements and physical side effects that cancer treatments are known to cause. Once treatment is completed, this is often the first time the individual has an opportunity to reflect on the impact of being diagnosed with a cancer and what that means to them as an individual, as a family member, and as a member of the wider community. At this stage survivors often begin to articulate their search for the understanding of their new "normal" and acceptance of their new self after the treatment journey. Health care professionals can provide timely and appropriate support into the transition period once the key issues and concerns of survivors at this time are understood.

The findings from this literature review were used to shape the development of the interview guide for this study in order to clarify the key issues and concerns of survivors. It is known that improved and timely education facilitates better psychological health in cancer patients and survivors**,** however this needs to be based on actual requirements; currently we do not understand the full range of gaps in knowledge relating to this cohort of survivors. The number of cancer survivors continues to rise, **t**he increasing number of cancer survivors is occurring alongside an increasing incidence in cancer diagnosis due in part to an ageing population. Health services will not be able to continue managing the increasing demand of new patients and survivors in the current model of care delivery, unless new models of care are developed to more efficiently meet individual patient needs. Research is vital to identify the issues for survivors in the transition period and to test new methods of survivorship care delivery across a continuum of care ranging from self management strategies due to nurse-led clinics and shared care models.

This study will contribute and build upon the current knowledge available in the survivorship continuum, by concentrating on an area of need that has not been wholly addressed in the research to date. That being, the specific timeline immediately after the completion of chemotherapy treatment, given than over half of all cancer patients will receive chemotherapy this study presents an opportunity to understand the needs of a sizable proportion of the survivorship community.

Chapter Three: Methodology

Introduction to the Chapter

This chapter describes the qualitative approach used for Phase One and the ethical considerations for this study. It illustrates the processes employed to collect and analyse the data and also discusses ethical considerations that occurred before and during the study. The purpose of this study was to ultimately improve the care of people as they transitioned into life after completion of chemotherapy treatment. There is minimal information related to this phase of the cancer trajectory, therefore this study was intentionally exploratory and descriptive.

In order to achieve the proposed outcome a two-phase approach was undertaken. In Phase One a Grounded Theory qualitative approach was followed to the descriptive level of data analysis. Data was collected via semi structured telephone interviews which elicited the descriptors of issues and experiences that arose for patients in the first six months following completion of chemotherapy. In Phase Two, findings from Phase One were used to embark on a quantitative approach in which an existing cancer survivorship instrument was amended with the intention of using the revised tool to explore survivorship issues that occur during the first three months following the completion of chemotherapy. The revised questionnaire was then tested for clarity, content validity and apparent internal consistency with an expert panel of senior chemotherapy nurses from a large tertiary cancer service in Western Australia.

To assist with clarity in reading this thesis, the methodology for Phase Two is presented in Chapter Five where it is described in conjunction with the results for Phase Two.

Phase One: Qualitative

The intention of this study was to contribute to a very limited body of knowledge regarding the early survivorship period of persons diagnosed with cancer. A qualitative research approach was chosen to facilitate the exploration of the phenomenon and to gain a richer understanding of the experiences of individuals. Qualitative research provides systematic processes to enable the researcher to explore behaviour, feelings and experiences of individuals and how they make sense of these

perceptions. This approach is particularly useful in areas where little is known or understood (Burns & Grove, 2009; Holloway & Wheeler, 2010; Liamputtong, 2009).

Grounded Theory

As previously described, this phase of the study was exploratory and employed the Grounded Theory approach to the descriptive level of analysis. Grounded Theory is an approach whereby theory is generated based on the data, which has been collected and analysed. The constant comparative method is utilised to analyse the data, and this necessitates comparing and contrasting the concepts identified in the data. Grounded Theory enables a problem to be studied from the perspective of the individuals affected. It captures social process within the social context and is a particularly useful approach when little is known about a particular area. Grounded Theory of health-related phenomena has implications for nursing practice; it identifies how individuals make sense of their experiences (Birks, Chapman, & Francis, 2006; Burns & Grove, 2009; Holloway & Tordes, 2010; Portney & Watkins, 2000; Walker & Myrick, 2006; Wuest, 1995). For people with a cancer diagnosis completing chemotherapy treatment, the use of Grounded Theory facilitated a greater understanding of their physical and psychological experiences. This perspective can lead to improvements in nursing care provision.

Grounded Theory was first described by Glaser & Strauss (1967) in their seminal work "The Discovery of Grounded Theory". Since this time the method has been both adopted and adapted by many other researchers in the social sciences and health care fields, especially in nursing (Carpenter, 1995; Charmaz, 2007; Corbin, 1986; Corbin & Strauss, 2008; Morse, 2001). Notably, Strauss & Corbin (1990) in their book "Basics of Qualitative Research: Techniques & Procedures for Developing Grounded Theory" detailed a significant refinement to the 1967 procedures. Grounded Theory is still a relatively new approach compared with other methods and therefore continues to be developed, transformed and critiqued. It is interesting to note that in later years Glaser and Strauss disagreed about the fundamental procedural issues of the methodology. These approaches subsequently became known as the Glaserian & Straussian approaches; the main differences surrounded data analysis and how theory was induced from the data (Birks, et al., 2006; Heath & Cowley, 2004; Walker & Myrick, 2006; Woods, 2003).

According to the literature, Grounded Theory originates from sociology, although Glaser (2005) has refuted this claim. The sociological roots are specifically

connected with symbolic interactionism, which theorises that meaning is negotiated and understood through interactions with others in social process (Blummer, 1986; Dey, 1999; Jeon, 2004; Polit & Beck, 2006; Starks & Brown, 2007). The epistemological basis of Grounded Theory in symbolic interactionism provides a great deal of congruence for the field of nursing and the strong links between Grounded Theory, symbolic interactionism and nursing are evident in the nursing literature (Milliken & Schreiber, 2001; Morse, 1994; Stern, 1994). Symbolic Interactionism was first noted in 1937 by Herbert Blummer and was constructed from the basis of many intellectuals. This perspective in partnership with Grounded Theory provides patterns of human behaviour, experiences, common perceptions, and how people make sense of their world in common circumstances.

As discussed, the purpose of this study to qualitatively identify, explore and describe the experience of cancer survivorship transition from chemotherapy to life a cancer survivor. Hence, Grounded Theory was used to the level of data analysis to identify the meaning described by cancer survivors and provide an insight into their own reality and perception of the interactions they had experienced during this period.

Research Setting

This study took place in one of three public tertiary hospitals in Western Australia, within the medical oncology and haematology departments. The departments provide care to over 2000 public and private patients per year from both metropolitan and rural Western Australia. All types of solid cancer tumours and haematological malignancies with the exception of allogeneic transplants are treated at this centre; there is also a strong culture of clinical trials. Care is provided using a multidisciplinary approach lead by haematologists, medical oncologists, a nurse practitioner and other senior cancer nurses. Patients cared for in this setting have complex treatment requirements and visit the hospital on multiple occasions during the course of their chemotherapy treatment. Oncology care is now primarily an out patient managed system of care delivery with inpatient episodes reserved for the exceptionally unwell person. As a state wide treatment centre the research setting provided the opportunity to draw from a wide range of candidates.

Sample Selection

The accessible population for this study were those patients treated at the cancer centre described in the research setting above. Participants were recruited from the

medical oncology and haematology departments and had a cancer diagnosis. As the hospital is a state-wide treatment centre for cancer it provided the opportunity to draw from a wide range of potential participants. The research sample for this study was drawn from a target population of all individuals who received chemotherapy in Western Australia.

A purposive sampling method was used. This approach enabled the researcher to select certain participants to ensure that a wide range of patient characteristics were represented in the data. In adopting this approach it was important to clearly indicate the characteristics and rationale for inclusion or exclusion when participants were selected (Burns & Grove, 2009; Gerrish & Lacey, 2010; Holloway & Wheeler, 2010). In keeping with the purposive sampling approach, a set of pre determined criteria were used to select chemotherapy patients for interview. Participants were selected to reflect varying experiences of the transition period between four and 24 weeks following completion of chemotherapy. This period of time was considered long enough for individuals to have recovered from the immediate physical effects of the final chemotherapy treatment, but not too long for participants to have forgotten the details of the experience. Participants had a minimum of four to six months of chemotherapy treatments; this was considered a long enough time period to have settled into a pattern of care and also reflected the average timeline for the most commonly delivered chemotherapy regimens. No exceptions to cancer type were made as the area of research interest related to the treatment rather than the disease. For this reason there were no specific requirements set for gender, geographical location, or family setting. Participants under the age of 25 years have been identified as a unique population with unique needs, which are being addressed at the national arena and were therefore excluded. Likewise, those participants already recruited into a clinical trial were intentionally excluded as they were already subject to intense data collection which usually includes mandated follow up visits within the trial period during which patients receive additional support. This was considered to potentially conflict with the current study. Further, participation would have placed these patients at risk of research burden..

Participants were recruited using the approaches of self-selection or active invitation. Posters and leaflets were posted in both departments with contact details made available; patients who were interested often spoke with the chemotherapy nurses requesting more information and then either phoned the researcher directly or asked the nurses to express interest on their behalf. This approach yielded only a small number of

participants (n=4). The second approach was to write to all eligible individual participants who were identified as meeting the inclusion sampling criteria by the chemotherapy nurses. Those who were invited were provided with a letter of introduction, a study information sheet, a tick box form to opt out, and an addressed reply paid envelope (Appendix A). This method was more successful. Of the 20 patients who were invited, 10 patients agreed to participate in the study and 10 patients chose to opt out by returning the opt out letter. Nine patients did not specify a reason for their decision to opt out and one patient chose not to participate as he felt too unwell.. The researcher made frequent visits to both departments providing education about the research and opportunities for discussion with the nursing team, in order to maintain the profile of the research and also the individual nurses understanding of the process to support discussion with potential participants. If an opt-out letter was not received by the date indicated in the letter then the potential participant was telephoned to ascertain their willingness to be a part of the process, if they agreed then the date and time for the interview was confirmed during this call. On the day of the interview a text message was sent confirming the interview time, telephone number and the contact details of the researcher if they wished to change the arrangement. At the agreed time the researcher telephoned the participant, confirmed the convenience for the individual, ascertained permission to record the interview once again and repeated the explanation about the study before the interview commenced.

Recruitment continued until theoretical saturation became evident. Theoretical saturation occurs when no new relevant codes or concepts are identified in comparison with the data already collected, only redundancy of previously collected data (Burns & Grove, 2009; Gerrish & Lacey, 2010; Munhall, 2007). A total of 14 participants were interviewed; ten were female and four were male. Ages ranged from 35 years to 78 years with a mean of 58 years. The length of time since completion of chemotherapy ranged from four weeks to 14 weeks, with an average time since completion of chemotherapy being ten weeks. The diagnosis of cancer included, gynaecological, colorectal, breast and haematological with six having a haematological malignancy and therefore being treated in the haematology department. The participants lived throughout Western Australia, with eight based in Perth and four living in the far north and south west regions of Western Australia (see Table 1).

Table 1

Demographic characteristics of cancer survivors who participated in the interviews

Demographic domains	**Variables**	***n***
Gender	Male	4
	Female	10
Age	30-60	8
	>60	6
Time since completing	4 weeks	1
treatment	6 weeks	1
	8 weeks	2
	9 weeks	1
	10 weeks	4
	11 weeks	3
	12 weeks	2
Cancer Types	Breast	1
	Colon	1
	Lymphoma	3
	Multiple Myeloma	5
	Ovary	4
Place of residence	Perth Metropolitan	10
	South West Region	3
	Pilbara Region	1

Theoretical Sensitivity

Theoretical sensitivity has been described as a key characteristic of Grounded Theory. Glaser (1967) highlighted the importance of a researcher's awareness of the subtleties of the data. Theoretical sensitivity provides the researcher with the ability to have insight, thus providing understanding and meaning to the data. This sensitivity may be gained from literature or from professional experience. The researcher of this study was a cancer nurse with over 25 years of cancer nursing experience; many of these years having been spent delivering chemotherapy and leading teams of nurses who care for these patients. Hence theoretical sensitivity was demonstrated as a key

component of this research process. As a new researcher, this was managed by honest reflection, memos and regular clarifying discussions with research supervisors.

Interviews

Interviews were chosen as the approach for data collection in this study. Interviews were semi-structured and undertaken by telephone at a time and in a place convenient to the participants. The flexibility of interviews enabled the researcher to explore the subject matter in greater detail than other available approaches such as the written survey. The support for interviews is robust in the qualitative academic environment as a means of data collection. Interviews are considered to provide a prime opportunity to capture an individual's feelings, experiences, perceptions, thoughts and social context; knowledge is produced as a result of interaction between the interviewer and the interviewee (Kvale, 1996; Liamputtong, 2009; Marshall & Rossman, 2006). An in-depth interview is considered the best approach for accessing the lived experience of health and illness from individuals who are disempowered by their illness, not only is this approach flexible but it allows statements to be followed up with additional prompting and questions to clarify meanings immediately (Holloway & Wheeler, 2010; Low, 2007). An exploratory approach was used with a semi-structured interview technique and the use of probes were used when opportunities arose to obtain further information in a specific area. The questions were intentionally broad e.g. " how long is it since you completed chemotherapy and how have you felt since then?". This enabled the interview to be directed by the participant rather than the researcher. The questions were contained within an interview guide (Appendix B). This was used to focus the interview on the main domains being explored. The sequencing of questions varied between individual participants. The guide ensured that the researcher had collected similar types of data from all the informants (Holloway & Wheeler, 2010).

Traditionally interviews take place in a face-to-face situation, however due to the tyranny of distance for many participants who lived rurally or in outer metropolitan regions, interviews in this study were conducted by telephone. Holloway & Wheeler (2010) supported the use of telephone interviews particularly relating to the benefits of convenience, cost savings, immediacy of responses and spontaneity between the researcher and the participant. A stated disadvantage of telephone interviews has been identified as a lack of deep interaction as the interviewer and participant know each other from a distance. The telephone interview approach required the researcher to rely on well-developed communication skills as non-verbal cues were not available to

establish how comfortable the participant was with the process. Equally the participant can be unclear how much they were being listened to. Therefore, in order to facilitate this discussion the researcher gave very clear instructions at the beginning of the interview so that the participant could decline answering any questions they were not comfortable to answer. The ability to use silence as a strategy to give the participant an opportunity to reflect is very limited in a telephone interview. The researcher frequently made small noises such as "um" or "yes" to indicate she was listening and encouraged the participant to continue talking. She also clarified participants' understanding of what had been said by reflecting the key statements back to the participant for confirmation. Occasionally participants checked the researcher was being attentive by asking questions such as "Do you know what I mean?" or "Does that make sense?"

As an approach, telephone interviews versus face to face interviews have been tested with no difference found between the number and quality of responses (Garbett & McCormack, 2001; Gerrish & Lacey, 2010; Midanik & Greenfield, 2003). The telephone interview requires a similar sequenced approach as in face-to-face interviews; greeting the person on the telephone, confirming the purpose of the call and clarifying that the time was convenient. Asking if the participant was comfortable and did they have a drink was also deemed important. The introduction offered the chance to build a rapport, explain what the study was aiming to address and clarifying any questions about the process, including confidentiality. At this stage, permission to digitally record the interview was obtained and consent to partake in the study was captured on the verbal recording. The interview then commenced with an open general question which set the scene by asking how long it had been since the participant had completed chemotherapy and how they had been in general since then.

The duration of the interviews was determined by the participant and ranged from 18-42 minutes. Interviews were recorded onto compact discs that were labelled with the date and a pseudonym. Pseudonyms were also used in the transcription process to ensure confidentiality. Demographic information was collected at the beginning of the interview including the participant's gender, age, treatment length, diagnosis (see Table 1). The interviews were transcribed verbatim by an experienced individual to ensure the participants' words were preserved as accurately as possible. The researcher who listened to the recordings many times in order to become immersed in the data checked the accuracy of the transcripts. The transcriber signed a confidentiality agreement (Appendix C) prior to commencement of this process.

Data Analysis

The analysis of data followed the Grounded Theory approach of the constant comparative method of data analysis first described by Glaser and Strauss (1967). The Grounded Theory approach was followed to the descriptive level only; this included the identification of codes, and the grouping of codes into themes. This method of analysis on the data provided during interviews by the survivors and provided a descriptive framework of their experiences at this time. The analysis did not follow Grounded Theory to the theoretical level which would have analysed and processed the data with the intent of generating theory and concepts which would have explained the survivors' actions. In the descriptive method of analysis the researcher moves through the analysis comparing each incident in the data with other incidents for similarities and differences; those found to be similar are grouped together with a higher level descriptor. In this process the researcher is able to differentiate one theme from another and identify specific issues related to each theme (Corbin & Strauss, 2008; Holloway & Wheeler, 2010).

Once transcription of each interview was complete, the document was formatted with page numbers and line numbers, as well as half sheet columns to leave space for theme identification. Open coding was used first where transcripts were read line by line and descriptive coding was applied identifying information, which was considered important; the codes labelled common themes or categories. Holloway & Wheeler (2010) suggested this type of coding prevents researchers from imposing their own framework and ideas on the data. Initially 82 codes were identified (Appendix D). The codes were then grouped together with codes of similar meaning that were linked to the same phenomenon. This phase is identified as axial coding and is the step which allows the researcher to connect different codes, identified in the initial coding. This organisation of the data enabled connections to be made between a major category and sub categories (Minicheiello, Aroni, & Hays, 2008). This new group of codes was then further condensed to a smaller number of common themes. To reduce the risk of inferential leaps by a novice researcher, constant discussion and exploration occurred with research supervisors. External research supervisors assessed the credibility and consistency of the thematic developments performing independent coding and analysis. Appendix E provides an overview of the development from initial codes to a major theme; this information may be used to establish the existence of an audit trail for this research study.

Trustworthiness and Rigour

There remains both confusion and disagreement within the qualitative research field of nursing in relation to ensuring and validating the quality of a research approach. There are numerous attempts to define what constitutes a good, trustworthy qualitative study (Rolfe, 2006; Sandelowski, 1986; Sandelowski & Barroso, 2002). However despite over 25 years of debate the one thing for which there does appear to be agreement is that reaching a consensus on quality criteria is unlikely in the immediate future (Morse, Barrett, Mayan, Olson, & Spiers, 2002). A solution to providing trustworthiness (rigour) of a study may be possible if the reader is able to appraise the events, influences and actions of the researcher (Koch, 2006)

Several approaches to demonstrate rigour have been demonstrated in the literature. Guba & Lincoln (1989) framed the domains which need to be addressed as credibility, transferability and dependability. Sandelowski (1986) and Beck (1993) both determine dependability to be auditability, meaning that another researcher can follow the decision trail employed by the investigator in the study. For the purpose of this piece of research the Beck (1993) criteria to demonstrate trustworthiness in order to facilitate the critique of qualitative research was applied to highlight the steps taken by the researcher to illustrate credibility, auditability and fittingness as detailed below.

Credibility

Demonstrating credibility requires the researcher to describe the phenomenon they are exploring in accurate detail. This description needs to be instantly recognisable to people who have had that experience, or have professional expertise in that area (Beck, 1993; Cooney, 2011; Glaser & Strauss, 1967; Guba & Lincoln, 1989). This study utilised the Grounded Theory approach to the descriptive level of data analysis which should enable the findings to accurately reflect the participant's experience. In order to demonstrate the credibility of the study the researcher opted to engage experts in the field. This approach is supported by Cooney (2011) and Cutcliffe (2005) who claimed that there is more resonance in the findings if credibility is agreed upon by an expert panel rather than those who provided the raw data in the first instance.

Auditibility

By developing a comprehensive record of all methodological decisions, the researcher creates an audit trail which provides sufficient detail to enable other researchers to repeat the study in the same setting (Beck, 1993; Guba & Lincoln, 1989; Jenks, 1995). In keeping with the Grounded Theory approach the researcher used

memos in sufficient detail to provide detail of the approach taken, whilst recognising that an audit trail is not a concept commonly described in Grounded Theory. The memos provided enough detail to demonstrate how the initial 82 codes developed into the themes (Appendix F) discussed in the findings chapter and supported by quotes from the participants.

Researcher reflexivity is considered an important component of the Grounded Theory approach (Cooney, 2011; Strauss & Corbin, 1998). An awareness and a demonstration of the researcher's personal assumptions, values and biases is an important part of the discussion process. As the researcher has considerable experience and expertise it was important to hold regular and frank discussions with the research supervisors particularly during the thematic development stage of the study, to ensure that bias was not determining the direction of the findings.

Fittingness

Otherwise described as transferability, fittingness determines that the findings should be meaningful to others in similar situations (Beck, 1993; Koch, 1994; Sandelowski, 1986). In order to demonstrate this criterion, the researcher has detailed in this methodology chapter, the study context, survivor participant demographic profile and characteristics of the study setting to enable future researchers to determine the transferability of the study.

In conclusion Beck's (1993) criteria of credibility, auditability and fittingness have been utilised to demonstrate the rigour of this study undertaking the Grounded Theory approach to the descriptive level of data analysis.

Ethical Considerations

Ethical approval to conduct this study was obtained from the Committees for Conduct of Ethical Research at Sir Charles Gairdner Hospital (HREC 2008-070) and Edith Cowan University (HREC 3706).

For Phase One, each patient participant received a letter of introduction and study information sheet describing the study (Appendix A) and inviting his/her involvement. The letter of invitation provided details regarding the purpose of the study, use of information and an assurance of anonymity. Verbal consent to take part in the study and have the interviews recorded was recorded at the beginning of each interview. The letter of introduction clarified that individuals were under no obligation to be involved in the study.

For Phase Two, potential participants were sent a letter of introduction to the study that provided details about the study and the requirements for participating in this phase. A copy of the QOL-CCS and survey tools used for the testing of clarity, content and apparent internal consistency was also included. Return of the completed survey tools was accepted as implied consent.

Sources of raw data, questionnaires and computer diskettes were secured in a locked filing cabinet in the office of the researcher at the Department of Health Western Australia. Shredding of written data and deletion of electronic files will occur five years following publication of findings in accordance with item 2.1 in the Australian Code for the Responsible Conduct of Research (2007). No name related information will be used in written reports or presentations, as only group data will be presented**.** Any data collected has been used exclusively for this study and will be destroyed at the individual's request at any stage. It was also made clear to participants they could withdraw from the study at any stage without repercussions to their treatment (patient participants) or employment (chemotherapy nurses). As previously stated the transcriber was required to sign a confidentiality contract and all recordings. Pseudonyms replaced the participants' names on the transcripts. A second researcher analysed the data to provide an unbiased view and ensure a validity check.

Conclusion

In summary, this chapter has described the qualitative methodology used for Phase One of the study as well as the ethical considerations for both phases. It has illustrated the processes employed to collect and analyse the data and finally discussed the ethical considerations that occurred before and during the study. The findings of this study are outlined in Chapter Four. Direct quotes from the interview transcripts have been used to highlight emerging themes. The participants are coded Survivor 1 (S01) onwards for identification and attribution throughout the chapter A discussion of the Phase Two quantitative methodological approach and findings for the study will be presented in Chapter Five.

Chapter Four

Phase One Findings

Introduction

This chapter presents the qualitative findings from Phase One of the study. Code numbers rather than names of the cancer survivors who were interviewed have been used. Analysis of the interview transcripts exposed cancer survivors' perceptions of completing chemotherapy treatment and the period immediately following this time. Findings have been configured into two major categories according to a timeline on the treatment journey. The first being experiences as chemotherapy completes, and the second being experiences as the cancer survivor transitions onto the next stage of the journey.

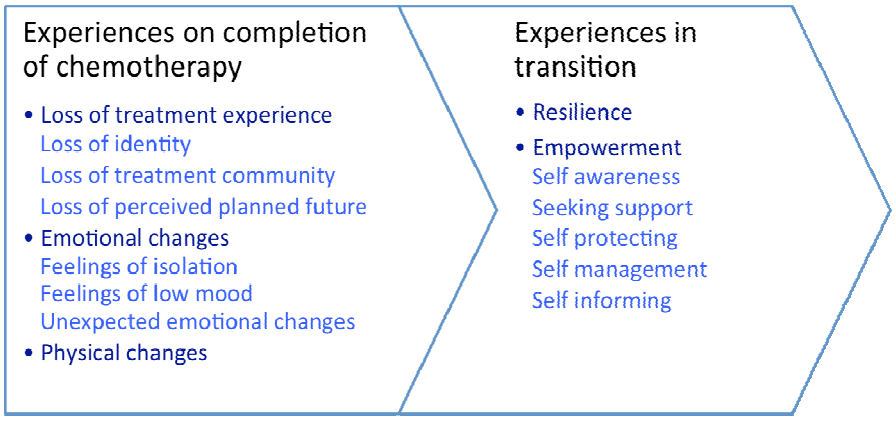

Figure 3. Illustration of findings displaying the relationships between timelines, categories and subcategories of cancer survivors' experiences.

Experiences on Completion of Chemotherapy

In this phase of the survivors' journey, experiences related to the loss of the treatment experience, emotional changes, and dealing with the physical effects of chemotherapy (NB Chemotherapy was usually referred to as "Chemo" by the participants in this study). Due to the complexity and interlinks between these categories further sub categories were generated for clarity. Loss of the treatment experience contains the following domains: loss of identity, loss of the treatment

community and loss of perceived planned future. The emotional changes category has been divided into the domains of: feelings of isolation, feelings of low mood and unexpected emotional changes.

Loss of the Treatment Experience.

Survivors who were interviewed described going through a time of change. Chemotherapy units, health care professionals, appointments for chemotherapy and blood tests had been their reality for at least six months previously. This experience occurred alongside other patients, family and friends and a community who supported and shared the treatment experience. As this episode of the treatment journey drew to a close, many adjustments were said to be required. This category was further divided to include the domains of: loss of identity, loss of the treatment community and loss of planned future; although they remain inextricably interlinked from the perspective of cancer survivors.

Loss of identity.

Loss of identity related to patients no longer understanding or feeling like they belonged and was a concept they struggled to express clearly, “It was a little bit, oh how would you explain, like it was, like it was all over and sort of a little bit lost.” (S05); and “In general [I am] feeling a bit lost in terms of where to go from here” (S04). The readjustment appeared to be in making sense of their new situation and feeling as though they no longer belonged, “I think I felt like I had landed back on Earth but in a foreign country” (S04). There was an awareness that changes had occurred either within themselves or their perceived place within society, “Just that sense of I can’t just re-join the flock again and carry on as before” (S04). The fundamental question at this time appeared to relate to finding their new place of belonging, “I am not who I was and I’m not receiving treatment, so who am I?” (S04).

These feelings appeared to be heightened by the lack of preparation at the end of treatment:

> Because when you’re sick you just deal with the sickness and you’ve got a task at hand but when all that’s over it’s just a different experience to that which I didn’t expect … I was cut completely free and that was it. (S07)

The end of treatment was perceived as a sudden event, despite most patients knowing their proposed treatment plan for months prior to completion:

> Suddenly you're an outpatient, ready or not the systems finished with you … You need an initiation back out from being a patient. It's almost like being homeless really. You're not in the cycle any more. You are not really being cared for in that sense (S04);

> Suddenly it was right you no longer need us any more so that's the end of that …because I was going through it for so long that when it came to an abrupt halt …you were a little bit lost (S11).

Loss of the treatment community.

Analysis of the interviews demonstrated that it wasn't solely the loss of structure and the task of being a patient that was being experienced, patients were also aware that they lost connections with the treatment community in the form of health care professionals and other patients: "There are a lot of nurses around that you can talk to and people who are feeling sick as well" (S07):

> There is such a sense of community I think when you are having chemo, the support you get from the staff, from other patients and from other patient's family and friends I found really quite inspiring. After the treatment, it's quite isolated. (S04)

When treatment ended, there was an awareness among participants that they didn't belong to this community any longer and a sense that they didn't know where to go next, "You can't really ring up the nurses because they are busy dealing with all the new people … the support stops and you are not sure where to go" (S03); "It's almost like being homeless really" (S04).

Another participant said:

> Well I know the girls there are really busy and they are really great and it was like "oh! Excuse me, remember me, remember you were treating me, now I'm here you don't need me anymore, I was special last week! How come I'm not special this week?" and I was probably being a bit silly but I think they just haven't got the time to fuss over, I mean I was being fussed over obviously I was having the needles and I was having the chemo and I was having all this and people were being sweet and kind and it was just lovely in that sense but suddenly it was right you are no longer need us any more so that's the end of it. (S11)

In summary, survivors valued the sense of community they experienced from fellow patients and health care professionals, they experienced an acute sense of loss in relation to the easy access to support that they received during their treatment episode.

Loss of perceived planned future.

At the end of treatment whilst all of the above mentioned losses were creating the turmoil as described, the opportunity to plan for the future appeared to be stifled by the fear of what the future might hold, "That feeling of ambivalence I think, about what I want to do in the future. What's the point if it is going to come back?" (S04).

The challenge for the survivor to deal with the depth of these feelings was indicated to be enormous:

> It [having cancer] knocks around your sense of stress and security and the confidence in the future and you just start feeling really vulnerable. And that was probably the biggest thing for me, the biggest hurdle for me to get over. (S07)

Another survivor explained:

> I really wasn't that happy for a long time afterwards to be honest – it sets you back and you sit around and you think you're going to live forever and then you realise you're going to kick the bucket and then you haven't got a chance anyway. (S08)

Some of the survivors realised this episode of chemotherapy was not automatically the end of their treatment journey, therefore the original plan they had focused on during treatment was lost and readjustment to a new plan was needed already, "It would be quite devastating to have done what I have done and then have a scan say that you didn't get a remission" (S07).Survivors also had an understanding that for them chemotherapy may not necessarily be the end of their treatment journey, this was especially problematic if the final chemotherapy date was in a state of flux:

> I think not having an end date and being up in the air deciding that I had radiation and also I had a mastectomy. So for me, chemo was sort of the end of treatment. I still had decisions to make. So there were still emotional personal things going on. So I guess what I'm saying is, I can't just say "I've finished chemo and there's no other stuff happening". Like still things in life to look at, and deal with. (S01)

The vulnerability experienced appeared to be strongly linked to the uncertainty of their prognosis, "I suppose afterwards I found that was the time I needed emotional support because that is the time I felt the most vulnerable" (S04); " I'd get quite weepy … So that I suppose knocks around your sense of stress and security and the confidence in the future and you just start feeling really vulnerable" (S07); "I think it is still in the back of my mind all the time, just worried that it is going to reappear" (S03).

One survivor recognised the fear caused her to have 'bad days':

> There are days when you wake up and think you've got through all this treatment and especially after I thought it was over and you didn't feel well on a particular day and you were thinking, God I've gone through all these months of this to no

> avail and I'm still feeling like this and you feel sorry for yourself … and you know that you have gone through all of this and are all the tests going to come back and say we're not much further ahead. (S10)

Survivors whilst not overtly discussing this fear on a regular and open basis were aware that it was an underpinning feature of their current emotional state. One survivor discussed how she prepared for the worst whilst going through treatment:

> When you are going for treatment you have a lot of time sitting in those waiting rooms and there are a lot of people who get to know each other and they talk across each other and you can't help but listen to what they have to say and your taking it all on board, I suppose how there treatments are going and all the time I was listening to things that they are doing and how much time they have off before being back again and I was actually preparing myself for all of that I was thinking oh well this is not curable or this is something that you are going to have to get on with. (S11)

In conclusion, the loss of the treatment episode of care in the survivors' journey encompassed experiences of loss of belonging and disconnect, loss of the patient role and its accompanying tasks, loss of the treatment community including ready access to support and finally a fear for their future knowing that treatment offered no guarantees.

Emotional Changes.

This category, whilst still concentrating on the end of treatment timeline, has been further divided into the sub-categories: feelings of isolation, fear for the future, feeling low in mood, and unexpected emotional changes. For all the survivors end of treatment was expressed as a time of great emotional turmoil. Survivors expressed the shock, vulnerability, isolation and fear that they experienced at this time. With a few powerful words they were able to express their complete disarray at this time, "It's really frightening. Like it's really frightening" (S01); "I'm a bit numb still" (S05). The sudden loss appeared to be such a shock to individuals, "I was cut free and that was it" (S07); "I think I found the first time I had chemo because you were used to going (for chemotherapy) when it was cut off, it was a major shock" (S03).

Feelings of isolation.

Even when expecting the feeling of isolation, the emotional turmoil was evident. This emotional turmoil encompassed a sense of isolation which strongly linked to the emotions felt to the losses or disconnects that survivors perceive experiencing, "I feel quite isolated that at the end you go 'Oh my God!' I've now got to navigate my own ship" (S04).

A survivor who had been through the journey before was prepared for this stage:

> The second time I was more prepared for it … I mean the second time my husband stopped work so I had someone here but I still felt, I don't know how to explain it because you are used to having that support and when it stops it is a lot different. (S03)

Another survivor explained how this isolation affected her, "Some days I would have a little bit of a cry to myself and feel a bit down … I would be home all alone … it was tedious sometimes" (S13).

These feelings were not solely limited to the treatment community, but also to the wider social circle of the survivor, "When you are sick and going through the treatment you've got people ringing and enquiring about you and that sort of thing and now that doesn't sort of happen." (S05). Conversely, another survivor described how her cancer diagnosis caused friends to avoid her:

> Some friends don't know how to react, so there are some friends who I haven't seen in ages … it's almost like they wait for you to be well again so they can cope and so you just have to understand that it where people are at. (S10)

Survivors felt that others did not understand what they were going through which enhanced their feelings of isolation and vulnerability, "Sometimes I'd feel as though nobody cared what I was going through" (S09); the lack of understanding is further compounded by the feeling of isolation:

> I would have thought that someone popping in to see how you were going probably would have unleashed an avalanche of tears if they had known what I had been through … I was too sick to be out and about. And you get a bit house bound as well so that didn't help. (S07)

In summary, survivors were experiencing an array of emotions whilst feeling generally isolated, this was compounded by a perceived lack of acknowledgment from others about their tumultuous experience.

Feelings of low mood.

Survivors expressed a range of negative emotions to demonstrate the low mood they experienced at the end of treatment, some felt too ill to feel any emotion at all, "You don't feel anything …You are just too sick to complain, you just want it to end. Just get through the next thing you had to get through, the next day or the next hour" (S07).

One survivor expressed feeling extremely low and suicidal on occasions towards the end of chemotherapy (S01), others expressed not only the depth of feeling

but also the duration of this emotional state, feeling frightened (S01); “On the inside I didn’t feel particularly great at all. I felt quite deflated” (S04). Another said, “It was what made me depressed or I would bounce around … generally sort of get down and sort of like a lot of people get depressed … it certainly affected all that year … I really wasn’t that happy for a long time afterwards to be honest” (S08).

One survivor described the unpredictable nature of recovery after treatment as particularly detrimental to her emotional health:

> I think it was the unpredictability of it that made it difficult, you know it’s not like anything you had before, when you have the flu and you start to get better and you think ok I’m on a roll, but with this you felt like it was one step forward and one step back. (S10)

Even when survivors were excited and positive about the prospect of finishing chemotherapy, emotional swings occurred:

> Initially I was quite excited to finish chemo and really sort of looking forward to that wishful thinking, you know all the things that you are going to do … And I was actually really surprised at how depressed I got and how emotional I became, probably about a month after treatment. (S04)

Survivors had clearly encountered many emotional changes along the journey to this point; they often appeared to have unanticipated emotions.

Unexpected emotional changes.

Survivors described events or people who upset them which appeared to take them by surprise:

> Psychologically, some unforeseen difficult and upsetting moments, which I didn’t anticipate. You know, emotionally fragile sometimes. A bit like post-traumatic stress, you know … I would start talking about my experience to somebody or I would see something on T.V which was about cancer or needles or something and I would get a bit upset and then I would need to have a real bawl and that took me by surprise … I was quick to get upset a few times with things and just beautiful things as well you know, gifts and people doing nice things for you. I’d cry a lot. Kindness made me cry a lot. (S07)

Survivors own expectations also contributed to the emotional turmoil experienced:

> I sort of expected myself to feel full of life and feel absolutely fabulous. But I didn’t … And the pressure to be, something new or, yeah there is a bit of pressure. Just got to be really happy. And every day is fabulous. (S04)

The desire to protect loved ones placed an additional burden on survivors:

> My sisters would ring each day but there's a need to protect the people that you love as well you know, but I didn't want to discuss what I was going through with them because they had gone through the journey with me already. So the more together you are the more they can relax and let go, I just wanted them to relax a bit. So I felt like I wore the emotional thing pretty deep. (S07)

External pressures such as financial responsibilities also contributed to the emotional burden:

> Well, I couldn't get sick leave … Because I don't own a house or anything like that but I've been saving pretty hard to try to get something like that. So because I had liquid assets they didn't find me eligible … So that, that's really stressful when you're a single woman who has been diagnosed, yeah, it's really stressful. (S01)

In conclusion, the completion of chemotherapy treatment is an emotionally tumultuous time; survivors expressed a myriad of mostly negative emotions including fears, isolation, low moods and unpredictable emotional behaviour. Coupled with the feeling of being disconnected and loss of structure from the treatment experience, this was clearly a very difficult all encompassing experience to navigate through.

Physical Changes.

On completion of chemotherapy physical changes are common, some transient, and some permanent. This section explores the physical effects experienced at the end of treatment. All of the survivors were dealing with physical changes, which were impacting on their day to day lives and emotions at the end of treatment. The range included unique complaints such as:

> The muscle wasting, fatigue, my stomach was sensitive to certain foods so I had aversions to certain foods, so I under ate for a while because I did have a perforated duodenum so I'm not sure if it was because of that or the drugs or both. I felt a slight passing nausea which made me not want to eat certain things. (S07)

Another survivor said:

> Okay except I'm having a lot of trouble when my body gets warm. I get these terrible itching all over me like ants crawling all over me . . . From the top of my head … its not like an ordinary itch, its like something crawling all over your body, you know, like ants. (S09)

Some physical changes were described by several survivors and included: - constipation, nausea, weight loss, swollen legs, hallucinations caused by drugs, joint stiffness, sore mouth, taste changes and memory impairment.

Hair loss was another common physical change experienced by several of the survivors. In addition, when hair had regrown the change in body image had a significant impact on one survivor:

> I have had a little cry, I look so different … I used to have long hair right the way down my back and it got all knotted with the chemotherapy and I had to shave it all off, I have white hair now … I look so different, it's a different ball game…I was a pretty little girl before now I look like a business tycoon. (S13)

The overwhelming physical change discussed was fatigue which was expressed as physical weakness and lack of energy, "Fatigue was the big one … physically I felt quite tired" (S04); "I think I just had a physical depression. I don't think I was mentally depressed, I think my body was depressed" (S07); "Tiredness, definitely … when I finished I was tired for quite a while" (S09). The awareness of fatigue was related to how much they were able to do:

> I've still been tired. It's better now though that the chemo has stopped. When I was going through the chemo, I was extremely tired but it is getting better, slowly … I was in bed at 7:30 or 8 o'clock every night. So that's not normal no. (S03)

> Mentally, I want to do things but physically I can do some small things but it gets very tiring because I have lost so much muscle and condition and God knows what else. (S14)

> No energy, not being able to get out of bed and each day was the same as the last, that's the awful thing, you think tomorrow you'll feel a bit better… I thought I was getting better and then I would have a day where I was completely without energy and completely exhausted. (S10)

The fatigue prevented survivors from working, "I was just obliterated so I stopped and I haven't done any work since then" (S01). Or the fatigue caused them to modify their work hours in a staged way, "I was working full time and then I went part time because I had to have a hysterectomy. So I had the six weeks off, I went back part time and then when my chemo changed I was too tired" (S04); "I can't work, I'm not physically strong enough to work yet, but luckily I have income protection" (S11). Survivors identified that doing simple things, such as walking short distances was challenging, "Well I started off just trying to walk to the corner because I had lost all my muscle strength. I was all floppy. Then I started walking around the block slowly, holding on to somebody" (S07).

Especially in comparison to pre treatment energy levels:

> I just have to pace myself, so it's like being old, you know, when you are continually pacing yourself and thinking no I can't do too much … I was working 10 hour days going out at night and I was pretty much doing what I wanted. (S10)

"I'm simply not as strong as I would like to be … I still have to work on doing a bit of exercise and more walking". (S12)

The frustration of having time to do things but not the energy was another challenge to survivors at the end of treatment:

> What I've noticed is that when people are getting treatment often they don't have the energy or time or resources to participate in anything else but after treatment you suddenly have all this time and you are not well enough to go back into your old life or your new life. (S04)

Fatigue was identified as a significant contributing factor to the challenge of remembering:

> I had a notebook and I would take that with me. 'Cause it's really hard when you're emotionally in there and you're so tired, to remember it all, so I didn't need to get myself to remember it off the top of my head. I always and I still do it, still mentally list stuff. (S01)

Survivors were aware that they weren't remembering important information that they wanted to retain: "I often felt like I knew that I couldn't get my brain to the places where it needed to go. It was just like my head was murky" (S10)

> Because you can't remember. If you are sick, then your memory is shot to pieces and if you are tired you are not absorbing information. So you know you have got to go see a doctor in four weeks but you can get easily confused **…** It hasn't been that great and I haven't really recovered that well and since the chemo has stopped there. (S07)

Fatigue had a strong negative effect on emotions and feelings:

> You are really weak and you want to look like you've got things together but I just drifted around and cried a bit because I just got so fed up trying to haul my body out of bed and you feel so weak. You feel weak like a kitten … when you get up you collapse … And that makes you feel so pathetic but then you feel pathetic emotionally….I was so low on energy that I just didn't feel anything to intensely it was just like a depression so I didn't feel anything that intensely but once I started to get better and my energy went up my emotions were more intense so it upsets you more. (S07)

However a positive effect was noted as fatigue improved, survivors were aware of even slight improvements in fatigue levels, "Physically, you know where you are physically

weak in the first few weeks. And then you get your energy back which is such a boost to your mood to get some energy back" (S07). Another said, "I have a reasonable level of energy, I can walk a little bit faster. Like last week I was aware I went to the garbage bin, and I did it without feeling like I needed to collapse was great" (S01).

The relationship between fatigue and level of mood is so intertwined it was said to be impossible to consider one without the other, a change in one has a corresponding effect on the other, "There's no way to disconnect the impact that physical exhaustion has on your spirit and emotion" (S01). Only one survivor (S11) did not have any issues with fatigue and described herself as having "absolutely bounds of energy" since completing treatment in comparison to feeling continually tired whilst having chemotherapy. Interestingly this survivor displayed positive self talk from diagnosis onwards:

> My conclusion was at the very beginning that my life would not be worth living if I let this get to me, that's how it would be, if I couldn't live my life as best I could and let this get to me then life would just be unbearable as far as I'm concerned. So I just incorporated it. (S11)

Survivors recognised that some changes were going to be long term; one survivor whose cancer had affected his back discussed the emotional toll of the physical change:

> I would like to have been how I was before …well that may happen but not to the same extent, I find it pretty boring just sitting at home, because I'm limited in the fact that I can't do a lot of exercise, I can't do any gardening or tinkering in the shed … I know myself that certain things won't happen that way again, you know the body's damaged it's never going to repair itself to the full extent … I may or may not have to wear a back brace for the rest of my life. (S14)

Over half the survivors experienced an unplanned/unexpected hospital admission, because they were so physically unwell at the end of chemotherapy generally due to infections. Survivors described being extremely unwell due to infections, adverse treatment events and allergic reactions, which for the individual were all encompassing and for some resulted in several weeks in hospital after the completion of treatment. Whilst the survivors were still connected with the treatment community they were not well enough to begin their transition onwards, physically they remained dependant on their hospital teams and psychologically they had not begun to experience the losses related to treatment end.

In summary, the time immediately after completion of chemotherapy was filled with experiences of loss in social, spiritual, psychological and physical domains. Social domains include the loss of relationships with the treating teams and fellow patients,

spiritually, self perception has often altered with a loss of self identity and an increased awareness that they have changed as a result of their journey; with a resulting need to revaluate their future. Psychologically survivors displayed a range of altered emotions including shock, vulnerability, isolation and fear. Physical changes were evident and common across all survivors, although there was variation across the range of physical changes; fatigue was common and compounding.

Experiences in Transition

For the purpose of this study, transition is defined as the process or period in which a person with a cancer diagnosis undergoes a change and passes from one stage or state to another. Cancer survivors often refer to their coping skills or ability to cope. In this study to cope is considered to represent the ability to deal successfully with a difficult problem or situation.

From the evidence provided thus far, it was clear that at the end of treatment survivors faced a series of personal challenges they felt physically unwell, emotionally in turmoil, socially disconnected with a lack of recognition of their suffering from others, and were questioning their future. Analysis of the interviews demonstrated that as survivors began to improve physically particularly from symptoms of fatigue, they also began the process of transition towards their new future. The process of transition involved dealing with the highlighted personal challenges whilst finding new balance, working towards their future goals and achieving a normal life.

As the all-encompassing effects of physical fatigue begin to recede, the intrinsic characteristics of human nature took over. This section has been divided into two categories resilience and empowerment; in the interests of clarity the empowerment section has been further sub categorised into self-awareness, self-protecting, self informing and self-management.

Resilience

As physical strength of the survivors began to return, their personal resolve also began to return. During the interviews survivors articulated a range of personal values and beliefs which helped them to cope with the process of transition, “I just live life as normal” (S02); “I mean my attitude is that I not going lie down and die” (S08). Another survivor explained:

> I’m quite a positive person I suppose and that seems to make a difference …Yeah, I suppose I am quite blessed as a person my observation is that everyone in life

> gets an opportunity to go through a crisis and that it is how you handle things rather than what is happening to you. Attitude is everything. (S04)

Another said, "I think . . . I know, I promised myself that no matter what happens . . . if I'm to die from this or if it came back or anything like that I would be okay if I make sure I'm true to myself" (S01). This survivor describes what the impact would be for her if she was not positive:

> I can't let this affect me … I can't let this get to me … I didn't even voice it, I just thought I'm going to do this and get through this as a part of my day or week and incorporate it into that … I can't imagine not being positive, that's me, it would be just awful to live negatively, I couldn't love that way, it's not how I live, life would not be worth living, If I had to live that way , it would be too miserable, far too miserable. (S11)

Survivors appeared to accept that this was their personal challenge:

> I think just accept what's what. You can't choose what is sent to you, can you? … You can choose the way you accept it. And I think most people can with a bit of a push, looking at it in the right light rather than the 'woe is me' attitude which I know a lot do have. There is nothing you can do about it. (S06)

Another survivor highlighted her personal balance:

> Where I am emotionally and mentally, that has been the biggest thing that I've protected. That doesn't mean that I haven't physically tried to take care of myself … a couple of months ago I pushed a little bit more than the average person would. I wasn't meaning to. I've always been like that as a person though, so there's some things you just can't straight away turn an off switch on … I'm not going to blame myself around that. I do things; I'm a do things person. (S01)

One survivor described how she was surprised to find the inner strength she had, "I don't know where that strength came from, it must have been the Lord, I don't know where I got the strength, I was really strong … it changed my whole life … I think I feel more confident now than when I started (S13).

Survivors displayed acceptance as they worked through the transition phase, that this is a long term journey from which they may not fully recover:

> Be prepared for the long haul, be prepared to be inconvenienced, it's your life, if you want it you've got to put up with it and follow what is told to you and don't expect miracles overnight … it's about five years before you know how things are going but at the moment you are in for the long haul … it's a long road to go before I get back to somewhere that I was before, if not totally back to where I was. (S14)

However being accepting did not mean giving in, “Well I’m not about to sit at home and think ‘I wish I had done this because a week down the track and my feet aren’t any better’” (S06). Survivors drew on their own personal resolve and coping skills during this period, “Something, just within myself has come up at a time when I needed it” (S01); “I just dealt with it by myself” (S03); “I’ll get through it like I normally do and that’s it” (S04); “I worked my way through it … I was down in the doldrums for a while so I worked my way through it” (S08).

Survivors displayed differing views on emotional resilience from firm views about anxiety and depression:

> No I don’t believe in that [Depression] sorry … Well the whole thing is if you let things get you down, and they do at times, like when your husband passes away. You don’t spend 42 years with someone and it doesn’t get to you and that took quite a few years to get over, I’ll admit. But when I think health is concerned, how can I put it? We were brought up to always look after our health so we were a healthy family … we are all of a similar outlook on life. Get on with it. (S06)

To actively managing potential emotional issues:

> I’ve been pretty proud of myself mentally; I wasn’t pushing myself to be positive, feeling what I was feeling. Ever since I was diagnosed I’ve been going to see a breast cancer counsellor and getting help regularly, it just helps me to process and get through it … I don’t want to be pushing down anything, stuff that I haven’t resolved. (S01)

There was also an awareness of the need to be kind to themselves:

> Be kind to yourself and take it slowly, don’t expect too much, you know it is going to go up and down and you are going to have bad days and sad days …you just have to pace yourself and the people around you have to understand that and be good to you too. (S10)

From the analysis it was clear that resilience is a complex web of personal values, attitudes and attributes that each person brings to their personal cancer journey. The importance of acceptance, understanding this is their challenge and maintaining a positive attitude appeared highly important to survivors. The resilient streak displayed here was not evident at the end of treatment when physical fatigue dominated the person’s outlook. It could therefore be concluded that human resilience changed a person’s focus as the process towards transition began.

Empowerment

Once survivors began to articulate and display their resilient spirit, the next step in the transition process was becoming self-empowered. This was displayed in a series of complex strategies which contributed to their self-empowerment and ability to take control of their destiny towards achieving their personal goal. The action of empowerment was further divided into four categories of actions: self-awareness, seeking support, self-protection, self informing and self-management were all found to be important aspects related to empowerment of the survivor.

Self-awareness.

Survivors were aware they had maintained a mostly passive role during treatment and that transition required a different behaviour from them:

> You kind of sit around and take what you need to take during the treatment but when you get better you don't want to do that anymore. You want to be a bit more pro-active and less passive. When you are sick you are happy just to lie there and let anyone jab anything in you, you know? But that is not suitable for when you are well. You need to be a bit more self-determining about your life. I could have gone six months without any follow up treatment if I hadn't followed it up. (S07)

Whilst survivors were able to take control of limited aspects of their treatment plan, the following survivor's emphasis has shifted from her need for treatment to her need for rest, … "and then I said, actually I'm due to start radiation in a couple of weeks … look, no, I need to go and have this holiday rather than change the dates again" (S01). This same survivor identified that she had personally changed and learnt the skill of assertion in order to meet her own needs:

> I did get through this, and I've learnt so much about myself, and I've learnt so much about, my ability to be assertive, my ability to sit in a doctor's office for once and know what I want and actually say to him "no, look what you've just said to me has made me feel incredibly anxious. (S01)

Survivors' ability to self manage their future included testing this control by rebelling against normal expected care, "Ironically, I started smoking, heavier than I have done for years and years and years in January. There was that bit of me that wanted to be really rebellious and you know I can and will and who is going stop me? … Almost a bit defiant" (S04).

However this individual soon reverted back to self-management processes that would support her goal of good physical health:

> I've just given up this week so I am feeling very virtuous and it is kind of that sense of I suppose that smoking for me is a coping mechanism. It's one of those things that I go to. Not healthily, I know that but old behaviour that dictates how I do feel about myself. I'm making some choices out of caring for myself rather than being rebellious. And I am sure it is part of this coming back out, actually being able to function for more than an hour at a time. (S04)

The ability to foster their personal resilience and take control of their destiny was not developed in isolation, for some recognition and support from others was an important enabler:

> I'm a bit angry now and I've identified that I have become a bit crabby and angry and my boss has said that 'I think you have spent so long being passive and accepting of everything that has been happening to you that now you've got your strength back you have become intolerant of things you don't want to put up with' making me a bit crabby. And I've got a lot of complaints about life at the moment! I don't like being like that so I have some issues … I'm always having to apologise to people for being so grumpy. (S07)

Another survivor identified:

> And also, he said to me "Ask lots of questions, ask lots of questions. You don't have to be a bitch about it, ask lots of questions. Because as soon as you start asking lots of questions they're going to give you more information, and they've realised you're interested."… he gave me this great pep talk, and it was really great. And he also gave me someone who is not your traditional Western medicine…. I think, it's not that I don't trust Western medicine but I just didn't want to hand myself over and go "what did you think?" (S01)

Seeking support.

Survivors were adept at finding emotional support that suited their needs, they displayed self awareness of whom they chose to reveal their inner emotions too, often rationally protecting their family and therefore indirectly themselves:

> I could talk to them [breast care nurses] in a way about stuff that maybe my family couldn't quite hear, because they might freak out a little bit. But I could just say life's really crap, I'm feeling a bit suicidal, or whatever was going on, you know? (S01)

Survivors protected themselves from the consequences of sharing their emotions, they were acutely aware of the impact of others and their need to create distance in order to reduce their own anxieties and emotional needs, one survivor chose to stay in the WA for treatment even though her family was on the east coast:

> But they're very stressful, emotionally (my family). So it was kind of good to have the distance, even though physically it was something your family could do, emotionally it was easier … I didn't need to protect them, this has been a big

> exercise for me learning to put myself first, emotionally and part of my family issue is that emotionally it would have been all about other people first … So when I'm saying protect I'm really meaning that I disclosed or didn't disclose things to protect myself, my emotions. (S01)

Survivors often sought professional emotional support to enable self control of their emotional health, their relationships and their personal goals:

> Ever since I got diagnosed I've been going to the breast cancer counsellor, and getting help quite regularly, it just helps me process and get through it …I don't want to be pushing down anything, stuff that I haven't resolved (S01);

> "I went to see a psychologist at the same time to kind of pre-empt that transition back into non-treatment" (S04); "I think it really helps to have someone else to listen to what you say and weigh it up a little bit and have some ideas to help" (S13).

Self-protecting.

Self-protecting proved to be another important empowerment strategy, once survivors had started to gather their resilience and take control of their destiny, there was a need to maintain a focus on a positive future even if there was a continual background fear for their future. Survivors were particularly focused on maintaining a positive outlook and approach in order to do this they avoided negative environments, situations and people as much as possible:

> Because I joined the cancer support group and that was good but it was also with people that were sort of the cancer has recurred the second, third and fourth time and I feel like I am in a really different place from them (S04).

Survivors were aware of the impact of others emotions on themselves and could focus clearly on self protecting distancing strategies:

> There is a lady who is from down this way as well and she is a few months behind me and she was a little bit negative and she was struggling mentally coping with the diagnosis and that type of thing and talking about death and that sort of stuff and I found that a bit hard to handle. It brought me down talking to her. But I'd always try to be positive about it. (S05)

Survivors were able to set boundaries around their information needs whilst managing their self-protection tactics:

> It really rattled my cage that flyer because I had been so motivated and I had been so positive about getting back and getting on top of things and feeling so great and I just felt that was a real crushing blow and I couldn't let that go without saying something … So if I could continue to receive information that wasn't anything to do with death and funerals I'd be happy to receive it. (S07)

Survivors used humour to hide their true feelings, either to protect family and friends:

> I'd get quite weepy but then I just laughed and told them not to take any notice, I do this a lot … there's a need to protect the people that you love as well … the more together you are the more they can relax and let go and I just wanted them to relax a bit. (S07)

Survivors also felt the need to appear in control, "you want to look like you've got things together" (S07); "I would crack jokes about it but I wasn't that happy about things" (S08). Survivors were aware of their self image to others and engaged close acquaintances to help manage these connections:

> Protect yourself from well wishers because you'll have to say your story over and over again and you are tired and exhausted so you don't want to have to repeat the same thing over and over again and upset them more because you sound so tired and weak they can hear it in your voice … Have someone to protect you. My mum stood between me and phone calls a bit, which was good. (S07)

In order to maintain her positive energy one survivor described her avoidance of dwelling on the past:

> … I try not to look back on it either, why don't I look back? I don't look back because that's past and I very rarely look back in the past anyway you know so I again it is a part of me and a part of the way I think so I guess it is forward always with me. (S11)

Another participant avoided the present issues in both her actions and how she thought about herself:

> I haven't even marked it on the calendar, I suppose a bit of an avoidance thing, I don't dwell on it, I hedge around it all the time, I don't let it get me down, I don't think I'm a cancer patient, I never think that … but I suppose I am though. (S13)

Distraction was also found to be a useful self-protection strategy; by keeping busy so there wasn't time to think about the particular areas of concern, "My thing would be to keep busy and you know I guess, don't let it get you down and find something to do that you can do without thinking about it" (S08).

Self-management strategies.

Survivors' personal beliefs were indicated as having a strong impact on how they developed strategies to manage the physical and psychological impacts of cancer and the chemotherapy treatment during this transition period. Physically survivors were able to monitor and modify their activity to support their recovery from fatigue and

their gradual physical improvement, by setting goals and targets and testing their abilities, their choices included who they wished to get support from and what help they wanted to aid recovery:

> Obviously not one hundred per cent, but relative to chemo I'm …waking up feeling reasonably awesome, and everything …I have a reasonable level of energy, I can walk a little bit faster. Like last week I was aware I went to the garbage bin, and I did it without feeling like I needed to collapse was great. So it's just really simple things, like, I've got more energy, I wouldn't say I've even maybe seventy per cent. But relative to how crap I was in chemo it feels like a hundred and fifty per cent. (S01)

Survivors were aware of different interactions in public, alongside the smallest physical improvements, "I really noticed that physically I was getting stronger. I started Pilates and making a commitment and now my hair has come back people don't automatically look at you and assume"(S04); "if its physical I get quite stiff, but I'm getting stronger and stronger in terms of fitness" (S08).

Survivors were adept at managing their lifestyle to their slowly improving fatigue levels; this appeared to be an intuitive approach rather than a strategically planned action, "You can't force anything, if your body doesn't want to do it, there is not much you can do" (S12).

Survivors discussed how they slowly adapted but constantly reassessed their ability and progress:

> I used to potter a little bit … Then I'd sit down and have a rest and then get up and do something else and sit down and have a rest …When I go food shopping, my husband always used to, we always used to go together . . . But I am starting to go a little bit on my own now. (S05)

> Well I started … just trying to walk to the corner because I had lost all my muscle strength. I was all floppy. Then I started walking around the block slowly, holding on to somebody and then I got a treadmill and so when I started back at work I started getting on the treadmill and then I started to do 30 minutes on 6 kilometres per hour … I was full time and exercising 5 mornings as week, on the bike once a week. Now I do it on the weekends as well. I just found the contrast between bad and good and did it when I felt good. (S07)

For other physical side effects of chemotherapy, some of which started during treatment and continued into the transition phase, survivors used a range of approaches, often dependent upon previous coping skills and strategies. Self-management of side

effects was demonstrated for many physical symptoms such as dealing with the problem of constipation, this survivor had a goal which they monitored, if they didn't achieve this, then they used prior knowledge to rectify the situation:

> If I don't go to the toilet one day then I'll take some prunes or have some oats or something the next day and if that doesn't work then I'll take the pill. I've never had to in my life before but when they say this can happen well I look after it so it doesn't happen. (S06)

Another survivor talked about how he self-managed insomnia, again he had a goal, monitoring and a solution in process to deal with this based on his own knowledge:

> I found the solution to my lack of sleep, the easiest way was listening to tapes if you watch TV or read a book you fall asleep then I'd wake up and I was worse. This way I fall asleep with the ear phones, they drop out and I don't hear anything anymore. (S08)

All of the above actions are based on previous knowledge and expectations, individuals have their own acceptable goals which they monitor and take action to rectify as needed. Survivors throughout the interviews described a range of areas where knowledge deficit hindered their ability to self-manage and cope with their physical and emotional recovery from chemotherapy and their transition onwards. This tended to be in domains that were previously unchartered by the patient, in other words they had no prior experience and knowledge on which to draw to rectify the situation. For example at the end of treatment one survivor said:

> I just felt like a malingerer, laying around, not doing anything and if someone had of said then "Most people take this long and you've had this happen and you are still doing really well. You don't need to rush." That sort of reassurance that I am doing normally or am I really sick or am I doing great? That would be good feedback. (S07)

As the survivor above couldn't reconcile prior knowledge and physical ability, she experienced a negative impact and perception of herself, she recognised that had she had the knowledge this would not have been the case. Whereas another survivor (from the quote below) felt more positively because she had a 'cause' or knowledge of why they were encountering this experience. She was able to accept and self-manage the period of fatigue. It is therefore evident that knowledge helped survivors to find personally acceptable causes for negative experiences:

> … just in part of my brain, from the conversation I'd had with people, there was just a seed that was planted that said, you might feel a bit down and know that it's just the drugs … It's just enough there to help me go, okay, to separate me and the process … It's really, really important, because otherwise it's like self-identifying as always down or always feeling fatigue. And just going, now hang on, there's a separation between who I am and what I'm capable of and the fact that I'm just going through this really debilitating, depressing phase (S01)

Survivors indicated that hearing about the physical experiences of other survivors helped them to understand, the information or 'lived experience' of other survivors helped them to understand and fill in a prior knowledge gap:

> One of the things that I understand now from talking to other cancer survivors that I didn't know is like body stiffness. Like getting pains in my hands in the middle of the night. It shifts around my body like in my hips which talking to other people post treatment they've all said "Oh yes. That's normal". (S04)

> And that might sound funny but if she's gone through it and you hear someone else say that it makes you go, "oh, okay I've finished chemo but it's going to take a while for my body to get over this". (S01)

Survivors who felt unable to self manage their experiences identified limitations in the new information they were given which limited their ability to prepare and instead encountered negative experiences and undue anxieties:

> Right from the word go I had been very annoyed that they give you an overview of what is going to happen … you read the documents on it and that gives you some of the side effects, had they have been clearer I would have been much more prepared … I know the effects are different for different people but if you've got that little bit of information you know what to expect … instead of thinking something has gone wrong. (S14)

This survivor felt that the limited explanations compromised his ability to self-care, "They don't explain the blood test very well … I had to ask for the blood test results … nobody told me whether this should or should not be a worry. If I had the blood count or the cell count then I would have responded properly" (S02).

Survivors were able to identify areas of knowledge deficit that would benefit from information and enhance their ability to understand and self manage situations. Survivors wanted to understand the impact that chemotherapy had on their body particularly the long term impacts of the drugs in their system:

> I would find it really useful to have some guidance around after chemo has done its job; I suppose I have this image of wanting to be able to clean my body out. And whether it does make any difference like a detox or a cleanse or that kind of thing. Maybe it's psychological but it's like I feel I have got residual chemicals in me that maybe are creating problems now. (S04)

Survivors were aware of their limited knowledge in regards to both treatment planning and how little they understood from their actual treatment. They sensed the fragmentation of health information relating to their care. This enhanced their anxiety about future care and the need to gain knowledge and take control, "I just sort of went with the flow and half the time I didn't even know what was going on" (S05); "They don't explain … They look at the results and they don't tell the patient very much … I need to know but the chemo guys don't tell you anything" (S02).

> It's hard because you get confused about everything and then the medical system and the doctors are using computers and whatever and the medical records and you go in there and you go to see the doctor/specialist and it is totally discontinuous and no one has got it … so it's very hard I think for them to know your allergies and how you are with chemo. (S08)

In the transition phase survivors expressed significant information gaps about plans for their future care and not knowing if the treatment had been beneficial, this prevented their ability to take control and self manage: "I got a CAT scan, I did it a month ago … they haven't told me what they are going to do yet" (S02).

Survivors continued to feel lost and had information gaps relating to support they could access: "… the support stops and you are not sure where to go" (S03), " in general feeling I'm a bit lost in terms of where to go from here" (S04). Knowledge was clearly an important commodity for survivors, with appropriate knowledge and their prior learnt behaviour survivors could take control by being assertive. If the survivor encounters an experience they have dealt with before they can draw on prior learning to forge a way through the issue no matter how arduous, even whilst still experiencing significant fatigue one survivor recounts how she managed to achieve antibiotic therapy at home:

> They sent me home with some antibiotics … and I had an allergic reaction to the oral antibiotics and they wanted me to get back in the car and go back up to Perth and I knew what the problem was so I chucked them (the antibiotics) in the bin and I said I am not going back up to Perth … I said it's ridiculous, we've got trained staff here in Bunbury, I need a new script, I need a different antibiotic and so I rang up my doctor and I rang up the haematology centre and I made them talk to each other and I can get a blood test down here and I can get a doctor to prescribe an appropriate drug down here. I don't need to travel 200km back to

> Perth and neither of them were happy. My GP wasn't too happy but the haematologist was quite co-operative in the end. (S07)

And how she managed her planned follow up care:

> In December I had to remind him (the doctor) about that (missed PET scan) and then by the time we had booked another one that was six months. The doctors plan was that I was to have Mabthera (a monoclonal antibody given IV after acute treatment for a period of several months) and that hadn't been initiated either I had to tell the girls that I needed that at the next appointment as well. I felt like I was managing myself completely without even a written plan from the doctor and then I had to double check and ask "Can you double check that I have done the right thing?" In my March appointment I booked myself to have Mabthera. (S07)

And how she clarified information about her treatment in order to manage future care episodes, realising that this may be important knowledge to have:

> I mean I didn't know what drug I'd had, I don't know if I've had the swine flu injection or not because I got treated as a swine flu patient at one point. I don't know what went on; it was all a bit of a blur. I just had to cross my fingers and hope they know what they are doing. I really should have some idea of what I have had. And I had to ring up and find out what the drug was that was making me sick four weeks ago because I thought 'I need to know what that antibiotic is that is making me sick. I've got no idea. (S07)

One survivor attempted to control the process so that she did not have to endure the period of awaiting results, this sadly did not come to fruition, "I asked if it was possible to get results by email rather than wait six weeks for an appointment, that was arranged and teed up and I never got it. And I didn't get onto it, I waited for the appointment, you know the resignation thing" (S07).

Knowledge also enabled the survivors to set realistic expectations, a central action to all the survivors' behaviour in coping throughout their journey whether it was immediately post treatment or in the transition phase as they started to recover from the impacts of chemotherapy was that of planning. Whilst on chemotherapy planning appeared wishful:

> Initially I was quite excited to finish chemo and really sort of looking forward to that wishful thinking, you know all the things that you are going to do. So I suppose having had chemo I spent a lot of time thinking of the resolutions if you like of the things I was going to do. (S04)

As survivors moved into the transition phase their planning became more hopeful and they started to set new goals which were solely focused on their physical abilities such as, actively thinking about employment:

> So now I am kind of looking at what am I going to do for a living now? … At one level I would have loved to have gone 'okay, I'll pack myself off to uni' or travel but at the moment I just want to work or see if some of this art therapy takes off. (S04)

> For others the desire was to return to normality, "It's best to certainly struggle on and that's it. People say ah well, it's all free go and live, run around see the world, for me it's just go back and live the way you always did" (S08). For some having things to look forward to in the short term was important, "I had a holiday at my sisters for nine days" (S13).

For those who had returned to work planning centered on maintaining normality and honoring work commitments:

> I've been very protective of my job and I haven't wanted to take any time off that I don't have to take off. CAT scans and doctors appointments I haven't been able to avoid but other than that I've been very reluctant to take time off … I did offer to be the co-coordinator of an after hours support group which was never taken up from my local leukaemia foundation support service co-coordinator … I cant take three hours off in the middle of the day, there must be other people like me who are back at work and integrating back into their life who might want to meet in the evening. (S07)

Finding work life balance was also important to survivors in the planning stage:

> So I've come to the conclusion that I'll at least get some part time work doing something to pay the bills and then the opportunities for me to do what I think is really important in my community … and I've also got to look at my own stress and energy levels and find a balance. (S04)

> I can't go back to fulltime work yet, I'm not up to that. But I'm wanting to go back two days, then three days, then maybe up to four days, I'll see how I go. (S01)

Survivors had obviously gone through the treatment and transition journey hoping that their cancer was cured; their initial plans would always centre on this premise even if the fear of recurrence was in the back of their mind. For those survivors who hadn't achieved the desired outcome from this round of treatment, the planning needed to start again and information was said to be vital in helping to reset realistic expectations:

> When the cancer came back the second time I found it more difficult to deal with than the first time. Because you think that with the first one because you beat it you aren't going to get it again. So when it comes back I think that it creates more anxiety for people. (S03)

> I didn't get remission out of my treatment. I found that out in March … So I'm feeling a little bit tired and emotionally I feel I need to spend more time thinking about things. And I just feel a bit rushed working full time and I want to contemplate my navel a little bit. So I'm feeling a little bit crabby now … it would be good if somebody had followed up that by saying if the result wasn't good then where to now instead of waiting three months for the next scan to see if it has grown. (S07)

Or in the longer term:

> It's given me a new lease in life, I want to train to be an enrolled nurse, I want to go travelling and I want to go to India and see the leprosy mission and see how they work with lepers, I want to go into nursing or OT (Occupational Therapist), It's always something I wanted to do. (S13)

Self-informing.

Where knowledge wasn't easily available survivors were incredibly adept at self informing. A range of skills throughout the interviews were displayed, survivors were acutely aware when they did not receive enough or timely information, analysis of the interviews displayed a range of information gathering strategies including non-government organisations such as breast cancer foundation (S01) and Cancer Council (S03) to other health care professionals not directly related to the chemotherapy experience i.e. chiropractor (S01), liver surgeon (S02). One survivor actively avoided written information believing that it planted ideas, she chose to gain her information by observing friends and family who had also been treated with chemotherapy:

> I'm not a great one for reading all that sort of stuff. I'm more inclined to … You know how we just discussed how many people were sick, I think if you know that more than half of the people that go in and have chemo are crook with the medication. To me that would make you think that you are expecting it so you would be down anyway so that may help that happen … my husband had bowel cancer. He didn't get sick with any of his chemo's. I've got another friend and he's got a multiple myeloma and he hasn't had any sickness with the actual treatment but he has had added side effects of other cancers come up so they don't know which is his first and which is his second so he is a different thing all together but he is bright and happy as well and looking forward to the rest of his life. I've never personally met anybody that I know that has let it get them down. So how it affects certain sections of the community I don't know. (S06)

Whilst others actively sought information and validation of the information they received:

> I have always supplemented the information I got from the hospital from people who've gone through chemo and friends who have, who've done it … I've just

> supplemented the information that I was given, and I've read through the booklets and all that stuff so that helps me, to get a realistic idea that as soon as chemo finished I'm not going to feel well. Like my friend was saying no, it was six or twelve months afterwards she was starting to feel back to herself, you know … if she's gone through it and you hear someone else say that it makes you go, "oh, okay I've finished chemo but it's going to take a while for my body to get over this. (S01)

Another survivor discussed the challenge in receiving, retaining and the timing of information:

> I realise people can try and give you all the information but there are questions you cant ask because you don't know and I would be much wiser knowing what I am asking or what the journey was going to be next time … I don't remember her telling me that information but it was probably that when she told me it wasn't relevant and I just flipped it out of my mind. (S10)

The gathering of information and planning for follow up appointments with the doctors helped survivors to take control and gain the information that they needed to plan for their future:

> Just information gathering that helped me, independent information gathering has helped me to have that ability to go "hang on, hang on". Making lots of lists before I went in to the doctors and taking that with me … the night before appointments I would review the literature again …I would ask myself the question …what do I want out of tomorrow's appointment? … it is a very good question because it's taking back charge as well and not being passive. (S01)

In summary, during the transition phase, analysis of the interviews has demonstrated the personal resolve the survivors drew from to begin to take control. This included resilience and empowerment through self-awareness, self-protection and self-management, all based upon their own individual beliefs, values and attitudes which one survivor summed up as " I dare to hope" (S11). In order to self-manage survivors needed new knowledge and life experience (acquired knowledge) to apply to the range of challenges that they may encounter during this transition period. Knowledge enabled the survivor to take control, set realistic expectations and find further information they required. Obviously to self manage one needed the ability to be self-aware, which was required for self-protection an important skill used by all the survivors in various forms. Self informing provided the necessary information to support self management.

Summary of Chapter Four

In conclusion, completing chemotherapy treatment for the survivors' encompassed experiences of loss of belonging and disconnect, loss of identity, loss of the treatment community including ready access to support and finally a fear for their future knowing that treatment offers no guarantees. The completion of chemotherapy treatment was an emotionally tumultuous time; survivors expressed a myriad of mostly negative emotions including fears, isolation, low moods and unpredictable emotional behaviour. This was clearly a very difficult all encompassing experience to navigate through. From the descriptions provided by survivors it is clear that in the weeks immediately post chemotherapy treatment, the survivors are clearly physically unwell and whilst they still have connections with the treatment community they are not well enough to begin their transition onwards.

Analysis of the interviews relating to the transition phase has demonstrated that personal resilience, knowledge and the ability to plan are all vital coping components for survivors during this part of their journey. Personal resilience detailed the personal resolve the survivors drew from to begin to take control. This included emotional resilience, empowerment, maintenance of a positive outlook through self-protection and a range of self-management strategies all based upon their own individual beliefs and values.

The information gaps identified by survivors related to understanding the physical changes, treatment side effects, and future plans. Survivors found themselves completing treatment and intending to move forwards without all the necessary detail to make informed decisions or begin to achieve an appropriate plan, whether that be back to work, back to social engagements or onto the next step in their treatment plan.

Following the qualitative analysis the literature was reviewed and gaps were identified in terms of information needs that survivors had identified. These will be discussed in greater detail in the Chapter Five.

Chapter Five

Phase Two: Instrument Development and Testing

Introduction and Background

This chapter describes the quantitative methodology used in Phase Two of this study; it illustrates the processes employed to collect and analyse the data and also the ethical considerations that occurred before and during the study. The process followed to modify an existing tool in this research was deliberately similar to the process followed when developing a new tool. Following Phase One of this study in which key qualitative findings were established, a comprehensive literature review was undertaken to identify whether a suitable tool existed for use with this population. It became evident that no valid and reliable instrument was currently available to assess the transition needs of cancer survivors on the completion of chemotherapy treatment. However, an instrument titled Quality of Life- Cancer Survivor (QOL-CS) was identified that was designed to explore longer-term survivorship (Ferrell, Dow et al., 1995) in cancer patients. The findings from the qualitative phase were used to adapt this existing cancer survivorship instrument with the permission of the original authors Ferrell, Dow et al. (1995) (Appendix G). The instrument was modified to allow the exploration of survivorship issues that occur during the first three months following the completion of chemotherapy as identified in this study. The revised questionnaire was then tested for clarity, content validity and apparent internal consistency with an expert panel of senior oncology nurses from a large tertiary cancer service in Western Australia.

Ferrell, Dow et al., (1995) developed and tested a quality of life instrument for long term cancer survivors that was based on the City of Hope quality of life model. The purpose of this instrument was to measure the specific concerns of this group of survivors. The instrument has been widely used in cancer care and adapted for several different cancer populations across a range of ages, tumour types and languages, for example: Hispanic patients with cancer (Juraz, et al., 1998), breast cancer survivors (Ferrell, et al., 1996), and ovarian cancer survivors (Ferrell, et al., 2003).

The Quality of Life-Cancer Survivor (QOL-CS) tool contains numerous items that were consistent with the key descriptors identified from the interviews conducted in this study. Given the universal acceptance and use of this tool, as well as the relevance of many of the items to the population of interest in this study, the researcher opted to make a minor adaptation to this instrument by adding seven additional items designed to capture the full scope of key descriptors (needs) identified from the qualitative phase of

this study. This adapted version of The QOL-CS was titled the QOL-CCS (Quality of Life- Chemotherapy Cancer Survivor). Following refinement of this new instrument, preliminary validity testing was undertaken to determine clarity, content validity and apparent internal consistency. This preliminary testing was conducted using six experienced oncology nurses from a major cancer treatment centre in Western Australia.

The QOL-CS tool initially described by Ferrell, Dow et al., (1995), recognised that most quality of life tools focused on measuring acute cancer and treatment side effects rather than a longer term view of cancer survivorship which results in a diverse and different range of side effects. Not surprisingly, the origin of quality of life assessment in the cancer population was initially linked to clinical trials (Gill & Feinstein, 1994). At this stage most tools used measures that had been determined by the clinicians based on their clinical experiences, rather than the experiences and perceptions of patient themselves. The QOL-CS tool was revised over a one year period following a series of interviews and focus groups with cancer survivors and for the first time, explored the construct of positive adjustment, following the City of Hope researchers recognition that most of the tools focused on the downside of having cancer.

Given the identified gap in the cancer literature related to the immediate transition needs of patients who complete chemotherapy, and the lack of a valid tool that could be used to plan individualised follow-up care, the need for a more contemporary survivorship instrument was identified by the researcher. It was considered appropriate that in order to ensure suitability of the new tool for chemotherapy transition survivorship, and in keeping with Ferrell's (1995) approach to item generation, new items generated for inclusion the revised QOL-CCS should be shaped by patients' own perceptions rather than those of health professionals. Therefore, the themes identified in the findings of the qualitative interviews were the source of the additional items for this revised tool.

The World Health Organisation (1997) defined quality of life as "an individual's perception of their position in life in the context of culture and value system in which they live and in relation to their goals, standards and concerns" (p. 1). Within the field of healthcare, quality of life is often regarded in terms of how it is negatively affected. It is well recognised that the meaning of health and life itself can be altered following a diagnosis of cancer, cancer survivors have reported struggles to achieve a balance in their lives and a sense of wholeness and life purpose after a life altering experience (Ferrell, 2004; Vachon, 2001).

Quality of life measures are now commonly used and reported in the literature and this widely used measure determines how individuals assess their own general well being. However, there is a lack of consensus on a health related quality of life definition. Ganz (2000) labelled the health effects of cancer and its treatments on perceived quality of life as “the price of survival”. (p. 324). Quality of life is generally accepted as a multidimensional construct for which many definitions exist. Ferrell’s body of work was focused on describing quality of life in cancer patients with early work leading to development of a model of quality of life (Ferrell, Grant, & Padilla, 1991; Ferrell, Wisdom, & Wenzl, 1989). This model was based on the following four domains of quality of life for cancer patients: physical well being; psychological well-being; spiritual well-being; and social well being. The QOL-CS (Ferrell, Dow, et al., 1995) was based on these core domains and specifically adapted for longer-term cancer survivors.

The QOL-CS instrument is considered simple and practical for use with it’s intended population of long term cancer survivors. It comprises 41 items representing the four domains of quality of life incorporating physical, psychological, social, and spiritual well being as the previously described. Psychometric testing was performed on a population of 686 respondents, and included measures of reliability and validity. Ferrell et al. (1995) reported two measures of reliability. The range of test-retest reliability scores were: physical (r = 0.88), psychological (r = 0.88), social (r = 0.81), and spiritual (r = 0.90), with an overall score of r=0.89. High internal consistency estimates were reported; Cronbach’s alpha subscale alphas ranged from r=0.93 overall; and r = 0.71 for spiritual well being, r = 0.77 for physical, r = 0.81 for social, and r = 0.89 for psychological subscales/domains (Ferrell, Hassey Dow, et al., 1995). Content validity was established by a panel of quality of life researchers and nurses with expertise in oncology, stepwise multiple regression was used to determine factors most predictive of overall quality of life in cancer survivors. Seventeen variables were found to be statistically significant accounting for 91% of the variance in overall quality of life. Pearson's correlations were used to estimate relationships between the subscales of QOL-CS and the subscales of the established FACT-G tool. The FACT-G tool is used the functional status of patients with specific cancer diagnosis. There was moderate to strong correlation between associated subscales including QOL-CS physical to FACT physical (r = 0.74), QOL-CS Psych to FACT Emotional (r = 0.65), quality of life Social to FACT Social (r = 0.44). Further measures of validity were used including correlations of individual items of the QOL-CS tool, factor analysis, and construct

validity discriminating known groups of cancer survivors. Findings showed the QOL-CS and its subscales adequately measured quality of life in the population of cancer survivors (Ferrell, Hassey Dow, et al., 1995)

Findings from the previous qualitative interviews undertaken with 14 cancer survivors who were in the transition phase following completion of chemotherapy were used to inform the generation of new items in the QOL-CCS (Quality of Life-Chemotherapy Cancer Survivor) tool developed in this study. As previously stated, this 48-item tool is a modified version of the 41-item QOL-CS. Table 2 demonstrates how the new questions generated linked specifically to themes identified in the analysis discussed in Chapter Four. Appendix E provides an overview of the development from initial codes to a major theme The other themes identified were considered to be covered by the original QOL-CS tool questions either directly or indirectly.

Table 2

Links between new questions and identified themes

New questions added	Related themes identified in qualitative analysis
q. 45 Did you receive enough information about physical changes at the end of chemotherapy treatment?	Physical
q. 46 Do you understand everything that happened during treatment?	Self management
q. 47 Do you understand your plan of care from now on, including timeframes?	Loss of identity Loss of community Isolation Self management
q. 48 Have you tried to find information from other places?	Self management Self informing Self awareness
q. 49 Were you provided with any written information about life after chemotherapy?	Self informing
q. 50 If you were provided with information, was it useful?	Self informing
q. 51 Have you been able to make any plans for your future?	Self management

Instrument Testing: Clarity, Content Validity and Apparent Internal Consistency

Given the time constraints of this Master's study, only preliminary psychometric assessment of the QOL-CCS was possible. This was undertaken between August and September 2011 at a large tertiary cancer centre in Western Australia. This centre cares for approximately 2000 cancer patients. The testing process used the method described by (Imle & Atwood, 1988) for assessing the validity and apparent internal consistency

of inductively generated domains. Apparent internal consistency is used to describe the non-quantitative assessment of homogeneity of content (Imle & Atwood, 1988). Three questions were addressed:

1. To what extent are the items in the QOL-CCS clear?
2. To what extent do the domains in the QOL-CCS confirm internal consistency?
3. To what extent do the domains in the QOL-CCS confirm content validity?

Target Population, Sample Size and Recruitment

In keeping with Aamodt's (1983) recommendations, raters should be drawn from the context within which the original data were generated. Six senior nurses with significant experience in chemotherapy delivery were recruited from the cancer division to form an expert panel. Each panel member met the following eligibility criteria:

- working as a senior cancer nurse in either a specialist or managerial role
- five years of experience with cancer patients who are receiving chemotherapy
- experience in caring for patients post chemotherapy in a variety of settings

These nurses all had many years experience of working with cancer patients, and use of this expert panel was in keeping with item generation for the original Ferrell's QOL-CS instrument first tested in 1995. This sample size was based on Lynn's (1986) method for determining the number of panel members needed to determine content validity. This estimate is obtained by calculating the proportion of the number of panel members who might agree out of the total number planned for use, and then setting the standard error of the proportion to identify the cut-off for chance versus real agreement. Using this formula, a minimum of five panel members is required to provide a sufficient level of control for chance agreement. The six expert nurses were asked to complete three tools determining the following domains of clarity, internal consistency and content validity (Appendix H). Prior to the testing process, panel members were informed there were seven new items in the instrument which were based on the information needs identified from the interviews. With six selected panel members, a minimum of five of whom should agree to attain a percentage agreement of at least 83%. Agreement of 83% (i.e. five of six experts rating each item acceptable) was pre-set as the minimum. This criterion is based on calculating the proportion of experts who might agree, out of the total number planned for use, and then setting the standard error of the proportion to identify cut-off for chance versus real agreement. According to Lynn (1986), this computation allows the researcher to establish a necessary level of percentage agreement at a 0.05 level of significance. For this phase of the study, nine

eligible nurses were invited to participate by letter (Appendix I). Six nurses returned the completed forms within the required timeline. Consent was therefore implied by return rather than in writing.

Data Analysis

Clarity rating.

Participants were asked to indicate whether the language used in the questionnaire was appropriate and whether items in the instrument were: a) clearly worded, b) belonged together, c) were relevant and d) were complete. Item clarity is desired to convey a single message or portion of the inductively generated concept (Imle & Atwood, 1988). Once it was established that survey instructions were clear, participants were asked to score each of the 48 items as clear or unclear. Space was provided for comments and opportunities to discuss the comments were provided. Information ascertained in relation to clarity was incorporated in the new instrument (Figure 4). To aid the reader, Ferrell's original QOL-CS is included in Appendix J

There was 100% agreement amongst the participants that the instructions on clarity rating were clear. The participants rated 46 of the 48 items at 83% or 100% agreement. Item 20 "time since chemotherapy was completed" was rated as being clear by only one participant. The five participants who rated this item as unclear all commented they did not understand the meaning or intention of this item. After consideration by the researcher, it was realised the QOL-CCS related solely to patients' experiences since completion of chemotherapy, hence the item was considered redundant and so the original statement was reinserted. Item 21 "how much anxiety do you have?" achieved agreement of 67% (i.e. four out of six participants). Comments regarding this question included the potential for patients to confuse anxiety with depression, depression was also considered to be a clinical term, the term "distress" is considered to be a less stigmatising term which reflects the mix of unpleasant emotions that cancer patients experience. This has been extensively validated in work undertaken in the development of the distress thermometer (Holland & Reznik, 2005). Item 21 was changed to reflect the term distress. Advocates of screening of cancer patients for emotional distress consider that a systematic approach will promote equitable access to psychological services rather than depending on clinician or patient initiated referrals (Vodermaier, Linden, & Siu, 2009). The QOL-CCS tool has been developed as a part of a research approach to learn more about a specific population at a specific time rather

than for ongoing screening, therefore a more significant integration of distress screening tools has not been considered appropriate in the revision of the instrument.

Apparent internal consistency.

Measurement of apparent internal consistency questions the homogeneity of the content. There was 100% agreement that all 41 items belonged together and belonged within the questionnaire. Despite this unanimous agreement for all items, item 20 was reinstated to the original format as discussed above.

Content validity.

Content validity assessment involved the evaluation of the extent to which items in the QOL-CCS "fitted" the conceptual domain of interest, in this case, transition from chemotherapy (Nunnally & Bernstein, 1994). Not only is it important to assess the adequacy of items in order to understand the meaning of the conceptual domain, it is also necessary to also determine whether any redundancy exists among scale items (Imle & Atwood, 1988). Assessment for content validity required the participants to confirm their agreement with the label and definition of the instrument. Agreement of 100% was achieved. Following this, each participant read each item and was asked to score "yes"or "no" in response to whether the item `fitted' the QOL-CCS label and definition. There was 100% agreement for 44 of the 45 items. Item 20 (as previously discussed) achieved a rating of 83%, as did item 30 "is your sexuality impacted by your illness". Items 21 and 22 related to anxiety and depression achieved 67% agreement, two out of the six raters questioned the position of the item within the QOL-CCS rather than the items themselves. As discussed in the clarity rating section, questions 21 and 22 have been changed following the expert panels comments to reflect language more commonly acceptable to the Australian population.

All three rating tools provided opportunity for comments. These included the suggestion for additional individual questions in the physical domain about diarrhoea and vomiting, as some patients will experience one symptom without the other. It was also recommended that menstrual changes and fertility should be separated and written as individual items, these suggestions have all been adopted in the revised instrument (Figure 4). There was a query as to whether people would understand the word "fatigue"; this was replaced with "fatigue (tiredness)". It is the opinion of the researcher that changes in language and chemotherapy agents in the past 15 years since the instruments were developed may account for the suggested changes. The new domain of

items related to “information needs” generated from interview findings from this study were rated consistently at 100% across all three psychometric assessments, in addition, no comments were provided by raters to change these items**.** The QOL-CCS tool with amendments based on the above analysis is displayed below in Figure 4 with the changes highlighted in Blue for ease of recognition.

Quality of Life Chemotherapy Cancer Survivor Version

Directions: we are interested in knowing how your experience of completing chemotherapy affects your quality of life. Please answer all of the following questions based on your life **at this time.**

Please circle the number from 0-10 that best describes your experiences:

Physical Well Being

To what extent are the following a problem for you:

1. Fatigue (Tiredness)

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

2. Appetite changes

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

3. Aches or pain

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

4. Sleep Changes

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

5. Constipation

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

6. Diarrohea

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

7. Nausea

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

8. Vomiting

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

9. Menstrual Changes

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

10. Fertility

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

11. Rate your **overall physical health**

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

Psychological Well Being Items

12. How difficult is it for you to **cope** today as a result of your disease and treatment?

not at all difficult	0	1	2	3	4	5	6	7	8	9	10	**very difficult**

13. How good is your **quality of life?**

extremely poor	0	1	2	3	4	5	6	7	8	9	10	**excellent**

14. How much **happiness** do you feel?

none at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

15. Do you feel like you are **in control** of things in your life?

not at all	0	1	2	3	4	5	6	7	8	9	10	**completely**

16. How **satisfying** is your life?

not at all	0	1	2	3	4	5	6	7	8	9	10	**completely**

17. How is your present ability to **concentrate or to remember** things?

extremely poor	0	1	2	3	4	5	6	7	8	9	10	**excellent**

18. How **useful** do you feel?

not at all	0	1	2	3	4	5	6	7	8	9	10	**Extremely**

19. Has your illness or treatment caused changes in your **appearance**?

not at all	0	1	2	3	4	5	6	7	8	9	10	**extremely**

20. Has your illness or treatment caused changes in your **self concept** (the way you see yourself) ?

not at all	0	1	2	3	4	5	6	7	8	9	10	**extremely**

How distressing were the following aspects of your illness and treatment?

21. **Initial diagnosis**

not at all distressing	0	1	2	3	4	5	6	7	8	9	10	**very distressing**

22. **Cancer treatments** (i.e. Chemotherapy, radiation or surgery)

not at all distressing	0	1	2	3	4	5	6	7	8	9	10	**very distressing**

23. **Time since my treatment** was completed

not at all distressing	0	1	2	3	4	5	6	7	8	9	10	**very distressing**

24. How much **anxiety** do you have?

not at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

25. How much **emotional distress** do you have?

not at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

To what extent are you fearful of:

26**. Future diagnostic tests**

no fear	0	1	2	3	4	5	6	7	8	9	10	**extreme fear**

27. **A second cancer**

no fear	0	1	2	3	4	5	6	7	8	9	10	**extreme fear**

28. **Recurrence of your cancer**

no fear	0	1	2	3	4	5	6	7	8	9	10	**extreme fear**

29. **Spreading (metastasis)** of your cancer

no fear	0	1	2	3	4	5	6	7	8	9	10	**extreme fear**

Social Concerns

30. How distressing has the illness been for your **family?**

not at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

31. Is the amount of **support** you receive from others sufficient to meet your needs?

not at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

32. Is your continuing health interfering with your **personal relationships**?

not at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

33. Is your **sexuality** impacted by your illness?

not at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

34. To what degree has your illness and treatment interfered with your **employment?**

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

35. To what degree has your illness and treatment interfered with your **activities at home**?

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

36. How much **isolation** do you feel is caused by your illness or treatment?

none	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

37. How much **financial burden** have you incurred as a result of your illness and treatment?

none	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

Spiritual Well Being

38. How important to you is your participation in **religious activities** such as praying, going to church?

not at all important	0	1	2	3	4	5	6	7	8	9	10	**very important**

39. How important to you are other **spiritual activities** such as meditation?

not at all important	0	1	2	3	4	5	6	7	8	9	10	**very important**

40. How much has your **spiritual life** changed as a result of cancer diagnosis?

less important	0	1	2	3	4	5	6	7	8	9	10	**more important**

41. How much **uncertainty** do you feel about your future?

not at all uncertain	0	1	2	3	4	5	6	7	8	9	10	**very uncertain**

42. To what extent has your illness made **positive changes** in your life?

not at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

43. Do you sense a **purpose/ mission** for your life or a reason for being alive?

none at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

44. How **hopeful** do you feel?

not at all hopeful	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

Information needs at the end of Chemotherapy treatment.

45. Did you receive enough **information about physical changes** at the end of chemotherapy treatment?

not at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

46. Do you understand everything that **happened to you during treatment**?

not at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

47. Do you **understand your plan of care** from now on, including timeframes?

not at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

48. Have you tried to find **information from other places**? (i.e. cancer council, internet, friends)

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

49. Were you provided with any **written information about life after chemotherapy**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

50. If you were provided with information, **was it useful?**

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

51. Have you been able to make any **plans for your future**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

Figure 4. Quality of Life – Chemotherapy Cancer Survivor Tool (changes to the original tool have been highlighted in blue).

Summary

Only preliminary assessment of clarity, content validity and apparent internal consistency was possible in this study due to the scope of the Master's study. The researcher plans to conduct a comprehensive psychometric assessment of the QOL-CCS following completion of this Masters thesis. This will include three further measures of validity: stepwise multiple regression to determine factors most predictive of overall quality of life in chemotherapy treatment; Pearson's correlations to estimate relationships between the subscales of QOL-CCS and the subscales of an established tool such as the FACT-G. Further measures of validity will be undertaken including: correlations of individual items of the QOL-CCS tool, factor analysis, and construct validity discriminating known groups of cancer survivors. Once the QOL-CCS has been validated it is anticipated the QOL-CCS will be used by clinicians to measure quality of life in a large cohort of survivors who have completed chemotherapy within a three-month period to determine the needs as they transition to life immediately following chemotherapy. This information will be utilised to plan approaches to assist in the transition period for chemotherapy survivors.

Chapter Six
Discussion and Conclusions

Introduction

This chapter will present and discuss the major findings of this two-phase study in association with current knowledge about methodological, theoretical and clinical domains in cancer survivorship. Following this discussion, the strengths and limitations of the study will be explored. This final chapter will then present both the conclusions of the study and the recommendations for future research, education, and clinical practice.

The purpose of Phase One was to identify, explore and describe the experience of cancer survivorship transition from chemotherapy patient to life after cancer treatment as a cancer survivor. During this process, factors which improved or exacerbated this transition were identified for consideration. Following this, the main themes identified in Phase One were utilised during Phase Two to modify an existing Quality of Life – Cancer Survivors tool (Ferrell et al., 1995) in order to later explore quantitatively the experiences of a larger number of patients. For the purposes of this study an expert panel reviewed the modified tool to ensure that it was clear, confirmed internal consistency and confirmed content validity. The experiences of people with cancer as they transition from the completion of chemotherapy to life after cancer is an under researched area, the findings of this study will therefore contribute to the understanding of this part of the cancer continuum from both an Australian and a time perspective. The study findings represent the experiences of 14 cancer survivors from a tertiary cancer centre in Western Australia.

This study was initiated following the researcher's search for information about this subject whilst preparing patient information plans in the clinical environment; the lack of available information and research findings were the impetus for this study. Findings from this study will add to the current knowledge deficit and provide a platform for a myriad of future research and clinical information developments.

This chapter is organised into two sections. Part one presents a discussion of the key findings in relation to the following themes identified in Phase One: the experience of loss; the experience of changing emotions; the experience of resilience and the experiences relating to empowerment. Part two presents a discussion in relation to Phase Two of this study which includes the adaptation and testing of the existing Quality of Life– Cancer Survivors tool based on the findings from Phase One.

Following this, strengths and limitations of the study will be considered, prior to the conclusions and recommendations that have been drawn from this research study.

Part one: qualitative phase (interviews)

Experiences on completion of chemotherapy

The experience of loss

The findings of this study indicated that participants were experiencing a range of losses including the: loss of the treatment experience; loss of identity; loss of treatment community and loss of the perceived planned future. The experience of loss in relation to cancer is not a new concept. There is detailed literature about loss when an individual is diagnosed with cancer and throughout the subsequent continuum including: loss of disease monitoring and loss of an action plan against cancer (Allen, et al., 2009; Shaha, Cox, Belcher, & Cohen, 2011); loss of a safety net and loss of contact and support with other cancer patients (Allen, et al., 2009; Doyle, 2008; Jefford, et al., 2008; Jefford, et al., 2011; Shaha, et al., 2011). There is also detailed discussion in the literature relating to the physical, psychosocial and spiritual losses that cancer survivors' experience. This literature acknowledges that facing a cancer diagnosis and the stress associated with medical choices and treatment side effects is a traumatic event for any individual to face (Alfano & Rowland, 2006; Allen, et al., 2009; Costanzo et al., 2007; Doyle, 2008; Pinquart, Silbereisen, & Frohlich, 2009; Shaha, et al., 2011).

Participants in this study found the time immediately following completion of chemotherapy, to be a time of change. During this time they moved from the structure and culture of being a chemotherapy patient in a community that supported and shared their experience, to an individual who was still dealing with the burden of treatment side effects without the supports they valued. The loss of identity from the status as a patient was a concept they clearly struggled with, alongside the awareness they had changed in the process of the cancer care to date. One survivor described the feeling of not belonging and not understanding her position in society now that she is no longer receiving treatment. This sentiment is certainly reflected in the literature with descriptors such as "warriors without a war" (Morgan, 2009). Despite the planned nature of chemotherapy, all participants expressed their shock at the abruptness of treatment ending, this was coupled with the vulnerability of not having ready access to health care professionals and fellow patients for support and information. The final and largest loss in terms of impact on the participants was the loss of their perceived

planned future and the vulnerability this brought with the lack of ability to plan for the future in case treatment had not been successful.

A small number of research studies that capture some of the domains of the current study have been identified in the literature. A quantitative study from the USA which addressed breast cancer survivors' adjustment to life after treatment by Costanzo, et al. (2007) identified that of the 89 participants in this study, 71.6% had received chemotherapy as a part of their cancer treatment. The survivors were surveyed during treatment, three weeks following the end of treatment and three months post treatment. Costanzo's (2007) study identified that fear of recurrence and side effects or physical problems were the greatest sources of stress at three weeks and three months post treatment. The sources of post treatment stress all reduced between the three-week and three month survey milestones (Costanzo, et al., 2007). Research identified that women who had received chemotherapy reported more worry about recurrence and cancer related intrusion than women who had received radiation therapy. This was attributed to the longer length of treatment and the severity of side effects experienced. Overall the post treatment period was identified as a distressing time when women not only dealt with physical side effects of treatment, including fatigue and lymphoedma, but also the distress of the unanticipated longevity of these treatment effects (Costanzo, et al., 2007). It was suggested the psychological struggle may be come to the fore, when survivors no longer had the treatment routines to distract from reflecting on the impact of a cancer diagnosis (Costanzo, et al., 2007; Karahalios, et al., 2007).

Another USA study of breast cancer patients as they transitioned from patient to survivor was undertaken (Allen, et al., 2009). This qualitative study used focus groups to capture the experiences of 47 women in this transition phase; the cohort's average time from completion of treatment was four months with the range between 1-14 months. It was not evident how many participants had received chemotherapy as a treatment. Overall the descriptors used to describe the findings of this study were congruent with the psychological experiences expressed by participants in the current study. The element that was not discussed in Allen et al's (2009) findings was that of physical impact, or the management of post treatment symptoms. Further, there was no discussion relating to fatigue or it's impact on psychological adaption, which was a key factor for participants in the current study.

An Australian study addressing survivorship issues following completion of treatment also used the focus group approach with 22 participants. Of these six had completed treatment within the previous year although the type of treatment received by

participants was not stated (Jefford, et al., 2008). Findings from this study were congruent with findings from the current study. Of the 12 key themes identified in that study the only disparity noted was in the descriptors relating to positive experiences of having a cancer diagnosis, which perhaps is attributable to the length of time in survivorship. The findings in relation to information needs were consistent with the findings in the current research, survivors wanted to know: What were signs that their cancer was returning? What they should do now treatment was over? How to improve their health and reduce their risk of a cancer recurrence? Who to contact for practical advice and support including resources? Finally if how they felt was normal? The Jefford team [Peter Mac Cancer Centre, Melbourne] has continued to build on these initial findings, testing new interventions such as written information (Jefford, et al., 2007) and nurse-led packages (Jefford, et al., 2011).

Lethborg, Kissane, Ivon Burns & Snyder (2000) interviewed eight women with early stage breast cancer who had completed adjuvant chemotherapy two to four weeks previously at a cancer centre in Victoria, Australia. The intention of the study was to identify issues, which arise as medical support becomes less intensive. This study identified three distinct time points for the women, firstly at the time of diagnosis when crisis, shock and bewilderment were the key experiences described. During treatment when trauma was identified as a key domain this encompassed confrontation with diagnosis, and physical and psychological impacts of cancer. Attempts to regain control and the importance of social support were also important during this treatment time. The final time point highlighted three main themes, recovery, ambivalence and fear; and processing the experience. The findings and discussion of this study are highly congruent with the findings from the current research study.

Overall the participants of Lethborg et al., (2000) study had a need to tell their story from diagnosis onwards. Once the trauma of treatment was completed the women began to process the impact of this journey and the spiritual issues that it had created. The survivors in the current study all had a story to tell and shared their experience willingly. In hindsight the interview itself provided an opportunity for survivors to reflect on their recent experience; like the Lethborg study, they were able to recall the exact diagnosis conversation as if it was yesterday.

Finally, a quantitative study assessing the unmet needs of Western Australian patients with haematological malignancies surveyed 66 participants who had completed treatment an average of eight months earlier. Again, it was not evident how many participants of this cohort had received chemotherapy. On the whole the top ten

identified needs were consistent with the views expressed by participants in the current study, although the language was different as it reflected the items in the quantitative surveys. For example, 33% of respondents identified the "need for an ongoing case manager to whom I can go and find out about services whenever they are needed" (Lobb et al., 2009).

The vast majority of literature focuses on survivors who are much further into their survivorship journey than those survivors in the current study. The main point of difference in findings between this study and the wider literature is the perceived positive impact of a diagnosis of cancer. A number of papers discuss cancer as a life changing experience with positive outcomes, recognizing that as humans go through life gains and losses are a normal part of life's trajectory. Further, whilst a cancer diagnosis may begin with negative associations, the longer the person lives past their diagnosis, the more likely positive associations and actions will be when survivors are reassessing their life to determine what is important in life and establish new priorities (Breaden, 1997; DeMarco, Picard, & Agretelis, 2004; Doyle, 2008; Leigh & Logan, 1991; Meraviglia, 2006; Pelusi, 1997; Pinquart, et al., 2009; Shaha, et al., 2011; Thornton, 2002; Vachon, 2001; Wallwork & Richardson, 1994). It has been suggested that survivors who report higher levels of stress early in the transition period tend to have a diminished longer term adjustment (Allen, et al., 2009). Therefore in identifying and reporting the true experiences in the early post treatment period, this study can contribute to the understanding of survivors as they begin their transition journey to life after cancer.

Apart from the current study, no other study has focused solely on the immediate transition time following the completion of chemotherapy. It may well be implied that survivors need time to recover and adjust from their diagnosis and treatment side effects before recognition of positive outcomes begin; as displayed in the longer-term survivorship research.

The literature supports the physical side effects identified by the participants in this study, in particular fatigue and it's impact on daily living (Alfano & Rowland, 2006; Broeckel, et al., 2000). Other previously reported outcomes such as goal setting and mixed emotional reactions were all congruent with the experiences of the survivors in this study (Cheung, Thompson, Ling, & Chan, 2005; Deimling, Sterns, Bowman, & Kahana, 2005; Dow, 2003; Dow, Ferrell, Haberman, & Eaton, 1999; Doyle, 2008; Ferrell, 1996; Lancee et al., 1994; Pinquart, et al., 2009; Vachon, 2001).

The positive emotion of elation related to treatment completion is often marred by negative emotions. The anxiety associated with the loss of contact with the treating hospital, grief and uncertainty about the future is well described in the literature and is consistent with the findings from this study (Auchincloss, 1995; Diamond, 1998; Dow, et al., 1999; Doyle, 2008; MacBride & Whyte, 1998; Mellon, Northouse, & Weiss, 2006; Mullen, 1985; Pelusi, 1997; Wallwork & Richardson, 1994).

Loss of a perceived planned future

Cancer survivors differ from other survivors because they live with a fear of cancer recurrence in addition to the physical, psychosocial and spiritual impacts related to their diagnosis and treatment (Breaden, 1997; Welch-McCaffrey, Hoffman, Leigh, Loescher, & Meyskens, 1989). Alfano & Rowland (2006) described the fear of recurrence as one of the most universal and durable legacies of surviving cancer; its prevalence is said to range between 5-89% of cancer survivors (Alfano & Rowland, 2006; Allen, et al., 2009; Costanzo, et al., 2007). The participants in the current study all expressed their inability or unwillingness to plan too far into the future, in case the treatment had not been effective or in case the cancer recurred. Uncertainty is a common element of discussion in cancer survivorship literature and a given part of a survivor's existence (Morgan, 2009). Uncertainty ranks in the top 10 of the 50 most distressing unmet needs (Lobb, et al., 2009; Moore, 2011; Schlairet, et al., 2010). Lobb et al. (2009) confirmed that 73% (n=66) of survivors identified their need for help to manage fears about cancer recurrence and 43% considered that this need remained unmet.

Many authors discussed the Damocles syndrome in association with cancer survivors, inferring there is an inability to enjoy living in the present due to the fear of cancer recurrence having recognised their own invulnerability and mortality (Auchincloss, 1995; Breaden, 1997; Doyle, 2008; Fritz, 2001; Koocher & O'Malley, 1981; Moore, 2011). The link between surviving cancer, fear of cancer recurrence and fear of death are said to be omnipresent (Cheung, et al., 2005; DeMarco, et al., 2004; Doyle, 2008; Koocher & O'Malley, 1981; Mellon, et al., 2006; Mullen, 1985; Pelusi, 1997; Vachon, 2001; Wallwork & Richardson, 1994), although this is disputed in one study of long term survivors who described that participants found the experience largely unremarkable (Killoran, Schiltz, & Lewis, 2002).

Conversely, Dizon (2009) identified that up to 40% (n=153) of women treated with chemotherapy experienced a degree of distress which persisted for up to 20 years

for some. Uncertainty has a huge impact on survivors spiritual well-being with frequent descriptions of survivors searching for the meaning of illness and the meaning of life; highlighting a sense of both mortality and vulnerability (Breaden, 1997; Doyle, 2008; Hassey Dow, 2003; Morgan, 2009; Shaha, et al., 2011; Shanfield, 1980). The days prior to a routine follow up appointment bring an experience of heightened anxiety with an increased fear that they may be informed that their cancer has returned, many survivors often have a scan or blood tests prior to the specialist appointment as a routine part of monitoring. The time between this procedure and the actual follow up appointment when they will get results is particularly traumatic (Jefford, et al., 2008).

Coping strategies related to dealing with uncertainty may be positive or negative (Morgan, 2009). Rowland & Baker (2005) discussed the belief that people are essentially goal orientated and for those people diagnosed with cancer there is a disruption in working towards personal goals whilst going through cancer treatments. The goals that people strive to achieve are what provide both meaning and quality of life; therefore a disruption to this process can in turn affect one's perceived quality of life. This belief is supported elsewhere (Breaden, 1997; Pinquart, et al., 2009).

The cancer survivors in this study were very aware of their vulnerability and uncertainty about the future, to the extent their ability to plan was virtually stifled in the early days following completion of treatment. Shaha et al. (2011) acknowledged these experiences related to anxiety, vulnerability, fear and loss of control all impair the individuals inability to cope. The literature discusses steps that survivors take to reassess values and embrace changes as they progress through the survivorship journey. Again, the disparity between the participants in this study and the wider literature appears to be time since treatment completion (Shaha, et al., 2011). As Doyle (2008) confirmed a researched model to find a new normal life after cancer is yet to be identified.

The Experience of Changed Emotions

There is overlap between the experience of loss and emotional change; it is not possible to feel a loss without feeling an emotional response. Findings from both this study and that of Costanzo et al. (2007), identified that cancer survivors in the early days following the completion of chemotherapy experienced a myriad of emotional changes, many of which were unexpected. Participants who were excited about the prospect of completing chemotherapy were caught unawares with emotional mood swings in the time period immediately following chemotherapy completion, recounting

how low in mood they felt. There is evidence in the literature that going through the experience of being diagnosed and treated for cancer changes a person's outlook, perceptions and expectations even though they hope to return to their usual normal pre cancer state (Doyle, 2008; Schlairet, et al., 2010). Fear of isolation and changes in existing relationships can impact on the survivor's positive responses to these changes.

The participants in the current study not only identified the physical isolation from their treatment community of health professionals and fellow patients, but also their emotional isolation from their own social community of family and friends. Upon removal from the treatment community the survivors expressed anxiety about needing to take responsibility for themselves, including their own self monitoring. In the literature this theme has been identified as "losing the safety net" (Allen, et al., 2009; Squiers, Finney Rutten, Treiman, Bright, and Hesse, 2005). The emotional isolation theme links with the previously identified experience of loss of identity, where survivors have recognised they are not the same person as they were pre diagnosis. The participants in this study identified some changes in the behaviour of friends and family on completion of treatment, for example loved ones no longer phoned to see how they were or else they avoided contact with the survivor all together. Others expected the survivor to "be back to normal" and therefore they no longer treated them like a patient experiencing limitations due to treatment side effects; these changes in behaviour occurred before the survivor was ready. The immediate post treatment period has been identified as a time when friends and family celebrate the survival from the cancer treatment and remind the survivor that they are "lucky to be alive". This makes it difficult for the person to express any fears or needs they may have at this time, particularly if they are feeling ambiguous about their cancer survival due to fears of recurrence or physical and psychological compromises (Itano & Taoko, 2005; Morgan, 2009).

In addition, one study found that survivors perceived that maintaining a positive outlook and getting on with life was the approach most respected by health professionals, family and friends (Leydon et al., 2000). It is acknowledged that people are comfortable talking about strokes or heart attacks, but that discussions about cancer remain difficult due to a general lack of understanding about the effects of the disease, treatment and the societal stigma attached to cancer (Carlisle, 2011). Additionally, following treatment completion survivors now have limited contact with health care professional further highlighting their isolation. Authors have suggested that more

rehabilitation assistance may therefore be required in this period (Breaden, 1997; MacBride & Whyte, 1998; Mah, Bezjak, Loblaw, Gotowiec, & Devins, 2010).

In a review of literature undertaken by Holland & Reznik (2005), it was determined that up to 45% of patients in ambulatory cancer centres may have significant levels of distress whilst only 10% are referred on to appropriate supportive care. This may well be an indication of the reluctance that cancer patients may have about asking for help with psychosocial concerns due to the stigma attached to issues related to mental health concerns (Earle, 2006). If Holland & Reznik's (2005) claims are correct, then as many as 35% of patients may complete cancer treatment with some level of unidentified emotional distress before they commence their transition journey. All the participants in this study experienced a tumultuous array of emotions in the immediate post treatment period, which was compounded by the social isolation due to the inability of non-cancer survivors to truly understand the experience.

The participant's experiences in the immediate post treatment period do not wholly correlate to the findings in the wider literature currently available. The negative experiences detailed are certainly congruent and mainly link to physical and psychological issues associated with treatment side effects and the meaning of illness (Doyle, 2008), however the positive life changing experiences illustrated in many long term studies are not evident at this period in time. Researchers have suggested the positive aspects of cancer survival are linked to experiences of personal growth, self improvement and appreciating life more (Doyle, 2008). This sentiment is supported suggesting that when people have confronted their own mortality and re evaluated their life goals and priorities a more positive outlook is achieved (Andrykowski & Hunt, 1993; Cordova, Cunningham and Carlson, 2001; Davies, 2009; Pemberger, Jagsch and Frey, 2005). Finding meaning in becoming a cancer survivor is clearly a process, which is either helped or hindered by all of the points discussed above. Survivors each bring pre existing experiences, ideas and assumptions that have evolved since early childhood. These assumptions shape how survivors view the world and their role within it (Lethborg, Aranda, Bloch and Kissane, 2006). A diagnosis of cancer and surviving the experience forces a shift in beliefs which the survivor has essentially held since childhood.

Perhaps time is of the essence in this transition period; fatigue described as a persistent lack of energy, is certainly the dominant all encompassing symptom described by all but one of the participants at this time. Several authors have identified the difficulty in achieving any goals towards personal growth when fatigue is present,

given the omnipresent and unrelenting nature of post treatment fatigue and the associated distress it causes. Fatigue is described as almost ubiquitous amongst cancer survivors disrupting routine activities and causing a negative impact on quality of life that is more alarming than pain or nausea as it cannot be relieved (Ahlberg, Ekman and Gaston-Johansson, 2005; Dizon, 2009; Donovan & Ward, 2005; Hjorleifsdottir, Halberg, Gunnarsdottir, & Bolmsjo, 2008; Karahalios, et al., 2007; Morgan, 2009; Pinquart, et al., 2009; Prue, Allen, Gracey, Rankin, and Cramp, 2010). Ahlberg (2005) stated that cancer-related fatigue is the most frequently reported unmanaged symptom that affects 70-100% of all cancer patients for months or years after treatment. Several studies have demonstrated that fatigue is a major obstacle to patients normal functioning and to their ability to achieve a good quality of life (Ahlberg, et al., 2005; Broeckel, et al., 2000; Loge, Abrahamsen, Ekeberg and Kaasa, 2000). This is disconcerting given the importance that quality of life holds for cancer survivors and their families (Ahlberg, et al., 2005; Ferrell, Dow, et al., 1995; Morgan, 2009).

There was certainly a notable change in the experiences described by participants in the current study. Fatigue was the most monitored of symptoms and as fatigue levels began to improve, there was a constantly identified awareness of new goals reached and improvement in mood levels. This became a recognizable next step in the participants' transition to life after cancer with some participants already able to identify that for them the "new normal" may have some physical limitations that were not present in the pre cancer days.

Experiences in transition

This part of the transition journey has been defined as the process or period in which the person with a cancer diagnosis undergoes a change and passes from one stage to another. For participants in this study this stage involved dealing with highlighted personal challenges whilst finding a new balance, working towards future goals and achieving a normal life. The discussion in this section has been divided into two sections: experiences in resilience and experiences in empowerment.

Experiences in resilience

Resilience has been described as the ability to bounce back or cope successfully after substantial adversity (Earvolino-Ramirez, 2007; Herrman, Stewart, Diaz-Granados, Berger, and Jackson, 2011). Resilience is depicted as having four characteristics to achieve this positive adaption:

1. Hardiness: - a dispositional characteristic that includes a sense of control over one's life.
2. Benefit finding: – the ability to make sense of adversity by focusing on positive changes and personal growth.
3. Thriving: – which occurs when the person not only returns to a pre stress level of functioning but attains a higher level of functioning with acquired skills knowledge, confidence or improved social relationships.
4. Post traumatic stress growth:- described as a stage beyond thriving and resilience which includes an increased appreciation of life, closer intimate relationships and a greater sense of personal strength (Earvolino-Ramirez, 2007; Herrman, et al., 2011). All of the above four characteristics rely on finding meaning in the experience of cancer and reprioritizing for the individual their own unique life goals. Resilience is the personal characteristic that enables the cancer survivor to cope and re frame meaning in the face of adversity. This does not occur in isolation and is intricately connected with the process of empowerment in order to achieve resilience.

As participants' energy levels returned, so do did their resilience. This was characterised by language which became much more focused on positive outlooks, fighting spirit and normalizing of experiences. Some participants accepted their cancer diagnosis as a personal challenge; this has been described in the literature as inevitability (Mok, 2001). In this study participants often referred to their coping skills or ability to cope, which is considered to represent the ability to deal successfully with a difficult problem or situation. Participants discussed their surprise at the inner strength they found to deal with their situation for some this was attributed to God and strengthened their spiritual beliefs. There were a variety of emotional resilience approaches displayed along a continuum, that ranged from choosing not to believe in depression and therefore not experiencing it, to acknowledging depression as a potential problem and seeking professional help early as a preventative measure. From the experiences shared by the survivors in this study it is clear that resilience is a complex web of personal values that is unique to each survivor.

The literature confirms the positive link between developing survivorship skills and coping mechanisms. Failure to cope has been identified as increasing the risk of more negative outcomes for the survivor (Hewitt, et al., 2006; Jefford, et al., 2011; Rendle, 1997). Studies with longer term cancer survivors have shown that coping mechanisms change over time for almost half of all survivors; the dominant coping styles that have been successfully adopted include optimism, supportive, confrontational

and self reliance (Rendle, 1997). Survivors in the current study were using optimism as their dominant coping style in partnership with maintenance of hope and avoidance of negative information. Hope has been closely associated with ability to cope and a perception of a positive quality of life and adjustment to illness amongst patients with cancer (Benzein, Norberg and Saveman, 2001; Herth, 1989; Hjorleifsdottir, et al., 2008; Vellone, Rega, Galletti and Cohen, 2006). Hope is represented in the literature as being present from the beginning of the cancer journey, even when initial descriptions about the shock of diagnosis are listed they are closely followed with actions towards a positive outcome such as maintaining normality, faith, hope and a belief that the treatment will be effective (Benzein, et al., 2001; Herth, 1989; Hjorleifsdottir, et al., 2008; Vellone, et al., 2006).

Hope has also been described as a universal human phenomenon essential for the overcoming of adversity and the fostering of resilience. It correlates strongly with health, wellness, strength of will and determination to endure rigorous medical treatments and strive towards a successful outcome (Hjorleifsdottir, et al., 2008; Leung, Silvius, Pimlott, Dalziel, and Drummond, 2009; Mattioli, Repinski and Chappy, 2008). Health professionals need to maintain a delicate balance between encouraging reasonable hope and creating unrealistic expectations. If health professionals fail to display a minimal sense of hope there is a risk that patients may become anxious and distressed, however, if patients' expectations about the normative experiences of cancer and it's treatment side effects are not adequately addressed then patients experience decreased satisfaction and increased distrust (Leung, et al., 2009; Saegrov and Lorensen, 2006). Survivors in this study provided examples of positive and negative experiences when the balance of information was correct, and this assisted them in managing their physical symptom at that time, or, when it was absent or diminished in importance to the point where it caused the participant an additional anxiety.

Hope and fear are interwoven and survivors are caught between their desire for more information and the avoidance of new information which may challenge their optimistic stance (Leydon, et al., 2000). In a qualitative study with 17 cancer survivors the narratives displayed a sense of hope yet were closely linked with fear. The survivors were described to be creating a façade of hopefulness which was indispensible to survival and interacted with information seeking in a complex way (Leydon, et al., 2000). In keeping with Leydon et al.'s (2000) findings, the participants in this research maintained hope on occasions by using periods of self censorship, searching by proxy (usually through other friends who had already successfully gone through cancer

treatment) or actively not seeking information. These actions prevent opportunities to experience negative information, which may have threatened their hopes. Hopes are beliefs concerning future outcomes in this study hope maintained the illusion of a positive outcome that the participants were seeking. These illusions of a positive nature can be powerful coping strategies in a time of immense stress (Houldin and Lewis, 2006).

The experience of resilience for participants in this study appeared to be a "light bulb" moment or an awakening from one stage to another that was embroiled in structure, treatment burden, treatment routine and passive acceptance and a transition to the next stage of life. To move into the new stage, participants were carefully and intuitively selecting information and support that met their criteria to maintain a realistic but positive future. The participants in this study were within the first three months of completion of chemotherapy but were already displaying some characteristics of hardiness and benefit finding.

The experience of empowerment

Traditionally when diagnosed with cancer and becoming a cancer patient an individual takes on a passive role as a recipient of health care from experts. Kvale and Bondevik (2008) found that whilst some patients had a strong desire for information and involvement in decision making other patients wanted to be informed about their disease and treatment but preferred the doctor to make the decisions. Salmon and Hall, (2004) postulated that information giving was a strategy to build relationships and maintain hope rather than as a basis for decision making about treatment. At the time of diagnosis there is often an inequality in the relationship between patients and health professionals, patients self determination at this stage can be enhanced or impeded by the professionals who are involved in their care. Empowerment is defined as a process that promotes individual mastery and control over one's life and decisions that affect his or her life, information is essential for patients to feel empowered and gain control (Anderson and Funnell, 2010; Buffum, 2004; Bulsara, Ward and Joske, 2004; Kvale and Bondevik, 2008; Mok, 2001). These sentiments appear to be a sensible and reasonable approach to promoting patient empowerment, however in the discussion to follow the complexity related to information sharing will be discussed further.

The participants in this study identified several stages that occurred in their empowerment journey which included: self awareness; seeking support; self protection; self informing; and self management. Self awareness appears to emerge as energy

levels begin to return; the person begins to reflect on the more passive role they have taken as a patient when going through treatment and their expectation that it is now their responsibility to become more pro active. Self awareness therefore for these participants appeared to represent their understanding and expectations of actions and responsibilities as the person with cancer. Participants were able to identify and enjoy positive outcomes such as improved self care in the form of assertiveness or health awareness.

In the early stages some participants did seek support from others, however they were very careful who they chose to gain support from. This action was very much about self protection; the participants were conscious of the consequences of sharing their feelings with others, health care professionals or someone not too closely connected were the favoured resource at this time. This behaviour has been described in other studies. Byrne, Ellershaw, Holcombe and Salmon (2002) found in their qualitative study that nearly all patients (n=28) interviewed described the importance of concealing distress and unhappiness from others. Patients in this study anticipated that the displaying of emotion would be catastrophic, the main reason patients had for this concealment was to protect other people, or to avoiding upsetting, displeasing or embarrassing others.

Whilst the participants in the current study did not wish to upset their friends and family, there was a strong self protective method in their approach as they were indirectly protecting themselves from exposure to more negative emotions. The self protecting strategies that participants intuitively adopted and described in their interviews were very much aimed at maintaining their hope and therefore positive outlook. Any potential for negative feedback was avoided whether that was support groups, individuals or written information. This behaviour was consistent with findings by Leydon et al. (2000), who described how patients often stopped information seeking at different times in their cancer journey because they were fearful of contradictory information. This self censorship functioned to preserve hope and avoid negative information thus helping to manage their fears. The participants were adept at hiding their feelings to maintain this façade of positive emotion, often using humour or storytelling to cover distress for others behaviours of avoidance and distraction helped to maintain the approach.

Patients recognised empowerment being displayed when they were respected, listened to, valued and given honest information. These actions not only increased their self worth, they also gave participants a sense of control (Kvale and Bondevik, 2008).

Encouraging self management and patient autonomy have been identified as important aspects of patient care (Jefford, et al., 2011; Karahalios, et al., 2007). Self management and self monitoring enabled the participants to assess their progress and set new goals, this positive and forward looking process strives towards improvement and maintains the positive approach. The constant evaluation and resetting of goals was discussed particularly in relation to fatigue-related limitations; this appeared to be the most frustrating symptom to monitor and assess because the participants had no prior knowledge of the recovery trajectory, but had expectations based on prior experiences of fatigue with flu related illnesses for example.

The study participants were very clear that this knowledge deficit affected their ability to cope and also highlighted their need for honest information, so that they could set realistic goals. At this stage participants were keen to learn from and listen to other survivors who understood their journey and needs. As the participants travelled further along the transition continuum their information needs changed and focused much more on the future, such as understanding the future management plan or planning future lifestyle goals and less on the individual treatment side effects. The participants in this study displayed an array of self informing skills that were delicately interlinked with their self protection and self management needs for the longer term. This enabled the survivors to continue towards their new normal with appropriate knowledge which didn't threaten their coping skills and facilitated the maintenance of a positive outlook. There is evidence to suggest that self management strategies are beneficial for patients as they transition from primary treatment to life after cancer, understand the signs and symptoms of disease recurrence, manage long term side effects of cancer and its treatments and re establish normal routines.

The experiences and wishes of the survivors in this study appeared consistent with other studies. Hindle (2010) stated that survivors wanted; support and information, to be empowered to take as much control as they wished, to be able to cope with life after cancer and to get their relationships back on track. Information needs have been constantly highlighted in the literature; the demand for better information in the post treatment phase includes subjects such as post treatment care, physical activity, help with everyday problems, and what measure to take to help them function better physically and emotionally (Karahalios, et al., 2007; Saegrov and Lorensen, 2006; Sanson-Fisher et al., 2000).

In summary, the major themes identified and described by survivors at this time of transition were: the experience of loss, the experience of changing emotions, the

experience of resilience and the experiences relating to empowerment. These themes have been discussed in relation to current available literature and identified congruence between the current study and available knowledge as well as gaps that this study begins to address. The factors which were identified as having improved or exacerbated the transition experience were intricately interwoven throughout this phase. Hope was the overarching positive determinant which improved the survivors' transition through this time, whilst an information limitation was identified as the overarching exacerbating factor. However, as discussed in the discussion, achieving stability between hope and information is a complex challenge that must be survivor-led, accessible, negotiable and achievable.

Phase Two: quantitative phase (Instrument development and testing)

Introduction

As previously discussed the aim of this phase of the research was to develop an instrument which could be used to explore the needs of a large population of cancer survivors as they transitioned from chemotherapy treatment to life after cancer. Rather than develop a new instrument, the decision was made to adapt the Quality of Life-Cancer Survivor (QOL-CS) tool as it comprises many items that were consistent with the key descriptors identified from the qualitative interviews conducted in this study. Given the universal acceptance and current use of this tool, as well as the relevance of many of the items to the population of interest in this study, the researcher opted to make a minor adaptation to this instrument by adding seven additional items designed to capture the full scope of key descriptors (needs) identified from the qualitative phase of this study.

The main identifiable distinctions between the items in the QOL-CS and the findings in Phase One of this study were in relation to information needs. Therefore the original questions in the instrument remained relevant and were not modified in any way. Seven additional items were added to reflect the key areas identified in relation to information seeking and deficits. These items were added to a new section titled, *Information needs at the end of chemotherapy treatment*.

The additional questions were:

- Did you receive enough information about physical changes at the end of chemotherapy treatment?
- Do you understand everything that happened to you during treatment?
- Do you understand your plan of care from now on, including timeframes?

- Have you tried to find information from other places? (i.e. cancer council, internet, friends)
- Were you provided with any written information about life after chemotherapy?
- If you were provided with information, was it useful?
- Have you been able to make any plans for your future?

The title of the original instrument was changed from the Quality of Life-Cancer Survivors (QOL-CS) to the Quality of Life- Chemotherapy Cancer Survivors (QOL-CCS).

The QOL-CCS was then tested by an expert panel of six chemotherapy nurses for clarity, apparent internal consistency and content validity. Expert panel members were recruited from the same tertiary centre as the participants in Phase One. Each panel member met the criteria that had previously been considered to ensure their expertise and therefore suitability to undertake the psychometric testing of the adapted instrument QOL-CCS. This process resulted in tiredness being added after the word fatigue in question one, diarrhoea, vomiting, menstrual changes and fertility all being developed into individual questions within the physical well being section. Question 25 changed from depression to emotional distress in an attempt to remove a medical diagnostic term and a word which carries a stigma in wider society.

The changes and suggestions identified by the expert panel are in part due to language changes or the awareness of language. It is now 17 years since the original tool was devised and during this time there has been a rapid rise in awareness of information provision in language that is acceptable to patients (Jefford, et al., 2007). Furthermore, there have been rapid advances in chemotherapy treatments in the past 17 years; physical side effect profiles have changed considerably, anticipatory nausea and vomiting once a constant research and publication topic is now minimal due to the introduction of highly effective anti-emetics changing the emesis profile of chemotherapy side effects (Sharma, Tobin, and Clarke, 2005). Likewise, diarrhoea is now recognised much more commonly as a chemotherapy side effect with the introduction of new chemotherapy agents (Richardson and Dobish, 2007). The changes that were recommended are therefore much more a reflection of physical changes related to treatment. The domains of psychological, social and spiritual apart from a slight language change as discussed appear to remain as relevant today as they were 17 years ago. In addition the newly added items based on feedback from in Phase One received no comments or scores less than 100%.

Summary

Overall the preliminary assessment of clarity, content validity and internal consistency was successfully achieved in keeping with the original purpose of this Master's study. The researcher plans a more comprehensive psychometric assessment of the QOL-CCS in future phases, as detailed in the summary of Chapter Five. Once the QOL-CCS has been validated it is anticipated it will be used for a much larger scale study with survivors in the first three months as they transition from chemotherapy to life after cancer. The findings of this larger population of survivors will then contribute to the care planning and information sharing that is currently delivered with a limited evidence base.

Limitations and Strengths

Limitations

The researcher acknowledges a number of limitations to this study. The first is the extent to which the findings of Phase One can be generalised to the wider survivorship community with any degree of certainty. Results from a population of 14 participants from one tertiary treatment centre cannot represent the many thousands of cancer survivors currently living in Australia.

Second, one third of the participants had the same haematological diagnosis of myeloma. The potential differences in needs between haematology and medical oncology patients were considered and discussed with the Director of Haematology prior to commencing the study. As the focus of the research was on patient needs in the immediate post chemotherapy treatment period it was considered appropriate to include both groups of patients to provide a baseline of information related to the immediate impact of chemotherapy treatment.

Third, the expert panel currently work in the same cancer centre and whilst this provides congruence to this study, it is not possible to be reflective of the many thousands of cancer health professionals practicing in Australia. In addition the panel were all from the same discipline of nursing. This may have been strengthened by the addition of a medical oncologist and haematologist. Finally, the scope ofthis study was limited by the time available for completion of a Master's research project.

Strengths

All the interviews and analysis were undertaken by the same researcher who was able to reflect not only the words, but the passions and inferences which were applied to the conversations. This ensured that a consistent approach of interpretation occurred across all 14 interviews. There is a high level of academic and clinical interest in the field of cancer survivorship, particularly within Australia. This study has provided a strong basis for a future program of research with an instrument that is ready to be utilised immediately. This will provide opportunities for study findings to be useful and clinically relevant in the very near future.

Conclusion

This study intended to explore and describe the experiences in transition from the completion of chemotherapy to life as a cancer survivor. The aims for Phase One and Phase Two of this study were achieved. Specifically, the experiences following the completion of chemotherapy have been themed following analysis using Grounded Theory to a descriptive level. These identified themes have been the key to adaptating and testing an instrument which is now considered ready for piloting in a large population of cancer survivors. The identified themes have been explored in the wider literature and whilst elements have demonstrated synergy, there has also been a demonstrated lack of research related to this cohort of cancer survivors at this particular time of transition. The development of the adapted instrument QOL-CCS will add to the current body of research evidence and provide a basis for a larger population study and the shaping of future cancer survivorship care delivery based upon its findings. The findings from Phase One provide a strong base on which chemotherapy nurses can begin to question the role that they play in preparing cancer patients for life after chemotherapy, particularly regarding the provision of information and resources which assist self-management.

Recommendations

Research

- The key recommendation from this study is build on this work by conducting a follow-up study to explore the psychometric properties of the revised QOL-CCS tool, followed by implementation of the tool in a large scale study of this population across all tertiary chemotherapy services in Western Australia.
- Once there is a more comprehensive understanding of this populations' needs at this particular time, then further research and developments would be warranted.
- The development and testing of delivery methods to facilitate self management of survivorship issues is also recommended.

Education

- The development of appropriate information materials such as pamphlets, DVD's web resources and methods of dissemination to reach all survivors in a timely manner.
- The introduction of transition education sessions to patients during the last two weeks of chemotherapy treatments and to chemotherapy nurses to further reinforce the information.

Clinical

- The development of peer led survivorship clinics,
- The introduction of psychosocial 'drop in' clinics where survivors could seek council from allied health, social work and legal teams regarding financial, social or psychological issues,
- The development of nurse-led clinics for patients post chemotherapy across a continuum from tertiary centres to practice nurses in primary care,
- The development of shared cared models immediately post chemotherapy between specialists and primary care.

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Appendix A: Invitation letter to participant

Opt out form

Participant information sheet

9th April 2010

Dear Participants name

We are writing to ask if you would be willing to be contacted about a project **"Issues and concerns after completing chemotherapy"** for which we hope to recruit suitable patients from this hospital. From our records you would appear to be a potential participant for this study.

We would like to improve the amount and type of information that we provide to people when they complete chemotherapy treatment. In order to understand how we can make these improvements we are conducting a research study which involves an interview by telephone. We would like to interview people who have completed chemotherapy within the last 1-4 months.

If you do not wish to hear more about this study, or be contacted further, could you please complete the attached slip and return in the envelope provided. If we do not hear from you within 3 weeks we will assume that you are willing to be contacted and Violet Platt will contact you shortly after this to give you more information regarding the study.

We have included an information sheet which provides further information about this study. If you are happy to be included or wish to discuss this further you do not need to do anything. You will be contacted during the week beginning 3rd May 2010 to discuss this further.

Whether or not you participate in this project, any future care you receive at this hospital will not be affected in any way.

This study has been approved by Sir Charles Gairdner Hospital and Edith Cowan University Ethics Committees and the confidentiality of all participants is assured.

Thanks for considering this request

Yours Sincerely

Violet Platt
Director of Nursing
WACPCN

Tina Crosbie
Haematology CNS
SCGH

PLEASE TICK THE BOX, THEN SIGN, DATE AND RETURN THE SLIP IN THE ENVELOPE PROVIDED.

☐ **Please do not contact me regarding my participation in the Study "Issues and concerns after completing chemotherapy treatment"**

Name: Participants name

Signature:…….

Date :……

Sir Charles Gairdner Hospital

PARTICIPANT INFORMATION SHEET

Lay Title
What are the needs of people in the first 3 months following the completion of chemotherapy?

Title of Study
Survivorship issues following completion of chemotherapy.

Investigator's Names
Mrs Violet Platt
A/Professor Leanne Monterosso
Ms Christina Crosbie

Please take time to read the following information carefully and discuss it with your friends, family and general practitioner if you wish. Ask us any question if some part of the information is not clear to you or if you would like more information. Please do this before you sign this consent form.

Who is funding this study?
This is a study for a Master in Research Nursing at Edith Cowan University. The study is funded by the student Mrs Violet Platt undertaking the research, and the School of Nursing, Midwifery and Postgraduate Medicine.

Contact persons:
Should you have questions about the study you may contact:

Mrs Violet Platt Phone No 0439 512 903 (after hours) 0439 512 903

All study participants will be provided with a copy of the Information Sheet and Consent Form for their personal records.

You may decide to be in the study or not take part at all. If you do decide to take part in this study, you may stop at any time. However, before you decide, it is important that you understand why this research is being done and what it will involve.

Whatever your decision, this decision will not lead to any penalty or affect your regular medical care or any benefit to which you are otherwise entitled.

The following information sheet will explain the study and will include details such as:

- Why this study might be suitable for you;

- The nature of your participation including how many visits you will make to the hospital
- Your rights and responsibilities

What is the purpose of the study?
This study will identify if there are common issues experienced by people when they complete chemotherapy treatment following a diagnosis of cancer, and whether the hospital team have provided appropriate information to deal with any issues that may arise. The study will take place at Sir Charles Gairdner Hospital in the medical oncology department. We will be inviting up to 24 people who are completing a minimum of four cycles of chemotherapy and have no further cancer treatment planned.

Why is this study suitable to me?
This study is suitable for patients with cancer who have completed chemotherapy and have no further cancer treatments planned.

How long will I be in this study?
This study will run over three months following the completion of your chemotherapy.

What will happen if I decide to be in this study?
If you decide to participate in this study, you will be given a small diary in which you can jot down issues as they occur to help your remember them. This is not compulsory.

You will also be asked to complete a brief interview with the researcher (Violet Platt) 12 weeks after your last chemotherapy treatment and no more than 16 weeks after this date. This will last no longer than 30-60 minutes and will take place by telephone at a time convenient to you. This interview will be audio taped and transcribed (typed into a written document) which will not contain any personal identifying information. The recording will then be destroyed.

The interviewer will ask questions about:
- Your overall quality of life in the weeks since completion of treatment, if any issues or side effects caused you trouble and if any further information could have been provided to support you during this time.

Personal details such as your age, gender, type of cancer, type of cancer treatment and when you commenced treatment will have been recorded at the time you agreed to be a part of the trial.

Your involvement in the study will cease following the telephone interview.

Are there any reasons I should not be in this study?
No

What are the costs to me?
No personal costs will be incurred.

What are the possible benefits of taking part?
We wish to discover if we are preparing people properly for moving back into life after cancer treatment. We hope to discover the issues that affect the quality of life in people who have received cancer chemotherapy in order to improve the way we care for, and prepare individuals more appropriately in the future.

How will my safety be ensured?
Taking part in this study will not affect your personal safety.

What alternatives do I have to going on this study?
You may choose not to be a part of this study. This will not affect the current care you are receiving.
What are the possible side effects, risks and discomforts of taking part?
None.

What if new information comes along during the study?
Sometimes new information about treatments becomes available as a study progresses. You will be told about any information that could be important to your decision to continue in the study. If you then want to continue in the study, you may be asked to sign a revised consent form.

Stopping study treatment early:
Sometimes a study needs to be stopped early due to unforeseen circumstances. If this occurs the reasons will be explained to you.

What happens if I change my mind after I have done the interview and wish to withdraw from the study?
If you decide to withdraw from the study after your interview, then simply inform the researcher and your interview will be deleted and all related information will be destroyed, none of your information will be used in the study.

What happens at the end of the study?
At the end of the study you will continue with your cancer care follow up plan as per normal department follow up.

What if something goes wrong?
In the unlikely event you experience any emotional distress during the interview, it will be stopped immediately. If you need to be referred to a health professional for emotional support, the research assistant will ensure this occurs as soon as possible.

This treatment will be provided at no cost to you.

Your participation in this study does not prejudice any right to compensation which you may have under statute or common law.

Will my taking part in this study be kept confidential?
The researchers will need to collect personal data about you, which may be sensitive (e.g. date of birth and relevant health information). The researchers may also need to get some of your health information form your medical records.

Any personal or health information will be kept private and confidential. It will be stored securely and only authorised persons, who understand it must be kept confidential, will have access to it. Your study details will be given a number so that your identity will not be apparent. The study records will be kept in a locked filing cabinet in the office of the Research supervisor at Edith Cowan University during the study and in a locked archive for at least 5 years from the time the study is closed, and will be destroyed at any time thereafter.

Authorised representatives of the study funders, the investigators, the Hospital Human Research Ethics and Research Governance Committees may require access to your study records to verify study procedures and/or data. In all cases when dealing with your information, these people are required to comply with privacy laws that protect you.

Will I find out the results of the study?
You will be sent a summary of the findings from this study. The result of the research will be made available to health professionals through medical journals or meetings, but you will not be identifiable in these communications. By taking part in this study you agree not to restrict the use of any data even if you withdraw. Your rights under any applicable data protection laws are not affected.

Who has reviewed the study?
The Human Research Ethics Committee of Sir Charles Gairdner Hospital has reviewed this study and given approval for the conduct of this research trial. If you have any ethical concerns regarding the study you can contact the secretary of the Sir Charles Gairdner Hospital Human Research Ethics Committee on telephone number (08) 93462999. The study is also approved by the Curtin University of Technology Human Research Ethics Committee (Approval Number HR 73/2008). If needed, verification of approval can be obtained from either by writing to the Curtin University Human Ethics Committee, c/o Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au. This study is also approved by Edith Cowan University Human research Ethics Committee c/o Research Ethics Office, Edith Cowan University, 270 Joondalup Drive, Joondalup, WA 6027 or by telephoning 6304 2170 or by emailing research.ethics@ecu.edu.au

CONSENT FORM

Survivorship issues following completion of chemotherapy

Investigators:
Mrs Violet Platt,
Ms Christine Crosbie,
A/Professor Leanne Monterosso

Participant Name:_____

Date of Birth: _____

1. I have been given clear information (verbal and written) about this study and have been given time to consider whether I want to take part.

2. I have been told about the possible advantages and risks of taking part in the study and I understand what I am being asked to do.

3. I have been able to have a member of my family or a friend with me while I was told about the study. I have been able to ask questions and all questions have been answered satisfactorily.

4. I know that I do not have to take part in the study and that I can withdraw at any time during the study without affecting my future medical care. My participation in the study does not affect any right to compensation, which I may have under statute or common law.

5. I agree to take part in this research study and for the data obtained to be published provided my name or other identifying information is not used.

If you are unclear about anything you have read in the Participant Information Sheet or this Consent Form, please speak to your doctor before signing this Consent Form.

Name of Participant Signature of Participant
Date

Name of Investigator Signature of Investigator
Date

The Sir Charles Gairdner Hospital Human Research Ethics Committee has given ethics approval for the conduct of this project. If you have any ethical concerns regarding the

study you can contact the secretary of the Sir Charles Gairdner Hospital Human Research Ethics Committee on telephone number (08) 93462999

All study participants will be provided with a copy of the Information Sheet and Consent Form for their personal records.

Appendix B: Interview questions

Welcome

- Ensure interviewee is comfortable, needs are met, drinks etc.
- Confirm interviewee is comfortable with the purpose and process around the interview and happy for this to be recorded.

Opening Question

How have the last 3 months been for you since completing treatment?

- Opening, question to set the scene and relax the person

Main questioning

1. Can you tell me about any side effects that you may have experienced?

    Prompts:
    Nausea & Vomiting
    Sore mouth – eating & drinking
    Constipation or diarrhoea
    Fatigue / tiredness
    Altered sleep patterns
    Pain
    Any other symptoms

2. How has it been for you in settling back into your life as it was before your cancer treatment?

    Prompts:
    Has anything been difficult?
    Work
    Family expectations
    Friends

3. How have you been feeling in the last (12) weeks?

    Prompts:
    Tearful
    Glad to be alive
    Anxiety about treatment success

4. Can you tell me about the information & support that you received?

    Prompts
    What else would you have liked to know?
    How and when would you like to know this?

5. Would you like to tell me about any support from GPs or hospital staff that you may have received?

6. Is there anything else that you would like to tell me about this time?

Finish with another thank you

Appendix C: Transcriber confidentiality form

(ECU Letterhead)

Transcriber Confidentiality Agreement Form

Applicants name:

As an employee of the research title …
I certify that I have read the sections of this document regarding the legislation and policies of the National Health & Medical Research council (NHMRC) and Edith Cowan University ("the University") that govern access to and use of participant and employee personal information.

I acknowledge that I have been instructed regarding the confidentiality of the project's activity and records, and except as required by law in the course of my duties or where instructed in writing by management, I am aware that all project raw data records, files and memoranda are to be treated in strict confidence.

I agree to keep project information confidential by observing the following:

- I will comply with the legislation, the policies of the NHMRC and the University that govern access to and use of information contained in employee and participant records and raw data and other university documents or systems.

- I will make a reasonable effort to access only the information/ data that is relevant and necessary for me to perform my duties for the project.

- I will be a responsible user of the information/data, whether it relates to my own project or other projects, by adhering to the University's rule of conduct whenever I use E-mails, handle files, and answer, telephone or fax queries.

- I will restrict access by others to any confidential information and/or data that I obtain, by following the University and the NHMRC policies regarding the storage of information and data under secure conditions.

- Before sharing information/data with others, electronically or otherwise, I will exercise reasonable care to ensure that the recipient is authorized to receive that information/ and understands his/her responsibilities as a receiver of this information/data.

- When sharing information with appropriately authorized personnel, I will ensure that I am in a private setting where others cannot hear, see or otherwise unduly access the confidential information.

- I will make every reasonable effort to interpret the information/data I obtain in an accurate, accountable, ethical and professional manner.

- I will use information/data that I obtain only for tasks specifically related to the project I have been employed under.

- I will log-off or secure any computer system that contains participant and/or employee information/data when I am not actively using it. (Securing the

information/data is considered to occur through the use of password-protected screen saver)

- I will keep any password(s) issued to me, ore devised by myself, confidential and will not disclose them to others unless my immediate supervisor authorizes such disclosure in writing.

- When working on my home computer, I will password protect any project information/data to ensure that there is no inappropriate access.

- I will not disseminate project information/data from my home computer without appropriate authorization from my supervisor for the release.

- I will dispose of confidential information/data when I have finished using them in a manner that will preserve the documents confidentiality (e.g. in accordance with ethics form requirements (where applicable) or NHMRC and/or University policies, which ever is the most stringent.)

- I understand that audits might be conducted on the project, such as financial telephone or E-mail usage, records, etc. and I acknowledge that I am required to ensure compliance with these audits.

- I understand that this confidentially agreement will remain in force until my employment on this project is terminated (either voluntary or involuntary)

- I understand that my employer has the right to take disciplinary action up to and including my termination of my employment for breaches of confidentiality.

Signature ----------

Date ----------

Witness ----------

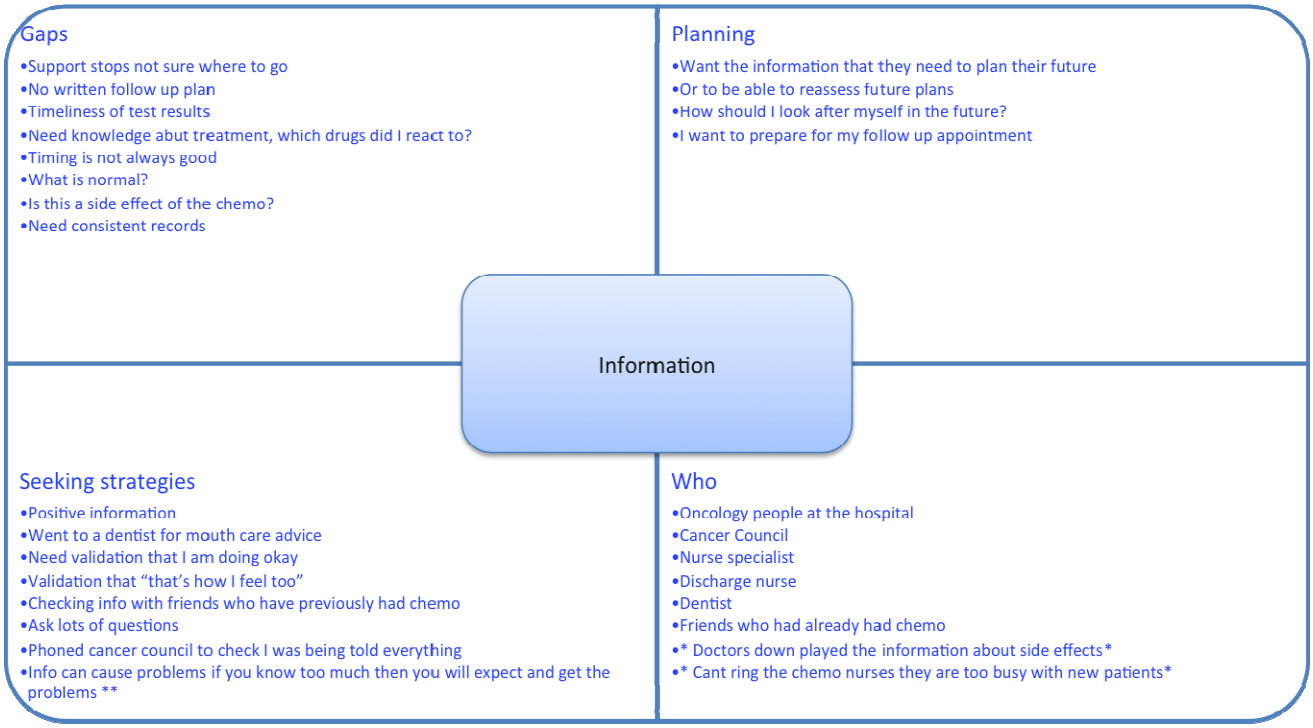
Date ----------

Appendix D: Open and axial codes identified.

	Level 1 Codes	Level 2
	Different phases	Planning
2	Looking ahead to the future	
3	Positive approach to finishing chemotherapy	
4	Planning for the future	
5	During chemotherapy / thinking time	chemotherapy
6	Rewards at the end of treatment	
7	Lots of support whilst on chemotherapy	
8	Transition to non treatment	Transition
9	On a journey	
10	Changes to work status	
11	Need to change from being a patient	
12	‘new life’	
13	Transition behavior	
14	Unexpected feelings	Emotion
15	Depression	
16	Emotional feeling deflated	
17	Glad its over – relief	
18	Enjoying all the little things	
19	Wants to celebrate	
20	Pressure to be different and happy	
21	Afterwards need emotional support – feel vulnerable	
22	Detox after chemotherapy	
23	Psychological – residual chemotherapy	
24	Enjoys meeting/ talking to others	
25	Get energy back and boost mood	
26	Exciting to get energy back	
27	Unforeseen upsetting moments	
28	Disruption to life after treatment	
29	Surprising – a challenge	
30	Time after treatment	Time
31	Later months physically stronger	
32	Four months, physically well, look normal	
33	On treatment no energy and lots of time	
34	After treatment lots of time, not well enough	
35	Physically weak in the first few weeks	
36	During treatment – don’t feel like a victim	Patient role / time
37	Lack of structure not in a cycle	Loss of patient structure Loss of patient identity Loss Role change and loss
38	Not having treatment, loss of identity	
39	After chemotherapy, isolation, not being cared for	
40	Loss of friendships	
41	Not belonging	
42	Out patient and the system has finished with you	
43	Finances	Finances
44	Tired	
45	Hair growth, eyebrows and alopecia	
46	Constipation	

47	Nausea	Physical
48	Mouth care	
49	Too tired to work	
50	Body stiffness / moving pains	
51	Don’t look different/ what others think	People and others expectations
52	Treated normally by others	
53	People are kind during treatment	
54	Miss the amazing conversations	
55	Key people ie psychologist	
56	Can’t avoid the feelings	Normalizing
57	Everyone goes through a crisis	
58	In a different place, not identifying with other survivors	Different
59	Sense of community- ‘looking for belonging’	
60	Tolerance	
61	Altered expectations	
62	Cant return to normal/ feel different after treatment	
63	Wants to meet other survivors without recurrence	Recurrence/ avoidance Recurrence
64	Worry about recurrence	
65	Wishful use of skills	Re evaluate
66	Reality of finances/ part time to exist	
67	Opportunities based on importance/ community benefit	
68	Wishful thoughts versus reality	
69	Need to find balance between stress, energy and priorities	
70	Questioning future directions and work role	
71	Making a commitment & ‘re-engaging’	
72	Getting on with it / keeping active	Values and attitude
73	Attitude/ approach important	
74	Assist ‘ long term benefit	
75	Feeling a bit lost, where to from here?	Information
76	Information timing and booklets	
77	Identify community support	
78	Doesn’t know what’s normal follow up	
79	Started smoking – rebelling	Taking control, making choices
80	Feeling virtuous – making health choices	
81	Coping mechanism – old behaviour	
82	Feelings about self	

Appendix E: How the codes developed to themes


Gaps
•Support stops not sure where to go
•No written follow up plan
•Timeliness of test results
•Need knowledge abut treatment, which drugs did I react to?
•Timing is not always good
•What is normal?
•Is this a side effect of the chemo?
•Need consistent records
Planning
•Want the information that they need to plan their future
•Or to be able to reassess future plans
•How should I look after myself in the future?
•I want to prepare for my follow up appointment
Information
Seeking strategies
•Positive information
•Went to a dentist for mouth care advice
•Need validation that I am doing okay
•Validation that "that's how I feel too"
•Checking info with friends who have previously had chemo
•Ask lots of questions
•Phoned cancer council to check I was being told everything
•Info can cause problems if you know too much then you will expect and get the problems **
Who
•Oncology people at the hospital
•Cancer Council
•Nurse specialist
•Discharge nurse
•Dentist
•Friends who had already had chemo
•* Doctors down played the information about side effects*
•* Cant ring the chemo nurses they are too busy with new patients*

Appendix F: Example of memo showing trail from codes to the themes

Example of a memo showing open data exploration from which open codes were identified.

Date: June 17th 2011

Properties and dimensions of the survivorship experience relating to feeling different.

"Initially I was quite excited to finish chemo and really looking forward to that, wishful thinking. You know, all the things that you are going to do. So I suppose having had chemo I spent a lot of time thinking of the resolutions if you like of things I was going to do. But I was actually quite surprised I went to see a psychologist at the same time to kind of pre-empt the transition back into non treatment and I was really surprised how depressed I got and how emotional I became probably about a month after treatment [stopped]. Talking to the psychologist, she said its actually quite common and was quite relieved to see me upset, its quite common because people don't have a structure anymore. And I think I felt like I had landed back on earth but in a foreign country, if that makes sense, just the sense that I cant just re join the flock again and carry on as before."

Quote from interview with survivor (S04)

Memo

This women is describing her experiences of how different or changed she feels following her diagnosis and treatment for cancer. The description is from her perspective, in the description she describes the properties of anticipation, planning, expectation, excitement, distraction, rewarding, surprise, low mood, mixed emotions, unexpected emotions, normalising, validation from others, not belonging.

Appendix G : Permission to utitlise Quality of Life – Cancer Survivor Tool

From: BFerrell
> To: violet platt
> Date: Fri, 23 Mar 2012 06:38:08 -0700
> Subject: Re: Quality of life patient/ cancer survivor version
>
> You are welcome to use and adapt any of our instruments. All are on our website http://prc.coh.org.
>
> Good luck with your research.
> Betty Ferrell
>
> ----- Original Message -----
> From: violet platt
> Sent: Friday, March 23, 2012 06:30 AM
> To: Ferrell, Betty
> Subject: Quality of life patient/ cancer survivor version
>
> Dear Dr Ferrell

> > I understand that you and Marcia Grant have been very generous in allowing duplication of the Quality of Life cancer survivor version tool. I would like to request permission to add some questions (7 in total to the tool) regarding information needs in this phase?
> > I have recently been under taking a Masters degree in nursing research, I am especially interested in survivors as they transition from chemotherapy treatment to life after cancer. As an oncology nurse I have found that myself and my team all have a different set of, end of treatment 'pep' talks based on our different experiences. Therefore my research set out to understand the patients experiences. I performed 14 interviews and identified a range of themes all of which harmonise very well with your tool.
> > As my interest is in ensuring that as chemotherapy nurses we prepare people in the most effective way, I would like to use your tool and add some information questions which will go through all the required psychometric testing before utilising with a larger population. I will fully acknowledge all of the great work that has been happening in City of Hope over the years which has been highly inspirational to me and I am more than happy to share my thesis (once marked) with your team, as a small contribution to your vast works.
> > Many Thanks for your consideration of this request
> Kindest Regards
> Violet Platt
> > Director of Nursing > WA Cancer and Palliative Care Network, Western Australia
>

Appendix H Tools utilised by the expert panel to assess clarity, internal consistency, content validity.

CLARITY

Instructions

This survey is based on a previous work by Ferrell et al. (1995). The original survey was designed to find out more about the long term quality of life issues of cancer survivors. I am interested in the issues for cancer survivors in the short term period up to 6 months after they complete chemotherapy. I have modified this survey to ensure that questions are relevant to cancer survivors as they transition from completion of chemotherapy. These modifications have been made based on the findings of qualitative interviews with cancer survivors who had recently completed chemotherapy. You are being asked to rate: (a) the instructions in the survey, and (b) each question in the survey on it's clarity since you are familiar with this content.

(a) Are the survey instructions clear? Circle either yes or no on the next line.

YES NO

(b) Read each question in the survey separately and respond to the same number on the response sheet. Beside each question number on the response sheet circle **C (clear)** or **U (unclear)** to indicate whether the question is **clear** or **unclear** to you.

After you finish you may wish discuss your comments with the researcher.

Thankyou for your assistance.

Code ____

RESPONSE SHEET: CLARITY

Please indicate whether each question is **C (clear)** or **U (unclear)** to you.

Circle One ***Comments***

Physical Well Being

1. C U

_____

2. C U

_____

3. C U

_____

4. C U

_____

5. C U

_____

6. C U

_____

7. C U

_____

8. C U

_____

Psychological Well Being

9. C U

_____

10. C U

_____

11. C U

_____

12 C U

_____

13. C U

_____

14. C U

_____

15. C U

_____

16. C U

_____

17. C U

_____

How distressing were the following aspects of your illness and treatment?

18 C U

_____

19. C U

_____

20. C U

_____

21. C U

_____

22. C U

_____

To what extend are you fearful of:

23. C U

_____

24. C U

_____

25. C U

_____

26. C U

_____

Social Concerns

27. C U

_____

28. C U

_____

29. C U

_____

30. C U

_____

31. C U

_____

32. C U

_____

33 C U

_____

34. C U

_____

Spiritual Well Being

35. C U

_____

36. C U

_____

37. C U

_____

38. C U

_____

39 C U

_____

40. C U

_____

41. C U

_____

42. C U

_____

Information needs at the end of chemotherapy treatment

43. C U

_____

44. C U

_____

45. C U

_____

46. C U

_____

47. C U

_____

48. C U

_____

CONSISTENCY

Instructions

In this section, you are being asked to look at the questions in the survey and decide if you think they seem to belong together.

Read the entire survey first. After you finish reading the survey, answer question (a) at the top of the Response Sheet, then answer the following question (b) for each question in the survey. Answer by circling the response you choose under question (b). Add any comments you wish to explain your answers.

Thankyou for your assistance.

Code ____

RESPONSE SHEET: CONSISTENCY

(a) Do these questions generally belong together?

YES ***NO***

(b) Does each question belong in the survey?

	Please circle		**Comments**
1.	Y	N	_____
2.	Y	N	_____
3.	Y	N	_____
4.	Y	N	_____
5.	Y	N	_____
6.	Y	N	_____
7.	Y	N	_____
8.	Y	N	_____
9.	Y	N	_____
10.	Y	N	_____
11.	Y	N	_____
12.	Y	N	_____
13.	Y	N	_____
14.	Y	N	_____
15.	Y	N	_____
16.	Y	N	_____
17.	Y	N	_____
18.	Y	N	_____
19.	Y	N	_____
20.	Y	N	_____
21.	Y	N	_____

22. Y N _____

23. Y N _____

24. Y N _____

25. Y N _____

26. Y N _____

27. Y N _____

28. Y N _____

29. Y N _____

30. Y N _____

31. Y N _____

32. Y N _____

33. Y N _____

34. Y N _____

35. Y N _____

36. Y N _____

37. Y N _____

38. Y N _____

39. Y N _____

40. Y N _____

41. Y N _____

42. Y N _____

43. Y N _____

44. Y N _____

45. Y N _____

46. Y N _____

47. Y N _____

48. Y N _____

CONTENT VALIDITY

Instructions

In this section, you are asked to look at the questions in the survey and decide if you think they seem to belong together.

Read the entire survey first. After you finish reading the survey, answer question (a) at the top of the response sheet – either **YES** or **NO**. Then answer question (b) for each question in the survey. Answer by circling the response you choose under question (b) – either **Y (YES)** or **N (NO)**. Please add any relevant comments you wish to explain your answers.

Thankyou for your assistance.

Code ____

RESPONSE SHEET: CONTENT VALIDITY

Label: Quality of Life Chemotherapy Cancer Survivor Version

Definition: The survey is intended to measure the quality of life of cancer survivors as they transition from completion of chemotherapy to life after cancer.

(a) In general, do the label and definition fit the whole set of questions in the survey? Answer once for the whole survey by circling either YES or **NO** on next line.

YES NO

(b) Does each question fit the label and definition? Please circle **Y (YES)** or **N (NO).**

	Circle One		***Comments***
1.	**Y**	**N**	
2.	**Y**	**N**	
3.	**Y**	**N**	
4.	**Y**	**N**	
5.	**Y**	**N**	
6.	**Y**	**N**	
7.	**Y**	**N**	
8.	**Y**	**N**	
9.	**Y**	**N**	
10.	**Y**	**N**	
11.	**Y**	**N**	

12 **Y** **N**

13. **Y** **N**

14. **Y** **N**

15. **Y** **N**

16. **Y** **N**

17. **Y** **N**

18 **Y** **N**

19. **Y** **N**

20. **Y** **N**

21. **Y** **N**

22. **Y** **N**

23. **Y** **N**

24. **Y** **N**

25. **Y** **N**

26. **Y** **N**

27. **Y** **N**

28. **Y** **N**

29. **Y** **N**

_____

30. **Y** **N**

_____

31. **Y** **N**

_____

32. **Y** **N**

_____

33 **Y** **N**

_____

34. **Y** **N**

_____

35. **Y** **N**

_____

36. **Y** **N**

_____

37. **Y** **N**

_____

38. **Y** **N**

_____

39 **Y** **N**

_____

40. **Y** **N**

_____

41. **Y** **N**

_____

42. **Y** **N**

_____

43. **Y** **N**

_____

44. **Y** **N**

_____

45. **Y** **N**

_____

46. **Y** **N**

_____

47. **Y** **N**

_____

48. **Y** **N**

_____

Code ____

(c) Is the question unique, i.e. not repetitious? Please circle **Y (YES)** or **N (NO).**

Circle One ***Comments***

1. **Y** **N**

_____

2. **Y** **N**

_____

3. **Y** **N**

_____

4. **Y** **N**

_____

5. **Y** **N**

_____

6. **Y** **N**

_____

7. **Y** **N**

_____

8. **Y** **N**

_____

9. **Y** **N**

_____

10. **Y** **N**

_____

11. **Y** **N**

_____

12 **Y** **N**

_____

13. **Y** **N**

_____

14. **Y** **N**

_____

15. **Y** **N**

_____

16. **Y** **N**

_____

17. **Y** **N**

_____

18 **Y** **N**

_____

19. **Y** **N**

_____

20. **Y** **N**

_____

21. **Y** **N**

_____

22. **Y** **N**

23. **Y** **N**

24. **Y** **N**

25. **Y** **N**

26. **Y** **N**

27. **Y** **N**

28. **Y** **N**

29. **Y** **N**

30. **Y** **N**

31. **Y** **N**

32. **Y** **N**

33 **Y** **N**

34. **Y** **N**

35. **Y** **N**

36. **Y** **N**

37. **Y** **N**

38. **Y** **N**

39 **Y** **N**

_____

40. **Y** **N**

_____

41. **Y** **N**

_____

42. **Y** **N**

_____

43. **Y** **N**

_____

44. **Y** **N**

_____

45. **Y** **N**

_____

46. **Y** **N**

_____

47. **Y** **N**

_____

48. **Y** **N**

_____

Code ____

(d) Are there any questions you think should be added to the survey?

Appendix I : Invitation letter to expert panel

189 Royal Street
East Perth
WA 6004
23 -09-2011

Dear

I am writing to ask for your assistance with my Masters Research study. As an expert in the field of cancer nursing and chemotherapy I would be grateful if you could review the adapted survey **Quality of Life Chemotherapy Cancer Survivor Version** for content validity, internal consistency and clarity the tools for this review are included.

The tool has been adapted from Ferrell et al (1995) Quality of Life cancer Survivor Version which was developed for long term cancer survivors, the adaption's that have been made are as a result of findings from recent qualitative interviews that I have undertaken with individuals who have completed chemotherapy within the previous 6 months.

The review should take approx 30 mins, I would be grateful if you could return your reviews by Monday 3rd October 2011. If you would like a paper copy of this review please let me know and I will arrange this

Thank you in anticipation

Kindest regards

Violet Platt

Appendix J: Original Quality of Life Cancer survivor tool

NATIONAL MEDICAL CENTER AND
BECKMAN RESEARCH INSTITUTE

Quality of Life Patient/Cancer Survivor Version

Dear Colleague:

The Quality of Life Instrument (CANCER PATIENT/CANCER SURVIVOR VERSION) is a forty one-item ordinal scale that measures the Quality of Life of a cancer patient. This tool can be useful in clinical practice as well as for research. This instrument can be administered by mail or in person. The instrument originated in our pain research and has been recently adapted for use in long term cancer survivors. A Hispanic version of this questionnaire is also included.

Directions: The patient is asked to read each question and decide if he/she agrees with the statement or disagrees. The patient is then asked to circle a number to indicate the degree to which he/she agrees or disagrees with the statement according to the word anchors on each end of the scale.

The scoring should be based on a scale of 0 = worst outcome to 10 = best outcome. Several items have reverse anchors and therefore when you code the items you will need to reverse the scores of those items. For example, if a subject circles "3" on such an item, (10-3 = 7) thus you would record a score of 7. The items to be reversed are: 1-7, 9, 16-27, & 29-34 and 38. Subscales can be created for analysis purposes by adding all of the items within a subscale and creating a mean score.

You are welcome to use this instrument in your research/clinical practice to gain information about Quality of Life of patients. You have permission to duplicate this tool.

The QOL instrument is based on previous versions of the QOL instrument by researchers at the City of Hope National Medical Center (Grant, Padilla, and Ferrell). This instrument was revised in cancer survivorship studies and includes 41 items representing the four domains of quality of life including physical well being, psychological well being, social well being and spiritual well being. A study was conducted in 1995 to evaluate the psychometrics of this revised instrument as a mail survey to the membership of the National Coalition for Cancer Survivorship. This survey included a Demographic tool, the QOL tool and the FACT-G tool developed by Cella. Psychometric analysis was performed on 686 respondents including measures of reliability and validity. Two measures of reliability included re-test and internal consistency. In order to perform test re-test reliability, a randomly selected sample of 150 subjects who completed the initial QOL survey were asked to repeat this tool approximately two weeks later. 110 of the 150 subjects responded for an overall response of 73%. Of the 110 respondents, only those with complete data sets on all variables were used (N=70). The overall QOL-CS tool test re-test reliability was .89 with subscales of physical r=.88, psychological r=.88, social r=.81, spiritual r=.90. The second measure of reliability was

computation of internal consistency using Cronbach's alpha co-efficient as a measure of agreement between items and subscales. Analysis revealed an overall r=.93. Subscale alphas ranged from r=.71 for spiritual well being, r=.77 for physical, r=.81 for social, and r=.89 for psychological. Several measures of validity were used to determine the extent to which the instrument measured the concept of QOL in cancer survivors. The first method of content validity was based on a panel of QOL researchers and nurses with expertise in oncology. The second measure used stepwide multiple regression to determine factors most predictive of overall QOL in cancer survivors. Seventeen variables were found to be statistically significant accounting for 91% of the variance in overall QOL. Variables accounting for the greatest percentage were control, aches and pain, uncertainty, satisfaction, future, appearance and fatigue. The fourth measure of validity used Pearson's correlations to estimate the relationships between the subscales of the QOL-CS and the subscales of the established FACT-G tool. There was moderate to strong correlation between associated scales including QOL-CS Physical to FACT Physical (r=.74), QOL-CS Psych to FACT Emotional (r=.65), QOL Social to FACT Social (r=.44). The overall QOL-CS correlation with the FACT-G was .78. Additional measures of validity included correlations of individual items of the QOL-CS tool, Factor Analysis, and Construct Validity discriminating known groups of cancer survivors. This psychometric data is reported in reference #1 and 2.

Good luck with your research!!

Betty R. Ferrell, RN, PhD, FAAN
Research Scientist

Marcia Grant, DNSc, FAAN
Research Scientist
Director Nursing Research & Education

City of Hope National Medical Center
1500 E. Duarte Road
Duarte, CA 91010

References from City of Hope Cancer Survivorship Studies:

1. Ferrell BR, Hassey-Dow K, Grant M. "Measurement of the QOL in Cancer Survivors." Quality of Life Research, 1995; 4:523-531.

2. Ferrell BR, Hassey-Dow K, Leigh S, Ly J, Gulasekaram P. "Quality of Life in Long-Term Cancer Survivors." Oncology Nursing Forum, 1995; 22(6):915-922.

3. Ferrell BR. "The Quality of Lives: 1,525 Voices of Cancer." Oncology Nursing Forum, 1996; 23(6):907-916.

4. Ferrell BR, Dow KH. "Portraits of Cancer Survivorship: A Glimpse through the Lens of Survivors' Eyes." Cancer Practice, 1996; 4(2):76-80.

5. Ferrell B, Hassey-Dow K. "Quality of Life Among Long-Term Cancer Survivors." Oncology, 1997; 11(4):565-576.

6. Juarez G, Ferrell BR, Borneman T. "Perceptions of Quality of Life in Hispanic Patients with Cancer." Cancer Practice, 1998; 6(6):318-324.

7. Hassey-Dow K, Ferrell B, Haberman M. "The Meaning of QOL in Cancer Survivors." Oncology Nursing Forum, 1999; 26(3):519-528.

8. Hassey-Dow K, Ferrell BR, Haberman MR, & Eaton L. "The meaning of quality of life in cancer survivorship." Oncology Nursing Forum, 1999; 26(3):519-528.

9. Ferrell B, Virani R, Smith S, Juarez G. "The Role of Oncology Nursing to Ensure Quality Care for Cancer Survivors: A Report Commissioned by the National Cancer Policy Board and Institute of Medicine." Oncology Nursing Forum, 2003; 30(1):E1-11 (online exclusive).

Note: Additional references from City of Hope Breast Cancer and Ovarian Cancer survivorship studies are listed under those headings.

Quality of Life Scale/CANCER PATIENT/CANCER SURVIVOR

Directions: We are interested in knowing how your experience of having cancer affects your Quality of Life. Please answer all of the following questions based on your life at this time.

Please circle the number from 0 - 10 that best describe your experiences:

Physical Well Being

To what extent are the following a problem for you:

1. **Fatigue**

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

2. **Appetite changes**

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

3. **Aches or pain**

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

4. **Sleep changes**

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

5. **Constipation**

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

6. **Nausea**

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

7. **Menstrual changes or fertility**

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

8. **Rate your overall physical health**

extremely poor	0	1	2	3	4	5	6	7	8	9	10	**excellent**

Psychological Well Being Items

9. How difficult is it for you to **cope** today as a result of your disease and treatment?

not at all difficult	0	1	2	3	4	5	6	7	8	9	10	**very difficult**

10. How good is your **quality of life**?

extremely poor	0	1	2	3	4	5	6	7	8	9	10	**excellent**

11. How much **happiness** do you feel?

none at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

12. Do you feel like you are **in control** of things in your life?

not at all	0	1	2	3	4	5	6	7	8	9	10	**completely**

13. How **satisfying** is your life?

not at all	0	1	2	3	4	5	6	7	8	9	10	**completely**

14. How is your present ability to **concentrate or to remember** things?

extremely poor	0	1	2	3	4	5	6	7	8	9	10	**excellent**

15. How **useful** do you feel?

not at all	0	1	2	3	4	5	6	7	8	9	10	**extremely**

16. Has your illness or treatment caused changes in your **appearance**?

not at all	0	1	2	3	4	5	6	7	8	9	10	**extremely**

17. Has your illness or treatment caused changes in your **self concept** (the way you see yourself)?

not at all	0	1	2	3	4	5	6	7	8	9	10	**extremely**

How distressing were the following aspects of your illness and treatment?

18. **Initial diagnosis**

not at all distressing	0	1	2	3	4	5	6	7	8	9	10	**very distressing**

19. **Cancer treatments** (i.e. chemotherapy, radiation, or surgery)

not at all distressing	0	1	2	3	4	5	6	7	8	9	10	**very distressing**

20. **Time since my treatment** was completed

not at all distressing	0	1	2	3	4	5	6	7	8	9	10	**very distressing**

21. How much **anxiety** do you have?

none at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

22. How much **depression** do you have?

none at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

To what extent are you <u>fearful</u> of:

23. **Future diagnostic tests**

no fear	0	1	2	3	4	5	6	7	8	9	10	**extreme fear**

24. **A second cancer**

no fear	0	1	2	3	4	5	6	7	8	9	10	**extreme fear**

25. **Recurrence** of your cancer

no fear	0	1	2	3	4	5	6	7	8	9	10	**extreme fear**

26. **Spreading (metastasis)** of your cancer

no fear	0	1	2	3	4	5	6	7	8	9	10	**extreme fear**

Social Concerns

27. How distressing has illness been for your **family**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

28. Is the amount of **support** you receive from others sufficient to meet your needs?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

29. Is your continuing health care interfering with your **personal relationships**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

30. Is your **sexuality** impacted by your illness?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

31. To what degree has your illness and treatment interfered with your **employment**?

no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

32. To what degree has your illness and treatment interfered with your **activities at home**?

no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

33. How much **isolation** do you feel is caused by your illness or treatment?

none 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

34. How much **financial burden** have you incurred as a result of your illness and treatment?

none 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

Spiritual Well Being

35. How important to you is your participation in **religious activities** such as praying, going to church?

not at all important	0	1	2	3	4	5	6	7	8	9	10	**very important**

36. How important to you are other **spiritual activities** such as meditation?

not at all important	0	1	2	3	4	5	6	7	8	9	10	**very important**

37. How much has your **spiritual life** changed as a result of cancer diagnosis?

less important	0	1	2	3	4	5	6	7	8	9	10	**more important**

38. How much **uncertainty** do you feel about your future?

not at all uncertain	0	1	2	3	4	5	6	7	8	9	10	**very uncertain**

39. To what extent has your illness made **positive changes** in your life?

none at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

40. Do you sense a **purpose/mission** for your life or a reason for being alive?

none at all	0	1	2	3	4	5	6	7	8	9	10	**a great deal**

41. How **hopeful** do you feel?

not at all hopeful	0	1	2	3	4	5	6	7	8	9	10	**very hopeful**