

2016

Factors influencing resilience among haematological cancer survivors

Katherine S. Gallagher
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Running head: RESILIENCE IN HC SURVIVORS

Factors Influencing Resilience among Haematological Cancer Survivors

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This thesis is submitted in partial fulfilment of the requirements for the award of

Doctor of Philosophy (Psychology)

29th March 2016

Abstract

Haematological cancers in bone marrow (leukaemia) and the immune system (lymphomas or myeloma) represent the sixth most common adult tumour group in Australia. These cancers often develop without warning and require intensive treatment regimes that last on average eight months, but may continue for a lifetime depending on the diagnosis. Encouragingly, advancing cancer treatments, a key accomplishment of cancer research over the past 40 years, have resulted in a growing community of cancer survivors. Approximately two in three adults diagnosed with haematological cancer (HC) can now expect to survive more than five years. However, they must attempt to navigate the potential side-effects of cancer treatment. Several studies have highlighted the negative physical, social and psychological consequences of a cancer diagnosis such as fear of reoccurrence, infertility, fatigue and depression. However, few studies have explored how these individuals adjust or cope following successful cancer treatment. Cancer survivors who maintain a positive outlook, effectively deal with their health issues and are able to resume normality in their lives are deemed to be resilient. This study aimed to investigate the resilience process that HC survivors adopt following treatment, in order to overcome such adversity. The goal was to enable identification of protective factors that lead to positive mental health outcomes, and risk factors that impede resilience, for the growing HC survivor population.

A two-phase, sequential, mixed methods design was adopted. The first (qualitative) developed a model of resilience, by exploring factors that fostered or inhibited HC survivors' abilities to cope with this health crisis. Data were collected through semi-structured, in-depth, interviews with 23 adult HC survivors from Western Australia (M age = 52.87, SD = 16.72). Thematic and Leximancer software analyses of the interview data identified four main themes and sub-themes pertaining to the cancer experience faced by these individuals: (1) the burden associated with a HC diagnosis; (2) resilience: coping with HC; (3) pathways and barriers to resilience; and, (4) survivor outcomes. These themes were then developed into a model, based on the current findings and those that had been identified in the literature.

Subsequently, in Phase Two (quantitative), a questionnaire was created using factors that surfaced during the interviews or were identified from the literature. It was first piloted (Stage I) among a convenience sample of 17 mixed cancer survivors to determine clarity, reliability and internal consistency. Afterwards, a large survey was conducted (Stage II) to test the validity of the model developed in Phase One. Twenty-four variables were investigated for their ability to predict resilience and 222 (M age = 54.35, SD = 14.31) eligible questionnaires

were obtained. Using a standard multiple regression analysis, the combined effect of the 24 variables accounted for 61% of the variance in resilience scores. Active coping, positive reframing, exercise and support from family and friends were found to positively influence resilience, while self-blame negatively predicted resilience. Only three variables, venting, self-distraction and substance use, did not contribute significantly. Greater scores on each of the remaining variables; emotional support, instrumental support, planning, acceptance, religion, humour, support (healthcare professional and significant other), appearance, researching information, alternative treatments, time-out and diet, were associated with higher levels of resilience, except for, behavioural disengagement and denial which were negatively correlated. The results identified that higher resilience levels were significantly associated with lower depression and anxiety. In addition, younger participants (< 40 years of age) or those more recently diagnosed (< 5 years) scored significantly higher on depression and anxiety and lower on resilience.

The findings highlight that the model developed in this thesis appropriately represented resilience factors identified among other cancer survivor populations. This research contributes to theory, policy and clinical practice, by providing greater insight into the experience of those living with HC and how these individuals cope. Clinicians including psychologists can use the study's results to improve their clinical assessment and therapeutic approaches to enhance cancer survivor wellbeing. In addition, this information can assist the federal and state governments in formulating improved support infrastructure. Future research should explore how these theoretical findings can be applied practically, and assess the application of this model across cultures.

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Signed: _____

Date: 29th March 2016

Acknowledgements

First and foremost, I would like to acknowledge my supervisors Professor Anne Wilkinson and Professor Ken Greenwood, for their insight and guidance over the last four years. More specifically, Anne for seeing the larger picture and her clinical expertise, and Ken for his precise editing abilities and eye for detail. Keeping me on track and organised at times must have proved challenging, so I am thankful to you both for your ongoing patience, wisdom and support. My appreciation also extends to Professor Lynne Cohen who was initially instrumental in guiding me in this research direction.

Second, I wish to sincerely thank all of the participants for sharing your personal stories and generously giving your time. As cancer survivors, I am truly inspired by your resilience and will forever be moved by your experiences. Thanks also to the many individuals within several Australian organisations, who willingly assisted with the recruitment of participants for the study. In particular, I would like to acknowledge Tanya Harris, Adriana Filippou, Quintin Hughes and Katie Armstrong at the NSW Cancer Council. A special mention of thanks also to Sue Hurt and Paul Magiatis whose enthusiasm and dedication was influential in assisting my research.

Furthermore, I would like to mention the support offered by so many special friends in particular Kryss, Bec, Nicky and Linda. After a decade of asking me about my studies, at last we can focus on other important matters ... like you!! To my university colleagues especially Greg, Geoff, Sam, Pauline, Mark and Katrina, thanks too for your ongoing encouragement and for sharing this journey. My gratitude also goes out to four special ladies Sue Sibma, Sally Smith, Denise Lomax and Vicky Warwick; your continued support did not go unnoticed.

Last, but not least, I would like to express my appreciation to my incredible family. First, thanks to my parents, siblings and in-laws, not only for your ongoing love and reassurance, but also for the practical help along the way. In particular, mum and dad who have always supported and encouraged me to be the best I can be, and, dad whose personal cancer journey has contributed to my motivation. To my children, Connor and Lauren who were too young to remember when mum wasn't studying, thanks for understanding that this was important to me. I hope I have shown you both that the world is full of opportunities and with a little hard work, you can achieve whatever you set your mind to. Finally, a huge thank you to my husband Mitch who handled *everything* in our lives with no complaints, allowing me the time and space I needed. Mitch without your patience, love, support, and understanding, the last twelve years would not have been possible.

This thesis has been a collective effort and I could not have done this without all of you. I feel so fortunate and blessed to have been surrounded by so many who believed in me.

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Operational Definitions

There is a great deal of debate in the cancer survivor literature about issues such as when cancer survivorship begins or the definition of terms such as resilience. These will be discussed in greater depth in the literature review chapter. However, for the purpose of the current study, the following operational definitions will be used within this thesis.

Active treatment: The period when a person is having surgery, chemotherapy, radiation therapy, or other treatment to slow, stop, or eliminate the cancer (ASCO, 2014)

Acute survivorship: A term describing the period when a person is diagnosed with cancer and/or receiving active treatment.

Adaptation: refers to the secondary response to stress, often after a crisis where the initial adjustment changes become inadequate. In this phase the response is often influenced by the initial response, appraisal of stress (strengths), family functioning and family resources (McCubbin, Thompson, Thompson, & Fromer, 1998).

Adjustment: refers to the initial response to the stress where changes are required to manage the stress (McCubbin, et al., 1998).

Advanced Cancer: Cancer that has spread (metastasized) which may be unlikely to be cured (Leukaemia Foundation, 2011).

Alopecia: Hair loss, a common side-effect of chemotherapy/radiotherapy, which is usually temporary (Leukaemia Foundation, 2011).

Anxiety: Feelings of nervousness, fear, apprehension, and worry (ASCO, 2014).

Bone marrow: The tissue found at the centre of many flat or large bones in the body. The bone marrow contains stem cells from which all blood cells are produced (Leukaemia Foundation, 2011).

Cancer: A general term for more than 100 life-threatening diseases characterized by the uncontrolled, abnormal growth of malignant cells.

Cancer Survivorship: The experience of living with, through and beyond a diagnosis of cancer (Feuerstein, 2007).

Cancer Patients: Refer to individuals who are clinically diagnosed for cancer and suffering with cancer and receiving treatment.

Case manager: A health care professional who helps coordinate a person's medical care before, during, and after treatment. At a medical centre, a case manager may provide a wide range of services including managing treatment plans, coordinating health insurance approvals, and locating support services. Insurance companies also employ case managers (ASCO, 2014).

Chemotherapy: is generally a combination drugs given to reduce the number of cancer cells that remain in nodes or circulating blood. It is delivered in a number of treatment cycles, which may take weeks to months. The purpose of these cycles is to enable the patient to recover from the more severe effects of treatment such as neutropenia before undertaking the next course.

Chronic illness: A significant illness or disability, which may be physical, emotional or cognitive and persists for at least six months, involving ongoing medical intervention to treat acute episodes and/or ongoing health complication (Vickers, Parris, & Bailey, 2004).

Clinical trial: A research study that involves volunteers. Many clinical trials test new approaches to treatment and/or prevention to find out whether they are safe, effective, and possibly better than the current standard of care (the best known treatment) (ASCO, 2014)

Complementary Therapy: Therapies such as reflexology or meditation, which are used in addition to medical treatment, to assist with the management of symptoms and side-effects (Leukaemia Foundation, 2011).

Coping: Coping is the individual's efforts to problem solve through the stressful event (Friedman, Bowden, & Jones, 2003; Lazarus, 1999)

Cure: To fully restore health. This term is sometimes used when a person's cancer has not returned for at least five years after treatment. However, the concept of "cure" is difficult to apply to cancer because undetected cancer cells can sometimes remain in the body after treatment, causing the cancer to return later. Recurrence after five years is still possible (ASCO, 2104)

Depression: Defined as having a low mood and/or feeling numb consistently for more than two weeks, every day and much of the day (ASCO, 2014)

Extended survivorship: A term describing the period when a person has just completed active treatment, usually measured in months (ASCO, 2014).

Follow-up care plan: A personalized schedule of follow-up examinations and tests that a doctor recommends after the active treatment period. This may include regular physical examinations and/or medical tests to monitor the person's recovery for the coming months and years. This may also be called a survivorship care plan; it is often used in conjunction with a treatment summary (ASCO, 2014).

Haematological Cancer: Cancers of the bone marrow (leukaemia) and the immune system (lymphoma and myeloma) (Lobb et al., 2009).

Health adversity: Defined as a change in health caused by illness both mental and physical health which has adverse effects either short-term or long-term.

High-dose therapy: Using higher than normal doses of chemotherapy to eradicate resistant cancer cells that have survived standard-dose therapy (Leukaemia Foundation, 2011).

Hodgkin's lymphoma: A type of lymphoma (cancer of the lymphatic system).

Late effects: Side-effects of cancer or its treatment that occur months or years after the active treatment period has ended (ASCO, 2014).

Leukaemia: A cancer of the blood and bone marrow characterised by uncontrolled, widespread production of large numbers of abnormal and/or immature blood cells. (Leukaemia Foundation, 2011).

Lymphatic system: A network of vessels, similar to blood vessels, that branch out into all the tissues of the body carrying a watery fluid containing lymphocytes (specialised white cells) responsible for protecting against disease and infection. Considered part of the immune system (Leukaemia Foundation, 2011).

Maintenance Treatment: Maintenance treatment is defined as treatment occurring in the period following active treatment with an aim to reduce the risk of recurrence. This may be in the form of ongoing oral chemotherapy. During maintenance treatment the HC survivor may experience ongoing but different stressors.

Medicare: Medicare is Australia's system for financing services provided by private doctors, public hospitals and additional health costs. It allows Australians have access to free or low cost medical, ancillary and hospital care. Medicare is jointly funded by the Australian government, State and Territory governments and is administered by State and Territory health departments.

Myeloma: Also referred to as myelomatosis or multiple myeloma is a cancer that usually arises in the bone marrow when mature B-lymphocytes known as plasma cells, undergo a malignant change (Leukaemia Foundation, 2011).

Neutropaenia: A reduction in the number of circulating neutrophils, an important type of white cell, which results in an increased risk of infection (Leukaemia Foundation, 2011).

Neutrophils: The most common type of white cell responsible for fighting infections especially bacteria and fungi (Leukaemia Foundation, 2011).

Neurological: Conditions causing disturbance in structure or functions of the nervous system such as epilepsy.

Non-Hodgkin lymphoma: Also known as B and T-cell lymphoma (cancer of the lymphatic system) and differs from Hodgkin lymphoma. Non-Hodgkin lymphoma can be slow growing (low grade) or fast growing (intermediate or high grade) (Leukaemia Foundation, 2011).

Oncologist: A doctor who specializes in treating cancer. The five main types are medical, surgical, radiation, gynaecologic, and paediatric oncologists (ASCO, 2014).

Oncology nurse: A nurse who specializes in caring for people with cancer (ASCO, 2014).

Permanent survivorship: A longer time that has passed since active treatment has finished (usually after 5 years) often measured in years. Also called long-term survivorship (ASCO, 2014).

Prevalence: Refers to the numbers of individuals who have previously received a cancer diagnosis and who are still alive at a given point in time (AIHW, 2014).

Prognosis: Chance of recovery; a prediction of the outcome of a disease.

Primary cancer: In survivorship care, this means the original (first) cancer with which a person was diagnosed (ASCO, 2014).

Psychologist/psychiatrist: Mental health professionals who work to address a person's emotional, psychological, and behavioural needs (ASCO, 2014).

Psychological Illness: A range of feelings and emotions that people experience in reaction to illness or its treatment such as depression or anxiety.

Quality of Life: A broad ranging concept based on person's physical health, culture, psychological state, personal beliefs, social relationships, and environment in relation to their goal, standards and concerns (World Health Organisation, 2007).

Radiotherapy: is typically administered as X-rays or gamma rays to destroy cancer cells and reduce the risk of a local recurrence. It is also completed in cycles over an extended period, for much the same reasons as chemotherapy (Leukaemia Foundation, 2011).

Recurrence: Cancer that has returned after a period during which the cancer could not be detected. Local recurrence means the cancer has come back in the same general area where the original cancer was located. Regional recurrence refers to cancer that has come back in the lymph nodes or other tissues near the original cancer site, usually by direct spread. Distant recurrence refers to cancer that has come back and has spread to other parts of the body, usually by traveling through the lymphatic system or bloodstream (ASCO, 2014).

Referral: Recommendation provided by a doctor to get help or information from another health care professional, specialist, or resource (ASCO, 2014).

Rehabilitation: Services and resources that help a person with cancer obtain the best physical, social, psychological, and work-related functioning during and after cancer treatment. The goal of rehabilitation is to help people regain control over many aspects of their lives and remain as independent and productive as possible (ASCO, 2014).

Remission: When there is no evidence of cancer detectable in the body. Remission differs from cure as relapse may still occur (Leukaemia Foundation, 2011).

Resilience: Refers to ability to bounce back from negative emotional experiences and to adapt to stressful experiences.

Respiratory disorders: Conditions that affects the respiratory system. Examples include: asthma, hay fever, croup, bronchiolitis, and emphysema.

Risk: The likelihood of an event (ASCO, 2014).

Secondary cancer: Describes either a new primary cancer (a different type of cancer) that develops after treatment for the first type of cancer, or cancer that has spread to other parts of the body from the place where it started (metastasized) (ASCO, 2014).

Staging: An assessment of the extent or spread of the disease (Leukaemia Foundation, 2011).

Stem cells: Are primitive blood cells that can give rise to more than one cell type. There are many types of stem cells in the body. Bone marrow (blood) stem cells have the ability to grow and produce all the various blood cells including red cells, white cells and platelets (Leukaemia Foundation, 2011).

Stem cell transplant: A treatment used to support high-dose chemotherapy and/or radiotherapy in the treatment of a wide range of blood cancers, certain solid tumours and other serious diseases.

Stress: Stress is the response of the individual's threat appraisal of an event (Friedman, et al., 2003; Lazarus, 1999).

Stressor: A stressor is the precipitating event(s) that activated the stress response (Lazarus, 1999; Lazarus & Folkman, 1984).

Support needs: The physical, psychological, social, informational and financial needs of an individual (ASCO, 2014).

Survivorship: This term means different things to different people. Two common definitions include having no disease after the completion of treatment and the process of living with, through, and beyond cancer (ASCO, 2014).

Systemic disorders: A medical condition that involves the body as a whole, not limited to conditions that affect particular parts of the body. Examples include: diabetes, anaphylaxis and metabolic disorders.

Targeted treatment: Treatment that targets specific genes, proteins, or other molecules that contributes to cancer growth and survival (ASCO, 2014).

Treatment summary: A written summary of the therapies that a person had during his or her active treatment period. This is often used in conjunction with a follow-up care plan to help monitor a survivor's long-term health (ASCO, 2014).

Chapter 1

Introduction

Chapter Overview

This chapter aims to outline the context and rationale for the current thesis. First, cancer and resilience research is briefly introduced, in order to provide a basic understanding of the population of interest. Next an overview of cancer, including a definition of a cancer survivor is explained to provide relevant background material. The research context will then be presented, with an overview of haematological cancer (HC) and the incidence of psychological distress among this population. This is followed by a discussion outlining the history of resilience research and a description of the relevant terminology. Finally, the justification for research will be summarized before outlining the aims and research questions for this study.

The Storm of Cancer

*“Before cancer, you’re sailing along in generally fair weather. You’re travelling in one direction. You have maps, navigation aids and provisions. You might even be part of a flotilla – you and some other boats, sailing in the same direction at the same speed. Life is fine, good even. Then a massive storm hits – **cancer**.*

Your boat is seriously damaged. Maybe parts of it are lost or broken. Your maps and provisions are swept overboard. In the eye of the storm you lose all sense of direction. Your main terror is that the boat will sink. Then your cancer team appear.

They are your lifeboat; your rescuers. They attach ropes, patch your boat up and keep it afloat; they come alongside you, and take control of the steering and direction. Slowly, they tow you back to port. Sometimes this journey towards the port is even stormier than the catastrophe itself. But you know you are not alone – you have the lifeboat staff, you make a good team. As the lifeboat tows your boat back to port you see friends and family on the shore waving and cheering. They are so relieved to have you back. But then your boat just stops. You are not quiet back in port. You can see the lights, and your happy loved ones. But you’re moored just outside the mouth of the harbour. Then your lifeboat, and its team goes.

They drop the ropes into the water and sail away. You might think: I can get back to port on my own. You’ve been there before after all. And you can see it right there, quite close. But it all feels different now. Your boat is still damaged. You need time for repairs. You need to get a new map and provisions. And you keep looking at the sky – is the storm coming back? You listen constantly, obsessively, to the weather forecast – you hear reports of hurricanes. They may be far away, but you can’t stop yourself from feeling that they are coming for you” (Goodhart & Atkins, 2011, p.1-2).

Setting the Context - The Cancer Resilience Research

The analogy provided above (Goodhart & Atkins, 2011) may seem long-winded. However, it accurately describes the challenges that approximately 370,000 Australian cancer survivors face following cancer therapy (AIHW, 2014). The intensive treatment required to treat cancer can be life changing and may involve painful procedures, multiple side-effects and long hospitalizations. Consequently, being diagnosed with cancer, a potentially terminal disease, is considered a traumatic and stressful experience affecting many aspects of an individual's life, including mental health (Hollingshaus & Utz, 2013).

Tedeschi and Calhoun (1995) identified four characteristics that make an event traumatic, being: sudden; unexpected; uncontrollable; and, producing ongoing, sometimes lifelong effects. All of these characteristics echo and reflect the cancer experience. The literature has found that treatment may affect an individual's quality of life (QOL). This could involve: physical suffering (i.e., fatigue, pain, scarring, weight changes and infertility) (Bennett, Goldstein, Friedlander, Hickie, & Lloyd et al., 2007; Deimling, Sterns, Bowman, & Kahana, 2005; Doyle, 2008); psychological difficulties (e.g., fear, uncertainty, anxiety, and depression) (Butow, Fardell, & Smith, 2015; Jefford et al., 2008; Llewellyn et al., 2013; Mitchell et al., 2011); and, altered social functioning (i.e., interpersonal relationships, isolation, financial stress, disruption of home and family roles) (Aziz, 2002; Lobb et al., 2009; Min et al., 2013; Mosher et al., 2011). These examples of the physical and psychosocial costs of surviving cancer, that may carry tremendous potential to cause morbidity, have been well documented (Aziz, 2002; Kelly & Dowling, 2011).

The literature describing the negative consequences of surviving cancer is a valued and comprehensive resource that will be discussed in more detail in the following chapter. However, there has been comparatively less research that explores how survivors cope with this experience (Stewart & Yuen, 2011). Several studies have recently suggested that many cancer survivors are able to avoid psychological distress and go on to live purposeful and fulfilling lives following treatment (Alim et al., 2008; McGrath & Clarke, 2003; Schumacher, Sauerland, Silling, Berdel, & Stelljes, 2014; Xuereb & Dunlop, 2003). However, this process, which may lead to better psychological wellbeing among cancer survivors, has not been fully investigated.

At the end of 2009, there were 861,057 Australians living, who had been diagnosed with cancer in the previous 28 years (from 1982 – 2009) (AIHW, 2012). Understanding the factors that influence positive outcomes in cancer survivors is an important topic for research, as these individuals, along with family and friends are searching for the strength and resources to navigate this traumatic time. The literature reports that the outcome of each individual's experience may be influenced by a variety of internal (i.e., individual coping or personality style) and external factors (i.e. treatment regime, support networks and healthcare resources)

(James et al., 2011; Knott, Turnbull, Olver, & Winefield, 2012). Yet, to date, there has been less attention given to research exploring how these, and other factors, may influence cancer survivor outcomes (Stewart & Yuen, 2011; Windle, Bennett, & Noyes, 2011). This will, therefore, be the emphasis of the current research.

The topic of survivorship of cancer has been of interest, predominantly within the medical field, since the early 1900's (Mukherjee, 2010). Earlier literature was dominated by extensive efforts to understand the causes, prevention and treatment of cancer. However, during this period the challenges faced by long-term survivors were not a priority, as, at that time, cancer was considered a likely death sentence (Mukherjee, 2010). Nevertheless, there have been many advances, predominantly since the 1980's, in earlier detection (i.e., enhanced imaging equipment), improved treatment (i.e., targeted chemotherapy, radiotherapy and surgery), and, lifestyle changes among the general population (Aziz, 2002; Mukherjee, 2010). These achievements have more recently led researchers to also consider the increasing number of individuals who survive cancer (Jefford, et al., 2008; Kelly & Dowling, 2011).

Worldwide, the number of cancer survivors is expected to triple from 25 million in 2008 to 75 million in 2030 (Ferlay et al., 2010). Statistics also indicate that, in the absence of any other competing causes of death, approximately 67% of Australian adults currently diagnosed can expect to live beyond five years (AIHW, 2014). However, it has only been in the last decade that research involving cancer survivors' issues, commonly referred to as "survivorship research" (to be discussed in the next chapter in more detail) has flourished (Ganz, 2011). Given the recency of this focus, several important gaps exist within the current cancer survivorship literature (Feuerstein, 2007b; Girgis & Butow, 2009; Jefford et al., 2008).

First, the emphasis of cancer research has been on childhood cancer survivors and adult survivors of more common cancers, such as breast and prostate cancer. For example, in a database search using PubMed, it was found that, between 2005 and 2015, there were 129,816 breast cancer and 58,564 prostate cancer citations compared with less common cancers, with only 15,249 papers referring to haematological cancers (HC). Accordingly, there is a need to investigate understudied cancers, such as HC's, survivors of which are the population of interest in this research. Haematological malignancies are cancers of the bone marrow (haematopoietic) and the immune system (lymphoid) and collectively represent the sixth most commonly diagnosed tumour group in Australia (AIHW, 2014). In 2002, there were approximately 8030 diagnoses of HC's in Australia, which increased by 28.5 % to 10,347 during 2011 (AIHW, 2014). There are many reasons why the HC survivor population has been selected for this research, several of which will be discussed shortly.

Second, although the negative physical and psychosocial consequences of cancer on survivors and their families have been well documented (Bevans et al., 2011; McGrath, 2004a; Stewart & Yuen, 2011), to date, there has been less focus on addressing how many individuals

manage to adapt and live with dignity and purpose, despite a cancer diagnosis (Swaminath & Ravi Shankar Rao, 2010). Researchers are beginning to recognise that many survivors may experience positive adjustment outcomes (Jefford et al., 2008; Llewellyn et al., 2011). For example, a growing body of literature suggests that cancer survivors may be highly resilient (Gouzman et al., 2015; Pieters, 2015; Schumacher et al., 2014). In this context, resilience refers to an individual's capacity to effectively adapt to psychosocial adversity, as a direct result of having been diagnosed and treated for cancer (Stewart & Yuen, 2011; Windle, Bennett, & Noyes, 2011; Wu, Sheen, Shu, Chang, & Hsiao, 2012). Some research reports that resilience has been inversely associated with depression, anxiety and perceived stress, whilst being positively associated with greater life satisfaction (Wagnild, 2009). Yet, conversely, it may be that resilience is defined by the absence of depression and anxiety and improved QOL (Agaibi & Wilson 2005). Therefore, resilience is an important concept to investigate, as there is a history of debate surrounding the definitional complexities and process of resilience. By clarifying the factors that influence the resilience process, clinicians and the extended community will better understand how to improve QOL and mental-wellbeing of HC survivors through appropriate interventions.

Third, research to date has concentrated on the initial diagnosis and earlier treatment phase in the survivorship trajectory, with less emphasis on long-term survivors; that is, the percentage of cancer patients who are alive after an elected time period (usually 5 years) relative to those without cancer (the survival rate) (Hewitt, Greenfield, & Stovall, 2005). Hence, there has been less research describing the experiences of a growing population who have been cancer survivors for over five years (Stanton et al., 2005). Previously, the possibility of long-term cancer survivors was unforeseen, especially among rare and aggressive cancers such as HC (Ananda & Scott, 2015). However, due to the previously described medical advances, there is now a growing population of survivors who are living beyond the five year marker, including those with HC (Chew & Roberts, 2015; Kelly & Dowling, 2011; Paul et al., 2011). Nevertheless, prognosis and survival rates do vary significantly among the different types of HC. For example, in adults diagnosed with myeloma, approximately 45% will survive beyond five years. However, the five-year survival rate increases to 72% for non-Hodgkin's lymphomas and to approximately 87% for those diagnosed with Hodgkin's lymphoma (AIHW, 2014).

The increasing 5-year relative survival rate is helpful in demonstrating progress in the early detection and treatment of many cancers. However, since cancer-related deaths can occur beyond 5 years after diagnosis, the reporting of survival rates do not differentiate between survivors who are still in treatment, those who have relapsed or survivors who are permanently cured (AIHW, 2014).

In addition, survival rates, while informative, only cover a fraction of the total impact. These figures do not reflect the overall personal and social costs of cancer (Boyle, 2006). For example, little is known about how the cancer survivor coped with the physical effects of illness, managed their roles at work, or interpersonal relationships and how these survivors adapted to cancer from a psychological perspective (Boyle, 2006). These additional questions are important, so that as a community we can address the level and type of care that will be required for the ongoing medical and psychosocial needs of this growing population.

In summary, it is imperative that we further investigate the experiences of those with less common, aggressive cancers such as HC, as these remain an under-researched population across the survivorship trajectory. In addition, research in cancer survivorship together with resilience across the lifespan, will improve progress toward enhancing the health and QOL of all cancer survivors and their families. The next section provides a more detailed overview of cancer.

An Overview of Cancer

Cancer is defined by the AIHW (2014) as a diverse group of more than 100 diseases in which several of the body's cells become abnormal. As a result of changes (mutations) in the genetic information of a cell, the cell begins to spread and multiply out of control (AIHW, 2014). The site in the body in which the disease originates is what differentiates cancers from each other. Not all cancers are invasive. Benign tumours are rarely life threatening and do not spread to other parts of the body (AIHW, 2014). However, malignant cancer may be life threatening, occurring when there is an invasion of abnormal cells that spread to other parts of the body through the lymphatic system or blood stream (AIHW, 2014). In this case, the original site of the tumour is known as the primary cancer and the spread or metastasis to another area in the body is referred to as the secondary cancer (AIHW, 2014).

In Australia, cancer has a greater impact on health than any other disease group, accounting for nearly one-fifth of the total disease burden (AIHW, 2014). On average, one in two Australians will be diagnosed with cancer and one in five will die from the disease before the age of 85 (AIHW, 2014). Although not all causes of cancer have been recognised, there are numerous risk factors that have been identified as increasing the incidence of cancer. Some of these include, but are not limited to: lifestyle factors (smoking, sexual behaviour, alcohol, diet and obesity); environmental elements (sunlight, pollution, occupational exposures, radiation); biomedical factors (hormones); genetic susceptibility; and, chronic infections (AIHW, 2014).

Approximately 123,920 new cases of cancer (excluding squamous and basal cell carcinomas of the skin) will be diagnosed during 2014 in Australia (AIHW, 2014). Of these, the six most commonly diagnosed cancers in Australia during 2007 included prostate, bowel, breast, melanoma, lung, and lymphoid cancers (AIHW, 2014). It is estimated that over fifty-

five percent of newly diagnosed cancers during 2014 were found in males. In addition, 70% of cases were diagnosed in individuals aged 60 years and older (AIHW, 2014). Cancer is predominantly a disease affecting the elderly and, as a result of the aging population, Australia is likely to experience an increase in the number of individuals diagnosed (AIHW, 2014). Consequently, cancer not only represents a significant cost to the economy and community, but also impacts on both the physical and emotional wellbeing of individuals and their families (ABS, 2012).

Although survival rates are not consistent across all forms of cancer, the proportion of cancer patients surviving five years or longer has generally increased. In Australia, between the years 1982-1986 to 2007-2011, the 5-year survival rate percentages increased from 52% to 68% for women and from 40% to 66% for men (AIHW, 2014). Between 2007 and 2011, the 5-year survival rate for all cancers combined was approximately 67% (AIHW, 2014). This large and growing community of cancer survivors is one of the key accomplishments of cancer research over the past 40 years (Aziz, 2002). For many, cancer is now regarded as either a chronic or curable disease, rather than representing its historical association involving a death sentence (Jefford et al., 2008). However, the cancer experience remains embedded within the larger context of one's life experiences, perceptions and future goals. Therefore, the predicted increase in cancer diagnoses, related to a rapidly increasing older population, warrants research that explores the context of this experience.

Definition

The word *survivor* originates from the Latin word '*supervivere*' to live more and from the middle French word '*survivre*' to outlive (Merriam-Webster, 2013; Platt, 2012). In the mid-1900s, when cancer represented a certain death sentence, family members were often regarded as the survivors, following the death of a loved one (Boyle, 2006; Leigh, 1990, Mukherjee, 2010).

However, the cancer survivorship movement that has arisen over the last three decades, due to the increasing number of survivors and an ageing population, has led to much debate. Izsak and Medalie (1971) were first credited with prompting this deliberation, suggesting that the historical medical model, previously used to classify cancer survivors, was not comprehensive enough (Boyle, 2006). Then, in July of 1985, a thought provoking paper entitled "Seasons of Survival: Reflections of a Physician with Cancer" appeared in The New England Journal of Medicine (Feuerstein, 2007). This paper, written by Dr. Fitzhugh Mullan, would become the starting point for a major medical and cultural shift in the United States (US) moving the discussion from just cancer 'patients' to cancer patients and cancer 'survivors' (Feuerstein, 2007; Hoffman & Stovall, 2006). Mullan addressed the shortcomings of the definitional paradigm at that time, stating that there was no "moment of cure" or

"invisible line" that a patient crossed to become a survivor (Boyle, 2006). Consequently, this has led to many proposed definitions. However, for several reasons, the precise meaning of cancer survivorship remains complex and controversial.

First, there is a lack of agreement in the literature as to when a patient becomes a cancer survivor (Rendle 1997). Do individuals slowly come to think of themselves as survivors following treatment, when they feel well again or, when and if they return to pre-cancer activities such as work (Dow et al., 1999, Little, Paul, Jordens, & Sayers, 2000)? Alternatively is this process influenced by the medical community's specified timeframe of 5-year survival rates, where patients then identify as survivors (Dow et al., 1999; Ganz, 2005)? If defined biomedically, survivorship may reflect the phase after treatment. However, if using a particular time frame, it may be classified as after 2, 5 or 10 years after diagnosis or completion of treatment, or as a treatment outcome when a cure is reached (Leigh, 1999). Some researchers believe the survivorship process begins at diagnosis (Dow, 1990; Little et al., 2000; Mullan, 1985), but Carter (1989, 1993) suggested that an individual should live for at least 5 years before being considered to be a survivor. More recently, however, many researchers are of the opinion that it is not important if there is recurrent disease, any patient living beyond a cancer diagnosis, should be considered a survivor (Hewitt, Greenfields, & Stoval, 2005; Jefford et al., 2008; Little et al., 2000).

Second, is 'cancer survivor' the best and most appropriate term to be used globally for those who have been diagnosed and treated for cancer? For example, Hewitt and colleagues (2005) implied that the term cancer survivor was less acceptable among Europeans, as a result of the previous holocaust associations. Consequently, in several European countries the term cancer survivor is not always used, rather cancer is regarded as "another chronic illness" (Feuerstein, 2007a). In addition, being linked with cancer may represent a negative social stigma and individuals may not appreciate being categorized as a survivor or being formally identified as different to others (Markus, 2004).

A recent study investigated how cancers survivors perceived themselves in the first one to three years post diagnosis (Park, Zlateva, & Blank, 2009). Several labels were proposed including, "victim", "patient" "survivor" or a "person with cancer". The most common label identified by these participants was "survivor" for 83% of the cohort (Park, Zlateva, & Blank, 2009). This study proposed that each identity term represented meaning for the participant that impacted not only interactions with others, but also with health behaviours. For example, those who identified with the "patient" label could potentially perceive feelings of less control and hope. In addition, these participants may also portray a more passive role by relinquishing responsibility for their health to their specialist or healthcare team. In this study, Park and colleagues (2009) found a relationship between identifying as "survivors" and having reduced

psychological distress. The results from this research were similar to a previous study involving long-term cancer survivors (Deimling, Kahana, & Schumacher, 1997).

Advances in medicine, which have greatly improved prognosis and survival, have led to more comprehensive definitions (Table 1). However, as can be seen in Table 1, there remains much deliberation by cancer organisations on how to comprehensively define a cancer survivor. A current and generally accepted definition is advocated by the National Coalition for Cancer Survivorship as, “the experience of living with, through, and beyond a diagnosis of cancer” (cited by Jefford et al., 2008, p. 20) to the end of life, also embracing family members and friends affected by the illness experience (Hewitt, Greenfield, & Stovall, 2005; Jefford et al., 2008; NCCS, 2012). As a result, cancer survivorship is beginning to signify a process through which not only the patient, but also their family, learns to live with the uncertainty of a life-threatening chronic illness, rather than with a terminal disease (Aziz, 2002; Feuerstein, 2007; Kelly et al., 2010). Moreover, survivorship includes those patients with recurrent metastatic disease, where prognosis may be measured in years not months, and patients who are in a ‘watch and wait’ scenario, neither cured nor dying (Maher & Fenlon, 2010).

Table. 1.1

Definitions of a Cancer Survivor

Organisation	Definition of a Survivor
National Coalition for Cancer Survivorship	An individual diagnosed with cancer from the moment of diagnosis and for the balance of life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition (NCCS, 2012).
NCI Office of Cancer Survivorship	A person with cancer from the time of diagnosis, through the balance of his or her life (Kelly, 2011).
MacMillian Cancer Support	Anyone who has concluded initial treatment with no evidence of active disease, is living with progressive disease and may be receiving treatment however is not in the terminal phase of illness, or an individual who has had cancer in the past (Kelly, 2011).
Livestrong/Lance Armstrong Foundation	A survivor might be the person diagnosed, a spouse, a child, a parent, a friend or any caregiver (Lance Armstrong Foundation, 2010).

In summary, the survivorship concept is relatively new. There are several challenges faced in proposing one accepted definition that holistically reflects who a cancer survivor is, and when the survivorship journey begins. In addition, the term ‘cancer survivor’ continues to be used interchangeably with associated terminology, such as ‘cancer aftercare’ and ‘people living after a cancer diagnosis’ (Doyle, 2008). A more comprehensive definition of cancer survivorship is likely to evolve as personal experiences following primary treatment, until end of life, continue to be substantiated (Feuerstein, 2007a). However, the general consensus from key researchers in this field is that cancer survivors have several unique needs, which are currently not fully appreciated or understood (Feuerstein, 2007b; Ganz, 2011; Girgis & Butow, 2009; Jefford et al., 2008). For this dissertation, cancer survivorship is deemed to represent any individual with cancer from the time of diagnosis, throughout his or her life. A more detailed overview of the history and contributors to the developing survivorship movement is presented (See Appendix 1), including a timeline highlighting key events (Appendix 2). The next section will focus on the population of interest, by describing HC and will also discuss its mental health implications.

Haematological Cancer Survivors and Psychological Distress

According to Lichtman (2008), the discovery of HCs began during the 19th century, when similarities were detected among patients with lymph node tumours and an enlarged spleen, which is now identified as Hodgkin's disease. Shortly after, other HCs including leukaemia and myeloma were discovered (Lichtman, 2008). To date, HC remains a life threatening illness, and, as a consequence, survivors face an uncertain future that can impact on their physical and mental wellbeing (Allart et al., 2013; Mitchell, Ferguson, Gill, Paul, & Symonds, 2013). According to research, many patients cope well, and their level of grief is considered a normal response to a diagnosis of cancer (Aziz, 2002; Mitchell et al., 2013). However, in times of crisis during the survivorship journey, the degree of these symptoms may fluctuate and result in psychological illness (Cunningham, 1995; Norris, Pratt-Chapman, Noblick, & Cowens-Alvarado, 2011; Swash, Hulbert-Williams, & Bramwell, 2014). Consequently, psychological screening has become recognized as an essential component of holistic oncology care (Syrjala et al., 2004) and is considered by some to be the ‘sixth vital sign’ (Bultz & Johansen, 2011).

Although the instruments used and estimates vary depending on the study population, the documented literature provides strong evidence that HC survivors are at greater risk of psychological distress than those diagnosed with other chronic illnesses (Krebber et al., 2014; Lobb et al., 2009; Mosher et al., 2011). This may be due to several unique and challenging characteristics involving HC (i.e., the specific treatment regime and lack of preventative screening) that will be discussed in the next chapter. The literature also reports that HC

survivors tend to take longer to recover from the impact of psychological sequelae, such as anxiety and depression, than the physical effects of cancer treatment (Syrjala et al., 2004). This means that HC survivors may be more likely to require psychological intervention. Yet, research reports that a cancer survivor's mental health is often overlooked by busy clinicians in many healthcare settings (Mitchell et al., 2011). This may be problematic, as evidence indicates that psychological distress may lead to reduced participation in medical care and potentially prolong hospitalization (Prieto et al., 2002).

However, understanding depression among cancer survivors can be a challenge, partly due to conflicting results. According to research, this is predominantly due to numerous methodological issues (i.e., instruments used, cancer type, prognosis and treatment phase) (Krebber et al., 2014; Mitchell et al., 2013; Walker, et al., 2013). For example, previous research has reported prevalence rates of depression that vary between 0% and 58% (Massie, 2004). Likewise, in two recent meta-analyses, the rates of depression among mixed cancer populations differed substantially, from 8% to 24% (Krebber et al., 2014) and from 1.0% to 77 % (Mitchell et al., 2013). In addition, anxiety, which is often overlooked as an outcome in cancer survivors, is also reported to be prevalent among cancer survivors (Mitchell et al., 2013). Research has found the rates to be double that of depression, among long-term survivors (Mitchell et al., 2013).

There are several other reported psychological disorders, including post-traumatic stress (PTSD) and adjustment disorders, among cancer survivors (Knobf, 2011; Rodin et al., 2013). However, depression and anxiety are reported in the literature to be the most common psychological problems causing distress among HC survivors (Lobb, et al., 2009; Mitchell et al., 2011) and will therefore be the main focus of this research. The next section defines resilience and related concepts before providing a background into the history of resilience research.

Resilience

Definition

Resilience originates from the Latin 'resilire' meaning 'to leap back' (Windle, Bennett, & Noyes, 2011). Research on resilience suggests that some individuals are better able to adapt to stress and hardship, whilst others are less able to cope (Luthar, Cicchetti, & Becker, 2000; Tedeschi & Calhoun, 2004). One of the simplest definitions of resilience is provided by Berk (2000) as "the ability to adapt effectively in the face of adversity" (p. 543). As this definition suggests, resilience could hold the key to explaining how individuals 'bounce back' and deal with various challenges, such as ill health throughout life. Although the concept of resilience is not recent, according to Stewart and Yuen (2011), approximately 85 percent of articles investigating resilience have been published in the last ten years. Consequently, the

complexity of defining the construct of resilience has been widely recognized and debated (Luthar, Cicchetti, & Becker, 2000; Vanderbilt Adriance & Shaw, 2008). This is largely due to issues in both terminology and definition, in what is required to be demonstrated by individuals in order to be labelled resilient, and, heterogeneity in the type and level (i.e., personal meaning) of risk experienced for a person to be termed 'resilient' (Davydov et al., 2010; Windle, Bennett, & Noyes, 2011).

For example, researchers have argued that the concept of resilience may be a set of individual traits (Rutter, 1966; Richardson, 2002), a process (Richardson, Neiger, Jensen, & Kumpfer, 1990), or a positive outcome (Masten, 2001; Olsson, Bond, Burns, Vella-Brodrick, & Sawyer, 2003). In addition, resilience has been viewed more recently as multidimensional construct that is influenced by context and culture (Pooley & Cohen, 2010; Ungar, 2001). This has resulted in more comprehensive definitions such as one provided by Ungar (2004), who describes resilience as "the outcome from the negotiations between individuals and their environments for the resources to define themselves as healthy amidst conditions collectively viewed as adverse" (p. 342).

Another recent definition was proposed by Windle, Bennett, and Noyes (2011) following a systematic review of 271 resilience-related articles, which identified three necessary requirements for resilience: "the need for a significant adversity/risk, the presence of assets or resources to offset the effects of the adversity, and positive adaptation or the avoidance of a negative outcome" (p. 163). Based on this review, which provided a useful benchmark, the following operational definition was proposed, as, according to Windle, Bennett, and Noyes, it encompassed all of the described key characteristics:

"Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity. Across the life course, the experience of resilience will vary" (Windle, Bennett, & Noyes, 2011, p. 163).

According to Masten (2007), many of the controversies surrounding the definition of resilience could be addressed by better science. This not only includes more rigorous attention to methodology, but also through clarification of related concepts, for example, by operationally defining resilience terminology in all settings. In this way, each research context will have a unique set of risks and positive outcomes that are dependent upon the resources and demands of that context.

While this addresses the differences between contexts, it does not address individual variations. For example, what represents a successful outcome in one context may not be extended to another, as perception of risks and positive outcomes can differ between

individuals within the same context (Luthar, Sawyer, & Brown, 2006; Ungar et al., 2007). This suggests that risks and positive outcomes are not only dependent on context; they are also dependent on how the person within the context perceives their circumstances. Take two individuals following the diagnosis of cancer, a situation collectively viewed as adverse. Within this context, one person may perceive their situation to be more adverse than the other. Hence, the way in which each individual manages this experience, including the resources available to them, may differ. For example, one individual may perceive the involvement in online support groups as a protective factor, whereas the other may perceive that situation as a risk, both of which impact in some manner on individual outcomes. Therefore, it is important to understand how each individual perceives the resources and restrictions available to them and how this may impact on their process of resilience following an adverse event such as HC. However, this is complex as specific analytical tools to assess such a model are not yet widely available. With this in mind, it is beneficial in this research to first outline resilience terminology, before providing a brief insight into the history of resilience research.

Terminology and Related Concepts

As discussed above, resilience has been operationalized in many ways. However, the majority of researchers view this phenomenon as a positive outcome resulting from protective factors in the context of risk or adversity (Luthar et al., 2000a). These risk and protective factors, reported to affect individual outcomes differently, operate concurrently at the individual, family and community level (Carver, 2005; Unger, 2008; Windle, Bennett, & Noyes, 2011). However, similar to the issues surrounding the definition, there is also controversy surrounding resilience semantics (Vanderbilt-Adriance & Shaw, 2005).

First, *risk factors* are conditions or situations, which have been linked to negative psychosocial outcomes. Risk factors, either singly or in combination, have the potential to decrease the chances of resilience (Masten, 2007; Ungar, 2008). Since the first identification of parental psychopathology as a risk factor for mental illness, many studies have identified and explored other risk factors mainly among children including: poverty (Rutter, 1979, Werner & Smith, 1982, 1993); maltreatment (Cicchetti & Rogosch, 1996); chronic illness (O'Dougherty & Wright, 1990); urban poverty and community violence (Gorman-Smith, Henry & Tolan, 2004; Hammack, Richards, Luo, Edlynn, & Roy, 2004; Richters & Martinez, 1993); and, repeated hospital admission (Rutter, 1982). While all of these factors are associated with negative outcomes, it is important to note that they are not necessarily equivalent in severity; rather, severity depends upon both the risk factor and the person in question (Vanderbilt-Adriance & Shaw, 2005). Thus, there may be vast contrast in the context of risk severity among diverse populations. For example, some researchers have included normative middle class samples (e.g., Masten et al., 1999), while others have investigated ethnically diverse

samples of children growing up in violent neighbourhoods (e.g., Gorman-Smith, Henry & Tolan, 2004).

Findings on risk factors have also led resilience researchers to propose the existence of factors that ‘protect’ individuals from poor outcomes. Thus, *protective factors* increase the likelihood of resilience. Research into protective factors moves away from the traditional deficit approach in resilience research, towards a more positive view of an individual’s skills and attributes (Masten & Powell, 2003). For example, Rutter (1992) defined three broad variables as protective factors: (a) personality coherence; (b) family cohesion; and, (c) social support. Personality factors include level of autonomy, self-esteem and self-efficacy, good temperament, and positive social outlook. In the area of traumatic stress research, Raphael and Wilson (1993) identified similar factors associated with resilience, which included internal locus of control, altruism, the perception of social and economic resources, self-disclosure, and the formation of a clear sense of identity as a survivor. External support systems, whether perceived or actually used, such as family cohesion, and a lack of family tension have also been identified as protective factors that promote resilience (Agaibi & Wilson, 2005; Garmezy & Masten, 1991).

Akin to the challenges surrounding the definition of resilience, controversy extends to the operationalization of protective factors. Some researchers have argued that a protective factor should interact with risk status to predict outcome (Garmezy, Masten, & Tellegen, 1984; Rutter, 1992). By this definition, only variables that are more strongly associated with positive outcomes in the context of high risk, as opposed to low risk, are considered to be protective. In more recent years, however, the term, protective factor, has been used to refer to all factors associated with positive outcomes (Vanderbilt-Adriance & Shaw, 2008). Likewise, there are important differences in the operationalization of ‘positive outcomes’ with some studies focusing on the absence of psychopathology, while others require more positive outcomes such as academic achievement, social competence, or meeting appropriate developmental milestones.

Whether resilience is operationalized as the absence of a negative outcome or the presence of a positive outcome (or the combination of both) is both a matter of theoretical perspective and the nature of the risk factor in question. For example, some risk factors are considered to be so powerful (i.e., child abuse) that the absence of mental illness may be quite remarkable, while other risk factors (i.e., parental separation) may necessitate more evidence of a positive outcome (Luther & Zelazo, 2003). As resilience is not an “all-or-nothing” phenomenon, Luther and Zelazo (2003) assert that it must be measured across multiple domains to ensure that an accurate portrait of positive adjustment is provided. For example, individuals may be doing well on external measures of functioning such as career

achievement, yet simultaneously demonstrate high levels of internal distress (Luther, 1991; Vanderbilt-Adriance & Shaw, 2008).

Finally, several other concepts related to resilience have been discussed in the literature, such as benefit finding, thriving and posttraumatic growth. Benefit finding is the capacity of an individual to make sense of adversity by focusing on personal growth or positive changes (Herman et al., 2011). Thriving is considered a step beyond resilience (Carver, 2010). This occurs when a person not only returns to a baseline or pre-stress level, but also achieves a higher level of functioning by gaining knowledge, new skills, increased confidence and improved relationships (Carver, 2010). Posttraumatic growth (PTG) goes beyond both resilience and thriving. This is a construct with multiple elements that include an ability to unearth new opportunities, enhanced appreciation of life, greater strength and personal satisfaction, more intimate relationships and increased spiritual development (Tedeschi & Calhoun, 2004). Although the concepts of thriving and PTG are gaining momentum within positive psychology, the present research aims to focus on the process of resilience. The next section moves to providing a brief history of resilience research.

History

The idea of resilience was first introduced during the 1970's in the field of developmental psychology (Vanderbilt-Adriance & Shaw, 2008). Norman Garmezy, Emmy Werner and Michael Rutter were among many of the influential contributors to earlier studies that were interested in stress-resistant children affected by risk, such as poor parenting and impoverished living conditions (Garmezy; 1983; Rutter, 1992; Vanderbilt-Adriance & Shaw, 2008). These earlier publications set the scene for more recent work by researchers, including Ann Masden, Glenn Richardson, Suniya Luther and Michael Ungar, to explore not only individual traits but also how protective factors might function as an evolving process across contexts and throughout the lifespan (Gartland, Bond, Olsson, Buzwell, & Sawyer, 2011). As a result, over the past few decades, research into resilience has flourished to include a more dynamic and broader ecological approach (Bronfenbrenner, 1986). This has embraced the contribution of both internal processes (such as personal, biological or psychological factors) and external processes (including environment, family or community systems) which influence resilience among individuals (Mandleco & Perry, 2000).

Previously resilience research stemmed from investigations, not of childhood resilience, but of childhood vulnerability. Researchers prior to the 1970's were more interested in the adverse outcomes resulting from traumatic situations rather than the positive aspect of adapting to adversity (Masten & Powell, 2003). For example, studies during the 1940's and 1950's attempted to understand the behaviour of patients with schizophrenia. In these early studies, patients who demonstrated more adaptive behaviour were considered a rarity and

largely ignored, as the focus at this time, was primarily on the patients with negative outcomes (Masten & Powell, 2003).

However, during the 1970's researchers began questioning why patients with the same apparent risk displayed marked differences in their coping abilities and health outcomes. According to Masten and Powell (2003), early investigations revealed the schizophrenic patients with the least severe courses of illness had remarkably similar premorbid histories of competence at work, in social and intimate relationships, including the capacity to fulfil responsibility. Researchers began to question whether specific factors could be identified which led to more successful behavioural outcomes for patients with schizophrenia. This represented one of the first suggestions that specific factors may be related to resilience, or more positive outcomes in otherwise unfavourable circumstances.

At the same time, researchers began to investigate the behavioural and mental health outcomes of children who were exposed to identified risk factors such as poverty, developmental problems and maltreatment (Hawley & DeHaan, 1996; Masten, 2001). For example, Garmezy (1974) investigated the behavioural and mental health outcomes of children with mentally ill parents, finding these children to be at a higher risk of experiencing neglect and adverse outcomes during their lifetime. However, some children seemed to be able to overcome this adversity and thrive. This prompted an interest among researchers on understanding individual variations in response to adversity. The results of this research indicated that some children demonstrated stable individual characteristics (i.e., high IQ) and were more resilient than others (Garmezy, 1974; Masten & Powell, 2003).

One of the largest studies examining risk and protective factors was undertaken in Kauai, Hawaii in the 1970's by Emmy Werner and Ruth Smith (Masten & Powell, 2003; Werner & Smith, 1982). This 40 year longitudinal study followed the development of 700 children born in 1955 at 1, 2, 10, 18 and 41 years of age. The study began as an exploration of the long-term negative effects of risk factors that included high poverty, mothers with little or no formal education, few material possessions, and a higher than average rate of premature births and perinatal stress (Werner & Smith, 1982). Most of the children ($n = 442$) were born without complications and grew up in supportive environments. Some, however, grew up in families where they experienced disadvantage and neglect and as a result, many of these children had serious coping problems (20%), committed serious offences (15%), and suffered mental illness (10%). However, Werner and Smith also identified 10% of the cohort who "worked well, played well, loved well, and expected well" (1982, p. xv). According to Werner and Smith, 'expected well' referred to feelings of hope and positivity shown by this cohort of children.

Thus, Werner and Smith (1982) examined the characteristics and life experiences of the children at high-risk who overcame adversity in this way, compared with those who had

developed serious behavioural, mental health or learning problems. Several processes were identified as contributing to the resilient outcomes for these children, but were absent from the lives of others who presented with problematic outcomes (Werner & Smith, 1982). First were characteristics of the individual, such as being active, physically strong, sensitive, nurturing, responsible, gentle, socially perceptive, and mature. Second were family characteristics such as having a close positive relationship with an adult. Finally, there were factors external to the family such as support outside the family unit such as access to caregivers (Werner & Smith, 1982).

This research by Werner and Smith (1982) and prior research by Rutter (1966, 1987, 1992) and Garmezy (1974) provided the foundation for subsequent resilience research. This has resulted in several waves of resilience research (Masten, 2007; Richardson, 2002). These approaches will be discussed in Chapter 3, as it is important to understand the changes in how resilience has been studied, defined, and measured including the manner in which a “resilient” individual is conceptualized. The relevance of the association between resilience and illness, including HC will now be highlighted. Following this, the underlying theoretical framework will be discussed, before closing with a brief summary and outlining the main research questions.

Haematological Cancer and Resilience

Due to the fairly universal outcome of death once diagnosed with cancer in earlier times, the majority of early research addressing resilience was among individuals with other physical illnesses, such as cardiovascular disease (Chan, Ho, Fu, & Chow, 2006; Helgeson, 1992), diabetes (Pollock, 1989), Parkinson’s disease and multiple sclerosis (De Ridder, Schreurs, & Bensing, 2000). In addition, diseases such as AIDS (Farber, Schwartz, Schaper, Moonen, & McDaniel, 2000), were also studied in the resilience literature, which is interesting given that AIDS resulted in an actual death sentence when first diagnosed in the early 1980’s, whereas cancers at the time had better overall survival rates. However, the increase in cancer diagnoses and survival rates has led to a more recent rise in resilience-related publications among mixed cancer patients, yet this is less evident in the HC survivor population.

Recently, Stewart and Yuen (2011) conducted a systematic review of 52 articles published between 1950 and 2009 that specifically investigated psychological resilience among individuals with physical illness, including cancer. The aim of this review was to determine the factors associated with promoting or predicting resilience among this specific population. The analysis by Stewart and Yuen (2011) acknowledged that several of the features reported to be predictive of resilience and to reflect positive adaptation in chronic illness (e.g., individual personality and psychological factors, social support and coping strategies) were those identified in earlier studies that did not focus on chronic illness. This

result is not unexpected, given that environmental, genetic, coping strategies and past events all contribute to resilience, despite the type of adversity experienced (Stewart & Yuen). However, this review also identified resilience factors specifically associated with, and pertinent to, physical illness. These included illness perceptions, self-care, compliance with treatment recommendations, health-related QOL, perception of pain and adherence to exercise (Stewart & Yuen). Other recurring psychological themes reported by patients successfully living with cancer included empowerment, determination and acceptance of illness (Bulsara, Ward, & Joske, 2004; Stewart & Yuen, 2011).

Importantly, this review discussed numerous notable omissions amid the research relating to resilience among the physically ill (Stewart & Yuen, 2011). For example, despite ‘family support’ being a protective factor in children, its relevance to resilience in physically ill adults was not examined specifically by any study, but only generally categorised under ‘social support’ (Stewart & Yuen). Additionally, despite the importance of the role of healthcare professionals reported in previous literature (Bulsara, Ward, & Joske, 2004; McGrath & Clarke, 2003), there was no mention of their part in contributing to resilience among the physically ill in the articles reviewed (Stewart & Yuen, 2011). This review provides further justification for the current study, as it outlined several deficits in our understanding of resilience among those with physical illness.

Summary

There are a number of significant reasons for the conduct of this research. First, although available published studies on resilience and cancer offer important data on the role of resilience in cancer, they are limited in number. Second, several studies have highlighted the negative consequences of a cancer diagnosis, yet there is less literature on how survivors adapt and cope following treatment. Finally, there has been less interest in the wellbeing of long-term survivors of less common cancers. Research to date has focused on the initial diagnosis and earlier treatment phase of more prevalent cancers in the survivorship trajectory. Consequently, although a few studies have explored the experiences of patients with HC, little is known about the resilience shown in these populations over the long-term. Those patients who have completed potentially curative treatment are not only at jeopardy of recurrence or secondary cancer, but also face many psychosocial challenges. This study takes the opportunity to address these limitations. In conclusion, as resilience is a dynamic construct that interacts with contextual variables (Stewart & Yuen, 2011), the factors associated with resilience may vary in this population as compared to others previously identified. A key question is whether the factors that lead to resilience among adult survivors of HC follow a similar profile to those found in other individuals with chronic illness (Windle, Bennett, & Noyes, 2011). The overarching aim in this research was, therefore, to identify the key factors

and processes that contribute to, or impede resilience in survivors of haematological cancer. The study aims and research questions will now be outlined.

Aim and Research Questions

The current research was conducted in two phases. The aim of the first phase was to develop a conceptual model that explained how HC survivors exhibit and maintain resilience. This involved in-depth, semi-structured interviews. The questions addressed in Phase One were:

1. As a result of their experience, what are the common individual, family and community level factors that the HC survivors identified as contributing to their positive or negative mental health outcomes?
2. Which key factors made it easier or more difficult for HC survivors to achieve and maintain their resilience? and,
3. Were there any factors mentioned during the interviews that were not previously identified in the proposed conceptual framework?

The aim of Phase Two was to test the validity of the developed model on a larger national sample of Australian HC survivors. The questions asked in Phase Two were:

1. What is the relationship between resilience and depression and anxiety?
2. What are the significant factors that contribute to resilience among HC survivors?
3. Who in the clinical team provides the most and least support and relevant information? and,
4. As a result of personal experience, what advice can current HC survivors provide to those who are newly-diagnosed that may help them to cope?

Chapter 2

Literature Review

Part A - Haematological Cancer and Cancer Survivorship

Chapter Overview

This section (comprising Part A and B) provides a review of available literature that specifically investigates resilience and illness, including the survivorship experience for individuals following the diagnosis and treatment of HC. The first section, Part A (Chapter 2) will begin by explaining the literature search strategy and provide an illustration that visually represents the structure and layout of this review. The treatment and associated challenges faced by those diagnosed with HC will follow. Cancer survivorship will then be described by highlighting the focus of current and previous research interventions and quality of life issues among survivors. Mullan's (1985) stages of cancer survivorship is then outlined, followed by a brief explanation of the many barriers to meeting the psychosocial needs of cancer survivors. The influence and importance of resilience will be deliberated in Part B (Chapter 3). This will also discuss positive and negative outcomes and conclude with a conceptual model of resilience.

Literature Search Strategy

The main focus of this literature search was on publications that discussed the resilience process and how related risk and protective factors impact on the psycho-social wellbeing of survivors. Electronic searches were performed in PsychINFO (1967 - 2015); CINHAL (1981 - 2015); PubMed (1946 - 2015); MEDLINE (1950 - 2015), and ProQuest Nursing & Allied Health Source (1996 - 2015) with final searches completed by September 2015. The main search strategy used combinations of keywords for resilience (coping OR positive adaptation OR adjustment OR wellbeing OR quality of life OR hardiness OR benefit finding OR growth OR psychological functioning) and haematological cancer (blood cancers OR leukaemia OR lymphoma OR myeloma OR oncology OR cancer survivorship) and psychological distress (psychosocial OR depression OR anxiety OR stress).

The inclusion process comprised four stages. First the initial search results were de-duplicated and titles were visually screened for relevance. Second, abstracts of remaining papers were compared to the inclusion criteria and those falling outside the criteria excluded. Third, papers with suitable abstracts were read in full by the author to determine which were eligible for inclusion. Finally, the reference lists of all included papers were screened for any further eligible studies that had not been found within the initial searches.

A total of 1,288 titles were identified by the combined searches. Initially, the inclusion criteria were broad, in order to capture as many articles as possible. English publications that examined resilience and related concepts associated with cancer were included regardless of age, gender or ethnicity of participants in the study. However, the majority of papers were excluded as they were either duplicated or not relevant (i.e., they discussed drug-related research trials), rather than cancer survivorship research. This resulted in 478 remaining titles. At this point, to further narrow the focus of the literature search, articles that investigated children or teenagers (<18 years of age) were excluded mainly due to the differences in the survivorship issues among these populations. In addition, those studies that referred specifically to the 'family experience', except from the viewpoint of the person diagnosed with cancer, were also omitted. As outlined in Figure 2.1 these procedures resulted in a final total of 58 articles included in this review.

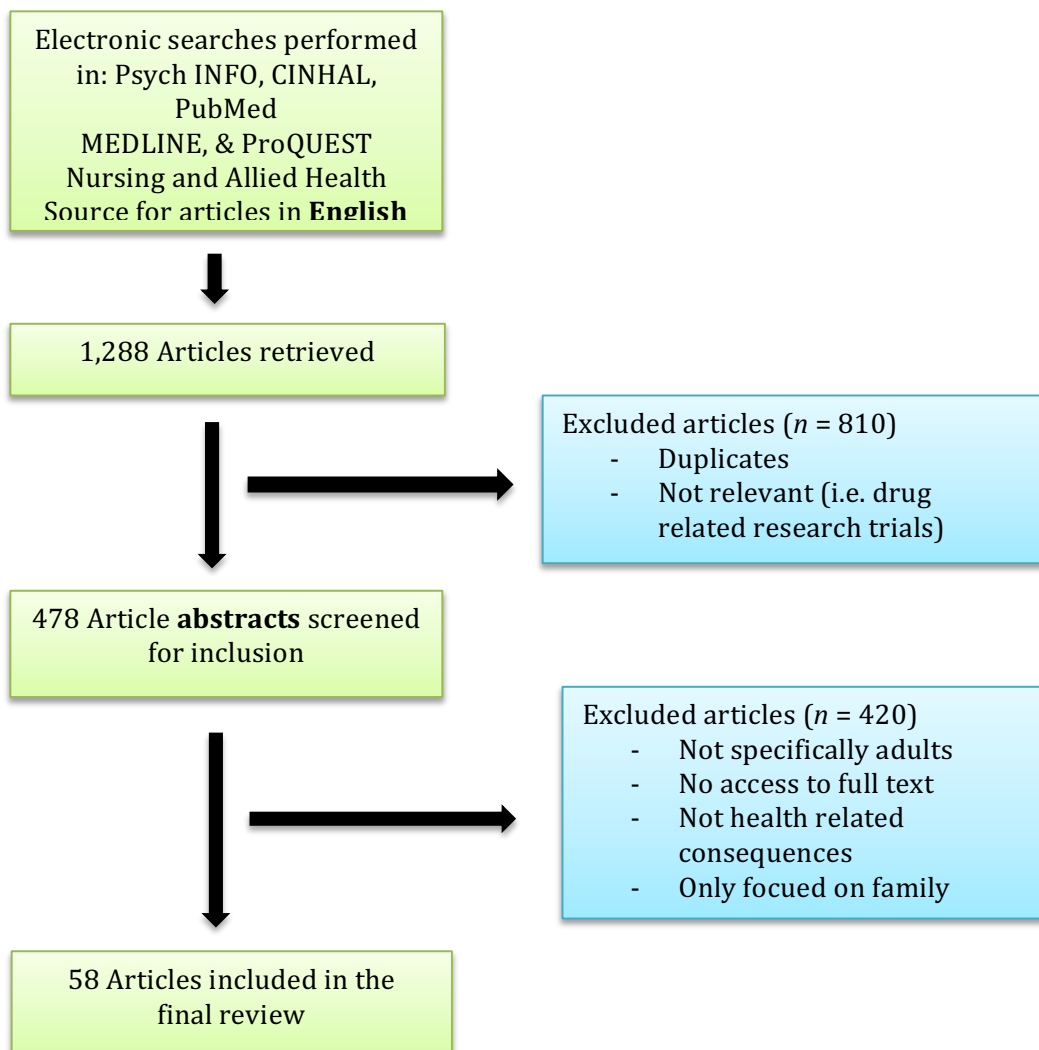


Figure 2.1. Literature review search and selection process

For the purposes of this review, studies were organised into two categories. First those papers outlining the challenges and risk factors (predicted to impede resilience) were grouped together. These studies included topics related to psychological distress, such as depression, anxiety, unmet needs, and psychosocial issues among HC survivors. The second group of articles investigated the protective factors (predicted to facilitate the resilience process). These included studies that discussed resilience-related topics such as coping and adaptation.

Among those articles that specifically examined resilience, the majority reported on more common cancers, childhood survivors and/or focused on patients in the earlier survivorship phases of diagnosis and treatment. Hence, to gain a more thorough understanding of the resilience process in short- and long-term survivors, it was necessary to also include articles that discussed psychosocial factors associated with enhanced coping and PTG, as well as articles that included mixed cancer populations. As discussed, 58 articles were included in the literature review due to their relevance, of these the six most pertinent articles have been more comprehensively outlined in Table 2.1. These include papers that will be referred to throughout this literature review and were selected as they focused solely on investigating the experiences of HC survivors, yet remain relatively recent (≤ 6 years).

Following Table 2.1, Figure 2.2 presents a visual illustration representing the HC survivor trajectory and outlines the potential resilience processes and possible outcomes as experienced by many cancer survivors. This illustration, which has been created by the author, based on her understanding of the literature, is intended to assist the reader by visually depicting the direction and layout of this literature review. It is hoped this will exemplify a similar journey, as experienced by many adults who are diagnosed with HC cancer. Thus, this review will begin by briefly outlining the non-modifiable factors (i.e., previous experience with adversity) that each individual may have developed prior to their cancer diagnosis. Next, the adverse event of an HC and the associated challenges will be described. This is followed by an outline of current cancer survivorship research and the stages proposed by Mullan (1985) that each survivor will transition through. As outlined in Figure 2.2, resilience is then reviewed in terms of the risk and protective factors among individuals, families and communities. Finally, the positive and negative outcomes that HC survivors experience, as part of this journey, will be discussed.

Table 2.1

Summary of Relevant Articles Investigating the HC Survivors Experience

Author/Year/Aim	Setting/Sample	Method/Design	Scales	HC	Findings	Relevance to Study
Korszun et al. (2014) Assess the impact of cancer (IOC) on psycho-social factors in long-term HC survivors	UK $n = 718$ 56.8% male $M = 37$ (age at diag) $M = 20.3$ (years since diagnosis)	Quantitative	EuroQOL IOC HADS Chalder fatigue Social support (SSI) Work & social adjustment (WSAS)	HL ($n = 280$) NHL ($n = 326$) AL ($n = 112$)	15% significant psych distress; 18% high level fatigue; 10% functional impairment. Higher –ve IOC scores significantly associated with psych distress, lower social support, high fatigue & functional impairment	Outlined the importance of understanding those who experience +ve & -ve IOC. Identified a subgroup that reports poor QOL with anxiety & depression most worrying problem.
Swash et al. (2014) Review studies Investigating the unmet psychosocial needs in HC survivors	UK 14,549 titles identified by search. Final inc18 papers reporting on 17 studies	Systematic review > 6 databases	N/A	Mixed HC	Key need areas identified inc: psychological, fear of reoccurrence, information, family & HCP need	Highlighted specific gaps in the current literature on unmet psychosocial needs among HC survivors especially among those who have ended treatment.

Table 2. *Continued*

Author/Year/Aim	Setting/Sample	Method/Design	Scales	HC	Findings	Relevance to Study
Schumacher et al. (2014) Examine resilience factors in patients after allogeneic stem cell transplant (alloSCT).	Germany <i>n</i> = 75 age range = (20-76 yrs) <i>M</i> Age = 48 60% males Time span ≥ Tx 6 mth to 7.6 years	Quantitative	Resilience Scale (RS-25) HADS EORTC QOL-C30	Leukaemia Lymphoma Myeloma & Aplastic	Resilience +ly correlated with QOL (0.587) & social functioning (0.472), negatively with anxiety anaemia (-0.491) & depression (-0.577). High resilience pts reported less anxiety depression, higher physical, emotional & social functioning & better QOL than low low resilience patient's Strong r/ship resilience & self-efficacy (r=0.698)	Identified a potential influence on time since diagnosis & resilience. Concluded that resilience is an important factor in HC survivors that has a positive impact on QOL and resuming normal life after treatment. More research suggested to further understand influencing factors
Allart et al. (2013) Review literature investigating the psychosocial factors linked to QOL in HC survivors	France 986 studies identified by search. Final inc 14 papers <i>M</i> Age = 48.1	Critical Review Medline Science Direct PsychInfo	N/A	Mixed HC	QOL +ly associated with sense of coherence; self-esteem, social support, global meaning locus of control & coping strategies. Helplessness-hopelessness +ly related to emotional distress	Outlined that clinical care could be better individualised by furthering research in the experience for HC survivors. Proposed impact on QOL may be influenced by age.

Table 2. *Continued*

Author/Year/Aim	Setting/Sample	Method/Design	Scales	HC	Findings	Relevance to Study
Paul et al. (2011) Identify the HP's patients & carers psychosocial research priorities for older adults with HC	Australian <i>n</i> = 117 partners/carer (31) patients (45) HCP's (41)	Quantitative	Value weighting web survey	Mixed	Patients rated the need to identify who is at risk of psychosocial issues and who is resilient as they're highest priority. Highest research priority given to newly diagnosed or Tx phase, less available for later stages	Highlighted that pts may feel psychosocial issues are not properly addressed by HCP's Suggested the need for more research to find interventions that can improve HC outcomes
Lobb et al. (2009) To determine emotional and informational & support needs at end of Tx	West Australian <i>n</i> = 66 Age range (18-80) < 1year post Tx	Questionnaire (self-report) & Qualitative for open ended questions	CaSUN Demographics	Mixed	59% stated it would have been helpful to discuss experience at end of Tx with a HCP. Most common reported unmet need related to 'care co-ordination and managing re-occurrence fears Those younger & single are more reliant on HCP support	Confirmed a sub group of pts who would have found it helpful to talk to with HCP at end of Tx as several unmet psychosocial needs were identified. Outlined that further research is required

Note. HC = Haematological Cancer; HL = Hodgkin's Lymphoma; NHL = Non Hodgkin Lymphoma; AL= Acute Leukaemia; IOC = Impact of Cancer; QOL = Quality of Life; n/a = Not Applicable; HCP = Healthcare Professional; Tx = Treatment; HADS = Hospital Anxiety Depression Scale; EORTC QOL C30 = European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire; CaSUN = Cancer Survivors Unmet Needs Measure; +ly = positively; -ly = negatively; pts = patients; Tx = treatment; inc = includes.

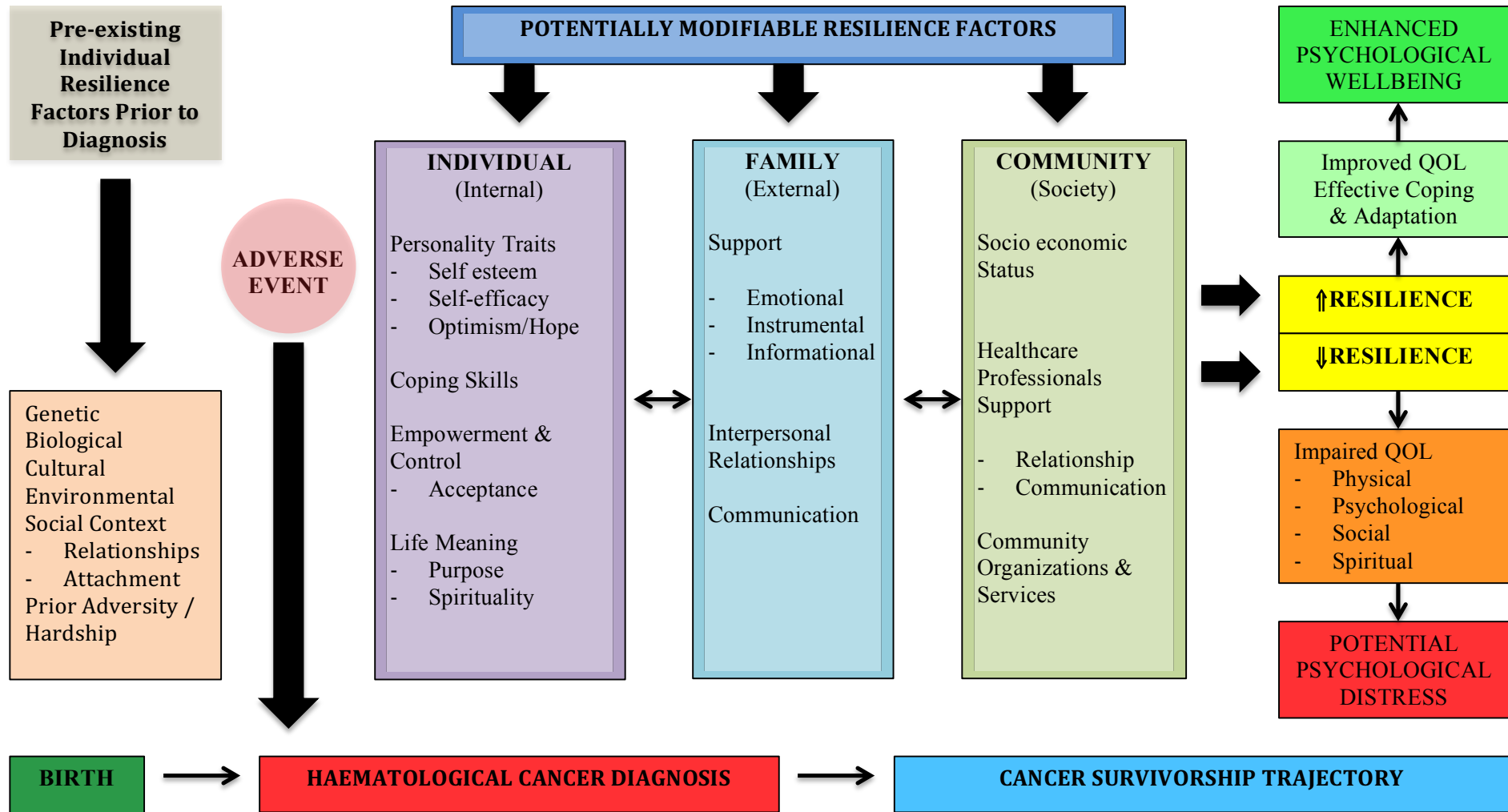


Figure 2.2. Visual representation of the HC survivor journey and factors influencing resilience outcomes.

Haematological Cancer

Each individual arrives at a crisis event, such as a HC diagnosis, with predetermined resilience characteristics (Richardson, 2002). These include genetic, biological, cultural, environmental and social factors (Szanton, Gill, & Thorpe, 2010). In addition, according to research, the previous experience that people have in overcoming adversity often predicts the manner in which they tend to cope with future crises (Richardson, 2002). Therefore, it is important to first identify and acknowledge that all individuals will present with an array of resilient traits and behaviours that have developed during previous life experiences. Yet, the majority of researchers also maintain that, despite pre-determined characteristics, all individuals have the potential to develop resilience (Masten, 2007; Pooley & Cohen, 2010; Ungar, 2008; Wagnild, 2009). Before describing the value of resilience from this perspective, it is first important to explain the HC survivor journey in more detail and explain why HC is considered such an adverse event.

Haematological Cancer Challenges and Treatment

There are pathological differences inherent in HC that lead to specific psychosocial challenges and which are unique to survivors (Swash, Hulbert-Williams, & Bramwell, 2014). Compared with those with solid tumour cancers, both the method and setting in which HC patients are treated can vary (Howell, 2011; Swash, Hulbert-Williams, & Bramwell, 2014). For example, surgery is often of central importance in treating individuals diagnosed with solid tumours, whereas for those with HC, rather than being curative, surgery is used more for diagnostic purposes (Allart et al., 2013). It is important to discuss the factors that are unique to survivors of HC, as treatment therapies can be more intensive, potentially resulting in a high burden of illness (Sherman, Cooke, & Grant, 2005).

There has been a recent and rapid improvement in molecular targeted therapies, which are best demonstrated by the advances in the management of haematological cancers (Hamilton, Gallipoli, Nicholson, & Holyoake, 2010). This has resulted in more HC survivors living long-term in the community. Previously in the 20th century, the discovery of x-radiation allowed palliative orthovoltage radiation therapy of Hodgkin's disease (Lichtman, 2008). Then following World War II, drug treatments for the HC's were also introduced (i.e., nitrogen mustard, and cortisone acetate) (Lichtman, 2008). However, over the last decade, the enhanced understanding of tumour biology has created the opportunity to develop new intelligent targeted therapeutic strategies (Ananda & Scott, 2015; Piccaluga, Martinelli, & Baccarani, 2006). Targeted therapy is defined as using a drug that specifically acts on a target area or biological pathway (Hamilton, et al., 2010; Ross et al., 2004). This triggers destruction or deterioration of the malignant process (Hamilton et al., 2010; Ross et al., 2004).

These targeted therapies are more effective and have a higher therapeutic index (a comparison of the amount of a therapeutic agent that causes the therapeutic effect to the amount that causes toxicity) (Hamilton et al., 2010). In addition, targeted therapies are less toxic than traditional chemotherapy regimens, as they are not as harmful to normal tissues (Hamilton et al., 2010). The last ten years has seen a rapidly growing awareness and recognition that targeting leukaemic stem cells may hold the key to minimising relapse and increasing survival rates in several HC's (Hamilton et al., 2010). As a result of the development of these treatment options, an improved survival rate has been observed for haematological malignancy (Chew & Roberts, 2015; Kelly & Dowling, 2011). This has changed the landscape for many patients, as the risks associated with treatment also become more acceptable (Hamilton, et al., 2010). However, while medical advances have resulted in impressive statistics on survival; in contrast, only a modest effort has been devoted to explain the psychological sequelae of the experience for HC survivors (Hamilton et al., 2010).

In addition, HC's often present in more advanced stages, providing another rationale for this research. Unlike more common cancers such as breast, prostate and colon cancer, there is no preventative-screening program routinely available to detect HC in the early stages (Lobb et al., 2009; Mukherjee, 2010). As a result, diagnosis generally only occurs as symptoms become apparent, at which point the stage of HC may be more advanced. This can result in the need for more aggressive therapies. In addition, unlike solid tumours, HC's are one of a few cancer types that are unable to rely on surgery as a curative treatment. Thus, other aggressive treatments are often necessary to target advanced cancer sites and these can have significant effects upon an individual's immune system and bone marrow function (Lobb et al., 2009; Rodin et al., 2013).

Despite the advances in targeted therapies discussed above, which have revolutionised haematological care over the last 10 years, monotherapy (one treatment type) with these drugs, is unlikely to be curative in the majority of cases (Roberts & He, 2008). Therefore, to improve clinical outcomes, the most hopeful future approach for those individuals diagnosed is to combine these targeted therapies with conventional cytotoxic chemotherapy (Roberts & He, 2008). This means that, while the majority of HC patients may survive longer due to recent advances in targeted therapy, the treatment may also require traditional chemotherapy (Roberts & He, 2008). Traditional chemotherapy is generally more toxic and debilitating than targeted therapy, and, therefore, can result in detrimental effects or post-treatment complications (Roberts & He, 2008). For example, this may affect the ability for patients to fulfil social, family and vocational responsibilities due to symptoms such as fatigue, depression, anxiety, fear, loss of identity and effects on sexuality and fertility (Lobb et al., Paul et al., 2011; Shrover, 2005)

Haematological cancer patients may also require more life-threatening treatments, such as a bone marrow transplantation (BMT) (Lobb et al., 2009). This is due to the specific

treatment effects upon normal bone marrow and immune function (Lobb et al., 2009). Haematopoietic stem cell transplant (HSCT) encompasses BMT and stem cell transplants from peripheral blood or umbilical cord blood (Copelan, 2006). Patients undergoing this therapy have unique needs due to the intensity of treatment necessary to prepare them for transplantation that may result in severe complications and a range of ongoing health problems (Bevans et al., 2011; Braamse et al., 2014; Pillay, Lee, Katona, Burney, & Avery, 2014). A HSCT may involve several stages, beginning with the collection of the stem cells, the administration of high doses of chemotherapy (with possible total body irradiation), then the re-infusion of stem cells, followed by the initial and long-term recovery phase (Bevans et al., 2011; Copelan, 2006). Allogeneic HSCT, which uses donor stem cells, may also lead to severe complications including a life-threatening illness referred to as graft-versus-host disease (GVHD) (Mosher, Redd, Rini, Burkhalter, & DuHamel, 2009; Syrjala et al., 2004). Studies by Syrjala and colleagues (2004) have reported that psychological and social recovery trails behind physical recovery in allogenic HSCT survivors.

As expected, when the disease is more serious or severe, levels of psychological distress are likely to be higher (Braamse et al., 2014). When compared to chemotherapy-only treated survivors, transplant recipients were reported to have more impaired emotional and social functioning at both five and ten years following transplantation (Syrjala, Abrams, Storer, & Martin, 2004). Studies have reported that approximately 25% of allogeneic HSCT recipients describe significant depressive symptoms one year post-transplant (Chang, Orav, McNamara, Tong, & Antin, 2005; Jenks, Kettmann, & Altmaier, 2008). In addition to disturbed psychological functioning, severe physical effects associated with toxicity and immunosuppression can result in major physical and functional impairment (Pillay et al., 2014). For example, physical side-effects of HSCT may involve sexual dysfunction and infertility in over 90% of cases (Hammond, Abrams, & Syrjala, 2007; Mosher et al., 2011).

The differences between HC and solid tumours that been identified in the literature (Swash, Hulbert-Williams, & Bramwell, 2014) warrant further investigation to highlight the potential distinctions in the psychosocial needs of this population (Swash, Hulbert-Williams & Bramwell, 2014). Psychosocial need implies a desire or requirement for support that underlies a person's psychological, social and emotional wellbeing (to be discussed in more detail at the end of this chapter). This is not a new concept in the wider cancer literature, yet remains a relatively unexplored area in relation to haematological malignancies. In addition, the challenges faced as a result of HC are experienced at different times and in varying levels of intensity. These directly influence each cancer survivors' ability to cope, which impacts on their QOL and mental wellbeing. As reported by Ganz (2001), disruption of function at any age may be distressing if it involves valued life activities or a change in goals. The next section highlights the current focus on survivorship research, internationally and within Australia.

Cancer Survivorship Research

Focus of Cancer Survivorship Research

According to Ganz (2011), the focus of survivorship care falls into three major conceptual domains: palliation of ongoing symptoms such as pain, fatigue or depression; prevention and monitoring of late effects of cancer treatment such as osteoporosis or secondary cancers; and, health promotion to maximize future wellness, which is often overlooked due to the focus on treatment and monitoring for cancer recurrence (Ganz, 2011).

The motive for the current focus on survivorship care is that, until the last decade, it had been largely overlooked (Ganz, 2011). The emphasis of cancer care had traditionally focused on medical diagnosis and treatment. Consequently, when compared with survivorship, there has been an abundance of literature published in these areas. For example, by 2004 the number of studies cited in PubMed relating to cancer survivorship ($n=374$) was minimal in contrast to the research addressing active cancer treatment and/or diagnosis ($n=23,736$) (Aziz & Rowland, 2003). However, there has been a considerable increase in published literature associated with cancer survivorship since 2005, with 179,366 citations available on the PubMed database in 2013.

There are two main reasons we have witnessed a significant rise in cancer survivorship research. First, as previously mentioned, the advances in cancer treatment have enabled long-term survival in a greater number of individuals we know little about (Boyle, 2006). Second, concerns over long-term and/or late effects of aggressive therapies, introduced during the 1970s, warranted consideration of treatment-related secondary cancers (Matesich & Shapiro, 2003; Marcu, Santos & Bezak, 2014; Theodoulou & Seidman, 2003).

Long-term effects relate to any side-effect that a cancer patient experiences as a result of treatment. These long-term effects, such as anxiety and/or issues with intimacy, begin during treatment and persist beyond the end of treatment (Aziz, 2002). Late effects refers to unrecognised toxicities that are absent at the end of therapy but which manifest later often as a result of treatment (Aziz, 2002). Late effects may occur at any stage following the completion of treatment and these have been well documented, some of which include: fatigue, lymphedema, cognitive difficulties, disfigurement, weight changes, problems with fertility, serious damage in major organs and secondary tumours (Aziz, 2002; Baker, Denniston, Smith, & West, 2005; Goldstein et al., 2012; Bennett et al., 2010; Brennan, Butow, Spillane, Marven, & Boyle, 2011; Hogkinson et al., 2007). These late effects may result in the cancer survivor having to adjust to a lifestyle they were not expecting (Aziz, 2002). This has resulted in research that has investigated ongoing psychosocial issues and QOL among survivors.

Surviving Cancer and Quality of Life

In 2008, Doyle published a conceptual analysis suggesting that the main themes of cancer survival experiences relate to physical, psychological, social and spiritual effects. These experiences represented below in Figure 2.3, have also been referred to under the umbrella of quality of life (QOL) factors (Pratt-Chapman, Simon, Patterson, Risendal, & Patierno, 2011). Internationally, and within Australia, several studies have attempted to report on the QOL issues faced by patients completing treatment for cancer. Many of these areas of interest have included: fear and anxiety related to cancer recurrence, the future and death (Butow, Fardell, & Smith, 2015; Jefford et al., 2008; Llewellyn et al., 2013); loneliness, uncertainty, isolation and abandonment (Boyle, 2006; Constanzo, Ryff, & Singer, 2009; Knobf, 2011); loss and grief (Ferrell & Dow, 1996); physical and psychological consequences, including late or longer term effects (Davydov et al., 2010; Foster, Wright, Hill, Hopkinson, & Roffe, 2009; Min et al., 2013; Mitchell et al., 2011; Mosher et al., 2011); changes to identity, body image, intimacy and sexuality (Doyle, 2008; Foster et al., 2009; Jefford et al., 2008); uncertainty about health and effects of treatment (Davies, 2009); unmet needs (Campbell et al., 2011; Hall, D'Este, Tzelepis, Lynagh, & Sanson-Fisher, 2014; Hwang et al., 2004); returning to work, employment discrimination, financial impact and ongoing challenges acquiring insurances and mortgages (Amir & Brocky, 2009; Boyle, 2006; Feuerstein, 2005; Grunfeld, Drudge-Coates, Rixon, Eaton, & Cooper, 2013; Hara & Blum, 2009); the impact of cancer on family and caregivers (Boyle, 2006; Mitchell et al., 2013; Rowland, Aziz, Tesauro, & Feuer, 2001); and, reassessing life priorities, spirituality, meaning and hope (Dunn, Occhipinti, Campbell, Ferguson, & Chambers 2011; McGrath & Clarke, 2003; Tedeschi & Calhoun, 2004; Turner-Sack, Menna & Setchell, 2012; Xuereb, 2003).

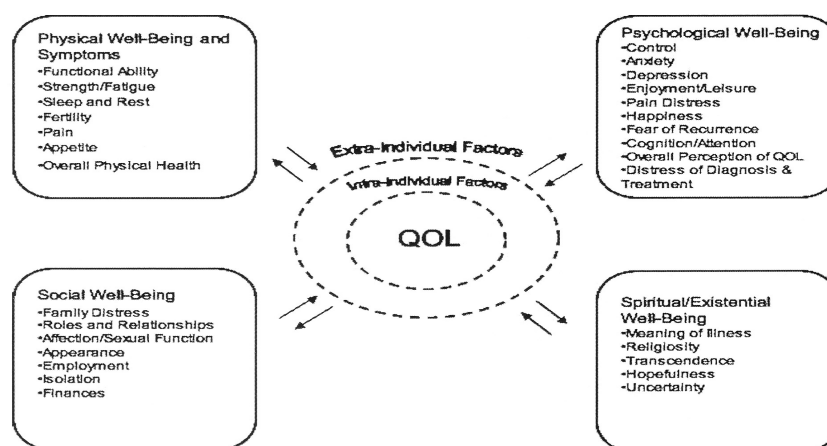


Figure 2.3. QOL model applied to cancer survivors, by Pratt-Chapman, M., Simon, M.A., Patterson, A. K., Risendal, B. C., & Patierno, S. (2011). Survivorship navigation outcome measures. *Cancer*, 117(S15), 3573-3582.

Interventions for Cancer Survivorship

In addition, there has been a rise in the amount of research undertaken to develop and test interventions to enrich QOL and the survivorship experience. These publications have included studies on: the use and delivery of models of follow-up care (Brennan, Butow, Spillane, & Boyle, 2008; Ganz & Hahn, 2008; Jefford et al., 2008; Morgan, 2009); various measures and screening tools (Holland & Reznik, 2005; Meneses & Benz, 2010); lifestyle and health promotion interventions (Aziz, 2002; James et al., 2011; Rabin, Morrow, Simpson, & Pinto, 2011); supporting patients with advanced cancer (Hudson et al., 2008); and, the needs of specific populations such as migrants (Butow et al., 2013; Hollinshaus & Utz, 2013), rural patients (White et al., 2011) and the indigenous population (Condon, Armstrong, Barnes, & Cunningham, 2003).

A number of researchers have also explored the individual's experience of being involved in specific interventions (Emery et al., 2008; Galvao & Newton, 2005); according to specific timeframes (Aziz, 2009; Bennett et al., 2010; Hogkinson et al., 2007); by tumour group (Bulsara, Ward, & Joske, 2004; Meneses & Benz, 2010; Maher & De Vries, 2001; Mosher et al., 2011); gender (Helgeson, Reynolds, & Tomich, 2006; Pudrovaska, 2010); and, age (Avis & Deimling, 2008; Bellizi, Mustian, Palesh, & Diefenbach, 2008; Rabin et al., 2011; Zebrack, 2011). However, despite the extensive amount of literature published on the consequences of cancer, what appears to be lacking is an understanding of the strategies used by these individuals to cope and/or maintain a level of resilience (Denz-Penhey & Campbell Murdoch, 2008; Mullen, 1985; Park et al., 2009; Pieters, 2015; Stewart & Yuen, 2011). In addition, when compared with international efforts, relatively few articles addressing cancer survivors have been published within the Australian context, especially among those with less common cancers (Girgis & Butow, 2009).

This is important to address, as earlier research indicates that there is a need to improve the care of cancer survivors. For example, earlier Australian research involving 888 cancer patients reported that 40% experienced unmet needs across several areas (Sanson-Fisher et al., 2000). More recent research also indicates that the survivorship needs of distressed cancer patients have not previously been sufficiently met by the Australian healthcare system (Knott et al., 2012).

This may be due, in part, to the fact that the approach to survivorship research in Australia has been rather fragmented. As reported by Girgis and Butow (2009), there have been very few integrated Australian efforts to formulate a comprehensive survivorship research agenda. Individual researchers have conducted a wide spectrum of research on survivorship in Australia, ranging from qualitative to epidemiological research that addressed several topics across the survivorship continuum. However, these isolated approaches to

survivorship research have made it challenging to direct and co-ordinate a national agenda (Breaden, 1997; Girgis & Butow, 2009).

One of a few Australian studies that have emphasised the psychosocial aspects of cancer survivorship is a qualitative study undertaken by Jefford and colleagues (2008) at the Peter MacCallum Cancer Institute (PMCI) in Melbourne, Victoria. This research involved one focus group of 22 cancer survivors and two focus groups of 20 health professionals, in which the participants were asked, in a semi-structured format, to focus on their experiences at treatment completion and at one-year post treatment.

The results indicated that the most commonly identified psychosocial issues included: dealing with fatigue; others expecting you to be back to normal; anxiety about cancer recurrence; having to create new expectations about physical ability; and, information needs and anxiety about leaving the hospital system (Jefford et al., 2008). The participants suggested strategies to meet these identified needs. These predominantly included a treatment completion session (where the patient has the opportunity to discuss concerns prior to leaving hospital) and adequate emotional and psychological support and reassurance, which was the most frequently identified need. Health professionals also emphasised a requirement for routine post-treatment psychosocial screening, whereas patients suggested occasional telephone follow-ups. This may reflect the health professionals' experience or indicate that survivors are unaware of the potential for psychological distress (Jefford et al., 2008).

Although this study was unable to achieve a sound representation for all cancer types, it was instrumental in identifying the psychosocial issues of cancer survivorship in the Australian context. This research resulted in the development of the Australian Survivorship Centre based at PMCI in Victoria. In addition, Jefford and colleagues' (2008) findings provided the foundation on which more explicit research can now contribute to the awareness of survivorship concerns in Australia. For example, in order to address many of the unmet needs identified in this study, an intervention referred to as SurvivorCare has since been trialed (Jefford et al., 2013). The SurvivorCare intervention was developed by a multidisciplinary team using 3 key principles: (1) to promote patient involvement and engagement; (2) to address the specific needs of individual patients; and, (3) to use evidence-based strategies to promote well-being and reduce treatment sequelae (Jefford et al., 2011). SurvivorCare included educational materials, a tailored survivorship care plan, a tailored, nurse-led, end-of-treatment consultation, and three follow-up telephone calls. According to Jefford et al. (2011), as a result of this initiative, SurvivorCare has become recognised as a well-received, comprehensive intervention aimed at improving QOL and reducing distress and unmet needs among cancer survivors.

In Western Australia, Lobb and colleagues (2009) published a study that aimed to determine patients' needs within the first year of completion of treatment for haematological cancer. A quantitative research method was adopted, that included 66 self-report

questionnaires completed by cancer survivors during the first 12 months post-treatment. Findings were consistent with those identified by Jefford (2008). The results indicated that the most frequently stated unmet patient needs related to care co-ordination and managing the fear of recurrence. Over half, 59% ($n = 39$) of patients suggested that it may have been helpful to discuss their experience at the completion of treatment with a HCP. Results also reported that patients without a partner were found to be more reliant on support from HCP's. In addition, younger patients indicated significantly more needs around emotional and relationship issues following treatment. This study concluded that further research in the area of survivorship is needed in order to assess different patient outcomes and different unmet needs at various stages of survivorship (Lobb et al., 2009).

Cancer survivorship research is recognised as way of organising a wealth of knowledge that will develop over time and ideally enhance the health and well-being of those diagnosed and treated for cancer (Feuerstein, 2007a). The summary provided above highlights that the focus of research currently undertaken in Australia is within the scope of survivorship research priority areas identified internationally. However, there continues to be growing evidence of unmet needs following treatment, with research indicating that one in four cancer survivors have at least five unmet physical or psychological needs (Lobb et al., 2009). Therefore, further efforts are required to further our understanding of survivorship issues beyond treatment within an Australian context (Girgis & Butow, 2009). The phases involved in the cancer trajectory and the associated challenges for survivors, will now be described in more detail.

Stages and Associated Challenges of Cancer Survivorship

Cancer survivorship has come to represent a series of phases through which any patient learns to adapt and live with a life-threatening, chronic illness (Jefford et al., 2008). Mullan (1985) originally proposed three stages (Table 2.2) that each cancer survivor may transition through and the potential psychosocial issues that could arise as a result of each. A "transition" entails progressing from one comparatively stable state, to an experience of disorganisation and upheaval, and then toward another relatively stable situation (Boyle, 2006; Clarke-Steffen, 1993). In general, transitions are regarded as stressful, as they lead to periods of readjustment, evoke anxiety and impose adaptational challenges (MacLean, Foley, Ruccione, & Sklar, 1996). Major adjustments within the cancer experience may involve changes in one's sense of self from 'well individual' to 'cancer patient' (upon diagnosis), 'cancer patient' to 'cancer survivor' (at the end of successful treatment), and again episodic changes during intermittent hospitalizations, follow-up tests or when recurrence is diagnosed (Boyle, 2007).

These distinct phases were first introduced by Mullan (1985) as a series of periods, which he labelled as acute, extended, and permanent survival. Although not all cancer survivors pass through every phase and the length of time in each phase may vary, this framework was useful in outlining the diverse challenges faced by patients during the cancer survivorship trajectory.

Table 2.2

Phases and Experiences of Cancer Survival (adapted from Mullan, 1985)

Acute Survival	Extended Survival	Permanent Survival
Extends from diagnosis to completion of initial treatment	After treatment completion and starting to return to normal life	The extended disease free period with low likelihood of disease recurrence
Dominated by cancer treatment coping with effects of therapy	Period of regular follow-up and 'watchful waiting' with treatment if required	Adjustment to a 'new normal'
Anxiety and fear are common emotions experienced	Managing the physical, social and psychological effects following treatment	Long-term physiological and psychological effects secondary to treatment
Confronting one's mortality reassessment of life goals	Period where psychosocial services are important	Financial, employment and health insurance concerns
Community, healthcare and family support are important	Period dominated by fear of recurrence	Health promotion and life change strategies become the focus

The 'acute' stage of survivorship commences when an individual receives a cancer diagnosis and extends to the completion of initial treatment (Mullan, 1985). This is also commonly referred to in the literature as a phase of 'living with cancer' (Wheeler, 2010). Although the timeframe varies between patients, the acute phase, as described by Mullan, is usually completed within one year. Whilst survivors are thankful to be ending treatment, many describe being unprepared to cope with the long-term and late effects of having had cancer (Maher & Fenlon, 2010).

The acute stage of survivorship has been well researched (Ganz, 2011; Knobf, 2011; Maher & Fenlon, 2010). This phase has been identified as being particularly stressful for patients, with concerns related to fear, uncertainty, and anxiety about their cancer and psychosexual and financial issues, including the impact on family, friends and work (Armes et al., 2009; Butow, Girgis, & Schofield, 2013; Ganz, 2011; Hwang et al., 2004; Webber et al., 2011). This period is dominated by focusing on 'getting through' treatment in order to be cured (Maher & Fenlon, 2010). Specific physical problems identified during this time may include fatigue (Bennett et al., 2007; Goldstein et al., 2012), nausea and pain (Armes et al.,

2009; Menshadi, Bar-Tal, & Barnoy, 2013). In addition, the lack of appropriate social support and/or information provided by clinicians can be another source of stress for patients (Maher & Fenlon, 2010).

The 'extended' stage begins with the completion of initial treatment for the primary cancer (Mullan, 1985). This phase has also been referred to as 'living through cancer' and a time when the patient not only experiences physical limitations following treatment, but also confronts the possibility of cancer recurrence (Wheeler, 2010). Survivors can feel elated, but also disoriented and confused following the end of treatment. In addition, they may have "no evidence of disease" or be pronounced "cancer free", but rarely are patients told they are cured (Rancour, 2008). Widespread reviews of the available literature report that the period after completion of treatment brings its own unique and, in some cases, still poorly understood challenges that may interfere with QOL, relationships and employment (Knott et al., 2012; Maher & Fenlon, 2010).

During this extended phase, most cancer survivors demonstrate a gradual improvement in overall QOL (Gang, 2001). However, this is often coupled with feelings of anxiety, uncertainty, and psychological distress that may continue (Deshields, Tibbs, Fan, & Taylor, 2006) because of unmet emotional and support needs (Campbell et al., 2011). Re-integration into everyday life, once therapy ends, can be challenging and stressful for several reasons (Knobf, 2011). For example, once the immediate symptoms of active treatment have been dealt with, an ongoing problem for some cancer survivors is their altered body image (Doyle, 2008; Foster et al., 2009). Earlier research by Charmaz (1983) identified how people with chronic illness lose their previously held body image, largely due to physical challenges such as permanent scarring and/or weight and hair changes that challenge the identity of the individual. Consequently, cancer survivors report that they find themselves in adjusting to a 'new normal' (Maher & Fenlon, 2010).

In addition, social and emotional support from family and friends may diminish as treatment needs cease. Physically, the cancer survivor has showed signs of recovery (i.e., hair regrowth) and they may also appear to be regaining strength and increased energy levels (Goldstein et al., 2012; Knobf, 2011). As a result, partners and caregivers may not perceive the need for the same level of support. This is indicated in the literature by a reported decline in support following treatment (Knobf, 2011; Knott et al., 2012; Wheeler, 2010). This often coincides with a point in time when many patients remain anxious about leaving the healthcare system and losing contact with their specialist and fellow patients, who they had previously seen on a regular basis (Wheeler, 2010). Conversely, some survivors may experience a desire to avoid appointments with their specialist, which could impact on their future lifestyle and health behaviour decisions (Carr, 2004).

Following treatment, cancer survivors have also expressed feeling powerless and unsure about their role of being personal health advocates (Carr, 2004). A systematic review of

information needs by Campbell et al. (2011) found that survivors wish to receive information in the year following treatment, including information on follow-up appointments, long-term effects and self-care (Maher & Fenlon, 2010). However, delivering a balance of information regarding follow-up care remains a challenge. The method, timing and amount of information provided requires consideration. For example, survivors have reported that it can be difficult to process large amounts of information given verbally following treatment (Hewitt, Bamundo, Day, & Harvey, 2007).

During the extended stage, the weeks leading up to the first follow-up appointment after treatment are also an anxious time. The cancer survivor and their family are faced with the stress of awaiting test results and the fear of recurrence (Boyle, 2006; Butow, Fardell, & Smith, 2015; O'Neill, 1975). In the current health care system, follow-up visits over the first year usually focus on the cancer status and assessment of physical symptoms (Knobf, 2011). In addition, these appointments may be brief and, unfortunately, the adoption of supportive care interventions, including psychological screening during routine follow-up appointments, is not yet widespread practice (Knobf, 2011).

The final stage, according to Mullan (1985), is referred to as 'permanent' survival and begins approximately five years following treatment. This phase is also described in the literature as 'living beyond cancer' and relates to post-treatment and long-term survivorship (Wheeler, 2010). Permanent survival is akin to the notion of "cure", when the likelihood of recurrence is minimal (Henderson, 1997). During this stage, most survivors go back to the care of their primary physician and, preferably, they will have formulated a long-term health care plan (Wheeler, 2010). However, long-term and late effects on health, due to secondary effects of cancer treatment and/or secondary cancers, may represent another area of risk and distress (Hewitt, Greenfield, & Stovall, 2005; Wheeler, 2010). Cancer survivors have expressed that being considered disease free does not mean being free from disease (Alfano & Rowland, 2006; Hewitt, Greenfield, & Stovall, 2005). While two out of three long-term survivors suggest that their lives return to normal, one-third report ongoing physical, psychosocial or financial challenges (Wheeler, 2010).

Koocher and O'Malley (1981) published one of the earliest studies on the long-term adjustment of cancer survivors (those who were at least 5 years free of disease). Forty-seven percent of survivors in this study reported psychological symptoms, including low self-esteem, depression, anxiety, and mood fluctuations. Koocher and O'Malley concluded that cancer survivors were more likely to achieve normal psychosocial adjustment if they were diagnosed at a very early age, experienced long periods of remission, and/or received open communication and family support. Since Koocher and O'Malley's study, clinicians have researched the psychosocial challenges experienced by cancer survivors (Henderson, 1997). However, the transition from diagnosis and active treatment to long-term survivorship is currently an understudied phase in the cancer trajectory (Hewitt, Greenfield, & Stovall, 2005;

Stanton et al., 2005). Research to date has focused on the effects of cancer diagnosis and treatment during the acute phase, rather than how we can assist cancer survivors to cope throughout their life.

Building on Mullan's three-stage model, more recent qualitative research has identified another way of viewing an individual's subjective experience of transitioning through the cancer survivorship trajectory. In one study by Little and colleagues (2000), an initial, acute phase of liminality was acknowledged. Liminality is derived from the Roman word 'limen' relating a place between two living spaces and is regarded as a state of being on the 'threshold' of, or between, two diverse existential planes (Little et al., 2000). According to Little and colleagues, survivors transition through the space of illness but do not return to their world as it was prior to illness. Rather, they experience disorientation, a loss of control and uncertainty, which is then followed by an adaptive phase in which the survivor constructs meaning from their experience. This view was also reinforced by other researchers, who implied that that surviving is a process, involving several phases without an endpoint and is, therefore, a lifelong journey (Deimling et al., 2005; Dow, 1991; Pelusi, 1997).

Several Australian studies also reported that, during the transitions in this lifelong journey, survivors not only experience a lack of communication, but also a loss of support when leaving health services, which is compounded by the expectations of society, that survivors will return to normal after treatment (Butow et al., 2011, 2013; Knott et al., 2012). This is supported by Jefford and colleagues (2008) who suggested that there is inadequate information not only on the duration and prevalence of psychological consequences, but also on the coping strategies employed by cancer survivors following treatment.

Healthcare Professional Factors Influencing Survivorship and QOL.

In order to promote and assist the cancer-coping process, in addition to individual factors, HCP's also need to consider social support and open communication (Butow et al., 2011; Knott et al., 2012). According to Knott and colleagues, this support should occur across the cancer trajectory and not just following a cancer diagnosis. The visual representation in Figure 2.4 suggests that cancer patients experience a loss of support when leaving the healthcare service following treatment (Knott et al., 2012). This Australian model represents the typical cancer pathway from initial diagnosis through to survival, with an emphasis on the support from family, social networks and HCP's and how this affects the cancer patient's ability to cope.

As identified in Knott and colleagues' (2012) model, any transition along the cancer pathway, implies leaving what is familiar and letting go of current roles, relationships and routines, which may be accompanied by a sense of reduced support, uncertainty and loss.

Several studies have publicised that the periods of highest distress among cancer survivors are associated with transition points, not only when treatment commences, but also when this ends (Hewitt, Greenfield, & Stovall, 2005; Jefford, et al., 2008; Kaplan, 2008; Knott et al., 2012; Wheeler, 2010).

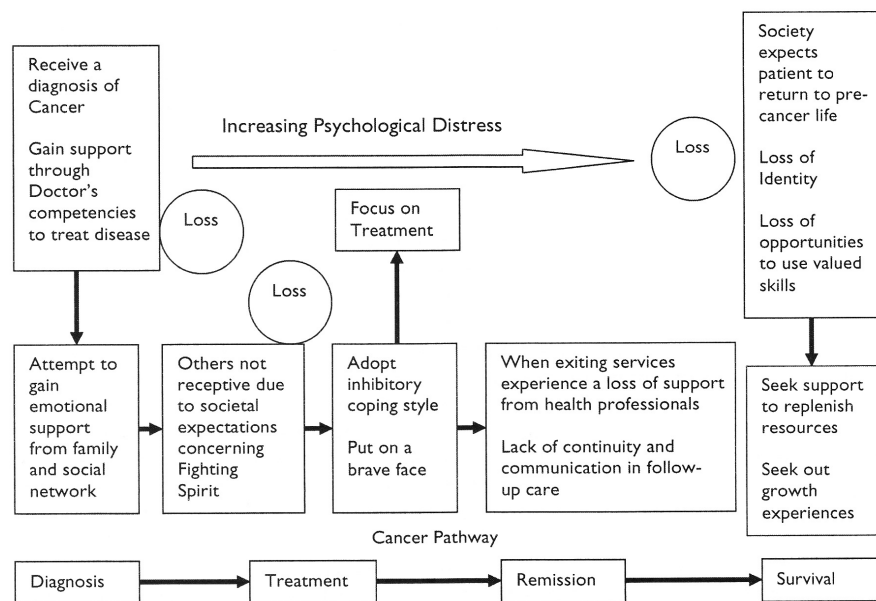


Figure 2.4. Model of the cancer-coping process, by Knott, V., Turnbull, D., Olver, I., & Winefield, A. (2012). A grounded theory approach to understand the cancer-coping process. *British Journal of Health Psychology*, 17(3), 551-564.

Although this is identified as a stressful time for many cancer survivors, these critical transition phases may also be opportunities to prepare patients for long-term survival by providing information on effective health practices (Denmark-Wahnefried, Aziz, Rowland & Pinto, 2005). For example, following cancer treatment, many patients want to be more responsible and involved in the self-management of their illness (Davies, 2009). Frequently cancer survivors ask how to deal with the effects of treatment, including where and how to access available support if required (Wilson 2008). In addition, survivors are keen to take up initiatives to improve their health, such as increasing exercise, improving their diet and maintaining health surveillance for osteoporosis, heart disease and secondary cancers (Demark-Wahnefried et al., 2000; Salminen, Bishop, Poussa, Drummond, & Salminen, 2004). This has been labelled by clinicians as a 'teachable moment' and a vital window in which to make a significant impact on the health decisions of cancer survivors (Maher & Fenlon, 2010).

The ultimate goal of successful treatment for cancer throughout each phase is not just continued existence, but a quality survival (Jefford et al., 2008). This involves the ability to

rise above the trauma of experiencing cancer, in order to acquire a lifestyle that is compatible with achieving life goals. However, in Australia, for many of the 126,800 individuals diagnosed with cancer each year (AIHW, 2014), returning to a life of normality following treatment may be especially challenging. Many questions may surface regarding the next steps in the care continuum and anxiety over cancer recurrence may overshadow the recovery process during this time (Alfano & Rowland, 2006; Jefford et al., 2008). At each stage of the cancer journey, coping challenges can be considered analogous to "parachuting into a jungle with no survival skills" (Ferrell, 1996, p. 76). With little, inappropriate, misleading or badly timed information and/or communication to guide adaptation, patients and families often confront this life-threatening experience feeling unprepared (Butow et al., 2011; Campbell, 2011; Jefford et al., 2008; Knott et al., 2012). These cancer-related challenges are particularly evident among migrant cancer survivors who also face language, cultural and social complexities. For example, more recent Australian research by Butow et al. (2013) identified a number of unmet needs among 596 cancer patients. The immigrant cancer patients ($n = 277$), predominately identified communication/language and information difficulties, whereas the Anglo-Australians ($n = 319$) referred more to fatigue and sexuality issues.

Several other mediating factors may also influence the coping ability of survivors, including: a stable family unit; the nature and degree of role responsibilities; communication style; patient age and/or gender; level of social support; spiritual orientation; information requirements; pre-morbid history of mental illness; and, access to coping resources (Matthews, 2003; Pudrovaska, 2010; Zebrack, 2011). The impact of many of these factors is not well understood (Boyle, 2006). In addition, as will be briefly discussed, there are also several barriers, predominantly within the healthcare system, to meeting the psychosocial needs of cancer survivors (Kaplan, 2008).

Barriers to Meeting Psychosocial Needs of Cancer Survivors

Whilst the intensive research effort into cancer detection and treatments has resulted in great success, the relative lack of comprehensive, evidence-based survivorship research has resulted in a failure to investigate, identify, and address the psychosocial needs of survivors (Davis & Batehup, 2011; Girgis & Butow, 2009; Kaplan, 2008). Although the neglect in this area is partly due to a lack of research, there are also several barriers that have contributed to difficulties in meeting the psychosocial needs of cancer survivors (Kaplan, 2008). These include: the limited time available during patient visits; the failure of many clinicians to ask about psychological wellbeing and consequently to refer patients for psychological assistance; the lack of simple and effective screening tools for emotional distress; a limited awareness of the psychosocial resources in the community; a general lack of knowledge of clinical practice guidelines for managing psychological distress; and, the stigma associated with seeking mental

health services (Girgis & Butow, 2009; Jefford et al., 2008; Kaplan, 2008).

A further issue has been the fragmentation of provision of care and lack of coordination and communication between various treatment centres (Kaplan, 2008). For example, the models for cancer follow-up services within Australia are not yet fully developed. Consequently, the transition from inpatient care to care by general practitioners and outpatient centres is still in its infancy (Jefford et al., 2008; Kaplan, 2008). A major concern also relates to identifying and implementing an appropriate model of follow-up care that is viable within the current economic climate (Davis & Batehup, 2011). For example, the current model of follow-up services may become unachievable when increasing numbers of cancer diagnoses, resource limitations, and a rising cancer survivor population is taken into consideration (Davis & Batehup, 2011).

Overview of Literature Review – Part A

Cancer survival has been described as a life-changing experience, which begins at diagnosis and transitions through phase's through-out life (Chapman, 2011; Mullan, 1985). The challenges faced by cancer survivors are multifaceted and are often referred to in the literature as the “price of survival” (Davies, 2009; Hewitt, Greenfield, & Stovall, 2005). In some circumstances, advances in cancer treatment have added years to life, but not necessarily life to years (Boyle, 2006). Patients have indicated that a cancer diagnosis increases anxiety, creates an awareness of mortality, uncertainty about the future, and leads to both positive and negative effects on health and lifestyle decisions (Chapman, 2011; Doyle 2008). Consequently, the complex nature of survivorship experiences effect many aspects of follow-up care, extending from prevention, screening, health promotion and rehabilitation, through to palliation and end-of-life care (Ganz, 2011; Morgan, 2009). These involve medical, physical, social, emotional, and economic health systems challenges, which will fluctuate over time (Doyle, 2008). Therefore, knowledge to manage and confront these issues will call for many diverse disciplines implementing several types of evidence-based research methodologies (Girgis & Butow, 2009; Feuerstein, 2007b).

Based on the literature reviewed, the current study builds upon the earlier Australian cancer survivorship research of Girgis and Butow (2009), Jefford et al. (2008), Lobb et al. (2009) and Knott et al. (2012) by specifically targeting HC survivors and the resilience process adopted by these individuals following initial treatment. This research is a significant addition to the existing literature in that it not only includes short-and long-term adult HC survivors, but also several types of HC cancer diagnoses that ensures those survivors that have less common HC's are represented. In addition, this work contributes to the literature in that the focus is on both positive (resilience) and negative mental health outcome measures (depression and anxiety). Although, it is not possible to include all variables, those modifiable factors reported

in the literature to influence resilience (i.e., personal coping strategies, social support, etc.) form the basis of the proposed conceptual model of resilience (discussed in more detail in the following chapter).

As stated by Leigh (1990), quality of cancer survival is in the eye of the beholder. It is, therefore, essential that survivors' needs are individually assessed. This includes model development to improve the quality of long-term survivorship and the detection of potential or real psychological distress that may compromise continued coping (Boyle, 2006; Hewitt & Rowland, 2002). While there can be no argument that a cancer diagnosis and treatment is a negative experience, many HC survivors also report unexpected positive adjustment outcomes due, in part, to resiliency (Dunn et al., 2011). This leads to questions of who can experience positive adjustment outcomes, how and under which circumstances? The next section of this literature review (Part B) aims to answer many of these questions by explaining resilience in more detail. First, an outline of previous approaches to resilience research will be presented. This will be followed by a review of research investigating the risk and protective factors among individuals, their family and the community, each of which is reported to influence the resilience process.

Chapter 3

Literature Review

Part B – Resilience

Chapter Overview

Part B of the literature review will comprehensively examine resilience. Initially, an outline on the previous approaches to resilience research is presented. This is followed by a review examining relevant risk and protective factors, from the perspective of individual, family and community levels. The potential psychological outcomes that may be experienced by HC survivors are then highlighted, with a specific focus on depression and anxiety. Last, this literature review concludes by presenting a preliminary conceptual model of resilience among HC survivors that is informed by the literature.

Resilience

Approaches to Resilience Research

According to Richardson (2002), the *first wave* of resilience research began with an “inquiry focused on the paradigm shift from looking at the risk factors that led to psychosocial problems to the identification of strengths of an individual” (p. 309). Specifically, researchers became interested in the ‘individual traits’ that highlighted personal characteristics useful in managing adversity (Richardson, 2002). A number of personality traits emerged from psychological research, some of which include self-control, self-efficacy, self-esteem, hope, optimism, coping strategies, happiness, self-determination, and forgiveness (Olsson et al., 2003; Richardson, 2002). Aside from personality attributes, individual traits such as intelligence, positive temperament, communication skills and sociability have been highlighted among resilient people (Olsson et al., 2003).

Although this list of individual characteristics has shown remarkable stability over the course of time (Masten, 2007), the examination of resilience by assessment of personality characteristics alone is contentious. The main point of controversy is that psychological resilience is viewed by some researchers as a fixed, stable personality trait and that others argue that resilience cannot be an observed trait (Rutter, 2007; Windle, Bennett, & Noyes, 2011). This perspective suggests that it is not possible to detect and examine individual factors of resilience. According to Windle, Bennett, and Noyes (2011), this could also imply that an individual who does not possess such attributes may be a failure or unable to ‘learn resilience’. Another further constraint is that the individual trait approach to resilience does not take into account the impact of external factors such as family support.

As resilience research developed, the focus shifted from the individual and their unique qualities to a broader ecological approach that acknowledged the impact of the individual's family, friends and extended community on their resilience (Bronfenbrenner, 1986). Hence, the *second wave* of resilience research focused on addressing these limitations by exposing the 'processes' that might account for the observed correlates of resilience (Masten, 2007). Examples of the second wave of research include research on attachment relationships and family interactions as potentially protective stress regulators (Gunnar, 2006).

The 'process' approach to resilience has resulted in comprehensive lists of possible risk and protective processes at various levels (Alvord & Grados, 2005; Kelly & Emery, 2003). For example, one organisational framework for resilience includes internal processes that are either biological (temperament, gender, general health genetic disposition) or psychological (personality characteristics, coping, cognitive capacity), and external processes that exist either within the family (parenting, siblings, home environment, extended family) or the community (organisations, social services) (Mandleco & Perry, 2000).

The Resiliency Model proposed by Richardson et al. (1990) highlighted the process approach. The underlying concept of the Resiliency Model is that resilience is developed through facing challenges, risks, and stressors. This process begins early in life, as individuals attempt to adapt to any challenge or disruption in an attempt to successfully cope. The Resiliency Model suggests that people decide, consciously or unconsciously, the outcomes of disruptions they encounter. This state is referred to as biopsychospiritual homeostasis, which refers to the combination of biological, psychological, and spiritual 'normal' functioning (Richardson et al., 1990). This homeostatic state is constantly at risk of disruption from various stressors. However, protective factors alleviate these effects and protect events from becoming too disturbing (Richardson, 2002; Richardson et al., 1990). However, according to Richardson's Resiliency Model, when protective factors fail to alleviate stressors, the individual's biopsychospiritual homeostasis becomes disrupted, resulting in one of three outcomes. First, 'resilient reintegration' is where the individual may exceed their initial homeostatic state, through accessing greater adaptive skills. Second is, 'homeostatic reintegration' where the individual returns to the state they were in prior to the stressor, or third 'maladaptive reintegration' when they may fail to reach their previous state. According to Richardson (2002), this may lead to 'dysfunctional reintegration' resulting in potential mental health problems if the homeostatic level is too low. The Resiliency model highlighted resilience as a function of the interaction between individual characteristics, risk and protective factors and the stressor, laying the foundation for subsequent research.

Despite progress in the study of resilience, the second wave of research also uncovered further complications. Many of the researchers began to acknowledge that understanding resilience occurring naturally would be a long-term challenge for multiple reasons including the scope of the phenomena encompassed by the broad umbrella of resilience, the complexity

of human lives, and the imprecision in many of the concepts, measures, and analytic methods available (Masten, 2007). In addition, while it was advantageous to identify potential lists of risk and protective processes that may influence resilience, these lists became somewhat inflexible and there was an attempt to apply the same guidelines to all individuals in order to achieve resilience (Luthar et al., 2000a). The recognition that risk and protective processes are not universal resulted in a third approach to resilience that placed a greater emphasis on context and the perceptions of the individual who had experienced the risk (Ungar, 2001).

The *third wave* in resilience research aimed to address resilience in terms of ‘outcomes’. In this approach, the previously developed lists of processes are acknowledged, however, there is no assumption that these processes will have the same impact in different contexts with different individuals. This approach focused on the individual’s ability to maintain normal functioning and demonstrate a lack of psychopathology (Masten, 2001; Olsson et al., 2003). For example, outcomes that constitute resilience have been identified as stable mental health, functional capacity, and social competence (Olsson et al., 2003). The ‘outcome’ approach led to numerous experiments that tested resilience ideas, directly through prevention and intervention. Some of the best evidence for the mediating role of specific protective processes in the resilience literature has come from experiments of this kind, including randomized controlled trials of interventions designed on the basis of resilience research to enhance protective processes (Luthar, 2006; Masten, 2007).

However, the view of success and of positive outcomes that is contextually and individually interpreted is also often ‘value laden’ (Kumpfer, 1999; Ungar, 2004). Hence, the absence of risk or stress may not always be indicative of resilience. For example, Luthar (1991) reported that children who were identified as the most resilient also exhibited greater anxiety and depression rates. However, these children were labelled ‘resilient’ as they were able to continue functioning well and adjust appropriately to societal norms and expectations. This suggests that being resilient does not necessarily reflect the absence of psychological disorders.

In addition, it also became apparent that what comprises a successful outcome in one context may not be extended to another (Kumpfer, 1999; Ungar et al., 2007). The lack of universality was emphasised by Ungar (2005) when he stated “arguably, the complexity of resilience, the myriad of ways individuals, families, and communities overcome adversity, cannot be simplified as to generate a single set of principles generalizable from one contextually specific study to the next” (p. xvii). Therefore, groups of processes may act as risk factors or protect individuals in some contexts, but these processes cannot be universally applied to all situations for every individual. For example, cultural beliefs may vary, therefore views of success in one culture may not be valued in another.

Research on resilience characterized by a more contemporary approach involving multidimensional and multileveled analysis represents the *fourth wave* of resilience research

(Masten, 2007). Within this conceptualisation, resilience is viewed using an ecological approach that is both outcome-oriented and process-oriented, taking into account both context and culture (Pooley & Cohen, 2010; Ungar, 2008). Outcomes within this approach refer to the interaction between an individual and their environment, while processes are those that contribute to these outcomes (Ungar et al., 2007). This approach also considers the availability and quality of resources that a person can access within their environment, including personal characteristics, to enable positive adaptability in the face of adversity (Ungar et al., 2007). This ecological approach emphasizes the significance of the environment in providing health-sustaining resources, which Ungar et al. (2007) argued need to be contextually and culturally pertinent.

The ecological approach was investigated by Ungar et al. (2007) through their study of 89 participants between the ages of 12-23 years involving 11 countries. This research suggested there were seven tensions (categories) which youth adopt to resolve difficult events and hardships. The seven tensions were defined factors within the individual's environment that impact on their level of resilience. These included access to material resources, identity, relationships, cohesion, power and control, social justice, and cultural adherence (Ungar et al., 2007). The researchers proposed that the resolution of these tensions is essential to experiences of resilience, as defined by the individual and the community (Ungar et al., 2007). In addition, there is no one definitive way to resolve these tensions, the navigation between the person, environment and outcome are unique to each individual (Ungar et al., 2007). Moreover, there is no definitive measure of success, which is influenced by culture and context and is, therefore, subjectively defined by the individual and community (Ungar et al., 2007). The ecological approach therefore highlighted the individuality of resilience, as well emphasizing the interaction between the individual and their environment.

Four principles have been outlined by Ungar et al. (2007) that provide a framework for an ecological understanding of resilience. The first is 'decentrality', concerned with the need to focus concurrently on the person as well as protective and risk factors within the environment (Ungar, 2011). Consequently, it is important to investigate what the environment provides the person in terms of potential adaptive resources as well as associated risks. The second principle is 'complexity' and refers to the complex nature of resilience. According to Ungar (2011), as resilience is ecologically based, it is not possible to determine a simple linear process. Resilience involves navigation and is, therefore, reliant on a multitude of interactive patterns that vary between people. The third principle is 'atypicality', which refers to the determining outcomes and processes that are contextually significant, that are not predetermined, but rather assist as an adaptive function for an individual within that context (Ungar, 2011). Hence, successful outcomes and processes adaptive in one context may be considered as risk in another. The fourth principle is 'cultural relativity' and signifies the culturally-based definitions of adversity and success, including, risk and protective

processes (Ungar, 2011).

In the ecological conceptualization of resilience, Ungar (2011) points out two important processes. First, the individual needs to be able to identify potential coping and protective resources. Second, resources need to be available to that individual so that they can be accessed. For example, a cancer survivor seeking social support groups must first be willing to actively reach out and join others; however, this may only be possible if such support exists in community. Ungar (2008) argued that if the environment does not or cannot provide health-sustaining resources (i.e., cancer support resources), the environment lacks resilience, not the individual. Thus, the individual including their context (family, social, cultural) are important aspects of resilience (Ungar, 2008, 2011).

As the fourth wave of resilience research expands, it is becoming clear that it will continue to surpass earlier research efforts to explain this phenomenon (Masten, 2007). For example, building on the work of Ungar and previous research, Pooley and Cohen (2010) explain resilience to be “the potential to exhibit resourcefulness by using available internal and external resources in response to different contextual and developmental challenges” (p. 34). This conceptualization not only included context and culture, but also the developmental and transitional aspects of resilience. Another example is provided by Davydov and colleagues (2010), who have investigated resilience and mental health from individual, group and cultural perspectives. They suggested that resilience surfaces from a multifaceted interaction of several forces at various levels. These integrate the individuals’ gene-environment reactions, the effect of positive and negative experiences throughout life and include the impact of a person’s social and cultural setting (Davydov et al., 2010). According to this research, in order to investigate resilience through such layered interactions there is a need to move beyond a narrow focus on one particular origin or a small group of causes and consider more thorough and multidisciplinary approaches (Davydov et al., 2010).

Regardless of the different perspectives on resilience, there is a general acceptance that this is a normal phenomenon and that all individuals have the potential to be resilient given appropriate resources (Masden, 2001). As stated by Windle, Bennett, and Noyes (2011), “the suggestion by Richardson (2002) that resilience may be the driving force that controls the universe may be a little overstated, but the capacity for ‘ordinary magic’ and the opportunity for positive adaptation should be an option for everyone” (p. 165).

In summary, the majority of the literature into resilience acknowledges that there are various systems and factors that contribute as an interactive dynamic process that increases resilience relative to adversity. Furthermore, there appears to be a consensus that resilience could be time and context specific and may not present across all life domains (Herrman et al., 2011; Masten and Powell, 2003). The current research investigating HC survivors is based on these contemporary principles of understanding how resilience operates in a specific context for different individuals and identifying how risk and protective factors function as processes.

Based on the available literature, the following section will now describe how risk and protective factors function as resilience processes within the individual, family and community.

Individual (Internal) Level Processes

Previous research has indicated that individual factors such as self-esteem, self-efficacy, locus of control, empowerment, coping skills, life meaning and spirituality play an important role in building resilience and QOL among cancer survivors (Allart et al., 2014; Llewellyn et al., 2013; Stewart & Yuen, 2011; Swash, Hulbert-Williams, Bramwell, 2014). In addition, demographic factors such as age, gender and time since diagnosis are reported to influence the resilience process (Aziz, 2009; Bennett et al., 2011; Foster et al., 2009; Pudrovaska, 2010b; Rabin et al., 2011). However, although the literature has highlighted that an effective armoury of individual coping strategies may buffer an individual from the effects of a cancer diagnosis, this interaction has not been comprehensively investigated among HC survivors (Schumacher et al., 2014). The next section will attempt to explain many of these factors. However, a thorough investigation of all individual traits is not feasible. Thus, using available literature as a reference, only the most influential factors will be discussed.

Self-Efficacy

Self-efficacy represents the perception of one's ability to alter events or manage new challenges appropriately (Bandura, 1977). Self-efficacy theory suggests that the greater an individual's confidence in their ability to manage a course of action, the higher the probability they will conquer desired goals (Bandura, 1977). In health psychology, self-efficacy is seen as a positive resource and a protective factor that contributes to a patient's adaptation of illness crises (Bandura, 1977).

One of the first known studies to investigate the importance of self-efficacy among HC cancer survivors was published by Schumacher et al. (2014) in Germany (Table 2). This recent study examined the relationship of resilience with QOL, self-efficacy, anxiety and depression among those with HC and blood-related diseases, following an allogeneic stem cell transplant (AlloSCT). The aim was to better identify which psychosocial variables are important factors for successful adaptation and re-integration following AlloSCT. The sample included 75 HC patients who were all in remission. The findings identified a high correlation between resilience and self-efficacy, indicating a strong relationship between the two concepts. The results also reported that resilience is positively correlated with QOL and social functioning and negatively with anxiety and depression. Although no effects on resilience were found for gender, age, and type of HC or disease, the results did point to a possible influence of time following the transplant on patients' resilience. This finding could be interpreted as a sign of coping by successfully managing the process of readapting. The

authors highlighted that fostering resilience and self-efficacy across the life span, would assist cancer survivors to resume their everyday life by adapting to the challenges they face in an uncertain future (Schumacher et al., 2014).

Previous research has also reported a positive relationship between self-efficacy and resilience, among individuals with solid tumours or chronic illness. For example, the role of self-efficacy: is positively correlated with family and social functioning in those with coronary heart disease (Sullivan, LaCroix, Russo, & Katon, 1988); impacts on the success of interventions to reduce distress in adults with type 1 diabetes (Fisher, Hessler, Masharani, & Strycker, 2014); including, the psychological wellbeing among individuals with ovarian cancer (Wenzel et al., 2002), rheumatoid arthritis (Schiaffino & Revenson, 1992), diabetes (Wu et al., 2013), and stroke victims (Robinson-Smith, Johnston, & Allen., 2000).

Self-Esteem

Self-esteem is an individual characteristic reported to influence resilience (Kumpfer, 1999; Masten & Coatsworth, 1998; Rutter, 1992). Self-esteem may be viewed as the subjective monitoring of others' reaction to oneself, which directly impacts on an individual's feelings of self-worth (Thompson & Kent, 2001). High self-esteem refers to increased appraisals of self and has been found to shield against psychological distress. For example, when individuals experience failure, maintaining a high self-esteem may protect individuals from feeling negatively about themselves (Brown, 2010). Conversely, low self-esteem generally occurs as a result of frequent rejections and interpersonal threats, where an individual's subjective monitor becomes highly sensitive to negative influences, often derived from their social and psychological environments (Baumeister, Campbell, Krueger, & Vohs, 2003; Goodman, Stryker, & Owens, 2001; Thompson & Kent, 2001).

In a recent meta-analysis, Sowislo and Orth (2013) highlight that self-esteem is a significant factor to consider in protecting against depression. This longitudinal analysis investigated the effects of self-esteem on depression (77 studies) and on anxiety (18 studies). The sample mean age was 27.7 years, with the sample size of the studies ranging between 44 and 6,813. The reviewed studies varied widely in sample type, country of origin, and the measurements used. As a result, the authors proposed a high level of generalizability, as one of the strengths in the findings of this analysis. The results indicated a clear relationship between self-esteem and depression. Low self-esteem significantly contributed to greater depression, while depression had only a weak effect on self-esteem, though, anxiety and self-esteem were reported to equally influence each other. The results could not provide clear evidence as to whether self-esteem influences anxiety, or whether anxiety impacts self-esteem. However, it was reported that regardless of age, gender, scales used, or sample (convenience, clinical or representative), low self-esteem remained a stable risk factor for depression. In addition,

findings from the analysis proposed that low self-esteem precedes depression, rather than the reverse.

Similar findings were outlined in a study by Rodin and colleagues (2013), which examined HC populations, reporting that self-esteem directly influences resilience among those with leukaemia. This research aimed to investigate the psychological impact, prevalence and correlates of post-traumatic stress among acute leukaemia patients. Two hundred and five leukaemia survivors, of which 58% were male (*M* age = 50 years), completed questionnaires comprising several psychosocial measures (i.e., Rosenberg Self-esteem Scale, Stanford Acute Stress Reaction Questionnaire). The multivariate regression analysis used to assess independent predictors of PTSD, reported that 14% of participants met criteria for acute stress disorder (ASD) with a further 18% for subsyndromal ASD. This study verified that clinically significant symptoms of traumatic stress are usual in leukaemia survivors, and importantly, are predominantly linked to physical suffering, satisfaction in relationships with clinicians and individual psychological characteristics. The authors acknowledged that it was difficult to determine a causal relationship, due to the cross-sectional nature of this study. However, the findings of this research support a relationship between high self-esteem, perceived social support and a high degree of resilience among those with HC.

Further research specifically investigating self-esteem in terms of its effect on resilience is limited among HC survivors. It was, therefore, necessary to elicit material from the literature investigating QOL and psychosocial adjustment. Previous findings from a longitudinal study involving 125 HC patients (ACL, CML and lymphoma) reported a positive correlation between high self-esteem and QOL three years following BMT (Broers, Kaplein, Le Cessie, Fibbe, & Hengeveld, 2000). The participants (*M* age = 37 years) completed questionnaires assessing anxiety, depression, self-esteem and locus of control at five independent time spans ranging from before treatment to three years following BMT. The results identified a positive relationship between self-esteem and psychosocial adjustment among in this population (Broers et al., 2000).

Self-esteem is also reportedly linked to enhanced QOL in several other studies that have examined: mixed cancer survivor populations (Constanzo, Ryff, & Singer, 2009); those with chronic illness (Symister & Friend, 2003); HIV populations (Faber et al., 2003); and, individuals living with disfigurement (Hardy & Cotterill, 1982). However, it is important to note that the majority of information concerning cancer survivor's self-esteem relates to variables influencing self-esteem, rather than how self-esteem may influence resilience. This is because the majority of the literature investigating self-esteem, within the area of chronic illness and cancer, has focused on applying self-esteem as an outcome measure, rather than a predictor variable.

In addition, while research indicates that high self-esteem is protective, as the relationship between self-esteem and resilience is correlational, and not necessarily causal, it may also be the result of other protective processes. Thus, negative outcomes may produce low self-esteem or low self-esteem may result in negative outcomes. For example, in the study by Rodin and colleagues (2013), leukaemia patients may have reported poor interpersonal relationships with HCP's as a result of experiencing low self-esteem or the reported low self-esteem may have been partially a consequence of ineffective interpersonal relationships with clinicians. Furthermore, in the study by Broers et al. (2000), traumatic stress may impact on current self-esteem measures, conversely low self-esteem may contribute to distress.

In summary, given the correlational nature of the evidence for a relationship between resilience and self-esteem, it is beneficial to understand the process of self-esteem, rather than simply collecting further data supporting the association between the two. There can be several processes occurring at the individual, family, and community level that impact an individual's self-esteem. This point of view, is supported by Harter (1999), who maintains that there are several pathways that shape an individual's self-esteem, each of which is influenced by context and is reliant on how each person perceives their situation.

Optimism and Hope

Positive trait dispositions, including hopefulness and optimism, can act as personal resources for cancer survivors and are reported in the literature to foster resilience (Dunn et al., 2011; Gartland et al., 2011; Ho, Ho, Bonanno, Chu, & Chan, 2011; Pieters, 2015). Dispositional optimism refers to a stable personality trait where an individual has a generalised expectation that the future will be positive, even when negative events occur (Scheier & Carver, 1985). Similarly, dispositional hope is defined as a motivated state to reach desired goals, together with a belief that an individual will be able to effectively engender a plan to accomplish them (Snyder et al., 1991). Higher hope is consistently linked with superior outcomes in physical and psychological adjustment (Snyder, 2002; Snyder et al., 2005).

The constructs of hope and optimism have been reported to facilitate resilience and PTG in individuals undergoing genetic testing for hereditary, colorectal cancer and in oral cavity cancer patients (Ho et al., 2010). There is also a discussion of the differential roles of hope and optimism in predicting growth and resilience. On a conceptual level, there has been interest in the amount of overlap and differences in the two constructs (Rand, 2009). For example, researchers maintain that hope and optimism might contribute differentially in the prediction of psychological adjustment and task performance (Gallagher, Lopez, & Preacher, 2009; Rand, 2009). Specifically, hope may play a more vital role in scenarios where the outcome is more dependent on behaviour or personal effort, yet optimism is more pertinent in situations where the outcomes rely on external events and are less within one's control (Rand,

2009). Optimism, the most studied positive emotion (Alim et al., 2008), will be detailed first, followed by a discussion on the literature outlining the benefits of hope.

Scheier and Carver's (1985) theory of optimism is based on expectancy-value models of motivation. Optimists hold positive future expectancies through positive emotions that keep individuals actively engaged in their goals, despite negative events. Conversely, pessimists are more likely to use avoidant coping in response to the negative emotions entrenched in their negative beliefs and expectancies. For example, research reports that optimists are more constructive in the use of health-related information and are inclined to exhibit more 'fighting spirit' as a coping mechanism, than pessimists (Schou, Ekeberg, Ruland, Sandvik, & Kåresen, 2004). Building on Scheier and Carver's theory, Seligman (1992) proposed that an optimistic person may attribute negative events to certain causes that are unstable and external. Yet, a pessimistic outlook attributes negative events to stable internal (individual) causes.

In other cancer research, optimism has been positively related to many aspects of QOL such as worry about health and sexual intimacy among both prostate cancer patients (Thornton & Perez, 2006) and ovarian cancer patients (Smith & Zutra, 2008). The link between optimism and goal adjustment has also received attention by researchers investigating QOL among individuals with chronic illness (Rasmussen, Wrosch, Scheier, & Carver, 2006). For example, the literature reports that optimism may assist in the recovery from psychiatric conditions (Alim et al., 2008); diabetes (Yi et al., 2008); coronary heart disease (Chan, Lai & Wong., 2006); and, multiple sclerosis and Parkinson's disease (De Ridder, Schreurs, & Bensing, 2000).

To date, there are very few publications specifically investigating the influence of dispositional optimism on resilience among cancer survivors. Consequently, the relationship between optimism and resilience is not fully understood in this group. For example, research carried out by Bowen, Morasca, and Meischke (2003) illustrated that optimism was not correlated to any of the variables they used to compose their resilience scale, suggesting that these factors may be quite distinctive. In addition, research by Knott et al. (2010) suggests that the pressure on cancer survivors, to maintain an optimistic attitude or a 'fighting spirit' can create an additional burden. Yet, other research suggests that an optimistic outlook can develop an individual's capacity to remain determined (Carver, 2010) and improve positive emotions (Alim et al., 2008) in times of adversity, therefore the relationship with resilience remains unclear.

In summary, Lepore and Revenson (2006) report that optimists are more likely to demonstrate positive outcomes following adversity by positively reframing negative life events, adopting new and more adaptive world-views and by readily eliciting social support resources more easily. While these findings are encouraging, further research is necessary to understand how optimism functions and its relationship with other protective processes. As Aspinwall and MacNamara (2005) assert, "positive emotions and beliefs seem not only to be

associated with good outcomes among people experiencing adversity, but also to play a role in realizing them” (p. 2549).

In addition to optimism, the second construct of *hope* is also reported to enhance psychological well-being and generally has an inverse relationship with depression (Snyder et al., 1991). The theory of hope was conceptualised by Snyder (2002) as three interrelated cognitive components: agency, goals and pathways. Agency thinking provides the mental energy and motivation in pursuing goals, while pathways reflect the cognitive ability to find the available routes to achieve goals. The emphasis of Snyder's hope model is that individual actions are goal-directed and these goals themselves are the cognitive anchors of hopeful thinking (Snyder, 2002). As such, Snyder's model assumes that when faced with negative events such as HC, although high-hope individuals may be distressed or troubled temporarily, they are more likely to create and achieve their life goals (Ho et al., 2010).

Snyder's hope model and Bandura's self-efficacy theory are similar in that they both refer to the motivation of goal-directed behaviour. However, Snyder (2002) maintains that the aetiology of emotions was not explicitly explained in Bandura's theory. Likewise, Rand (2009) concurs with Snyder proposing that, “hope goes beyond self-efficacy in that it also consists of agency thinking, the appraisal of available energy/motivation to use one's abilities in goal pursuits” (p. 253). As such, hope theory highlights whether an individual intends to initiate their actions, whereas Bandura suggested that people evaluate their capacity to carry out the actions to achieve a goal. Thus, perhaps Bandura emphasizes the “can do” while Snyder emphasized the “will do” (Rand, 2009; Snyder, 2002).

Several studies have reported that feeling hopeful about the future is linked with improved QOL in leukaemia and lymphoma survivors (O'Connor et al., 2007; Zebrack, 2000). Although these studies only comprised small heterogeneous samples and cross-sectional designs, other research also supports these findings. Breast cancer research by Stanton, Danoffburg, and Huggins (2002) stated that high-hope women adopted problem-focused coping strategies and adjusted better one year following their cancer diagnosis. According to more recent research by Folkman (2010), hope was also an essential, practical support for participants' motivations and corresponding actions, both in fighting cancer ‘medically’ for survival and maintaining psychosocial and spiritual wellbeing. In addition, research involving 234 Chinese colorectal cancer patients, identified a sample of resilient individuals, who reported higher scores on hope and optimism scales and demonstrated less emotional distress (Hou, Law, Yin, & Fu, 2010).

Empowerment, Locus of Control & Fatalism

An individual's view of self is not only related to their sense of worth but also how they face challenges, such as a cancer diagnosis. This is composed of many inter-related factors, including one's ability to feel empowered to overcome challenges, perceived internal or external locus of control, and fatalistic beliefs (Cartmell & Coles, 2000). These individual factors will each be outlined to explain how they function as protective factors to enhance resilience among those with chronic illness and cancer.

First, a sense of *empowerment* is reported to assist the way people develop control over their circumstances (Cartmell & Coles, 2000; Stewart & Yuen, 2011). Empowerment is described by Rappaport (1984) as a means by which individuals gain control or mastery by initiating an active and participatory role in personal life events (cited by Bulsara, Ward & Joske, 2004). The role that empowerment plays as a protective factor is undisputed. Consequently, this has been a topic of interest among researchers including those investigating HC survivors.

For example, a Western Australian qualitative study by Bulsara, Ward, and Joske (2004) sought to identify the common factors that HC patients believed enabled them to remain empowered while managing their cancer. Using a phenomenological approach, regardless of stage of illness or prognosis, seven HC patients (i.e., lymphoma and myeloma) including three spouses, took part in semi-structured interviews. The aim was to identify the coping strategies that patients and spouses felt assisted them to maintain control in managing HC. These patients were identified as having developed a high sense of empowerment during an earlier pilot study.

Although generalisations about the findings of this study are limited, due to the small purposive sample, the results indicated that empowerment was influenced by three main factors. These included the patient's determination to remain in control of the illness and treatment side-effects, the support of family and significant others, and, maintaining hope and having illness acceptance (Bulsara, Ward, & Joske, 2004). All factors were seen as inter-related vital coping strategies. However, each were experienced by patients in varying degrees. It was evident from this study that these patients created ways of gaining mastery over their situation despite their prognoses. The authors concluded that the desired end result is not merely a case of increased survival, but rather empowering patients and their families through open communication, to have a degree of illness control through positivity and a readiness to accept their prognosis (Bulsara, Ward, & Joske, 2004).

The second factor, *locus of control*, is a process that can affect resilience and is reported to be a major determinant in how cancer survivors manage their illness (Park, Edmondson, Fenster, & Blank, 2008). For example, a high external locus of control is linked with vulnerability, or the sense that an individual has little control over their life and is a risk

factor for negative health outcomes (Zimmerman, Ramirez-Valles, & Maton, 1999). Thus, as cancer is considered a life-threatening yet low-control condition (Thompson, Sobolew-Shubin, Galbruith, Schwankovsky, & Cruzen, 1993), those affected may be at greater risk of developing maladaptive coping strategies, such as avoidance behaviours (Turk & Okifuji, 2002) and psychological distress.

Conversely, an internal locus of control represents the confidence that a person can influence the events that occur in their life and is usually associated with effective adaptation following traumatic events (Luthar, 1991). A high internal locus of control has been found to have a positive relationship with other potential protective processes, including attachment, assertiveness, self-efficacy, increased feelings of competency and meaningful involvement (Luthar, 1991; Ungar, 2004). Hence, individuals with a high internal locus of control generally exhibit better psychological adjustment and enhanced resilience (Stewart & Yuen, 2011).

This view is supported in quantitative research by Park et al. (2008) reporting that cancer survivors who have a higher perceived internal locus of control, implement more positive health behaviour, resulting in better physical and psychological outcomes. This cross-sectional study involved 250 mixed cancer survivors (*M* age = 45.2) of which 172 were female, and 89 percent were Caucasian. Applying a stress and coping model, the authors aimed to examine positive and negative health behaviour changes among cancer survivors. Although it was difficult to establish causality and the results were suggestive rather than definitive, the findings indicated that sense of control over illness, social support, life meaning and approach coping were related to positive behaviour changes. Similarly, earlier research by Link, Robbins, Mancuso, and Charlson (2004) identified that survivors who made pro-active attempts to control their situation (i.e., sought treatment, re-prioritised life, and altered their diet) had less depressive symptoms.

These results are supported by earlier Australian research by Xuereb and Dunlop (2003) who investigated the experience of leukaemia patients. This qualitative study in Sydney examined the experience of ten HC patients, of which six were male, who required a BMT. The focus of this study was on the meaning this adverse experience held for these individuals. However, all the participants belonged to a support group, and, consequently, the results may be biased. Nevertheless, the findings suggested that a capacity to control valued aspects of one's life following cancer treatment was essential to HC survivor recovery.

Despite the available research supporting an internal locus of control as a protective process, there is some evidence that an external locus of control is more protective following certain types of illness. For instance, an earlier study among those with rheumatoid arthritis (Schiaffino & Revenson, 1992) found external locus of control to be more adaptive, and another on individuals with chronic diseases in India (Dalal, 2000) found no significant difference between internal and external control. However, it is also important to note that both

of the previous studies have since been rated as methodologically ‘poor’ in a more recent systematic review (Stewart & Yuen, 2011).

There have been other methodological issues worthy of consideration. For example, the majority of previous research has involved Caucasians. Therefore, the results may have varied if there was a more even cultural representation. The belief by an individual that they can control events is informed by cultural gender ideals (Martin, Ruble, & Szkrybalo, 2002) and shapes the perception of, and response to, a challenge (Dedovic, Wadiwalla, Engert, & Pruessner, 2009). Thus, cultural values will impact on locus of control and resilient capacities of individuals (Szanton, Gill, & Thorpe, 2010). For example, it has been suggested that Koreans and Mexican Americans are more likely to have an external locus of control due to belief systems involving luck or chance (Coolen, 2012).

The third factor, referred to as *fatalism*, is defined by Straughan and Seow (1998) as the view that health issues are triggered by fate, luck or destiny, rather than an individual’s behaviour. According to Taylor, Lichtman, and Wood (1984), people with cancer not only ruminate about the causes of their disease, but may also create ideas about whether they can influence or control the cancer, both of which are impacted by an individual’s level of fatalism. Moreover, the extent to which survivors believe they can control their cancer may be directly linked with health behaviour change (Park et al., 2008). This is evident in previous research by Rabin and Pinto (2006) that investigated breast cancer survivors. Improved diet and increased exercise were related to less fatalism and higher beliefs by participants that their health behaviour was related to the cause of their cancer, or would avert recurrence. An earlier study, also involving breast cancer survivors, found that higher fatalism responses were associated with higher psychological distress when assessed at one and seven months following diagnosis (Ferrero, Barrento, & Toledo, 1994).

In summary, the ability to cope with the management of HC requires patients to adopt specific strategies and coping mechanisms in the face of an unclear illness trajectory. The combination of optimism, confidence that the effects of cancer are controllable and determination to actively deal with the situation, has been labelled ‘fighting spirit’ (Wills & O’Carroll Bantum, 2012). This group of factors might serve to enhance resilience and result in better psychological adjustment. For example, positive outcome expectancies could reduce the impact of the diagnosis on fear and worry, active problem solving may assist in sustaining beneficial physical health status (i.e., through healthy diet, exercise & adherence to medication), and perceived control could trigger perseverance in dealing with setbacks. Thus, all of these individual protective factors may work together to reduce the impact of the risk following a cancer treatment (Wills & O’Carroll Bantum, 2012).

Coping Skills

Lazarus and Folkman (1984) first identified the processes of cognitive appraisal and coping as central for adaptation to stressful events. Coping can be defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). Thus, an individual diagnosed with HC will evaluate the situation by determining the threat or challenge the diagnosis represents, and will respond with certain cognitive or behavioural interventions in order to adapt and manage the associated stress. Although most HC survivors do not experience major psychopathology, negative cognitive appraisals due to the stressors of a HC diagnosis can result in psychological symptoms such as anger, depression, and anxiety.

In the coping literature, various conceptual models have been described to explain responses to stress, each of which appear pertinent to cancer survivorship. These include: primary (enhance ones control over environmental situations) and secondary control strategies (efforts to adapt to the circumstances) (Rothbaum, Weisz & Snyder, 1982); problem-focused versus emotion-focused coping (Lazarus & Folkman, 1984); and, the approach versus avoidance model (Roth & Cohen, 1986).

Research based on the traditional coping paradigm (Lazarus & Folkman, 1984) typically differentiates between *problem-focused coping* (PFC) and *emotion-focused coping* (EFC). First, PFC involves the efforts of an individual to alter the demands imposed upon them by defining the stress, generating ideas and then acting on a solution to change the threat. Alternatively, EFC entails attempts to appropriately express the emotions experienced by providing selective attention (i.e., lessen, avoid or minimize), in order to alter the way the individual thinks or feels (Lazarus & Folkman, 1984).

In resilience research, it would seem that PFC or approach coping has been associated with higher functioning and more resilient outcomes. However, there is some speculation in the cancer-related literature that both coping styles may be beneficial when used concurrently. For example, Austenfeld and Stanton (2004) highlight that when individuals engage in both PFC and EFC, improvements in psychological well-being are evident, yet each may function differently. It is proposed that PFC may led to instrumental achievements such as scheduling necessary medical appointments, while EFC might lead to seeking emotional support, which could help reduce depression and anxiety (Wills & O’Carroll Bantum, 2012).

Yet, researchers largely agree that PFC is more effective in managing the stress of cancer than negative styles. Positive coping styles include problem-solving, control, optimism, and seeking support as protective factors that assist people with cancer to adjust (Haase, 2004; Pieters, 2015). Previous evidence has also attested that optimism is one of the most important contributing factors in maintaining positive PFC strategies (Haase, 2004). In situations when

PFC is not possible for an individual, optimists are able to adapt and implement EFC by involving positive reframing, acceptance and humour (Rasmussen et al., 2006).

Conversely, a negative or depressive coping style (i.e., impatience, ruminating) among breast cancer survivors has been reported to be associated with a greater fear of recurrence (Mehnert, Berg, Henrich, & Herschbach, 2009), including an adverse effect on health-related QOL (Shim et al., 2006). Similarly another study involving breast cancer survivors by Zwingmann, Wirtz, Müller, Körber, and Murken (2006) reported that a depressive coping style was positively and significantly linked to anxiety and depression, where-as an active or positive coping style was not significantly related to either disorder.

In addition to the model described by Lazarus and Folkman, (1984), coping has also been discussed in the literature in terms of *approach* (e.g., problem-solving, reappraisal) versus *avoidance* (e.g., mental and behavioural disengagement) styles (Bellizzi & Blank, 2006). Studies of individuals living with prostate cancer suggest that approach-focused coping is largely helpful, whereas avoidance coping strategies are inclined to be associated with poorer outcomes (Roesch et al., 2005). Research by Park (2008) confirm this standpoint, reporting that approach coping among cancer survivors is related to positive health behaviour changes, whereas avoidance coping is linked to negative changes. However, there is literature to suggest that the type of coping style may be influenced by situational factors, such as the stage of cancer survivorship.

For example, a meta-analysis of studies that investigated coping during various stress encounters supports the hypothesis involving phase-specific adaptivity. Avoidance coping was associated with more positive adaptation in the short-term, but, over time, approach coping seemed more adaptive (Suls & Fletcher, 1985). Similarly, among cancer survivors, an avoidant cognitive coping style may be a more adaptive resilience factor in the acute phase, yet for long-term survivors it may be a risk factor and related to higher psychological distress (Wenninger et al., 2013).

Moreover, avoidant coping or EFC has also been reported to be advantageous for uncontrollable stressors (i.e., invasive medical procedures) (Compas, Malcarne, & Fondacaro, 1988, Weisz et al., 1994). This suggests avoidant or EFC may provide immediate or short-term benefits for cancer survivors by acting as a safeguard. However, persistent use of defensive coping may led to negative consequences. This perspective is shared by Di Gallo, Amsler, Gwerder, and Bürgin (2003), who concluded from their research of adult childhood cancer survivors that, “successful integration of the experience of cancer may be associated with the ability to accept painful feelings and to allow them to emerge (p. 666)”. Therefore, it may be imperative to consider time since diagnosis, when evaluating the coping and adaptive behaviour of individuals with cancer.

In addition to PFC, approach coping and positive reframing, other strategies such as *acceptance* have been shown to foster better outcomes in dealing with a cancer diagnosis

(Carver, 1993; Lazarus & Folkman, 1984). For example, acceptance coping response at the time of diagnosis was described by Stanton, Danoff-burg, and Huggins (2002) to be associated with improved psychological adjustment twelve months later, leading the authors to suggest that earlier acceptance might be linked to better adaptability and a more active approach to treatment and recovery. Active coping and distraction have also been reported to be beneficial coping skills. Research by Lauver, Connolly-Nelson, and Vang (2007) aimed to determine the coping strategies that primary breast and gynaecologic cancers survivors used following treatment. The results of this study report that active coping strategies including *distraction* and *problem-solving* were found to be positively associated with improved mood and better psychological wellbeing (Lauver et al., 2007).

In summary, coping is considered a significant area of research across the cancer trajectory. The stress-coping model (Lazarus & Folkman, 1984; Lazarus & DeLongis, 1983) proposes that the coping strategies one employs to manage stress are largely based on risk and the personal meaning that the individual has assigned to the situation. Thus, there is no universally effective or ineffective form of coping. Cognitive coping and positive problem-oriented coping could be deemed as protective factors that foster recovery in cancer survivors in the long-term. However, the research remains unclear as to which coping strategies are most effective, when and in which circumstances (Wu et al., 2012).

Finding Meaning and Benefit-Finding

While the psycho-oncology literature has largely focused on negative and psychopathological outcomes of living with cancer, researchers have started to consider positive psychological outcomes. For example, cancer survivors often report finding meaning within the event, which been synonymously referred to as benefit-finding. Finding meaning in life has been shown to be related to many favourable outcomes in cancer survivors (Laubmeier, Zakowski, & Bair, 2004; Powell, Shahabi, & Thoresen, 2003; van der Spek et al., 2013), an effect speculated to be mediated through the adoption of more adaptive coping (Breitbart, 2002).

The conceptualization of 'life meaning' was detailed by Viktor Frankl (1959), a psychiatrist who survived a Nazi concentration camp (Szanton, Gill, & Thorpe, 2010). Adverse circumstances, Frankl (1963) stated, can have a positive impact on personal development by providing opportunities for "meaning-making," which he believed to be a basic human need. Thus, a growing body of evidence has since reported that survivors of a variety of traumatic life events frequently describe finding a meaning or sense of purpose, and having benefitted from their experience. A sense of purpose is linked to resilience and reflects that the individual feels there is a benefit to belonging in society (Alim et al., 2008).

It has been suggested that, among those with serious illness, positive growth occurs as a result of cognitive restructuring which alter traumatic experiences into the acquisition of wisdom, personal growth, enhanced interpersonal interactions, and more meaningful and productive lives (Llewlyn, 2013; Thornton, 2002). Hence, finding something positive in a negative experience may render the experience less aversive overall by lessening the discrepancy between the meaning of the event and positive global beliefs (Thornton, 2002).

Empirical studies, involving both quantitative and qualitative research methods, have been conducted to explore both meaning and benefit finding. For example, in a systematic review, Stewart and Yuen (2011) report several studies indicating that benefit-finders were better adjusted, had lower morbidity over time, and better mental well-being. Moreover, benefit-finding was shown to increase over the course of illness (Stewart & Yuen, 2011). In other research, Gotay, Isaacs and Pagano (2004) explored the qualities of cancer patients who had surpassed their life expectancies, in spite of a grim prognosis. The authors discovered that, with a cancer diagnosis where risk factors and outcomes are unpredictable, unexpected survival was attributed to the cancer patient's capacity to foster resilience and a sense of meaning. Equally, Wenzel et al. (2002) discovered that a significant percentage of ovarian cancer survivors, described experiencing resilience and personal growth as a consequence of their experience that, in turn, enhanced a sense of wellbeing. Research has also stated that those who report higher levels of meaningfulness or purpose in life also tend to report lower levels of anxiety, hostility, depression and stress (Thornton, 2002).

However, the results are not definitive, as other studies have reported no or negative outcomes from finding meaning or benefit. Research by Sherman, Cooke, and Grant (2005) stated that, after facing a life-threatening illness, many transplant patients expressed difficulty in finding meaning, including redefining themselves, their priorities and their values. In a study that investigated both psychosocial sequelae of BMT patients, Fromm, Andrykowski, and Hunt (1996) reported that finding benefits was not associated with improved QOL or psychological adjustment. In addition, Cordova et al. (2001) stated that, although breast cancer patients described personal growth, their growth did not have significant relationships to depression, relating to others, spiritual change, personal strength, or appreciation of life.

Tomich and Helgeson (2004) also discovered that finding benefit predicted elevated distress three to nine months after breast cancer diagnosis. Thus, the association between benefit finding and reduced psychological distress is inconclusive (Tallman, Garcia, & Altmaier, 2007). The conflicting results may arise due to variability among cancer survivors as they attempt to restructure their expectations following traumatic events. Individual differences, such as in optimism, may influence how individuals view the world, during and following trauma (Tallman, Garcia, & Altmaier, 2007). This suggests that finding meaning and benefit may also be closely linked to other individual personality traits.

Spirituality. Finding meaning in life when faced with adversity is reported to enhance the consideration of an individual's own spirituality and/or faith (Adejoh, Temilola, & Olayiwola, 2013; Walsh, 2003). While there is no agreed definition in the literature (McGrath, 2004), several researchers have defined spirituality as broader than religion, involving the ability to look beyond oneself, in order to make greater sense of existence (Choumanova, Wanat, Barrett, & Koopman, 2006; Walsh, 2006). The main point highlighted in previous research is that religion and spirituality provide a framework within which individuals can positively appraise adverse experiences and attempt to manage psychological distress (Sears, Stanton, & Danoff-Burg, 2003).

For example, a recent study by Adejoh, Temilola, and Olayiwola (2013) in Nigeria, involving HC survivors, reported that spirituality or religion was viewed as an escape from worrying about their health problems. This qualitative study that involved 20 leukaemia survivors is supported by previous studies suggesting that spirituality has an important role in helping individuals comprehend the cause of cancer and can help them maintain a sense of justice (Choumanova et al., 2006; Strang & Strang, 2001).

Another Australian study investigating HC survivors by McGrath and Clarke (2003) discussed the importance of creating space for spiritual communication. This research focused on investigating the concept of spirituality, while also proposing suitable ways to respond to spiritual issues in order to cope with serious illness. The results that emerged from this research partly affirm the notion of spirituality as 'meaning making'. Although for some, spirituality embraced religiosity (McGrath & Newell, 2001), for most participants spirituality referred to the meaning individuals make out of their life and illness experience. Moreover, the findings also proposed 'connection' as another vital dimension of spirituality (McGrath & Clarke, 2003). The indications were that HC survivors required a strong connection with life, through others, in order to make sense of the challenge of serious illness. However, this association can be threatened by dissatisfaction with life through physical and identity losses or the breakdown in expected relationships. Hence, if the disconnection is viewed as adverse, spiritual pain may occur, resulting in an emptiness that challenges the individual's ability to construct meaning from their existence (McGrath & Clarke, 2003). The findings of this study implied that survivors require the opportunity to discuss their experience and the meaning they are assigning to their lives through changes brought about by the experience of serious illness (McGrath & Clarke, 2003).

Among breast cancer survivors, Choumanova et al. (2006) also explored the meaning of spirituality among 27 Chilean women. In this study, the women reported religion and spirituality as the primary resources for them during their cancer journey. The authors identified that a belief in God and spiritual faith assisted the women to recover. Similarly, interviews with 24 women, in a study by Taylor (2000), indicated that personal spirituality was

related to each woman's ability to see her own transformation as a process of growth from the breast cancer. Although these studies were small qualitative studies, other researchers have expanded on different aspects of spirituality exploring variability in spiritual responses.

For example, using spirituality seems to present the individual with a sense of empowerment associated with taking control of their life and recovery following treatment (Gall et al., 2005). Spiritual support is described as a group of coping strategies that a person applies both subconsciously (positive appraisal, believing in good outcomes) and actively (meditation, connection with nature, prayer) (Gall et al., 2005; Reynolds, 2006). The ability of the individual to use these strategies effectively to reduce stress assists them in the process of adjustment.

In summary, while the diagnosis and treatment of cancer is both distressing and disruptive, inquiry among other cancer groups has established that there are some aspects of the experience that survivors describe as positive or beneficial (Llewlyn, 2013). Despite the multiplicity of problems faced by HC survivors, some report positive growth and increased appreciation of life since diagnosis (Bulsara, Ward, & Joske, 2004; McGrath, 2004a). This implies other HC survivors may be able to adapt following cancer, if provided with the appropriate support. In order to more clearly assess how meaning or spirituality interacts with other aspects of psychological adjustment, mixed-method studies with both qualitative and quantitative methodology are necessary (Dunn et al., 2011).

Conclusion Individual Level Processes

In conclusion, although mortality associated with HC remains high, the number of survivors is also increasing annually, and is likely to continue in the future (Aziz, 2009). Thus, it is important to understand more about the resilience and adaptability of these individuals. Research has identified that mobilising individual resources (i.e., coping skills) may be central in fostering resilience and reducing psychological distress, yet more research among the HC survivor population is necessary to fully understand these individual factors. In addition to the described internal processes that influence resilience, cancer survivors are also affected by risk and protective processes, within their home environment. Specifically, family resources are external resources that are provided by the family or peers to manage adversity, which will now be discussed.

Family (External) Level Factors

One of the most influential family resources is social support, which has been documented across several studies to have a major influence on an individual's resilience (Hjemdal, Friborg, Stiles, Rosenvinge, & Martinussen, 2006; McCabe & Cronin, 2011; Ozbay et al., 2007). Yet, although the majority of research identifies that social support forms part of

the individual's or family's support system, researchers often fail to specify what is meant by social support (Black & Lobo, 2008). Thus, it is important to define social support and social networks, including the role of effective communication and how this impacts on the resilience of HC survivors. The social support specifically provided by communities and healthcare professionals will be addressed in the following section outlining community factors.

Social Support

Social support has been one of the most extensively studied psychosocial constructs (Ozbay et al., 2007) and its relationship with psychological well-being has been widely reported (Cohen, 2004). Social support involves real or perceived resources, provided through social connections that empowers a person to feel part of a network of communication in which they are valued (Galván, Buki & Garcés, 2009).

Theoretical models of social support stipulate two important features. The first is a 'structural' element, which includes the frequency of social interactions and network size. The majority of research has established that quality of relationships is a better predictor of psychological health than quantity of relationships, yet both play an essential role (Ozbay et al., 2007).

The second is a 'functional' element involving emotional, instrumental and informational characteristics (House, 1981). *Emotional* support relates to the perception of interpersonal help and allows for emotional expression and venting (Cohen, 2004). This is often influenced by the strengths of communication (i.e., love, trust, understanding and empathy) within the family (Teasdale & Bradley-Engen, 2010). *Instrumental* support refers to practical or tangible aid (i.e., meals, transport) that directly helps an individual in need, thus reducing the impact of negative events (House, 1981; Cohen, 2004). Finally, *informational* support relates to the delivery of advice, suggestions, and information (i.e., cancer treatment options) that an individual can draw upon, to manage ongoing challenges (Galván, Buki, & Garcés, 2009; Cohen, 2004).

Social support has been recognized as being crucial in enabling individuals to cope with the challenges of illness (McCabe & Cronin, 2011; Yu, Lee, Kwong, Thompson, & Woo, 2008). Most of the literature associates social support with a decrease in negative emotions, yet the relationship seems to be indirect, with social support having either a stress-buffering or stress-mobilising effect (McCabe & Cronin, 2011; Pieters et al., 2007).

How social support mobilises coping resources is not fully understood (McCabe & Cronin, 2011). It has been proposed that social support assists individuals to: handle stress (Kynge et al. 2001); foster resilience (King, Willoughby, Specht, & Brown, 2006); prevent negative appraisals (Ozbay et al., 2007); provide relief from knowing that others care and are reliable (Lundman & Jansson 2007); improve self-care (Park et al., 2008; Yu et al., 2008);

enhance self-efficacy (Monsivais, 2005); foster emotional expression and confidence (Wills & O'Carroll Bantum, 2012); encourage illness caused adjustments to lifestyle (Nagelkerk, Reick, & Meengs, 2006); and, provide support in treatment decision making (Butow et al., 2011, 2014; Sheppard, Kumar, Buckley, Shaw, & Raza, 2008) and treatment adherence (Magai et al., 2007; McCabe & Cronin, 2011).

In a systematic review involving those with physical illness, including cancer, Stewart and Yuen (2011) highlighted that social support was predictive of various aspects of resilience in several studies. This included better psychological health, successfully living with illness, benefit-finding, hardiness and self-esteem. In contrast, a lack of social support has been widely recognized as a risk factor for: psychological illness (Korszun et al., 2014; Parker, Baile, Moor, & Cohen 2003); poor QOL (Allart et al., 2013); and, increased mortality (Kroenke et al., 2012).

Research by Parker et al. (2003) recommend that evaluating patients' levels of social support is possibly the most accurate way to identify those patients most prone to anxiety, depression or distress following the diagnosis and treatment of cancer. Likewise, Frick Borasio, Zehentner, Fischer, & Bumedner (2004) reinforced this in research involving 126 HC patients, who explored their health values and coping styles preceding autologous stem cell transplantation. Participants completed several surveys addressing health-related control expectancies, causes of personal illness and coping with their illness. The results indicated that supportive relationships with others, including close family, are important for managing their disease (McCabe & Cronin, 2011).

The beneficial effect of social support has been reported in several other studies investigating HC patients. For example, effective social support was positively correlated with: improved emotional and psychological QOL among HC patients (Santos, Kozasa, Chauffaille, Colleoni, & Leite, 2006; Smith et al., 2010); and, acceptable interactions with family and friends (Zebrack, 2000). In one study, fulfilment with social support predicted improved QOL in long-term survivors of leukaemia and lymphoma (Lim & Zebrack, 2006).

A more recent systematic review reported on the negative factors impacting on social support and affecting QOL in HC patients (Allart et al., 2013). For example, conflicts with friends or family are reported to lower the satisfaction with support and may lead to feelings of uncertainty, impacting on ability to cope with cancer. This is supported by previous research highlighting that ineffective social support within interpersonal relationships can lead to negative outcomes, such as increasing a survivor's feeling of isolation (Landmark, Strandmark, & Wahl, 2002). In addition, this review by Allart and colleagues also reported that one study found that the size of the social network was not related to QOL (Lim & Zebrack, 2006). This implies that relationship quality, and not just network size, matters to survivors (Allart et al., 2013).

In summary, the research highlights that naturally occurring social networks influence resilience among those with cancer. However, it remains uncertain as to how social support specifically functions to have a positive effect on adjustment to HC, and why some individuals employ more effective social support strategies than others. The idea that social support may have a positive effect on self-esteem and self-efficacy has been suggested (Robinson, 1997). The likelihood that a low level of social support is an outcome, rather than a cause, of poor adjustment has also been proposed (Moss, 1997). For example, a negative self-appraisal may result in social withdrawal that, in turn, reduces social support opportunities (Moss, 1997). It may also be that optimistic cancer survivors are more likely to seek support groups and be active in their communities (Korszun et al., 2014). The literature has not specifically identified what aspects of social support networks are most influential among HC survivors. It is, therefore, essential to investigate social support in more depth as it is clear that social support is a significant protective factor among those with cancer.

Communication

Communication between family members is another important factor influencing psychological outcomes (Knobf, 2011). Effective communication processes facilitate the understanding of not only the information provided, but also the central context of the message (Friedman, Bowden, & Jones, 2003; Friesen, Bowden, & Jones, 2003). Functional styles of communications are apparent when individuals communicate clearly and openly, while clarifying feelings and inviting feedback. Research has reported that functional communication among cancer survivors is associated with lower emotional distress and better marital satisfaction (Manne et al., 2006). Moreover, the capacity for couples to effectively communicate about the challenges associated with cancer is reported to enhance positive outcomes among cancer survivor (Morgan et al., 2005).

Conversely, dysfunctional communication styles are less effective as the message tends to lack clarity, is more assuming and judgmental, and provides little opportunity for emotional expression and feedback (Friedman, Bowden, & Jones, 2003; Greenstein, 2006). In a study involving 58 couples, in which the female had a breast cancer diagnosis, adjustment and communication difficulties early in the survivorship trajectory predicted an increased risk for poorer adjustment one year following diagnosis (Northouse, Templin, & Mood, 2001). Likewise, in situations in which dysfunctional communication occurs, cancer survivors may perceive lack of interest and recognition in their cancer experience by significant others (Gatchel, Mayer, Kidner, & McGeary, 2005).

Communication styles between cancer survivors and family members are also reported to change over time. For example, Lauver, Connolly-Nelson and Vang (2007) investigated the communication changes among HC survivors at different times following their diagnosis. The

frequency with which communicating with a partner was a stressor increased over time by approximately 13% to 23%. This pattern is consistent with other research maintaining that many couples place the communication issues in a relationship on hold during treatment (Gatchel et al., 2005). Hence, following treatment the attention shifts away from addressing immediate challenges, and relationship issues become more prominent.

In summary, research has explored factors in relation to communication, identifying a positive influence of effective communication between family members (Forrest, Plumb, Ziebland, & Stein, 2009; Harris & Templeton, 2001). However, there are often several factors that affect communication styles within families. For example, the culture of the family will influence the styles of communication and the hierarchy of communication between family members (Fukui, Ogawa, Ohtsuka, & Fukui, 2009). There are several factors impacting on communication many of which are not yet fully understood among cancer survivor populations.

Conclusion Family Level Processes

In conclusion, there are processes within the home environment that can impact on both an individual's risk or protective processes. In particular, social support, effective communication and cohesion offered by families and friends, are seen to create a positive climate that may facilitate resilience in HC survivors. Finally, while it is also apparent that risk and protective processes may be operating at the individual and family level, there is also some contribution from the community, which will now be discussed.

Community Level Factors

The community provides a context, which either promotes protective processes or increases risk. For example, a key risk factor among cancer survivors at the community level is low socioeconomic status. However, a protective factor may include the ability to return to work (Amir & Brocky, 2009; Feuerstein, 2005; Grunfeld et al., 2013) or access to community healthcare services (Gatchel et al., 2005). According to Hollingshaus and Utz (2013) community factors have a strong influence on the perception that cancer survivors hold of their experience, and how they cope with illness. Thus, although community-level factors have been less comprehensively studied than features of the individual and family, they are also important in cancer survivor outcomes (Vanderbilt-Adriance & Shaw, 2008). Those community factors particularly relevant in the survivor context will now be outlined.

Socio-economic Status

A well-established risk factor that may exist in any community is low socioeconomic status (SES). It has been suggested that low SES among cancer survivors increases the risk of anxiety, partly due to their reduced capacity to communicate successfully with health professionals (Isaksen, Thuen, & Hanestad, 2003). According to Isaksen and colleagues (2003), those with lower education levels often experience increased problems in understanding medical terminology, which may result in feelings of disempowerment. Therefore, these individuals tend to withdraw from their healthcare communities thus receiving less support. Conversely, research by Butow et al. (2013), found that among immigrants, SES was not related to information/support and physical needs, which is in contrast to previous studies. However, it may be that the accessibility and uptake of support services among low SES communities is influenced by linguistic, financial and cultural factors (Butow et al., 2013; Galván, Buki, and Garcés, 2009). For example, Galván, Buki, and Garcés (2009) reported that there is often limited availability for social support among minority ethnic groups. This results in a decreased awareness and access to key information that can promote healthy adjustment to cancer, including the underutilization of mental health treatment (Galván, Buki & Garcés, 2009).

Thus, SES is an important consideration, as research has established a direct link between the availability and access of community health services and an overall adjustment to cancer (Isaksen, Thuen, & Hanestad, 2003). In addition, more attention to multicultural factors could lead to more positive outcomes, such as compliance with treatment, empowerment and uptake of community health services (Butow et al., 2011, 2013). However, research in this area is limited (Galván, Buki, & Garcés, 2009).

Healthcare Professional Support

Support from HCP's within the community has been identified as a significant protective factor among cancer survivors (Butow et al., 2007; Doyle, 2008; Roundtree, Giordano, Price, & Suarez-Almazor, 2011). Yet, notably missing from illness and resilience research is the influence and role of clinicians (Knott et al., 2012). There is no consistent definition for health professional support, primarily due to the range of services available in the community. However, health professional support is generally considered to include the aid provided by non-family members such as doctors, allied healthcare professionals, community groups and internet information (Friedman, Bowden, & Jones, 2003).

In a recent study, Adejoh, Temilola, and Olayiwola (2013) stated that supportive interpersonal relationships with HCP's enhanced the compliance to treatments and helped participants develop hope and self-efficacy in adjusting to living with HC. Twenty leukaemia survivors took part in this qualitative research reporting that emotional support characterised

by respect, understanding, listening, compassion and reassurance are particularly important in a cancer patient's adjustment to their illness. Furthermore, this study reaffirmed previous research highlighting the importance of empathy and rapport (Knott et al., 2012), including a warm and trusting environment, in which the patient feels valued and is treated as an individual (Butow et al., 2011; Xuereb & Dunlop, 2003).

However, several studies have identified that this is not always the reality experienced by cancer survivors (Knobf, 2011). The support is noted to lack continuity and participants in several studies have described a need for increased information and emotional support from the health professionals (Butow et al., 2013; Landmark, Strandmark, & Wahl, 2002; Roundtree et al., 2011; Swash, Hulbert-Williams, & Bramwell, 2014). For example, Lobb et al. (2009) stated that 59% of HC survivors in their study believed it would have been helpful to meet with a HCP at the end of treatment. This would have helped prepare the patients during this transition phase (Lobb et al., 2011).

Research by Knott et al. (2012) concurs with this view, having identified that, for some cancer survivors, the dissatisfaction with the health care system becomes more apparent following the acute illness phase. Despite the practical support provided at the time of diagnosis, when treatment ends participants find that support and communication cease (Knott et al., 2012). In later survivorship phases, the patient's focus generally shifts from merely getting through treatment, towards a more comprehensive view of QOL and ongoing survival. According to Knott and colleagues, it is during this phase of transition when patients often notice a sense of loss and failure by the healthcare system. There remains a focus on treating disease, rather than considering the survivor holistically. However, as reported in this study, participants highlighted the importance of follow-up communication and continuity in care following treatment (Knott et al., 2012).

Research by Roundtree and colleagues (2011) also underscored the importance of physician communication. In this qualitative study involving eight focus groups ($n = 33$) of breast cancer survivors, several issues were identified. Many of these included barriers to screening, feeling in limbo in the healthcare system and difficulties in communication and relationships with physicians. This study concluded that the survivors' experiences are fraught with challenges, especially in finding a doctor who can both address their individual needs and coordinate their care (Roundtree et al., 2011).

Communication between clinicians, the cancer patient and their family is integral to the concept of social support. Limited communication with HCP's about physical and psychological symptom distress, can result in adverse psychological morbidity (Knobf, 2007). Moreover, the communication in each context is dependent on the different needs of each individual and their interpretation of the relationship (Ungar et al., 2007), as not all individuals or clinicians will communicate in the same manner. The medical profession tends to have a different style of communication, which mainly focuses on treating the illness, thus patients

may perceive their doctors to be less concerned in their personal experience (Ofri, 2004). In addition, appointments with clinicians are typically short, with an extra minute only cited as being provided for patients with psychosocial issues (Howie et al., 1999). These time constraints can mean that patients' concerns with mental health are not always dealt with appropriately (Swash, Hulbert-Williams, & Bramwell., 2014).

Numerous studies have highlighted the importance of communication between clinicians and cancer patients, especially in regard to providing relevant cancer-related information. In a study by Rabin et al. (2011), 84% of cancer survivors expressed a need for information-based interventions. This view is supported in recent research stating that cancer patients and their family require informational and educational support, in order to cope effectively following diagnosis and treatment (Adejoh, Temilola, & Olayiwola, 2013). In addition, previous qualitative research among 73 migrants by Butow et al. (2011) reported that cultural isolation, language and communication difficulties with HCP's and interpreter issues all contributed to making their recovery more difficult. A systematic review by Swash and colleagues (2014), which solely addressed HC survivors, agrees with these findings (Table 2.1). As well as the fear of reoccurrence, information provided by HCP's was the other key area of need identified (Swash, Hulbert-Williams, & Bramwell, 2014).

In summary, the level of resilience exhibited by individuals with illness can be significantly affected by the level of support and communication with multidisciplinary teams of professionals responsible their care, contributing as either a risk or as a protective process (Deimling et al., 2005; Knobf, 2011; Mellon, Berry-Bobovski, Gold, Levin, & Tainsky 2006). The outlined literature highlights that adequate information and support from HCP's across the trajectory are vital protective factors among cancer survivors. Describing how and when her cancer treatment ended, the support also ceased, Carr (2004) aptly described the feeling "the party, such as it was, was over" (p. 89).

Community Services and Organisations

The role of community organisations in the support of individuals facing a health adversity has been explored in several studies (Badger, Segrin, & Meek, 2004; Northouse, Kershaw, Mood, & Schafenacker, 2005; Zabalegui, Sanchez, Sanchez, & Juando, 2005). Individuals who participate in community groups are more likely to be resilient, have an increased sense of belonging and develop more adaptive skills (Laursen & Birmingham, 2003). However, researchers have identified a general reluctance by clinicians and general practitioners (GP's) to refer cancer survivors to community support organisations (Brennan et al., 2011; Gunn, Turnbull, McWha, Davies, & Olver 2013; Kam, Knott, Wilson, & Chambers 2012).

Community services, such as internet information and counselling groups, all form a part of the oncology network that provides support for individuals with the cancer. In addition, there are several other community-level resources available to cancer survivors, designed to assist both emotional and physical recovery. These may involve: participating in music therapy (Docherty et al., 2013); use of complementary therapies (Beatty, Koczwara, Knott, & Wade, 2011; Jones & Demark-Wahnefried, 2006); relaxation (i.e., yoga, meditation, mindfulness, deep breathing, massage, laughter) (Rabin et al., 2011; Sharplin et al., 2010); and, lifestyle programs, such as exercise (James et al., 2011) or nutrition groups (Rabin et al., 2011).

The role of lifestyle interventions aimed at preventing recurrence, secondary cancers and psychological illness, is an emerging area of research (James et al., 2011). For example, physical activity in cancer survivors is linked with lower risk of disease recurrence and longer survival (Aziz, 2002; James et al., 2011). The benefits for cancer survivors include improved cardiovascular fitness, maintaining a healthy weight, assisting with recovery from treatment and reducing fatigue (James et al., 2011; Rabin et al., 2011). In addition, cancer survivors have identified an improvement in mental health, QOL, relaxation, sleep and self-esteem levels (James et al., 2011). Yet, despite the emerging evidence of the advantages of lifestyle behaviours in promoting improved health and recovery for cancer survivors, there are limited services specifically targeting cancer survivors following treatment (James et al., 2011).

Nevertheless, research has identified that patients would like access to such support services (James et al., 2011). For example, several cancer survivors have noted that it was difficult to receive appropriate support from family or friends, as they often became distressed while discussing the cancer diagnosis and were unable to remain objective (Rabin et al., 2011). Cancer survivors have found benefit in community support groups that provided an environment in which they were more able to share their story and normalise their experience (Rabin et al., 2011).

However, an important consideration in relation to community support is that the type of service provided should match the survivor's needs (Butow et al., 2007; Steginga et al., 2008). For example, the type of support group is known to influence the ongoing participation by the cancer patient. Butow et al. (2007) identified the main reasons for ongoing group attendance included feeling connected, having a sense of community, receiving current medical information and effective group leadership. This sample of 417 cancer survivors also reported that support services should be flexible and consider all survivors, as the requirements changed as the patients were further along their cancer trajectory.

Rabin et al. (2011) confirmed these findings also reporting that participants described receiving more benefit if other program participants were comparable in age, cancer type, time since diagnosis, gender, treatment history and life situation. In many circumstances, HCPs who care for cancer survivors are already aware of the requirement for support and services. For example, Rankin, Butow, Price, & Evans (2011) canvassed the priorities of health

professionals in providing effective support to cancer patients. Among the twelve priority areas identified, participants noted that improving follow-up assessment, referral and patient management was important. In addition, support services and research that included specific populations including the elderly and less common cancers such as HC, were noted as a priority (Rankin et al., 2011).

Kam et al. (2012) also reported that even those cancer survivors who experience significant distress fail to receive appropriate support services that might address mental health problems. This study identified the two key barriers preventing patients from attending community support services. They included the lack of referrals, recommendations and advice from clinicians (13%), and a lack of knowledge of the service (34%). Oncology clinicians stated that their main reason for non-referral was a lack of awareness of services (Kam et al., 2012). Yet, of those clinicians who were aware, 70% had not advised patients on the availability of community groups, despite rating those services as being 'useful' or 'extremely useful' (Kam et al., 2012).

Brennan et al. (2011) identified a lack of referral by GP's in breast cancer survivors, despite them being ideally placed to manage these issues. Similarly, a lack of services, or knowledge about available services, particularly for males, was noted (Knott et al., 2012). Earlier research among ovarian cancer survivors also reported that 56% of participants reported that they would have joined a support program if it had been recommended (Wenzel et al., 2002). The literature has reported that other barriers to referral by clinicians include: work burnout (Alacacioglu, Yavuzsen, Dirioz, Oztop, & Yilmuz, 2009); the belief that issues related to psychosocial wellbeing are outside their professional responsibilities (Johnson, Girgis, Paul, & Currow, 2008); a lack of trust in the effectiveness of existing services (Snow et al., 2009); and, concerns about distance to services (Andrykowski & Birris, 2009).

Gunn et al. (2013) investigated psycho-social service use from the perspective of rural Australian cancer patients. Seventeen purposively sampled cancer survivors, who lived outside metropolitan Adelaide, participated in semi-structured, face-to-face interviews. The most dominant theme was that rural cancer patients who access psychosocial services valued them highly. The results identified that, despite their isolation, rural cancer patients believe there is a need for more transparent communication among HCPs and more defined referral pathways to psychosocial care. The authors concluded that more systematic screening of distress, and the involvement of appropriate services, may help address the communication and referral issues for rural patients (Gunn et al., 2013).

The literature discussed has identified that there is a low referral rate by clinicians to many community support services, despite cancer survivor requests (Kam et al., 2012; Wenzel et al., 2002). However, research has highlighted that community support services are important and may be able to address many of the issues that matter most to cancer survivors (Brennan et al., 2011, Rankin et al., 2011; Swash, Hulbert-Williams, & Bramwell, 2014).

The community surrounding a cancer survivor can influence them through either the provision or lack of both human and material resources. However, it is important to note that the influence of the community as a risk or protective process is dependent on the characteristics of the community. As discussed, positive community influences among HC survivors include the accessibility of healthcare services, effective relationships with health professionals and community support (Galván, Buki & Garcés, 2009). Yet, there are cultural minority groups and those with low SES who are more at risk (Butow et al., 2013). According to the literature, supporting emotional needs can often be addressed at the community level, although it is not possible to suggest that all community services contribute to resilient outcomes, as each community varies and will have different risk and protective processes operating. It is, therefore, important to research community-level protective factors to further understand their role in promoting resilience (Gorman-Smith, Henry, & Tolan, 2004; Vanderbilt-Adriance & Shaw, 2008).

The final section of this literature review will describe positive and negative mental health outcomes that may result as a consequence of HC. Based on the available literature, this will be followed by presenting a conceptual model of resilience among HC survivors.

Positive and Negative Outcomes

Most survivors of HC seem resilient and are able to adapt well (Schumacher et al., 2014). However, there are a number of studies that also report significantly elevated levels of psychological distress among survivors on specific measures of anxiety, depression, and interpersonal problems (Wenninger et al., 2013). This is important to investigate as research has identified a significant correlation between low resilience and higher levels of depression and anxiety in several studies (Krepper et al., 2014; Mitchell et al., 2013; Walker et al., 2013). For example, research by Korszun et al. (2014) identified a distinct subgroup of cancer survivors that reported poor QOL. Several psychosocial factors were found to be associated with this finding, yet this study noted that the most consistent association was with high depression and anxiety scores (Korszun et al., 2014).

However, understanding depression among cancer survivors can be a challenge, partly due to conflicting results. For example, a meta-analysis by Mitchell and colleagues (2011) found the prevalence of depression ranged immensely (1.0% – 77.5 %). This research reviewed 70 studies on mood disorder in haematological and oncological settings, involving 10,071 individuals across 14 countries. Mitchell et al. (2011) also reported a significant variation in documented depression rates among cancer survivors over time. In studies published up to 1990, the reported prevalence of depression was 23.3 %, in those published from 1991 to 2000 it was 15.5%, and in those published since 2001 it was 13.4 %. This may suggest that rates of depression have reduced over time. An alternative explanation, according

to Mitchell and colleagues (2011), is that recent studies tend to be more methodologically sound (i.e., use more rigorous definitions of depression) and therefore report more realistic rates than older studies.

As a result of this review, Mitchell et al. (2011) concluded that approximately 16.6 % patients with cancer have depression. These rates are notably higher than the prevalence of depression in general population, which is reported to be approximately six percent (ABS, 2007). The results are not unexpected, given the trauma and uncertainty faced by those with serious illness. However, it has also been suggested that, in some situations, the rates are also higher in cancer patients when compared with individuals with other chronic illness (Härter et al., 2007). For example, in two separate studies, the relative risk of depression in patients with cancer exceeded that of patients who had diabetes, heart disease and those who had suffered a stroke (Patten et al., 2005; Polsky et al., 2005).

Although the exact rates remain unclear, depression has been the most extensively investigated mood disorder among cancer patients (Mitchell et al., 2013). This may have limited our understanding of psychological distress among cancer survivors. According to more recent research by Mitchell et al. (2013), increased rates of anxiety were found following a cancer diagnosis and these tend to persist, whereas increased rates of depression were less enduring. Although depression was reported to be twice as common in the first two years following a cancer diagnosis, an increased risk of anxiety disorders were found to persist beyond ten years. This suggests that anxiety, rather than depression, may be the most common problem in long-term cancer survivors. This is not dissimilar to rates among populations without cancer, where anxiety levels are reported to have a 12-month prevalence of 18% that is approximately twice as common as depression. These results provide support for earlier research with similar findings (Alacacioglu et al., 2010; Brown, Kroenke, Theobald, Wu, & Tu, 2010). Therefore, it is important to also investigate anxiety, not only because the prevalence may be higher among cancer survivors, but also as screening for anxiety has often been overlooked in comparison to depression and distress (Mitchell et al., 2013).

In general, according to many researchers, it is also important to recognize that psychological distress levels reported in long-term cancer survivors vary as rates may be influenced by the cancer type and the associated physical complications (Krebber et al., 2014; Mitchell et al., 2013; Walker et al., 2013). However, as HC remains relatively understudied, the extent to which HC survivors experience psychological distress and the factors that influence psychological wellbeing remain unclear.

In summary, the literature has highlighted that both positive and negative outcomes may present as a result of being diagnosed and treated for HC cancer. In spite of experiencing the initial shock at diagnosis, including a potentially aggressive treatment regime, many long-term survivors report positive outcomes (Schumacher et al., 2014), yet others report poor QOL and psychological distress (Allart et al., 2013; Korszun et al., 2014; Schumacher et al., 2014).

The key to improving positive outcomes may be resilience, which is described as a phenomenon that acts as an antidote to stress (Schumacher et al., 2014). However, as resilience is a dynamic concept, it can be influenced by life circumstances, the external environment, including situational and contextual factors. Therefore, stress and negative experiences can cause temporary disturbances even in the most resilient individuals (Schumacher et al., 2014). Thus, being resilient may not necessarily result in the absence of psychopathology. However, substantial research has found a significant correlation between resilience and mental health in those with physical illness (Schumacher et al., 2014). This is perhaps because resilient individuals are more able to maintain or restore their ability to function, despite adversity (Masten, 2007; Pooley & Cohen, 2010; Rutter, 1995; Ungar, 2008).

Conceptual Model

A preliminary conceptual model of resilience among HC survivors (Figure 3.1) is presented below, which outlines the main factors identified in the literature, to be moderated by resilience. Moderators are referred to as variables that can influence the relationship strength between other variables (Baron & Kenny, 1986). Thus, resilience is understood to moderate interactions in regression by influencing the direction and/or strength of a relationship between other variables such as coping skills.

The following modifiable variables have been identified as having a direct relationship with positive outcomes in HC survivors. First, within the individual: coping skills, a sense of control, global meaning and self-efficacy are four factors that are reliably correlated with either resilience and or QOL in numerous studies (Allart, 2013; Bulsara, Ward, & Joske, 2004; Denz-Penhey & Campbell Murdoch, 2008; Kelly & Dowling; 2011). Second, within the family, social support and effective communication are consistently referred to as important factors (Adejoh, Temilola, & Olayiwola, 2013; Allart et al., 2013; Dunn et al., 2011; Korszun et al., 2014; Rodin et al., 2013; Schumacher et al., 2014). Finally, there is an overall consensus that interpersonal relationships with healthcare professionals are significantly influential in improving psychological wellbeing (Lobb et al., 2009; Swash, Hulbert-Williams, & Bramwell, 2014). Therefore, these are the factors that were included in this model.

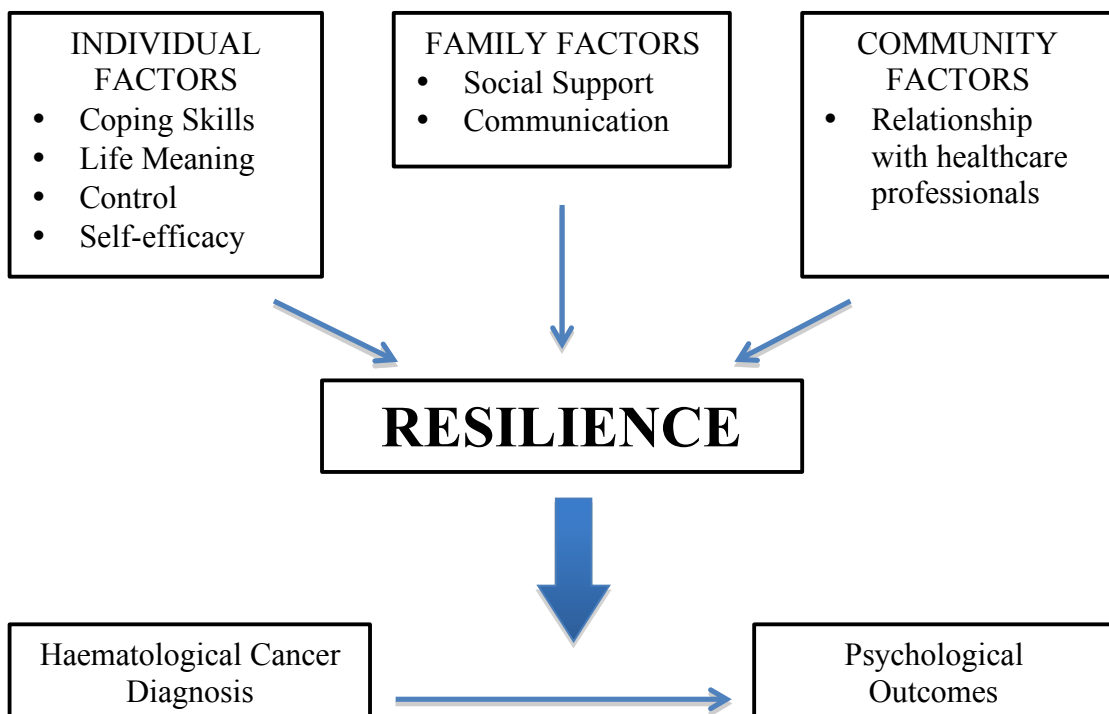


Figure 3.1. Conceptual model of factors that influence the resilience process and moderate psychological outcomes in HC survivors.

Overview of Literature Review

This review has highlighted that, although the HC experience brings significant challenges and stress before, during, and after treatment, there is very little research that specifically examines resilience and its relationship to the cancer experience among this patient population. Yet, the literature has reported that the ability to mobilise resources, either within the individual, family or community, does increase the likelihood of better psychological outcomes (Llewellyn et al., 2013). However, due to limited research, the process is still unclear as to how, when and to what extent these internal and external factors influence resilience among the HC survivor population (Llewellyn et al., 2013). This topic will become increasingly relevant as we witness an increasing number of HC survivors.

The following chapter will outline the methodology selected for this study. Qualitative and quantitative approaches are considered complementary, thus both will inform this research. It is anticipated that this mixed-method research will gain the most comprehensive understanding of the HC survivor population. The literature review findings highlight the importance of seeking the views of HC survivors, as only they will have a true understanding of the risk and protective processes that are operating in their lives. In addition, the HC survivors' perception and experience of relevant processes may be dissimilar from the views of current and previous research investigators. Therefore, it is important to hear the personal story from the perspective of HC survivors themselves. First, qualitative data will be collected in order to provide a glimpse into the participant's narrative, which aims to be relatively untainted by researcher assumptions. This will then inform further instrument development for a second larger quantitative study. The specific details entailing this research methodology will be explained in the next chapter.

Chapter 4

Research Design and Methodology

Chapter Overview

The purpose of this chapter is to explain the research design and methodology employed in each of the two phases included in this study. First the study's philosophical framework and research approach are outlined. This includes a discussion of social constructionism and post positivism including the rationale for using a mixed method exploratory sequential design. Second, the research paradigms, methodology, data collection process and analyses of each phase are described. This includes the steps taken to ensure rigour and the process involved in developing the final questionnaire. Last, the ethical concerns and data analysis issues surrounding resilience research are presented.

Philosophical Framework

Prior to selecting an appropriate methodology, it was essential to adopt a suitable research paradigm that provided a philosophical framework for this research. The research paradigm is a "basic set of beliefs that guides action" (Guba, 1990, p. 17). More explicitly, "paradigms are frameworks that function as maps or guides for scientific communities, determining important problems or issues for its members to address and defining acceptable theories or explanations, methods, and techniques to solve the defined problems" (Usher, 1996, p. 15). There are several different paradigms that researchers may choose to include. In the current study, two paradigms, namely social constructionism and post positivism were selected, as each provided a framework for the research process that complemented both the qualitative and quantitative methodologies (mixed method) involved in this study.

As mentioned earlier, the overarching question in this research was to identify the key factors and processes that contribute to, or impede, resilience in HC survivors. The aim of the first phase was to develop a conceptual model that explained how individual HC survivors exhibit and maintain resilience. The aim of the second phase was to test the developed model on a larger national sample of Australian HC survivors. In order to achieve both these aims and answer the research question, it was necessary to adopt a combination of both a qualitative and quantitative approaches.

This framework also enabled both inductive and deductive reasoning to be applied, resulting in a more thorough understanding of the research problem (Johnstone, 2004). Inductive reasoning (bottom-up approach) is research that begins with a base of specific observations and slowly starts to look for broader patterns or generalisations in order to build

on a theory or model that describes the phenomenon (Trochim, 2000). Inductive reasoning is generally more open-ended and exploratory. Conversely, deductive reasoning (top-down approach) functions in the opposite way, working from the more general observations to be more specific. Thus, a theory is first formulated, which is then narrowed down into more specific hypotheses that can be tested. Observations are then collected that ultimately result in a confirmation (or not) of initial theory (Trochim, 2000). Similar to this study, much of the social research investigating mixed-cancer survivors to date has involved a combination of both inductive and deductive reasoning processes.

In Phase One (qualitative) when exploring the resilience experience among HC survivors, a social constructionism paradigm guided the phenomenological methodology. The methods of data collection involved semi-structured interviews that were interpreted using thematic analysis (Braun & Clarke, 2006). Yet, in the following phase (quantitative) when developing and implementing the questionnaire, a post positivist paradigm was employed. The methodology included survey sampling that was interpreted through statistical analyses. The research paradigms, methodology, data collection methods and analyses, relating to each phase, are discussed following an outline of the research approach.

The Research Approach

Once the philosophical framework was ascertained, it was important to identify and adopt the most appropriate research methodology to guide the study (Creswell, 2003; Mertens, 2005). According to Johnson and Onwuegbuzie (2004), the only “correct” methodology is the one that provides the most effective data in order to answer the research question. A mixed method approach employing a sequential transformation strategy was considered the most appropriate methodology for this study, as it is a research methodology that was not restrictive, but rather supported, the use of multiple paradigms and offered freedom to shift from one paradigm to another. Mixed methods are defined as “the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study” (Johnson & Onwuegbuzie, 2004, p.17). Many researchers have described mixed method research as the “third wave” of research methodology (Creswell, 2003; Johnson & Onwuegbuzie, 2004; Patton, 2002; Tashakkori & Teddlie, 2003) and was the most appropriate for this study for a number of reasons.

First, this approach suited the research objectives of this study by providing the flexibility to elicit and capture the resilience experiences and support needs of individual HC survivors, as well as testing the findings in a broader context. Within resilience research, Curtis and Cicchetti (2003) and Rutter (2006) have both claimed that a comprehensive research agenda is required, spanning biological, cognitive and social domains, utilizing qualitative and quantitative approaches (Davydov et al., 2010).

Second, mixed methods provided a practical way of addressing the research problem by allowing the use of multiple paradigms (Creswell & Plano Clark, 2011; Tashakkori & Teddlie, 2003). Hence, mixed methods allowed the collection of new data utilising a social constructionist paradigm and then using these data in a systemic post positivist paradigm to obtain a validated questionnaire. Further, following this process of development, whereby the results from one method helped develop and inform the other method, the validity of the results obtained would be strengthened (Creswell & Plano Clark, 2011).

Third, mixed methods designs use the strengths of each methodology, which results in the disadvantages of each potentially being offset (Creswell & Plano Clark, 2011). For example, one limitation of a quantitative approach is the apparent lack of in-depth and rich knowledge about the individual being researched. To eliminate this disadvantage, qualitative data may be included to provide a deeper appreciation of the quantitative data. Thus, mixed methods offered a highly robust, realistic and flexible framework for undertaking this study, which was based on the need to explore a relatively unknown area.

Just as there are valid arguments for employing mixed methods there are also limitations. As this study involved the collection of both qualitative and quantitative data the researcher had to be well versed in the different methodologies and have the necessary skills to be able to mix multiple methods appropriately (Johnson & Onwuegbuzie, 2004). There is also a longstanding view that research paradigms that are different in terms of beliefs, foundations and methods should not be combined due to the complexity involved (Greene & Caracelli, 2003; Guba & Lincoln, 1989). Yet, several researchers now support the use of competing paradigms in a single study, in order to holistically comprehend the phenomena being researched (Creswell, 2013; Denzin & Lincoln, 2005; Hassard, 1993; Greene & Caracelli, 2003; Patton, 1988). Within this perspective, including mixed methods provides differing, yet valuable, insights into the understanding of humans and their social world (Greene & Caracelli, 2003). As Patton (1988) pointed out, “there is no logical reason why qualitative and quantitative approaches cannot be used together” (p. 117). Combining results from both the qualitative and quantitative parts of any study are more likely to produce a richer account of the experiences. Therefore, a mixed methods approach was believed to be the most appropriate for this study.

Exploratory Sequential Design.

Once the methodology for the study was selected, the next stage involved formulating the research design. Research design refers to the plan of action that links philosophical assumptions to specific methods (Creswell, 2003; Crotty, 1998). The first step in planning the research design, in a mixed method study, is choosing whether the data should be collected in stages (sequentially) or at the same time (concurrently) (Creswell & Plano Clark, 2011). Taking the research objectives into consideration, a sequential approach was undertaken.

This approach involved collecting qualitative and quantitative data in succession where the findings identified following the first phase led to the formulation of questions, data collection, and data analysis in subsequent phases (Mertens, 2005). One of the most frequently used sequential mixed method designs involves a qualitative study followed by a quantitative research (Morgan, 1998). The exploratory sequential design is based on the idea that exploration of a phenomenon is required as there is either little theory that has been developed that can guide the research, important variables relating to the phenomenon are not yet widely recognised, or quantitative instruments are not available (Creswell & Plano Clarke, 2011). In sequential transformation strategies, the method that is first used for data collection depends upon the theoretical base that the researcher is addressing (Creswell, 2003). In the current thesis, as discussed in the literature review, little is known about the factors that influence resilience among individual HC survivors. This issue had not been previously explored within this context or within the wider HC survivor population. Therefore, Phase One involved a qualitative design, which comprised in-depth interviews with HC survivors. In conducting the qualitative stage first, greater exploration of the theory (resilience) and phenomenon (living with HC) was achieved. The objective was to provide new insights and lines of inquiry for theory development relating to the process of resilience in this population. The qualitative phase was then followed by a quantitative stage, involving a larger sample, where the issues identified were tested and confirmed using a survey. It was expected that this would result in a more complete picture of influential resilience factors that could be generalised in HC survivors across Australia and overseas. Such data would help enhance our understanding of the phenomena involved and strengthen any recommendations proposed at completion of the study (Newman & Benz, 1998).

Adopting a sequential, mixed method design also has other advantages. According to Creswell (2003), this design is relatively straightforward to implement, describe and report. Sequential designs are also viewed as the most appropriate design when testing elements of an emerging theory that result from a qualitative phase. In addition, this model has been cited as being especially advantageous when developing a questionnaire. The initial qualitative phase assists in identifying the key areas that need to be addressed in the questionnaire, while the quantitative phase gives an opportunity to validate and test the questionnaire (Creswell, 1999).

In summary, the aims and agenda outlined by the current study, fit with the procedure of the exploratory sequential design. Phase One was interested in exploring factors that influenced resilience, while subsequent phases developed a questionnaire to test these factors. The research design chart below (Figure 4.1) presents a visual representation of the two major phases of data collection and analysis to be conducted in this study.

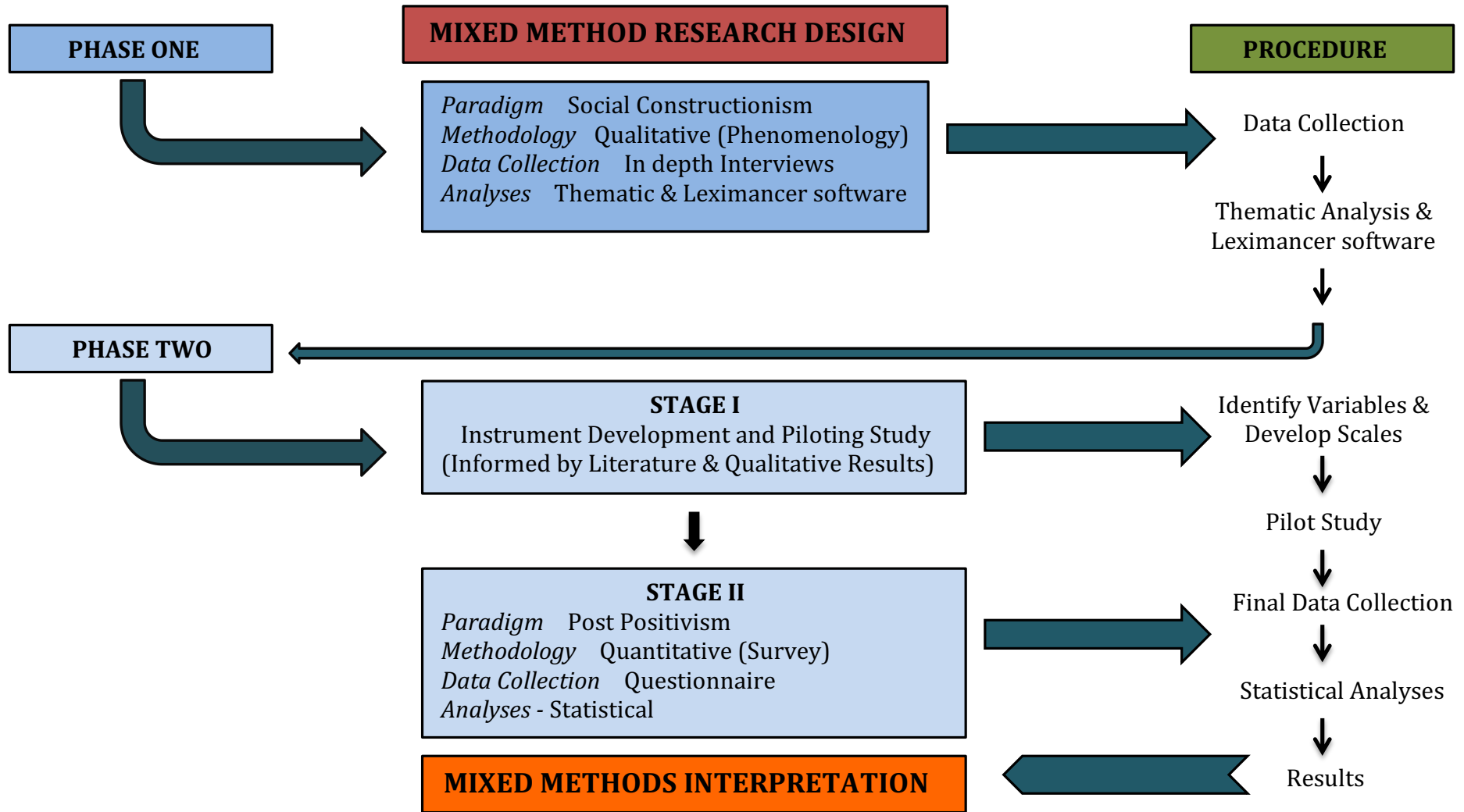


Figure 4.1 – Overview of mixed method research design and methodology.

Phase One – Qualitative Study

As discussed, a mixed methods research design was used for this study. The qualitative findings (Phase One) were used to guide the quantitative methodology (Phase Two) and to validate the interpretation and understanding of the quantitative data. The next section outlining the first qualitative study begins by providing an overview of social constructionism. Second, a description of phenomenology outlining the steps taken to maintain research quality and rigour are presented. Third, the data collection (interviews) instruments and recruitment procedures are discussed. Finally, the rationale for the analyses employed in Phase One (thematic analysis and Leximancer software analysis), are described.

Paradigm - Social Constructionism

The paradigm that guided the first qualitative phase was social constructionism, described as information formed through conversations (Talja, Tuominen, & Savolainen, 2005). Social constructionism according to Holloway (1997) emphasises the interactive process that assists an individual in the construction of knowledge and understanding, as individuals engage with the world they are interpreting. Constructionism argues that multiple truths can exist within one reality, as reality itself is fluid and shaped by subjective experiences, which are impacted by personal history and social traditions (Guba, 1990). To put this more simply, constructionism is based on the premise that humans interpret their world according to their social and cultural perspectives (Creswell, 2011; Crotty, 2003). Social constructionism is most commonly used in exploratory research projects that attempt to understand individuals' perceptions of their experiences (Schwartz, 2005).

Social constructionism is often used interchangeably with the terms “constructivism” and/or “social constructivism”. As Raskin (2001) states, they “are employed so idiosyncratically and inconsistently that at times they seem to defy definition” (p. 1). Although these terms are similar, there are also subtle differences between each paradigm (Raskin, 2002; Talja, Tuominen, & Savolainen, 2005).

Essentially, constructivism is the knowledge created by people as a result of their observations and experiences (Talja, Tuominen, & Savolainen, 2005). Social constructivism builds on this framework to also include the meaning individual's construct through interaction with others that is also influenced by societal conventions, history and their interpretations of that world (Crotty, 1998). Social constructivism is analogous to the knowledge attained within a social constructionism framework, however social constructionism occurs more at a collectivist level, rather than an individual level (Crotty, 1998). Along similar lines, Daly (2007) suggests that constructivism is the individual cognitive process of making meaning while constructionism is the interactive construction of meaning. Illness recovery has been

likened to a social experience involving the collective interactions between patients, their families, clinicians and allied health professionals, and, as such, the meaning lends itself to research conducted from a social constructionist standpoint (Dewey, 1963).

In support, Ungar (2004) reasoned that resilience is best understood in terms of a social constructionist perspective, suggesting that the relationship between risk and protective factors is a phenomenon that can only be comprehended within a context and is made meaningful by the individuals' interaction with others. Thus, risk and protective factors are also created at a social level. Therefore, it is the individual's interaction within a social context that governs the meaning and significance of risk and protective factors, including a sense of healthy well-being (Ungar, 2004).

When considering the researcher, social constructionists maintain that research is a product of the values of the researchers and cannot be independent of them (Mertens, 2005). The researcher is viewed as a "passionate participant" who interacts with the respondents to construct the outcome of the inquiry (Guba & Lincoln, 1994). As such, the assumptions of the constructionist paradigm are subjective and the created knowledge is dependent on the interaction between the interviewer and the respondent. Hence, it is imperative for researchers to understand the complex world of lived experiences from the point of view of those who live in it (Guba & Lincoln, 1994; Schwandt, 2000).

Therefore, when applied to the current study, social constructionism required the researcher to authentically engage with the research subjects, in order to more accurately understand their world. This allowed the research data to emerge through the interaction between the researcher and the researched (Holloway, 1997). The manner in which HC survivors consider themselves to be resilient emerged during this interaction between the researcher and participant, and through the meaning each attributes to their interpretation of events and processes that have influenced their cancer survivor experience. From this perspective, HC survivors may encounter their illness experiences in a variety of ways. For example, some cancer survivors may prefer to access social support services in order to cope following treatment. However, other HC survivors may turn to the support of family or find that they adjust better following the recommencement of activities (i.e., exercise) that were previously considered normal for them.

With this premise, the goal of social constructionism, when investigating resilience was to focus on the individual's account and interpretation of the situation, including the context in which that situation occurred (Creswell, 2013; Guba, 1990). Advocates of the social constructionism approach prefer using qualitative methods such as interviews and observations to comprehensively understand human experiences in context (Creswell, 2013; Mertens, 2005). Hence, the designed questions tend to be broad and open-ended so as to enable the individual to best recount their experiences and to elicit rich information (Creswell, 2013).

Within this paradigm, the researcher interpreted the stories of individuals who experienced life following diagnosis and treatment for HC. The researcher strived to understand how these individuals constructed their meaning of being a HC survivor, including the resilience factors they perceive to be resilient or contribute to risk.

In summary, from the social constructionist position, knowledge is created and modified through experiences and interactions with the world and other people (Talja Tuominen, & Savolainen, 2005). Thus, social constructionism was essential to this phase of the research. In this study, each HC survivor had their own unique story to tell, and social constructionism allowed the researcher to understand each individual's exclusive experience, whilst allowing for the identification of overarching themes and generalisations. As highlighted by Sarantakos (2005) "what people perceive as reality is not 'the reality', but what they constructed through experiences and interpretations" (p. 37).

Research Methodology - Qualitative (Phenomenology)

Qualitative research aims to explore and describe individual experiences such as the interpretations, accounts and meanings that people ascribe to social phenomena (Hansen, 2006). A comprehensive definition of qualitative research has been offered by Denzin and Lincoln (2005):

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic setting, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them (p. 3).

Qualitative researchers support the belief that there are many realities and that individuals construct their reality as they interact with the environment. Therefore, methodologically, qualitative researchers predominantly interact with their participants in their natural setting (Denzin & Lincoln, 1998; Glesne & Peshkin, 1992). Research conducted within an individual's own environment, such as their home or neutral territory, has been shown to help participants feel less anxious and more at ease, allowing for more open and candid responses (Glesne & Peshkin, 1992).

Conversely, in quantitative research, it is not always possible for participants to articulate their feelings or point of view. This is because the participant's involvement is limited by set choice responses or information sought through the completion of surveys and

psychometric tests. For example, quantitative data may specify participants' reported levels of personal characteristics such as self-efficacy, but do not deliver an explanation of the levels and meaning of self-efficacy. Qualitative enquiry helps researchers to understand the "how and why" by canvassing the in-depth experiences of the participants, thereby examining phenomena holistically in context (Denzin & Lincoln, 1998; Liamputtong & Ezzy, 2009).

Qualitative methodologies are distinguished by the collection and analysis of descriptive data that can be represented through observations, transcripts, interviews and other 'word enriched' documents (Hansen, 2006; Patton, 2002). Only by this manner, according to qualitative researchers, can human behaviour begin to be understood (Hansen, 2006). There are many different qualitative methods that are employed to gather and explore social experiences. These include: phenomenology (i.e., study the lived experiences of people); ethnography (i.e., the study of culture) (Daly, 2007; Hansen, 2006); and, grounded theory (which explains how individuals generate theory and define reality) (Hansen, 2006). For the current study, phenomenology was the selected as the qualitative method, an outline is provided below.

Phenomenology.

According to Holstein and Miller (1993) social constructionism has its roots embedded within phenomenology (Holstein & Miller 1993), and, therefore the two perspectives are interrelated. Although there are similarities, it is valuable to include both perspectives, as social constructionism tends to advocate a paradigm in which all that occurs, exists within relationships, where as phenomenology is more individually focused. Creswell (1990) states that by adopting a phenomenological perspective, "researchers search for essentials, invariant structure (or essence) or the central underlying meaning of the experience and emphasize the intentionality of consciousness where experiences contain both the outward appearance and inward consciousness based on memory, image and meaning" (p. 52). Put more simply, the focus of phenomenology lies in the investigation of an individual's lived experience, and how they experience it (Holloway, 1997; Liamputtong & Ezzy, 2009).

The phenomenological method was first conceived by Edmund Husserl, who, in the 1960's, stated that only the individual themselves can know what they experience (Lincoln & Guba, 2000). Hence, it is not possible for all research inquiry to engage in "science of facts", as there are no absolute facts, we are only able to establish "knowledge of essences" (Schwandt, 2000). Liamputtong (2009) concurs, suggesting that people must have lived an experience to be able to truly describe what it was like, or its essence (van Manen, 1990).

Phenomenology's methods of inquiry generally include in-depth interviews, life histories, and narrative techniques (Liamputtong, 2009). However, there are two perspectives involved in phenomenological analysis. The first is the individuals themselves who are living through the experience of a phenomenon. The second is that of the researcher, who generally

has great interest invested in the phenomenon. As phenomenological research is an interpretative methodology, it is imperative the researcher has awareness of their own experience, as this will influence both their engagement in the interviews and the analysis of data (van Manen, 1990).

In order to fully understand an experience, the researcher is required to 'bracket out' (i.e., recognize personal bias by disregarding their own related experiences) (Creswell, 2011; Liamputtong, 2009; van Manen, 1990). However, it is often impossible to detach personal interpretations from the phenomenon that are personally interesting. One analysis principle was suggested by Rossman and Raliis (1998), who argued that "phenomenological analysis requires that the researcher approach the texts with an open mind, seeking what meaning and structures emerge" (p. 184).

Phenomenological data analysis advances through the process of reduction, the analysis of explicit statements and themes, and an exploration of all possible meanings (Creswell, 1999). During this process, as much as possible, the researcher needs to set aside all prejudgments, bracketing his or her experiences (Creswell, 1999). This assists the researcher to discover the true essence of the reality in question, as it limits personal experience from influencing the interpretation of the examined lived experience.

In summary, phenomenological methods are very effective at bringing to the fore the experiences of individuals from their own perception of events (Creswell, 1999). This study explored the experiences of individuals who had faced HC. Thus, the study sought to gain an in-depth description of these experiences and to capture the meaning, essence, and characteristics of resilience during this phase. In using a phenomenological approach, these outcomes could be achieved. In addition, the social constructionism paradigm focused on the meaning of the lived experience formed by the individual's social context. The next section will outline the efforts taken during the qualitative phase of the thesis to ensure rigour and quality of inquiry, were maintained.

Rigour.

As discussed, qualitative research is based on the assumption that knowledge can be generated from narrative data that represents the participant's experience (Liamputtong & Ezzy, 2009). Yet, as there is no concrete way to test for quality, it requires the research process to be rigorous (Robson, 2002). Rigour has been likened to the qualitative equivalent of quantitative reliability and validity, representing research accuracy and truth, including the degree to which research can be repeated (Martin, 2004; Robson, 2002).

According to Nagy and Viney (1994), within a social constructionist philosophical approach, there are several realities that are expressed by the participants, including the interaction between the participants, researcher and the context, all of which result in the constructs of reliability and validity being less helpful. These dissimilarities create challenges

in repeating the research and obtaining similar results (Corbin & Strauss, 2008).

Notwithstanding these issues, steps need to be taken to ensure that qualitative research is rigorous and denotes the participants' views and is not simply the "idiosyncratic opinion" of the researcher (Johnson & Onwuegbuzie, 2004; Seale, 1999). While there is much controversy as to what specifically constitutes rigour, it is generally deemed to be a matter of trustworthiness (Martin, 2004; Robson, 2002).

Trustworthiness is viewed as similar to the conventional concepts of internal validity, external validity, reliability and objectivity (Smith, 1990) and addresses the "methods that can ensure one has carried out the research process correctly" (Guba & Lincoln, 1989, p. 245). A set of criteria has been proposed for building and enhancing the trustworthiness of the qualitative research. These criteria can include credibility (comparable to internal validity), transferability (comparable to external validity), dependability (comparable to reliability) and confirmability (comparable to objectivity) (Guba & Lincoln, 1989). However, there remains much controversy within qualitative research as to the most effective methods for judging rigour, and no universal method has been established. Consequently, numerous attempts to define what constitutes a suitable, trustworthy qualitative study have been proposed (Rolfe, 2006). For example, Sandelowski (1986) and Beck (1993) both further clarify dependability to be auditability, suggesting that another researcher can follow the decision trail employed by the investigator in the study. In addition, Maxwell (1992) discusses the descriptive, interpretive, theoretical, generalisability and evaluative validity of research rigour. More recently, Hansen (2006) advocates purposive sampling, respondent validation, transparency of methods and analysis, and reflexivity to enhance rigour. Many researchers have established their own criteria for ensuring rigour through appraising the events, influences and actions of the researcher (Koch, 2006). For the purpose of this study, the methods of rigour are adopted from the criteria outlined by both Lincoln and Guba (1985) and Hansen (2006). This allowed for an eclectic style that ensured each concern is comprehensively addressed. The following techniques are used: purposive sampling, credibility, dependability, confirmability, transferability and reflexivity. Each of which will be discussed in turn:

Purposive sampling is the selection of participants founded on specific common characteristics, instead of random selection, to ensure that interpretations are established through a rich and comprehensive pool of data (Hansen, 2006). As such, sampling individuals can offer different and even conflicting viewpoints, which can greatly strengthen the description of the phenomenon (Polit & Beck, 2006). In this study, purposive sampling was implemented to ensure that there was a level of diversity in the participants recruited. The final sample consisted of participants with different characteristics such as: age, gender, time since diagnosis, type of HC, and geographical location. This diversity aided in assembling a wide

range of experiences by these HC survivors and provided a comprehensive account of their resilience experiences in the real world, thereby enhancing rigour.

Credibility is one of the most important factors in establishing trustworthiness and refers to the extent to which the findings of the study represent the multiple realities of the participants involved (Shenton, 2004). Credibility can be affected if the researcher lets their prior expectations or beliefs affect how the data are analysed and interpreted instead of being directed by the data (Miles & Huberman, 1994). Several techniques have been suggested that can assist researchers in establishing credibility of the findings (Guba & Lincoln, 1989). For example, credibility can be enhanced by examining the meaning of common terms and clarifying ambiguous words or phrases to guarantee the communication of the participants is correctly interpreted (Miles & Huberman, 1994). This can be managed by providing credibility checks, involving multiple qualitative analysts to review the data for discrepancies or errors, thus comparing two or more varied perspectives. In the current study two researchers (supervisors) not involved in the data collection, viewed the transcripts and participated in the full analysis process to ensure an accurate representation of findings from the narrative data.

Credibility was also enhanced through triangulation, a method of rigour advocated by many authors (Corbin & Strauss, 2008; Guba & Lincoln, 1994; Nagy & Viney, 1994). Triangulation arises when data are included from multiple sources (i.e., participants, methods) that help to validate the study (Corbin & Strauss, 2008). Investigator triangulation involves the use of several researchers from different perspectives partaking in the data analysis process (Denzin & Lincoln, 2005). In the current study, triangulation was also achieved by accumulating data through different methods (i.e., individual interviews and surveys) and by including different participants in each phase. As such, the model developed through Phase One interviews was presented to a different sample in Phase Two through a different methodology, achieving triangulation and thus enhancing credibility and validity.

Finally, another technique to ensure credibility refers to prolonged engagement, which involves the researcher spending sufficient time in data collection activities to have an in-depth understanding of the views of the participants under study (Polit & Beck, 2006). This technique is used to build trust and rapport with the participants and establish credibility of the findings. In the first phase of this study, the researcher met the demands of prolonged engagement by:

- attending relevant symposiums conducted on topics relating to cancer and resilience to gain a better understanding of the world of these survivors;
- engaging with the participants at the time of recruitment in order to develop rapport with them;
- conducting interviews in convenient locations and spending sufficient time with the participants at the commencement of the interviews to assist in building trust;

- ensuring familiarity with healthcare facilities and relevant social settings that become part of the cancer patients environment;
- frequently listening to the interview tapes and re-reading the transcripts;
- taking part in peer debriefing through discussions held with objective peers to review and explore various aspects of the inquiry assisted to maintain reflexivity (Polit & Beck, 2006). This allowed the researcher to broaden her views of the phenomenon and identify any flaws in the research (Shenton, 2004). Collaborating with the peers throughout the data collection and analysis stages, helped improve the credibility of the findings;
- using the experience of being a nurse and a psychologist and having had prior exposure to caring for cancer patients. These experiences helped the researcher gain a better understanding of the reality of the situation for these survivors; and,
- the ongoing observations that were carried out throughout the study, such as note taking which enabled the researcher to focus on relevant and important issues during the data collection, analysis stage and interpretation.

Confirmability signifies the ability of the researcher to demonstrate that the findings and interpretations are clearly linked to the participants, rather than of the preferences of the researcher (Liamputtong, 2009). In the current study confirmability of the research findings were addressed by situating the sample. This means that the demographics of the sample are described along with the life circumstance or experience about which they are being interviewed, to allow the reader to comprehend who the findings of the research may be relevant to. In this study, all audio recordings were transcribed by the researcher shortly after the interview. This was to ensure that intricacies in each interview were easily identified and that the researcher accurately portrayed the meanings participants were attempting to express. Each interview was also replayed and checked against the corresponding transcript. In addition, five of the transcripts and identified themes/codes were sent for feedback to the interviewees, who all confirmed the accuracy of the findings.

Transferability refers to the extent to which the findings from the data can be transferred to other settings or groups (Merriam, 1998; Polit & Beck, 2006). In order to demonstrate transferability of the findings, researchers are required to provide thick description in the study; that is, a rich, thorough description of the research process observed during the inquiry, for readers to evaluate the applicability of the data to other contexts (Erlandson, 1993). In the first phase of the study, sufficiently detailed descriptions of the settings, participants, data collection methods and analysis procedures are presented to the reader. In addition, direct quotations from the participants are used to allow the reader to have a better understanding of the context. This thick description will hopefully enable others

interested in applying the findings within their research context to reach a conclusion about the transferability of the findings.

Last, *reflexivity* is concerned with the results during interviews or storytellings, which are constructed in the “joint enterprise between interviewer and interviewee” (Hyden, 1994, p. 99). This refers to the researcher’s appreciation of their own beliefs, characteristics and how this may impact the research process (Hansen, 2006). To be reflexive, the researcher is required to critically evaluate their emotional investment and biases, in relation to the participants, and how these may act as potential influences on the results (Wilkinson, 1998). Reflexivity was maintained throughout the current project through two strategies. First, it was important to disclose relevant beliefs and assumptions in advance. This required the researcher to acknowledge her values, interests and the significance of these in understanding resilience. This enables the reader to interpret data more transparently and consider possible alternatives. Thus, as the main researcher, two related areas motivated my interest in this study. First, my curiosity about subjectivity and how individuals give voice to their experiences following health crises. In addition, my interest in understanding how some individuals living with chronic illness are able to develop and maintain resilience, while others find this more difficult provided a second motivation.

Second, reflexivity was preserved through detailed records via a journal that showed evidence of all the planning and research interactions (Schatzman & Strauss, 1973). This journal was also a compilation of captured thoughts, ideas, feelings, emotions, and observations regarding data collection and analysis. This enabled a continual reassessment and self-appraisal process, with the acknowledgement that my own personal experiences could influence the analysis and interpretation of the data. For example, as the interviewer, a relevant difference between myself and participants particularly for a study of this nature was my status as a person that had not experienced cancer. However, 20 years of working within healthcare would have influenced my interpretation to some degree. To address reflexivity, during the interviews, the researcher openly explained to the participants that she was a nurse and a psychologist, but was currently in the role of researcher wishing to understand their perspective.

In summary, to guarantee that the research was accurate, the methods of rigour used in the current study included: purposive sampling, credibility, dependability, confirmability, transferability and reflexivity. These became an essential feature of each phase of the research process, as the quality of the research was dependent on the trustworthiness with which it was conducted. In addition, the methods of rigour helped to ensure that the research was a genuine representation of the beliefs of the participants. This aspect of rigour was crucial, as the aim of this research was not to identify the researchers’ understanding of resilience, but rather that of each HC survivor.

Data Collection – In-depth Semi Structured Interviews

Phase One aimed to identify those risk and protective factors which contribute to the process of resilience from the subjective viewpoint of individual HC survivor undertaking the experience. Hence, in this first phase, in-depth, flexible, semi-structured interviews were chosen as the preferred method to collect data. Interviews are known as “...conversations with a purpose...” (Holloway, 1997, p. 94) and fit appropriately within the social constructionism framework, including the phenomenological method of data collection. As there was limited knowledge about resilience among HC survivors, face-to-face, in-depth interviews were necessary to further explore the experiences, views and needs of this population. This data collection method is supported by Osborne and colleagues (2012), who investigated the issues that matter most to HC survivors, specifically those with multiple myeloma. Their systematic review recommended more inductive qualitative research using in-depth interviews, in order to effectively identify the meaning and issues important from the patient’s perspective across the disease trajectory (Osborne et al., 2012).

Conducting interviews served several purposes. First, there are limited methods available that can provide as much detailed information as in-depth interviews. Interviews are the best method to elicit participants’ experiences as they allow for the collection of thick and rich data (Liamputting, 2009; Erlandson, 1993). The interviews in this study explored and gathered each participant’s narrative that offered a broad understanding of the phenomenon being researched, namely resilience (van Manen, 1990). Each interview allowed for a conversation between the interviewer and interviewee about the meaning of this experience (van Manen, 1997). Hence, within the research process, the interpretation of, and meaning given to, the interview data was co-constructed between the researcher and the participant (Charmaz, 2000). In-depth interviews not only empower participants but also allow researchers to uncover the thoughts, perceptions and feelings experienced by these participants in the context of their daily lives (Minichiello, 1995). Finally, in-depth interviews generally provide a more relaxed atmosphere in which to collect information, especially in situations when the research involves sensitive topics (Boyce & Neale, 2006).

The delivery of research interviews may present in varying formats (i.e., unstructured, semi-structure or structured). As such, interview methods can be identified along a continuum, with structured interviews and unstructured (in-depth) interviews being on opposite ends (Minichiello, 1995). Unlike structured interviews, semi-structured interviewing is mainly characterised by flexibility (Taylor & Bogdan, 1998). There are other differences between these methods that will be briefly highlighted.

The structured interview technique usually involves asking the same pre-defined, closed-ended questions, in the same order to each new interviewee, that is delivered in a standardised and rigid style (Minichiello, 1995; Taylor & Bogdan, 1998). In this scenario, the

researcher tends to control the flow and direction of the interview. Thus, the researcher has a specific understanding of what is required and what questions to ask in order for this to be addressed.

Conversely, the unstructured (in-depth) interview is open-ended, delivered one-on-one, generally face-to-face, and involves much greater disclosure of the interviewee compared to other interviewing methods (Liamputtong, 2009; Taylor & Bogdan, 1998). During an in-depth interview, the flow of the conversation tends to be controlled by both the participant and the interviewer. As a result, there is a more mutual stance on the share of power and influence between both individuals (Minichiello, 1995). In this circumstance, the content of what the interviewee is sharing is highly valued. Therefore, the interviewer will monitor the content of the interviewee and delicately re-direct conversation toward information that addresses the purpose of the interview (Minichiello, 1995). Thus, the participant's view of the world and the language they use to express meaning, knowledge and understanding is considered central to in-depth interviewing (Minichiello, 1995).

The in-depth, semi-structured interview sits between the structured and unstructured (in-depth) interviews. The researcher delivering a semi-structured interview has several pre-determined areas that they wish to explore with open-ended questions (Ayres, 2008). Prior to the interviews, the researcher designs an interview schedule that contains topics that need to be included (Ayres, 2008). These topics are devised by the research questions pertinent to the study (Minichiello, 1995). The schedule is considered dynamic, as following each interview, new areas worthy of further investigation may be added to the interview schedule or questions may be revised or removed. This approach of interviewing was suitable to employ in the current study as there were specific areas investigated (i.e., cancer and resilience) that still necessitated an in-depth personal account so as to fully comprehend each participants' experience of living with HC, including their resilience within that context.

Finally as inductive, phenomenological, qualitative work, the reporting of the current findings is based on a commitment to the participants' point of view. In this stance, the researcher played the role of co-participant in the discovery and understanding of what the realities are of the phenomena studied (Holloway 1997). Therefore, in this study, as outlined by Grbich (1999), a narrative account dominates, with a clear distinction between the presentation of the exact words of each participant documented in the findings chapter and the interpretation in the following discussion chapter.

In summary, as with any method, there are a few limitations of using in-depth interviews that need to be outlined. Delivering the interviews and analysing the data can be extremely intense and time-consuming (Tashakkorie & Teddlie, 2003). It is also difficult to preserve total anonymity of the respondents when conducting in-depth interviews (Tashakkorie & Teddlie, 2003). Finally, the interviewer must be proficient in interviewing

techniques in order to capture detailed, rich information from the respondents (Boyce & Neale, 2006). Yet, despite these limitations, in-depth interviews are still deemed as the most suitable method for acquiring new knowledge about specific populations.

Instruments.

An information letter (Appendix C) was provided to the participants prior to the commencement of each interview. This informed each HC survivor of the nature of the study and how this may impact on them as participants. A consent form (Appendix D) was made available, which also outlined the participant's rights and explained that the interviewer was not a qualified psychologist and that the interview was non-therapeutic. As survivorship is a complex phenomenon, the interviews had the potential to be upsetting, therefore each participant was also given a list of contacts for counselling and supportive services (Appendix E) to refer to if required. Prior to the interview, participants were asked to provide demographic details (i.e., age and cancer diagnosis) (Appendix F). A semi-structured schedule of open-ended questions was used to conduct each interview. Examples of questions included, "Please can you tell me about your experience following your HC diagnosis?" "Do you believe that you have coped well during this time?" and "What has helped you to adjust?" The interview schedule was altered after initial interviews to include new concepts raised, which therefore informed subsequent interviews. The final version of the interview schedule is provided in Appendix G). Following each participant's written consent, the interviews were digitally recorded.

The SPSS statistical analysis program (Version 22) was used to analyse the demographic data. To assist with a more valid explication of the data, a further qualitative analysis was also undertaken using Leximancer (4.0) a software program developed by Dr Andrew Smith at The University of Queensland's Faculty of Social and Behavioural Sciences. Leximancer is a text analytic tool that identifies 'meaning' within large, unstructured, text based documents, by searching for key themes, concepts and ideas (to be discussed in more detail in the following analysis section) (Leximancer 4 Manual, 2011).

Procedure

Recruitment.

Purposive sampling was used to select the participants for the in-depth interviews. This type of sampling involved the researcher targeting subjects who, in their opinion, were pertinent to the research topic (Creswell, 2003). According to Creswell (2003), purposive sampling is usual in situations where the researcher wants to explore and identify particular types of cases for in-depth investigation. Further, this type of sampling is central to qualitative research, as it enhances the researcher's ability to discover different patterns and problems that occur in the context of the study (Creswell, 2003; Patton, 2002). The participants were selected

on the basis of pre-determined criteria. These include the following: aged 18 years or above; had been diagnosed with HC at least twelve months prior; not currently an in-patient receiving chemotherapy or transplant; proficient in English; and, not suffering from a diagnosed mental illness. There were three stages taken in the recruitment of each participant for this study.

The first stage comprised the assistance of support agencies including the Cancer Council of Western Australia (CCWA) and the Leukaemia Foundation of Western Australia who were approached to support this study. A Cancer Council representative was instrumental in providing the names and contact details of relevant healthcare professionals who were able to assist in brainstorming ideas for the recruitment of participants. Following this, the Leukaemia Foundation willingly disseminated the details of this study, among various key stakeholders (i.e., support group leaders) within their agency and to HC survivors on their email lists. This led to the recruitment of five participants. In addition, Edith Cowan University also distributed an email detailing this research to staff and students though out the Faculty of Health, Engineering and Science, resulting in a further three participants.

The second stage in the recruitment process involved applying a modified chain referral technique (Watters & Biernacki, 1989). This technique required the researcher to ask family, friends and associates if they knew of any HC survivors who might be willing to participate in the study. Implementing this technique had a number of advantages: it ensured that the recruitment was initially kept independent of the researcher, thus preventing respondents from being pressured into participating; the privacy of respondents who refused to participate was retained; and, there was a higher probability that the introduced respondents would qualify for the study. This was due to the fact that the researcher was able to first outline the selection criteria to associates/friends prior to them approaching any potential participants. The modified chain referral technique resulted in the recruitment of seven participants.

The final step in recruitment involved snowball sampling, which is described as a method that uses current participants to identify other individuals of the population who meet the necessary criteria (Robson, 2002). This was particularly pertinent in this study, as the majority of HC survivors knew of others (i.e., they had met during treatment or through support groups) who had also been diagnosed and treated for HC. Snowball sampling accounted for the remaining eight participants. Despite the advantages of both the modified chain referral technique and snowball sampling, there was also the possibility that HC survivors might feel some pressure to participate. This was addressed by not making contact with the participants, until they had contacted the researcher.

Interviews.

The same researcher conducted phase one data collection between December 2012 and April 2013. Each interview ranged in duration from 22 to 107 minutes ($M = 48$ min). The interviews were carried out until a point of information redundancy was reached (Lincoln & Guba, 1985), meaning that the interviews no longer offered any new insights into the experiences of these HC survivors.

Participants who contacted the researcher were offered the information letter and consent form that outlined the details of the study, also highlighting specific requirements. Those that met the necessary criteria and were willing to be involved in the study were invited to participate in a face-to-face interview. A mutually acceptable time and place was arranged. This was either during the initial contact, or later, after the participants had read the research information letter and consent form. Before commencing each interview, interviewees were encouraged to ask any further questions, prior to collection of the signed consent forms. The consent included details such as permission to audio record the interviews and requesting permission to contact them, if necessary, at a later date for clarification or feedback in relation to the researcher's interpretations of their interview. In addition, brief demographic details about the interviewee were also sought. The demographic information was deliberately obtained at the start of the interview, mainly as it provided a better understanding of the participant's circumstances and allowed the framing of questions in a more relevant manner. In the interests of gaining the most ecologically valid¹ account of HC survivor experience, the semi-structured interview remained flexible and the questions open-ended. The researcher guided the areas to be explored, based on current literature and clinical experience, whilst encouraging the participants to pursue their own thought processes and conversation. Attending through active listening, eye contact, a relaxed manner and using strategies such as clarification and paraphrasing enhanced rapport. This also assisted the flow of interviews, toward collecting richer data and facilitated a positive experience for interviewees.

The interview process was not expected to cause distress. However, all participants were provided with a list of available supportive and counselling services in the event they experienced any stress or discomfort. Participants were also encouraged to contact the researcher by telephone or email if they had any further queries or information they wished to add following the interview. In addition, following the interview, the participants were sent a letter, once again reminding them of supportive services available to them and to thank each individual for their participation (Appendix H). Each interview was then transcribed verbatim to ensure an accurate representation of the conversation. Pseudonyms were used during the interview to ensure anonymity of each participant.

¹ Ecological validity the ability to generalize findings to real-life settings

Analyses

Thematic Analysis.

Thematic analysis is a method for ascertaining themes, categories and concepts within qualitative data, which can be expanded into groups in order to develop more abstract concepts (Braun & Clarke, 2006; Liamputtong & Ezzy, 2009). The documented data are transcribed, coded and arranged into themes categorised by certain characteristics. According to Braun and Clarke (2006), a theme “captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (p. 82). This analysis aimed to unravel the narrative data in order to reflect the deeper meaning of this personal journey with HC survivors. The six stages of thematic analysis are outlined in Figure 4.2.

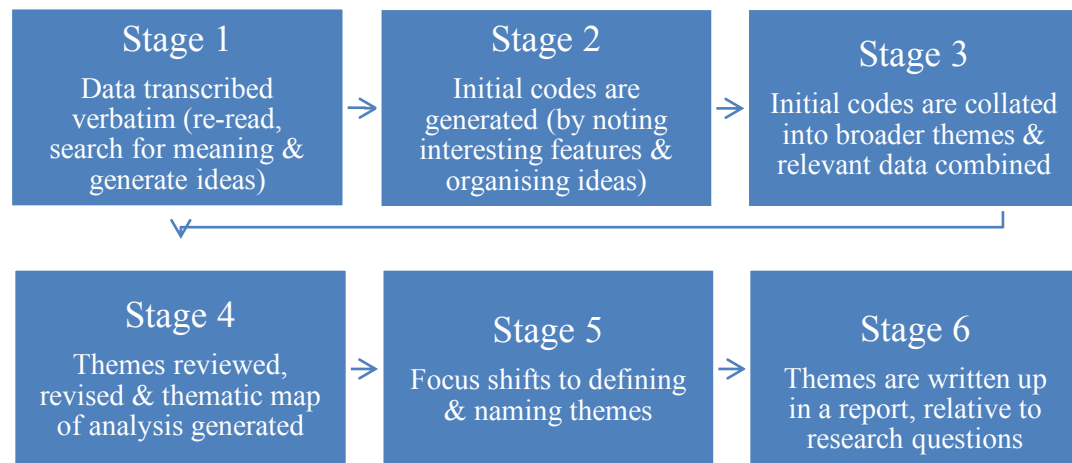


Figure 4.2. Six stages of thematic analysis outlined by Braun and Clarke (2006).

Step 1: According to Braun and Clarke (2006), in order to completely familiarise the researcher with the data, the first stage in thematic analysis involves actively reading and re-reading each transcript, whilst generating ideas (i.e., by searching for meaning). In this study, the researcher transcribed all of the collected qualitative data and therefore had a solid understanding of the interview material prior to re-reading each interview transcript.

Step 2: The recurring topics within each transcript were grouped and coded by the researcher. A cut and sort method (Miles & Huberman, 1994) was used by the researcher once key phrases were identified. For example, the different features and ideas were printed in various colour fonts to allow for easy identification by the researcher. These were then cut and printed on separate paper sheets according to their features.

Step 3: The groups of phrases and initial codes were placed into broad themes so that an overarching theme or sub-theme was produced.

Step 4: A thematic map was created which linked initial themes and identified any overlapping features in the analysis. At this point of the thematic analysis, the variation between participants' resilience in terms of protective and risk factors began to surface. An example of this was phrases relating to 'challenges in dealing with uncertainty', which most participants discussed in some detail. The themes were then defined as either important details of the data relating to the research question (i.e., coping strategies implemented) or those which represented a patterned response (i.e., those recurring across transcripts). The transcripts were also revisited as new themes emerged from the analysis to identify any missing phrases.

Step 5: Underlying assumptions began to emerge with each successive refinement of analysis of the data. This level of data analysis is referred to as latent thematic analysis (Braun & Clarke, 2006), where the researcher explores the material beyond the semantic content level to include underlying ideas shaping the data. Therefore, the researcher examined the transcripts for broader assumptions within the data that were not always clearly discussed by interviewees. For example, the exploration of the theme related to 'employment' was examined and found to reveal an extended theme including 'loss' that impacted on the participant's ability to be resilient. Hence, this stage involved defining the essence of the theme and identifying what the narrative data represented.

Step 6: The final step of this analysis was to produce a report that summarised the personal experience of each participant and determined relevant links between protective and/or risk factors that influenced the resilience process.

In this analysis the researcher used an inductive approach, identifying themes convincingly related to the data, without trying to fit the data into pre-existing codes (Braun & Clarke, 2006). However, in this qualitative research, the initial instrument for analysis was the researcher. Therefore, it is recognised that this qualitative analysis is subjective in nature (Starks & Trinidad, 2007). Hence, as discussed earlier, several methods were incorporated in order to enhance the validity and reliability of the analysis methods, reduce bias and ensure theoretical and procedural rigour. For example, as discussed previously, to ensure researcher confidence in the objective approach to the data analyses, the transcripts and identified themes/codes were sent to five of the interviewees for feedback. The responses indicated that the transcripts correctly portrayed the participants experience and, therefore, no major changes were necessary. In addition, at various points in time throughout the coding process the researcher also met with her supervisors, who were able to assist in the verification and confirmation of code names and themes. Finally, as a validity test, this study also used the Leximancer analytic software to further analyse the interview data.

Leximancer software analysis.

Leximancer analysis provides a platform for qualitative interpretation of concepts in interview transcripts (Smith & Humphreys, 2006). The Leximancer tool searches for concepts within multiple transcripts, visually represents these within the data and also provides a forum to view related concepts in one place (Cretchley, Rooney, & Gallois, 2010). Leximancer differentiates between concepts and words, with concepts being the most semantically important words. This information is then visually presented as a 'concept map' that provides a bird's eye view of the analysis. As explained by Cretchley, Rooney and Gallois (2010), "this map visually represents the strength of association between concepts and provides a conceptual overview of the semantic structure of the data" (p. 319).

In order to summarise the main idea in a particular cluster, each cluster of concepts, are also grouped by theme circles. The theme is labelled after the most significant concept in that group, which is also represented by the largest dot in the theme cluster (Cretchley, Rooney, & Gallois, 2010). In addition, Leximancer creates a list, referred to as a 'thesaurus', of closely associated words linked by proximity to a particular concept. This proved particularly useful for the researcher when making comparisons between different participants on one concept.

There are several advantages in using Leximancer software. First, this program visually displayed the presence of defining concepts, identified the strength of connections between each concept and also provided links to the original text, thus assisting the researcher to identify specific concepts and their relationships (Leximancer 4 Manual, 2011). Second, this method varies from standard content analysis in that specific word strings are not needed. Rather, Leximancer recognises what concepts exist in a set of texts, enabling concepts to be automatically coded (Cretchley, Rooney, & Gallois, 2010). Another attribute of Leximancer's analysis is its reliability, measured in two ways: stability (i.e., equivalent to intercoder reliability) and reproducibility (Smith & Humphreys, 2006). Leximancer is consistent in the manner it organises text and recognises relationships between concepts, hence the same result is produced, irrespective of how many times a data set is coded and recoded (Cretchley, Rooney, & Gallois, 2010; Smith & Humphreys, 2006). Finally, Leximancer's automatic 'concept extraction' ensures that the concepts emerge from the actual data, rather than the researcher instructing or directing the program (Smith & Humphreys, 2006). This enabled an unbiased, objective analysis and a second means of exploring the transcripts done by hand, thus further enhancing the reliability and validity of these results.

The next section outlines Phase Two (quantitative) and the methodological processes carried out in the development of an appropriate questionnaire for the final study. First, the pilot study undertaken to test the reliability and credibility of the developed scales (Stage I) is outlined, followed by the methodology involved in the final questionnaire (Stage II).

Phase Two – Quantitative Study

Instrument Development and Pilot Study (Stage I)

Stage I of the second phase of this research involved the development and testing of questionnaire items. Questionnaires are one of the most common types of measurement tools used when adopting a post positivist approach (Neuman, 2011) and are a useful component of mixed method studies (Creswell & Plano Clark, 2011). A pilot study was also implemented to test the developed questionnaire and ensure the final instrument was reliable, valid and simple to complete, prior to dissemination among a larger sample of HC survivors in Stage II.

Various methods were included in the development of the questionnaire (Stage I). First, the resilience factors identified in Phase One of the study along with knowledge gained from current literature were included as relevant factors in the questionnaire. Once the measures had been selected, the next step was to develop relevant questions to use in the pilot survey in order to obtain the most accurate demographic and personal information. This was achieved by adhering to the fundamental issues in questionnaire design, specifically the wording type and sequence of questions (Boynton & Greenhalgh, 2004). The pilot questionnaire was then distributed to university experts (supervisors) to ensure that all areas of concern were comprehensively addressed. Throughout this stage, the content and design of the pilot questionnaire was refined. The combination of these methods, which will be discussed in more detail, helped to ensure face, construct and content validity of the final questionnaire. Finally, the draft questionnaire was then informally pre-tested for clarity and readability using a convenience sample of mixed cancer survivors.

Questionnaire Development

Questionnaires provide a simple way of sampling behaviours, attitudes, and beliefs, whilst providing anonymity and highlighting patterns among responses (Robson, 2002). One of the main strengths of questionnaires is their usefulness in obtaining data from a large number of participants quickly, easily and efficiently, especially if these are self-administered (De Vaus, 2002; Wadsworth, 1997). According to Angus and Katona (1953), “it is this capacity for wide application and broad coverage which gives the survey technique its great usefulness...” (p.16). Questionnaires can also be easily disseminated to varied locations, thus providing access to a geographically diverse sample (Nardi, 2006). This is a significant factor as it provides a better representation of the population and assists in enhancing the validity of the developed questionnaire and the interpretations derived from the responses (Nardi, 2006). Further, questionnaires are comparatively easy to create, code and interpret and are generally cost effective and less time consuming than other methods (Dillman, 1983).

Questionnaires are also a very reliable method as they include questions with uniform definitions that guarantee all participants are asked the same questions in the same way (Hagino, 2002). Another advantage of using a questionnaire, especially for this study, where the questions were personal in nature, was the high degree of anonymity it offered respondents. Participants could complete the questionnaire in their own time, respond in private and at a place convenient to them. In addition, as anonymity and confidentiality were ensured, participants could be more honest and accurate in their responses, that were free from interviewer bias (Bernard, 2000; Dillman, 1983). Finally, questionnaires can also measure variables that cannot be observed (i.e., opinions and feelings) and allow for numerous topics to be dealt with concurrently (De Vaus, 2002; Nardi, 2006).

However, like any research method, there are limitations to using questionnaires. One of the key issues is that questionnaires are generally linked with lower response rates (Mertens, 2005; Neuman, 2011). This can be credited to the impersonal nature of questionnaires where there is no occasion for the participants to build rapport with the researcher (Gliner & Morgan, 2000). Another disadvantage is the structure of questionnaires, which limits the kind of questions researchers can include and makes it challenging for researchers to examine complex issues and opinions (Neuman, 2011). Hence, even when open-ended questions are included, researchers may find it difficult to obtain rich in-depth information, as most of the answers provided by respondents tend to lack complexity (Wadsworth, 1996). Lastly, researchers are unable to limit the situations under which the questionnaire is completed. For example, the researcher has no way of knowing who actually filled out the questionnaire or if the respondent has completely understood the questions. Yet, in spite of these limitations, in this study, questionnaires were still considered the most comprehensive and efficient way of gathering information.

Pilot Study

Instrument Development Data Collection.

Based on the literature review a questionnaire was developed and piloted. The pilot questionnaire was tested on a convenience sample of mixed cancer survivors, all of whom spoke English and lived within the Perth metropolitan area of Western Australia. It was not necessary at this stage to only include HC survivors for the pilot study, as the purpose of this pre-test was to first investigate the reliability, validity and feasibility of the developed questionnaire. Qualtrics (by Smith, Smith, Smith, & Orgill in 2002) was used to develop and distribute the on-line, self-administered pilot questionnaire (Appendix IA through to IE). The participants all received an information flyer (Appendix J) that was attached to the emails and explained the purpose of the research, outlined participation criteria, discussed

privacy/confidentiality issues and requested participation. This information was also included in the first section of the Qualtrics survey to ensure all participants were informed.

In order to establish the representativeness of the sample, a range of demographic details were obtained. Participants were asked information regarding their age, sex, cancer diagnosis, treatment type, time since diagnosis, cancer relapse details, ethnicity, educational level, religious affiliation, relationship status, and occupation. In addition, the inclusion of the participant's postcode allowed for geographic categorisation. At the completion of this section of the survey, participants were asked to comment on any questions they had difficulty answering. The following sections outline the scales sourced for the pilot study. These were selected on the basis of their suitability and the majority had been validated in previous research efforts.

The pilot survey contained 20 items measuring demographic variables and 5 scales comprising 103 items measuring 30 variables. Twenty-two of the 30 variables were examined due to the base of evidence that they measured the domains from both the literature on resilience and the findings identified during the interviews. These included family support, support from friends, healthcare professionals and significant others, self-distraction, active coping, denial, substance use, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, self-blame, exercise, diet modification, care in appearance and taking time out. Therefore, the final pre-test instrument contained all the relevant questions (including standardized instruments) designed to obtain the most accurate information about the factors of interest in this dissertation regarding resilience. These scales are discussed in more detail below.

Instruments.

Coping Strategies. The Brief-COPE is a validated, multidimensional inventory which assesses situational coping (Carver, 1997). The Brief-COPE is a shorter version of the original COPE Inventory (Carver, Scheier, & Weintraub, 1989), which Carver (1997) later refined. The 60-item inventory was reduced to 28 items by removing two scales proven to be less reliable and through reducing other redundant items from the remaining scales. The short-form version of the COPE assesses coping strategies on 14 conceptually different subscales with internal consistency ratings for each ranging from .50 to .90 (Carver, 1997). Scores range from 1 ('generally don't') to 4 ('generally a lot'), with higher scores indicating greater use of a particular coping style. Carver indicated that the Brief-COPE scale is not designed to have an overall coping score and that each item should be assessed individually.

Social Support. The Multidimensional Scale of Perceived Social Support (MSPSS) is a self-report measure of subjective feeling towards degree of social support (Zimet, Dahlem, Zimet, & Farley, 1988). This 12-item scale measures perceived social support

received from family, friends and significant others. Examples of the items include: “My family really tries to help me”; “I can talk about my problems with my friends”; and “There is a special person in my life who cares about my feelings”. High internal consistency for the overall scale was reported ($\alpha = .88$), and Cronbach’s coefficient for the significant other, family and friends subscales were .91, .87 and .85 respectively (Zimet et al., 1988). Test-retest reliability for the total scale was found to be high ($r = .85$). Similarly, subscale test-retest reliability were also shown to be high (i.e., significant other $r = .72$; family $r = .85$; friends $r = .75$) (Zimet et al., 1988).

The literature maintains that it is important to investigate different sources of social support, rather than measure it as an overall construct (Mustanski & Liu, 2013; Mustanski et al., 2011). With this in mind, and as a result of the findings from Phase One, four additional items that importantly measured *healthcare professional support* were added to this scale. For example, “I get the emotional support I need from my healthcare provider”. Thus, all subscales contained four items each (in total 16 items) on a 7-point Likert scale (ranging from 1 = *strongly disagree* to 7 = *strongly agree*). Higher scores indicate greater social support from either family, friends, significant others or healthcare professionals.

It was important to include the MSPSS in this pilot study as research suggests that adjustment and social support are not only key elements of coping and social well-being (Hahn et al., 2010, McCabe & Cronin, 2011), but are also associated with low levels of depression and anxiety (Zimet et al., 1988). The MSPSS was selected among others scales that assessed social support, as it presented in a manner that was self-explanatory and straightforward to complete. Moreover, the scale was also considered useful as a subjective assessment of social support from multiple sources.

Resilience. The Resilience Scale for Adults (RSA) consists of 33 items with semantic differential response (bipolar) options (Friborg et al., 2005). This means that each item has a negative and a positive attribute at each end of the scale continuum. The RSA intended to measure protective resources that correspond accurately with the overarching classification of resilience (Friborg, Hjemdal, Rosenvinge, & Martinussen, 2003). According to previous literature these include: personal/dispositional attributes, family support and external/community support systems (Garmezy, 1993; Rutter, 1990; Werner, 1989; Werner, 1993).

Thus, the RSA comprises five factors measuring **personal competence** (personal strength, social competence and structured style), **family cohesion** and **social resources**. The first category, ‘personal strength’ contains two primary factors. The first factor, measures *perception of self* (i.e., views of current strengths and abilities, self-liking, hope, determination) and the second *planned future* (realising future plans and goals). ‘*Social competence*’ measures social adaptiveness, communication skills, mood, extraversion,

initiation of activities and social flexibility. The third factor in this category, *structured style*, measures the ability to plan, organise and adhere to daily routines. In the second category 'family cohesion' was determined by *family coherence*, which measures cooperation, stability, family conflict and loyalty. The final category, *external support systems* included the factor *social resources*, measuring intimacy and access to external support from relatives and friends (Friborg et al., 2003; Friborg et al., 2005). An example of one item on the RSA is, "I feel that my future looks", where the negative attribute is "uncertain" and the positive attribute is "very promising". In response, the participant selects the attribute that best describes them. Cronbach's alpha for these items resulted in high reliability ($\alpha = .89$).

The RSA is recognised as a valid and reliable measure in health and clinical psychology to assess the presence of protective factors essential for maintaining mental health and aiding recovery (Friborg et al., 2003; Friborg, Hjemdal, Martinussen, & Rosenvinge, (2009). Several previous reviews investigating resilience measures concur with these findings and further support the RSA as a scale to include (Ahern, Kiehl, Sole, & Byers, 2006; Davydov et al., 2010). A systematic review of resilience measures published by Windle, Bennett, and Noyes (2011) found the RSA to have the highest test-retest reliability. According to Windle and colleagues, this provides, "some indication of the measure's stability, and an early indication of the potential for it to be able to detect clinically important change, as opposed to measurement error" (p. 16). The RSA was also one of three scales developed for use with an adult population, which received the highest overall ratings. Windle, Bennett, and Noyes argued that, "whilst a strong sense of personal agency is important for negotiating adversity, the availability of resources from the level of family and community are also important" (p. 14). Ideally, one should include a measurement instrument capable of assessing a range of protective mechanisms within multiple domains. The RSA is one such measure that evaluates resilience as a dynamic process of adaptation to adversity, by examining resilience across multiple levels (Windle, Bennett, & Noyes, 2011).

Similar reliability and validity results to those found by Windle and colleagues (2011) were also reported in earlier studies. Based on a review of instruments measuring resilience, the RSA was one of three instruments found to have acceptable internal reliability (Ahern et al., 2006). In addition, more recent results using a healthy sample supported the validity of the RSA, as it was identified that individuals scoring high on this scale were psychologically healthier, better adjusted, and thus more resilient (Davydov et al., 2010).

Depression and Anxiety. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) is a 14-item questionnaire that assesses anxiety and depression. The HADS has been extensively used in various patient groups, including cancer survivors, and has proven to be a valid and reliable independent measure (Llewellyn et al., 2013; Mitchell et al, 2011; Vodermaier, Linden, & Siu, 2009). For example, an internal consistency of .93 for

the anxiety subscale and .90 for the depression subscale were reported when the HADS was administered to a group of cancer patients (Greer, Moorey, & Baruch, 1991).

Each question included in the HADS has four possible answers rated from zero to three, thus scores can range from 0 – 21 for each subscale (anxiety and depression). Examples include: “I still enjoy the things I used to enjoy” and “Worrying thoughts go through my mind”. Higher scores (>15) are suggestive of a clinical depressive/anxiety disorder, scores between 11 and 21 suggest subclinical depression/anxiety, whereas lower scores (< 7) are considered normal.

The HADS was considered appropriate for this study for several reasons. First, the scale was designed specifically to be a measure of psychological distress among those individuals living with physical illness such as cancer. The HADS focuses more on the cognitive (psychological) function rather than the somatic (physiological/physical) function of the individual. In addition, the HADS is a measure of recent episodes of anxiety and depression (i.e. patients’ experiences in the last seven days). Therefore, this will help assess how both short- and long-term survivors are currently managing with their mental health.

Health Behaviour Change. The qualitative findings of this study, completed during Phase One (Chapter 5), indicated that many HC survivors maintained their resilience through proactive health behaviour reform. Many of these included, but were not limited to: partaking in a hobby, finding time for themselves, taking care of their appearance, complying with treatment recommendations, participating in complementary/alternative health practises, modifying their diet, increasing their level of exercise, planning and being more organised with their health appointments, researching cancer-related information and proactively seeking support (i.e., internet, clinician, community, family).

In order to limit the length of this survey, seven Phase One participants were contacted and asked to rate the top four health or behavioural factors that they believed contributed the most in maintaining their resilience. The results suggested that exercise, dietary changes, care in self-appearance and taking time out for oneself were most influential. Consequently, 12 items were developed to measure these four factors. For example, “When I take time out for myself I cope better” and “My concerns are less when I do some form of regular exercise”. The respondents were asked to rate each item on a 6-point Likert-type of rating scale ranging from ‘strongly disagree’ to ‘strongly agree’. After completing the scale participants were asked if there were any questions they found difficult or confusing to answer. In addition, a final open-ended question in this pilot study asked if there was anything important missed in how they had each coped and if so to provide further details.

Phase Two – Quantitative Study (Stage II)

The next section outlines the final quantitative study, which begins by providing an overview of the paradigm employed (post positivism). The methodology including a description of survey development is then explained. Third, the data collection (questionnaire) final instrument and recruitment procedure are outlined, followed by the data collection process. Finally, the rationale for the statistical analyses employed in the second stage of Phase Two are explained.

Paradigm - Post Positivism

In comparison to social constructionism, the positivist paradigm believes that the social world occurs externally and should therefore be measured through objective methodologies rather than being understood subjectively (Easterby-Smith, Thorpe, & Lowe, 1991). Positivism was the paradigm that informed early psychological literature and supported the implementation of scientific methods to discover objective truths (Lincoln & Guba, 2003).

Positivists searched for the “truth” by using the most effective and unbiased methods in order to elicit information that was factual (De Laine, 1997). Such an approach required the research inquiry to be value free, with the investigator and the phenomenon being independent of each other (Guba & Lincoln, 1989). From this perspective, positivists used quantitative methods, such as surveys to measure and analyse causal relationships between variables and to test existing theories, thus providing results that were replicable and generalisable (Creswell, 2003; Deshpande, 1983). The positivists believed in empiricism, which refers to the belief that observation and measurement was central to the scientific agenda and the goal of knowledge was to describe the phenomena that individual’s experience (Creswell, 2003).

Despite comparable ideals to that of positivism, the post positivism paradigm identifies that knowledge can always be flawed (Creswell, 2009; Crotty, 1998; Daly, 2007). The positivists believed the goal of science was to uncover the truth. Yet, the post positivist believes that the goal of science is to hold true to the goal of getting reality correct, even though we can never entirely achieve that goal (Trochim, 2000). Post positivists rejected the idea that any person can see the world perfectly (as it really is) as our observations are “theory laden” and therefore biased by previous experience (Daly, 2007; Trochim, 2000).

One of the most universal forms of post positivism is a philosophy referred to as critical realism (Trochim, 2000). According to Trochim (2006), a critical realist “believes that there is a reality that is independent of our thinking about it that science can study” (p. 2). Although positivists were considered realists, post positivists are also critical of the researcher’s ability to know reality with certainty. As such, the difference is that post positivists are critical realists in that they acknowledge that observation may be in error, is fallible and that all theory is revisable (Daly, 2007; Trochim, 2000). Thus, as theory and/or

hypotheses can never be proven as true, instead evidence needs to be collated in order to reject it or prove it wrong (Crotty, 1998). Post positivism still considers objectivity and empiricism as important values, hence quantitative methods are well established within this paradigm.

In the current study, post positivism was considered an appropriate paradigm for Phase Two, as it involved quantitative methods with the aim of further developing and validating the findings from Phase One. According to post positivists, our best prospect for realising objectivity is to triangulate across many fallible viewpoints, whilst acknowledging that each of these may still contain different types of error (Trochim, 2000).

In summary, within the two paradigms discussed, first social constructionism provided a framework for understanding the context of the individual (i.e., their interpretations, cultural influence, meanings, and experience of what it was like to be a HC survivor). Second, post positivism ensured reliability, objectivity and empirical evidence so that variables identified in Phase One could be applied to a larger sample and tested for their relevance. The next section outlines the research methodology and the rationale for selecting a quantitative survey design and correlational research.

Research Methodology – Quantitative Survey

Quantitative research methods aim to explain phenomena by collecting numerical data that are analysed using mathematical methods often involving statistical techniques (Creswell, 2003; Martin, 2004). In general, a study commences with the collection of data that is based on a theory or hypothesis, which is followed by the use of descriptive or inferential statistical methods (Muijs, 2004). The causal relationships are examined by manipulating factors considered to influence the phenomena of concern, while controlling other variables pertinent to the experimental outcomes (Creswell, 2003; Patton, 2002).

Quantitative research is generally based on positivist/post positivist paradigms, objectivity, reliability and empiricism (Martin, 2004; Muijs, 2004). In addition, quantitative research is deductive, seeking to test theory/hypotheses or measure variables (Muijs, 2004; Neuman, 2011). A strength of quantitative research is that results are considered as factual, reliable and, thus, have the ability to be generalised to a larger population (Steckler, McLeroy, Goodman, Bird, & McCormick, 1992).

This quantitative study involved a combination of descriptive and correlational research. It is descriptive, in that its rationale was to generalize variables to a larger sample of HC survivors. However, this research was also correlational, as it investigated the relationship between variables (Martin, 2004). The process of collecting data within Phase Two was via the use of survey research and so, for the purposes of the current study, the design used in Phase Two was considered as a survey. However, the aspects of the correlational design will also be outlined below.

Surveys.

Quantitative surveys are widely used by psychologists, where statistics such as the proportion of respondents who display one or more psychological traits are reported. In such surveys, respondents are asked a set of structured questions and their responses are tabulated. There are several quantitative research designs that include: experimental studies, quasi-experimental studies (i.e., cause and effect studies that involve variable manipulation); descriptive/survey research (i.e., to describe a particular sample); and, correlational research/survey research (i.e., used to explore associations between variables) (Martin, 2004; Mertens, 2003; Nardi, 2006). The process of gathering data within Phase Two was through the use of surveys.

According to Goodwin (2008), a survey is a “structured set of questions or statements given to a group of people to measure their attitudes, beliefs, values, or tendencies to act” (p. 435). Thus, surveys gather data in various formats including questionnaires, observations and interviews (individual, group, face-to-face, telephone) (De Vaus, 2002). The terms questionnaire and surveys are often referred to interchangeably (Giles, 2002). However, there is a subtle difference in that questionnaires are considered the tools that are used to collect the data, where as surveys relate more to the actual method of conducting research (Giles, 2002).

In order to achieve generalisation, large, randomised samples are usually selected when conducting survey research (Neuman, 2011). There are two types of survey designs: longitudinal and cross-sectional. Longitudinal designs collect data from the same sample at different points in time. As a result, longitudinal designs enable patterns of change to emerge over a period of time (Neuman, 2011). Hence, comparisons are made between the different points of data collection. Conversely, in cross-sectional designs, surveys are collected at a single point in time and only administered once to a selected sample (Giles, 2002). Cross-sectional designs are beneficial, in that they enable data to be collected from two or more different groups simultaneously, which can allow for comparisons and are therefore relatively cost and time efficient (Giles, 2002; Neuman, 2011).

Correlational research.

Correlational research enables the researcher to explore individual differences in the sample by observing variables in their natural state and also the relationships between them (Goodwin, 2008). However, without manipulation it is unknown which variable influenced the other, or whether a third extraneous variable explains the relationship. Therefore, only the associations between variables can be identified, and the reasons why these variables are related are often unable to be established (Mitchell & Jolly, 2010).

Conversely, experimental research manipulates variables in an attempt to control and limit individual differences, with the intent of exploring cause-effect relationships (Goodwin,

2008). Yet, it is not always possible to manipulate or control variables within the social sciences, thus correlational research provides a flexible option to test variables in a given context. Experimental research can stem from correlational research by further investigating relationships. However, in this study, correlational research is a useful starting point to examine the relationship of variables that have not been manipulated or controlled.

In summary, a cross-sectional survey design that employed correlational research was used in Phase Two (Stage II) of this research. This allowed for data collection of a large sample in a cost efficient manner to be completed in the limited timeframe available. The use of a survey design enabled the researcher to examine the generalisability of variables and to conduct correlational research within a single application. Therefore, this study enabled the researcher to explore and examine the relationship between variables (i.e., the contextualised model developed during Phase One) to a more generalised measure of protective processes related to resilience.

Data Collection – Questionnaire

Final Instrument.

As previously outlined in the description of the pilot study (Stage I), the validated measures included in the final questionnaire comprised the: Brief Cope (Carver, 1997); Multidimensional Scale of Perceived Social Support (MSPPS) (Zimet et al., 1988); Resilience Scale for Adults (RSA) (Friborg et al., 2005); and, the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). In addition, several items developed to measure positive health behaviour change (HBC) (i.e., exercise, diet etc.) were also included.

However, it is not yet known if additional research measures are required in the final questionnaire, as this will be guided by the findings of the pilot study. For example, there may be additional items relating to various coping strategies or health behaviour change that emerge though the pilot study findings. Therefore the final instrument tool will be outlined in detail in Chapter 7, following the pilot study results.

Procedure

Recruitment.

There were several recruitment methods implemented concurrently. First, purposive sampling (a deliberate process of choosing people to ensure representation of key characteristics) was used, in which an email with a hyperlink and an attached information letter with consent information (Appendix K) was disseminated. This requested that only individuals diagnosed with HC, who were over the age of 18 and English speaking participated. This was sent to friends, family, cancer and social communities, research institutes, including a database of interstate HC survivors (who contacted the researcher during

Phase One, but were unable to participate in the interviews). Several of these individuals then forwarded the study details onto other key stakeholders and potential participants.

Social media was another medium used to advertise the study. A Facebook page was created with appropriate privacy settings that initially advertised the study and had a hyperlink on the home page. Permission was then sought from the administrator of 15 different national and international HC-related Facebook sites (i.e., Leukaemia Sucks, Delete Blood Cancer, Multiple Myeloma Awareness, The Lymphoma Club, CLL Society, Chronic Myeloid Leukaemia, etc.). In addition, the study was publicized on the Facebook pages of the Harry Perkins Institute of Medical Research, Ride to Conquer and the CML support group for Australia. The respective administrators went on to post the study information on other Facebook forums including CML survivors, Multiple Myeloma Awareness, and Lymphoma Club. The administrators also provided friend suggestions, which led to individual friend requests. Although over 300 friend suggestions were sent to this Facebook page, in order to maintain individual privacy, only those who sent friend requests were accepted. This resulted in 215 friends all of whom could view the study information and forward the hyperlink to other potential participants. In addition, an 'event' was also created on this Facebook site, which resulted in 25 individuals choosing to attend. However, this was not necessarily representative of participation, as some individuals may have elected not to participate or may not have met the study criteria. The created event not only provided a forum to advertise the study, but also enabled the invited guests to share the study hyperlink with other HC survivor Facebook friends. The study was not posted on any Facebook site by the researcher without administrator permission. The Facebook site was frequently monitored for posted messages, comments or queries.

The third recruitment method comprised the assistance of support agencies and healthcare providers including the Leukaemia Foundation of Western Australia and The Perth Blood Institute. A representative of each agency was instrumental in disseminating both emails and hard copies of the survey details to potential participants, predominantly at support group meetings or social gatherings. Finally, assistance was sought from the NSW Cancer Council through their 'Join a Research Group' initiative. This research initiative involved previous cancer survivors volunteering to partake in future cancer-related research. An application was successful in granting permission for the researcher to access the contact details of 64 individuals currently listed on this survivor database. In the event that individuals' contact details may have changed, it was advised by the NSW Cancer Council to email and also post hard copies to each person. As part of the distributed email and mailed copy, each individual was asked to forward the study information to others they knew that met the study criteria.

It is acknowledged that, in targeting agencies and volunteer participant databases, it could potentially skew results towards those with high social support, due to these individuals

active involvement in support and research communities. However, it was intended that by also recruiting through several avenues, including word of mouth, healthcare providers, research institutes and through the Facebook page, that sampling bias may have been reduced.

Analyses - Statistical

As this study is interested in answering several questions, a number of analyses were required to be performed among the sample. Prior to statistical testing, the data were first evaluated to test for normality (Kolmogorov-Smirnov and Shapiro-Wilks), linearity and homoscedasticity assumptions (inspecting the normal probability plot of standardised residuals and scatterplot of standardised residuals against standardised predicted values) (Tabachnick & Fidell, 2007).

Second, independent t-tests, one-way ANOVAs and correlation analyses (i.e., Pearson's r and Spearman's ρ) were conducted to measure the significance of differences and the strengths of linear relationships between variables and to investigate the relative influence of selected demographics (gender, age and time since diagnosis). Last, as the main focus of this study was to assess the ability of the model to explain variance in resilience and to identify significant explanatory variables, a standard multiple regression analysis (MRA) was conducted. All explanatory variables were entered simultaneously into the regression model to explain variance in resilience. Zero-order correlations between these variables and the outcome measures were also reported.

This section has detailed the quantitative methodologies that were employed, including the methods of data collection and analyses for each stage of this project. The following section discusses the ethical considerations concerned with this research followed by an outline of the data analysis issues involved in resilience research.

Ethical Considerations and Approval

The study was submitted to, and approved by, the Edith Cowan University Human Research Ethics Committee (project # 8481). Ethics is an integral part of research planning and implementation that helps to define the benefits of the research versus the risks to participants. For a research study to be considered ethical, it must satisfy the principles of research merit and integrity, justice, beneficence and respect (Mertens, 2005) and these principles will guide the ethical framework for this thesis. The following section explains how these four ethical principles were addressed in this study.

Research merit and integrity.

A study cannot be ethically justifiable unless the proposed research has merit and the researchers who are going to carry out the research have integrity (National Health and Medical Research Council (NHMRC), 2007) (Crowden, 2010). The research merit and

integrity of this study was satisfied in the following ways. First, the study provided a better understanding of the support needs of HC survivors in Australia. This is an important contribution as this area previously been under researched. Furthermore, the study provided valuable data that could assist healthcare professionals to deliver more proactive and responsive approaches to quality care.

Justice.

The notion of justice involves ensuring that those who assume the burden of the research should be the individuals who benefit. In addition, the procedures for the recruitment of participants should be fairly administered and reasonable (Mertens, 2005). Justice in this study was attended to in several ways. Although there was no direct benefit to the participants, the information gained in this study aimed to enhance our understanding of HC survivors. The information gained helped in developing a questionnaire that provided valuable data for the planning and delivery of better support services for survivors. The participants were also given the right to be informed about the results of this study on request. Further, the recruitment process was fair and there was no coercion of participants. Informed consent was obtained from all participants involved in the study. Last, the inclusion and exclusion criteria used in the recruitment process were clearly stated and justified.

Beneficence.

Beneficence involves maximising the possible benefits for research participants and minimising or avoiding unnecessary harm or risk (Mertens, 2005). In this study, the concept of beneficence was addressed in the following ways. During the study there was a possibility of psychological distress for the participants. However, the care of cancer survivors was paramount, as most HC survivors have already been through significant trauma as a result of this illness. It was essential that this research did not cause participant's further distress. Thus, a list was provided with the contact details of support including psychological and counselling services should participants wish to discuss any issues that arose as a result of the interviews.

Moreover, as qualitative interviews are unpredictable in nature, it was not possible to know exactly how each participants will feel during and following their interview (Rosenblatt, 1995). Therefore, all participants had the option of discontinuing the interview at any time and of being referred to counselling if required. Participants were also contacted within four weeks of their interview to remind informants of the supportive services agencies available and to thank them for their participation.

In addition, all information obtained was treated confidentially and the privacy of the participants was maintained. During the interview and analysis phases each participant was assigned a pseudonym, and all identifying information was kept separate from the collected information. In addition, all the study data including interview transcripts, questionnaires, computer discs and audiotapes were stored securely in a locked filing cabinet in the

researcher's office. The tape recordings were also erased following the transcription and data will be stored for a period of five years according to NHMRC guidelines, after which time they will be destroyed.

Respect.

Of the four principles of ethics, respect is deemed to be the most central. Respect involves treating people with regard and courtesy as well as providing protection to those with reduced autonomy (Mertens, 2005). In this study, the concept of respect was addressed in the following ways. Participation was entirely voluntary and issues of confidentiality were reinforced. Participants were also assured prior to interviews that this research would not impact on any current services they may be receiving. Information sheets were sent out to all participants prior to each phase of the study to ensure they were fully informed. During the in-depth interviews, written informed consent was obtained from all participants, while in the quantitative study consent was assumed on return of the completed questionnaires to the researcher. Finally, all participants were given the contact details for the primary researcher, supervisors and ethics officers at Edith Cowan University in case they had any concerns or complaints about the conduct of the research.

This last section briefly highlights the methodological issues pertaining specifically to resilience research and how this study attempts to address these problems.

Data Analysis Issues in Resilience Research

Although theory and empirical data concerning resilience are growing, integrating the literature is complex. This is mainly due to definitional and methodological variability, limited breadth (i.e., most include individual factors only) and/or inadequate measurement tools (Gartland et al., 2011; Thornton, 2002; Windle; 2011). Thus, although the presence of resilience across a spectrum of specific crisis events confirms its salience, interpreting the findings obtained from different samples presents numerous problems (Thornton, 2002).

For example, one of the methodological issues is that, until recently, resilience was conceptualized mainly in terms of mono-causal models (i.e., separately in biomedical, psychological, or sociocultural domains of resilience), with little attempt to integrate these within a general theoretical framework (Bonanno, 2004; Davydov et al., 2012). As such, Davydov and colleagues (2012) argue that the resilience concept in mental health research is currently hindered by poor definition and the lack of a unified methodology (Davydov et al., 2010).

According to Barton (2005), another relevant issue in current resilience research is the lack of qualitative inquiry and previous reliance on positivist paradigms involving quantitative methodologies (Barton, 2005). Quantitative methodology is valuable for analysing known variables and the associations among them, yet this method fails to explain the nature of the

known variables or unearth new processes (Ungar, 2004). Subsequently, quantitative designs add to our understanding of relationships between variables, but do not extend or broaden the interpretation of resilience. For example, coping strategies are often used as a measure of resilience, yet quantitative methods only show correlational relationships between coping strategies and other variables, but do not describe what comprises coping strategies. Therefore, solely including the quantitative approach to resilience research is problematic, as there may be a supposition that it is unnecessary to search for other factors, as all of the influential factors associated with resilience have been identified (Barton, 2005). In addition, the quality and the characteristics of the variables being examined can also be less obvious when the variables are only examined within statistical analyses. Thus, if the aim of resilience research is to advocate positive change in the lives of individuals who have experienced risk such as cancer, it is crucial to comprehend which processes led to positive change and how these processes function.

Another important issue in resilience methodology is that context is rarely considered in research. This is an issue as risks, protective processes, and positive outcomes may vary between contexts because of the resources and constraints of each context. Presently, research in resilience is being developed across cultures and a number of discussion papers have contributed substantially to the study of resilience (Ungar et al., 2007). However, in most cases these papers have been mainly entrenched within the discipline of developmental psychology and derived from studies of children and adolescents (Windle, Bennett, & Noyes, 2011). Although this literature is rich and informative, a substantial majority has not originated from a clear methodological approach. For example, methods for obtaining the results are not comprehensively presented (Windle, Bennett, & Noyes, 2011). In addition, limited research exists among those suffering from mental health problems (Davydov et al., 2010) or among those with chronic illness (Windle, Bennett, & Noyes, 2011). Therefore, research should be considered within specific contexts so that the risk, protective processes and positive outcomes are relevant to that context.

According to Windle, Bennett, and Noyes (2011) many of the methodological differences include the variables measured, the time after exposure to the risk and the selected assessment. Specifically, in most studies involving cancer survivors, the measures focus on resilience only at the individual level (Windle, Bennett, & Noyes, 2011). While a personal strength is an important component of negotiating adversity, so too is the availability of resources from the level of family and community. Yet, in the review by Windle and colleagues (2011), only five of the fifteen resilience scales that had been used to measure resilience examined this concept across multiple levels. As such, the selected scales can produce different results, as they measure different level factors. Other resilience measures have included some environmental factors, but these are limited in scope and detail (Windle,

Bennett, & Noyes, 2011). As there is no gold standard, researchers have little robust evidence to inform their selection of a resilience scale, which may lead to an inappropriate selection for the population and context of interest (Windle, Bennett, & Noyes, 2011). These differences do not invalidate the concept of resilience, rather they highlight that variable selection and instrument choice are important and can influence the measurement of resilience.

Variations in resilience over time may also arise because of the various risks experienced by the participants in the studies. Rutter (2007) states that, “people can be resilient in relation to some kinds of environmental hazards but not others. Equally, they may be resilient with respect to some outcomes, but not all” (p. 205). Therefore, it is not that the individual is resilient at one point, and non-resilient at another, it is that they may be experiencing different forms of adversity or only showing positive outcomes in some areas (e.g., academic or social competence).

Finally, it is necessary to establish if an individual needs to be resilient throughout their life to be labelled resilient. For example, can a person be deemed resilient if they have effectively recovered from the risk of abandonment during childhood and thrived during adolescence, yet experience periods of dysfunction such as severe anxiety/depression during adulthood? The stance taken in the current study is that the construct of resilience is not necessary during every phase in an individual’s life in order for long-term positive outcomes to be realised. Hence, resilience is about being positive in the foreseeable future, acknowledging that we may not sustain resilience at all times.

Improving Future Research Methodology.

As a result of the issues described, in order to broaden the interpretation of resilience, it is necessary for future methodology to utilize both quantitative and qualitative approaches and to position the experiences of individuals in varying contexts. These considerations will ensure that the conceptualisation of resilience is not restricted to factors identified in previous studies and that the contextual variances are understood. In the future, Luthar, Sawyer and Brown (2006) proposes that, in resilience research, the risk and protective processes need to be malleable, generative, enduring and salient. Therefore, they should have a lasting effect, be relevant to a large group of individuals, investigate a phenomenon that can be improved and, if possible, also create positive changes in other contexts.

Many of these methodological issues were considered when developing the current study. The design is mixed methods and employs both quantitative and qualitative approaches to identify relationships between variables and to develop new theory. The qualitative data will also provide a rich description of the processes that occur from the risk experienced with a cancer diagnosis, to the experience of positive outcomes, such as psychological wellbeing. In addition, the perceptions of HC survivors from a specific context are included to ensure that

the risks, protective processes, and positive outcomes are applicable to their experiences. In this way the findings will be relevant to HC survivors within this context.

In terms of the quantitative methodology, further considerations require addressing. As advised by Windle (2011), researchers performing cross-sectional surveys need to consider implementing resilience measures that exhibit good internal consistency and good content and construct validity. This may provide some assurance that the concept being measured is theoretically robust. Research findings indicate that resilience is a multi-dimensional construct, hence resilience in one context does not automatically confer resilience in other contexts. Thus, it is vital to examine resilience more broadly.

Conclusion

This chapter presented a discussion of the research design and methodology pertaining to this study. A two phase, sequential, mixed method design was chosen to help achieve the objectives of the study, which were to initially explore and then to validate the resilience process among HC survivors. First, the philosophical framework and two paradigms that underpinned the phases of this study were described, before providing an overview of the mixed method approach. Next, research methodology, data collection methods and analyses of each study were outlined in detail. Finally, relevant ethical considerations were presented along with a discussion of the methodological issues surrounding resilience research. The following chapter describes in detail the findings pertaining to the qualitative phase of this investigation.

Chapter 5

Phase One – Interviews Exploring Resilience in HC Survivors

Chapter Overview

Chapter 5 describes the qualitative findings of the first phase of this project. First, the aims and research questions that led this qualitative study are highlighted. An analysis outlining the participant demographics is then presented. Following presentation of the profile of participants, the results are discussed and interpreted with reference to previous research. This chapter concludes by presenting a revised conceptual model of resilience in HC survivors.

Aim and Research Questions

The aim of the first phase was to develop a conceptual model that explained how HC survivors exhibit and maintain resilience. This involved in-depth, semi-structured interviews.

The questions addressed in Phase One were:

- 1 As a result of their experience, what are the common individual, family and community level factors that the HC survivors identified as contributing to their positive or negative mental health outcomes?
- 2 Which key factors made it easier or more difficult for HC survivors to achieve and maintain their resilience? and,
- 3 Were there any factors mentioned during the interviews that were not previously identified in the proposed conceptual framework?

Analysis – Phase One

Profile of Participants

A total of 23 participants were included in this study, all of which were English speaking and living in metropolitan ($n = 21$) and rural Western Australia ($n = 2$). The majority of those interviewed were Caucasian and of Australian or north-west European origin ($n = 19$; 83%), however the sample also included Italian and Asian descendants. As outlined in Table 5.1, slightly more females ($n = 14$; 61 %) than males were interviewed. The ages of interviewees ranged from 22 to 84 years ($M = 52.87$, $SD = 16.72$), ensuring the widest possible diversity among adult participants. The length of time since diagnosis ranged from 1 to 17 years ($M = 5.13$, $SD = 3.79$). Fourteen participants in this sample (61%) were diagnosed within the last five years, with the remaining nine participants (39%) distributed among the permanent (> 5 years) survival phase. Five years following cancer treatment is considered an important milestone that often signals cure in terms of oncology and may provide a different perspective on resilience. It was, therefore, important to include HC survivors distributed

between both the extended (1-5 years) and permanent (> 5 years) survivorship phases of cancer survival (Mullan, 1985). As indicated in Table 5.1, the 23 survivors interviewed included seven different HC diagnoses. The majority of HC survivors reported undergoing a combination of treatments including oral medication, chemotherapy and radiotherapy. However, six participants also required either a BMT (bone marrow transplant) or SCT (stem cell transplant). In addition, since their initial diagnosis and treatment, three of the participants reported a relapse.

Table 5.1

Profile of the Participants in Phase One

Pseudonym	Sex	Age	Diagnosed HC	Years Since Diagnosis
Natasha	F	22	Non-Hodgkin Lymphoma (NHL)	3
Travis	M	23	Acute Myeloid Leukaemia (AML)	4
Sharon	F	31	Non-Hodgkin Lymphoma (NHL)	2
Zac	M	34	Acute Myeloid Leukaemia (AML)	4
Imogen	F	34	Chronic Myeloid Leukaemia (CML)	1
Max	M	40	Acute Myeloid Leukaemia (AML)	6
Megan	F	43	Acute Lymphoblastic Leukaemia (ALL)	2
Karen	F	43	Chronic Myeloid Leukaemia (CML)	3
Lara	F	44	Hodgkin Lymphoma (HL)	17
Fiona	F	51	Chronic Myeloid Leukaemia (CML)	1
Alyssa	F	57	Chronic Lymphocytic Leukaemia (CLL)	5
Ellen	F	58	Chronic Myeloid Leukaemia (CML)	6
John	M	60	Non-Hodgkin Lymphoma (NHL)	11
Ben	M	60	Chronic Lymphocytic Leukaemia (CLL)	1
Helen	F	62	Non-Hodgkin Lymphoma (NHL)	3
Pete	M	63	Non-Hodgkin Lymphoma (NHL)	3
Lily	F	64	Chronic Lymphocytic Leukaemia (CLL)	10
Colin	M	66	Non-Hodgkin Lymphoma (NHL)	6
Anna	F	68	Acute Promyelocytic Leukaemia (APML)	6
Tess	F	69	Chronic Myeloid Leukaemia (CML)	3
Jack	M	70	Non-Hodgkin Lymphoma (NHL)	5
Maria	F	70	Burkitt's Lymphoma	7
Fred	M	84	Chronic Lymphocytic Leukaemia (CLL)	9
		$M = 52.87$ $SD = 16.72$		$M = 5.13$ $SD = 3.79$

Note. Pseudonyms were used to protect the identities of participants.

The findings and interpretations of Phase One will now be discussed. This will provide the links that connect previous literature and the current qualitative findings to the revised conceptual model, which will be presented following these results.

Findings and Interpretations

The aim of Phase One was to explore the experience of individuals who had been diagnosed with HC. A particular focus was on how each survivor was, or was not, able to navigate their way to protective resources that facilitate resilience, therefore enhancing successful adaptation and psychological wellbeing. The collective findings from both the qualitative thematic analysis and Leximancer analytic software are discussed below as each research question is addressed concurrently.

Interview Research Question 1. As a result of their experience, what are the common individual, family and community level factors that the HC survivors identified as contributing to their positive or negative mental health outcomes?

Together the thematic and Leximancer analyses produced data that highlighted four main themes that impacted on the positive and negative mental health outcomes of HC survivors. These are presented in Table 5.2, along with sub-themes that emerged through both qualitative data analyses. Each theme and sub-theme will be explained and interpreted with reference to previous research literature. Participant quotes are also referred to in order to substantiate the relevance of each theme and/or sub-theme.

Table 5.2

Themes and Sub-themes Common to HC survivors' Experience

Core Themes	Sub-themes
The burden associated with a HC diagnosis	Physical impact Psychological impact Social impact Unexpected loss
Resilience: Coping with HC	Social support network Personal coping strategies Positive health behaviour change Importance of time Self-Education
Pathways and barriers to resilience	Employment Relationships Communication Information and Resources Unmet needs
Survivor outcomes	Transition: a new normal Re-prioritisation and growth Self-reflection

The burden associated with a HC Diagnosis

There were four sub-themes that survivors in this study attributed to as factors associated with the burden of having being diagnosed and treated with HC. These included the physical impact, psychological impact, social impact and unexpected loss.

Physical Impact.

Research maintains that treatment regimens can be harrowing and physical side-effects are common (Bennett et al., 2007; Butow, Girgis, & Schofield, 2013; Deimling et al., 2005; Doyle, 2008; Jefford et al., 2008). All of the survivors discussed dealing with physical changes, which impacted on them daily. For example, fatigue, which participants highlighted as the most debilitating symptom, was a major physical limitation in their lives that continued well beyond treatment. As commented by interviewees:

Just trying to recover all the time is tiring and it's ongoing (Pete, 63yr)

I was so tired. Trying to do everything as normal was exhausting and frustrating, it all just becomes slower (Ellen, 58yr)

The participants also described numerous other physical challenges such as loss of taste sensation, skin problems and extreme nausea. Although some of these effects were not serious, they were annoying, and were a constant reminder to the participants of their cancer journey.

At that time the anti-nausea medication was rubbish so I spent my time with my head in the toilet, it was like the movie Philadelphia where he was vomiting constantly. It was like that. (Lara, 44yr)

The worst thing is trying to get back your normal body functions, like just cleaning your teeth you start gagging. All the things you like you can't taste. You get a reminder of the smell of that muck truck food trolley coming in the hospital and you know you can't eat it. (Pete, 63yr)

My weak point was my skin and it still is, I've lost probably three quarters of my skin colour, I've also lost eyelashes, toenails and fingernails. (Ellen, 58yr)

Although it was observed during the interviews that sexuality was an uncomfortable topic to discuss, a number of participants did share their experience with sexual dysfunction. For example, Colin spoke of his concerns about impotence, which had greatly impacted on his marriage stating, "My sexual function that's totally gone.... so yeah there's been some major changes like that." In addition, according to Colin these issues were not openly discussed or explained by his medical team. However, Colin also acknowledged that he found the topic sensitive and had not raised the issues with his GP or medical team.

Many of the survivors continue to endure long-term physical issues, such as chronic graft versus host disease (GVHD)², and complaints regarding the medication side-effects. Participants discussed issues with low immunity, insomnia and joint pain as other difficult physical side-effects:

*I also seem to get complications from colds or the flu very easily which can take longer to recover from. Like many others, it took ages to gain my taste for food. I get achy joints [and] I'm still fatigued and have trouble sleeping.
(Max, 40yr)*

Another more long-term impediment mentioned by many participants was diminished memory and concentration. This was often met with humour and commentaries during the interview as they discussed their “chemo brain”. For example, Imogen stated, “You become vaguer than ten pregnant women. It’s like your brain doesn’t function properly.” This was also experienced by Colin:

Other things that have changed that get little bit frustrating are the blanks of memory, big patches are just gone. There's about a four-year period, for example I can't remember a car we had for about four years. When my wife shows me pictures of it there's nothing but snippets.

As described in the literature, the physical impact of experiencing HC was clearly evident and highlighted by all participants. Many of these physical challenges were transient. For example, in support of previous literature (Kelly & Dowling, 2011), hair loss, referred to as alopecia, featured extensively as a challenge in this sample, yet this was short lived. However, other burdens associated with HC were described as more permanent. As Max summed it up, “Physically you put your body through hell. Some problems come and go, but others such as fatigue linger on for years.”

Psychological impact.

The psychological impact of HC has been well documented (Krebber et al., 2014; Lobb et al., 2009; Mosher et al., 2011; Xuereb & Dunlop, 2003). The majority of emotional reactions for the all participants were consistent with this literature and ranged from a sense of being overwhelmed and out of control to complete shock and fear.

Most of the survivors were impacted by feelings of uncertainty. In general, this uncertainty was associated with the fear of recurrence of their illness and knowing that, for many, treatment offered no guarantees. This fear was evident in all of the participants’ interviews. For many of the survivors it governed their lives and each had to find a way to navigate this fear. Anna who had previously worked in the medical field shared: “I think you stop becoming a professional and you just become a scared patient” and Max commented:

² GVHD is a possible complication following a bone marrow or stem cell transplant from another person that can last several months to years. GVHD occurs when donated white blood cells (T cells) attack the patients own body cells which they recognize as foreign. GVHD commonly affects the skin, digestive system and liver but may extend to complications involving the eyes, lungs and joints.

“Mentally you struggle with the fear of dying and overcoming the hurdles that come with having cancer.” Luke summed it up by commenting: “It just mucks with my head space daily... you know getting used to the whole thing...thinking what if it comes back... that sort of stuff.” There was also a strong emotional reaction to an unforeseen threat to life, which was common to many of the participants. The following narrative is an exemplar of this:

Your life changes so much when you are told you have cancer. I clearly remember it felt like someone stabbed me; I went all hot in the face. My heart was pounding and I went blank. It's all a bit of a blur. The hardest part is also not knowing the future: what's next, what's it going to involve and will I die? (Natasha, 22yr)

Many survivors experienced psychological trauma as a result of physical complications that resulted in urgent and unplanned hospital admissions. As Ellen shared:

In one of my emergency admissions there was just blood everywhere coming out of my pores, my nose my eyes, everything, even my skin, there was a plasma it was like you can touch it. It was wet and was a bit weird.

Lara also described two frightening events that led to emergency admissions as a result of physical trauma during and following treatment:

On the second lot of chemo my oesophagus and the stomach lining got so burnt. I was rushed back and stayed in hospital for several days, and I was in agony, I turned around to my husband...and it's the only time I ever said that I just wanted to die. On another occasion I had a huge nosebleed and started choking on blood, I had no platelets, that was actually quite scary because I was literally drowning in my blood and I did not know what to do... the blood was all over...coming out my nose into my mouth down my throat, it just wouldn't stop.

Several participants also described being over-vigilant and almost obsessed by any health-related symptoms. For example Lara commented: “The next time you get sick, even just a flu or a cold or whatever you freak out because you like, oh God it's an enlarged node.” Another fear disclosed during the interviews related specifically to living with HC. There was a sense of despair described by several participants with the realisation that surgery was not a treatment option and that their cancer was different in that respect to many solid tumours. Two participants shared an example of this:

What's particularly difficult about leukaemia, it's scary to know it's running through your body and it's not like having a tumour which they can just cut out. I have previously had a mass removed from my ovary, which ended up being benign. But the fear is different even when I did not know the result it's much more easier to cope when you can have it cut out and think oh that's a relief its gone. (Fiona, 51yr)

This type of cancer is difficult to process. I feel like I've got it running around my body all the time. It's not like I can go and have an operation and have it chopped out. That may be easier because I could visualise in my mind the cancer being removed. (Megan, 43yr)

Consistent with the literature (Wenninger et al., 2013), these findings support the idea that, although most survivors are well adjusted, several in this sample experienced elevated psychological distress. In face of a highly adverse event such as HC, a variety of recurrent

thoughts can help people to make sense and attempt to problem-solve. Conversely, recurrent thoughts that are unproductive may contribute to anxiety or depression (Tedeschi & Calhoun, 2004). This was clearly evident in this study. For example, several interviewees spoke of experiencing anxiety at various times. Lara commented that, “At check-up time my thoughts were consuming, I used to keep a brown paper bag in a car because I’d hyperventilate and panic” and Anna shared, “I did in effect actually develop panic attacks... that was probably a low point.” Several participants also acknowledged they had suffered from depression with one survivor feeling exceptionally low and at times suicidal:

You've got to be careful, you get suicidal, when I first got diagnosed I thought what's the easiest way to top myself, I got a bit depressed. (Pete, 63yr)

Interestingly, for many participants, depression did not seem to occur until several months following treatment. As Megan commented on her experience after chemotherapy, “It was almost as though I was scared to be myself; it was very weird, I've never felt like that before.” Also, as reported by other participants:

I struggled about 6 months after the transplant. I probably suffered depression. My GP didn't really pick it, but to be fair I didn't tell him much either. It may have helped if he had asked more about how I was coping mentally. (Zac, 34yr)

Six months after treatment you have a big 'what if' going on up in your head and I know that other patients I spoke to had the same thing, in your head you start thinking about what if I had died? I think that hit me quite strongly especially the second time because I'd look at my kids and I'd think I may not have been here and I still do that now all these years later. So that was a big issue for me. (Lara, 44yr)

The survivor’s own expectations also added to their emotional instability. Max tells of his experience: “It was almost as though I had thrown everything at fighting this and I have nothing left to give. For the first time ever I experienced what it may be like to give up hope... perhaps I was unrealistic.” Even when expecting the feelings of emotional turmoil, Sharon illustrated: “I just remember feeling like my world would never be the same again... it felt a bit unsafe and unpredictable.”

The diagnosis and treatment for HC is an emotionally turbulent time. The survivors in this study voiced a myriad of typically adverse emotions including fears, uncertainty and low mood. This was psychologically a very challenging, all-encompassing time to navigate. However, one survivor also provided an account that highlighted a more positive perspective resulting from her diagnosis and treatment. Ellen described her relief once diagnosed and treated by commenting: “At this stage I wasn't feeling too upset by the news I was more relieved that they had worked out what was wrong. So for me I had a name and I had a drug, which was a relief.” Ellen went on to say, “thank goodness if there's a name for it then there's some sort of history behind it, even if there is one other person I'll find them. I'll make the most of this opportunity.”

Social Impact.

The literature states that each cancer survivor's experience is also impacted by social influences (Kelly & Dowling, 2011; Waldrop, O'Connor, & Trabold, 2011). In the current interviews, several participants illustrate how family, peers, co-workers, and others in the survivor's social setting impacted their HC experience. In particular, participants shared the need to protect others close to them. This supports previous research stating that those diagnosed with cancer often try to protect significant people in their lives (Kelly & Dowling, 2011; McGrath & Clarke, 2003). For example, Ellen mentioned: "The worst part was telling my parents, I had to set them up with other people who could support them" and Ben commented: "I think about it sometimes being the type of person I am, I keep a lot to myself on the basis of not wanting to worry others." This concern for significant others was confirmed by Fiona:

Your thinking how are you going tell your kids? When am I going to die? How am I going to die? and, What this can look like? I didn't want to give them the impression that this is a huge disaster that we couldn't deal with.

Other participants felt it was important to put on a brave face at the expense of sharing their true feelings:

It's uncomfortable when they're telling me I'm looking much better even though that's not how I'm feeling inside because I feel as though I need to pretend so as not to upset them. (Megan, 43yr)

I guess sometimes it's just difficult when others say you looked great or look really well but on the inside you're like screaming out well actually I feel like crap. (Lily, 64yr)

Family-related concerns were expressed as worries and/or guilt about how the illness was impacting on loved ones. Participants described a heightened awareness of how their cancer treatment caused changes that affected their families. For example, Zac, who was self-employed, grappled with voicing his concerns for his wife and son:

This was a very difficult time because I was not able to see my son, at the time no children were allowed to visit because of the infection risk. This must have also been so hard on my wife. Having a baby and sick husband... she also got stuck with managing a lot of the books for the business.

Colin also explained:

What I understand is that my wife just took over really with all the decision-making, but I never felt as though I was missing anything I never even realised. There are still times when I know that that's a burden. I think the biggest thing once you come out of the chemo world some of the residual effects like a chemo brain when I can't remember everything, but it's sort of like a guilt, in terms of what I've put all the others through.

Participants who were mothers expressed concerns for how their children were being affected by their treatment-related symptoms. Lara, who was diagnosed with Hodgkin's lymphoma while she was pregnant, spoke of having to leave her newborn son for prolonged periods during her chemotherapy:

When my son was born early, he went into special care for two weeks and literally the day after I had him they sent me for another scan, which showed the cancer had taken off. They gave me one week and then I started chemotherapy. It was really hard because I couldn't hold my son, I was radioactive.

A number of participants also described how this experience impacted on their social lives. Colin commented, "socially it took its toll... you had plans but then you just feel bombed out and it got a bit embarrassing cause you're not doing things with people you wanna do." Several participants also commented on the impact on international travel. As Fiona shared, "I got that sting of oh, now I'm one of those, a liability, so I had a bit of a 'pity party' about that" and Pete commented, "Everything changes even with flying, either they don't insure you or you pay a premium price. These are things that have made it more difficult."

Lily, who was diagnosed with CCL the year following the death of her husband who also fought leukaemia for ten years, highlighted another social perspective. Lily was particularly concerned that she would drive friends away. Lily summed up how determined she was not to follow in her late husband's footsteps:

All my husband talked about was his illness, it started to affect our social life he couldn't understand why people stopped coming over, but it was like an overload for them all the time. It's really hard to know what the balance is but I don't want anyone to think I'm whinging and push my friends away like my husband had and I am aware of what they dealt with when my husband was so sick.

Unexpected loss.

Analysis of the transcripts exposed diverse emotional responses to loss during and following treatment. In addition to the functional loss (i.e., sexual, cognitive impairment) previously discussed, several other areas of reoccurring and unexpected loss were prevalent. For example, many interviewees revealed the added strain as a result of financial loss. Travis highlighted: "I know this has been really hard on my parents financially" and Max reiterated "you also suffer financial strain because you are unable to work fulltime."

Pete not only raised the issue of time off work but also lost time, stating: "You've got those waits in hospital, time off work attending clinics and all that. When you go for a blood test you sit there looking at the goldfish, but it's half a day gone." Other participants shared Pete's view commenting that, "It had a massive effect, I was tired all the time and spent a lot of time alone because of my infection risk" (Travis) and, "I often waited hours for my clinic appointment and I spent the whole time looking at all the other patients thinking, they look sick" (Imogen).

As many of the survivors began to realise that their treatment journey was ongoing, they identified with the loss of a perceived planned future. These results support previous literature by Grunfeld et al. (2013) who reported that cancer survivors frequently convey sorrow and regret about being unable to accomplish ambitions and perceive missed opportunities. During these interviews, Imogen became teary as she conveyed details about her lost pregnancy:

I accidentally got pregnant...I was having a moral dilemma because of the treatment, being on Gleevec³ and I was told there would be all of these birth defects and taking into account my health. I made a hard decision for a termination.

Anna also detailed the loss of opportunity related to her career:

I do miss the people and the camaraderie and having a skill that's acknowledged. I was doing on-call 24/7 so I was working a lot. Especially, when you don't have a family, your profession is a big part of who you are. I miss that.

The most significant loss expressed by the participants involved their identity. The loss of identity and altered self-concept has also been widely discussed in the cancer survivor literature (Aziz, 2002; Kelly & Dowling, 2011; McGaughan, Prue, Parahoo, McIlfatrick, & McKenna, 2012). For most participants, the perception of who they were previously had changed. The survivors commented that they no longer felt connected to their bodies, which contributed to an altered body image. For Imogen, there was an abrupt realisation that her body had changed: "Suddenly I was ten kilograms heavier and nothing fitted. That was hard." The physical changes and the altered body image impacted on the self-esteem of several survivors. Their bodies now felt alien, and, for some, the transformation in body image was so apparent that it left them devastated. The following account by Lara illustrates this:

My self-esteem was at its lowest when my hair come out, the steroids had caused my face to blow out, I had a grey green colour to my skin and I was really skinny because I'd been vomiting for nine months. I was gutted and just wanted my old self back.

In addition, interviewees discussed their reluctance to identify as the "sick person with cancer" (Natasha). This supports previous research by Wallace, Harcourt, Rumsey, and Foot (2007), who reported the importance to cancer survivors to appear 'normal' and unchanged in the eyes of others.

However, for the majority of survivors an altered appearance following treatment resulted in difficulty in them being perceived as 'normal'. For example, appearance changes such as hair loss were an indication of illness that allowed others to identify them as different. There were also frequent instances where participants communicated how their identity, self-image and self-esteem had been transformed in some way. As shared by two participants:

³ The drug imatinib mesylate (Gleevec) was one of the early success stories in the search for targeted therapies. This oral medication that directly inhibits the activity of cancer causing protein was approved as a first-line treatment for CML in 2001.

When my mum is telling friends what happened to me, it's almost as though she's talking about someone else. It's surreal. It's like my body has been a battlefield. I'm trying to get back into the way I used to think, but I've changed, you think differently.
(Megan, 43yr)

I was still modelling the day before I had my son even when I had cancer. Part of my identity were my looks, my self-esteem absolutely plummeted because everything I had always done had been on looks, then all of a sudden you're like who the hell am I now?
(Lara, 44yr)

Appearance issues were a significant part of the illness experience and of extreme concern. However, even when participants spoke of discontent in their current appearance, some demonstrated the ability to reinterpret this in a more optimistic manner. For example, Natasha used the opportunity to explore different hairstyles she would not normally have tried before her hair fell out, as she stated: “there is always a positive.”

In addition, hospitalisation is often associated with loss of autonomy and control (Xuereb & Dunlop, 2003). Several of the HC survivors expressed the importance of trying to preserve some personal control while in hospital. However, Anna described how challenging this was during her admission.

Just watching people walk out back into the real world, that was really hard, knowing I couldn't. People are just leaving and you're thinking I'm stuck here. Also exercise was a big thing because I exercised six times a week. And suddenly it stopped and I felt lost. They probably thought I was just too weak but I wasn't.

The interviewees also wanted to be able to trust in their physical health and plan their future. However, all interviewees shared experiences through stories relating how their lives had been altered through loss of control especially in terms of their independence. This was particularly evident in Megan’s interview:

Well it's really changed my life. I used to live in the hills and I was on a quarter acre block, I was very independent I used to do a lot of gardening and then I had to sell my house, my mum and friends had to help pack it up. I tried to do a few bits and pieces but they pretty much moved everything while I was in and out of hospital. I don't have that freedom anymore and I am relying on others and that is so hard.

In summary, the burden associated with a HC diagnosis was filled with experiences of loss in physical, psychological and social domains. As Max stated: “Well, when you hear the big ‘C’, your life changes and is never the same.” The physical changes were widespread among survivors. However, fatigue and cognitive impairment were common and long-lasting. Psychologically, the participants experienced an array of negative emotions comprising shock, vulnerability, isolation, fear and uncertainty. Social domains predominantly included the loss of perceived opportunities, time, identity, self-perception, independence and control. However, despite this adversity, many interviewees also demonstrated evidence of resilience and of positive emotional outcomes. This supports recent research in which participants referred to

their diagnosis as a “two-edged sword” and an “eye-opener” allowing each an opportunity to also re-evaluate the focus of their lives (Grunfeld et al., 2013).

Resilience: Coping with HC

The emphasis on resilience in this study involved investigating risk and protective factors, including successful adaptation, as a result of experiencing adversity, namely living with HC. Risk factors are conditions or situations that have been linked to negative psychosocial outcomes and have the potential to decrease the chances of resilience (i.e., lack of social support) (Masten, 2007; Ungar, 2008). Alternatively, protective factors promote resilience (i.e., personal coping strategies) and, therefore, decrease the negative influence of being at risk (Garmezy & Masten, 1991).

The literature has shown that resilient individuals are more likely to successfully adjust after facing adversity (Richardson et al., 1990; Wagnild, 2009). This is supported by the findings of this research highlighting that personal resiliency provided a vehicle for HC survivors that assisted them to navigate their world following HC. As will be outlined, resilience enabled their illness to become secondary to their connection with life. The majority of participants in this study maintained resilience through available social support, personal coping strategies, self-education, self-care, and by taking timeout. This also supports previous research, as many of these factors are commonly discussed in the cancer-related literature (Allart et al., 2014; Lau & van Niekerk, 2011; Llewellyn et al., 2013; McGaughan et al., 2012; Stewart & Yuen, 2011; Swash, Hulbert-Williams, Bramwell, 2014; Wenzel et al., 2002).

For many participants, remaining resilient was a challenge, as Sharon commented:

I definitely went through a difficult patch about six to twelve months following my treatment. A lot of negative thoughts. Why me? What would my future look like? How am I going to live the best way I can to give myself the best opportunity? All of those sort of questions consumed me and at times it all seemed overwhelming.

However, as the physical and psychological strength of the participants started to improve, their personal resilience also began to rally. In most instances, the interviewees drew strength from their experience of overcoming previous adversity. For example, Fred commented: “When I was a kid castor oil was the medicine for everything and I think it was like poison and it made me sick. We had no fresh water, no money, but all this helped me learn how to be a survivor.” Similarly, others agreed:

About 6 years before my diagnosis our family went through a really traumatic experience. It wasn't health-related but it was very painful and public. Even though it was a very different scenario I felt as though I'd overcome those feelings of not being in control. So it was like, you know what, you've done this before if we keep calm and were honest with each other we can get through this and I know we could all get through difficult things not because of what I'd read but because of what we've been through previously.
(Fiona, 51yr)

I lost both my parents tragically in separate circumstances, one as a teenager and one in my early 20s. I definitely think that experience has helped prepare me for coping with cancer and has a lot to do with how well I've managed so far. (Sharon, 31yr)

This belief is consistent with previous research regarding resilience. Wagnild (2009) depicted a resilient individual as being able to conquer, learn, and flourish from adversity. In addition, as the resiliency model proposed by Richardson et al. (1990) highlights, resilience is developed through facing challenges, risks, and stressors. This process begins early in life, as individuals attempt to adapt to any challenge or disruption in an attempt to successfully cope.

As discussed earlier, some participants became depressed, anxious and considered suicide. Such findings may suggest a lack of resilience, as depression, anxiety and suicidal ideation may be perceived as unsuccessfully coping with adversity (Richardson et al., 1990). However, these participants managed to overcome these problems and went on to achieve psychological wellbeing. For this reason, it is preferable to evaluate resilience over time, rather than on one occasion. These results support the view that resilience is a dynamic process and successful adaptation to adversity may take time (Richardson et al., 1990).

In addition to overcoming previous adversity, the resilience factors that emerged within this study broadly relate to social support, education and coping strategies (i.e., perceived control, purpose, attitude, hope, etc.). These have been viewed as protective factors within previous literature (e.g., Herman et al., 2011; Masten & Powell, 2003; Raphael & Wilson, 1993; Stewart & Yuen, 2011). However, the findings of this study have also identified additional factors (i.e., self-care and time-out) that are reported by this sample of HC survivors to combat adversity.

Social support networks.

Much has been written about social support contributing to personal resilience (Kelly & Dowling, 2011; Lau & van Niekerk, 2011; McGaughan et al., 2012). Moreover, the literature reports that seeking social support has been highly endorsed as an important coping strategy that is directly related to improved physical wellbeing (Bloom, Kang, Petersen, & Stewart, 2001; Northouse et al., 2007). There is evidence that cancer survivors who have more social support experience less distress (Waldrop O'Connor, & Trabold, 2011). The results of the current study further illuminates the importance of support offered by family, peers, neighbours, medical staff, the community (including strangers), and how this plays a key role in the HC survivor experience. Participants of all ages also referred to the Internet as a means of support. The following statements provide exemplars of the valued support received, in one instance from strangers.

I didn't realise until later how amazing my wife was. You could not have possibly have survived in that way without that support. (Colin, 66yr)

My mates would come and annoy me whenever they could. They also brought in junk food and watched movies stuff like that. (Travis, 23yr)

One of my really good friends would always email me an inspirational text or picture every day. What a commitment. (Natasha, 22yr)

More importantly strangers like here at the shop the cleaners they will call me by my name and talk to me and this helps me more. It is not so much those who you think are your friends who help you. It has surprised me that a lot of support has come from strangers. Strangers can be very helpful, especially when you don't expect this. (Maria, 70yr)

Additionally, according to Wills and O'Carroll Bantum (2012) available support from others enhances aspects of self-control involving behavioural action (i.e., adherence to treatment). The current findings are consistent with this research, as highlighted by Fiona:

I remember ringing a girlfriend who is a nurse, as I really didn't want to take this medication because I'd figured it must be pretty potent and I remember my friend saying to me "take the bloody tablet and put it in your mouth with a glass of water and thank God that you live in a country where this medication is available, just swallow the fucking tablet, and that was it, that's what I needed and it got me back on track.

Previous research also indicates that a crucial factor in preserving a positive outlook is the support that patients are provided by their health professionals (McGrath, 2004). However, like many types of cancer, one complication of a HC diagnosis is the need to involve several different specialists. Despite some exceptions, participants in this study were largely satisfied with the health care support they received, with some instances of unexpected support. As Anna reported: "One doctor used to send me a picture on my phone every morning like a rose or the view from Bethesda⁴. Things like that to show you that we're thinking of you and there is a world outside." In other circumstances, participants actively pursued professional support to facilitate self-control of their relationships, emotional wellbeing, and their personal goals. Seven interviewees received psychological interventions and commented on the contribution this support provided, as Lily remarked:

My psychologist is amazing. I get a lot out of it because there are things you don't want to tell your family and friends she's totally neutral and I can tell her anything and she is someone I can trust and I think that's really important.

Of particular interest was the number of interviewees ($n = 20$) who deliberately sought ways to interact and assist others with similar problems. This was particularly common in survivors living alone. Participants expressed the advantages of conversing with other patients who had similar cancers. These participants appreciated any opportunity to talk about their illness, primarily because they did not always want to burden their family and friends. The participants also suggested that hearing about the experiences of other HC cancer survivors

⁴ A private hospital located in Perth, Western Australia

assisted them to better understand their illness, the experience of others and further educate themselves. As mentioned by Megan, who had a rare type of leukaemia:

It was very important for me to meet someone with the same cancer as me because they will be able to relate more to what I've been through, but apparently there may only be five/or six in my circumstance in Perth. I've had extremely intensive treatment...I've nearly died three times so I felt it was important to meet a survivor who had been through the same journey as me.

Interestingly, the interviewees who elected not to be involved in support groups stated that they either found it a negative experience, preferred the company of significant others, or did not want to be constantly reminded of their cancer. However, this group of HC survivors ($n = 3$) each stated that they considered themselves to be resilient individuals and on observation each demonstrated resilient traits (i.e., optimism). Therefore, one could conclude, that the type of social support accessible is not as influential to cancer survivors as the perception that social support is available, which remains an important factor.

Spiritual support was another important source highlighted by the participants. However, there was great variety among the interviewees. Similar results have been reported in the literature (McGrath, 2004a; McGrath & Clarke, 2003; Tedeschi & Calhoun, 2004). Over half the sample considered themselves to be raised as Christians, but were not affiliated with any particular church. Yet, there were others, for whom religion was already a central factor in their life, and continued to be a key source of strength throughout diagnosis and treatment. As shared by Colin, "We belong to a church and our faith is an enormous part of dealing with stuff." Fiona similarly shared, "I consider myself a Christian...God has helped me in the past so I just embrace that love." In contrast, other participants described themselves as more spiritual and provided examples of meditation, walking, yoga and music in an attempt to cope with their cancer. These activities provided support by allowing participants a break from thinking about their cancer. For example, Alyssa remarked:

I learnt transcendental meditation in my early 20's and I had always done it on and off, now however I do this daily I find that this keeps me balanced and helps get rid of stress. Music too has kept me sane all my life. I couldn't imagine my life without it.

Whether religious or not, all of these avenues provided support and personal direction, allowing time to refocus. This supports research by McGrath (2004a) who stated that there are several cognitive or spiritual frameworks that people implement to assist them maintain and develop positive orientations.

The social support received in this sample was found to have both positive and negative influences on the participants. The results of this study agree with other research, which acknowledged social issues and a lack of understanding from the participant's families and friends as having a detrimental effect on their recovery (Kelly & Dowling, 2011). For example, Fiona's mother who is in her 80s says to her, "Oh just get over it, it's just anaemia"

as her mother calls it. In addition, the lack of a supportive partner was also clearly evident in Karen and Imogen's interviews, which impacted negatively on their ability to cope.

My ex-husband was the worst because he walked away completely he didn't want to know about it, it was like he didn't believe that I had leukaemia and it was almost like 'here we go again' she's done this to get me to come back. (Karen, 43yr)

My ex-partner was really unsupportive, we'd only split last year and I was diagnosed in the March. When I was in hospital he was trying to take custody of my children and I had to get out a restraining order. I don't think I've dealt with having the CML because I've had all that other stuff to deal with. My ex-partner is my major issue at the moment, having cancer is more fun than dealing with him. (Imogen, 34yr)

However, this was the minority. Most interviewees received tremendous support in numerous ways ranging from practical support, as was the case for Imogen, who had friends who would just say "I am coming to cook dinner", without giving her a chance to refuse, or in the form of emotional support:

It was very helpful. Two of my nursing friends, midwives, would come in and stay the night on a most uncomfortable little bunk bed. For about four to five nights they did that. One of them worked all day and had a family of her own and would leave them at home with her partner and would come in and sleep the night with me. (Anna, 68yrs)

According to Kelly and Dowling (2011), support networks are central to cancer survivors and their ability to cope. This study not only supports these findings, but also established that participants were proficient at finding emotional support that matched their specific needs. For example, they exhibited self-awareness in terms of whom they would elect to share their inner feelings with, often judiciously protecting their family. In addition, each interviewee stressed the importance of at least one other individual who offered constant and ongoing emotional support. However, this is an area that requires further investigation as research is still not clear as to which methods of social support are deemed the most beneficial to those with HC, or, indeed, if this is dependent on the individual in question.

Personal coping strategies.

Coping is defined as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). The literature generally refers to two types of coping within the resilience research. The first, emotion-focused coping (EFC), involves avoidant behaviour, ignoring the problem, worry, and/or wishful thinking. Conversely, problem-focused coping (PFC) is recognised as being proactive in identifying the problem then creating and acting on solutions (Lazarus & Folkman, 1984).

The participants in this study demonstrated a combination of both EFC and PFC. For example, the coping strategies discussed by interviewees ranged from blocking or avoidance to the active management of their illness. However, the general trend appeared from the data to be predominantly EFC in the early post-treatment phase, with participants transitioning

towards a PFC approach later in the survivorship trajectory. According to research, this demonstrates an effective way of coping. Previous literature suggests that in the earlier cancer phase, EFC (i.e., avoidance) may be an adaptive aspect of resilience, with PFC more effective in the long-term (Wenninger et al., 2013). However, if PFC strategies are not executed there is more chance of psychological distress (Wenninger et al., 2013). Thus, if negative maladaptive cognitions continue to be suppressed, or not attended to, they may persist. As Di Gallo et al. (2003) argue, “successful integration of the experience of cancer may be associated with the ability to accept painful feelings and to allow them to emerge” (p. 666). The interviewees’ employment of both PFC and EFC strategies are illustrated below.

Emotion-Focused Coping.

According to the literature when cancer survivors implement EFC they are attempting to control the feelings associated with having cancer rather than attempting in a practical manner to solve every problem associated with their diagnosis (McGrath, 2004; Waldrop, O’Connor, & Trabold, 2011). The findings in this study supports this perspective, as many participants described ways in which they attended to their emotions through activity-focused strategies, creativity, pursuing relaxing diversions as well as denial, avoidance and distancing. Two examples of avoidance, were described by Lily, involving herself and her late husband:

One thing with my husband’s cancer, he handed his care over to me, he didn’t ask questions he asked me to do everything for him, he didn’t want to know. It was consuming it took over our lives and I didn’t want to go down that path.

The relaxing diversions served to distance many survivors for periods of time in order to give themselves a break from thinking about their cancer. Taking this ‘rest time’ was well illustrated by Lara, who had experienced a relapse. She said, “I take time-out every single day whether it’s sitting at the beach for half an hour or just do something for myself...me time” This coping strategy was not exclusive to Lara; rather this was a common theme among participants. Many felt it important to ‘take a break from cancer’ and enjoy activities that served as effective distractions. For example, Lily did a lot of jigsaws, stating, “That does sound queer but that’s my quiet time, my meditation time; when I’m doing jigsaws I think of nothing else.”

According to research, taking part in activity-focused coping strategies assists cancer survivors to manage physical and psychosocial stressors (McGrath, 2004; Waldrop, O’Connor, & Trabold, 2011). For these participants, activity-focused strategies were often considered a way of remaining focused on something other than cancer. These activities provide a welcome distraction by grounding participants and assisting them to maintaining normality. As Colin mentioned, “Keeping busy was important, even though the busyness was not very busy in the first twelve months, it got me out of bed.” The majority of participants also described how

scheduling helped. Alyssa commented, “I tend to book Pilates classes into my diary and work around them.” Likewise, Tess described ongoing projects that continue to keep her busy:

I have got so many hobbies, I sew, and I keep up with a lot of Medscape and read all the journals. I research my large extended family through genealogy. I keep up with my friends and we often have family here on a weekend. We are also so busy with the kids and grandkids I don't have time to think about my cancer. I have a very busy life, but we go with the flow.

While EFC was highlighted as an essential coping strategy by these interviewees, earlier resilience research also suggests that EFC is linked with the absence of resilience (Olsson et al., 2003). However, EFC (i.e., diversion) did prove beneficial to these interviewees as it assisted them to ease their stress (Lazarus & Folkman, 1984). In addition, by engaging in EFC strategies early in the cancer trajectory, the participants were more equipped at a later date to engage in PFC strategies to identify solutions. Sharon's excerpt highlighted this:

There were days when I just didn't feel like being strong and I think I've learnt when that happens to just let it be, move on to something that can take my mind off cancer. I have now got to the point where I have more good days than bad and this is when I'm more productive.

As the initial shock of having cancer subsided, there was a notable shift towards a part of life that was, importantly, not related to their cancer. For example, Helen went on a holiday with her husband stating: “We also planned a holiday to Queensland at Christmas and that was really good because it gave my husband the chance to spend time with me.” Others like Ben, preferred to get back to work: “I also kept myself busy I think from the first treatment I was back at work and I was not sitting around.”

Problem-Focused Coping.

As mentioned in this study, PFC generally surfaced among participants following the use of EFC. PFC involved critically processing and reasoning about their experience and addressing ongoing challenges. Participants in this study achieved this in four ways: implementing cognitive strategies, taking action to deal with problems, discussing openly how they felt with others, and/or diarising their feelings. For example, Ellen commented how in some instances, she was proactive in accepting help from others: “Some woman sat with me all night just rubbing my back, I have learnt to allow people to engage.” Colin, on the other hand preferred to process his experience in writing, commenting: “I used to keep a diary...from day one and I would write something each day. That, in itself, was very therapeutic.”

Cognitive strategies referred to ways that participants dealt with their thoughts, fears, and responses to the physical and psychosocial challenges they experienced. In this study, the attitudes (i.e., acceptance, determination, persistence, hope, optimism, perceived control,

ownership and mental flexibility) of each participant aided in their ability to implement successful cognitive strategies.

First, in terms of positive attitude, all the interviewees demonstrated a strong sense of acceptance. Several comments included: “I sucked it up...put one foot in front of the other and didn’t dwell on it” (Tess) and “I quickly learned that this was an illness that I would need to manage” (Alyssa). They also accepted the need for medication: “I beat to my own drum...it required me coming to terms with life-long treatment” (Ellen). Similarly, Fiona made the following statement: “Face your fears and grapple with them... because I think until you finally confront and accept the reality of death you can't really enjoyed the abundance of life.” However, being accepting did not always mean that the participants were happy about it. Rather, they came to the realisation that they didn’t have a choice. As Ben stated: “It's important to accept the situation and deal with it. You don't have to like it, but it's fact” and “think positive and accept it, if it is meant to be, it is meant to be. No matter how you feel the thing is there” (Maria). The participants’ stories went on to demonstrate sheer determination, assertiveness, persistence, and occasionally stubbornness, all of which reflected qualities beneficial to maintaining resilience. This is evident in following statements:

A lot of being able to cope has been my personality I am very determined and maybe even being stubborn at times is important. (Lara, 44yr)

I wanted to survive so much, to continue to be there and witness the many joys that come with life. (Helen, 62yr)

My determination, I don't like to give up on anything. It's like I say to myself 'Yay me I'm a single mum with two kids who works three days a week and is building a house... oh and I've got leukaemia. (Imogen, 34yr)

In addition, maintaining hope and optimism tended to redistribute the focus away from disease and toward oneself and the confidence in one’s ability to reach an obtainable goal. This supports a number of previous studies proposing that hope facilitates belief among cancer survivors and assists in maintaining the motivation necessary for them to pursue their goals (Bulsara, Ward, & Joske, 2004; Denz-Penhey & Campbell Murdoch, 2008; Folkman, 2010). For all participants, it was vital to maintain realistic hope while also acknowledging the actuality of their circumstances.

Although many interviewees accepted the gravity of HC cancer, they were also focused on maintaining a positive outlook. As Pete shared: “I suppose I've got a positive frame of mind. I don't fixate on why me.” In order to achieve optimism participants frequently avoided negative environments by distancing themselves from situations that they believed impeded their recovery. For example, participants strongly protected their optimism by rejecting anyone who they perceived did not support them. In part, this might be helped them maintain a sense of control or this could be understood as a way to conserve personal resources to accomplish their goals (Hobfoll, 2002). As mentioned by Anna:

I have always felt that you should make the most of your life, I don't waste my time with people who bring me down. (Anna, 68yr)

However, participants commented about the ongoing challenge associated with continuing to remain positive and hopeful. Similar results have been discussed in previous research (Folkman, 2010; McGrath, 2004). Indeed, positivity is not a given, but rather a process dependent on the changing situation of the individual. This can be appreciated by the following statements provided first by Lily and subsequently Fiona:

At the beginning when I was diagnosed I was very negative. I had been through ten years of watching my husband deal with leukaemia. Even though your intellect tells you that they are two separate leukaemia's, whenever something happens you think here we go again.

In general the relentlessness of life's demands made it more difficult to stay positive.

In addition to the positive attitudes discussed above, individual personality characteristics, including mental flexibility, assertiveness, and taking ownership, also contributed to facilitating resilience. Those participants who exhibited mental flexibility demonstrated an ability to operate whole-heartedly in order to attain what they considered of significant importance to them. According to research by Denz-Penhey and Campbell Murdoch (2008), mental agility also enables those with cancer to alter direction. Therefore, mental flexibility suggests individuals can adapt their lifestyle or change their minds in response to further treatment or managing their recovery (Denz-Penhey & Campbell Murdoch, 2008). As stated by Lara:

My doctor said "What do you want to do? If you don't do anything you've got approximately 3 years" and I just looked at him and said "I have got two children, do what you have to do. I just want to live. Get rid of it" and that was my attitude, just do what you have to do to get rid of it.

Further research has also established the relationships between perceived control, taking ownership, remaining active in decision-making and less stress, fewer depressive symptoms, and greater self-efficacy (Denz-Penhey & Campbell Murdoch, 2008; Roundtree et al., 2011; Waldrop, O'Connor, & Trabold, 2011; Wenninger et al. 2012). Behavioural strategies, such as taking control or ownership and decision-making, were discussed by several interviewees. This is highlighted by John who witnessed his brother endure intensive treatment for the same cancer: "I asked my specialist if we could go the soft option first, because I wanted to leave the big guns for later." These results highlight a process by which participants assertively consider the stressors of illness and treatment and actively engage in decision-making about how to manage their distress. Similar results were noted in this sample. As Ellen remarked:

I have project-led my own condition. So I changed on all my sheets from patient to cancer client. I am not a patient I am 'cancer client'. Are you going to manage this or aren't you? That's your choice. Sometimes you need to stand true to yourself to begin with and I stand solid, that's important.

Ellen went on to add the discussion she had with her specialist:

"I will look after myself if you look after me" I said to my doctor "This is how we are going to do this, you go to every conference you can, do all the things you need to do...but I'll also do my part and we will care share me.

Similarly other participants commented:

I learnt very quickly that if I needed to get anywhere it was only me that was going to do it. (Lara, 44yr)

From my point of view I was running the ship. I live by the motto that has basically helped me. It's to "deal with the things that I can change, accept the things I can't change and the wisdom to know the difference" and I acknowledge that it's a prayer, but it's also my philosophy. (Colin, 66yr)

Serious illness is a catastrophic scenario in which the predictable world of a healthy and self-reliant individual unexpectedly transforms into one where the control is in the hands of strangers. As patients, the ability to plan or predict their future is taken by others, and this can be an isolating and disempowering experience (Xuereb & Dunlop, 2003). Previous research has reported that, in order to remain in control, those with chronic illness such as cancer may rebel against the normal expected care by refusing to attend check-ups, take recommended treatment, or, alternatively, will participate in risk-taking behaviour (Denz-Penhey & Campbell Murdoch, 2008; McGrath & Clarke, 2003). However, this issue was not apparent among the current participants. Rather, the majority were vigilant in conforming to medical advice and took active steps to improve their health and wellbeing. Ben stated: "I'm trying my hardest to exercise and go for walks, I'm trying to do things to help with my weight and take some control over what I can." As part of PFC, other cognitive strategies included 'self-talk'. Lily in recalling her husband cancer journey, shared how she had learned to effectively manage her thoughts, "I have to say stop! It's not the same. Stop panicking. It's silly but I guess it's natural because I went through so much trauma with my husband."

Similarly, PFC behavioural strategies were equally effective in assisting participants to plan, organise and document their treatment regime. Ellen illustrated how she charted her progress: "I keep a diary and documented everything, all my results and side-effects and I use a USB that's encrypted so I don't have to remember everything." This supports previous research identifying that intentional cognitive and behavioural strategies can be effective when coping with health-related life changes (Waldrop, O'Connor, & Trabold, 2011).

Finally, an important behavioural strategy that built resilience and was emphasised by all participants was the *benefit of finding purpose or meaning in their life* or "a reason to get

up each day.” As Zac reiterated, “It’s important to find your passion and don’t wait... go for it.” As discussed in the literature review, the concept of man’s search for meaning was first introduced by Viktor Frankl. Since then, several themes denoting the search for meaning have emulated beliefs in triumph over adversity in numerous qualitative studies involving chronic illness and traumatic injury (Denz-Penhey & Campbell Murdoch, 2008; Lau & van Niekerk, 2011; Moi & Gjengedal, 2008; Park et al., 2008; Williams et al., 2004). First Ellen and then Colin also echoed the importance of maintaining a sense of meaning in life:

One of the big things is when you're very ill and your life becomes smaller it becomes quite content. It might be just sitting, so it becomes smaller it organically happens. You don't necessarily become happier but your life means more and you become more content.

I'm involved in the church a fair bit, and I love gardening and seeing friends. In terms of my personality, bit of a doer and is probably part of my spiritual dimension, meditation has always been part of my life. I like to be involved in things socially, that is very important. We have two or three different groups of friends that are very close. I'm involved in volunteer work and reading for the Blind. I've been involved in basketball, and that still keeps me busy this all helps to give meaning to my life.

The following participants received their sense of purpose by either giving back to the community or by being an advocate: “I became part of a buddy system, people would phone up and talk me about stem cell transplants which helped those who were very frightened” (Lara). Walsh (2003, p. 56) defined this “transcendence from personal tragedy and suffering to concern and action on behalf of others” as a central feature of resilience. This is also nicely demonstrated first by Ellen and then Fiona who fittingly shared:

People say giving back to the community I think that is a terrible word, you give forward. If you give back then that stops the negotiation, you give forward to the community, that gives you the opportunities in life. Those sorts of things are the cornerstones of coping better. Don't ever just receive. I think with the political situation the one who screams the loudest get acknowledged. I've always said you live with cancer you don't live it. I've never lived my condition except I voice it. You can't take things personally when people don't understand. I believe it is important to show people you can live well with CML.

I have a personal mission in that I'd like to live my life and in some way make a contribution. If I can do my little bit too allay fears that cancer is not the end of life, if you get a cancer diagnosis it isn't the worst thing that can happen.

The results of this study indicate that both EFC and PFC strategies can be helpful at different stages in the coping process. A previous meta-analysis of studies on coping with various stress experiences supports the hypothesis of a phase-specific adaptivity (Suls & Fletcher, 1985). As the current study identified, avoidance was associated with more positive adaptation in the short-term, but, over time, attending to the experience seemed more adaptive (Suls & Fletcher, 1985; Wenninger, 2012). It seems that coping is dependent on the individual

concerned, the adversity, available resources, and the time following diagnosis. Regardless, the participants in the current study highlighted the effectiveness of both EFC and PFC strategies in maintaining resilience. However, further research is necessary to explore how different coping strategies are used collectively over time to accomplish positive outcomes in cancer survivors.

Positive Health and Behavioural Change

The benefits of positive health and behavioural modifications (e.g., lifestyle and self-care behaviours) have been discussed within the cancer-related literature. For example, several studies maintain that exercise, diet, and relaxation have a positive influence on those living with cancer (James et al., 2011; Rabin et al., 2011; Schwartz, 2004). The results of this research concurs with several common themes discussed by the majority of interviewees ($n = 20$), who emphasized these benefits, including a new respect for their inner health. These benefits comprised helping with recovery from treatment, improving mental health, facilitating weight loss, promoting relaxation, and feeling stronger physically.

First, lifestyle changes appeared to be even more important for the participants following their cancer diagnosis and were effective in reducing the risks associated with treatment. As Lara explained: “I definitely watch my diet, and try to keep fit by exercising. I have noticed since having cancer that if I slip up and get slack, I feel more tired and sluggish.” In addition, the participants reiterated the importance of maintaining the lifestyle that they were accustomed to prior to their diagnosis, even during their hospital treatment. This was beneficial to Pete’s recovery as he commented:

I was also training in the hospital, I took dumbbells in, and I walked up and down the ward and found a stationary pushbike. It was like I wanted to keep my routine and to prove that it wasn't getting the better of me. Basically when I do my exercises it definitely helps me psychologically. I have always been fit and exercised and for me this is back to the normal me and I am much more able to cope.

The majority of interviewees also participated in some form of relaxation, such as music, art, yoga, and meditation or additional complementary approaches including reflexology, tapping therapy, acupuncture and massage. As mentioned by Maria:

Every now and then I will go for yoga but this is funny to watch because I am old and I'm not an exercise person or I might go for meditation. I'm not too sure if this works because you know my mind wanders but I feel so good afterwards.

Another area of self-care identified by participants as paramount to their overall psychological wellbeing involved taking care of their appearance. The main benefits included: feeling in control, being treated more normally by others, improving their self-esteem, increasing their energy levels and generally enhancing their mood. For example, Maria, who was going through a difficult time, shared: “I'm finding it hard getting up, but when I make an

effort and dress nicely, I do feel better.” Pete stated: “Yeah if I bother to shave, I do feel half alive.” Further examples are first described by Helen and then Sharon:

Most days, whenever I could, making the effort to get up out of bed and get dressed, wear a pretty scarf put a bit of lipstick on all helped my state of mind and get on with things.

I would always put my lipply on in hospital before the doctors came in. That was like my mantra and helped me feel less crappy and more in control.

Several comments related to remaining vigilant in other areas of their physical health. Ellen stated: “I always have regular check-ups with my GP for my ongoing health... dental visits, the optometrist.... things like that.” Finally, self-care encompassed several areas, but importantly there was an awareness of the need to be kind to themselves. As commented by Sharon: “I treat myself gently and I give myself lots of rewards... I make sure I have lots of things to look forward to and I always listen to my body.” Although some participants did highlight at least one practical barrier, such as limited time available for maintaining self-care because of work and family commitments, the majority of participants considered self-care a priority.

Influence of time.

Previous literature has highlighted the importance for cancer survivors to take ‘time-out’ (Kelly & Dowling, 2011; McGrath, 2004; McGrath & Clarke, 2003). However, with the exception of one article by Gartland et al. (2011), no other study could be found that has directly related this to resilience. This research by Gartland and colleagues involved adolescent cancer survivors and identified the importance of having the ‘time and space to think’ (i.e., to work through the meaning behind the cancer event and why) as an important factor in maintaining resilience. This was also found to be necessary for the participants within this study. It was observed that interviewees acquired self-confidence in their ability to face cancer-related challenges if they were able to take the time necessary, and, importantly, process this at their own pace. At times, this allowed the participants a break from the expectation to remain positive. In some circumstances, the opportunity to attend to their own feelings in their own time was of more value than talking to or being with others. As stated by these participants:

I was glad to have some space and time when I was first diagnosed and not to have to put on a public face because I had to get my head around the fact that it was going to affect me for the rest of my life. I was very self-conscious about my appearance, my round face.
(Fiona, 51yr)

I needed the space from people and importantly time to accept the diagnosis. It takes a long time for your body to recover; it's not like a broken leg that everybody can see.
(Lara, 44yr)

I find it's helpful to spend time by myself, switch off the phone, not talk to anyone. Give myself the chance to deal with it on my own. (Megan, 43yr)

The participants also discussed the importance of getting help at the right time. However this varied between individuals. This supports research by McGrath and Clarke (2003) who identified that timing was the most important factor reported by cancer survivors, in effectively providing the opportunity to 'talk' about their illness experience. This research highlighted that there are times during the survivorship trajectory when talking with others is ineffectual, conversely there are other moments where getting help and sharing experiences is beneficial. Likewise, many participants in this study expressed a specific need for help at particular stages in their survivorship trajectory. For example, Lara referred to a definite phase during her cancer journey when she felt vulnerable and the support provided at that time was not only ineffective but created more stress:

I didn't really get any help until several months after my treatment at which point they gave me a whole lot of information and reading about my cancer. This was also when I just hit that "what if phase" so it actually made me really sad and wasn't helpful. So I think it is crucial to be given the information about your cancer at the right time which is probably when you're at your most positive and this may be different for everyone but definitely not six months following treatment.

In addition, illness often compels patients to consider many factors, such as the time it will take to be treated, quality time remaining and, potentially, time left until death. The literature reports that, as a consequence of focusing on their own mortality, some patients cope by making significant changes to their lifestyle and reassessing how they prioritise spending their time (Grunfeld et al., 2013). This was also apparent in the results of this study. Participants reported that they now considered their time to be more precious. For example, Helen stated: "I just need to make the most of every minute."

Previous research reports that perspective on time may also change for individuals who have faced a life threatening illness (Sherman, Cooke, & Grant, 2005). As Colin remarked: "It is very surreal as the chemo progresses. It's like you are living in a parallel place in time." However, a key point that surfaced was also the ability to accept that recovery would take time and that health challenges were transient. As Karen commented: "It's all circumstantial depending on what's happening at the time, some days are better than others, but I guess this is no different to my life before cancer." In addition, Anna remarked on the change in her anxiety as time went by:

I mean when you're first having the blood tests every two weeks you sort of worry... as soon as I heard the fax machine even if it was 2 o'clock in the morning, I'd be out of bed running down the stairs to look at it, but now I sort of think I'll look at them in the morning, I'm not getting out of bed. This sort of thing so confidence increases as time goes by.

Self-Education.

The final sub-theme described by participants as contributing to their resilience was their ability to proactively self-educate or become self-informed. This supports previous research reporting that cancer patients who remain informed are more likely to experience positive outcomes, and that lack of adequate information can be a source of substantial stress (McGrath, 2004; Rabin et al., 2011; Xuereb & Dunlop, 2003).

The gathering of information predominantly helped the participants to have some control over decisions regarding their future. As Max commented, “I learnt as much as I could so that I felt more informed about the decisions regarding my therapy.” Likewise: “I wanted as much information as I could get. That way I could make choices and feel in control, in an uncontrolled situation” (Colin). Participants would actively seek a second medical opinion, if deemed appropriate, and, at times, the information provided was not always taken for granted. As Fred explained:

If a GP gives me a prescription I don't just take it. I study it and get the book. I never believe everything just because they give it to me, we have to be responsible to look after our health and check it out yourself.

In circumstances when information wasn't easily accessible, the interviewees were incredibly effective at self-educating. The participants gathered information from several sources, some of which included the Leukaemia Foundation, their specialist, the library, the Internet and social media. Two participants summed up the benefits of being self-educated in these words:

My doctor apart from the verbal, he didn't give me anything. So got the phone directory out and looked under the Leukaemia Foundation and rang them. I'm a book type of person so I wanted something visual to read... they sent me a package and in that was one particular booklet on CML. After this I went online but I was very careful because of some of the information was not always correct. So I've got a CML section in my filing cabinet and it's there for my kids if they want. (Fiona, 51yr)

First of all is the acceptance of it and then being able to go and research it, If you're not educating yourself enough speak to someone else about it I believe that resilient people have a wider grasp and understanding of the world they live in. (Ellen, 58yr)

In summary, the analysis of the interviews has identified a personal resolve that each HC survivor demonstrated to maintain resilience. The experience of living through HC led many of the interviewees to reassess their lives, be less focused on material goals, and strengthened relationships. It is clear from the results of this study that personal resilience is a complex multifaceted web of attitudes and values that are facilitated through: self-awareness (i.e., through acceptance, self-education and personal attributes); self-protection (i.e., through coping strategies, available resources and social support); and, self-management (i.e., through decision making, self-care, and utilisation of resources). As Ben concluded: “Lots of things together not just one big thing has helped me be resilient.”

Pathways and barriers to resilience

Although participants in this study identified themselves as resilient, many acknowledged situations in which their resilience was challenged. The next major theme identified by the analyses was the various pathways and barriers to resilience. Five sub-themes were highlighted by the participants, as factors that either assisted or impeded their ability to maintain resilience. These included factors related to employment, relationships, communication, information and resources and unmet needs.

Employment.

Research evidence indicates that resuming work after illness is associated with improved physical and psychological functioning (Grunfeld et al., 2013; Hara & Blum, 2009). Conversely, being out of work is thought to contribute to adverse health outcomes (van Dijk, Ojajärvi, Taskila, de Boer, & Verbeek, 2009). This has been widely reported among males (Grunfeld et al., 2013), however the current study also found that employment was equally pertinent to females.

A variety of benefits were described by those participants who returned work including social interaction, financial reward, a sense of purpose, routine and a sense of normality. As shared by Pete: “I missed my work, it is a big part of who I am, and they were excellent, absolutely brilliant. I was able to go back part-time which was really helpful, it gave me reason to keep going” and also Zac: “I am self-employed, so it has been a relief to be back at work doing something useful for a change.” According to the literature, work is a vital component of an individual’s self-identity (Grunfeld et al., 2013) with approximately 63% of cancer survivors returning to work following treatment (Hara & Blum, 2009). The figures in this study are similar, however many of the participants who returned to work were no longer able to work full-time, in addition their focus shifted to finding a work-life balance. As shared by Ellen:

When I was extremely unwell they changed my job description which was fantastic because I didn't have to make many decisions. I've reduced my hours. At 2 o'clock I'm done. So I think this is the best job for me so, that I can also do all my community work. It's not the main focus of my life.

However, there were also negative consequences associated with returning to work. Several participants discussed as a sense of uneasiness and identified a lack of confidence in their ability to carry out their work role effectively. This was due in part to the survivor’s time away from the workplace and concerns over treatment side-effects, such as fatigue and memory loss. Another concern for some participants was the disclosure of their cancer diagnosis to their employer. Several reasons for this included: feelings of embarrassment; the culture or ‘sigma’ of cancer; to avoid unwelcome attention; and, wanting to appear normal and capable in their ability to do the job. As commented by Max:

How much do you tell them all about your cancer or do you play it down? I was having lots of days off work, I felt like I had no choice. It's definitely harder. I will perhaps always have to disclose my leukaemia as I often travel in my job, which impacts on health insurance but others can be quick to discriminate or prejudge and that's hard to cope with.

However, the majority agreed that by disclosing their cancer diagnosis they had received advice and support from not only their managers, but also from colleagues they least expected. This supports previous research highlighting that the self-disclosure of a cancer diagnosis in the workplace is associated with positive outcomes including better adjustment (Hagedoorn et al., 2011). This is most often due to the provision of role adaptations and/or practical support offered by employers (Hagedoorn et al., 2011). As Colin confirmed:

My manager told me to take as much time off as I needed to get my head around it and my body used to the medication, so it was good to have that breathing space.

Relationships.

According to all participants, their interpersonal relationships also impacted on the resilience process, both inside and outside the home. However, this varied within the group as both positive and negative interactions were encountered involving partners, family and peers, and/or relationships with physicians and other allied health professionals.

Several interviewees referred to their partners and immediate family as being their main source of strength. However, the positive effects of other close relationships were equally important. For example, Alyssa commented: "My children were incredible, but I also have special friends with whom I now have a deeper connection." For other survivors, the focus was on repairing relationships and resolving any conflicts, to reduce ongoing negativity. However, either way, it was clear from the interviews that close relationships mattered. As Helen explained:

I just had a new granddaughter who was five days old so I wasn't going anywhere. Having all of my grandchildren, daughters and my husband keeps me resilient, motivated, and alive.

Nevertheless, there were also situations in which the relationships created stress and impeded resilience. For example, many participants found it difficult to cope with others' expectations, especially in relation to how they should behave. As Ellen shared: "People have an expectation of what they think you should be and how you should act" and Megan said: "It's hard work to keep pretending to others that you are feeling well, which is what my family wants to see."

There was a general consensus that the HC experience could only be understood by others who had been through this experience. Several participants recognised that many of their friends were unable to appreciate what they had endured. Specifically, the ignorance of others was challenging for many survivors. For example, Ellen commented that a colleague,

after finding out she had leukaemia, said to her: “That’s not good my dad died of leukaemia” and likewise Colin pointed out that: “It’s not helpful to hear about what happened to aunt Martha.” Similarly, Megan found it very upsetting after losing 20 kilograms, as a result of severe nausea, when her friend stated: “I hope you are not trying to stay thin by not eating?” These results support previous literature affirming that comments and presumptions by others who had not been through a similar illness are perceived negatively (McGrath & Clarke, 2003).

As a consequence of HC, participants also shared stories about long-term friends, family and even partners who had distanced themselves. For example, Helen commented: “My relationship changed with my husband and became a bit distant because he couldn’t cope with it...he didn’t talk about it.” Other participants also sensed that intimate relationships were affected because they had personally changed. As Lara remarked: “I have noticed a change in the relationship with my husband, when I started my chemo he was great at looking after me, but now that’s over, I’ve moved on and I don’t want that anymore...I’m a different person.” Travis too summed up his post-cancer relationship dilemmas by sharing:

Chicks too, who wants a guy who has had cancer. I know that it shouldn’t matter, but that is just another thing you think about. I don’t have a girlfriend at the moment but it’s that whole part of having to tell a girl you like. When do you do this? How much to say? All that crap.

In addition to friends and family, participants highlighted that a trusting and positive relationship with healthcare professionals was regarded as essential in fostering resilience. This supports previous research reporting that many cancer patients have faith in their health care providers (Bulsara, Ward, & Joske, 2004; Knott et al., 2012; Roundtree et al., 2011). In this study, there were numerous examples of positive relationships with healthcare professionals. For example: “They are genuinely interested and I’m not just another patient and another number” (Pete). Lily also confirmed this: “My specialist is incredible. He’s like a friend. I trust him one hundred percent and I know that I can call him at any time.” Anna too believed that her relationship was paramount to her recovery stating:

The positivity of my specialist is one of the huge parts of getting me through. I would have to almost put that at the top of the things that helped me.

However, as with family and friends, negative relationships were also mentioned by a number of interviewees. Imogen found the interaction with her physician challenging, especially in relation to issues regarding her appearance. The lack of empathy was highlighted when her specialist stated: “Well, it’s a bit of weight gain or you die... what’s the better option?” In response, during the interview, Imogen commented: “I’m a single mum with two kids and I’ve also got to have some quality of life. I get what he’s saying, but it’s hard that my specialist can’t acknowledge some of what’s important to me.”

Finally, in addition to the relationship with the immediate treatment team, participants also referred to several influential relationships, often transient, that had an impact on their resilience process. Many of these included: psychologists, pharmacists, phlebotomists, drug company representatives and the hospital ancillary staff (i.e., cooks, cleaners and clerks) who were all mentioned in a positive light. As Jack commented: “The medical receptionist was amazing we knew what was happening 12 months ahead with appointment bookings, so that we were able to plan our lives.” Anna too was very moved by an unexpected relationship that assisted her recovery:

There is a delightful old nun at the hospital, she is well into her 80's and she tries to see every patient in the morning and before they go to bed at night. She comes around and tucks you in, she is amazing. She would bring you a little prayer which I still have by the bed, and knowing how old she was and you are thinking “You're the one that should be in bed.” So things like that all helped to get me through.

In essence, these participants believed that healthcare relationships were influential and either contributed to, or hampered, their resilience. This experience was often reliant on how satisfactory the survivors believed their needs were met and whether interviewees felt they could express their feelings in a supportive environment. However, as McGrath (2004) highlights: “In short, the health professional can nourish the patient with support, honesty, compassion, and a realistic appreciation of their situation, but the hard work of maintaining a positive attitude must come from and be sustained by the patient themselves” (p. 32).

Communication.

Probably the most important factor in the relationships of each participant was effective communication. This supports the literature stating that open, honest, sensitive and transparent communication styles can empower survivors and thus facilitate a more trusting relationship (Bulsara, Ward, & Joske, 2004; Butow et al., 2011; McGrath, 2004; Parry et al., 2011). Most participants felt the need to have their concerns acknowledged and taken seriously in all relationships. However, for the participants in this study, the communication between family, friends and healthcare professionals varied considerably, with both positive and negative experiences encountered.

First, the communication styles used by the participants ranged immensely. Many interviewees considered an open communication style to be essential. This was particularly pertinent within their interpersonal relationships, stating that open communication resulted in a sense of support, transparency and closeness, which was paramount to their recovery. As Karen was advised by a friend: “Tell everybody that you have cancer then people are aware and you can get the support and you know where you stand.” Likewise, when Fiona was first diagnosed, when telling her children it was particularly important to her that she was honest:

I tended to focus on the positives when I was talking to them and minimise the negatives, but I never ever lied to them and said that I would be cured.

However, on the other end of the spectrum, several participants elected to be more guarded in their communication. This was described as an attempt to maintain control, reduce distress and also to protect others. However, according to McGrath and Clarke (2003), a more closed communication style can impact on the support offered and may also be misinterpreted. This is evident in Lara's situation:

I tended to keep it all to myself. So you know I remember somebody saying that I was in denial, but I don't think that's denial, I just didn't want to worry them. It was on a need to know basis.

Second, participants' attitudes regarding their communication style with healthcare providers played an important factor in their ability to maintain resilience. Although these HC survivors generally expressed trust in their physician's advice, they also disclosed much trepidation. The main concern related to communication issues such as: questions left unanswered; a lack of attention; contradicting information; a lack of empathy; and, the use of medical jargon. This supports the literature stating that communication between cancer patients and their specialist has been identified as an area of potential stress (Butow et al., 2011; Roundtree et al., 2011; Xuereb & Dunlop, 2003). For example, Pete described the communication provided by a doctor and a nurse while he was in hospital:

The doc said to me: "We will just put a line in" what does a line mean? Is that a line with a pen? What does that entail? It's a whole new world of language you feel like you're travelling blind. Then the nurses have got their protective stuff on, aprons and masks, and they have got syringes with what looks like red cordial. I asked them once: "why are you dolled up like that?" and the nurse said: "it's dangerous stuff it can kill you this stuff" while she's busy pumping it into me.

Imogen and Lara also both experienced specialists to lack empathy and to be inappropriate and not forthcoming with correct information:

When I saw my doctor he said: "So you have got CML. Good news, ten years ago you would have died... take this pill and you'll be fine." I just remember thinking, seriously are you for real but that's just him. (Imogen, 34yr)

They never told me pregnancy wasn't a good idea they just said I would never fall pregnant again. Well I fell pregnant and then my specialist just put a whole dampener on the situation and said you can't have it. (Lara, 44yr)

Lara also found herself in a situation where the disclosure of her personal information was mismanaged:

I was at the hospital the first time on my own and I needed to see another doctor so the hospital staff gave me my medical report with my whole history...they just gave it to me...and of course what did I do? What would anyone do? You look at it and the first thing I saw was 'poor prognosis' written right there smack in front of me basically saying my days were numbered. That was probably one of the first times I actually completely broke down.

However, the majority of participants were complimentary about most healthcare professionals who were sensitive to their communication needs. The most positive scenarios

involved physicians who identified a way of relating to the participants and who met their needs in terms of providing an empathic response. The following excerpts are examples of this:

My haematologist told me upfront it's incurable, it won't go, it will pop up again and we'll deal with it if it does. That's why I liked my doctor he was straight with me.

(Colin, 66yr)

I told my specialist: "All I want of you is to be there if we get into the trenches and that you can walk away and say I did all I could do." That surgeon...I remember him kissing me on the forehead and saying: "Just remember if you die tonight don't ever forget you have been loved and cared about." It was just him communicating those things and the kindness of somebody giving you that. To know that you may die and they were his last words.

(Ellen, 58yr)

My specialist didn't try to talk me out of it he just said: "You do whatever you feel you need to do, I know what you went through with your husband's cancer." He was trying every avenue to be helpful.

(Lily, 64yr)

However, getting the balance and timing of information correct is not an easy feat. This is particularly the case in haematology where treatments are aggressive and invasive (McGrath & Clarke, 2003). Consequently, some of the literature has queried the need to cause further worry by overloading patients with information, decisions or through excessive explanations (McGrath & Clarke, 2003). This was discussed by some participants. As Ellen stated: "You've got all these decisions to make, it's overwhelming and there becomes a frustration." Knott et al. (2012) found, in their study of cancer patients, that when participants were asked if they were content with the treatment options provided, many implied that they were not provided with options. However, those interviewed were not dissatisfied, as they presumed that it was the specialist's role to communicate appropriate advice on treatment recommendations. Similar results were found in this research, as is evident in Pete's comment:

I'm a great believer in research and drugs, partly because of the job that I do. I trust the medical system I don't question it at all, I just wanted to know what they would do in the same situation. Whatever was good for him was good for me.

Nevertheless, there were other participants who clearly communicated their need for control over treatment decisions that impacted on their lives. As Lily highlighted:

I think when the disease took off and I had to make that decision "Do I have treatment or not?" and it was my decision to make because I always said after my husband's cancer journey that if I ever had anything like that I would never go there.

Finally, the use of humour across all age groups invited a lighter perspective on the HC experience. For example, Maria's interview was particularly humorous and it was evident that her sense of humour had contributed toward her resilience. As Maria shared: "I also used to embarrass the doctor, I would tease him all the time and say he was good looking. I think that made him blush but it also made me laugh." Humour was mainly used to actively distract

participants, make others feel more at ease and in attempts to down play the seriousness of their illness. As other participants highlighted:

Probably one thing that was significant was that my close mates mucked around. You know they still gave me shit and kept that sense humour. I really appreciated that at the time. (Travis, 23y)

One day the priest came round and I'm not very religious and I gave him cheek every time but he saw the funny side of it. I think humour is important. (Pete, 63yr)

Our kids now have a thing where they say 'first world problem' meaning it is not a big issue and we have a laugh about that. (Fiona, 51yr)

Information and Resources.

The anecdotes provided by these interviewees highlighted that the knowledge gained through the delivery of information and available resources allowed the survivors to have a sense of control and to set realistic expectations. The literature confirms the importance of offering the right amount of quality information that is also appropriately timed. However, it can be difficult to achieve the right balance (McGaughan et al., 2012; McGrath, 2004b; Rabin et al., 2011; Xuereb & Dunlop, 2003). The results of this study support the literature, with many participants finding that, although they were eager to understand their HC, they also felt overwhelmed by the information provided.

First, several participants believed that the 'timing' of information delivery was essential. Many felt that they were given important facts at times when they were unable to process the information. For example, Jack commented: "I was in shock, I did not remember everything they told me in the beginning" and this was reiterated by Megan: "My sisters came with me a few times when I've met with doctors, because I haven't always found it easy to take in the information." Lara's excerpt also provided another perspective:

The timing is important, I think it's helpful to get small amounts of information more often and I don't think you need to know absolutely everything, but it's different for everyone. I actually stopped at one point and thought I've dealt with it...I don't need to know any more.

Karen shared this opinion and found the information confronting, especially when first diagnosed. Karen was adamant that she did not want the survival statistics or intricate medical facts. When Karen's mother asked her specialist: "What are her chances?" Karen replied: "Don't ask that, I don't need or want to know all that stuff." As is reported in previous research (Xuereb & Dunlop, 2003), for many participants receiving less information in the initial diagnosis phase, helped to reduce their anxiety. Anna highlighted this:

I didn't want people to bring me information about five-year survival and things like that. I was happy with the haematologist and what he told me. I didn't want to go into all those details at this stage.

Other participants like Lily and Pete just felt completely overloaded and at times this was stifling.

I felt totally overloaded by information so I shut a lot of that out. I just did not want to travel that road again. (Lily, 64yr)

I was flooded with information. Someone gives you one bit of information and then someone else gives you other information. The information scares the pants off you... You learn all the new words like 'neutropenia' but some of the information is too involved. They tell you about all the things that can go wrong...and I thought my God it's a bit overwhelming. (Pete, 63yr)

Another important factor was the quality of information provided. Having a lack of adequate information was expressed as a source of significant stress by many interviewees. For example, many participants were predominantly interested in the tangible way that HC would impact on their life, rather than the statistical details. As Lara shared:

The statistics are really bad and when they tell you these it's a shock, but these don't take into account your personal situation... your age and how fit you are? The type of person you are? It doesn't take into account any of that. I just wanted to know how it was going to affect my quality of life.

Many of those interviewed were able to recognise deficits in their knowledge and areas in which they needed more information. Research reports that when patients ask for more information it is often in an attempt to gain some control and hope in their current circumstances (Xuereb & Dunlop, 2003). Like Lara, in order to take care of their health, several other participants wanted to know the impact that treatment would have on their short- and long-term QOL and wellbeing. As these participants commented:

I also wish I was told more about the long-term side-effects of treatment. I was not prepared for that at all. I did not know that the fatigue would continue, my fingers would go numb, that it may send me into early menopause, I would get lots of ulcers and sores and also depression that was initially a big one for me. (Sharon, 31yr)

I would have liked to be more prepared for medical tests. I had never been in hospital...then suddenly you're getting pricked with needles. (Natasha, 22yr)

I think it was really important just to know what the treatments going to do. If you know there's nothing unusual about it then you don't react to it. There was a certain calmness because I knew what to expect. Although I wouldn't have taken it all in I wanted as much information as I could get. That way I could make choices and feel in control. (Colin, 66yr)

To compensate for the information gaps, the participants became more pro-active in finding their own resources. Some interviewees wanted to fully understand their condition and be up to date on the most recent literature. As Ellen explained to her specialist: "One of these days we're going to have a conversation about this cancer and I want it to be an equal conversation." Zac provided another example:

Even through this, I still managed to seek out more positive information from various resources and focus my energy on educating myself. I wanted to learn all about my leukaemia. (Zac, 34yr)

Several participants also discussed effective strategies they employed to retain information. For example, many interviewees went with family members to appointments, they took the initiative to ask questions, employed note taking, used recording devices, read various resources, watched DVD's, joined support agencies and, in some circumstances, sought out a second opinion. The majority of participants in this study also articulated the use and importance of the Internet. The Internet, including social media, acted as a vehicle that enabled independence, reduced feelings of isolation, provided cancer-related information, and, connected participants with other cancer survivors. This is highlighted in the following examples:

The Internet and Facebook can be helpful to people, for example if someone says: "I get these side-effects" and fifty other people respond and say: "yes I do too", it can be quite supportive and reassuring and this response can be instantaneous and from all over the world. This can be quite comforting and less isolating. (Tess, 69yr)

I was ill for weeks until I got onto the Internet and contacted someone in America who said: "I think you're taking the drugs the wrong way". (Ellen, 58yr)

One of the things that helped me cope was chatting to others online, who I could talk with anytime. Sometimes I would post stuff asking about my cancer, I would almost instantly get a response from someone in the world. I would often log on at night when I couldn't sleep especially when I felt lonely. I also used the Internet and my phone, so they helped me feel less alone and I was able to search a lot of information. (Natasha, 22yr)

In this study, the benefits of social media and the Internet were clearly apparent. However, two participants also commented on the negative aspects of using the Internet such as the quality and reliability of the information available. First, Karen described a scenario involving her parents who received inaccurate information about her type of leukaemia.

Both mom and dad came in wearing dark sunglasses. They had been on the Internet all night of course and had discovered on some site that said I had two years to live. Luckily, my specialist came in and said: "No if she takes a pill and responds well she should be fine." (Karen, 43yr)

Sharon too confirmed the benefits of using the Internet but was also realistic about the use of social media:

I had regular contact on the Internet with friends and would read various blogs from other survivors. This was encouraging but some of the posts were also very confronting. It did help me feel less isolated but I take social media with a grain of salt as not everything you read will relate to your journey. (Sharon, 31yr)

In this study, the information gained through various avenues was clearly an important commodity for HC survivors. However, the amount, delivery method and timing of

information proved to be a double-edged sword, as the knowledge gained was not always beneficial (McGrath, 2004b). As outlined in this study, there was diversity in how information and resources were required by participants. Thus, in order to form the basis for a positive coping experience, the main challenge is to ascertain the individual patient needs and match information delivery accordingly (Xuereb & Dunlop, 2003).

Unmet needs.

The final sub-theme impacting on the resilience process for participants involved unmet needs, particularly following treatment. This supports the literature highlighting that numerous stressors often accompany the completion of treatment and/or transition to survivorship (Knott et al., 2012; Roundtree et al., 2011; Waldrop, O'Connor, & Trabold, 2011). For example, several triggers evoked by particular events and/or surroundings can bring back painful memories and intensify feelings of uncertainty among survivors. In addition, Stanton et al. (2005) have identified four myths that may be experienced by cancer survivors following treatment. These include the belief that, as a survivor: I should feel well; I should be the pre-cancer me; I should be celebrating; and, I should be able to cope with minimal support. However, as expressed in this study, although this was how many participants wanted to feel, it was not their reality. A number of those interviewed struggled to maintain resilience as a result of unmet needs.

The most common unmet need occurred at the completion of treatment when the participants described feeling: 'in limbo', 'uneasy', 'lost', 'dismissed' and in 'unknown territory', mainly due to the lack of support following treatment. For example, Zac noticed the support from family and friends fell away stating: "I think people thought, he's OK now... so we won't talk about it anymore...while really, I was still struggling with everything. So this was a difficult time for me." The same feelings were shared by Helen:

I'd say the first few months after treatment were the hardest. My family went back to Queensland and I think I felt really lost after this. I think they thought: "it's all right now the treatment is finished." Whereas you have so many people ringing and visiting during the earlier stages worried about you and you're seeing people every few weeks, but all of a sudden it stops and you feel very isolated and lonely. It may have helped to have somebody call once a month even up to 8 months after treatment because that was a difficult time. You do get a bit lonely after being so fussed over in hospital.

Research maintains that additional support is particularly valuable, not only at the time of diagnosis, but also when patients are transitioning at treatment completion (Knott et al., 2012; Rabin et al., 2011). Yet, this is also a point in time when assistance and support from health care professionals is being withdrawn (Rabin et al., 2011). This was also a time that many interviewees stated that they would have most benefitted from the offer of counselling or support groups. As these participants stressed:

It would have helped to have a support group contact me at home after my treatment. I was given a lot of information and I really wanted to contact them but I just didn't get round to it. I know if someone had phoned me and said: "We hear that you have just completed treatment and we are available for support." I would have signed up for some help, but I just never took that extra step myself to contact them which I regret.
(Sharon, 31yr)

Possibly help with the sexual function and I know there is information at the Cancer Council I probably should have pursued that. Like the Leukaemia Foundation, if one of their sessions had been on sexual dysfunction I would have probably attended but at the time they were more general topics.
(Colin, 66yr)

Although the majority of participants indicated benefits in hearing 'success stories' by talking to other survivors, such connections were not always available following treatment. In some circumstances the interviewees had lost contact with other patients who had left the hospital or they had since passed away. Another downside was mentioned by Megan, who attempted to join a support group only to find that the other patients did not understand her aggressive leukaemia. As Megan commented:

This one lady went on about me not cleaning my house, she didn't understand that I couldn't as it was a huge infection risk to me. She had a chronic cancer not an acute leukaemia like mine but she went on about a 'don't feel sorry for yourself attitude'. I would come away thinking there was something wrong with me. I felt as though they thought I was imagining it and I thought to myself that isn't what I came here for.

Many participants also referred to the lack of time with their specialists. As Max stated, "It takes time to talk about uncomfortable issues, I couldn't just blurt it out in a few minutes...but I was well aware of the queue outside in the waiting room." This is concerning for cancer survivors, as many important issues remain unanswered due to the lack of time available during medical appointments (Kelly & Dowling, 2011; McGrath, 2004b). Pete also summarised his perspective and shared what he believed would have been beneficial to him:

What would really help is if someone could come into your environment with pamphlets that are easy to follow, and sit with you one-on-one to answer your questions. When you go to the haematology department you've got one million questions, the interns been briefed by the doctors, lots of people are waiting and you've only got 5 to 10 minutes and they speak code, so it's very hard to get the information you need. It would be really beneficial to have someone come your own home just before you are due to go to hospital and once you've had a few weeks to let the diagnosis sink in to have a coffee with you and explain anything you don't understand. That would be the best thing.

Participants were also discouraged by what they perceived were barriers to care. For example, some felt unsure about the follow-up process and screening they would receive. Others referred to the lack of resources, ongoing costs and the 'black tape' surrounding the availability of medications through the public benefit scheme (PBS). For example, Ellen discussed in depth her frustration in getting her prescribed medication through the PBS:

Issues with PBS made it very difficult. I spend lots of time on the phone, it absolutely does my head in. If only I could get into their office and tell them how their stupidity and incompetence impacts on the health and care of cancer patients. They need an overhaul, they only let you have minimal repeats so there are no spares and they take too long getting new scripts, so you run out. They also change the coding but they forget to tell the pharmacist. I say to them: "Do you want me to not take drugs for four months, so your computer system marries together." They don't understand sometimes they say, "Can you have another drug instead?" It's a nightmare for me, my specialist and my pharmacist and it happens all the time. I know patients who have borrowed drugs from other patients to keep them going until they get a script. It becomes an administration nightmare...these people seem to have no medical background or knowledge yet their decision to change to the drugs and the codes makes a big difference to my life.

The final unmet need described by the majority of participants referred to feelings of loneliness and vulnerability, mainly due to isolation. The interviewees felt that the lack of normal contact with others made it difficult to remain resilient. This was particularly the case when friends and family were unable to visit due to their low immunity and when admitted to hospital isolation rooms. As Ben stated: "You are locked away alone in a room feeling pretty awful" and Luke confirmed: "Another thing that was crap was that shit isolation room... for a guy you just want like a set of weights or something." Colin and then Anna also described this experience in more detail:

It's like a darkness, not a depression darkness but you feel like you're in your own world and isolated and not connected and you don't realise how much other people are actually doing to allow you to maintain your health.

There are two isolation rooms in the hospital that look out on a boring courtyard. On the other side is the road, St Joseph's, the football and other things happening and okay there are funerals at St Joseph's but that's not so bad as you can actually see there's a world out there. But instead you get this window and it just looks out on a little walkway and nothing much else and you can't go out anyway as you're in isolation. It would be much better if it were reversed.

In order to cope with this sense of isolation and loneliness while in hospital, participants employed several strategies. For example, Zac would do his best to stay in contact with friends and family even if he couldn't see them face-to-face. Natasha commented that she would log on to the Internet when she felt lonely and was unable to sleep. Lara too shared another strategy that helped her cope:

My husband had set up a video thing for me and I went through all our camcorder stuff and put it on to tapes so while I was in hospital I could watch old videos of happy times so that was really good.

However, several participants also discussed how difficult and lonely the nights were at home, suggesting that this experience goes beyond the hospital. This was particularly relevant among the single female participants who commented that they found it hard to sleep and spent hours lying awake feeling alone. As shared by two participants:

I literally cried every night. I felt really lonely and quite isolated in the evening especially. When the kids have gone to bed or they were not at home I found it very difficult. (Imogen, 34yr)

The most difficult time for me is being alone especially at night. My sleep patterns have been disrupted and I wake up in the middle of the night feeling isolated and anxious wondering round the house until eventually I might take a sleeping tablet or an anti-histamine to help me sleep. (Karen, 43yr)

During these interviews, various factors that either assisted or made it more difficult for participants to maintain resilience were identified. The influential topics discussed included: employment, relationships, communication, information and resources and unmet needs. Although the analyses highlighted factors contributing to resilience (i.e., open communication), several other factors created barriers (i.e., lack of time with specialists). This supports several studies indicating that the survivorship needs of distressed cancer patients have not previously been sufficiently met by the Australian healthcare system (Girgis & Butow, 2009; Jefford et al., 2008; Knott et al., 2012; Lobb et al., 2009). However, the resilience process could be improved by addressing many of the modifiable factors identified by these participants (i.e., offering counselling following treatment; improving communication, information and resources, providing regular contact; addressing isolation issues etc.).

Survivor Outcomes

The final theme identified in this study relates to survivor outcomes. As a result of living with HC, there were three main sub-themes that participants attributed to as factors associated with personal outcomes. These included, transition - finding a new normal; re-prioritisation and growth; and, self-reflection. According to Roundtree et al. (2011), cancer survivors usually define survivorship in terms of what it means to experience cancer. Likewise, the participants in this study sought to find meaning in order to explain and cope with their HC experience.

The interviewees reflected on this journey from two time frames; prior to and post cancer. Life before cancer involved the participants' sense of who they were, which was largely based on external roles, responsibilities and tangible material gains. Conversely, life following cancer comprised shifting away from outward (external) thinking, to involve more inward (internal) thoughts. For example, many participants described issues pertaining to 'personal achievement' and 'self-development', such as fully embracing life, discovering the purpose of their existence and wanting to make a difference in the world. For all participants this journey resulted in a significant transformation and a term that several referred to as 'a new normal'. This supports previous research reporting that the need to find a 'new normal' is

a common phenomenon among cancer survivors (McGaughan et al., 2012; Wallace et al., 2007).

Transition: Finding a new normal.

In this study, the participants highlighted that once the main crisis of HC cancer had subsided, their distress levels lowered. At this point, several participants recognised that they then began to focus their attention on positively adapting and moving on in their personal lives. However, the majority of participants found themselves lost in transition between their pre- and post-cancer lives. For example, Colin stated: “I suppose post-treatment you begin to get on with life again, but it’s like you live in that parallel universe, like you are just in a dream world for a while I guess.”

Following treatment, this sense of being ‘adrift’ and in ‘no man’s land’ was described by Little, Jordens, Paul, and Sayers (2001), who referred to this phenomenon as ‘liminality’. According to Little and colleagues, survivors’ transition through the space of illness, but do not return to their world as it was prior to illness. Rather they experience disorientation, which is then followed by an adaptive phase, in which the survivor constructs meaning from their experience. Other researchers have also implied that surviving is a process, involving several phases of change without an endpoint and is, therefore, a lifelong journey (Deimling et al., 2005; Dow, 1991; Pelusi, 1997).

Similarly, after treatment, many participant anecdotes alluded to persistent physical, psychological and social changes. As Ellen commented, “I’m far less tolerant ...it becomes the new normal, it becomes part of you and you can’t change it.” Moreover, this ‘new normal’ was viewed as something that set these HC survivors apart from others in society who had not experienced cancer. For example, Ellen went on to say:

Unlike most of my friends who haven’t had cancer, I don’t go out at night much anymore, I’m usually asleep early. So now my new normal is going out for breakfast and lunch instead.

Likewise Imogen had adjusted to changes in her routine:

I need to set my alarm at 4:30 in the morning to have my tablets because you’ve got to fast before you can have them. So this is normal now and these are the things that I have had to adjust to.

Re-prioritisation and Growth.

In addition to establishing a new normal, all participants discussed re-prioritising their lives and the subsequent outcome of personal growth following this experience. According to research, as is common after facing a life-threatening illness, cancer survivors often develop a more realistic and positive outlook on life and are not as easily upset by everyday stress (Bulsara, Ward, & Joske, 2004; McGrath & Clarke, 2003; Wallace et al., 2007). Similarly, in this study strength, optimism, acceptance, appreciation, determination, and the ability to process everyday stress in perspective were amongst many qualities that were reflected in the

interviews. As stated by Zac: “I now know how strong I can be, nothing has ever challenged me like this. It’s comforting to know if it does come back again I can cope, I have already done it.” Likewise several other participants shared the same view:

It's not all tragic or bad or sad. There are still all the good things in life that are happening...we still holiday, and I don't sweat the small stuff. I think that stands you in good stead, otherwise you're fighting and that can only give you ulcers and anxiety.
(Colin, 66yr)

That's another thing I don't judge people at all any more. Not that I used to very much, but now I definitely don't, knowing that you have no clue what they've been through.
(Lara, 44yr)

The way I positively interact with my diagnosis is more helpful definitely for myself as the first beneficiary and then also for others that can then witness me. (Fiona, 51yr)

These participants were acutely aware of life’s fragility, believing they had been given a second chance. This provided the momentum for participants to re-assess and re-prioritise their lives. As Fiona stated: “So for me it's like, well I have got it, it doesn't define me, I’m going to live a very full life, in fact it’s going to inform me in a better way.” Similarly, Alyssa commented: “Generally speaking I'm getting on with my life without letting leukaemia define who I am, I live with the disease not against the disease.” For other participants, their perspective on time had changed. This awareness empowered many to ‘seize the moment’. This was pivotal to their recovery and highlighted a quality that many believed was not present prior to their cancer diagnosis. As these participants explained:

It has been so beneficial for me to not stress about the future. We now take more holidays and enjoy the present. I guess I live much more day-to-day. I used to be too serious, a planner and saver! So much is different.
(Zac, 34yr)

I probably cope by living more in the moment. I know my future is important but that is unknown so I try to enjoy stuff now.
(Jack, 70Yr)

I've decided to live life and really enjoy myself, I don't worry about what's happening in six months time or in a year.
(Helen, 62yr)

In several circumstances participants also sought to optimistically re-appraise their lives. As the following participants remarked:

Sometimes I feel I'm in front because I'm in remission and they are keeping an eye on me. It's not as though I am walking around on the street without knowing I have got cancer. Even if they find something it's likely to be in the early stages so I guess that's a good position to be in.
(Pete, 63y)

It was kind of like a gift because it pulls you up and you never take life for granted. You think okay today is a beautiful sunny day and I want to make the most of it. So you live more in the moment and thinking about positive and less of the past. I have more trust in the goodness of humanity and the world generally. In some ways I feel more connected. The cancer experience has just given me another opportunity to step up.
(Fiona, 51yr)

Equally, other participants also commented that they had experienced personal growth and felt more liberated. Research in the area of post-traumatic growth (PTG) maintains that there can be signs of positive growth following cancer treatment (Tedeschi & Calhoun, 2004; Wenzel et al., 2002). According to Tedeschi and Calhoun (2004), PTG is “positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (p.1). One of the excerpts by Lara highlighted this:

I have grown as a person. Having cancer has definitely made me stronger mentally. You do go through the anger and all that and then you go through a stage where you're very carefree and then all these years later you come to a plateau. The little things don't matter, I am more at peace and I surround myself with people who are positive. I'm a better person for this experience.

Although PTG is achievable, it is not necessarily inevitable (Tedeschi & Calhoun, 2004). This is demonstrated in the current study in which a minority group ($n=3$) were undecided about whether they had experienced personal growth. However, these three participants who also maintained that they were coping well were all early in the survivorship trajectory (under 2 years). As Sharon stated:

It's early days and I feel like I am going ok, but I haven't had the chance to see the positives yet, you know properly take it all in.

Therefore, one could speculate that ‘time’ is an important factor in processing the cancer experience and that the absence of PTG does not necessarily denote a lack of resilience. Although this is beyond the scope of this study, future research into the relationship between PTG research and resilience would be beneficial in enhancing our understanding of personal growth and psychological well-being following cancer.

Self-reflection.

The final sub-theme, that was apparent in the majority of participant's interview transcripts, involved self-reflection. Each participant contemplated many aspects of this cancer journey and shared several areas in which they questioned not only personal choices but also highlighted several regrets. For example, several participants commented that they regret not expressing their emotions, taking time-out for themselves and/or keeping written anecdotes. This is highlighted in the following excerpts:

I wish had written down or recorded more information. I have forgotten a lot of stuff. I wish that I had gone out more for short walks or done gentle exercise that sort of thing. I think allocating that time may have helped my headspace. (Jack, 70Yr)

I wish I had allowed myself to vent more and not bottle up my feelings and keep a diary, as there is a lot I simply can't remember. (Helen, 62yr)

Others participants reflected on situations that left them feeling frustrated in areas they believed others were accountable. For example Anna stated: “I wish that I was offered the opportunity to exercise, it is probably the only thing that really could have made a difference

to my recovery.” Likewise Ellen remarked: “I wish I had been offered more thorough tests than I may have been diagnosed earlier.” In contrast, other participants reflected on their own need to take ownership. For example, some discussed the importance of prioritising and acknowledging their own limitations. As Alyssa stated: “I have come to realise my health comes first” and Ellen said: “Without burning the candle at both ends I still do what I can.” Similarly, Lily reflected on her part in being responsible for her health:

I used to fight it but one thing I've learnt through my psychologist is to listen to my body, when it tells me it's enough it's enough, and I do now. I gain courage from the easy days and take the difficult days one day at a time. When I think back, I used to feel guilty, but now I will actually lie on the couch. So I'm listening to my body now.

In summary, the previous discussion has outlined four main themes (and sub-themes) that the HC survivors in this study identified as contributing to their positive or negative mental health outcomes. These included: the burden associated with a HC diagnosis; resilience - coping with HC; pathways and barriers to resilience; and, survivor outcomes. This qualitative analysis has confirmed that over time many factors contributed to the process of resilience among these HC survivors. Thus, there is no unanimously effective or ineffective form of coping. Equally, Compas (1987) maintains that, in order to comprehend the coping response, one must consider the resources accessible within various individual, family and community levels. Therefore, if the resources alter or vary, the response to coping may also change. Ultimately, it is likely that the most beneficial coping response is shaped by one’s ability to adapt to an eclectic coping style that is not only influenced by available resources, but also the individual themselves (Moss, 1997). The following statements highlight such examples:

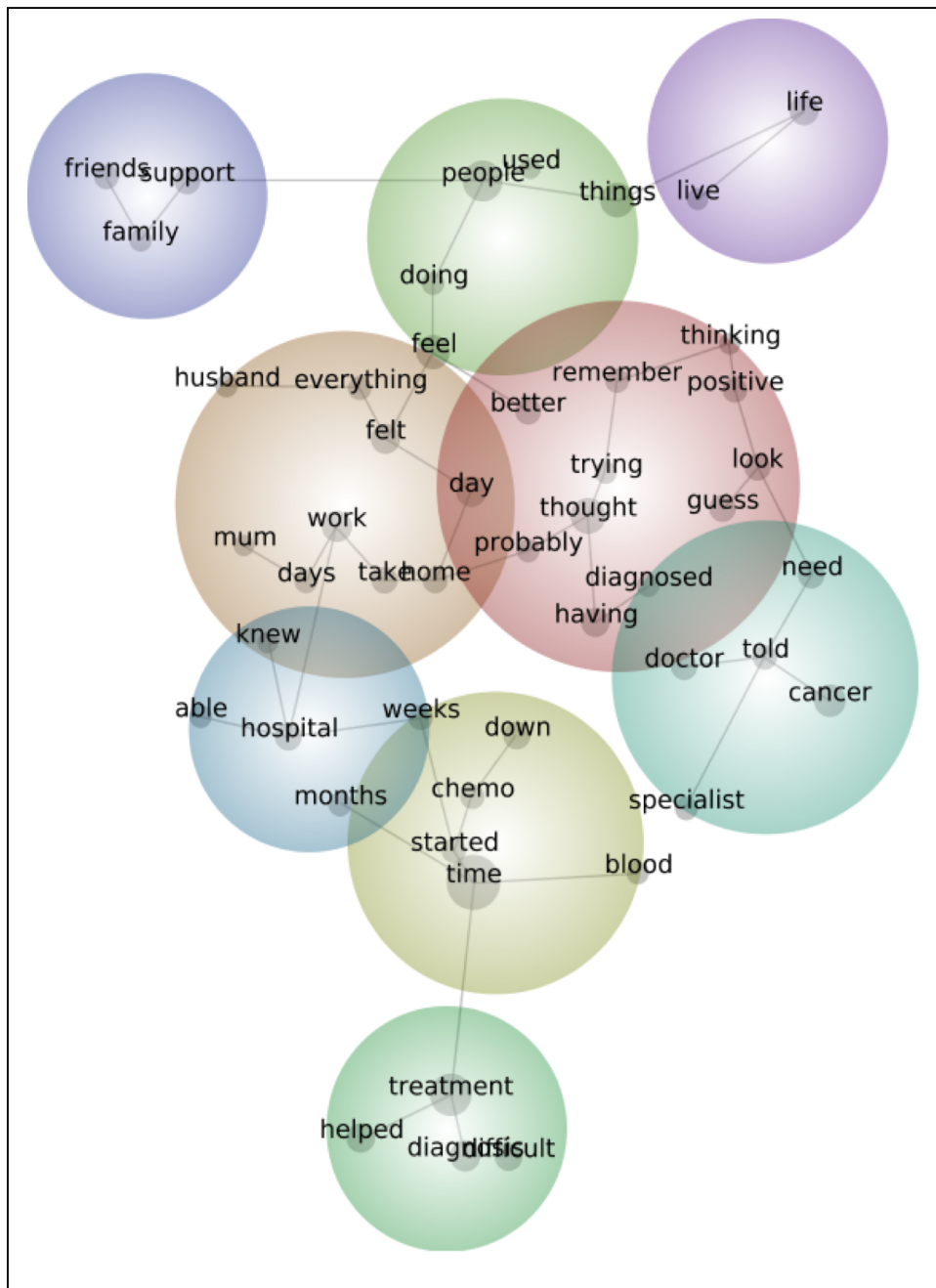
In terms of my personality, my friend thinks I'm like a dog with a bone. I won't give up on anything and I tend to stick with things. So I suppose resilience is just the same as that, you just stick at it and just get on with it and do the best you can. So I think that's my character to keep on keeping on, I won't give in. So I probably don't think about it consciously but I would say this attitude probably kept me going and helped me cope.
(Anna, 68yr)

I guess it's my mental approach to it all and remaining positive that helped me to be resilient. But if I'd got too many knocks at once, if too many other difficult things had occurred at the same time I could certainly see that would sooner or later impact on how resilient I would be. But having cancer has made me stronger and more determined.
(Ben, 60yr)

Leximancer Results

As previously mentioned, the collective findings of both qualitative thematic analysis and Leximancer analytic software contributed to the above results. There was an overlap of approximately 80% of the concepts/factors identified between the thematic and Leximancer analysis. For example social support, friends, family, work, remaining positive, treatment side-effects and the relationship with doctors/specialists were all commonly highlighted equally throughout both analyses. However, one advantage of including the Leximancer analysis was that it further highlighted 'time' as the most significant concept shared among the participants, further adding to the accuracy of data interpretation. Therefore, both the thematic analysis and use of Leximancer software had advantages, each of which contributed to a more valid analysis of the data.

A visual concept map produced by Leximancer is presented to further highlight the main themes and word concepts of the qualitative data provided by interviewees (Figure 5.1). Themes are 'heat mapped' to reflect importance. Thus, the hottest or more important themes appear in red (i.e., thought) then orange (i.e., work) and so on, followed by the colder colours, denoting less relevance (according to the colour wheel). This outlines the overlap of several concepts/factors identified between the thematic and Leximancer analysis. For example, remaining positive, social support, friends, family, work, treatment side-effects, the hospital experience and the relationship with doctors/specialists were all commonly highlighted. However, interestingly the individual factors such as positive thinking (red), work (orange), and down-time (yellow) were ranked as more important than the support from friends and family (blue). In addition to the themes, the ranked word concepts are also identified by the size of the black circles. As shown in Figure 5.1, the largest black dot representing the most frequently referred to word by interviewees was 'time' in the yellow circle (with 179 statement hits), the second was 'people' (with 145 statement hits) followed by the word 'treatment' (with 128 statement hits). Statement hits refer to the number of times these words appeared in separate statements within the data.



Note: □ Red □ Orange (warmer colours indicate most important themes)
□ Green □ Blue (cooler colours indicate less important themes)
 ● Larger size black dots represents most frequently referred to words

Figure 5.1 Concept map.

Interview Research Question 2. Which key factors made it easier or more difficult for HC survivors to achieve and maintain their resilience?

In order to answer this question, participants were asked to list the *top three protective factors* that either helped or hindered their resilience. In the first instance, interviewees identified what they believed facilitated their resilience. As can be seen from Table 5.3, the majority of participants ($n = 19$; 82%) referred to social support as one of their top three factors. This is not unexpected given the proliferation of literature confirming the significance of providing support to cancer survivors (Girgis & Butow, 2009; Jefford et al., 2008; Knott et al., 2012; Lobb et al., 2009; Stewart & Yuen, 2011).

However, what is of relevance is the imbalance between individual, family and community level factors. For example, when analysing all responses (i.e., three responses by each participant), 57% identified individual factors. This suggests that over half of participants believed (as opposed to their family or the community) most factors that facilitated their resilience were individually influenced (e.g., self-care, positive attitude, finding purpose, etc.). Of the eleven participants who listed community factors, the majority referred to their medical team ($n = 7$; 64%) followed by support agencies ($n = 2$; 18%) or medical accessibility ($n = 1$; 9%), with one participant also highlighting their workplace as being paramount.

Variations among participants also appeared to be related to demographic factors. For example, both participants under 30 years of age identified social media as the second most important factor. In addition, there are differences noted between short-and long-term survivors. The importance of finding purpose or life meaning was listed by 78% of long-term survivors, as opposed to only 28% of short-term survivors. However, self-care was more paramount in the early survivorship trajectory, particularly among the younger cohort. The difference in these cohort results are worthy of future consideration in terms of the both promoting individual protective level factors and providing beneficial methods of support across age and survivorship trajectory.

Table 5.3

The Most Influential Individual, Family or Community Related Protective Factors that Foster Resilience as Identified by HC Survivors

Participant	Age	Factors 1	2	3
Natasha	22	Social support	Social Media	Support groups
Travis	23	Social support	Social Media	Self-care
Sharon	31	Positivity/Focus	Social support	Self-care
Zac	34	Social support	Self-care	HC Professionals
Imogen	34	Social support	Workplace support	Accepting help
Max	40	Social support	Self-care	Purpose/Meaning
Megan	43	Genuine doctors	Purpose	Self-care
Karen	43	Social support	Faith	Remaining Positive
Lara	44	Social support	Personal outlook	Purpose
Fiona	51	Faith	Treatment accessibility	Financial stability
Alyssa	57	Social support	Purpose/meaning	Music
Ellen	58	Understanding self	Financial backing	Purpose - engagement
John	60	Acceptance	Positive attitude	Purpose - keeping busy
Ben	60	Social support	Positive attitude	HC Professionals
Helen	62	Social support	General Practitioner	Self-care
Pete	63	Social support	Self-care	Belief in self
Lily	64	Social support	Medical Specialist	Time alone/meditate
Colin	66	Social support	Purpose/keep busy	Trusting treatment plan
Anna	68	Doctors optimism	Social support	Trusting health regime
Tess	69	Social support/pets	Purpose/keep busy	Competent specialist
Jack	70	Social support	Positive attitude	Enjoying each day
Maria	70	Purpose/Meaning	Leukaemia Foundation	Sense of humour
Fred	84	Hope	Social support	Purpose - Learning

Note: Individual level Family/combined level Community level
 1-5yrs post treatment >5 years post treatment

The second part of question two aimed to highlight the *top three risk factors* that each participants found prevented, or made it more difficult for them to maintain their resilience (Table 5.4). As can be seen in Table 5.4, the individual factors were separated into either physical, psychological or social/community. In addition, several responses fell into more than one category, so these were labelled as combined level factors.

Many of the participants (16/23; 70%) listed individual factors as impacting on their resilience. Of the total individual factors identified (26/69), the majority of participants believed that psychological ($n = 18$; 70%), rather than physical ($n = 8$; 30%), effects impacted on their resilience the most. There were no specific family-related factors identified by this sample (in the top three). However, community/social factors (e.g., issues with specialists or employers) were selected by 43% interviewees and accounted for 17% of the total responses.

The majority of participants (18/24; 75%) considered that combined factors largely impacted on their ability to maintain resilience. For example, social isolation and/or loneliness (identified particularly among the female and younger survivors) that may lead to psychological issues can have implications for the individual, family and community. Likewise, the inability to work or forced early retirement can impact on the individual (physical, social, psychological), family and the community. The concerns over finances and forced retirement were particularly pertinent among long-term survivors. This result suggests that the risk factors impeding resilience are multi-layered (i.e., involve all levels). Therefore, supporting these individuals will likely require a broad, interdisciplinary approach that holistically addresses several facets of the HC survivor's world.

Table 5.4

The most Influential Individual, Family or Community Related Risk Factors that Impede Resilience as identified by HC Survivors

Participant	Age	Factors 1	2	3
Natasha	22	Social isolation	Loss of normality	Altered appearance
Travis	23	Isolation/Loneliness	Tx side-effects	Fear of reoccurrence
Sharon	31	Fear of future	Tx side-effects	Not offered counselling
Zac	34	Inability to work	Fear of death	Mental challenges
Imogen	34	Lack ex partner support	Unhelpful specialist	Unknown future
Max	40	Inability to work	Guilt family sacrifices	Financial impact
Megan	43	Fatigue/Nausea	Inability to plan future	Psychological impact
Karen	43	Being alone	Expectations of others	Lack of recognition
Lara	44	Physical/nausea	Lack of social support	Information timing
Fiona	51	Fear future health	Life's other demands	Recent previous trauma
Alyssa	57	Unknown future	Earlier isolation	Lack of control
Ellen	58	GP not listening	Ignorance of others	Issues with PBS Tx regime
John	60	Challenges/recurrence	Tx inconsistency	Impact on work
Ben	60	Medical incompetence	HC accessibility	Inability to work
Helen	62	Physical/ulcers	Fear of reoccurrence	Tx side-effects
Pete	63	Fear of reoccurrence	Issues with hospital	Loss of normality
Lily	64	Fear	Loneliness at night	Inability to work
Colin	66	Fatigue	Early retirement/ \$ loss	Tx side-effects
Anna	68	Panic attacks	Early retirement	Lack exercise opportunity
Tess	69	Physical side-effects	Adhering to Tx	Lack of Acceptance
Jack	70	Check-up anxiety	Fear of reoccurrence	Difficult to plan future
Maria	70	Unsupportive employer	Unexpected fear	HC Communication
Fred	84	Language barrier	Dealing with doctors	Fatigue

Note: Physical Psychological Community/Social Combined
 1-5yrs post Tx >5 years post Tx

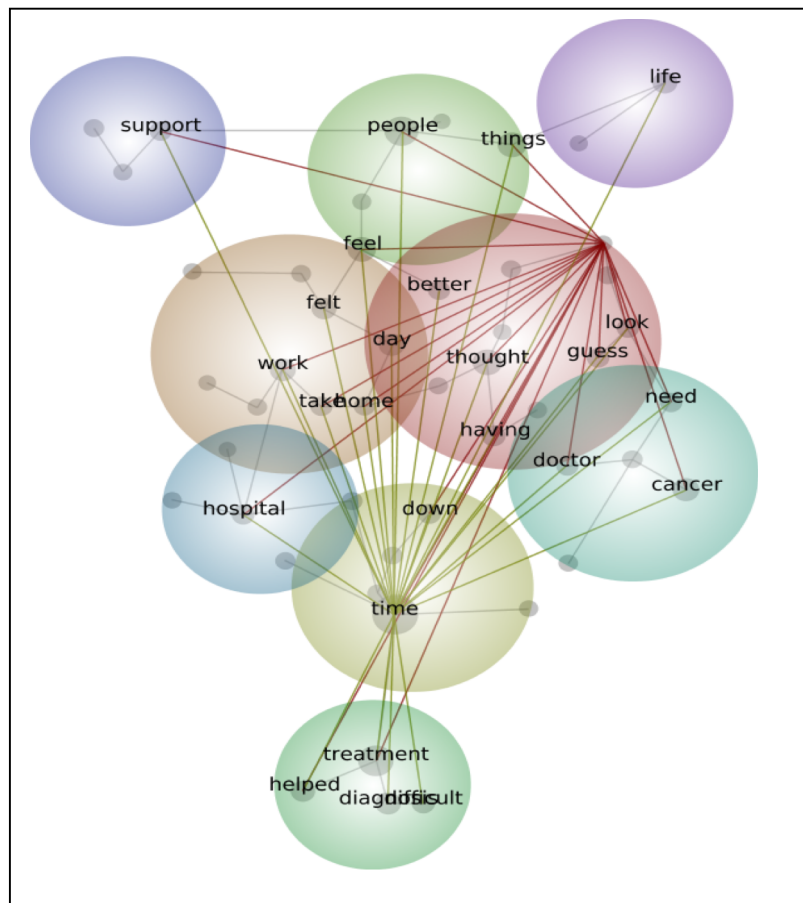
Tx = Treatment; PBS = Pharmaceutical Benefit Scheme; HC =Healthcare; \$ = financial.

Interview Research Question 3. Were there any factors mentioned during the interviews that were not previously identified in the proposed conceptual framework?

Several of the individual factors reported to be predictive of resilience in this study support those previously identified in the resilience literature. Many of these include, but are not limited to: perceived control, optimism, mastery, social support, self-efficacy, self-esteem, hope, empowerment, acceptance, determination, social support, coping strategies, spirituality, cognitive appraisal, and a sense of coherence. According to a meta-analysis by Stewart and Yuen (2011), this is not unexpected, given that past experiences, coping factors, genetics and the environment all influence resilience, regardless of the type of adversity faced.

However, this research also unearthed several factors directly salient to this population of HC survivors that were not identified as major contributing factors in the proposed conceptual model. These included aspects of positive health behaviours (such as making an effort with one's appearance, sustaining a healthy diet, and adherence to treatment). In addition, a sense of feeling connected to the physical environment was another unexpected factor that was not widely emphasised in the cancer-related literature. This was, however discussed in one study by Denz-Penhey and Campbell Murdoch (2008), who proposed that connectedness to the physical environment was important, as this provided the means for those with illness to achieve access to their inner wisdom. As they stated, "we would suggest that inner wisdom is the experiential source of knowing, energy and motivation for becoming a more whole and resilient person and that this inner wisdom has been shown to be often accessed through their positive relationship with self-selected aspects of their physical environment" (Denz-Penhey & Campbell Murdoch, 2008, p. 402). Many of the participants shared stories of how their sense of connectedness within their physical environment facilitated an inner peace impacting positively on their psychological wellbeing. For example, Helen discussed in depth, how moving to bush land had facilitated her recovery. Similarly, Anna and Fred both expressed the importance for them of living near the coast and having a view of the ocean.

The final relevant factor regarding the HC experience that had not been anticipated to such an extent in the analysis was the impact of time. The Leximancer software supported this finding and identified 'time' to be the most frequently referred to word expressed by participants. This is illustrated in Figure 5.2, which provides a visual representation of the significant links between the word concept 'time' and other relevant core concepts.



Note: □ Red □ Orange (warmer colours indicate most important themes)
□ Green □ Blue (cooler colours indicate less important themes)
 - Solid lines indicate significant relationships between concepts

Figure 5.2 Time-related concept map with core concepts indicated by a solid line.

As can be seen in Figure 5.2, 'time' was linked to many concepts (i.e., time in hospital, with people, at work, getting treatment, etc.). However, the most significant link identified in this study by interviewees was the need to take time (i.e., time-out, down-time, alone-time etc.). In doing so, the resilience process was nurtured, as time enabled the participants the 'space' necessary to process this adverse experience. As remarked by Fiona who believed she did not have time on her side:

I guess the fact that my cancer diagnosis came so soon after our other trauma and I really didn't have time to grieve. I have probably got unresolved grief that has carried over which has affected my resilience.

The impact and importance of time is also aptly expressed in this analogy by Alyssa:

If you imagine a hurdler running in a race. If the hurdles were too close together the runner wouldn't be able to get over them, but by giving space between them the runner is able to recover and is ready for the next hurdle. This is what I believe resilience looks like in some respects. So I guess if you have too many traumatic experiences without the time in between to recover this would be difficult.

The majority of factors identified as influencing resilience in this study support those discussed among previous literature investigating other cancer survivors (including other types of cancer). As can be seen from Table 5.5, the majority of factors are similar to those that emerged as a result of this study.

Table 5.5

Summary of the Factors Identified as Influencing Resilience among Cancer Survivors

Factors Identified in the Literature (All types of cancer)	Factors Identified in this Study (Haematological Cancer)
Personal Coping Strategies <ul style="list-style-type: none"> - Denial/Self-Blame - Emotion-focused - Problem-focused - Hope/Humour - Optimism - Acceptance - Mental flexibility - Determination - Risk-taking behaviours <ul style="list-style-type: none"> o Alcohol/drugs Adherence to treatment (Non-compliant or Compliant) Empowerment <ul style="list-style-type: none"> - Decision-making control Social support Relationships <ul style="list-style-type: none"> - Family/friends/community - Healthcare professionals Communication Self-care Self-education Treatment options Information/Resources Purpose/Life Meaning <ul style="list-style-type: none"> - Employment - Community Spirit - Hobbies - Spirituality 	Personal Coping Strategies <ul style="list-style-type: none"> - - Emotion-focused - Problem-focused - Hope/Humour - Optimism - Acceptance - Mental Flexibility - Determination Adherence to treatment Empowerment <ul style="list-style-type: none"> - Decision making control Communication Relationships <ul style="list-style-type: none"> - Family/friends/community - Healthcare professionals Social Support Self-care specifically: <ul style="list-style-type: none"> - Health behaviour change (care with appearance) (diet, exercise) (taking time-out for oneself) Self-education Treatment options Information/Resources Purpose/Life Meaning <ul style="list-style-type: none"> - Employment - Community spirit - Hobbies - Spirituality

Note: □ Factors not identified in this sample of HC survivors

□ Relatively unique factors highlighted in this HC survivor sample

The only relatively unique factor in this research influencing resilience, related to certain areas of positive health behaviour change (i.e., taking time-out). Although aspects of health behaviour change (i.e., diet and exercise) have been discussed in several studies (James,

et al., 2011; Murphy, 2013; Park et al., 2008) involving cancer survivors, these factors have not been linked to maintaining resilience among this population. In addition, several studies discuss self-blame, denial, non-adherence to treatment and risk taking behaviour as a negative coping strategy (Block, Drafter, & Greenwalk, 2006; Friedman et al., 2010; Lynagh et al., 2015; Marjerrison, Hendershot, & Nathan, 2014; Phelan et al., 2013). This was not apparent among the HC survivors involved in this study. Table 5.5 provides a summary of the protective factors not only common to those identified among previous research but also those unique to this study.

Modified Conceptual Model

Many of the factors influencing resilience in this study are reliant on personal qualities (i.e., values and beliefs), trait characteristics (e.g., optimism, flexibility, and determination, and persistence), environmental factors (i.e., family and community social support) and can be considered part of a process (keeping busy, taking charge and contributing in the community). As stated by Denz-Penhey and Campbell Murdoch (2008), “resiliency can be thought of as starting with the inner-most depth of individual being, moving through social relationships to the person’s relationship with their physical environment” (p. 400).

Therefore, these results support resilience research that is based on an ecological framework (Masten, 2007; Richardson, 2002; Ungar, 2008; Ungar et al., 2007), in which risks and protective processes are understood through either the individual, family, and community levels. However, the model in the current research deviates slightly from this context, as many of the significant resilience processes for participants are also interconnected within these levels. For example, effective communication, finding meaning and self-care were all protective process identified by participants. However, these transpired across all levels through individual, family, and community processes.

With these results in mind, the modified model of resilience shown in Figure 5.3 visually represents the three levels (individual, family and community) as circles. Resilience has been identified as a process that is not stagnant or stationary. The circles, therefore, reflect the continual movement (like a wheel) of each level over time. In addition, the levels intersect each other to highlight that resilience is multi-layered, thus not solely reliant on individual, family or community factors, but rather the integration of each. This conceptual framework enables us to gain a deeper understanding into each key process of resilience, and can be used by healthcare providers in advising the patient, family members and the wider community on what to expect during the initial and extended stages following a HC diagnosis.

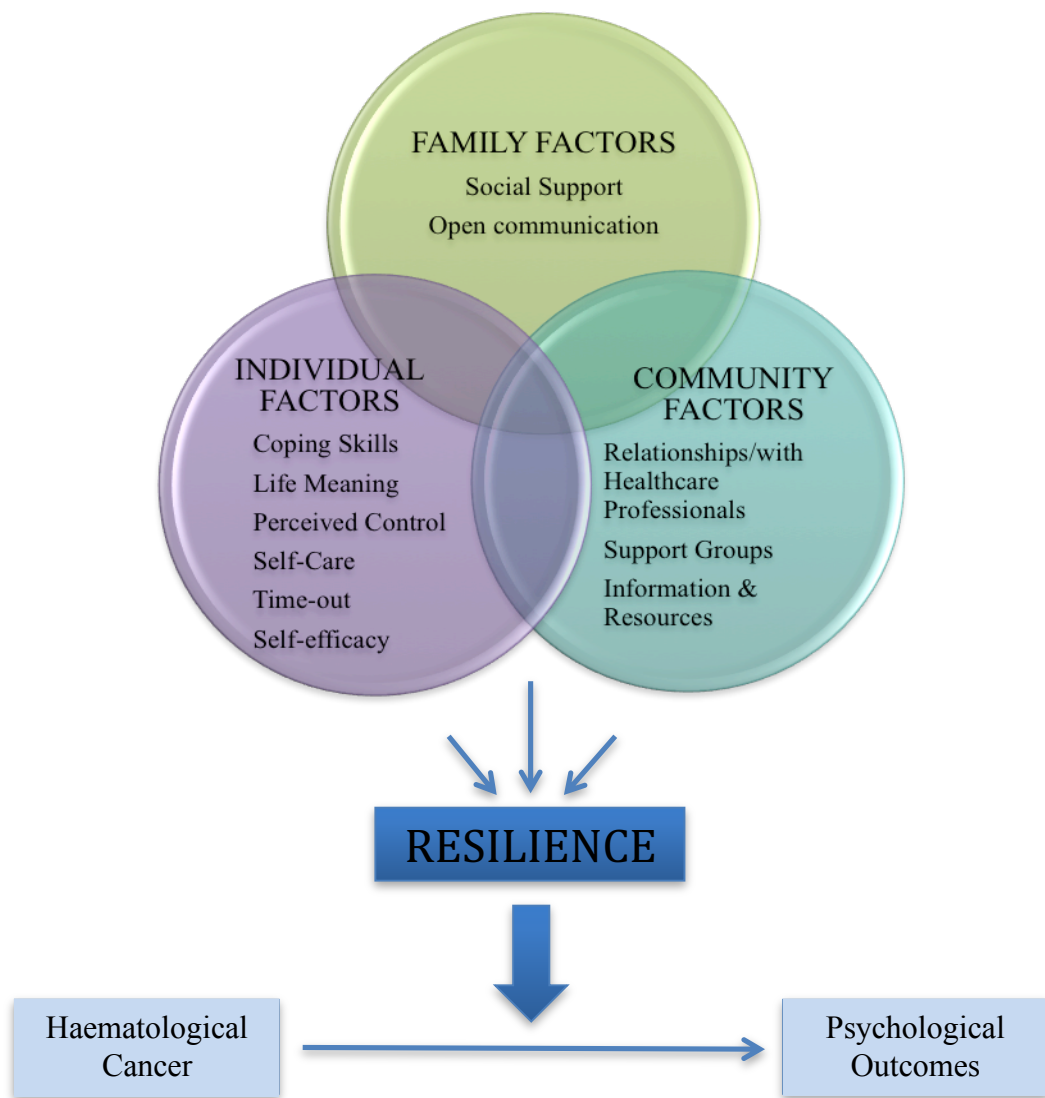


Figure 5.3 Modified conceptual model of resilience factors influencing psychological outcomes among HC survivors that is best reflected by the ecological approach to resilience.

Conclusion: Phase One

The findings suggest that the psychological response to cancer is multi-dimensional and that resilience is not a static concept. The interviewees all discussed the distressing physical, psychological and social impact of HC, including areas of immense loss. However, importantly, this analysis also highlighted several protective processes that may contribute to the resilient strength of individuals when faced with HC. This analysis exposed the varying level of support provided by family, peers, healthcare professionals and the extended community and how this impacted on their overall functioning. In addition, individual personal coping strategies (i.e., attitude), self-care, time and being self-informed, were among many modifiable factors that facilitated resilience in this population. For example, many participants reported the positive influence of effective health behaviour change (i.e., exercise, diet, etc.) and how taking time-out (i.e., relaxation) to process this experience assisted their recovery.

Moreover, the results not only illustrated the significance of the emotional impact of cancer on the survivors, but also highlighted individual differences. For example, the interviewees varied greatly in their need for information. Although the timing, quality and quantity were important, some survivors were more keen than others to be fully armed with informational resources. These participants spoke of sourcing extra information from the Internet to supplement the resources from healthcare providers and support groups. Conversely, there were others who felt overwhelmed and inundated by large amounts of information, preferring to focus on the essential facts. Therefore, the transcripts support the observation that individuals can exhibit resilience in different ways, and in ways that others find challenging. Resilience factors were also exhibited differently depending on demographic factors, such as the age of the survivor during diagnosis, employment status, time since diagnosis, financial circumstances and previous experience.

While most participants managed their day-to-day lives, they also acknowledged situations they found challenging. Therefore, delving beyond factors that enhance resilience, the findings also discussed barriers/risks to resilience such as fear (future uncertainty), lack of support, inadequate resources, unmet needs and ongoing challenges related to the healthcare system. Many of these barriers were cultivated by physical, psychological and social reminders of the disease. For example, several survivors were reminded of their HC experience each time they attended medical check-ups or felt unwell. However, given appropriate support and resources, the majority of HC survivors were able to identify, implement and maintain personal strategies to enhance their resilience.

Finally, in order to successfully navigate a 'new normal', the results highlighted the way in which many participants, reflected and re-prioritised their current and future lives. For the majority of participants, the HC experience offered them the opportunity to learn, adapt and grow as individuals. For example, survivors became more aware of their vulnerability,

and, as a consequence, previous priorities such as material gains became less important. The HC survivor outcomes reflect a deeper appreciation of life, largely based upon their current environment and individual core beliefs and values.

Summary of Qualitative Analyses

Chapter 5 began with an outline of the main aim and research questions. The overall objective of Phase One was to examine factors that facilitate the resilience process among HC survivors. Phase One also aimed to identify particular risk factors related to chronic illness that negatively affect mental well-being. Although resilience has been extensively studied among healthy individuals (Min et al., 2013), to date, less is known about the factors associated with resilience in cancer survivors, including patients with HC.

Following outlining the study objectives, the profile of the participants and the findings were then presented. To enable a valid and rich account, the current study explicated these experiences using rigorous qualitative methodology, by including both thematic analysis and Leximancer analytic software. The results of this qualitative inquiry, involving 23 in-depth interviews, were then presented through the classification of major and sub-themes that emerged from the transcripts. To comprehensively explain this resilience process, exemplars were presented and interpreted in conjunction with reference to previous research. The results suggest that, although there was great diversity among participants, the majority shared a similar journey.

This chapter presented the participants' experiences as they described their response to HC. As stated by Lau and van Niekerk (2011, p. 1177), "rather than imposing *expert* judgment on experiences...survivors are offered the space to draw on their own strengths and contextual *realities* as defined by their gender, culture, history, and social location." Moreover, this information supports, and yet expands on, the available literature addressing chronic illness and personal resilience. The findings from the interviews provide the reader with an in-depth description of the challenges and support needs among this population. It seems that the key processes of resilience (i.e., coping strategies, social support, attitude etc.) are constantly evolving, with each dimension affecting the outcome of the other. This dynamic process was visually captured in a revised conceptual model of resilience in HC survivors.

The next chapter (Phase Two) outlines the item development and a pilot study (Stage I) that aimed to collate relevant measures to be included in a larger questionnaire (Stage II). The purpose of the pilot study was not only to test the findings of the qualitative interviews, but also to examine the reliability and validity of the measures included.

Chapter 6

Phase Two (Stage I) – Development of Questionnaire and Pilot Study

Chapter Overview

The development and implementation of the pilot questionnaire is discussed in this chapter. First the rationale, preliminary considerations and pilot study aims are highlighted. The methodology is then described which details the data collection procedures and a description of the cancer survivor pilot study participants. The information and findings relating to the reliability and validity results of the questionnaire are then presented. The chapter concludes with a discussion of the developed questionnaire.

Introduction

The earlier qualitative phase of this study used interviews to investigate the experiences of individuals that had been diagnosed with haematological cancer. A key objective of this qualitative inquiry was to explore how each HC survivor coped with such adversity. Four core themes that were identified following the interview analyses included: (1) the burden associated with a HC diagnosis; (2) resilience - coping with HC; (3) pathways and barriers to resilience; and, (4) survivor outcomes. Many of the influential resilience factors shared by the current participants, support those discussed in the cancer-related literature. For example, the analyses revealed several factors that were considered by participants to be either protective (i.e., contribute to resilient outcomes such as optimism) or contribute to risk (i.e., conditions or situations which can decrease the chances of resilience, such as lack of social support) (Masten, 2007; Ungar, 2008).

Protective and risk factors that emerged from the interview analyses together with factors identified in the literature offered direction and ultimately guided the selection of measures to be included in the Phase Two data collection survey questionnaire. Protective factors have been identified as *coping strategies*, such as acceptance, positivity, active coping, humour, planning, self-distraction and religion/spirituality. However, it was unclear, from literature and the results from the survivor interviews conducted for this study, exactly which coping strategies have the most influence on resilience among HC survivors. Therefore, the Brief-COPE (Carver, 1997) was included as a measure in order to differentiate protective factors in the survey data collection phase of this pilot study. In addition, the analysis of the interview data identified varying levels of *social support* provided by family, peers, healthcare professionals and the extended community and how this impacted on the respondent's overall functioning. Social support is widely discussed in the literature as being a significant factor

contributing to resilience. However, what is less understood is who, when and how social support impacts on the resilience process, or indeed, if this is dependent on other external factors (i.e., time since diagnosis). Consequently, the Multidimensional Scale of Perceived Social Support (MSPSS) was also included as a measure of social support. Moreover, the interview data also revealed several factors salient to this population of HC survivors that were not identified as major contributing factors in the proposed conceptual model developed from the literature review. These new factors included the implementation of diet modification, exercise, taking care of one's appearance and taking time out for oneself. Therefore, in order to identify the effect on various types of *health behaviours* on resilience, a final scale with these four factors was created to reflect each HC survivor's positive health behaviour strategies.

Several outcome measures that assessed *mental health* (i.e., anxiety and depression) and *resilience* were also included. It was important to measure anxiety and depression, as both the literature and the interview results indicated that many HC survivors experience negative mental health outcomes as a result of their diagnosis. Resilience is reported to buffer against depression and anxiety. It was, therefore, essential to include a validated resilience scale. By including both of these outcome measures, the relationship between mental health and resilience will be better understood. In total, the questionnaire used in this pilot study consisted of 5 scales with 30 items.

It is acknowledged that many other individual factors reported to be predictive of resilience in this study, are consistent with those previously identified in the cancer resilience literature. Several of these include, but are not limited to: meaning/purpose in life, perceived control, mastery, self-efficacy, self-esteem, hope, connectedness and empowerment (Alim et al., 2008; Bulsara, Ward, & Joske, 2004; Denz-Penhey & Campbell Murdoch, 2008; Folkman, 2010; Groopman, 2004; Hou, Law, Yin, & Fu, 2010; Llewlyn et al., 2013; McGrath, 2004a; Rodin et al., 2013; Schumacher et al., 2014; Stewart & Yuen, 2011). However, these factors have not been included as specific measures in this pilot study for two reasons. First, it is not possible to include every factor in the survey. Second, the majority of reports concur that these individual factors are indeed influential. Therefore, as we would not be contributing new findings, the above-mentioned factors have been omitted to ensure that the pilot survey is succinct.

Pilot Study Focus and Preliminary Considerations

The main focus of Phase Two (Stage I) of this thesis is to use the findings from the qualitative enquiry, including evidence from the literature, to inform and guide an appropriate survey for the final quantitative study (Stage II). While the majority of findings between previous literature and interviews represented an overlap, there were notable differences. For example, the interview findings suggest that the majority of HC survivors actively seek the

opportunity for positive health behaviour change. Although aspects of self-care (e.g., diet, exercise) are highlighted in the literature as factors that assist coping, additional factors, such as care in appearance and taking time out for oneself, were not widely discussed. In addition, among some cancer survivor populations (i.e., liver, cancer etc.), self-blame is commonly reported, in which substance abuse may present as a risk factor. Yet these factors were not identified during the interview results or reported in literature specifically investigating HC survivors. It is not clear whether these differences are due to the small sample size or if indeed there are variations between HC and other cancer types. Therefore, these results need further verification among a larger sample, in order to substantiate the findings.

However, prior to conducting this survey involving a larger sample of HC survivors, various preliminary considerations concerning the survey required addressing. The majority of items used in this study are valid and reliable published scales. Nonetheless, based on the interview findings, there are additional items included that have not been psychometrically tested. It was, therefore, important to assess the validity, reliability and feasibility of the proposed questionnaire items. Reliability (repeatability and consistency) refers to whether the results are more than a one-off finding and can be replicated (Babbie, 2010). Test validity is an indicator of how much meaning can be placed on the results. This includes face validity (at face value, whether the instrument appears to be representative and of high-quality); criterion validity (whether a measure reflects a certain set of abilities); construct validity (whether the test actually measures what is intended); and, content validity (whether a measure represents every element of a construct). Last, feasibility is an evaluation and analysis of the proposed tool (Gatewood, Field, & Barrick, 2008; Tabachnick & Fidell, 2007).

Aims of the Pilot Study

The first aim of the pilot study was to identify and/or create appropriate measures. It is essential that these measures either reflect significant factors that emerged from the qualitative interviews conducted in Phase One (i.e., taking time out, diet modifications) or have been referred to, within cancer resilience research, as having a considerable effect on health-related outcomes (i.e., types of coping strategies, social support).

The second aim of this pilot study involved reviewing the statistical properties of the scales included in the questionnaire. This included the mean, range, skewness, and kurtosis of the measures used within the questionnaire. In addition, the reliability (i.e., both internal consistency and stability) over a 2-week interval were assessed.

The final aim was to acquire feedback from participants concerning their experience of completing the survey. In particular, it was important to ensure the survey instructions were clear to understand and that items were easy to read and complete. In receiving participant feedback, it is also essential to establish that the content of items is accurate and if any

additional measures needed to be included. Research indicates that developing a questionnaire that includes issues that are pertinent to respondents, may promote higher response rates, potentially reduce non-response error and help in data coding and analysis (Bernard, 2000; Dillman, Smyth, & Christian, 2009; Williams, 2003). Importantly, the questionnaire design literature offered beneficial advice, regarding the various ways of organising the current survey to best obtain relevant information that would address the research question (Hagino, 2002).

Pilot Study Data Collection

Materials

Qualtrics was used to develop and distribute the on-line, self-administered pilot questionnaire (Appendix IA through to IE). The participants all received an information flyer (Appendix J) that was attached to the emails and explained the purpose of the research, outlined participation criteria, discussed privacy/confidentiality issues and requested participation. The pilot questionnaire contained a total of 5 scales (30 items), as well as 20 items that assessed demographic characteristics. The scales included in the pilot study were previously outlined in detail in Chapter 4 (Methodology).

Twenty-two of the 30 items were examined due to the base of evidence that they measured the domains from both the literature on resilience and the findings identified during the interviews. These included family support, support from friends, healthcare professionals and significant others, self-distraction, active coping, denial, substance use, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, self-blame, exercise, diet modification, care in appearance and taking time out. Therefore, the final pre-test instrument contained all the relevant questions (including standardized instruments) designed to obtain the most accurate information about the factors of interest in this dissertation regarding resilience.

Findings and Discussion

Profile of Participants

The pilot questionnaire was tested on a convenience sample of 17 mixed cancer survivors, all of whom spoke English and lived within the Perth metropolitan area of Western Australia. As this pilot study was investigating reliability and face, content and construct validity, it was not necessary to only include HC survivors. The questionnaire took approximately 20-30 minutes to complete. The majority of those interviewed were Australian ($n = 8$; 47%). However, the sample also included participants from the United Kingdom ($n = 6$; 35%), Europe ($n = 2$) and one from South Africa. As outlined in Table 6.1, one more female ($n = 9$; 53 %) than male ($n = 8$; 47%) was interviewed. The ages of interviewees varied from 28 to 74 years ($M = 55.35$, $SD = 12.05$) and the years since diagnosis ranged from one to nine years ($M = 4.53$; $SD = 3.28$). As indicated in Table 6.1, the 17 survivors interviewed represented seven different cancer diagnoses. The majority of cancer survivors reported undergoing a combination of treatments including: chemotherapy, radiotherapy, surgery, immunotherapy, oral medication, brachytherapy⁵ and hormonal implants. In addition, since their initial diagnosis and treatment, one of the participants reported experiencing a relapse.

The majority (71%) of the sample was either employed full-time ($n = 6$), or part-time ($n = 6$); the remainder were either retired ($n = 4$) with one participant on a pension, and another a stay-at-home mother. There were 68% of participants with either a tertiary diploma/trade (35%), tertiary undergraduate (42%) or postgraduate (6%) degree; 12% had completed Year 12/HSC; while 18% had completed Year 10/11, with one participant finishing prior to Year 10 level. Although the relationship status of participants varied, the majority were married ($n = 11$; 65%), the other participants were either *de facto*/partnered ($n = 2$), separated ($n = 2$) and, of the remainder, one was single and the other a widow. Slightly more than half the participants did not consider themselves religious ($n = 10$; 59%). In this sample, the majority of participants had children ($n = 13$; 76%).

⁵ Brachytherapy is a procedure that involves implanting 'radioactive seeds' in the prostate which emit small amounts of radiation to prevent cancerous cells from growing.

Table 6.1

Profile of the Pilot Study Participants

Participant	Sex	Age	Cancer	Treatment Type	Years Since Diagnosis
1	M	28	Testicular	C, S	4
2	F	36	Breast	S	2
3	F	43	Breast	R, C, O, S	1
4	M	48	Bowel	C, S	6
5	M	49	Skin	R, S	6
6	F	52	Ovarian	C, S	4
7	F	54	Breast	S	10
8	F	56	Breast	R, C, S	10
9	M	57	Prostate	S	1
10	F	58	Melanoma	I	1
11	M	59	Prostate	S	1
12	F	60	Breast	C, S	10
13	M	63	Bowel	S	2
14	F	66	Breast	S, O	6
15	F	68	Bowel	S	7
16	M	70	Prostate	B	2
17	M	74	Prostate	R, H	4
		$M = 55.35$ ($SD = 12.05$)			$M = 4.53$ ($SD = 3.28$)

Note: C = Chemotherapy; R = Radiotherapy; S = Surgery; I = Immunotherapy; H = Hormonal implant; B = Brachytherapy; O = Oral medication

Instrument Development

The *first aim* of the pilot study was to identify and create appropriate measures to meet face and construct validity. This was accomplished by ensuring that the measures included either reflect significant factors that surfaced from the qualitative interviews conducted in Phase One or have been referred to within cancer resilience research. In addition, the majority of measures included well-validated published tests. A total of 5 scales (30 items) were selected for this pilot study, as previously discussed in detail in Chapter 4 (methodology).

Psychometric Properties

The *second aim* of the pilot study was to assess for reliability including criterion and content validity by statistically assessing the psychometric properties of each measure (see Table 6.2). Significant deviations from normality were calculated using the following formula (Field, 2009), where S = the skewness value and K = the kurtosis value.

$$Z_{\text{skewness}} = \frac{S - 0}{SE_{\text{skewness}}}$$

$$Z_{\text{kurtosis}} = \frac{K - 0}{SE_{\text{kurtosis}}}$$

A Z-score above ± 1.96 within small samples indicates a significant deviation from normality. Using this criterion, approximately half the measures within this study were not normally distributed. Those factors that were normally distributed included: planning, acceptance, religion, support from healthcare professionals, exercise, including all resilience, depression and anxiety factors.

To assess the internal consistency reliability, Cronbach's Alpha (α) was calculated. Denial ($\alpha = .33$); venting ($\alpha = .10$); planning ($\alpha = .55$); acceptance ($\alpha = .31$); family support ($\alpha = .66$) and diet ($\alpha = .56$) initially produced a poor internal consistency score. It may be that the low participant numbers ($n = 17$) contributed to these results. However, two outliers were identified and when these were removed all internal reliability scores reached acceptable levels ($>.70$). Therefore, all published items remained in the final questionnaire, except for one of the created items measuring 'diet' which was subsequently deleted as it demonstrated a poor internal consistency reliability.

In testing the reliability of measures over a 2-week time period (test-retest reliability), either Spearman's correlation coefficient (ρ) or Pearson's correlation coefficient (r) was calculated, depending on the measure's normality (see Table 6.2). Active coping ($\rho = .52$), fell below an acceptable test-retest correlation. However, the internal consistency reliability was high ($\alpha = .84$). A closer inspection of responses on this measure indicated a significant outlier. This case was excluded from the test-retest reliability analysis and subsequently produced an acceptable correlation coefficient ($\rho = .71$). The HADS results also fell below an acceptable level ($r = .54$). However, the HADS which is considered a reliable and valid scale, is time-specific, in that it requires participants to respond to items for the previous week, and therefore scores may differ between the initial and the follow-up survey. All other measures produced acceptable test-retest reliabilities.

Table 6.2

Psychometric Properties of the Measures within the Pilot Questionnaire

Scale	N	M	SD	α	Pearson's (<i>r</i>)	Range		Skewness	Kurtosis
					Spearman's (ρ)	Potential	Actual		
Self Distraction	17	5.88	2.29	.81	.81 _a	2-8	2-8	-1.38	-0.83
Active coping	17	6.12	1.73	.84	.52 _a	2-8	2-8	-1.72	0.87
Denial	17	2.76	0.97	.33	.68 _a	2-8	2-5	1.81	-0.81
Substance use	17	2.24	0.66	1.00	.70 _a	2-8	2-4	7.74	5.18
Emotional support	17	6.71	1.57	.90	.87 _a	2-8	2-8	-3.17	3.86
Instrumental support	17	6.00	1.94	.84	.90 _a	2-8	2-8	-1.81	0.22
Behavioural disengagement	17	2.35	1.00	.78	.99 _a	2-8	2-5	4.75	5.12
Venting	17	4.65	1.32	.10	.86 _a	2-8	2-6	-2.00	0.13
Positive Reframing	17	5.94	2.01	.80	.80 _a	2-8	2-8	-1.44	-0.34
Planning	17	6.29	1.45	.55	.87 _b	2-8	3-8	-1.32	0.19
Humour	17	5.24	2.46	.98	.90 _a	2-8	2-8	-0.51	-1.45
Acceptance	17	6.60	1.23	.31	.82 _b	2-8	4-8	-0.84	-0.50
Religion	17	4.47	1.84	.89	.92 _b	2-8	2-8	0.41	-0.87
Self Blame	17	3.06	1.30	.79	.93 _a	2-8	2-6	1.90	0.03
BRIEF COPE (Total)	17	68.29	12.02	.87	.95 _a	28-112	34-87	-2.66	3.27
Family support	17	25.06	2.38	.66	.73 _a	4-28	20-28	-0.83	0.10
Friends support	17	25.76	2.80	.94	.71 _a	4-28	20-28	-1.94	0.06
Significant others	17	25.00	5.82	.99	.66 _a	4-28	4-28	-5.93	11.15
Healthcare professionals	17	23.18	3.54	.85	.79 _b	4-28	16-28	-0.81	0.40
MSPSS (Total)	17	99.00	9.54	.85	.61 _a	16-112	77-109	-2.06	0.54

Table 6.2

(continued)

Scale	<i>N</i>	<i>M</i>	<i>SD</i>	α	Pearson's (<i>r</i>)	Range		Skewness	Kurtosis
					Spearman's (ρ)	Potential	Actual		
Time out	17	14.29	3.74	.93	.98 _a	3-18	3-18	-3.29	4.26
Exercise	17	14.82	2.06	.92	.87 _b	3-18	10-18	-0.64	-1.02
Diet	17	14.82	2.81	.56	.94 _b	3-18	10-18	-1.35	1.18
Appearance	17	13.24	3.65	.80	.94 _a	3-18	7-18	-0.88	-0.84
HBC (Total)	17	57.18	9.96	.90	.97 _a	12-72	38-69	-1.38	-0.74
RSA (Total)	17	195.24	17.5	.89	.90 _b	33-231	157-224	-0.61	-0.07
HADS (Total)	17	9.29	4.02	.68	.54 _b	0-42	2-17	0.08	0.31

Note. MSPSS = Multidimensional Scale of Perceived Social Support; HBC = Health Behaviour Change; RSA = Resilience Scale for Adults; HADS = Hospital Anxiety and Depression Scale.

a = Test-retest for normally distributed data using Pearson's correlation (*r*).

b = Test-retest for data that is not normally distributed using Spearman's correlation (ρ).

Qualitative Results

A *final aim* was to acquire feedback from participants concerning their experience of completing the survey in order to evaluate face validity (personal judgement) and feasibility (evaluation of the tool). This qualitative information was designed to refine the instrument content in terms of ease of completion and comprehension. All participants understood the instructions and found the questionnaire easy to complete. However, there were several items in which the participants either responded to differently or provided feedback suggesting that improvements could be implemented.

First, there was feedback in relation to the item asking about when participants last had treatment. For example, one participant queried this, as she was required to take lifetime treatment in the form of oral medication and therefore found this question difficult to answer. This question was subsequently changed to ask, "Which scenario best describes your current treatment regime?" The participants could choose from the following options: "N/A I did not require active treatment"; "I am currently undergoing treatment which will NOT continue indefinitely"; "My treatment is ongoing (i.e., I will always need to take medication)"; "I have completed treatment for my cancer (if so how many years ago)?" or "Other – please specify" where participants could write their own response. Additionally, in the same section of the pilot survey, when entering data the researcher realised that when she asked participants, "Your age at onset of cancer?" it required her to manually calculate how many years since the participant was diagnosed, based on their current age. Consequently, this item was altered to instead ask, "How long ago were you diagnosed with cancer (in years)?"

Second, many participants seemed confused by the question relating to their ethnicity. This was identified through the range of responses offered by several participants detailing various descriptions of the same ethnicity. For example, the range of responses for one particular ethnicity was White European, Irish, Caucasian, White South African, Aussie, Born in England and Australian. This item was consequently altered from a qualitative response to categorical, where participants chose from one of the following responses: "White (including Caucasian, Anglo, European; not Hispanic)"; "Hispanic or Latino (including Mexican American, Central American, and others)"; "Asian (including Chinese, Japanese, Korean and others)"; "Middle Eastern"; "Black (including African, African American, African Australian, African-European)"; "Aboriginal"; "Torres Strait Islander"; and "Other" where participants could write a response.

A similar scenario occurred with the question asking if participants belonged to any religion. Like ethnicity, there was a range of responses offered by several participants detailing various descriptions of the same religion. For example Christian, Anglican, Christian-Anglican, Catholic and Buddhist were some of the responses. Consequently, this item was

reworded to ask, “Which best describes your religious beliefs?” The participants could select from the following categorical options: “Non-practising”; “Christian (including Uniting, Anglican, Baptist, Catholic and others)”; “Buddhist”; “Islamic”; “Hindu”; “Jewish”; and “Other” where participants could add their own response.

Third, in relation to relationship status, two of the participants added ‘separated’ in the “Other” option with the provided text box. In response, ‘separated’ was added as a categorical option. Likewise, on the item asking about employment status, one participant added home duties to the “Other” text box and another self-employed in the section asking for feedback. For the purposes of the current study the categories of home duties and self-employed were also included to more accurately reflect the activities of those who care for children full-time or run their own business.

Fourth, there were issues identified in section of the survey asking about social support (MSPPS scale). In this pilot questionnaire, healthcare providers (HCP) were referred to as a group not as individuals. Consequently, one participant found this difficult to answer as she had diverse experiences stating that, *“I have an alternative medicine general practitioner who is awesome but have found conventional doctors are closed to alternative treatment and thus I have little support from them. When I pursue those treatments in conjunction with conventional treatment I have experienced some awful treatment from some specialists”*. Subsequently, the wording in the instructions was changed to ask participant to consider the HCP who was most helpful to them when answering the following questions. In addition, an open-ended section was added to the end of the final survey, which allowed participants the opportunity to explain in more detail who in their clinical team was least and most helpful following their cancer diagnosis. It is hoped that this may provide further insight into the support, or lack of, offered by clinicians.

Fifth, at the completion of the pilot survey there was an open-ended section asking “Is there anything that is missed in how you have coped?” Several participants contributed feedback that suggested two other factors influence resilient outcomes. Two participants felt very strongly about the value of receiving alternative/complementary therapies. Another two commented that staying informed and proactively searching for cancer related information was vital to them. As one participant stated, *“I feel more able to cope when I actively source the latest treatment and information about my cancer”*. In relation to alternative therapies and seeking cancer-related information, the earlier interviews indicated mixed results, which are important to highlight.

The results from the earlier qualitative study not only illustrated the significance of HC survivors being informed and offered treatment options, but also highlighted individual differences. The interviewees varied greatly in their need for cancer-related information and their use of alternative/complimentary therapies. For example, as mentioned previously,

although the timing, quality and quantity were important, some survivors were eager to be fully armed with informational resources. Conversely, there were others that felt overwhelmed and inundated by large amounts of information, preferring to focus on the essential facts. Likewise, some HC survivors sought out various alternative treatments, while others preferred to follow conventional treatment. Therefore, it was considered important to include *information seeking* and *alternative/complementary therapies* as factors in the final questionnaire, as it is still unclear how, and to what extent, these influence resilience.

The results on the dietary items also proved to be less reliable ($\alpha = .56$) when compared to the other items on this scale. Cronbach's alpha highlighted potential issues with the reliability of the item asking, "I worry more when I don't eat properly" and this question was subsequently reworded to, "taking care of my dietary needs is important to me". In addition, negatively worded items were included in an attempt to encourage participants to be more focused on each individual question and reduce bias. Finally, due to the high response rate on the last item that asked if any influential factors had been missed, a similar open-ended question was also included in the final questionnaire. This final question asks, "Based on your personal experience is there anything else you would like to share that may assist others to cope when facing a similar situation?"

Overview - Final Questionnaire

In terms of the final instrument, the pilot study indicated strong internal consistency among the majority of scales including high test-retest reliability over 2-week period. However, as a result of feedback from the pilot study participants, there were several amendments made to improve the items in the final questionnaire. For example, various responses that related to ethnicity, relationship status, religion, employment position, treatment regime, time since cancer diagnosis and HCP support, were modified either to reduce the necessity for qualitative responses and/or to provide more clarification. In addition, as a result of the feedback offered by several participants, two additional factors were added to the final questionnaire. These included items investigating '*information seeking*' and the use of '*alternative/complementary therapies*' as each of these were considered influential factors by several participants. Finally, three additional questions were added at the end of the questionnaire that provided participants a further opportunity to share their experience through open-ended responses. In conclusion, the earlier qualitative enquiry (interview data) including findings from the literature together with the results of this pilot study, all contributed in guiding an appropriate survey design for the final quantitative phase.

Summary of Questionnaire Development and Pilot Study

This chapter has detailed the development and implementation of a pilot questionnaire (Phase Two – Stage I) for the purpose of guiding a larger quantitative study (Stage II). Overall, the preliminary assessment of validity, reliability, and feasibility was successfully achieved in keeping with the original purpose of this research study. Initially, the rationale and aims were highlighted. The first aim of the pilot study was to identify and/or create appropriate measures. The second aim of this pilot study involved reviewing the statistical properties of the questionnaire. A final aim was to acquire feedback from participants concerning their experience of completing the survey. Following the aims, a description of the cancer survivors who participated was discussed. Information and results relating to the reliability and validity of the questionnaire was then presented. The chapter concluded with an overview of the developed questionnaire. The next chapter outlines the results of the final quantitative study (Phase Two – Stage II) in which the modified final questionnaire (see Appendix K) is distributed to a larger sample of HC survivors.

Chapter 7

Phase Two (Stage II) – Quantitative Data Collection Findings

Chapter Overview

The previous chapter outlined the process involved in the questionnaire item development. This was followed by the results of the pilot study that provided tests of validity and reliability and highlighted areas for further improvement.

This chapter discusses the quantitative results of the final stage this research, involving a large sample of HC survivors. First, aims and research questions are revisited after which the profile of respondents and questionnaire completion process are outlined. The statistical analyses and results are then presented.

Introduction

The review of the literature highlighted that being diagnosed with HC, a potentially terminal disease, is regarded as a traumatic and stressful experience affecting many aspects of an individual's life, including their mental health (Hollingshaus & Utz, 2013). Those patients who require treatment are not only at risk of recurrence or secondary cancer, but also face many psychosocial challenges.

There were a number of limitations identified within the literature that provided directions for the current study. First, research in this area has mainly focused on improving detection and treatment regimens of those with more common cancers such as breast and prostate cancer (Aziz, 2002; Ganz, 2011; Jefford et al., 2008; Mukherjee, 2010). Second, there has been more attention directed towards the experience of cancer patients following diagnosis and during the treatment phase than in remission or survivorship (Hewitt, Greenfield, & Stovall, 2005). Thus, less is known about the psychosocial challenges and coping experience in these populations over the long-term (Hewitt, Greenfield, & Stovall, 2005). Third, there is an abundance of research investigating the negative consequences of cancer-related stressors (Bevans et al., 2011; McGrath, 2004a; Stewart & Yuen, 2011). However, to date there has been less emphasis on examining protective factors that may help mitigate such stress and contribute to positive mental health (Stewart & Yuen, 2011; Windle, Bennett, & Noyes, 2011).

Researchers are beginning to recognise that many survivors may experience positive adjustment outcomes (Jefford et al., 2008; Llewellyn et al., 2011). For example, a growing body of literature suggests that cancer survivors may be highly resilient (Gouzman et al., 2015; Pieters, 2015; Schumacher et al., 2014). Resilience is believed to facilitate ways of coping in order to cultivate positive emotions and has consequently become a major focus of clinical interventions in psychology over the past two decades (Manne et al., 2015). Resilience is also

considered to be inversely associated with depression, anxiety and perceived stress, whilst being linked with greater life satisfaction (Wagnild, 2009; Windle, Bennett, & Noyes, 2011). The few studies that have specifically investigated resilience among cancer survivors, have reported resilience to be associated with a greater sense of adaptation, psychological wellbeing (Wenzel et al., 2002) and improved QOL (Denz-Penhey & Campbell Murdoch, 2008; Stewart & Yuen, 2011; Wu et al., 2012). In particular, there are limited publications investigating resilience within the context of HC survivors. It is, therefore, unknown how resilience contributes to positive mental health for those who have been diagnosed with HC.

Several possible risk and protective factors that could influence the resilience of HC survivors were discovered through the findings of Phase One as well as a review of the literature. These factors included: active coping, denial, behavioural disengagement, emotional support, instrumental support, positive reframing, planning, time-out, acceptance, religion, self-distraction, substance abuse, venting, humour, self blame, social support (significant others, HCP, family, and friends), exercise, appearance, researching information, alternative treatments and diet. However, these factors have yet to be examined within the larger context of HC survivors and so their influence on resilience is relatively unknown. A key question is whether the factors that lead to resilience among adult survivors of HC follow a similar profile to those found in other cancer populations (Windle, Bennett, & Noyes, 2011). The current study will use the final questionnaire, including all these factors, to explore resilience and mental health outcomes among a larger sample of HC survivors.

Aims and Research Questions

The aim of Phase Two (Stage II) was to test the validity of the model of resilience in HC survivors. As Robson (2002) stated, questionnaires can provide insight into patterns and responses and is an effective method of sampling attitudes, beliefs and behaviours. This will be useful in the current study, as the interrelationships of variables measured in the questionnaires can be compared to responses provided during the qualitative phase of the research. The main focus was to investigate if the identified risk and protective factors influenced resilience among HC survivors. Guided by previous research, Phase Two (Stage II) focused on addressing the following questions:

- 1) What is the relationship between resilience and depression and anxiety?
- 2) What are the significant factors that contribute to resilience among HC survivors?
- 3) Who in the clinical team provides the most and least support and relevant information? and,
- 4) As a result of personal experience, what advice can current HC survivors provide to those who are newly-diagnosed that may help them to cope?

Data Collection - Final Instrument

The final instrument (Appendix L) was systematically compiled as a result of a thorough literature search, the interview findings (Phase One) and the results of the previous pilot study. The information, consent, demographic questions and research measures included in the final questionnaire, as presented in the online Qualtrics format, are outlined below in Table 7.1.

Table 7.1

Design and Measures of Final Questionnaire

Section	Content/Factors	Scale	Author	Items (<i>n</i>)
1	Research background Ethics Contact Details Informed consent	n/a	n/a	n/a
2	Personal Data Demographic Details	n/a	n/a	18
3	Coping Strategies	Brief-COPE	(Carver, 1997)	14
4	Social Support	MSPSS	(Zimet et al., 1988)	4
5	Resilience	RSA	(Friborg et al., 2005)	6
6	Mental Health	HADS	(Zigmond & Snaith, 1983)	2
7	HBC	created	n/a	6
8	Opened-ended	created	n/a	n/a

Note. n/a = not applicable; MSPSS = Multidimensional Scale of Perceived Social Support; RSA = Resilience Scale for Adults; HBC = Health behaviour change; HADS = Hospital Anxiety and Depression Scale.

Quantitative Findings

Survey Questionnaire

The item development and content of each scale included in this questionnaire were described in detail in Chapter 6. To assess internal consistency, Cronbach's Alpha (α) was again calculated among the entire sample ($N = 222$) and, as reported in Table 7.2, most scales indicated high internal consistency. The items measuring denial ($\alpha = .56$) and venting ($\alpha = .58$) initially produced a poor internal consistency score. According to Field (2009), this suggests

that the items were poor at measuring their respective constructs. However, denial and venting were kept in final analyses for two reasons. First, they are part of the Brief Cope Inventory, which is a well-validated scale, and, second, when these variables were removed they made no difference to the results of the final model.

Table 7.2

Internal Consistency Reliability of the Final Questionnaire Scales (N = 222)

Scale	α
Self distraction	.94
Active coping	.74
Denial	.56
Substance use	.94
Emotional support	.87
Instrumental support	.81
Behavioural disengagement	.69
Venting	.58
Positive Reframing	.79
Planning	.75
Humour	.87
Acceptance	.74
Religion	.91
Self Blame	.65
BRIEF COPE (Total)	.76
Family support	.88
Friends support	.93
Significant others	.93
Healthcare professionals	.84
MSPSS (Total)	.86
Time out	.72
Exercise	.71
Diet	.80
Appearance	.71
Researching	.67
Alternative Tx	.83
HBC (Total)	.77
HADS Anxiety Scale	.86
HADS Depression Scale	.81
HADS (Total)	.76
RSA (Total)	.89

Note. MSPSS = Multidimensional Scale of Perceived Social Support; HBC = Health Behaviour Change; RSA = Resilience Scale for Adults; HADS = Hospital Anxiety and Depression Scale; Tx = Treatment.

Questionnaire Completion.

Questionnaires were completed between May and August 2015. The majority of completed surveys were submitted electronically ($n = 170$). However, several were also mailed hard copies ($n = 52$). The electronic survey required respondents to click on a hyperlink, which initially presented the information and informed consent details (described earlier; see (Appendix J). Once respondents had nominated their consent to continue, they were presented with the questionnaire, which took approximately 30 minutes to complete. The hard copy questionnaires that were distributed through The Perth Blood Institute, Leukaemia Foundation and those mailed to respondents involved in the NSW Cancer Council research database, all included reply-paid, self-addressed envelopes.

An overall response rate could not be calculated accurately as the survey was designed to remove responses that were not complete, although at one point 52 surveys were noted on Qualtrics as incomplete. Likewise, it was not possible to identify social media participation rates, yet, as can be seen from Table 7.3, approximately 42% of respondents were recruited through social media. However, it was possible to match participant details with the 42 returned responses from the NSW Cancer Council database, which indicated a participation rate of 66%. Details of the final participant recruitment process are presented in Table 7.3.

Table 7.3

Participant Recruitment Setting

Recruitment	Total sample ($N = 222$)
Word of Mouth	11.3% ($n = 25$)
Social Media (Facebook)	42.3% ($n = 94$)
Email	19.4% ($n = 43$)
Mailed letter	12.2% ($n = 27$)
NSW Cancer Council (via mail)	11.3% ($n = 25$)
Leukaemia Foundation	0.9% ($n = 2$)
Cancer Council (unspecified)	0.9% ($n = 2$)
Perth Blood Institute	1.8% ($n = 4$)

Data Screening

Prior to analysis, data were first examined for accuracy of data entry and missing values. There were no missing values and all participant data entry was complete. The Qualtrics online survey was set up to include forced responses, meaning that respondents had to respond to each question before continuing with the survey, this assisted in reducing missing values. However, as previously discussed, one mailed survey and 52 online surveys were incomplete, and these had already been excluded prior to data screening. All cases were also checked for systematic responses (i.e., the same answer was given to all of the questions). No systematic responses were evident.

Profile of Respondents

A total of 293 HC survivors completed the on-line survey, of which 222 were included in the data analysis after data screening. This represented a 79% completion rate (179 online and 52 hardcopies). Sixty-one online surveys and one mailed survey were not included due to incomplete information. In addition, a further nine surveys were removed from the analysis as the respondents were either too recently diagnosed ($n = 8$) or had been diagnosed with a blood disease ($n = 1$), not a blood cancer. One of the inclusion criteria was diagnosis with cancer at least 12 months prior, however it was decided to also include HC survivors over ten months post-diagnosis.

The majority of respondents were female HC survivors (62.2%, $n = 138$) who spoke English as their main language ($n = 219$; 98.6%) and were of Caucasian/European descent ($n = 207$; 93.2%) (See Table 7.4). The age of interviewees varied from 19 to 86 years ($M = 54.35$, $SD = 14.31$) and the years since diagnosis ranged from 1 to 34 years ($M = 7.73$; $SD = 6.14$). The respondents were equally divided between permanent (1-5 years) and extended survivorship (6+ years) phases. The majority of survey respondents lived in Australia ($n = 151$; 68%). However, the sample also included respondents from the United Kingdom/Europe ($n = 32$; 14.4%), USA/Canada ($n = 35$; 15.8%), and, Africa/Asia/New Zealand ($n = 4$; 1.8%). The sample comprised mainly urban residents ($n = 176$, 75%).

As indicated in Table 7.1, the 222 survivors surveyed represented 12 different HC cancer diagnoses comprising various leukemias ($n = 131$; 59%), lymphomas ($n = 83$; 37.4%), and myeloma ($n = 8$; 3.6%). There was also a representation of both acute and chronic blood cancers. The term “acute” means that the abnormal cells are immature and continue to build up. The cancer can progress quickly and can be fatal within a few months, thus patients require urgent treatment. Conversely, in “chronic” HC’s, the cells can mature partly, but not completely. These cells may appear normal, however, they do not function properly and tend to live longer and crowd out normal cells. Therefore, chronic blood cancers may develop slowly over a period of years, but can be more complex in the long-term to treat. The diversity

in this sample of HC's meant that there were several different cancer trajectories experienced.

Most of the respondents were currently undergoing some form of treatment ($n = 128$; 57.7%). The majority of cancer survivors reported undergoing chemotherapy ($n = 117$; 52.7%). However, in addition to chemotherapy, several respondents also required a combination of treatments including many of the following: radiotherapy, surgery, transplants (BMT/SCT), and immunotherapy/oral medication ($n = 86$; 38.5%). Of this sample, 47 respondents experienced a HC relapse (21.2%). In addition, 30 respondents (13.5%) required a transplant and 18 respondents (8%) were diagnosed with a secondary cancer.

Over half (56.4%) of the sample was employed either full-time ($n = 68$), part-time ($n = 39$), or were self-employed ($n = 18$); the remainder were either retired ($n = 48$), on a pension ($n = 25$), a homemaker/carer ($n = 11$), a student ($n = 8$), or unemployed ($n = 5$).

Respondents were well educated, with 26.1% ($n = 58$) completing a tertiary diploma/trade; 23.9% ($n = 53$) completing a tertiary undergraduate or postgraduate ($n = 39$; 17.6%) degree, while 47 respondents (21.2%) had completed Year 12/HSC and 25 (11.3%) respondents completed Year 10/11. Although the relationship status of respondents varied, over half the respondents were married ($n = 122$; 55%). The other respondents were either single ($n = 44$; 19.8%), *de facto*/partnered ($n = 22$; 9.9%), separated/divorced ($n = 15$; 6.8%), widowed ($n = 18$; 8.1%) and one respondent described himself as polyamorous. Slightly less than half the respondents considered themselves Christian (Uniting Church, Anglican, Baptist, Catholic, etc.) ($n = 106$; 47.7%), a further 21 (9.6%) comprised other religions (Buddhist, Hindu, Islamic, Jewish and Druid), and the remainder described themselves as either non-practicing ($n = 86$; 38.2%) or non-believers ($n = 9$; 4.1%). In this sample, the majority of respondents had children ($n = 167$; 75.2%). The respondents were not asked to provide further information on their children's ages or whether they still lived at home.

Based on analysis of the demographic data, in general, this population is representative of the HC survivors required to answer the research questions. It would have been ideal to capture a more ethnically diverse representation, which is one limitation of this research. Of note too, is that a large percentage of the respondents were diagnosed with CML ($n = 107$; 48%). It is likely that this occurred as a result of active social media promotion through the CML Facebook site. However, the contribution from CML survivors is considered advantageous to this study, as CML is a particularly rare form of leukaemia, for which there is currently no cure. Thus, the input from CML survivors is important, as these individuals are required to manage their cancer and treatment side-effects on a daily basis for the rest of their lives.

Table 7.4

Demographic Profile of Total Sample (N = 222)

Variable	Total (N = 222)
Mean age at time of study (years)	54.40 (<i>SD</i> = 14.31)
Distribution of Age (years)	
18 – 40	16.2% (<i>n</i> = 36)
41 – 60	47.7% (<i>n</i> = 106)
61+	36.0% (<i>n</i> = 80)
Males	37.8% (<i>n</i> = 84)
Females	62.2% (<i>n</i> = 138)
HC Cancer Diagnoses	
Non-Hodgkin's Lymphoma (NHL)	29.7% (<i>n</i> = 66)
Hodgkin's Lymphoma (HL)	7.2% (<i>n</i> = 16)
Small Lymphocytic Lymphoma (SLL)	0.5% (<i>n</i> = 1)
Acute Lymphoblastic Leukaemia (ALL)	0.9% (<i>n</i> = 2)
Acute Promyelocytic Leukaemia (APML)	0.5% (<i>n</i> = 1)
Acute Myeloid Leukaemia (AML)	2.3% (<i>n</i> = 5)
Chronic Lymphocytic Leukaemia (CLL)	5.4% (<i>n</i> = 12)
Chronic Myeloid Leukaemia (CML)	48.2% (<i>n</i> = 107)
Chronic Myelomonocytic Leukaemia (CMML)	0.5% (<i>n</i> = 1)
Hairy Cell Leukaemia (HCL)	0.9% (<i>n</i> = 2)
Biphenotypic Leukaemia (AML & ALL)	0.5% (<i>n</i> = 1)
Multiple Myeloma (MM)	3.6% (<i>n</i> = 8)
Mean time since diagnosis (years)	7.73 (<i>SD</i> = 6.14)
Years Since Diagnosis	
1 – 5	50% (<i>n</i> = 111)
6+	50% (<i>n</i> = 111)
Initial Treatment Required	
Radiotherapy only	3.2% (<i>n</i> = 7)
Chemotherapy only	15.5% (<i>n</i> = 34)
IV/Oral/Immunotherapy	38.3% (<i>n</i> = 85)
Combination (R,C,I,BMT,SCT)	38.7% (<i>n</i> = 86)
No treatment required	4.5% (<i>n</i> = 10)
Current Treatment Regime	
Require ongoing treatment	48.6% (<i>n</i> = 108)
Completed treatment	43.7% (<i>n</i> = 97)
Treatment was not required	5.0% (<i>n</i> = 11)
Currently on treatment cycle (which is temporary)	1.8% (<i>n</i> = 4)
Undergoing treatment trial	0.9% (<i>n</i> = 2)
Required BMT/SCT	
No	86.5% (<i>n</i> = 192)
Yes	13.5% (<i>n</i> = 30)
Experienced HC Relapse	
No	78.8% (<i>n</i> = 175)
Yes	21.2% (<i>n</i> = 47)

Table 7.4
(continued)

Variable	Total (<i>N</i> = 222)
Diagnosed with Secondary Cancer	
No	91.9% (<i>n</i> = 204)
Yes (Type):	
Breast	1.4% (<i>n</i> = 3)
Bowel	0.9% (<i>n</i> = 2)
Prostate	1.4% (<i>n</i> = 3)
Lymphoma	0.9% (<i>n</i> = 2)
Skin Cancers (Melanoma, etc.)	2.7% (<i>n</i> = 6)
Thyroid	0.5% (<i>n</i> = 1)
Chronic Myeloid Leukaemia	0.5% (<i>n</i> = 1)
Relationship Status	
Married	55.0% (<i>n</i> = 122)
Single	19.8% (<i>n</i> = 44)
Divorced	1.8% (<i>n</i> = 4)
De facto/Partnered	9.9% (<i>n</i> = 22)
Widowed	8.1% (<i>n</i> = 18)
Separated	5.0% (<i>n</i> = 11)
Polyamorous	0.5% (<i>n</i> = 1)
Dependents	
0	24.8% (<i>n</i> = 55)
1	14.0% (<i>n</i> = 31)
2	36.0% (<i>n</i> = 80)
3	16.2% (<i>n</i> = 36)
4	6.8% (<i>n</i> = 15)
5	2.3% (<i>n</i> = 5)
Employment	
Full-time	30.6% (<i>n</i> = 68)
Part-time	17.6% (<i>n</i> = 39)
Retired	21.6% (<i>n</i> = 48)
Unemployed (including redundancy)	2.3% (<i>n</i> = 5)
Pensioner	11.3% (<i>n</i> = 25)
Student	3.6% (<i>n</i> = 8)
Self-employed (Full-time or Part-time)	8.1% (<i>n</i> = 18)
Homemaker	4.1% (<i>n</i> = 9)
Carer	0.9% (<i>n</i> = 2)
Education	
Year 10-11 High school level	11.3% (<i>n</i> = 25)
High school graduate	21.2% (<i>n</i> = 47)
Tertiary diploma/Trade or TAFE certificate	26.1% (<i>n</i> = 58)
Tertiary degree	23.9% (<i>n</i> = 53)
Postgraduate degree	17.6% (<i>n</i> = 39)
Main language spoken at home	
English	98.6% (<i>n</i> = 219)
Chinese	0.5% (<i>n</i> = 1)
Japanese	0.5% (<i>n</i> = 1)
Urdu	0.5% (<i>n</i> = 1)

Table 7.4
(continued)

Variable	Total ($N = 222$)
Ethnicity	
White/Caucasian/European	93.2% ($n = 207$)
Asian (Chinese, Japanese, Korean)	3.2% ($n = 7$)
Hispanic or Latino	0.9% ($n = 2$)
Middle Eastern	2.3% ($n = 5$)
Aboriginal	0.5% ($n = 1$)
Residence	
Australia	68.0% ($n = 151$)
United Kingdom and Europe	14.4% ($n = 32$)
North America (USA and Canada)	15.8% ($n = 35$)
Other (i.e., Africa, Asia, New Zealand)	1.8% ($n = 4$)
Area of residence	
Urban	75.2% ($n = 167$)
Rural/country	24.8% ($n = 55$)
Religious Beliefs	
Christian (i.e., Uniting Church, Anglican, Catholic, etc.)	47.7% ($n = 106$)
Non-practising	38.2% ($n = 55$)
Buddhist	4.5% ($n = 10$)
Hindu	0.5% ($n = 1$)
Islamic	1.4% ($n = 3$)
Jewish	2.7% ($n = 6$)
Druid	0.5% ($n = 1$)
Non-believer (i.e., Agnostic or Atheist)	4.1% ($n = 9$)

Quality of the Data and Data Analysis Assumptions

Prior to statistical testing of relationships among variables in the data set the data were evaluated to determine if the data met normality, linearity and homoscedasticity assumptions.

Normality, linearity and homoscedasticity – Analysis of the statistical tests of normality (Kolmogorov-Smirnov and Shapiro-Wilks) indicated that the data were not normally distributed ($p < .05$) as would be expected with a large sample size, when even small deviation from normality will be shown to be statistically significant. However, in regard to these statistical tests, Tabachnick and Fidell (2007) state that “they are very sensitive and often signal departures from normality that do not really matter” (p. 46). Consequently, it is recommended that more visual graphical results also be developed and analysed in addition to statistical tests. These graphical tests (e.g., normal Q-Q plots, detrended normal Q-Q plots) indicated that the majority of variables data were approximately normally distributed (Appendix M).

In addition, the assumptions of linearity and homoscedasticity of residuals were met. This was achieved by inspecting the normal probability plot of standardised residuals (Appendix N) and the scatterplot of standardised residuals against standardised predicted values (Appendix O). This suggests a linear relationship between the variables and the variability in one variable should be similar across all values of the other variable (Tabachnick & Fidell, 2007).

Independent t-tests and One way ANOVA Analyses Assumptions

Analyses were used to identify what influence resilience may have on depression and anxiety in this sample of respondents. Independent *t*-tests, one-way ANOVAs and correlation analyses were conducted to measure the significance of differences and the strengths of linear relationships between these variables and to investigate the influence of selected demographics (gender, age and time since diagnosis).

As normality was not consistently found, both parametric (i.e., Pearson's *r*) and nonparametric (i.e., Spearman's ρ) tests were conducted when testing the correlation among relationships. Likewise, the assumption of normality may have been violated for other analyses that compare means (i.e., *t*-test, ANOVA), thus equivalent non-parametric tests (Mann-Whitney U, Kruskal-Wallis ANOVA by ranks) were also performed to ensure accuracy. Parametric tests were reported unless the results of the parametric and non-parametric tests differed (See Appendix P for comparisons between tests).

Standard Multiple Regression Analyses Assumptions

The main focus of this study was to conduct a standard multiple regression analysis (MRA) to assess the ability of the model to predict resilience and to identify significant predictor variables (Research Question 2). According to Tabachnick and Fidell (2007), there are several additional assumptions, outlined below, that require testing prior to conducting the analysis and interpreting the results.

Ratio of cases to the independent variable - In order to produce a reliable regression model, a reasonable ratio of cases to predictors is required. Tabachnick and Fidell (2007) suggest that the number of respondents should ideally be $50 + 8m$ (where m = number of independent variables). Investigating 24 predictor variables required a sample size of 240 respondents). Although the present sample size fell slightly short, one of the principal research supervisors (an experienced statistician), deemed the sample size to be adequate. In addition, what is considered a 'reasonable' sample size tends to vary between experts, with other researchers such as Guadagnoli and Velicer (1988) maintaining that a sample size > 200 is a reasonable and fair sample.

Absence of univariate and multivariate outliers - MRA is sensitive to univariate and multivariate outliers (Tabachnick & Fidell, 2007). It was, therefore, important to screen for these. First univariate outliers were screened for: 1) incorrect data entry; 2) incorrectly coded

missing-values; and, 3) cases that were not members of the intended sample population, but resulted in extreme scores outside the normal distribution (Tabachnick & Fidell, 2007). All outliers within the data were cases from the intended population, but contained extreme values outside the normal distribution, i.e., those that exceeded Z scores of ± 3.3 (Tabachnick & Fidell 2007). Fifteen of the 24 variables contained either extreme score or outliers. In addition, two outliers were detected among the dependent variable of resilience. Following recommendations, the values of these scores were altered so that they became less problematic and fell within the Z score range of ± 3.3 (Tabachnick & Fidell, 2007).

Second, six multivariate outliers were detected using Mahalanobis' distance, using $\alpha = .001$. Mahalanobis' distance exceeded the critical χ^2 (24) of 51.18 in the six influential cases in the data file. These cases were not deleted because, after re-running the analysis without them, they had no impact upon the regression model.

Absence of multicollinearity - According to Tabachnick and Fidell (2007), high correlations (e.g., $r \geq .85$) between predictors can render a regression analysis difficult to interpret and unstable. Multicollinearity was assessed by inspecting tolerance and VIF (variance inflation factor) levels. This assumption was met, as: there were no VIF scores greater than 10; the average VIF (current sample = 2.05) did not substantially differ from 1; and, there were no tolerance levels below 0.2 or 0.1.

In summary it can be presumed from the preliminary assumption analyses discussed, that the data are a good enough fit to be used to answer the research questions.

Results

Frequency Analysis

Descriptive analyses were conducted on all variables. As noted in Table 7.5, inspection of the mean scores indicated that respondents scored high relative to total possible scores, across several measures: self distraction, active coping, emotional support, instrumental support, positive reframing, planning, acceptance, social support (friends, family, significant others and HCP), time out, diet, exercise, appearance and researching information. Lower mean scores were noted for denial, substance use, behavioural disengagement, venting and self-blame. In addition, the mean score for anxiety was higher ($M = 6.72$) than depression ($M = 3.94$). However, both anxiety and depression mean scores were low when compared to a maximum score for each of 21.

Table 7.5

Descriptive Statistics of Variables within the Final Questionnaire

Scale	N	M	SD	Range		Skewness	Kurtosis
				Potential	Actual		
Self distraction	222	5.42	1.85	2-8	2-8	-0.39	-0.91
Active coping	222	6.18	1.61	2-8	2-8	-0.78	-0.04
Denial	222	2.55	1.10	2-8	2-8	2.46	6.81
Substance use	222	2.61	1.29	2-8	2-8	2.50	6.33
Emotional support	222	5.77	1.85	2-8	2-8	-0.45	-0.78
Instrumental support	222	5.26	1.89	2-8	2-8	-0.14	-1.03
Behavioural disengagement	222	2.49	1.08	2-8	2-8	2.62	7.53
Venting	222	3.65	1.42	2-8	2-8	0.84	0.67
Positive reframing	222	5.90	1.81	2-8	2-8	-6.20	-0.48
Planning	222	5.66	1.81	2-8	2-8	-0.41	-0.70
Humour	222	4.96	2.25	2-8	2-8	-0.03	-1.42
Acceptance	222	7.09	1.24	2-8	2-8	-1.42	2.10
Religion	222	4.34	2.30	2-8	2-8	0.42	-1.34
Self blame	222	3.03	1.36	2-8	2-8	1.60	2.48
BRIEF COPE (Total)	222	64.91	11.52	28-112	35-100	0-.12	-0.15
Family support	222	21.73	6.34	4-28	4-28	-1.33	1.15
Friends support	222	21.54	6.14	4-28	4-28	-1.15	0.66
Significant others	222	22.96	6.36	4-28	4-28	-1.54	1.73
Healthcare professionals	222	19.90	5.38	4-28	4-28	-0.95	0.73
MSPSS (Total)	222	86.13	20.26	16-112	19-112	-1.35	1.41

Table 7.5

(continued)

Scale	<i>N</i>	<i>M</i>	<i>SD</i>	Range		Skewness	Kurtosis
				Potential	Actual		
Time out	222	14.72	3.14	3-18	3-18	-0.65	0.07
Exercise	222	13.02	3.52	3-18	3-18	-0.46	-0.54
Diet	222	14.39	2.86	3-18	3-18	-0.86	0.98
Appearance	222	13.74	2.59	3-18	3-18	-0.42	-0.04
Researching information	222	13.15	3.17	3-18	4-18	-0.36	-0.27
Alternative Tx	222	10.04	4.07	3-18	3-18	-0.02	-0.80
HBC (Total)	222	78.72	13.63	12-108	34-106	-0.41	-0.15
Depression	222	3.94	3.27	1-21	0-17	1.01	0.89
Anxiety	222	6.72	3.88	1-21	0-19	0.66	0.09
HADS (Total)	222	10.65	6.44	0-42	0-33	0.82	0.11
RSA (Total)	222	169.20	27.13	33-231	76-221	-0.65	0.19

Note. MSPSS = Multidimensional Scale of Perceived Social Support; HBC = Health Behaviour Change; RSA = Resilience Scale for Adults; HADS = Hospital Anxiety and Depression Scale; Tx = Treatment

Resilience. The RSA does not classify specific levels of resilience (i.e., low, moderate, high, etc.). However, inspection of the mean scores and standard deviations revealed that, overall, respondents scored above average ($M = 169.20$), of a maximum possible score of 231, when compared to normative populations on measures of resilience. The distribution of the six mean factor scores comprising the RSA are shown in Table 7.6, ranging from a low 16.33 to a high of 40.18. The results indicate relatively high mean scores across most factors, in particular, social resources, family cohesion and perception of self. However, there was variability between the resilience measures. For example, the highest resilience measure reported was social resources ($M = 40.18$), which was above average when compared with normative populations. Yet for structured style ($M = 16.33$) a lower score was observed. In addition, some of the standard deviations seem large, indicating that there is more variability in the group of scores on those measures of resilience.

Several previous studies support the use of the RSA instrument as a resilience predictor, for example among those with psychiatric illness following stressful events (Hjemdal et al., 2006), in relation to Extraversion-Intraversion, Psychoticism and Neuroticism (Annalakshmi, 2007), as a predictor of hopelessness (Hjemdal, Friborg, & Stiles, 2012), and more recently among HIV-positive South Africans (Dageid & Grønlie, 2015).

Table 7.6

Distribution of Mean Scores across RSA Factors

RSA factors	<i>M</i>	<i>SD</i>	Maximum Score Possible
Perception of self (6 items)	31.46	6.72	42
Planned future (4 items)	19.62	5.22	28
Social competence (6 items)	29.72	6.48	42
Family cohesion (6 items)	31.89	7.58	42
Social resources (7 items)	40.18	7.06	49
Structured style (4 items)	16.33	3.83	28

Note. RSA = Resilience Scale for Adults (Friborg et al., 2003)

Mental Health. The mean scores on negative mental health outcomes were low when compared to other cancer population (Table 7.4). As presented in Table 7.7, the majority of respondents' scores were classified as being 'normal' in severity across both depression (83%) and anxiety (65%). However, the results presented indicate that a higher proportion of HC survivors experience anxiety than depression. For example, when comparing both the

moderate and severe ranges combined, more respondents reported anxiety ($n = 37$; 17%) as compared to depression ($n = 8$; 4%).

Table 7.7

Distribution of Severity Levels of Depression and Anxiety Measured by the HADS (N = 222)

Outcome measure and severity level	Score	Frequency (%)
Depression		
Normal	0 – 7	185 (83)
Mild	8 – 10	29 (13)
Moderate	11 – 14	7 (3)
Severe	15 – 21	1 (1)
Anxiety		
Normal	0 – 7	145 (65)
Mild	8 – 10	40 (18)
Moderate	11 – 14	26 (12)
Severe	15 – 21	11 (5)

Note. HADS = The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

Age, Gender, Time Since Diagnosis. Descriptive statistics on resilience were also explored across several demographic variables including age, gender and years since diagnosis (Table 7.8).

Table 7.8

Mean Resilience, Depression and Anxiety Scores According to Age, Gender and Time since Diagnosis

Demographic Variable	Depression		Anxiety		Resilience	
	M	(SD)	M	(SD)	M	(SD)
Gender						
Male	3.68	(3.28)	6.11	(3.31)	170.36	(25.41)
Female	4.09	(3.26)	7.09	(4.16)	168.50	(28.19)
Age						
YA (18 – 40)	3.86	(4.21)	8.03	(3.99)	170.25	(30.48)
MA (41 – 60)	4.19	(3.27)	6.88	(3.91)	167.63	(26.15)
OA (61+)	3.64	(2.76)	5.91	(3.65)	170.81	(27.06)
Years Since Diagnosis						
(1 – 5)	4.41	(3.16)	7.21	(4.02)	166.32	(26.18)
(6+)	3.47	(3.31)	6.23	(3.69)	172.09	(27.87)

Note. TSM = Total Sample Mean; YA = Young Adult; MA = Middle Age Adult; OA = Older Adult.

Descriptive statistics of male to female scores indicated slightly lower resilience levels and slightly higher scores for depression and anxiety for females. Middle-aged adults reported the lowest level of resilience and highest level of depression among the three age categories, yet younger adults reported the highest anxiety level. Finally, long-term survivors (6+ years since diagnosis) reported slightly lower depression and anxiety levels, including higher resilience levels than those more recently diagnosed (< 5 years).

Survey Research Question 1:

What is the relationship between resilience and depression and anxiety?

As outlined in the literature review, resilience is believed to be influenced by several and risk and protective factors. Yet, within the literature there is also a suggestion that developing or fostering resilience is, in itself, a protective factor. With this in mind, Research Question 1 aimed to explore the relationship between resilience and negative mental health outcomes (i.e., depression and anxiety).

To assess the size and direction of the linear relationship between anxiety, depression and resilience, bivariate Spearman's rho correlation coefficients were calculated. The results indicated the presence of a strong *negative* correlation between resilience and depression ($r_s = -.621, p < .001$) and a moderate relationship between resilience and anxiety ($r_s = -.445, p < .001$).

Demographic Characteristics, Mental Health and Resilience. Demographic variables were also explored to further examine their relationship to mental health and resilience. First, independent samples *t* tests were used to examine the effects of *gender* on reported depression, anxiety and resilience scores. Neither Shapiro-Wilk's statistic was significant, indicating that the assumption of normality was not violated. Levene's test was also not significant and thus, equal variances can be assumed. The *t* tests were not significant across gender for depression, $t(220) = -0.92, p > .05$; anxiety, $t(220) = -1.83, p > .05$; and resilience, $t(220) = 0.49, p > .05$.

Second, when examining the effects of *time since diagnosis* on reported resilience, depression and anxiety scores, it was noted that the results differed between parametric and non-parametric tests (see Appendix P). As normality was not consistently found, to ensure accuracy, non-parametric tests were reported for time since diagnosis differences. A Mann-Whitney *U* test indicated that resilience scores of long-term survivors (6+ years) (Mean Rank = 120.56, $n = 111$) were significantly higher than those of short-term survivors (< 5 years) (Mean Rank = 102.44, $n = 111$), $U = 5155.00, Z = -2.10$ (corrected for ties), $p = .036$, two-tailed. The depression scores of long-term survivors (Mean Rank = 100.09; $n = 111$), were

significantly lower than short-term survivors (Mean Rank = 122.91, $n = 111$), $U = 4894.00$, $Z = -2.67$ (corrected for ties), $p = .008$, two-tailed. Likewise, the anxiety score among long-term survivors were also significantly lower (Mean Rank = 102.63, $n = 111$) than short-term survivors (Mean Rank = 120.37, $n = 111$), $U = 5175.50$, $Z = -2.07$ (corrected for ties), $p = .039$, two-tailed. This effect can be described as small for resilience ($r = -.14$), depression ($r = .18$), and anxiety ($r = .14$).

Third, one-way, between groups ANOVA's were used to test whether depression, anxiety and resilience varied between three age categories (18 – 40, 41 – 60 and 61+ years). The results indicated that there was no significant relationship between age category and resilience, $F(2,219) = 0.34$, $p > .05$, or depression, $F(2,219) = 0.66$, $p > .05$. However, a significant effect was found for anxiety, $F(2,219) = 3.96$, $p > .05$, with *post hoc* analyses revealing a difference between the young (<40 years) and older (61+ years) age categories, with the younger people reporting higher anxiety.

Survey Research Question 2: What are the significant factors that contribute to resilience among HC survivors?

A standard multiple regression analysis (MRA) was conducted on the sample ($n = 222$). Congruent with literature in the area, the model in Research Question 2 explored the effects of risk and protective factors with regards to resilience. Resilience was, therefore, again considered as an outcome measure in the analysis.

Based on previous research and the results of Phase 1, the proposed model in this study predicted that individual, family and community factors would all be associated with resilience. First, *individual factors* such as greater use of adaptive coping strategies (i.e., active coping, acceptance, planning), as well as higher levels of optimism, perceived control, life meaning and self-care/positive health behaviours were expected to enhance resilience. In addition, *family factors* such as social support and open communication, as well as *community factors* (i.e., relationships with HCP's, information and resources, support groups etc.) were also predicted to contribute to the resilience process.

All 24 predictor variables were entered simultaneously into the regression model to predict resilience. Zero-order correlations between these variables and the outcome measure are shown in Table 7.9. As predicted, active coping, emotional support, instrumental support, positive reframing, planning, humour, time-out, acceptance, religion, social support (significant others, HCP, family, and friends), exercise, appearance, researching information, alternative treatments and diet were all significantly and positively related to resilience.

Therefore, higher scores among these variables were related to greater resilience scores. Conversely, denial, behavioural disengagement and self-blame were negatively associated with resilience such that higher scores on these variables were related to lower resilience scores.

Table 7.9

(continued)

Variable	13.	14.	15.	16.	17.	18.	19.	20.	21.	22.	23.	24.
Resilience	.161*	-.357**	.443**	.359**	.591**	.536**	.200**	.263**	.300**	.150*	.189**	.249**
1. SD	.174**	.205**	-.002	.012	.137*	.082	.181**	.197**	.198**	.169*	.078	.029
2. AC	.326**	-.061	.213**	.245**	.272**	.297**	.298**	.248**	.222**	.154*	.282**	.234
3. DE	-.042	-.130	-.152*	.124	-.075	-.087	-.204**	.139*	.184**	-.073	-.164*	-.102
4. SA	.028	.273**	.070	-.062	-.043	-.042	-.005	.060	.014	.051	.105	-.019
5. ES	.207**	.083	.547**	.401**	.615**	.597**	.278**	.232**	.394**	.201**	.216**	.196**
6. IS	.277**	.074	.293**	.231**	.418**	.456**	.312**	.176**	.350**	.335**	.339**	.081
7. BD	-.034	.249**	-.287**	-.276**	-.333**	-.349**	-.239**	-.117	-.245**	-.188**	-.147*	-.168*
8. VE	.222**	.144*	.087	.050	.054	-.002	.221**	.151*	.063	.109	.126	.134*
9. PO	.311**	-.011	.126	.249**	.230**	.376**	.283**	.206**	.240**	-.017	.265**	.216**
10. PL	.369**	.033	.291**	.294**	.347**	.303**	.458**	.395**	.328**	.260**	.294**	.289**
11. HU	.194**	.113	.084	.121	.248**	.369**	.219**	.157*	.148*	.166*	.180**	-.019
12. ACC	.038	-.229**	.141*	.248**	.217**	.254**	.085	.108	.060	-.017	-.103	.132

Table 7.9

(continued)

Variable	13.	14.	15.	16.	17.	18.	19.	20.	21.	22.	23.	24.
13. REL	-	-.049	.138*	.238**	.209**	.198**	.328**	.200**	.162*	.272**	.394**	.199*
14. SB	-	-	-.156*	-.145*	-.151*	-.134*	.000	-.011	.064	.037	-.015	-.148*
15. SO	-	-	-	-.451**	.623**	.392**	.196**	.183**	.185**	.217**	.149*	.180**
16 HCP	-	-	-	-	.509**	.467**	.275**	.145*	.136*	.148*	.190**	.220**
17. FAM	-	-	-	-	-	.644**	.260**	.153*	.301**	.222**	.206**	.137*
18. FRI	-	-	-	-	-	-	.253**	.155*	.334**	.145*	.256**	.181**
19. TO	-	-	-	-	-	-	-	-.433**	.465**	.400**	.417**	.502**
20. EX	-	-	-	-	-	-	-	-	.431**	.265**	.279**	.514**
21. APP	-	-	-	-	-	-	-	-	-	.284**	.292**	.346**
22. RES	-	-	-	-	-	-	-	-	-	-	.328**	.245**
23. ATx	-	-	-	-	-	-	-	-	-	-	-	.259**
24. DIET	-	-	-	-	-	-	-	-	-	-	-	-

Note. SD = Self-distraction; AC = Active coping; DE = Denial; SA = Substance abuse; ES = Emotional support; IS = Instrumental support; BD = Behavioural disengagement; VE = Venting; P0 = Positive reframing; PL = Planning; HU = Humour; ACC = Acceptance; REL = Religion; SB = Self-blame; SO = Significant other support; HCP = Healthcare Professional support; FAM = Family support; FRI = Friends support; TO = Time out; EX = Exercise; APP = Appearance; RES = Researching information; ATx = Alternative Treatment.
* p < 0.5, ** p < .01, *** p < .001

Predictor Variables and Resilience. In addition to identifying factors that are correlated with resilience (See Table 7.9), MRA also reported on the specific factors that made a unique and significant contribution to the regression model. As can be seen in Table 7.10, the model significantly accounted for 61% of the variance in resilience scores, $R^2 = .609$, adjusted $R^2 = .526$, $F(24, 197) = 12.80$, $p < .001$. As observed in Table 7.10, predictors that made a unique and significant contribution to the regression model were: active coping, positive reframing, self-blame, family support, friend support and exercise. With the exception of self-blame, these predictor variables were significantly and positively related to resilience. Only, self-blame was negatively associated with resilience. The majority of these results support the proposed model. The exception is self-blame, which was not discussed widely among previous research exploring HC survivors and did not emerge during the interviews as a significant factor.

Table 7.10

Summary of Standard Regression Analyses for Variables Predicting Resilience

Variable	<i>B</i>	[95% CI]	SE	β
Constant	100.48	[72.11, 128.85]	14.38	-
Self-distraction	-1.42	[-3.07, 0.22]	0.83	-.09
Active coping	3.69	[1.34, 6.04]	1.19	.21**
Denial	-0.44	[-3.11, 2.23]	1.35	-.01
Substance use	-0.13	[-2.33, 2.06]	1.11	-.00
Emotional support	1.15	[-1.08, 3.39]	1.13	.07
Instrumental support	-1.10	[-3.06, 0.86]	0.99	-.07
Behavioural Disengagement	0.81	[-2.20, 3.82]	1.52	.03
Venting	-0.79	[-2.72, 1.13]	0.98	-.04
Positive reframing	2.28	[0.23, 4.34]	1.04	.15*
Planning	-0.31	[-2.64, 2.03]	1.18	-.02
Humour	-0.49	[-.91, 0.92]	0.72	-.04
Acceptance	-0.07	[-2.33, 2.19]	1.14	-.00
Religion	-0.11	[-1.32, 1.09]	0.61	-.01
Self-blame	-4.41	[-6.61, -2.20]	1.11	-.22**
SO support	0.20	[-0.42, 0.83]	0.32	.04
HCP support	-0.22	[-0.83, 0.37]	0.30	-.04
Family support	1.43	[0.71, 2.14]	0.36	.33***
Friends support	0.98	[0.36, 1.60]	0.31	.22**
Timeout	-0.35	[-1.45, 0.75]	0.56	-.04
Exercise	1.15	[0.23, 2.07]	0.46	.15*
Appearance	0.29	[-0.77, 1.37]	0.54	.03
Research information	0.56	[-0.36, 1.50]	0.47	.06
Alternative Treatment	-0.42	[-1.18, 0.34]	0.38	-.06
Diet	-0.67	[-1.84, 0.49]	0.59	-.07

Note. *B* = unstandardized regression coefficient; CI = confidence interval; SE = standard error; β = standardised regression coefficient; SO = significant other; HCP = healthcare professional* $p < .05$, ** $p < .01$, *** $p < .001$

Survey Research Question 3: Who in the clinical team provided the most and least support and relevant information?

The empirical evidence suggests that support and information resources that are provided by HCP's are very important to survivors. However, what is less understood is from whom (i.e., general medical practitioners, specialists, nurses, pharmacists, psychologists, etc.) HC survivors receive this support and who, in particular, is most instrumental in providing cancer survivors with appropriate cancer-related information. In order to answer these questions, respondents were asked to select the most influential clinical team member who provided them with effective support, as well as the individual they believed was least supportive. In addition, a third question asked about who they felt was responsible for providing them with the most useful cancer-related information. As Table 7.11 highlights, responses to these questions about support and information provided by clinicians and allied health professionals were extremely varied.

First, the majority of respondents reported that their medical specialist, nurse, general medical practitioner, psychologist or a combination of each provided the most support ($n = 203$; 91.4%). A tiny minority also mentioned their pharmacist, clinical trial co-ordinator and alternative medicine doctor ($n = 3$), with one participant suggesting 'she' provided herself with the most support (maintaining that she was also part of her clinical team). With regard to the 'lack of support', 62 respondents (28%) stated that their specialist, nurse or GP was responsible for a lack of support. However, a much larger percentage of respondents did not report anyone in their clinical team as lacking in providing support ($n = 152$; 68%). Second, 40% ($n = 90$) of respondents suggested that their specialist was most influential in providing cancer-related information while a significant number of respondents also received cancer-specific information from the internet/social media ($n = 52$; 23%), the Leukaemia foundation ($n = 27$; 12%) and nursing staff ($n = 22$; 10%). A minority (2%) reported themselves as being responsible for the information that they received (See Table 7.11).

Table 7.11

The Influence of Clinical and Community Team Members on Providing Support and Cancer-Related Information as Perceived by HC Survivors

Clinical Team Member	Support (Most) N (%)	Support (Least) N (%)	Information N (%)
Specialist doctor	86 (38.7)	36 (16.2)	90 (40.5)
Combined clinical team	38 (17.1)	-	1 (0.5)
Nurses	39 (17.6)	10 (4.5)	22 (9.9)
General Practitioner	26 (11)	16 (7)	4 (1.8)
Psychologist/Counsellor	14 (6.3)	-	1 (0.5)
Leukaemia Foundation	2 (0.9)	-	27 (12.5)
Alternative Medicine Dr	1 (0.5)	-	-
Clinical Trial Co-ordinator	1 (0.5)	-	-
Myself	1 (0.5)	-	4 (1.9)
n/a no-one	10 (4.5)	152 (68.5)	-
Finance officer	-	2 (0.9)	-
Pharmacist	4 (1.8)	1 (0.5)	-
Social worker	-	2 (0.9)	-
Hospital administration	-	2 (0.9)	-
Anaesthetist	-	1 (0.5)	-
Internet/Social media	-	-	52 (23.4)
Other cancer survivors	-	-	21 (9.5)

Note. N = number of respondents; n/a = Not Applicable

Survey Research Question 4: As a result of personal experience, what advice can current HC survivors provide to those who are newly-diagnosed that may help them to cope?

Although questionnaires have numerous advantages, one disadvantage is the inability for respondents to expand on their personal experience. In view of this, a final open-ended question was included to allow respondents the opportunity to share further information. Specifically, this question asked respondents to provide advice (based on their personal experience) that they believed would be beneficial to newly diagnosed HC patients. Of the total sample ($n = 222$), over half of respondents ($n = 156$; 66%) provided feedback. This information was provided in the form of written text, which was analysed using thematic analysis (Braun & Clarke, 2006) as outlined in Chapter 4.

In summary, the emerging themes provided by the respondents are consistent with previous research, including information collected during both Phase One (Qualitative) and Phase Two (Quantitative). The majority of respondents referred to factors that improved their long-term mental health, rather than factors that assisted them to control short-term effects of

treatment. For example, many respondents referred to the importance of: implementing life-long, positive, health behaviour choices (e.g., yoga, meditation, exercise, diet, etc.); proactively researching information; taking control in decision-making; and, remaining positive, hopeful and realistic. Many also discussed the mental health benefits of: being a cancer survivor advocate; seeking and accepting all support; taking one day at a time; trusting the clinical team; and, realising personal limitations.

A full excerpt of the advice and recommendations provided by current survey respondents is transcribed verbatim (Appendix Q). The following quote offered by one respondent accurately summarises the coping experience of the majority of HC survivors in this survey study:

“Accept your diagnosis. Ask as many questions as possible. If you are unhappy with your specialist or their treatment plan ask for a second opinion. Be honest and open with your family, tell them when you get the diagnosis, obviously there will be tears and despair but this passes and their support is invaluable. Tell people that you deal with regularly e.g. friends or work colleagues. I found it much easier if they knew and I didn't have to pretend if I was having a bad time. Accept help! Don't try and answer every message of goodwill, accept them for the expressions of care that they are. Love your family and confide in them - they go on this journey with you and will love you regardless of what happens. Indulge yourself buy that dress that you like, have that decadent piece of cake. Stop and smell the roses, give yourself time, dream, listen to music, sing, pray, meditate, cuddle the dog or cat, go for a walk, cry, shout or scream - it is your disease and your journey - own it! Believe in yourself and all those caring for you. Try not to listen to those who will try and give you negative advice. It is a tough journey but one you have a good chance of surviving, a positive attitude makes the world of difference. Realise you and your life may never be the same, accept any deficiencies or any ongoing side-effects... you are alive to enjoy the things you thought you would never be able to do”.

(Participant No. 96)

Chapter 8

Discussion

Chapter Overview

This mixed-methods study has investigated both qualitative and quantitative data pertaining to factors that influence resilience and how this impacts on mental health outcomes among HC survivors. The main findings of each study were presented within the respective Chapters 5 through 7. Chapter 8 now presents a detailed discussion of these results, emphasizing the similarities and differences between these findings and existing research. These summaries are structured around the aims and research questions for each phase. Finally, the limitations and strengths of the current study are presented.

Discussion of Qualitative Findings (Phase One)

A total of 23 HC survivors were interviewed in this study, all of which were English speaking and living in Western Australia. These in-depth, semi-structured interviews explored a number of areas associated with the experience of living with a HC diagnosis. The main focus of this qualitative phase was to identify potential factors that may contribute to or impede the resilience of HC survivors. Together, both thematic and Leximancer software analyses produced data that provided insight into the personal worlds of this HC population and assisted in answering three key questions.

Interview Discussion - Research Question 1:

As a result of their experience, what are the common individual, family and community level factors that the HC survivors identified as contributing to their positive or negative mental health outcomes?

Four main themes and associated sub-themes that impacted on the positive and negative mental health outcomes of HC survivors were identified. These themes and sub-themes reported in Chapter 5 following the qualitative study are revisited below in Table 8.1, followed by a discussion of the findings and relevant literature.

Table 8.1

Review of the Themes and Sub-themes Common to HC survivors' Experience

Core Themes	Sub-themes
The burden associated with a HC diagnosis	Physical impact Psychological impact Social impact Unexpected loss
Resilience: Coping with HC	Social support network Personal coping strategies Positive health behaviour change Importance of time Self-Education
Pathways and barriers to resilience	Employment Relationships Communication Information and Resources Unmet needs
Survivor outcomes	Transition: a new normal Re-prioritisation and growth Self-reflection

The Burden Associated with a HC Diagnosis

There were four sub-themes that survivors in this study identified as factors associated with the burden of having being diagnosed and treated with HC. These included the physical, psychological, and social impact, including unexpected loss.

Physical impact. First, the majority of cancer survivors in this study reported a number of ongoing physical complaints such as: bone, joint and nerve pain; memory loss; digestive, heart, lung and hormonal problems; lymphoedema; early menopause; infertility and sexual dysfunction. However, the most commonly experienced physical effect was fatigue, resulting in decreased physical functioning and QOL. The participants commented that many physical effects began during treatment and often lingered on for years. These results support recent research stating that, up to 5 years following a stem cell transplant, patients continue to experience side-effects and being out of shape, fatigue, reduced muscle strength and tingling extremities were most frequently reported among HC patients (Braamse et al., 2015). Participants were also unprepared for the side-effects that took years following treatment to develop, and, for some, this included secondary cancers. Turcotte et al. (2015) supports this finding in the US among a cohort of 3,171 ageing childhood survivors. Compared with the

general population, survivors in this study were found to have a twofold risk of developing a second cancer after age 40, and this risk remains into the fifth and sixth decade of life.

Psychological impact. As physical recovery progressed, the unexpected psychological effects took many participants by surprise. The range of negative emotions experienced by this sample included anger, guilt, depression, general distress, anxiety, and isolation. Getting life back to normal with its predictability and control was reassuring for those who completed treatment. Yet, many participants worried about their future health, with the ‘fear of recurrence’ being the most commonly discussed concern. Most survivors maintained that, although their bodies were potentially cancer free, their minds were consumed with worry. Chapman (2015), a cancer survivor who recently published his personal experience, supported this perspective stating that “...the psychological issues of a near death experience begin to find a place in my thoughts as the physical issues abate...suffice to say, facing one’s own ‘use by date’ is confronting and there is not always appropriate help available in the community” (p.74). The findings in this study also confirm recent research reporting that fear of cancer recurrence continues to be one of the most common, persistent and unmet supportive care need among cancer survivors (Butow, Fardell, & Smith, 2015; Marker, 2015).

Social impact. The third sub-theme associated with the burden of a HC diagnosis was the social impact. Many participants explained how family, peers, co-workers, and others in the survivor’s social setting impacted their HC experience. Many of the interviewee’s described a degree of insecurity, lack of intimacy and social isolation within their interpersonal relationships. In addition, several participants discovered that many of their friends were unable to relate what they had been through. In some cases, this reflected how much the participants perceived they had changed since their HC diagnosis. These findings concur with other studies suggesting that an appreciation of one’s cancer journey is often more genuinely accepted from those who have undergone a similar experience (Aziz, 2002; Kelly & Dowling, 2011; McGaughan et al., 2012). A number of participants also felt guilty about the impact of their cancer on their loved ones. As a result, several participants put on a brave face at the expense of sharing their true feelings in order to protect others close to them. This supports previous research stating that those diagnosed with cancer often try to shelter significant people in their lives (Kelly & Dowling, 2011; McGrath & Clarke, 2003).

Unexpected loss. The final sub-theme expressed by current participants as contributing to the burden of their HC diagnosis was unexpected loss. The loss of control, especially in terms of their independence and autonomy, was the main theme highlighted by this sample of HC survivors. Several participants expressed the importance of trying to preserve some personal control while in hospital. While for others, this occurred following treatment when they began to contemplate their futures or reminisce about the life that they

once had, which seemed predictable. Many participants also grieved the loss of: life roles; career opportunities and finances; physical (i.e., infertility) and mental (i.e., lost memory) functioning; and, identity. Once survivors began to realise that their cancer journey was ongoing, they also identified with the loss of time, a perceived planned future and meaning in their lives. These findings on the losses experienced by this cohort of HC survivors support previous research (Aziz, 2002; Bulsara, Ward, & Joske, 2004; Grunfeld et al. 2013; Kelly & Dowling, 2011; McGaughan et al., 2012; Norris et al., 2011; van der Spek et al., 2013; Xuereb & Dunlop, 2003).

Resilience: Coping with HC

The second major theme to emerge from the interviews was resilience and coping with HC that highlighted the way in which individuals cope with the burden of cancer. The majority of participants in this study maintained resilience through available social support, personal coping strategies, self-education, health behaviour change and by taking time out, each of which will be briefly summarized. These findings support previous research, as many of these factors are commonly discussed in the cancer-related literature (Allart et al., 2014; Llewellyn et al., 2013; Stewart & Yuen, 2011; Swash, Hulbert-Williams, & Bramwell, 2014; Wenzel et al., 2002). The interviewees also drew strength from their experience of overcoming previous adversity, which is well documented (Molina et al., 2014; Pieters, 2015; Richardson et al., 1990).

Social support network. The social support from family, friends and significant others was the first sub-theme contributing to the resilience among the interviewees. According to Kelly and Dowling (2011), support networks are central to cancer survivors and their ability to cope. In addition, the amount and quality of social support has been found to improve psychological outcomes, including growth (Molina et al., 2014). The results of this study concur with these findings. However, the social support received in this sample was also found to have both positive and negative influences on the participants. For example, a lack of understanding from the participant's families and friends led to detrimental effects on their recovery. The results of this study agree with previous research, which also acknowledged the potential negative impact of social support (Kelly & Dowling, 2011). Thus, it was important to the majority of interviewees to also receive social support from others with similar diagnoses. The results of this study and previous research also identified that a crucial factor in preserving a positive outlook is the support that patients are provided by their HCP's (McGrath, 2004b).

Personal coping strategies. The second sub-theme to influence resilience involved personal coping strategies. In this study, the participants used both emotion-focused coping (EFC) and problem-focused coping (PFC). First, EFC involved pursuing creative activities and relaxing diversions that were considered a way of remaining focused on something other than

cancer. Conversely, PFC involved critically processing, reasoning and planning their cancer experience and actively addressing ongoing challenges. Previous research has identified similar findings, however, there are mixed opinions among the experts. For example, earlier resilience research suggests that EFC is linked with the absence of resilience (Olsson et al., 2003), yet other researchers maintain that EFC benefits cancer survivor assisting them to process feelings prior to attempting, in a practical manner, to problem solve cancer-related issues (McGrath, 2004b; Lazarus & Folkman, 1984; Waldrop, O'Connor, & Trabold, 2011; Wenninger et al., 2013). The findings in this study concur, as many participants described ways in which EFC provided a welcome distraction, allowing them to take a break from cancer and maintain normality.

In addition, *positive attitudes* such as acceptance, determination, persistence, hope, optimism, perceived control, ownership and mental flexibility also aided in the participants' ability to implement successful cognitive strategies. Similar findings are reported in several studies (Bulsara, Ward, & Joske, 2004; Denz-Penhey & Campbell Murdoch, 2008; Folkman, 2010; Griffiths, 2014; McGrath, 2004a; Pieters, 2015; Wenninger et al., 2012). However, these participants also discussed the challenges associated with the perceived pressure placed by significant others associated with remaining positive and/or hopeful. Likewise, McGrath (2004b) reported that, at various times (i.e., cancer relapse), it was vital for patients to cycle through and acknowledge the process of despair or negativity and then readjust in their own time, before it was possible to maintain positivity. McGrath suggested that a hopeful position cannot be imposed, but rather requires time and nurturing by others, including clinicians, to allow the expression of a full range of emotions in a supportive environment. It was, however, acknowledged that the work of remaining optimistic must also be initiated and sustained by the patients themselves (McGrath, 2004b).

Similarly, the literature warns against the potential harm of creating '*false hope*' (Groopman, 2004). For example, Dr. Jerome Groopman, a haematologist who published a book titled *Anatomy of Hope: How People Prevail in the Face of Illness*, asserts that it is only '*true hope*' that results in courage and resilience. Groopman, who practiced medicine for several decades, was himself a patient suffering from a chronic back condition for nearly 20 years. During this time, Groopman discovered that hope was a mechanism that optimized his ability to function. Groopman determined that hope is perhaps the difference between wanting to achieve goals versus having to. As a consequence of his personal experience and research on HC survivors (CCL), Groopman came to realise that *false hope* only served to temporarily protect patients. As, once the inevitable reality of the patient's circumstances becomes apparent to them, patients are often left with a sense of uncertainty potentially resulting in more distress, than would otherwise be the case, if the hope provided were more accurate and/or truthful. Yet the focus of *true hope*, Groopman highlighted, is not to completely

eliminate emotions, such as fear or anxiety that are often hope's greatest obstacles. Rather, a balance needs to be reached by integrating the genuine threats that exist (i.e., fear of recurrence) and proposing strategies to manage them. In summary, what is clear from Groopman's findings is that hope is an active process in which cancer survivors are required to create, and at times reinvent, a positive future which can be emotionally challenging.

Finally, another important personal coping strategy emphasized by participants was the benefit of *finding purpose or meaning* in their life. Numerous qualitative studies of chronic illness have identified meaning in life as an important factor that is strongly correlated with psychological well-being (Denz-Penhey & Campbell Murdoch, 2008; Lau & van Niekerk, 2011; Miller & Tang, 2015; Park et al., 2008; van der Spek et al., 2013). Spirituality was one way of finding meaning highlighted by the participants, which supports previous research (Gall, 2004; Min et al., 2013; Wenzel et al., 2002). However, there was also great variation among the interviewees, as several did not affiliate with any specific religion or claim spirituality as a way of coping. It appeared from the results in this study that coping is dependent on the individual, the adversity experienced, available resources, and time since diagnosis.

Positive health behaviour modification. The third sub-theme that contributed to resilience in the majority of HC survivors interviewed was health behaviour modification. The benefits of self-care have been discussed within the cancer-related literature, yet research in this area is relatively recent. For example, several studies maintain that exercising, consuming a healthy diet and relaxation techniques have a positive influence on those living with cancer (Gouzman et al., 2015; James et al., 2011; Rabin et al., 2011). However, the direct influence on health behaviour modification in enhancing resilience is not widely documented in the literature. Therefore, health behaviour modification was not initially included as a major contributing factor in the proposed conceptual model. However, the interview results found that the transition to survivorship provided a strong motivation for the participants to modify their health behaviours. For example, the interviewees asserted that making positive lifestyle changes assisted with their long-term recovery, improved mental and physical health, facilitated weight loss and promoted relaxation.

Importance of time. The significance of time was another sub-theme that participants acknowledged as contributing to their resilience. Research shows that illness often compels patients to reassess and consider many factors such as: getting help at the right time; the time it will take to be treated; quality time remaining; taking time out; and, potentially, time left until death (Gartland et al., 2011; Kelly & Dowling, 2011; McGrath & Clarke, 2003). These factors were discussed by several of the participants in this study. The interviewees also outlined the importance of prioritizing their time. This supports research showing that perspectives of time may also change for individuals who have faced a life threatening illness

as their time becomes more precious (Charmaz, 1983; Grunfeld et al., 2013; Sherman, Cooke, & Grant, 2005). However, initially 'time' was not included as part of the proposed conceptual model, as there was little evidence in the literature of influence of time on resilience. Yet, surprisingly time as a theme was not only identified through thematic analysis, but, also was the most frequently referred to word spoken by interviewees, identified by the Leximancer software analysis, underscoring its importance to participant survivors.

Self-education. The final sub-theme that facilitated resilience was self-education. The participants required information to: help them understand the cancer experience; locate supportive resources; and, provide them with some control over decisions regarding their future. The participants pro-actively collected information from several sources, some of which included the Leukaemia Foundation, their specialist, the library, the Internet and social media. The results support previous research findings that cancer patients who remain informed are more likely to experience positive outcomes, and that the lack of satisfactory information can be a source of considerable stress (Butow et al., 2011; McGrath, 2004a; Murphy, 2013; Rabin et al., 2011; Xuereb & Dunlop, 2003).

Pathways and Barriers to Resilience

The next major theme identified by the analyses was the various pathways that assisted, or barriers that hindered, resilience. Five sub-themes were highlighted by the participants as factors that either assisted or impeded their ability to maintain resilience. The main conclusions of each will be briefly discussed.

Employment. First, according to this sample, employment was a major factor that positively influenced resilience. A variety of benefits were described by those participants who returned work, including, a sense of routine and normality, social interaction, financial reward, and a sense of purpose. This supports the majority of studies reporting that resuming work after illness is a vital component of an individual's self-identity and is associated with improved physical and psychological functioning (van Dijk et al., 2009; Grunfeld et al., 2013; Hara & Blum, 2009; Marker, 2015). However, there were also negative consequences associated with returning to work. Some participants found the transition back into the workforce overwhelming, due, in part, to a lack of confidence in their ability to carry out their work role effectively. Another concern for participants was the disclosure of their cancer diagnosis to their employer. However, the majority agreed that by disclosing their cancer diagnosis they received valuable support. The results concur with previous research highlighting that the self-disclosure of a cancer diagnosis in the workplace is generally associated with positive consequences (Hagedoorn et al., 2011).

Relationships. According to all participants, their interpersonal relationships also impacted on the resilience process. However, this varied within the group as both positive and

negative interactions were encountered involving partners, family and peers, and/or relationships with physicians and other allied health professionals. Several interviewees referred to their partners and immediate family as being their main source of strength. Close relationships with others, especially those who have been through a similar experience, are also identified among previous research as one of the most important sources of meaning (McGrath & Clark, 2003; van der Spek et al., 2013). In addition, a trusting and positive relationship with HCP's was regarded as essential in fostering resilience. This supports previous research reporting that many cancer patients have depended on effective relationships with HCP's (Bulsara, Ward, & Joske, 2004; Knott et al., 2012; Roundtree et al., 2011). Conversely, there were also situations in which close relationships caused stress and impeded resilience. The participants shared stories in which friends, family and even partners had distanced themselves. These changes impacted on their self-confidence, sense of attractiveness and self-image. Several participants stated that their intimate relationships were also affected due in part to sexual dysfunction, and these findings concur with previous research (Jefford et al., 2008; Lobb et al., 2009; Mosher et al., 2011; Ussher, Wong, & Perz, 2011; Zebrack, 2011).

Communication. The third sub-theme that either impeded or enhanced resilience was interpersonal communication. For the participants in this study, the communication between family, friends and HCP's varied considerably, with both positive and negative experiences encountered. First, by establishing an open communication style the participants were better able to adapt to the changes HC had caused within their relationships. This supports the literature stating that an open and transparent communication styles can empower survivors and thus facilitate a more trusting relationship (Bulsara, Ward, & Joske, 2004; Butow et al., 2011; McGrath, 2004b; Parry et al., 2011). However, at the other end of the spectrum, several participants elected to be more guarded in their communication. This was described as an attempt to maintain control, reduce distress and also to protect others. The communication style with HCP's also played an important factor in the participant's ability to maintain resilience. The majority of participants were complimentary about HCP's who were sensitive to their communication needs, yet several shared concerns related to communication issues (i.e., unanswered questions; the use of medical jargon; contradicting information; a lack of empathy, etc.). This validates previous literature stating that communication between cancer patients and their specialist is an area of potential stress (Butow et al., 2013; Roundtree et al., 2011; Xuereb & Dunlop, 2003).

Information and resources. Fourth, interviewees highlighted that, for the majority, available information and resources enhanced their resilience. Several important factors were discussed in relation to the appropriate amount, timing and delivery of cancer-related information. This facilitated resilience by enabling participants the opportunity to process vital information, set realistic expectations and by providing them with a sense of control. The

literature confirms the importance of offering the right amount of quality information that is also appropriately timed. However, research states that it can be difficult to achieve the right balance (Carey et al., 2012; McGaughan et al., 2012; Rabin et al., 2011; Xuereb & Dunlop, 2003). The results of this study support the literature, with many participants reporting that, although they were keen to understand their HC, they also felt overwhelmed and found it difficult to retain the information provided. To overcome this issue, participants used effective strategies to remember information (i.e., taking family members to appointments, note-taking, using recording devices etc.)

Another important consideration highlighted by participants is that the community resources offered should match their unique needs. For example, for one cancer survivor an active exercise program may be considered protective, however this may present a risk for another. Thus, one of the main challenges identified in this study is the ability for HCP's and the community to ascertain the individual patient needs and match resources and information delivery accordingly.

Unmet needs. The final sub-theme identified by the participants that impeded their resilience were their unmet needs. The most common unmet need occurred at the completion of treatment when the participants faced unknown territory feeling lost, lonely, isolated and dismissed, mainly due to the lack of support following treatment. This was also a time that many interviewees stated that they would have most benefitted from the offer of counselling or support groups. These results concur with previous research highlighting that numerous stressors often accompany the completion of treatment and when additional support is particularly valuable (Knott et al., 2012; Rabin et al., 2011; Roundtree et al., 2011; Stanton et al., 2005; Waldrop, O'Connor, & Trabold, 2011). Many participants also felt rushed during their specialist appointments. Research reports that this is concerning for cancer survivors, as important issues remain unanswered due to the lack of time available during medical appointments (Kelly & Dowling, 2011; O'Leary, 2013).

Survivor outcomes

The final theme identified by participants in this study was survivor outcomes, which occurred as a result of being diagnosed with HC. In line with previous research (McGaughan et al., 2012; Roundtree et al., 2011; Wallace et al., 2007), all participants expressed the need to re-establish their lives following their HC experience, which resulted in a diverse range of survivor outcomes. Despite the negative impact of living with HC, there were also many positive outcomes also shared by the participants. For example, there were several examples of healthy, well-adjusted survivors who described their determination in achieving optimal health outcomes. There were three main sub-themes that participants attributed as factors associated with personal outcomes.

Transition: a new normal. The first sub-theme identified as an outcome involved each HC survivor's transition to a new normal. In this study, the majority of participants experienced a sense of disorientation between their pre- and post-cancer lives. This supports the work of Little and colleagues (2001), who describe this phase of 'liminality', in which survivors progress through the space of illness, but do not return to their pre-illness world. Other researchers agree suggesting that surviving cancer is a lifelong journey involving several phases of change (Deimling et al., 2005; Dow, 1991; Pelusi, 1997). In line with recent research (Pieters, 2015), the current interviewees highlighted that resilience did not simply occur instinctively. Rather, resilience required conscious dedication, persistence and effective self-management skills on their behalf, to move toward establishing a new normal. These results also appropriately reflect the experience described by Chapman (2015), a ten-year cancer survivor, who recently published an article detailing his personal journey. Chapman agreed, stating "I found it beneficial to be my own advocate and my own case manager as I navigated both the treatment and the survivorship space. By self-managing where possible, and then seeking good quality professional help when your need exceeds your own capabilities, it is possible to rebuild your new normal in a positive and useful way" (p. 75.).

Re-prioritisation and growth. In addition to establishing a new normal, most participants discussed their re-prioritisation and growth in relation to survivor outcomes. First, in terms of re-prioritization, the ability to process everyday stress in perspective and not 'sweat the small stuff' were amongst many qualities that were reflected in the interviews. An example of re-prioritizing was also highlighted by 25 year-old former Olympian and Hockeyroo's player Fiona Boyce, a Hodgkin's lymphoma survivor. Boyce stated that "having cancer has changed me and stopped me being such a perfectionist and I know now that doing your best is all you can ask. It's made me grateful for all the good things I have" (O'Leary, 2014, p.5).

Second, in relation to personal growth, this study supports previous research suggesting that, following cancer, survivors often develop new life perspectives and priorities (Bulsara, Ward, & Joske, 2004; McGrath & Clarke, 2003; Wallace et al., 2007). For example, the majority of participants described their search for meaning and purpose, which allowed them to optimistically re-appraise their lives and begin the healing process. In line with previous research (Connerty & Knott, 2013; Miller & Tang, 2015), several interviewees also found that assisting others in similar situations (i.e., through volunteer work) helped them to create value and meaning from their cancer experience. However, the findings of this study identified that meaning making among cancer survivors is usually a multifaceted process. For example, in areas such as personal relationships many participants attributed more importance, yet, in other facets of their life, such as their careers, meaning tended to diminish. This inconsistency has also been reported in previous research (van der Spek et al., 2013).

Self-reflection. The final sub-theme that was discussed by each participant in relation to personal outcomes involved their self-reflection. Many participants questioned not only why they were diagnosed with cancer, but also how they survived when others did not. As a result, the interviewees reflected on their cancer experience as a “wake up call” and began to question current roles and relationships within their family, among friends and at the workplace. For example, a recurrent theme shared by the majority of participants involved questioning themselves on what are the most important aspects in my life now. Similar findings have been reported in previous research (Pieters, 2015; van der Spek et al., 2013). Several participants also discussed the need to seek professional help, not only at the point of diagnosis, but also following treatment, in order to find solace and answers to such questions.

In summary, the previous section has outlined four main themes (and sub-themes) that the HC interviewees in this study acknowledged as contributing to their positive or negative mental health outcomes. These included: the burden associated with a HC diagnosis; resilience - coping with HC; pathways and barriers to resilience; and, survivor outcomes. This qualitative analysis has confirmed that, over time, several factors contributed to or impeded the process of resilience among these HC survivors.

Interview Discussion - Research Question 2:

Which key factors made it easier or more difficult for HC survivors to achieve and maintain their resilience?

Participants were asked to list the *top three factors* that either helped or hindered their resilience. First interviewees identified what they believed facilitated their resilience with the majority of participants referring to social support as one of their top three factors. This supports a proliferation of literature confirming the significance of providing support to cancer survivors (Butow, Grigis, & Schofield, 2013; Grigis & Butow, 2009; Jefford et al., 2008; Knott et al., 2012; Lobb et al., 2009; Stewart & Yuen, 2011). Other commonly referred to factors included self-care and keeping busy or having a purpose/meaning.

However, when analysing all responses together, a difference was noted in the overall results between individual, family and community level factors. Over half of the interviewees identified individual factors (e.g., self-care, finding purpose, keeping busy etc.) as being most influential. This suggests that many participants consider that individual factors are important to address when building resilience. There were also demographic variations noted. For example, participants under 30 years of age highlighted social media as the second most important factor. In addition, the importance of finding purpose or life meaning was listed by 78% of long-term survivors, as opposed to only 28% of short-term survivors. However, self-

care was more important in the early survivorship trajectory, particularly among the younger cohort. These cohort differences are worthy of future consideration, in order to ensure the implementation of individualised interventions.

The second part of question two aimed to highlight the top three risk factors that each participant found made it more difficult for them to maintain their resilience. Again, the majority of the participants listed individual factors as impacting on their resilience. Of the total individual factors identified, the majority of participants believed that psychological rather than physical effects impacted on their resilience the most. Seventy-five percent of participants also considered that combined factors largely impacted on their ability to maintain resilience. For example, a forced early retirement can impact on the individual (physical, social, psychological), family and the community. These results highlight that the risk factors impeding resilience are complex and multi-layered. Given this, supporting HC survivors will require a broad, interdisciplinary approach.

Interview Discussion - Research Question 3:

Were there any factors mentioned during the interviews that were not previously identified in the proposed conceptual framework?

Most of the individual factors reported to be predictive of resilience in this study support those previously identified in the resilience literature. This is not unexpected, given that past experiences, coping factors, genetics and the environment all influence resilience, regardless of the type of adversity faced (Stewart & Yuen, 2011). However, this research also revealed factors that were not described as major contributing factors in the proposed conceptual model. This included aspects of *positive health behaviours* (i.e., care with one's appearance and maintaining a healthy diet). Another relevant factor regarding the HC experience that emerged from both the thematic and Leximancer analyses, and had not been predicted to such an extent in the analysis was the impact of time which was linked to many concepts, the most important of which was the need to take *time* (i.e., time-out, down-time, alone-time etc.). In doing so, the resilience process was nurtured, as time enabled the participants the 'space' necessary to process this adverse experience.

Conclusion –Interview Discussion

The 23 HC survivors interviewed offered significant insights that highlighted resilience as a natural and dynamic process within each individual, that connects their past, present, and their anticipated future. The majority of factors identified as influencing resilience in this qualitative study support those discussed among previous literature investigating other cancer survivors (including other types of cancer). The only relatively unique factor in this research influencing resilience, related to time out and certain areas of positive health behaviour change (i.e., diet). Although aspects of health behaviour change (i.e., exercise) have been discussed in several studies (Gouzman et al., 2015; James et al., 2011; Levin, Greenwood, Singh, Tsoi, & Newton, 2015; Rabin et al., 2011) involving cancer survivors, these factors have not been linked to maintaining resilience among this population. Phase One (Qualitative) provided new insight into the experience of living with HC.

Discussion of Quantitative Findings (Phase Two)

Phase Two of this research examined a number of areas associated with the experience of living with a HC diagnosis, through the distribution of a survey questionnaire. The main focus of the survey phase was to validate themes identified in the literature and through the qualitative interviews regarding factors that contribute to the resilience in a larger sample of HC survivors. This chapter intended to explore several questions, the results of which will now be discussed in relation to previous literature, and the qualitative findings presented in Phase One (Qualitative) and Phase Two (Quantitative).

Survey Discussion - Research Question 1:

What influence does resilience have on depression and anxiety?

According to the literature, it is essential to recognize that psychological distress levels reported in long-term cancer survivors vary, as rates may be influenced by the cancer type and the associated physical complications (Krebber et al., 2014; Mitchell et al., 2013; Walker et al., 2013). According to Schumacher et al. (2014), survivors of HC appear resilient and are able to adapt well, and the results of this study agree with this. Yet, there are a number of studies that also report significantly elevated levels of psychological distress among survivors on specific measures of anxiety and depression (Allart et al., 2013; Korszun et al., 2014; Wenninger et al., 2013). Mental health is important to investigate, as research has identified a significant correlation between low resilience and higher levels of depression and anxiety in several studies (Krebber et al., 2014; Mitchell et al., 2013; Walker et al., 2013; Wu et al., 2012).

Depression. Although the exact rates remain unclear, depression has been the most comprehensively investigated mood disorder among cancer patients (Mitchell et al., 2013). In the current survey sample of HC survivors, higher levels of resilience were associated with decreased scores on depression and anxiety. This significant correlation between resilience and mental health in those with cancer has also been reported in the literature (Schumacher et al., 2014; Wu et al., 2012). In comparison with depression rates among other cancer survivors identified in the literature (Krebber et al., 2014; Massie, 2004; Mitchell et al., 2013; Wenninger et al., 2013), the survey sample of HC survivors reported low levels of depression. When combined, only 4% reported either moderate or severe levels.

However, understanding depression among cancer survivors is not easy, partly due to a wide variety of research designs used, conflicting results and differing depression measures used. For example, a meta-analysis by Mitchell et al. (2011) reviewing 70 studies on mood disorders in haematological and oncological settings, involving 10,071 individuals across 14 countries, found the prevalence of depression ranged considerably (1.0% – 77.5 %). According

to Mitchell et al. (2011), the variation in rates may be due, in part, to variations in research methodology. More recent studies tend to be more methodologically sound and, therefore, report more accurate rates than the older studies that report higher rates of depression. As a result of this review, Mitchell and colleagues (2011) concluded that approximately 16% of patients with cancer are depressed, substantially more than found in the survey sample included in this study. The survey results are also substantially lower than the rates (6.2%) in the general population (ABS, 2007). These survey results are surprising, as one would expect the rates to be higher than in the general population, given the trauma and uncertainty faced by those with serious illness. However, this indicates that the survey sample was potentially biased towards those who were coping better. It is possible that more of the depressed HC survivors were among those individuals who elected not to participate. As with all research it is difficult not to obtain a biased sample, and this is discussed later as a limitation of this research. Yet, it is not expected that potential sampling bias has undermined all the findings of this mixed method study, as the sample included in both studies still comprised a varied demographic. However, in the future, different research designs (i.e., targeting hospital settings via follow up appointments) may be more effective at recruiting a broader cohort of individuals, and, therefore, improve potential sampling bias.

Anxiety. The focus in the literature on assessing depression in cancer survivors may have illuminated our understanding of the impact depression may have on resilience; however, this singular focus may have also limited our understanding of other of psychological distress among cancer survivors. According to recent research, in addition to increased rates of depression, increased rates of *anxiety* have also been found in patients following a cancer diagnosis. More importantly, these high rates of anxiety tend to persist over time, whereas increased rates of depression were less enduring (Mitchell et al., 2013). This implies that anxiety, rather than depression, may be more problematic in long-term cancer survivors. This is not unlike rates among populations without cancer, where anxiety levels are reported to have a 12-month prevalence of 18% that is approximately twice as common as depression.

The results of the survey showed that four times more respondents reported either moderate or high levels of anxiety (17%) than those reporting depression (4%). These results concur with earlier research, which found higher levels of anxiety versus depression in both adult colorectal and mixed-cancer patients (Alacacioglu et al., 2010; Brown et al., 2010). Therefore, it is important to investigate anxiety, not only because the prevalence may be higher among cancer survivors, but also because screening for anxiety has often been overlooked in clinical care in comparison to depression and distress (unpleasant feelings or emotions) (Mitchell et al., 2013).

Demographic variables. Demographic variables were examined to further explore their influence on mental health and resilience. It was beyond the scope of this study to

investigate all demographic factors. However, gender, age and time since diagnosis were selected, given that there are well-documented relationships, yet conflicting results, in the literature, as to how these demographic factors influence coping, adaptation and QOL among cancer survivors (Knobf, 2011). Demographic factors are also important, as certain cohorts may be at higher risk of negative mental health outcomes, which would be of significance to clinical practice (Avis & Deimling, 2008; Bennett et al., 2010; Foster et al., 2009; Pudrovaska, 2010; Rabin et al., 2011; Zebrack, 2011).

Survey results showed that there was no significant difference on either depression or anxiety levels according to gender. However, Mann-Whitney *U* tests indicated that resilience levels of long-term survivors (6+ years) were significantly *higher* than for those of short-term survivors (< 5 years). Conversely, depression and anxiety levels were significantly *lower* among long-term survivors. These findings obtained during Phase One (Qualitative Interviews), were consistent with previous literature (Ganz, 2011; Knobf, 2011; Maher & Fenlon, 2010) and suggest that psychological interventions would be best targeted to individuals earlier in the survivorship trajectory, as this is a time when HC survivors report lower levels of resilience and higher levels of depression and anxiety.

Finally, analyses also identified a significant difference between the young (<40 years) and older (61+ years) survey respondents, with the younger adults reporting *higher* anxiety levels. Earlier research has revealed extensive differences in distress among cancer survivors according to age, suggesting that younger adults may be more vulnerable to negative mental health outcomes than older survivors (Constanzo, Ryff, & Singer, 2009). Developmental theorists propose that “off-time” life events occurring outside of typical age ranges are more likely to cause distress (Neugarten & Hagestad, 1976), and this may also be the case with a cancer diagnosis. The higher anxiety levels among the young adults found in this study concurs with previous research. For example, Wu et al. (2012) investigated the relationships among coping, anxiety and resilience in adolescents and young adults undergoing cancer treatment. This cross-sectional design, involving 131 adolescent and young adult respondents, reported that over 20% had high scores on worry. Wu et al. (2012) concluded that anxiety is the main psychological disturbance in adolescents with cancer. In addition, Zebrack (2011) proposed that younger cancer survivors face several age-related issues associated with their developmental stage, such as issues with self-esteem, confidence, identity and uncertainty about acceptance by others (Zebrack, 2011). Another related issue for young adults is the decision regarding the sharing of cancer-related information with their friends and peers, including new acquaintances and employers (Zebrack, 2011), which may lead to increased levels of anxiety.

In summary, higher anxiety levels were identified among young adults. The overall results also indicated that those with higher levels of resilience reported decreased levels of

depression and anxiety. This suggests that interventions designed to increase resilience might be influential in improving mental health outcomes. However, as resilience is a dynamic concept, it can be influenced by life circumstances, the external environment, including situational and contextual factors. Therefore, negative experiences can cause temporary disturbances, even in the most resilient individuals (Schumacher et al., 2014). Thus, being resilient does not necessarily imply the absence of psychopathology (Ungar, 2011). In addition, it is possible for those who report negative mental health issues, such as anxiety, to successfully achieve positive mental health outcomes by implementing or accessing available resources.

Survey Discussion - Research Question 2: What are the significant factors that contribute to resilience among HC survivors?

The main aim of this research was to explore risk and protective factors that influence resilience among HC survivors. Resilience among cancer survivor has been a topic of interest for some time; however, publications to date have focused on the more common cancers. Of interest, then, is whether the factors contributing to resilience among HC survivors, a relatively understudied population, are similar to those identified among other cancer populations, such as breast and prostate cancers. Based on the literature review and the findings from Phase One (Qualitative Interviews) a wide variety of factors were identified that reportedly influence resilience. Consequently, a conceptual model was proposed that highlighted factors which may contribute most to/negate resilience. This earlier conceptual model comprised *individual* (e.g., coping strategies, self-care, etc.); *family* (e.g., emotional support, etc.); and, *community* (e.g., HCP relationships, support, information, etc.) level factors (See Figure 5.3 p. 168). Therefore, the current survey study aimed to test this model in order to validate these earlier findings among a larger population of HC survivors.

Regression Analysis. The 24 variables: self-distraction, active coping, denial, substance use, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, self-blame, social support (significant others, HCP, family and friends), time out, exercise, self-appearance, researching information, alternative treatment and diet, were entered *simultaneously into a regression model*. The results indicated that the model accounted for a significant 61% of the variance in resilience scores. Of the 24 variables, 21 variables were useful in predicting resilience among HC survivors. Only three variables, self-distraction, substance abuse, and venting, had a non-significant zero-order correlation with resilience.

Six of the 21 variables, that significantly contributed to the model of resilience when combined with all the other 24 variables, included *active coping*, *positive reframing*, *self-blame*, *family support*, *friend support* and *exercise*. One variable, self-blame, was a negative predictor of resilience; meaning that higher scores were related to lower resilience scores. Consistent with the results of the qualitative interviews and previous research, the majority of the predictor variables significantly correlated with resilience. However, there were some exceptions.

Active Coping. Confirming previous research, this survey found that *active coping* ($\beta = .21$) contributed positively to enhance resilience and reduce negative mental health outcomes (Haase, 2004; Lauver, Connolly-Nelson, & Vang, 2007; Pieters, 2015; Roesch et al., 2005; Wu et al., 2012). Active coping or problem-focused coping (PFC) involves the efforts of an individual to persevere in altering the demands imposed upon them by defining the stress, generating ideas and, then, in acting on a solution to change the threat (Lazarus & Folkman, 1984; Pieters, 2015). Thus, active coping engages problem-solving, control, optimism, and seeking support as protective factors that assist people with cancer to adjust (Haase, 2004; Pieters, 2015).

There is speculation in the cancer-related literature that emotion-focused coping (EFC) when used concurrently with PFC is also beneficial (Austenfeld & Stanton, 2004; Wills & O'Carroll Bantum, 2012). Rather than PFC/active coping, EFC entails attempts to appropriately deal with the emotions experienced by providing selective attention (i.e., lessen, avoid or minimize) in order to alter the way the individual thinks or feels (Lazarus & Folkman, 1984). However, the results of this survey study suggest that, of the two styles of coping, PFC or active coping is associated with more resilient outcomes. This concurs with earlier research by Frick et al. (2004) that involved 126 HC patients, and explored coping styles prior to autologous stem cell transplantation. Respondents completed several surveys addressing health-related control expectancies and coping with their illness, in which active coping proved to be the most effective coping style. A more recent study by Wu and colleagues (2012), involving 131 cancer survivors, half of whom had leukaemia, also found resilience to be positively correlated with cognitive coping and active/problem-oriented coping. Similar results have recently been reported among other cancer populations. For example, active coping was identified among mixed cancer survivors in Nigeria to be associated with better social and functional wellbeing (Asuzu & Elumelu, 2013) and psychological wellbeing in the Netherlands (Aarts et al., 2015). It has also been associated with: improved QOL among those with gastrointestinal cancer in Singapore (Cheng et al., 2012); and, in enhancing the coping abilities among Egyptian women with breast cancer (Elshestawy, Abo-Elez, Ashour, Farouk, & El Zaafarany, 2014).

Positive Reframing. In the survey study, *positive reframing* ($\beta = .15$) also significantly contributed to the model of resilience. Positivity, which is reported in the literature to foster resilience (Dunn et al., 2011; Gartland et al., 2011; Ho et al., 2011), refers to a stable personality trait where an individual has a generalized expectation that the future will be positive, even when negative events occur (Pieters, 2015; Scheier & Carver, 1985). However, these results are not fully consistent with the earlier interview findings during Phase One, or concur conclusively with previous research, which has produced mixed findings. For example, the results of the survey study differ from earlier research carried out by Bowen, Morasca, and Meischke (2003), who stated that optimism was not correlated to any of the variables they used to compose their resilience scale.

According to McGrath et al. (2006), research on positive reframing in cancer focuses on two broad hypotheses. *First*, ‘medical research’ proposes that positivity increases the likelihood of a better outcome. Yet, there is no clinical evidence that positive thinking affects the progress or outcome of illness by preventing or curing cancer. However, positivity may assist to maintain hope and protect cancer survivors from emotional pain and negativity (Youll & Meekosha, 2015). For example, an earlier study involving breast cancer survivors, who were on average cancer-free for nine years, reported that 60% of women credited their lack of recurrence to positive reframing, yet only 4% attributed this the use of tamoxifen⁶ (Stewart et al., 2001). *Second*, ‘social research’ maintains that a positive attitude enables cancer survivors to cope better with treatment and the illness experience (Youll & Meekosha, 2015). The results of this study generally support this perspective, which is shared among other researchers. For example, Lepore and Revenson (2006) report that optimists are more likely to demonstrate positive outcomes following adversity by positively reframing negative life events, adopting new and more adaptive world-views and by more readily eliciting social support resources. Likewise, in more recent research involving gynaecological cancer survivors in the USA ($n = 281$), it was found that positive reframing functioned as a mediator in the association between resilience and QOL (Manne et al., 2015).

However, although the survey respondents reported positive reframing as influential in building resilience, the interview results do not fully support these findings. Although the participants involved in the interviews discussed their optimism, several also commented about the ongoing challenge associated with the expectations of others to consistently remain positive. Similar results have been discussed in previous research in which the burden associated with maintaining ‘fighting spirit’ (Knott et al., 2012), or remaining positive can lead to further stress and anxiety (Folkman, 2010; McGrath, 2004). Therefore, although positive reframing was significantly related to resilience in Phase Two (quantitative), this was not as

⁶ Tamoxifen is a medication prescribed to women for the prevention and treatment of breast cancer which blocks the actions of estrogen

apparent during Phase One (qualitative). Rather, the earlier interview data analyses suggest that, although positive reframing is widely advocated and encouraged among those with serious illness (Youll & Meekosha, 2015), it is also important to be aware of the moral pressure societies place on individuals to maintain positivity. As Ehrenreich (2009) emphasizes “failure to think positively can weigh on cancer patients like a second disease” (p. 43). Thus, as a community we need to consider that positivity is not a given, but rather a process dependent on the changing circumstances of the person.

Social Support. One of the most influential resources available to cancer survivors is *social support*, which has been documented across several studies to have a major influence on an individual’s resilience and psychological well-being (Hjemdal, et al., 2006; McCabe & Cronin, 2011; Ozbay et al., 2007). Social support refers to the real or perceived resources received through social interactions with others that enable an individual to feel valued and respected (Galván, Buki, & Garcés, 2009). Confirming previous research, social support in both phases of this study was found to contribute positively to resilience. More specifically, within the survey study results, family support was the most influential variable within the model ($\beta = .33$), followed closely by friend support ($\beta = .22$). Zebrack (2011) similarly identified family support and cohesiveness as the most central contributors to positive adjustment among adolescents and young adults. Family and friends are viewed as also a major source of support for cancer patients in other age cohorts (Gatchel et al., 2007; Hjemdal, et al., 2006; McCabe & Cronin, 2011).

In a systematic review involving those with physical illness, including cancer, Stewart and Yuen (2011) highlighted that social support was predictive of various aspects of resilience in several studies. In addition, the support from family and friends has been recognized as being crucial in: enabling individuals to cope with the challenges of illness (McCabe & Cronin, 2011; Yu et al., 2008); improving self-care (Park et al., 2008); encouraging treatment adherence (Magai, Consedine, Neugut, & Hershman, 2007; McCabe & Cronin, 2011); enhancing emotional expression, self-control and confidence (Wills & O’Carroll Bantum, 2012); and, boosting self-efficacy (Monsivais, 2005). The beneficial effect of social support has also been reported in several other studies to positively correlate with improved emotional and psychological QOL among HC patients (Lim & Zebrack, 2006; Korszun et al., 2014; Santos et al., 2006).

Conversely, a lack of social support has been widely recognized as a risk factor for psychological illness (Korszun et al., 2014; Parker et al., 2003) and increased mortality (Kroenke et al., 2012). In addition, a recent systematic review reported that a lack of social support affected QOL in HC patients (Allart et al., 2013). This is supported by previous research highlighting that ineffective social support within interpersonal relationships can lead to negative outcomes, such as increasing a survivor’s feeling of isolation (Landmark,

Strandmark, & Wahl, 2002). As mentioned previously, research by Parker et al. (2003) recommend that assessing patients' levels of social support is possibly the most accurate way to identify those patients most prone to anxiety, depression or distress following the diagnosis and treatment of cancer.

It has been reported that some cancer survivors find it difficult to receive appropriate support from family or friends, as significant people in their lives often became distressed while discussing their cancer diagnosis and are unable to remain objective (Rabin et al., 2011). In such situations, cancer survivors rely on support from their clinical team and community support groups that provide an environment in which they are more able to normalize their experience (Rabin et al., 2011). Although support from HCP's did not appear in the model, it did show a positive relationship with resilience in this study, suggesting that HCP's also play an important role. Therefore, it is critical that clinicians not only consider the social resources that cancer patients have available when exploring differential responses to disease management but also recognize their responsibility in providing support.

Exercise. Another factor in this study that significantly predicted resilience is *exercise* ($\beta = .15$). This supports the results from Phase One and previous research asserting that engaging in physical exercise is one of the best prescriptions to reduce the side-effects of cancer treatment (Cormie et al., 2015; Singh et al., 2015). Decades of research have pointed to the benefits of exercise in: improving QOL, relaxation, sleep and self-esteem levels (James et al., 2011); reducing cancer re-occurrence (Aziz, 2002; James et al., 2011); and, improving psychological distress, fatigue, sexual dysfunction and pain (Cormie et al., 2015; Midtgaard et al., 2011; Murphy, 2013). For example, research by Min et al. (2013) proposes that physical exercise, especially aerobic exercise, is also helpful in enhancing resilience among patients with depression and/or anxiety disorders. In addition, recent research has reported on the benefits of exercise among adolescents and young adult cancer survivors (Murnane, Gough, Thompson, Holland, & Conyers, 2015) and in two exploratory case studies involving female patients with brain cancer (Levin et al., 2015).

However, despite the benefits of exercise, studies suggest that physical activity usually decreases significantly after a cancer diagnosis and rarely returns to pre-diagnosis levels (Love et al., 2013; Murphy, 2013). In addition, research indicates that more than one-third of survivors, considered to be of normal weight prior to diagnosis, tend to be overweight by the time treatment ends (Love & Sabiston, 2011). Yet, many cancer survivors are eager to initiate changes in their health behaviours when faced with cancer (Gouzman et al., 2015). Thus, clinicians have a responsibility to use this as a 'teachable moment' to encourage healthy lifestyle practices. In situations in which a patient is unable to exercise (i.e., due to treatment side-effects or co-morbidities), other positive health behaviour changes should be promoted.

The results of this study also identified a significant correlation with other positive self-care behaviours, including improving dietary intake, taking care of appearance, taking time-out, and seeking alternative/complementary treatments. Cancer survivors would benefit from being educated on the importance of lifestyle behaviour changes, not only to assist their recovery, but also to potentially reduce the risk of cancer recurring (Murphy & Girot, 2013). The results of this study have confirmed that a healthy lifestyle contributes significantly to personal resilience, which, in turn, reduces psychological illness.

Self-blame. The final factor, and the only negative predictor of resilience, was *self-blame* ($\beta = -.22$). Respondents who blamed themselves for their cancer diagnosis reported significantly lower levels of resilience. Although self-blame was not a factor that emerged during Phase One interviews, self-blame has been reported in previous cancer-related literature since the 1970's. Among those with cancer, several factors allegedly contribute to the manifestation of self-blame. These may include the type and severity of the diagnosis, whether addictive behaviours such as smoking or alcohol use are involved, perceived lifestyle stress, the personality style of the individual and whether there is a history of psychological illness (Block, Drafter, & Greenwald, 2006). Consequently, self-blame rates vary significantly among the cancer survivor population. For example, earlier research among those with head and neck cancers has identified that approximately 50% blame themselves for their diagnosis (Block, Drafter, & Greenwald, 2006) as opposed to 25% of colorectal survivors (Phelan et al., 2013).

Self-blame can be either *behavioural* which is the guilt about one's behaviour (i.e., smoking) or *characterological* which involves blame about oneself (i.e., belief that you are the type who just gets sick) (Janoff-Bulman, 1979). Self-blame is an important issue to address, as reportedly both types are highly correlated with depression and anxiety (Block et al., 2006).

Research in the USA among lung, breast and prostate cancer survivors found that respondents who hold internal causal attributions for their cancer report poorer psychological outcomes (Else-Quest, Hyde, Schiller, & LoConte, 2009). Likewise, research reports that breast cancer survivors (Friedman et al., 2010) and men with colorectal cancer (Phelan et al., 2013) who blame themselves report poorer QOL and more mood disturbance. A significant inverse relationship between self-blame and physical wellbeing is also identified among 237 mixed-cancer survivors in Nigeria (Asuzu & Elumelu, 2013).

The survey study highlights that it is imperative that clinicians not only identify those cancer survivors who are at risk of experiencing self-blame, but also assist them to normalise their psychological distress. A common myth cancer patients adopt is that they must maintain a positive outlook in order to cure their cancer. Consequently, this can lead to self-blame when their own (normal) shock, anger or fear reactions occur during difficult times. As a society we also need to challenge the myth that all negative emotions are harmful. Negative emotions can assist to mobilise health behaviour change to lower cancer risks, and to comply with medical

treatment (Block et al., 2006). For example, fear may motivate a patient toward active coping behaviours (i.e., such as finding help, gathering information, planning).

Survey Discussion - Research Question 3: Who in the clinical team provided the most and least support and relevant information?

Clinical Support. Despite not appearing in the survey results as a predictor in the model, like several other factors, HCP support did show a positive relationship with resilience in the survey data, suggesting that the healthcare team also play an important role. These survey results concur with the earlier Phase One interview findings, and previous literature (Adejoh, Temilola, & Olayiwola, 2013; Doyle, 2008; Roundtree et al., 2011), which also revealed that clinicians play an important role in assisting cancer survivors to maintain resilience. However, according to Butow et al. (2011; 2014) and Knott et al. (2012), this is an area that requires further investigation. For example, notably missing are more specific details (i.e., follow-up support, information related to post-treatment care etc.) about the role of HCP's in enhancing resilience. This study has attempted to address this gap in the research by adding HCP's as a group included among social support sources in the survey study, and by asking respondents particular questions relating to their clinical team.

The first of three questions in this section of the survey questionnaire aimed to understand which individual in the clinical team provided the *most effective support*. The results indicated that, for the majority of respondents, the specialist provided the most support. However, many stated that the collaborative team of HCP's was also responsible (including the specialist, nurses, general medical practitioners, psychologists, pharmacists and community support agencies). This has implications for clinical practice, as HCP's need to be mindful that, either as individuals or as part of an interdisciplinary team, they are all influential in providing the HC survivors with support.

However, according to research, the clinical team are also responsible at times for a lack of support (Knobf, 2011; Knott et al., 2012; O'Callaghan et al., 2016). Consequently, a second question asked survey respondents who in the clinical team they considered to be *least supportive*? On a positive note, the majority of respondents in this study (68%) could not identify anyone in their clinical team as being responsible for a lack of support. Yet, of the remaining survey respondents, the majority listed medical specialists, general medical practitioners and nurses. These results concur with previous research acknowledging that support is sometimes lacking (Butow et al., 2011, 2013; Landmark, Strandmark, & Wahl, 2002; Lobb et al., 2011). This is particularly evident in later survivorship phases when the

patient's focus shifts from merely getting through treatment, towards a more comprehensive view of recovery. It is during this phase of transition that patients often notice a withdrawal of support by the healthcare system (Knott et al., 2013).

Clinical Information. A third question for survey respondents was aimed at identifying where the majority of cancer-related *information* was obtained. A recent study in the USA by Goldfarb and Casillas (2014) reported on the unmet information and support needs of newly diagnosed young adults with thyroid cancer. Of the 1,113 respondents, more than 80% rated receiving information about medical or physical matters as very or extremely important with 70% also rating emotional/psychological information issues to be very or extremely important. Yet, the results suggested that very few recalled receiving any information besides that surrounding surgery and treatment. In addition, according to Boyle (2006), patients are often consumed with getting through treatment. Therefore, their ability to process new information about life following treatment may be limited. Thus, important information needs regarding survivorship concerns are largely unmet. However, Marker (2015) asserts that cancer survivors wish to understand the complex challenges they could face throughout their cancer journey and appreciate effective clinician communication involving authenticity and honesty. Numerous other studies have stressed the importance of providing relevant cancer-related information. In a study by Rabin et al. (2011), 84% of cancer survivors expressed a need for information-based interventions. This view is supported in other research stating that cancer patients and their family require informational and educational support, in order to cope effectively following diagnosis and treatment (Butow et al., 2011; Adejoh, Temilola, & Olayiwola, 2013). A recent systematic review by Swash and colleagues (2014), which solely addressed HC survivors, agreed with these findings.

The majority of survey respondents reported that they sourced most of the necessary cancer-related information through specialists. These survey results concur with recent research that also emphasized the importance of the clinical team in the delivery of cancer-related information. A literature review by Rood et al. (2014), found that HC patients expressed a high need for medical information and they preferred to receive this predominantly from doctors, followed by nurses. In addition, the perceived need for information differed strongly between patients. Therefore, in clinical practice more attention is required in tailoring the information delivery to the patient by taking into account their coping style, support networks, age, sex, diagnosis severity and time since diagnosis (Rood et al., 2014).

Several respondents also stated that community support groups, other cancer survivors and social media/internet were instrumental in information delivery. Similar findings were reported in a large-scale cross-sectional study involving rehabilitating breast cancer survivors ($n = 465$) in Belgium. The most popular sources of cancer-related information and support

were reportedly either informative brochures, a consultation with a psychologist, community information sessions or an informative website (Pauwels, Charlier, De Bourdenaudhuij, Lechner, & Van Hoof, 2011). In order to address the issues with clinical support and information delivery, several research teams have begun to trial ‘end-of-treatment care plans’ (Maher & Fenlon, 2010). These include information about potential side-effects of treatment, follow-up tests, and a variety of evidence-based, educational interventions. These care plans are vital, as limited communication with HCP’s about physical, psychological and social symptom distress can result in adverse psychological morbidity (Knobf, 2007). Thus, effective communication and delivery of information between clinicians, the cancer patient and their family is integral to the concept of social support. This study has highlighted that adequate support and information from HCP’s across the trajectory are vital protective factors among cancer survivors.

Survey Discussion - Research Question 4:

As a result of personal experience, what advice can current HC survivors provide to those who are newly-diagnosed that may help them to cope?

The number of survivors is increasing annually and is likely to continue to increase in the future (Aziz, 2009). Therefore, it is important to understand as much as possible about resilience and the adaptability of these individuals. The final question for survey respondents was in an open-ended format, with the purpose of addressing the response restrictions commonly linked with questionnaires by eliciting as much information as possible. This question asked respondents to provide advice, based on their own experience of coping with HC, that would benefit newly-diagnosed HC patients. The themes discussed by the survey respondents in answering this question support those that have been highlighted during both Phase One interviews and in previous research. For example, most of the survey respondents that answered this open-ended question identified the importance of implementing *individual level resources* (i.e., positivity, active coping, acceptance, finding meaning and purpose, planning, health seeking behaviours, etc.). There was the belief that accessing individual resources may be central in fostering resilience and reducing psychological distress. Several survey respondents also discussed the importance of taking ownership of their situation by asking themselves, “What can I do to help myself?” and “Where can I get the help I need?”

In addition to the outlined internal processes that influence resilience, cancer survivors are also affected by risk and protective processes within their home environment. Specifically, resources provided by family and friends are *external resources* that assist HC survivors in

coping and maintaining resilience. The advice provided by survey respondents was to seek support and accept help. The survey respondents shared that processes within the home environment, in particular social support, effective communication and cohesion, could facilitate resilience in HC survivors.

Finally, while it was evident that risk and protective processes operated at the individual and family level, there were also contributions from *community levels*. Current survey respondents acknowledged that the community surrounding a cancer survivor impacts greatly on their survivorship experience. This supports research suggesting that the wider community can influence individuals, through either the provision or lack of both human and material resources (Gorman-Smith, Henry, & Tolan, 2004; Vanderbilt-Adriance & Shaw, 2008).

As previously discussed, positive community influences among HC survivors include the accessibility of healthcare services, effective relationships with HCP's and community support (Galván, Buki, & Garcés, 2009). The influence of HCP's was emphasized by the majority of these respondents, who highlighted the importance of effective communication and trust in the medical team. In addition, respondents suggested that proactively case managing their treatment by being actively involved in the decision-making and seeking second opinions when deemed necessary was also valuable. This population of HC survivors also credited religious communities, support groups such as the Leukaemia Foundation and the internet/social media as assisting their journey following diagnosis. The role of community organisations in the support of individuals facing a health adversity has been explored in several studies (Badger, Sergrin, & Meek, 2004; Northouse et al., 2005; Zabalegui et al., 2005). Individuals who participate in community groups are more likely to be resilient, have an increased sense of belonging and develop more adaptive skills (Laursen & Birmingham, 2003). It is apparent from the survey results that community services, including Internet information and counselling groups, all form a part of the oncology network that provides support for individuals with the cancer. As highlighted, the feedback provided by current respondents supports the factors previously identified during the interview phase and previous cancer-related literature.

Conclusion – Survey Discussion

The main objective of Phase Two was to examine the impact of 24 variables that were sourced from the results of Phase One and previous literature on resilience between HC and other cancer survivors. These variables included self-distraction, active coping, denial, substance use, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, self blame, social support

(significant others, HCP, family and friends), time out, exercise, self-appearance, researching information, alternative treatment and diet.

The results of this survey study indicated that the 24 variables, when combined, predicted a substantial amount of variance in resilience among HC survivors. Consistent with previous research, active coping, positive reframing, support from family and friends as well as exercise were shown to positively impact resilience. Self-blame, a factor that is widely discussed in the cancer-related literature, yet not identified in the results of Phase One, was found to inhibit a person's ability to cope and adapt.

Second, the survey results indicated that higher levels of resilience were associated with decreased scores on depression and anxiety. Although, the majority of scores for both depression and anxiety fell within the normal range, consistent with recent research, anxiety levels were higher than depression levels among this population of HC survivors, and this was particularly evident among young adults.

This study was also interested in understanding which individuals in the clinical team provided the most effective support, or lack of, including cancer-related information. The results indicate that a collaborative team of HCP's contribute to supporting cancer survivor. However, at times the clinical team were also responsible for a lack of support. The majority of cancer-related information was received through specialists, community support groups, other cancer survivors and social media/internet.

This survey study concluded with an open-ended question asking respondents if they had any words of advice for newly diagnosed HC patients. The feedback and recommendations are consistent with the themes previously discussed in the literature and throughout both Phases of this study (Appendix Q).

Study Limitations

Whilst the current study contributes to the literature concerning psychological resilience and HC survivorship, there are also several noteworthy limitations. First, although an advantage of this research is that the findings are relevant to a specific context involving HC survivors; this also limits the generalizability of the results to other cancer populations. The majority of participants were also well-educated, English-speaking, white Australians, therefore, generalizations to ethnically diverse cancer survivor populations cannot be assumed. The number of non-English speaking, culturally diverse populations are increasing in Australia, and, there is evidence to suggest that social class and ethnicity influences health outcomes (Butow et al., 2013; Denz-Penhey & Campbell Murdoch, 2008; O'Callaghan et al., 2016; Ussher, Tim Wong, & Perz, 2011). In addition, the concept of resilience may have cultural ramifications as ethnic factors are reported to influence reactions to illness (Denz-Penhey & Campbell Murdoch, 2008; Stewart & Yuen, 2011). Therefore, it would be

advantageous to evaluate personal resiliency among a diverse range of cultures across the lifespan in order to understand their unique need.

In addition, the subjective experiences of these participants may not reflect the experiences of other HC survivors who had elected not to participate. In this study, HC survivors were either asked to contact the researcher to express their interest in being interviewed or asked to complete a survey. Each scenario required a level of motivation, which may have deterred many potential participants. Due to the nature of this study, many HC survivors may not have felt comfortable discussing their experience. For example, it is possible that long-term survivors did not wish to revisit their encounter with cancer. Conversely, HC survivors who were actively engaged in the community may have been more willingly to share their experience. The low depression and anxiety scores, relative to other groups, indicate that the survey sample is likely not particularly representative of all individuals with HC.

Third, many participants were accessed via email, thus the study was to a large extent, limited to individuals who had access to the Internet and computer skills. Although information letters and survey hard copies were also posted, this was not the preferred sampling method and, therefore, those with no computer access were less likely to be informed of the study. In addition, participants that were sourced solely from community support settings (i.e., the Leukaemia Foundation, Cancer Council) were already in contact with support services and may differ as compared to those who are not engaged with community support. However, this study attempted to reduce potential sampling bias through recruitment of participants from alternative settings such as the Blood Institute and the Harry Perkins Research Centre, as well as social media through the use of Facebook. Moreover, an additional 52 surveys were not included in the total sample of ($n=222$) as Qualtrics reported these as incomplete. A decision was made not to include any incomplete questionnaires, which has resulted in a smaller sample of participants.

This study was also cross-sectional as each participant in this study took part on one occasion (at least ten months following their diagnosis). This is a useful starting point, however, it means that causal relationships should be cautiously inferred. For example, participants may feel differently if their HC relapses. Therefore, how each HC survivor interprets their situation may change over time. Longitudinal research involving participants at different stages during their survivorship trajectories would enhance our understanding of HC survivor adjustment.

Study Strengths

Despite these limitations, this study has provided valuable information, through triangulation of data, in an area previously unexplored in great detail. A key strength of this research is that it has focused specifically on HC survivors, forming a homogeneous population that is understudied (Swash, Hulbert-Williams, & Bramwell, 2014). This research used mixed methods to generate both qualitative and quantitative data about the factors influencing resilience among both male and female HC survivors of varying ages and stages of survivorship. These attributes have allowed the findings of this study to be more generalizable.

First, the *interviews* resulted in a wealth of information about the experience of having cancer. The value of researching a patient's personal experience is becoming more widely understood in health-related studies. The same researcher undertook all the interviews and analyses; this ensured that a uniform approach to interpretation across all 23 interviews. Although the coding of study data relied, to some degree, upon subjective interpretation, the use of Leximancer data analysis software reduced the potential for subjectivity and/or bias in the qualitative study outcomes.

Second, in order to elaborate findings the *questionnaire* included a broader spectrum of HC survivors from a larger sample of Australian and overseas HC communities. This research was conducted through several avenues and resulted in a relatively high participation rate. In addition, there was an equal representation of short- and long-term survivors (ranging from 1 – 34 years). This gap in the literature needed to be addressed as most previous psycho-oncology studies have focused on those who have been recently diagnosed (Gouzman et al., 2015; Swash, Hulbert-Williams, & Bramwell, 2014). Thus, a more definitive conclusion about resilience and psychological adjustment of short and long-term survivors was achieved. Previous research also reports little mention of the HCP's roles in enhancing resilience among those with chronic illness (Stewart & Yuen, 2011). Consequently, this study attended to this gap by including the influence of HCP's in this study.

Finally, survivors of rare cancers have reported difficulty in having their voice heard. This research attempted to address this limitation by targeting those individuals diagnosed with less common types of HC. For example, this study was further enriched by the inclusion of a large sample of CML survivors, which is a rare subgroup of HC's that have been understudied in prior survivorship research.

Chapter 9

General Conclusions

Chapter Overview

The general conclusions, clinical significance and recommendations are presented in this chapter. First, a brief introduction will revisit the relevance of this research. Chapter 9 will then summarize the key findings identified as a result of this mixed method study. The contributions and implications of the current research with regard to theory, policy and practice within health and psychology are then discussed. Several ideas for future research will then be presented. Chapter 9 concludes by proposing a number of recommendations that involve government policy, HC survivors, employers, community agencies, and, the interdisciplinary clinical team, with a particular focus on psychological interventions.

Introduction

There has been considerable progress in the field of ‘cancer survivorship’, particularly since the Institute of Medicine landmark report, *Lost in Transition*, was published in 2006. This report acknowledged the inadequately coordinated, follow-up care of individuals completing cancer treatment, with the community and healthcare support systems often failing to meet the needs of cancer survivors. As a result, much of the research that followed focused on the diagnosis and initial treatment phases of more widespread cancer populations. Accordingly, researching the needs of long-term survivors of less common cancers was of less priority. In addition, much of the literature reported on the unmet needs of cancer survivors, including the negative outcomes such as psychological distress. Consequently, there has been less focus on positive psychosocial processes, such as factors that lead to resilient outcomes (Molina et al., 2014). Although resilience has been extensively studied among healthy individuals (Min et al., 2013; Stewart & Yuen, 2011), to date, little is known about the factors associated with resilience in cancer survivors, including patients with HC.

It was intended that this study would address these limitations, whilst also building on the Australian cancer survivorship research of Girgis and Butow (2009), Jefford et al. (2008), Lobb et al. (2009) and Knott et al. (2012). To achieve this aim, a two-phase study was conducted. The first phase, involving in-depth interviews, explored the experience of living with HC. The purpose of the first phase was to develop a conceptual model that explained how HC survivors exhibit and maintain resilience. Phase One also aimed to identify particular risk factors related to chronic illness that negatively affect mental well-being. The qualitative

findings and previous research were then used in the second phase (Stage 1) to develop and pilot a survey instrument.

Subsequently, in Stage 11, a final questionnaire was used to validate the earlier findings among a larger sample of HC survivors. The objective of Phase Two was also to examine the relationship between resilience, depression and anxiety. A summation of the key findings will now be presented, followed by the implications for theory, policy and clinical practice.

Summation of Key Findings

There are four valuable outcomes that were identified as a result of this study. Previous research concurs with the majority of these findings. However, there are some exceptions, which will be highlighted. *First, importantly this study has identified that that HC survivor population seem to cope remarkably well.* Although there are limitations in this study, which have been discussed, this result was relatively unexpected, given the challenges associated with a HC diagnosis. However, although the majority of depression and anxiety scores reported were in the normal range, relative to depression scores, *anxiety was found to be four times higher among this sample of HC survivors.* Previously, depression has dominated in the literature, however more recent research (Marker, 2015; Mitchell et al., 2013) has also highlighted anxiety as a concern among cancer patients. Therefore, future interventions may need to consider targeting anxiety-related issues (i.e., fear of recurrence) among cancer survivors.

Another key finding relates to the demographic outcomes among this sample of HC survivors. These results identified that *younger HC survivors (18-39 years) are more vulnerable to negative mental health outcomes than older HC survivors (60+ years).* In addition, those survivors *more recently diagnosed (< 5 years) were found to have significantly lower resilience scores and higher negative mental health outcomes than long-term survivors (+5 years).* This suggests that individuals under the age of 40 years, who are within 5 years of being diagnosed with HC, may be an 'at risk' cohort that is more susceptible to anxiety or depression. Similar findings have been reported in the literature.

The third important outcome relates to the factors found to influence resilience. Twenty-four variables were examined for their influence on resilience among HC survivors. *The results indicated that the model was successful in predicting resilience, as the combined effect of the 24 variables was able to account for a significant 61% of variability in resilience scores.* The factors that made a unique and significant contribution to the model were *active coping, positive reframing, self-blame, family support, friend support and exercise.* With the exception of self-blame, these significant predictor variables were all positively related to resilience. In addition, it was found, among this population of HC survivors, that only three of

the twenty-four variables (self-distraction, substance abuse and venting), did not significantly influence resilience. These factors are comparable to those identified in other cancer populations.

However, there were also mixed results. For example, self-blame is a factor that did not emerge during the interviews in Phase One, yet significantly contributed to the model in Phase Two as impeding resilience. Previous literature has reported on self-blame as a factor influencing cancer survivors. However, this has tended to dominate among other cancer populations (i.e., lung and head and neck cancers) in which there has been a higher possibility that the individual's health behaviour may have contributed (i.e., by smoking). There is little research discussing self-blame among HC survivors. Nevertheless, the findings in Phase Two, reported that self-blame is an influential factor. Therefore, it would be reasonable to propose that those HC survivors who blame themselves for their diagnosis, demonstrate reduced resilience. Conversely, substance abuse is a factor that was not identified in either phase of this study. This implies that, in general, HC survivors do not rely on substances in order to cope, which supports previous research among HC survivors. However, this differs from the findings among other cancer populations (i.e., liver and lung cancer patients) who report otherwise. This is likely due to the fact that substance abuse is not generally referred to in the literature as a cause for HC, whereas substance abuse has been identified as a potential cause among many other types of cancer.

The last key finding is that several additional factors identified among other chronic illness and cancer populations, but not well identified in HC population research, also significantly influenced resilience. *The other factors that enhanced resilience, but did not make a unique contribution to the model included: emotional support, instrumental support, planning, humour, time-out, acceptance, religion, social support (significant others and HCP's), self-care/appearance, researching information, alternative treatments and diet.* In addition, denial and behavioural disengagement were negatively associated with resilience, such that higher scores on these variables were related to lower resilience scores. This has important implications for clinicians, because it highlights the flexibility in fostering other protective factors. For example, exercise was reported to make a unique contribution to the model. However, in situations in which exercise is not possible, other health behaviours (i.e., maintaining a healthy diet, alternative therapies and taking time out) may also be helpful in enhancing resilience. In addition, many of the existing interventions known to assist other cancer populations will likely also be effective among HC survivors, as the majority of factors known to influence resilience are similar. These important findings have significant implications each of which are outlined below.

Significance and Implications for Research, Policy and Practice

It is becoming clear that the impact of cancer does not end with active therapy. As more individuals are surviving cancer, a patient's longevity is no longer the only focus. Therefore, understanding how survivors cope following treatment is also increasingly important. This has significant implications for theory, policy and practice.

Theory

Research that is theoretically informed is vital in order to drive the innovation within the survivorship agenda and enhance patient outcomes across the entire journey. Although HC patients are living longer, we continue to have a limited understanding of how time influences their psychological health status (Aziz, 2009) and resilience (Hall et al., 2013; Schumacher et al., 2013). However, if we are to develop effective research priorities related to cancer survivorship, there are a number of key considerations that need to be taken into account. For example, cancer survivors consist of individuals with varying needs at different points along the survivorship trajectory. Thus, in order to acquire a comprehensive understanding, it is essential to identify a broader spectrum of psychosocial factors influencing patient's well-being that better matches this variability and longitudinality of survivorship. Some of the key findings are: the high percentage of survivors identified with anxiety across the survivor samples; that younger survivors appeared to experience more distress than older survivors; that the research to date appears to encompass the survivor experience fairly well, irrespective of cancer type, albeit with some notable exceptions (e.g., self-blame); and, that survivor research in other illness populations may have valuable contributions to cancer survivor research. This study has contributed to theoretical progress in this area, as detailed in the following discussion.

Resilience.

First, this study contributed to resilience theory by highlighting the importance of modifiable factors that contribute to resilient outcomes and by confirming a number of exploratory conclusions about resilience including: a) that resilience involves maintaining well-being under adversity including recovery; b) that resilience can be developed and is therefore not solely a fixed trait; c) resilience is impacted by previous experience and underlying psychological make-up, yet modifiable factors, such as health behaviour change, can facilitate resilience; d) that several multi-level individual, family and community factors contribute to personal resiliency; and, e) that in order to be effective, clinical interventions need to reflect these dynamic interactions across these different levels, and not merely focus on fostering individual strengths.

Age-Related Differences.

Another important finding in this study related to resilience theory was the significant difference in resilience and mental health outcomes between younger and older respondents. Age-related factors are an important variable to consider, as the literature suggests that the impact of cancer and cancer treatment is strongly associated with the patient's age at the time of diagnosis (Aziz, 2003; Northouse, 1994; Zebrack, 2011). However, exactly how age impacts on resilience and mental health is still largely unexplained and, therefore, interventions are not able to appropriately address this factors influence. Although an extensive body of literature exists among young adult survivors of childhood cancer, few empirical studies have identified the unique psychosocial issues of those who were diagnosed and treated for cancer as young adults (Zebrack, 2011). For several reasons, this age group has been described as the "orphaned cohort" in cancer survivorship literature (Hara & Blum, 2009). In general, young adults are the least represented in clinical trials, and are the cohort least likely to be referred to a tertiary care centre (Hara & Blum). Moreover, follow-up care for young adults tends to be the most neglected of all cohorts, partly as they are often combined with other age groups as part of larger studies (Hara & Blum, 2009). For example, Haase and Phillips (2004) refer to a common practice of combining young adults (i.e., 18 - 35 years) with either paediatric or older adult populations. This has resulted in a lack of knowledge of the cancer experience among young individuals diagnosed in their late teens or early adult years (Zebrack, 2011).

Likewise, age-related factors may also be particularly relevant among older adults, as in the future we will observe a significant increase in the number of individuals over 65 years of age living with cancer (Bellizzi et al., 2008). Many of these older adults will be in the short- or long-term survivorship phase following treatment, whilst potentially managing several co-morbidities and treatment side-effects. Surprisingly, despite the probability of having more co-morbidities, the findings of this research suggest that older HC survivors (60+ years) cope well. In this study, older survivors reported higher resilience and lower anxiety and depression scores when compared with those between 18 - 39 years of age. This may be partly due to the experience of overcoming previous adversity during their lifetime, however there are likely to be other reasons. Thus, the study of age-related factors among HC survivors provides a fertile area of research that may highlight how adults of all ages, perceive and process information in order to effectively adjusting to life following treatment.

Long-term effects.

In addition, this study incorporated long-term survivors, a neglected aspect of resilience theory and research, as the majority of what we understand about cancer survivorship to date still centres largely on the time between diagnosis and just 2 years following treatment (Aziz, 2003). The long-term psychosocial consequences and adaptability

of less common, adult-onset cancers remain poorly documented (Hall et al., 2013; Swash, Hulbert-Williams, & Bramwell, 2014). A systematic review by Swash, Hulbert-Williams, and Bramwell (2014) in the UK that recently investigated the unmet psychosocial needs in HC patients only found two articles (from 14,549 titles identified by the search) that specifically included haematology-only samples in the post treatment phase. The first was an Australian study by Lobb et al. (2009) that focused on short-term survivors following treatment. The most frequently reported unmet need was help to manage concerns about cancer reoccurrence (42%), the need for an on-going case manager (33%) and the need to know that doctors communicate and coordinate care with each other (31%). The second study by Hammond et al. (2008) assessed needs of more long-term HC survivors during the follow-up phase. However, this study only focused on the presence of unmet information needs specifically relating to fertility and sexual functioning, reporting that, in young people, (61 %) expressed the need for more information about fertility issues (cited by Swash, Hulbert-Williams, & Bramwell, 2014). This current study attempted to address this limitation, however, much remains unknown regarding the late or long-term effects of cancer treatment and how to attend to them.

Patient Advocacy.

Finally, in terms of resilience theory contributions, two of the six factors that made a unique contribution to the model of resilience in the quantitative study were *active coping strategies* and being able to *positively reframe the cancer experience*. The interviews in Phase One also highlighted that, for the many interviewees, one way of positively reframing the cancer experience and actively coping was through *patient advocacy participation*. Assisting community support agencies and/or partaking in fundraising initiatives are examples of individual patient advocacy. In doing so, advocacy provides a sense of purpose/meaning and the belief that, as survivors, they are contributing to making a difference in the lives of others with cancer. However, it is important, to highlight that there are differences between consumer involvement in decision making, individual advocacy and system level advocacy (e.g. grass roots lobbying to improve cancer care/support for everyone). For example, there are organisations such as Cancer Voices for patients who are interested in becoming involved in system level advocacy.

More recently, the beneficial role to the survivor themselves, as well as to the research endeavour of patient advocates in the evaluation of *research submissions* is also becoming more widely acknowledged. According to Wagstaff (2015), patient advocates consider that their involvement in the research decision-making process is paramount to ensure that appropriate questions are explored in the correct manner. In 2011, Alessandro Liberati, a clinical statistician with multiple myeloma, appealed for a new research governance strategy, highlighting the disparity between what patients actually require and the issues researchers tend to investigate. For example, topics that are often investigated include matters that are

central to pharmaceutical companies and researchers. Yet, inevitably those priorities are not always shared by the individuals who are most affected, such as the patients and their clinical team. Liberati advocated for redefining the research agenda in the interests of patients, using a collaborative process that would include all stakeholders (Wagstaff, 2015).

Positive steps toward involving patients in research initiatives are underway. In the UK, patient advocate involvement has been included in the UK's National Cancer Research Institute guidelines (Wagstaff, 2015). In general, the patient advocate's role is to examine trial applications from the patient perspective, ensuring they address relevant questions and are sufficiently attractive to patients in order to realise recruitment goals. For example, the purpose of the clinical trial has to be clear and reflect the concerns of patients, either for themselves or for individuals with similar diagnosis in the future (Wagstaff, 2015). Similar efforts to involve patient advocates in research initiatives have begun within Australia. For example, as part of the Consumer Involvement in Research Program at Cancer Council NSW, specifically trained cancer survivors, patients and carers can represent the community by examining funding applications. Following a peer-review process, the patient advocate's role is to identify research submissions that are of most benefit to them as consumers (Miller & Tang, 2015). Importantly, cancer not only affects the patient, but can also impact on the emotional balance of the family. It is, therefore, essential to also include carers as research advocates. As the healthcare system is under constant pressure to discharge cancer patients as soon as possible, the responsibility of providing care often falls to family members. This will become especially pertinent as we witness an ageing population. Miller and Tang (2015) state that cancer survivors and carers should have the opportunity to be the focus of research given their personal understanding of the issues confronting those living with cancer.

Knowledge is power and for many cancer patients, life meaning and finding positives from the cancer experience can be achieved by having a voice in the decisions regarding cancer survivorship research initiatives. For example, patient advocate and cancer survivor, Chapman (2015), expressed his desire that, in the future, every major oncology centre would provide a cancer survivor 'coach' on staff, to support cancer patients navigate the various issues that arise as a result of having cancer. However, for these improvements to occur, a change in the research culture is required to acknowledge the full involvement of 'expert' patients in research. This will take time and commitment from all stakeholders.

This study has contributed to theoretical progress in several areas including: the concept of resilience, demographic variations (e.g., age-related factors) among HC survivors, the long-term effects experienced, and, by highlighting the benefits of participating as a patient advocate. However, these research findings also have implications for national and state government policy, which will be detailed.

Policy

Research that takes into consideration the relevant national and state policy implications is also important, as policy decisions can impact on the healthcare services and quality of care that cancer survivors receive. For example, the management of chronic illness among an ageing population is one of several major health priorities for government policy. In the future, we are faced with not only an increase in the number of individuals living with cancer, but also a reduction in the number of people contributing to the workforce. In addition, the majority of these cancer survivors will present with numerous other health problems. Data from Medicare beneficiaries in the US (patients 65+ years) indicates that 90% of cancer patients have at least one other chronic illness and a further 20% of patients will have five or more chronic conditions (Koczwara, 2015). A relevant question for government policy is how Australia's healthcare system will manage to deliver effective care to the increasing number of those living with chronic illness in the future. Initiating the development of cost-effective models of care, promoting community involvement and funding research into rare cancers that have a high mortality may assist toward accomplishing this objective.

Models of Follow-up Care.

This research has identified that HC survivors present with diverse needs. For example, the result of this study found younger HC survivors to be more at risk of experiencing anxiety than older cancer survivors. Therefore, in order to provide a holistic healthcare service, the models of follow-up care delivered to HC survivors need to be flexible and individualised. This has implications for state and federal policy as we witness an increase in the number, and a change in demographics, of those living with cancer. These findings concur with Koczwara (2015), who proposes that it is unlikely one model will be effective across all settings at all times. It more is probable, that different models will be required to suit different contexts.

There are various models of follow-up care for cancer survivors that have been trialed within Australia and overseas. Many of these may include shared care between specialists and GPs, nurse-led follow-up clinics and/or one-off consultation by specialist physicians (Brennan & Jefford, 2009; Koczwara, 2015). However, currently little data exist on which of these models is most useful. In addition, according to Brennan and Jefford (2009), the diversity of settings and scenarios create the greatest challenge in successful model development. For example, a particular model may work within one specific context (e.g., clinical team, cancer type, patient demographic and geographical area, etc.) but may be unsuitable in another setting. One suggestion offered by Brennan and Jefford (2009) is the inclusion of general practitioner specialists. As providers of continuous care throughout an individual's life, general medical practitioners are ideally placed to oversee long-term cancer survivorship issues. However, their specific role would require further investigation as specialized medical

practitioners may not be suitable for all patients (Brennan & Jefford, 2009).

The emerging movement to improve follow-up care models among Australian cancer survivors is well underway. In 2012, the Clinical Oncology Society of Australia (COSA) established a Cancer Survivorship Group to address the concerns of not only survivors, but also their caregivers and HCP's regarding the challenges of delivering patient-centred high-quality care (Dhillon, 2015). More recently, COSA led a national discussion among its members regarding a model of survivorship care most suitable for the Australian healthcare system. COSA's Model of Survivorship Care, which was launched at a recent Australian conference, is now in the process of evaluation (Dhillon, 2015).

In addition, a recent article published in *The West Australian* newspaper, highlighted a newly established Survivorship collaborative set up by the WA Cancer and Palliative Care Network, which will investigate the development and implementation of care plans in order to optimise each patient's long-term health (Rasdien, 2015). According to Christobel Saunders, collaborative member and Winthrop Professor of surgical oncology at the University of Western Australia, deliberations are under way to open clinics, initially, for breast cancer patients in two major Perth hospitals. The purpose is to ensure patients receive the opportunity for an 'exit interview' with their clinical team. The main aim is to enable survivors to improve their overall health and wellbeing when active treatment ends, stating, "we should use that brush with health services as a chance to do preventative treatment not just as a response to illness" (p.2). According to Professor Saunders, implementing such models also has potential implications for state policy in terms of reducing health service costs suggesting that "if you can try to get people back into a healthy frame of mind and take care of their own health afterwards then ultimately we will be saving a lot of money for our health services in the future and doing people good" (Rasdien, 2015, p.2).

Community and Not-For-Profit Involvement.

Another important finding in this research was the beneficial influence for HC survivors of community and non-for-profit agencies. Community agencies not only provided support to HC survivors and their families, but also advocated for public health initiatives to improve cancer survival and potentially lower the incidence of cancer diagnoses. For instance, over the last ten years, the Cancer Council NSW has encouraged cancer survivors to become actively involved by sharing their personal narratives, in order to generate policy change. Through the CanAct community campaigns, cancer survivors have achieved policy reform in areas such as: increased funding for bowel cancer screening; increases to subsidy rates; patient-assisted transport; smoke-free legislation; and, the prohibition of tobacco displays in shops (Miller & Tang, 2015). More recent efforts are also evident, for example the Cancer Council of Western Australia (WA) has enlisted 50,000 patients and supporters to address important cancer issues, such as healthcare staff deficiencies, as an election priority. WA

Cancer Council president Christobel Saunders expects there will be powerful community support for priorities identified stating that, “it is estimated there are also more than 75,000 people in WA living with cancer” and “with almost 11,000 West Australians diagnosed with cancer a year, this translates to many thousands more family, friends and colleagues who are also impacted” (O’Leary, 2015 p. 4).

Patient survivors who have a vision of survivorship care and involvement within the community can be a positive experience for cancer survivors, which was evident in the results of the current study. However, few HC survivors are prepared to participate in consumer advocacy roles that highlight several areas of improvement for policy makers. Some of the barriers preventing community and patient involvement include a lack of confidence, training, financial reimbursement and awareness regarding survivor led initiatives (Marker, 2015). However, cancer survivors and their families are a valuable source of ideas and knowledge about survivorship, including the solutions we as a society face in the future. Therefore, community and consumer engagement is imperative, this also includes health disciplines that traditionally had less involvement outside their own area of expertise, but are essential if we are to address the healthcare challenges of cancer survivors.

Unified Theory/Research Agenda for Rare Cancers.

The common themes persisting throughout the literature, including this study, are the need for unified research of rare cancers, including HC. One particular issue raised by current participants was the need for more cancer-related information. This was particularly evident among those with more rare types of HC (i.e., CML). More specifically, the HC survivors in this research, highly valued being fully informed about advances in new treatment regimens for their specific diagnosis. This information provided a sense of control, helped these individuals to plan ahead and also facilitated acceptance. However, providing patients with up-to-date cancer-related information on every type of HC can be challenging. Blood cancers are noticeably heterogeneous, with over 35 subtypes of non-Hodgkin lymphoma, 35 subtypes of acute leukaemia’s and six subtypes of Hodgkin lymphoma currently documented (Chew & Roberts, 2015). While HCs account for approximately one-sixth of all cancer diagnoses (excluding skin cancers), each individual subtype of HC is rare.

This study has highlighted that a lack of cancer-related information may impede resilience among the HC survivor population, potentially impacting on their QOL. However, experts within the cancer survivorship field have acknowledged that there is less information available on rare cancers and are making progress toward addressing this research gap. For example, a support program has been provided by a charity called Rare Cancers Australia, whose aim is to increase awareness and provide support to Australian patients and their families with rare and less common cancers (Ananda & Scott, 2015). In addition, in Western Australia, many cancer survivors are participating in one of the world’s largest studies run by

the Cancer Council of Victoria of ‘forgotten cancers’. The aim is to recruit 15,000 individuals nationally, comprising leukaemia, pancreatic and brain cancer patients, to explore the causes of less common cancers (O’Leary, 2015). This is important, as, although these cancers are considered rare, they account for over half of all cancer deaths. According to researcher Fiona Bruinsma, “historically research dollars have been spent on the five most common cancers, which is reasonable given the number of people affected, but while they account for 54% of diagnoses, they are only responsible for 46% of cancer deaths” (O’Leary, 2015, p.4). Thus, to date, and due to their low profile, less common cancers have tended to miss out on the majority of research and funding.

According to Swash, Hulbert-Williams, and Bramwell (2014), given the inadequate evidence concerning patient needs among those with blood cancers, more research is required to establish the most suitable approach to the assessment and care of this patient group. Consequently, this has implications regarding the government policy on research funding allocations, which requires a more fair and equal distribution among all cancers. If government policy is to address the diversity among the increasing numbers of cancer survivors, together with workforce reduction issues, much effort is required. This includes paying attention to the lack of information available (i.e., treatment options) about less common cancers. On a national policy level, as Michal Jefford the Australian Cancer Survivorship Centre Director, stated, “there are gaps and there are barriers and, if we have a greater push for much better care and much more attention to the post-treatment phase, we will be able to see things improve further” (Rasdien, 2015, p.2).

Practice

Finally, this study identified many factors that are important to HC survivors, yet the results also highlighted a disparity between what is beneficial for cancer patients and what actually occurs in clinical practice. For example, although psychosocial interventions by clinicians are widely recommended, many participants in this study felt abandoned stating that their psychological needs were not always met by the healthcare system following treatment. Participants expressed that they had health-related concerns, but did always know whom to ask or where to find help. Addressing this gap will not only improve the quality of care, but also assist to normalise psychosocial service use and facilitate the breakdown other attitudinal barriers. HCP’s working with cancer survivors should to be aware of the type of psychosocial needs most commonly experienced by their patients. This may be achieved through: effective therapeutic relationships; appropriate screening and assessment; timely interventions; and, relevant referrals to other allied HCP’s by clinicians. The practical implications of these interventions, each of which will be discussed, will assist HC survivors enjoy improved QOL, rather than just living longer.

Clinician's Therapeutic Relationship.

First, according to the literature and the participants in this research, the ability of clinicians to empathize and connect with patients is perceived as a vital aspect of holistic care. One of the most important contributions clinicians can provide their HC patients is the gift of understanding (Munhall, 1994). By communicating an understanding of the lived experience of a cancer diagnosis, clinicians can portray a sense of empathy (perceive and communicate understanding of the meanings and feelings of another person). For example, providing reassurance, listening actively to fears and concerns, asking about the patient's emotional status, and, being sensitive, hopeful, yet remaining honest, will assist in maintaining an effective therapeutic relationship. Likewise, respondents in this research also highlighted an appreciation of clinicians who were able to respond with humour. When initiated by the patient, humour was one of many factors considered to be an invaluable form of emotional support. Therefore, having a sense of what it is like to experience a HC diagnosis can help each clinician build a stronger therapeutic relationship.

However, there are many healthcare system deficiencies, one of which is the lack of resources and time available for patient appointments. It can, therefore, be challenging for clinicians to provide holistic patient-centred care. Yet, according to Miller and Tang (2015), HCP's are very influential advocates for patients. Therefore, despite the healthcare system inadequacies, each clinician should challenge himself or herself to bring about improvements within their own healthcare setting. One way this may be achieved is through the recognition of their interpersonal strengths and weaknesses and by participating in ongoing professional development. Even among busy healthcare settings, clinicians can reduce stress and learning how to best assist patients by appropriately attending to their needs.

Screening and Assessment.

Second, in terms of practical implications, this study also highlighted the importance of effective and timely patient screening and assessment. This is essential as many psychosocial health concerns experienced by cancer patients are not identified by clinicians and remain untreated (Butow et al., 2015; Girgis, Delaney, & Miller, 2015). For instance, research has shown that cancer patients experience more distress at the completion of active treatment, a point in time when expected routines end, placing patients in a position of uncertainty (Knott et al., 2012). Therefore, a useful time to ask patients about coping is before they enter the next phase following treatment.

The findings of this research invite a more systematic approach in clinical assessment and follow-up that screens for anxiety, rather than just depression. Questions such as, "How much time do you spend worrying about your cancer?" and "What helps you to best cope or not?" may also assist clinicians to better recognize what support each HC survivor requires. Considering these questions, in conjunction with an awareness of when distress is most likely

to occur for cancer survivors, will ultimately improve patient care. These findings are consistent with recent Australian research among adult cancer patients that investigated a clinical pathway, developed for the screening, assessment and management of anxiety and depression to improve quality of care. This study by Butow et al. (2015), involved reviewing existing guidelines, structured interviews with 12 multidisciplinary staff, an online Delphi process including two rounds of feedback from 87 Psycho-Oncology Co-operative Research Group stakeholders, and input from an expert advisory panel. The results recommended that a formalized stepped care model should be included for all cancer patients, at key points along their survivorship trajectory, to screen for anxiety/depression. It was also suggested that if anxiety and/or depression is detected, the assessment, referral and follow-up care of cancer patients should be co-ordinated by one member of the treating team, taking into account patient preference (Butow et al., 2015). As discussed by Butow et al. (2015), using appropriate assessment tools is one way of identifying psychologically vulnerable patients early in the treatment process. Assessment tools are valuable as they can highlight the need for more timely provision of emotional support and other relevant psychosocial interventions.

Patient Assessment Tools.

A vital step toward achieving patient-centred care is through the use of survivorship care plans (SCP's). In general, SCP's consist of a treatment summary, follow-up care plan and communication tools to promote patient education, treatment compliance and long-term health management. However, since the introduction of SCP's a decade ago, there has been limited success in their implementation by clinicians due to several barriers. Some of these include the time required to complete a SCP, absence of role clarity and co-ordination between HCP's and the lack of financial reimbursement for preparation time (Mayer et al., 2014). The above obstacles, identified through research evaluations by the American Society of Clinical Oncology (ASCO) members, resulted in the issue of a new SCP template that is easy to complete, takes less time and is more focused on critical patient information (Mayer et al., 2014). This highlights the necessity for clinicians to regularly evaluate existing care plans in order to gauge their effectiveness. Research that evaluates assessment tools may also help to develop a more accurate and systematic responses by clinicians to the crucial needs of individual patients. Moreover, future research into cancer-specific templates and support tools may be considered to better understand the benefits of SCP's in providing individualised quality care for cancer survivors.

In addition to the face-to-face implementation of paper-based SCP's between patients and clinicians, evaluating the effectiveness of other assessment delivery methods is also beneficial. For example, in order to capture those cancer survivors with fewer socioeconomic resources and physical limitations such as those in remote communities, interventions need to be cost-effective and portable (i.e., Internet or telephone-based). Within Australia, in NSW, an

ehealth system is being piloted which supports Electronic Patient Reported Outcomes (ePRO). According to Girgis, Delaney, and Miller (2015), ePRO's: can be delivered in a range of languages; provide automated scoring; and, produce real-time feedback reports to clinicians and enable access to resources that assist survivors to better manage their own health behaviour. Thus, in certain situations, ePro's are considered to be more effective than paper-based assessments. However, more research is required to evaluate the effectiveness of alternative assessment tools.

Education and Information Resources.

Participants in this study also alluded to their informational needs and the lack of education provided to them by their clinical team. For example, many participants wanted to know more information about their illness, the possibility of recurrence and how to improve their health through nutrition, complementary and alternative health services, exercise and mental health programs. Public interventions and resources can be improved to help develop resilience- building factors highlighted within this study. More specifically, strategies that help increase *healthy behaviour* choices may be of particular importance. An effective way to establish this might be through education packages that ideally comprise individually-tailored information based on a thorough assessment of survivors' educational needs. A theme that surfaced when participants discussed programs designed for cancer survivors was the importance of similarity (i.e., age, diagnosis, gender, treatment history, etc.). Likewise, although it is challenging to incorporate all participants' preferences, programs may be prove more appealing if they provide participants with some level of choice in how they achieve behaviour change goals.

The current research also identified the need for HCP'S to not only understand the resources their patients use, but also where they source this information and whether it is reliable and readily accessible. The 2006 IOM report noted that in order to meet the needs of all individuals, survivorship information should be available in a wide variety of formats (face-to-face, audio, video, print, Internet, radio, and telephone). For example, Web-based programs may be particularly attractive to young adults, as this demographic is generally very accustomed to using Internet technology. However, the challenge will be accomplishing this in an all-inclusive and cost-effective manner. To achieve this, more thorough trials of educational interventions are needed, with larger sample sizes and longer follow-up assessments.

Health Behaviour Change.

The current findings suggest that the majority of HC survivors make conscious steps toward positive health behaviours (exercise, diet, self-care, etc.), re-evaluate what is important to them and attempt to find purpose in their lives. Of interest is why it takes a health crisis for these changes to occur? Specifically, health behaviour change, following a cancer diagnosis, is a relatively new area of investigation, which has implications for clinical practice.

According to several studies (Bellizzi et al., 2008; Cormie et al., 2015; Murphy, 2013), due to lack of research, clinicians have a limited understanding of the most effective approaches to health behaviour modification; including: (1) the ideal delivery method for behavioural interventions (i.e., couples, group, individual home-based or community based, etc.); (2) the most effectual frequency, mode and duration for behavioural interventions; (3) the most beneficial types of behavioural interventions (i.e., traditional western or alternative interventions); and, (4) the HCP's who are best qualified to deliver the health behaviour change interventions (e.g., psychologists, dieticians, nurses, exercise physiologists, etc.).

Specifically, exercise was found to make a unique contribution to the model of resilience in this study. This has important implications, as, despite endorsement from major cancer organisations and the findings from previous research, the majority of Australian cancer survivors are not achieving adequate levels of physical activity (Cormie et al., 2015). Survivor-led exercise programs can offer insights into addressing this challenge. However, our current health system is not fully coordinated or prepared to manage all of the allied health systems required to assist cancer survivors initiate health behaviour change (Marker, 2015). For example, more effective referral pathways need to be established.

Referral Intentions.

The insight of this thesis provides clinicians with knowledge regarding the experience of cancer survivorship and the need for support not only at the time of diagnosis and during treatment but for many years afterwards. Thus, the current results also have implications for other allied health practitioners, working with HC survivors across the survivorship trajectory. Although the literature reports on the importance of allied healthcare providers, for several reasons many clinicians/specialists are not adequately referring to these services. Some of these reasons include a lack of time and awareness of the allied healthcare services available. Yet, the present findings concur with the literature, recognizing that many HC survivors would have found it helpful to attend other available allied healthcare services (i.e., psychologist, dietician, exercise physiologist, etc.). Therefore, more effective strategies are required by clinicians to ensure that appropriate referrals to the 'right professional at the right time' are provided.

Psychological Interventions. This study has indicated several areas that are relevant to psychologists working therapeutically with individuals. For example, depression anxiety and stress are disorders that psychologists are skilled at assessing, monitoring, and treating. More specifically, addressing the fear of recurrence and uncertainty associated with a cancer diagnosis is of particular interest within psycho-oncology. For example, according to Butow, Fardell, and Smith (2015), there are currently at least two registered research interventions underway in Australia that are delivered by psychologists and psychiatrists, that specifically focus on the fear of cancer recurrence. The first is a multi-centre randomised trial

comparing a psychological intervention titled ‘Conquer Fear’ to relaxation training for cancer patients. The second is also a randomised trial, but compares a psycho-educational intervention among melanoma patients to the current standard care.

Although such interventions to reduce fear, anxiety, distress, and depression are important, this study has shown that it is also beneficial to focus on strengthening positive emotions such as resilience, to enhance long-term adjustment and improved QOL.

Psychological strategies to reduce the focus on negative information, and direct the cancer survivor’s attention to positive information would help facilitate emotional wellbeing.

Individual therapy is a suitable platform to teach coping strategies that strengthen self-efficacy, encourages realistic optimism and builds acceptance of negative events that are outside one’s control. Strategies can also be put into place to help reduce or eliminate risk factors, such as self-blame, and help motivate HC survivors to implement more adaptive coping strategies and/or positive health behaviours. This is particularly salient given the negative impact of self-blame on resilience identified in the current survey study.

Several psychological treatments (described in more detail in the following recommendations section) that may be useful in achieving the above outcomes include *cognitive behavioural therapy (CBT)*, *acceptance and commitment therapy (ACT)*, and *logotherapy*. Logotherapy, developed by Viktor Frankl, is a well-known therapeutic technique, which focuses on improving an individual’s awareness of their personal life meaning, through attitude modification (Schulenberg, Hutzell, Nassif, & Rogina, 2013). Logotherapy has an extensive clinical evidence base, with research reporting on the effectiveness of logo therapy in treating: despair associated with incurable diseases, alcoholism, depression, anxiety, psychosis, aging, rehabilitation, family therapy, work-related stress and relationship counselling (Batthyany & Guttmann, 2006; Schulenberg et al., 2013). Recent research by Ebrahimi, Bahari and Zare-Bahramabadi (2014), has also identified that group logotherapy enhanced hope among leukaemia patients. A variety of logotherapy tools have been implemented over the years, to quantify and study the meaning construct. One example is the The Purpose in Life (PIL) test, which is one of the earliest and most widely studied and validated Logotherapy measures (Crumbaugh & Maholick, 1964).

In addition, relaxation therapies such as *mindfulness techniques* are also reported in the literature to benefit cancer survivors. A recent Australian study reported that mindfulness based interventions effectively increased QOL including spiritual wellbeing, and reduced psychological distress in cancer survivors and carers (Fish, Ettridge, Sharplin, Hancock, & Knott, 2014). Furthermore, according to a recent article in The West Australian newspaper (Health and Medicine), a mindfulness program has assisted Elaine Burtnewshaw a lymphoma survivor to achieve a sense of peace (Rasdien, 2015b). Ms Burtnewshaw stated that “...cancer unfortunately is going to be with me for the rest of my life now, so I had to find an equilibrium

and have my mind rested...mindfulness restores balance and allows you to get perspective in life, because we let our thoughts get away from us, we catastrophize everything and before you know it we have got ourselves in a real state” (p. 3). Ms Burtshaw maintains that mindfulness has been a valuable tool in overcoming numerous obstacles in her life following cancer (Rasdien, 2015b).

In summary, psychologists are well positioned to help to normalize and validate the cancer experience by dedicating time to explore these factors. This research has provided important contributions, as understanding how survivors cope will assist psychologists to develop more effective strategies and therapeutic interventions (i.e., health promotion). This will help to build personal resilience and assist each HC survivor to maintain or at least work toward a healthy well-being.

Conclusion – Theory, Policy and Practice

Greater knowledge regarding risk and protective factors within the context of HC survivors has been provided by this study, with findings contributing to theory, policy and practise. Based on an understanding of the factors that usually enhance resilience and how each patient has successfully dealt with severe stress in the past, each clinician can learn to reinforce optimal responses to adversity. For example, clinicians may be able to identify protective or risk characteristics (e.g., purpose in life, lack of purpose) and then facilitate coping by responding appropriately to the individual needs of each survivor. This could be as simple as expressing concern, providing information, helping with problem solving or referring on to other more suitable services. This therapeutic approach pertains to all cancer patients at any stage, as this research has identified that the characteristics and outcomes of resilience, are relatively similar across all cancer types throughout all phases of the cancer trajectory.

Given the number of people who will be diagnosed with cancer in their lifetime, and if health system reform is to be effective, improving cancer survivorship must be a common goal throughout the healthcare system. When HCP’s isolate survivorship in various stages, for which someone else is accountable, we miss opportunities to improve the care of cancer patients. Therefore, initiating the discussion between all HCP’s, consumer groups, cancer support agencies, government bodies and individuals affected by cancer has the potential to have a notable impact on cancer-related care. Moving forward, more efficient targeting and provision of clinical services that meet these needs should be deemed as a key objective for healthcare services in the future. However, due to the limited research evidence relating to needs of HC survivors long-term, more investigation is necessary. The next section will outline a number of these beneficial areas for future research. The final section of this thesis, will propose several recommendations that are based on the findings of this study.

Future Research

As more individuals survive cancer, greater consideration is being given to QOL outcomes and how people adapt to this chronic disease. The knowledge gained from this study has improved our understanding of the patient experience of living with HC and highlighted resiliency factors that may improve psychological wellbeing. Yet, the findings raise further questions regarding psychological adjustment and the conditions under which resilience occurs in those with cancer. Consequently, there are several worthwhile directions for future research.

First, the current study only recruited a small number of rural HC survivors and, therefore, did not provide a clear understanding of this sample of individuals. A cancer survivor's geographical location can limit access to support, with those living in remote areas reportedly experiencing greater unmet needs and poorer outcomes (Hutchinson et al., 2011; Marker, 2015). Thus, further research recruiting from rural areas is recommended.

This study also targeted an adult population and those under 18 years of age were excluded from this sample. Data on adolescents and children could have identified other distinctive coping styles and risk factors. For example, the ability of a younger HC survivor to implement internal coping strategies may be limited, as they may not have the same learned experience as an older survivor. Conversely, as we have an ageing population in Australia and the burden of disease is increasing, more thorough research among older adults would be valuable. Older adults may experience additional challenges as the long-term effects of cancer often coexist along with co-morbid health problems associated with aging. This is also important, as cancer is predominantly a disease of the elderly, with 70% of diagnoses in those over 60 years of age (AIHW, 2014). Thus, it is essential to identify subgroups of older cancer survivors at greatest risk, such as those who have low social support, poor functioning or whom require aggressive treatment.

In addition, larger sample sizes, that include a much wider diversity of respondents, are necessary if a more complete and thorough understanding of the experience of HC is to be obtained. For example, stigma around a cancer diagnosis can be an influential barrier in some communities such as indigenous populations. Therefore, it is important to consider not only the patient's life stage, but also cultural differences and variables that may affect how people utilise internal and external resources. The ethnic profile of survivors will change, as Australian society becomes a more heterogeneous cultural mix. Different recruitment methods through improved design development could be employed in order to capture minority ethnic or low socioeconomic groups, including those individuals with lower education levels or those who are not proficient in the English language. This is imperative as culturally prescribed norms may affect the availability of family support, health-seeking behaviour and self-care practices.

Fourth, this study focused on survivors, therefore the perspective of others, such as HCP's, community organisations or carers were not included. It is imperative that cancer survivors are included early in the research process so that the collected data deliver a meaningful direction to prevention and intervention plans. Yet, studies of resilience among significant others may be beneficial and would further inform this population, particularly given the findings on the importance of social support. Diverse contexts create varying needs and the impact of risks and protective processes are dependent on these contexts. Therefore, future research should examine not only the cancer survivor's experience, but also include other significant parties involved in the patient's journey.

In addition, while survivors in this study were classified in psychosocial terms as being in the extended and permanent phases of survival, data on specific disease stage were not available. It is likely that resilient outcomes and or psychological needs differ according to disease stage. In future studies, the examination of the relationship between stage of cancer and levels of distress will provide a deeper perspective. This is important, as research suggests that psychosocial needs are not being met adequately for those who are in the advanced stages of cancer, but have not yet reached the palliative care phase (Maher & Fenlon, 2010). Moreover, prospective cohort studies that have the potential to follow patients throughout the diagnostic, treatment and recovery phases, would add further valuable knowledge as to the antecedents of a resilient outcome and provide valuable information as to whether 'resilience' fluctuates or varies throughout these stages.

Finally, in the evolving cancer survivorship environment, ensuring that care is holistic, cost effective, evidence-based and adaptable to different health settings remains an ongoing challenge. Yet, delivering quality care to cancer survivors is not simply about effective medical treatment, but rather improving overall QOL through effective healthcare initiatives. Future research involving the effort of experts within diverse interdisciplinary teams will be of benefit, given the challenges and complexity facing cancer survivorship care.

Recommendations

Based on the current research findings, the following recommendations are proposed. These recommendations have been categorised according to their relevance for state/federal policy, employers, HC survivors, community support networks and the clinical team, with particular reference to psychologists.

State/Federal Policy

The field of cancer survivorship has evolved due to the combined international and Australian endeavours involving researchers, survivor advocates and HCP's. The incentive to attend to the needs of the increasing cancer survivor population has in part motivated these initiatives. Lobbying the federal and state government may achieve supportive government responses. The following recommendations directed at federal and state policy could further enhance research in the area of cancer survivorship.

- *Promote national advocacy*
 - Guiding public policy decisions involving cancer care (i.e., by providing links and information online for HC survivors to be informed about national public policy)
- *Increase public awareness*
 - Available resources for cancer survivors via several avenues (i.e., healthcare literature, media, online)
 - Relevant issues faced by HC survivors and their families in Australia
- *Provide relevant information and resources available to rural communities*
 - To overcome the unique issues faced by these individuals by improving referral pathways and communication between healthcare providers
- *Greater improvement in the access to care* such as:
 - Counselling and allied healthcare services
 - Respite care
 - Financial assistance for those experiencing difficulty
- *Evaluate existing funding policies* to assess their effectiveness, for example:
 - Conducting a review of current cancer survivor entitlements and assessing the suitability of these payments
 - The flexibility in accessing financial government funding and how this can be most effectively utilised
- *Promote ongoing research* to evaluate and improve the development and testing of various survivorship care models
 - Re-evaluate funding allocation for rarer cancers

Employer/Organisations

Greater assistance by employers could alleviate some of the stress and anxiety associated with returning to work. However, initiating changes in the workplace remains a challenge. Many organisations have an emphasis on productivity and are dealing with cost cutting. Yet, the findings in this study indicate that returning to work is important for HC survivors in their recovery as employment provides an essential source of social and financial

support. Therefore, the following initiatives by organisations/employers are recommended to benefit HC survivors.

- *Raising awareness* is the first step towards improving support
 - Provide training to employers to assist them be more informed as to the needs of cancer survivors
- *Provide easy access to information* on support services and employee entitlements
- *Identify barriers* that inhibit employers from implementing supportive policies in the workplace
- *Introduce flexible working hours* to assist with:
 - Attending medical appointments
 - Transitioning back into the workforce
 - Increasing employee productivity

HC Survivors

The challenge for every HC survivor is identifying how to return to everyday life while adjusting to the effects of the cancer and its treatment (ASCO, 2014). An important theme throughout this study emphasised what HC survivors can do to help themselves in order to cope more effectively. As a result of these findings and previous research, there are a several recommended coping strategies that survivors can *personally* employ in order to enhance their personal resilience and improve their mental wellbeing.

1. *Be aware of your emotions* – avoid ignoring fear, anxiety and depression as these feelings may intensify. Consider:
 - Discussing your concerns with clinical team members
 - Expressing your thoughts in a diary
 - starts a process of self-discovery
 - Blogging/using social media – as a more public forum helps you gather information and may also connect you with people with similar diagnoses
 - Joining cancer-related support groups
 - Re-evaluating priorities – exploring what is most important in your life
 - Avoid taking everything personally
2. *Use alternative resources* – some cancer survivors do not find cancer-related support groups beneficial. In this scenario consider other coping strategies that may include:
 - Talking with family, friends, religious communities or significant others
 - Consider a referral for individual counselling
 - having regular professional consultation even when life is going well will enhance resilience (Rees, 2011).
 - Participate in other enjoyable activities
 - Allow space and time to process

3. *Self-care* - provides a sense of control, reduces the chances of cancer recurrence, and improves psychological well-being and QOL. For example:
 - Maintain a healthy diet
 - Do regular and appropriate exercise
 - Get adequate sleep
 - Use community services such as “Look Good....Feel Better”
 - They provide supportive care in appearance i.e., makeup, wigs etc.
 - Limit or cease alcohol consumption, smoking, recreational drug taking
 - Manage your stress
 - Relaxation - meditating, reading, drawing, playing music, yoga, etc.
 - Alternative/Complementary therapies – acupuncture, etc.
 - Know your limitations – learn to say no!
 - Recognising your challenges - know how and when to ask for support

 4. *Effective communication is essential.* **Question** your clinical team regarding:
 - Cancer recurrence –symptoms to watch for, is this likely?
 - Survivorship – additional treatment, role of your healthcare team
 - Long- and short-term side-effects – screening, management, secondary cancers
 - Follow-up care plan – who will oversee my care and how often?
 - Emotional wellbeing- ways of dealing with fear, anxiety, uncertainty
 - Spiritual support – available organisations or services
 - Relationships – intimacy, sexuality, parenting
 - Having children – cancer-related fertility issues
 - Employment concerns – planning return to work, work culture, privacy/disclosure with co-workers, disability management programs, flexible working hours, legal rights
 - Finances – assistance with medical bills, insurance cover
 - Cancer rehabilitation - health behaviour change, available services
 - Allied health support - dietician, psychologist, exercise physiologist, etc.

 5. *Participate as a self-advocate* by being an informed healthcare consumer and supporting your specific cause. Cancer survivors often aspire to ‘give back’ to the community. This can facilitate not only personal recovery but also provide a sense of control while supporting others. **Personal advocacy** can be achieved by:
 - Collecting accurate medical information and keeping a personal health record
 - Use a survivorship or follow-up care plan/passport to monitor future health and follow-up visits
 - Seek second opinions if necessary
 - Locate and access resources – wigs, scarves, books etc.
 - Take part in and/or facilitate support groups
 - Provide education and awareness to schools, workplaces, social media, etc.
 - Volunteer in fundraising and event planning
 - Participate on committees and speak publicly about survivorship issues
 - Involvement in peer support groups, information sharing and research
 - Collaborate in the design and development of health systems planning
 - Advocate for employment, access to health, insurance and privacy rights
- (ASCO, 2014; Connerty & Knott, 2013; Hoffman & Stovall, 2006; Marker, 2015; Rees, 2011).

Community Support Agencies

The findings indicated that community-based organisations played a significant role in supporting cancer survivors and their families. Cancer councils across Australia have a range of community-based services to support cancer survivors, such as access to financial, legal, and return to work assistance and emotional support, yet many do not utilise the services provided. Community and cancer support networks can also be an essential partner to HCP's by complementing clinical care, throughout survivorship (Dhillon, 2015). According to Miller and Tang (2015), the community and not-for-profit sector can be successfully integrated into the cancer care team. The following recommendations are proposed in order to improve the service delivery and uptake of cancer-related community organisations.

1. *Support the community network*
 - In the form of education and counselling for employees and volunteers
2. *Engage survivors in the advocacy work of cancer support services*
 - Provides a voice on the issues that matter most to cancer survivors
3. *Facilitate cancer rehabilitation* - encourage HC survivors to remain independent, productive and regain control over their lives by implementing programs to:
 - Improving physical strength and psychological wellbeing
 - Educate HC survivors on way to become more independent and less reliant on caregivers
4. *Educational resources and interventions*
 - Provide transition education sessions for HC survivors during the last month of treatment:
 - assists cancer patients as they transition from active treatment.
 - Offer multicultural education to:
 - cater for cultural diversities
 - enhance support among those with ethnic differences
 - Develop a wider variety of educational resources
 - to meet the specific needs of cancer survivors and to improve patients' satisfaction with the information they receive (i.e., web-based, one-to-one contact, telephone service, DVD's, reading material, etc.)
 - Inform patients on the significance of their family and peer support network
 - considered a strong predictor of adjustment and coping.
 - Educate family members and carers of those with cancer
 - empower carers by providing intervention programs to assist with managing cancer-related problems among loved ones. i.e., enhance skills that provide 'invisible support' so as to avoid enabling learned helplessness among cancer survivors (Hou et al., 2010).

5. *Improve and deliver appropriate cancer-related support programs that take into account the following considerations:*
 - Clear outline of group aim - i.e., educational or counselling
 - Participant criteria
 - offer survivor-matching programs - many cancer patients prefer groups with similar diagnosis, gender, ages, time since diagnosis etc.
 - size of group
 - cancer patients, carers or family
 - Facilitator experience
 - i.e., volunteer cancer survivor advocates or qualified professionals
 - Atmosphere/setting and structure
 - venue, time, frequency
 - Follow-up processes
 - Evaluation

Clinicians and Allied Health Professionals

The results of this study emphasised the importance of clinicians and allied HCP's in the recovery process of HC survivors. In order to improve the QOL, physical health and mental wellbeing among HC survivors, the following recommendations for HCP's are offered.

- *Effective Interpersonal Skills and Holistic Care*
 - When interacting with HC patients:
 - avoid medical jargon and insensitive remarks
 - involve patients in the decision-making process
 - provide timely and useful information about your patient's health in an honest, direct, factual, and compassionate manner
 - maintain a realistic appreciation of your patient's situation
 - respect patient's concerns
 - avoid unwelcome pressure on HC survivors to always be positive
 - be optimistic in interactions with patients but do not create false hope
 - Consider the needs of family and carers:
 - provide clear information to ensure understanding regarding treatment and expected changes (i.e., relationship issues, coping style, autonomy, fear, etc.)
 - A brief conversation may be enough to encourage families, carers and HC survivors to initiate action themselves to locate services that support their recovery
 - Contemplate a gradual decrease in support by tapering off appointments, rather than suddenly ceasing contact following treatment
- *Appropriate Assessments*
 - Complete a mental health/distress assessment. Recognising the existence of signs of distress is a first step in enabling HCP's to provide suitable support:
 - awareness of anxiety and fear experienced, not just at the time of diagnosis or during treatment, but also follow up appointments
 - ask your HC patient, "How are you coping? "What helps you to cope?"
 - encourage positive psychosocial outcomes and become familiar with methods of adaptation most likely to foster positive psychosocial outcomes and promote resilience

- Anticipate potential obstacles to coping (i.e., a lack of service coordination) or potential triggers for anxiety and depression
 - a service that is well-coordinated, but lacks cohesion and effective communication between HCP's, can impact on patient recovery (Norris et al., 2011).
 - look for persistent failures to cope
 - Identify potential protective or risk factors concerning psychosocial outcomes
 - Ensure, as a HCP, that you are educated on the necessary skills to identify those cancer patients experiencing difficulty with coping. Research reports that a subgroup of HC survivors would likely have benefited from a completion of treatment interview in which effects of cancer and treatment could be investigated (Lobb et al., 2009).
 - emotions can be easily misinterpreted by HCP's which may lead to inaccurate assessments
 - examine premorbid risk factors
 - Involve feedback from significant others (i.e., family, carers, etc.)
 - Where possible conduct longer appointments.
 - Facilitate exit interviews after treatment
 - Coordinate immediate access to test results
 - anxiety is exacerbated by long waits for follow-up appointments to receive results (Marker, 2015).
 - Arrange follow up by telephone calls/email if appropriate (i.e., six-monthly)
- *Timely Interventions*
 - Provide clinically appropriate interventions at the time of diagnosis, during, and beyond treatment:
 - HCP's should offer timely counselling services and/or clinical interventions that can effectively target those identified as at risk of psychological distress
 - Focus on interventions targeted during the first year following diagnosis and/or treatment:
 - the stress of recurrence anxiety dominates during this phase
 - Individualise interventions:
 - focus on survivor preference with attention to minimising deficits and reinforcing strengths
 - Consider utilising rehabilitation programs
 - provides a practical intervention to maximize the dignity and independence in cancer survivors
 - have the potential to help make positive changes to patients health behaviours
 - *Relevant information, resources and education*
 - Ensure HC survivors are aware of existing resources:
 - through cancer registries, at events sponsored by cancer-related organisations, in specialist waiting rooms, social media, etc.
 - Offer educational forums to enhance coping skills and minimise uncertainty during long-term survival
 - information and education should be offered with equal intensity as those provided at time of diagnosis (Mullan, 1984).
 - individual sessions, workshops, and group education for both survivors and families, written and web-based materials from reputable sources etc.

- *Referral and ongoing support*
 - Understand how, when, and where to refer patients who require specialised allied health care services, some of which are provided by:
 - Dieticians
 - Occupational Therapists
 - Social workers
 - Exercise Physiologists
 - Psychologists/Counsellors
 - Inform HC survivors of supportive care, advocacy and research opportunities available within their community
 - Collaborate with community organisations such as Cancer Council.
 - provide a gateway to many services that HC survivors can access over their lifetime

Psychologists.

Psychologists offer an important role at critical times along the cancer patient's survivorship journey, and are in a unique position to deliver long-term management. For example, psychologists keep cancer patients engaged in life by: providing emotional and practical support; delivering advice on a range of psychological issues related to illness; promoting healthy behaviour choices; and, assisting cancer survivors to maintain a sense of normality. This occurs, in part, through the use of effective psychosocial interventions and a positive therapeutic relationship. The following are examples of therapeutic interventions recommended for psychologists working with cancer patients. These five interventions have been selected as they are reported in the literature to promote and foster protective factors, shown in this study to boost resilience.

- *Cognitive Behavioural Therapy (CBT)* – helps individuals to change unhealthy thoughts, feelings and behaviours. CBT reduces anxiety, stress, depression, fear and uncertainty by assisting cancer survivors to:
 - reframe obstacles as challenges
 - recognise negative self-talk and dysfunctional thought patterns
 - learn distraction techniques to prevent rumination about their cancer
 - explore previous adversity and identifying coping strategies that were successful in the past
 - improve emotion- and problem-focused coping
 - identify personally meaningful goals
 - motivate positive health behaviour change
 (Maher & Fenlon, 2010; Molina et al., 2014; Norris et al., 2011)
- *Mindfulness* involves, in a non-judgmental way, deliberately paying attention to thoughts and sensations of an experience, in the present moment (e.g., form of meditation) (Sharplin et al., 2010). Mindfulness improves physical and mental wellbeing by allowing patients to take a break from thinking about their cancer. This leads to improved QOL and spiritual wellbeing (Bartley, 2012; Fish et al., 2014). Other benefits of mindfulness include:

- stress relief and reducing rumination
 - improving sleep
 - reducing pain
 - improving cognitive flexibility
 - boosting memory and focus
 - decreasing emotional reactivity
 - enhancing self-insight thus motivating positive behaviour change
- *Logotherapy* is a ‘meaning centred’ psychotherapy approach founded by Viktor Frankl (1905-1997). Frankl believed that the desire to find meaning is the primary motivation of human beings. In practice, physiologically, logotherapy is recognised for its effectiveness in reducing despair in unavoidable suffering. Psychologically and spiritually, logotherapy also helps individuals to reduce anxiety by overcoming feelings of emptiness and reestablishing purpose in their lives (Schulenber et al., 2008). The literature (Ameli & Dattilio, 2013; Saraswathi, 2014; van der Spek et al., 2013), reports that logotherapy can also assist HC survivors by:
 - facilitating the development of an individual’s sense of purpose
 - protecting against emotional instability
 - assisting in perceiving and removing factors that hinder the pursuit of meaningful goals
 - enabling survivors to cope with cancer-related symptoms by regaining control and by building empowerment, self-determination and hope.
 - providing opportunities to develop mastery in areas that are meaningful
 - encouraging autonomous behaviour.
 - guiding in achieving self-efficacy, openness, flexibility and optimism
 - *Acceptance and Commitment Therapy (ACT)* helps cancer survivors to develop clarity about what is important in their life and assists to establish behavioural goals in accordance with those values. ACT also offers clinically useful strategies for treating fear of cancer recurrence by:
 - facilitating change by encouraging patients’ flexibility and acceptance of what cannot be altered and focusing their efforts to what can be achieved
 - redirecting their perceptions of stressful experiences and focusing on positive reframing and personal growth (Butow, Fardell, & Smith, 2013; Carver, 2005).
 - *Visualisation and Guided Imagery* is effective in easing the side-effects of treatment (i.e., pain and fatigue), reducing anxiety and facilitating relaxation and promoting a sense of control over the cancer experience (Rossman, 2002; Serra et al., 2012).

Conclusion

As a growing number of individuals survive HC, it is becoming increasingly clear that prolonging life is not the only criterion for effective cancer treatment. For many patients, enduring cancer and treatment is just one step of an arduous journey, in which their QOL can change dramatically. For example, many HC survivors experience diverse late or long-lasting physical and/or psychosocial effects, which may impact on their mental health. Therefore, cancer survivorship is considered a potentially traumatic, yet, unique journey for every individual, who has to find their own way of navigating the challenges that occur as a result of living with cancer.

Encouragingly, resilience is reported to play a vital role in the success in coping with cancer-related adversity. Indeed, studies have reported that resilience can be enhanced in people at any stage in life and should be the emphasis of psychosocial interventions with cancer patients. For example, personal traits and/or factors such as self-efficacy, self-esteem, purpose/meaning in life, and perceived control have all been identified as resilience enhancing factors in the literature, and the results of this research concur. However, more detailed evidence-based research was required, in order to better understand this resilience process. Thus, the purpose of this research was to identify and then examine other factors that may also influence resilience. The broad aim was to develop a model of resilience for HC survivors.

This mixed method study identified several factors, both positive and negative, that contributed to or impeded the ability of HC survivors to cope following their HC diagnosis. In addition, elements of the model that emerged from this study also found that multiple individual, family and community level processes occurred simultaneously in the resilience process. The six variables that significantly contributed to the model of resilience, when combined with the other 18 variables, included *active coping, positive reframing, self-blame, family support, friend support and exercise*. One variable, self-blame, was related to lower resilience scores. Other factors found to enhance resilience included emotional and instrumental support, planning, humour, acceptance, religion, social support (HCP's and significant others), time out, care in appearance, researching information, alternative treatments and diet. The other negatively correlated factors included denial and behavioural disengagement, which impeded resilience among these respondents. This study also identified that resilience protects against depression and anxiety, which highlights the importance of developing resilience among HC survivors. In addition, through this research, a potential 'at risk cohort' was identified. Younger adults and those within five years of diagnosis were found to have significantly higher scores on depression and anxiety. The present results further support the majority of earlier research findings identified among other chronic illness populations.

Several recommendations based on the sound empirical evidence resulting from this study were offered for the deliberation of relevant stakeholders. Should these recommendations be implemented in an efficient and timely manner, the psychosocial wellbeing of HC cancer survivors could be considerably enhanced. However, the dilemmas and challenges of survivorship are complex and require considerable practice improvements. In addition, our understanding of the cancer survivorship trajectory, especially among less common cancers, is still in the early stages. Therefore, it is essential that clinicians remain informed and involved in future research. For example, psychologists have the potential to contribute significantly to this body of literature by documenting their experiences with cancer survivors and by providing data on successful psychosocial interventions.

With the help of this study, we now have both qualitative and quantitative data about the challenges and support needs of HC survivors. Understanding all the relevant aspects of the cancer survivorship experience will certainly move toward closing the gap between medical treatment and more holistic patient outcomes. In the future, as our appreciation of cancer survivorship improves, clinicians will need to ensure the desires of cancer survivors are central to their care, not merely an afterthought once therapy has ended. Such awareness will empower clinicians to provide more effective individualized patient-centred care, which attends to patients' unique needs. However, various avenues of support identified in this study can only be addressed through a collective and coordinated effort across different sectors. The federal and state governments, employers, organisations, and HCP's can all play a vital role in better supporting HC survivors.

The findings of the current study have offered insights into important factors that influence resilience. This is a worthwhile endeavour that will assist every HC survivor live and function more effectively with his or her illness. Finally, it seems fitting to conclude this thesis with a quote that was communicated in an article about Kareem Abdul-Jabbar, an American National Basketball Association athlete, activist, writer, and leukaemia survivor (Gallo, 2010). This advice was conveyed by a 'savvy' doctor whose perspective appropriately expresses the viewpoint also shared by many of the HC participants in this study.

“If you want to live a long life, do not dismay at a sudden and surprising diagnosis, just confront it and take care of it. Consider the intrusion of this, as your unwelcome malady and something you have to put in its place” (Gallo, 2010).

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Appendix A

History and Attributes to the Developing Cancer Survivorship Movement

The historical construct of survivorship as a concept was associated with living through unexpected atrocities, such as being captive as a prisoner of war or surviving natural disasters (Boyle, 2008; Dow, 1990). The term survivorship first became apparent in the medical literature in the 1960s, with mention to life following a myocardial infarction (Lew, 1967). However, as the number of cancer survivors increased throughout the 1970s and 1980s, a cancer survivorship community arose (Doyle, 2008).

In 1980, Shanfield identified the psychological consequences of surviving cancer, prior to this there had been insignificant research efforts on the survivorship topic, in relation to adults (Doyle, 2008; Shanfield, 1980). The research prior to this point, had focused on paediatric survivors reaching adulthood, as it was in this arena that the most dramatic treatment success stories were witnessed (Rowland & Baker, 2005). Shanfield suggested that the cancer experience lasted a lifetime and was characterized by an enduring sense of one's own mortality and vulnerability, coupled with vivid memories of the illness and recovery period.

Then in July of 1985, Mullan published his paper entitled "Seasons of Survival: Reflections of a Physician with Cancer" in *The New England Journal of Medicine* (Feuerstein, 2007a). This article written by Dr. Fitzhugh Mullan, would create a major medical and cultural shift in the United States (US) moving from cancer 'patients' to cancer 'survivors' (Feuerstein, 2007a; Hoffman & Stovall, 2006).

Mullan (1985) projected that survivorship should be researched as a cancer experience in itself, rather than an afterthought of medical research on treatment. In addition, Mullan's view of survivorship reflected more a "diverse experience" involving phases that cancer patient's transitioned through. Mullan referred to these as "seasons of survival" that included acute, extended, and permanent stages following a cancer diagnosis (which will be discussed shortly in more detail). Mullan also detailed many of the challenges faced by those living with a cancer diagnosis and argued the need for a fresh way of perceiving surviving with cancer (Feuerstein, 2007a). Survivorship, Mullan maintained, should be viewed as a concept that can be used to help

explain, describe, better manage, and avert the many challenges and inadequacies faced by those living with a diagnosis of cancer (Feuerstein, 2007c; Mullan, 1985).

At this time, researchers had begun collecting statistics on survival rates in order to reflect the severity and prognosis of cancer. However, Mullan was the first to represent the experience of cancer from diagnosis to the end of life (Bartels, 2010). Mullan was instrumental in founding the National Coalition for Cancer Survivorship (NCCS) in 1986. As a result, clinicians began to acknowledge what cancer patients required, beyond the initial diagnosis and immediate medical treatment (Hoffman & Stovall, 2006). For example, medical, physical, psychosocial, economic and legal issues were slowly starting to be realised as a potential cost of having had cancer (Doyle, 2008; Feuerstein, 2007a). Accordingly, the survivorship movement slowly began to appear in the cancer-related literature (Doyle, 2008).

By the 1990s, there was an increase in autobiographical literature recounting the experience of surviving cancer from the individual's perspective, which extended throughout the cancer trajectory (Doyle, 2008). This interest initiated the beginning of influential cancer survivorship associations. For example, in the United States (US) in 1996, the National Cancer Institute (NCI) established the Office of Cancer Survivorship (OCS). Following the foundation of OCS, related organisations, such as the American Cancer Society and the American Institute for Cancer Research, consequently placed "survivorship" as a primary focus for their research initiatives (NCCS, 2012). Hence, within the past decade, the survivorship movement has encouraged a radical redefinition of care, with health care professionals highlighting an emphasis on the survivor trajectory (Hewitt, Greenfield, & Stovall, 2005). In the US during 2004, The Centers for Disease Control and Prevention, along with the Lance Armstrong Foundation, took a lead in these efforts by delivering a National Action Plan for Cancer Survivorship (Bartels, 2009).

In 2005, the Psycho-oncology Co-operative Research Group (PoCoG) was established between Australia and New Zealand in response to an identified need to develop a synchronized partnership for the conduct of large-scale, multi-centre psycho-oncology and supportive care research (Hagerty & Butow, 2006; Rankin, 2011). With a membership of over 480 individuals PoCoG, represented the majority of key stakeholders involved in psycho-oncology in Australia and New Zealand (Rankin et al, 2011). One of the main concerns for PoCoG was to ensure that research activities

supported clinical practice, in order to enhance psychosocial care for cancer patients nationwide (Rankin et al., 2011).

Then, in the US during 2006, the Institute of Medicine (IOM) published a landmark study, “From Cancer Patient to Cancer Survivor: Lost in Transition”, which presented effective protocols for improving the QOL and the long-term care of survivors (Hewitt, Greenfield, & Stovall, 2005). The four central elements of survivorship care include prevention, surveillance, intervention and co-ordination (Brennan & Jefford, 2009). The IOM report included ten recommendations, seven dealt with the need for legislative change, while three were targeted at health care providers (Wheeler, 2010). It was during this time that an extensive body of literature was published, in relation to the treatment and care provided by clinicians (Bartels, 2009; Feuerstein, 2007a). In addition, a proliferation of survivorship terminology became accessible within the cancer survivorship forums, on websites, within support agencies and through autobiographies by those personally affected (Bartels, 2009).

In the same year, The National Services Improvement Framework for Cancer was formulated in Australia, which recommended a guiding principle behind the survivorship movement (Girgis & Butow, 2009). This principle proposed that cancer support should span the continuum of care that includes the life course of the illness. It was recognised that there was a need to embrace prevention, screening, diagnosis, management, rehabilitation, living with the condition and palliation where required (Girgis & Butow). This report also concluded that, within Australia, the relative lack of attention outside the treatment context was due to the absence of information regarding current practice and effective guidelines (Girgis & Butow). In addition, according to Girgis and Butow (2009), there had been no co-ordinated Australian efforts to develop a specific survivorship agenda.

As discussed, despite being a relatively new field, there has been a significant increase in survivorship research over the last 10 years. The historical progression of the survivorship movement discussed above can be viewed in Table 2. This not only outlines a visual timeline detailing the influential contributors in developing the cancer survivorship movement from 1985-2006, but also illustrates the agenda and research considerations.

Appendix B

Cancer Survivorship Development Timeline from 1985-2006

Table A1.

Cancer Survivorship Development Timeline from 1985-2006

Year	Contributors and Agenda towards the Cancer Survivorship Movement
1985 -	Fitzhugh Mullan, a physician diagnosed with anaplastic seminoma, proposed the first survivorship model that focused on the patient and also recognized the impact of family, friends, extended community and clinicians (Mullan, 1985).
1986 -	Building on Mullan's model, representatives from 20 organisations re-defined survivorship after founding the NCCS. This coalition advocated on behalf of cancer survivors by identifying different needs experienced across the course of the illness and recovery (Hoffman & Stovall, 2006; Wheeler, 2010).
1989 -	Mullan's framework was later supported by Carter (1989) in her review of research on the cancer survivor topic, which was adopted by NCCS as their membership criterion (Wheeler, 2010).
1995 -	National Cancer Institute (NCI) sponsored the First National Congress on Cancer Survivorship (NCCS). The NCCS clearly set the agenda for cancer survivorship research by addressing the physical, psychosocial and economic realms of a cancer diagnosis and its treatments (NCCS, 2012).
1996 -	The Office of Cancer Survivorship was founded at the NCI in response to consumer backing for more thorough understanding of the unique and poorly identified needs of cancer survivors. The directive of the OCS was to improve the length and quality of life of those diagnosed with cancer (Wheeler, 2010).
2005 -	A panel was invited by the IOM to research the variety of medical and psychosocial issues faced by adult cancer survivors. The first goal was to educate clinicians and the community of the unique needs of cancer survivors and to establish cancer survivorship as a distinct phase of cancer care (Brennan & Jefford, 2009).
2005 -	Psycho-oncology Co-operative Research Group (PoCoG) was established in Australia and New Zealand. The main agenda was to ensure that research activities maintained broad application within clinical practice to improve psychosocial care for cancer patients nationwide (Rankin, 2011)
2006 -	The IOM in the United States released a landmark report written by Hewitt, Greenfields and Stoval titled ' <i>From cancer patient to cancer survivor – lost in transition</i> '. This report portrayed survivorship as a distinct phase in the cancer journey (Brennan & Jefford, 2009).
2006 -	The National Services Improvement Framework for Cancer in Australia proposed a guiding principle behind the survivorship framework. This principle proposed that cancer support should span the continuum of care that includes the life course of the illness (Girgis & Butow, 2009).

Appendix C

Interview Participant Invitation Letter



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ABN 54 361 485 361 CRICOS IPC 00279B

Thank you for your time.....

My name is Kate Gallagher and I am currently completing a PhD in Psychology at Edith Cowan University (ECU). I am writing to invite you to participate in my thesis, which has been approved by the Human Research Ethics Committee at ECU.

I am researching the experiences of haematological cancer survivors. I have chosen this research, as I feel it is important to understand how you and others in your situation have coped. I hope this research will identify what was most or least helpful in dealing with your illness. It is expected that this information will assist others who face similar circumstances.

If you were diagnosed at least 12 months ago and are not currently undergoing inpatient hospital treatment for your cancer, would you be interested in participating in a short interview? This will be at a time and place convenient to you. Each interview will take approximately 30-40 minutes. All interviews will remain confidential, therefore only I will know your identity. The interviews will be digitally recorded and then transcribed afterwards, following which all identifying features will be removed from the paperwork and recordings will be erased. Results from this project may be shared in conferences or publications, but no participants will be identified. You are free to withdraw participation at any time during the interview process, in which case any information you have already provided will be destroyed.

If you are over 18 years of age and willing, I would like to invite you to participate in this research by contacting me either by phone or email (details below). If you have any queries regarding this research or require further information, please don't hesitate to contact me, or one of my supervisors, Professor Ken Greenwood (*6304 2769 or k.greenwood@ecu.edu.au*) and Professor Anne Wilkinson (*6304 3540 or anne.wilkinson@ecu.edu.au*). Alternatively, if you would like to speak with an independent person please contact the ECU Research Ethics Officer, Kim Gifkins on (*08*) *6304 2170*.

It is expected that the interview will not be distressing. However, if you experience any stress or are uncomfortable, the interview will stop and a list of counselling and support services will be provided.

Thank you, I appreciate your time and consideration and I look forward to your participation in this valuable research.

Kate Gallagher

Kate Gallagher (School of Psychology, Edith Cowan University)

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Appendix D

Interview Consent Form



JOONDALUP CAMPUS
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Informed Consent

In signing this letter of consent, you agree to the following:

- I have read the information sheet provided, understand the nature and purpose of the study and have freely agreed to participate.
- I have been given opportunity to ask questions and received satisfactory answers in regard to all aspects of the research.
- I am aware that the researcher is not a counsellor and that the interview is non-therapeutic.
- I understand that participation in this project will involve an interview that will be audio recorded.
- I am aware that the information obtained from the interview will form the basis for a publishable report.
- I understand that the audio recording will be transcribed after the interview (possibly by a third party who will not know my identity).
- I give permission to be contacted by the researcher to clarify information.
- I am aware that all efforts will be made to maintain confidentiality and understand that the researcher will secure all documentation relating to myself and my interview whilst the research project is ongoing.
- I understand that, at the completion of the research project, all identifying information will be destroyed, and all transcripts, questionnaires, and consent forms will be stored by Edith Cowan University for a period of five years before being destroyed.
- I understand that my participation is voluntary and I may withdraw permission or cease to participate at any time.
- I understand that the researcher will advise me if my results indicate possible clinical levels of depression or anxiety.

Participant Signature _____ Date _____
 Contact Details: Email _____ Mb _____
 Participant Name (Printed) _____
 Researcher Signature _____ Date _____

Name of Investigator: Kate Gallager

Name of Supervisors: (Professor Ken Greenwood and Professor Anne Wilkinson)

Appendix E

Support Services Information

After discussing your experience following treatment for cancer, you may have encountered some unresolved issues. These may not seem significant however it is important that if you feel this way, you seek help. This is to ensure that no underlying events raised as a result of this research study continue to cause a negative impact on you currently and/or in the future. This brochure has been compiled to provide you with a list of available support services that you may wish to contact if you want to further discuss any concerns.

Cancer Related Support/ Counselling

Cancer Council Helpline

13 11 20 or

www.cancerwa.asn.au

(A non government, community supported organisation that provides a comprehensive and professional counselling service for people diagnosed with cancer, including family and friends)

Leukaemia Foundation

1800 620 420 (Mon – Fri) or

www.leukaemia.org.au

(Provides support to individuals and families who have experienced haematological cancer through emotional support, counselling, practical assistance, peer support, education and seminars)

Psychological Support Services

ECU Psychological Services Centre

9301 0011

Joondalup House, 8 Davidson Terrace, Joondalup

(Provides psychological counselling, treatment and assessment)

Centrecare

9300 7300

Level 1/85 Boas Ave, Joondalup

(Provides workshops, in home visiting and individual, couple and family counselling)

Psychologists (Fee Based)

To find a psychologist in your area visit:

<http://www.psychology.org.au/FindaPsychologist>

Telephone Support

Life Line WA

13 11 14

(24 hour

support)

Mental Health Direct

1800 220 400

Appendix F**Interview Participant Demographic Information Sheet**

Name:
Age:
Sex:
Marital status:
Number of children:
Country of Birth/Nationality:
Current or Previous Occupation:
Current employment status:
Residential postcode:
Haematological cancer diagnosis:
Date of diagnosis:
Type(s) of treatment:

Date of last treatment:
Treating hospital:
Current medications

Any relapses, significant illness information or complications since last treatment:

Have you been diagnosed with any other health problems or illnesses (these may be in addition to your cancer diagnosis)

If applicable have you been prescribed psychotropic medications (for mental health or psychiatric illness). If so please provide details:

Current status of cancer diagnosis (Please circle)

- A - Cured
- B - In remission
- C - Not sure

Thank you for your time...

Appendix G

Participant Interview Schedule

1. Please can you tell me about your experience following treatment for haematological cancer?
2. How has this experience changed your life?
3. Do you believe that you have coped well during this time?
4. What has helped you to adjust?
 - Prompts: Social support (partner, children, friends, support groups)
Personal characteristics (personality traits, psychological factors)
External factors (employment, hobbies, physical exercise)
Cancer related (health care professional and facility support)
5. What else may have helped you following treatment?
6. Please describe the most difficult time for you since ending treatment and why?
 - Prompts: What got you through this?
7. Some individuals consider themselves to be resilient, can you tell me what this means to you?
 - Prompts: Do you consider yourself resilient?
What has helped you become resilient?
What has made it difficult for you to be resilient?
How has this been affected by your cancer experience?
8. On a scale of 1 – 10 (with 10 being excellent) how would you rate your current mental health?
9. What three factors have helped you the most to recover following treatment?
10. What three factors have resulted in recovery being more difficult for you?
11. What advice would you give to a cancer survivor who has just completed treatment that would help their recovery process?

Appendix H

Interview Thankyou Letter



DATE

JOONDALUP CAMPUS
270 Joondalup Drive, Joondalup
Western Australia 6027
☎ 134 328
www.ecu.edu.au
ABN 54 361 485 361 CRICOS IPC 00279B

ADDRESS

Dear _____

Thank you for taking the time to participate in my research investigating resilience among haematological cancer survivors. Your input is important, as it will allow us to better understand how you have coped since diagnosis. This may help to identify those survivors at risk of developing psychological illness such as depression and anxiety. This will also contribute to the body of knowledge among cancer survivors and better inform healthcare professionals of patients' needs following haematological cancer treatment.

Over the past few weeks if you have experienced any distress, which may be as a result of participation in this research, please contact one of the counselling services listed on your information sheet.

Thank you for your time and consideration. It is with your assistance that our research can be successful. I wish you all the best in the future.

Yours sincerely,

Kate Gallager

School of Psychology, Edith Cowan University
kgallage@our.ecu.edu.au

Appendix IA – E
Pilot Questionnaire Scales

Multidimensional Scale of Perceived Social Support
(Zimet, Dahlem, Zimet, & Farley, 1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement

Circle the “1” if you Very Strongly Disagree

Circle the “2” if you Strongly Disagree

Circle the “3” if you Mildly Disagree

Circle the “4” if you are Neutral

Circle the “5” if you Mildly Agree

Circle the “6” if you Strongly Agree

Circle the “7” if you Very Strongly Agree

- | | | | | | | | | | |
|-----|---|---|---|---|---|---|---|---|-----|
| 1. | There is a special person who is around when I am in need | 1 | 2 | 3 | 4 | 5 | 6 | 7 | SO |
| 2. | There is a special person with whom I can share my joys and sorrows | 1 | 2 | 3 | 4 | 5 | 6 | 7 | SO |
| 3. | My family really tries to help me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Fam |
| 4. | I get the emotional help and support I need from my family | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Fam |
| 5. | I have a special person who is a real source of comfort to me | 1 | 2 | 3 | 4 | 5 | 6 | 7 | SO |
| 6. | My friends really try to help me | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Fri |
| 7. | I can count on my friends when things go wrong | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Fri |
| 8. | I can talk about my problems with my family | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Fam |
| 9. | I have friends with whom I can share my joys and sorrows | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Fri |
| 10. | There is a special person in my life who cares about my feelings | 1 | 2 | 3 | 4 | 5 | 6 | 7 | SO |
| 11. | My family is willing to help me make decisions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Fam |
| 12. | I can talk about my problems with my friends | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Fri |

The items tended to divide into factor groups relating to the social support, namely family (Fam), friends (Fri) or significant other (SO).

Appendix IB

Brief COPE Scale (Carver, 1997)

These items deal with ways you've been coping with the stress of surviving the diagnosis and treatment for haematological cancer. There are many ways to try to deal with problems. These items ask what you've been doing to cope. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with your experiences following haematological cancer treatment. Each item says something about a particular way of coping. We want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not – just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

The rating scale is as follows:

- 1 I haven't been doing this at all
 - 2 I've been doing this a little bit
 - 3 I've been doing this a medium amount
 - 4 I've been doing this a lot
-

I've been turning to work or other activities to take my mind off things	1	2	3	4
I've been concentrating my efforts on doing something about the situation I'm in	1	2	3	4
I've been saying to myself "this isn't real."	1	2	3	4
I've been using alcohol or other drugs to make myself feel better	1	2	3	4
I've been getting emotional support from others	1	2	3	4
I've been giving up trying to deal with it	1	2	3	4
I've been taking action to try and make the situation better	1	2	3	4
I've been refusing to believe that it has happened	1	2	3	4
I've been saying things to let my unpleasant feelings escape	1	2	3	4
I've been getting help and advice from other people	1	2	3	4
I've been using alcohol or other drugs to help me get through it	1	2	3	4
I've been trying to see it in a different light, to make it seem more positive	1	2	3	4
I've been criticising myself	1	2	3	4

I've been trying to come up with a strategy about what to do	1	2	3	4
I've been getting comfort and understanding from someone	1	2	3	4
I've been giving up the attempt to cope	1	2	3	4
I've been looking for something good in what is happening	1	2	3	4
I've been making jokes about it	1	2	3	4
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping or shopping	1	2	3	4
I've been accepting the reality of the fact that it has happened	1	2	3	4
I've been expressing my negative feelings	1	2	3	4
I've been trying to find comfort in my religion or spiritual beliefs	1	2	3	4
I've been trying to get advice or help from other people about what to do	1	2	3	4
I've been learning to live with it	1	2	3	4
I've been thinking hard about what steps to take	1	2	3	4
I've been blaming myself for things that happened	1	2	3	4
I've been praying or meditating	1	2	3	4
I've been making fun of the situation	1	2	3	4

Appendix IC

Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) (Scale was purchased as per copyright guidelines)

Clinicians are aware that emotions play an important part in most illnesses. This questionnaire is designed to help better understand how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

I feel tense or 'wound up

Most of the time
A lot of the time
From time to time, occasionally
Not at all

I still enjoy the things I used to enjoy

Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling as if something awful is about to happen

Very definitely and quite badly
Yes, but not too badly

A little but it doesn't worry me
Not at all

I can laugh and see the funny side of things

As much as I always could
Not quite so much now
Definitely not so much now
Not at all

Worrying thoughts go through my mind

A great deal of the time
A lot of the time
Not too often
Very little

I feel as if I am slowed down

Nearly all the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach

Not at all
Occasionally
Quite often
Very often

I have lost interest appearance in my appearance

Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

I feel restless as if I have to be on the move

Very much indeed
Quite a lot
Not very much
Not at all

I look forward with enjoyment to things

As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

I feel cheerful

Never
Not often
Sometimes
Most of the time

I can sit at ease and feel relaxed

Definitely
Usually
Not at all
Not at all

I get sudden feelings of panic

Very often indeed
Quite often
Not very often
Not at all

**I can enjoy a good book or radio
or Television program**

Often
Sometimes
Not often
Very seldom

Appendix ID

Resilience Scale for Adults (Hjemdal & Friborg)
(Scale was used with author permission)

Instructions: Please think about how you usually are, or how you have been the last month, how you think and feel about yourself, and about important people surrounding you. Please cross the option box that is closest to the end statement that describes you best.

Example

I frequently worry about my cancer returning

NEVER ALWAYS

By crossing the 6th box along, you are suggesting that you think about your cancer returning most of the time

If you were to cross the 2nd box along, you would be suggesting that you rarely worry about you cancer returning. If you were to cross the 4th box along, you would be suggesting that you feel neutral about how often you worry.

1. My plans for the future are	Difficult to accomplish	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Possible to accomplish
2. When something unforeseen happens	I always find a solution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I often feel bewildered
3. My family's understanding of what is important in life is	Quite different than mine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very similar to mine
4. I feel that my future looks	Very promising	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Uncertain
5. My future goals	I know how to accomplish	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I am unsure how to accomplish
6. I can discuss personal issues with	No one	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Friends/family members
7. I feel	Very happy with my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very unhappy with my family
8. I enjoy being	Together with other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	By myself
9. Those who are good at encouraging me are	Some close friends/family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	No where
10. The bonds among my friends is	Weak	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Strong
11. My personal problems	Are unsolvable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I know how to solve
12. When a family member experiences a crisis/emergency	I am informed right away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	It takes quite a while before I am told

13. My family is characterised by	Disconnection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Healthy coherence
14. To be flexible in social settings	Is not important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Is really important to me
15. I get support from	Friends/family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	No one
16. In difficult periods my family	Keeps a positive outlook on the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Views the future as gloomy
17. My abilities	I strongly believe in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I am uncertain about
18. My judgment and decisions	I often doubt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I trust completely
19. New friendships are something	I make easily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I have difficulty making
20. When needed, I have	No one who can help me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Always someone who can help me
21. I am at my best when I	Have a clear goal to strive for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Can take one day at a time
22. Meeting new people is	Difficult for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Something I am good at
23. When I am with others	I easily laugh	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I seldom laugh
24. When I start on new projects/things	I rarely plan ahead, just get on with it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I prefer to have a thorough plan
25. Facing other people, our family acts	Unsupportive of one another	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Loyal towards one another
26. For me, thinking of good topics for conversation is	Difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Easy
27. My close friends/family members	Appreciate my qualities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Dislike my qualities
28. I am good at	Organising my time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Wasting my time
29. In my family we like to	Do things on our own	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Do things together
30. Rules and regular routines	Are absent in my everyday life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Simplify my everyday life
31. In difficult periods I have a tendency to	View everything gloomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Find something good that help me thrive/ Prosper

32. My goals for the future are	Unclear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Well thought through
33. Events in my life that I cannot influence	I manage to come to terms with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Are a constant source of worry/ concern

Appendix J

Invitation to Participate in Pilot Study



JOONDALUP CAMPUS
270 Joondalup Drive, Joondalup
Western Australia 6027
☎ 134 328

www.ecu.edu.au

ABN 54 361 485 361 CRICOS IPC 00279B

Dear Potential Participant

I am conducting a **pilot study** as part of a PhD that aims to explore the **resilience** shown by cancer survivors. I am hoping you would be able to help by participating. It would involve you answering two 15 min surveys. The first now and the next one in two weeks, this is to make sure it is good enough to use. The results of this pilot test are important as they will form the basis for a larger study.

I have included the link below if you are able to assist me.

Importantly, you will also see a question asking you to make up a **personal ID** (on the first page when you open the survey). This is because I will be asking you to take the survey again in two weeks and will need to match the surveys.

Survey link: to click or (copy and paste):

https://ecuai.qualtrics.com/SE/?SID=SV_6YGrABsDXFVxY2N

The study has been approved by the Human Research Ethics Committee at ECU.

If you have any queries regarding this research or require further information, please don't hesitate to contact me (details below), or my supervisors, Professor Ken Greenwood [k.greenwood@ecu.edu.au] and Professor Anne Wilkinson [anne.wilkinson@ecu.edu.au]. Alternatively, if you would like to speak with an independent person, please contact the ECU Research Ethics Officer, Kim Gifkins on (08) 6304 2170.

Thanking you in advance for your consideration.

Kate Gallager
(School of Psychology, Edith Cowan University)
kgallage@our.ecu.edu.au

Appendix K

Final Survey Information and Consent



JOONDALUP CAMPUS

270 Joondalup Drive, Joondalup
Western Australia 6027
☎ 134 328

www.ecu.edu.au

ABN 54 361 485 361 CRICOS IPC 00279B

Thank you for your interest. My name is Kate Gallagher and I am currently completing a PhD in Psychology at Edith Cowan University (ECU) in Perth, Western Australia. I am writing to invite you to participate in my thesis, which has been approved by the Human Research Ethics Committee at ECU.

I am conducting research that aims to explore the resilience shown by haematological (i.e., blood and lymph node) cancer survivors. **I hope this research will identify what was most or least helpful in dealing with your illness following your diagnosis.** It is expected that this information will assist others who face similar circumstances. All information will remain confidential. Results from this project may be shared in conferences or publications, but no participants will be identified.

If you meet the following criteria I would like to invite you to participate in this valuable research:

- over 18 years of age,
- English speaking and
- diagnosed with haematological cancer (i.e., Leukaemia, Lymphoma, Myeloma)

To be involved, you will be asked to complete an online survey by copying and pasting the online link provided below:

https://ecuau.qualtrics.com/SE/?SID=SV_8CgEblKwPxMgUpT

If you would like more information prior to proceeding, please feel free to contact either myself or my supervisors. Alternatively, if you have any concerns or complaints about the research and wish to talk to an independent person you may contact the ECU Research Ethics Officer, Kim Gifkins by email research.ethics@ecu.edu.au

It is not expected that you will experience any distress as a result of completing this survey. However, if you experience any discomfort, I encourage you to contact your local counselling and support services. If you reside in Australia these are listed below.

<i>Leukaemia Foundation</i>	1800 620 420 (Free call)
<i>Cancer Council Helpline</i>	13 11 20
<i>Lifeline WA</i>	13 11 14 (available 7 days a week, 24 hours)

Continued:

INFORMED CONSENT

I understand that:

- * Participation in this study will involve completion of an on-line survey
- * My responses will be recorded electronically through the Qualtrics Survey tool
- * I have read the information and understand the nature and purpose of the study
- * I am aware that the information obtained from the survey will form the basis for a publishable report.
- * The researcher will secure all information relating to my responses whilst the study is ongoing.
- * At the completion of the research project, all survey responses will be stored by ECU for a period of seven years.
- * I may cease to participate at any time during the on-line survey.

In completing the survey, it will be assumed that you meet the necessary criteria and have provided consent to participant in the research.

- I understand and accept the conditions
- I do not accept

Thank you for your time and consideration, I look forward to your participation.

Kate Gallagher

Principle Researcher

Kate Gallagher [PhD Candidate School of Psychology and Social Science ECU]

Email: kgallage@our.ecu.edu.au or katherine.gallager@bigpond.com

Supervisors:

Professor Ken Greenwood, k.greenwood@ecu.edu.au

Professor Anne Wilkinson, anne.wilkinson@ecu.edu.au

Appendix L

Final Survey Questionnaire

Thank you for your assistance.

My name is Kate Gallager and I am currently completing a PhD in Psychology at Edith Cowan University (ECU) in Perth, Western Australia. I am conducting research that aims to explore the resilience shown by haematological (i.e., blood and lymph node) cancer survivors. **I hope this research will identify what was most or least helpful in dealing with your illness following your diagnosis.** It is expected that this information will assist others who face similar circumstances.

If you have previously been diagnosed with haematological cancer, are over 18 years of age and English speaking, I would like to invite you to participate in this study, which has been approved by the Human Research Ethics Committee at ECU. Participation is purely voluntary and all information provided by you is strictly confidential, only the researcher and supervisors will have access to it. However, the results from this project may be shared in conferences or publications, but no participants will be identified.

If you would like more information prior to proceeding, please feel free to contact either myself, or my supervisors. Alternatively, if you have any concerns or complaints about the research and wish to talk to an independent person you may contact the ECU Research Ethics Officer, Kim Gifkins by email research.ethics@ecu.edu.au

Kate Gallager

PhD Candidate

School of Psychology and Social Science ECU

Mb..... or kgallage@our.ecu.edu.au or

Supervisors:

Professor Ken Greenwood, [08 63045979](tel:0863045979)

Professor Anne Wilkinson, 08 63043450

It is not expected that you will experience any distress as a result of completing this survey. However, if you experience any discomfort, I encourage you to contact your local counselling and support services. If you reside in Australia these are listed below.

Leukaemia Foundation 1800 620 420 (Free call)

Cancer Council Helpline 13 11 20

Lifeline WA 13 11 14 (available 7 days a week, 24 hours)

INFORMED CONSENT

I understand that:

- * Participation in this study will involve completion of an on-line survey
- * My responses will be recorded electronically through the Qualtrics Survey tool
- * I have read the information and understand the nature and purpose of the study.
- * I am aware that the information obtained from the survey will form the basis for a publishable report.
- * The researcher will secure all information relating to my responses whilst the study is ongoing.
- * At the completion of the research project, all survey responses will be stored by ECU for a period of seven years.
- * I may cease to participate at any time during the on-line survey.

In completing the survey, it will be assumed that you meet the necessary criteria and have provided consent to participant in the research.

- I understand and accept the conditions
- I do not accept

If I do not accept Is Selected, Then Skip To End of Survey

Q1.2 INSTRUCTIONS FOR COMPLETING THE SURVEY Below are a series of demographic questions and statements relating to haematological cancer. Each question requires a response. Your progress through the survey is indicated by the bar at the bottom of each page. The answers to most questions are in the form of multiple choices or a scale. To answer these questions you need to select the option that best represents your level of agreement. You may save a partially completed survey to continue later, but you may only submit one completed survey. Thanking you in advance for taking part. Please click on the >> arrow below to begin.

2.1 Are you 18 years of age or over?

- Yes
- No

If No Is Selected, Then Skip To End of Survey

Q2.2 What is your age (in years)

Q2.3 Are you?

- Male
- Female

Q2.4 What was your haematological cancer diagnosis?

- Hodgkin Lymphoma/Hodgkins Disease
- Non-Hodgkins Lymphoma (NHL)
- Acute Myeloid Leukaemia (AML)
- Acute Lymphoblastic Leukaemia (ALL)
- Chronic Myeloid Leukaemia (CML)
- Chronic Lymphocytic Leukaemia (CLL)
- Multiple Myeloma
- Other - Please specify

Q2.5 What type of treatment did you/do you require? (please select those applicable)

- Radiotherapy
- Chemotherapy
- Oral Medication
- Stem cell transplant
- Bone marrow transplant
- N/A - No treatment was required
- Other - please specify

Q2.6 How long ago were you diagnosed with cancer (in years)?

Q2.7 Which scenario best describes your current treatment regime

- I have completed treatment for my cancer (If so how many years ago?)
- N/A - I did not require active treatment
- I am currently undergoing active treatment (which WILL NOT continue indefinitely)
- My treatment is ongoing (i.e., at this point in time I will always need to take some form of medication)
- Other - please specify

Q2.8 Have you experienced a cancer relapse?

- Yes
- No

Q2.9 Have you since been diagnosed with a secondary cancer?

- If Yes - please specify cancer type
- No

Q2.10 What is your ethnic background?

- White; (including Caucasian, Anglo, European and others - NOT HISPANIC)
- Hispanic or Latino; (including Central American, Mexican American and others)
- Asian; (including Chinese, Japanese, Korean and others)
- Middle Eastern
- Black; including African American, African, African-European, African Australian
- Aboriginal
- Torres Strait Islander
- Other - Please specify

Q2.11 What is the main language spoken at home?

- English
- Other - please specify

Q2.12 Which best describes your religious beliefs?

- Non-practising
- Christian (including Uniting, Anglican, Baptist, Catholic and others)
- Buddhist
- Hindu
- Islamic
- Jewish
- Other - please specify

Q2.13 Where do you live?

- Postal Code/Zip code
- State
- City/Town
- Country

Q2.14 What area best describes where you live?

- Urban
- Rural/Country

Q2.15 What type of relationship do you have?

- Single
- Married
- De-facto/Partnered
- Widowed
- Separated
- Other - please specify

Q2.16 How many children do you have?

Q2.17 Are you MAINLY:

- Employed full-time
- Employed part-time
- Unemployed
- A student
- Retired
- A pensioner or on security benefits
- A homemaker
- Self-employed - please specify part or full-time
- Other - please specify

Q2.18 What is the highest level of education you completed?

- Year 10-11/ prior to final school year
- Year 12 / VCE / HSC/ Graduated Final school year
- Tertiary diploma or trade certificate / TAFE
- Tertiary Degree
- Post graduate degree
- Word of mouth (i.e. family or friends)
- Social Media (i.e., Facebook)
- Email
- Leukaemia Foundation
- Mailed Letter
- Other - please specify

Q3 These items deal with ways you've GENERALLY coped with stress since being diagnosed and/or treated for haematological cancer. There are many ways to deal with cancer-related stress and each item says something about a particular way of coping. Cancer survivors deal with stress in different ways, but I would like to know to what extent you GENERALLY do what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not - just whether or not you're doing it. Try to rate each item separately in your mind from the others. Please make your answers as true FOR YOU as you can.

	Generally don't (1)	Generally a little amount (2)	Generally a medium amount (3)	Generally a lot (4)
I turn to work or other activities to take my mind off things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I concentrate my efforts on doing something about the situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I say to myself "this isn't real"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I use alcohol or other drugs to make myself feel better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get emotional support from others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been giving up trying to deal with it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I take action to try to make the situation better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I refuse to believe that it has happened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I say things to let my unpleasant feelings escape	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get help and advice from other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I use alcohol or drugs to help me get through it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to see things in a different light, to make them seem more positive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I criticize myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to come up with a strategy about what to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get comfort and understanding from someone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been giving up the attempt to cope	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I look for something good in what's happening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I make jokes about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do something to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

think about things, such as going to movies, watching TV, reading, daydreaming, sleeping or shopping				
I accept the reality of the fact that it has happened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I express my negative feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to find comfort in my religious or spiritual beliefs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to get advice or help from other people about what to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I learn to live with it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think hard about what steps to take	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I blame myself for the things that happened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I pray or meditate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I make fun of the situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q5 These questions investigate the way in which people are resilient. Please think about how you usually are or have been in the last month how you think and feel about yourself, and about important people surrounding you. Please the option that is closest to the end statement that describes you best.

1. My plans for the future are	Difficult to accomplish	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Possible to accomplish
2. When something unforeseen happens	I always find a solution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I often feel bewildered
3. My family's understanding of what is important in life is	Quite different than mine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very similar to mine
4. I feel that my future looks	Very promising	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Uncertain
5. My future goals	I know how to accomplish	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I am unsure how to accomplish
6. I can discuss personal issues with	No one	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Friends/family members
7. I feel	Very happy with my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very unhappy with my family
8. I enjoy being	Together with other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	By myself
9. Those who are good at encouraging me are	Some close friends/family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	No where
10. The bonds among my friends is	Weak	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Strong
11. My personal problems	Are unsolvable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I know how to solve
12. When a family member experiences a crisis/emergency	I am informed right away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	It takes quite a while before I am told
13. My family is characterised by	Disconnection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Healthy coherence
14. To be flexible in social settings	Is not important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Is really important to me
15. I get support from	Friends/family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	No one
16. In difficult periods my family	Keeps a positive outlook on the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Views the future as gloomy
17. My abilities	I strongly believe in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I am uncertain about
18. My judgment and decisions	I often doubt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I trust completely
19. New friendships are something	I make easily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I have difficulty making

20. When needed, I have	No one who can help me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Always someone who can help me
21. I am at my best when I	Have a clear goal to strive for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Can take one day at a time
22. Meeting new people is	Difficult for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Something I am good at
23. When I am with others	I easily laugh	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I seldom laugh
24. When I start on new projects/things	I rarely plan ahead, just get on with it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	I prefer to have a thorough plan
25. Facing other people, our family acts	Unsupportive of one another	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Loyal towards one another
26. For me, thinking of good topics for conversation is	Difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Easy
27. My close friends/family members	Appreciate my qualities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Dislike my qualities
28. I am good at	Organising my time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Wasting my time
29. In my family we like to	Do things on our own	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Do things together
30. Rules and regular routines	Are absent in my everyday life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Simplify my everyday life
31. In difficult periods I have a tendency to	View everything gloomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Find something good that help me thrive/ Prosper
32. My goals for the future are	Unclear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Well thought through
33. Events in my life that I cannot influence	I manage to come to terms with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Are a constant source of worry/ concern

Q6 INSTRUCTIONS: The next set of questions relate to how you feel. Please read each question and select the option that best describes how YOU have been feeling in the past week. To access the questions please click on the arrow >> (on the right side) below

Q6.1 I feel tense or wound up

- Most of the time (3)
- A lot of the time (2)
- From time to time, occasionally (1)
- Not at all (0)

Q6.2 I still enjoy the things I used to enjoy

- Definitely as much (0)
- Not quite so much (1)
- Only a little (2)
- Hardly at all (3)

Q6.3 I get a sort of frightened feeling as if something awful is about to happen

- Very definitely and quite badly (3)
- Yes, but not too badly (2)
- A little, but it doesn't worry me (1)
- Not at all (0)

Q6.4 I can laugh and see the funny side of things

- As much as I always could (0)
- Not quite so much now (1)
- Definitely not so much now (2)
- Not at all (3)

Q6.5 Worrying thoughts go through my mind

- A great deal of the time (3)
- A lot of the time (2)
- Not too often (1)
- Very little (0)

Q6.6 I feel cheerful

- Never (3)
- Not often (2)
- Sometimes (1)
- Most of the time (0)

Q6.7 I can sit at ease and feel relaxed

- Definitely (0)
- Usually (1)
- Not often (2)
- Not at all (3)

Q6.8 I feel as if I am slowed down

- Nearly all the time (3)
- Very often (2)
- Sometimes (1)
- Not at all (0)

Q6.9 I get a sort of frightened feeling like butterflies in the stomach

- Not at all (0)
- Occasionally (1)
- Quite often (2)
- Very often (3)

Q6.10 I have lost interest in my appearance

- Definitely (3)
- I don't take as much care as I should (2)
- I may not take quite as much care (1)
- I take just as much care as ever (0)

Q6.11 I feel restless as if I have to be on the move

- Very much indeed (3)
- Quite a lot (2)
- Not very much (1)
- Not at all (0)

Q6.12 I look forward with enjoyment to things

- As much as I ever did (0)
- Rather less than I used to (1)
- Definitely less than I used to (2)
- Hardly at all (3)

Q6.13 I get sudden feels of panic

- Very often indeed (3)
- Quite often (2)
- Not very often (1)
- Not at all (0)

Q6.14 I can enjoy a good book or radio or television programme

- Often (0)
- Sometimes (1)
- Not often (2)
- Very seldom (3)

Q8 This final section allows you the opportunity to provide more details on your personal coping experience. Thank you for taking the time to participate. To access the questions please click on the >> arrow (on the right side below).

Q8.1 Where did you receive the MOST HELPFUL cancer related INFORMATION? Please select the most appropriate answer below.

- Medical Specialist (i.e., oncologist, haematologist and others) (1)
- Nurses (2)
- Community support group (i.e., Cancer council, leukaemia foundation and others) (3)
- Internet (i.e., Facebook, social media) (4)
- General Practitioner (5)
- Other cancer survivors (7)
- Psychologist/Counsellor (8)
- Other - please specify (9)

Q8.2 In your experience who in your CLINICAL TEAM has HELPED OR SUPPORTED you the MOST following your cancer diagnosis? (i.e. specialist, nurses, psychologist, general practitioner, pharmacist or others). Please provide details below.

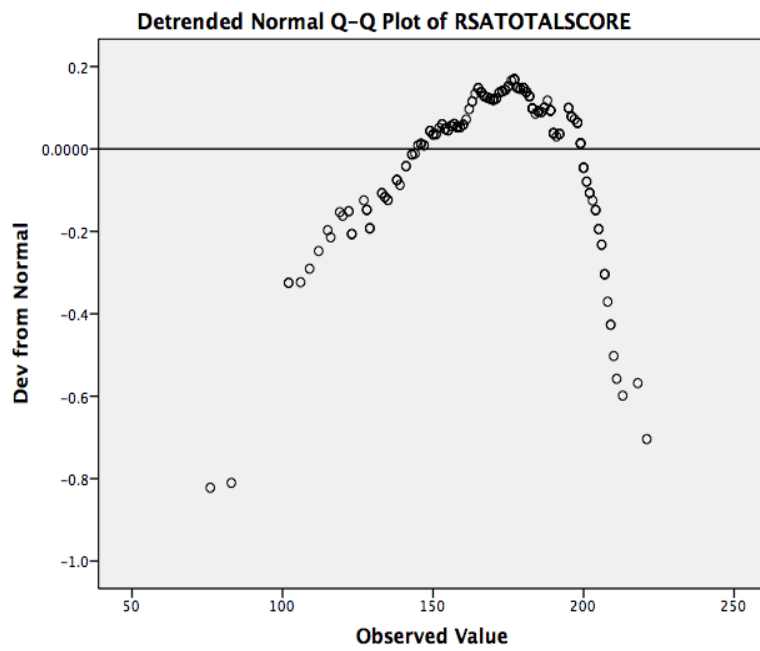
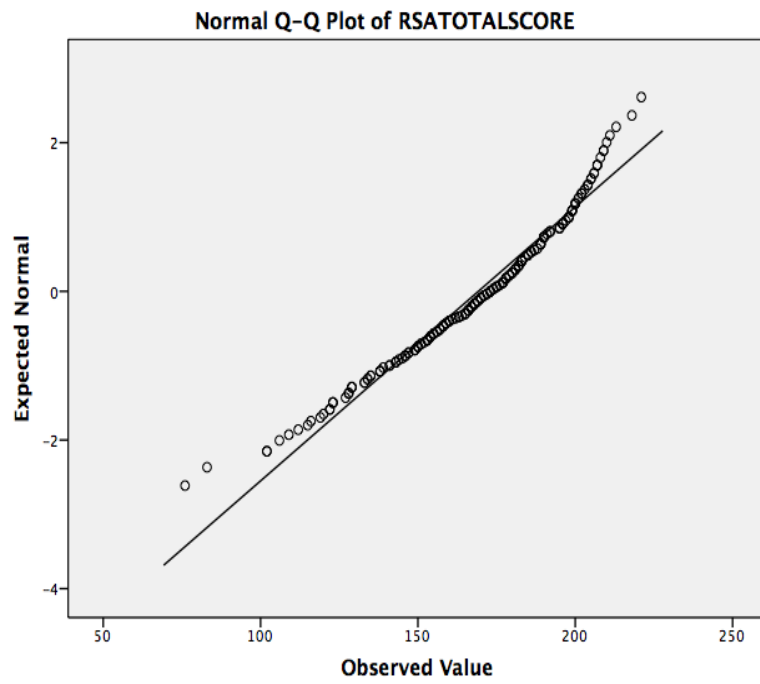
Q8.3 If applicable, who in your clinical team was the LEAST supportive? Please provide anonymous details.

Q8.4 Based on your personal experience is there anything else you would like to share that may assist others to cope when facing a similar situation. Please provide details below.

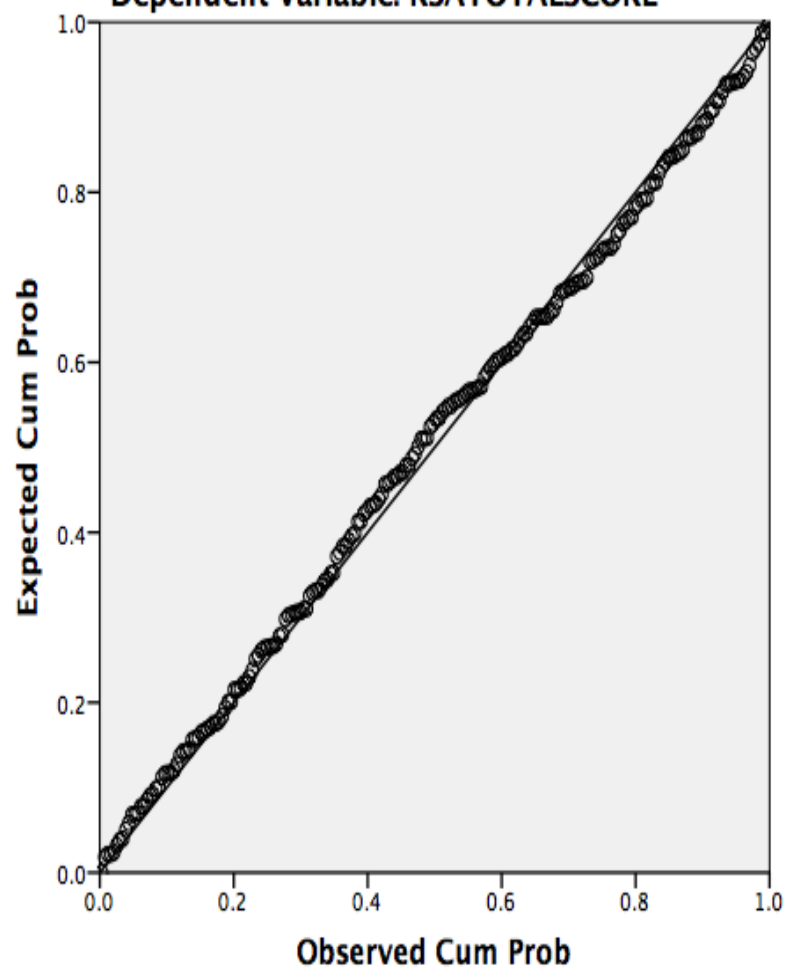
YOUR PERSONAL EXPERIENCE IS IMPORTANT!! THANK YOU FOR YOUR PARTICIPATION 😊😊

Appendix M

Normal Q-Q (Quantile-Quantile) and Detrended Normal Q-Q Plot of Normal Distribution of Data

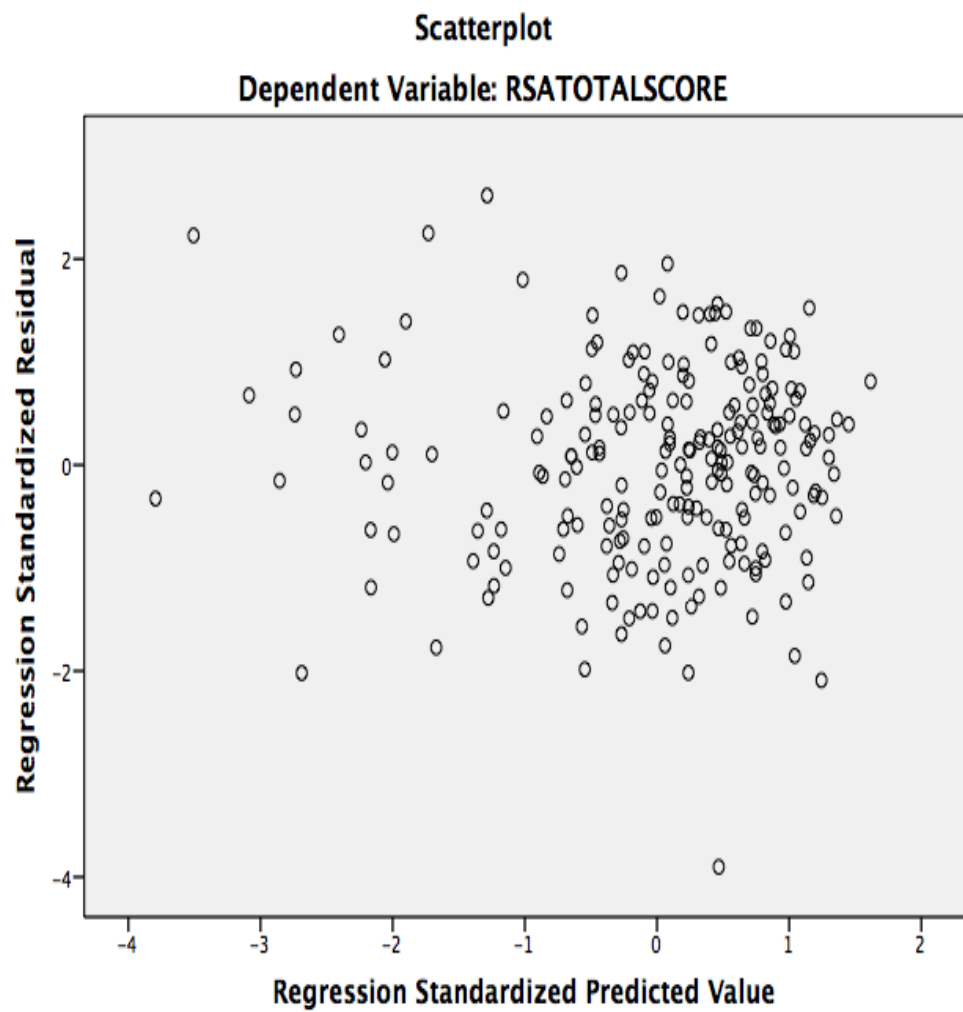


Appendix N

**Normal Probability Plot of Standardised Residuals for Predicting
Resilience among HC survivors****Normal P-P Plot of Regression Standardized Residual
Dependent Variable: RSATOTALSCORE**

Appendix O

**Scatterplots of Standardised Residuals and Standardised Predicted Values
for Predicting Resilience among HC survivors**



Appendix P

Non-Parametric vs Parametric Tests Comparing Demographic Outcomes Among HC Survivors.

Table 2A

Non-Parametric and Parametric Tests Investigating Differences in Resilience, Depression and Anxiety Across Years Since Diagnosis

	Mann-Whitney <i>U</i> Test				Independent <i>t</i> -test			
	STS	LTS	STS vs. LTS		STS	LTS	STS vs. LTS	
	<i>Mean Rank</i>	<i>Mean Rank</i>	χ^2	<i>p</i>	<i>M</i>	<i>M</i>	<i>t</i>	<i>p</i>
Time Since Diagnosis								
Resilience	102.44	120.56	-2.10	<.05	166.32	172.09	-1.60	ns
Depression	122.37	100.63	-2.67	<.05	4.41	3.47	2.15	ns
Anxiety	120.37	102.63	-2.07	<.05	7.21	6.23	1.90	ns

Note. STS = Short-term survivors (< 5 years); LTS = Long-term survivors (6 + years); ns = Non-significant

Table 2B

Non-Parametric and Parametric Tests Investigating Differences in Resilience, Depression and Anxiety Across Gender

	Mann-Whitney <i>U</i> Test				Independent <i>t</i> -test			
	Male	Female	Male vs. Female		Male	Female	Male vs. Female	
	<i>Mean Rank</i>	<i>Mean Rank</i>	χ^2	<i>p</i>	<i>M</i>	<i>M</i>	<i>t</i>	<i>p</i>
Resilience	112.12	111.06	-0.13	ns	170.36	168.50	0.49	ns
Depression	105.18	115.35	-1.15	ns	3.68	4.09	-0.92	ns
Anxiety	104.85	115.85	-1.30	ns	6.11	7.09	-1.83	ns

Note. Mdn = ns = Non-significant

Table 2C

Non-Parametric and Parametric Tests Investigating Differences in Resilience, Depression and Anxiety Across Age

	Kruskal-Wallis Test			One-way ANOVA		
	YA vs. MA vs. OA			YA vs. MA vs. OA		
	<i>Mean Rank</i>	χ^2	<i>p</i>	<i>M</i>	<i>t</i>	<i>p</i>
Resilience	118.13 vs. 106.41 vs. 115.26	1.32	ns	170.25 vs. 167.63 vs. 169.20	0.34	ns
Depression	100.64 vs. 117.12 vs. 108.94	2.00	ns	3.86 vs. 4.19 vs. 3.64	0.66	ns
Anxiety	133.68 vs. 113.90 vs. 98.34	7.86	<.05	8.03 vs. 6.88 vs. 5.91	3.96	<.05

Note. YA = Young Adult (18–40 years); MA = Middle Age Adult (41-60 years); OA = Older Adult (61 + years);
ns = Non-significant

Appendix Q

Survey Participant's Advice to Newly Diagnosed Individuals

Participant Number	Advice
	<ol style="list-style-type: none"> 1. Do not see myself as a patient but a cancer client, therefore be part of decision making - being educated and informed on condition - be your own wellness advocate 2. Spiritual Beliefs 3. For me research is a good tool and also finding a support group. It's these people who really understand you and what you are going through! 4. Find a support group. If you're not happy with your GP or specialist find a new one this is a long-term relationship and it has to work for you. 5. Go to support groups. 6. Take your time to absorb all the information 7. Make holiday plans and get away. 8. Stay away from the Internet for information until you have spoken to a specialist (oncologist, haematologist, etc.) as the amount of information available on the Web can be overwhelming and quite scary. Each person's journey through this illness is different and with new therapies, prognoses are so much better than some websites make it appear. 9. Keep a positive attitude, it works wonders. Don't concentrate on side-effects or problems more than needed. Do as many of the things that you did before diagnosis to keep a normal life. 11 Looking back, although I didn't believe it at the time, I was in denial. I was going through some pretty significant side-effects and drugs to try and combat them, and consequently was quite detrimental to my health. I pushed myself to do things, so that it looked like I was coping and wasn't going to give in. I was very fortunate that I had a very supportive boss and staff who helped carry me as I had a very demanding job. At lunchtime, I would sit in my car and have a 20 minute power nap if I didn't have meetings so that I didn't go to sleep at my desk! Having the power nap was really beneficial in coping. The first 2 years were the hardest. Having been a nurse, I was very pedantic about researching and discovering as much as I could about my cancer and o this end, I spent hours on the internet, CML groups getting support and then in turn giving support. I also do not like not being in control and have a mandate about being my own advocate and ensuring that I am getting best practice care and feel confident in my medical team that we are on the "same" page. When my GP would refer me to another specialist for a pre existing illness, he would say to me " don't expect Dr X to be touchy feely and sit and talk to you", he knew me so well. Whether it's family, friend or a fellow cancer patient, it is important you have someone you can talk to and express your feelings , fears, frustrations etc. without feeling like you are whinging all the time and believe me I have done more than that! I used to feel guilty about it, especially when there is always someone worse off and I wasn't having "conventional" chemo, so didn't look sick as such, except that my whole appearance changed dramatically in the first year due to the drug I was on and among things, couldn't wear makeup any more, put on weight and felt bloated all the time, was fatigued, felt sick and was hard to enjoy a lot of things. I was lucky, I was able to change drugs and with the new drug felt a new person 12 Learn ALL you can about yourself and your medications. Don't take any medication you don't absolutely have to have to live. Eat healthy, exercise, stay hydrated, don't depend too much on others, and look inward for strength. If you're a person of faith talk to the creator on a regular basis. 15 Nothing I can think of. I was fortunate to have my CML diagnosed early so did not have the problems many others have had. 16 Cowboy Up as we say. Don't feel sorry for yourself. Deal with it. Your attitude is your strongest medicine. 17 There is always something good/positive to find in ANY situation. Your attitude can be your best ally or worst enemy.

- 18 While I try to laugh and find funny things to keep me occupied, I have a near constant anger that makes me more cynical. In fact, I'm seriously angry and have no one or thing at which to direct the anger (which makes it even more frustrating). Any semblance of religious belief I may have had before diagnosis is gone. CML is my second bout with cancer in addition to a neuromuscular disease. When people tell me that everything happens for a reason, I always hit back with something like, "Really?, find me a *ing reason for this." I really find that I'm happier when I don't have to deal with other people and their stupid platitudes.
- 21 When first diagnosed, my mantra was one day at a time; not looking too far ahead. I read everything I could and saw the best Dr. for my cml (Dr. Druker) to ease my worry. I worked hard at staying positive, not that it will change the outcome of things, it will make you feel much better. I still do this 10 years later, but focus on doing things I enjoy doing, spending time with family, doing yoga and meditation and exercise daily. These help control worry and negative thoughts
- 22 Trust your doctor. Follow your medicine routine. Research you condition and various treatments - knowledge is power. Be positive about your treatment outcomes. Join social media groups with similar cancers. Be an example to others. Share your progress and failures. Trust your own judgement and decisions. Live for the day.
- 23 Don't blame every ache and pain on your cancer or meds.
- 26 I wish there were more support groups locally
- 27 Believe in your treatment. Listen to your body and take time out when you need it, no matter when or where. Don't listen to negative stories.
- 30 It has been much, much harder to deal with my blood cancer than with my previous tumour based cancer which had a very clear end of treatment
- 35 People with same problem are the safest sort of support
- 36 Doctors don't always recognize symptoms as side-effects of medicines. Trust your own instincts and fight for the answers.
- 38 Positive mental attitude is the key to coping. You can't do anything about your diagnosis so don't waste your life feeling sorry for yourself - life it to the full!! Also support groups are great - you are never alone
- 42 Make your decision on the outcome you want and be a part of your medical solution.
- 43 Stay strong, retain a positive attitude, always look on the bright side, live your life to the full, retain your sense of humour, another day is a bonus in your life
- 47 Join a social media group. I joined the Chronic Myloid Leukaemia group and talking to people with the same condition as me has helped immensely
- 49 For me having all the information right from the start. I got all info from the Internet initially and got tremendous info and support from a website cml.org.uk I then changed Dr's and hospital and now have the best care I could hope for
- 51 You need medical and psychological help when you're told you have a cancer that can't be cut out, blasted or cured! It's a very hard journey and the NHS doesn't factor that into your care programme. As long as you respond to the drugs and your blood count go back to normal then you're ok... In reality, you're far from it.
- 52 Connect with other patients and support groups
- 53 Specialist to be more sympathetic. Told had CML on a Wednesday chemo on Friday! Told go back to work Monday!!! Given leaflet with outdated information and I had 5 years to live!!!!!! No follow up by any nurses or medical professionals!!! Felt completely alone and lost.
- 54 I joined a CML support group on social media which is monitored really well and I found talking to other people in the same situation as me really did help.
- 55 Join a support group asap.
- 56 Medical staff do not take a holistic view of you - they are only interested in treating the problem, they have little consideration for your emotional well-being. Also in my experience they are completely disinterested in any side-effects you experience as long as the treatment is keeping the cancer in check. Specialists also carefully need to consider how they phrase things at consultations to ensure you do not experience unnecessary worry especially when they do not have much experience of your particular type of blood cancer - I would think more of them if they actually admitted they were not sure and needed to liaise with colleagues/centers of excellence rather than trying to bluff their way through things. There have been several occasions when my specialist has asserted

- something contrary to what conversations on the CML Facebook area would seem to indicate other CML sufferers have experienced. The Facebook CML community info usually turns out to be right leaving my specialist trying to justify themselves. I am currently pursuing a change of hospital and am willing to travel any distance to attend a Centre of Excellence for my particular type of blood cancer.
- 57 Remain positive, because life still goes on.
 - 59 Don't be afraid to ask questions. Don't just role over and die. Demand support.
 - 60 For me, CML is a "lonely" disease since I have never personally met anyone with the disease other than on Facebook or the internet. I have no one who can give me advice on coping.
 - 65 Be prepared to go through this primarily alone. In my opinion it is better that way. People don't need to be dragged down by feeling obligated to give a hoot.
 - 66 Easy availability of TKIs must be helpful with competitive price.
 - 68 Having a good doctor makes all the difference. Also have found Facebook a great help in finding out about the illness direct from other sufferers
 - 69 Be prepared for a new normal. It's ok to take time to assimilate to a new lifestyle. The cancer is not all you are.
 - 70 Find a good Psychiatrist and Psychologist as you will need them, but ABOVE ALL. find a GREAT GP one who you can call by her / his first name, one who will not hurry you up as your 20 minute slot is up.....I did mention that all G.P. appointments should be 2 minutes i.e. a DOUBLE ;) things will happen between visits to Haematology / Oncology. Your GP is usually closer and can take the time to go through it with you and help you :) Try to find yourself a "Cancer Buddy, Blood Sister" these are people who will be there for you even just a short you are doing alright is all it takes.... (This person must have a cancer, better still a cancer like yours, the best if it is the same and you are on the same drug combo, same gender and roughly same stage)
 - 71 Everyone's response to their diagnosis is individual and you're entitled to the way YOU feel. It is okay to be sad, it is okay to use black humour, it is okay to cope one day and not the next. The hidden cancer is the hardest- you look well on the outside but inside your body is fighting really hard. Let people know that you're tired, you have bone pain, you feel like poos. If people don't know, they will assume you are fine. CML is not the best cancer to have if you're going to get a cancer. All cancers come with their own level of shittiness!!
 - 72 In the first few months it is just horrific but you just have to get through it with the love and help of your doctors, family, friends and prayer I think I am very lucky as I had a wonderful support group and wanted to survive. Luckily I did survive and now enjoy every single day
 - 74 Stay hopeful and ask yourself what are you doing to improve your situation. We can't always rely on others
 - 75 Maintain a positive attitude. Accept realities of treatment side-effects.
 - 76 Exercise everyday in some way
 - 77 Get all the information you can from reputable sources and reject anything that is not supported by sound evidence. Find a good doctor whom you can trust but also question.
 - 78 I felt guilty that I had to put my partner (x) and child through this I wish I received counselling to make me realise early on that I should not have to feel that way
 - 79 Ensure you surround yourself with family who can support you on an ongoing basis.
 - 80 Ask what you are doing to help yourself and be accountable for your own choices and decisions
 - 81 Keep a sense of humour
 - 82 It is important to give yourself time to process your diagnosis
 - 83 Look after your general health. Take a list of questions to the doctor when you have appts as they are busy and it's easy to forget.
 - 84 I have found meditation to be helpful and knowledge is power
 - 85 Just go with it and don't stress too much!
 - 87 In my situation I did not dwell on the fact that I had cancer, discovered at stage 4. After the initial shock my thoughts and actions were purely related to what was required to battle the cancer and get better for my family. My specialist (Professor Ross Baker) was also a major support; and his straight forward and truthful approach about my situation was very much appreciated and a benefit.

- 91 Remain positive, be kind to yourself, pick your battles and put yourself first during this time. !!
- 92 Keep up your social contacts, your exercise and as many as possible of the activities you pursued prior to diagnosis and treatment. In other words don't allow the disease to define you.
- 93 This one is hard because everyone is different. But you have to fight - and fight hard. But stay positive. And don't get bitter that it was you that got cancer - never ask "Why me?" . That's just wasting your time.
- 94 I have read many people's stories so survival and courage. Connecting with people who have cancer or are in remission is credible and encouraging. So I would offer all options I'd ways to get support outside of family and loved ones so there is multiple options.
- 95 As mine is an indolent cancer -Waldstrom's syndrome- I have had no trouble with coping over the years., but I could offer no advice for anyone with a different cancer .I was supported by my very positive wife until her death recently. Be open about it discuss with family and friends --lots of moral support.
- 96 Accept your diagnosis. Ask as many questions as possible. If you are unhappy with your specialist or their treatment plan ask for a second opinion. Be honest and open with your family, tell them when you get the diagnosis, obviously there will be tears and despair but this passes and their support is invaluable. Tell people that you deal with regularly e.g. friends or work colleagues. I found it much easier if they knew and I didn't have to pretend if I was having a bad time. Accept help! Don't try and answer every message of goodwill, accept them for the expressions of care that they are. Love your family and confide in them - they go on this journey with you and will love you regardless of what happens. Indulge yourself, buy that dress that you like, have that decadent piece of cake. Stop and smell the roses, give yourself time, dream, listen to music, sing, pray, meditate, cuddle the dog or cat, go for a walk, cry, shout or scream - it is your disease and your journey - own it! Believe in yourself and all those caring for you. Try not to listen to those who will try and give you negative advice. It is a tough journey but one you have a good chance of surviving, a positive attitude makes the world of difference. Realise you and your life may never be the same, accept any deficiencies or any ongoing side-effects - you are alive to enjoy the things you thought you would never be able to do.
- 97 Have Faith in a higher Deity .
- 98 If you find a lump go straight away to the doctor-don't forget it, as I did!!!
- 99 Make sure you have a sympathetic specialist who is careful to check condition, and encouraging to persist. Not too keen to tell all the worse things that can develop, but rather encouraging patient to live normally and keeps a careful watching brief.
- 100 I found these questions strange they assume that the experience of cancer was traumatic. I was diagnosed because my wife took me to our Doctor after I was eating very well and still losing weight. After an ultrasound when a lump the size of a fist was found in my abdomen and a sample returned a positive diagnosis I cancelled a holiday to Alaska and started Chemo. I also went to Sydney for radiology. My only problems have been some hyperactivity after prednisone injections after Chemo and nausea the evening after the first radiology treatment. I have never been depressed or concerned at having cancer it just happened to me. There is no use crying over spilt milk. I was a lucky survivor and have since had prostate cancer with a prostatectomy, squamous cell and basal cell carcinomas all of which I have so far survived. If others could be more pragmatic and maybe stoical perhaps they could manage their stresses better. I fear I feel a fraud when I hear how people cope heroically with their cancers mine were not problems for me.
- 101 I held the belief I should just ignore and work through the treatment period, when I realised this was not possible and accepted the fact it was a lot easier. A supportive boss and work colleagues really helped, as did relaxation CD.
- 102 Learn to accept, listen to your specialist, ask questions and get on with life and enjoy as much as possible. It helps if you have a very supportive partner who is an RN and who can explain anything you missed with the specialist.
- 103 Positive attitude is extremely important to recovery.
- 104 Up until you are diagnosed you are going down hill. Once diagnosed you are on the road to recovery. Stay on that road and do not let the procedures no matter how daunting allow you to waiver. Enjoy every carer be it Dr, nurse, family or friends and celebrate every day. People feel better if you let them help in their own way so let them. It is a win win situation. Do not look for the negatives because they are there ready to bring you

- down. You being strong helps other around you feel strong. Do not push yourself to maintain your old routine, let your body rest and get on with healing and fighting. Good luck with your PhD
- 105 Belong to as many support/social groups as you have time for. Keep busy if you are well enough. I was lucky to be able to continue all my activities during and after treatment.
- 106 Always believe in yourself and don't pay too much attention to the negative opinions of others. You are the person with the cancer and you know how you feel better than anyone else. People are generally ignorant when it comes to understanding the different types of some cancers and are of the opinion that once someone is diagnosed then they are as good as dead. Don't let opinions like that get you down and keep a positive attitude. I had no idea how important a positive attitude is until I was diagnosed. It can make the difference between survival and giving up leading to a premature and unnecessary death.
- 108 Being informed of what is happening and why is critical, do not choose to ignore what is happening.
- 109 Keep a positive mind, Don't think the worse...
- 110 Do not listen to negative people, who only see doom and gloom. Have faith in your treating specialist and ask questions.
- 111 talk to others with cancer. I found that solaris care support group were very open and helpful.
- 113 All I can suggest is to seek a support group and talk to other's that are in the same boat.
- 114 1. Joining a support group has been very helpful and supportive.
2. Informing yourself about the condition / treatment options.
3. Taking a holistic approach to your health - treating your whole body / mind (healthy diet / exercise / mindfulness / etc.)
- 116 Remain positive
- 117 Please give answers when first diagnosed as it would of made me feel a lot better understanding CLL. I was told I had Leukaemia by my GP & not to ask questions & did not see the specialist for over a month! I was left high & dry & would not like anyone to go through that horrible feeling of not knowing. I purchased books on Leukaemia to even hand out to patients when first diagnosed. The Leukaemia foundation has been wonderful & I should of contacted them straight away for the information & they would of sent it to me straight away.
- 118 I'm always unsure of what to say when it comes to these questions...I've learnt that everyone's experiences are individual, from the treatment ups & downs to character of the people they have supporting them. The medical team I was under at Royal North Shore in Sydney were brilliant; the booklets provided by the Leukaemia Foundation and Cancer Council were very helpful to me & my family in understanding my disease and treatment; there was nothing better for me than having my husband and Mum by my side all the way. Therefore in my experience, I'd say your best to surround yourself with supportive people (Family, Friends, Nurses, Psychologist's etc.) they'll be with you through the highs and lows of the journey, they'll help bring out the best in you when it feels lost.
- 119 Take ownership of you situation and do all you can to recover.
- 121 We all have to face challenges at some point. Keep informed and look after your health and expect it to take time to fully accept your diagnosis.
- 122 Accept help don't be a martyr
- 123 You have good and bad days. Take each day at a time. Don't rush your recovery.
- 124 Spend time with your mates as much as you can
- 125 Get in contact with others who are going through the same treatment. No one else can fully understand unless they walk in your shoes
- 128 Just to be treated like a person not a patient
- 129 Get as much information as possible and join a group with others with the same cancer it is very comforting and very helpful to have contact either others going through the same things , the same treatment side-effects
- 133 Mindfulness techniques were really helpful, as was linking up with an alternative health center for supportive therapies alongside conventional ones. on-line groups
- 134 I recently joined a social media group. This has given me a boost.
- 135 You are going to have a long-term relationship with your specialist and GP so make sure you are a 'good fit' and can communicate and understand each other well. If you are not feeling supported - change doctor.

- 136 Sometimes I think we don't always get enough answers from our specialist mostly because in the beginning and even now for me I still do not always know what questions to ask. And then when I do it's always straight after I have had my check up and weeks away from my next opportunity.
- 137 I saw a hypnotherapist who helped me a lot
- 138 Viewing blogs can be depressing when you see how many issues others have with the TKI's. You must remember that everyone's journey is different and not allow yourself to be sucked into the negatives. Just sitting on your butt and doing nothing, feeling sorry for yourself and not taking charge of your cancer, only makes it more of a mental challenge. Don't be afraid to share with others and if you get worn down, go to bed and don't feel guilty about it. You control your fate.
- 141 Things have been difficult but also routine. It's been painful, emotional and can take a lot of your life. I have found discrimination in the workplace and in social settings. Generally I have heard a lot of people having a relatively easy process however there are cases (including mine) that have constant hiccups and ups and down's, my latest is the T315l mutation. My experience is to take and deal with each step as it comes. This illness is like a game of poker, it's not about the hand you're dealt but the way in which you play it.
- 143 Positive attitude that I don't have
- 144 Stay active!
- 145 Get a second opinion make your haematologist take the time to listen to you. Don't worry that they are busy, make them listen to you and understand what you are dealing with. Join a social network with other dealing with the same things.
- 146 I'm a late comer to social media. It is now a much better source of information for me than it was at diagnosis. At diagnosis, meeting someone else with the same disease was the most important thing for me other than the basic information provided by the Leukaemia Foundation printed information, which was wonderful for me and for sharing. 1. good source of clinical info to refer to as much or as little as you need 2. social support through others in the same boat
- 148 Be informed. Ask lots of questions. Speak to other patients/survivors. As my Oncologist told me "Exercise, Nobody does too much!" Research shows the physical benefits, helping you cope with chemo, but it also has a massive part to play mentally. It was one of my ways to fight, instead of allowing myself to focus on the disease or treatment. All of this was supported by my family, friends and faith community.
- 149 Support groups and information sessions with other people
- 151 I became extremely active with the Leukemia & Lymphoma Society and did a lot of fundraising for research grants by joining Team in Training. I volunteer by speaking with newly diagnosed patients who have the exact form of the disease as I do. I know that I benefit other people as well as myself by doing this. Unfortunately, I have an unrelated secondary cancer which was diagnosed right after I lost my husband so there has been a lot going on to cope with. But I'm getting professional help with all of this.
- 152 Learn about your disease and talk with others who have been similarly diagnosed. Online support groups are essential
- 155 There is always my GP to turn to, I am very fortunate, my GP and I are both Christians and can discuss prayer and my belief in God, that HE is always by my side caring for me.
- 157 Fellow CML patients just getting together and sharing ideas helps
- 158 We are all going to drop off the perch, maintain your sense of humour.
- 159 I would have really appreciated counselling at the time of diagnosis. It was not offered + I probably didn't know how to access amongst the chaos. I think long-term this has been an issue as I coped alone. Despite support "cancer" is a very lonely experience. You/I protect family from the truth and reality of how I really felt at risk of hurting them.
- 160 Very helpful to join support group (i.e., leukaemia foundation - specific to diagnosis) to meet others with same - support, friendship etc
- 161 Green smoothies helped with 'brain fog'. Exercise is good too. 'Rest' - I wasn't working the first 4 months it helped to be at home. Everyone is surprisingly lovely which has helped so much because I felt so 'lost' its not depression its the drugs - I am on 'sprycel'. Again leukaemia foundation. They seek you out which is good as you need help + don't know where to turn. I am glad they found me. The doctors should really give the hand outs as well - they don't. They are left in the rooms & usually all one. I was lucky on day after 3 months there was a lady there (from the leukaemia foundation) who found me &

talked to me. I was still a mess. Also the drug company had a nurse that calls & checks on you, but again you have to sign to receive the info et to receive service. The drug company had to call chemist and asked them several times to contact me. Why didn't the specialist organise these things?

- 162 I was too casual after finding the lump in my neck and promptly 'forgot about it' NOT a good idea. I refuse to look on the 'dark side' although ALL of my immediate family have died from various cancers (I think it must be the POM in my upbringing KEEP CAM DON'T PANIC. Kate - How can I possibly make a fuss. Both my parents faced cancer and death so bravely. I cannot let the side down - however it is early in my diagnosis. Dad was 46 Mum 59 + 11 months.
- 172 Look forward not back. Stay positive
- 180 Be Positive
- 184 I believe cancer has been a blessing for me and helped me see the REAL importance of living life while I still have it.
- 185 Join groups eg. exercise group, walking group, Keep in touch with colleagues. Thus you always have support and activities to keep you busy and interested in life.
- 186 In my particular case (CLL) the cancer has made little change in the 6.5 years since diagnosis, INDOLENT is the term used by the haematologist. Therefore I have not shared the fact that I have cancer with my friends, only my family. I think in a way this as helped me to generally ignore the fact that I have cancer and to get on with enjoying life. I would not enjoy being questioned every time I ran into friends on how I was feeling. Should my condition worsen and the need for treatment arise then I would seek the support of friends. In the mean time my partner gives me the emotional support I need and a smile from the haematologist on my once a year check ups relieves any anxieties I might have.
- 188 Never give up and think you are not going to survive. Keep a positive attitude and trust in your doctor.
- 189 If possible get on with life, enjoy family and friends, have goals, know that you have cancer and take steps to keep it at bay eg. diet, exercise, social gatherings
- 190 Finding a cure for the continual pain and numbness in feet. Numbness in fingers
- 192 The situation can be "made better" with an unemotional pragmatic assessment one's situation - ie look at the stats and percentages, the advances in medical science, the amount of time and \$ being spent on research. Also consider the poor bastards outside any oncology clinic - most of them much worse off and see this positively.
- 193 Provide as much info on the costs involved i.e. meds tests as it can get expensive. Openly discuss fertility and possible affects from the very start Carers also need support too!
- 194 That when the word 'cancer' is mentioned it is not a death sentence, it is a journey
- 195 Try to continue with as normal a life as possible. Accept the situation and don't try to be super human.
- 196 The clinic I attended was purely focused on administering treatment and did an excellent and friendly caring job but no additional support services were offered. There was a rack of brochures but little else. Having finished treatment a vacuum exists - here appear to be very few programs designed to communicate and support patients who after intensive and prolonged treatment - and ensuring communication- are suddenly cut off after completion. There is a considerable period of adjustment which can be very difficult especially for those returning to regional and remote areas. Access to a network of "fellow travellers" would seem to be a solution (shared experience). It is totally understandable that urgency and focus is placed on the immediacy of treatment but adjustment during post recovery phase can be a very prolonged process, which appears to be of little interest to the cancer "industry" (If I was a researcher I would be extremely interested in studying the issues of communication and isolation during the post recovery period). I think cancer "peak" bodies have failed in this regard and are impersonal bureaucracies a minor issue relates to the seemingly officially supported dominance of "pink" in cancer promotions, research and campaigns. This is very evident even in hospitals and can be quite disconcerting to those male & females suffering from other cancers.
- 197 Get all the correct information you can
- 198 I think persons coping ability is different. I have always just got on with life as normally as possible. I don't give my diagnosis any thought at all. Too busy and I just don't need to think about it at all.
- 199 I found that being positive and having a sense of humour helped me a lot
- 201 Avoid religion for atheists - like me

- 202 Don't feel ashamed to tell other people you fear your future. Have someone close to you that you can vent and cry to. Do not dwell on it too much. Find activities to keep your mind on other thoughts. Keep busy.
- 203 Ask questions! The more you find out the easier it is to cope. Ask about the side-effects of the drugs so you don't get any nasty shocks.
- 204 Anyone who has been told they have cancer needs to join a group with similar cancer. You gain so much knowledge from like-minded people. Also take your partner or family member with you to any meetings or Dr appts. There is too much information that those with cancer cannot take in, especially in the beginning. The brain seems to shut down. Don't try and cope alone. Also ask questions as many as you can.
- 205 Stay strong.
- 208 Taking time everyday to just "be" and reflect on your own journey. There is so much to be grateful for.
- 209 Suck it up, be grateful for being alive, keep busy with a normal life. Don't "live your disease". Keep thinking about what others need and trying to be useful and helpful.
- 211 Don't give in. Best motto...."To strive, to serve and not to yield"
- 211 Ask yourself what can I do? Others can help but ultimately you are responsible for your wellbeing!
- 213 Join support groups on-line (ie Facebook). No one really knows how we feel unless they are dealing with the same issues.
- 214 In all my years as a CML patient I have truly been blessed with an amazing doctor and team to keep me alive as when I was dx'd. I was given 3 yrs. to live....people today don't get that death sentence that so many of us got....but....if you cannot say what I have stated above with the excellent care I have received then you might want to search for a doc & team that will fight for you to keep you alive...this is your life....you have a choice....make it one you will have no doubt with them doing everything they can 24/7, 365 to keep you alive! God bless!
- 215 Practise being in the now. Worrying about the future creates stress. Commit to believing in a positive outcome. Express your fears and worries to those that care about you.
- 216 Live each day to its fullest. If you are not happy with your doctor, change.
- 218 To have family and friends around you supporting, BUT I firmly believe it was much harder for the family as they felt helpless, whilst I felt I knew I could cope. The other great thing was the alternative treatment which I began to take after treatment was completed. I still take it to this day and the clinical team cannot believe I am still here, they are amazed. I had amazing support from my church family both near and far and with my faith and their constant prayers for me I was constantly reassured which I'm sure helped me recover feeling loved and needed. God bless.
- 219 For me "Acceptance" of the situation and changes to my health and lifestyle! I have had NHL for 22 years, 7 relapses, lost my hair 5 times so acceptance did not happen easily, it took time!
- 221 If other ongoing medical issues persist, keep talking to your doctors about them to find a solution. I have noticed many people undergoing the treatments that I am with TKIs are often fatigued. I have kept talking to my doctors and now starting to investigate the issue through referral to a sleep study to at least ensure that there are no sleep cycle problems compounding the fatigue issue.
- 222 This is no longer the death sentence it used to be. These medications that save your life but are obscenely expensive. DO NOT be ashamed to ask for financial assistance. Every oncologist should have ways to get the meds for you at little or no cost. It would be inhuman on the part of the pharmaceuticals to withhold medications that can save your life. Take your meds, live your life, warrior on.... 🙏
-