Rural encounters with cancer: A study of the lived experience of people in the Central West of New South Wales

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Certificate of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Charles Sturt University or any other educational institution, except where due acknowledgment is made in the thesis.

Any contribution made to the research by colleagues with whom I have worked at Charles Sturt University or elsewhere during my candidature is fully acknowledged. I agree that this thesis be accessible for the purpose of study and research in accordance with the normal conditions established by the Executive Director, Division of Library Services or nominee, for the care, loan and reproduction of theses.

Name: Ruth Jones
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This thesis is about people with cancer and their lives and so I dedicate it to my Aunt – we miss you and wish your cancer journey had been different…
Professional Editorial Assistance

Professional editing of this thesis was provided by Frances Guinness at Guinness Literary Services and was limited to formatting, grammar and style (Australian Standard for Editing Practice (ASEP) Standard D – Language and Illustrations, ASEP Standard E – Completeness and Consistency) and must not alter or improve the substantive content or conceptual organisation of the thesis. Where a professional editor provides advice to a candidate on matters of structure (ASEP Standard C – Substance and Structure) exemplars only should be given.
Abstract

This qualitative phenomenological study aims to contribute to a deeper understanding of the cancer journey in a rural context by exploring, articulating and analysing the unique challenges faced by people following a cancer diagnosis in the Central West of NSW. Cancer survival rates in Australia rival the best across the world, yet there is clear evidence that people with cancer in rural and regional areas have not had equitable access to the range of services considered best cancer care.

The two main aims of the study are to: (i) identify, explore and fully describe people’s experiences of the processes involved in receiving a diagnosis of cancer; and (ii) interpret the meaning this phenomenon holds for people with cancer in the context of rural NSW.

The research question for the study was:

*What are the experiences of people in the Central West of NSW in relation to being diagnosed with cancer?*

Criterion sampling was used to recruit eight participants ensuring each had experience with the phenomena of a cancer diagnosis in the Central West region. Using Moustakas’ (1994) phenomenological approach enabled the development of a rich description of the experience of a diagnosis of cancer and the meaning embedded in that experience. Semi-structured interviews generated data and the language used; the words, phrases, images and metaphors chosen by the participants shaped the research and illuminated each individual experience of a cancer diagnosis.

The participants described the journey of cancer and the impact on his or her life. Four primary themes emerged: *Shock at the diagnosis, Grief for the life that’s lost, A thirst for information and A new life.* For many the impact of cancer was dramatic and all-encompassing; the chaos of a cancer diagnosis was profound and individual. The *Impact of Rurality* was a theme which cut powerfully across the primary themes revealing the burden faced by each
participant in this context. Participants spoke of feeling isolated, uncertain, and lacking support during their cancer diagnosis and treatment period.

For each participant, their cancer ‘life world’ became a long-term search for meaning which resulted in changing their concept of ‘who I was’ to ‘who I am now’; that is, how to live with, through and beyond cancer. Participants felt the absence of care coordination, education and support from health professionals throughout their journey contributed to their existential crisis following diagnosis.

Each cancer journey is a unique experience for both the person affected and their loved ones, and this was evident from the interviews with the participants. This study revealed the importance of a primary and community health, nurse-led model of care coordination, supported by medical specialists, a multidisciplinary team and clinical practice guidelines. This would ensure information and support with navigating the health care system would be provided across the continuum of care. In the rural context, staff development and education are imperative, both online and face to face, to increase awareness of the inherently life changing nature of cancer and provide a knowledge base for nurses and other clinicians.

The development of eSupport, which utilises technology to provide virtual psychological support, information and education would reduce the isolation felt by people with cancer in rural communities and enable efficient use of resources, regardless of location. Other recommendations include the need for recognition by general practitioners, surgeons and specialists that people with cancer have a fundamental right to access patient-held, person-centred, customised treatment plans that function as a living document, provide people with information and diminish the profound impacts of a cancer diagnosis.
CHAPTER One – Introduction

1.1 Background to the Study
This chapter offers an insight into my background and interest in developing an understanding of a person’s experiences following a diagnosis of cancer. Thirty years ago, I began my career as a registered nurse, progressing to clinical nurse specialist, clinical nurse consultant and health service manager. During this time, I was privileged to provide clinical care to people with cancer and other advanced life limiting illnesses. In providing clinical care to people with cancer I worked in a range of settings including hospital surgical wards, inpatient and outpatient oncology, chemotherapy, bone marrow transplant, radiotherapy, and palliative care in both metropolitan and rural locations. Working as a nurse in the field of palliative care enabled me to provide a consultative service for people in many locations: hospital, home, residential aged care facilities, and to those who moved between settings over time. This also enabled me to work in partnership with health care providers who are not usually key members of the multidisciplinary team in the inpatient or hospital ward setting.

In each clinical setting, the relationships were established well after people received a diagnosis of cancer. My understanding of the difficult experience of various investigations, procedures and processes each person had undertaken leading to a diagnosis of cancer was conceptual rather than observed. Unfortunately, I had not truly appreciated the often arduous and complicated journey the person travelled prior to arriving at the point of care where I first encountered them. I was not aware of the overwhelming effect a diagnosis of cancer would have on a person, other than as an observer.

Moving into the management of health care services across a vast geographical region in NSW, (see Figure 1, page 3) I developed an awareness of the need for each person with cancer, or a suspected cancer, to be resilient and have effective ‘navigation skills’ to find their way through the complexities of the health care systems. Indeed, this was often revealed when a person had encountered significant difficulties or delays in diagnostic or treatment services,
rather than providing a robust proactive support system as his or her journey unfolded over time. It is important to note my experiences led to subjective beliefs and assumptions relating to people’s experiences of health care for cancer, and because I had not personally had a diagnosis of cancer or worked in primary care as a nurse or a health manager, many of the experiences recounted by the participants in the study were new to me. Through the participants’ stories, I learnt of the experience of cancer, not the experience of health care. Acknowledging my prior experiences as a researcher conducting this study and ensuring that they did not influence the questions asked or lead the discussions with the participants, was vital, and is explored further in Chapter Four.

This insight led me to realise that the organisation and arrangement of the array of Australian health care services are not designed or resourced to respond to each person’s devastating experience following a diagnosis of cancer. My background and experience which led to development of this premise and progression of the thesis are outlined in this chapter.

1.2 Context of Cancer in Rural Australia
Cancer affects everyone as either a person with the diagnosis, or as a friend or family member of a person who has been diagnosed. For many the impact of cancer is dramatic and all-encompassing, and for a number of decades it has been well documented in the literature as a dreadful, traumatic and life changing occurrence (Godding, 2014; Jong et al., 2004; McConigley et al., 2011a; Mercuri & Kallady, 2005; National Rural Health Alliance, 2016 (NRHA); Tracey & Roder, 2010). While fewer people than ever are likely to die from cancer, increasing numbers of Australians will be faced with such a diagnosis in their lifetime. Australia has survival rates to rival the best across the world, yet people with cancer in rural areas have not had equal access to the range of services considered best cancer care.

Cancer is a group of diseases where abnormal cells multiply and invade adjacent tissues. These can then spread, or metastasise, to other parts of the body. Cancer cells replace healthy cells, which results in a loss of function of the structure in the body or organ invaded by the cancer. The impact on
individuals, families and communities is substantial resulting from fear, lack of knowledge, often prolonged treatments, premature death and the burden on health services. It has been estimated that this year, 396 people will be diagnosed with cancer each day in Australia (Australian Institute of Health and Welfare, 2019 (AIHW)).

This study focused on people with cancer living in the Central West of NSW, a region of the Western NSW Local Health District (WNSW LHD) which covers a vast geographical area of 246,676 square kilometres or 31 percent of NSW. It extends from Oberon and Mudgee in the east to beyond Cobar and Bourke in the west, and Lightning Ridge to the Queensland border in the North. It provides health services to an estimated population of 279,667 across this vast geography; equivalent to approximately 1.1 people per square kilometre. The District has the highest proportion of Aboriginal people in NSW at 11.1 percent of the total population in comparison with other Local Health Districts (NSW Health, 2019, para. 1).

In the WNSW LHD it is projected that in the year 2021, 2,055 people each year will be newly diagnosed with some form of cancer (Cancer Institute NSW, 2019c (CINSW)). In the latest available data, it is revealed that in 2015 in the WNSW LHD, 806 people were diagnosed with cancer, and 594 deaths were cancer related (CINSW, 2019c). Cancer was the leading cause of all male deaths and the second leading cause of all female deaths in WNSW LHD.
1.3 Cancer Services in the Central West

When I commenced managing cancer and palliative care services in 2006, all specialist medical providers who worked in the region were based at metropolitan services and provided fly-in fly-out services overseeing clinical care provided by specialist nurses, general practitioners and the generalist nursing and allied health workforce. The fly-in fly-out services were primarily provided in the outpatient setting, with clinic appointments for patients prioritised on an as-needs basis due to time constraints associated with the fly-in fly-out model of care. Patients who were inpatients when the visiting specialists were holding clinics were either reviewed in the outpatient setting or visited on the ward after regular clinic hours. This was not an unusual arrangement outside metropolitan areas, and these rural clinics continue in parts of NSW today. A key component of this model of care involved a specialist oncology nurse ‘sitting in’ on clinic appointments and ward visits, taking notes to ensure good communication of assessment and treatment plans. This firsthand knowledge and the clinical notes taken were particularly helpful during the time between
patient reviews in clinic and when the transcribed specialist’s letter arrived from Sydney, often several weeks later.

Patients in the Central West were treated with many chemotherapy regimens in the hub sites of Bathurst and Orange; however, more complex treatments were only provided at cancer centres in Sydney. Patients who required radiotherapy were able to have an initial assessment in a rural outpatient clinic, then referred to public radiotherapy treatment centres in metropolitan locations including Sydney, Newcastle, Wollongong and Canberra. This imposed significant financial, social and personal stressors due to the travel required for the six to eight weeks of treatment. For some patients this cost, both financial and personal or family-related, was perceived as too great and therefore decisions not to proceed with radiotherapy treatment were not uncommon. Many patients chose to seek radiotherapy treatment at a centre close to where they had family or friends living so that they could stay with them during this time, and the oncologists and specialist nurses encouraged this, recognising the importance of the social and emotional support and reduced financial impact for patients. Consequently, whilst there was a usual referral pattern for radiotherapy treatment, patients may have selected a treatment site which had no outreach connection to their place of residence. This added to the complexity in coordinating care and communicating between health care professionals and often impacted on effective follow up care.

Since 2011 cancer care services in the Central West have matured with the recruitment of a range of cancer care specialists. The presence of these locally based medical specialists has resulted in a paradigm shift in the volume and type of treatment services available. Coupled with the gradual expansion of nursing, allied health, technical, and administrative staff, people in local communities now rarely leave the district for cancer care, however, travel remains a fact of life for people as services are primarily located in hub sites. A cancer nurse coordinator’s position was established in Orange in 2006, and by 2013 an additional position was based in Bathurst. Breast care nurse roles, funded by the McGrath Foundation, were also established, as has one prostate cancer specialist nursing position funded by the Prostate Cancer Foundation of Australia. These nursing roles support people with cancer and their families and
carers by providing education and information, assisting them to understand their treatment pathways and often coordinating or ‘navigating’ care for patients once they are referred to cancer services. Demand for chemotherapy and other systemic treatment continues to grow and is provided in Bathurst, Orange, and the outreach sites of Cowra and Parkes.

In the Central West, radiotherapy treatment became available in Orange in 2011. The availability of rurally based radiotherapy treatment services has led to a significant increase in the number of people from the region accessing treatment. With electronic medical records in use in cancer services, local data is collected and is now available for analysis to measure health care service performance and outcomes for people with cancer. People diagnosed with cancers requiring highly specialised care are referred to metropolitan centres.

While fewer people than ever are likely to die from cancer, increasing numbers of Australians continue to be faced with a diagnosis in their lifetime. Australia has survival rates to rival the best in the world, yet people with cancer in rural areas have not had equal access to the range of services considered best cancer care. For many there has been the requirement to travel for diagnostic tests, surgery, radiotherapy, and at times, chemotherapy treatment, which causes significant social, emotional and financial strain for not just the individual, but also his or her family. As I embarked on this study and my understanding grew, my insight and even my language changed – I no longer thought of ‘cancer patients’, rather of ‘people with cancer’.

Whilst extensive research and literature on cancer and cancer treatments has been published, as has the patient experience of cancer care, there was an apparent gap in the knowledge of understanding the experience of people living in the Central West of NSW with a cancer diagnosis; their cancer journey from diagnosis onward. The lived experience of a cancer diagnosis has an intense effect on a person’s relationship with freedom, independence and personal identity, each of which is central to emotional wellbeing. Prior to a diagnosis of cancer, each person is living their life with their own individual strengths and challenges when suddenly they are thrust into a chaotic world with little control over what is to come.
The intent of this study was to provide a rich description of the experience of receiving a diagnosis of cancer and the meaning embedded in that experience. In addition, I was keen to understand if health care services provided the necessary support to people during this time in his or her life, and what improvements might make a difference for local people with cancer.

1.4 Study Aim
The aim of this study was to explore, articulate and analyse the meaning of the lived experience of a diagnosis of cancer in people residing in the Central West of NSW. Acknowledging the intersection between culture and personal experience, I chose to focus on the Central West, keen to develop an understanding of the personal experience of the participants and the part rurality plays in that experience. The purpose of this study was to enhance the understanding of the lived experience of a diagnosis of cancer by individuals in the Central West of NSW and to identify improvements needed to better support rural people during this traumatic time in his or her life.

1.5 The Structure of the Thesis
Chapter One of this thesis has introduced the background to the study undertaken and provides an overview of the context of cancer in rural NSW. It informs my perspective on the need for the study and provides an overview of the context. Chapter Two provides a review of the literature related to cancer, rural life and health care, grief and loss, and roles of oncology or cancer nurses. Australian and international studies and reports relevant to the topic provide evidence of the gap in understanding of the cancer experience.

Chapter Three provides a discussion of phenomenology and the methodology upon which this study was based. It also considers the role of phenomenology research and nursing. Chapter Four presents my implementation of the chosen methodology and method for this study and describes the data analysis process undertaken. It also includes a discussion on the ethical considerations for the study.
Chapter Five introduces the participants, with brief descriptions of each individual and their stories which they so willingly shared with me. A pseudonym has been allocated to each participant to ensure his or her privacy and anonymity. This chapter focuses on the thematic analysis, describing the main themes and subthemes, and the theme of Shock at the diagnosis of a cancer is explored. This theme addresses analogies provided by the participants which became subthemes including ‘having the rug pulled out from under me’, ‘a roller coaster of emotions’ and ‘white-water rafting’.

Chapter Six is devoted to exploring the theme of Grief for the life that’s lost and focuses on grief and loss issues associated with a diagnosis of cancer. For all participants, feelings of grief relating to an abrupt loss of the life he or she was expecting to live were described. The words of the participants offered powerful illustrations of this, including ‘anger that this has happened’ and ‘the fear of recurrence’ of the disease which plagued participants.

Chapter Seven presents a discussion of the strong theme of a Thirst for information within the paradigm of rural living, exploring the subthemes derived from participants’ words noting that these words describing the experience of receiving a diagnosis of cancer were emotive and at times haunting. The human condition naturally seeks information in circumstances such as a diagnosis of cancer in order to gain knowledge and understanding and if possible, to be able to incorporate the diagnosis into his or her view of self.

Chapter Eight offers a discussion of the theme of A new life following the devastating challenge of a cancer diagnosis. Participants reflected on who they had become as individuals and revealed the impact cancer had on them. This exposed the trauma that cancer inflicted on their lives, leading to the struggle to ‘transition to a new normal’. For most it was difficult with negative outcomes, however, for some this led to personal growth following the trauma.

A discussion of the Impact of Rurality is the focus of Chapter Nine: the theme which cut across all four main themes. With the disparities of living in a rural location in Australia, the trials and tribulations associated with geographical distance and isolation are an everyday part of life. A quarter of the population in
NSW live in rural areas and for many there is limited access to health care services, particularly specialist health care services including cancer-related surgery, chemotherapy and other systemic treatments, radiotherapy and follow up supportive care. The prevailing perception in rural communities that cancer leads to death is explored. Also examined in this light are the difficulties of accessing general practitioners, and a lack of locally based medical specialists. The need to travel for part or all of their specialist consultations and cancer treatment had a large impact on the experience, as did the lack of good communication between health care providers and locations. Finally, the financial cost associated with cancer in rural areas was found to be up to five times more than that of a person living in a metropolitan location.

Chapter Ten concludes the thesis with a summary of the study, significant findings, and offers recommendations arising from the study. Limitations identified within the study are also presented with a recommendation for further research offered for consideration.
CHAPTER Two – Literature Review

This chapter commences with a background to provide an understanding of cancer as a disease, and its prevalence in Australia, NSW and the Central West. The review then presents information relating to rurality – including health issues and outcomes – and more specifically to cancer in rural populations including Aboriginal Australians. The focus then moves to the research relating to loss and grief as they are inescapable outcomes of a diagnosis of cancer for many people, and frequently lead to an existential crisis. The final section relates to the role and function of oncology nurses who strive to support people during this overwhelming and life changing experience.

To understand the experience of a diagnosis of cancer in the Central West of NSW, it is crucial to review relevant literature related to cancer diagnosis and treatment, and the cancer journey faced by so many. An effective critical review of the literature provides the foundation for a study (Turner, 2018). It facilitates a systematic understanding of the subject, enables connection of the specifics of the research topic with wider themes and previous research (Turner, 2018), and positions the research to provide a new and novel contribution (Bettany-Saltikov, 2012). This literature review focuses on identifying relevant studies and gaps in current knowledge. Reviewing previous research provides a deep foundation of knowledge and enables this research to add new information and insight.

2.1 Introduction
Cancer is a subject that has been written about in a vast array of sources resulting in an enormous body of literature that reveals the complexity of the disease. Cancer and its impact were subjects found in wide-ranging fields of research, from the physical and biological sciences, to the humanities and the arts. Exploring the literature from this breadth of disciplines facilitated a wide-ranging understanding of cancer and the power it has in people’s lives. Much of the literature was appropriately dedicated to disease and treatment side effect management, followed by a focus on clinical outcomes.
A significant gap exists in the published literature relating to the lived experience of a cancer diagnosis in regional or rural NSW.

2.2 Method of the Review
My aim was to review the literature relating to cancer and rural people’s experience of a diagnosis of cancer and subsequent treatment in order to draw out implications for nurses and health care services. My search strategies were to use the search words cancer, rural, oncology nurse/oncology nursing and experience. Databases searched included EBSCO Host, Medline/PubMed, Embase, CINAHL, PsycInfo, JSTOR, Cochrane Library, ScienceDirect and CancerLit. Subject-related sites, governmental sites and professional association sites were also searched.

Using ‘cancer’ as a search term resulted in a range of clinically focused articles and papers which presented information relating to the disease or treatment rather than presenting information which addressed the experience of cancer from the person/patient perspective. This clinically focused literature was excluded, as were non-English language articles. The inclusion criteria I used was a requirement for English language, and studies from 1998 – 2019. Further exploration of the literature relating to rurality, loss and grief, and existentialism led me back to 1950 to capture the development of the concepts in order to gain an increased understanding. Abstracts for all articles located were read, and articles meeting the inclusion criteria were retrieved, analysed and summarised. Those not found to meet the inclusion criteria were excluded.

2.3 Background

2.3.1 History of Cancer
Cancer was identified in ancient times; however, it has become a focus of modern society (Mukherjee, 2010). An Egyptian physician, Imhotep, was the first to document a case of cancer in 2500 BC. The next known case is that of the mummified body of a young woman in a Peruvian grave which dates back 1,000 years. Thus, despite cancer’s reputation as a significant problem of modern society, it is actually extremely old (Mukherjee, 2010). Hippocrates is credited with attributing the Greek word for crab, karkinos to cancer in around 400 BC. This was due to his observation that a tumour grabs surrounding tissue.
as it grows within the body; similar to the way a crab grabs sand with its claws (Mukherjee, 2010). This visual representation of the crab has endured as the symbol of cancer (Mukherjee, 2010).

2.3.2 An Overview of Cancer
Cancer and its impact are experienced by individuals, families and communities; indeed, it affects us all as more people in our communities and countries are now living with cancer as a chronic disease. Cancer continues to increase in Australia and is the leading burden of disease, ahead of cardiovascular disease (Bates, Callander, Lindsay, & Watt, 2018). Cancer is now recognised as the leading cause of morbidity and mortality in Australia (AIHW, 2019) and has a substantial impact socially and economically for both the person diagnosed and the community in which they live (AIHW, 2019).

The term cancer refers to a wide group of approximately 100 diseases (Song, Samulski, & van Dyke, 2005) where the body’s cells become abnormal and start to multiply without restraint as a result of changes or mutations in the genetic information of a cell (Corner, 2008; Reed, 2005). When this occurs, cells do not die as they naturally should, and new cells form when the body does not require them (Chmielowski, 2017). These abnormal cells can form an invasive or malignant tumour capable of invading and damaging the surrounding area and spreading to other parts of the body via the bloodstream or lymphatic system (Newton, Hickey, & Brant, 2016). If the spread of the disease is not regulated or controlled, cancer is likely to lead to death (Minn & Massague, 2005).

The location where a cancer begins is referred to as the primary cancer, and where it spreads to is referred to as a metastasis or secondary site; it is possible for a cancer to spread to a number of secondary sites (Newton et al., 2016). Most cancers are labelled by the organ or type of cell where they originate – for example, cancer that begins in the colon is referred to as colon cancer, and prostate cancer is one that begins in a man’s prostate gland. Cancer types are grouped into broader categories such as a carcinoma which has its origins in the skin or tissues that coat internal organs. Sarcomas arise in transformed cells of bone, cartilage, muscle, fat, blood vessels, or in another connective or supportive tissue (Corner, 2008). A cancer that arises in the
blood-forming cells including the bone marrow and results in large numbers of abnormal blood cells being released into the blood stream is a leukaemia. A cancer which forms in the cells of the immune system can be a lymphoma or myeloma, and central nervous system cancers are those which arise in the tissues of the brain and spinal cord (Chmielowski, 2017).

Survival from cancer has been linked to the extent of the disease at the time of diagnosis and commencement of treatment, such as surgical removal of a tumour, chemotherapy, immunotherapy and radiotherapy (Tracey & Roder, 2010). Surgical resection for pancreatic cancer in NSW has been found to have significant variability depending upon location of residence in the state, with surgical rates of between eight and twenty-one percent (Creighton et al., 2017). Chemotherapy refers to the use of drugs with the ability to kill cancer cells. Immunotherapy refers to a range of sophisticated targeted treatments for a specific cancer type (Song et al., 2005) which act at the cellular level of a person’s immune system in the battle against cancer. Immunotherapy includes a range of treatments which activate or suppress the immune system to target cancer. Radiotherapy is the use of ionizing radiation, delivered usually via a linear accelerator, to kill cancer cells (Chmielowski, 2017). Radiotherapy has been found to be synergistic in the treatment of cancer in combination with chemotherapy, either before, during or following a course of radiotherapy treatments (Chmielowski, 2017).

A special communication from the Global Burden of Disease Cancer Collaboration published in the Journal of the American Medical Association found that “in 2015, there were 17.5 million cancer cases worldwide and 8.7 million deaths” (Global Burden of Disease Cancer Collaboration, 2016, p. E1). Analysing the global burden of disease using data from 195 countries, the disability-adjusted life years (DALYs) for thirty-two cancers across the globe in 2015 were estimated as 208.3 million. To determine the burden of disease, each DALY is considered one lost year of life compared with a person who is healthy when applied across the population. Therefore, the 208.3 million DALYs which were estimated due to cancer in 2015 represent the amount of ‘healthy’ years lost in addition to the 8.7 million deaths reported (Global Burden of Disease Cancer Collaboration, 2016).
2.3.3 Risk Factors for Developing Cancer

A number of identified risk factors are involved in the development of cancer, however, the presence of a risk factor does not indicate that a person will develop cancer – indeed many people have risk factors for cancer but do not develop cancer, while others with cancer may have no known risk factors (Garber & Offit, 2005; Hawley & Pandolffy, 2005). Biomedical, lifestyle and environmental factors are the three main groupings of cancer risk factors.

Biomedical factors include a genetic susceptibility, and hormonal factors in women. A mutation of the BRCA 1 and BRCA 2\(^1\) genes in women with breast cancer is an example of genetic predisposition. Women who have faulty BRCA 1 and BRCA 2 genes have a significantly higher chance of developing breast cancer at an early age than women who do not (Garber & Offit, 2005; Hawley & Pandolffy, 2005). However, it is important to note that most women who develop breast cancer do not have these genes, thus most breast cancer is not caused by a high risk inherited gene fault. It has been estimated that only five to ten percent of women with breast cancer have faulty BRCA 1 and BRCA 2 genes. Colon cancer is another example of a cancer where some people in the general population have a genetic predisposition (Chmielowski, 2017).

Many cancers in Australia are linked to lifestyle factors such as smoking, alcohol, diet, or obesity (CINSW, 2016; Zorbas, 2016). Tobacco smoking has been clearly identified as the greatest cause of cancers – approximately 20-30 percent of all cancers are linked to active and passive smoking, including lung cancer, as well as stomach cancer, pancreatic cancer, liver cancer, cervical cancer and leukaemias (Chmielowski, 2017). It has been determined that the association between smoking and cancer is dose-related: with longer exposure and increasing consumption of tobacco the chance of developing cancer increases (Hecht, 2005). A recent publication (Arriaga et al., 2019) used data linkage from seven prospective study cohorts to determine the burden of pancreatic cancers in Australia resulting from smoking. Smoking intensity, or

\(^1\) Breast Cancer susceptibility genes (BRCA 1 and BRCA 2) act in a protective role in the body by naturally suppressing tumours, however, when a mutation occurs to these genes a woman’s lifetime risk of developing breast and/or ovarian cancer is significantly increased.
the number of cigarettes per day, and high body mass index are established as increasing the risk of pancreatic cancer. The authors contend that nearly one-fifth of future pancreatic cancers are attributable to smoking and that reducing smoking in Australians under sixty-five years of age would provide the most significant reduction of pancreatic cancers (Arriaga et al., 2019). Large consumption of alcohol is associated with cancer of the oral cavity, pharynx, larynx, oesophagus, liver, colon and rectum, and is compounded when people also smoke tobacco (AIHW, 2019).

In the western world, many people eat large amounts of red and processed meats, and smaller amounts of fresh fruit and vegetables. This type of diet is known to increase the risk of cancer cells (Chmielowski, 2017). Most types of cancer become more common as we age, as the changes that cause a cell to become cancerous usually take a long time to develop (Reed, 2005). The longer we live, the more time there is for genetic mistakes to happen in our cells. The risk of developing many types of cancer can be reduced by incorporating healthy lifestyle habits, such as eating a healthy diet, getting regular exercise, and not smoking (AIHW, 2019; CINSW, 2016; Henderson & Bernstein, 2005; Ullrich, 2005). It is also important to note that the earlier a cancer is diagnosed, and treated, the better the chance of a successful outcome (AIHW, 2019; Chmielowski, 2017).

Occupational exposure to particular chemicals, dust (including asbestos) and industrial processes account for approximately 5,000 cases of cancer each year in Australia (AIHW, 2019; Yuspa & Shields, 2005). Chronic infections can also lead to the development of cancer, for example, the human papilloma virus is linked to cervical cancer in women and hepatitis B and C can lead to liver cancer (Chmielowski, 2017). Antiviral therapy is effective in the treatment of hepatitis B and C and can prevent a person from going on to develop liver cancer. Yet primary liver cancer is now the leading cause of cancer deaths in Australia, indicating that treatment of hepatitis B and C is a major public health issue to be addressed (Cancer Australia, 2018; Maclachlan & Cowie, 2012).
2.3.4 Cancer in Australia

As the Australian population increases and, more importantly, ages, there has been a steady increase in the number of people diagnosed with cancer. One in two Australians will be diagnosed with cancer, and one in five will die from their cancer prior to 85 years of age. The Australian Institute of Health and Welfare (2019) uses cancer incidence data from 2006 – 2015 to estimate that 144,713 new cancer diagnoses will have occurred in 2019 across Australia. Of the total disease burden in Australia, cancer represents 20 percent. Early, untimely death from cancer constitutes 94 percent of the cancer disease burden (McGill & Carter, 2017). It continues to be acknowledged as the leading cause of premature death in Australia (Cancer Council NSW, 2009 (CCNSW)).

A study published in 2018 focused on estimating the national Australian workforce rates for people with cancer. The researchers found that 40 percent of people diagnosed with cancer are of working age (24 – 48 years) and that nearly half of these were not working, leading to $1.7 billion loss to the Australian gross domestic product. Interestingly, people in the same age group without cancer "were three times more likely to be employed full time compared to people with cancer, after adjusting for age, sex, educational attainment and rurality" (Bates et al., 2018, p. 375). An earlier report, the Cost of Cancer in NSW, noted “the total expected lifetime economic cost of cancer for people diagnosed in 2005 in NSW is around $32.5 billion” (Access Economics, 2007, p. vi). The cost impact has been similarly recognised in other countries, including in a study of breast cancer survivors who were treated with curative intent. The study found ill health was the greatest predictor of early retirement from the workforce in Scandinavian countries (Lindbohm et al., 2014).

2.3.5 Cancer in NSW

Approximately every 13 minutes a person receives a cancer diagnosis in NSW, with 43,378 people diagnosed in 2015. The top five cancer diagnoses for people in NSW are listed in the table below.
For men, the most common cancers in NSW are prostate followed by bowel, melanoma, lung and non-Hodgkin lymphoma; and for women, breast, bowel, melanoma, lung and uterine cancers. NSW has the largest population of the states in Australia, yet it has the third highest incidence of cancer in the country. With the growth and the ageing of our population, the incidence of “cancer in NSW is expected to increase to 53,000 by 2021” (CINSW, 2016, p. 4). Cancers such as breast and prostate are expected to increase with more people living following their diagnosis (CINSW, 2016).

### Table 1: Most Common Cancer Types in NSW

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Number of cases, 2011 - 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate</td>
<td>34,357</td>
</tr>
<tr>
<td>Breast</td>
<td>26,612</td>
</tr>
<tr>
<td>Melanoma of the skin</td>
<td>21,382</td>
</tr>
<tr>
<td>Lung</td>
<td>18,943</td>
</tr>
<tr>
<td>Colon</td>
<td>16,830</td>
</tr>
</tbody>
</table>

Source: Cancer Institute NSW, 2019 statistics module online

2.3.6 Cancer Mortality in NSW

According to the latest available data, 14,035 people in NSW died as a result of their cancer in 2015. Whilst survival from cancer is consistently improving, the five-year overall survival rate for people with a cancer diagnosis in NSW from 2005 - 2009 was 67 percent, with males recorded at two percentage points higher than females (CINSW, 2016). This survival rate includes all diagnoses of cancer regardless of the stage or extent of the cancer disease; people with localised cancer have significantly higher survival rates than those whose cancer has spread from the site of origin to distant areas in the body. The NSW Cancer Plan 2016 (CINSW, 2016) identifies the need for further work focused on improving cancer outcomes for Aboriginal people and rural and remote populations where there are disproportionately lower rates of survival from cancer.

Australians living in rural areas “are more likely to die within five years of a cancer diagnosis than people from metropolitan areas… the rural–urban differential is actually widening” (Emery et al., 2013, p. 294). The perception of a worse outcome following a cancer diagnosis is prevalent in rural communities.
Cancer remains a disease which is strongly associated with death and accompanied with the rural qualities of stoicism and machismo (Moser et al., 2014); individuals and families have a culture of fear associated with cancer in rural Australia. This fear of death associated with cancer prevails and shapes people’s ability and motivations to seek health care when experiencing possible symptoms of cancer (Emery et al., 2013) leading to a later diagnosis and increased mortality (Emery et al., 2013; Heathcote & Armstrong, 2007; Smith, 2012). The stoicism associated with rural communities is exemplified by the language used. The ‘battle with cancer’ theme reinforces the fear of cancer and the inherent message is the need to draw on ‘our fighting spirit’ in this battle, as has been done in times of war (Smith, Humphreys, & Wilson, 2008).

A significant report in 2010 (Tracey & Roder, 2010) found survival from cancer in NSW in a twenty-year period was most influenced by the extent of a person’s disease at diagnosis. Location of residence ranked seventh after age, extent of disease at diagnosis, year of diagnosis, sex, socioeconomic status and country of birth. However, it was noted that increased numbers of people living in rural and remote communities are diagnosed with more advanced disease as opposed to a localised cancer. Factors influencing survival were assessed not on relative survival but rather using “proportional hazards regression modelling”\(^2\) (Tracey & Roder, 2010, p. 1) which evaluated the chances of a person in NSW being diagnosed with localised cancer. Data from 1980 to 2003 from the NSW Central Cancer Registry was utilised, including reports of cause of cancer deaths from pathology reports and full death certificates, which was considered to offer increased specificity.

Predictors for the proportional hazard regression modelling were age, sex, period of diagnosis, extent of cancer and geographical location based on Area Health Service. More than half a million patients diagnosed with cancer were followed to the end of 2004. The extent of cancer disease at the time of diagnosis was the most significant factor influencing survival; those with metastatic disease were determined to be nine times more likely to have succumbed to their illness. Older age was the second strongest factor, with

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\(^2\) Cox proportional hazards regression modelling enables the computation of the hazard ratio and adjustment for the impacts of the other covariates (Soh & Saw, 2010, p. 4).
elderly people over the age of 80 three times more likely to have died. The third strongest factor influencing survival related to the year of diagnosis; people diagnosed in the latter years of the study period were found to have increased survival in comparison with those diagnosed in the 1980s, undoubtedly related to the advances in cancer treatment over time.

Assessing gender revealed that men were more likely to have died than women, and when socioeconomic status was considered it was found that people in lower socioeconomic groups were more likely to have died. People with cancer who were born in Australia were less likely to have died than those born overseas, however, the study did not take into account Aboriginality due to the low numbers of data available (Tracey & Roder, 2010). At the time of this report in 2010, the NSW state government Department of Health organised health services into eight Area Health Services (AHS) based on geographic groupings of Local Government Areas. In two of the three rural AHSs the likelihood of death was greater than for the other AHSs combined. The likelihood of death in the third rural AHS was lower and one urban AHS had a higher likelihood of death (Tracey & Roder, 2010).

Extent of disease at diagnosis was considered the most significant factor influencing survival (Tracey & Roder, 2010). Factors influencing the likelihood of a person presenting with early stage disease were assessed and it was determined that younger age groups were more likely to be diagnosed with localised disease. People diagnosed in more recent years and those born in Australia were also more likely to present with early stage cancer, whilst people from lower socioeconomic groups and men were more likely to have more advanced cancer at diagnosis. People from urban AHS were more likely to be diagnosed with localised cancer than those from rural AHS; however, differences were found when specific cancers were considered. No difference was found between rural and urban AHS for people diagnosed with breast and bowel cancer, however, with prostate cancer there was a four percent difference between rural and urban locations, with men from rural areas more likely to have more advanced disease. Most significantly, it was found that rural people diagnosed with lung cancer were 23 percent less likely to be diagnosed with localised disease (Tracey & Roder, 2010).
Limitations of this analysis include the inability to account for co-morbidities or surgical and medical oncology treatment differences which may exist in rural and urban locations. These differences relate to the accessibility of cancer care services generally and the lack of subspecialty cancer services\(^3\) which are available in metropolitan areas.

The *Cancer Survival in NSW 2002 – 2006* report identifies that despite the meaningful increases in survival rates in the last couple of decades, significant effort is necessary to reduce the burden of cancer “where the cancer has progressed between a person first experiencing symptoms and the disease being diagnosed” (CINSW, 2012, p. 6). Lung cancer, the leading cause of cancer related deaths in Australia, is an example where diagnosis often occurs at an advanced stage associated with poor quality of life. Addressing evidence-practice gaps in the detection and management of lung cancer begins with research to map, understand and correct problem areas and missed opportunities along the illness trajectory (McGregor et al., 2017). Implementing evidence into routine care would provide the most significant impact on current lung cancer outcomes.

**2.4 Living in Rural areas**

It has been clearly established for a number of years that people living in rural and remote locations in Australia have “poorer health than those in metropolitan areas” (Shepherd, Goldstein, Olver, & Parle, 2008, p. 423), and on average they live shorter lives (AIHW, 2019; Bureau of Health Information, 2016 (BHI); Dixon & Welch, 2001; Hall, Holman, & Sheiner, 2004; Jong et al., 2004; McConigley et al., 2011a; McGrath, 2000). People who live in rural and regional locations in Australia know well the trials and tribulations associated with geographical distance and isolation. This is coupled with higher levels of disadvantage related to education, employment prospects and income (AIHW, 2019). In NSW, a quarter of the population live in rural areas.

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\(^3\) Subspecialty services in cancer care refer to the specialisation of clinicians and care planning at metropolitan cancer centres which is based on tumour streams; for example, surgeons, radiation oncologists and medical oncologists who focus in their clinical practice on the care of women with breast cancer or men with prostate cancer.
Defining what is ‘rural’ or what constitutes ‘rurality’ has been a contentious issue for the last century, with Gilbert (1982) reporting that a range of definitions have been argued since early in the twentieth century. Differentiating between rural and remote is indeed contentious, with authors such as Nichol (1990) clearly distinguishing between the two. Other authors consider remote to be a sub-category of rural rather than a discrete entity. Three broad components of rurality were identified: ecology, occupation and culture (Bealer, Willits, & Kuvlesky, 1965), however, this description was expanded by proposing that rural represents “lots of space, few people, small towns, workforces slanted towards agriculture” (Luloff, Miller, & Beaulieu, 1986, p. 10) and a community which expresses more conservative people and thinking patterns. Some American studies have focused on the cultural and social characteristics of communities (Smith & Zopf, 1970; Spears, Combs, & Bailey, 1990). These are centred on the size of communities, density of populations and the limited range of occupations available.

In Australia, distance and accessibility to services are a significant focus. The Accessibility Remoteness Index of Australia (ARIA) classification system was developed by the Australian Government in 1997 to unambiguously define relative remoteness from goods and services in any location in Australia (AIHW, 2004). The following map illustrates the remoteness areas for Australia within the ARIA classification system.
The system has five ARIA classes based on road distance to service centres: Highly Accessible, Accessible, Moderately Accessible, Remote and Very Remote. The Highly Accessible category, with an ARIA score ranging from 0 – 1.84, describes locations with fairly unlimited “accessibility to a wide range of goods and services and opportunities for social interaction” (Department of Health, 2011 (DOH), p. 7). In comparison the Very Remote category, with an ARIA score of greater than 9.08, portrays communities where there is “only very little accessibility of goods, services and opportunities for social interaction” (DOH, 2011).

When comparing rural and urban populations, rural people have “lower levels of education and higher levels of socioeconomic disadvantage” than their urban counterparts (BHI, 2016, p. 10). However, there are social benefits which
 accompany living in a rural location, including a greater degree of social unity, community commitment and engagement, and a stronger sense of security (Hogan, Polidano, Russell, & Stakelum, 2008). Commonly, the demographics of rural and remote locations characterise older populations with high levels of health risk and chronic disease, which is exacerbated by poorer access to health care services (NRHA, 2019). Rural people utilise the local Emergency Department more than metropolitan people for issues which are treatable by general practitioners. They are also hospitalised at a higher rate than their urban counterparts for health-related issues which are deemed potentially preventable (BHI, 2016). There are a number of well documented health differences in rural populations including: (i) higher mortality rates and lower life expectancy; (ii) higher road injury and fatality rates; (iii) higher reported rates of high blood pressure, diabetes, and obesity; (iv) higher death rates from chronic disease including cancer; (v) higher prevalence of mental health problems; (vi) higher rates of alcohol abuse and smoking; and (vii) poorer dental health (BHI, 2016).

It is important to note that there are significant variations in rural people’s health, health care requirements, and the services accessible to them. The available health care workforce in rural areas is frequently challenging for organisations providing health care due to difficulties recruiting suitably qualified and trained staff (Gibb, 2001; Hegney, 1996), and the capacity of the organisation to provide leave relief for those staff (BHI, 2016). The NSW Rural Health Plan: Towards 2021 identifies a range of strategies which aim to improve the health and wellbeing of people in rural areas, including a key strategy relating to the enhancement of the rural health workforce (NSW Health, 2014). A commitment to ensure there is a focus on reducing the disparity in health outcomes via system change within health care is an enormous challenge to which the Cancer Institute and NSW Health are committed (CINSW, 2016).

A range of government-funded initiatives and programs are well established in NSW including the financial assistance for people travelling for health care, available through the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS). This state government-funded scheme provides modest refunds of costs associated with travel and accommodation for people whose
access to health care is disadvantaged due to their place of residence. The Australian Government provides funds to the NSW Rural Doctors Network to support a coordinated general practitioner-obstetrician and midwife service for Aboriginal women and babies in a number of locations. The Central West of NSW sits within the Western NSW Local Health District, which is the second least densely populated local health district in NSW. In an effort to improve access to health care, a robust Patient Flow Unit works with clinicians across the district to support the provision of clinical care at the most appropriate location and time (BHI, 2016). This includes coordinating patient transport and available inpatient beds where clinical services are available, particularly in the larger towns of the Central West.

The National Rural Health Alliance (NRHA) calls for further government action to address poorer health outcomes and access to health resources. Seven million Australians live in rural Australia, including 70 percent of the national Aboriginal and Torres Strait Islander population, yet rural populations are older, and have higher levels of health-related risks and higher rates of chronic disease (National Rural Health Alliance, 2016 (NRHA); 2019). Despite increased levels of need, people in this demographic face a maldistribution of the medical, dental and health workforce in Australia (NRHA, 2012; 2016, 2019), therefore, they have less access to health services. Health policy makers continue to focus the vast majority of resources and initiatives on models designed to meet metropolitan needs, which are less than ideal in rural and remote Australia.

Improved investment and focus on the health continuum, from prevention and primary care to acute care and community-based care for people living in rural communities, is needed to meet the health care demand. Indeed, it needs to be viewed as an investment in future productivity and reduced health spending (NRHA, 2016). Coupled with an over-arching principle of providing appropriate, comprehensive health care as closely as possible to where people live is the need for a nationally funded and coordinated program to support people requiring complex medical care in metropolitan locations through improved
reimbursement of travel costs and increased availability of accommodation at tertiary health care locations (NRHA, 2016).

A collaborative review undertaken in 2007 – 2008 by the Cancer Council NSW and Can Assist⁴ reported on the nature and appropriateness of available patient accommodation, requirements to meet accommodation needs in the future, and possible options. The review outlined how accommodation challenges alter a person’s cancer journey (CCNSW, 2009).

Analysis of all cause cancer mortality data of rectal cancers in Queensland found distance the key to variations in mortality rates, with a six percent increase in mortality for each 100 kilometres a person lives from a radiotherapy treatment facility (Baade, Youlden, Coory, & Chambers, 2011). These cancers were not more advanced at time of diagnosis or treatment, nor was age a factor in increased mortality. This finding challenges the traditional centralised model of radiotherapy in Queensland and proposes that there is a need to integrate policy with clinical care to improve survival, whilst focusing on culturally appropriate support for rural and remote residents with rectal cancer, particularly for Aboriginal people.

Two medical oncologists working in rural NSW (Fox & Boyce, 2014) reported on the range of health inequalities in regional and remote Australia, ranging from increased mortality associated with distance from radiotherapy treatment centres to suboptimal treatment for early breast cancers, diagnostic delays and poor cancer screening rates. Recommendations focus on the need for ongoing funding to be allocated from both state and federal governments (Fox & Boyce, 2014) to enable health services to recruit and employ locally based oncology teams to provide best practice care.

A research study investigating the use of complementary and alternative medicine (CAM) by women found a significantly higher use of CAM in women from rural and remote areas at 32 percent and 30 percent respectively when

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⁴ Can Assist is a community-based charity focused on supporting country families in NSW affected by cancer through the provision of financial and home-based support and accommodation services for those who travel to attend cancer treatment services.
compared with women living in urban areas at 28 percent, indicating that CAM may play a key role in health and well-being activities of women living outside metropolitan areas (Adams, Sibbritt, & Chi-Wai, 2011). The researchers based their definition of the use of CAM on a consultation with an alternative health practitioner, excluding any of the participant’s reports of self-prescribing of CAM, which previous research has determined to be at a higher incidence. This shortcoming necessitates a prospective study comparing the use of all CAM in urban, rural and remote populations to better understand the reasons for its use (Adams et al., 2011) and determine the use of CAM in people with cancer.

2.5 Central West NSW
This study was focused on people with cancer living in the Central West of NSW in Australia where there are varying ARIA classes ranging from Highly Accessible to Remote. The Central West of NSW is an area of 63,000 square kilometres that lies west of the Blue Mountains, approximately 200 kilometres west of Sydney. The region includes the inland cities and towns of Bathurst, Orange, Cowra, Forbes and Parkes and has a population of approximately 177,000 people (Regional Development Australia - Central West, 2019). Smaller towns in the region include Blayney, Carcoar, Cudal, Cumnock, Manildra and Molong. The two main population hubs of the Central West are the inland cities of Bathurst and Orange, both of which sit within the ARIA Highly Accessible category with scores of 1.26 and 1.62 respectively. Manufacturing, mining and agribusiness form the backbone of the region’s growing and diverse economy. The Lachlan Valley River system in the west supports large holdings of land which are licensed for irrigation use.

The Central West also has strong education and social assistance sectors which provide employment for approximately 19 percent of the region’s population (RDA, 2019). Building on the strong agricultural base, including wool, cattle and wheat, are the growth of dairy farming, viticulture and horticulture. Tourism in the region has become an important sector with the development of a growing reputation for fine food and wine attracting three million visitors to the region annually (RDA, 2019).
The Bathurst region has a population of 42,242 people whilst the city of Orange has a population of 41,809 (Hogan et al., 2008). The population of both cities at the time of the last national census in 2016 is predominantly Australian-born in comparison with the national rate of 69.8 percent – Bathurst reported that 86.1 percent and Orange 85.3 percent of local residents were born in Australia; indeed less than four percent of the population of either Bathurst or Orange reported speaking a language other than English at home (Australian Bureau of Statistics, 2016(ABS)). The national percentage of the population reported as Aboriginal is 2.5 percent, whilst Orange and Bathurst reported significantly higher proportions at 5.4 percent and 4.6 percent respectively.

2.6 Cancer in Rural Populations

Almost a third of the Australian population resides in a rural area and whilst cancer incidence is comparable to that of metropolitan populations, “mortality is higher for those individuals who live in rural regions” (White, 2007, p. 22). In a landmark article from 2004, data was analysed regarding variations in cancer incidence and survival rates, rather than incidence and mortality rates which have been historically studied (Jong et al., 2004). Reference is made to research from the US in 1991 which revealed differences in the stage of cancers at time of diagnosis across rural and urban populations. This difference is considered likely to be a result of poor access to and use of quality cancer screening, diagnostic and treatment services.

In Australia, health inequalities remain for people who live outside metropolitan areas, worsening with distance and isolation, and socioeconomic disadvantage (Godding, 2014), and requiring governments to ‘pull the right levers’ for rural health care to improve (Kamerman, 2014). Policy makers acknowledge the disadvantage which is experienced by people in rural and remote areas (Tracey, McCaughan, Young, & Armstrong, 2016). Rural residents have been found to have worse survival outcomes when compared with people from metropolitan areas across a wide number of cancers (CCNSW, 2009; Fox & Boyce, 2014; McConigley et al., 2011a; NRHA, 2019). People residing in remote locations were found to be 35 percent “more likely to die as a result of their cancer over the ensuing five years than are people living in areas with the greatest access to services” (Jong et al., 2004, p. 620).
Thirty-six percent of new cancers in Australia are diagnosed among people living in regional, rural and remote areas, while the proportion of the Australian population living in regional, rural and remote areas is 32 percent (Gordon, Ferguson, Chambers, & Dunn, 2009). This Queensland study found that new cancer diagnoses were over-represented in rural Australians in comparison with the rest of the population.

The NRHA reports that a third of people with cancer in Australia live in regional and rural locations and have worse survival rates than their city counterparts. People living in remote areas with prostate and cervical cancer are up to three times more likely to succumb to their cancer illness than those in regional and city areas (NRHA, 2019). Studies have determined that a lack of access to tertiary cancer care in regional areas influences survival rates. The NRHA reports contributing factors to poorer cancer survival rates as: fewer diagnostic and treatment services, later diagnosis, lower socioeconomic status, reduced physical activity rates, higher rates of alcohol consumption, increased rates of smoking, higher proportion of Aboriginal people and higher sun exposure (NRHA, 2016). The increased financial costs for people from rural and remote areas associated with accessing specialist cancer care services requires government support to ensure greater financial assistance is available.

Mercuri and Kallady (2005) reported the literature acknowledges rural people with cancer have higher levels of unmet needs in comparison with the corresponding urban/metropolitan population. More recent authors corroborate this finding with reasons proposed including: reduced access to specialist care, people having further advanced cancer at the time of diagnosis and lower quality cancer services, including less follow-up and supportive care availability in rural locations (Mercuri & Kallady, 2005; Bettencourt, Schlegel, Talley & Molix, 2007; McConigley, Platt, Holloway & Smith, 2011; Martin, Coory & Baade, 2012; Baade, Dasgupta, Aitken & Turrell, 2013; Afshar, English & Milne, 2019).

The Clinical Oncological Society of Australia (COSA) report Mapping Rural and Regional Oncology Services in Australia, which compared regional hospitals
providing chemotherapy to people with cancer to three metropolitan and larger urban centres highlighted significant issues for people living in regional and rural locations across the nation. Access to services – including medical and surgical specialties and allied health staff to provide multidisciplinary and psychosocial care – and quality and safety issues regarding administration of chemotherapy were demonstrated. Unsurprisingly, the more remote the location, the poorer the access to quality care (Begbie & Underhill, 2007).

Regional Cancer Centres of Excellence were proposed as a solution to this situation, however, inadequate access to electronic clinical data systems restricts the information available for analysis on a population basis in rural and regional areas. Coupled with a well-documented shortage of specialist cancer care professionals, locally based access to quality cancer care will be difficult to achieve. Adequate resources and support to grow regional oncology centres is crucial, as is meeting the travel and accommodation needs of patients from rural locations who access care in regional centres. To achieve this, Begbie and Underhill (2007) conclude that all levels of government must be committed to ensuring quality cancer care for all Australians.

Six years later in 2013, the Australian Government funded the establishment of regional cancer centres, investing $672 million across the country (DOH, 2019) with the aim to improve access to services and improve cancer outcomes in regional Australia. There are now twenty-five regional cancer centres providing radiotherapy, chemotherapy and other systemic treatments, with each state government providing funding for service delivery and staffing costs. The model of cancer care for people in rural and regional areas varies across Australia; facilitating access to metropolitan services in Perth and Bunbury in Western Australia, and Adelaide in South Australia, for the majority of people living outside these locations, is the focus. Victoria with its smaller geography and larger population density has benefitted from regional cancer centres. A qualitative study investigating the fly in-fly out model of visiting oncologists to rural and regional centres found while the infrastructure investment in regional cancer centres is helpful, funding to enable locally based comprehensive specialist staffing for the centres is lacking in many locations (Grimison et al.,
Without this additional resourcing for specialist staffing, the inequities in rural cancer outcomes will persist.

In NSW, geography and population density tend to govern access to care close to home. For some rural people whilst cancer care is provided in a range of locations, travel for specialist services remains a way of life. An example of this is found in the Central West, with Orange having a range of cancer care available locally, yet for people who live in Bathurst, Cowra, Forbes, Parkes and locations between, travel to Orange is still required. Whilst closer to home than a metropolitan centre, people are still significantly impacted when needing services not available where they live. It is important to have streamlined referral patterns for the expertise required for rarer, highly specialised cancers such as oesophageal and pancreatic cancer, and specialised treatment is best provided in a centre of excellence in a metropolitan location (CINSW, 2019b).

In other countries, similar findings relating to rural people have been found. High rates of known risk factor behaviours, including smoking and poor diet, coupled with less uptake of cancer screening activities and delayed diagnoses of cancer all contribute to the increased burden of cancer in rural people were found in one US study (Vanderpool, Kornfeld, Mills, & Byrne, 2011). These are equally significant issues for rural Australians. The authors went on to conclude that the lack of awareness of the value of clinical trials in rural communities was a key factor in the significantly low number of rural people participating in cancer treatment trials (Vanderpool et al., 2011).

An Australian longitudinal study examined death rates in rural and metropolitan women and found increased mortality from lung cancer and chronic obstructive pulmonary disease despite no differences in smoking rates or smoking histories (Dobson, McLaughlin, Vagenas, & Wong, 2010), concluding that inequalities in health care and environmental hazards be investigated. A separate study found people with non-small cell lung cancer who reside outside of metropolitan areas have significantly worse outcomes as many are not referred to specialist thoracic surgical centres where staging and potentially curable surgery could be performed (Tracey et al., 2016). In order for these referrals to function, the
health care system must inject meaningful increases in support for patients and their families.

A New Zealand review into lung cancer found barriers to quality cancer care impacted more on people from lower socio-economic groups and those from minority populations, particularly those living in rural locations (Stevens & Murray, 2010). The authors noted that poor survival outcomes associated with lung cancer resulted from the later diagnosis of lung cancer in rural and minority groups, therefore treatment is no longer curative in intent (Stevens & Murray, 2010).

Since the commencement of a limited national screening program for bowel cancer in 2008, Weller (2010) reported early uptake of screening activities is significantly lower in deprived populations, males and ethnic subgroups, and a similar result was found in a UK pilot study. To achieve successful recruitment to a bowel screening program, Weller (2010) indicates that strategies to overcome psychological and attitudinal barriers are essential, including tailored approaches for certain groups within populations. General practitioners in rural Australia were identified as ideal key players to adapt screening messages to suit their local communities (Goldsbury et al., 2013), however, this requires an extension of primary care’s well-established roles to include education and promotion of bowel cancer screening to increase uptake of this important population-based screening program.

2.6.1 Rural People – Cancer Screening
Population-based screening for bowel cancer has a positive impact on colorectal cancer survival (Paddison & Yip, 2010). A South Australian study examined factors influencing men in their decision to participate in bowel cancer screening using the faecal occult blood test (FOBT) in a regional community. Perceptions of physical discomfort and embarrassment regarding screening activities have been established in the literature, and the study found that men who had a perception that other cancer screening activities such as for breast and prostate are embarrassing or cause physical discomfort were less likely to participate in bowel screening (Paddison & Yip, 2010).
Those authors recommended that further research include assessment of perceptions of the value of the screening activity to detect cancer and increase survival, and increased detail relating to embarrassment and discomfort, particularly in regional communities. Increased understanding of these perceptions in communities would enable education and information campaigns to target these issues, thereby increasing participation rates. A limitation of the study was that participants were a convenience sample of male members of a service club in a regional location with an average age of 59. Paddison and Yip (2010) recommend a multi-location, randomised recruitment strategy be utilised in future research.

In an attempt to address the disadvantage in access to health care in rural areas, researchers sought to understand rural people’s ability to access general practitioners, costs, the travel required, and service suitability in the rural context, by seeking information from people living in small towns in NSW and Victoria. The survey tool was delivered to households and asked people to report their experiences, as the researchers aimed to build on previous research focused on improved models of primary health care in rural and remote areas including population-based cancer screening (Russell et al., 2013). Recommendations for policy makers included increased numbers of general practitioners, increased health promotion activities relating to detecting cancer, and the impact of social disadvantage for this population (Russell et al., 2013).

### 2.6.2 Cancer Care in the Aboriginal population

The literature relating to cancer in the rural and regional populations is incomplete without a discussion of cancer in the Aboriginal population. Cancer outcomes among Aboriginal Australians are far worse when compared to the non-Aboriginal population, including significantly higher death rates (Jagadish, 2006). This reflects patterns of reduced access to and engagement with health care services (Green, Anderson, Griffiths, Garvey, & Cunningham, 2018). Aboriginal people on average die 20 years younger than other Australians, and cancer is now the third leading burden of disease in the Aboriginal community (Cancer Australia, 2018). In fact, Aboriginal people “experience a different pattern of cancer incidence and significant disparities in cancer outcomes
compared with non-Indigenous Australians” (Cancer Australia & Cancer Council, 2018, p i). A recent data analysis report found that Aboriginal people were of a younger age at the time of a cancer diagnosis, with a higher proportion of cancers of the breast and bowel diagnosed prior to the recommended screening age of 50 years (Tervonen, Morrell, Roder, You, & Currow, 2019).

The term Aboriginal is used in this context to include both Aboriginal and Torres Strait Islander people, in recognition that Aboriginal people are the original inhabitants of NSW (Aboriginal Health & Medical Research Council of New South Wales, 2011). A pattern of under-reporting Aboriginal status in health care related data collections and statistics on cancer has been noted (Women's Health Goulburn North East, 2010). Although improving, this adds complexity when determining future strategies relating to health care provision for Aboriginal people.

As discussed previously, participation by Aboriginal people in cancer screening programs is usually lower than non-Aboriginal people, and as a population group they are more likely to be diagnosed with cancer when it is advanced disease (Cancer Australia, 2015, 2018), along with lower hospitalisation rates for cancer care. Death from cancer in Aboriginal people is, on average, 40 percent higher than for non-Indigenous Australians (AIHW, 2018b). Aboriginal people in rural areas often have less access to health care due to a range of issues, including socio-economic disadvantage, cultural and geographical challenges (AIHW, 2018b). This is similar to reports from other indigenous populations in Canada, New Zealand and the USA where there are comparable histories of colonisation and marginalisation (Taylor et al., 2018).

In the Tobacco Strategy (NSW Health, 2018) the self-reporting rate of smoking in 2017 amongst the general population is reported at 15.2 percent, whilst 28.2 percent of Aboriginal adults identified as daily smokers. This is a significant finding given that approximately 20 - 30 percent of all cancers are linked to active and passive smoking (AIHW, 2018b). The low-level uptake of cancer screening programs by Aboriginal people, including cervical pap smear testing and the National Bowel Cancer Screening Program for Australians, has resulted
in a recommendation for culturally appropriate education to ensure Aboriginal people receive appropriate cancer screening and early detection (Cancer Australia, 2015; CCNSW, 2008).

The lack of culturally appropriate screening, diagnostic and cancer treatment services directly contributes to poorer cancer outcomes in the Aboriginal community (Cancer Australia, 2018; Shahid, Finn, Bessarab, & Thompson, 2011). The lower income and standard of living experienced by many Aboriginal people also impact access to the transport and accommodation services required to participate in cancer screening, diagnostic and treatment services in both regional and metropolitan locations.

It has been recognised that Aboriginal and Torres Strait Islander women face cultural, linguistic and geographic barriers to cervical screening (Kirk, 1998; Reath & Carey, 2008). State and territory cervical screening programs have developed initiatives to increase participation of Indigenous women in cervical screening, such as the employment of Aboriginal and Torres Strait Islander health practitioners, and the development of principles, standards and guidelines for screening Aboriginal and Torres Strait Islander women (Reath & Carey, 2008). However, without being able to measure participation in cervical screening by Indigenous status, the overall effectiveness of these initiatives is not known. Aboriginal Australians are succumbing primarily to cancer of the lung, female genital organs (most commonly cervical carcinoma) and liver ... whose prognoses among non-Aboriginal people have been dramatically improved by prophylactic screening, immunisation and superior treatment option. (Jagadish, 2006, p. 213)

A widening mortality rate from cancer between Aboriginal people and non-Aboriginal people is increasing. Aboriginal people’s mortality from cancer has continued to increase where for non-Aboriginal people mortality rates from cancer have decreased. Therefore, as cancer is the second highest cause of death in Aboriginal people, the burden of disease is significant (Cancer Australia, 2018).

Whilst cancer screening activities have aided in the earlier diagnosis of cancer for the general population, Aboriginal Australians “are diagnosed at a more advanced stage of cancer; have poorer continuity of care; lower compliance
Aboriginal mortality from lung cancer is approximately 3.6 times higher than for the non-Aboriginal population, whilst Aboriginal women have almost 10 times the risk of dying from cervical cancer, and Aboriginal Australians are nearly 12 times more likely to die from hepatocellular carcinoma (Jagadish, 2006).

This inequality in cancer outcomes requires remedial action from both cancer care services and primary health care providers. Recommendations to increase participation rates of cancer screening and treatment within the Aboriginal population include focusing on the key aspects of transport, accommodation, hospital environment, Aboriginal support and liaison, and transfer of care with the involvement of Aboriginal Elders and health workers as key players in the process, building communication, trust and cultural safety (Shahid et al., 2011). Cultural awareness training for health care staff is considered a first step towards providing culturally appropriate treatment and support (Taylor et al., 2018).

The Cancer Institute NSW (2017) identified the need for the organisation to contribute to improved outcomes from cancer for Aboriginal communities; an innovative Reconciliation Action Plan was developed to guide activities. A project in southern NSW which aimed to remedy the local rural and regional health services’ capacity to develop accessible, culturally appropriate and safe health services for Aboriginal people with cancer (Simpson, Reid, Zubrzycki, & Jones, 2011). This project focused on building collaborative relationships and partnerships between Aboriginal health workers (AHW), Aboriginal health care services and cancer care clinicians. The project goal of ‘working together’ commenced with consultation with six of nine Aboriginal communities in the region, and was guided by the “values of respect, integrity and reciprocity” (Simpson et al., 2011, p. 14).

An historic partnership agreement between four health and community organisations focuses on working together to improve Aboriginal cancer outcomes in a local community in Sydney (National Aboriginal Community Controlled Health Organisation, 2012 (NACCHO)). Through partnering, these organisations resolved to highlight to their community the risk factors associated
with cancer and enhance access to local cancer services (NACCHO, 2012) so that larger numbers of Aboriginal people receive earlier diagnosis and treatment for cancer.

Within Aboriginal communities, fear of cancer frequently leads to the situation of late diagnosis of cancer, when acute physical symptoms are unable to be ignored (Simpson et al., 2011). A low level of confidence in specialist cancer care services accessibility and availability were identified, as were past experiences of racism and a lack of community education within this population. A brochure on available cancer services was developed by a group of AHW and non-Aboriginal cancer care clinicians, with input from an Aboriginal artist, and promoted within the six participating Aboriginal communities. Cultural awareness training for non-Aboriginal cancer care clinicians was undertaken to improve clinicians' understanding of Aboriginal culture, health status and issues with chronic diseases, and the need to provide services in a culturally respectful manner (Simpson et al., 2011).

Willis et al (2011, p. 100) report that the literature overwhelmingly acknowledges two main issues for Aboriginal women with a gynaecological cancer; “poor access to health services, including lack of resources, and culturally inappropriate care”. Aboriginal women have a higher than average rate of gynaecological cancers, especially those residing in rural and remote areas of the country, where there is “a lack of accessible primary health care services and access to cancer specialists” (Willis et al., 2011, p. 100). Thus, screening activities, diagnostic services and cancer treatments are arduous for this population group. Locally based health care services, particularly Aboriginal health care services, are acknowledged as being ideally positioned to be able to provide high quality care, however, it is recognised that current funding levels may be insufficient to accomplish this (Willis et al., 2011). This results in a requirement to travel or relocate to a metropolitan location for cancer treatment, which causes both the patient and the family to experience both the social dislocation and financial hardship faced by the general population living in rural and remote Australia, exacerbated by “the cultural inappropriateness of health services ... described as being alienating and threatening, and lack of access to
appropriate care has been linked to poor screening participation rates, and high ovarian cancer mortality rates” (Willis et al., 2011, p. 100).

It has been reported that Aboriginal women often describe sacrificing their own cultural beliefs and values when choosing to access health care services. The importance of a holistic approach to health care provision has resonance in the literature (Willis et al., 2011), where the importance of supporting medical and nursing care in a manner that does not compromise the cultural beliefs and practices of all patients is emphasised. This supports the institution of cultural awareness training for non-Aboriginal cancer care staff reported above (Simpson et al., 2011).

The importance of Aboriginal Health Workers who are able to function as a bridge between Aboriginal culture and doctors and nurses was identified and clearly articulated in one recent small study in rural and remote Aboriginal women (Willis et al., 2011). The Aboriginal women from a regional centre were less concerned about the sex of the doctors and nurses caring for them than those from a more remote location, leading the authors to conclude that much of what is found in the literature must be considered as context specific and not able to be generalised to all Aboriginal women (Willis et al., 2011).

The urgent need for tools and approaches to measuring Aboriginal people’s experience of specialist cancer care services has been identified as fundamental for services to learn how to gain trust and meet the needs of Aboriginal people with cancer (Green et al., 2018).

Cancer Australia and the Cancer Council have joined to develop and publish an Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer (Cancer Australia & Cancer Council, 2018) aimed at reducing disparities and improving outcomes for Aboriginal and Torres Strait Islander people with cancer through the provision of culturally safe cancer care.

2.6.3 Rural People – Cancer Treatment

Living in a rural area can impact on the treatment choices made by people with cancer. A Victorian retrospective study from 1993-2000 comparing surgical procedures for breast cancer detected via screening activities found that urban
women “consistently had higher rates of BCS (Breast Conserving Surgery) compared to rural women despite increased overall adoption of BCS” (Kok et al., 2006, p. 50).

Similarly, a Western Australian study found that women aged between 30 and 89 living in rural locations were more inclined to opt for modified radical mastectomy for stages I and II breast cancer than breast conserving surgery. This decision was reported by the participants after receiving information and advice from surgeons, family and general practitioners (Mastaglia & Kristjanson, 2001). Fear of breast cancer recurrence and fear of dying from cancer were noted as significant considerations for the participants in the study, as was poor access to radiotherapy services. People living in rural areas of Western Australia experience significant travel and dislocation from family and support networks in order to seek radiotherapy treatment in Perth or Bunbury.

A study of the management of breast cancers detected by BreastScreen Victoria between 1993 and 2000 aimed to establish if there were any differences in the surgical treatment provided to women in rural and urban populations (Kok et al., 2006). Urban women with invasive breast cancer were found to have higher rates of breast conserving surgery than their rural counterparts independent of “tumour size, surgeon caseload, patient’s age, and socioeconomic status” and this trend continued over the study period (Kok et al., 2006, p. 50). The researchers were not clear on the causes for the disparity and called for further studies to explore the differences in the pattern of care for breast cancer in the state.

A prospective study of approximately 2000 women with early breast cancer in the Australian Capital Territory (ACT) and South Eastern NSW from 1997 to 2006 measured compliance with evidence based best practice guidelines, comparing urban and rural treatment locations for significant differences (Craft et al., 2010). Rural women who chose to be treated in the metropolitan centres were included in the urban results. Women living in rural areas made up 36.5 percent of the cohort, however, of these, 63 percent chose the metropolitan setting for treatment, thus the rural treatment location group were less than 10 percent of those enrolled. It was noted that enrolment in the study was via their
treating clinicians and that this may enable selective enrolment, however, the enrolment rate was compared with early breast cancer incidence from the ACT Cancer Registry, demonstrating a 90 percent participation rate. No such comparison was able to be undertaken for the patients in South Eastern NSW (Craft et al., 2010).

Assessment against a number of quality indicators from the Australian National Breast Cancer Audit included axillary lymph node dissection and sentinel node biopsy usage, adequacy of surgical margins, post-operative radiotherapy, chemotherapy and endocrine treatments. Recurrence rates and survival measures were the outcomes investigated in this study. Women who had surgery in rural locations were found to be generally older and more likely to be post-menopausal than the women treated in the urban locations. There were no significant differences found in mastectomy rates when comparing treatment locations.

Women accessing treatment in the rural locations were more likely to experience a recurrence of their breast cancer and less likely to receive post-operative radiotherapy. Inconvenience associated with the travel, costs and social dislocation associated with attending a course of radiotherapy was postulated as reasons for patients choosing not to seek radiotherapy treatment. Breast surgery caseloads were compared between surgeons in rural and urban locations and it was found that the urban surgeons had caseloads at least four times greater over the nine-year period than their rural counterparts (Craft et al., 2010). No significant differences were detected regarding systemic chemotherapy and endocrine treatments in the two groups.

Assessing the impact of the location of surgical intervention on the risk of death was undertaken using proportional hazards regression modelling which adjusted for “demographic factors, tumour characteristics and treatment” (Craft et al., 2010, p. 397). Mortality from breast cancer following surgery in rural locations was significantly higher than those from the urban treatment location group.
Differences in prostate cancer outcomes in rural versus urban areas were analysed using data from the Australian Institute of Health and Welfare. The incidence trends of prostate cancer reveal similar rates in men aged 50-79 years of age (Baade et al., 2011). The five-year relative survival from prostate cancer in Australia has increased substantially over the last 30 years to be among the highest in the world. However, for men in rural areas it was poorer and the gap between urban and rural men increased over time (Baade et al., 2011). Mortality rates for all causes for men in rural areas was higher than for those living in cities, and this remained consistent for prostate cancer where the difference between rural and urban demonstrated an increasing trend: those in urban locations fared better than the rural cohort (Baade et al., 2011).

A Western Australian (WA) report into a model of rural cancer care noted that mortality rates from cancer for people living in rural locations across the country are higher than for their counterparts living in a metropolitan location, “with mortality rates for lung, colorectal and prostate cancer significantly higher in rural areas of Australia compared with urban centres” (McConigley, Platt, Holloway, & Smith, 2011b, p. 324). The authors report that a number of studies reveal that patients with cancer in rural WA “receive less than optimal treatment and experience poorer outcomes than metropolitan cancer patients, particularly in regard to the type of surgery performed”, and that access to radiotherapy services was difficult (McConigley et al., 2011b, p. 324). People with cancer experienced longer delays when consulting specialist medical staff and “their general practitioner appeared to make referral decisions based on familiarity and ease of access to services, rather than clinical indicators or need for multidisciplinary care” (McConigley et al., 2011b, p. 324).

The rural cancer care model is a network formalising “links between country and city cancer care providers and offers benefits for consumers and health professionals” (McConigley et al., 2011b, p. 325). The goal of the network was to address the limited access rural patients have to cancer care services and “that standards of cancer care received by rural people often does not meet best-practice guidelines” (McConigley et al., 2011b, p. 325). Implementation of the model enabled people with cancer living in the southern part of WA locally based cancer care coordination, improved access to specialist medical staff in
Albany, telehealth consultations to medical specialists in Perth and the ability to have chemotherapy closer to home. The model was developed with consumer input as a key factor.

A Canadian qualitative study involved older people from rural areas with advanced cancer receiving palliative care, and palliative care health professionals investigated their access to care and ability to determine place of death (Duggleby et al., 2011). As in Australia, rural Canadians have a larger number of health risks, poorer health status, shorter life expectancy and higher mortality rates than Canadians living in urban areas and it has been proposed that the level of health care services available is a significant factor in these differences. The situation is expected to become worse with the ageing of the population and the associated increase in complex chronic diseases. Findings of the study articulated the complexity of both end of life care and living in a rural location, and the impact of this context on the experiences of both care givers and people with advanced cancer (Duggleby et al., 2011).

2.6.4 Demographics of Cancer in the Central West of NSW

The Central West of NSW sits in the eastern and southern parts of the Western NSW Local Health District (WNSWLHD) which covers a vast geographical region of NSW stretching from Oberon and Mudgee in the east to beyond Cobar and Bourke in the west, and Lightning Ridge to the Queensland border in the North. The WNSWLHD includes 23 local government areas, of which eight are remote, however, the Central West represents only 11 of these local government areas, with no remote areas.

It is projected that by the year 2021 within the WNSWLHD, 2,055 people each year will be newly diagnosed with some form of cancer. The latest available data from 2015 reveals that 1,806 people within the WNSWLHD were diagnosed with cancer, and 594 deaths were cancer related (CINSW, 2019c). In the two largest population hubs in the Central West of NSW the cancer statistics show small variation.

In 2015 in Bathurst Regional local government area, 108 women and 137 men were diagnosed with cancer. Between the years 2011 – 2015, the most
common clinical cancer group in Bathurst Regional area was urogenital with 24.7 percent, followed by breast cancers at 12.5 percent, skin cancers at 11.3 percent and bowel cancers at 10.8 percent. The fifth most common clinical cancer group was respiratory cancers at 10.3 percent. The extent of disease at the time of diagnosis was:

**Table 2: All Cancers, persons, by extent of disease – Bathurst Regional LGA, 2011 – 2015**

<table>
<thead>
<tr>
<th>Extent of Disease</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Localised</td>
<td>43.2 percent</td>
</tr>
<tr>
<td>Regional</td>
<td>17 percent</td>
</tr>
<tr>
<td>Distant</td>
<td>13.7 percent</td>
</tr>
<tr>
<td>Unknown</td>
<td>26.1 percent</td>
</tr>
</tbody>
</table>

Source: Cancer Institute NSW, 2019 statistics module online

In 2015, the Orange local government area reported that 78 women and 127 men were similarly diagnosed with cancer. Between the years 2011 – 2015, the most common clinical cancer group in Orange was urogenital with 20.7 percent, followed by bowel cancers at 13.3 percent, skin cancers at 11.9 percent and breast cancers at 11.6 percent. The fifth most common clinical cancer group was respiratory cancers at 10.7 percent.

**Table 3: All Cancers, persons, by extent of disease – Orange LGA, 2011 – 2015**

<table>
<thead>
<tr>
<th>Extent of Disease</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Localised</td>
<td>37.4 percent</td>
</tr>
<tr>
<td>Regional</td>
<td>19.3 percent</td>
</tr>
<tr>
<td>Distant</td>
<td>13.1 percent</td>
</tr>
<tr>
<td>Unknown</td>
<td>30.3 percent</td>
</tr>
</tbody>
</table>

Source: Cancer Institute NSW, 2019 statistics module online

Varying levels of specialist cancer care is provided across the Central West of NSW, with radiotherapy treatment services only available in Orange. Chemotherapy and other systemic therapies are provided at hubs in Bathurst and Orange, with low risk treatments provided at outreach clinics in Cowra and Parkes.

**2.7 Encountering Cancer**

The literature contains a vast array of studies describing treatment-related effects and issues encountered by cancer patients having radiotherapy, chemotherapy or other systemic treatments. Understanding the journey – the ‘individual-ness’ and complexities which patients face, offers a glimpse into the whole experience of a cancer diagnosis. One such recent study of men with
prostate cancer reveals the journey is ‘not a straight line’ (Schildmeijer, Frykholm, Kneck, & Ekstedt, 2019). This Swedish study exposes that people with cancer don’t encounter cancer within the concept of a standardised care pathway. Standardised care pathways are based on mapped journeys to produce templates for patient care planning. In mapping the journey of a prostate cancer patient, a linear approach is inherently utilised, however, this did not resonate with the experiences of men with cancer who participated in the study. For the men, it was about ‘walking a tightrope’ (Schildmeijer et al., 2019) and learning to wait, and to adjust to the changes in their bodies.

Additional themes of ‘adjusting to a different life’ line’ (Schildmeijer et al., 2019) and the challenges of finding the information each felt they needed were outside the standardised care pathway of the health care system. The authors noted that even when the care pathway was followed, the men spoke of feeling left in limbo. The powerful emotions and experiences associated with the frequent waiting – for a diagnostic test, a consultation with a specialist, to be scheduled for treatment – were summarised as feeling powerless and anxious that the journey was mired. The impact of incontinence and impotence following treatment was overwhelming for some, and previous coping methods no longer supported them. The participants wanted additional information related to treatment; and then following treatment, information on how to cope with the adverse effects of treatment (Schildmeijer et al., 2019).

Until referral to cancer services, people in the Central West of NSW have limited education and support available locally, other than that offered by general practitioners and surgeons. For many, the need to develop robust coping strategies is the result of living with a diagnosis of cancer.

2.7.1 Cancer, Resilience and Survivorship
A review of the literature by Lashbrook and others (2018) concerning the coping strategies used by people who had survived breast, prostate or colorectal cancer found that the strategies differed by the type of cancer and across the survivorship journey. Each of these cancers are characterised by longer survival rates in Australia, therefore understanding how people cope with ‘surviving cancer’ is important. The literature search found more than two thousand
articles, however, only nineteen met the criteria of coping mechanisms in people with a diagnosis of breast, prostate or colorectal cancer who had completed primary cancer treatment (Lashbrook et al., 2018). The authors found that coping mechanisms varied between people, and indeed a person’s style of coping changed over time. Breast cancer patients were likely to focus on accepting their diagnosis and undertaking activities which they found to be supportive; socially and emotionally. Colorectal patients were focused on attaining information to manage their circumstances, including colostomies, so they could reengage in social activities. For men with prostate cancer, their personality was a powerful determinant in coping during survivorship. Monitoring patients on survivorship care plans is important to determine if individual coping strategies are helpful, or if additional support is required during transition from treatment to survivorship (Lashbrook et al., 2018).

Another study of women with breast cancer during survivorship found that many felt abandoned by the system which had provided treatment and support (Matthews & Semper, 2017). Ongoing feelings of the physical and psychological impact of the disease plagued participants. The unmet needs reported by the participants led to increased stress and feelings of isolation. This was coupled with a decrease in support from their personal support networks once treatment was completed (Matthews & Semper, 2017). Participants also reflected on the lack of support for their spouse and family during this period of their lives. Each woman with breast cancer has differing supportive care needs which the current system is not routinely meeting.

A further study focusing on coping, resilience and perceived quality of life in women with gynaecological cancers who were enrolled in a separate clinical trial found that those who were resilient experienced a better quality of life than those who do not cope as well. These women were in the treatment phase of their illness living in the United States. Utilising multiple questionnaires to evaluate psychological wellbeing, the role of resilience was highly suggestive of impacting on the individual’s ability to find a positive outcome of their diagnosis. This appeared to lead to them finding meaning in their lives whilst fostering a sense of peace (Manne et al., 2015).
A longitudinal study of the impact of beliefs relating to cancer undertaken in Canada found that those patients who had their negative beliefs regarding the outcome of their cancer illness reinforced at the time of first surgical intervention were more likely to suffer psychological distress. Symptoms were found to include insomnia, anxiety, fear of cancer recurrence and depression (Desautels, Trudel-Fitzgerald, Ruel, Ivers, & Savard, 2017). These were found to be more severe than in people without negative beliefs regarding the outcome of their cancer illness. Although the study was a secondary analysis of data gathered for an insomnia study, it had a large sample size of people with a range of cancers.

An American report in 2007 predicted the numbers of people diagnosed and living with cancer will rise by 81 percent by 2020 (Association of American Medical Colleges, 2007) and while in Australia we do not have data to support the claim of the increase in the number of people living with cancer, the more chronic nature of cancer is recognised. Acknowledging the psychological challenges associated with a diagnosis of cancer is important as each person copes with the physical, social and psychological impacts. The array of emotions, decisions needed, and the impact of the disease leads to experiences of grief and loss for a person with a diagnosis of cancer. The chronic aspect of living with cancer does not diminish the ongoing the psychological challenges.

2.8 Grief and Loss

Understanding grief and loss is a challenge, despite each concept being experiences that affect everyone at some time during their life (Rubin, Malkinson, & Witztum, 2012). Grief and mourning as phenomena are experienced worldwide, yet individual expressions are influenced by a range of factors including culture, ethnicity, gender, age and religious beliefs. Social factors including socioeconomic status and education are also recognised as influences in how a person responds to his or her loss. (Granek & Peleg-Sagy, 2017).
2.8.1 Historical Perspectives of Grief

Present understanding of grief and grief theory has resulted from historical perspectives which catalogue the development of thought and concepts. The first chief theoretical influence which fashioned professional intervention for almost half a century was provided by Sigmund Freud in his book *Mourning and Melancholia* (Archer, 1999). Freud proposed that grief was a process to be worked through, such that the bereaved person must detach emotionally from the person who had died and redirect this energy into other possibilities in their lives. This cerebral adjustment involved three features: firstly, freeing the bereaved from bondage to the deceased, next, readjustment to new life circumstances without the deceased, and finally building new relationships.

Freud considered that this disconnection entailed the vigorous practice of acknowledging and expressing painful emotions such as guilt and anger. The belief held was that if the bereaved person failed to participate in or finish their grief work, the grief process would become complicated and raise the risk of mental and physical illnesses, leading to a compromised recovery from the loss of their loved one. Subsequently, Freud’s work has been considered by more recent theorists as the basis for the concept of ‘pathological mourning’ (Archer, 1999; Stroebe, Hansson, Schut, & Stroebe, 2008).

In *Mourning and Melancholia*, Freud declared ‘mourning’ and ‘melancholia’ were two distinct entities as they are each context specific. He proposed that grief resulting from being bereaved was ‘mourning’, as opposed to grief resulting from other losses, which was ‘melancholia’ (Freud, 1917/1957). He emphasised:

> In mourning we found that the inhibition and loss of interest are fully accounted for by the work of mourning in which the ego is absorbed. In melancholia, the unknown loss will result in a similar internal work and will therefore, be responsible for the melancholic inhibition. The difference is that the inhibition of the melancholic seems puzzling to us because we cannot see what it is that is absorbing him so entirely (Freud, 1917/1957, p. 254).

Therefore, Freud interpreted mourning as a standard, yet slow and arduous reaction, to bereavement, whereas melancholia had the risk of becoming pathological. It was a response which happened externally to any understandable perspective (Granek, 2010).
In 1927 Karl Abraham, an alternative theorist from the same era, acknowledged that Freud’s mourning and melancholia were two distinct conditions (Hagman, 2001). Freud focused on the transfer of liberating energy following bereavement, whereas Abraham concentrated on the integration of the deceased into a person to accomplish healing from the loss they had experienced. Despite both Freud and Abraham conceptualising grief as a process to be worked through without a clear ending, Helene Deutsch offered an alternative theory in her essay, *The Absence of Grief* (1937):

> The process of mourning as a reaction to the real loss of a loved person must be carried to completion. As long as the early libidinal or aggressive attachments persist, the painful affect continues to flourish, or vice versa, the attachments are unresolved as long as the affective process of mourning has not been accomplished (Deutsch, 1937, in Hagman, 2016, p. 21).

The chief assertion of Deutsch was that for grief to be resolved, it needed to be focused into the person’s consciousness or it will reveal itself in other ways (Hagman, 2016). She labelled this hidden energy, as ‘absent’ or ‘repressed’ grief, and considered it could result in the bereaved person developing psychological imbalance should they not undertake their ‘grief work’ (Hagman, 2016). This interpretation remains fundamental to contemporary psychological hypotheses regarding the concept of grief, as it proposed that hidden grief can be as equally pathological and damaging as chronic grief (Granek, 2010).

Freud is generally considered to be the first theorist to present the concept of grief in the field of psychology, and yet, he was preceded by other researchers. Robert Burton was the initial theorist to explain the concept of grief in psychological terms, when he authored *The Anatomy of Melancholy*, describing bereavement, which was published posthumously in 1651 (Archer, 1999). Burton recognised grief as a type of ‘transitory melancholy’ that each person needs to experience at times in life in reaction to loss and bereavement.

Burton also highlighted the difference between melancholy as a normal response to a loss, and as a disease which can occur when an individual is consistently melancholic in their nature (Archer, 1999). In 1703 Konrad Vogther’s thesis, *On Pathological Grief*, was accepted by a German university,
however, it was all but ignored (Parkes, 2011). A century later, Burton’s impression of grief as a disease became apparent in later publications on grief, including the work of Benjamin Rush who authored *The Diseases of the Mind* in 1812, in which he described an array of emotional and physiological symptoms characteristic of grieving people, including fever, sighing, loss of memory, aphasia, and even the development of grey hair (Archer, 1999; Hagman, 2016). He declared a number of thought-provoking treatments which he considered would cure grief, including the use of opiates, crying, and in severe cases, bloodletting and purging (Archer, 1999; Hagman, 2016).

Charles Darwin has also been recognised for his significant influence on grief theory. In *The Expression of Emotions in Man and Animals*, Darwin depicted in detail the manifestations of depression and grief in both human beings and apes (Darwin & Ekman, 1998). In addition, Darwin distinguished between a dynamic, anxious type of grief, and a more passive, depressive type which he postulated arose from different aetiologies (Darwin & Ekman, 1998). This fuelled further study and exploration of the expressions and manifestations of grief at the time, with Alexander Shand credited as the initial researcher to undertake thorough research relating to the psychology of grief (Lloyd, 2018). In *The Foundations of Character* published in 1920, four categories of grief reactions were determined by Shand (Lloyd, 2018): active and aggressive, depressive and lethargic, suppressed, and hysterical and frantic. Shand also considered alternative influences on grief, including the need for social support, the trauma related to the sudden death of a loved one, and relationship ties with the deceased person (Lloyd, 2018).

Erich Lindemann’s work on grief and mourning offers an understanding of the shift of grief from the psychoanalytic paradigm to a psychiatric one (Hagman, 2016; Lloyd, 2018). Lindemann’s 1944 publication *Symptomatology and the Management of Acute Grief*, was the first to offer empirical research with bereaved participants (Lloyd, 2018). With the interviews of 101 participants who were bereaved recently, Lindemann made a number of significant assumptions when he asserted that he had produced a methodologically comprehensive depiction of the process of grieving, providing a detailed explanation for the requirement to pathologise and treat grief (Lindemann, 1991; Lloyd, 2018).
Firstly, Lindemann maintained that grief was a psychological disorder, asserting that grief is a specific condition containing psychological and somatic symptomatology (Lindemann, 1991). Secondly, he outlined a list of precise grief symptoms and patterns of grief which he reported distinguished normal grief from pathological grief. Lastly, built on the concept that grief could be understood as a disorder with a specific aetiology that was possible to predict and treat, Lindemann (1991) proposed that professionals be accountable for ensuring support and treatment were provided to people when they encountered a loss in their lives. He asserted that psychiatrists were the experts in the field and as such needed to take the responsibility to assess and monitor people who were bereaved, ensuring that they did their ‘grief work’ appropriately. This grief work included separation from the deceased, modification to their new situation without the deceased person, and the building of new connections and ties to those who were living. His construct required a person to accomplish these tasks within the first couple of months or years for them to be grieving their loss properly. Disruption, avoidance, or any lengthy delay in the completion of these tasks was thus interpreted as a pathological grief response based on his theory (Lindemann, 1991).

Lindemann’s assertions of having produced a methodologically comprehensive depiction of the process of grieving has been challenged. Concerned that the scientific basis for grief counselling was not robust, studies undertaken since have questioned the benefits of ‘grief work’. A 2003 study reviewed recent publications of research, where bereaved people were randomly assigned to receive either counselling or no counselling. When followed up, neither group showed any measurable difference in outcomes (Currier, Neimeyer, & Berman, 2008; Jordan & Neimeyer, 2003). Three possible outcomes were proposed to interpret these findings: (i) formal intervention in bereavement may not be required as often as previously assumed; (ii) the type and structure of grief counselling used in research studies may be too limited to be effective; and (iii) the true benefits of grief counselling may be hidden by the methodology of research studies (Currier et al., 2008; Jordan & Neimeyer, 2003).
During the 1950s several theorists reiterated or expanded on Linde
emann’s ideas about grief work, however, none had a significant in-
fluence in the field of grief and loss. Numerous theories of grief were pro-
posed in the late part of the last century which provided a key change in the psy-
chology domain, with each having a focus on the processes, phases, or tasks of grief (Bowlby, 1969, 1980; Gorer, 1967; Hogan, Morse, & Tason, 1996; Kubler-Ross, 1969; Lazare, 1979; Parkes, 1965a, 1965b, 1971; Rando, 1984; Shuchter & Zisook, 1986, 1993). Aligned with the concept of ‘grief work’, most theorists identified grief as a distinctive repetition of yearning which ultimately settles following several months or years ‘working through’ the grief experienced by the person. Whilst Rando (1993) insisted that grief may never be ‘completed’, other theorists agreed that pathological grief occurs when the bereaved person is not able to surrender the connection or ties with the deceased person and consequently is not able to ‘recover’ within the ‘expected’ time period.

The surrendering of attachment ties was also at the core of three grief theorists’ work: Bowlby (1961, 1980), Bugen (1977), and Worden (1982, 1991). Parkes’ clinical studies (1965a, 1965b, 1971) paralleled Lindemann’s earlier research by offering additional support for the pathologisation of grief and the role of psychology to heal it. Gorer (1967) and Lazare (1979) identified a range of behaviours which were found in ‘unresolved’ grief, including a person refusing to part with belongings of the deceased person, and acquiring mementos to recognise the absence of the deceased on special occasions and anniversaries. The five stages of dying proposed by Elizabeth Kubler-Ross (1969) – denial, anger, bargaining, depression and acceptance – were similarly directed to explain and understand grief. Kubler-Ross proposed these ideas to understand the dying process; however, end-of-life issues have been merged with bereavement in health professional training and, as such, contribute to misunderstandings by health care providers (Genevro, Marshall, Miller, & Center for the Advancement of Health, 2004). The stages were broadly adopted by a range of health professionals, despite the criticism of the conceptual model as methodologically flawed and lacking empirical validation (Corr, 1993).

Bowlby’s theory of attachment (1980) also offers insight into bereavement distress (Stroebe & Schut, 1999; Stroebe, Abakoumkin, & Stroebe, 2010),
holding that individuals have an innate desire for connection with significant others. Threats to this connection will likely trigger protest and, in the case of bereavement, the individual may experience ongoing distress (Bowlby, 1980). Those who have not developed secure attachment to a parental figure early in life are at greater risk of complex grief issues over time (Stroebe, Schut, & Boermer, 2010).

According to Neimeyer and Sands (2011), the death of a loved one affects one’s self narrative, triggering a search for meaning as the bereaved person readjusts to life. These authors suggest deaths that are expected and normative are less likely to prompt a search for meaning, while deaths that challenge one’s worldview, for example, a death by violence, will require greater adjustment.

2.8.2 Current Understandings of Grief

Theories which focused on stages of grief were able to predict possible outcomes of grief; however, they had limited use and became unpopular because they were deemed too rigid. Popular belief that grief needs to be ‘worked through’ in a designated way has taken firm hold with people in society, the media and some who provide bereavement services. This can result in bereaved people experiencing failure if his or her grief does not coincide with popular views (Breen & O’Connor, 2007; Neimeyer & Sands, 2011). Linear stage theories lack a focus on the vast range of losses, stressors and adjustments which a bereaved person endures, and when combined with understanding complexity of loss and stress-related grief, have resulted in a paradigm shift from linear stage theories towards theories which focus on the process of bereavement (Stroebe & Schut, 1999).

Models of grief utilising time frames do not address the multiplicity of physical, psychological, social and spiritual needs suffered by a bereaved person, their families, friends and communities. Additionally, they are unable to portray the complex and diverse character of the grieving experience. Grief responses occur within the larger context of the individual’s life, and therefore these responses are unlikely to progress in a linear manner. Thus, coping with bereavement needs to be understood not as a distinct number of reactions,
rather as a set of simultaneous responses to a particular loss (Corr, 1993; Hall, 2014; Wortman & Silver, 2001).

Grief models developed in more recent times highlight the meaning of recognising the individuality of the grief experience. Concepts which utilise phases have replaced those models with stages, as they offer an understanding that qualitatively distinct paths through bereavement can occur. The Dual Process Model conceived by Stroebe and Schut (1999), and the Task-Based Model proposed by Worden (2009) are two of the most influential theories at the present time. Originally, a Two-Track Model of Bereavement was proposed by Rubin (1999), which had a focus on both the bereaved person’s functioning ability, and the quality and character of the ongoing attachment bond. Stroebe and Schut (1999) offered their Dual Process Model of coping with bereavement, in which the bereaved person swings between loss-oriented (focusing on the deceased) and restoration-oriented relationships (distraction from grief, avoidance, investment in new roles and relationships). The two models differ from stage or process models of grief as they believe that coping with bereavement requires a multifaceted guiding process of confrontation and avoidance, rather than the subsequent detachment from the deceased person and healing from grief. Each offers an understanding that coping is often different moment to moment, from one person to another, and across societies and cultures.

2.8.3 The Dual Process Model of Bereavement

Utilising the cognitive stress theory (Lazarus & Folkman, 1984) and the stress response syndrome (Horowitz, 1976), Stroebe and Schut (1999) created the Dual Process Model (DPM) describing the back-and-forth relationship between the many stressors resulting from bereavement and the grieving person’s coping tactics, which can vary from adaptive to maladaptive (Stroebe et al., 2008). Stress response theory proposes that responses to an occurrence may also involuntarily waver between intrusive re-experiencing and avoidance as a way of attempting to cope; with grief this wavering ensues between confrontation and avoidance. The DPM is based on the concept of rival stressors in the spheres of loss and restoration activities, as the bereaved person changes their attention when dealing with stressors. Grief is the main
stressor at the centre of loss-orientation and is mainly emotional in nature. Restoration orientation focuses on the bereaved person’s attempts to adjust to life without the deceased person, and entails emphasis on secondary stressors such as employment, or activities related to daily living. Both spheres are stressful, as the bereaved person wavers between the two, however, the wavering does offer relief from one sphere while his or her focus is on the other.

Over time, the dynamics of the process will change so that the person slowly adjusts to the loss (Stroebe & Schut, 1999). This model provides a level of insight into grief processes for researchers and clinicians alike. Where there is ongoing intense grief, the bereaved may concentrate on the loss rather than endeavouring to focus on restoration. Some people may focus on restoration, busying themselves with practical issues in an endeavour to evade the emotional facets of death. For others, such as those experiencing traumatic grief responses, the problem may lie with the process of wavering itself, such that the process of switching between loss and restoration is not able to occur effortlessly, for example, where a person may find themselves experiencing intrusive thoughts, and/or avoidance of reminders (Stroebe et al., 2008). Since the development of DPM, a significant amount of research has demonstrated support for the appropriateness of the model. For example, Shear, Frank, Houck, and Reynolds (2005) evaluated the effectiveness of Complicated Grief Treatment (CGT) against Interpersonal Psychotherapy (IPT) using the DPM as a framework for the intervention. They determined that CGT was more effective than IPT. The DPM also harmonises with cultural expressions of grief where society can inflict tenets on the bereaved person, with a bias focused on either loss or restoration (Klass & Chow, 2011).

A model of grief devised by Worden (2002, 2009) consists of four tasks which are to be completed to enable ‘successful’ adjustment after a loss. These include: accepting the loss, experiencing the pain of grief, adjusting to the environment without the deceased person, and maintaining attachment bonds with the deceased in the midst of embarking on a new life (Worden, 2009). Worden also identified seven mediating factors which are vital to understand the bereaved person’s experience: (i) who was the person who died; (ii) the nature of the attachment to the deceased; (iii) how the person died; (iv) historical
experiences of the bereaved; (v) personality differences; (vi) social mediators; and (vii) coexisting stressors.

These elements include a number of the risk and protective factors identified in the research literature and provide an important context for appreciating the idiosyncratic character of the grief experience. Issues such as the strength and type of the attachment to the deceased person, the importance of the relationship with the deceased person, the accessibility and acceptance of social support, and the scale of conflict and ambivalence with the deceased person are crucial factors.

This paradigm shift addresses the broader environment of grief reactions and responses and is beneficial as it reduces the pathologisation of distress and suffering when someone does not follow usual grief symptoms. Unrealistic beliefs held by many healthcare professionals and society at large can increase the intensity of distress for bereaved people, and lead to an increasingly isolated grieving experience (Doka, 2002). Consequently, whilst it is important for healthcare professionals to identify pathological responses in order to provide effective treatment, this goal should not preclude the recognition of alternative experiences of adjusting to loss.

2.8.4 Grief as Normal or Complex
The manifestation of grief, even in the early Freudian psycho-analytic tradition, was difficult as there was no way of distinguishing between what could be considered ‘normal’ in relation to ‘abnormal’ or pathological grief (Granek, 2010). According to Granek (2010), Freud viewed most grief disorders as existing on a continuum with normal or non-pathological responses at one end and abnormal and pathological on the other. It was acknowledged that where a person may be on that continuum at any given time was likely to move over time, based on what was happening for the person at that point in their life. Holland, Neimeyer, Boelen and Prigerson (2009) reported their research, adding to the concept that grief reactions may sit on a continuum where resilience and adaptive coping is at one end, and debilitating and lingering suffering is at the other. A bereaved person’s initial response to a loss is noted by Shear (2005) as “…a strong yearning, longing, and sadness.” (Shear et al.,
where the bereaved person instinctively ruminates about the deceased yet has a level of disbelief that this person is no longer alive. She notes that individuals can withdraw from their regular activities, often revealing sadness, depression or anxiety, accompanied by physical symptoms, including changes in cardio-vascular function, disruption of sleep, and increased release of cortisol.

Research demonstrates that there are only a small number of bereaved people who are not able to shift from the early acute phase of grief and become debilitated by their grief and are at risk of poor health outcomes (Bryant, 2013; Zisook & Shear, 2009). Grief has been shown to affect immune function where the bereaved person is more likely to develop psychological and somatic health difficulties and be at higher risk of death, through habits of poor nutrition, lack of exercise, drug and/or alcohol use, and even suicide, particularly in the earlier bereavement period (Stroebe, Stroebe, & Schut, 2003). These authors agree there is evidence that psychiatric morbidity including depression is increased, and at times, can be detrimental to relationships, social activity, concentration and work performance.

2.8.5 A Conceptual Model of Complicated Grief

Rando (1993) is critical of the recent propensity of clinicians to measure grief-related distress, rather than focusing on the process of grieving. She proposes that complicated or prolonged grief debate contains mistaken understandings of prolonged grief disorder that diminish the intricacies of complicated grief; for example, the connection with grief-related major depression is an obstacle to developing a theoretical model for complicated grief. Rando proposes a range of elements to be included in a conceptual model including: (i) the individual nature of grief; (ii) the use of explanatory theories; (iii) underlying coping mechanisms; (iv) primary issues and current functioning of the bereaved person; (v) the function of grief in the individual; (vi) the form grief takes; and (vii) the postulated operational course of grief.

A conceptual model comprising these elements offers a range of advantages, valuing the various aspects of complicated grief whilst allowing for those in a subclinical group. Grief remains a highly debated issue (Knoll, 2012; Rando,
1993; Rosen, 2002), with environmental and cultural environments frequently not included (Granek & Peleg-Sagy, 2017). Given the lack of consensus on the theoretical constructs of grief, it is meaningful to review the risk and resilience factors associated with prolonged or complicated grieving processes.

2.8.6 Risk and Resilience Factors Associated with Grieving
A significant volume of research has been focused on identifying both risk and resilience factors related to poor bereavement outcomes (Relf, 2005; Stroebe et al., 2007), with risk factors and protective factors conceivably at each end of a continuum (Stroebe, Folkman, Hansson, & Schut, 2006). In a review of research related to the predictors of complicated grief, Lobb and colleagues (2010) identified many factors to be highly predictive for complicated grief, which include insecure attachment styles, dependence on the deceased person, the closeness of the relationship with the deceased person, childhood experiences of adversity, and parents’ reactions after the death of their child. This is by no means a comprehensive or complete list of predictors. Parkes (1995) grouped phenomena associated with poor bereavement outcomes as ‘antecedent factors’ (a mental health diagnosis), ‘concurrent factors’ (age, religious affiliation and commitment), and ‘subsequent factors’ (social isolation). He proposed that an accrual of these facets would lead to a lack of effective bereavement adaptation. Stroebe and Schut (2010) included ‘situational factors’, including sudden or traumatic death, and ‘personal factors’ made up of personality traits. Given the difficulties posed by assessing grief-related distress (Rando, 1993) health care providers working in palliative care and bereavement fields frequently utilise an assessment of risk and resilience factors associated with grieving in their practice.

2.8.7 Popular Assumptions about Grief
Breen and O’Connor (2007) suggest that the theories outlined above have shaped our understanding of grief. The dominant understanding of grief is that grief follows a common pattern, grief is of short duration and ends, grief is a linear process of discrete stages, grief can be worked through, grief commences when a death is anticipated, meaning and positive outcomes must be sought, detachment from the deceased should be achieved, and ongoing grief that does not conform with these parameters is abnormal (Breen &
O’Connor, 2007). Wortman and Silver (1989) also hold that such widely held erroneous assumptions have become enduring myths that will be difficult to change because people have a tendency to resist evidence to the contrary. Such myths, they say, are potentially harmful to the bereaved resulting in inappropriate support from both social networks and professional service providers.

Erroneous views, when held by health professionals, deem that those whose grief differs from the prevailing societal experience are regarded as having abnormal or pathological responses to grief (Breen & O’Connor, 2007; Klass & Chow, 2011). Engel (2012) points out that grief has many similarities with physical diseases, such as a known cause and group of symptoms that may cause functional impairment, runs its course, and may be amenable to treatment. He supports this argument by stating that bereaved people often consult doctors for assistance with their troublesome symptoms. A study of public opinion about norms and expectations of grief, (Penman, Breen, Hewitt, & Prigerson, 2014) found that three-quarters of participants believed that grief could be regarded as a mental health disorder if it remained at an intense level and affected function. Rando (1993) is of the opinion that many clinicians would also support a complicated or complex grief diagnostic category, and a survey of counsellors and psychologists found that just over half believed that recognition of complicated grief would lead to improved treatment for such clients (Ogden & Simmonds, 2014). These debates highlight the complexity of grief and the many issues in need of consideration in the assessment of bereavement.

Grief and loss are an important, realistic response to a diagnosis of cancer. The shock of hearing the diagnosis segues into feelings of grief which in turn lead most people with cancer to face questions of mortality and priorities in life. The need for a re-definition of ‘who I am’ is the existential crossroads or crisis people find themselves confronting.

2.9 Existentialism

It is not a simple process to define existentialism, as the movement has had wide-ranging and at times ambiguous descriptions; yet others distinguish
existentialism as an agile, fluctuating attitude (Kaufmann, 1956). Indeed, some key scholars in the field oppose contracting it into a precise collection of ideas. The themes and concepts explored by the various existentialists are interconnected. Existential philosophy primarily shines a light on the meaning of human existence. How human beings live in the world captivates existentialists. The focus is how people feel and understand themselves and how they interrelate and respond to others encountered in their lives. The facts of a person, which can be viewed from the perspective of a third person, include age, race, class, body, personality traits, beliefs and desires. Yet there is a complex relationship which human beings have with these features according to existentialists. A person interprets the facts of his or her life according to the meaning they have for him or her; unable to view him or herself as other people are able to do. There is ownership of each person’s ‘facticity’ with an individual perspective which adds to the development of each person’s sense of unique existence.

Whilst existentialists assert that as human beings each has the capacity to surpass the fundamentals of his or her existence, it is also asserted that the lives human beings live are intrinsically entwined with the history, society and culture within which they live. The self and the world are enmeshed as a whole, described by Heidegger as “being in the world” (Heidegger, 1927/1962, p. 65). Transcendence allows each person to create endeavours within the world in which he or she lives; yet each is constrained by that world. Each person can transcend his or her situations, however, none is able to transcend the parameters of the world in which he or she is positioned. As human beings, each is not limited as a result of historical or cultural training, rather each has the capacity and potential to choose how he or she responds to that world.

As humans we invent or design religions and frameworks to bring order and purpose to the world. Whilst acknowledging that religious and Christian forms of existentialism exist, the major existential thinkers dispute that the world has meaning because human beings have created meaning for it. Existentialists contend that each individual is entirely responsible for his or her life, and parallels the increasingly secular views in Europe post-World War II. Nietzsche questioned the legitimacy of a universal moral code, which led to the
development of the proposition that human life is meaningful because humanity has determined that it is.

As humans we are unable to escape freedom since, according to Sartre, to exist is to be freely involved in the world: “Man is condemned to be free” (Sartre, 2003, p. 34). The absurd is the tension between human beings’ absorption in the world in which we live and the basis for that absorption. In the Myth of Sisyphus, Camus (2005) argues that absurdity does not inevitably result in nihilistic hopelessness. Endeavouring to overcome the absurdity of our existence leads human beings to choose to act. For existentialiists, using phenomenological analysis of moods and feeling exposes the deep-seated components of the self. As a group, existentialists utilise words such as anguish and angst to illustrate how freedom is revealed to human consciousness; the “permanent possibility of non-being, outside us and within, conditions our questions about being” (Sartre, 2003, p. 48). A person becomes anguished or ridden with angst when he or she becomes consciously aware of the capacity to nihilate things, that is, to be separate from the things around him or herself. Heidegger indicates that this experience provides a person with a significant individualising power (Heidegger, 1927/1962). A state of angst is experienced when the traditional meanings of things fades away and objects which were previously familiar become unfamiliar, challenging that person’s understanding of him or herself and the world in which he or she lives. Through the experience of angst, the person can grasp that he or she has the power to influence the meaning of his or her life by actively existing. Sartre (2003) continues:

Death is the limit, but also a constituent of my freedom…
If a being was endowed with temporal infinity, he could realise all his possibilities… he would disappear with respect both to individuality… and to freedom (Sartre, 2003, p. 52)

The finite nature of life renders freedom meaningful and feasible; for if a person’s life was infinite the freedom would be meaningless. For Heidegger, death is also vitally meaningful, proposing a profound relationship between the authentic nature of a person’s life and the foreboding of how finite human life is. When a person is able to understand the parameters of his or her existence, the significance of taking responsibility for his or her decisions, actions and alternatives in life emerge. Conversely, despite the importance of considering
death and experiencing angst, human beings innately seek to challenge and escape them.

Having an understanding of the grief and loss, and existentialism, which people with cancer face is vital to providing appropriate, empathetic clinical nursing care. The complexity of the experience, and the fluctuating ability of an individual to cope, are important factors for oncology nurses and cancer care coordinators to understand as they provide treatment and supportive care to people with cancer. Reflecting the complexity of cancer care, there is a need for a diverse team of professionals to provide cancer care. In 1999 the Institute of Medicine (IOM) published *Ensuring Quality Cancer Care*, which identified an oncology nurse as a core component of the interdisciplinary cancer care team required to ensure high quality care for cancer patients (Institute of Medicine, 1999 (IOM)). By 2013, the IOM report, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* (IOM, 2013); included patient navigators as team members, recognising that patient care frequently lacks coordination between the clinicians and team members. This results in patients unwittingly navigating the complexities of the cancer care continuum themselves without the skill or knowledge to inform them. The ideal that high quality cancer care “depends on the workforce providing competent, trusted interprofessional care that is aligned with the patients’ needs, values, and preferences” (IOM, 2013, p. 153) is short sighted when coordination of communication and care is lacking. The need for navigation and coordination of the complexities of care has been well documented in the literature (Berglund, Gustafsson, Johansson, & Bergenmar, 2015; Gordon & Chan, 2017; Shockney, 2018; Yates, 2015).

### 2.10 Oncology Nurses

Advanced clinical expertise and knowledge are the hallmarks of oncology nurses in the care they provide to people with cancer and their loved ones. Oncology nurses are specialist nurses who use advanced clinical skills and experience each day to assess, plan and implement a wide array of nursing interventions during therapeutic encounters with each person (Bakker et al., 2013; Berglund et al., 2015; Haylock, 2011; Spinks et al., 2012; Wall & Rawson, 2016). Each person’s cancer journey is unique; each has challenges and
moments of relief different from others. Oncology nurses establish and continue to develop therapeutic relationships and communication, providing support and education which influences the person’s journey with cancer. They have the specialist clinical skills to provide nursing care in a number of oncology settings, including oncology surgical inpatient wards, outpatient chemotherapy, clinical trials units, and radiotherapy centres. Cancer care coordinators are also specialist nurses, however, their focus is utilising the skills and knowledge they have to provide care coordination and navigation of the poorly connected aspects of health care, including access and communication between specialist medical and allied health professionals (Bakker et al., 2013; Lie, Hauken, & Solvang, 2018). Providing ongoing support and education are frequently aspects of the care coordination role. Both oncology specialist nurses and cancer care coordinators 'go on the journey' with people and their families during the crises and plateaus which characterise a cancer experience (Brown & Wood, 2009; Lie et al., 2018; Wall & Rawson, 2016).

2.10.1 Evolution of Oncology Nursing

When I commenced working as an oncology nurse in a metropolitan area almost thirty years ago, the perception amongst other nurses and the general community was that of a bleak workplace. This was due to the suffering associated with treatment-related symptoms which were poorly managed despite best efforts, coupled with modest survival rates for patients. Inpatient surgical interventions were frequently the major treatment modality followed by courses of chemotherapy and/or radiotherapy (Cohen, Haberman, Steeves, & Deatrick, 1994). Much of a patient’s treatment journey took place within the inpatient setting on specialist wards. Symptom support was limited by the medications available; skilled clinical assessments, comfort measures and emotional support for patients and families were important nursing roles across the treatment trajectory (Cohen et al., 1994; Hilkemeyer, 1985). End of life care was also provided in the inpatient oncology ward with oncology nurses advocating for relief of symptoms for patients during this difficult time.

During the 1990s, interest in oncology nursing increased, and nursing journals dedicated to oncology nursing and related interest groups developed. Outpatient chemotherapy clinics were able to treat more patients as
revolutionary antiemetics controlled chemotherapy-related nausea and vomiting, and the role of the oncology nurse expanded to include expert assessment skills and liaison with specialist medical teams as needed. This was a paradigm shift from the oncology nursing role in the inpatient setting where the medical team assessed patients each day. In Australia, the Cancer Nurses Society of Australia (CNSA) was founded in 1998, developing from the Nurses Group of the Clinical Oncological Society of Australia (COSA). As an independent body for cancer nurses across the country, CNSA is committed to realising excellence in cancer care through the professional contribution of nurses (Cancer Nurses Society of Australia, 2019, (CNSA)) and is a resource for cancer nurses promoting contemporary evidence-based oncology nursing care. This standardised approach to oncology nursing has led to improved patient care and outcomes, and professional satisfaction (Bowyer & Schofield, 2014; Cohen & Palos, 2001; Haylock, 2011; Kendall, 2006; Wall & Rawson, 2016).

Oncology nurses augment evidence-based care with personal and professional experience, which shapes individual nurses’ professional development (Cohen & Palos, 2001; Dowling, 2008; Kendall, 2006; Quinn, 2003). Fundamental to oncology nursing is knowledge of cancer and how it affects people, their families and society. Using a holistic approach to nursing care to meet the physical, psychosocial and spiritual needs of people with cancer is a tenet of oncology nursing. Following the lead of the Oncology Nursing Society in the United States, the Canadian Association of Nurses in Oncology developed clinical practice standards and competencies as a framework for patient care (Canadian Association of Nurses in Oncology, 2006 (CANO)). In the United States and Canada, certification programs are available for nurses choosing to specialise in oncology nursing. This process validates the knowledge and expertise of specialist registered nurses working in the oncology setting (CANO, 2006; Oncology Nursing Society, 2018 (ONS)).

In Australia, the Cancer Institute NSW developed an online, evidence-based suite of education modules to provide a consistent minimum level of education for oncology nurses (CINSW, 2019a). This competency-based education is usually augmented with postgraduate studies when registered nurses choose
oncology nursing as their speciality. Annual conferences both within Australia and across the world offer further professional development and networking opportunities.

2.10.2 The Work of Oncology Nurses

There are a number of specific roles within the scope of oncology nursing in the Central West of NSW, once people are referred to cancer services. Providing targeted education to people with cancer prior to commencement of chemotherapy has always been a core component of the role, as has taking responsibility for monitoring pathology results, assessment of symptoms, and quality of life (Yarbro, Frogge, & Goodman, 2004; Yarbro, Gobel, & Wujcik, 2013). These roles are fundamental to the judicious use of chemotherapy to treat cancer. Administering chemotherapy, immunotherapy and other systemic treatments remains the role most associated with being an oncology nurse and requires technical skill and expertise to prevent undue side effects (CINSW, 2019a; CNSA, 2019; ONS, 2018). In the radiotherapy treatment setting, alleviating treatment-related side effects, and management of pain and other cancer-related symptoms are important components of the role (Rose & Yates, 2015). Providing education, clinical assessment and referral to appropriate allied health professionals are also important, as is the expertise related to managing skin sensitivities to reduce discomfort and long-lasting effects (Haylock, 2011; Yarbro et al., 2004; Yarbro et al., 2013).

The introduction of a range of specialist oncology nurses aligned with specific tumour-streams in the last twenty-five years has seen the rise of breast and prostate cancer nurses focusing on providing support, education and coordination of care. Large metropolitan cancer centres also utilise specialist oncology nurses for a range of tumour-specific groups with examples including gynaec-oncology, neuro-oncology, haematology and colorectal cancer-focused clinical nurse consultants. In many locations, these roles aligned with tumour-streams have evolved into cancer care coordinator roles regardless of the position’s title. Cancer care coordination for people with complex cancer care needs are now well entrenched within specialist cancer services (Yates, 2015) to provide education, support and coordination/navigation for people with multiple interventions at multiple levels. These levels include the health care
system, health care, and patient level interventions (Yates, 2015). In rural areas, where workforce resources are modest in comparison with metropolitan locations, a specific focus of any cancer care coordinator role is the complexities associated with assisting patients who are required to travel for cancer care treatment.

Once people are referred to specialist cancer services, they are met by nurses at each juncture of their cancer journey, and the goal underlying nursing activities and interventions is the intent to assist people to cope with their individual cancer experience. Cancer care in the Central West of NSW is provided by a multidisciplinary health care team consisting of physicians, nurses, radiation therapists, social workers, dietitians and speech therapists. Although nurses make up only one part of this team, in most locations they represent the greatest number of individuals within the team and have the most contact with patients (Appleton, Poole, & Wall, 2018; O'Baugh, Wilkes, Luke, & George, 2008).

American studies of oncology nurses in the last few decades have focused on investigating the perceptions oncology nurses have of their work (Cohen, Ferrell, Vrabel, Visovsky, & Schaefer, 2010; Dunniece & Slevin, 2008; Ferrell & Coyle, 2008; O'Baugh et al., 2008; Rohan & Bausch, 2009; Steeves, Cohen, & Wise, 1994; Vinckx, Bossuyt, & Dierckx de Casterle, 2018; Wilkinson, 1994). Protecting and advocating for patients was of fundamental importance to the oncology nurses and involved clinical assessment and monitoring, providing high quality education and supporting patients’ goals. Caring for patients over time as they journey through their cancer experience led oncology nurses to describe ‘being present’ with patients, a sharing of the experience. This led to oncology nurses being able to clarify information for patients to ensure they had access to accurate information to inform their decision making (Cohen et al., 2010; Dunniece & Slevin, 2008; Ferrell & Coyle, 2008; Steeves et al., 1994; Vinckx et al., 2018).

In providing care to patients and families, oncology nurses bring warmth, comfort and humanness to the experience of suffering that can accompany cancer (Ferrell & Coyle, 2008). Parse (1998) suggests that presence is a
special way of being with others as they live their experience and is integral in nursing. In being with others the nurse is open to the patients’ experiences as they understand them. Nurses’ physical presence helps them to build rapport with patients and their families (Dunniece & Slevin, 2008; Rohan & Bausch, 2009). Through touch, eye contact and body language, and by using themselves as therapeutic tools, nurses build relationships and connect with patients and their families. The physical act of being present, over time, assists nurses as they begin to help patients explore and understand their cancer experiences (Dunniece & Slevin, 2008; Quinn, 2003).

Administering chemotherapy, immunotherapy and other systemic treatments are the predominant role of oncology nursing care. These agents are cytotoxic and/or potentially harmful (Colbourne, 2008; Yarbro et al., 2013) and administration requires strict observance of a range of workplace safety criteria, including donning personal protective equipment such as impermeable gowns, gloves, and protective eye wear. For oncology nurses, administering chemotherapy can support feelings of hope, and be seen as a conduit to another chance at life (Brown & Wood, 2009; Saltmarsh & de Vries, 2008) while simultaneously impacting on it with unpleasant and, at times, life threatening side effects. The ongoing risk of death, as part of cancer and its treatment, is an everyday challenge for oncology nurses to cope with. Recognising the grief and loss that oncology nurses encounter, which can lead to reflecting on individual mortality, is important for ongoing personal and professional wellbeing (Brown & Wood, 2009).

Treatment for cancer leads to a collection of physical and emotional responses in patients (Colbourne, 2008; Yarbro et al., 2004), with the time of diagnosis, start of treatment and end of treatment as the times when patients are most vulnerable to clinically significant anxiety and depression, exhaustion and pain. The more complex the treatment plan, the increased risk of anxiety and depression (Appleton et al., 2018). A British study found that patients receiving treatment at cancer services for lung, colorectal, and head and neck cancers were positively impacted by the relationships with cancer services’ nurses and other patients, and felt they were ‘in safe hands’ (Appleton et al., 2018). Nurses who were responsive, courteous and capable of informing patients of current
and upcoming treatment plans assisted patients to live with cancer. Meeting individual information needs was highly valued as belonging to reliable and effective nurses who would safeguard the needs of the individual patients at various stages of the treatment pathway. The need for cancer services’ staff to be aware of the need to promote peer support for patients and strategies to improve communication during treatment were noted.

The nurse practitioner role has been recognised in Australia for over 15 years and is a designated role for registered nurses with master’s level education who are authorised to work as an advanced nurse in an extended clinical role. Aims of the role include: (i) improving access for patients to treatment; (ii) providing care which is cost effective; (iii) focusing on populations within communities which are at risk; (iv) providing outreach to rural and remote communities; and (v) providing mentoring and clinical expertise to other health professionals in the multidisciplinary team (Australian College of Nurse Practitioners, 2019 (ACNP)).

In oncology, the nurse practitioner role functions within the multidisciplinary team to meet a range of complex needs of cancer patients. The oncology nurse practitioner works in partnership with a medical oncologist offering high level clinically focused nursing care (Campbell, Cusack, & Green, 2016). This role differs from other advanced practice nursing roles by granting authorisation to order diagnostic tests and prescribe medication within an agreed formulary. As nurses generally have additional time with patients compared with medical oncologists, the ability to educate, detect and treat symptoms, and provide follow up is well accepted. Whilst there are only a small number of oncology nurse practitioners in Australia, the potential to positively impact on care for cancer patients is clear (ACNP, 2019).

### 2.10.3 Cancer Care Coordination

People with complex needs, including cancer patients, have been a focus of care coordination efforts since the late twentieth century when nurses embarked on roles which evolved into nursing cancer care coordinators. The unintentional complexity of Australia’s health care systems has resulted in the need for care coordination (Langbecker, Hunt, & Yates, 2014). The literature relating to care coordination is broader than cancer: chronic care, mental health and disability care are also areas where this concept has been embraced to improve patient
reported outcomes and health service utilisation (Conway, O’Donnell, & Yates, 2017). Care coordination provided by non-nurses regularly uses the ‘navigator’ term and primarily guides people through the health care system. The National Coalition on Care Coordination (2011) has defined care coordination as a “person-centred, assessment based, interdisciplinary approach to integrating health care and social support services in a cost-effective manner in which an individual’s needs and preferences are assessed, a comprehensive care plan is developed and services are managed and monitored by an evidence-based process which typically involves a designated lead care coordinator” (National Coalition on Care Coordination (N3C), 2011, p. 1).

A review of nurse care coordination roles (Conway et al., 2017) demonstrated improved outcomes when nurses provided frequent, face to face interactions with patients and families, and a focus on providing long term follow-up to monitor disease and symptoms. Patient satisfaction and quality of life measures have been used to measure the effectiveness of the role when functioning as a nurse case manager (Conway et al., 2017).

Cancer care coordination requires expert oncology nurses to take a holistic approach to the care they provide at both the patient and system levels (Lie et al., 2018). To meet the complex care needs of people with cancer, the need for individualised, coordinated cancer care has been recognised as a core component in ensuring person centred care within the health care system. The cancer care coordination role is frequently a discrete role within the oncology nursing team and may be aligned to tumour streams, particularly in metropolitan areas. In 2012 the need to improve cancer care coordination was legislated in Norway, leading to 130 cancer care coordinators being established across the country within primary healthcare services. The overarching goal for these positions was twofold – to coordinate local services, following the patients’ plan of care, and to ensure the support needs of people with cancer and their families are met. Responsibility to operationalise these roles was devolved to local authorities, leading to a range of interpretations and position descriptions developed with no national evaluation or outcome measures levels (Lie et al., 2018).

Themes uncovered by the Norwegian study of twenty-six of these new care coordinators included finding a place in the team, meeting the needs of cancer
patients to support them to cope better with their illness, and promoting functional cancer care systems levels (Lie et al., 2018). As newly constituted positions, the need to find a place in the team and establish the function of the role is understandable, as is striving to meet the needs of cancer patients. Developing a map of the person’s cancer plan of care and providing psychological support are fundamental roles in other countries where positions have been established. The third theme of advocate and change agent relating to taking on system-level activities to align providers and services on behalf of patients, appears to be an innovative understanding of the complexity of the role. This theme focuses not only on individual patients, but on improving the gaps and challenges in the system itself. Employing a collaborative approach, these nurses have become catalysts for change utilising local resources and care networks levels (Lie et al., 2018). Recognition of the importance of the care coordinators acting at the local level is an important finding for regional and rural services in NSW as oncology nurses strive to provide care to their patients as close to home as possible.

2.11 Summary remarks

This comprehensive review of the relevant literature exposed the lack of clear solutions to remedy the inequities associated with cancer, and disparities in outcomes for people living in rural areas and for Aboriginal Australians. These predominantly Australian studies and policy documents articulate a range of contributing factors, including distance from metropolitan cancer services and socioeconomic disadvantage, yet do not present solutions which can be readily implemented in rural communities.

Although the evidence may not be definitive, there appears to be little ambiguity that the earlier a cancer diagnosis is made, and a plan of treatment determined and undertaken, the better the outcome for the person with cancer. This raises the question of the impact rurality has on the process of diagnosis of cancer for a person living in a rural location, including access to services. Despite the vast range of information, there is a lack of understanding regarding the personal experience of receiving a diagnosis of cancer outside of metropolitan areas. The feelings of grief and loss which people with a cancer diagnosis face are distressing and challenging and require psychological support. My study was
focused on implications for the nursing profession of the experience of cancer at the individual level: how nurses within the Australian health care setting can rise to the challenge of providing effective and meaningful support for people with cancer.

2.12 Aim and Significance of the Study
To date, whilst there has been a considerable amount of research focused on cancer care and the cancer patient experience, there has been insufficient research focusing on the lived experience of people with cancer in rural areas. The study aimed to address this gap and inform the current body of literature; that is, to explore, articulate and analyse the meaning of the lived experience of a diagnosis of cancer by individuals in the Central West of NSW. The two main aims of the study are to:

- Identify, explore and fully describe people’s experiences of the processes involved in receiving a diagnosis of cancer;
- Interpret the meaning this phenomenon holds for people with cancer in the context of rural NSW.

The research question for the study is:

*What are the experiences of people in the Central West of NSW in relation to being diagnosed with cancer?*

In order to deeply understand the experiences of people being diagnosed with cancer in this rural area, there was a need to gather, explore, articulate and analyse information. To accomplish this, there was a need to utilise an approach which would enable the experience of people with a cancer diagnosis to be revealed. This guided the choice of phenomenology as the methodology for this study which is addressed in Chapter Three.
Chapter Three – Methodology

This chapter outlines the methodology underpinning development of this study with a detailed discussion of the philosophical framework of phenomenology, and its relevance to how people in the Central West of NSW experience a diagnosis of cancer. The chapter begins with a general introduction to phenomenology and its evolution over time. This is followed by a rationale for each methodological decision to enable clarity in relation to the research design and method.

The aim of the study was to explore, articulate and analyse the meaning of the lived experience of a diagnosis of cancer in people residing in the Central West of NSW. In light of the nature of the study, a qualitative methodology was considered the most appropriate way to capture new understandings of the meaning of the phenomenon in question. Furthermore, phenomenology reveals a deep understanding of the lived experience of the participants who all had been diagnosed with cancer, as it focuses on people’s perceptions of the world.

3.1 Phenomenology

Phenomenology is complex in that it is a philosophy, an approach and a qualitative methodology. Phenomenological philosophy emerged towards the end of the nineteenth century. Building on the work of Franz Brentano who wrote *Psychology from an Empirical Standpoint* in 1874, it was developed by Edmund Husserl (Davidsen, 2013). The word phenomenon comes from the Greek word *phaenesthai*, which means to reveal or show itself, to appear (Moustakas, 1994). It has been defined as the study of lived experience, offering a ‘window-view’ into a person’s lived experience of a specific occurrence, happening or feeling (Beck, 2006; Benner, 1994; Laverty, 2003; van Manen, 1990). Phenomenology offers a rich descriptive account of a range of aspects of the phenomenon being studied; the perception of the “things in their appearing” (Langridge, 2007, p. 3). For the researcher, it is focused on examining experiences from the standpoint of each individual, based on a paradigm of individual knowledge and perspective (Connelly, 2010; Dowling, 2007; Lester, 1999; von Eckartsberg, 1998).
A phenomenological approach honours personal experience; it can be seen as a philosophical and methodological approach interested in understanding what the meaning of being human is (Benner, 1994; Creswell, 2003; Munhall, 1994; Smith, Flower, & Larkin, 2009). Phenomenology aims to establish a renewed link with original experience (van Manen, 1997); it is descriptive, seeks common essences and provides a framework for researching human experience. van Manen describes phenomenology as the study of the ‘life world’ – the world as we personally experience it, rather than how we think, classify, or reflect upon it (van Manen, 1997). It can be understood as the investigation and description of the essence of things as they are lived by each person; a vantage point to view the world in which people live, thereby acquiring a thorough comprehension of the meaning of their everyday experiences (van Manen, 1997). Hermeneutic phenomenology utilises a person’s own firsthand experience to describe, explore and interpret the phenomena of interest, however, it also seeks to build on these individual experiences to uncover similarities with others’ experience of the essence of the phenomenon.

Phenomenological research seeks a range of perspectives through the use of interviews, personal accounts and writings in the pursuit of patterns to explicate the phenomenon. Therefore, sampling is seldom random, and usually includes individuals who have experienced the phenomena under investigation in an attempt to gain direct reports that are as complete as possible. Thus, the purpose of the research is to focus on each individual’s experiences whilst seeking general qualities and features to better understand the essential nature of the phenomenon; to explain the meanings of everyday life as it is lived by each person (van Manen, 1997).

Phenomenology encompasses three main schools of thought. Holloway and Wheeler (1995) propose these schools are interconnected as they all aim to generate understanding of the phenomenon in question. The three phenomenological schools of thought are: descriptive or transcendental phenomenology, hermeneutic or interpretative phenomenology, and existentialism. Edmund Husserl focused on ‘pure’ or descriptive phenomenology, the first of these schools of thought. Modifying Husserl’s work,
Martin Heidegger developed the second school of thought, hermeneutic or interpretative phenomenology, which was further developed by Hans-Georg Gadamer. Maurice Merleau-Ponty and Jean-Paul Sartre were existentialists (Andén, 2019; Beck, 2006; Berry, 2019; Holloway & Wheeler, 1995; Moustakas, 1994). Each of these pioneers is further discussed below.

3.1.1 Husserl

Edmund Husserl is considered the father of phenomenology (van Manen, 1997). He created a philosophical system grounded in personal honesty which was ridiculed by the scientists of his day (Berry, 2019; Moustakas, 1994). He believed the basis of knowledge was the phenomenal experience of humanity, thus, the keystone of science and philosophy; his primary concepts included “intentionality, essences and phenomenological reduction (bracketing)” (Holloway & Wheeler, 1995, p. 174). Husserl’s writings about phenomenology evolved over time, initially concentrating on the transcendent ego or consciousness and evolving to encompass a person’s pre-reflective life world experiences. His major focus was to articulate meaning and knowledge as they represent themselves in people’s consciousness. He deemed that essence and intuition precede empirical knowledge of the world (Berry, 2019; Moustakas, 1994) as we understand it and he strived to explain phenomena as they appear in our consciousness. Husserl sought to not only acquire knowledge, but to contemplate how new knowledge occurs: to question the building blocks of knowledge by excluding all empirical interpretations and existential assertions, and capture what is inwardly experienced or intuited as untainted experiences and therefore an exemplary basis for fact (Kwok, 2019; van Manen, 1997). He did not assert that transcendental phenomenology was the method to gain knowledge of human existence, instead he proposed it was a science of ‘pure possibilities’; it makes possible the empirical sciences described as the sciences of actualities (Moustakas, 1994).

Husserl developed two major themes in his work: the phenomenological reduction or ‘epoche’, and the concept of intentionality. Phenomenological reduction is a method he developed to approach the elements of human consciousness without pre-conceptions or judgement (Berry, 2019; van Manen, 1997). Phenomena can only be described after they have been experienced,
and this process involves reflection and conceptualisation. He proposed deferring judgement and pre-conception to rather concentrate on the phenomena as it is presented to us; considered therefore a descriptive method of phenomenology. For van Manen, phenomenological study involves reflection on the experience which has been lived through, rather than self-reflection by the researcher (van Manen, 1997).

Husserl further developed the concept of intentionality, a theory of his mentor Brentano, which represents the indivisible links each human being has with the world (van Manen, 1997). Intentionality refers to how consciousness is constantly focused towards something ‘other’. It is the relationship between how an object emerges in our consciousness and the object itself; Husserl did not consider this to contradict the inseparability of ourselves from the world. Rather, the two aspects of intentionality remained inseparable; the noema and the noesis, neither of which can exist without the other (Beck, 2006; Berry, 2019; Moustakas, 1994). The noema is how the object emerges or appears in our consciousness - it is the focus, whilst noesis is the interpretive act, or how we perceive the noema. The essence of a phenomenon is the amalgamation of these two illuminated in a person’s consciousness (van Manen, 1997). The integration of these form the meanings (Berry, 2019; Moustakas, 1994) of the phenomena in question.

To seek the essences of an experience Husserl sought to explore human consciousness to find what was known, firstly by endeavouring to defer pre-conceptions and judgements through phenomenological reduction and secondly to expose the invariant structure of consciousness (Holloway & Wheeler, 1995). Husserl considered consciousness a transcendent domain existing separately from a person’s specific experiences (Moustakas, 1994). He also developed the concept of ‘life world’ which accepted a person’s lived experience (Holloway & Wheeler, 1995).

### 3.1.2 Heidegger

As a student and assistant of Husserl (McLeod, 2001), Heidegger acknowledged his teacher’s insights and considered his own ideas to be an extension of Husserl’s work. He was primarily focused on what it meant to be in
the world; what it is to be or live in a world of meaning. His viewpoint was about
the nature of being (ontology) rather than the philosophy of the nature of
knowledge (epistemology). He labelled this viewpoint as *Dasein*; the human
ability to wonder about our experience and inquire into our own being (van
Manen, 1997). That is, ‘to exist’, ‘to be there’ or ‘to be here in the moment’
(Benner, 1994; Inwood, 1997; O’Brien, 2002).

Heidegger sought to understand what it means to perceive things as meaningful
in our individual world. Thus, his quest shifted from Husserl’s transcendent
domain of consciousness to lived experience where consciousness is only one
facet. Heidegger recognised the role of the researcher as a rightful component
of the research. For Heidegger the meaning of the description of a phenomenon
was found in the interpretation of the descriptive text; and is hermeneutic in
nature (Inwood, 1997; Kwok, 2019; van Manen, 1997). Heidegger was familiar
with hermeneutics due to his theological studies, where there was a focus on
interpretation of biblical texts. He combined phenomenology and hermeneutics
proposing they both should be viewed as fundamental, harmonising aspects of
any acceptable method of understanding human existence (Kwok, 2019;
McLeod, 2001). Underlying Heidegger’s approach is the concept of the ‘natural
attitude’ and his challenge to the concept of bracketing pre-conceptions
(Inwood, 1997; McLeod, 2001). He believed that rather than attempting
phenomenological reduction, researchers must be open to investigating their
pre-suppositions and making them more overt (Holloway & Wheeler, 1995;
Inwood, 1997; O’Brien, 2002) allowing them to acknowledge and explore any
pre-conceptions or biases rather than to exclude them. Gadamer distinguished
between the methods of Husserl and Heidegger by proposing that Husserl
would define Heidegger’s function of interpreting the meaning of a description of
a phenomenon was, in reality, interpreting an interpretation (van Manen, 1997).

In his epistemology Heidegger identified three chief characteristics of being and
existence. Firstly, that people exist in and through time and to be completely
cognisant of human existence necessitates acknowledging the finality of death;
living with an awareness of future possibility, together with the possibility of
death (Holloway & Wheeler, 1995; Inwood, 1997; McLeod, 2001). Next, that our
existence is built around action; structured in relation to what we do in the world,
and with what is within our domain. The third feature of our everyday lives “is care: we are connected to the world through our anxiety, dread, and resoluteness” (McLeod, 2001, p. 60).

Heidegger's examination of *being-in-the-world* has been criticised, and his support for National Socialism during the Nazi era in Germany, coupled with his failure to condemn the Holocaust, added to the perception of the inadequacy of his philosophy. Other phenomenological researchers including Foucault, Levinas and Derrida, have built on Heidegger's principles (Benner, 1994; Inwood, 1997; McLeod, 2001), however, each has created their own personal strategies and methods to understand the nature of existence.

Foucault, a French philosopher who described himself as an ‘historian of systems of thought’, is generally accepted as the most influential social theorist of the second half of the twentieth century (Bell, 1992; Stokes, 2004). His definition of philosophy differed from most as he believed it focused on the critique of truth by conceiving it as inextricable from a critique of history. The theme that runs through Foucault’s writing is the relationship between knowledge and power, and how power is used to control and categorise knowledge particularly within social systems (Bell, 1992; Misselbrook, 2013; Stokes, 2004). Exploring ways in which social control is built, he related the concept to the practice of medicine. The power structure of ‘the medical gaze’ wherein doctors revise a patient’s story to suit the paradigm of biomedicine, removes the non-biomedical information. This ‘gaze’ is the use of power to determine relevant elements of the story and illustrates how doctors are not patient-oriented, rather they are medically focused. This results in a power structure which is abusive and dominating (Misselbrook, 2013).

Levinas, another French philosopher, was a Jewish thinker who studied under Husserl and Heidegger. He joined their rejection of philosophy’s traditional preoccupation with metaphysical questions regarding ‘being’ and epistemological questions regarding ‘how we know’; indeed, he became influential for his translations of Husserl and Heidegger into French. After World War II, however, Levinas clearly distanced himself from Heidegger due to the latter’s support for Nazi activities. His philosophy has been described as a
constructivist approach that made personal ethical responsibility to others the starting point for philosophy rather than a secondary reflection that followed explorations of the nature of existence and the validity of knowledge. When a human being is in direct contact with another, Levinas proposed the ethical dimension prevails, as we see the responsibilities of human existence (Casey, 2006; Steiner, 1991).

Derrida was a French intellectual who flourished in the late twentieth century as a celebrated and notoriously difficult to understand philosopher (Beck, 2006; Coker, 2008). He became known as the father of deconstruction, a method of inquiry which asserted that all writing was full of confusion and contradiction which an author’s intent could not overcome. Derrida acknowledged the importance of the works of Husserl and Heidegger upon whom he structured his work (Coker, 2008). While not providing a precise definition of deconstruction, he described it as a method which resulted in texts being robbed of truthfulness, absolute meaning and permanence. Many intellectual philosophers have embraced his method of breaking down text to reveal prejudices and inconsistencies in the writings of Plato, Aristotle, Shakespeare and other white male icons of western culture.

3.1.3 Merleau-Ponty
Merleau-Ponty also acknowledged the influence of Husserl, however, he concentrated on perception and broadened the idea of ‘being in the world’ to include the way we exist implicitly in the world through our bodies (Andén, 2019; Barbaras, 2004). He believed, “We are in the world, mingled with it, compromised with it” (Merleau-Ponty, 1948/1964, p. 147) and the world is an extension of our bodies. The ‘lived experience’ thus develops into an embodied experience which we cannot avoid (Adamo, 2002; Andén, 2019); living the world through our body, experiencing all we feel and know.

Merleau-Ponty (1945/2004) describes consciousness as ‘openness to the world’, in the sense that consciousness is a constant interplay between the person and the world. As we are wholly within the world, we cannot view it therefore from an exterior vantage point. Abram (1996) asserts that to Merleau-Ponty, participating in life is a defining quality of insight; the way we perceive is
intrinsically a result of our role as a participant. Fundamental to Merleau-Ponty’s perspective was the rejection of bracketing; by attempting the reduction, the hopelessness of achieving a complete reduction is demonstrated (Merleau-Ponty, 1962). He argued instead that being in the world we live in is central to who we are and cannot be reduced. For Merleau-Ponty, phenomenology was about the study of essences, and those phenomenological essences are revealed through thoughtful and empathetic reflection on the embodied lived experience of the individual.

Both Heidegger and Merleau-Ponty (1962) acknowledge the work of Husserl and deem their work to be a further development of his insights. The theme throughout remains the study of phenomena as they appear for us, and in particular how they appear for us in our pre-reflective lived experience of being in the world. While Husserl believed a full reduction was possible through the ‘epoche’ involving a transcendent ego or consciousness, Heidegger and Merleau-Ponty placed consciousness, and therefore phenomena, fully in the world as an inseparable relationship between a person and their world. Rather than distinguishing between the ‘transcendent’ phenomenology of Husserl and the ‘existentialist’ phenomenology of Merleau-Ponty, it is possible to view the distinction as a successive development of phenomenology. Despite clear differences of philosophical viewpoints, the common aim of the classical phenomenologists was to search for the essence of phenomena in lived experience.

3.2 Moustakas’ Phenomenological Design and Method

The phenomenological design and method articulated by Moustakas was chosen as the basis for this study. Moustakas was an American psychologist who developed and integrated the processes and phases of his research methods into his own studies (Blau, Bach, Scott, & Rubin, 2013). He acknowledges being heavily influenced by the work of “Husserl and by his students and other phenomenological thinkers” (Moustakas, 1994, p. ix), in the development of his methodology of transcendental phenomenology. Qualitative transcendental phenomenology enables researchers to return to experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience (Moustakas, 1994, p. 13).
Moustakas recommended that each researcher wanting to use a phenomenological approach address two key questions: “What are the experiences of people with a given phenomenon? And in what context or situations do they experience it?” (Moustakas, 1994, p. 78). This second question is particularly pertinent in developing an understanding of differences between metropolitan and regional/rural people in their experience of the process leading to the diagnosis of cancer.

Moustakas’ approach includes a system and process to guide researchers. The system focuses on preparation, data collection, organisation and analysis of data whilst the process or procedures form a method and provide a direction and steps to be followed to bring a study to life (Moustakas, 1994). The goal of this phenomenological approach is to describe the phenomenon under investigation, and to endeavour to unearth the meaning within and from the participants’ reported experiences. Moustakas proposed that the essential criteria for a research participant in a phenomenological study are that he or she:

Has experienced the phenomenon, is intensely interested in understanding its nature and meanings, is willing to participate in a lengthy interview (Moustakas, 1994, p. 107).

Phenomenological research depends on data generated during in-depth interviews with people who have experienced the phenomenon under consideration. Phenomenology as described by Moustakas (1994) depends upon the researcher conducting in-depth interviews with each participant, and from these interviews building textural and structural descriptions of the phenomenon being studied. The arrangement and analysis of the data commences as the researcher examines and scrutinises the transcribed interviews as per the stages of phenomenological analysis developed by Moustakas. These stages are presented in Figure 3 below, followed by a description.
As a new researcher, it was important to gain familiarity with the language of phenomenology. *Intentionality* in phenomenology refers to "the internal experience of being conscious of something" (Moustakas, 1994, p. 28) wherein the act of being conscious and the object of consciousness become intentionally connected. *Directedness* is the inherent characteristic of intentionality as the mind becomes focused on the object or event (Moustakas, 1994). Ihde (1977) proposed that *intentionality* correlated what is experienced with the style of experience; the ‘what’ and ‘how’. The ‘what’ is not the real...
experience, rather the ‘how’ is the manner in which it is experienced. The *Noesis* is the act of experiencing a thing: the feeling, perceiving, remembering, thinking and judging of things instilled with meanings which are hidden from consciousness. The *Noema* on the other hand is the thing which the person experienced. The relationship between that which is experienced, and the manner in which it is experienced, is at the core of phenomenology (Ihde, 1977). Analysis of the data is accomplished when the meanings have been revealed.

For every person the events they experience appear against a backdrop or *horizon* (Keen, 1975) and events always have many meanings simultaneously for the person who is experiencing them; that is, there are many *horizons*. Keen (1975) emphasizes that the horizons are functioning simultaneously; developing the strata of meaning intrinsic to the phenomenon therefore is vital to develop an understanding of the context in which the person experiences the event. Moustakas (1994) proposes that these horizons are the ‘how’ of the ‘what’ that has occurred in the phenomenon, and this is discussed further in Phase Four.

### 3.2.1 Phase 1: The Epoche

Epoche, the initial step of the phenomenological process, entails a deliberate attitude or approach to be taken by the researcher when commencing the study prior to conducting the interviews: biases, prejudgements, or preconceptions can be put aside and thus not affect the interview process. According to Sokolowski, the epoche is a Greek word meaning “to refrain from judgment, to abstain from or stay away from the everyday, ordinary way of perceiving things” (Sokolowski, 2006, p. 49). This involves the researcher deferring all personal preconceptions, hypotheses, beliefs and preconceived notions to be able to effectively delve into the consciousness of the interviewees. Indeed, judgment about the phenomenon in question is suspended until the facts are revealed from the data generated.

Moustakas suggests it is important researchers do not hold opinions or positions; nothing has been predetermined and no references are made to the perceptions and judgments of others, leaving the researcher equipped to observe and recognise a phenomenon (Moustakas, 1994). In the epoche phase
the researcher must demonstrate an impartial attitude, be open and willing to understand the phenomenon, and be completely focused on the words chosen by the participants regarding their experience.

3.2.2 Phase 2: Phenomenological Reduction

Moustakas proposed that the task of phenomenological reduction is a textural description of the phenomenon where the attributes of the experience grow to be the focus (Moustakas, 1994). This assists the researcher to describe the meanings and essences of the phenomenon from the elements of the experience emerging from participants’ thoughts and memories. Moustakas focuses on the attributes and qualities of the experience without influence from pre-conceptual ideas.

A number of stages are involved in phenomenological reduction using the Moustakas method, commencing with horizontalisation. This is achieved by identifying significant statements, and discerning invariant meaning units or themes. Invariant refers to the unchanging nature of statements in relation to their meaning or essence. The horizon is the grounding or state of the phenomenon which gives it a discrete nature (Moustakas, 1994). As each horizon and its textural qualities are examined, the experience of the participant can be considered through the researcher’s own self-awareness of reflection on the participants words. The process of horizontalisation is the initial step in data analysis, it requires the entire recorded interview to be transcribed so every statement of the participant’s experience is included and can be afforded equal value as the researcher seeks to uncover its nature and essence.

From horizontalised records, statements made by the participants are recognised within the transcripts, offering information about the experiences of each of the participants. The significant statements are gathered word for word from the transcripts and reviewed to enable a visual understanding of the range of views regarding the phenomenon. At this stage, no attempt is made to group or order the significant statements in any way, they are merely listed. Reading through the participants’ statements allows information to be gathered regarding how individuals experienced the phenomenon in question.
With every significant statement initially considered as having equal value, the next step is to remove statements which are not relevant to the topic, and those which are repeated or overlap with other statements. By meticulously examining the identified significant statements, the researcher can then cluster them into common categories or themes. This phase of data analysis is distinguished by dividing the data into parts or units based on a perception of the meaning.

3.2.3 Phase 3: Individual Textural and Structural Descriptions in Imaginative Variation

A separate textural description from each participant is created from the invariant meaning units or constituents that have been clustered into themes. Textural description denotes the ‘what’ of the participants’ reported experience. Each textural description is then reflected upon to build an individual structural description. Structural descriptions refer to ‘how’ the phenomenon is experienced, in its context. It can be achieved by considering textural descriptions and searching for additional meanings from different perspectives, roles, and functions. This process of imaginative variation leads to the essential structures of the phenomenon.

The purpose of imaginative variation is to develop a structural narrative of the essences of experience, offering a picture of the circumstances which lead to an experience, and join or bond with it (Moustakas, 1994). It aims to reveal the fundamental factors which explain the participants’ experiences; illuminating the ‘what’ of each person’s experience and explaining how the phenomenon became what was experienced. It involves deleting parts of a theme, then questioning if the essence of the phenomenon remains. Polt (1996) described it as a technique of creatively removing one characteristic, then another, until the essential characteristics are uncovered, as well as those which are non-essential or accidental.

3.2.4 Phase 4: Composite Textural and Composite Structural Descriptions

From the total group of individual textural descriptions, a composite textural description is developed. The horizons or invariant meaning units, and the themes of each participant, are studied to portray the experiences of the group as a whole. From the merged textural descriptions, utilising imaginative
variation, a composite structural description representing the group of participants as a whole is built. This provides a way of understanding the group experience of the phenomenon.

3.2.5 Phase 5: Synthesis and Integration in Intuitive Integration

The final phase in the phenomenological method proposed by Moustakas is the synthesising and integrating of insights contained in the changed horizons into a reliable description of the structure of the phenomenon. This requires intuitive and reflective integration of the composite textural and composite structural descriptions which offer a synthesis of the meanings and essences of the experience. Writing is not just revealing an individual’s personal knowledge; indeed, it can be the outcome of reflective inquiry and the discovery of knowledge (van Manen, 1999). The description develops into the essential, invariant structure of a definitive essence which captures the meaning attributed to the experience. This is concluded with an awareness that essences of an experience are never completely exhausted, and any deep textural-structural synthesis represents the essences at one particular time and place, as witnessed from the vantage point of a singular researcher utilising an intuitive and reflective study of the phenomenon (Moustakas, 1994). This phenomenological approach relies on individual experiences reported from participants’ voices, not those of the researcher or individuals reporting studies in the literature. It is consistent with human science research where the use of imagination and intuition is acknowledged, but is restricted from affecting the description of a participants’ experience. This synthesis and integration represents a universal description of the group of research participants as a whole (Moustakas 1994).

3.3 Reasoning for use of Phenomenology

Phenomenology has been used widely in nursing research over the last decades (Benner, 1994; Izumi, Konishi, Yahiro, & Kodama, 2006; Munhall & Boyd, 1999; Streubert & Carpenter, 1995). Phenomenology aims to reveal the lived experience of people in a variety of settings enabling others to understand that experience, in that setting, at that time. It is a process of shared creation between the participant and the researcher to enable new knowledge to be generated as explicated through the human experience. According to van
Manen (1990) the aim to acquire a deeper understanding of the character and significance of everyday experiences of people (van Manen, 1990) is at the core of phenomenology. This is supported by Benner’s proposition that phenomenology is a methodology focused on human concerns and matters by filling in gaps and developing a growing understanding that can be used to change health policy and practice (Benner, 1994).

The applicability of phenomenology to the experience of a cancer diagnosis in people in rural areas is reflected in the questions posed by Moustakas (1994) as ‘what are the experiences of people relating to a particular phenomenon’ and ‘in what context do they experience it’? The context of the experience is particularly relevant to my desire to develop an understanding of regional/rural people with a cancer diagnosis.

Although significant literature relating to a person having cancer is available, there is a specific ‘gap’ in understanding cancer in the context of rural NSW. As presented in the previous chapter, living in a rural location outside a metropolitan city creates sizable challenges and disadvantages for people in these communities. Utilising a phenomenological approach has enabled an understanding of disadvantage as it relates to the availability of the range of health care options required to diagnose, treat and support a person with cancer. Being able to build on understanding through interpreting the lived experiences of people in the Central West of NSW is important to inform improvements and enhancements to health care for rural people.

3.4 Conclusion
In this chapter I have presented an overview of phenomenology as it evolved during the twentieth century. In particular I have focused on the design and methodology of Moustakas (1994), developed to assist postgraduate students in the field of psychology and other researchers to apply phenomenology in their studies. His design and methods resonated with me from the initial two questions for a researcher relating to the phenomena in question and the context in which they occur, to the structured processes articulated for phenomenological research. As the fundamental purpose of this study was to understand the lived experience of a person with a cancer diagnosis in Central
I have also provided a rationale for the choice of phenomenology as the research method. The next chapter describes how I utilised the phenomenological design and methodology of Moustakas for this study.
CHAPTER Four – Method for this Study

4.1 Introduction
Chapter Four builds on the previous chapter’s description of phenomenology, and in particular Moustakas’ methodology, with a discussion of the research design and method used for this study. The chapter also addresses the ethical considerations of the study, the sample and the recruitment of participants. Following an introduction to the participants, data collection and the data analysis procedures are presented.

4.2 Research Design and Method
The existential nature a cancer diagnosis represents, and the consequent search for meaning, is a major challenge for our generation (Leeder, 2013). Whilst there is a vast range of information regarding cancer diagnosis and treatment, there is a lack of clear understanding regarding the lived experience of a diagnosis of cancer in regional areas of Australia such as the Central West of NSW. The use of qualitative methods to study the lived experiences of participants who live outside a metropolitan environment provides the opportunity to address gaps in current research. For Moustakas (1994), phenomenology is dedicated to the descriptions of a person’s or group’s experience as opposed to explanations and/or analyses. “Descriptions keep a phenomenon alive” (Moustakas, 1994, p. 59); indeed, the language used, the words, phrases, images and metaphors chosen by the participants shape the research and illuminate each individual’s experience of a cancer diagnosis. The research method reveals the participants experiences, their views, beliefs and the social constructs which influenced their journey following a diagnosis of cancer.

Qualitative design methods have been utilised in similar studies to improve understanding of patient experiences and behaviours in cancer care (Morse & Field, 1995; Moustakas, 1994; Patton, 2002; van Manen, 1990). They provide an opportunity for the researcher to grasp the essence or core meaning of each individual’s experience. People who are diagnosed with cancer engage in the experience of learning about their disease, treatment options and the meaning this has for their lives. Therefore, the description and interpretation of the
experience of becoming a person with cancer engaging in this journey is of interest. By listening carefully to the participants’ responses in the interviews I was seeking to understand their world. The intent was to provide a rich description of the experience of having a diagnosis of cancer in the context of regional/rural NSW and the meaning embedded in that experience.

As a phenomenological approach provides a sound method to acquire perspectives from participants and develop an understanding of what they have experienced, it is appropriate for use in developing a deeper understanding of the personal impact when receiving a diagnosis of cancer. To answer the research question, the method Moustakas described in *Phenomenological Research Methods* (1994) was applied. As discussed in Chapter Three, Moustakas was heavily influenced by Husserl's writings and there are similarities in their approach. Utilising his own research skills and knowledge coupled with the advice he had provided to researchers, Moustakas (Moustakas) developed a method to provide assistance to a wider audience. Moustakas’ (1994) proposed a method that should act as a guide for researchers rather than being prescriptive in nature. This structure offered a method which would guide me yet allow for personal variances to coexist comfortably with Moustakas' processes and stages.

It is important to note that the methods and procedures which are chosen and used are dependent upon the unique requirements of each study with no definitive or exclusive pre-requisites (Moustakas, 1994). Rather, research studies are individual and determine the suitability of the range of methods and procedures available, to best suit the phenomenon to be studied and the smooth and effective collection of data. Meeting the phenomena as it exists and not attempting to mould it to fit pre-conceptions (Keen, 1975) is at the basis of phenomenological research. The choices are made with the aim of supporting the phenomenon to reveal its essences, thereby uncovering the layers within (Keen, 1975). When an individual experiences a phenomenon, it is usual for the meanings associated with the phenomenon to be implicit and at times even vague. Selecting methods and procedures for data analysis provides the opportunity to make explicit that which is implicit.
The focus of this study was not on the specifics of diagnosing cancer. Instead, it was on revealing key elements within the context of participant’s lived experience so the information gained could inform health service planning and provision. The potential to provide fresh insight into the needs of people with cancer who live in rural areas could inform improvements in local health care systems, so they become more responsive and supportive during their illness journey.

4.2.1 The Role of the Researcher

It is important to acknowledge from the outset my personal and professional background relating to the care of people with cancer in metropolitan and rural locations. My career as a nurse working with people with cancer began thirty years ago. As discussed in Chapter One, I have held a number of nursing positions during the time I provided skilled clinical care to people with cancer, working in a range of settings in both metropolitan and rural locations.

In each clinical setting, the relationships with patients, their families and carers only became established well after people received a diagnosis of cancer. Unfortunately, I had not appreciated the often arduous and complicated journey each person had travelled prior to arriving at the point of care where I first encountered them, yet I had substantial interest in the experience of patients, both within the health care setting and in the influence cancer had on each person’s life. As no member of my family had been diagnosed with cancer when I commenced my study, I only had the perspective of nurse or friend to inform me. As a nurse I was often passionate in my advocacy on behalf of patients to ensure the journey they had with the treatment of cancer was as coordinated and simplified as possible.

After a number of years working in a rural environment, I moved into the management of cancer care services across a vast geographical region in NSW. I soon developed an awareness of the need for each person with cancer or a suspected cancer to have resilient ‘navigation skills’ to find their way through the complexities of the health care system. Indeed, this was often revealed when a person had encountered significant difficulties or delays in diagnostic or treatment services rather than as a robust proactive support
system provided to people as his or her journey unfolded over time. It is important to note my experiences led to subjective beliefs and assumptions relating to people's experiences of cancer care. However, because I had not personally experienced a diagnosis of cancer or worked in primary health care management, many of the experiences recounted by the participants in the study were new to me. My level of interest and perception relating to the phenomenon I had chosen to study aligned well with the prerequisite to undertake this type of inquiry as identified in the phenomenology literature (Moustakas, 1994; Munhall & Boyd, 1999; Sokolowski, 2006; van Manen, 1990).

Acknowledging prior experiences as a researcher and ensuring they would not influence the experiences shared by the participants, required careful development of proposed questions for the interview guide. I was aware of the importance of not leading participants when seeking information, rather to utilise open ended questions which would allow the participants to share their experience freely. During analysis of the data it was important to reflect and muse over my prior understandings of the phenomenon and ensure they did not impact on or change the meanings of the words of the participants regarding the phenomenon. Moustakas (1994) discussed the importance of the researcher having no opinions or position on the phenomenon; that is to suspend all judgement, yet I did not feel this was entirely possible in relation to some aspects, as I was immersed in the provision of cancer care in my working life. Other leading phenomenologists including Heidegger and Merleau-Ponty have challenged the concept of the researcher bracketing their previous experiences without compromising the process of seeking to understand the lived experience of others (Annells, 1996; Dowling, 2007; Draucker, 1999; Merleau-Ponty, 1962; Overgaard, 2010). Thus, I chose to acknowledge my previous experience and knowledge and open myself to interpreting the data from the participants.

4.3 Study sample

The sample in this study included eight adults diagnosed with cancer in the last six years who lived in the Central West of NSW. The goal was to acquire a sample of six to ten participants, which is considered an adequate number for a
phenomenological study (Mason, 2010; Morse & Field, 1995; Moustakas, 1994; Smith et al., 2009); despite the realisation that there are actually an infinite number of individual lived experiences relating to cancer outside the metropolitan context. Based on the methods literature, this sample size is considered suitable to gather the necessary data regarding the experience, to demonstrate meaningful similarities and differences between the participants, and to yield a rich description of the phenomena being studied (Cohen, Kahn, & Steeves, 2000; Munhall, 2007; Polit & Beck, 2006; Smith et al., 2009).

Achieving saturation in a qualitative study has do to with the type and scope of study, and the selection criteria. It is also easier to achieve saturation in the design of certain studies, for example, an experience relating to a specific group rather than an experience of the general population. In phenomenology a sample size may range from five or six participants up to 25 (Morse, Barratt, Mayan, Olson, & Spiers, 2002). What is of greater importance than saturation is validity of the data. One method to ensure this, is the concurrent gathering of data from appropriately sampled participants who have lived experience of the phenomena.

I was also conscious of the resources and time available, and the ‘law of diminishing returns’ which proposes that at a particular stage, no new significant information will be gained (Kvale & Brinkman, 2009). This point of diminishing return refers to an acknowledgement that increased amounts of data gathered does not lead to increased knowledge for a researcher (Kvale & Brinkman, 2009; Mason, 2010). In qualitative research frequency in the data is not the goal; rather one or two occurrences are considered as important as many more. The focus is concerned with meaning and being able to generalise that meaning across a population.

In this study I utilised criterion sampling, a form of purposive sampling (Polit & Beck, 2012). This requires the selected participants to have experienced the phenomena being studied and thus they are homogenous in general characteristics according to the criteria of the method. This sampling approach is designed to ensure data appropriateness and data adequacy (Morse & Field, 1995). The ability to understand and speak English was an inclusion criterion,
as access to culturally appropriate translation or support services could not be
guaranteed. Appreciating language is a mechanism for describing the lived
experience and how meaning is found when interpreting interviews (Gadamer,
1990); thus, I considered it vital to ensure each participant had the ability to
understand and speak English.

Individuals aged less than 18 years were excluded as the study aimed to focus
on adults who had a cancer diagnosis in the last six years. Individuals over the
age of 70 were similarly excluded as it may have been physically taxing for
them to participate in the interviews. Individuals who did not have the capacity
to make their own health care decisions were also excluded.

4.4 Ethical considerations
Following application to the Charles Sturt University Human Research Ethics
Committee approval to undertake this research project was received (approval
number 2014/162); Appendix One contains a copy of the approval letter dated
10 September 2014. Two public notices a week apart seeking participants for
interview were placed in the Western Advocate. The public notices were
augmented by a newspaper and online article resulting from an interview by a
local reporter describing the intended research. The criteria for participation
were to: (i) be between the ages of 18 and 70, (ii) have had a cancer diagnosis
within the last 6 years, and (iii) usually make health care decisions for
themselves – that is, able to give consent.

Having had a diagnosis of cancer is an essential criterion to be able to reflect on
the experience, and the timeframe of six years provides currency in relation to
the participant’s ability to recall the events associated with the process involved.
It is important the participants reside in the Central West in order to capture the
themes relative to their experience that may be specific to this geographical
location.

I received telephone contact from 12 individuals expressing interest in
participating. After the initial phone calls, which determined if potential
participants met the inclusion criteria, I provided each applicant with information
regarding the study by mailing to them hard copies of the participant information
sheet and the participant consent form for their consideration (see Appendices). Four people who contacted me after reading about the study in the newspaper did not meet the study’s inclusion criteria. I listened while each potential participant briefly introduced themselves, and after determining their eligibility, I thanked each person for the interest shown. I made a follow up telephone call a week later to determine if those interested and eligible remained willing to participate. Once I received phone confirmation that the applicant remained interested in participating, a mutually convenient day and time was selected for the interview. All eight eligible people chose to be interviewed.

Participants were given the opportunity to have a spouse or support person present, yet this was not taken up by any of the participants. Individual one-on-one interviews occurred with eight participants. Each interview was digitally recorded and ranged from 55 to 90 minutes. This timeframe excluded introducing myself and chatting prior to the interview when establishing rapport with each participant. Chatting following conclusion of the interview was also excluded from the interview time. I felt it was important for each participant to have a glimpse of me as a person, rather than a cold researcher who simply wished to interview them. It was also important to convey how privileged I felt that they were willing to share such a personal part of their life and that I would honour these precious stories. It was important to create a situation where the participants felt they could be true to their experience rather than tell me what they thought I wanted to hear.

To ensure adequate comfort and privacy for the participants, each interview occurred in a meeting room at the Bathurst Regional Library or the participant’s home, based on the participant’s preference. This was designed to ensure the participant would feel unrushed and comfortable to tell their story. It is important to be cognisant of the language used in conversation (van Manen, 1990); the way words are said and when silence is a component of the conversation, as they offer an insight into the feelings of a participant at that moment. I was conscious of the words I used, ensuring my questions were not hurried or leading in nature. I found with the participants there were few moments of silence and when they occurred, I was aware of the need to allow the participant to take the time needed to continue without prompting.
In recounting their experience, participants may become distressed as they reflect on such an emotionally difficult time in their lives. The management of this situation was carefully considered prior to the interviews. Due to the possibility of distress, emotional support and access to counselling services was offered to all participants. Very little is currently known about the experiences of people living in the Central West of NSW regarding receiving a diagnosis of cancer, therefore I considered it important to be prepared to offer immediate support if needed, in addition to the information provided regarding other services. One participant became tearful as she recounted her sister-in-law’s decision not to have treatment; she spoke of the impact this had on her brother and how distressed she felt for him.

As described in the ethical approval granted, participants who became distressed were offered the opportunity to pause the interview, to continue, to delay until a future date and time, or to cease the interview. None of the participants appeared significantly distressed, despite the emotional nature of the subject and none asked to pause, suspend or cease the interview.

To supplement the participant information sheet and the participant consent form I discussed with each participant the purpose of my study, how I planned to collect the data for the study and the approximate length of time the interview was likely to take. The process of the digital recording and the security processes in place to ensure confidentiality, including the use of a pseudonym for each participant were explained. After reminding each that they were free to withdraw from the study at any time without any penalty, I then asked each participant if they wished to proceed. Upon a positive reply, they were invited to sign an informed participant consent form.

4.5 Participants

An introduction to the participants who were interviewed for this study follows, including information relating to the type of cancer in relation to the life they were living. To maintain anonymity a pseudonym for each is used to report the interview findings. The participants are presented in chronological order of their enrolment in the study.
### Table 4: Characteristics of Participants

<table>
<thead>
<tr>
<th>Order</th>
<th>Assigned Pseudonym</th>
<th>Age Group</th>
<th>Cancer Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Karen</td>
<td>60-69</td>
<td>Breast cancer</td>
</tr>
<tr>
<td>2</td>
<td>Peter</td>
<td>50-59</td>
<td>Bladder cancer</td>
</tr>
<tr>
<td>3</td>
<td>Cathy</td>
<td>50-59</td>
<td>Ovarian cancer</td>
</tr>
<tr>
<td>4</td>
<td>Diane</td>
<td>60-69</td>
<td>Breast cancer</td>
</tr>
<tr>
<td>5</td>
<td>Pam</td>
<td>50-59</td>
<td>Breast cancer</td>
</tr>
<tr>
<td>6</td>
<td>Len</td>
<td>40-49</td>
<td>Bladder cancer</td>
</tr>
<tr>
<td>7</td>
<td>Sally</td>
<td>30-39</td>
<td>Cervical cancer</td>
</tr>
<tr>
<td>8</td>
<td>Anthony</td>
<td>40-49</td>
<td>Colon cancer</td>
</tr>
</tbody>
</table>

### 4.5.1 Participant Stories

**Participant #1: Karen**

Karen was an articulate woman in her sixties who demonstrated a sense of humour and referred to it during the interview as a useful coping strategy during her illness. She described her marriage to her husband as very successful and had two grown children. She reflected on her passion for teaching as a career including diversifying from her traditional primary school role to teach music, including at the local conservatorium. Karen reported she had lived in the same house for all thirty-six years of her marriage. Karen spoke of stressors in her life which took an enormous toll a number of years prior to her cancer diagnosis, including being an active carer for her elderly father and father-in-law, her husband who had an autoimmune disease and their two teenage children who had mental health issues.

A self-confessed control freak, she spoke of liking to manage both situations and her own emotions. Karen had a diagnosis of breast cancer following reporting a fluttering feeling in her breast and had been coping with treatment for this for nearly two years; she summed up that she wasn’t in anyway prepared for this to happen to her. She felt she didn’t have a plan for how to cope, let alone the usual back-up plan she liked to have in place to feel comfortable with challenges in life. Her cancer diagnosis was a defining
moment in her life and the discomfort which persists is a physical reminder of the emotional battering she’s had.

Knowing who she is as a person, after cancer has been a challenge – she has recognised that she isn’t the same person she was – and finding her talents and strengths after cancer hasn’t been an easy process for her.

**Participant #2: Peter**

Peter was a man in his late fifties who had been a psychologist for most of his working life. He was happy to chat when we met; he mentioned how he hoped sharing his story would be of use. He had lived with his wife in the Central West for close to thirty years after moving from Sydney for a work opportunity. He and his wife had two adult children and he described them as being ‘empty nesters’ despite one son living with them at the time of our interview.

Following the shock of his diagnosis Peter felt it was important to know as much as possible about his illness, and indicated that being tertiary educated provided useful skills to enable him to seek information independently so he was then equipped to ask the right questions during specialist appointments. He described himself as a person with liberal humanism beliefs and indicated that those beliefs allowed him to get through a diagnosis of cancer. Peter was diagnosed with bladder cancer and six months later retired early due to his illness. He spoke of being pragmatic and stoic yet ruminating on what he considered ‘the worst-case scenario’ and he worried about how difficult this was for his wife.

Peter described his life since retiring as being at home most days of the week and acknowledged that having cancer has really changed him as a person. He referred to having no plan as to treating his cancer – each specialist appointment provided verbal information and a specific task to undertake, yet no long-term plan was shared with him. With cancer and other chronic illnesses, Peter spoke of his struggle to identify the lead clinician for his general health at times, particularly when he experienced a new symptom or had an abnormal blood result.
Participant #3: Cathy

Cathy was a bright and chatty woman in her fifties who was married for the second time after divorcing her first husband. She spoke fondly of her current husband and indicated that they were a happy unit who had supported each through life’s ups and downs. Being born and bred in the Central West, she felt being an active member of the community had always been important to her, particularly volunteering her time to support a local charity. Cathy had worked part time for the last few years in the local retail industry and spoke of how she enjoyed being with people in whatever she was doing. She spoke of her beloved dogs and how sensitive they were to how she was feeling.

Describing herself as someone whom people would have thought of as ‘happy go lucky’, she revealed she was actually someone who expressed her feelings at home in a different way to her public side. She reflected on her happy disposition as being only one part of her personality and that she didn’t share her feelings of sadness or worry with many, indeed she was actually rather a private person and felt it was important to have some level of privacy living in a rural area.

Cathy had been diagnosed with ovarian cancer three years ago after an episode of what she thought was nasty food poisoning which didn’t seem to really get better. She had ongoing treatment for her cancer and indicated most people weren’t aware that she felt she wasn’t going to beat the cancer despite everything she had been through. Cathy shared that it was probably time to share the extent of her illness with her extended family. She spoke of the choices she was planning to make as probably the only control she had against a cancer that wouldn’t go away.

Participant #4: Diane

Diane was a woman in her fifties who as a University academic and teacher who loved to travel and be active, playing lots of sport. She spoke of being a child of seven and had been living with her adoring husband in the Central West for approximately 20 years. Diane was proud of her two grown children and their chosen areas of work in Melbourne and Canberra.
As a ‘lefty’, social justice was very important to her and she was really pleased both her children had similar views, and as both are gainfully employed and happy, she felt she’d been successful as a parent. Family was important to her feeling that if her kids and husband were happy then she was also happy. Diane was diagnosed with breast cancer after feeling what she thought could have been a cyst towards the centre of her chest, and she had a family history with her sister also having breast cancer. She indicated her diagnosis sent shock waves through the local medical community as a new GP had removed the ‘cyst’ in the surgery rather than referring her to a surgeon or for diagnostic radiology. He then phoned her a few days later to ask her to come for an appointment disclosing the pathology had come back as breast cancer.

She later learned it was a stage two breast cancer, triple negative disease and therefore was going to be difficult to treat. Her treatment had included a surgical lumpectomy and chemotherapy, followed by radiotherapy. Diane disclosed that she would likely need to continue to have treatment as the cancer hadn’t responded as well as had been anticipated. Having what seems like the world’s largest collection of scarfs to use when her hair fell out; Diane reflected that the scarf had become physical evidence of the cancer cells in her body.

**Participant #5: Pam**

Pam was a fifty-year-old woman who said a number of times that she hoped by telling her story other people wouldn’t face some of the difficulties she had. She was a mother of four; explaining that three were biological children and one was adopted. She was also excited to share that she and her husband were adopting another little girl who needed a home and they felt they could offer her one. Pam was a proud grandmother to her first grandson who was nine months old.

Working full time for a major retail chain, Pam’s life was busy, and she described it as being uneventful around the time of her diagnosis of breast cancer. She had regular pap tests and a mammogram not long before she felt a lump in her breast one day when she was showering. She felt the surgeon to whom she was referred treated her as an irritation and was lacking in his ‘bedside manner’, saying to her he was one hundred percent sure the lump
wasn’t cancer and didn’t need to be removed. When she spoke of her concerns, he grudgingly told her he would do a biopsy but that it was a waste of taxpayers’ money.

Nine weeks and three surgical procedures later, Pam had a confirmed diagnosis of breast cancer and a mastectomy yet felt she had been treated as a number by the surgeon and not received any emotional support until she met the McGrath Breast Care Nurse after her final surgical procedure. With the information and support from this nurse, she found the further treatment needed for her breast cancer arduous. Yet, Pam spoke of how she was determined to persevere and not let the cancer beat her.

**Participant #6: Len**

Len was a man who told me he was 65 years old and had just recently retired. He was married with three adult children, one of whom lived at home and required care due to an intellectual disability. He spoke of his wife with a gentle voice and told me how important she was to him and of all she did to support their son who lived with them.

Len had worked for many years in the printery attached to the local university, and he believed the long-term use of chemicals may have been a factor in developing cancer. In recent years exercise had become really important to Len, getting up at 5 am to go to the gym had become his routine whenever possible. He was also someone who spoke of the intense need to ‘give back’ and did regular voluntary work at a local retirement village, saying he was a general dog’s body to help the residents and taking responsibility for looking after the caged birds. The social aspect was enjoyable but so was the feeling there was some purpose in his life.

He found life had become more difficult as he always needed to pass small amounts of urine. Upon discussion with his GP a year prior to his diagnosis he was told this was just a part of getting older and so tried to accommodate this need in his everyday life; finding the toilet in a shopping mall or entertainment centre had become a priority. A final event he described as humiliating occurred when on holiday in Adelaide: he’d had to duck between the grape vines to pass
urine due to the urgency he felt. Upon returning home, a different GP whom he happened to see immediately investigated, and he was diagnosed with bladder cancer three years ago.

**Participant #7: Sally**
Sally was a bright and bubbly 37-year-old who chatted about life being exciting lately and how important it was to enjoy every minute of it – her birthday had been the week prior to our interview and her wedding six weeks earlier. Married to an amazing man, she had one biological child who was 17, and one stepdaughter aged five who lives with the family, and whom she considers as her own child.

After finishing school, Sally volunteered as a St John’s Ambulance officer but found she wasn’t able to meet the strength requirements of NSW Ambulance due to an old injury. Still interested in health she started working in a pharmacy and then trained to manage pharmacies. Feeling the need for a change she studied accounting and embarked on a very short career doing tax and accounting work. Another foray into retail, Sally had changed to working at a car dealership four months prior to the interview, and found she loved it.

After a long period of feeling generally unwell including bleeding after sexual intercourse, Sally had visited GPs and emergency department doctors who had focused on gastrointestinal issues diagnosing an apparent gluten intolerance. Visiting the GP for her annual pap test she experienced a large loss of blood at the end of the procedure; however, the GP indicated no concern. Sally was told of her diagnosis of cervical cancer over the phone in her lunch break at work.

**Participant #8: Anthony**
Anthony was a man in his forties who had been married twice and was living with a partner of two years. Having had one very difficult divorce, he admitted he was hesitant to commit fully to a new partner but felt that his current relationship was strong. He had two school age boys he saw only one weekend a fortnight, yet felt they had a good relationship and enjoyed the time they spent together.
Working in a government department, whilst not relevant to his degree and not completely satisfying, had been a lifeline due to the leave entitlements he had been able to access with his illness. Financially he had managed and not felt pressure to return to work until he felt ready.

After abdominal pain and vomiting for a few days, Anthony was admitted to hospital via the emergency department to have his appendix removed. Whilst this occurred, the surgeon also removed a bowel tumour which extended out of the lumen of his bowel. A referral for chemotherapy followed his recovery from the surgery and he had found this very difficult.

4.6 Data Collection Procedures

4.6.1 Role of Interviews in Phenomenology:
Interviewing is a means of gathering information in phenomenological research and is used to endeavour to unearth meaning in and from the reported experiences, thus developing a rich and deep understanding of the deeply personal phenomenon (Moustakas, 1994; van Manen, 1990). During semi-structured interviews, interaction with the participant is an important aspect when they are sharing personal experiences, stories and incidents. It enables the interviewer ‘a way in’ to the lived experience of each participant. Reflection on an experience by the participant during an interview is an acknowledged method of portraying how it is personal and unique (Moustakas, 1994; van Manen, 1990). Interviewing gathers the information and enables the development of an understanding of a phenomenon (Moustakas, 1994; van Manen, 1990).

Patton (2002) refutes that open-ended interviewing puts things in someone’s mind; instead, it is to access a participant’s perspective:

We interview people to find out from them things we cannot directly observe ... We cannot observe feelings, thoughts, and intentions … and the meanings they attach to what goes on in the world – we have to ask people questions about those things… (Patton, 2002, p. 196)

The format of semi-structured interviews varies as the goal is to always use open-ended questions to maximise the emergence of information. Moustakas (1994) clarifies that whilst a series of questions is best prepared in advance;
these questions may be modified, changed or not even asked according to the flow of information as the interview unfolds (Moustakas, 1994). This resonated with me as it fit well with my established style of interviewing and I found that using the questions as the ‘core requirements’ allowed for changes where I felt it was useful for serendipitous data collection. Patton refers to a "guided interview approach" where topics are covered based on pre-prepared questions (Patton, 2002, p. 206); however, the wording of questions and the order in which they are used is flexible during the interview. This allows for a more conversational interchange and encourages spontaneous sharing of information from the participant. Given the preparation for the interview there is sufficient structure to achieve complete and methodical data collection (Patton, 2002). I believed the structure would be important in order to keep the interviews focused and make sure the most important issues were covered in each session.

Giorgi (1971) advised phenomenological researchers to focus primarily on seeking a detailed description of the ‘what’ the person experienced prior to asking precise questions regarding the phenomena being described. Once the participant seems to have finished the description, it is appropriate for the researcher to focus on the precise but open-ended questions relating to the ‘how’ of the phenomenon. Following this technique is likely to result in the researcher learning far more of the experience from the individual perspective of each participant. The design of the questions to guide the interviews applied the principle of focusing on the ‘what’ followed by the ‘how’ and was useful in gaining insight into the phenomenon.

Through interpretative analysis, the essence of the participant’s experiences are revealed in the text from each interview. The themes form the structures of the experience so that when analysing the phenomenon and determining the themes, the experiential structures are uncovered or revealed (Moustakas, 1994; van Manen, 1997). Discussion of how I utilised Moustakas’ phenomenological approach (1994) is included later in this chapter, including how the themes of each participant were studied to reveal the experiences of the group as a whole. From the merged textural descriptions and utilising imaginative variation, an amalgamated description representing the group of
participants as a whole is built. This presents an understanding of the group experience of the phenomenon.

Each interview began with me introducing myself, then outlining the plan for the interview and asking if each participant was comfortable. I sought to develop a relationship with each person and indicated that I had some broad questions to ask, explaining that they could ask questions at any time and could come back to something they had said later on in the interview if something came to mind. The participants were then asked to provide an introduction to themselves, regarding family and life in the Central West to assist me in gaining an insight into the participant's life. This also provided an opportunity to ensure each participant felt comfortable and relaxed. The remaining open-ended interview questions focused on a discussion of their experiences with the diagnosis of cancer, who was involved in their cancer diagnosis, the processes involved, and what was occurring in their life leading up to this time. (A list of the interview questions is available in Appendix E). During the interviews, some questions were asked in response to information the participant was sharing at the time. The interview questions developed to guide the interviews had been reviewed and revised, following feedback from my supervisors and prior to the interviews commencing.

During the collection of data, I focused on the whole person and the entirety of the experience which was being described by the participant. I was interested in sifting through the voiced thoughts and feelings of the participants; in how they spoke of the experience of a cancer diagnosis and the interactions with others which were described. Each person's experience of learning about their diagnosis and what followed was captured when each participant discussed their own experiences during the interview. However, it became apparent that any one experience, despite its significance, cannot be isolated without the benefit of hearing the whole story from each participant within the context of their life.

The participants were generous with their time and in recounting the very personal experiences and feelings following the diagnosis of cancer. At times I prompted participants during the interview, usually to request further information
regarding something mentioned by the participant earlier in the interview. Each prompt led to the participant providing further open descriptions relating to that event or experience. Three participants referred to information they had gathered when recounting his or her experiences; these included diaries and patient information booklets provided by health professionals. One participant also brought pages printed from the internet showing the personal investigation he had undertaken in an effort to better understand his cancer and how it would likely be treated. All of this assisted in revealing the layers of meaning for the individual participant.

4.7 Data Management

All of the digitally recorded interviews were coded, and no other person knows the identity of the participants. All study-related information is stored in a locked filing cabinet in a locked office, and saved electronically to a secure network site. A hired transcriber completed verbatim transcriptions of the interviews when I encountered difficulties with this task, and these sets of documents were compared for completeness. Prior to analysis of the transcripts, I reviewed the typed transcripts against the audio taped interviews and edited the transcripts to ensure accuracy. Compliance with the requirements of the appropriate privacy legislation and code of practice has been integral to this study and no names or other personal or identifying information was used for any purpose other than the study. The securely stored password-protected data will be destroyed five years after the completion of this research thesis, including the computer files of both the interviews and transcripts. No identifying data has been stored with the interview transcripts.

4.8 Adaptation of Moustakas’ Method

4.8.1 Phase 1: The Epoche

The Epoche is the initial step of the phenomenological process described by Moustakas (1994), although I deviated somewhat from his method. The Epoche entails a deliberate attitude or approach taken by the researcher to suspend all previously held beliefs, preconceptions and theories prior to conducting interviews, so biases, prejudgments, or preconceptions are recognised and put aside. The aim is to ensure that the researcher is open to the phenomenon and
does not affect or influence the interview process. This is acknowledged as “a difficult task” (Moustakas, 1994, p. 86). Whilst keen to be approachable and sympathetic, I was wary of conveying any assumptions of their experience. As described previously, I was also careful to avoid leading the participants in any way, using open ended questions and not prompting when a participant took a moment to come up with the word they were seeking to use in the interview. Rather, I was vigilant to allow the participant to provide the direction of the interview.

When commencing this study, my clinical and managerial background had not encompassed the care of people in the community who are given a diagnosis of cancer. My background has included working with people with an established cancer diagnosis and those providing clinical care to them. Despite never having cancer or providing care to people in community when they receive a diagnosis of cancer, I felt it was impossible to completely ‘set aside’ my attitudes and knowledge about the concept of cancer as this has been the main focus of my professional career. However, I was able to ensure my judgements and assumptions of the process, and the impact of receiving a diagnosis of cancer, did not influence the interviews and could be acknowledged. It was important to be open to develop a better understanding of the lived experience of the participants.

4.8.2 Phase 2: Phenomenological Reduction

Moustakas proposed the task of phenomenological reduction as developing a textural description of the phenomenon; “the qualities of the experience become the focus” (Moustakas, 1994, p. 34). This phase helped me to develop an informed description from the transcripts, thereby revealing meanings and essences which the participants disclosed about their experiences during the interviews. Searching for the description of the meaning of the experience, rather than the experience itself, became a primary focus in this phase.

I commenced by attempting to transcribe the eight interviews word for word. Although this expanded my awareness of the depth and complexity of the phenomenon being investigated, I became aware I did not have the technical expertise required for transcribing. Following discussion with my supervisors, a
professional was engaged to transcribe the interviews. Confidentiality was maintained by having no participant names in the digital recordings and each interview was identified by a number indicating the sequence. I was then able to scan and survey the transcripts. Initially, I gathered descriptions of the phenomenon as a whole, reading each transcript through a number of times in combination with listening to the digital recordings for nuances which may have been lost in the transcription process.

I then reviewed the transcripts, identified significant statements from the participants and considered each statement to be of equal value. This phase was a concentrated study of the data which resulted in a pre-reflective description of things just as they appear. Following Moustakas’ entreaty to "look and describe; look again and describe; look again and describe; always with reference to textural qualities" (Moustakas, 1994, p. 90), I reviewed the data multiple times as I wanted to do justice to the richness of the data. Next, I spent time in a deeply reflective process where my goal was to begin “grasping the full nature of a phenomenon” (Moustakas, 1994, p. 93). This process was helpful in gaining familiarity with the content of the interviews and gaining confidence in ensuring the context of the statements remained intact. It enabled me to gain a larger picture of the phenomenon from the experience of the participants and led to a clearer awareness of what was texturally meaningful.

Following the period of deep reflection, I removed statements which did not appear to be relevant to the experience of a cancer diagnosis, were repeated information, or transitioning one statement into another. This process enabled clear identification of significant statements which were classified into shared themes or meaning units. This phase in the process was characterised by separating the data into groups based on differences in meaning. When a theme stood separately from the rest of the data, I was able to determine that it was a meaning unit. Colour coding segments of transcripts was also valuable during this phase as it enabled me to reflect on where statements best fitted within the themes. At this stage all themes were considered to have similar depth; each theme was significant in explaining the meaning of the experience. With this repetitive looking, over and again, gradually an experiential structure began to appear and enabled me to find a clearer sense of what was texturally
meaningful and essential to the experience. Returning to the audio recordings of the interviews I was then able to gain context which assisted in the clustering of the significant statements. During this process I made notes when an inkling of a possible theme or element emerged. I referred back to these notes later in the process. The goal of the continued looking and reflection on the data is to obtain complete descriptions.

Resisting an initial desire to impose my own order on the data and following the process of phenomenological reduction led to the emergence of meaning units. Over time, as I dwelt within the vast array of data fragments in an immersive and contemplative manner, organisational structures began to emerge. With further reflection, increased clarity brought forward patterns in the participants’ descriptions of the phenomenon.

**4.8.3 Phase 3: Individual Textural and Structural Descriptions in Imaginative Variation**

For each participant I created a textural description based on the statements that had been clustered into the themed groups. This textural description described the ‘what’ of the reported experience from each participant while the structural descriptions referred to the ‘how’, in its context, the phenomenon was experienced. I spent time reflecting on each description in order to build an individual structural description of the phenomenon. I then considered the textural descriptions and probed for further meanings and listening to the interview audio recordings again was helpful during this phase.

I determined that a meaning unit had to be able to stand apart from the rest of the data and statements. Repetitive or overlapping statements and those irrelevant to the research question were removed. Expressions that remained stood out as invariant (unchanging) qualities of the experience. Over time, my aim was to arrive at a complete textural description of the experience of a cancer diagnosis within the context of rural/regional NSW.

This process of imaginative variation leads to the essential structures of the phenomenon. I was seeking meanings by viewing the statements from different perspectives and considering a wide range of structural qualities or dynamics to
suggest textural qualities. Seeking to understand the ‘how’ of the experience by reflecting on factors which influence what the person experienced reveals more of the ‘what’ that was experienced. A component of this process involved deleting a theme, then questioning if the essence of the phenomenon remains. It is a technique of imaginatively subtracting one feature, then another, to discover which features are essential and which are not (Polt, 1996). Reflecting on the result after subtracting an aspect was vital to maintaining meaning or context. When subtracting a feature, if the experience was altered, it became clear the theme was essential. It was helpful to remove themes of secondary importance, while keeping others which appeared essential to the experience. This eventually left only the essential themes, those defining the essence of the experience of a diagnosis of cancer for the participants. During the process of analysis, 74 significant statements were identified. The organisational categories and strata of the data began to reveal themselves.

4.8.4 Phase 4: Composite Textural and Composite Structural Descriptions

I continued to study the meaning units, focusing on the qualities of the experience of a cancer diagnosis with the aim of explicating the essential nature of the phenomenon. Bringing order to the vast range of data fragments was an arduous task. I was conscious of again resisting any inclination to impose an organisation of my own on the data and remained focused on viewing each snippet of data within the context of the whole.

Having arrived at a final group of individual textural descriptions, it was possible to build the composite descriptions. These were then studied to reveal the experiences common to the group as a whole, despite the diversity of the participants and their differing diagnoses of cancer. I maintained the exact wording of the participants wherever possible in a conscious effort to keep the meanings or subtle nuances of their words. I did not want to risk reducing the rich data to thematic descriptions which would lack soul or emotional substance. It was paramount to be true to the data.

From the merged textural descriptions, a composite structural description representing the group of participants as a whole was created; it offered an approach to begin understanding how the group experienced a phenomenon.
Each participant’s experience was accepted as offered during the interview and these experiences layered and intertwined to reveal the profound tapestry of the lived experience of a cancer diagnosis in the Central West of NSW.

4.8.5 Phase 5: Synthesis and Integration in Intuitive Integration

The final phase in Moustakas’ phenomenological method was to synthesise and integrate the insights into a description which honoured the participants’ words and their meaning to develop the structure of the experience of a cancer diagnosis in the Central West of NSW as a phenomenon. From continued reflection, clarity appeared; patterns started to emerge in the research participants’ descriptions of behaviours, feelings, thoughts, and beliefs. I found this blending a highly creative process, with intellectual rigor. Moustakas refers to this synthesis being built through the research process as “intuitive integration” (1994, p. 100). As the patterns and categories emerged from the data, I clustered horizons into core themes and attached labels. Next, I integrated the textural constituents and themes from each participant into individual textural descriptions of the experience of a cancer diagnosis. This resulted in an integration of the individual textural descriptions into a composite textural description.

Although this was a lengthy process, it flowed logically by combining the composite textural and composite structural descriptions to present a written synthesis of the meanings and essences of this lived experience; “writing is not just externalising internal knowledge; ...it is the very act of reflective inquiry and of discovery” (van Manen, 1999, p. viii) and, a process of mutual creation between the participants and the researcher to support new knowledge to be generated as revealed through the human experience.

The description grows and develops into the essential, unchanging structure of definitive essences which encapsulate the meaning of the experience. This phase was undertaken by acknowledging that the essences of the experience can always be further developed and any deep textural-structural synthesis presents the essences as a snapshot of the recounted lived experiences of the participants (Moustakas, 1994). I had the freedom to utilise intuitive and reflective study of the collective presentation of the phenomenon.
This phenomenological approach relied on the participants’ firsthand experience of a diagnosis of cancer. The participants’ voices and accounts were of primary importance. Utilising phenomenological analysis and reduction of the data, an understanding emerged of the experience of a cancer diagnosis as it is lived in the world. Despite the many differing circumstances surrounding the experience of a cancer diagnosis, this process extended beyond my imaginings and suppositions. I acquired a larger, universal picture of the actual experience of those affected in the Central West of NSW.

4.9 Rigour

The issue of attaining rigour in relation to qualitative research has been challenged in the literature, with several researchers arguing that only the terms ‘reliability’ and ‘validity’ are applicable to this type of research (Leininger, 1994; Lincoln & Guba, 1985; Rubin & Rubin, 1995). Validity in qualitative research is achieved by the researcher returning to the descriptive accounts of the research participants’ lived experiences; that is, the source material. Other criteria proposed by Lincoln and Guba (1985) for adoption in qualitative research to ensure rigour exchanged reliability and validity for the analogous concept of ‘trustworthiness’. When implemented, this is confirmed via credibility, transferability, dependability, and confirmability (Koch, 1996; Lincoln & Guba, 1985).

Credibility addresses the degree of fit between participants’ narrative and how the researcher represents them (Schwandt, 2001) in the analysis and can be viewed as a form of internal validity. Therefore, it seeks evidence to support the description as credible. Credibility of the current study was addressed using summaries at the time of interview (paraphrasing the participants’ words as understood), and discussion and review by the supervisory team (Lincoln, 1995).

As a qualitative researcher, it was vital to ensure I was engaged with the participants’ experiences via the subjective meanings in the data, whilst remaining as objective as possible (Leedy & Ormond, 2010). To achieve this, the literature proposes researchers must utilise a number of confirmation
strategies and self-correcting procedures at each phase in the research process (Morse et al., 2002; Ryan-Nicholls & Will, 2009; Tobin & Begley, 2004). By doing so, the researcher will have confidence the research process is rigorous (Leedy & Ormond, 2010; Morse et al., 2002).

In this study, there were instances where I was uncertain whether the data reduction, horizontalisation or rephrasing maintained the full meaning, intent, and integrity of the participant’s original narrative description. The use of reflection and listening again to the digital recordings was particularly helpful; it enabled me to clarify if concerns were of value or able to be dismissed. I discussed with my supervisors the themes and elements as they emerged from the data and this also assisted in developing clarity. When analysing the interviews, the exact wording of the participants was used wherever possible. I condensed, revised, or eliminated overlapping, repetitive, or irrelevant words and phrases, taking great care not to change the meanings or subtle nuances of the research participant’s original language.

Transferability indicates the generalisability of the research findings process (Tobin & Begley, 2004) and acts as a form of external validity. There are two key foci to increase transferability for qualitative researchers: (i) the closeness of the participant’s link to the phenomenon being studied, and (ii) the contextual limitations of the findings (Jensen, 2008). In this study concerned with cancer in the Central West of NSW, all participants recruited had experienced a diagnosis of cancer whilst living in this area, thereby addressing the first focus. In relation to the contextual limitations or boundaries, it is likely the findings can be generalised to regional/rural areas with similar populations and characteristics to the Central West of NSW, however, given the health care systems involved in the care of people with a diagnosis of cancer, it is unlikely this could extend to countries other than Australia (Horsburgh, 2003).

Dependability, which is comparable to reliability, is best attained via auditing procedures (Tobin & Begley, 2004) undertaken by researchers in order to demonstrate the appropriateness of the research process. This is achieved by ensuring the process is logical, traceable, and clearly documented (Schwandt, 2001). In this study, using Moustakas’ methods as the guide, I chose to record
reflections of my interpretation of the data as a means of demonstrating transparency. I conducted an initial literature review prior to the interviews, leaving the comprehensive review until the data analysis was completed. This offered a mechanism by which to preserve the inductive integrity of the study (Creswell, 2003).

Confirmability, which is comparable to objectivity, concerns how neutral or free from bias are the research findings (Ryan-Nicholls & Will, 2009). It is important to note that findings in qualitative research are not neutral or value-free (Creswell, 2003; Horsburgh, 2003). Rather, as the researcher, I acknowledge my personal beliefs, assumptions and values as part of the phenomenological process. Therefore, some researchers conclude that confirmability is not the most appropriate measure to judge rigour (de Witt & Ploeg, 2006), whilst others defend confirmability as a focus on confirming that the interpretations of the findings are clearly derived from the data (Tobin & Begley, 2004). In effect, it can be seen that confirmability is attained through the fulfilment of the three criteria discussed previously.

4.10 Conclusion to the Chapter
This chapter describes the conceptual framework of the phenomenological research model I employed. The methods and procedures applied for collecting and analysing data, the selection and preparation of participants, the interview and phenomenological data analysis processes are outlined in detail. Also presented is a brief overview of the story of the lives of the people who participated in this study seeking to come to an understanding of what it is to have a diagnosis of cancer in the Central West of NSW. As a group, they have fairly diverse lifestyles and differing cancer diagnoses. Each brings to life their unique experience of life after a diagnosis of cancer.

I was truly affected by the analysis of the data from the interviews. The intimate, open manner of the participants revealed narratives of emotion, profoundly personal central issues and beliefs integral to their lives. The raw data from the interviews revealed a far-reaching group of vivid descriptions of a diagnosis of cancer in the Central West. As a new researcher, the challenge of discovering central themes and unearthing essences of the experience was immensely
rewarding. The next chapter begins the discussion of the themes which emerged from the data.
CHAPTER Five – Cancer Diagnosis: An Existential Crossroads

5.1 Introduction
In the previous chapter I discussed the processes utilised to analyse the data leading to the emergence of the themes. This chapter introduces the themes which emerged from the participants’ experiences within this study, and then focuses on the first theme. The stories of our lives, the events and happenings, are inextricably entwined and give meaning to our experiences. The depth and breadth of each participant’s experience are revealed to uncover the essence of the experience of a diagnosis of cancer for people living in the Central West of NSW. The data analysis for this study is reported as themes and elements contained within the themes using the participant’s language.

5.2 The Themes
Four primary themes emerged: shock at the diagnosis, grief for the life that’s lost, a thirst for information and a new life. Cutting across all of these was the powerful theme of the impact of rurality and the subsequent additional issues the participants faced with a diagnosis of cancer. This issue of rurality was wrapped within each of the primary themes and revealed a burden with which each participant was forced to grapple. Each theme had a similar depth, and each was significant in explicating the meaning of the experience. The narratives from the participants are utilised in a way to ensure each is considered the primary source of knowledge in relation to the phenomena being studied (Moustakas, 1994). Transcript excerpts have been selected as exemplars of each theme and the related key thematic elements.

Using thematic analysis, the elements which constitute the phenomenon of a cancer diagnosis in the Central West of NSW were revealed. As findings, these elements remain unchanged in order to maintain the integrity of the meaning of the experience. With the elements integrated, the themes emerged. Although the themes are reported as framing the experience for all participants, they did not appear in the same sequence or in any fixed order for each participant.
Each theme contains elements that cluster around key points and are listed in the table below, accompanied by transcript excerpts to illustrate the themes.

### Table 5: Summary of the Primary Themes and Elements

<table>
<thead>
<tr>
<th>Theme</th>
<th>Elements</th>
<th>Issue of Rurality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shock at the diagnosis</td>
<td>Having the rug pulled out from me</td>
<td>I couldn’t hear much after he said I had cancer – just that we had to go to Orange for everything</td>
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<td></td>
<td></td>
<td>I can’t have the surgery here; I have to travel each time and after the third time it takes a real toll</td>
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<td></td>
<td></td>
<td>Experiencing a roller coaster of emotions</td>
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<td></td>
<td></td>
<td>First, they told me to stay away from here – they said, ‘you’re not having any treatment in there, you know, for the best chance, you come to Sydney’ and I said, ‘oh okay’. Then they told me it’s okay to have surgery here!</td>
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<tr>
<td></td>
<td></td>
<td>It’s like white water rafting</td>
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<td></td>
<td></td>
<td>When something goes wrong it’s hard because here, they don’t know me and my story. You’d think there’d be a way for my records to come where I live not just stay where I had to go to have surgery</td>
</tr>
<tr>
<td>Grief for the life that’s</td>
<td>Anger that this has happened to me</td>
<td>Why aren’t there all the services I need here?</td>
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<tr>
<td>lost</td>
<td></td>
<td>I’ve lived a healthy life and can’t believe I still got cancer. It’s so unfair.</td>
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<tr>
<td></td>
<td>Realisation that things in my life will never again be as anticipated or hoped for</td>
<td>We should have more options here not have to travel each time to see the specialist</td>
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<tr>
<td></td>
<td></td>
<td>Looking back, I know I was frightened for myself; … because this wasn’t the life, I expected to have, and it’s wrapped up with having to go to Orange</td>
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</tbody>
</table>

Chapter Five – Cancer Diagnosis: An Existential Crossroads
<table>
<thead>
<tr>
<th>Theme</th>
<th>Elements</th>
<th>Issue of Rurality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grief for the life that’s</td>
<td>Anxiety related to worrying about any new physical symptom; questioning</td>
<td>When things go wrong no one here has my records or knows me – I constantly</td>
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<tr>
<td>lost (cont.)</td>
<td>its relevance to the cancer illness</td>
<td>worry this is the cancer back</td>
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<td></td>
<td></td>
<td>I don’t want to have to think about cancer all the time but each time I get</td>
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<tr>
<td></td>
<td></td>
<td>an ache or a pain I worry, and fret and I have to go to Orange to get answers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Everything leads back to having cancer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I never thought this would happen to me – do you go to Sydney; do you go</td>
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<tr>
<td></td>
<td></td>
<td>to Orange or do you stay in town – what do you do?</td>
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<td></td>
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<td>Travelling to attend a support group was really difficult and painful – the</td>
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<td></td>
<td></td>
<td>road is unmade for about half the journey and that makes it so hard … but I</td>
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<tr>
<td></td>
<td></td>
<td>was stranded and alone unless my husband could take me somewhere</td>
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<td></td>
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<tr>
<td>A thirst for information</td>
<td>So much to learn</td>
<td>There wasn’t anyone here to see to learn what I needed to know.</td>
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<td></td>
<td></td>
<td>They should have said, here’s the name and number of a nurse who can answer</td>
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<tr>
<td></td>
<td></td>
<td>your questions. I would have been okay with just a phone call to someone</td>
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<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td>I didn’t know how to find support here; we don’t have everything like people in</td>
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<tr>
<td></td>
<td></td>
<td>the city</td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td>Who takes the lead position coordinating my health care – are they local or not?</td>
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</tbody>
</table>

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<table>
<thead>
<tr>
<th>Theme</th>
<th>Elements</th>
<th>Issue of Rurality</th>
</tr>
</thead>
<tbody>
<tr>
<td>A thirst for</td>
<td>Who can tell me what I need? (cont)</td>
<td>There is so much you want to know about but short of the internet and ‘Dr google’ there are no answers …some guru of a nurse to speak with would be ideal</td>
</tr>
<tr>
<td>information (cont)</td>
<td></td>
<td>How will we pay the cost of accommodation in Sydney for radiotherapy – it goes on for weeks – and no one tells you this stuff</td>
</tr>
<tr>
<td>A new life</td>
<td>Finding meaning after a cancer diagnosis</td>
<td>I say there’s before cancer and after cancer; nothing is as it was and my confidence in my local area has been shaken</td>
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<tr>
<td></td>
<td></td>
<td>I’m not the same person I was – and it’s taken me quite some time and effort to be able to pinpoint who I am now, what are my talents now, my strengths now. I’m very aware of my shortcomings as the person I am now</td>
</tr>
<tr>
<td>Who am I now?</td>
<td></td>
<td>I’m not who I was, both my body and my mind – mores the pity!</td>
</tr>
<tr>
<td>Transition to a ‘new normal’</td>
<td></td>
<td>I can’t…find a language to describe me… I don’t see myself as a cancer survivor, because I don’t know that I’ve survived it. And I don’t see myself as a victim, I don’t see myself as a cancer patient, and I don’t have cancer, so I don’t see that I fit on any kind of spectrum</td>
</tr>
</tbody>
</table>
5.3 Elements of the themes

The elements forming the first theme of *Shock at the diagnosis* were: (i) ‘having the rug pulled out from me’; (ii) experiencing ‘a roller coaster of emotions’; and (iii) ‘it’s like white water rafting’. The language of the participants described the strong impact the diagnosis of cancer had on them and their lives. Being faced unexpectedly with the diagnosis, led to feelings of being caught off guard, particularly for those who considered themselves fit and healthy. Despite the ages of the participants, only one was not stunned when told of the diagnosis due to the severity of his symptoms and the length of time it took to arrive at a definitive diagnosis of cancer. Even then, he spoke of feeling unprepared. The profound impact of this diagnosis was compounded by the perception that people die from cancer.

The next two elements were interesting analogies to describe the cancer journey experienced. One participant described the emotional highs and lows as ‘a roller coaster’ when speaking of the diagnosis and treatment planning. This description of these days and weeks in the cancer journey resonated across the experience of the other participants. These were strong and the participants found them difficult to manage as there was the sense of a loss of control over what was happening to them. This loss of control related to the physical aspects of cancer and psychological aspects of the impact on their lives of such overwhelming information. ‘It’s like white water rafting’ conveyed the sudden changes cancer brings despite the plan for treatment provided by

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<td>But cancer has really made me reflect on who I’ve become and where I see my life and my boys’ lives going. I am still me, but I had to realise I’m a different me. Having cancer and all the options here for treatment which was naive.</td>
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specialists – this was again a lack of control over what was happening and difficult to cope with due to the symptoms of shock which some participants found lasted for quite some time.

For the second theme, Grief for the life that’s lost, the elements included: (i) ‘anger that this has happened to me’; (ii) realisation that ‘things in my life will never again be as anticipated or hoped for’; (iii) ‘anxiety related to worrying about any new physical symptom’, and questioning its relevance to the cancer illness; and (iv) ‘everything leads back to having cancer’. Anger was one consequence of the unexpected diagnosis of cancer involving both anger at the disease and anger that the services needed were not available where they lived. The cost of medical specialists and travel was for some participants also an aspect of the anger felt.

The element of realising that ‘things in my life will never again be as anticipated or hoped for’ was expressed as sadness and dismay in relation to the lack of control over how their life would now unfold. Differing diagnoses of cancer with differing likely outcomes did not appear to affect the predominance of this element with all participants speaking of life having changed. The fear of cancer recurrence or progression was expressed as anxiety relating to worrying about any new physical symptom and the questioning of its relevance to the cancer illness. This was a particularly strong element felt by all participants and associated with being unable to return to their previous peace of mind regarding their health. An outcome of this element was expressed in terms of being hyper-vigilant regarding any bodily changes including aches and pains, and led into the last element of this theme: ‘everything leads back to cancer’. This element revealed the all-encompassing nature of cancer impacting on all aspects of life.

A thirst for information was the third theme formed from the following elements: (i) ‘so much to learn’; (ii) ‘what do I need to know’; and (iii) ‘who can tell me what I need?’ These elements were inter-related, and participants found them very challenging as they reflected on the feeling of never having been able to attain sufficient information. While participants were shocked and distressed following the diagnosis of cancer, they were all clear in their interviews on the driving need for information which was not met. This need was magnified by the lack of
clarity regarding the expected outcome of cancer and the perception of cancer leading to death. Therefore, they had a need to learn, juxtaposed with not knowing what it was they needed to know. This led to the element of seeking someone in a trusted position who could tell them what they needed to know.

‘Finding meaning after a cancer diagnosis’ was the first element of the fourth theme, *A new life*. The other elements of this theme were: ‘who am I now?’ and ‘transition to a new normal’. These were the attempts of the participants to integrate cancer into the person they had previously been, whilst recognising the changes in themselves since the diagnosis. The participants were reflective of the changes they were aware of within themselves, both negative and positive and how they were focused on learning to live within the spectre of cancer. For some participants there was a new awareness and ability to speak about feelings which was considered a positive consequence of the trauma associated with having cancer.

When the data is presented in this way, the process appears linear. However, each participant’s experience of cancer may have related to different points along the cancer journey experience. For example, some were still engaged in the treatment process whilst others had completed treatment and were well. For those whose cancer had progressed, some of the elements had been experienced at both the time of diagnosis and at relapse. The decision to no longer have treatment had been made by one participant. In describing the experience of a diagnosis of cancer, the participants discussed events which were important to them and frequently used emotive language to convey the intensity of the experience. Most of the participants appeared to journey through the process of a diagnosis of cancer in a similar manner: that is, develop an understanding of the disease, experience strong feelings of loss and grief, ‘regroup’ to be able to focus on treatment, then emerge in a different space in a dynamic ebb and flow of coming to understand the meaning of the experience. The existential crisis experienced during this process was powerfully expressed through the words the participants used and echoed in the literature on this subject.
As participants worked through their individual cancer journey, they searched for the meaning of their experience and sought to understand their new role within their family and their place in society. As discussed in the review of the literature in Chapter Two, the facts of a person, which can be viewed from the perspective of a third person, include age, race, class, body, personality traits, beliefs and desires. Yet there is a complex relationship which human beings have with these features, according to existentialists. Participants placed different emphasis on the facts of themselves. For example, some of retirement age spoke of being able to attend to the business of a cancer diagnosis and treatment without the same complexity required of younger working adults. Moreover, different personality types, educational level and spiritual beliefs influenced the participants’ ability to identify what had not been part of their journey, which if provided would have improved the experience.

A person interprets the facts of their life according to the meaning they ascribe to them; they are unable to view themselves as other people are able see them. In the context of rurality and access to services the participants utilised these interpretations and meanings to guide decision making and expectations for treatment options. For some there was an expectation that all the services needed would be available locally and were distressed when these were only available in Orange. Yet for others, the need to travel to Orange for treatment was seen within the context of no longer having to travel to a metropolitan location and therefore viewed more positively. There is ownership of each person’s ‘facticity’, or authenticity, within each individual perspective which adds to the development of each person’s sense of unique existence. Participants were constrained by their rural lifestyles, particularly in relation to the perception within the community that most people die from cancer and this impacted on the longing for information and answers about their cancer and the fear of recurrence.

5.4 Analysis of the Themes

5.4.1 Shock at the Diagnosis of Cancer – the First Theme

Each participant described what was happening in their life during the time leading up to the diagnosis of cancer and what happened after the diagnosis.
Upon hearing the news of their diagnosis, the participants revealed their fears of the diagnosis of cancer, and how they needed to process or come to terms with those fears to be able to focus on the diagnosis and treatment. The transcripts resonated with the shock at the diagnosis of cancer. The feeling of being in shock when a person is told they have a diagnosis of cancer is well documented in the literature (Boehmke & Dickerson, 2006; Ervik, Nordoy, & Asplund, 2010; Griffiths, Humphris, Skirrow, & Rogers, 2008; Kollberg et al., 2017; Lee, 2008; Missel & Birkelund, 2011; Missel, Pedersen, Hendriksen, Tewes, & Adamsen, 2015; Saegrov & Halding, 2004). The moment of diagnosis is inherently stressful because each person experiences it as a breathtaking incident and an existential crossroads in their life. The event comes as a shock, changing a person’s entire life from that moment on, forcing them to face a critical life situation (Missel et al., 2015).

Such a critical life situation inevitably leads to existential questioning, or indeed, an existential crisis. Heidegger identified characteristics of being and existence; that people exist in and through time and to be completely aware of our human existence requires the acknowledgement of the finality of death. Most of us live with an awareness of future possibility, together with the possibility of death (McLeod, 2001). For the participants this acknowledgement changed from a concept to a reality.

“so, I was stunned – being told I had cancer – and I’m thinking, ‘oh, I will probably die from this… and all that meant for how my family would have to manage; you know with my wife not being all that well and our son at home who needs lots of help to manage.” Len

Psychological shock results from a single distressing experience or trauma or repeated events where a person feels overwhelmed (Missel & Birkelund, 2011) and is considered a phenomenon with a range of reactions and feelings. It is a subjective experience to which different individuals may react with an array of symptoms. These include the hallmark feeling of a surge of adrenalin in the body which can cause a person to feel jittery or nauseated. The desire to withdraw or escape is also often part of the reaction a person may experience resulting from the body’s fight or flight responses of the autonomic nervous system. The feeling of being in a daze is common as is the inability to process information and participate actively in conversation. The *Diagnostic and
Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013 (APA)) defines a psychological traumatic event as exposure to actual or threatened death, serious injury or violence including sexual violence, which can lead to psychological shock. Shock is an intense experience which can lead to feeling unable to understand or follow instructions. Intense feelings of anger, restlessness and insomnia can accompany a shocking event as can emotional exhaustion, emotional detachment or dissociation where a person feels numb.

“I was kind of stuck; I realised didn’t know what was really going on because although I heard what she said, I couldn’t think or say much. So, like a daze…” Sally

Indeed, the event of the possibly fatal diagnosis of cancer is traumatic for the person, leaving a long-lasting memory. Diane spoke of the unusual lead up to her diagnosis of breast cancer where she had been to a new general practitioner regarding a supposed ‘cyst’ towards the centre of her chest. Rather than being referred for diagnostic radiology or to a surgeon for a consultation, the general practitioner removed it in the surgery. She reflected on how painful the procedure had been and how she often remembers that this was unexpected and frightening;

“I’d had those other cysts removed, but it hadn’t hurt the way this one had. I can still almost feel it…” Diane

Having had previous cysts in other locations on her body she expected the pathology report to reflect similar findings and was not concerned; rather she continued to reflect on how difficult it had been to cope with the procedure itself. She then spoke of being completely taken by surprise during a phone call from the general practitioner, and that she had not even considered cancer as a possibility:

“He called me and said, ‘oh I’d like to talk with you about the breast cancer, your examination. Can you come in today?’ and I said, ‘is it bad?’ and he said, ‘well, yes its breast cancer’… I liken it to – if you had chucked a bucket of cold water over me. It was like I was just frozen to the spot. I didn’t cry, I was just stunned ‘cause it was going to be nothing and now he’s saying its breast cancer… There’s no explaining the shock.” Diane

Despite having a sister who had died as a result of breast cancer, Diane had not considered it a possibility for herself and found the shock of the diagnosis did not resolve quickly. She recalled feeling like she was walking around in a
daze for weeks – unable to focus clearly and process the information provided to her on treatment options. Indeed, to her, she functioned within a daze and initially recalls being in a daze, more than what actually occurred. As someone who acknowledged herself to be quick thinking and quick acting usually, the feeling for Diane of being unable to focus on what needed to happen in the time frame from diagnosis to establishing a routine with treatment was very difficult. Our existence is built around action; structured in relation to what we do in the world and with what is within our domain. Feeling dazed left her with a strong sense of isolation which she found testing as she was usually quite a sociable person.

“I still felt frozen – I know that I retreat into myself when something tough comes along, but I had never felt so alone … It was like being cold and shivery on the inside – I guess that’s what shock is, but let me tell you, it was there for a really long time. Just on and off but when it was there it was powerful, and I felt wobbly … And I didn’t have any experience in how to get it to stop.” Diane

The phenomenon of ‘moderated shock’ (Miles, Wardle, & Atkin, 2003) describes the feelings of shock which are experienced with a diagnosis of cancer when the person feels the cancer had been detected early, and therefore treatment should be more effective or successful. Karen recounted how she felt ‘the rug had been pulled out from under her’ when she was told she had breast cancer. She had sought medical advice initially from her general practitioner for a fluttering feeling in her right breast. This occurred immediately following the joy of the birth of her first grandchild and just two months after a clear mammogram.

Merleau-Ponty (1948/1964) wrote of the how we are in the world and the inseparable relationship we have with the world was evident from the extremes of Karen’s experiences around the time of her diagnosis. She spoke of how her clear mammogram had enabled her to feel free from the concerns and worries of the fluttering. She had been involved in the celebrations of the birth of her first grandchild and these two factors influenced her perception of her life. The meaning of this diagnosis occurring immediately following the birth of her first grandchild echoed Heidegger’s work of seeking to understand what it means to understand experiences in our individual world (McLeod, 2001). Karen spoke of
how she felt devastated and that she was no longer in control of her life from that moment on.

“So, I felt stunned and completely unprepared for anything. I sat in the car for a while and tried to regroup – I’m someone who is very much in control and suddenly I didn’t feel like I was. So, I rang him and said, ‘I think we need to go and have a drink because I think I need to talk to you about some possibilities.’ And I said to him over that drink that my world was crashing in on me... And so, I was really up and down. I started to think about all the possible outcomes ... it was like having the rug pulled out from under me – I wasn’t ready or prepared, I couldn’t seem to control anything that was happening to me at the time and it felt like I’d fallen on my face.” Karen

For Karen, a self-confessed agenda driven person, she wanted to be able to problem solve her way around this situation. She had previously utilised her skills and training to enable her to respond to difficult circumstances in her life, including guiding and supporting her children who had mental health conditions. Karen began to realise her existing methods of dealing with issues and disappointments in life were not the solution to the situation in which she found herself. This realisation involved a deep sadness as she was no longer able to do anything to influence the outcome of this diagnosis. Her perception of herself had been destabilised and she spoke of feeling she needed to focus her thoughts on considering ways to attempt to deal with this confronting challenge. She wanted to at least have control over how she acted in response to having cancer. With a two week wait to see a local surgeon due to school holidays:

“I sat on the garden swing in the back, I call it ‘my thinking chair’, and tried to compose myself really. Which is how I like to do things – I’m a control freak, I like to manage situations, and be the manager of my own emotions. But it seemed there was nothing for me to do just then.” Karen

Anthony told of his experience of being unwell and admitted to hospital to have his appendix removed. He had been miserable with abdominal pain and vomiting for nearly two days; however, he clearly recalls doctors telling him he’d be fine once they ‘whip out that appendix’. He recalled going into the operation thinking this was only an inconvenience that many people experience and so felt calm in the knowledge this was a simple operation. However, during the surgical procedure, the surgeon found and removed a tumour from his colon. After he had woken up post operatively, the surgeon visited him to let him know that he’d found the tumour and removed it, saying he was pretty sure it was
cancer. Anthony remembers being told they would get the pathology results in about a week. He recounted how suddenly this was no longer just being unwell and needing routine surgery. He hadn’t been scared before the operation, because he was aware people have that type of surgery every day, yet now he felt engulfed with fear that the tumour was cancer. He remembers holding out hope that the tumour would not turn out to be serious. A week later, his worst fears were confirmed when the surgeon told him the tumour was in fact cancer.

Anthony described the cognitive changes associated with this shock. He found he had to move his mind to accept that this had happened to him, how shocked he was as it was so unexpected, and what a bumpy ride it was:

“...I think of it as being like white water rafting – it’s going to be rough but it’s not all the time, it’s boom; I felt so out of control. I have learned that I really like being in control in my life and during this time, I was shocked and almost stunned that this was happening to me – and I mean, to me. The hits weren’t predictable; like being in the rapids, it’s just boom and we’re off again...I was too shocked to know what to do.” Anthony

The phenomenon of shock is frequently multifaceted in nature, not limited to a single event or situation, and was described by Anthony as feelings he experienced when the possibility of requiring chemotherapy was raised with him during an appointment with the surgeon. Knowing he had cancer and the surgeon had removed it led him to question who he was and what was important to him in life. With complicated relationships in his past and the ongoing need to engage with his ex-wife, Anthony found himself trying to work through an existential crossroads. He realised his boys and his current partner were what mattered most to him. He felt determined to regain his strength and move on with his life.

Yet, hearing he was likely to need chemotherapy, he realised cancer was continuing to disrupt his life; he felt this failure of his body and the need to remedy the situation had become a marathon rather than a sprint.

“...when he said I needed to see the oncologist about having chemotherapy it was back to the rapids in the white water for me and I felt like that day I hadn’t taken my oar with me when I got on the raft!” Anthony

Anthony’s feelings that his body had let him down resonated with Merleau-Ponty’s (1948/1964) view that we live the world through our bodies. This was a
powerful, lasting feeling for him faced with the confronting presence of a colostomy to cope with. In addition, he had experienced pain, discomfort, and fatigue which changed how he was able to live his life. This altered his perception of himself which he described as his ego ‘taking a hit’.

Anthony then visited the oncologist and was told of the program of chemotherapy he needed. Hearing of the need for chemotherapy often occurs in a busy outpatient clinic or doctor’s surgery (Ervik et al., 2010) and leads to an awareness that this is not an event he or she expected to face. People find this event feels like an unreal situation which is arduous to grasp and leads to feelings of helplessness. With the limited time available during outpatient clinic appointments, a person experiencing shock is likely to find processing the information difficult, responding with questions limited to the immediate requirements of ‘what comes next’. The necessity for treatment in the form of chemotherapy compounds the existential challenge of a life-threatening illness such as cancer, which is explored further in Chapter Six.

Even for people who suspected that the symptoms being investigated were serious, hearing the word cancer was frightening. Hearing a diagnosis of cancer instantly leads to existential questions about life and death (Ervik et al., 2010) and for many people shines a light on the meaning of their existence. Being confronted with a diagnosis of cancer which is universally considered a serious threat to health and wellbeing, each person finds themselves reflecting on how they feel and understand themselves, and how he or she interrelates and responds to others encountered in their lives. Peter, a health professional himself, who realised his symptoms of frank blood in his urine followed by an inability to pass urine were likely to be serious, still found himself shocked when he was told of his bladder cancer.

“...the cat scan was the next step… I realized I was in a kind of shock state – that this crisis in my life was actually happening to me and I couldn’t control what was to happen. At all.” Peter

In attempting to understand how this would impact on his life, and that of his family, he found he needed to be patient with himself as the situation unfolded. This was difficult as he wanted action; to be doing something rather than waiting. He was not provided with a plan to guide him and found this difficult as
he was frequently turning possibilities over in his mind. News that a referral to a medical oncologist for consideration that chemotherapy was required came as a shock due to no pre-warning that this was a possibility. His understanding had been the urologist would direct his cancer treatments. He spoke of feeling unprepared for such a serious step in his cancer treatment, of realising cancer was in control of his body as it had spread from his bladder. The emotions associated with the shock of the news were powerful. Whilst describing himself as pragmatic and stoic, he related his feelings of loss of control in this experience to a roller coaster:

“No plan – it was very much we will do this and then after that you find out what’s next. There was initially no mention of any possibility of needing chemotherapy. The urologist one day said that he thought I needed to have a referral to a medical oncologist to see if a course of chemotherapy would be useful given the cancer had spread out from my bladder. Stunned – I was actually stunned because this hadn’t been raised at all previously ... It was back to the roller coaster – up and down and having no control…” Peter

As a woman in her fifties, Cathy spoke of how she was someone whom people would describe as ‘happy go lucky’, yet she had powerful feelings of grief and loss resulting in prolonged sadness since her diagnosis of cancer. She spoke of how she had always preferred to maintain a level of privacy whilst living in a large town, acknowledging so many people know each other’s business. She had an awareness of being a part of the social openness of the society in which she and her family lived, enabling knowledge of each other’s lives. So, whilst she was intrinsically intertwined with the community, she chose to maintain some distance within that social structure, enabling her life to be more private than most. To guard her privacy, she opted not to readily sharing her feelings with those outside her immediate family.

When Cathy was told she had ovarian cancer she described it as a new and rather terrifying experience, something she was unprepared for. She found herself unable to take in what she was being told; in attempting to focus on ‘what’s next’, she had to ask the specialist to repeat information for her. Over time she became aware that there was information provided at that appointment of which she simply had no recollection.

“I think my brain stopped working – I couldn’t process what he was saying to me. I just sat there stunned and I suppose in shock at the news and realised he was still speaking but I wasn’t taking
any of it in. He asked if I had any questions and I couldn’t think of anything; I was numb. Eventually I asked him to go over what I needed to do next again, and it turns out I still didn’t hear everything.” Cathy

Cathy spoke of feeling foolish when the doctor would say words like, ‘as I said the day we met’, given she had little memory of the event other than learning she had cancer. Her memory of the room she was in and the clock on the wall indicating how long she had waited to see the doctor was powerful. This connection to the world involved her even being able to recall the colour of the fabric of the chairs. This was the lived space of which van Manen (1990) wrote; the space in which a person finds themselves affecting how they feel. The shock she felt upon hearing the diagnosis of cancer lingered, leaving Cathy feeling unable to cope with the enormity of it for a number of weeks after. The diagnosis of cancer required her to find space or room in her life for the diagnosis and its treatment.

Pam was also diagnosed with breast cancer and felt the overwhelming impact it had on her when finally, the surgeon said it was cancer. She recounted her experience of finding a lump in her breast followed by the ambivalence of the surgeon to whom the general practitioner had referred her. The surgeon initially indicated he didn’t want to remove the lump and she vividly recalls him saying he was convinced the lump wasn’t cancer. Pam felt the lump was a threat to her body and was determined to have the lump investigated and removed, thus pushing for further investigation. This feeling was her way of identifying with Merleau-Ponty’s (1948/1964) concept of how we live the world through our body. Yet she found herself totally unprepared when the diagnosis was made, and the existential crisis it led her to face:

“The bottom line was that I felt like my world was coming to an end; it was overwhelming, it was like I could do nothing – I couldn’t … the impact was huge it was like, I don’t know, like being knocked over by a truck, a semi-trailer and not being able to get back up or being dunked by a wave, it was just huge. I felt like – I can’t do anything; this is just too big; just bigger than Ben Hur. Can’t deal with it, can’t comprehend it, can’t understand it…” Pam

Emotional shock associated with a diagnosis of prostate cancer was found to be correlated with feelings of low self-esteem, isolation and anxiety (Kollberg et al., 2017). Len, a recent retiree, spoke about hearing his general practitioner tell
him it was very likely he had cancer of the bladder, and how difficult it was to broach the subject with his wife. He told me of their relationship, which had always been close, and how important his wife was to him, yet he was shocked and overwhelmed with the news and knew it would cause her sadness and worry. He realised he hadn’t been able to focus on the details about which the general practitioner had spoken relating to the next steps for him. After hearing the word cancer, he was then only able to focus on the need to travel to visit the urologist in Orange.

“She just looked at me and said, ‘you do realise what I’m telling you; that there’s a 100% chance you have bladder cancer’. I said, ‘oh really’ and that was the end of it. I went home and I think you could say that I was in a state of shock – you know really not clear about what had happened. I had to tell my wife – I had seen the GP on my own as I had always done... I sat in the car and wondered what this would mean. But I just felt so overwhelmed that I didn’t really say much more to her than, ‘they say I’ve got cancer’.” Len

Feeling confronted and wounded, Len was profoundly conflicted when faced with cancer as he had always felt his purpose in life was to support and take care of others. Sartre (2003) asserted that one exists only to the extent that they are fulfilled by their choices and actions. This was apparent in how Len spoke of himself, his family and his life choices. He had approached his home and work lives with the intention of achieving what he set out to do so he could feel pride and that he was a contributing member of his community. With a diagnosis of cancer, he was no longer able to overcome the limitations of his body despite an unwillingness to surrender to his disease.

Sally was a woman in her late thirties who has been diagnosed with cervical cancer following a routine pap smear. She vividly recalled her general practitioner telling her by phone whilst at work that she had cancer, and how incredibly difficult it was to hear this unexpected news. She had previously had troubling symptoms which had led to a possible diagnosis of Crohn’s disease. Despite changes to her diet, her pain and vaginal bleeding had persisted, and she had been embarrassed to seek further medical advice. At the time of the diagnosis she had been planning her wedding to her long-time partner and an overseas trip. When she was told by phone during her lunchbreak, she recalled bursting in to tears, and a friend at work contacted her partner to take her home. She cried when he arrived to collect her and for much of the afternoon.
“Late that night I realised that I was kind of in shock; I couldn’t remember much about the evening ... I was stunned – I couldn’t process what he (my partner) was telling me – I realised it was a type of shock ... I was scared shitless and couldn’t even think to say anything... You know, you think about all the people you hear about who died because of cancer and it’s like you get paralysed inside. The outside works okay but the inside is screaming.” Sally

During the phone call, the general practitioner asked her to come to the surgery for an appointment the next day to discuss a plan of action. Despite her partner offering to go with her, she chose to go to the appointment alone. She felt overwhelmed yet focused on trying not to let it affect her behaviour. She had relied on not allowing her internal distress to be evident at other difficult times in her life, and felt that she utilised this coping method without really thinking about it. This protective mechanism was robust despite her fear of death. Her internal numbness was characteristic of shock and this lasted for nearly a week.

“I remember her apologising to me ... She said, ‘You’re the first person I’ve ever had to tell that you’ve got cancer’. She said, ‘I didn’t know the best way to do it’; she said, ‘I thought I’d do it where there were people around you, so you weren’t going to be alone’.

Then she said, ‘I thought I’d do it, so you’d have all your crying and everything done last night and this morning you’d come focused on what we have to do’. I didn’t say anything, but I was really kind of numb inside, not that you’d know it to look at me ‘cause I’m good at hiding how I feel.” Sally

Sally was concerned her general practitioner found it difficult to tell her and reflected that amongst all the feelings of shock at her diagnosis, she had worried about her doctor in the following days. This basic human capacity to care for others remained, even during her time of shock. Similarly, men with prostate cancer have reported concern for clinicians who deal with people with cancer and how difficult it would be (Ervik et al., 2010). Acknowledging the emotional impact on clinicians was identified by one participant in this study.

Following the initial surgical procedure to biopsy the cancer, the feeling of shock took hold again for Sally and her experience was of feeling she was in a daze. She wanted to withdraw into herself in order to not focus on the fear of death which she felt was a large part of the shock she was feeling. Heidegger (1927/1962) contended a fundamental part of human existence is to be concerned about oneself and to ‘care’ about the type and quality of our
existence. Her experience describes the fear of the threat to her existence as well as care for others.

“So, I had the cone biopsy done and then I don’t remember getting the results back, but I was booked in for a hysterectomy. I think I don’t remember because I really was in a bit of a daze – you know in shock – looking ok on the outside but such a mess inside. My stomach would churn, and my head felt like it was full of cotton wool and I would just have a lie down and try to sleep. But of course, sleeping is actually really hard when you’re all worked up. It was either that or I would think to myself ‘I’m going to die from cancer’ and I’d be really low and teary.” Sally

Feelings of devastation and crushing upheaval are also identified as being associated with the shock of a cancer diagnosis (Mattioli, Repinski, & Chappy, 2008). Following the initial shock, Len spoke of the feelings of being in a daze and the loss of control regarding what was happening to him. Processing information relating to his diagnosis of cancer had become really difficult. Sartre contended that the ability of each individual’s consciousness to reflect on themselves, provides the ability to select, determine, act and intervene throughout life’s possibilities. Len indicated that he decided his strategy for dealing with the uncertainty associated with the process was to try to embrace it rather than challenge it.

“You know, I think you’ve just got to grasp what’s happening and go with it; go with the flow of it, ride it, ride the wave or that darn roller coaster!” Len

5.5 Summary
This chapter has presented the analysis of the data illuminating the first theme of the shock at the diagnosis of a cancer which had been experienced by all the participants. The experience of cancer and diagnosis is a subjective one. The words of the participants illustrate the experience as an amalgam of emotions that can be overwhelming, and at times last for weeks. For most people, the psychological and emotional responses to a cancer diagnosis relate to the belief that cancer is a life-threatening diagnosis with no clear pathway to a cure (Chaturvedi, 2012). A stigma associated with cancer in rural communities is the traditionally held view of the strong link between a diagnosis of cancer and the inevitability of death (Mukherjee, 2010). This is evidenced in rural communities in the way people remain uncomfortable discussing cancer, with the evolution of
everyday use of terms such as ‘the big C’ and the ‘C word’ as more comfortable alternatives.

Whilst cancer as a disease has more societal awareness and is discussed more widely in the present day, there remains a stigma of uncertainty which leads to fears relating to death and dying for many (Butts Stahly, 2008). Participants expressed the initial feeling that their cancer diagnosis was akin to learning they were going to die, supported by a study which found no significant differences of perceived stigma based on the type of cancer diagnosis (Chambers et al., 2012).

The further thematic analysis chapters to follow are organised by a description of the theme in the context of current knowledge and providing examples of the themes using the participants’ words. The next chapter focuses on the theme of grief for the life that’s lost and the strong subtheme of fear of recurrence of cancer.
 CHAPTER Six – Grief and Loss in a Cancer Diagnosis

Utilising phenomenology for this study required a commitment to the participants’ experience in their ‘life world’ and articulating the knowledge and meanings which surfaced from those experiences. Overwhelming feelings of grief and loss in a cancer diagnosis were experienced by all participants as the second theme; therefore, this chapter furnishes an exploration of grief and loss and links these concepts both to the context and feelings they experienced. The fear of recurrence of cancer by people who have had a diagnosis of cancer is then explored as this was a relevant subtheme of grief and loss. All the participants described feelings of grief related to an abrupt loss of the life they had been expecting to live. The words of the participants offer powerful illustrations through individual descriptions.

6.1 Grief and Loss
Developing a meaningful understanding of grief and loss is a challenge, despite each concept being an experience that affects everyone at some time during their lives (Rubin et al., 2012). Grief and mourning as phenomena are experienced universally, yet individual expressions are influenced by a range of factors including culture, ethnicity, gender, age and religious beliefs. Feelings of loss trigger the grief experience. Social factors including socioeconomic status and education are also recognised as influences in how a person responds to his or her loss (Granek & Peleg-Sagy, 2017).

The terms grief, mourning, and bereavement are often used interchangeably when considering loss as a concept, and yet they are not synonymous. There are distinct variations in the way they are interpreted which are essential to understanding these terms when looking at bereavement experiences. Grief has been defined as the responses a person experiences, both internal and external to the loss experienced (Stroebe & Stroebe, 1987; Worden, 2009). Grief as a concept is a process rather than a state in which a person finds themselves (Worden, 2009). This process suggests that the grieving person undertake structured, step-by-step tasks to enable them to move through his or her grief, adjust to their different life and adapt to his or her position and
functions in their family and community (Dent, 2005). The loss leading to the experience of grief is most often considered to be the death of someone close to the person; however, a fuller understanding of the concept is needed when there is the inclusion of other losses such as divorce, diagnosis of a disease, children leaving home, loss of a home, or even bankruptcy.

Mourning is defined as the public expression of grief with a “set of practices and acts” (Malkinson, 2001, p. 3) that are usually determined by socio-cultural factors. It is commonly focused on the process through which a bereaved person navigates, to undo the psychological ties that bind them to the loss following the death of an individual (Rando, 1984; Worden, 2009). Bereavement is best defined as a state or circumstance of having experienced a loss, a state in which a grieving individual is considered to be, and to which he or she needs to learn to adjust (Worden, 2009).

The field of grief and bereavement has undergone major transformation in how the individual experience of loss is recognised and fathomed by our society. Long-held beliefs and understandings regarding the grief and loss experience have been abandoned, with research overturning early stage-based models. These models described grief as a predictable emotional pathway. Modern theorists propose that grief can no longer be constructed as a rigid or linear progression from suffering and distress to recovery and healing (Hall, 2014). This is accompanied by an acknowledgement that successful grieving does not necessitate the breaking of attachment bonds. Rather, an ongoing move occurs towards the would-be healthy stance of maintaining continued bonds with the deceased person (Field, 2006; Klass, Silverman, & Nickman, 1996).

6.2 Implications for People with a Diagnosis of Cancer

Nearly every person at some stage in his or her life will be confronted with a loss which is significant for them. It can be assumed that most people will react with significant sorrow when they face the loss of someone close to them, a divorce, a life-threatening illness or similar challenging event. van Manen described these events as part of our ‘life world’; the world as we personally experience it, and for the participants, the knowledge that having cancer changed how they saw their life in the world and led to feelings of loss.
A sense of the unfairness of developing cancer resonated through the narratives of the participants. For some it was about being active and healthy, feeling that this would offer protection from cancer, and discovering that there was no protection. Husserl’s principle of ‘intentionality’ whereby we have an internal experience of being conscious of a thing, was evident when Diane spoke of how she had lived her life. She had been conscious of ensuring she was healthy, yet this did not prevent her from getting cancer. Diane felt cancer had invaded her body and this changed how she felt about the body she had been intimately connected to.

“... ‘why me? I’ve played by the rules basically, I’ve done all the right things; I’ve always exercised, always looked after my diet... This isn’t right ... for me at the time, I was in a very overwhelmed place – probably a little bit of a dark space.” Diane

For Anthony the diagnosis led to feelings of anger and isolation which resulted in low moods and an unwillingness to want to socialise outside the immediate family. He felt he was too young to have cancer and with his connection to or consciousness of his body, the suffering his body would endure left him angry. He spoke of withdrawing from others without realising he was doing so, and the isolation and anger left him feeling disheartened.

“I got so angry that I’d had to put my body through this whole awful process when I didn’t consider myself to be old enough to have this happen to me – got right into the whole, ‘it’s really unfair’ thing and that really brought me low.” Anthony

Grief is a highly emotional, nevertheless entirely normal, reaction to loss (Gewirtz, Erbes, Polusny, Forgatch, & DeGarmo, 2011; Haine, Ayers, Sandler, & Wolchik, 2008), and this may require the person to take action to fully acknowledge and adapt (Green, Krupnick, & Stockton 2001; Stroebe, Gergen, Gergen, & Stroebe, 1992). Therefore, the grief reaction is deemed to be a normal and natural response to the loss, and a reaction which is expected to diminish over time (Stroebe et al., 2008). The participants spoke of grief as a process of oscillating emotions which had greater and lesser intensity following their diagnosis of cancer. On days when they felt well, the grief for their life before cancer was less, and when feeling unwell, the grief felt deeper. This concept of fluctuation of emotions is aligned with Stroebe and Schut’s (1999)
Dual-Process Model and Rubin’s (1999) Two-Track Model of bereavement, both of which stress the lack of a linear progression of grief. The previous experiences a participant associated with cancer impacted significantly on the feelings of grief and loss. For Pam, not seeing anyone she knew survive cancer meant that her ‘life world’ was challenged. She became fatalistic, focusing on the inevitability of death.

“I had never seen someone walk away from cancer before, you know? So, all I saw was ‘this is it’ – I’m going down this track and I’m going to get sicker and sicker and they’re going to give me more and more drugs and the world as I know it ceases.” Pam

When the diagnosis of cancer occurred, participants spoke of a number of losses, from the loss of the healthy body they had prior to the diagnosis, to the disruption to life and work. A further component was awareness about the way society sees a person who has had cancer. Len spoke of his body not having the resilience he expected of it and how that impacted on his sense of self. He was also disturbed by the way people he’d known for many years began to treat him differently once they learned of his diagnosis. He grieved for the person he’d been in their eyes, knowing they would always think of him as someone who had cancer.

“I hate the way they speak to me so gently and ask more than once how I am. They never used to do that… and then when the conversation gets a bit awkward, they go straight to talking about the weather. I’ve never talked about the weather so much!” Len

Diane was really troubled that her long term wish to donate her organs upon death for someone else’s benefit was no longer possible, with the exception of her corneas. She spoke of the conversations over the years she’d had with her family, wanting to ensure there was no confusion if the situation ever arose to consider organ donation. She realised her inability to make a difference for someone else caused her to feel devalued as a member in society. This left her feeling appreciably ‘less’ than she had prior to the cancer diagnosis.

“And the other thing that I’m really distressed about, I’ve, we’ve always made it clear all my organs were to be harvested. But now they will only accept my corneas since I’ve had breast cancer. And what’s more I can’t be a blood donor anymore... see in so many ways, I’m not the same person after cancer. My bits aren’t any good anymore. I mean not only have you had cancer but your bits and pieces which are kicking along nicely aren’t any good anymore.” Diane
For participants, the far-ranging impact of cancer was a fundamental aspect of the experience. It was larger than an illness which had to be negotiated and wider than how it affected relationships. Relationships with spouses were impacted; cancer was not a situation they were able to keep to themselves. Yet different personalities spoke of this from different perspectives. For Len it was distressing to reflect on the effect his cancer had had on his wife. It was his connection with and concern for his wife which came through his words.

“I knew things would never be the same … in my life. This cancer thing affects more than the person who gets it — it has… tentacles like an octopus! … My wife was so upset and teary and worried about me. It affected her sleep and her usual plans for how she spent her time. She had to take time to be with me for appointments and procedures and she was so tired. I could tell. We talk about it but it didn’t change how different life had become.” Len

Peter spoke differently about the effect his cancer had on his wife. His focus was on acknowledging how hard his wife was finding the situation. He didn’t speak of effective communication about it; rather he discussed their different personalities, which led to difficulties in coming together to support each other. Their connection was obviously strong and clearly important to him, yet from his story, it was evident that at that time they were not able to function as an effective unit.

“I think it was difficult for my wife … she lost her father to cancer as well, so it was difficult for her. She tends to get quite emotional where I don’t — I’m very pragmatic, you know stoic… So, it’s difficult for her. And it’s hard for us to discuss anything other than the next appointment or whatever.” Peter

Certain triggers brought the grief to the forefront of life, often when one of the participants was trying to move on with life. Although described differently by the participants, each had events or scenarios which brought back the feelings of grief for the life that was no longer theirs.

“Every time I got a blockage or had to go and have the procedure in Orange, it affected people at home and that made me feel like a real burden. I guess that each of those times I was brought back to longing for my old life where I thought I was in control and everything was going along well.” Len

Diane found she had a physical trigger to remind her daily of her cancer when she lost her hair during chemotherapy treatment. She spoke of how the scarf she wore on her head reminded her she had cancer in her body each time she
caught a glimpse in the mirror, even when just washing her hands. However, she found it was also a physical trigger for others, after an encounter when out shopping. The woman who approached her appeared to have a connection with Diane, despite not knowing each other, and that allowed her to reach out to connect with her. The meaning the scarf conveyed to a stranger was based on that woman’s personal experience and as part of the world we each live in, that meaning was shared.

“And the scarf is the physical evidence that you have cancer cells inside you... it speaks to people... I was in Woollies one day when a woman, a total stranger came up to me and tapped me on the shoulder, and she said, ‘and how are you doing love?’ It didn’t even occur to me she was talking about my scarf, and I said, ‘oh, oh I’m fantastic; I’m doing really well’. She said to me, ‘its 10 years today since I was like that’ so she felt the need to tell a total stranger something so personal. It comes back to having cancer”. Diane

Cathy said she’d found the language to describe her feelings after watching a war movie with her husband a few months prior to the interview. She indicated she had been waging war against her cancer and the toll on her body from the lengthy treatments was collateral damage. The metaphor became clearer as she disclosed how she felt,

“…this cancer will most likely beat me... I’ve put up a good battle but my life as it was is gone.” Cathy

Living the grief for her life before cancer, she had not disclosed that she expected cancer would take her life as she felt having to do so would overwhelm her. Their love, care and sympathy would leave her unable to function and it was important to her to live the life she had now for as long as she could. Her being in the world was on her own terms, allowing her to exercise the small amount of control left to her.

For most human beings who have experienced loss, it is anticipated they will adjust and revert to a normal state of living in society, yet the participants felt changed by the diagnosis. A person with a cancer diagnosis may not find this possible as the impact can lead to long lasting worry. Len described his ongoing worry about not only how cancer might continue to affect him, but also his wife. He spoke of having ‘a line in the sand’ which separated his life from what he called his ‘old life’ and his life with cancer. He had awareness that his cancer
diagnosis had caused him to confront his own death as a possible outcome. His concern for his wife and how she would manage if he were to die was a core component of his grief for his old life. Whilst focused on his life with cancer, the loss of his ‘old life’ had caused some disconnection between the two.

“…inside I’m thinking about all that’s happening to me and my life being so far from what I thought it was going to be – I had always thought I’d have a nice quiet retirement – you know, potter about and do things I liked doing. And let’s face it, my body had let me down and I knew things would never be the same again in my life. I worry about what will actually happen to me and also what that will do to my family. My wife will be, I don’t know how she will cope as she gets really upset and I guess she’ll have to rely on the boys or friends to get her through. Life wasn’t meant to be like this.” Len

6.2.1 Fear of Cancer Recurrence

With so many people in Australia affected by a diagnosis of cancer, long-term wellbeing presents significant repercussions for society. These repercussions relate to the contribution individuals are capable of making within family life, work life and the communities where they live. Cancer survivors face a number of quality of life concerns after diagnosis and treatment of cancer as they work to assimilate the experience into a life which has been altered. For people with cancer the most frequent concern affecting quality of life is that of the fear of recurrence. Acknowledging that cancer had infiltrated their body once, there is the ongoing fear that it could again.

“I don’t want to be someone who goes around saying they’ve beaten cancer ‘cause it could be back any day. As I said, I can’t believe that there isn’t one single cancer cell left in my body and if I got it once, I could get it again. And with my triple negative diagnosis there aren’t too many treatment options. It really does change everything. It’s hard to feel content ‘cause I see it as lurking ready to pounce.” Diane

The literature recognises the fear of recurrence as a chief cause of distress faced by between 40 percent and 90 percent of cancer survivors (Bloom, Stewart, Chang, & Banks, 2004; Costa, Smith, & Fardell, 2016; de Haes, Curran, Aaronson, & Fentiman, 2003; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998; Hartl et al., 2003; Mast, 1998; Northouse, 1981; Welch-McCaffrey, Hoffman, Leigh, Loescher, & Meyskens, 1989). The scientific advances enabling the detection of cancer at either routine screening or the first signs of a change which a person may experience, coupled with improved
treatments have led to increasing numbers of people who have survived following a cancer diagnosis. Recognising that the fear of recurrence remains throughout a cancer survivor’s lifetime in varying intensities, the impact of this fear on quality of life is therefore an important focus to be explored and understood (Ferrell et al., 1998; Northouse, 1981; Vickberg, 2001; Welch-McCaffrey et al., 1989). Len felt he had no control over his cancer if it were to stay under control, as it had been for the previous couple of months and had dissociated from his body in this regard. He offered a visual description of his fear of his cancer returning and metastasising in his body.

“I say I’m on parole at the moment – you know good behaviour at the moment ... yeah so, it’s one of those things that was totally unexpected and seems to be never ending... I’m on the rollercoaster of cancer and sometimes you just have to hold your breath and hope for the best, even knowing that it won’t turn out like you hope... any day a secondary could shoot out the bladder wall and go for a bit of a trip and decide, ‘this looks like a good spot’ and pull up here and start causing trouble. I dwell on it a lot but don’t talk to others about it because it will make them feel miserable too.” Len

Although a range of descriptive research relating to the fear of recurrence exists in the literature and is a growing sphere of exploration, there is no literature focusing on the experience of people living in rural settings. There is also a lack of focus on identifying central and modifiable precursors and influences of this fear. Women who have survived breast cancer report the impact fear of recurrence has on their quality of life. Vast numbers of affected women recount that the fear of recurrence significantly diminishes their wider sense of wellbeing and ability to fully enjoy life (Cimprich, Ronis, & Martinez-Ramos, 2002; Spencer et al., 1999). For Pam, the fear of recurrence was factored into her decision to go ahead and have a mastectomy following pathology results. Her concept of self was threatened, and she was focused on the mastectomy being the start of losing multiple parts of her body.

“... now I have to lose my breast, yes it's preventative; it's all very rational now that it was preventative; they’d found nothing in my lymph nodes. It hadn’t spread but if I left this I would be living with this constant fear of it coming back ... I thought ‘oh gosh, if they take this breast, what are they going to take next? Is there going to be anything left of me at the end of this?’ I still think it could come back anytime.” Pam

For Sally with cervical cancer, being told she had completed all the necessary treatment was really challenging. Lacking follow up support, her fear cancer
would return left her worrying and without the ability to readily enjoy her life.
Without a plan for surveillance and survivorship, she felt plagued with uncertainty that there was no cancer in her body.

“They’re like, ‘see ya later, we’ve cut you open we took it out bye bye!’ So, I’m left wondering what do I do? Am I really OK now; am I good to go now? ... I’m supposed to be in the prime of my life and happy that I don’t have cancer anymore but how do I really know what’s going on inside me? I know that if it spreads you don’t have any hope really.” Sally

This fear of recurrence is well understood to negatively affect cancer survivors’ communication abilities with doctors and other healthcare team members. This has led to the desire for people with cancer or living after cancer to avoid engagement with healthcare related activities and reviews (Vickberg, 2001; Welch-McCaffrey et al., 1989). Pam felt hesitant to disclose any concerns to her doctors despite facing worries that her body would betray her again and the cancer would return. This was due to the difficult relationship she had had with her surgeon. Despite knowing he was an expert in his field, she had little trust in him as he had initially discounted her breast lump, saying it was not cancer. She felt if anything was noticed during follow up appointments it would be investigated and that would suffice. Levinas proposed the ethical dimension of contact between human beings was based on the responsibility of human existence (Casey, 2006; Steiner, 1991) and Pam was relying on this. Her strategy, however, did not stave off the fear of recurrence or build self-esteem.

“I remind myself not to be a hypochondriac but each time I notice something seems different with my body; you know an ache or pain or I get indigestion, my mind runs at a million miles an hour with all kinds of bad thoughts. It’s really hard to get them to go away. But I don’t want to be running off to the doctor each time and have him think I’m making things up.” Pam

The perceived risk of recurrence of cancer for each individual is the feeling or sense of how probable a recurrence is over his or her lifetime. Thoughts that a recurrence is likely, based on information relating to disease stage, may increase fear of recurrence. Knowing someone who has had a recurrence may trigger fear of recurrence, however, it has not been determined if this is a lasting antecedent (Vickberg, 2001).
6.2.2 Fear of Recurrence is Costly

Living with a fear of cancer recurrence can have major financial implications for cancer survivors, including additional, unnecessary consultations with healthcare providers and diagnostic investigations, resulting in added costs. This fear experienced by survivors can also lead to volatile behaviour where he or she may either become preoccupied with symptoms being experienced, or avoid all engagement with healthcare environments for fear of bad news confirming his or her concerns (Smith et al., 1999; Welch-McCaffrey et al., 1989). Sally found she had visited her general practitioner to gain reassurance after being told she did not need any further follow up with her specialist. Self-preservation was her goal, and she required confirmation that nothing further was required.

“Then I start to wonder if they can be sure that I don’t need any more treatment – it’s not like I wanted to have it, but I sure didn’t want the cancer to take over my body either; ‘cause that’s when you end up dying no matter what treatment they try. So, I had to go and ask the GP about blood tests or anything else to check – you know, so I could be sure. That way, when I worry, I remind myself they think it’s gone.” Sally

Cancer survivors who experience this fear may habitually scrutinise ambiguous symptoms they encounter believing them to be an indication of disease recurrence, despite repeated reassurance from credible medical and healthcare providers. Historically, a range of diagnostic imaging was performed on people who had survived cancer, and the outcomes of these investigations formed a large component of reassurance for these individuals. This process led asymptomatic cancer survivors to trust that their disease had not spread. It was established in the literature prior to 2000 however that relying on these diagnostics was no more effective in detecting disease spread, or metastasis, in a more timely way than medical clinicians regularly performing a vigilant history and physical examination (Smith et al., 1999).

“Every ache and pain I have I immediately start worrying that the cancer is back and affecting a different bit of my body. I obsess over having a poo every day; I think any change is likely to mean something really bad is going on inside me. It hangs over me like a cloud as I try to live this different life; I guess I’m afraid really that the cancer is not completely gone or its going to spread and it will kill me.” Anthony
An initiative of the American Society of Clinical Oncologists (ASCO), initially developed in 1998 and revised in 2012 (Khatcheressian et al., 2012) was designed with the goal to assist medical clinicians and other healthcare providers to develop up to date knowledge relating to evidence-based follow-up routines. This initiative did not identify any noteworthy differences in care for people living in rural areas despite the well-documented issues relating to access of health care services which these individuals and communities face. Whilst improving the provision of evidence-based care, there was also the intention to reduce financial costs through the elimination of unnecessary diagnostic testing in survivors of cancer who had completed treatment (Khatcheressian et al., 2012). It has been recognised that patient desire for diagnostic testing to reduce fear of recurrence has not been well addressed by medical clinicians and healthcare providers; taking the opportunity to educate patients and family members that these investigations do not ensure improved survival or decreased morbidity.

“... people who work in health ask this simple question when they’re doing something to you: ‘are you ok’. I was so far from ok, worrying this cancer was spreading out all over me, yet I just say ‘yes’ because I felt like that’s what they want to hear. I wanted a test for it. They don’t reassure you that things are under control, and that’s what I want to hear.” Len

There is not a great deal of literature relating to the long-term concerns which are faced by people who have survived cancer, despite the numbers of people for whom this is a significant portion of their lives. The Institute of Medicine (IOM, 2006) paper on enhancing ongoing care for cancer survivors recommends a focus on improving the awareness of the psychosocial outcomes of having a cancer diagnosis and treatment and the development of clearly defined follow up care for these individuals. Once a developed plan for best practice follow up has been established, there is a need to identify policy and strategies to enable the healthcare community to successfully implement it (IOM, 2006). The report also identifies the fear associated with cancer recurrence as the single most predominant long-term psychosocial outcome of a cancer diagnosis. It is also acknowledged that this fear remains with a person who has had cancer for the majority of his or her life (Ferrell et al., 1998; Northouse, 1981; Vickberg, 2001; Welch-McCaffrey et al., 1989). The Institute of Medicine paper (IOM, 2006) articulates phases or seasons within the concept
of survival and the varying concerns which are identified in each. None of the participants shared information relating to a plan for follow up care beyond six monthly or annual visits to their specialist.

An initial study with 30 women who were breast cancer survivors determined that the number of individuals who were involved in a breast cancer survivor’s social support network and the number of those who understood their health concerns was linked to levels of fear of recurrence (Northouse, 1981). The more support a survivor reported, the lower the level of fear. Interestingly this metropolitan-based study also found that breast cancer survivors described that only 10 percent of their healthcare team conveyed that they understood the concerns which are faced by a cancer survivor. More recently, this has been demonstrated to apply to people with a range of cancers (Andrykowski & Kangas, 2010; Rustad, David, & Currier, 2012). Peter reflected his experience relating to the grief he experienced and his fear of recurrence, realising this had not been addressed during his care.

“you know I said I was a psychologist; well no one really tried to address my psychological state, coping strategies or even demonstrate empathy towards me. They need to do that and maybe they do it for others, but they didn’t for me.” Peter

As concepts, both fear and anxiety are discrete entities. With fear, a person is able to identify the object or incident which stimulates the feelings of fear, whereas when anxiety occurs, the person is uncertain as to the object or incident which precipitated it. For a person with cancer, the fear of recurrence can be a powerful and specific fear rather than a general uncertainty of the future. It is also a component within the theme of a new life for the participants who feel changed as a result of a diagnosis of cancer.

6.3 Summary
This chapter focused on the theme of grief for the life that’s lost and has offered a discussion of the concepts of grief and loss, informed by the historical account presented in Chapter Two, the literature review. The evolution of theories relating to the concepts the grief and loss inform our understanding of the profound feelings experienced by a person with a diagnosis of cancer. The subtheme of fear of recurrence of cancer has been explored and is
acknowledged as the predominant long-term psychosocial concern for a person with a cancer diagnosis. The themes of *a thirst for information* and *a new life* are explored in the following chapter.
7.1 Introduction

Further to the themes introduced in the previous chapters, this chapter presents a discussion of the theme ‘A thirst for information’, as experienced by study participants following their cancer diagnoses within the paradigm of rural living in the Central West of NSW. The theme will be explored in the context of participant quotes and the related key thematic elements, namely ‘so much to learn,’ ‘what do I need to know’ and ‘who can tell me what I need?’ The participants’ deep need for information, the types of information sought and their common experience are derived from their stories during the semi-structured interviews, which I found emotive and moving.

The literature review in Chapter Two outlined how people living in rural locations in Australia have poorer health outcomes than their city counterparts and on average live shorter lives (AIHW, 2019; Shepherd et al., 2008). For those who live in rural and regional locations in NSW and indeed Australia, the trials and tribulations associated with geographical distance and isolation are an everyday part of life. A quarter of the population in NSW live in rural areas and for many there is limited access to health care services, particularly specialist health care services such as cancer-related surgery, chemotherapy and other systemic treatments, radiotherapy and follow up supportive care. Participants in this study had encountered the need to chart their course between services for specialist consultations and differing treatments where they were available.

7.2 A Thirst for Information

As human beings, each individual is naturally alarmed and on alert when experiencing seemingly random, previously unknown events and situations. New situations and difficulties lead each person to develop new responses to life and how each lives life. The feeling of being thrust into situations in which each lack order leads to the overwhelming need for information to bring control to the chaos. The human condition naturally seeks information in circumstances
such as a diagnosis of cancer in order to gain knowledge and understanding, and if possible, to be able to incorporate the diagnosis into their view of self. It was evident that the participants identified the importance of the role of information and the struggle to find it as a significant challenge.

As with any significant or life-threatening diagnosis people have a deep need for information as an attempt to assimilate the diagnosis into his or her life (Cordova et al., 2007; Kangas, Henry, & Bryant, 2002). For a diagnosis of cancer this is particularly important. Cancer as a concept and disease is made up of many types and stages to form the collective term ‘cancer’ (Corner, 2008). The associated treatment options and life changing morbidities which can eventuate are also wide ranging. When a person has a cancer diagnosis it has a profound impact on their life and results in the need for a variety of health information across the cancer care continuum (Finney Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Indeed, most people seek additional information about the diagnosis, possible treatment options, and the prognosis for their specific situation in order to find meaning and be able to carry on with life.

The powerful drive from within for information was evident when Sally was recounting her story; she found information provided to her was process related. It focused on appointments for specialists and further investigations; however, it did not provide her with an ability to begin to understand the diagnosis and what it was likely to mean for her life.

“So, when I got my diagnosis, yes there was lots of information given, but no there wasn’t. I got information about where I had to go and what I had to do but nothing else; you know, like nothing about what was happening to me.” Sally

For Sally there was a strong desire to know what cancer would mean for her body. This led to her worrying at night about the cancer cells in her body and what damage they were causing. This was a threat to self, exacerbated by the lack of information. Carl Rogers and Abraham Maslow promoted the notion of self-concept, emphasising that as human beings we look within ourselves for confirmation of who we are and what is happening in our lives (Aronson, Wilson, & Akert, 2007). Sally saw herself as having been invaded by cancer which, even after surgery, left her anxious that there was cancer remaining in her body and that she would never be the same.
Diane found she initially struggled because she did not understand what the general practitioner meant when he told her that she had ductal carcinoma rather than a cyst. Information was important to her to be able to function effectively and yet it was only after the consultation with the surgeon post operatively that she began to gain insight into her cancer.

"After I got the diagnosis … I didn’t understand any of it. (Husband) was trying to be calm but I just didn’t get it… The surgeon was the one who said it was triple negative and I said, ‘what does that mean’ and he said, ‘it means you have to have chemo and radiotherapy now…’ And this was different from my sister’s cancer.” Diane

Another participant spoke of craving information as he wanted to understand the mechanics of cancer, what it would do to his body and how this would affect him. Len wanted to know the power cancer would have over his life and how his family would be affected. He expressed how he had suddenly felt vulnerable and unsure of himself and his place in the world; his previous confidence was undermined. His desire to integrate the diagnosis into his life in the world was strong. Sokolowski (2006) describes the world we live in as the ‘whole’ and ‘I’ as the ‘centre’, and together they are the perspective for everything. Seeking control over his situation, Len wanted to comprehend what his life would be like and who he would become as a result of cancer. Like Sally, the information he received related to the process of diagnosis and treatment, which did not meet his need.

“They give you information about when to make a follow up appointment and things like that but not about what’s happening to your body and nothing that relates to the long term. And let’s face it, my body had let me down and I knew things would never be the same again in my life.” Len

Other information which participants sought related to disease progression and relapse, continuing or starting complementary and alternative medicines, legal and financial implications, and how best to live after a cancer diagnosis. The range of information participants felt they wanted to know was summed up by Peter who spoke of feeling there was ‘so much to learn’. Cathy spoke of having an intense desire to carry on with life as usual whilst ‘fitting’ cancer into it rather than letting it take over. This aspiration became increasingly difficult as she found she needed information to guide her efforts to normalise her new
situation. She discovered after the first six to eight weeks that she was ignoring her cancer rather than actually ‘fitting’ it into her life, and that this was not sustainable. Cathy spoke of not having answers to all the issues she wanted clarified and how difficult that was to cope with.

“That’s so, I just went to work and tried to manage… but it’s a strain you know – there’s so much you want to know about but short of the internet and trusting ‘Dr google’ there are no answers…”

Cathy

Another participant spoke of how his ‘thirst for information’ was meshed with his inability to know who he was with a diagnosis of cancer. Anthony’s diagnosis had occurred without warning as he had been told he had appendicitis; that it was a small operation to remove the appendix followed by a speedy recovery. Instead when he woke from the anaesthetic, he learned a tumour had caused his symptoms and the surgeon indicated it was likely cancer. A week later the diagnosis of cancer was confirmed and referral for chemotherapy was required. Anthony spoke of struggling to cope; who he was and what his life now was and what it would become. Heidegger called this ‘Dasein’, or our ability as a human being to wonder about our experience and inquire into our own being (van Manen, 1997). For Anthony the need for a prognosis was fundamental to his ability to integrate cancer into his life.

“I was still ‘muddle headed’ but the surgeon said he’d removed a tumour from my bowel, and he was pretty sure it was cancer. Then after I recovered from the surgery, I was told it was cancer and that I would need to see an oncologist for chemotherapy… everything seemed chaotic and I was really struggling for some control in my life. Needing information was such a strong feeling; like if I knew more, I’d get control of my life.” Anthony

7.2.1 Sources of Information

Whilst pursuing information enables a person with cancer to attempt to meet those information needs, identifying ‘who’ can provide it from the range of available sources challenged the participants. The literature indicates that whilst the vast majority rely on specialist healthcare providers, others turn to the internet, and government and non-profit organisations with varying levels of success (Chou, Liu, Post, & Hesse, 2011; Finney Rutten et al., 2005). Participants in this study spoke of receiving information from general practitioners, oncology treating nurses and specialists including surgeons, oncologists and urologists, however, it was not sufficient to meet their needs.
“… You know initially I made a pact with myself that I wasn’t going to check ‘Dr google’ or anything else on the internet etc— that I would rely solely on what the doctors have told me because a lot of the stuff out there is crap, a lot of it is very good, but how do you distinguish between the two, you know, which is which?”

Peter

When the search or yearning for information was not fulfilled locally, one participant, Pam, contacted the Cancer Council’s Helpline; she indicated she felt she had no other resources available to her locally; setting her apart from people in the city. With a diagnosis of breast cancer, finding the phone answered by a male nurse was difficult, however she spoke of how he was able to put her at ease. His ability impressed her and although she felt he was mainly being supportive, she felt better informed for the journey ahead. She was aware that he did not have knowledge of local services or the health care team and found that limiting.

“I didn’t know how to find support here; we don’t have everything like people in the city, so I called them … I didn’t want to talk to a man, but he was just lovely. I realised I wanted information – and someone to perhaps tell me what I needed to know. I was coming to realise that there was such a lot I didn’t know. I felt better after talking to him… like a weight had been lifted off me. But he didn’t know who to talk to here, or where to go to get information here.” Pam

Some participants spoke of feelings of relief when they encountered a health care professional who provided meaningful information. Anthony finally had information to take home and read following his consultation with the oncologist for chemotherapy treatment. It was the first time he had been given information, and he valued it. The information itself was difficult as it focused on all the possible side effects of chemotherapy treatment, yet the physical presence of the information provided a reassuring level of support for him.

“I didn’t get given information to take home to read about cancer until I went … for the appointment about chemo… they gave me a folder of information and whilst it was sometimes scary information, at least I had it with me at home to read.” Anthony

Another participant spoke of the joy of finally finding an answer to a troublesome chemotherapy side effect. Not only did Karen find an answer to an issue she was encountering, she realised her brain was still able to process information. She spoke of experiencing the feeling that her ability to think clearly and problem solve had disappeared and learned this was commonly referred to
as ‘chemo brain’. Realising she heard and understood the information the oncology nurses offered was a moment of elation for her.

“…when finally the fabulous oncology nurses explained to me why my nose seemed to be running all the time; just learning that the cilia that are up in my nose fell out like my hair did, that was so reassuring. I could understand through the haze of ‘chemo brain’ that there was a reason for this and that it wouldn’t last forever – what a wonderful moment during such a crap time!” Karen

7.2.2 Information Needs

Despite the need for information described by participants, few studies clearly focus on information needs as a concept (Adams, Boulton, & Watson, 2009; Nikoletti et al., 2008). Outside of healthcare the concept of information needs is widely used yet not clearly differentiated from learning needs and educational needs (Timmins, 2006). Information need as a concept is not easily observed, thus surrogate measures including the cause of and reason for seeking information are often utilised (Nikoletti et al., 2008). This assumes that one internal need leads to all information seeking behaviours, yet the literature indicates that there are at least three aspects to the concept: seeking answers, reducing uncertainty and anxiety, and making sense of situations. Timmins (2006) proposes that attributes of information needs are individual and expressed by both patients and/or next of kin in the health care setting. They often form the starting point for the provision of information by clinicians to patients and families, even though at times the type of information is decided by healthcare professionals.

Defining information needs as individual and primarily focused on assisting the person to cope with the stressful event he or she is facing, the explication of that need may be expressed spontaneously in order to cope with events (Timmins, 2006). One participant, Pam, spoke of the uncertainty of what she needed to know and initially how to find it. Pam felt strongly that she had competing priorities: soul searching and a powerful need for information. The referral to the McGrath Breast Care Nurse in Orange, after multiple operations, provided some support, however she was aware that this nurse provided a service to a number of women. This impacted on the amount of time she was able to spend with Pam, reducing the perceived level of information provided.

“…it was quite horrific, um just soul searching… and wondering what I needed to know, to learn… I was eventually referred to the
Jane McGrath Nurse in Orange, but she has so many ladies to help it felt a bit rushed. So, I had support from a distance which although great, would have been so much better if it had been someone local, but I guess we’re just lucky to have someone. I still have contact with her; you know it’s never over. “Pam

Pam’s words, “you know it’s never over” were potent in describing her feelings of powerlessness against her diagnosis of cancer and what this would mean for her life. For another participant, acknowledging that cancer was in control, resulted in a strong feeling of lack of control. Using Merleau-Ponty’s (1945/2004) belief of the inseparable relationship between each of us and the world, Cathy was now living in the ‘cancer world’. She experienced pain and fatigue each day and was aware that the outcome of cancer in her body would be her death. She spoke of feeling that the only sense of control she had in her life now would be the choices she made as to how her last months and weeks were lived. This weighed on her mind and she was only willing to share her circumstances with her husband.

“Only my husband knows that the cancer hasn’t gone away; I haven’t really told anyone. I know that I want to live my life to the max until I can’t and then I just want to quietly slip away. I don’t want to have any more treatment; the chemo didn’t work so I’m not going to put myself through more of that. I will find out as much as I can because I want to decide, when the time is right, how things are going to go.” Cathy

For one participant in this study the need for information mirrored the desire to finally have a clear diagnosis for his symptoms. Len spoke of how difficult it was to have a period of surgical procedures over nearly three months before finally being told by the urologist that he had bladder cancer. His only contact with the health care system had been the general practitioner followed by the specialist. Despite growing anxiety, he did not know of any way to find information or support during this indeterminate time. He spoke of the difficulty of having to wait for the final diagnosis.

“I had a couple of visits where I was expecting, waiting for him to say, ‘you’ve got bladder cancer’ but I had to hear, ‘it’s likely that you have bladder cancer, but we need to do this or that to confirm it’… That isn’t fun, you’re preparing yourself to hear ‘you’ve got cancer’ and yet it’s ‘actually we aren’t able to confirm it’ – that’s challenging to have it drawn out. There’s not a lot of information for you when you’re in that holding pattern of ‘you probably do have cancer, but we can’t confirm it for you’.” Len
As discussed in the previous chapter, grief for the life that is now not as anticipated, coupled with the fear of recurrence of cancer which plagues a person who has a diagnosis of cancer, are significant and at times overwhelming feelings. For one participant, treatment for ovarian cancer resulted in a sudden onset of menopause which she had not expected. Cathy was in her forties when diagnosed with ovarian cancer and she did not feel prepared for this eventuality; it was a further significant crisis within the chaos of a cancer diagnosis. It challenged her perception of herself as a woman.

“So, everyone says, ‘you’ve got cancer and need surgery’ and I was ok about that, but later I was having these weird symptoms which I realised could be the menopause. I tell the doctor and he’s like ‘oh, didn’t you realise that was going to happen’. I said, ‘no and no one told me’. So that really challenged me. First its cancer, now its menopause! Seriously isn’t one enough?”

The literature substantiates the participants’ experience of a significant need for information directly following his or her diagnosis and that these information needs are not well met (Hewitt, Greenfield, & Stovall, 2006; Iconomou, Viha, Koutras, Vagenakis, & Kalofonos, 2002; Jenkins, Fallowfield, & Saul, 2001; Kimiafar, Sarbaz, Sales, Esmaeili, & Ghazvini, 2016; Matsuyama, Kuhn, Molisani, & Wilson-Genderson, 2013; McQueen, 2009). The driving need for information can be a source of frustration and lead to feelings of decreasing satisfaction with health care providers and medical specialists, resulting in lower health-related quality of life during a person’s cancer journey (Halkett et al., 2012). Determining which groups of people with cancer have a higher risk of unmet information need has not been consistently demonstrated in the literature, with varying studies proposing alternative criteria (Sheehy et al., 2018).

“The information I got was from discussions with the doctors at appointments; I wasn’t given anything to take home to read. It was just talked about at the time. So, I would often go over conversations with doctors in my head – I guess I was clarifying the information with myself; reminding myself of what had been said to me. It would have been significantly easier if I’d been given information in a booklet or just a sheet of paper – that way I could have referred to it later when I had a thought and wanted to check out what the doctor was going to do or the treatment I was going to need.”

The thirst for information can be ongoing when a person has a cancer diagnosis. Whilst there may be different information sought, the need remains.
Sally described herself as no longer having cancer, yet she still felt an ongoing desire for information and reassurance. The fear of recurrence of cancer as discussed in the previous chapter is powerful, and participants described information as a method they used to cope.

“I’m like, what do I do? How will I know if the ache in my back is important or just from gardening; you know is that ache, the cancer back and its spread? I don’t have a guidebook to help me… when I understand what’s going on, I feel a bit better and can tell myself ‘it’s not cancer’ and that really helps.” Sally

One study focused on reviewing the websites participants (people with cancer) accessed, and by determining their internet usage demonstrated that they sought information relating to all aspects of cancer (Maddock, Lewis, Ahmad, & Sullivan, 2011). A separate study found most of the participants indicated they were seeking information about everything relating to cancer, treatment side effects, and the likelihood of things of getting worse, even if it was bad news (Matsuyama et al., 2013). In this study Anthony reflected on how difficult it was for him to find information he wanted on the internet; he searched but did not find the specifics he wanted. He spoke of never finding enough information and feeling anger and frustration that as a competent user of the internet, the information was not available to him.

“There’s information on the internet about the tests and procedures, but that’s actually not what I was wanting. I wanted to know about what this cancer was going to do to me, you know, how was it going to affect me. Would it take over my life or be a hiccup that I needed to navigate? How bad was I going to feel and was I going to die?” Anthony

By comparison, Balka, Krueger, Holmes and Stephen (2010) found in their study on cancer patients’ information needs that some women with breast cancer did not want any additional information. This may have been due to the study being undertaken in a metropolitan area, and/or the vast array of information and support provided to women with breast cancer, which is far superior to that for other cancers. Moreover, the findings of the study were not congruent with the experience of Karen who reflected on her thirst for information. She had access to tailored information related to breast cancer; however she wanted more information and did not have a way of finding it where she lived.

“I get sent the kit – and the information in the spiral book was so helpful as I was going through every single stage as it was laid...
out in the book. I knew that I wanted more information but was unsure as to what and who I could get it from. We don’t have information on tap here the way it is in the city…” Karen

7.2.3 Types of Information

For people with cancer, seeking information would appear to encompass the need for support from providers of a range of health-related information. One study matched the informational needs of people with cancer to those identified in a systematic review of the cancer information needs literature (Finney Rutten et al., 2005) which identified categories of information sought. These categories include information which is cancer specific, treatment related, prognosis related, surveillance requirements and recommendations, and general health. Further information needs were related to coping with cancer, how to navigate complex health care systems, psychosocial information, financial and legal information.

In the context of rurality, navigating the health care system was challenging for participants in this study. For them learning the ‘who’ and the ‘how’ of the cancer journey was an important aspect of their search for information. Peter spoke of the challenges he encountered with the health care system, despite the benefit he believed he had as a well-educated health professional himself. He expressed concern for people who lacked his background knowledge and ability to ask questions in this situation. He felt it was more important to ask questions than to be concerned if health care professionals perceived him and his wife as forceful and insistent. He felt he was being assertive, however, acknowledged that at times he was probably considered somewhat aggressive. He emphasised that he was pleasant but did ask many questions as he sought to clarify the information the specialist provided during the consultations.

“A lot of information isn’t volunteered, but if you ask the right questions you get information and answers. I think it’s advantageous that I have a tertiary educated background to be able to ask the right questions… And so, both my wife and I were probably seen as ‘a bit difficult’ but we wanted information and answers… and to check we understood what the urologist was saying. I was pushy at times, but not rude or anything; I just wanted more.” Peter

For another participant, the referral to a metropolitan specialist service led to her being advised to have surgery and any further treatment in Sydney. Sally
summed up the information provided at the initial consultation as a message that staying locally for any treatment was not her best option. She was then mentally prepared to travel to Sydney. She revealed feeling confused and unsettled when later, she was informed she could have her surgery locally. She felt this led to a lack of confidence that she would get the best care and it would affect the outcome of her surgery. Without any other support, guidance or coordination of her care she did not feel the journey through the health care system was clear or the advice constructive.

“…they told me to stay away from here – they said, ‘you know, for the best chance, you come to Sydney’ and I said, ‘oh OK’. And we accepted that… But now I was meant to think it was ok to have this done (here) rather than Sydney – I mean, I’d rather not have to travel but I’d been told it was what I would need to do. So I’m in Sydney hearing that I can have the cone biopsy done here – no way I would have guessed that would be ok. But somehow it sort of felt like a run-around. You know, I was wondering if I’d really needed to go to Sydney at all or should I trust that having it done in here is really ok? There’s no one to guide you or answer questions – you just bounce from doctor to doctor, appointment to appointment.” Sally

Understanding cancer-specific information was important to participants in this study. Diane recounted very early in her interview:

“So, I was diagnosed with breast cancer, stage 2 – triple negative, so non-responsive to drugs, so the only option is chemo followed by radio; if that doesn't work, well if it doesn't work, I'll have to have more chemo until the game's over.” Diane

Having a clear understanding of her disease and the impact of the staging and receptor status on her treatment options gave her a sense that she knew what was happening with her life. Diane spoke of her daughter being a scientist and how she approached learning about the options in a scientific manner which was helpful for her daughter. She also spoke of the level of support her daughter provided, revealing the valuable link between information and support. Acknowledging that she was fortunate to have a supportive and loving husband emphasised the importance of family and relationships and was spoken of by other participants. For some it was a strong sense that a solid relationship can survive a cancer diagnosis; providing support and being resilient in the face of changes within the person:

“My husband is such a good bloke; he’s always been there for me as we’ve faced the ups and downs in life. Together we’re
solid and that has never been so important to me as it is now I have this cancer… We just wanted to know everything.” Diane

Karen described her marriage of over thirty years as very successful and was quick to acknowledge the support she had from her husband from the moment she told him her diagnosis. She spoke of them as a team having faced previous challenges in their lives, and the strength of their marriage as the basis for her being able to cope when life was particularly difficult. This powerful connection with her spouse was a fundamental component of who she was in the world.

“And he said, ‘will I come?’ and I said, ‘no it will be fine’ and then he said, ‘I think I’ll come’. And he did and the doctor said, ‘good to see you both’ and took us in and he just said ‘here it is’ he brought it up on the screen – we saw ‘grade 3’, the words ‘acute, invasive’. He held my hand and, in a way, hasn’t stopped holding my hand all this time”. Karen

Treatment-related information incorporates information relating to the person’s treatment and the range of treatment options available, side effects from treatment, and clinical trials (Maddock et al., 2011; Shea-Budgell, Kostaras, Myhill, & Hagen, 2014). Supportive care medication information also fits within this category. Shea-Budgell et al. (2014) found that most patients reported that detail about treatment was the most important type of information for people with cancer, searching for information about treatment options such as chemotherapy, radiotherapy, and surgery. Whilst seeking information relating to specific treatment options raised by the surgeon or oncologist, people with cancer also seek information about the range of treatment options suitable for his or her cancer (Castleton et al., 2011). If this need for information is not met, participants described feeling overwhelmed. Karen spoke of the time after her surgeon advised that a mastectomy was the best treatment option as particularly harrowing, as she had no support from the health care system.

“I had a three-week gap between the lumpectomy and the mastectomy – there was no support here that I could find to get any information… I withdrew into myself to try to cope. I felt lost and so sad. I didn’t sleep well, and it seemed like months, not 3 weeks.” Karen

There is also a strong desire to seek information relating to the range of side effects of treatment (Castleton et al., 2011; Chou et al., 2011) and information regarding how best to manage them (Castleton et al., 2011; Tustin, 2010). One longitudinal study of the information needs of women receiving radiotherapy for
breast cancer found that the women sought information about treatment side effects and the impact of treatment on their general health and life (Halkett et al., 2012). Not having information post-operatively to guide a good recovery from the surgery was encountered by a participant. Karen’s mastectomy led to a lack of full range of movement in her shoulder on the affected side. She had not been aware of the importance of exercising her arm to reduce the likelihood of restricted movement, revealing she should have been educated about this and referred for assessment to avoid the situation. Encountering this side effect of her surgery compounded her feeling of grief, sadness and a sense of isolation, once again bringing to consciousness Merleau-Ponty’s (1945/2004) position of living our world through our body.

“After the mastectomy I ended up with, like a frozen shoulder, and had to take myself off to a private physio because I didn’t know that was a common risk for mastectomy patients; no one told me or warned me. They should have taught me this at the hospital and referred me to a physio to check everything was ok before it became a big deal. It added to the misery.” Karen

People with cancer also seek information beyond standard treatment options, such as integrative, and complementary and alternative medicine (CAM) options (Castleton et al., 2011; Finney Rutten et al., 2005). In our society, the use of CAM therapies for many people is a way of life. Two participants discussed wanting to know more about CAMs and if they had a role in their cancer treatment. Each was focused on the complementary nature of CAM rather than the alternative medicines some people utilise to treat cancer. However, neither raised the issue with their treating specialist.

“I wanted to know if there were herbs or other treatments which would work but no one talks to you about those and I was too afraid that the oncologist would think I didn’t trust his chemo that I had to let it go. But you know, I often thought about it and sometimes used google…” Cathy

Participants in this study all described how and when each had received information about his or her cancer over time and when the information was provided by the health care team. For all the participants, the desire for more information was profound, and the language used in the interviews reveals the strong need for that information. The important gaps related to not knowing what questions to ask and wanting written information provided to them to take home – it was such a powerful *thirst for information* and support. The following
description from Peter reveals the extent to which seeking information was so important for the participants.

“And you see, you don’t get given anything much in writing, you know like a map of what needs to happen or what might happen. They give you information about when to make a follow up appointment and things like that but not about what’s happening to your body and nothing that relates to the long term. And let’s face it, my body had let me down and I knew things would never be the same again in my life. But it’s the great unknown – so just a booklet or a map would be helpful. Or some guru of a nurse….”

Peter

A consistent theme from the participants in this study was not knowing what to ask or who could provide the information he or she was seeking. The powerful drive to understand the meaning of the diagnosis and the impact it would have on his or her life came through clearly in the interviews. Following Peter’s thoughts on “some guru of a nurse”, other participants had also determined the value of specific support to gain information. This is well demonstrated in the words Karen used when she described how busy general practitioners and specialists are and how she did not expect more from them specifically. Rather she felt the need to give patients a connection to a nurse for support and information to guide people through the process of a cancer diagnosis.

“I didn’t really know what I needed to ask; the doctors only give you what seems like general information about what’s next. I wanted to know about my cancer; later realising I wanted to know why I got it, if it would kill me, what treatment I needed and why. But I just didn’t get it and I didn’t know where to get it. It shouldn’t be so hard; you know they should say – ‘here’s the name and number of a nurse who can help you through this’. That would have made a big difference to me, and I don’t think I’m that different from most people.”

Karen

Reflecting on her life since her diagnosis of breast cancer, Karen was clear about what information she was seeking, yet at the time she did not know what she most wanted to learn. She was clear that this made things difficult for her. For Cathy, not knowing anything positive about cancer, let alone having any previous knowledge of ovarian cancer, was a very real struggle. Her fear that she would die from cancer overlayed her thirst for information.

“…you know, now I know there are lots of stories of women who’ve come out the other end, but at the time, I didn’t know anyone that had survived cancer, and I just knew about people who died from the cancer – so I wanted to find out information but didn’t know who to ask, or even what to ask. Looking back, I
know I was frightened for myself; I just needed to know more.”
Cathy

The concept of a single point of contact was raised by four of the participants; each in the context of having one health care provider with whom to connect. Identifying that a nurse would be an ideal role to provide this information and support was established. This was supported by the female participants with breast cancer who had contact with a McGrath Breast Care Nurse, describing this as an overwhelmingly positive experience, with one participant noting that people with other cancers do not have that service. One participant likened the need for such a role when reflecting on her father’s experience with kidney cancer and the lack of information and support available to him:

“I saw my father’s journey with no information and support, or coordination and it was awful. Whilst I always wanted to know more, my own journey has been so much better because of the Jane McGrath Nurse...I wish everyone with cancer had those sort of resources – if everyone had that sort of support it would make a huge difference. And it needs to be full time – in regional areas so often we have part time this and part time that. Part time is useless – we need full time!” Pam

For Len, the provision of only basic information was challenging. He felt that the impact of the diagnosis influenced his ability to seek information and even to recall what he had been told during consultations:

“… they basically gave me the basic information, which probably didn’t mean a lot to me because once they said, “you have cancer”, you don’t, you just can’t hear. And so, I’d get home and not really be able to explain things. I’d try to remember but really all I was able to take in was about what the next step was.” Len

Len realised he wanted to have information in written form given to him by his treating specialist so that he could understand more about his cancer and the treatment steps he was to undertake, yet he did not receive brochures, pamphlets or information sheets. This was identified by another participant, Pam, as an unmet need following her diagnosis of cancer:

“And I just didn’t get information – only conversation which I was meant to remember. So, nothing on paper for me to take home to read, let alone share with my family. That was really hard.” Pam

7.2.4 Common Experience
The common denominator of each participant having a diagnosis of cancer leads to a significant overlap in experience. While this was anticipated given the
criterion-based sampling of participants utilised for this study, it does speak to the distinctive aspects of this experience specific to cancer. Each person, when recounting his or her experience, took a similar narrative route suggestive of the shared humanity inherent in a diagnosis of cancer. Thus, the importance of illuminating these commonalities among participants gives weight to the necessity of understanding how deeply a diagnosis of cancer affected the lives of people in the Central West of NSW. For each diagnosis of cancer, the trajectory of disease differs dependent upon the type of disease, treatment options including surgery, radiotherapy and chemotherapy, and other systemic treatments which increasingly include immunotherapy.

The literature has recognised phases within the cancer trajectory or journey which include periods of transition, when a person with cancer moves from one phase into another evolving phase (Goodman, Schlossberg, & Anderson, 2006; Selder, 1989). Recovering from a surgical procedure is a milestone in itself, yet for a person with cancer it may be only one step on the pathway of his or her journey. Likewise, upon completing a course of chemotherapy, a person may experience elation that he or she would no longer have to have this treatment, only to discover that the next phase for them involves regular hormonal therapy for a number of years. Each transition usually brings elation coupled with despondency. Another phase which a person with cancer may face is stopping treatment or learning that the cancer is no longer responding to treatment. Each of the many transitions are challenging periods for a person with cancer when he or she experiences increased uncertainty, vulnerability and a strong desire for information (Finney Rutten et al., 2005; Kimiafar et al., 2016; Maddock et al., 2011; Matsuyama et al., 2013).

In the context of information needs, the theory of transitions is complex; therefore, for the purposes of this study, transition describes a person with cancer moving across phases in the cancer trajectory. Cancer information needs are noted to be at their highest during the diagnosis and treatment phases. The perceived need for information following treatment may decrease, however, the need is present across the cancer care continuum (Finney Rutten et al., 2005; Maddock et al., 2011; Matsuyama et al., 2013). For Len, advice from a friend with cancer proved valuable and something he felt that everyone
with cancer needed to know. With the lack of information provided to take home, the use of a ‘cancer diary’ had been a constructive strategy to utilise.

“A friend of mine who is also a cancer patient said, ‘keep a diary, keep a medical diary’ and so that’s what I’ve done and keep doing. So you see, I’ve got this book here, it’s in chronological order, it contains the contents of my conversations with my doctors – what they did and what they didn’t say so I can go back in time, put everything into a timeline … I write in it after every appointment. It’s the only way to keep track of what I need to know ‘cause they don’t give you much. I guess they think you’re going to remember what they say and I’m up and down the highway to Orange for all these appointments.” Len

The amount of information people with cancer seek differs from a person who may desire no further information about their cancer to one who wants to learn everything about the cancer and to enable them to feel ready to face a range of possible treatments and outcomes. Inextricably woven into the ‘thirst for information’ brought out by the participants is the desire for support and psychological counselling, however, this was not met for most of them. Lack of locally based support and information provision was another element; the expectation to have to travel for diagnosis, treatment and follow up care was evident in six of the eight participants.

“Up and down the highway which gets pretty draining after a while. And each place didn’t have a record of what had happened at the other place – so again I’m having to tell the story. At one stage I got a bit worked up thinking that I’d told the story in the wrong order of things and that might lead to a problem with what they were planning to do. I mean, I got really worked up and became shaky and my heart was pounding. The nurse said not to worry, but that didn’t really make me feel any better. Every time I got a blockage and had to go to hospital or when I had to have the procedure in Orange, it affected people at home and that made me feel like a real burden.” Len

For Diane, there was real passion in her voice as she spoke of not having to go to Sydney to have treatment. She considered travel to Orange for treatment so much better than the experience of her friends, that the almost 140-kilometre journey each day was a welcome alternative. In this aspect of her cancer journey, the inseparable relationship between herself and the world (Merleau-Ponty, 1945/2004) only required modification, not redefinition. She was relieved she could live in her own home and try to be as normal as possible during the daily radiotherapy treatments.

“…it’s a brilliant facility and it’s in Orange… I mean I had friends who in the past had to go to Sydney for their treatment – you
know it’s really a quick thing every day, like two minutes a day max to have radiotherapy, and then you’re at a loose end – and they had to do that in Sydney which was just unimaginable. I had a roster of friends to take me so I would travel up and back and then come home to my bed for a rest, take a bike ride; I still had a bit of a life, even though it was tiring having treatment and going up and back to Orange 26 times”. Diane

Only one participant discussed attending a cancer support group in an attempt to feel connected with others. For the other participants, the focus was on seeking information rather than connecting with others with cancer for support and education. Perhaps some of the isolation and information needs of the participants could have been addressed through attendance at a support group, however, most groups are not available locally. Pam felt it would be beneficial for her after the McGrath Breast Care Nurse recommended it, but the group met in Orange. She spoke of the arduous task of getting to Orange; how painful and difficult it was to determine when she would be physically strong enough to make the trek.

“Travel is a huge part of the experience – to consultations, for surgery – twice – for the breast cancer support group. I get tired because I’m on hormone treatment and get night sweats and not a lot of sleep. Oh and pot holes hurt so much when you’re hurting after surgery: I needed to ‘drug up’ to go in the car to cope with the pain to get to the support group… Driving a 4 wheel drive that’s manual just isn’t something I could do 8 weeks after surgery – you can’t change gear, can’t get the hand brake off – so that was really tough. We need 4-wheel drive vehicles because we’re out of town, but I was stranded and alone unless my husband could take me somewhere.” Pam

7.3 Summary
This chapter has provided a discussion of the powerful theme which emerged from the participants, ‘A thirst for information’. This theme threaded through the consciousness and ‘life world’ of all the participants, who spoke of it in language which suggested that each was seeking a fundamental, yet barely understood, implicit need. Indeed, there was often a lack of clarity for participants during their cancer journey of what to ask or even who to ask. Living in a rural community compounded the lack of locally available resources and provision of information from the time of diagnosis to completion of treatment and into survivorship. The participants did not feel that the information provided at consultations with general practitioners or specialist was sufficient or appropriate to meet their needs. They felt that it was essential for information to
be provided in hard copy to take home and identified a strong link between information and individual support. They believed that all people with cancer should routinely be connected with a specific health care provider to be able pursue further information during their cancer journey, and half of the participants recognised that a nurse would be ideal to meet this need. The next chapter presents the fourth theme from this study: *a new life* discussing how participants feel fundamentally changed following a diagnosis of cancer. This is followed by the discussion of the impact of rurality in Chapter Nine.
Further to the themes presented in the previous chapters, this chapter presents a discussion of the fourth theme, *A new life* after the experience of a cancer diagnosis for participants living in the Central West of NSW. People with cancer are inexorably changed after the diagnosis, usually regardless of the outcome, and a re-evaluation of life choices and priorities occurs. The participants’ stories described the elements of *a ‘new life’* as ‘*finding meaning after a cancer diagnosis*’, ‘*who am I now*’, and ‘*transition to a new normal*’.

### 8.1 Outline of the Chapter

This chapter explores the impact cancer has on the participants, exposing the traumatic nature of the impact on their lives as they struggle with ‘*transition to a new normal*’. This leads to the possibility of growth from trauma for some and a discussion of problems associated with survivorship for others. The participants were incredibly open and forthcoming with extremely personal information and my goal is to honour their words and willingness to share. Paul Ricoeur (1988) and Martin Heidegger (1927/1962) acknowledged the power of words and language and that meaning is created through dialogue. As linguistic beings, individuals make connections with other individuals and the world at large. In phenomenology, researchers are able to access the ‘life world’ of another human being through listening to their stories. For centuries, researchers in various cultures have utilised storytelling to inspire hope, share meanings and purpose, and to understand the world in which we live (Welch, 2006).

Each person exists in a state of being. Existing can be an occasion, an episode and an ongoing progression in the existential need to find meaning in existence (Heidegger, 1927/1962). Defining moments in life, such as a diagnosis of cancer, can be described as a sudden, dramatic immersion into the greater narrative of existence, leading to confusion, fear and anxiety. The character of the world has been described as a total experience of chaos and a lack of world order (Oaklander, 2006) and this resonated during the interviews. As discussed in previous chapters, the life we live as individuals is intrinsically entwined with the history, society, culture and relationships within which we live. Whilst each can transcend their situations, none is able to transcend the parameters of the
world in which they are positioned. However, the ability to acknowledge the capacity, and potential to choose how we respond to that world, is vital in ‘making sense’ of chaos.

8.2 Finding Meaning After a Cancer Diagnosis

Anyone who has not experienced cancer can only imagine how it is ever-present. For most people it attacks all facets of life and brings overwhelming devastation to the integrity of the individual. One participant felt clearly that he was different from before he had cancer. He had completed his working life and retired, chose to volunteer within his community as a means of contribution to the common good, and was looking forward to spending time with his wife. Instead, he was diagnosed with cancer and had repeated surgical procedures and treatments to keep it under control. He was extremely aware that his cancer was not cured, and he was able to reveal that a positive outcome would be that it remained contained. He had spent time and effort to learn that this was his new reality. His relationships within the family had been strained at times due to the diagnosis of cancer and he worried about its impact on them, particularly his wife.

“…there was a new me and a new normal…” Len

Personal identity is challenged and changed, and the participants revealed this with stirring accounts. For some it involved feeling shaken and concerned that they were physically not as capable as they had been prior to cancer. Karen was particularly articulate on the nature of changes in herself following a cancer diagnosis. She realised she was different to the way she had been and being able to accurately describe herself now had been something she had been considering for quite some time. She felt she had lost some of her natural confidence and that her personality had altered. No longer did she think of achievements and abilities or enjoy being part of her previous social circle. Karen felt she had found a very honest understanding of herself.

“I'm not the same person I was – and it's taken me quite some time and effort to be able to pinpoint who I am now, what are my talents now, my strengths now. I'm very aware of my shortcomings as the person I am now. I'm no longer as confident as I used to be; I get very nervous in crowds now ...I cry a lot more than I used to...I'm a bit reserved and held back now and I wasn't before...I'm just not the same anymore” Karen
For one participant it was a real challenge to describe the person she now was:

“\(\text{I can’t... find a language to describe me – which I think is interesting. I don’t see myself as a cancer survivor, because I don’t know that I’ve survived it. I don’t think you ever truly know that you’ve survived it; not completely... And I don’t see myself as a victim; I don’t see myself as a cancer patient, and I don’t have cancer, so I don’t see that I fit on any kind of spectrum.}\)”

Diane

For another participant it was an opportunity to reframe his identity and what was important to him; the people he valued most and the things he wanted to accomplish, including seeing his sons grow up. Diagnosed in his early forties, Anthony spoke of how he was now a more reflective person and focused on communicating how he felt and what he thought. He realised he had previously been less self-aware than he liked and quite closed off whenever things were difficult or challenging, considering these to be typically Australian manly traits. Anthony had previously needed to define himself as a dad who did not have a positive relationship with his ex-wife, and he had considered this process arduous. Yet he reflected that his cancer diagnosis was far more confronting. Another challenging aspect of this related to expectations that, despite living in a rural community, most health care was readily available where he lived.

“I don’t think I’d ever really sat down and pondered who I was all that much; I mean after my messy divorce I had to work out how to be a Dad only having the boys every second weekend and that wasn’t easy. But cancer has really made me reflect on who I’ve become and where I see my life and my boys’ lives going. I so want to be here for them and see what kind of adults they turn into. I am still me, but I had to realise I’m a different me. Having cancer and all the treatment was pretty traumatic. I know it changed me and my assumptions that we have all the options here for treatment which was naive.” Anthony

8.2.1 Who am I Now?

The literature has acknowledged for decades that for most people with a diagnosis of cancer, the battle which each will face is unknown, provokes fear and challenges the individual perception of self (Bush, 2009; Welch-McCaffrey et al., 1989). The impact of a cancer diagnosis lingers and is multifaceted for individuals, both physically, psychologically and spiritually. One of the participants in this study, Diane, explained how she had gathered a collection of fabulous scarves in preference to using a wig when she lost her hair during chemotherapy treatment. She came to realise that wearing a scarf constantly
reminded her she had cancer cells in her body. However, she also discovered that wearing the scarves announced loudly to the world that she had cancer and that it had different meanings for different people she encountered.

“I've now got the world’s biggest collection of scarves… It's a constant reminder when perhaps you’ve popped out for a coffee and would love to have someone say ‘hi’ and treat you like you. But in our society, you are now different because you have cancer. And the scarf is the physical evidence that you have cancer cells inside you; make no mistake, you’ve got cancer! I think it would be interesting for me to do some writing about the discourse of the scarf – how it speaks to people, the meaning for people you encounter as you go about your day. My cancer becomes something for others as well as myself and I don't think I expected that.” Diane

Over the last thirty years, researchers and clinicians have reported that people who have survived cancer experience stress or trauma-related symptoms (Alter et al., 1996; Andrykowski & Kangas, 2010; Kornblith et al., 1992a; Kornblith et al., 1992b; Rustad et al., 2012). These include avoidance behaviours, heightened awareness and anxiety, with an exacting fear of cancer recurring, and the presence of intrusive thoughts. Such symptoms mirror those of people who have endured traumatic events, including violent personal attacks, living through natural disasters and members of armed forces who have been in combat situations. The collection of these symptoms following a traumatic event has been classified as Post-Traumatic Stress Disorder (PTSD) (APA, 2013). The DSM-5 also has a listing for acute stress disorder, or Post-Traumatic Stress (PTS), which has similar features to that of PTSD and does include the diagnosis of a life-threatening illness as a possible trauma, however the criteria refers to symptoms arising within four weeks of the experience of trauma (APA, 2013; Andrykowski & Kangas, 2010; Rustad et al., 2012). It is therefore appropriate to consider post-traumatic stress as a fitting description for the trauma-related symptoms which a person with cancer may experience.

8.2.2 Post-Traumatic Stress (PTS) in People with Cancer

PTS has been studied in people who have experienced a range of cancers (Andrykowski & Kangas, 2010; Rustad et al., 2012) including melanoma, Hodgkin lymphoma, breast cancer, and mixed cancers, and they reveal varying results. Using PTS symptoms as a measurement of incidence in people with cancer, as opposed to the more rigid PTSD criteria, between 35 percent and 80
percent of people with cancer reported these feelings along the continuum from early diagnosis through treatment and recovery, as did those who have a recurrence of their disease. Studies have reported factors which might indicate a person was at increased risk of PTS as including younger age groups, lower income and fewer years of formal education (Andrykowski & Kangas, 2010; Cordova et al., 1995; Rustad et al., 2012). Other studies found that experiencing a previous traumatic event has been considered a significant psychosocial risk factor for developing PTS symptoms (Andrykowski & Cordova, 1998; Baider & Sarell, 1984; Butler, Koopman, Classen, & Spiegel, 1999; Davidson & Foa, 1991; Green et al., 2000; Shelby, Golden-Kreutz, & Andersen, 2005).

An example of PTS-type symptoms was disclosed by a participant in this study as she spoke of how the fear of cancer recurrence plagued her. She spoke of how she wanted to be able to enjoy life after having a cancer diagnosis which had been treated successfully, however was held back by fear of it returning. A core component of the fear was her understanding that when cancer metastasises it leads to death. As a bright, bubbly woman in her late thirties, she revealed she had a darker side to her personality following cancer and did not know how to let go of the feelings when they were triggered.

“I talk to myself inside about every little niggle and worry about it being cancer. I’m supposed to be in the prime of my life and happy that I don’t have cancer anymore but how do I really know what’s going on inside me? I know that if it spreads you don’t have any hope really – maybe chemo or something but really, it’s not going to end well. So, it’s been done, it’s ripped out – that’s it! Or is it? I’m left with questions and its challenging... I’m left wondering and those thoughts don’t seem to go away...at times I get worked up about it, you know anxious.” Sally

Two other participants spoke of ruminating at night when trying to get to sleep, with thoughts focused on the possible outcomes of the cancer illness. For one, the need to actively redirect his thoughts was only somewhat successful. Peter spoke of the stress and strain associated with not being able to put these thoughts out of his mind despite his training as a psychologist. The reality of cancer did not respond to the tactics he knew to control rumination and anxiety building. Frustration that he found himself in this situation was apparent and he described never having issues previously that he was unable to put out of his
mind. As someone who saw himself as a strong human being, he realised this challenged who he was as a man.

“It’s so draining; if I don’t get off to sleep straight away, I’m stuck in this spiral of negative thoughts. Some of them are quite reasonable and others are just my mind focusing on the worst possible scenarios. I try so hard to tell myself not to do this, but I can’t stop the pondering and worrying. Sometimes I end up so upset I have to get up and walk around to try to settle myself.”

Peter

For another participant the experiences of ongoing intrusive thoughts had led to him choosing to avoid certain situations. By avoiding social situations, where he feels he will be constantly asked how he is, Len feels more in control of his thoughts. Previously, he and his wife had been part of a large circle of friends and often attended functions, yet he had found that limiting these interactions assisted in managing his feelings of sadness, grief and anxiety. He acknowledged his outgoing personality had not survived his diagnosis of cancer and this left him feeling sad and at times morose. Part of these feelings was facing the impact his decision had had on his wife, and she deciding whether to attend events knowing he would not accompany her. He acknowledged he felt he had let her down by putting his needs ahead of hers.

“I just can’t be talking to every man and his dog about this; it makes me feel worse, even if there isn’t anything that bad to have to say. So, I deliberately don’t go to some social events my wife and I used to attend. I think it helps…” Len

Whilst no definitive factors have been identified to determine who may be at higher risk for the development of PTS and PTSD, the need for support during each person’s cancer journey is vital for a positive outcome. A study of men and women who had undergone a bone marrow transplantation (Jacobsen, Sadler, Booth-Jones et al, 2002) found that decreased levels of social support and using avoidance coping mechanisms correlated significantly with a greater number of PTSD-like symptoms. Similarly, in women with early-stage breast cancer, the availability of social support is associated with fewer stress response symptoms (Cordova et al., 1995; Rustad et al., 2012). The use of treatment modalities employed for people with PTSD has been accepted as appropriate for a person with cancer who has PTS (Andrykowski & Kangas, 2010; Rustad et al., 2012).
Importantly, the availability and timeliness of accurate health-related information may also offer a level of protection from stress response symptoms. Women who were unaware of their cancer stage reported higher stress response symptoms than those who were more knowledgeable about the stage of their disease (Mundy et al., 2000; Widows, Jacobsen, & Fields, 2000). To the extent that adequacy of information reflects the quality of a patient's relationship with medical staff, another protective factor may be the quality of those relationships. Difficult patient-staff relationships have been reported to be predictors of stress response symptoms in women with cancer (McGarvey et al., 1998; Naidich & Motta, 2008; Widows et al., 2000). For one participant, the relationship with her surgeon was particularly difficult and she spoke of feeling that he treated her like a number rather than a person.

After finding a lump in her breast, Pam spoke of finding herself in a consultation with a surgeon who was reluctant to arrange a biopsy. She felt a biopsy was imperative as she had known women with breast cancer and feared the same for herself. Pam spoke of this incident twice in the interview and each time was passionate in her description of the surgeon telling her he was sure the lump was nothing serious; firstly using the phrase ‘one hundred percent sure’ and the second time, the phrase ‘he’d stake his life on it not being cancer’. After reluctantly referring her for a biopsy under ultrasound, she had the procedure and returned to the surgeon for the results. As her story unfolded, she went on to describe the consultation and the surgeon saying that the biopsy had revealed cancer and then asked her how she felt. She reported being indignant and at a loss as to why he would ask her that. He did not acknowledge he had nearly sent her away with cancer in her body, and she felt that led to her anger with him. Interestingly she felt comfortable to separate the expertise of the surgeon from his communication skills. The trust aspect of the doctor-patient relationship was tenuous, and she expressed that doctors should be responsible enough to communicate better with their patients.

Shaping us as human beings is the essential intersection between culture and our own experiences. As people we have a need to feel we are living our own life and take responsibility for decisions and actions which form our successes.
or failures. Pam did not consider the surgeon had taken responsibility for his role in causing her increased anger and anxiety during the diagnosis of cancer.

“I went to the surgeon who said it was nothing – he said he’d guarantee; he’d stake his life on it not being cancer because he’s the surgeon and he’d seen a million of these and he decided he wasn’t going to do anything about it. And I said, ‘you’re joking!’ and he said, ‘just to put your mind at ease, and waste taxpayers’ money, we’ll send you for an ultrasound and biopsy…. and then went back to the breast surgeon two and a half weeks later and he looked at the notes and just said to me, ‘oh well, they’ve detected cancer, how do you feel?’ I think that if I’d had a weapon, I would have belted him with it.” Pam

The relationship deteriorated further over of nine weeks, and after two surgical procedures she finally needed to undergo a mastectomy. Pam felt unable to respect him despite knowing he was a senior surgeon. She felt his communication style compounded the trauma of the diagnosis and listening to him advise her was challenging. She acknowledged that disclosing how she felt he treated her made her anger flare; she could still feel his condescending manner despite the time that had passed.

“And the surgeon was still a shit! I felt he needed to get some bedside manners.” Pam

One important psychosocial risk factor associated with PTS symptoms is the experience of past traumatic events (Andrykowski & Kangas, 2010; Baider & Sarell, 1984; Davidson & Foa, 1991; Shelby et al., 2005). A previous history of trauma in combination with current stressful life events were also noted as risk factors for the development of PTS symptoms. Ensuring people with cancer are adequately and appropriately screened for PTS is considered best practice, yet determining timeframes for these assessments is problematic (Andrykowski, Cordova, Studts, & Miller, 1998; Andrykowski & Kangas, 2010; Deimling, Kahana, Bowman, & Schaefer, 2002; Greenberg et al., 1994). The time of diagnosis is critical to the experience of cancer, as it is often the precursor to a continuum of repeated traumas over varying timeframes. The literature indicates that a person with cancer may display the symptoms of PTS across that continuum from diagnosis, undergoing treatment, completing treatment, and spread or recurrence of cancer (Andrykowski & Kangas, 2010; Deimling et al., 2002). It is important to note that PTS symptoms are likely to fluctuate throughout the experience of cancer and life after cancer.
Challenges to the concept of PTS in people with cancer are based on how the criteria for PTS are applied in the context of cancer and survivorship. The basic tenant of an extreme traumatic stressor is an event connected to a personal experience that involves actual or threat of death or serious injury (Andrykowski & Kangas, 2010; Rustad et al., 2012; Shakespeare-Finch & Morris, 2010).

Whilst the events related to cancer can be extended or ongoing, it is more often a single event such as a natural disaster, physical attack or rape that trigger such symptoms. Yet when a person with cancer exhibits symptoms of PTS there is usually a lack of clarity as to the specific nature of the trauma. The person may not be able to identify if the trauma relates to the diagnosis, the treatments which he or she has undergone, a clinician explaining the cancer has spread or recurred, or the development of a symptom after treatment which may indicate that the cancer has not gone. Determining the discrete stressor when faced with the multiple catastrophes that constitute a cancer experience can be more challenging than for other traumas. In one study of patients with breast cancer who underwent autologous bone marrow transplants, more PTSD symptoms were reported at the time of initial diagnosis (Andrykowski & Kangas, 2010; Cordova et al., 1995).

Another concern regarding the conceptual fit of PTS within cancer is related to re-experiencing the trauma. The DSM 5 diagnostic criterion requires persistent re-experiencing of the traumatic event, implying that the patient would first encounter a trauma and then, at a later time, re-experience it in various ways (APA, 2013). In a study of women with early-stage breast cancer, however, researchers found that the traumatising aspects of the cancer experience were receiving the diagnosis and waiting for test results from node dissection (Andrykowski & Kangas, 2010; Cordova et al., 1995). Arguing that information traumas cause intrusive worry about the future – not intrusive recollections of past events – raises the question as to whether cancer fits a conceptual model of PTS and PTSD trauma. Over the last twenty years reviews have contended both for and against the continued use of trauma models to conceptualise the experience of cancer (Andrykowski & Kangas, 2010; Cordova, Studts, Hann, Jacobsen, & Andrykowski, 2000; Gurevich, Devins, & Rodin, 2002; Palmer, Kägee, Coyne, & DeMichele, 2004; Rustad et al., 2012; Shelby et al., 2005).
8.2.3 Post Traumatic Growth (PTG)

Multiple crises which arise during the cancer journey are inherently stressful and challenging for each person. Studies which focus on post-trauma outcomes note that in addition to PTS and PTSD, there are positive outcomes which can also arise (Cordova et al., 2007; Kangas et al., 2002). There is a growing body of evidence that a cancer diagnosis has led to a positive effect on the life of the person. This may manifest through “opportunity, empowerment, and social connection” (Andrykowski & Cordova, 1998, p. 200) and encourage appreciation of the value of life and relationships (Andrykowski & Kangas, 2010; Wise, 2009). When these positive life changes arise, they have been described as PTG as they occur after surviving a traumatic experience (Andrykowski & Kangas, 2010; Rustad et al., 2012; Shakespeare-Finch & Morris, 2010).

Not all people who face the trauma of cancer and subsequent treatment automatically achieve a positive post-trauma outcome. Factors which have been identified as influencing a positive life change include the type of diagnosis and types of treatments, and the potential for recurrence (Kangas et al., 2002). As previously discussed, the fear of recurrence of cancer is based upon the perception of the likelihood of cancer returning or indeed spreading. For a number of people this eventuality may become a reality and is therefore a powerful ongoing concern. The factors identified above are key components of a diagnosis of cancer, yet it is important to acknowledge that a person with cancer can have both positive and negative psychological outcomes (Stanton, Bower, & Low, 2006) in tandem. This leads to the work of psycho-oncology clinicians which aims to provide supportive care and reduce the psychological impact of a cancer diagnosis. This level of support had not been provided to participants who would likely have benefitted from it.

“It’s still really raw, about what this is going to mean to me – I’m tired, I’m so tired. And anyone who’s very tired is either going to get very cranky or very emotional and maybe have a few too many wines and then cry; curl up and cry... No one had told me how long it will take for this to feel better, but I guess I haven’t really spoken about it. You know I just realised while saying this I probably would see a counsellor if someone told me it would help.” Karen
A model of PTG which addresses the processes arising from traumatic experiences that may result in positive life changes (Calhoun & Tedeschi, 2006) builds on the work of Janoff-Bulman (1997) which identifies the incidents of trauma being seismic in nature. The incidents are a channel for spontaneous and invasive rumination (Shakespeare-Finch & Morris, 2010). Rumination and social support are key components of these models. The sociocultural background of each person influences their personal assessment of trauma, may provide social support, and may have the potential to affect the nature of rumination and emotional responses. The model demonstrates how more purposeful the intrusive rumination following a traumatic event becomes. This assists with the development of novel patterns of thought and the life narrative of the person and facilitates PTG for the person and the development of general life wisdom (Alter et al., 1996; Baider & Sarell, 1984; Solomon, Garb, Bleich, & Grupper, 1987). Several participants used their stories to illustrate the concept of PTG. This was evident with Cathy as she described how her battle with cancer was one she would not win. Knowing her treatment options were limited, she had chosen to stop treatment and live as well as she was able; this had been a profoundly difficult decision for Cathy. Yet she spoke proudly of how she was a stronger person since her diagnosis of cancer.

“although I’m battle weary, I know I’m a stronger person for having been through this…” Cathy

Anthony used humour to relate to how he had experienced personal growth after cancer. He had been significantly confronted by having cancer, despising the physical changes he would likely live with for the rest of his life. How he related to the world had changed; he discovered he was more self-aware, increasingly focused on the important relationships in his life and how he communicated his thoughts and feelings.

“…who knew I would be someone who could learn to be more open about my feelings and my life? I have survived so far, so anything’s possible. I hold onto that.” Anthony

8.2.4 Transitioning to a ‘New Normal’

The concept of cancer has undergone a paradigm shift during the last twenty years in relation to the expected trajectory of the disease for those diagnosed with cancer, and the models of care provided. Cancer survivorship continues to
increase due to improvements in cancer screening, earlier diagnosis, and the range of treatments available. Whilst cancer survivorship is seen as a positive side effect of successful cancer treatment (Moser & Meunier, 2014), for the person with cancer, the experience of survivorship can be demanding and perplexing; indeed, a person living with and beyond cancer may find his or herself experiencing survivorship as a burden. The supportive care needed across the continuum of cancer has been described in terms of providing services to people with cancer (Liu, Wang, Wang, Su, & Wang, 2014) or affected by cancer to assist them to cope with a range of needs, including physical, informational, functional, emotional, social, and spiritual needs (Cordova, 2008).

Health care clinicians strive to empower people with cancer to take a pivotal role in his or her care (McCorkle et al., 2011) and this has a synergy with the focus on improving the experience of living with and beyond cancer and reducing the ‘burden’ of cancer for survivors. A vast body of literature has identified that cancer survivors experience symptom burden: the severity and impact of biopsychosocial consequences of cancer and its array of treatments (Macmillan Cancer Support, 2013, 2014a, 2014b). There is also a growing body of evidence that suggests individuals living with chronic conditions such as cancer experience treatment burden: the ‘work’ required of them in managing their condition and its symptoms, and its impact on functioning and well-being (Tran, Barnes, Montori, Falissard, & Ravaud, 2015; Tran et al., 2014).

As one participant in this study explained, the ongoing nature of the procedures required at regular intervals coupled with acute urinary retention led him to feel there was always something happening related to cancer. This was wearing and although Peter was pleased that he was not acutely unwell, the chronic nature of treatment and symptoms was a burden. Components of the burden were the associated travel to Orange and the visits to the local hospital where there were no shared medical records with the private hospital where he had his procedures done. Peter felt frustrated that the onus was on him to tell the medical team at the local hospital about the treatment he had and plans for further procedures. He spoke of the health care system letting him down.
“But from that point on I was, yeah every 3 months I was back up in Orange having the same procedure at the Dudley. And it just went on and on and on. I really came to think that my life would never be the same again – between having blockages and going to the local hospital and regular procedures at Dudley. Up and down the highway which gets pretty draining after a while. And each place didn’t have a record of what had happened at the other place – so again I’m having to tell the story.” Peter

Another burden of his survivorship which was difficult for him related to how he negotiates his way through health care providers and systems with no clear supervision or coordination of his health care. Each health provider appeared to him to be concerned only with components or diseases rather than him as one person with a range of issues to be managed. He had a desire for a lead clinician to guide him, however, feeling unsupported, was left to organise and manage his own health care.

“My big concern now is that it’s difficult to understand who takes the lead role... I see a physician to manage my diabetes, I see a medical oncologist to manage my cancer, I see a urologist to manage my stoma and stuff like that… to me there’s a lack of clarity as to who should take the lead position and how that would be activated. That causes frustration and tension at times for me. So, it’s a cast of players – if I get a new symptom, where am I going with it? Do I wait for an appointment that I’ve got scheduled or do I need to do something sooner? I have to coordinate my health care.” Peter

Living with cancer requires people to cope with and adapt to their symptoms, treatment plan and follow up consultations. Support is needed for people with cancer as they endeavour to minimise the burden of the work of managing their illness. Chronic care literature suggests that patients with chronic conditions are seeking an organised and convenient system of care which provides improved levels of information and communication and this can be readily applied in the cancer setting (Deravin-Malone & Anderson, 2016). This would appear to echo the needs of participants as people with cancer.

Telling the story is important and therapeutic for people and forms the basis for the development of cancer support groups. Support groups function well when people move in and out of the group as needed rather than having a permanent membership. Other avenues are necessary however as not all people with cancer feel comfortable sharing their story and feelings.
“Yeah, so there you go. I’m not who I was, both my body and my mind – more’s the pity! I wouldn’t wish this on anyone; it changes so many aspects of your life, so much more than you ever would think. I haven’t joined a group or anything ‘cause that’s not my thing… I’ve become a bit of a different person – you know, one who thinks about being on parole, and one who is always aware that the cancer could just take off and spread any day it feels like it. It feels good to tell you all this Ruth…I plan to live the best I can until I can’t.” Peter

8.3 Summary

The chaos of a cancer diagnosis is profound and individual, as a person may still be receiving a course of treatment with a planned end date, be living with continual treatment, have completed treatment or find themselves living life after cancer. For the participants, cancer had become more of a long-term search for meaning which resulted in changing their concept of ‘who I was’ to ‘who I am now’. Survivorship is a powerful concept, not only to be thought of as long-term survival; rather, it encompasses the quality of life from diagnosis of cancer onwards; that is, to be able to live with, through and beyond cancer.

This chapter has provided a discussion on a powerful and substantial theme which emerged from the participants. The theme of ‘a new life’ contains myriad facets, from the stressors faced by the participants, the trauma associated with cancer and its treatment and for some, the personal growth he or she had become aware of following the traumas of cancer. The following chapter provides a discussion of the study with the focus on rurality, leading to recommendations in Chapter Ten.
CHAPTER Nine – Discussion: *Impact of Rurality*

The purpose of this study was to explore the lived experience of a cancer diagnosis in the Central West of NSW. This chapter briefly summarises the findings particularly in relation to the impact of rurality. The findings of the study are positioned in relation to the literature review in Chapter Two.

Health care professionals working in cancer care – nurses, doctors, and allied health professionals – strive to offer each person with cancer high quality treatment and care. Despite this, there were significant gaps along the traumatic cancer journey where participants did not have sufficient information, education about their cancer, the plan of care or emotional support. The lived experience of the participants revealed distressing and turbulent times, emphasising the period of initial diagnosis and surgical treatment prior to referral for specialist cancer care, and following completion of treatment. General practitioners and other specialist medical practitioners were key players early in the participants’ cancer journey.

In the previous chapters, the phenomenological approach utilised is presented. This approach focused on examining the lived experience of the participants; achieving that ‘window-view’ into a person’s lived experience of a cancer diagnosis. The participants told their stories of having a cancer diagnosis from the time in their lives leading up to the diagnosis onward. Each participant’s experience is revealed and has been honoured from their standpoint as a human being. Using Moustakas’ (1994) methods and processes to guide me, I began with the key questions: ‘What are the experiences of people with a given phenomenon? And in what context or situations do they experience it?’ (Moustakas, 1994). This second question is particularly pertinent in developing an understanding of differences between metropolitan and regional/rural people in their experience of a diagnosis of cancer. During the phenomenological process the interview data was synthesised and integrated to develop the structure of the experience (Moustakas, 1994) of a cancer diagnosis in the Central West. Clarity appeared through continued reflection; patterns emerged in the research participants’ descriptions of feelings, thoughts, beliefs and behaviours. As discussed in Chapter Five, the patterns and categories which
emerged from the data were clustered into core themes and labelled. The phenomenological approach relies on the participants' firsthand experience of a diagnosis of cancer; therefore, the participants' experiences are reported using their voices.

An understanding of the experience of a cancer diagnosis in the Central West of NSW, as it is lived in the world, emerged through phenomenological analysis and immersion in the data. Despite the differing circumstances surrounding the experience of a cancer diagnosis, I was taken beyond what I imagined this experience to be; acquiring a larger, universal picture of the actual experience of the participants. I shifted from thinking and speaking of 'a cancer patient' to using the language of 'a person with cancer' or 'people with cancer'. As a nurse who has spent 25 years focusing on caring for people with cancer, and now leading the management of specialist cancer services, this was a paradigm shift. There was so much more revealed in the experience and journey of cancer than the components of the cancer journey provided by specialist cancer services. Learning of the impact of the diagnosis in each participant's life was a profound process of appreciating the full trauma and ramifications of cancer.

The existential crisis experienced by participants following the diagnosis of cancer was powerfully expressed through the words each used, from the time of diagnosis onwards. Participants were fundamentally changed by the experience regardless of the outcome of their illness, and clear gaps requiring remediation by health care providers emerged. The need for additional expert nursing support and coordination of care in regional and rural communities, functioning as an extension of primary care, is addressed in the next chapter.

9.1 The Impact of Rurality

Whilst four main themes were identified from the data, the major theme which cut across all was the impact of rurality. This revealed the distinctive consequent issues, challenges and burdens the participants faced following a diagnosis of cancer in the Central West of NSW. Those living in rural and regional locations in NSW, and indeed Australia, face trials and tribulations associated with geographical distance and isolation as part of everyday life. This aligned with the literature relating to rural communities presented in
Chapter Two (AIHW, 2017; BHI, 2016; Dixon & Welch, 2001; Emery et al., 2013; Hall et al., 2004; Jong et al., 2004; McConigley et al., 2011a; McGrath, 2000; Moser et al., 2014; Shepherd et al., 2008). However, for the duration of each participant’s cancer journey there were significant difficulties encountered associated with living in the Central West of NSW which are discussed below.

9.1.1 Cancer Leads to Death

A core component of the existential crisis experienced by the participants was fear of death from the cancer diagnosis, and this contributed to the fear of recurrence of the disease. In modern society, cancer continues to instil fear and a sense of isolation despite how many of the population are affected by it (The Lancet Oncology, 2016). A prevailing perception in rural communities that cancer leads to death was powerfully expressed; witnessing the cycle of diagnosis of cancer and death within communities is potent (Espinosa de los Monteros & Gallo, 2011; Niederdeppe & Levy, 2007; Powe & Finnie, 2003; Schmidt, 2007). For one participant, the only experience of cancer in family or friends was of a long illness followed by an awful death. The stigma of the uncertain nature of cancer was powerfully described by the participants. Not having a reference point relating to survival was particularly difficult and noticeably increased the overwhelming impact and stigma of a cancer diagnosis.

For other participants, the perception that most people with cancer die from it was intricately woven into the context of their experience. This affected how each approached their cancer journey and impacted on interpersonal relationships and communication with spouses, families, friends and health care providers. Despite survival rates from cancer in Australia equalling some of the best in the world (CINSW, 2019c) with seven in every ten people diagnosed with cancer surviving at least five years (AIHW, 2019), the same participants expressed concerns that a diagnosis of cancer was a ‘battle against death’ and not won easily, if at all. A fatalistic perception that cancer inevitably leads to death is endemic in rural communities and other disadvantaged populations (Cohen, 2013; Espinosa de los Monteros & Gallo, 2011; Schmidt, 2007) and this perception has been identified as a barrier to engagement with cancer screening activities, reporting early symptoms and undergoing treatment for
cancer (Powe & Finnie, 2003). Fatalism manifests as feelings of powerlessness when faced with cancer and is seen as a fight for life against overwhelming odds (Powe & Finnie, 2003). For rural people, the concerning statistics of poorer health outcomes and leading causes of death promoted by the media and rural clinicians does not alter the perception of the fatalistic nature of cancer (AIHW, 2019; CINSW, 2019c).

The perception that cancer leads to death (Cohen, 2013; Powe & Finnie, 2003), coupled with the expectation that specialist cancer-related services are traditionally provided in metropolitan areas has been a focus for a range of support from cancer-related charities (Can Assist, 2019; CCNSW, 2019; Leukaemia Foundation Australia, 2019, (LFA)). Considerable fundraising is undertaken by local rural people for local rural people to assist and support them across the cancer journey. This includes financial assistance with payment of treatment-related costs including medications, payment of electricity, phone and internet bills when people with cancer are unable to work and payment of accommodation costs in Orange and metropolitan areas when having radiotherapy treatment. Some charities such as the Leukaemia Foundation provide accommodation units in the city with transport staffed by volunteers to and from treatment centres to support rural people (LFA, 2019). Many of the towns in the Central West participate in the NSW Cancer Council’s *Relay for Life* events where the focus is on team sponsorship to raise funds which are used in the ‘battle against cancer’ and to support local people. Indeed, the widely publicised slogan, “Will you join the Relay for Life movement and fight back?” (CCNSW, 2019) embodies this community held belief of the fatalistic nature of cancer.

One participant, Diane, spoke of participating in fund raising events, but she was not willing to identify herself as a cancer survivor. She felt there was an almost inevitability that her cancer would return. As with Merleau-Ponty’s (1945/2004) concept that we live the world through our bodies, Diane felt that she was now part of the cancer world. She spoke of having an awareness that she could not assume she was a survivor and as discussed in the previous Chapter, had difficulty articulating a label for who she was now.
Accompanying the looming perception of cancer fatalism are the qualities of stoicism and machismo which remain part of the fabric of rural life (Emery et al., 2013; Smith et al., 2008). Outside of ‘sea change’ locations, the socio-cultural nature of non-metropolitan Australia is of older, more traditional and more religious populations (ABS, 2016). Karen described how her background had led to firmly entrenched religious views of life unfolding according to God’s plan, despite no longer considering herself religious. The stoicism expected of oneself was important to her despite having had difficulties coping with a diagnosis of cancer.

“I’m not religious now, but this was part of God’s plan, and as God’s plan, your job is to face it, deal with it, take the pain, take the pain and then get over it. There’s no time frame for things, just you’re over it, when you are.” Karen

A key part of the fabric of rural communities is the language of the ‘battle with cancer’; the formidable challenge to be faced with a fighting spirit. These qualities have not served rural communities well; lower rates of screening and late presentation of cancer at the time of diagnosis are examples. Lack of easy access to services and ability to step away from responsibilities for those on properties are components of this multifaceted situation (Emery et al., 2013). Participants spoke of symptoms they attempted to ignore rather than to seek medical attention prior to diagnosis, which may have impacted on the stage of cancer at the time of diagnosis. Expressions relating to ‘getting on with life’ despite experiencing symptoms, or even a suspicion of cancer, are frequently encountered by medical and nursing teams in Cancer Services in the Central West. Ongoing media campaigns and general practice encouragement to participate in cancer screening activities, including mammograms and the faecal occult blood tests aiming to detect early breast and colorectal cancers have not reversed these strongly entrenched perceptions.

9.1.2 Timely Access to General Practitioners

Participants raised the difficulties relating to timely access to general practitioners at differing times along their cancer journey. Access to consultation appointments was difficult when needed relatively quickly; for three participants there was a need to disclose personal information to reception staff to ‘convince’ the staff of this need, rather than accepting the appointment offered. The appointments offered usually required a one to two week wait, leaving
participants feeling discouraged when seeking more timely appointments. This was described by the participants as both disappointment and concern that the system was unable to support them when needed.

“I started to feel like I needed to plan to get sick or have symptoms which needed the doctor... I couldn’t get appointments easily without having to tell the receptionist that I had cancer and ‘was in strife’. Usually they offered me an appointment in ten days or two weeks’ time. That’s hopeless. I know we have a shortage of GPs out here but goodness me! I don’t know what will happen when things get bad; maybe I’ll have to go to the hospital if the GP can’t see me...” Cathy

General practitioners in regional and rural areas continue to be fewer in number per head of population than in metropolitan areas leading to issues of adequate access for local communities (Access Economics, 2002; AIHW, 2018a; Health Workforce Australia, 2014; Russell, McGrail, Humphreys, & Wakerman, 2011; Russell, 2017). The shortage of general practitioners in rural areas is not unusual and is worse in towns with smaller populations and further distance from metropolitan locations (Wakerman & Humphreys, 2013; Walters et al., 2017).

Additionally, participants worried they were likely to be labelled as ‘difficult patients’ by the practice if they tried to get more timely appointments. This worry led to them referencing the inability to ‘just go to another doctor’ as many rural practices do not accept new patients due to the volume of patients and the small number of doctors. All participants acknowledged the important role of general practitioners, particularly early in the cancer journey. For those with long term relationships with their general practitioner, the guidance offered was particularly trusted and valued. For other participants, the general practitioner consulted at the time of the diagnosis of cancer was someone not previously known which impacted the quality of the interaction and perceived level of any ongoing support.

General practice in rural areas has been evolving over the last decade (Eley, 2016; Health Workforce Queensland and New South Wales Rural Doctors Network, 2008; Russell et al., 2013) from traditional single practitioners or group practices, with stable staffing of medical and support staff and strong relationships between patients and clinicians developed over time, to larger
group practices and medical centres. These larger practices and corporate medical centres frequently have a sizeable part time medical workforce (Eley, 2016; Russell et al., 2011; Walters et al., 2017). With increasing numbers of part time clinicians, there is a substantially decreased likelihood of people with cancer seeing the same general practitioner regularly. Thus, the relationships and attachments formed are different to the historical ‘cradle to grave’ role of country general practitioners (Walters et al., 2017). The lack of a long-term supportive relationship with a general practitioner was identified by participants as contributing to the stress and distress of the diagnosis of cancer. The expectations on general practitioners to provide adequate and appropriate quality information and education to their patients is discussed further in the chapter, within the theme of the thirst for information.

9.1.3 Specialist Medical Practitioners

In addition to general practitioners, surgeons and other medical specialists were considered key players in the cancer journey, particularly in the early phase. These specialists were the initial source of information, surgical intervention and support for participants prior to referral for chemotherapy or radiotherapy which brought them into contact with specialist cancer services. The specialists were discussed as experts in their field, yet the information and education provided to participants was recalled relating to the processes; that is, focusing on ‘what’s next’. The participants all sought information to take home and wanted a holistic understanding of how cancer had taken over their lives, but felt neither were provided. Some participants reflected that the specialists did not have time to provide the information and education they sought and proposed being referred to a single point of contact who could help them.

Following referral from the general practitioner, each of the specialists was visited in their rooms for consultations by participants, except those occurring immediately pre or post operatively; these occurred during the inpatient hospital admission. Follow up consultations also occurred in the specialist’s rooms. Participants who had no previous significant contact with the health care system in Australia found the disjointed nature of ‘the system’ perplexing, preferring the concept of a ‘one stop shop’ for consultations, diagnostic and staging investigations, inpatient surgical treatment and follow up care. Within the fog of
shock and fear of death from cancer, the multiple locations to negotiate along the cancer journey were challenging. Not all imaging services were available locally which added to the complexity of arranging these encounters. Anthony spoke of lacking understanding as to how the ‘system’ worked, asking the wrong clinician for specific assistance. This led him to feel confused and embarrassed that he was unaware of ‘who did what’ within the system as he struggled to cope with his cancer diagnosis.

“I got caught out asking the wrong doctor about how to go about getting the things I needed for my colostomy. I felt stupid that I didn’t realise there was a protocol, if you will, about who looks after what and which things aren’t their job…I found out the surgeon isn’t the person to ask about different options with bags and other stuff. So, then I needed an appointment with my GP to ask about this as I had some issues with the stuff they had set me up with. When I saw him, he sent me off to a nurse who was fabulous, and actually the right person to ask. But it was all a bit of a run around.” Anthony

The participants who spoke of having private health insurance commented on the inability to utilise their insurance to claim the gap payment for consultations in specialists’ rooms, having expected it would have been of assistance. The cost of consultations with specialists in their rooms was raised by two of the participants as they encountered larger gaps than expected between the cost and the rebate from Medicare. The financial cost of cancer fuelled anger for some and is discussed further in this chapter in the themes shock at the diagnosis and grief for the life that’s lost.

The expectation that the specialists needed for the battle against cancer would be local was dashed when told by general practitioners of the need to travel for consultations and subsequent treatment. This is a widespread issue for rural people who don’t have the same access to services as their metropolitan counterparts (Dixon & Welch, 2001; Hall et al., 2004; Jong et al., 2004; McConigley et al., 2011a; McGrath, 2000). Some felt anger that their local area didn’t have the specialist medical services they needed, feeling it was reasonable to expect it. This added to feeling overwhelmed and two participants spoke of the travel required causing them to feel needy, dependent and somehow less of a person than before the diagnosis.

“the up and down the highway to Orange is tiring and needing someone to come with me was really a bit embarrassing … I’m usually the one helping others. But after trying to manage it all myself, eventually I had to ask Community Transport which was a
“bit humiliating. You know I felt less somehow, because I couldn’t manage on my own ...” Len

Others expressed a resigned belief that it was too much to expect local services to meet all the needs of people with cancer. Indeed, one participant, Diane, expressed gratitude that the travel required was only to Orange rather than Sydney. Having had friends who needed to go to Sydney for treatment a few years prior, she felt it was good progress that radiotherapy treatment for cancer was now provided in Orange.

“...the cancer unit at Orange is to die for, they are just so professional... They were amazing and it’s a brilliant facility and it’s in Orange which is fabulous for us.” Diane

9.1.4 Travel for Consultations and Treatment

Much of the participants’ cancer journey involved travel for specialist consultations, surgical procedures and radiotherapy treatment which was challenging and tiring. The emotional impact of the cancer diagnosis made coordinating travel, including the mundane aspect of regularly refuelling the car, far more challenging than participants expected. As people who had previously felt in control of their life, feeling overwhelmed at having cancer dramatically reduced their ability to cope. Some felt well enough to drive themselves early in their journey, which they equated with feeling less dependent and less of a burden on family or friends.

Travel to and from Orange had differing challenges for the participants. For some it was inconvenient and exhausting due to the effects of treatment for cancer, including side effects. To address some of the exhaustion associated with the trip, participants spoke of ways to combat the stress associated with the travel. Two male participants found they were able to drive to Orange, but on the trip back they became very tired. Each had reported the need to pull over on the trip home to eat the snack they had prepared and brought with them, yet this was important as it meant they were able to retain their independence and not need to bother others to assist them.

Len found it was increasingly difficult to manage when feeling unwell or following a procedure, adding to feelings of stress and anxiety. The inability of his wife to drive the distance required, due to a restriction on her licence, led
him to drive them both home despite having had a procedure involving sedation; he had not understood just how debilitated he would feel. He spoke of needing to stop frequently and as he approached home, pulled over and asked his wife to drive. He acknowledged he was exhausted and relieved to have managed to get back without incident. Realising it was not safe, Len decided to contact the community transport provider in his community to arrange transport for future procedures.

“I decided after that I won’t do it again…we were lucky to get back safely. It was a bit of a wakeup call that I can’t manage it all myself.”

Len

Other participants recounted stopping halfway home for coffee and a sandwich each day when travelling to Orange for daily radiotherapy treatment. Despite the necessity, this became a surprisingly social activity for one who generally guarded her privacy. Two other couples were similarly stopping off at a café after treatment. After a week of noticing these same two couples at the café, the participant recalled feeling brave enough to begin a conversation with them as Diane, and her roster of friends who drove her each day during six weeks of treatment, were placing their orders. Being able to chat in a neutral location over a late lunch she felt they were comrades who understood her experience. They disclosed to each other how intensely life had changed since being diagnosed with cancer and the range of treatments required, including radiotherapy. Diane found it unexpectedly supportive to have someone else with a different cancer talk about feeling the same way she did. She had found a new micro community to which she belonged, and this new sense of connectedness was a positive experience during this time. As the weeks progressed, one of the couples was no longer at the café and she learned this was due to completing treatment. Interestingly, she wondered if she should instigate contact with the couple as she had not had the opportunity to say goodbye. Concerns of overstepping the couple’s privacy held her back, yet she felt they had a shared experience of travel and treatment for cancer. Despite the exhaustion associated with radiotherapy which became increasingly unpleasant as the weeks of treatment progressed, these encounters in the café were overwhelmingly supportive during this time.

“I was surprised how much I enjoyed our conversations there; I hadn’t expected to want to chat with other people going through the same thing… And when I learnt they weren’t going to be there again
I really considered making contact, but that would have been too much.” Diane

For another participant, the travel was painful and difficult following surgery, and required medication prior to leaving home to cope with the large pot holes on the unsealed roads for nearly half the trip. As she healed this became less of an issue however, she spoke of continuing to take medication for fear of the pain she had previously experienced returning. She had decided to travel to Orange to attend a breast cancer support group meeting, as she felt this would help her, and there wasn’t one near where she lived. However, she discovered how difficult and painful it was to manage the manual transmission of their four-wheel drive vehicle. Living out of town, four-wheel drive vehicles are a necessity and yet this meant by the time she arrived in Orange the first time, she was teary and did not feel able to speak up at the meeting. She wanted to tell the group that her tears related to the travel over to Orange but didn’t feel strong enough. She waited for another three months before attempting the travel and found this to be less arduous. Despite her difficulties, expressions of gratitude that the trip wasn’t longer, and concern for others who need to travel further, was integrated into the narrative.

“... it was so hard and the pain so intense I can remember it clearly. And I’m not the only one who has to do this. Lots of us living here have to travel for more than just treatment; there isn’t an option if you don’t have what you need where you live.” Pam

Travel for consultations and treatment also impacts on those closest to people with cancer (Mercuri & Kallady, 2005). Despite a preference to undertake the trip independently when it was not available locally, for participants this was not possible due to either treatment-related fatigue or driving restrictions following a surgical procedure. Needing support and assistance resulted in feeling they were a burden on spouse or family and compounded this psychological impact of a cancer diagnosis. One participant spoke of wanting to keep life as normal as possible, which meant he was the one to support others, yet he had to come to terms with this impossibility. He spoke of feelings of being emasculated and demoralised when he needed his wife to accompany him to Orange and then drive him home. He reported this was an aspect of the impact cancer had on their relationship and that it had been difficult for him to navigate.
Concern relating to a spouse missing work on the day of a consultation, or daily for six weeks whilst the participant had radiotherapy, was also raised, as this impacted on both lives. Participants felt they became dependent on their spouse during this part of their cancer journey, which was psychologically demanding, and for those with their own business, financially demanding. A participant spoke of the travel as both distance and a personal challenge. Two participants felt concern for the future: having had a glimpse of the disruption the travel caused in their life, they worried about the impact of travel if their cancer progressed. The travel, the associated fatigue and emotional distress came to represent the unknown difficulties anticipated if the cancer progressed or returned following treatment. One participant felt

“...it’s almost a metaphor for what life will become if things don’t go well with these treatments for the cancer ...you know it’ll be difficult and tiring; well, arduous because I’ll be weaker if the cancer spreads.” Peter

9.1.5 Lack of Communication

The lack of a coordinated communication strategy via a universal electronic medical record added strain and angst for participants along the cancer journey. Attending consultations in the specialists’ rooms and having surgery at the private hospital, both in Orange, meant that only the general practitioners received communication from the specialist relating to diagnosis and treatment. This frustrated participants, led to communication breakdowns and resulted in the participants feeling that they had the responsibility to tell the story of their disease and treatment. This was particularly evident when issues arose requiring urgent intervention via the emergency department of the local hospital after hours. The lack of shared medical records meant having to tell the story of their cancer journey to multiple doctors and nurses. It required a clear head, often during particularly difficult times, to recall the details. This was very irritating, since for one participant the responsibility was extremely stressful when he thought he’d forgotten to report a key piece of information of his cancer journey. Each visit to the local hospital involved a doctor and nurse who hadn’t heard the story previously, leading to ‘story fatigue’ and adding to the burden on the person with cancer to be the conduit for communication.

Two participants spoke of assuming the information would have been in ‘the records’ at the hospital despite not having attended there for consultations or
treatment, likening it to banks and other financial institutions where information is accessible at any branch. The literature relating to burdens associated with a cancer diagnosis identifies disease-related and treatment-related burdens (Gapstur, 2007; Macmillan Cancer Support, 2013; Sav et al., 2013; Sav et al., 2015; Tran et al., 2015). However, in this study, the lack of effective communication processes was an additional burden faced by participants. To reduce this burden, one participant spoke of his ‘cancer diary’. On the recommendation of a friend with cancer, he had diarised all his consultations and treatments, aware of the importance of capturing the events and information gleaned along the cancer journey. His strategy to combat the lack of electronic medical records across the different parts of the health care system was to carry the diary with him on the off chance he would need to provide information if he became unwell and had to go to the emergency department.

So you see, I’ve got this book here, it’s in chronological order, it contains the contents of my conversations with my doctors – what they did and what they didn’t say so I can go back in time, put everything into a timeline … I write in it after every appointment. It’s the only way to keep track of what I need to know…or what the casualty doctor will need to know if I turn up there”. Len

There is a clear need for an integrated electronic medical record for people with cancer. The introduction of *My Health Record* is likely to go some way to addressing this need, however, its success is entirely dependent upon people with cancer participating in the initiative, and all health care providers participating and systematically uploading all aspects of consultations and treatments, regardless of the location of care. At an estimated cost in excess of $1.2 million, NSW has a consumer participation rate of 90 percent (Australian Digital Health Agency, 2019), however, Table 6 below reveals that nationally, there are low rates of health care providers participating.
Table 6: Provider Organisation Statistics – My Health Record

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Practice Organisations</td>
<td>7,100</td>
</tr>
<tr>
<td>Public Hospitals and Health Services</td>
<td>832</td>
</tr>
<tr>
<td>Private Hospitals and Clinics</td>
<td>188</td>
</tr>
<tr>
<td>Pharmacies</td>
<td>4,730</td>
</tr>
<tr>
<td>Aged Care Residential Services</td>
<td>236</td>
</tr>
<tr>
<td>Pathology and Diagnostic Imaging Services</td>
<td>103</td>
</tr>
<tr>
<td>Other categories of healthcare providers including Allied Health</td>
<td>2,750</td>
</tr>
</tbody>
</table>

*Organisation type based on Healthcare Provider Organisation (HPI-O) data, except Public Hospitals and Health Service registrations are reported by jurisdictions. Number of organisations with a cancelled registration are no longer reported, as they cannot interact with the MHR system.

All organisation registration counts are rounded to three significant figures; therefore, some totals may not correspond with the sum of separate counts.

Source: Australian Digital Health Agency, as at 26 May 2019

9.1.6 Mixed Messages

Accessing tertiary specialist teams in Sydney was both reassuring and confusing for a participant due to encountering mixed messages relating to the capacity of local health care services. Having engaged with the tertiary services on the understanding they were the best place to be, referral back to local services was unexpected and worrying. With the community perception that metropolitan health care services are superior to local services, it was unsettling when the experience with such a service was not positive. Indeed, for Sally, it left her feeling unsure of which health care team to trust, which was an additional stress during a particularly difficult time.

“…they told me to stay away from here – they said, ‘you know, for the best chance, you come to Sydney’ and I said, ‘oh OK’. And we accepted that… But now I was meant to think it was ok to have this done (here) rather than Sydney – I mean, I’d rather not have to travel but I’d been told it was what I would need to do… But somehow it sort of felt like a run-around…” Sally

Regional Cancer Centres utilise metropolitan tertiary specialist teams for comprehensive diagnosis and treatment of rare cancers or those where specialised centres of excellence provide best practice care, such as gynaecological, pancreatic and oesophageal cancers (CINSW, 2016). However, for rural people with cancer to receive best care at the most appropriate
location, improved communication, shared multidisciplinary team meetings and care planning with referral mechanisms to and from these centres is imperative, yet not routinely achieved.

When cancer was one of a number of chronic health conditions experienced by a participant, there were challenges as to whom to contact for information or when a new symptom developed. The lack of a clear health care coordinator to communicate with the various medical specialists and general practitioner was difficult and added to the burden of cancer. Unless particularly unwell, there were no plans to visit to the general practitioner, and symptoms and pathology results were not easily categorised according to the medical specialty; many of the ongoing results were applicable to more than one specialist. Peter found that the different specialists and the general practitioner offered conflicting information at times regarding unexpected symptoms or pathology results. He raised not having a health professional who was the single point of contact to provide support as needed and, along with other participants, raised the need for a nurse to contact to discuss issues as a remedy for the situation, with recognition that cancer is unpredictable and leads to ever changing challenges in a person’s life. This need was particularly important to participants in the immediate period following diagnosis, surgery and in survivorship. Once connected with oncology nurses or specialist breast care nurses, participants felt they had a nurse with the knowledge to inform, educate and support them as the journey progressed. This need for cancer nurse coordinators in rural areas is discussed later in this chapter.

### 9.1.7 Financial Cost of Cancer in Rural Areas

Regardless of where someone lives when diagnosed with cancer, there are significant financial costs encountered, including health care costs from pre-diagnosis, initial treatment, and ongoing care to palliative and end of life care (McCaffrey, 2017). The participants found the experience of a diagnosis of cancer involved significant financial costs due to where they lived and where treatment was provided. They acknowledged cancer had a big financial impact on their life, their family and career aspirations. Anthony spoke of his leave entitlements at work providing a safety net as he had not been able to work for long periods when he was unwell following treatment. Having financial
commitments to his ex-wife in relation to his sons, he spoke of how anxious he would be if he was not able to meet those commitments, as it might affect his ability to spend time with his sons. He was aware that for some people in the region this would be a debilitating financial experience if they did not have similar leave entitlements.

Having to divert resources to meet financial costs was identified by the participants as stressful, as was the unknown timeframe of these costs. Fuel for the travel required was identified by participants as the first cost, with reimbursement for travel and accommodation costs through the government funded travel assistance program only covering a fraction of the cost incurred by the person with cancer and their family. It has been identified that the cost of cancer care for a rural dweller can be up to five times that of a metropolitan dweller (Can Assist, 2019) due to the travel and accommodation costs of treatment. Medical specialist and surgical procedures in the private setting were also significant costs with large out of pocket costs for some. This was presented within the context of no known end date for these costs and the anxiety of how this would impact the family financial situation. Cathy spoke of feeling bad when she focused on the financial aspects resulting from cancer however it was an ongoing concern. She spoke of her husband reassuring her that there would always be enough money for her to have treatment even if they had to travel to Orange regularly, yet she worried that the costs were mounting. Part of her concern was fearing that her husband would choose to forgo other things, putting her needs above his. She said this led to feelings of guilt, however, she wasn’t able to raise her concerns with her husband as he always offered reassurance without engaging with her feelings.

“he’s so wonderful but whenever I say I’m concerned about something costing a lot, he always says, ‘it’ll be fine’. Even this lovely electric recliner that’s so comfortable when I have pain, it was really expensive…I feel bad, you know, guilty that we’ve had to spend money on it when our lounge was fairly new and quite lovely. But out here there’s nowhere to hire one like there would be in Sydney.” Cathy

Other financial impacts related to a spouse needing to take time from work, and this was particularly difficult for those who were self-employed; an emotional response describing themselves as a drain on their family was often included. Pam spoke of the family business being the main source of income when she
was unable to continue in her full-time retail role. This was particularly stressful as her husband needed to work longer hours for the family to be financially secure. Each time she needed him to take her to appointments or for treatment, she felt guilty and that she was a drain on the family when he was working so hard to maintain their financial situation.

“...well if he doesn't work he doesn’t earn enough in the business to pay himself. Anytime in the past when there’d been a bit of a downturn, he always made sure the blokes who worked for him were paid first. But without my wage it became really worrying for me... I hated being dependent on him, you know it was more than needing him emotionally.” Pam

Further financial costs raised by participants related to medications, accessing allied health support when there was a lack at the local public hospital, and medical supplies and equipment required as a consequence of their cancer.

9.2 The Shock at the Diagnosis
Shock at the diagnosis was the first main theme, discussed in Chapter Five. Hearing a diagnosis of cancer is a breathtaking event; the shock and devastation changes a person’s life from that moment on. It forces a person to face a critical life situation, leading to an existential crossroads in their life. The feeling of being in a daze was common for participants, as was the inability to process information and participate actively in conversation.

Participants experienced shock in different ways and from differing mind sets. Some reflected on being taken completely by surprise, not even considering cancer as a possibility at that time in their lives. They were left feeling no longer in control of their lives from that moment on. The diagnosis was a terrifying experience; feeling unable to cope for weeks and struggling to focus on what needed to happen next. Even for participants who suspected their symptoms were serious, hearing the word cancer was frightening, instantly leading to existential questions about life and death.

A vivid component of the shock at the diagnosis was the devastating fear of dying from cancer. The fatalistic expectation that cancer causes death, as discussed earlier in the chapter, overlayed the shock at the diagnosis for participants; not knowing anyone who had survived cancer impacted on
expectations when hearing the diagnosis. The truly personal feelings of shock and grief associated with the experiences of a diagnosis were powerful, affected relationships with family and friends and leading to feelings of vulnerability and for some, long term stress.

Participants expressed the unmet need for support, information and education upon diagnosis or as soon as cancer was suspected. Most felt the general practitioners, surgeons and other specialists were professional and expert in their fields, yet for all the participants, none provided the support and information sought. The participants felt they were inadequately equipped to brief their families and friends, as the information provided only related to the next step in the cancer journey – whether that was the next diagnostic or staging investigation or a surgical procedure, they were left without any written information. One participant spoke of trying to remember what he had been told whilst he was driving home from Orange and realising he did not have a lot of information to share, other than the diagnosis of cancer.

Three participants acknowledged that they felt they had not heard much of the content of the consultation after learning they had cancer, and that it was likely more information had been provided than they were able to remember. Two participants spoke of feeling emotionally detached and not able to process information for a number of weeks. For one participant this may have led to the development of a frozen shoulder as she did not recall being educated about it as a post-operative risk. This resulted in the need for private physiotherapy to resolve it. All spoke of receiving no psychological support during this time from any health care professional and, in retrospect, felt this was a significant gap in ‘the system’ where they lived.

_Grief for the life that’s lost_ explored the feelings of grief encountered as a response to the diagnosis of cancer; the knowledge life would no longer be as each had anticipated. The words of the participants revealed the powerful feelings behind this normal response to such a loss, and previous experiences of cancer in others impacted significantly on feelings of grief and loss. Expressing anger and feeling isolated, both common symptoms of grief, were
components of this theme and led to a low mood and an unwillingness to socialise outside the immediate family in the early part of their journey.

Grief for the impact of cancer was a fundamental aspect of the experience. It was bigger than an illness to be negotiated, and wider than how it affected relationships. There was the initial grief for the life they would no longer have and the person they would no longer be. This was followed by anticipatory grief for what could happen, with a focus on disease progression, additional treatment, or learning the cancer would no longer respond to treatment. This anticipatory grief impacted on relationships with their spouses, feeling they would become a burden to the family, and on their ability to engage with family and friends in social situations for a long period after the diagnosis of cancer.

Over time, certain triggers brought the grief to the forefront, often when trying to move on with life. Although described differently by the participants each experienced events or scenarios which brought back the feelings of grief for the life that was no longer theirs. As human beings, adjusting to grief and reverting to normal living in society is considered usual, yet the participants felt fundamentally changed by their diagnosis. The grief experience was embodied by the awareness that they were now no longer the person they had been.

Living with a fear of cancer recurrence was an aspect of life which resulted in feelings of grief. This fear is grounded in the fear of death from cancer and this led to volatile behaviour at times; tearfulness and anger were fundamental components of this experience. Preoccupation with new symptoms and the awareness that this was something which had not been a part of life before the diagnosis of cancer compounded the grief experienced. The fear of recurrence was a powerful and specific fear to live with, rather than just a general uncertainty of the future. Again, the participants spoke of not being offered or referred to any psychological support; they felt unable to initiate seeking support at that time yet were driven to gain information and education about what their cancer meant for their life.

*A thirst for information* resulted from the chaos of the diagnosis of cancer. The need for information was profound and individual; for all participants, this was
strongest in intensity early in the cancer journey, whilst some found they were again seeking information regarding how to live after cancer. At the time of the interviews, participants were at differing stages of the cancer journey. These stages varied from receiving a course of treatment with a planned end date, to receiving ongoing treatment, whilst some had completed treatment and found themselves living life after cancer. This variation impacted on how participants spoke of this need despite it being a common theme for all. People naturally strive to seek information to attempt to gain an understanding of an illness and how to cope. That is, how to live with, through and beyond cancer.

The participants’ stories of their cancer diagnoses reflected it leading to an existential crossroads or crisis. The crossroads or crisis of ‘who I thought I was’ versus ‘who I am with cancer and if I will die as a result of it’, was an overwhelming experience for some. For others it was distressing but an event they were able to cope with. In attempting to gain some level of control over their lives, the need for information became paramount. This powerful drive from within for information was evident, both in the way in which the participants spoke, and the words chosen.

Information was needed about the diagnosis, possible treatment options, and the prognosis for the specific cancer. Other information being sought related to disease relapse, continuing or starting complementary and alternative therapies, financial implications, legal issues and how best to live after a cancer diagnosis.

The ongoing need for information resulted in personal searches from the range of sources available, though at times the participants were uncertain of what they were seeking to learn and how to find it. Information became the instrument by which to find meaning and the ability to carry on with life in the absence of psychological support. This theme encapsulated the insatiable feeling of needing more information to integrate cancer into life now, and to plan the future. In seeking information there was a desire to understand the effect cancer would have on how to live life, and how family and friends would be affected. Alone in the diagnosis and without supportive resources, feelings of
vulnerability powered the *thirst for information* and none of the participants felt this need had been met.

Frameworks for general practitioners in primary care to guide improvements in managing cancer diagnosis focus on improving system and education issues to support early detection and referral to specialist services for people with suspicious symptoms (Mitchell, Rubin, & Macleod, 2012; National Institute for Health and Care Excellence, 2019, (NIHCE)). Components of frameworks in both Australia and the United Kingdom include the responsibility of general practitioners to prepare and educate patients prior to referral to specialist services, the assessment of psychological distress and referral to mental health services if needed (NIHCE, Mitchell et al., 2012; 2019). Whilst this holistic approach would improve the experience of people with cancer, the realities of ten-minute appointments in general practice are unlikely to enable these to be comprehensively adopted by primary care.

The theme of *A new life* involved living with the ongoing fear of recurrence for those whose cancer has responded to treatment and this fear informed choices and decisions in how to live life. The impact of a cancer diagnosis lingers and is multifaceted for individuals; physically, psychologically and spiritually. Reflection on ‘who I am now’ was part of the process of discovering the differences pre- and post-cancer diagnosis. Challenging aspects included grief for the person each no longer was; that naive person without a life-threatening illness that could return at any time. Development of knowledge about cancer and the treatments participants were to have was important and each discussed the type and stage of cancer and prognosis as they understood it, aware that this was fundamental to their life now.

The incredibly stressful nature of a diagnosis of cancer led to feelings associated with PTS for some of the participants, particularly ruminating when trying to get to sleep. Thoughts at this quiet time of night focused on the many possible outcomes of a cancer illness, increasing the stress and strain of living with or after cancer. Those who had been through a protracted process to get to a cancer diagnosis had a greater intensity of experience relating to intrusive thoughts and ruminating on potentially catastrophic outcomes of their illness.
Managing intrusive thoughts led to avoidance behaviours for certain social situations in order to avoid responding to questions about cancer and coping. Acknowledgement was articulated that cancer led to times of desperation and brought tears and feelings of vulnerability which had not been part of life in the past; for most confidence was fragile in a new life. Discovering a new life was not supported by the health care system despite best practice identifying the need for routine psychological support. No participants encountered offers of psychological support prior to being referred for radiotherapy or chemotherapy, nor there had been offers of support for the one participant who had surgery only.

From trauma there was also growth; indeed, an opportunity to reframe identity and priorities in life. Resilience, relationships and focus on accomplishments yet to be undertaken were key components of a new life following a cancer diagnosis. Discussion of feelings was shared by men and women participating in the study, with the men aware that life before cancer did not include being comfortable to talk about their feelings. In fact, the development of wisdom and acknowledgement of the role of their spouse in supporting them sensitively through this ordeal was important. Identifying what was now important in life was a component of this theme; priorities had shifted.

People with cancer grieve for the life they had prior to cancer, with cancer taking control of their lives. For all clinical teams who interact with people with cancer, understanding the feeling of not being in control of your life leading to feelings of anxiety, isolation and low mood, is important. Without support, information and education from nurses and other clinical roles, these feelings escalate.

9.3 The Australian Health Care System
Health care in Australia is a complex system which aims to provide high quality care which is safe and affordable for all citizens. The universal health care system created in 1984 – Medicare – comprises medical care, public hospitals and medications (Biggs, 2016), yet it is challenged by the ageing of the population, high rates of chronic disease, increasing costs of technology,
research and innovation, and the need for improved use of health care data (DOH, 2019).

Funding for cancer care in Australia is a component of the funding mechanisms of the health care system which is complex and involves all levels of government, private health insurers, non-government organisations and individuals, and represents nearly 10 percent of the gross domestic product (DOH, 2019). The $181 billion cost of health care in this country in 2016–17 was funded 41 percent by the federal government, 27 percent by state and territory governments, 17 percent by individuals, nine percent by private health insurers and six percent by non-government organisations.

Whilst the federal government funds most of the medical services via Medicare and subsidised medications, it shares responsibility with state and territory governments for funding public hospitals. The state and territory governments fund many of the community health services across the country, whilst the federal government funds aged care and the health care of veterans (Biggs, 2016).

Health care systems require the crucial qualities of efficiency and effectiveness, integrated with acceptability, accessibility, appropriateness, competence, continuity of care and safety. As demand on the nation’s health care system continues to grow, improving efficiency is vital. All of these aspects are complex, and Figure 4 below illustrates this complexity.
Figure 4: Australia’s Health Landscape

Source: Australian Government, 2019
For rural people with cancer, the complexity of the system is compounded by the unavailability of services in their own community and navigating to where services are available was overwhelming due to inexperience and the psychological impact of their diagnosis. Participants all articulated the need for guidance by an expert nurse who would provide support and information as needed along the cancer journey.

9.4 Cancer Care Coordinators for Rural Communities

There is a clear need for the establishment of community-based cancer care coordinator roles in regional and rural communities to address the unmet needs as identified by the participants. The need for care coordination, support and information for people from the point of a diagnosis of cancer was evident from the data in this study. Participants spoke of feeling isolated, uncertain, and lacking support during this period.

"it shouldn’t be so hard, you know they should say, ‘here’s the name and number of a nurse who can help you through this’. That would have made a big difference to me.” Karen

To be effective, routine referral by general practitioners, surgeons and other specialists for all people newly diagnosed with cancer to a community-based cancer care coordinator would improve the experience of a cancer diagnosis in the Central West. The purpose of the role would be to support people in navigating the health care system, provide care coordination and information, psychological support and function as a member of the cancer multidisciplinary team to ensure integration with specialist cancer services as needed.

“…some guru of a nurse to speak with would be ideal.” Peter

Face to face interactions are not necessary where nurses have the skills to operate in a virtual environment where they are competent and confident to utilise the range of available technological options. For rural areas this would function well, offering efficiency in addition to improved levels of service for people with cancer.

The participants were quick to identify that the missing role would best be filled by a nurse. Nurses have been rated by national and international surveys as the most trusted profession (Lampert, 2016) indicating the respect in which the profession is held. In the last decade, the influence of research and progress in science and technologies on how cancer is treated, and the journey each person with cancer
faces, has had enormous impact on cancer care and treatment (Hebdon, Foli, & McComb, 2015; Rasmussen & Elverdam, 2007; Richer & Ezer, 2000). By embedding community-based cancer care coordinators into primary care to support general practice, support and information would be available to address issues as they arise early in the cancer journey of newly diagnosed people. Providing information when and where appropriate and offering emotional support to those suffering from the shock of a diagnosis of cancer would be beneficial for people with cancer living in regional and rural communities.

9.5 Principles of Primary Health Care

Primary health care is fundamentally a holistic approach to the provision of health care, responding to the social determinants of health (Barnes et al., 1995; Fooks, 2004). As a model of care for communities, identifying and treating illness and disease is not the focus, rather attention is directed towards promoting health and preventing physical and psychological disease (World Health Organization, 2008 (WHO)). Primary health care has its roots in the establishment of the World Health Organization in 1948, with the principles outlined in the preamble to the constitution of the organisation. These principles include acknowledging that health

“is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity ... The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition ... The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health ... Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people ... Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.” (WHO, 2008)

These principles were further articulated in the Health for All agenda set out in the Alma-Ata declaration made during the International Conference on Primary Health Care in 1978 (WHO, 1978) where equity is paramount.

Primary health care principles are well suited, as strategic guidance, to the organisation of health care services, and using them to guide the development and implementation of the role would ensure people with cancer in regional and rural
locations have appropriate, affordable access to support and expert guidance through the complexities of the health care system.

Both the increasing incidence of cancer in Australia discussed in Chapter Two, and the ageing of the population, bring additional challenges for health care services, including a range of pre-existing comorbidities and social constraints, and which are important issues in the impact of cancer diagnosis, treatment and survival. Community-based cancer care coordinators would effectively prepare, support and guide people through services as needed thus improving efficiencies within the system. Utilising screening for distress and partnering with Mental Health services to ensure smooth referral for people requiring additional psychological support and treatment would also be essential to the optimal functioning of the role.

“To be able to phone up a nurse who would know the answers to my questions would have made such a difference.” Len

An additional component of the role would relate to the increasing number of people living with cancer. As mortality rates from cancer decline, for many people cancer has become a chronic condition to be managed and assimilated into their lives, requiring support and education from advanced practice oncology nurses. As discussed in Chapter Two, Norwegian legislation established additional cancer care coordinators in the primary care sector, acknowledging the gap in service. These roles however coordinate services following the plan of care for the person with cancer. I believe the role is required to connect with people as early in their cancer journey as possible, prior to a formalised plan of care, to ensure that support and information would be provided in the crucial pre- and post-surgical interval, and prior to referral to cancer services.

Cancer surgery is regularly considered a key component of a multifaceted plan of care which may include chemotherapy, radiation therapy, hormone therapy or immunotherapy. Multidisciplinary cancer care planning through multidisciplinary team meetings are best practice in cancer care, with the development of a plan of care to deliver the best outcomes for a person with a cancer diagnosis. Experienced cancer nurses are active participants in these discussions, able to advocate for patients and their families as required during the meetings.
The role of advance practice nurses in the care of people with a range of chronic illnesses, including some cancer types, is well recognised and has been integrated into clinical practice at a national and international level. Both the McGrath Foundation and the Prostate Cancer Foundation of Australia have developed clinical practice guidelines to aid in the definition of a best practice model for the Breast Care and Prostate Cancer Specialist nurses within the Australian context. These guidelines build on the Australian Nursing and Midwifery Council Registered Nurse Competency Framework and the National Cancer Nursing Education Project Professional Development Framework for the Specialist Cancer Nurse, as each is acknowledged as best evidence frameworks for nursing practice in Australia.

These clinical practice guidelines recognise the value and importance of the specialist nurse position providing information and support to newly diagnosed people. Indeed, each identify that, where possible, the specialist nurse’s presence at the time the person is given a breast or prostate cancer diagnosis will ensure the development of a therapeutic relationship and well-timed discussion following the patient’s consultation with their surgeon or urologist. If not achievable at the point of diagnosis, it is recommended that the specialist nurse contact the person as soon as possible, to ensure he or she receives adequate support and information during the time when they are likely to be experiencing high anxiety. These specialist nurses also play a vital role in helping individuals with the decision-making process following a diagnosis and remain a key contact person for the patient throughout the care continuum. Building on these existing roles, the community-based cancer care coordinator role would bridge the gap in services from primary care to specialist services, providing expert assessment, support and education.

9.6 Summary
This chapter has presented a discussion of the findings, positioning them in relation to the findings of the literature review in Chapter Two. By positioning my findings within the context of previous research, the findings reveal where they replicate previous knowledge and where they differ. Four main themes and the powerfully cross cutting theme of rurality were brought together into a composite textural description of the experience of a cancer diagnosis in the Central West of NSW. Employing imaginative variation, a composite structural description was
developed. Both the composite textural description and the composite structural description were integrated to reveal meanings and essences. These themes and findings contribute to body of knowledge. The following chapter presents a summary of the thesis, offers recommendations, and recognises limitations of the study.
CHAPTER Ten – Conclusions, Recommendations and Implications

This chapter concludes the thesis and presents recommendations arising from the study. Clinicians working in the health care systems across Australia – general practitioners, surgeons, urologists and other specialists, oncologists, nurses, allied health professionals and other support services – endeavour to ensure people accessing services receive high quality treatment and care. Despite this, the lived experience of cancer revealed by the participants was of a distressing and turbulent time in their lives, from diagnosis onward. General practitioners and other specialist medical practitioners were the key players early in the cancer journey. This chapter begins by briefly revisiting the process and findings of this study which provide the basis for the recommendations.

10.1 Summary of the Study
Each participant’s experience was revealed and honoured from their standpoint as a human being. During the phenomenological process, data generated from the interviews was synthesised and integrated to develop the structure of the experience of a cancer diagnosis in the Central West. Using continued reflection on the data, clarity appeared; patterns emerged in the research participants’ descriptions of feelings, thoughts, beliefs and behaviours. As discussed in Chapter Four, the patterns and categories which emerged from the data were clustered into core themes and labelled. The phenomenological approach relies on the participants’ firsthand experience of a diagnosis of cancer therefore; I placed importance on the participants’ accounts using their voices.

Through phenomenological analysis and reduction of the data, an understanding of the experience of a cancer diagnosis, as it is lived in the world, emerged. Despite the many differing circumstances surrounding the experience of a cancer diagnosis, I was taken beyond what I imagined this experience to be; acquiring a larger, universal picture of the actual experience of those affected in the Central West. I moved away from thinking and speaking of ‘a cancer patient’ to using the language of ‘people with cancer’. This was a paradigm shift from the medical model of cancer to a social model of cancer; that is a person ‘living with cancer’ or ‘living after cancer’. Recognising that the health of an individual is influenced by a
diverse range of factors, social models of health consider individual, relational, societal, environmental, cultural and economic factors. These influencing factors are considered the social determinants of health (Eckersley, 2015; Marmot, 2005; Yuill, Crinson, & Duncan, 2010) which challenge viewing health and illness from biological, physiological and anatomical perspectives. Indeed, the social determinants of health inform perceptions of what constitutes a just and caring society (Eckersley, 2015; Marmot, 2005).

10.2 Synopsis of Findings Informing Recommendations

Shock at the diagnosis was the first of four themes identified and discussed in earlier chapters. Hearing a diagnosis of cancer is a breathtaking event; the shock and devastation changes a person’s life from that moment on. It forces a person to face a critical life situation, often leading to an existential crossroads where the meaning of individual existence is questioned. The existential crisis experienced by participants followed the confirmation of diagnosis of cancer and continued to the day of the participants’ interviews, as powerfully expressed within their new life world. The feeling of being in a daze was common, as was the inability to process information and participate actively in conversation. Participants reported various experiences of shock, and differing time frames for the feelings to resolve.

Grief for the life that’s lost explored the feelings of grief the participants experienced in response to their diagnosis. This theme encompassed feelings of anguish that their lives would no longer be what each had anticipated and hoped for, with heartache over the impact of cancer. This was the formation of understanding that cancer was far more than an illness to be negotiated in this new life world, with profound impacts on family and relationships.

Ongoing feelings of grief resulted from the uncertainty of living with a fear of cancer recurrence. Anxiety and concern about any new symptoms, and the vigilance associated with making decisions about their relatedness to the participants’ cancer had become an ongoing part of life; these were key components of this experience.

A thirst for information was the third main theme revealing the struggle the participants encountered to find order from the chaos of the diagnosis of cancer. Whilst an almost insatiable need for information was primary, a key aspect was the
overwhelming desire to gain an understanding of the illness, the prognosis, and how to cope; that is, the desire to learn how to live with, through and beyond cancer. Aspects of this theme included the lack of a plan of care for participants coupled with a lack of education relating to their specific cancer.

A new life involved developing a construct of the impact a cancer diagnosis had on the participants as individuals; physically, psychologically and spiritually. The participants reported being different as a person following a cancer diagnosis, and all had reflected on these changes, including ‘who am I now?’. The fear of recurrence was a major influencing factor, however physical and emotional changes were all discussed in the context of being fundamentally changed by cancer. This included sadly identifying personality changes, while some found personal growth from the experience.

The theme of impact of rurality cut across all four main themes, bringing out the resulting, distinctive issues, challenges and burdens faced by the participants. The prevailing view that many people with cancer die, coupled with the qualities of stoicism which is also a trait in rural communities, added to the distress and grief of a diagnosis of cancer. Poor access to locally based services resulted in the need for participants to travel for part or all of their cancer consultations and treatment. This led to fragmentation of communication and medical records and exacerbated the physical symptoms experienced by the participants. The impact of rurality revealed the additional burden rural people face when diagnosed with cancer.

10.3 Research Limitations
This study focused on people with a cancer diagnosis up to six years prior to the interviews being undertaken and cast a wide net by not concentrating on any single cancer. The goal was to gain an understanding of the phenomena regardless of the type of cancer participants had, and this was successful. Despite this there are research limitations to this study that are noteworthy. First, and most importantly, is the definition of rurality. Whilst I have specified the context for Central West of NSW, the literature had a wide range of descriptions and criteria to define rural communities, with some not offering a specific definition, thus making comparison difficult.
Next it is important to note that the participants in this study were not representative of the demographics or cancer incidence of the Central West, and differed in cancer stage and treatments, and general health status. Some cancers were represented by only one participant whilst other cancers had representation from multiple participants. Recognising the different treatment trajectories of various cancers, it would be useful to sample rural people with specific tumour types and analyse for differences in themes. Thus, it is difficult to know if the findings are reflective of people with cancer in the Central West – the likelihood that others who did not respond to the call for participants had other significant stories of experience to share. Another limitation is that I have approached this study from a nursing perspective which may not reflect the approach of other disciplines. A final limitation was focusing on the Central West of NSW and therefore it would be beneficial to replicate the study in similar non-metropolitan locations seeking validation of the lived experience. People who chose not to have treatment for a diagnosed cancer were not represented and this is a limitation.

10.4 Recommendations Emerging from this Study

Each cancer journey is a unique, overwhelming subjective experience for both the person affected and their loved ones. People have complex needs during their cancer journey, including but not limited to support, education, navigation of the health care system, and coordination of care. The additional stress and anguish of the impact of rurality exposed unmet needs despite clinical consultations with general practitioners, surgeons and other specialist medical clinicians.

1. Cancer is an inherently stressful experience

Education is required for all health care providers, including nurses, allied health and medical practitioners to more fully understand the stressful nature of a diagnosis of cancer. Throughout this study, it was evident the level of stress associated with a diagnosis of cancer in the Central West was poorly addressed. Health care clinicians need to acknowledge the stress of a cancer diagnosis, within the context of rurality, to enable appropriate assessment of the individual needs of each person with cancer. There is much to grapple with for a person hearing a diagnosis of cancer; including being able to effectively ‘hear’ what is said during consultations. Shock at the diagnosis precludes effective listening and processing of information and does not resolve quickly. Despite inherent differences in people, reassurance by clinicians that feelings of shock are normal
would provide a level of support to a newly diagnosed person, and trigger the opportunity to consider referral for additional psychosocial support.

A component of the stress associated with a diagnosis of cancer is the fear that cancer will lead to death, and this is a particularly prevalent perception in rural areas. Providing support and encouragement through information about treatment options is important and this must be provided in writing, so individuals and their families are able to review it following a consultation. For nurses and other health care practitioners, there is an increased need to listen as well as to inform and educate about what is to come.

People with cancer grieve for the life they had prior to cancer, with cancer taking control of their lives. Understanding that not feeling in control of your life leads to feelings of anxiety, isolation and low mood is important for all clinical teams who interact with people with cancer. Without support and information from nurses and other clinical roles these feelings escalate.

**Recommendation 1** – Development of online and face to face education modules to increase awareness of the inherently stressful nature of cancer and provide a knowledge base for nurses and other health practitioners to utilise in clinical practice.

2. **The Australian health care system is complex**

People require guidance to navigate the health care system. Health care clinicians must acknowledge the complexity of the system for people who are not part of it. From primary care, diagnostic services, cancer screening services and referral to medical specialists in their rooms for consultation through to outpatient hospital-based treatments, effectively navigating the diagnosis – treatment pathway is complex and particularly difficult for those without experience. Some families have experience with the functioning of various parts of the health care system, and manage well, yet for many others, it is challenging and frustrating to attend the range of appointments, let alone ensuring they occur in the correct order, during this stressful time.

Diagnosis can be streamlined or protracted; even tortuous depending on the type of cancer and the presenting issues which trigger the exploration for a diagnosis of
cancer. The range of cancers have differing diagnostic and staging requirements and there is no generic pathway which will function effectively for all people with cancer. There is a need for increased awareness of the time frames for the range of diagnostic tests and specialist appointments and to ensure assistance is offered with coordinating arrangements.

People react differently during stressful periods and require information and financial implications to be explained clearly in order to cope. General practitioners and medical specialists routinely have a limited amount of time to spend with each person; therefore, the consultation is not able to address all the needs of a person with cancer.

**Recommendation 2** – Recognition by general practitioners, surgeons and specialists of the need for guidance through the health care system for people with a cancer diagnosis or potential diagnosis is vital to improve their experience. Widespread education and dissemination of information to people with cancer and their families is necessary to increase recognition. Primary Health Care Networks and specialist medical and surgical colleagues are ideally placed to take lead roles in educating and informing rural communities.

3. **Treatment for cancer is individualised**

People require support and education to understand their treatment plan. From this study it was evident patients were provided with information one step at a time, without additional information relating to possible next steps. Whilst it is important not to overwhelm people with too much information, only providing details of the next step fails to adequately support the person in the interim. Treatments can include combinations of modalities such as surgery, chemotherapy and/or other systemic treatments, and radiation therapy, each ranging from a curative intent to a more palliative approach to care.

In this study, participants sought written information to take home. For people who experience the *shock at the diagnosis*, the ability to remember details can be affected. Participants found this challenging when attempting to share diagnosis details with family and friends. Provision of a general treatment plan which outlines possible phases of treatment is necessary to address the information needs of people with cancer. Ideally this plan would be updated at each consultation to
reflect current treatment and each next step, and include treatment possibilities in the future. The provision of a patient-held, person-centred, customised treatment plan would lessen the impact when referral for additional treatment is required. When these referral discussions occurred, participants found them unexpected and shocking, despite being perceived by health professionals as standard practice for their specific cancer.

**Recommendation 3** – The provision of a patient-held, person-centred, customised treatment plan would equip people with information and decrease the impact when referral for additional treatment is required. Functioning as a living document, people would build a picture of cancer care and treatment relating to their cancer diagnosis, and learn how to live with, through and beyond cancer.

4. **eSupport for people with cancer in rural areas**

   To decrease feelings of isolation and increase education there is a need for virtual, online support for people with a cancer diagnosis in rural communities. Acknowledging the inherently stressful nature of cancer and the complexity of the Australian health care system, coupled with the individualised nature of cancer treatment, people with cancer have a well-defined need for support. Participants were able to obtain information related to diagnostic tests yet expressed the desire for more information and connection with someone to answer questions as they arose. Providing information regarding specific cancers and the range of treatments to people as close to diagnosis as possible would be supportive, providing a map of usual treatment options. *eSupport* would assist with the seemingly insatiable *thirst for information*.

   The opportunity to explore the provision of support via the available sophisticated electronic means accessible in rural areas is vital. Virtual health care (*Telehealth*) is utilised to varying degrees across NSW to reduce unnecessary travel to medical consultations for people in rural areas. There is a need for a virtual service providing psychosocial and informational support; one on one with health professionals and in a virtual group environment. The continuing growth of technology skills in rural communities would enable individuals with cancer to participate in these activities despite their geographical isolation, thereby overcoming some of the challenges associated with rural living.
An American free app for smart phones and tablets/iPads has been developed, based on a popular book, *After Shock: Facing a Serious Diagnosis*, by Jessie Gruman. This book provides a simple roadmap, guiding people through the first days and weeks following diagnosis (Center for Advancing Health, n.d.). Advice is offered on a range of topics including coping with the shock of a diagnosis and specific diagnoses and treatment options. This demonstrates the capacity for technology to support people regardless of location and would form an ideal basis for the development of a similar app suitable for the Australian health care context. The vast majority of the population have embraced technology in other aspects of their lives and would be likely to benefit from such an endeavour.

**Recommendation 4** – The provision of eSupport utilising technology to provide virtual psychological support, information and education would reduce the isolation felt by people with cancer in rural communities and enable efficient use of resources, regardless of location. A guide to cancer, including treatment and care via an app, would assist people with feelings of shock and grief across the cancer journey.

5. **Requirement for the establishment of community-based Cancer Care Coordinators in rural areas**

It was evident from this study that there is a need for a cancer nurse with the experience and advanced practice skills to provide a care coordination role in the community for people in the Central West of NSW. It is imperative that this specialist nurse is available from the point of a diagnosis of cancer, as all participants spoke of feeling isolated, uncertain, and lacking support and understanding during this period.

The establishment of community-based, cancer care coordinator roles in regional and rural areas is vital to improve the experience of cancer. The purpose of the role would be to support people in navigating the health care system, provide care coordination and information, and function as a member of the cancer multidisciplinary team, thereby ensuring integration with specialist cancer services. Implementing for all people newly diagnosed with cancer a routine referral to a community-based cancer care coordinator would improve the experience of a cancer diagnosis in the Central West. Embedding the roles in the community
setting and utilising primary health care principles would support people along their
cancer journey, provide support for those people living with cancer as a chronic
illness, and for those who fear recurrence of cancer.

In the last decade, the influence of research and progress in science and
technologies on cancer, its treatment, and the journey each person with cancer
faces, has had an enormously positive impact on cancer care and treatment.
Community-based cancer care coordinator roles would have strong links with
primary care professionals such as general practitioners. Both the increasing
incidence of cancer in Australia discussed in Chapter Two, and the ageing
population bring additional challenges for health care services, including a range
of pre-existing comorbidities and social constraints which impact on the effects of
cancer diagnosis, treatment and survival. Community-based cancer care
coordinators would effectively prepare, support and guide people through services
as needed, thus improving efficiencies within the system.

An additional component of the role relates to the increasing number of people
living with cancer. As mortality rates from cancer decline, for many people cancer
has become a chronic condition to be managed and integrated into their lives, yet
there is little support and education available. For those living after cancer, the
need for follow up and monitoring of new issues can lead to confusion and anxiety.

As discussed in Chapter Two, Norwegian legislation established the requirement
to provide additional cancer care coordinators in the primary care sector,
acknowledging the gap in service. However, these Norwegian roles coordinate
services following the plan of care for the person with cancer. The nursing role I
recommend would engage with people earlier in their cancer journey to ensure
that support and information would be provided in the crucial pre and post-surgical
interval, prior to referral to specialist cancer services in addition to coordinating
services in accordance with their plan of care and/or follow up.

The role of advance practice nurses in the care of people with a range of chronic
illnesses, including some cancer types, is well recognised and has been integrated
into clinical practice at a national and international level. These guidelines intersect
with the *Australian Nursing and Midwifery Council Registered Nurse Competency
Framework* and the *National Cancer Nursing Education Project Professional*
These clinical practice guidelines recognise the value and importance of the specialist nurse position providing information and support to newly diagnosed people. Indeed, each identify, where possible, the specialist nurse’s presence at the time the person is given a breast or prostate cancer diagnosis will ensure the development of a therapeutic relationship and well-timed discussion following the patient’s consultation with their surgeon or urologist. If this is not achievable, it is recommended that the specialist nurse contact the person as soon as possible, to ensure he or she receives adequate support and information during the time when they are likely to be experiencing high anxiety. These specialist nurses also play a vital role in helping individuals with the decision-making process following a diagnosis and remain a key contact person for the patient throughout the care continuum.

Community-based cancer care coordinator roles would provide holistic nursing care along the cancer journey, as needed by people with cancer to support their differing needs over time. Intense support would be expected early in the cancer journey, followed by intermittent support requirements at other times. Participants in this study encountered challenges as they learned to live through and for some, after cancer, as they became aware of how they were changed by the experience.

**Recommendation 5 a** – The establishment of community-based cancer care coordinator roles in rural areas to bridge the gap in services, commencing with primary care and along the cancer journey to specialist services. These nursing roles would provide expert assessment, support and education to people regardless cancer type. With virtual technology as the vehicle for access to these positions, the geographical challenges of living in rural areas would be reduced.

**Recommendation 5 b** – The development of clinical practice guidelines to guide clinical nursing practice and role development of community-based cancer care coordinator roles in rural areas would ensure consistency for people with cancer, regardless of location.
10.5 Implications for Future Research

Phenomenology, as both a philosophy and an approach to inquiry, was an appropriate framework to choose for this study. The process provided clarity to form an understanding of the lived experience of a cancer diagnosis in the Central West of NSW. The lack of support and information provided, particularly from the time of diagnosis, and the participants’ lack of knowledge of available services outside their location suggest there is significant work to do to raise community awareness.

The findings of this study will offer the health care system the opportunity to accept the need for additional resources and infrastructure to support people in rural areas and enable in improved experience when diagnosed with cancer. Exploration of potential partnerships between the public health care system and non-government organisations to facilitate the development of virtual eSupport services for people with cancer in rural areas would be an appropriate next step. The development of a locally informed app would benefit from a research designed initiative to achieve optimum results.

There are implications for the nursing profession: how nurses within the Australian health care setting can rise to the challenge of providing effective and meaningful support for people with cancer within the rural context. This requires additional recognition and education regarding cancer as a complex, inherently stressful disease entity which requires people to traverse many components of the health care system.

There is also the opportunity for the nursing profession to consider approaches and models of care which embrace the use of virtual technology wherever possible. Challenging current ways of ‘doing business’ to increase efficient, effective use of resources, and equity of access to services and support, requires further inquiry to ascertain acceptability for nurses and people with cancer.

The clear need for community-based cancer care coordinators identified in this study, if established, would be ideally suited to support and guide people from the point of diagnosis of cancer providing information, coordination of care through the health care system and allaying fears and concerns as they arise. Utilising an action research approach to the implementation of these roles would enable the
Critical reflection within a research method to determine the most appropriate model of care and nuances of the role.

Finally, although this study focused on the experience of people with a diagnosis of cancer, this does not occur in a vacuum. The participants described how the experience affected not only them as an individual but was also difficult for their partners and immediate family. Therefore, further research on the impact of a diagnosis of cancer on a spouse or family member, and the emotional needs which arise, is recommended.

10.6 Final Thoughts
This study was focused on understanding the lived experience of a cancer diagnosis in people who lived in a rural area; searching for the meanings and essences of this phenomenon. The study arose from my desire to better understand the experience of a diagnosis of cancer from the time of diagnosis onward. This was important for me as I had the desire to gain knowledge which could be utilised to create positive change in the provision of health care, and in particular, relating this to the nursing profession.

Acknowledging the intersection between culture and personal experience, I chose the Central West of NSW to learn about the lived experience of participants and the impact of rurality. This study led me to make a paradigm shift away from focusing on the medical model of cancer to a social model of cancer by acknowledging the wide-ranging effects this diagnosis has on a person.
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References


Appendices

A. Ethics Approval
B. Participant Information Sheet
C. Consent Form
D. Article in *Bathurst Western Advocate*
E. Questions to Guide Interviews
F. Conference Presentations
10 September 2014

Ms Ruth Jones
Health Service Development
building
Bloomfield Campus
Locked Bag 6008
ORANGE NSW 2800

Dear Ms Jones,

Thank you for the additional information forwarded in response to a request from the Human Research Ethics Committee (HREC).

The CSU HREC reviews projects in accordance with the National Health and Medical Research Council’s *National Statement on Ethical Conduct in Research Involving Humans*.

I am pleased to advise that your project entitled “Factors influencing cancer diagnosis—understanding the lived experience of people with cancer in the central west of NSW” meets the requirements of the *National Statement*, and ethical approval for this research is granted for a twelve-month period from 10 September 2014.

The protocol number issued with respect to this project is 2014/162. Please be sure to quote this number when responding to any request made by the Committee.

Please note the following conditions of approval:

- all Consent Forms and Information Sheets are to be printed on Charles Sturt University letterhead. Students should liaise with their Supervisor to arrange to have these documents printed;
- you must notify the Committee immediately in writing should your research differ in any way from that proposed. Forms are available at: http://www.csu.edu.au/_data/assets/word_doc/0012/963768/Report-on-Research-Project_20130503.doc (please copy and paste the address into your browser);
- you must notify the Committee immediately if any serious and or unexpected adverse events or outcomes occur associated with your research, that might affect the participants and therefore ethical acceptability of the project. An Adverse Incident form is available from the website: as above,

www.csu.edu.au

Last updated: February 2014
Next review: February 2015

Appendices
• amendments to the research design must be reviewed and approved by the Human Research Ethics Committee before commencement. Forms are available at the website above;
• if an extension of the approval period is required, a request must be submitted to the Human Research Ethics Committee. Forms are available at the website above;
• you are required to complete a Progress Report form, which can be downloaded as above, by 14 August 2015 if your research has not been completed by that date;
• you are required to submit a final report, the form is available from the website above.

YOU ARE REMINDED THAT AN APPROVAL LETTER FROM THE CSU HREC CONSTITUTES ETHICAL APPROVAL ONLY.

If your research involves the use of radiation, biological materials, chemicals or animals a separate approval is required from the appropriate University Committee.

The Committee wishes you well in your research and please do not hesitate to contact the Executive Officer on telephone (02) 6338 4628 or email ethics@csu.edu.au if you have any enquiries.

Yours sincerely

[Signature]

Julie Hicks
Executive Officer
Human Research Ethics Committee
Direct Telephone: (02) 6338 4628
Email: ethics@csu.edu.au
Cc: Associate Professor Andrew Crowther & Sally Ann de Vietty Smith

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007)

Approval after further information.doc

Last updated: February 2014
Next review: February 2015
B. Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Factors influencing cancer diagnosis – understanding the lived experience of people with cancer in the central west of NSW

Chief Investigator: Ruth Jones, PhD student
Supervisors:
Dr. Andrew Crowther
Associate Professor
School of Nursing, Midwifery & Indigenous Health

Dr. Sally-Ann de-Vitry Smith
Lecturer
School of Nursing, Midwifery & Indigenous Health

Dr. Linda Goddard
Senior Lecturer
School of Nursing, Midwifery & Indigenous Health

Invitation
You are invited to participate in a research study on understanding the experiences of people from the Central West of NSW with their diagnosis of cancer.

The study is being conducted by Ruth Jones, a PhD student from the School of Nursing, Midwifery and Indigenous Health at the Charles Sturt University and is separate to her work with Western NSW Local Health District. Ruth Jones can be contacted on 0408 618 472. Dr. Andrew Crowther is the principal supervisor for this research and can be contacted on 02 6933 4534. Contact details for the other supervisors are: Dr. Linda Goddard, 02 6051 9134 and Dr. Sally-Ann de-Vitry Smith 02 6933 2605.

Before you decide whether or not you wish to participate in this study, it is important you understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. What is the purpose of this study?
People with cancer who live in rural areas in Australia continue to not fare as well as those who live in the cities. This research project is designed to develop an understanding of the experiences of people with cancer who live in the central west of NSW relating to their diagnosis of cancer. This is new research which will offer cancer care providers and cancer policy agencies a unique understanding from each patient’s perspective. By developing a better understanding of these experiences we hope that improvements can be made in the processes involved in a person receiving a diagnosis of cancer.

2. Why have I been invited to participate in this study?
We are seeking people aged between 18 and 70 who have had a diagnosis of cancer and live in the central west of NSW to participate in this project. Participants need to have had their diagnosis of cancer in the last 5 years and be willing to talk about their experiences.

3. What does this study involve?
If you agree to participate, you will be asked to tell your story, describing your experience during the time you received your diagnosis of cancer.

www.csu.edu.au
CPD Code Provider Numbers for Charles Sturt University are 00905 (NSW), 010476 (QLD), and 005006 (ACT). ABN: 81 078 768 161
Once you have indicated your interest in being involved, Ruth Jones will contact you and arrange a time for an interview. This will involve completing a consent form to provide information on a voluntary basis for the purpose of the project. The interview will last approximately 1 hour and will be digitally recorded to ensure a complete record of the interview. This will then be transcribed. The transcript of the interview will be used for analysis of major themes and will be documented in a PhD thesis. Both the digital recording and the transcript will be destroyed 5 years after the completion of the study. You can request the recording and transcript be destroyed at any time prior to the submission of the PhD thesis.

You have been asked to participate in this study because of your experience of having a diagnosis of cancer.

4. Are there risks and benefits to me in taking part in this study?
There is a possibility that you may become emotionally upset during the interview. You are free to pause the digital recording and/or stop the interview at any time if you do not feel comfortable. You can decide to withdraw your consent at any time. If the interview causes you to become distressed, you can access counselling support from Lifeline Australia on phone number 13 11 14 at any time.

Choosing to participate in the project may be therapeutic. You will be listened to as you share your story and experiences about the time when you received your diagnosis of cancer. The major themes from the information gathered during the project will provide a unique understanding from the patient’s perspective. By developing a better understanding of these experiences it is hoped that improvements can be made to the processes involved in a person receiving a diagnosis of cancer.

5. How is this study being paid for?
The study is being funded by the PhD student.

6. Will taking part in this study (or travelling to) cost me anything, and will I be paid?
You will not be paid for participating in this study. The interviews will be undertaken on the Charles Sturt University campus in Bathurst and there is no cost to participants.

7. What if I don’t want to take part in this study?
Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate is your decision and will not disadvantage you.

If you do decide to participate, you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data, which identifies you.

8. What if I participate and want to withdraw later?
If you choose to withdraw from the project, you can request that your transcript not be included in the project. You can request the recording and transcript be destroyed at any time prior to the submission of the PhD thesis.

9. How will my confidentiality be protected?
The transcript of the interview will be used for analysis of major themes and will be documented in a PhD thesis. To ensure your privacy, it will not contain your name, and any information that could be used to identify you will not be used in the thesis or any articles in professional journals. A copy of your transcript will be made available to you upon request. During the course of the project, all information gathered will be stored in a locked, metal filing cabinet. Both the digital recording and the transcript will be destroyed 5 years after the completion of the study.

10. What will happen to the information that I give you?
Only the major themes which come from the information gathered from participants in this project will be used in Ruth Jones’ PhD thesis and articles in professional journals. To ensure your privacy, your name
will not be used so you will not be able to be identified. Any information or personal details gathered in the course of the project are confidential.

A copy of the transcript of your digitally recorded interview will be available to you as a paper copy if you request it.

11. What should I do if I want to discuss this study further before I decide?
If you would like further information please contact Ruth Jones on 0408 618 472.

12. Who should I contact if I have concerns about the conduct of this study?
NOTE: Charles Sturt University's Human Research Ethics Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:

The Executive Officer
Human Research Ethics Committee
Tel: (02) 6338 4628
Email: ethics@csu.edu.au

Thank you for considering this invitation.
This information sheet is for you to keep.
C. Consent Form

CONSENT FORM

Factors influencing cancer diagnosis – understanding the lived experience of people with cancer in the central west of NSW

Chief Investigator: Ruth Jones, PhD student
Supervisors:

Dr Andrew Crowther
Associate Professor
School of Nursing,
Midwifery & Indigenous Health

Dr Sally-Ann de-Vitry Smith
Lecturer
School of Nursing,
Midwifery & Indigenous Health

Dr Linda Goddard
Senior Lecturer
School of Nursing,
Midwifery & Indigenous Health

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I consent to participating in an interview which will be digitally recorded.

I understand that my personal information will remain confidential to the researchers.

I have had the opportunity to have questions answered to my satisfaction.

Print Name: ______________________
Signature: ______________________
Date: ________________
Cancer patients needed for CSU research project

RACHEL FERRETT

NOVEMBER 13 2014 - 4:00AM

HAVE you been diagnosed with cancer in the past six years?

Charles Sturt University PhD student Ruth Jones is looking for local residents aged 18-70 who have been diagnosed with the disease to participate in a research project.

The aim of the project is to develop an understanding of the experiences local people have had relating to their diagnosis.

"It is really an opportunity to get their stories out there about being diagnosed with cancer," Ms Jones said.

People involved in the study will be asked about their experiences leading up to the diagnosis, including the changes they noticed in their bodies and what prompted them to seek treatment.

They will also be asked about the moment they were told they had cancer.
Ideally Ms Jones would like to see people who are in remission, but those still fighting cancer are welcome to participate and share their experiences.

“In doing the research, reading the literature already available, people have actually spoken about how therapeutic it is talking about it,” Ms Jones said.

Participants can disclose their stories in a very private manner.

Ms Jones is a registered nurse and has a masters degree in cancer research, so she is very understanding and sympathetic of participants’ situations. She hopes to see a minimum of 10 people in the study from a range of ages, genders and types of cancers.

To get involved in the study, contact Ms Jones on 0408 618 472. Consent forms will be provided that explain the process and ensure confidentiality.
E. Questions to Guide Interviews

**Please tell me about yourself so I can get to know you a little**

This question is designed as a non-threatening, conversational way to commence the interviews and to allow for the development of a rapport to commence. This type of question allows a participant the freedom to talk about what is important to them.

**Please tell me about the type of cancer you were diagnosed with**

Again, a conversational opening to enable a participant to feel comfortable to begin to tell their own story in their own words, describing what is important to them.

**Please tell me what else was happening in your life at the time leading up to your diagnosis of cancer**

**Talk me through the process of you being diagnosed with cancer**

**Please tell me about how you were diagnosed with cancer – who was involved and what happened?**

The only further prompts that will be used are those that are designed to assist the participant to explore the situation more fully. For example:

- “Tell me more about ...?”
- “Please give me an example of ...?”
- “What happened next?”
- “What did you feel?”
- “How did that feel?”
- “What did you think?”
- “Please describe that in more detail for me?”
- “What was it like?”
### F. Conference Presentations

|------|----------------------------------------------------------------------------------------------------------------------------------|