

**Exploring the Experience of Recurrence with Advanced
Cancer for People Who Perceived Themselves to Be
Cancer Free: A Grounded Theory Study**

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

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Abstract

Exploring the Experience of Advanced Cancer Recurrence in People Who Perceived Themselves to be Cancer Free: A Grounded Theory Study

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Background: Evolving treatment options for people with cancer mean that increased numbers survive after diagnosis and enter a period where they perceive themselves as cancer free. Unfortunately, some experience a cancer recurrence, which can be at an advanced stage. Their prior treatment experience may influence their approach to this recurrence. New treatments are available to people in this illness stage. This experience is not well understood.

Aim: To describe the experience of advanced cancer recurrence in people who have perceived themselves to be cancer free.

Methods: A constructivist grounded theory approach. Qualitative interviews ($n = 15$) with people living a minimum of 2 or more years cancer free, with an advanced incurable cancer recurrence. Constant comparative method was used with theoretical sampling. Initial coding and focused coding enabled the development of final concepts. Concepts were substantiated using focused narrative synthesis literature review.

Results: An inductively-developed understanding of three interactive concepts: Reluctant Acceptance, Seeking Life Through Continuous Treatment, and Hope in the Face of an Uncertain Future. These describe the experience from diagnosis of advanced cancer recurrence, with initial anger and sadness that the cancer is no longer curable. This shifts to a state of reluctant acceptance, which is a catalyst to seeking life through continuous treatment. Seeking life through continuous treatment creates hope in the face of an uncertain future, which then influences seeking life through continuous treatment.

Conclusion: The experience of advanced cancer recurrence within the context of newly evolving treatment options leads to seeking treatment for advanced-stage cancer that is understood to be incurable but treatable. Seeking life through continuous treatment and hope in the face of an uncertain future are interactively linked to each other, creating a state of personal equilibrium for this population. This study illuminates the ways in which advanced cancer and treatment are perceived by this population. It provides direction for future research, which should focus on testing the model in a variety of settings, and developing understanding about the expectations and needs of people with advanced cancer recurrence.

Key Words

advanced cancer recurrence; continuous treatment; hope; uncertainty; reluctant acceptance; context

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Chapter 1: Introduction to Thesis

1.1 Introduction

Cancer remains the number one cause of death in the United States (U.S.) for people over the age of 60 (American Cancer Society, 2016b, p. 59). But while cancer continues to kill people, treatment options have successfully extended patients' survival rates. Immunotherapy and focused treatments have resulted in a larger number of people living with cancer with high risk for recurrence (Miller et al., 2016).

Defining this population as 'survivor' or 'in survivorship' is a point of controversy, as these terms do not adequately capture the specific population or location and trajectory of their disease (Dirven, van de Poll-Franse, Aaronson, & Reijneveld, 2015). The focus of this thesis is to understand the experience of advanced cancer recurrence in people who believed themselves to be cancer free.

This chapter provides an introduction to the motivation for completing this study as well as historical context for the concepts of cancer survivors and cancer survivorship and the culture of United States (U.S.) health care. This research contributes to the broader discussion around the controversy that exists between healthcare providers and people with cancer using these terms of survivor and survivorship as the sole means for defining this population. Defining this population as survivor ignores the cultural and contextual influence of people with cancer in the U.S.

1.2 Motivation for This Study

As an oncology nurse working with newly diagnosed patients or patients with recurrent disease, I have found that their primary concern is to understand their prognosis and potential for cure. Patients are given 5-year survival statistics, which may give the impression that if they survive 5-years without a recurrence they will be cured of their cancer disease (Deimling, Sterns, Bowman, & Kahana, 2007). Additionally, in the U.S., professional and advocacy organizations have added to the confusion regarding prognosis by defining anyone diagnosed with cancer as a 'survivor' (Hewitt, Greenfield, & Stovall, 2006). As discussed above, this overarching definition of survivor fails to provide a clear description of the target population and a more restricted definition for the purpose of research is needed (Dirven et al., 2015).

My position in the Division of Nursing Research has included training nurses to provide survivorship care and develop Survivorship Care Plans (SCPs) to meet the Commission on Cancer requirements to maintain accreditation. Focusing on long-term effects of cancer and cancer treatments, the potential for recurrence with advanced disease was not discussed even for those with a significant risk for recurrence. Although in my current position I do not provide direct care to cancer patients I have wondered what the response might be for people with cancer who experience a cancer recurrence.

This study aimed to explore the experience of advanced cancer recurrence in people who believed themselves to be cancer free. This central aim was supported by the following 4 questions:

1. What does prognosis or 5-year survival mean to people with cancer?
2. How do people with cancer understand risks for recurrence?
3. What do the terms cancer survivor, or cancer survivorship mean, when patients are seeking treatment, are actively receiving treatment, are in remission, or are dealing with recurrence?
4. How do people diagnosed with cancer recurrence after perceiving themselves to be cured understand this experience?

1.3 Contextual Positioning of This Work

The healthcare system within the United States is funded by four primary organizations: Federal government-supported Medicare for people over 65 years old, Medicaid system for low-income earners without access to employer-related insurance, Veterans Administration health care for U.S. veterans, and the American Indian Health Care coverage for Americans with greater than 1/16th American Indian ancestry. All others must be able to purchase private pay insurance through their employer or pay for it themselves through independent health insurance plans. This study began as the Affordable Care Act was in place, which offered multiple insurance plans at a lower cost that included different levels of coverage and deductibles depending on amount of coverage desired. This is important to understand, as it impacts patients' ability to seek cancer treatments regardless of their disease stage. Drug companies market their drugs directly to the population through television and radio advertisements, which further influence patient requests for medications and influences health care planning between patients and their physicians. Although this access to care will change in the

future as the U.S. struggles to continue to provide this level of care to paying patients, this was the environment in which this research took place.

This environment of cancer care is different than experienced in other countries. In the United Kingdom as in Australia, universal publicly funded health care provides free care to its population and has tight controls on what treatments are possible (Jefford et al., 2013). The potential to allow patients to receive treatments without evidence to back their use in specific situations is seemingly less likely in publicly funded programs.

1.4 Cancer and Prognosis

Cancer remains the number one cause of death in the U.S. for people over the age of sixty (American Cancer Society, 2016b). The estimated number of new cancer cases in the United States in 2016 was 1.685 million for all cancer sites, and there were 595,690 estimated deaths from cancer that year (p. 1). Although survival rates may be increasing, the American Cancer Society (2016b) cautions that they cannot be applied to all people with cancer, as 'treatment, other illnesses, and biological or behavioural differences' (p. 3) will impact individual survival.

Survival is described based on 5-year relative survival rates calculated by the percentage of people who are living 5 years after a cancer diagnosis (American Cancer Society, 2016b). The number of those survivors who are cured, on treatment, or experiencing recurrence is not reflected in that number, as that number is evidencing the people living after a cancer diagnosis but does not specify where in the trajectory they are. Recurrence or cure is relative to disease, stage, and other comorbidities that influence

disease progression, and disease can recur well beyond the five-year mark after diagnosis (Folkesson et al., 2005). The five-year statistics reported in the *Cancer Facts and Figures (2016a)* are developed using the trends reported in the nine oldest reports from the Surveillance, Epidemiology and End Results Program (SEER). Therefore these data were based on people diagnosed with cancer from 1975 through 2012 and a methodology of projecting for 4 years ahead for new cancer cases and deaths. This report provides some insight into the complicated analysis done in an attempt to anticipate cancer occurrence and deaths and the need for better methods to understand survival, recurrence, and death in cancer epidemiology. Probabilities are calculated based on the average experiences in the general population and are not able to include individual risk factors that impact the development of cancer and recurrence. In light of what is known about individual factors that increase a person's risk for developing cancer or influence cancer recurrence, this methodology seems unreliable (Goldman, 1984; Kelly et al., 2013). It contributes to the overall confusion people with cancer experience related to prognosis and risks for recurrence.

This confusion around what recurrence means and how people with cancer experience advanced recurrence was amplified at the onset of my study by limited research focusing on this particular population. At the time of this writing, more research is beginning to focus on the experience of cancer recurrence. A meta-ethnography published subsequent to my literature review looked at patients' experience with cancer recurrence (Wanat, Boulton, & Watson, 2016). The 17 articles chosen described the experience from primarily breast and ovarian cancer participants living with advanced

recurrence. This meta-ethnography helped to highlight the limited amount of research around a deeper understanding of this growing population experiencing advanced cancer recurrence in light of the changes in the evolving treatment context.

1.5 Cancer Recurrence

There are growing numbers of people living with cancer as well as people who have had cancer, received treatment, and continue to face a risk for recurrence. There is less known about cancer recurrence as compared to initial diagnosis but there are data reporting that 1 in 6 people with cancer will recur with advanced disease (Ng & Travis, 2008, p. 1). However, one cannot predict who they will be. There is data that describes potential five-year survival based on disease type, stage, treatment choice, age, and socioeconomic status (Cossetti, Tyldesley, Speers, Zheng, & Gelmon, 2015; Hooning et al., 2006; Soerjomataram, Louwman, Ribot, Roukema, & Coebergh, 2008). For instance, in breast cancer survivors with higher-stage disease and grade there is an increased hazard rate of relapse (HRR) related to higher percentage of HER2 positive and ER-Negative/HER2-negative subtypes which are more-aggressive types of breast cancer (Cossetti et al., 2015). Woman diagnosed at a younger age and premenopausal women have worse early rates of recurrence compared to postmenopausal women who are older at diagnosis (Cortesi et al., 2012; Kneubil et al., 2013). Late recurrence in ER-positive women with breast cancer can occur even after 10 years and there is a spike in early recurrence rates within five years post diagnosis and treatment in ER-negative breast cancer patients (Cossetti et al., 2015).

People with colon-rectal carcinoma experience cancer recurrence dependent also on stage and type of treatment they received as their initial treatment (Camma et al., 2000; Compton, 2002; Glimelius, Gronberg, Jarhult, Wallgren, & Cavallin-Stahl, 2003). A study done to evaluate the overall survival rates and local recurrence rates found that radiation prior to surgical resection provided an increase in overall survival rate and the local recurrence rate benefited from 26% local recurrence without radiation prior to surgery to 9% recurrence in those who had been radiated prior to surgery (Folkesson et al., 2005, p. 5645). Distant metastases for these patients though did not change regardless of radiation and 34% did develop distant metastases as far out as 12 years post-surgery (p. 5646).

The numbers of cancer survivors are growing and as of January 2017 these accounted for 5% of the population in the U.S. (Mayer, Nasso, & Earp, 2017, p. E11). This may be related to the growing numbers of people being diagnosed with cancer as the population is aging and living longer and therefore at higher risk for developing cancer (American Cancer Society, 2016b; de Moor et al., 2013; Gilbert, Miller, Hollenbeck, Montie, & Wei, 2008; Mayer et al., 2017). Sixty-four percent (64%) of all survivors are five or more years post diagnosis (de Moor et al., 2013, p. 561). Recent improvements in cancer treatment and earlier diagnoses of cancer that improve outcomes of treatments all support the growing numbers of cancer survivors, but cancer-related deaths have continued to account for over a half million deaths each year in the United States (American Cancer Society, 2016b; Deimling, Bowman, & Wagner, 2007; Lobb et al., 2015). From first diagnosis to death, people with cancer are facing recurrence and living and dying from cancer

with little research focused on the specific phase of advanced recurrence (de Moor et al., 2013; Ferrell, Munevar, & Sun, 2011). In the United States, these people who have been diagnosed with cancer across all stages of the disease trajectory are all referred to as cancer survivors regardless of their disease status (National Academy of Sciences, 2005; National Coalition of Cancer Survivors [NCCS], 2018).

1.6 Complexity of the Term Survivor

The term 'cancer survivor' is used broadly in the literature to advocate for the needs of all people from the time of a cancer diagnosis, during treatment, across the trajectory of their lives until the time of death (Jefford et al., 2013; Khan, Rose, & Evans, 2012; Mayer et al., 2017; Morgan, 2009). The term *cancer survivor* was introduced by Fitzhugh Mullan, a physician who was also diagnosed with cancer, and the term cancer survivor was promoted by the National Coalition of Cancer Survivors (NCCS) in 1986. The goal of the NCCS was to support people who had cancer and believed a more optimistic label that evoked a positive outcome, and encompassed a developing concept of being a cancer survivor as opposed to early terms like cancer victim or cancer patient (Bell & Ristovski-Slijepcevic, 2013; Deimling, Bowman, & Wagner, 2007; Morgan, 2009). The NCCS (2018), which as an advocacy group was recognising the growing numbers of cancer survivors, was seeking federal funding increases for survivorship research and care. This interest in research funding as well as education of clinicians grew into the survivorship movement which followed the growing efforts in the U.S. to cure cancer (Khan, Harrison, Rose, Ward, & Evans, 2012). The 'war on cancer' was the term used to identify the increased national investment in cancer care promoting earlier

diagnosis, new treatments, and the search to 'cure' cancer (Sporn, 1996). The literal meaning of surviving is related to living through a traumatic event and coming out the other side, but with an expectation that the threat is past and survivorship is permanent (Surbone, Annunziata, Santoro, Tirelli, & Tralongo, 2013). Julia Rowland (2008), as the director of the Office for Cancer Survivorship at the National Cancer Institute in the U.S. stated that being free of disease does not mean the individual is free from cancer. People are living longer after having cancer and professionals in health care recognise that identifying clinical practice concerns and research on this population is needed (Bell & Ristovski-Slijepcevic, 2013; Feuerstein, 2007; Mayer et al., 2017; Surbone & Tralongo, 2016).

The NCCS defines this experience of being a survivor as on a lifespan continuum:

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers (carers) are also impacted by the survivorship experience and are therefore included in this definition (Hewitt et al., 2006, p. 29).

Therefore, anyone who has been diagnosed with cancer and is living with cancer is a survivor. This concept of cancer survivor is related to having experienced the trauma of a cancer diagnosis and the physiological and psychological aspects these people share, which label them as a cancer survivor (Bell & Ristovski-Slijepcevic, 2013; Deimling, Bowman, et al., 2007; Mayer et al., 2017). Dr. Mullan (1985) described the concept of cancer

survivors as related to the phase of cancer survivorship extending from diagnosis, the experience of treatment, then to an extended phase following treatment, and finally a permanent phase which was considered as being cured. The use of the term survivor is complex and the term itself does not provide any insight into who this person who has experienced a cancer diagnosis is. The term survivor is not helpful and may be used to describe someone who has had an early-stage cancer, was treated and cured but also used to describe someone with advanced recurrence who will not have an option for cure. Referring to everyone who has ever been diagnosed with cancer as a survivor is not useful and prevents research from describing clearly who the population is that the research is being applied too. What does survivor really mean?

1.7 Meaning of Survivorship

The term survivorship is meant to include understanding the clinical needs, advocacy, educational needs, and research related to all people living with cancer (Bell & Ristovski-Slijepcevic, 2013; Mayer et al., 2017). The term survivorship relates to the very broad needs of people with cancer as across phases of prevention, screening, rehabilitation, symptom management, palliative care, and end-of-life care (Mayer et al., 2017; Morgan, 2009). The terms cancer survivor and cancer survivorship are often used interchangeably but the concept of cancer survivorship was developed to provide an inclusive term that defines the population of survivors with a generic set of needs. Literature has however documented that there is great diversity in needs for all people living with cancer (Doyle, 2008; Hewitt et al., 2006; Khan, Rose, et al., 2012; Morgan, 2009; Mullan, 1985).

The problem with these concepts is the belief that this label or set of generic needs fits all people who have cancer. Research around the acceptance of the term cancer survivor by the people who have experienced cancer has shown that this term is not universally accepted (Feuerstein, 2007; Khan, Rose, et al., 2012; Mayer et al., 2017; Surbone & Tralongo, 2016). Many people who have experienced cancer recognise its impact on their lives but would rather not be defined by that experience (Surbone et al., 2013). Feuerstein (2007) called for an evidence-based definition but also acknowledged that one definition may not be possible. Doyle (2008) described cancer survivorship as 'unique to the individual but has some universality' (p. 499). Rather than focusing on identifying one definition Khan, Rose, & Evans (2012), highlight the importance of the fight against cancer rather than defining the outcome of the fight. Many people who have had cancer do not support this term that suggests they will not face cancer again, when they are aware that they had advanced disease at diagnosis, and do not believe they are cured (Khan, Rose, et al., 2012). Once diagnosed, whether cancer free or not, the fight is never ending. This is especially relevant in the current context of evolving treatment options. The term can alienate people who do not feel included and may be experiencing multiple side effects, continuing disease or cancer recurrence, and have difficulty in being called a survivor or feeling optimistic (Mayer et al., 2017; Surbone & Tralongo, 2016).

Understanding the concepts of survivor and survivorship as described by early researchers helps provide an understanding of the development of these terms and an attempt to define the needs of people who have experienced cancer under a single general label (Doyle, 2008; Mullan, 1985). Doyle (2008)

described a model of cancer survivorship that includes the attributes and consequences of a cancer diagnosis and includes the positive and negative aspects. These attributes have consequences related to the four domains of quality of life, physical wellbeing, psychological wellbeing, social wellbeing, and spiritual wellbeing. The diagnosis of cancer and the uncertainty that follows can be a life-changing experience that may have both positive and negative effects on the person with cancer. Although Doyle refers to this as 'an individual experience with universality' (p. 505) these attributes are broadly supported by earlier work of Mullan (1985) and continue to be part of the survivorship discussion today (Doyle, 2008, p. 505; Mayer et al., 2017; Mullan, 1985; Surbone & Tralongo, 2016).

People with cancer do experience general phases related to where they are in the continuum process from diagnosis with cancer through an acute phase related to diagnosis and treatment, and an extended phase that follows treatment (Mullan, 1985). This post treatment period includes remission and relapse or a permanent phase that is termed 'long-term survivorship', which includes late effects of disease or treatments and a continued risk for second cancers or distant metastasis. So there is a sense of the universality of phases of the continuum, but the point of the terms being used remains confusing and only seems to muddy the water.

Certain cancer diseases have a greater potential for long-term survival than others; for instance the long-term survival rate for thyroid cancer and germinal testicular cancer are greater than 90% (Surbone & Tralongo, 2016, p. 3373). This is in sharp contrast to other cancer diseases such as pancreatic cancer

or lung cancer, which have a much lower chance of long-term survival. It is important to note that none of these descriptions of phases of survivorship include the final phase of end of life (Doyle, 2008; Miller, Merry, & Miller, 2008; Mullan, 1985; Surbone & Tralongo, 2016), which correlates with the literal meaning of survivor or survivorship implying that permanent cure is achieved. The early years of the evolving survivorship movement created language to the point of the choice of those words advocating for a future where a cancer diagnosis did not mean death.

As researchers have begun to conduct qualitative studies to understand how the individual experiences cancer, new perspectives on defining this experience have been revealed (Khan, Rose, et al., 2012; Surbone et al., 2013). The many meanings around the concepts of survivor and survivorship have been described by multiple researchers (Mayer et al., 2017; Miller et al., 2008; Mullan, 1985; Surbone et al., 2013). The lack of clarity remains a barrier in the clinical and biomedical research of survivors and survivorship today (Surbone & Tralongo, 2016). There is a need to categorise the specific context of the population of people with cancer being studied to improve the understanding of prognostic indicators around recurrence as well as other needs of long-term cancer survivors (Bell & Ristovski-Slijepcevic, 2013; Surbone & Tralongo, 2016). There is a need for research to explore very distinct phases beyond a cancer diagnosis, beyond a generic label, or single umbrella that focuses on the universality of this shared experience (Doyle, 2008, p. 502; Mayer et al., 2017; Surbone & Tralongo, 2016).

This early history of the cancer survivorship movement is provided to help establish the importance of describing this study's specific population and the perspectives of people with cancer who thought they were cured, but now experience recurrence of advanced disease. Although supporting people with cancer with optimism and hope is important, there may be better ways to provide care and support needed. Understanding how a specific disease, individual risk factors, and prognosis with different diseases impacts advanced recurrence can provide information for a specific population that is not well understood (Mayer et al., 2017; Surbone & Tralongo, 2016).

1.8 The Research Focus

The problem for this research is focused on describing a period of time that is experienced by people with cancer along the continuum of living with cancer. This study aims to capture a specific moment in the disease trajectory of people with cancer who experience advanced cancer recurrence after perceiving themselves as cancer free at a time when treatment options are evolving for people with advanced cancer. It will provide meaning and insight into this specific moment of time marked by evolving treatment options, and give insights into factors this population is focused on. Therefore, understanding the experience from the participants' voice is important and finding a method that allows an interactive process to develop their meaning of this experience is needed.

1.9 The Aims of This Study

The aims of this study are twofold:

1. to describe the experience of people with cancer who have been cancer free for an extended period and believe themselves to be cured and recur with a diagnosis of advanced cancer, and
2. to develop a conceptual model that will provide a deeper understanding of this specific experience of advanced cancer recurrence in people who perceived themselves to be cancer free in a context of evolving treatment options, and guide future research.

1.10 Thesis Outline

The structure of the thesis is outlined below.

Chapter 2: Methodology/Methods describe, the methodology of the study and the rationale for choosing a qualitative approach for this research. It describes the method chosen and also elaborates on the constructivist grounded theory approach and clarifies the reasons for a delayed literature review. It provides a description of the general process used per constructivist grounded theory to develop the subcategories, categories, and conceptualisation of the conceptual model

Chapter 3: Findings describes the findings related to the participant interviews and the conceptualisation of the meaning of advanced cancer recurrence in people who perceived themselves as cancer free. As this is a constructivist grounded theory method, data analysis occurs simultaneously with data collection. The newly developed conceptual model is introduced in preparation for the next chapter using a diagram that visualises the conceptual process.

Chapter 4: Literature Review offers a review and synthesis of the literature in relation to the concepts identified within the conceptual framework developing from the constructivist grounded theory method. This is a focused review to substantiate the developing conceptual model related to this specific population of people experiencing advanced cancer recurrence after believing themselves to be cured.

Chapter 5: Discussion/Conclusion describes the conceptual model as substantiated by the literature review. Related concepts provide support for the conceptual model of Reluctant Acceptance of Living with Advanced Cancer Recurrence. A diagram of the conceptual model is provided. Strengths and limitations of the study, as well as implications and recommendations for future research, are included. A conclusion is presented to provide final thoughts related to the study's contributions to the fields of palliative care and cancer survivorship.

1.11 Summary

Significant improvements have been achieved in cancer treatments which have resulted in the rising number of survivors and prolonged lifespan trajectory. These advances have impacted the person living with cancer's perceptions of late-stage cancer and recurrence as well as treatment decisions. Greater understanding is needed about this specific point along the disease trajectory in order to advance understanding and improve the quality of care for patients living with cancer and their families. Additionally, defining the population of people who believed themselves to be cancer free and then recur with advanced disease will help future researchers accurately describe

the population of focus without depending on data referring to a generic set of people with very different trajectories for their future.

This chapter has identified the confusion associated with the meaning and use of the terms cancer survivor or survivorship (Bell & Ristovski-Slijepcevic, 2013; Feuerstein, 2007; Surbone & Tralongo, 2016). In an effort to clarify the exact population that this research is focused on, the term cancer survivor is not used. This population is referred to as 'people living with advanced cancer recurrence'.

Chapter 2: Methodology and Methods

2.1 Introduction

This chapter describes the methodology and methods selected to answer the research question: What is the experience of people with cancer when they are diagnosed with advanced cancer recurrence after a period of time where they considered themselves to be cancer free?

As indicated by Bryman (2008) and Lincoln, Lynham, & Guba (2011) using a particular methodology helps to frame the study and supports the research data-gathering and -analysis to achieve meaning and significance. A qualitative constructivist grounded theory methodology was adopted, and is justified and explored within this chapter, including a rationale for delaying the substantive literature review until after data collection and analysis.

Two things were especially important in the planning of this study's method:

1. the ability to allow the participants' voices to be heard in relation to this experience of having believed they were disease free and subsequently having advanced cancer recurrence; and
2. the development of a conceptual model that represents the participants' experience with advanced cancer recurrence after having believed they were cancer free.

2.2 Methodological Overview

Planning and conducting a research study to explore patients' experiences with advanced cancer recurrence after having believed they were cancer free requires a thoughtful selection of research method. The various approaches of

qualitative or quantitative methods bring about different perspectives and produce different knowledge about a topic of study (Seale, 1999; Whittemore, Chase, & Mandle, 2001). Establishing the specific approach to be followed allows the study to be systematically developed and maintains the transparency of the process, all the while supporting trustworthiness and credibility, which then ensures truthfulness of the study (Bryman, 2008; Caelli, Ray, & Mill, 2003; Whittemore et al., 2001).

2.3 Paradigms That Guided This Inquiry

In research, there are key paradigms that guide the method of inquiry and the methodology supported by the researcher (Polit & Hungler, 1991; Seale, 1999). Paradigms are 'sets of beliefs and practices, shared by communities of researchers which regulate inquiry within disciplines' (Weaver & Olson, 2006, p. 459). Paradigms guide a researcher's approach to science (Denzin & Lincoln, 2000) and are sets of 'philosophical underpinnings from which specific research approaches flow' (Weaver & Olson, 2006, p. 459) (e.g. qualitative or quantitative methods).

Paradigms consist of the following: ontology, epistemology, and methodology (Denzin & Lincoln, 2000; Lincoln, Lynham, & Guba, 2011), which are explained below, and raise the following set of questions:

1. Ontology: What is the relationship between the researcher and knowledge? And how is that knowledge justified?
2. Epistemology: What is the nature of knowledge or reality?
3. Methodology: How should the inquirer go about choosing a research design?

Table 1 Paradigms of Research, below draws on five paradigms of research described in Denzin & Lincoln et al. (2011), and aims to establish the relationship between different paradigms of research, and the objectives of this proposed research (p. 100). Denzin & Lincoln list a number of general descriptors for each paradigm for researchers to use to provide a framework for choosing the epistemological stance that best supports the aim of this study: positivism, post-positivism, critical theories, constructivism or interpretivism and participatory (Gibson, 2017; Lincoln et al., 2011; Tuli, 2010). The methodology chosen by a researcher is determined by the researcher's position within these paradigms (Guba & Lincoln, 1994; Lincoln et al., 2011; Tuli, 2010).

Positivism applies natural science to the study of social reality. The positivist paradigm offers a 'scientific explanation' (Tuli, 2010, p. 99) of behaviour, which is the product of empirical information that exists independent of human construction. Positivists maintain that knowledge is objective and is best described in experimental studies and quantitative methods of observation and data collection (Bryman, 2008; Ulin, Robinson, & Tolley, 2005). From the ontological perspective, a positivist approaches research to either nullify a hypothesis or prove it. There are established facts or laws that are believed to be present. From the epistemological perspective, empirical information exists independent of human construction. Therefore, the appropriate methodology for this paradigm would be experimental and focused on verification of a hypothesis. As this current research study is not hypothesis-driven, and understands the relationship between the research and knowledge to be a human construction of meaning, this study does not conform to a methodology

Table 1

Paradigms of Research

Paradigm	Positivist	Post-positivist	Critical theories	Constructivist (or Interpretivist)	Participatory
Ontology	<p>Verified hypothesis; established facts or laws</p> <p>* Research aims hypothesis-driven, therefore not congruent with this study's aims</p>	<p>Nonfalsified hypotheses that are probably facts or laws</p> <p>* Research aims hypothesis-driven, therefore not congruent with this study's aims</p>	<p>Structural/historical insights; reality shaped by social, political, cultural, economic, ethnic, and gender values</p> <p>* Research aims are value-based, therefore not congruent with this study's aims</p>	<p>Individual relativism and specific co-constructed realities</p> <p>* Research aims allow co-construction of the participants' meaning and is therefore congruent with this study's aims</p>	<p>Primacy of practical knowing; critical subjectivity; living knowledge</p> <p>* Research aims maintain constructivist/interpretivist traits but broad interpretation related to changing the world, therefore only somewhat congruent with this study's aims</p>
Epistemology	<p>Empirical information that exists independent of human construction</p> <p>* Research aim does not account for human construction of meaning, therefore not congruent with this study's aims</p>	<p>Knowledge is absolute and external</p> <p>* Research aims consider knowledge absolute and objective, therefore not congruent with this study's aims</p>	<p>Knowledge is subject- and value-driven</p> <p>* Research aims impose a critical structure and therefore not congruent with this study's aims (it is more explorative in nature)</p>	<p>Knowledge is contextual, subject, and, co-constructed</p> <p>* Research aims are congruent with this study's aims</p>	<p>Knowledge is subjective but produced for the purpose of impacting world change</p> <p>* Research aims are somewhat congruent with this study's aims (this study is not meant to change the world)</p>

Paradigm	Positivist	Post-positivist	Critical theories	Constructivist (or Interpretivist)	Participatory
Methodology	Experimental/ verification of hypotheses; primarily quantitative methods * Research aim quantitative in nature, therefore not congruent with this qualitative study's aims	Modified experimental; hypothesis may include qualitative methods * Research aims quantitative in nature and hypothesis-driven, therefore not congruent with this qualitative study's aims	Dialogical, relating to the values described in the dialog of the researched * Research aims transformative and activist, and therefore, although qualitative in nature, it is activist- driven and therefore only somewhat congruent with this study's aims	Qualitative methods are hermeneutical—naturalist perspective and interpretive understanding of the human experience. The researcher's perspective voice helps decide the qualitative method to use: Voices may be mixed with participants, or researcher may not want to provide any direction to the participant's experience * Research aim reflects the focus of this study and is therefore congruent	Self-reflective, qualitative, and experience-driven; political participation in collaborative action inquiry from a shared experiential context * Research aims are political in nature, intent on changing the world and therefore somewhat congruent with this study's aims

Note. Adapted from “Paradigmatic Controversies, Contradictions, and Emerging Confluences, Revisited”, by Y. S. Lincoln, S. A. Lynham, & E. G. Guba, 2011, *The SAGE Handbook of Qualitative Research* (4th ed., p. 100).

* Implication on the aims of this study.

for a positivist paradigm. *Post-positivists* do not agree that knowledge is absolute and only external and data-driven (Gibson, 2017). They begin to consider the qualitative aspect of understanding the relationship between the researcher and knowledge. What makes them different than the interpretivist/constructivist approach is they do not agree with co-construction of knowledge with others or the significance of context (Gibson, 2017).

The *critical theories* paradigm is focused on oppression or power struggles that may shape the reality of a situation from a social, political, cultural, economic, ethnic, or gender perspective (Lincoln et al., 2011). As this research is not value-based, seeking to understand the overall value or meaning is not congruent with the aim of this study.

A *constructivist* or *interpretivist* approach focuses on symbolic interactionism and places significance on the context of the participant as well as the researcher in understanding the meaning of the researched phenomenon (Altheide & Johnson, 2011). It includes co-constructed realities contextually and subjectively interpreted to describe the phenomenon. This tenet is congruent with the aim of this research. Moreover, it is a methodology that allows the flexibility and depth of the participants' voices to be explored in order to understand the meaning of their experience.

And finally, the *participatory* paradigm is an approach that understands knowledge is the product of an active human mind, engaged with the world. This paradigm approaches inquiry with the intent of changing the world. As such, the process of gathering information includes a constructivist understanding of how knowledge is understood, but the outcome of the

participatory paradigm has a social advocacy element to it. It seeks to place a meaning of the experience relative to the larger world. This element extends beyond the aim of this study, which is focused on understanding the experience of a specific phenomenon from the participant's point of view, and not in relationship to the broader experience as it interfaces with society or the world (Lincoln et al., 2011).

Having selected a constructivist focus, choosing a research design that allows a co-construction of the experience under study in order to explore this phenomenon from the participant's words was necessary (Charmaz, 2006; Mills, Bonner, & Francis, 2006). *Co-construction* is a process that allows the researcher to be involved in the exploration of a phenomenon and conceptualise an abstract understanding of the phenomenon from the participant's words (Charmaz, 2014; Holton, 2007). Developing knowledge requires an active process of hearing, understanding of information, and co-constructing the meaning of the phenomenon as exchanged between the researcher and the participant's words (M. M. Braungart & Braungart, 2018; Mills et al., 2006).

2.4 Choosing an Appropriate Research Design

Based on the above descriptions and my understanding of the constructivist impact on knowledge development, a qualitative methodology that provided for the participant's experience to be deeply understood was selected. The interactive co-construction of the participants' understanding is an important aspect of this research, and supports the aim to explore and understand this defined period during the cancer trajectory by collecting information from the

participants through open-ended dialogue. A qualitative approach allows an understanding of this complex human experience and provides the ability to put that into words (Richards & Morse, 2000; Silverman, 2000).

2.4.1 Qualitative approaches considered.

As described in Denzin & Lincoln (2011), the reality of qualitative research includes multiple interpretive practices. How the researcher sees the development of knowledge and the type of data considered to research the phenomenon of interest will decide which qualitative method is most appropriate. Different qualitative designs were evaluated for their support of this research study (Bryman, 2012; Charmaz, 2014; Creswell, 2014; Mason, 2002). Table 2 considers thematic approaches, ethnography, phenomenology, grounded theory, narrative methods and case study in relation to their potential utility to the research question.

As the focus of this research study is to explore this experience for people with cancer recurrence at the specific transition from believing themselves to be cancer free to advanced cancer recurrence, the interactive process of co-construction allowed the participants' words to provide meaning for their experience. All of the qualitative methods described above include the same interpretive design focus but vary in terms of how the phenomena are described, how the meaning is understood by the researcher, and whether there is a theoretical framework identified from the outset of the research. Grounded theory, which demonstrates the greatest congruence with the research question, allows meaning to develop as theoretical sampling and constant comparative analysis takes place and specifically does not start with

Table 2

Potential Qualitative Approaches Related to the Research Question

Research question:

What is the experience of people with cancer when they are diagnosed with advanced cancer recurrence after a period of time where they considered themselves to be cancer free?

Description	Thematic approach	Ethnography	Phenomenology	Grounded theory	Narrative methods	Case study
Overview	Provides the primary themes identified by the participants	Provides an ethnographical understanding of the population studied; allows researchers to immerse themselves in the social setting to observe behaviour and listen to conversations	Attempts to understand the lived experience; uses deductive reasoning to describe the experience	Attempts to understand the meaning of the phenomenon, inductively allowing participants' stories to unfold; through constant comparative analysis, the researcher co-constructs the meaning with the participant	Attempts to understand how people temporarily make sense of their experiences	Intensive analysis of a single case that provides complex details about the nature of the case being observed; it can be a single community, a single family, a single organization, a single event, or a single person

Description	Thematic approach	Ethnography	Phenomenology	Grounded theory	Narrative methods	Case study
Utility related to this research	May have utility, but does not provide the in-depth ability to explore the meaning of the experience	Utility limited for this study as it is focused on observation and analysis of the conversations and does not include the co-construction of the meaning of the experience	May have utility but also does not allow the co-construction of the meaning of the experience	Has utility, as it allows the in-depth understanding with constant comparative analysis and co-construction of the meaning of the experience	May have utility, as it recognises the context of the participant's story-telling but does not include the co-construction of the meaning of the experience	Little utility, as it is limited to 1-3 cases for comparative purposes, and would not allow the ability to provide an in-depth understanding of the experience of this population

a theoretical framework but seeks to inductively develop one from the data (Charmaz, 2014).

2.5 Grounded Theory

As noted above, the planning of this study's method involved two distinct but related steps: (a) The ability to allow the participants' voices to be heard in relation to their experience of having believed they were cancer free and subsequently having advanced cancer recurrence, and; (b) to be able to develop a conceptual model describing the participants' meaning of this experience. So while grounded theory, as Charmaz (2014) has pointed out, 'has had a long history of raising and answering analytic "why?" questions in addition to "what?" and "how?"' (p. 228), in this study my intent is to explore specifically the 'what?' and 'how?' questions, rather than moving into an exploration of analytic 'why?' questions. As such, by asking participants to voice what they are experiencing and then proceeding by constructing a conceptual model that reflects how the participants' experiences interrelate and are shared, my study constructs a broader conceptual understanding that rests on the interrelationship between the categories of the experiences voiced by the participants.

Grounded theory is an approach to qualitative research that provides a framework for social research based on symbolic interactionism (Glaser & Strauss, 1967). *Symbolic interactionism* provides a theoretical perspective whereby people construct themselves, reality, and society through interactions (Altheide & Johnson, 2011). It is an active, dynamic process where people develop and modify meaning through constant comparative analysis and

theoretical sampling (Charmaz, 2014; McCann & Clark, 2003). By categorizing the experiences of the participants and then conceptualizing how these categories of experience interrelate, this study follows the inquiry model set up by grounded theory. Grounded theory seeks to provide a description of a situation that conceptualizes the participants' perspective through the inductive organization of the data provided and co-construction by the researcher (Morse, 2001; Timmermans & Tavory, 2012). As noted by Charmaz (2012) the grounded theory method, 'begins but does not end with inductive inquiry, it is a comparative, iterative, and interactive method' (p. 2). This method provides a framework that allows both the methodology and methods of the research study to work together.

According to Glaser & Strauss (1967), traditional grounded theory's goal is to understand the meaning behind human behaviour. Where ethnography is the observation of interactions, grounded theory methodology provides empirical insight as described directly by the participant (Charmaz, 2012; Timmermans & Tavory, 2012).

Grounded theory allows the researcher to consider a relationship between various categories to conceptualise the experience and provide a conceptual model related to the phenomenon (Burns & Grove, 2001; Charmaz, 2014)

2.5.1 Different perspectives of grounded theory.

Grounded theory has broadly developed into three approaches: traditional, evolved, and constructivist grounded theory (Mills et al., 2006). Traditional grounded theory was developed by Glaser & Strauss (1967). Strauss & Corbin (1997) developed the evolved version and, most recently, Charmaz delineated

constructivist grounded theory (Charmaz, 2006; Glaser & Strauss, 1967; Mills et al., 2006; A. Strauss & Corbin, 1997). Table 3 provides a comparison of the three approaches to grounded theory and a description of the epistemology, ontology, sampling, and coding processes for each.

Table 3

Comparison of Grounded Theory Approaches

Qualitative research criteria	Glaser & Strauss (1967) (Traditional)	Strauss (1987) / Strauss & Corbin (1990) (Evolved)	Charmaz (2006, 2014) (Constructivist)
Epistemology	Positivism	Less-positivistic-interpretivist	Interpretivist
Ontology	Objectivist	Constructivist	Constructivist
Sampling	Theoretical sampling	Theoretical sampling	Theoretical sampling
Sampling method	Interview and observations Literature review to support emerging theory	Interview and observations Limited literature review to enhance theoretical sensitivity	Interview and observations Literature review related to newly developed conceptual model
Coding approach	Constant comparative method Inductive, verification Open-coding Core categories Theoretical memos	Technical procedures-preconceived categories Constant comparative method Deductive, inductive, verification Open-coding Axial-coding-relate categories-sub-categories Selective-coding Hypothesis testing Theoretical memos	Interpretative rendering co-constructed synthesis Constant comparative method Initial word by word, incident to incident Focused coding, sifts, sorts, synthesizes, and analyses Inductive, verification Theoretical memos

There are methods used that are essential for a study to be called a grounded theory study (Birks & Mills, 2011). Glaser & Strauss maintain that the data

inductively guide the research (Glaser, 1978, 1992; Glaser & Strauss, 1967). Strauss & Corbin (1997), however, maintain that the researcher applies deductive verification to create themes and categories that arise from patterns in the data. Using induction, deduction, and verification as part of the research process, the researcher continuously refines the categories based on each participant's data (Glaser & Strauss, 1967; Heath & Cowley, 2003; A. Strauss & Corbin, 1990).

A. Strauss & Corbin (1997) propose that Glaser's process may not allow new information to emerge. In contrast, Glaser argues that Strauss's & Corbin's use of guiding questions may force the data in a specific direction (Glaser, 2001). Table 3 provides a comparison of these methods with some detail into the coding components. An essential piece of this review was to clarify the epistemology and ontology of the approaches. This research aims to understand in depth the meaning of the experience of advanced cancer recurrence from the participant's words and co-construction with the researcher. The interpretive process of conceptualisation used in the constructivist grounded theory (CGT) method as co-construction of the meaning provides a methodology that allows a verification of concepts through theoretical sampling and memoing that goes beyond the classic method of Glaser & Strauss (1967) or Strauss & Corbin (1997). Therefore, using classic Glasarian grounded theory (Glaser & Strauss, 1967) or Strauss & Corbin's (1997) evolved grounded theory methods were not congruent because they did not allow the co-constructive element and flexible format to explore the conceptual development of the experience.

2.5.2 Constructivist grounded theory.

Charmaz (2006) further evolved grounded theory to allow more flexibility and synergy with other qualitative analysis methods. This Charmazian grounded theory approach is less mechanical and allows the researcher to become a participant in the construction process to describe a phenomenon (Charmaz, 2014, p. 13). Taking the epistemological understanding of knowledge within grounded theory, Charmaz (2006) delineates both a constructivist grounded theory and an objectivist grounded theory. A constructivist grounded theory approach 'looks at the phenomena of study and sees both data and analysis as co-created from shared experiences and relationships' (p. 130). In this, the researcher's perspective is relevant to the final conceptual model (Charmaz, 2006; Mills et al., 2006). Constructivist grounded theory shares the necessary components of any grounded theory research including the following areas: theoretical sensitivity, theoretical sampling, constant comparative analysis, coding and categorizing the data, literature as a source of data, and memo writing, which is described in greater detail in Section 2.9. It also includes the co-construction process for the development of a conceptual model (Charmaz, 2014; McCann & Clark, 2003).

The objectivist grounded theory as described by Charmaz (2014) is focused on the positivist epistemology, which sees data as real but is not focused on the process of how those data are known. Therefore the conceptual model is discovered from data that are already in the world and the researcher provides the discovered model from a neutral perspective without the inclusion of social context (Charmaz, 2014).

Constructivist grounded theory (CGT) is particularly appropriate to examine the experience of advanced cancer recurrence in people with cancer who have perceived themselves as cancer free. By placing the researcher into the participant's story, CGT permits the co-creation of a conceptual model within the context of the experience, while retaining the participant's voice. The researcher's ontological view of constructionism and epistemological stance on interpretivism logically leads to the constructivist grounded theory approach. This approach guides how knowledge in a growing area of research, such as the experience of advanced cancer recurrence within the changing context of new treatments that include immunotherapy and focused treatment options, becomes known. Through the use of in-depth interviews within CGT, insight is gained into the human experience being studied, which supports the generation of new knowledge (Crouch & McKenzie, 2006). The constructivist grounded theory method provides the conceptual model necessary to answer the research question. The newly developed conceptual model will allow others to understand the patient phenomena (Mills et al., 2006). These particular features illustrate why this method of qualitative research was selected for this research study.

2.6 Research Methods

2.6.1 Research question.

As stated at the beginning of this chapter, the research question for this study is as follows: What is the experience of people with cancer when they are diagnosed with advanced cancer recurrence after a period of time where they considered themselves to be cancer free?

2.6.2 Participant selection.

2.6.2.1 Population.

The population of interest for this study are those who have experienced an advanced cancer recurrence, following a period where they considered themselves cancer free. As noted in Chapter 1, advanced cancer recurrence for this study refers to an advanced recurrence of the primary disease at stage III or IV.

The population for this study is unique in that, unlike the population of people with cancer who do not experience a recurrence but live with a fear of cancer recurrence, the participants in this study have experienced advanced cancer recurrence after believing they were cancer free (Simonelli, Siegel, & Duffy, 2017). Secondly, for the participants in this study, the transition to advanced cancer recurrence was not contiguous to the original diagnosis. Thirdly, the context within which these participants experience cancer recurrence is unique in that within this last decade current advances in advanced cancer care presents participants with a number of treatment options. As noted by Couzin-Frankel (2013), the year 2013 'marks a turning point in cancer, as long-sought efforts to unleash the immune system against tumours are paying off' (Couzin-Frankel, 2013, p. 1432). In her article, Couzin-Frankel refers to the development of this new age of cancer immunotherapy as a 'sense of paradigm shifting' (p. 1432).

Filling the gap in knowledge about what the experience of transitioning out of a state of believing to be cancer free into advanced cancer recurrence consists of providing insight into what motivates these people with advanced

cancer recurrence for future research. It is appropriate, therefore, to refine the population to those who have experienced a gap between the end of active treatment and the diagnosis of their advanced cancer recurrence after at least 2 years to capture this transition.

Solid tumours, breast, colorectal, lung, prostate, cervical, and ovary cancers are primarily the types of cancer with a typical trajectory which manifests with recurrence of advanced disease after a period where the person may have perceived themselves to be cancer free (American Cancer Society, 2016b; Simard et al., 2013). For that reason, the initial population focus for this study was on those with lung, colorectal, breast, or ovarian cancers. This criteria was later extended (following Internal Review Board approvals) to include head and neck cancers in order to increase recruitment and attempt to have different tumour types included.

2.6.2.2 Inclusion and exclusion criteria.

The inclusion and exclusion criteria that were operationalized to identify people from this population of interest are detailed in Table 4.

2.6.3 Setting.

The City of Hope Medical Center is a National Cancer Institute (NCI)-designated, free-standing cancer hospital in Southern California in the U.S. City of Hope is one of eight comprehensive cancer centres in California and, as a free-standing cancer hospital, is engaged only in cancer research. Given that the major focus of cancer care provided at the City of Hope is cancer

Table 4

Inclusion/Exclusion Criteria

Criteria	Included	Excluded
Cancer status	People with solid tumour cancers (lung, colorectal, ovarian, breast, and head & neck) who have been cancer free for 2 or more years and recur with stage III or IV cancer without potential for cure (verified by treating physician and documented in the medical record)	People with haematological cancers or tumours other than lung, colorectal, ovarian, breast, and head & neck cancers
Time availability and mental health	Able to complete a 1-2 hour, in-depth interview	People who are not able to comply with the requirements of the study due to cognitive deficits or distress caused by the interview process as assessed by the treating physician who initially introduced the study
Age	Age 18 or older	Younger than age 18
Language	English-speaking	Non-English speaking

research, the patient population is comprised of a high number of advanced cancer patients, and patients experiencing recurrence. These patients are seeking access to what they perceive as state-of-the-science cancer treatment.

This setting provides care to nearly 6,000 new cancer patients per year per cancer registry September 2016. As this study was conducted by a single researcher employed in this setting, the sample size and access to participants was believed to be appropriate and achievable. As a senior research specialist in the Department of Nursing Research and Education, my role has been to recruit and manage data for two major survivorship grants over the last 10 years. I did not work in the clinical setting and therefore did

not have relationships with potential participants for this study. Additional aspects of reflexivity are discussed in Section 2.11.

2.6.4 Sampling.

Sampling began with a purposive approach of choosing participants who met the inclusion criteria and therefore had experienced the phenomenon being studied (Charmaz, 2014; Patton, 1990). This process is congruent with a CGT approach to sampling. In line with CGT, theoretical sampling occurred as dictated by the analysis as theoretical concepts developed. As theoretical concepts were compared through constant comparison analysis (detailed below), new themes were developed and defined until saturation of themes occurred (Baker & Edwards, 2012; Bryman, 2012; Charmaz, 2014; Crouch & McKenzie, 2006). This process allowed verification of the developing concepts.

The sample size estimated for the Internal Review Board was between 12 to 20 participants, reflecting that CGT is not focused on a generalisable sample size but seeks to provide in-depth data to describe the studied phenomenon and achieve saturation of themes (Charmaz, 2006; Glaser & Strauss, 1967; Hallberg, 2006). A sample size of 15 participants was achieved and is described in Chapter 3.

2.6.5 Theoretical sampling.

Theoretical sampling is a method of data collection used in grounded theory that describes the process of sampling based on theoretical development (Draucker, Martsof, Ross, & Rusk, 2007). Charmaz (2014, p. 212) describes theoretical sampling as a process that 'advanced your analysis' (p. 212) and

allows the researcher to follow an 'emergent' (p. 212) process to evaluate categories and clarify relationships. It permits the checking and refining of categories in order to evaluate the emerging concepts of the developing conceptual model and interrelationships of the categories that lead to the substantiation of the developing conceptual model (Breckenridge & Jones, 2009; Charmaz, 2014; Coyne, 1997; Hallberg, 2006). This type of sampling is not intended to provide a representative sample of the population, but rather to develop a conceptual model that is grounded in the information provided by the participants who have been living for an extended period of time cancer free and recur with advanced cancer.

Integrating memos throughout the process permitted theoretical concepts to be built which were refined using theoretical sampling to assess specific new categories and themes and identify gaps in the categories (Charmaz, 2006). Theoretical sampling substantiated the developing conceptual model and ended with the saturation of concepts identified by the participants and affirmed in the interview process.

2.6.6 Recruitment.

Medical oncologists and their advanced practice nurses were approached through the disease teams in breast, lung, colorectal, gynaecological, and head and neck cancer during their weekly disease team meetings and by email to introduce the study and request their assistance in identifying appropriate patients. These disease teams see high numbers of recurrent cancer patients and were believed to have the potential to provide participants that would meet the inclusion criteria.

The medical oncologists and nurse, treating physician, or nurse practitioner identified potential participants based on the inclusion and exclusion criteria and provided the patient's medical record number to the researcher. The patient's medical record was reviewed for verification of 'time since treatment', and whether there had been an actual remission or 'perceived cured' statement documented in the records. This recruitment procedure was approved by the Institutional Review Board at the research setting.

The potential participants were introduced to the researcher during their clinic visit or their treating physician asked if the researcher could contact them by phone to introduce the study. For those interested in participating, the researcher met and discussed the study and took written consent. A copy of the consent form (Appendix A), the patient bill of rights included in the consent form were provided to the participant. The research protocol (Appendix B) described the purpose of this research—to understand the experience of advanced recurrence—the method of in-depth interviews to be used to collect the data, and the fact that this was a PhD student conducting the research. As a PhD student the recruitment and consent was obtained directly by me. I clearly explained to the participants their right to refuse to participate at any time without concern for prejudice or impact on their treatment or relationship with their health care team.

2.6.7 Ethics approval.

The research protocol related to this study was approved through the City of Hope Institutional Review Board and through the Faculty of Health and Medicine Research Ethics Committee (FHMREC) at Lancaster University. The

appendices to this dissertation include copies of the submitted U.S. protocol (Appendix B), and FHMREC protocol (Appendix C), letters of approval (Appendix D, E, F), renewal (Appendix G), and closure (Appendix H).

2.7 Data Collection

2.7.1 Interviews.

After consenting to participate in this study, semi-structured, face-to-face interviews were scheduled at a mutually convenient time at the City of Hope Medical Center. In constructivist grounded theory, intensive interviewing facilitates the gathering of in-depth information to explore the desired phenomenon in an unrestricted manner (Charmaz, 2014). Most participants chose to arrange the interview for their next clinic appointment, which was usually within one week of signing the consent. If participants asked to be interviewed on the day of consent, an office designated for participant interviews was reserved and the interview was completed.

The interviews were digitally audio-recorded. The interviews consisted of initial open-ended questions. An interview guide was followed to help consistently focus on areas of interest related to this study's research question. (Appendix I) As theoretical sampling occurred, the questions were altered to provide insight into newly developing concepts relating to the emerging conceptual model. The questions were developed consistent with grounded theory to elicit the participants' experiences. Therefore, according to a grounded theory approach, interview questions changed as codes were categorised within each interview.

In constructivist grounded theory, the role of the researcher is to discover the concepts as related in the interview. The interview data and the analysis are a process of interpretation, and a contextual understanding is essential to identify the meaning of the experience for the patient at the time of the interview (Birks & Mills, 2011; Charmaz, 2006). Through careful listening during the interviews and the use of probes to elicit more information, the developing concepts were further understood. A copy of the interview guide can be found in Appendix I.

2.7.2 Data management.

Interviews were digitally recorded and transcribed using a professional transcription service where anonymity was maintained. Participants were numbered prior to the interview and recordings were transferred through secure password-required methods. The interviews were then reviewed and the audio and written transcripts were compared for accuracy. Any identifying information in the written transcript was anonymised immediately. This process is described in the protocol and FHMREC application (Appendix B & C).

2.7.3 Data analysis.

Transcripts were read numerous times so I could become familiar with the words and narratives. The recordings were also reviewed to hear the participants' voices and emotions. Grounded theory requires that data collection and analysis be conducted simultaneously (A. Strauss & Corbin, 1997). Constant comparative analysis is essential within grounded theory to process the data and immediately start inductively synthesising to understand

and begin development of subcategories and categories for theoretical sampling and building a conceptual model (Birks & Mills, 2011; Charmaz, 2014; Holton, 2007).

Constant comparative analysis provides a method of comparing data between participants, and codes with codes, subcategories to subcategories, to ultimately compare categories with categories, in a continuous process beginning with participant 1 to participant 2, then participant 1, 2, and 3, and so on, adding with each new data set. This process allows the development of abstract concepts as I move through the data to inductively evaluate individual data and compare iteratively as the categories continue to build until saturation of themes is achieved (Charmaz, 2014). From the interview transcripts, initial codes, and theoretical memos focused codes were developed into detailed subcategories, and categories led to the concepts.

The concurrent data collection and analysis within a constant comparative approach involved moving from participant codes to detailed subcategories and categories; using theoretical sampling and refining of the interview questions to investigate and support the categories and development of the final concepts. Theoretical memos helped to focus theoretical sampling and guided the development of the emerging conceptual model (see Box 1, with detailed examples of the category to concept development described in Chapter 3, Tables 6, 7, and 8).

Participant 2: 'You are a little tired, you are six years older too. It took a little longer to get back to fighting mode as far as we're going to still beat this thing'.

Theoretical Memo: Does older age impact response to advance cancer recurrence and accepting of the incurable status?

Box 1. Using theoretical memos in practice.

2.8 Coding and Sampling Lead to Conceptualisation

Using constant comparative analysis, interview transcripts were evaluated and initially coded using a line-by-line process. The interviews were iteratively compared as the initial codes were coded into focused codes using action words that would illustrate their meanings as developed through co-construction between the researcher and the participant. A sample of coded transcript can be found in Appendix J. Gerunds are recommended for coding in grounded theory as they provide an action-focused understanding of the meanings, which help the researcher co-construct the conceptual model and maintain the meaning from the participant (Charmaz, 2014). As pointed out by Charmaz (2012), 'Gerunds build action right into codes, Hence, coding in gerunds allows us to see processes that otherwise might remain invisible' (p. 5). Codes were discussed with supervisors to verify agreement with coding decisions. These processes required extensive time to conceptualize categories and begin to apply focused coding and develop theoretical categories and define possible relationships between categories.

As depicted in Figure 1, initial codes were grouped related to similar meanings and focused codes emerged. These focused codes were developed into subcategories that were then reflected as categories that were co-constructed and conceptualized into the final meanings. In order to verify that these categories accurately reflected the participants meaning I used theoretical sampling and analysis. This constructivist grounded theory approach of theoretical sampling and analysis led to emerging themes to inform interpretation by comparing patterns between participants and identifying connections. Focused codes were combined and used to develop subcategories which reflected patterns and identifying connections between participants. These patterns that developed through the subcategories to categories became the final concepts that were then used to explain the experience of people with cancer who had perceived themselves to be cancer free for two or more years who then recur with advanced cancer. As Charmaz (2014) proclaims, the strength of this process lies in the 'focus and flexibility' (p. 320) followed to engage this method of constructivist grounded theory development. These categories described the overall meaning of the actions of the participants related to the researched phenomenon.

Box 2 below shows coding in practice as it developed from participant words to Memo to code to category.

2.9 Memo-Writing

An important part of the grounded theory process is theoretically guided memo-writing. Memo-writing is concerned with making comparisons and allows me to constantly record observations, read and analyse the data for

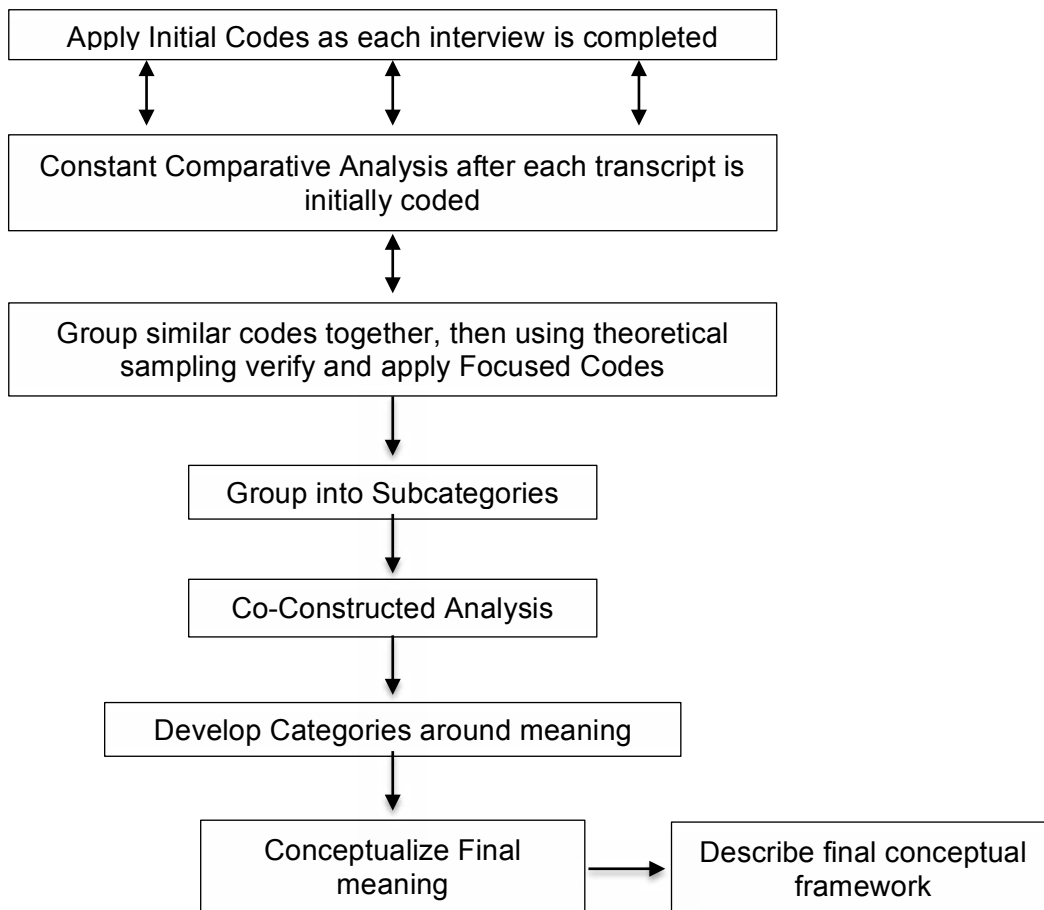


Figure 1. Coding process, constructivist grounded theory.

Participant 2: 'You are a little tired, you are six years older too. It took a little longer to get back to fighting mode as far as we're going to still beat this thing.'

Theoretical Memo: Does older age impact response to advance cancer recurrence and accepting of the incurable status?

1. Initial code: feeling tired, age related to disease.
2. Focused code: age impact on cancer
3. Subcategory: Age-developmental and temporal
4. Category: Behaviour and Attitude Toward Recurrence
5. Concept: Reluctant Acceptance

Box 2. Coding in practice.

theoretical focus, and refine categories for co-construction of the final concepts (Charmaz, 2006). This began the process of identifying the concepts emerging within the data. Advanced memo-writing builds upon the initial memos to describe how the category emerges and to make comparisons (Birks & Mills, 2011; Charmaz, 2006). Advanced memos reflect on the analysis of the data and help maintain the rigour of the study. Memo-writing provided an area where coding rationale was documented. By keeping memos, I was able to write thoughts or potential codes after each participant interview. This process aided the constant comparative reviews. Additionally, it allowed for potential categories to be written down and considered between each interview. Memos relating to the initial code about ageing, for instance, allowed the code to be considered, and subsequent theoretical interviews examined participants' meanings about age and how it related to recurrence.

Comments were used within the initial analysis section as an opportunity to capture thoughts about the specific interview and consider the nuances of what was said. In grounded theory, comments may be descriptive, and include personal observations and reactions during the interview. In this research, the comments were tied to specific sections of patient interviews while memos were related to the overall project. Memos and comments were integrated into the analysis process using Atlas-Ti (described in the following section) and handwritten comments on transcripts were therefore part of the project documentation.

2.10 Atlas-Ti Qualitative Analysis Tool

Atlas-Ti qualitative data analysis tool was used to support coding and the development of concepts (Friese, 2014). Atlas-Ti training tools and resources

are listed in Appendix K. This software allows memos to be used while coding as well as provides a space for specific memos related to concept development and the researcher's field notes to be documented and filed within the program for convenience and accuracy (Friese, 2014).

2.11 Reflexivity

Reflexivity pertains to the awareness of the researcher's own knowledge of the area being researched, and how biases, values, and presence impact the researcher's findings (Bryman, 2012). Providing a reflexive piece to one's analysis as part of memo-writing is necessary to prevent insertion of the researcher's personal beliefs into the patient's story (Birks & Mills, 2011). As a Senior Research Specialist in this setting I participate primarily in nursing education-focused grants. I do not provide direct patient care or work directly with any of the medical staff other than to introduce research protocols and recently to recruit for this study.

In constructivist grounded theory, it is necessary to focus on reflexivity to actively document the researcher's input into the meaningful links between the patient's story and the researcher's analysis. Providing a transparent process from the time of patient interview through coding, theming, and the development of a conceptual model is an essential part of cocreation in constructivist grounded theory research (McGhee, Marland, & Atkinson, 2007). Glaser (2001) cautions that reflexivity, as a part of analysis, can lead to 'reflexivity paralysis' (p. 47) if the researchers' attempts to identify their theoretical concepts are done in such a way that they lose sight of their analysis.

Reflexivity in constructivist grounded theory is meant to provide an opportunity to expand the memo-writing to document the reasoning for coding in a particular way and help to provide a distinction between patient description and the researcher's own personal thoughts (Glaser, 1978). As noted above, comments and theoretical memo-writing were used to document the researchers thoughts related to codes or patient remarks (see Box 1).

Within constructivist grounded theory, the researcher is more than an observer of the data but actually meant to co-construct the meaning from the participants' words (Charmaz, 2014). Therefore, maintaining constant awareness of what the participants say and what the researcher hears requires diligent thinking about the co-constructed meaning and assuring that the final concepts are in fact from the participants' meanings and not the researcher's alone. As I have experience with this population in general, as people who have cancer, careful attention was paid to theoretical memos and researcher comments as the conceptual model of advanced cancer recurrence was developed.

2.12 Ethical Concerns in Qualitative Research

Providing safeguards when planning a research study is important regardless of the methodology being used. In relation to qualitative research, protecting participants is essential, especially when dealing with people with advanced cancer experiencing incurable disease, as in this research (REF). Issues related to recruiting within this population and the effects this type of questioning may have on participants must be considered (Clarke, 2006; Orb, Eisenhauer, & Wynaden, 2001).

Principles essential to the ethical conduct of a study include autonomy, beneficence, nonmaleficence, and justice. Autonomy is related to treating participants with respect protecting their right to act independently and with full consent. In research, this included supporting a recruitment process that was free from coercion. Because the setting was a research-focused cancer centre, there was concern that participants might feel obligated to participate in research studies. Participants were assured through the consenting process of their right to refuse to participate at any time without concern for prejudice or impact on their treatment or relationship with their health care team. I was the only person available to obtain consent in this study.

The principle of beneficence and nonmaleficence, preventing harm and doing well for others, requires the researcher to be very clear about how the research was conducted. During the research process, privacy and confidentiality was maintained. Preventing harm to the participants because of the very sensitive focus of the interviews was important. During the interviews I was careful to observe the participant for stress or anxiety. The consent included a statement providing access to a social worker should they feel they needed to discuss issues raised during the interview. There was an ethical obligation to maintain anonymity. Participants were assigned numbers and interviews were immediately de-identified to maintain anonymity.

Finally, the principle of justice requires that participants be treated equally and fairly. As a grounded theory study, the participant's words are the focus of the coding process and co-construction of the conceptual model using the words to describe concepts was done carefully and thoughtfully.

2.13 Summary of Methods and Methodology

This chapter has defined how constructivist grounded theory informed the methodology chosen for this study. The qualitative research designs were described and the rationale for this methodological choice was made related to the aims of this research. As described earlier, because this is a constructivist grounded theory study, the literature review is provided in Chapter 4 to further substantiate the constructivist grounded theory analysis and conceptual model. Chapter 3 (Findings) describes the codes and categories that were conceptualised from the participant data and uses these to develop a conceptual model.

Chapter 3: Core Findings

3.1 Introduction

The constructivist grounded theory approach described in Chapter 2 details the analytic approach including the development of the coding plan, subcategories, categories, and concepts. The concepts, their intersections, and the cross-cutting subcategories allow the diagramming of the development of the subcategories and categories into the model to be described, as appropriate to constructivist grounded theory (Charmaz, 2014).

This chapter first presents participant demographics, describes the coding process leading to concept development, and introduces the developed concepts. Second, the findings are presented along with descriptions of the co-constructed meaning of the participants' own words and my interpretation of those words. Finally, the patterns and intersections between the categories, subcategories, and the developed concepts are identified and discussed.

3.2 Participant Demographics

Fifteen participants (13 women and two men) participated in the study. The participants ranged in age from 44 to 77 years old. Initial diagnoses included breast cancer ($n = 12$), lung cancer ($n = 1$), ovarian cancer ($n = 1$), and ovarian and breast cancer ($n = 1$). At the time of the study, eight participants were receiving standard chemotherapy treatment, two were receiving biological treatment, and five were receiving bisphosphonates as supportive treatment. The time between their initial diagnoses with cancer to advanced cancer recurrence ranged from two years to 20 years. All 15 participants had lived two years or more cancer free prior to their diagnosis of advanced

cancer recurrence; 3 lived two years cancer free, 12 lived four or more years cancer free, and seven of the 12 lived a period of 10 years or more cancer free. Table 5 provides an overview of the demographic details of all participants.

Table 5

Participant Demographics (N = 15)

Characteristic	<i>n</i>
Gender	
Female	13
Male	2
Age	Mean age yrs. (Female 67.5 / Male 75)
40 – 50 years	1
51 – 60 years	0
61 – 70 years	11
71 – 80 years	3
Cancer diagnosis	
Breast cancer	12
Ovarian cancer	1
Lung cancer	1
Breast and ovarian cancer	1
Time since diagnosis to identification of advanced disease	Mean time to recurrence in years (Female 9.5 years / Male 3 years)
2 years	3
3 years	
4 years	1
5 years	
6 years	2
7 years	1
8 years	
9 years	
10 years	3
11 years	1

Characteristic	<i>n</i>
12 years	2
13 years	
14 years	1
> 15 years	1 (diagnosed twice with advanced disease); 20 years since second diagnosis of advanced cancer
Current treatments	
Chemotherapy	8
Biologicals	2
Bisphosphonates	5

3.2.1 Participant confidentiality.

To protect participants' confidentiality, participants are referred to as "P" and identified by their participant number. For participant quotations, in-text citation includes participant number and transcript line number.

3.3 Coding Process Leading to Concept Development

The initial coding provided 235 codes that were described in action terms, consistent with grounded theory methodology (Charmaz, 2014). Examples of gerund type action codes developed using the constructivist grounded theory method include acknowledging, being, believing, coping, describing, fearing, feeling, fighting, focusing, ignoring, living, maintaining, pursuing, recognising, refusing, uncertainty, and working (Charmaz, 2014; Glaser & Strauss, 1967). Initial codes evidenced below in Box 3 therefore include direct quotes from the participants. For instance, as illustrated below in Box 4, *pursuing* 'chemotherapy treatments again', *recognizing* 'cancer is no longer curable', *acknowledging* 'never once did I think this wasn't going to work out'. Subcategories included the sense of 'again', which was categorised for

Behaviour and Attitude Toward Recurrence, as in cancer occurring again. Positive-accepting described codes applied to the category of Coping–Working/Existential. Additionally, codes were applied to the category of Treatment Focused.

fearing	maintaining
feeling	pursuing
fighting	recognizing
focusing	refusing
ignoring	uncertainty
living	working

Box 3. Exemplar initial codes

Pursuing “*chemotherapy treatments again*”

Recognizing “*cancer is no longer curable*”,

Acknowledging – positive outlook “*never once did I think this wasn’t going to work out*”

Hoping “*I feel fortunate, I’m hoping to have a few more years*”

Box 4. Exemplar initial coding with associated quotes

Appendix L presents the complete list of initial and focused codes to subcategories and categories and finally developed concepts. The following 19 subcategories were developed: minimising gravity of disease, focusing on treatment, established treatment plan, positive attitude, seeking knowledge, age-temporal and developmental, meaning of illness, anger and sadness, family support, spiritual faith, pursuing healthy living (self-advocacy), ‘not

curable but treatable', faith in physician, humour and laughter to minimise disease, future orientation, focusing on others, uncertain future, realisation incurable cancer, and hope. These subcategories represented the building blocks that led to the following categories: Behaviour and Attitude Toward Recurrence, Treatment Focused, and Coping–Working and Existential.

3.4 Introduction to Developed Concepts

Following the analytic process explained in Chapter 2, the three categories (Behaviour and Attitude Toward Recurrence, Treatment Focused, and Coping–Working and Existential) were co-constructed and conceptualised into three concepts: Reluctant Acceptance, Seeking Life Through Continuous Treatment, and Hope in the Face of an Uncertain Future. These three concepts comprise the conceptual model of this constructivist grounded theory study. While 'why' questions lead to explanatory findings, this study is focused on describing the 'what' and 'how,' as in, 'what' the experience of advanced recurrence consists of for people diagnosed with advanced recurrence after believing themselves to be cancer free, and 'how' this experience motivates them through this experience (Charmaz, 2014, p. 228). This research is not introducing a theoretical analysis of the relationships described in this experience.

Results from this study's 'what' and 'how' questions led to the subcategories that, through co-construction, led to the categories. The description of what that experience was for them formed the basis for these subcategories. Using the inductive process of reasoning, I combined these subcategories into distinct categories. These distinct categories and the relationships between

these categories' subcategories led to the development of the three concepts mentioned above. These three concepts—Reluctant Acceptance, Seeking Life Through Continuous Treatment, and Hope in the Face of an Uncertain Future—represent 'how' the participants see their experience. The resulting conceptual model consists of these three concepts and their interrelated and co-constructed categories and subcategories.

Following Charmaz (2014), I used diagramming as a way to represent this study's categories, subcategories, and concepts and their relationships (p. 218). Diagrams provide a concrete visual of the dynamic relationships between a study's categories, subcategories, and resulting concepts, thereby providing a conceptual map guiding the analysis for this study's findings (Burns & Grove, 2001; Charmaz, 2014). As detailed below, the Venn diagram (Figure 2) provides a diagram and conceptual map for this study.

In the next sections, each concept is presented, along with its categories and related subcategories.

3.4.1 The concept of Reluctant Acceptance.

The concept of Reluctant Acceptance was conceptualised from the category of Behaviour and Attitude Toward Recurrence and is distinctly underpinned by the subcategories of age-temporal and developmental; anger and sadness; uncertain future; and realisation incurable cancer. Each of these is discussed in the following sections. Figure 3 highlights this portion of the overall Venn diagram. A table at the end of this section summarises, with examples, how empirical data were used to construct this concept.

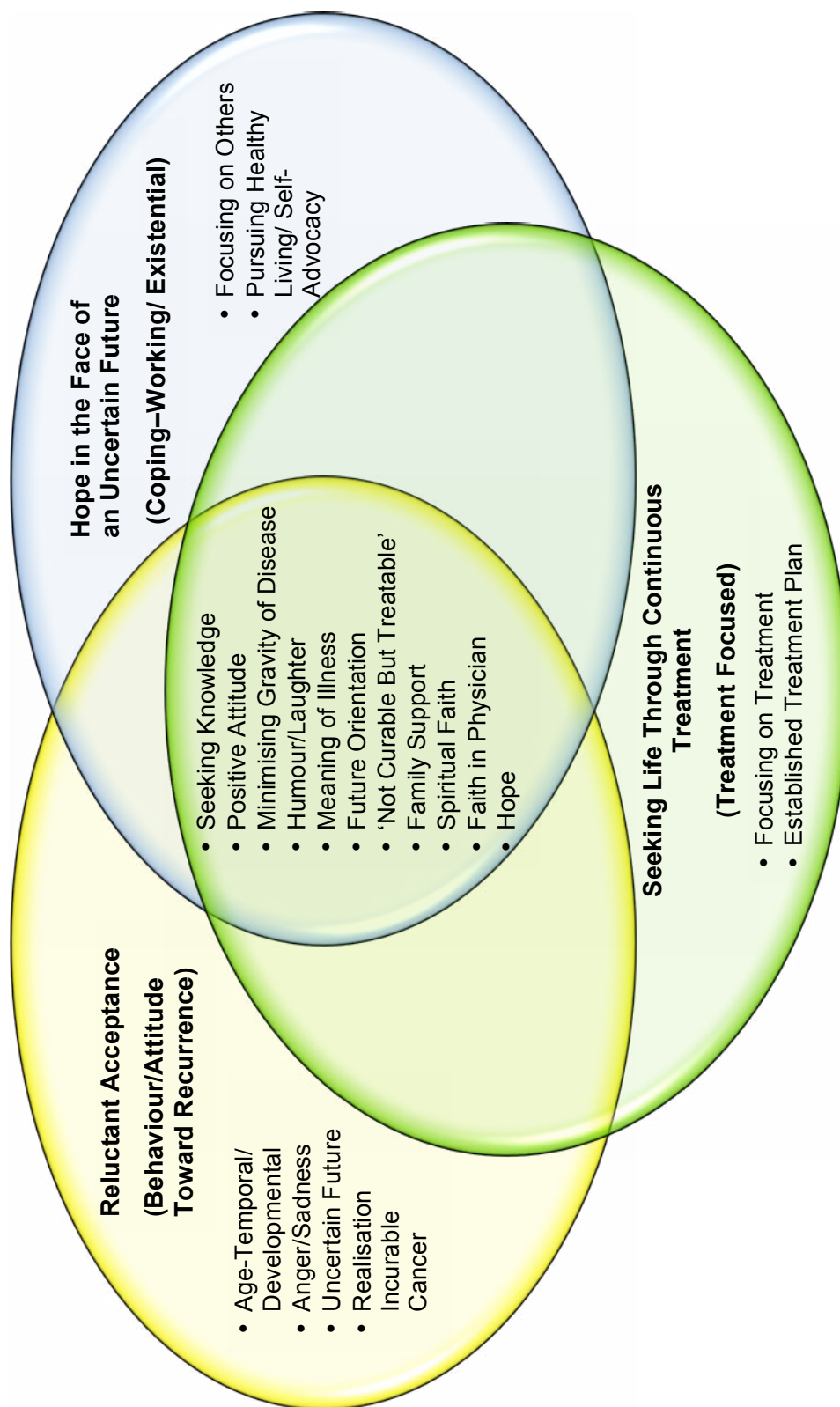


Figure 2. Relationship and intersections between the three concepts of the experience of advanced cancer recurrence.

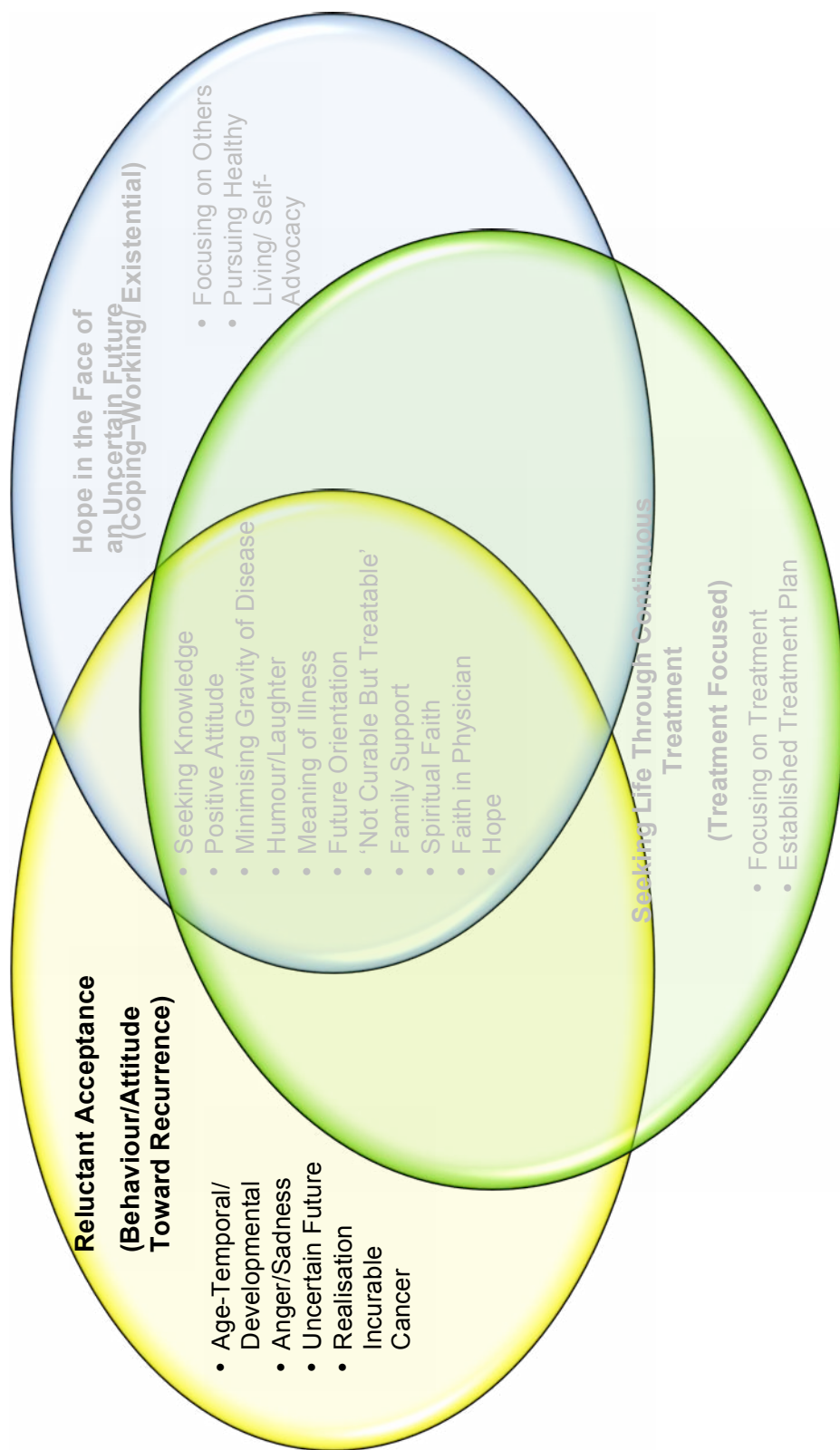


Figure 3. Reluctant Acceptance: Category and subcategories.

3.4.1.1 Age-temporal and developmental.

The passing of time since their initial cancer diagnosis meant that participants often acknowledged that they were at a different life stage. The recurrence was experienced in the context of their current life stage, encompassing the time that had passed since their initial cancer diagnosis. Inevitably, they understood that they were closer to death. Age impacts the concept of Reluctant Acceptance in two ways: the developmental changes associated with growing older, and as the temporal concept of passing of time. Although mortality, as related to being older and the advanced disease stage, was apparent, there was not a focus on personal mortality. Instead the focus was on implications in terms of age and mortality in general, with an acceptance of the possibility of death. Participant 1 represented this idea, stating:

Um, I don't know, maybe as you get older you accept mortality, start looking into your mortality more, as you get older. (P1:61)

. . . and it's like waking up and its cancer. I really have cancer and it could take my life, you know, this time, you know, I'm older and it's harder to fight it each time. It's hard like . . . it's just become more serious to me now as I'm older. I think that's what it is. (P1:483–485)

Even though death was understood in relation to age and cancer, it wasn't until diagnosed with advanced cancer recurrence that death was implicitly recognised as a possible result of cancer. There was a temporal component as well as an underlying acceptance of morbidity with aging:

. . . having the chemo and saying, 'You have no cancer in your body. And you are good to go'. And then to have that change, it was—I wish I was better at explaining that because it was definitely an entirely—and you are a little tireder from—and you are six years older, too. [Laughs] You are a little tireder. It took a little longer to get back to fighting mode as far as, 'we're going to still beat this thing'. (P2:110–111)

Accepting the diagnosis was important for these participants, as their attitude and behaviours described how their age and life experiences framed the meaning of this recurrence. Recognition of the time spent cancer free and the development of an advanced recurrence signalled a new phase in the trajectory between diagnosis, believing cured, and recurrence at an older age. The statement below expresses how age impacts the diagnosis of an incurable advanced cancer recurrence relates to the initial diagnosis.

I lived 10 years cancer-free, enjoyed watching my grandson grow up. He's gone off to college now, and if I was to go now, at least I've had a good life, you know, and done just about everything I want to do, but we're all gonna die eventually, I mean really. We're all terminal, you know? (P12:30–31)

For the purpose of this study, aging is understood in relation to recurrence. So even though the reality of the relationship between aging and the incidence of cancer is understood by these participants, reflecting on their age and their recurrence revealed a greater sense of reluctant acceptance:

The only negative factor I think I have at the moment is the fact that I'm 10 years older. So I realize that, but the fact that I've been through chemo before I kind of know what to anticipate. (P9:66)

Participants described how accepting death is a part of aging and yet they are reluctant to give up on life and they seek treatment to continue living. The contribution of age to the appreciation of the reality of their situation (with increased risk of cancer in older people and the length of time they already had to experience life) led to expressed feelings that younger participants might be more distressed to be diagnosed with recurrent cancer than people who had lived a full life before cancer was diagnosed, as described by this participant:

You're younger so you think you haven't had the time to do what, what you want to do when you're older then you feel okay; it's also an age-related disease. (P14:224)

The impact of age on the diagnosis of recurrent cancer provided a background for the sadness or anger described by the participants about how they had been here before and were now uncertain about their future.

3.4.1.2 Anger and sadness.

Anger and sadness, a subcategory of the category of Attitude and Behaviour Toward Recurrence, was initially expressed as anger, with a focus on the cancer recurring despite their efforts to live a healthy lifestyle; participants expressed feeling defeated by the recurrence of cancer:

That's the anger for me for reoccurrence is that I did everything right. [Laughs] I can't sit on that and feel sorry for myself and let that be the life I lead. I have to stand up. (P2:66–79)

Anger also arose from the recognition that cancer is unpredictable:

Cancer's wicked. It goes where it wants. (P12:256)

Yet even with this recognition, there was a movement beyond the emotion of anger, to shift focus on what could be done to continue living with this recurrence. They then moved beyond the anger to action, and focused on treatment options. Participants described the experience of recurrence from initial anger and sadness to focusing on a plan of care:

I had my 2 or 3 days of like, you know sadness and like, you know, not feeling good about it, but that was it really. To be honest with you, that was it. Then it was like, 'Ok, now what are we going to do?' (P10:49)

Accepting the uncertainty of a future with advanced cancer that is no longer curable was a choice made to minimise anger, depression, or negative emotions that could immobilise them if they allowed it to, and prohibit moving forward. Therefore, although this was still a very difficult time, participants were determined to manage their emotions rather than dwell in a negative emotional state, and responded to the recurrence by actively seeking information, considering options, and planning for life changes to accommodate treatment.

That way you're gonna be sad or you're gonna be depressed or you're gonna be whatever, you know, it is. And who would choose to be like

that? You know, unless it was a real mental illness or something, you can't . . . you don't have a choice, but I think you just have to, you know, you just have to get past it and think, 'I have a choice. I can wallow in this or I cannot'. (P10:60)

Accepting anger and sadness in response to advanced cancer recurrence was an active choice that allowed participants to move forward and accept their uncertain future.

3.4.1.3 Uncertain future.

The subcategory of uncertain future that surrounded this period of recurrence with advanced cancer was clear to the participants that it was different from the first diagnosis, where treatment was done with curable intent. Noted along with this sense of uncertainty was an attempt to face it with a positive attitude and hope for continued life:

Well, I kind of think what's going to happen down the road, you know? How much time do I have? I mean, they don't tell you. They just say, 'Well, some people can go another 10 to 15 years', you know? . . . So I kind of grabbed on to that thinking, well that's good [laughs]. (P12:132–134)

Approaching the advanced recurrence by embracing the uncertain future with a positive attitude and a focus on good things is described by these three participants.

Just the news, the tragedies that happen occur, and just when you think they can't top themselves 9/11 comes along. It's like,

unbelievable. The things that I have I feel fortunate. I'm hoping to have a few more years, I don't know, and make the best of them. (P5:50–51)

Well I just think that I don't think I'm gonna, you know, I don't know what my years are . . . that I have left. But you know, I mean, I kind of have to face reality about it too. (P12:360–362)

Like, maybe I won't get more than five years or 10 years or whatever, but I've just got to deal with it day by day. I don't think you can really look into the future and get all crazy about it. I think that obstructs the purpose of trying to stay healthy. (P12:364)

Participants describe the importance of staying positive to support their coping with this new advanced cancer recurrence. Allowing the uncertainty to remain there as well as a loose look at reality maintains their hope and support of living with this cancer recurrence. 'Maybe I won't get more than 5 or 10 years' acknowledges the unknown reality of prognosis in people with advanced-stage cancers but also, I believe, displays an ignorance regarding what is known about advanced-stage cancers. Living five to 10 more years would be too many people unthinkable with advanced-stage cancer, at least in the past. This new environment where treatment is an option may be changing those perceptions.

3.4.1.4 Realisation of incurable cancer.

The need to move forward was significant in making decisions to seek treatment. Despite a history of two cancers, treatment, and an 11-year period cancer free, one participant expressed anger but was focused on 'living with

it': *'It's like, you know, what have I done that I'm going through this a third time? And this time it won't be cured. I just have to live with it' (P13:90).*

The realisation of incurable cancer was not always seen as absolute. Some were cautiously hopeful that there would be more time:

I don't think I am ever going to be cured of this, but I think that if it [treatment] buys me more time, I'm willing to, you know, try and make the best of it because I have 12 grandkids. I don't want to, you know . . . (P12:142)

Participants were open about the effect of the devastating news of recurrence and their anger and sadness, but they believed that when dwelling in this emotion they were not in control of their actions. Instead, they actively moved forward with hope for treatment and a positive attitude. The choice between anger and sadness or accepting the diagnosis of advanced cancer recurrence was made to allow them to regain control and pursue treatment. They pursued this plan believing they could have a similar outcome as they previously had and achieve a successful remission again:

I would say that the best thing is just to keep positive, you know, because it, it's hard to go through it the second time because you already know how bad it was the first time. . . . It just kind of a bad battle, but you have to go through it again. But you gotta stay positive because it's so hard if you're not. You get up and you're depressed and you're anxious and you just have to talk and work through it and if they can do it, it's worth it to try and beat it you know? Get more years on your life. (P12:261–264)

Table 6 describes the development of the concept of Reluctant Acceptance from the participants' words to the final concept.

3.4.1.5 Summary of the concept of Reluctant Acceptance.

I lived it and I enjoyed it and I shared it [life after cancer] and when it got bad again I just said, "I'll deal with it". (P3:114)

Together, the category of Behaviour and Attitude Toward Recurrence and its subcategories (age-temporal and developmental, anger and sadness, uncertain future, and realisation of incurable cancer) were developed into the concept of Reluctant Acceptance. These subcategories represented the initial response to the diagnosis of advanced recurrence and help to describe the feelings that motivated participants to make decisions about their next steps. The acceptance of this diagnosis was necessary for participants experiencing advanced recurrence to move forward with what to do next. Having experienced cancer before, the participants moved immediately into coping strategies to reduce their distress and find a personal equilibrium between advanced cancer and continuing to live with incurable cancer. This state of Reluctant Acceptance motivated the participants to cope with this new stage of dealing with cancer and coming to terms with no longer having a curable disease. This concept describes the overall understanding of what behaviours and attitudes toward advanced recurrence are and the stimulus those attitudes provide for the energy to seek continued life.

Table 6

Examples Illustrating the Development of the Concept of Reluctant Acceptance

Participant	1. Interview transcript	2. Initial codes	Theoretical memo	3. Focused codes	4. Subcategories	5. Category	6. Final concept
2	‘You are a little tired from—you are six years older too. It took a little longer to get back to fighting mode as far as “we’re going to still beat this thing”.’ (P2:110–111)	Feeling more tired; acknowledging age related to disease	Does older age, impact response to advanced cancer recurrence and accepting of the incurable status?	<ul style="list-style-type: none"> • Age impact on cancer • Positive attitude • Reluctantly Accepting 	<ul style="list-style-type: none"> • Age-temporal/developmental 	Behaviour/Attitude Toward Recurrence	Reluctant Acceptance
9	‘The only negative factor I think I have at the moment is the fact that I’m 10 years older. But I don’t think that is going to be a problem.’ (P9:33–37)	Acknowledging age related to disease		<ul style="list-style-type: none"> • Age impact on cancer • Minimising gravity of disease 	<ul style="list-style-type: none"> • Age-temporal/developmental 		
1	‘Um, I don’t know, maybe as you get older you accept mortality.’ (P1:61)	Acknowledging mortality with being older		<ul style="list-style-type: none"> • Age-accepting mortality 	<ul style="list-style-type: none"> • Age-temporal/developmental 		

Participant	1. Interview transcript	2. Initial codes	Theoretical memo	3. Focused codes	4. Subcategories	5. Category	6. Final concept
10	'I know I have cancer now and it is not curable but its treatable, for how long who knows, we will see.' (P10:30–33)	Recognising cancer not curable—uncertain future		<ul style="list-style-type: none"> • Uncertain future • Realisation not curable 	<ul style="list-style-type: none"> • Realisation incurable cancer • Uncertain future • Hope 		
2	'That's the anger for me for recurrence is that I did everything right. Are you kidding me? I can't sit on that and feel sorry for myself and let that be the life I lead. I have to stand up.' (P2:66–79)	Anger at recurrence—refusing to feel sorry for self	Angry at recurrence but not allowing it to consume their focus; instead turning to positive emotion and hoping for future	<ul style="list-style-type: none"> • Anger/sadness • Self-advocacy • Reluctantly accepting 	<ul style="list-style-type: none"> • Anger/ sadness • Future orientation 	Behaviour/Attitude Toward Recurrence	Reluctant Acceptance
8	'It is something I don't want to accept it, but you have to. You have no other choice. I do what I can do and you do it for as long as you can do it.' (P8:144)	Refusing to accept but does anyway		<ul style="list-style-type: none"> • Reluctantly accept—just deal with it • Focus on treatment • Hope for future 	<ul style="list-style-type: none"> • Uncertain future • Positive attitude • Hope 		

3.4.2 The concept of Hope in the Face of an Uncertain Future

The concept of Hope in the Face of an Uncertain Future developed from the category of Coping–Working and Existential, which in turn consisted of two subcategories: focusing on others and pursuing healthy living. The subcategories were developed from codes that focused on coping with an uncertain future and methods allowing participants to be less afraid of their new advanced cancer recurrence. The category of Coping–Working and Existential was underpinned by the subcategories of focusing on others and pursuing healthy living/self-advocacy, which are described below. Figure 4 highlights this portion of the Venn diagram.

3.4.2.1 Focusing on others.

Focusing on others provided a method of coping by reducing anxiety. It may have also contributed to finding meaning in this experience of advanced cancer recurrence, as described by this participant:

I pray every day, but I don't pray for me, I pray for others. I find caring about others first helps me. (P10:69–70)

The need to focus on others allowed participants to concentrate on something outside of their diagnosis and concerns and provided a means of coping that also helped them consider the meaning of this experience.

It's especially [needed] now because cancer is very prevalent, it's time that we wake up to the reality. I'm really, really committed myself to doing that [sharing my story to improve cultural response to cancer in

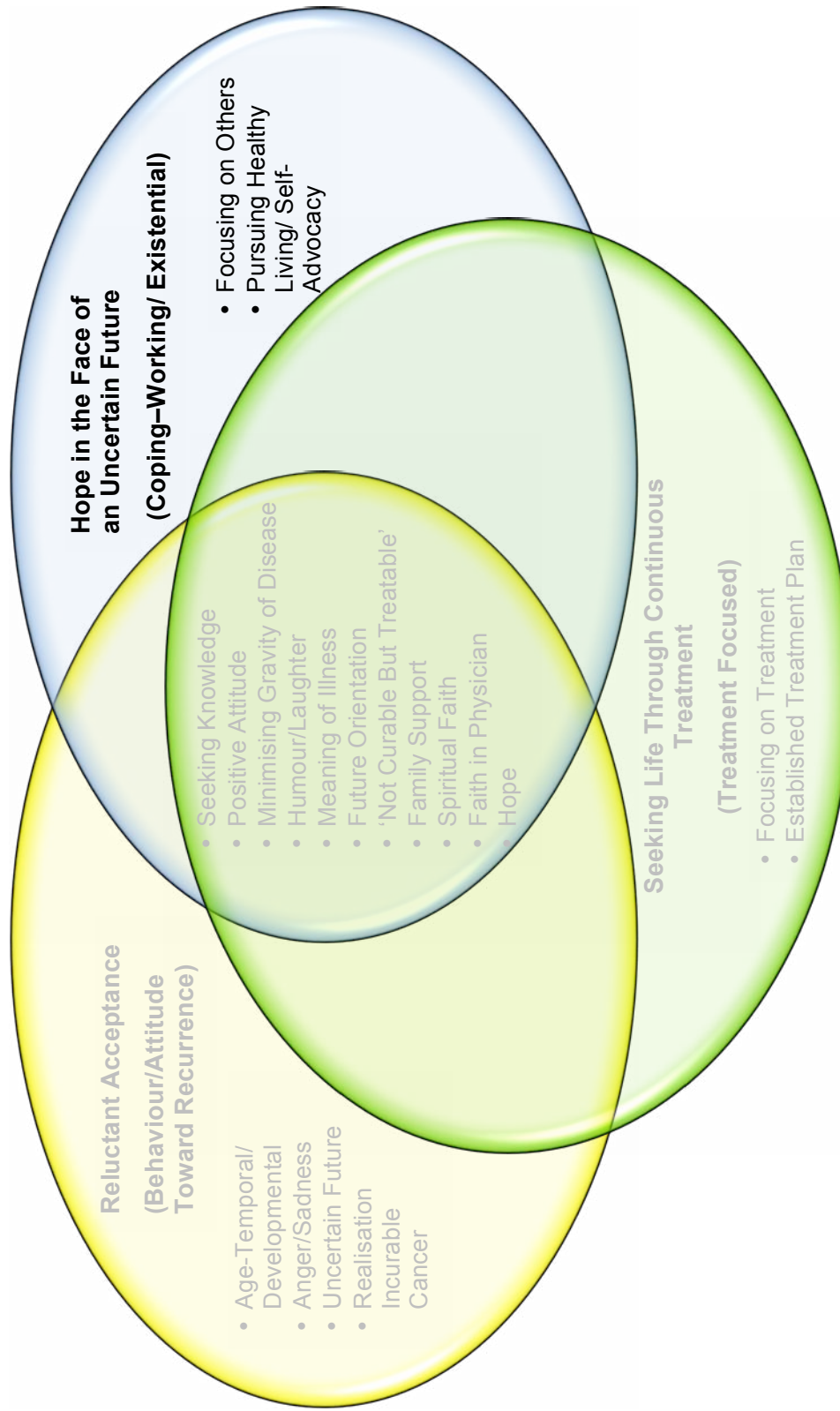


Figure 4. Hope in the Face of an Uncertain Future: Category and subcategories.

Africa]. I encourage people on what we women need to help us through this kind of process. So I find myself thinking God has really used me as a vessel. And I'm very humbled by it. . . . I have work to do [helping others with breast cancer]. (P7:203–239)

3.4.2.2 Seeking healthy living/self-advocacy.

Healthy living strategies provided a sense of control and self-advocacy to cope with advanced cancer recurrence. Participants strongly believed in their own body's ability to fight the recurrent disease. They expressed the view that by actively pursuing healthy living activities, they would support their body in protecting itself and fighting the cancer. Pursuing healthy living was believed to positively impact their immune system and support living life. Even if it was acknowledged that such practices had not prevented the cancer from recurring, there was still an effort to follow those practices. There was also an acknowledgment that not maintaining optimal health may have contributed to recurrence.

The other part is that, when after I had the cancer and I did all the reading and I really felt if I kept my immune system really, really healthy that it would um, help protect me from—from cancer again and that if I kept my stress under control. I did not keep my stress under control; however healthy, I became a vegetarian. I ate well. I exercised. I ran. I did everything to keep my body in a position where it could fight off anything. (P2:116–123)

The change in activities and lifestyle after their initial recurrence and previous cancer treatment and subsequently during the time they believed themselves to be cured was a common focus for participants.

Also I changed my diet, you know, I ate a lot of red meat before that, and so I'd change the diet with less red meat, uh, and more fish and chicken, you know, and um, also ate lots of vegetables, you know, and uh. . . . Just originally I did that to uh, prevent cancer, thinking it would help to give me antibodies, you know. (P11:34–40)

The participants had pursued a healthy living strategy after their initial diagnosis as a means to take control of their bodies, so they could continue to live and fight their cancer. After their successful treatment, they experienced years of what they perceived as healthy living free of cancer. Once their cancer recurred, they pursued whatever means they could to continue to live now with the new reality of advanced cancer.

I have lost 30 pounds, I'm so happy about that. I didn't lose much weight in the first one. . . . I think the reason is my son's got me on organics and he's making me shakes and alkaline water. I'm eating healthy and I haven't been eating healthy. That's contributing to my weight loss. This time I am doing it [become more healthy] for myself. (P5:192)

Table 7 provides details related to the transcripts, codes, subcategories, and categories associated with the category of Coping–Working and Existential and the construction of the concept of Hope in the Face of an Uncertain Future.

Table 7

Examples Illustrating the Development of the Concept of Hope in the Face of an Uncertain Future

Participant	1. Interview transcript	2. Initial codes	Theoretical memo	3. Focused codes	4. Subcategories	5. Category	6. Final concept
2	'We talked about amount of time and she gave me a number and I can beat that because I'm very competitive.' (P2:22-25)	<ul style="list-style-type: none"> Believing I can beat this disease 	<p>Coping mechanisms were focused on minimising anxiety and maintaining hope for a future living with cancer.</p> <p>Not transitioning to no treatment or palliative care.</p> <p>Participants are working at maintaining positive attitude and continue living.</p>	<ul style="list-style-type: none"> Future orientation 	<ul style="list-style-type: none"> Hope Humour & laughter Positive attitude 	Coping –Working and Existential	Hope in the Face of an Uncertain Future

Participant	1. Interview transcript	2. Initial codes	Theoretical memo	3. Focused codes	4. Subcategories	5. Category	6. Final concept
3	'Hey this is not too bad, you know attitude-wise I wasn't too bad. I have been through this. I figured if I did it once I could do it again.' (P3:26–28)	<ul style="list-style-type: none"> • Maintaining positive attitude • Believing did it once, can do it again • Hoping for a future 		<ul style="list-style-type: none"> • Positive attitude • Hope for treatment response 	<ul style="list-style-type: none"> • Minimising gravity of disease • Positive attitude • Hope 		
5	'Do what you have to do. . . I should ask her [doctor] if there's anything extra I should be doing.' (P5:202–203)	<ul style="list-style-type: none"> • Seeking knowledge—coping • Asking if anything extra I can do 		<ul style="list-style-type: none"> • Seeking knowledge 	<ul style="list-style-type: none"> • Seeking knowledge 		
2	'I became a vegetarian. I ate well. I exercised. I ran. I did everything to keep my body in a position where it could fight off anything.' (P2:116–123)	<ul style="list-style-type: none"> • Practicing healthy living strategies 		<ul style="list-style-type: none"> • Self-advocacy 	<ul style="list-style-type: none"> • Pursuing healthy living • Hope 		

Hope in the Face of an Uncertain Future

Coping –Working and Existential

Hope in the Face of an Uncertain Future

Coping –Working and Existential

Participant	1. Interview transcript	2. Initial codes	Theoretical memo	3. Focused codes	4. Subcategories	5. Category	6. Final concept
5	<p>'The things that I have I feel fortunate. I'm hoping to have a few more years, I don't know, and make the best of them.' (P5:63)</p>	<ul style="list-style-type: none"> • Feel fortunate—make the best of the future 	<p>What is it about this positive outlook and accepting the diagnosis of recurrence? Not spending a lot of time contemplating the diagnosis, just moving into treatment.</p>	<ul style="list-style-type: none"> • Uncertain future • Positive attitude • Hope for future 	<ul style="list-style-type: none"> • Realisation incurable cancer • Uncertain future • Hope 		
8	<p>'I don't like it. But it's the way it is. I could have to do dialysis. I have a cousin who's on dialysis three times a week. I don't have to do dialysis so this [having chemo] is minor in comparison.' (P8:194)</p>	<ul style="list-style-type: none"> • Minimising disease by comparing to other chronic illness 	<p>This population is working at living and not ready to discuss a future without treatment.</p>	<ul style="list-style-type: none"> • Minimising gravity of disease 	<ul style="list-style-type: none"> • Minimising gravity of disease 		
3	<p>'I feel I can keep my attitude positive, I can keep going. . . . I'll buy some time. I'll get through this thing. I'll have some more good years.' (P3:234–237)</p>	<ul style="list-style-type: none"> • Maintaining positive attitude about a future 		<ul style="list-style-type: none"> • Positive attitude • Future orientation • Hope for future 	<ul style="list-style-type: none"> • Positive attitude • Uncertain future • Hope 		

Participant	1. Interview transcript	2. Initial codes	Theoretical memo	3. Focused codes	4. Subcategories	5. Category	6. Final concept
6	<p>'There are a lot of other diseases that are just as life-threatening—like I could have a heart attack or bad diabetes.' (P6:14–16)</p>	<ul style="list-style-type: none"> Minimising cancer—relate to other chronic disease 	<p>Minimising disease allows participants to believe they can continue to live even with advanced disease—it becomes relative to this stage as opposed to their initial diagnosis. They see them separately.</p>	<ul style="list-style-type: none"> Minimising gravity of disease 	<ul style="list-style-type: none"> Realisation incurable cancer Minimising gravity of disease 	Coping –Working and Existential	Hope in the Face of an Uncertain Future
8	<p>'I found out everything there is to know about the medicine. That's how I deal with it. I think if you are acquainted with it you can better help the doctor with your treatment and care.' (P8:418–424)</p>	<ul style="list-style-type: none"> Seeking information, that's how I deal with it 		<ul style="list-style-type: none"> Seeking knowledge Self-advocacy 			

Participant	1. Interview transcript	2. Initial codes	Theoretical memo	3. Focused codes	4. Subcategories	5. Category	6. Final concept
10	'I pray every day, but I don't pray for me, I pray for others. I find caring about others first helps me.' (P10:69–70)	<ul style="list-style-type: none"> • Focusing on others to cope with illness • Coping by spiritual support 		<ul style="list-style-type: none"> • Focusing on others • Spiritual faith 	<ul style="list-style-type: none"> • Spiritual faith 	Coping –Working and Existential	Hope in the Face of an Uncertain Future
13	'Well, I try to just live my life; I don't want to say I joke about it, but I try to laugh at some of the stuff that happens. Um, it's my coping mechanism, I guess, because you can't change it.' (P13:173)	<ul style="list-style-type: none"> • Try to laugh about it; can't change it (acceptance) 		<ul style="list-style-type: none"> • Humour and laughter • Acceptance 	<ul style="list-style-type: none"> • Humour & laughter to minimise disease 		

Participant	1. Interview transcript	2. Initial codes	Theoretical memo	3. Focused codes	4. Subcategories	5. Category	6. Final concept
9	'I think there's very little if any cancer present at the moment. I think this is their way of being aggressive and were gonna be on top of this [cont. treatment]. And were gonna be sure there isn't any cancer in there, but I feel quite positive about it.' (P9:48).	<ul style="list-style-type: none"> Minimising disease to maintain hope 		<ul style="list-style-type: none"> Minimising disease Focus on treatment Positive attitude 	<ul style="list-style-type: none"> Minimising gravity of disease Positive attitude 	Coping –Working and Existential	Hope in the Face of an Uncertain Future
7	'I just had to accept, and then educate myself, educate my family, and just figure out how we were going to get through this.' (P7:419–420)	<ul style="list-style-type: none"> Seeking knowledge to minimise fear 		<ul style="list-style-type: none"> Seeking knowledge 	<ul style="list-style-type: none"> Seeking knowledge Future orientation Hope 		

3.4.2.3 Summary of the concept of Hope in the Face of an Uncertain Future.

Coping strategies provided the momentum for moving away from anger and toward seeking treatment and living with cancer recurrence. These strategies provided a source of hope that the participants could live longer with cancer.

The categories of Coping–Working and Existential and Treatment Focused revolve around hope, amidst an uncertain future. Multiple subcategories contributed to the concept of hope in uncertainty which overlapped with the concept of seeking treatment, including the following: family support, spiritual support, and faith in their physician.

Hope existed with the ability to receive treatment, as the two seemed to reinforce each other. The participants focused on being positive and hoping for a future, while recognising their disease was no longer curable. They chose to move forward with treatment and be hopeful.

So that's good. I'm always looking at that positive part of it, you know. It's not curable, ok that's a bummer, you know, ok I have my 3 or 4 days of this is really awful, but you have options, you know. You can continue to feel sorry for yourself and whatever or you can put your big girl panties on and you move forward. And, you know, that's . . . what you have to do. You know, because I feel you still have an option. I mean why, why wouldn't you choose to do that? Because your life will be better. (P10:20–23)

The category and the developed concept of Hope in the Face of Uncertainty supported the maintenance of hope as participants faced the new recurrence diagnosis and remained positive throughout treatment. The acceptance of the new disease status allowed them to be hopeful and proceed with treatment.

There were multiple subcategories associated with coping that worked together to reinforce the concept of Reluctant Acceptance. These overlapping subcategories contributed to the development of the concepts and the dynamic movement described between the diagnosis of advanced cancer recurrence and how participants proceeded to manage this new experience. These shared subcategories are discussed in Section 3.7 below.

3.4.3 The concept of Seeking Life Through Continuous Treatment

The concept of Seeking Life Through Continuous Treatment developed from the category of Treatment Focused, which was underpinned by the subcategories of focusing on treatment and the importance of an established treatment plan. During the transitioning phase between believing they had been cancer free survivors to finding they had recurred with advanced incurable cancer, participants were focused on the availability of treatments and coping strategies that provided hope and reassurance that treatment was available and a long-term remission was possible. This was captured in the words of one participant:

It's not curable but treatable. (P10:141)

The meaning of this recurrence was transcendent for many and allowed them to regroup and have hope for their uncertain future. Participants acknowledged that this advanced recurrence was incurable and therefore different than the initial diagnosis of cancer. All of the participants chose to seek treatment and believed that having treatment options symbolized hope that they could live, albeit live with cancer. Figure 5 highlights the portion of the Venn diagram related to this concept.

In the following section the subcategories of focusing on treatment and the importance of an established treatment plan are discussed.

3.4.3.1 Focusing on treatment.

As noted above, participants expressed a desire to keep moving forward, and as part of this did not want to discuss the possibility of dying from their disease. Instead their focus was on continuing to live with cancer. There was confidence in their ability to successfully live with recurrent disease, believing that remission was possible because they had achieved that in the past.

How did it feel? Gosh. I guess obviously upset, but I knew that there were so many treatments available that it wasn't like I thought, 'Oh my God, you're gonna die' or something. I just ploughed right ahead. (P6:24).

Believing that there were 'so many treatments available' allowed hope for a future and contributed to believing there was life through treatment.

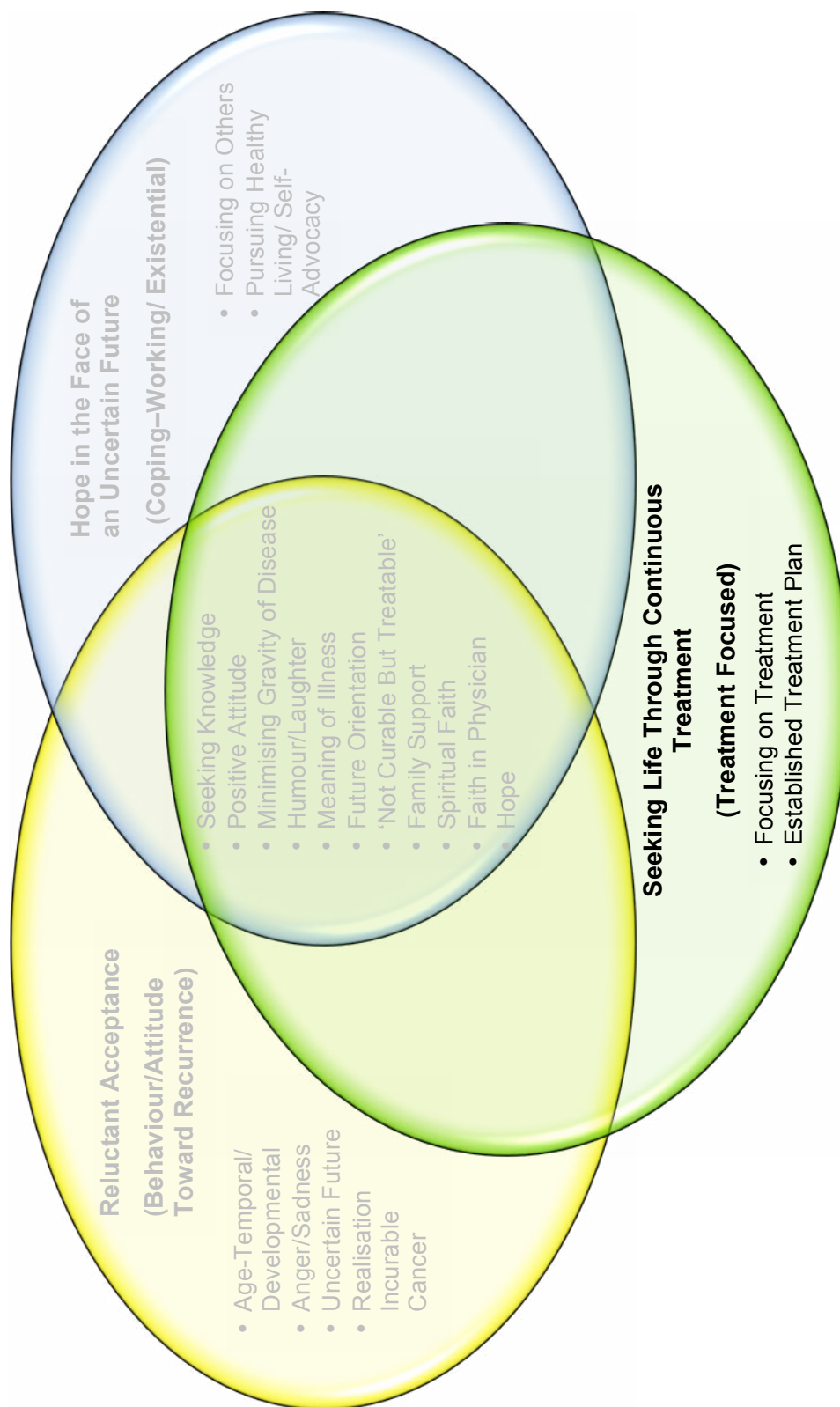


Figure 5. Seeking Life Through Continuous Treatment: Category and subcategories.

I have oral chemo . . . but if I have to do it, I'll do it; I'm not, you know, ready to throw in the towel because I'll hear people say, 'I have heard of people saying "No, I don't want to do this anymore"'. I definitely am not at that point. I just can't imagine . . . (P5:108–111)

Participants sought new treatments for their recurrent disease in order to live and were willing to remain on treatments continuously. Even as participants described their initial response to be of anger and sadness to the advanced cancer recurrence, they uniformly shifted to a focus on treatment after acceptance rather than on the possibility of death. Having completed chemotherapy treatment as part of their initial cancer, seeking treatment again sustained a belief in the possibility of treatment leading to remission again, as described by this participant:

I'm considered in remission, however, I have to continue my therapy indefinitely because of the kind of cancer I do have. (P7:50)

Participants described the benefits of planned treatments and their overall beliefs for treatment outcomes.

They wanted me to start on this pill that can attack this mutated type of thing. So I started it now going on 4 weeks. I have been through this. I figured if I did it once I could do it again. (P3:24–28)

The concept of Seeking Life through Continuous Treatment is shared with the other concepts of Hope in the Face of an Uncertain Future and Reluctant Acceptance, and therefore contains the subcategories that are seen within these respective concepts. These subcategories were shared as they

overlapped with how participants responded to the acceptance of advanced cancer recurrence and were involved in seeking treatment.

3.4.3.2 Established treatment plan.

The significance of having an option for treatment was important. The willingness to participate in treatments and follow the doctor's recommendations was apparent. Knowing the doctor had a plan for treatments gave participants focus and energy to seek survival.

I just make the best of it. Do what you have to do. You know, and that's how I feel, I'll just do what I need to do and when I talked to the doctor I should have asked her if there's anything extra I should be doing.
(P5:202–203)

Believing in the doctor's recommendations even when acknowledging it was not a cure was important. There was hope in this comment as well. Also maintaining the uncertainty allowed the participant to stay hopeful and cope with the knowledge that this treatment is not focused on a cure: 'I was told it's not a cure, but it's something that might help, to shrink the tumour' (P1:129–130).

This focus on treatment to keep living was a driving force that gave hope for a future. The acceptance of 'it's not curable but treatable' as described by participants included the different subcategories, such as focusing on treatment and the meaning behind having an established treatment plan. It was the hope for remission and continued life and also displayed the positive

attitude that was described by participants as well, looking for the positive side.

Table 8 provides details related to the transcripts, codes, subcategories, and categories associated with the category of Treatment Focused and the construction of the concept of Seeking Life Through Continuous Treatment.

3.4.3.3 Summary of the concept of Seeking Life Through Continuous Treatment.

The concept of Seeking Life Through Continuous Treatment is underpinned by the understanding that this cancer recurrence is not curable, but treatable. Unlike with participants' initial cancer treatments, where the goal was to cure, there was understanding that a cure was no longer a realistic goal. Having a treatment plan signified hope for a future and reinforced the belief that their disease was treatable. They described a concern that treatment might now be harder than for their initial cancer experience because they were older, and uncertainty about whether they would have more difficulty with the illness, but they still chose to be treated. The subcategory of focusing on treatment provided insight into what the participants believed about their disease prognosis and goals for care.

This category, Treatment Focused, and the subcategories described above were the ones that provided the overall meaning of advanced recurrence and the interrelated concepts with the primary desire of those experiencing it as seeking treatment to continue living. While I present the findings individually related to the development of the concepts, the interrelatedness is seen in the

Table 8

Examples Illustrating the Development of the Concept of Seeking Life Through Continuous Treatment

Participant	1. Interview transcript	2. Initial codes	Theoretical memo	3. Focused codes	4. Subcategories	5. Category	6. Final concept
1	'I was told it's not a cure, but it's something that might help, to shrink the tumour.' (P1:129–130)	<ul style="list-style-type: none"> • Recognising incurable disease • Believing treatment might help 	<p>Continuous treatment with goal of continued life.</p> <p>Believing recurrent cancer is not curable but treatable. This attitude toward recurrence also relates to reluctant acceptance.</p>	<ul style="list-style-type: none"> • Focusing on treatment • Not curable but treatable 	<ul style="list-style-type: none"> • Focusing on treatment • 'Not curable but treatable' • Hope • Established treatment plan 	Treatment Focused	Seeking Life Through Continuous Treatment
3	'They wanted me to start on this pill that can attack this mutated type of thing. So I started it now going on 4 weeks. I have been through this. I figured if I did it once I could do it again.' (P3:24–28)	<ul style="list-style-type: none"> • Treatment worked before I could do it again • Believing in continuous treatment 	<p>Continuous treatment with goal of continued life.</p> <p>Believing recurrent cancer is not curable but treatable. This attitude toward recurrence also relates to reluctant acceptance.</p>	<ul style="list-style-type: none"> • Focusing on treatment • Future orientation • Positive attitude 	<ul style="list-style-type: none"> • Focusing on treatment • Future orientation • Positive attitude 	Treatment Focused	Seeking Life Through Continuous Treatment

Seeking Life Through Continuous Treatment

Participant	1. Interview transcript	Theoretical memo	3. Focused codes	4. Subcategories	5. Category	6. Final concept
7	<p>'I'm considered in remission, however, I have to continue my therapy indefinitely because of the kind of cancer I do have.' (P7:50)</p>		<ul style="list-style-type: none"> • Focusing on treatment 	<ul style="list-style-type: none"> • Focusing on treatment 		
10	<p>'I don't think you have any option other than to move forward [have treatment] and be positive about whatever outcome there is. I still feel positive about it. It's not a great result but it's treatable.' (P10:64–66)</p>	<ul style="list-style-type: none"> • Treatment to live • Feeling positive • Hope in treatment 	<ul style="list-style-type: none"> • Focusing on treatment • Positive attitude 	<ul style="list-style-type: none"> • Focusing on treatment • Positive attitude 		
11	<p>'I would probably never be cancer free at this point but what they could do, it would be like a fire—medications they would give me would keep it down to like a low little ember burning. Keep it under control so I could have a longer more enjoyable life. And so that's what I'm believing is the plan.' (P11:81–89)</p>	<ul style="list-style-type: none"> • Believe in a treatment plan to prolong life • Hoping for treatment response • Recognising incurable disease 	<ul style="list-style-type: none"> • Focusing on treatment/plan • Positive attitude • Realisation not curable 	<ul style="list-style-type: none"> • Focusing on treatment • Established treatment plan • Positive attitude • 'Not curable but treatable' 	Treatment Focused	

Participant	1. Interview transcript	2. Initial codes	Theoretical memo	3. Focused codes	4. Subcategories	5. Category	6. Final concept
5	'I will have chemo, I have already had round one. I'm not ready to throw in the towel. I have heard of people saying no, I don't want to do this anymore. I definitely am not at that point. I just can't imagine ... giving up.' (P5:108-111)	<ul style="list-style-type: none"> • Chemo means not giving up 		<ul style="list-style-type: none"> • Established treatment plan • Focusing on future • Positive attitude 	<ul style="list-style-type: none"> • Established treatment plan • Future orientation • Positive attitude 	Continuous Treatment	Seeking Life Through Continuous Treatment
10	'You know, I got my attitude is like I am doing the most aggressive treatment that I can handle. And I think I can handle a lot.' (P10:142-143)	<ul style="list-style-type: none"> • Believing in treatment • Importance of having a plan 		<ul style="list-style-type: none"> • Focused on treatment • Established treatment plan • Positive attitude 	<ul style="list-style-type: none"> • Focusing on treatment • Established treatment plan • Positive attitude 		

shared subcategories and helps to provide a rationale for the conceptual model that shows the interactive feedback loop action taken by participants in this moment of time. The shared subcategories are seen within each concept but maintained a separateness that was encompassed by the reactions as a whole. Therefore, the model was not seen as a single circle surrounding all of these categories the concepts Reluctant Acceptance, Seeking Life Through Continuous Treatment, and Hope in the Face of an Uncertain Future provides the framework that holds the experience together.

3.5 Intersections of the Three Concepts

Understanding the interrelationships between concepts is critical to understanding the iterative and temporal nature of the model presented in Chapter 5. Figure 2 provides the overall description of how the intersections are related to the three concepts; Figure 6 highlights just the areas where all concepts overlap. As described above, these shared subcategories are seen in all of the concepts and were constructed from the categories of Behaviour and Attitude toward Recurrence, Treatment Focused, and Coping–Working and Existential. These are a motivation to find personal equilibrium and support seeking life.

The overlapping subcategories demonstrate a relationship between two or all of the categories of Behaviour and Attitude toward Recurrence, Coping–Working and Existential, and Treatment Focused, and serve to support or increase the impact on the concepts as they provide coping strategies and hope for the participant. These shared subcategories included seeking knowledge, positive attitude, minimising gravity of disease, humour/laughter,

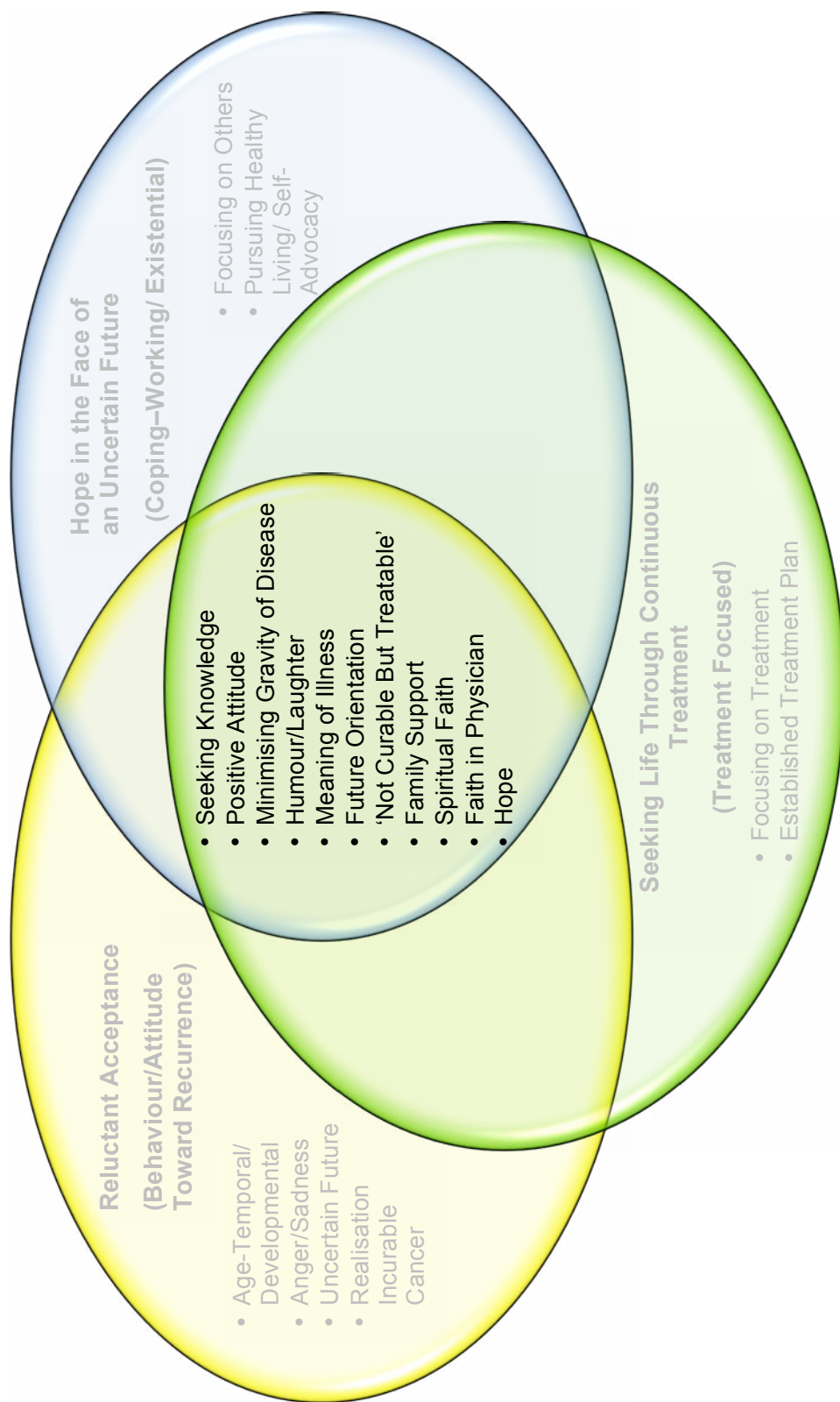


Figure 6. The shared subcategories between Reluctant Acceptance, Seeking Life Through Continuous Treatment, and Hope in the Face of an Uncertain Future.

meaning of illness, future orientation, 'not curable but treatable', family support, spiritual faith, faith in physician, and hope. The non-overlapping areas display subcategories for the respective categories.

The degree to which the concepts and their related categories and subcategories intersected varied between the individual participants and depended on the context and significance they placed on each category. The shared concepts of Hope in the Face of an Uncertain Future and Seeking Life through Continuous Treatment seemed to happen simultaneously after the concept of Reluctant Acceptance. Reluctant acceptance was the catalyst that allowed the transition to treatment and hope, as described in the following participant quotations.

I'm going to give it my best shot and what happens is going to happen. But I'm going to make the best of it. I'm still planning . . . I'm getting things done . . . I'm also making plans for next month to go out of town for a few days. (P3:309–315)

Hey, this is not too bad, you know, attitude-wise I wasn't too bad. I have been through this. I figured if I did it once I could do it again. (P3:110–112)

The overlap of subcategories and concepts can be seen in this transcript:

So I had to kind of pray and deal with it. Faith is a big support. And I have my kids. They are really supportive that way too. So I have all this family that can help out . . . and they give me a lot of positive

accolades. It is really positive and it helped me stay positive. (P12:88–92)

This comment illustrates how subcategories of positive attitude, spiritual faith, and family support together developed into the concepts of Hope in the Face of an Uncertain Future and Seeking Life through Continuous Treatment. Each of the subcategories can be isolated but they are not mutually exclusive and are instead all constantly present.

Participants described their experience and the interrelationship of the concepts as they supported their pursuit for continued life. The following section describes the shared subcategories among the three concepts.

3.5.1 Seeking knowledge.

The participants' words as related to the meaning of seeking knowledge describe a way to understand their previous treatment, and why the cancer recurred. They also relate to Reluctant Acceptance as they begin seeking knowledge about the diagnosis of advanced recurrence, which in turn promotes treatment-seeking behaviour. Seeking information was linked to a sense of control. It was important to participants to research ways to treat their recurrent disease and know of all treatment options to enhance the likelihood and hope that they could achieve stable disease with acceptable quality of life.

Receiving the diagnosis of recurrent disease often caused participants to review their prior treatments and compare their treatment history to other cancer patients, and treatment guidelines they found in publically available literature or on the Internet. For some participants, seeking knowledge was

not only about what might help in the future but also about what went wrong in the past that contributed to them now being diagnosed with recurrence. Describing the stage of breast cancer at initial diagnosis, one participant said,

I wasn't really worried about the breast because breast was 2B, at least that's the way they staged it. (P2:30–31)

This participant expressed that she may have been undertreated initially related to possibly being mis-staged, and therefore recurred:

But looking back on it, I mean, they could have mis-staged this whole thing because I was at—for my original, who knows. (P2:240–241)

Concerns about misdiagnoses speak to the importance of knowledge and information about treatment plans.

I knew it had to be a mistake because no one in my family on either side had ever had breast cancer. It had to be a mistake. I then I was very angry about my care at [cancer treatment centre]. I saw [oncology physicians], they were supposed to be the best but I did not get the right care. [First diagnosis oncology physician] doesn't know anything about aftercare and [first diagnosis oncology physician] never offered me hormone therapy. All the big shots. So I was the first person from [cancer treatment centre] to go to [first diagnosis physician]. He told me I did not have an infection in my breast. I did not have mastitis. I had all of it. He did not take care of me. I was very mad at him. (P4:14–24)

By voicing their treatment concerns, participants questioned whether they had received the right treatments with their initial cancer. They wondered if their

initial treatment had been different, perhaps they might not have experienced recurrence. They described information they had found on the Internet or recommendations they had read about that would help them understand why their cancer recurred. It was as if seeking and finding information about their previous treatments would help them understand why the disease recurred and also what could be done differently in the next phase of treatment to avoid future recurrence:

So I just knew that it was something that I just had to accept and then, you know, educate myself, educate my family and just figure out how we were going to get through this. (P7:19–20)

This theme of seeking information was a means of moving from reluctant acceptance and avoiding a trajectory toward death to regaining control. Their years of being identified as survivors, people who successfully defeated cancer, had prepared them to respond to this recurrence and continue to live, even if it meant living with cancer.

3.5.2 Positive attitude.

The overlap of Reluctant Acceptance, Hope in the Face of an Uncertain Future, and Seeking Life through Continuous Treatment is seen through the positive accepting attitude that participants describe as they plan to do whatever is needed. This attitude continued to be present in the three concepts and provided a means of coping and acceptance. It promoted energy and acceptance and hope for a future.

I'm working through all that and I continue to try to be positive about everything. . . . It's just a competition. I'm going to . . . I'm going to live. I'm going to do everything once again that I need to do to take care of my body and see how long we can keep this thing back. (P2:284–289)

This positive attitude saturates all the concepts by allowing acceptance of the disease and focus on treatment. One participant said,

And from the moment I came in the door and from the very first doctor I saw, everybody continued with this positive attitude and never once did I think this wasn't going to work out. (P09:8)

This subcategory was seen between all three concepts as it impacts Reluctant Acceptance, Hope in the Face of an Uncertain Future, and Seeking Life through Continuous Treatment.

3.5.3 Minimising the gravity of disease.

As participants faced their recurrence and began to accept the new reality, they often concluded that the situation could be worse. The attitude that 'it could be worse' was identified through theoretical sampling as a minimisation strategy used by participants that contributed to their sense of Reluctant Acceptance and overlapped with their Hope in the Face of an Uncertain Future and their Seeking Life Through Continuous Treatment. Minimising was a coping strategy that allowed participants to believe that their disease, although incurable, could be worse. Therefore, there was hope for another remission or stabilisation of disease that would allow them to continue living with cancer. Participants were focused on the extent of the recurrence,

involvement of lymph nodes, or the extent of metastasis as a means of gathering information to plan their best treatment. In cases where diagnostic tests had revealed less extensive disease than they had first feared, participants saw this news as an indicator that they would live longer:

When I had the PET scan the news was good that it was only in the three lymph nodes. (P8:176)

This is an example of how participants minimised the gravity of their disease.

Another participant stated:

But I could see in the uh, when they did the CT scan—the bone scan rather, I could see um, in a little computer image above—it was very small, but I could see little spots that were highlighted. So I'm thinking okay, those are the tumours in the bones, but at least it wasn't the whole bone system. (P11:24)

Minimising the gravity of their cancer allowed participants to believe they could continue living with incurable disease for many years. Having fewer lymph nodes or bone metastases was perceived as meaning the disease was controllable. They did not deny that they had advanced cancer but chose not to dwell on the gravity associated with advanced cancer but focused instead on treatment and stabilisation of their disease. To survive meant to minimise the gravity of the disease, to accept their disease and sustain hope that treatment would prolong their life.

3.5.4 Humour and laughter.

Participants used humour and laughter to cope with the emotions of their advanced disease and maintain Hope in the Face of an Uncertain Future. At times, participants also used humour to face the possibility of death. Humour softened the intense reaction to the reality that they could die from this recurrence.

Oh, my husband and I sat up there and cried when we first got home from the diagnosis. And yet eventually there was a humour because I was all ticked off because I worked all my life and I'm not going to get to draw Social Security [laughs]. (P2:355–358)

When describing their advanced disease, other participants used humour and laughter to reduce anxiety and fear and maintain a feeling that treatment could work again.

Interviewer: So do you ever think about what would happen if it didn't go away?

Participant: No.

Interviewer: Stay positive?

Participant: I don't really address that. [Laughs] I mean I know that could happen, you know, and if it does well, you know, that's the way it is, but, uh, I'm not going to do anything to discourage myself, you know. And I don't like to think things like that cause I think, 'Ok, let's don't go there. We don't know that's a possibility, you know. Just take today,

you know. That's what we got.' [Participant laughing throughout conversation] (P9:79–82)

Participants also used humour and laughter to negotiate their identity as cancer patients.

I would come here, you know, for my regular check-ups. Which I never missed. I always, you know, came here and I'd think all these poor sick people. And [laughs] and I guess I was one of them too, but I just didn't, you know, I didn't think like that. (P11:30–31)

Humour and laughter was used to minimise the fear around the recurrence and what it meant. It allowed them to avoid the seriousness of this recurrence at this time as they focused towards future treatment.

Participant: I just, you know, every situation I've ever been in, I've tried to make the best of it. It doesn't, I try to find humour in it, I try to . . .

Interviewer: And so knowing its stage 4 and your, your attitude is?

Participant: 'Here we go. What's this new adventure? Let's see what happens,' you know. (P5:190)

There was an attempt to keep the conversation light and move the conversation toward hope and positive remarks about their future. Humour and laughter were used for Reluctant Acceptance of their diagnosis, Seeking Life Through Continuous Treatment, and sustaining Hope in the Face of an Uncertain Future.

3.5.5 Meaning of illness.

The meaning of illness drove much of the participants' reflection on their experience with advanced cancer recurrence. These reflections extended throughout their entire cancer experience, from the time of their initial diagnosis and treatment, through the time of remission and now with disease recurrence.

But what I'm saying is, disease changing you, changes you. And although you don't think about it, you have a new wisdom about life. And, you know, cancer survivors always say, 'Oh, you know, I survived and I bless this disease because it taught me how to live. It taught me how to appreciate everything. Everything looks new to me. I appreciate things I look at, which I took for granted. I appreciate the people around me which I never noticed before.' It's true. It gives you an awareness of what's important. Really, sharp awareness. And that is a blessing. Now, I don't want this awareness to go. I don't want my body, [to die—but did not say the words] now I found this new wisdom I want to use it, you know? (P14:186–190)

In reflecting on the meaning of the illness, some of the participants expressed how their lives were significantly changed and others described the faith in living day to day.

I want to be strong and just what I'm saying is that I want to do everything I can to live a quality life for as long as I can. I would want that for anyone. I understand that in the very beginning, you are disseminating a whole bunch of information and looking at your life

being shortened. But as long as we're here and we can do everything that we can to make that a quality life, I'm all about that. That's probably what I would share with them is it's every day one foot in front of the other and just—you know, I still get up every single morning and go open my window and look at the sun just starting to peak up and gather light. It's the most beautiful sight in the world. It's my new day. I got a new day. I can stand there and applaud. (P2:15–28)

The meaning of the illness includes both the initial cancer diagnosis and making sense of this advanced cancer recurrence and pervaded the three concepts. Initially with the diagnosis of advanced cancer participants questioned why, and sought a meaning for this recurrence. The meaning they attributed to the experience permeated their rationale for why treatment would work and supported hope for treatment. Establishing meaning gave them a purpose for seeking living.

3.5.6 Future orientation.

It was necessary for participants to focus on their future and that idea is what supports all three concepts. Initially with Reluctant Acceptance, to believe they had a future was necessary and provided them with Hope in the Face of an Uncertain Future and supported focusing on treatment to Seek Life Through Continuous Treatment:

I don't think you have any option other than to move forward [have treatment] and be positive about whatever outcome there is. I still feel positive about it. It's not a great result but it's treatable. (P10:64–66)

Future orientation included maintaining a positive attitude. It allowed a belief that life could go on:

I feel I can keep my attitude positive, I can keep going . . . I'll buy some time. I'll get through this thing. I'll have some more good years.
(P3:234–237)

This is also an example of maintaining a positive attitude as described in Hope in the Face of an Uncertain Future, and although it is uncertain, believing there is a chance. As participants all chose to seek treatment and describe hope they have for continued life, their belief in a future was clearly in place. The overlapping concepts are seen throughout this experience of advanced cancer recurrence. This particular subcategory clearly relates as seeking treatment gives hope and knowing treatment is possible allows acceptance.

Participants in this study were early in the time of recurrence and remained focused on the hope for extended survival. While there was some mention of potential death in the interviews, the participants remained largely concerned with continued living and they did not speak about hope for a peaceful death as described in the literature. As in the participant comment below, treatment would keep the disease 'in control':

She [the physician] told me that I would probably never be cancer free at this point but what I, but what they could do, it would be like a fire. And it would be . . . the medications they would give me and everything would keep it down to like a low little ember burning, so they could keep it under control so that I could have a longer, more enjoyable life, you

know, and not let it get out of control to consume me, you know? And so that's what I'm believing is . . . is the plan. (P11:81–84)

A treatment plan provided hope for continued life for the participants. Achieving a response did not necessarily mean that treatment would end, but rather that all participants assumed that treatment would continue indefinitely. Remaining under treatment and having a long-term treatment plan supported the goal of living with cancer, not dying from cancer.

I'm considered in remission; however, I have to continue my therapy indefinitely because of that, you know, the kind of cancer I do have . . . disease that it is, you know, he doesn't want to put to chance that if we stop therapy. That, you know, there might be a chance that it comes back and we don't want that. So that's why I'm here today. (P7:50–54)

Confidence in cancer treatment and believing that their treatment options were more advanced today and more effective than what they had received with their initial cancer diagnosis promoted acceptance, hope, and treatment. They felt that this current era of cancer treatment options offered greater hope and would yield better responses.

Participant: Well, yeah. I know that I'm getting state-of-the-art, up-to-the-minute medical benefits from [cancer treatment centre] which instead of antiquated systems, you know, like now for instance. Instead of giving me radiation for my bone cancer, and causing other problems and other horrible side effects from that, they give you a shot, you know? A shot in the arm, or a shot in the butt, and it does this wonderful work on you.

Interviewer: Building your bones.

Participant: Yeah, so it really addresses the problem and takes care of it. So the quality of life is still good. (P11:189–193)

The belief in the availability of treatments that promised living longer impacted the attitudes of these participants and their decisions. They reluctantly accepted the diagnosis of advanced recurrence and moved forward in a new reality of living with cancer. Participants reflected on treatment options when first diagnosed and how the many new advances in recent years are a source of hope.

3.5.7 ‘Not curable but treatable’.

The concepts of Reluctant Acceptance and Hope in the Face of an Uncertain Future revolved around the belief that even though the recurrent disease was different than their initial cancer experience, the cancer was still treatable. They accepted the fact that this recurrence was not curable and turned their hope to it being treatable hence the subcategory ‘not curable but treatable’.

Well, I . . . I know the cancer I have now is not curable. I know it’s treatable. How long it will be treatable? I don’t know, you know, we’ll see. I got my attitude is like I am doing the most aggressive treatment that I can handle. And I think I can handle a lot. And so, you know, there are times I think, ‘Ok what am I going to do? What’s going to be the treatment when I’m done with this?’ But I don’t go forward with that, you know, I just say, ‘When I get there I’ll get there’, and, you know what I mean? I don’t go beyond that and saying one I’m not going to be

able to have this treatment, I am going to have to have something else. You know, I don't think like that. I just think this is my treatment. I know, I'm intelligent. I know that someday that's not going to work and I'm going to have to do something else, but I don't bother thinking about that is the point. There's no point until that happens, and who knows?
(P10:141–150)

Participants described the belief that there would always be another treatment available should their current treatment not achieve remission. They described the treatment, remission, recurrence, and return to treatment cycle for the recurrence that would maintain their life. Remaining on treatment was also based on hope that new treatments or cures might be discovered if the participants could just stay alive until that time. Participants described this need for continuous cancer treatment and compared cancer treatments to chronic disease management.

I don't know. I think, I think a friend of mine just said to me, she did not know I had this recurrence. And we were . . . see, she has rheumatoid arthritis. And she said, 'Bad news is we have this disease. The good news is there is treatment for it.' And I look at it that way. Bad news is, you know, it's there and we have it. The good news is there's treatment and we're treating it. (P8:28)

This comparison to rheumatoid arthritis allowed this participant to accept continuous treatment as something she shared with other people with chronic disease who were also living with their illness. Participants described being hopeful because the new treatment options available for their recurrent cancer

were better than earlier chemotherapy or radiation therapy used for their initial diagnosis. They were able to accept a new life that would include ongoing treatment if that would allow them to remain alive. Participants with advanced recurrence now had an understanding that treatment would be life-long, and they would manage their disease as others manage chronic illness. Participants described their goal as living for as long as they can, as well as they can. If living required chemotherapy continuously to maintain remission, they were willing to have continuous chemotherapy treatments.

And I was on those for December, January, and February. Then I repeated the CAT scans and all of that and not only had the tumours not receded, but they had grown and I had new ones. So that was probably, that was one of the more difficult times because, you know, 3 months of infusions and the concurrent side-effects and then somebody just, and then you're just like they've done . . . not only has it not gotten better, it's gotten worse. So then at the beginning of [month] I started on treatment number 3, which is the oral, um, chemotherapy, uh, [treatment name]. (P6:27–33)

There was an acceptance of doing whatever it takes including treatment after treatment to maintain life with stable disease.

My friends, some of them want to know I'm done with this. And they don't understand I'm gonna be in treatment for the rest of my life. I have to keep saying that. They said, 'You're going to [cancer treatment centre] for what?' I said, 'For my monthly treatment'. 'You still have to go there? Well I thought you were in remission.' 'Yes I am, but this . . . I

will have this for the rest of my life'. And it's having to explain that. And you say it over and over again and finally you internalize it. (P8:144–145)

Participants described that at the time of their initial diagnosis they were seen by their families or themselves as either a patient with cancer or a person whose cancer was 'in remission' or 'cured'. Now, they view the cancer as not ever being in remission, rather in a stable situation due to treatment and assume their life is now a life similar to other chronic illnesses. Continuing treatment and viewing cancer as a chronic disease was related to the concept of hope, as continuous treatment signified the potential to live with recurrent disease.

3.5.8 Family support.

The subcategory of family support was described by all of the participants as a source of strength in dealing with their cancer recurrence. Family support was critical, allowing them to have Hope in the Face of an Uncertain Future and to continue to live with cancer. Participants described the importance of their families' support at recurrence and through seeking a treatment plan and receiving treatment. Caregivers and family were not interviewed as part of this study. Family support provided optimism and helped them deal with their disease and added to their sense of hope.

So you play the best possible hand you can gather. And I'm very, very, very lucky, because okay, I, I've got this one bad card, but I've got a fantastic doctor, got fantastic husband, my family's wonderful. They all came to . . . from [describing where they came from to visit] one after

the other to visit. My sister is here, my brother was here last month, my mother was there the month before. So, I mean, I am so lucky to have these huge things in life. Some people don't have this. (P14:292)

Thirteen of the 15 participants came to the interview appointment with their significant others or a family member. Family members were described by the participant as helping them remain focused on the future, as reflected by these participants.

Support of your family is the most important. (P1: 399)

Focusing on family motivated participants to keep moving forward.

When I was feeling really bad, I would just go out there and sit and watch [grandchildren playing in the pool] with a huge smile on my face. This last week we've been able to do a few things together. So it's been—it's just been great. (P2:323–326)

3.5.9 Spiritual faith.

Spiritual faith was identified as an important subcategory in supporting their feelings of hope and seeking treatment. Spiritual faith ranged from strong religious identification, such as believing their diagnosis and treatment was an act of God, to a Jungian belief that promoted a transcendent aspect of coping without a belief in a God.

Interviewer: So you actually do think about the future and think and kind of draw a line, it could be this or it could be that?

Participant: Yes. You know, and I do have religion, I am spiritual.

Interviewer: Spiritual?

Participant: Spiritual. I just had to go back to the mantra of 'your only problem is today'. No matter what any doctor says, they are not going to put an expiration date on you. That's between you and God. And it's today. (P2:177–184)

Placing faith in God provided hope and a sense that there was something else, a greater power that guided their path.

But see, who knew then now that I was going to deal with this and be in a place where, you know what I mean? I think God just is divine and puts things in order for me, 'Okay, you know what', and then you look back and you're like, 'Oh that's why you did this'. [Laughs] (P7:254)

Believing in God or other spiritual forces created a sense of hope, described as a hope that God would see them through this crisis. Faith provided a shared experience of not only hope for a future, but supported a positive attitude and future orientation. Family support and spiritual faith contributed to support for seeking treatment and living with the cancer recurrence.

3.5.10 Faith in physician.

The subcategory of faith in physician speaks to trust in physicians and treatment. Trusting in their physicians and believing that their physician cared about them and shared their desire for survival allowed participants to cope with recurrence and hope for a future through treatment. The belief that the physician had the knowledge and the ability to provide the treatment to keep them alive was important. Participant 9 described her feelings about treatment

for this recurrence and seeking a second opinion in which staff were more positive:

Then I went on from there to [from one hospital to another] [and it] was a complete opposite viewpoints. 'You definitely will survive. You do exactly what we tell you, you will survive'. And from the moment I came in, the door of [the second hospital] and the very first doctor I saw, everybody continued with this positive attitude and never once did I think this wasn't going to work out. (P9:10)

Participants described the faith they had in their physicians and the impact it had on their hope for continued life. Participants believed physicians communicated hope by providing reassurance about their treatment options and ability to live with cancer.

I told my sister, you look at him you know right away what he's thinking, what he's feeling. Like the day that I went and the colour drained from his face. I mean you can see and she said, 'You're right'. She goes, 'He was practically doing cartwheels because your test came back so good'. (P8:214–215)

This faith in their physician was interrelated with coping and seeking treatment, as participants reported that when their physician was hopeful, and treatment was offered, they were hopeful for a future.

3.5.11 Hope.

As a subcategory, hope speaks to seeking treatment for continued survival in uncertain future and resulting acceptance. Hope is how they coped with the

distress of the diagnosis of advanced cancer recurrence, and provided support to seeking treatment. Participant 7 commented:

Accept it and figure out how to deal with it and be open about it. (P7:29)

Hope did influence their actions to seek treatment for survival and allowed participants to cope with recurrence by providing them a plan with which to focus their actions and influence positive coping in an uncertain future. Participant 1 stated:

I know I was told it's not a cure, but it's something that might help, you know, to shrink the tumour. (P1:169–170)

Hope for a treatment was evident as participants sought to have a response to treatment in light of their incurable stage of disease. Positive relationships and family were cited in the interviews as key supports at this time of recurrence, and family members provided hope by strongly encouraging the participants to seek treatment for their advanced disease. For one participant, her child played a pivotal role in her deciding to seek treatment.

She had a lot to do with it 'cause she didn't want me to give up. She says, 'I want to look into this. I want to talk to so and so'. She was more involved this time, I would say, in my treatment procedures. (P1:495–496)

These participants again describe the energy that is used to keep them moving forward and seeking life in light of the uncertainty experienced with advanced cancer recurrence and knowing it is incurable. One participant said, 'I learned to fight better than I ever have in my life', clearly recognising the

seriousness of this diagnosis yet maintaining a positive hope for a future and describing no other choice:

My own personal philosophy is to be positive. Every day be positive, because I learned to fight better than I ever have in my life. . . . I'm gonna be a survivor. I'm a survivor I have to fight every day. I have to think positive. (P9:56–57)

As participants considered how they would live now with recurrent cancer, they sought ways to actively cope by pursuing strategies they believed would help them control their health and future.

I feel I can keep my attitude positive, I can keep going. And I can get myself physically built back up strength-wise and mentally-wise, physically I'll be alright. I'll buy some time. I'll get through this thing. I'll have some more good years. And that's my attitude. It's the way I'm looking at it. (P3:9–14)

This participant clearly describes the importance of a positive attitude to 'keep going' and the importance of feeling physically and mentally strong. Participant 3 illustrates the meaning of these concepts as they relate to continued life.

As a force that motions participants forward, hope underlies their ability to seek treatment in the face of the uncertain future. The positive attitude reflected feeling hopeful, even when at times it came from a place of sadness. For instance,

Participant: Well, it, it is sad. But I don't want to dwell on it, uh, I just can't. What good does it do? And I have a hope.

Interviewer: You have hope?

Participant: I have hope. I just make the best of it. Do what you have to do. You know, and that's how I feel, I'll just, I'm doing what I need to do.

(P5:207)

The following section presents a summary of the intersections of the three concepts.

3.5.12 Summary of the intersections of the three concepts.

As illustrated in Figure 2, the concepts developed from the subcategories and categories constantly interrelate to support the concept of participants seeking life. Seeking knowledge and minimizing gravity of their disease as coping strategies help participants find acceptance and allow them to cope with the uncertainty of this new phase of their cancer trajectory.

This section has described the subcategories that were evident in each of the constructed concepts. Participants described how these subcategories impacted their reluctant acceptance of their advanced recurrence and chose to seek treatment as family support and hope for a remission influenced how they sought their future. As people remain biological, psychological, social, and spiritual beings, no one moves through decisions—especially life threatening decisions—without being influenced by multiple factors as illustrated by these subcategories.

The reality is that the dynamic interplay between these subcategories in the conceptual overlap between the concepts provides an abstract understanding of these relationships. The interrelationship of the concepts provides a baseline for a deeper study of the relationships capturing this particular moment of time of advanced cancer recurrence for theory development in the future.

3.6 Summary of the Core Findings

This grounded theory approach has led to the identification of three concepts: Reluctant Acceptance, Seeking Life Through Continuous Treatment, and Hope in the Face of an Uncertain Future. The next chapter examines literature related to these three concepts and how these concepts relate to previous research. Significantly, for the most part, the context in which the studies occurred does not reflect the evolving treatment options available to the population for my study.

Chapter 4: Literature Review

4.1 Objective of the Literature Review

As described in Chapter 1, although the number of people achieving cure is growing in the U.S., many will recur with advanced disease years after completing treatment (American Cancer Society, 2016a; Ng & Travis, 2008). This research seeks to understand the experience of advanced cancer recurrence using a constructivist grounded theory methodology (Charmaz, 2014). The objective of this literature review then is to examine relevant literature to further support and substantiate the newly developed conceptual model describing this experience, of Reluctant Acceptance of Living with Advanced Cancer Recurrence and how the model fits into the broader relevant literature. The literature review allows refinement of the newly developed model related to the findings in the reviewed literature and positions the newly developed model to answer the research question (Charmaz, 2014). This newly developed model will be discussed in detail in chapter 5.

4.2 Rationale for Positioning of the Literature Review

This literature review was conducted after analysis of the data. This design is guided by grounded theorists' recommendations for the literature review to be delayed until after data analysis and theoretical findings are completed as a means to improve rigour of the developed findings (Charmaz, 2014; Chiovitti & Piran, 2003; Dunne, 2011; Giles, King, & de Lacey, 2013; Glaser & Strauss, 1967). There are multiple reasons described by grounded theorists to support a delayed literature review:

1. A delayed literature review avoids biasing of the outcomes by incorporating preconceived knowledge into the theoretical findings (Charmaz, 2014; Chiovitti & Piran, 2003; Dunne, 2011; Giles et al., 2013). By reviewing literature prior to conducting research, there is the risk of unconsciously testing a hypothesis rather than observing a phenomenon (Andersen, 1993, p. 635; Suddaby, 2006).
2. Charmaz (2014) acknowledges that investigators begin their research with some background and thoughts related to relevant literature. The challenge is to maintain a 'theoretical agnosticism' (Henwood & Pidgeon, 2003, p. 138). By ignoring knowledge on a related theory, the researcher is less likely to subconsciously integrate or force the developing findings around an established theory. Therefore delaying the literature review reduces the risk of incorporating other established theories into the new findings.
3. The qualitative literature review is done after analysis of the data to further support the trustworthiness of the newly developed findings (Chiovitti & Piran, 2003; Glaser & Strauss, 1967; Seale, 1999). The investigator can compare the findings of the grounded theory findings to other quantitative and qualitative studies with similar or diverse populations to understand the concepts of interest across studies and how they relate to the newly developed model.

4.3 Methods of the Literature Review

4.3.1 Aim of literature review.

The aim of this literature review is to support or substantiate the newly developed conceptual model describing the experiences of people with cancer

who have been cancer free for two or more years of time and recur with a diagnosis of advanced cancer in literature relevant to the conceptual model and key concepts.

This review describes the concepts within the newly developed model through focused literature related to this population with advanced-stage cancer.

4.3.2 The narrative synthesis review design.

4.3.2.1 Introduction of elements of narrative synthesis review.

To allow the literature review to achieve the aims of supporting or refuting the key concepts described in the theoretical model, a narrative synthesis was selected. Although a narrative synthesis is often used as part of a systematic review, it also allows the related literature to be evaluated and serve to provide an understanding of the state of the science to date (Popay et al., 2006). Furthermore, it also allows for comparison of concepts to support or refute the new, inductively developed findings (Britten et al., 2002). In an effort to improve the trustworthiness and transparency of this method, a systematically constructed, conceptually led approach was undertaken. This method provides a transparency process that can be followed clearly for future studies as recommended for credibility and transferability of a research study (Bryman, 2012; Whitemore et al., 2001).

A narrative synthesis review provides a framework designed to support a 'systematic review and synthesis of findings from multiple studies' (Popay et al., 2006, p. 5), which focuses on the words and text of the included literature to build new knowledge. It provides a systematic guide to improve the

transparency of the process and support the literature review findings. Narrative synthesis is an approach that aims to establish the current state of knowledge related to the specific review question, and is not meant to include all literature related to the topics in general, only as they relate to my study's conceptual model (Popay et al., 2006).

The four main elements of the narrative synthesis as recommended by Popay et al. (2006) include the following:

- 1) Developing a conceptual model that answers the research question as to how, why, and for whom;
- 2) Developing a preliminary synthesis of findings of included studies;
- 3) Exploring the relationships in the data; and
- 4) Assessing the robustness of the synthesis (p. 12).

4.3.2.2 Justification for the narrative synthesis review.

The narrative synthesis is designed to include literature chosen as it relates to the specific concepts of the newly developed model. This review did not include all research related to the topic and did not include grey literature, only specific peer-reviewed published literature related to the three concepts of the newly developed model.

To meet the requirements of researching literature from the constructivist grounded theory approach, after the development of the conceptual model, the narrative synthesis method fits the purpose of this review by providing an approach that arranges heterogeneous literature into homogenous groups by making the context and characteristics of the research study more lucid (Barnett-Page & Thomas, 2009; Lucas, Baird, Arai, Law, & Roberts, 2007). A

synthesis of the concepts as identified within the included literature is a process that allows multiple views to be evaluated in relationship to the conceptual model. Grouping based on homogeneity can be helpful to synthesize different types of research such as qualitative and quantitative. An important consideration of this focused literature review, though, must include making careful conclusions, as through homogeneity there may not be much diversity of context and therefore if one is looking for specific concepts one may find only those specific concepts (Lucas et al., 2007).

This process is similar to the constructivist grounded theory methodology of this research. It allows the reviewed literature to be constantly compared to the concepts in the conceptual model and seeks to identify others' findings related to the meaning of advanced recurrence from the participant's perspective. The qualitative literature in this review is looking for broad themes and experiences reported in other literature related to people living with advanced cancer recurrence and reviewing their designs and contexts related to the newly developed conceptual model to compare and contrast the findings. This supports the co-construction aspect of the constructivist approach of this research.

This model-driven review is related to the review question and the three concepts of the developed model (Reluctant Acceptance, Seeking Life Through Continuous Treatment, and Hope in the Face of an Uncertain Future); the general guidelines for the narrative synthesis were followed. The development of the synthesis process allowed literature that included some or all of the three concepts to be included. The literature findings were described

as relating to the concepts of the model and the contexts and temporal variables of the research (Lucas et al., 2007). The specific population of focus in this study of people with advanced cancer recurrence has not been largely studied, within the context of newly recognised treatment options for people with advanced recurrent cancer, and therefore demanded a broader search of literature in an attempt to examine findings that include advanced cancer recurrence, treatments received, and data that relate to the concepts of this newly developed conceptual model.

This conceptual model describes the transition phase of cancer free to advanced recurrence and incurable disease within a context of time where new opportunities for treatment have come available. Therefore, the narrative synthesis review allows the comparison of this qualitative data and its significance to the convergence and divergence from the theoretical findings and the developed conceptual model (Barnett-Page & Thomas, 2009; Dixon-Woods et al., 2006). By applying a systematic approach to the data search, extraction, and analysis of the literature review, transparency and rigour were maintained (Bryman, 2012). The convergence or divergence from the relevant literature allows the conceptual model to establish a starting point from which future research questions may be developed.

4.4 Literature Review Method

4.4.1 Method introduction.

The development of the search strategy required a thoughtful attempt to locate literature related to a specific moment in time in the participant's cancer experience, namely, diagnosis with advanced cancer recurrence after a period

of time of being cancer free, occurring at a time when treatment opportunities for late-stage cancers have improved (American Society of Clinical Oncology [ASCO], 2018). This strategy required using a broad set of inclusion and exclusion criteria in an effort to find literature that related to advanced cancer recurrence, although locating studies where initial treatment led to two or more years of cancer free time and the belief in having been cured was minimal. Despite broad criteria and a comprehensive search, there were very few studies that related to this specific population. A description of the literature review strategy and how it was developed follows.

4.5 Inclusion and Exclusion Criteria

Table 9 describes the inclusion and exclusion criteria followed for the literature review. Two papers believed to reflect similar populations were identified and evaluated to examine search strategies for if they were included in the search results it helped to verify the search strategy as most likely to provide appropriate literature (Nierop-Van Baalen, Grypdonck, Van Hecke, & Verhaeghe, 2016; Vivar, Whyte, & Mcqueen, 2010).

4.6 Literature Review Strategy

The overall literature review strategy (as shown in Table 10) included identifying the participant's experience of advanced cancer recurrence by starting with 'advanced'; the words used to identify advanced disease included palliative care, hospice care, and palliative medicine, as these would gather studies focused on late-stage diseases and patients at end of life. Additionally, neoplasm metastasis and stage IV were added. Cancer was identified using

Table 9

Inclusion and Exclusion Criteria for Literature Review

Category	Inclusion Criteria	Exclusion Criteria
Language	English language	Grey literature
Content	Qualitative research studies reporting empirical data related to the three concepts of the conceptual model: Reluctant Acceptance, Seeking Life Through Continuous Treatment, and Hope in the face of an Uncertain Future from the patient's perspective	Theoretical papers and publications describing expert opinions and not including patient perspectives.
Journal type	Peer-reviewed journals	Non-peer-reviewed journals
Secondary content	Secondary analysis of qualitative research studies reporting empirical data from the patient's perspective on advanced cancer and published in peer reviewed journals.	
Patient perspective	Studies where participants describe the experience of advanced recurrence but this may not be the focus of the study.	Studies that do not include the patients' experience from their perspective

cancer, carcinoma, oncology, or neoplasms. Identifying meaning was searched by including the terms attitude, psychosocial aspects of illness, and adaptation. Multiple other words used to capture meaning, including experience, feel, view, voice, attitude, perspective, understanding, believe, belief, meaning, significance, and hope. And finally to focus the review on qualitative studies, search terms included surveys, interviews, narratives, focus groups, qualitative research, personal narratives, and ethnography.

Table 10

Brief Overview of Concepts and Search Terms

Concept	Controlled vocabulary terms (MeSH or other)	Text keywords
Advanced	"palliative care"[mh] OR "hospice care"[mh] OR "palliative medicine"[mh] "Neoplasm metastasis" [mh] MW "PA"	Palliative OR Hospice OR "end of life" stage IV
Cancer	Neoplasms[mh] OR Cancer Patients [mh]	Cancer OR Oncology OR Carcinoma OR Neoplasms OR
Identifying meaning	Attitude[mh] OR Psychosocial Aspects of Illness [mh] Adaptation, psychological [mh]	Experience* OR Feel* OR view* OR voice*OR attitude* OR perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope
Qualitative	"Surveys and Questionnaires"[mh] OR "interviews as topic"[mh] OR Narration[mh] OR "focus groups"[mh] OR "qualitative research"[mh] OR "personal narratives"[publication type]	Survey OR Questionnaire OR Interview OR "focus group" OR case study OR qualitative OR narrative OR ethnology OR ethnograph*

Note. [mh] refers to mesh headings; * allows all endings applied to that word to be included in search.

4.7 Search Process

Searches using the concepts in Table 10 were conducted across four databases (CINAHL, PubMed, PsychINFO, and Web of Science) according to their particular search terms and architecture. These sources were chosen for their breadth of medical, nursing, behavioural, and social science coverage where the most relevant literature would be anticipated to be found. Searches were conducted up to September 28, 2016. Detailed descriptions of each database search are located in Appendixes M, N, O, and P. An additional search including neoplasm metastasis and stage IV were conducted in PubMed and Web of Science to identify further studies that may have been missed by not including those words directly to gather advanced disease literature.

4.8 Study Selection

The importance of providing a systematic narrative synthesis allows the transparency of the selection and synthesis process to support the rigour of the study. The goal of this review, in light of the specific population, required broad inclusion criteria to attempt to discover literature with related information specific to the key concepts of the conceptual model. Therefore, any study that met inclusion criteria was included in the literature review.

The PRISMA figure (Figure 7) describes the screening process with a stop date of September 28, 2016. The search yielded 12,505 plus an additional 7 records identified through reference reviews that were not identified in the literature search results. Duplicates were removed and a total of 8,058 articles were screened. Based on title and abstract review, 7,957 were excluded, leaving 101 articles that were evaluated for inclusion using full text. Of those,

51 were excluded and are described with reasons for exclusion in Appendix Q. The final number of included studies was 50.

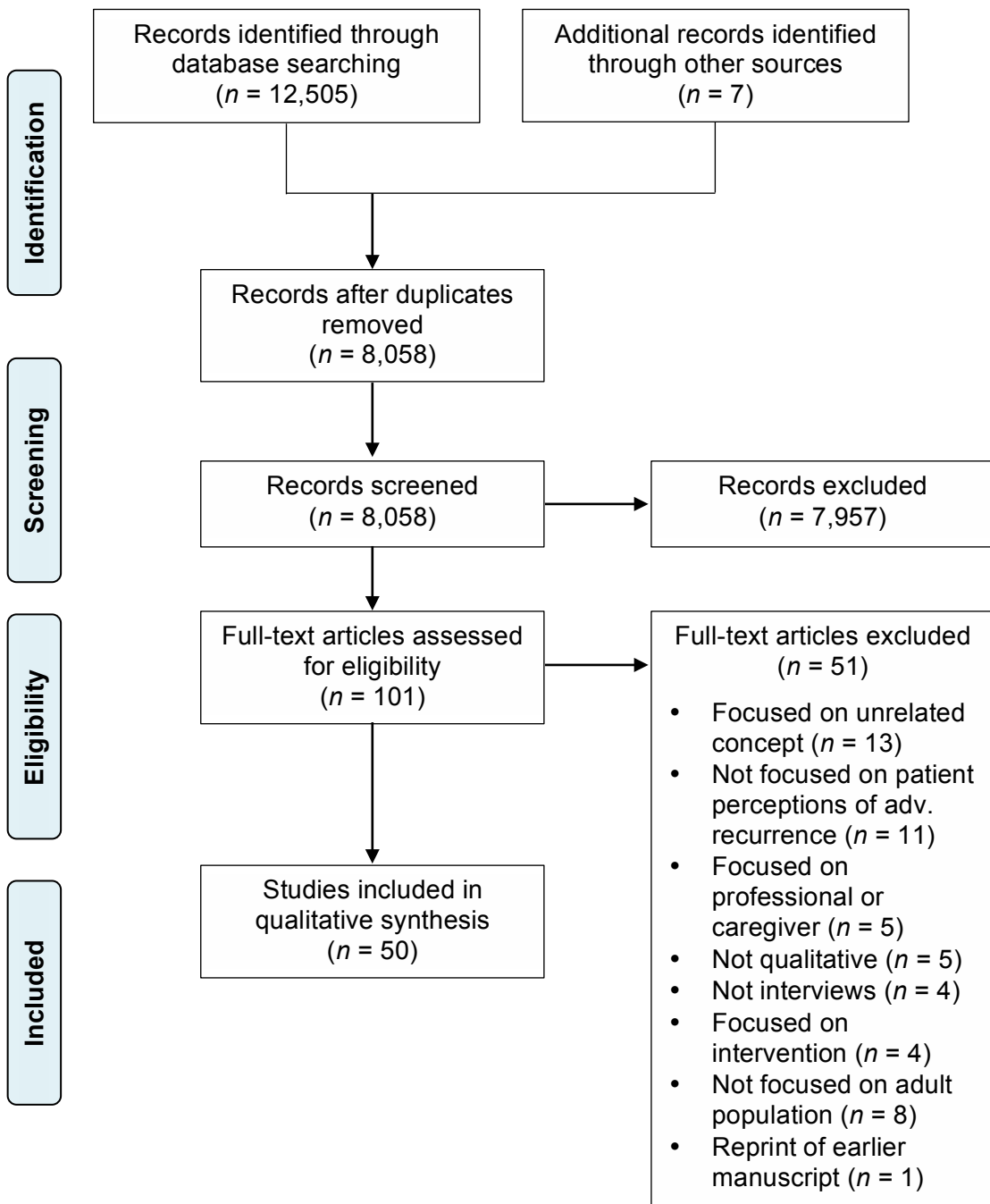


Figure 7. PRISMA flow diagram.

4.9 Assessment of Quality

The purpose of a quality assessment of included literature in a review is to evaluate the quality of the reported research and the circumstances around

which it was carried out, to achieve a trustworthiness as to the validity of the data (Maxwell, 1992). Two reasons for completing a quality assessment of literature are described as (a) to evaluate the clarity of the researcher's concept and its impact on what it is meant to describe and (b) the rigour of the process (Toye et al., 2013). As an additional component of providing rigour to a literature review, a clear assessment process is important to establish the quality of the research literature being evaluated for its contribution to the newly developed conceptual model (Bryman, 2012; Chiovitti & Piran, 2003; Dixon-Woods, 2011; Toye et al., 2013). Mishler (1990) adds a relative side to the discussion on what the concept of validity means in qualitative research and primarily describes the inability to apply a standard model since the meaning of validity or trustworthiness in qualitative evaluations is focused on meaning and interpretation. Mishler proposes that 'scientific knowledge is socially constructed' (p. 415), therefore establishing validity as a mutual acknowledgement of its value is shown by the researchers' use of the literature in their review.

Describing validity-related qualitative research includes five considerations as described by Maxwell (1992). These provide a philosophical structure to apply to qualitative assessment. Maxwell divides the types of validity as follows: (a) Descriptive validity: Is the report accurate? (b) Interpretive validity: Are the participants' meanings and experiences accurately understood by the researcher? (c) Theoretical validity: Is the theory or theoretical discussion about the research accurate and appropriate? (d) Generalizability: Is this related to the value and implications of the research for others not directly studied? This term is not used in the same way as the term is used in

quantitative research appraisal. And finally, (e) Evaluative validity: Has there been an evaluative framework used?

Others have argued there is a problem with quality assessment in qualitative research (Carroll, Booth, & Lloyd-Jones, 2012; Dixon-Woods, Shaw, Agarwal, & Smith, 2004; Eakin & Mykhalovskiy, 2003; Toye et al., 2013). The criteria debate is focused on what criteria are used in qualitative assessment and using one standard general set of assessment tools does not take into account the epistemological and ontological stance of the researcher (Eakin & Mykhalovskiy, 2003). The key argument is that appraising the quality of 'insight and interpretation' (Dixon-Woods et al., 2004, p. 223) is reliant on subjective judgement. Therefore, knowing how the reviewer is approaching and analysing the content of the research is not an easy or straightforward approach (Eakin & Mykhalovskiy, 2003). The problem though still exists that within qualitative research there needs to be a process that is identified and followed, attempting to establish some assurance that the quality of reviewed literature is trustworthy prior to incorporating the findings into, as in this instance, a newly developed conceptual model.

Establishing a framework to evaluate the quality of the included studies is part of a narrative synthesis literature review process and is meant to provide clarity and a standard of rigour and trustworthiness to the review (Bryman, 2012; Carroll et al., 2012; Chiovitti & Piran, 2003; Eakin & Mykhalovskiy, 2003; Popay et al., 2006; Toye et al., 2013). Therefore, a method was chosen to follow that allowed the most opportunity to consider the important contributions and methods of the reviewed literature. After examining different

quality appraisal frameworks, the Critical Appraisal Skills Programme (CASP) model, discussed below, was used, as it has been used with narrative synthesis review in other research (CASP, 2013).

The CASP model provides ten questions for appraising qualitative research for inclusion in meta-ethnography reviews (CASP, 2013). Although this review is a narrative review, the use of the CASP model is considered applicable and allows the process appraisal process to be clearly described. The questions focus on reflexivity noted within the research and provide an opportunity to describe the value of the research. The CASP questions were used in this review to provide a framework for assessing the quality of the included literature and believed to be acceptable to the appraisal required by the narrative synthesis review (Britten et al., 2002; 2013). Compared to other briefer assessment guides, the CASP 10-question tool was believed to be more comprehensive by providing more evaluation criteria (Carroll et al., 2012; Eakin & Mykhalovskiy, 2003; Joanna Briggs Institute). Literature was evaluated and graded as defined by Dixon-Woods, Shaw, Agarwal, & Smith (2004) as KP (key paper providing rich conceptual insights), SAT (satisfactory paper), FF (fatally flawed), and IRR (irrelevant: not meeting inclusion criteria). As the literature included had already been evaluated as meeting the inclusion criteria, none of the papers in my review were labelled as FF or IRR. One paper that is described later was considered SAT but with further review had FF components (Kuhl, 2011). It lacked a literature review and the method for participant selection was unclear. Participants were referred to as 'co-researchers' but in limitations the author indicates that these 'co-researchers' had difficulty in describing their experience therefore making developing

themes difficult. As a result this paper was minimally used for this literature review. Five papers were seen as KP and provided rich conceptual insights and guidance for the review (Garcia-Rueda, Carvajal Valcarcel, Saracibar-Razquin, & Arantzamendi Solabarrieta, 2016; Mahon & Casperson, 1997; Nierop-Van Baalen et al., 2016; Vivar et al., 2010; Wanat et al., 2016). All answers to the CASP questions were 'yes' except for a few where direct comments identifying contextual understanding were unclear and data were not present in the article (e.g., Have relationships between researcher and participant been considered?). The papers reviewed are given equal authority to describe shared themes related to their context and the concepts of the conceptual model. Because this literature review included only peer-reviewed journals, it was accepted that the manuscripts had already met professional standards required for publication and therefore met the CASP recommendations (Bryman, 2012).

How the data were extracted and managed is discussed next, providing clarity to the process to allow transferability of outcomes for future research.

4.10 Data Extraction Grids

As part of the narrative synthesis exploring the relationships between the studies and comparing information related to the key concepts of the conceptual model, a data extraction grid was developed in Excel. It includes the authors and article rating, year, research question, title, country, journal, design/ methodological orientation, population, setting, and data collection method. Additionally, columns were added to include the three key concepts of the conceptual model: Reluctant Acceptance, Seeking Life Through

Continuous Treatment, and Hope in the Face of an Uncertain Future where relationships in the concepts of the findings could be described. Two more columns were added: (a) To compare any differences in the data concepts that were unrelated to the current developed concepts and (b) A column to describe major findings in the article for synthesis focusing on results, contexts, and characteristics (Appendix R).

4.11 Extraction and Synthesis of Literature

Focusing on the characteristics of the narrative synthesis, the key concepts of the conceptual model directed the analysis. Each paper was preliminarily reviewed to identify data related to the participant's experience with advanced cancer and any content related to reluctant acceptance, continuous treatment, or hope that was described by the participant. Synthesis of the literature therefore occurred iteratively as each article was graded, compared, and contrasted to the newly developed conceptual model and to the other articles to evaluate and compare concepts shared with other research describing the experiences of advanced cancer recurrence.

The contexts of the interviews relating to setting and population as well as methodological components of the study were evaluated. Palliative and hospice care are accessed differently within the United States in comparison to European countries. This is due to U.S. payment systems which provide hospice benefits only to patients who are within 6 months of death and are no longer receiving chemotherapy or other curative treatments. Palliative care is limited in the United States and is not provided consistently across settings (Hui & Bruera, 2016). This fact was important to understand the context of the

current research setting to compare to the setting where the reviewed study took place. This topic is discussed further in Chapter 5: Strengths and Limitations. For instance, in studies where participants were interviewed in the inpatient hospice care units, there were more feelings of hopelessness related to loss of mobility (Davies & Sque, 2002; Kuhl, 2011; Mak, Wood, & Elwyn, 2005). This perspective would be different for the current researched population who were all outpatients in a cancer hospital that does not provide inpatient hospice services. Synthesis of the literature with consideration of context was then compared and contrasted to the newly developed conceptual model for confirmation of applicability.

4.12 Results

A total of 50 articles met the inclusion criteria and were included in the systematically developed narrative review. The detailed synthesis of the reviewed literature related to the three concepts is detailed in Appendix R. The CASP results are provided in Appendix S.

The three primary theoretical concepts as described in detail in Chapter 3 are Reluctant Acceptance, Seeking Life Through Continuous Treatment, and Hope in the Face of an Uncertain Future. Any findings or concepts that refuted the conceptual model are also discussed. The conceptual model was developed through a constructivist grounded theory methodology as described in Chapter 2, and therefore it is related directly to the participants' words and co-constructed through the researcher; so although the conceptual model itself was not expected to change, identifying what others found in similar populations would allow refinement of the model concepts if needed.

4.13 Reluctant Acceptance

4.13.1 Concept description.

Throughout the literature, acceptance is described as a coping mechanism that allows patients to accept the disease and move on to seek treatment (Brown & de Graaf, 2013; Pineros, Cuartas, & Davalos, 2015; Saeteren, Lindstrom, & Naden, 2011). Brown & de Graaf (2013) found that patients with advanced-stage cancer experienced high levels of vulnerability and uncertainty, but also that the patients redefined it in a positive way, so that uncertainty allowed them to compartmentalise negative feelings about their future. This allowed patients to experience the risk of death as real, but the uncertainty of proximity of death helped them to remain positive (Gibson et al., 2016). Brown & de Graaf (2013) also found that the uncertainty related to the participants' terminal prognosis and availability of clinical trials led to a 'wealth of uncertainties' (p. 545). As the treatment options for advanced cancer recurrence are growing, more research is needed in this area to understand the impact on decision-making and informational needs. Seeking knowledge about treatments remains an important strategy for people with advanced cancer recurrence to help manage the uncertainty and cope with advanced disease. Several studies cite the need to have control through knowledge or health promotion, which allowed patients to accept their diagnosis and control their future (Volker, Kahn, & Penticuff, 2004; Warmenhoven et al., 2016). Wanat, Boulton, & Watson (2016) in their meta-ethnography, stated that 'providing information and communication were integral to patients' experience of recurrence' (p. 248). In Clavarino, Najman, & Beadle (2003), although participants were told they had advanced terminal cancer, they were

receiving treatment and chose to believe it was incurable but not fatal. In Ekwall, Ternestedt, & Sorbe (2007) understanding the extent of their disease as being incurable was described as well as focusing on a positive attitude to keep living despite despair of disease. The concept of reluctant acceptance was the starting point for dealing with the diagnosis of advanced recurrence and described similarly in the reviewed literature. This acceptance often reflected how participants coped in their initial diagnosis and how they coped with the news of recurrence (Saeteren et al., 2011).

4.13.2 Synthesis of the literature regarding Reluctant Acceptance.

The concept of Reluctant Acceptance is related to acknowledging the transitional meaning of this diagnosis from believing cured to incurable disease and moving into a new phase of living with advanced cancer recurrence. Studies in the literature reported how patients recognised death as a possibility and yet focused on continuing to live (Brown & de Graaf, 2013; Chen et al., 2015; Coyle, 2006; Gibson et al., 2016). Patients are reported in these studies as describing the need to sensitise themselves to the new reality of advanced disease and worked to prolong life (Banning & Tanzeem, 2013; McWilliam, Ward-Griffin, Oudshoorn, & Krestick, 2008). Using adaptation and acceptance as a coping mechanism, participants integrate the experience into their lives, move forward, and live with their disease (Davies & Sque, 2002; Krigel, Myers, Befort, Krebill, & Klemp, 2014; Pineros et al., 2015; Saeteren et al., 2011). They hope for remission and a longer life with reluctant acceptance, which helps them adapt to change and live with new meaning as they personally re-evaluate the acceptable parameters of quality of life (Garcia-Rueda et al., 2016).

Previous literature consistently describes a component of this reluctant acceptance as related to faith in God or the belief in God's will (Lin, 2008; Mak, 2002; Montoya-Juarez et al., 2013). Studies describe how religious faith facilitated this reluctant acceptance as patients described faith as a belief and trust in God, who has the power to heal. This faith allowed patients to adapt to this advanced disease yet maintain hope and a fighting spirit (Montoya-Juarez et al., 2013; Pineros et al., 2015; Saeteren et al., 2011; Svensson, Brandberg, Einbeigi, Hatschek, & Ahlberg, 2009).

4.13.3 Application of literature regarding Reluctant Acceptance with the newly developed conceptual model.

The concept of Reluctant Acceptance is reported in previous literature as avoidance of death. In Chinese studies, (Mak, 2002; Mak et al., 2005), 'letting go' allowed participants to maintain control of dying. This was described as not allowing death to direct them, but instead letting go of the fear of death to focus on living, which provided participants with hope and reduced their fear and suffering (Mak et al., 2005; Mok et al., 2010). Both of these studies discussed the concept of acceptance as maintaining control of the situation.

MacArtney et al. (2015) described how patients accept a change in plans to transition to palliative care. The authors described the potential downside of resilience and acceptance as disruptive at end of life and negatively affecting quality of life. From MacArtney et al.'s perspective, a participant's reluctant acceptance and focus on living longer prevents the transition to palliative care or hospice care, as the participant continues to seek more treatments. Gibson et al. (2016) also describe how the attitude of seeking treatment and focusing

on surviving a cancer recurrence also prevents discussions about mortality and planning for end of life. The concept of Reluctant Acceptance includes making a decision to seek treatment and choose not to focus on death or dying from their advanced cancer recurrence.

Anger for the study population in this grounded theory analysis was an initial response to the realization of their diagnosis of advanced recurrent cancer and contributed to the concept of Reluctant Acceptance; it was not identified similarly in a literal sense in the literature. This difference may be related to the issue of most literature having included participants closer to the end of life as compared to this study's focus on people who had recently received unexpected news of advanced recurrence and were receiving outpatient care. The participants in this research study experienced anger but then refocused their energy to seek knowledge and locate potential treatments to prolong their lives. The literature review related to this concept may have had less anger described as anger per se, but may have been due to cultural or religious beliefs that speaking or acknowledging anger or cancer could attract negative feelings or bad results (Banning & Tanzeem, 2013; Chen, Komaromy, & Valentine, 2015). Participants who describe feelings of alienation, such as 'living in limbo' (Ekwall et al., 2007), could have included a sense of anger or sadness associated with those feelings.

4.13.4 Summary.

Reluctant Acceptance is the catalyst to seek treatment and to move forward. Reluctant Acceptance was related to the positive attitude and positive approach that participants in this study exhibited with their new diagnosis.

Age, minimisation gravity of disease status, and seeking knowledge were subcategories that supported the concept of accepting their recurrence and working to prolong life while confronting the prospect of death (Chen et al., 2015; Coyle, 2006; Dale & Johnston, 2011). These factors and concepts were supported by the literature (Best, Butow, & Olver, 2014; Brown & de Graaf, 2013; Montoya-Juarez et al., 2013; Nierop-Van Baalen et al., 2016; Pineros et al., 2015). This catalyst motivated participants to seek treatment as they gathered energy from the knowledge that treatments were available and the hope they felt related to their treatment options (Brown & de Graaf, 2013; Chen et al., 2015; Coyle, 2006; Daneault et al., 2016; Garcia-Rueda et al., 2016; Karlsson, Friberg, Wallengren, & Ohlen, 2014).

4.14 Seeking Life Through Continuous Treatment

4.14.1 Concept description.

The concept of Seeking Life Through Continuous Treatment is related to participants' focus on aggressively fighting the cancer amidst advanced recurrence to continue living. The inclusion of this concept in the development of the conceptual model was clearly described by participants and reinforced through the reviewed literature.

4.14.2 Synthesis of the reviewed literature regarding Seeking Life Through Continuous Treatment in the newly developed conceptual model.

Multiple articles reviewed included participants' specific comments related to treatment and the importance of having treatment options available. Hope for a future was related to having treatment options available for their advanced

cancer (Banning & Tanzeem, 2013; Brown & de Graaf, 2013; Chen et al., 2015; Clavarino et al., 2003; Coyle, 2006; Garcia-Rueda et al., 2016; Karlsson et al., 2014; Lin, 2008; Mahon & Casperson, 1997; McCarthy & Dowling, 2009; McTiernan & O'Connell, 2015; Nissim, Rennie, et al., 2012; Pineros et al., 2015; Reynolds, 2008; Robinson, 2012; Saeteren et al., 2011; Sarenmalm, Thoren-Jonsson, Gaston-Johansson, & Ohlen, 2009; Svensson et al., 2009; Weeks et al., 2012). Participants described the opportunity to receive treatments to prolong their life as providing hope for a future and the belief that because treatment worked for them earlier in their diagnoses, it will work again (Brown & de Graaf, 2013; Clavarino et al., 2003; Mahon & Casperson, 1997; Svensson et al., 2009).

Karlsson et al. (2014) completed a phenomenological study to understand uncertainty in participants receiving palliative treatment with advanced gastrointestinal cancer. The ability to receive treatment supported the participants' feelings of existential certainty and contributed to decreasing their sense of vulnerability and uncertainty. The option to receive treatment, regardless of the disease stage, reinforced a belief related to prognosis as incurable, rather than fatal (Clavarino et al., 2003).

McCarthy & Dowling (2009) completed a phenomenology study of participants' living with non-small cell lung cancer. Their findings were very similar to my current study with key themes echoing maintaining normal life and continuing treatment. Similar to this current study, the population in McCarthy & Dowling (2009) was very focused on the importance of treatment to maintain living. The fear of stopping treatment and its consequences were

also expressed by these participants as not an option and were consistent with this study's findings. McCarthy & Dowling's study findings of lung cancer patients support the concept of continued treatment and the conceptual model describing the experience of living with advanced cancer recurrence.

4.14.3 Differences noted between literature review and current research.

Two studies found that the need to continue treatment was identified as the means to prolong life, but the studies also described the downside of continuous treatment (MacArtney et al., 2015; McKechnie & MacLeod, 2007). These studies both took place in inpatient hospice units, which may account for patients' negative views on continuous treatment. These participants were within days to weeks of death, which was unlike this recent grounded theory study whose participants were very functional and receiving outpatient treatment. In McKechnie & MacLeod's (2007) study, participants described treatment as 'haphazard' (p. 258), and reported having a sense of not knowing what treatment would or could achieve. MacArtney et al. (2015) recognized the downside of uncertain treatment and prolonging life in the face of inevitable death. MacArtney et al. described seeking treatment as a 'toxic resilience' (p. 9) that can be 'counter-productive' (p. 9) to the participants' quality of life, as they transition to end of life. The population in the MacArtney et al.'s study were inpatient hospice patients and were transitioning to end of life, unlike the population with whom this conceptual model was developed: those who continued treatment and were not focused on end of life but on survival.

The key differences rest in the population in this evolving conceptual model as more recent experience of recurrence as compared to previous studies whose participants were often receiving hospice over a longer length of time and closer to death. Studies in the reviewed literature took place in multiple settings and in multiple countries, reinforcing the strategy used by participants in my research to prolong life through continuous treatment (Garcia-Rueda et al., 2016; Gibson et al., 2016; Mahon & Casperson, 1997; Reynolds, 2008; Svensson et al., 2009).

4.14.4 Summary.

Participants' response to newly recurrent advanced cancer was a desire to seek treatment with the hope of living longer. Reynolds (2008) reinforced the findings in this current study. Although the timing of the interviews in relation to the time of diagnosis were not clearly specified in many of the studies examined, participants living in inpatient hospices without access to further treatments were focused on end of life and not anticipating living a longer life with continuous treatment (Karlsson et al., 2014; Mak, 2002; Mak et al., 2005; Mok et al., 2010). When treatment was available, participants focused on the reality that although this disease was not curable, it was treatable (Clavarino et al., 2003; Pineros et al., 2015; Weeks et al., 2012).

The similarity between the reviewed literature and this newly developed model were related to continued hope across studies and a focus on maintaining quality of life. This focus on the ability to receive treatment and its meaning that continued life is possible is a universal belief regardless of stage of cancer diagnosis or recurrence. The current treatment options available for

people with advanced cancer continue to reinforce the meaning of Seeking Life Through Continuous Treatment.

4.15 Hope in the Face of an Uncertain Future

4.15.1 Concept description.

The concept of hope, referred to in my research as the concept of Hope in the Face of an Uncertain Future was described in the reviewed literature as complex, abstract, and individual, making it difficult to define (Elliott & Olver, 2007; Johnson, 2007; McClement & Chochinov, 2008). In the articles reviewed, participants' feelings about the concept of hope were related to a feeling of expectation and desire for something to happen. Hope was defined by Dufault & Martocchio (1985) as the expectation that something important to the individual is realistically possible, even if it is uncertain. Hope with uncertainty in this current literature review provides the foundation of the framework for the newly developed conceptual model. Subcategories as described in Chapter 3 that contributed to the concept of Hope in the Face of an Uncertain Future, included faith in their physician, family support, spiritual faith, meaning of illness, and minimising feelings through humour and laughter. Many of these subcategories were reflected in the literature synthesis and are described below.

4.15.2 Synthesis of the literature regarding hope.

The concept of hope related to advanced cancer, and advanced cancer recurrence was described in 40 of the 50 articles. The concepts of hope related to the specific articles are included in Table 11.

Table 11 displays the papers in the literature review where the concept of hope was identified. Additional themes are identified that were within the research findings of the included literature.

Table 11

Hope-Related Concepts in Reviewed Literature: Author and Year

Hope concepts and themes included in reviewed literature	Lead author (year)
Hope	Clayton (2005) Daneault (2016) McWilliams (2008) Mok (2010) Neirop-Van Baalan (2016) Reynolds (2008) Vivar (2009) Yedida (2001)
Hope / age	Duggleby (2004, 2005)
Hope / age 20-59	Pineros (2015)
Hope / psychosocial meaning	Schildmann (2013) Montoya-Juarez (2013)
Hope / age / psychosocial meaning	Mahon (1997)
Hope / age / cultural impact	Chen (2015)
Hope / cultural impact	Banning (2013)
Hope / spirituality	Best (2014)
Hope / faith	Lin (2008)
Hope / positive attitude / being strong	Lewis (2016)
Hope / belief in curability / treatment	Clavarino (2003)
Hope / living with cancer	Coyle (2004, 2006) Davies (2002) Esteves (2015) McCarthy (2009) Penson (2007) Robinson (2012) Saeteron (2010)

Hope concepts and themes included in reviewed literature	Lead author (year)
Hope / uncertainty	Brown (2013) Karlsson (2014) Svensson (2009)
Hope / uncertainty / normalcy	Krigel (2014)
Hope / treatment	Sarenmalm (2009)
Hope / prolonging life w/treatment	Wanat (2016)
Hope / dying	Nissim (2012)
Hope / dying / uncertain future	Ekwall (2007) McTiernan (2015) Elliott (2009)
Hope / acceptance of dying	Mak (2002)
Hope / meaning in palliative care / living with cancer	Flemming (1997)
Hope / resilience–transition to palliative care at end of life	MacArtney (2015)

4.15.3 Hope and interconnectedness.

Hope was expanded by the interconnectedness between the participant, family, and friends supporting the desire to live a longer life (Chen et al., 2015; McTiernan & O'Connell, 2015). Research describes how, in the Chinese culture, the family is very important and participants admitted 'staying alive for their significant others' (Chen et al., 2015, p. 162). Others described the importance of social contact and family and the connectedness within the larger community: 'If it becomes too much for me, I look for someone to talk with, for a while. And now I have found someone to talk to through an organization of volunteers' (Warmenhoven et al., 2016, p. 4).

4.15.4 Hope as a motivator.

Hope was described across studies as a feeling supporting self-motivation, a positive attitude (Elliott & Olver, 2009; Garcia-Rueda et al., 2016; McCarthy & Dowling, 2009). Hope was described as providing courage to deal with the future as well as present problems. Lewis, Willis, Yee, & Kilbreath (2016) described how positive thinking, hopefulness, and being strong helped with anxiety, uncertainty, and fear. Hope was seen as an essential part of being human; it was described as necessary for existence (Elliott & Olver, 2009). Hope was seen as a buffer against challenges and that maintaining hope allowed them to keep going. As Elliott & Olver (2009) reported from a participant's interview, 'Well, put it this way, without hope, I think there would be nothing'. (p. 616). They described a sense of energy included with this human need to maintain hope even in dying patients (Elliott & Olver, 2007).

A participant in Duggleby & Wright's 2004 study said, 'I would say if you don't have any hope, I would just slowly wither away. If you don't have any hope, then you have nothing for the future or even for the present' (p. 355). A secondary analysis done by Nierop-Van Baalen et al. (2016) described their work on maintaining hope, described as something that gives energy and takes energy. The positive aspect of gaining energy allowed them to maintain hope and focus on living longer. Hope was described a motivator for life (McCarthy & Dowling, 2009; Reynolds, 2008). Chen et al. (2015) explained: 'When days cannot be added to life, add life to days' (p. 161).

4.15.5 Hope and living longer.

Participants in the included studies described their feelings of hope as hoping for a cure or remission that would allow a longer life, while at the same time recognizing the stage of their disease as being incurable, and hoping for a good or peaceful death (Chen et al., 2015; Coyle, 2006; Daneault et al., 2016; Elliott & Olver, 2009; Flemming, 1997; McWilliam et al., 2008; Svensson et al., 2009). Duggleby & Wright (2005) described transforming hope and the process of living with hope, and acknowledging 'life the way it is' (p. 77). This idea was seen in other studies where hope and acceptance of the advanced diagnosis of cancer was dealt with by focusing on living day-to-day. Focusing on living and keeping going was important (Duggleby & Wright, 2005). Maintaining hope for a cure was shown to improve quality of life for participants and support resilience (Robinson, 2012). Even in light of terminal disease, participants described a hope for healing and life: 'What is important is that there is hope that I can recover' (Montoya-Juarez, 2013 p 59). This motivation to choose life and focus on each day gave them the ability to maintain the possibility of living longer.

4.15.6 Hope and spirituality.

Spirituality and spiritual well-being contributed to the ability to find strength and courage to go forward. Best et al. (2014), in a study with advanced cancer patients, found the relationship between self, family, and God was intrinsic to quality of life and a sense of wholeness. Duggleby & Wright (2004) described the importance of faith in God in their participants and the belief that faith supported hope by believing that God would help them and reduce their

suffering, 'I think without God I don't have any hope at all. He certainly does provide a spot or a garden for our thoughts' (p. 357). As many others did describe, faith supported hope and a sense of normalcy (Coyle, 2006; Garcia-Rueda et al., 2016; Lin, 2008; Mok et al., 2010). Religious faiths facilitated eternal life and hope for a future (Mak, 2002; Reynolds, 2008).

4.15.7 Hope and treatment.

The concept of hope as increasing from the ability to receive treatment formed a key part of the conceptual model of Reluctant Acceptance of Living with Advanced Cancer Recurrence. Treatment represented a chance to live and a source of hope (Garcia-Rueda et al., 2016; Nierop-Van Baalen et al., 2016; Svensson et al., 2009). Although this sense of having an option for treatment meant hope, the intent of the treatment was not understood as described in Weeks et al. (2012). Those authors studied 1,193 patients within 4 months of receiving a diagnosis of metastatic stage IV lung or colorectal cancer who opted for chemotherapy for incurable cancer. In this study, 69% of the lung cancer patients and 81% of the colorectal cancer patients did not understand that receiving chemotherapy was not an option for cure (Weeks et al., 2012, p. 1616). Treatment gave hope for more time to live, in a study done by Chen et al. (2015). Chinese patients, regardless of their cultural traditions or their spiritual beliefs in Buddhism or Taoism in which death is a normal expected part of life, they were also motivated to seek continued life. Hoping for the best helped them find meaning and 'stay engaged in living while shouldering the burden of an uncertain future' (Chen et al., 2015, p. 161).

4.15.8 Summary.

The concept of hope over the participant's continuum of the experience of cancer recurrence was about prolonging life, but if that was not possible, patients transitioned to hoping for a good quality of life (Daneault et al., 2016; Pineros et al., 2015). A key finding within this synthesis of literature is the understanding of hope as a dynamic concept that changes over the course of disease and may be related to symptoms experienced, such as unrelieved pain or the realization that death is inevitable (Duggleby & Wright, 2004; Robinson, 2012). Brown & de Graaf (2013) referred to this transition as the spectrum of uncertainty, as hope moved from active to passive. There was a consistent focus in the literature on the future in this dynamic process of living—while at the same time dying—with incurable disease (Clayton, Butow, Arnold, & Tattersall, 2005a; Coyle, 2006; Ekwall et al., 2007; McTiernan & O'Connell, 2015). The concept of the hope continuum appears to transcend cultures. Chen et al. (2015) explored the experience of end of life among older patients in China. They described the patients' desire to live longer, even with recognition they were dying. Banning & Tanzeem (2013) describe the experience of women in Pakistan being treated for advanced breast cancer; they had more descriptions of 'knowing I will die' (p. 256) and noted cultural discrimination and stigma of cancer and lack of support, and yet were still positive and hopeful for a future: 'Life is beautiful and when a person is alive she is hopeful' (p. 257).

The review of literature above reinforces the concepts of the conceptual model of Reluctant Acceptance of Living with Advanced Cancer Recurrence. Hope is

an essential element of the experience impacting the lives of these people as they make treatment decisions and face the uncertainty of their lives.

4.15.9 Differences between literature review and conceptual model developed from my study's findings

In comparing all of the included literature to the results of the current research, five studies described a finding of hopelessness in patients with advanced disease. These studies described feelings of hopelessness resulting from patients' advanced disease and their realization that they would die (Banning & Tanzeem, 2013; Coyle & Sculco, 2004; Davies & Sque, 2002; Kuhl, 2011; Mak et al., 2005). These studies describe patients' social isolation and their need to build a new identity within this life experience of advanced cancer recurrence. Unrelieved symptoms, fear of loss of dignity, and 'unendurable' (Coyle & Sculco, 2004, p. 699) suffering are areas where people with advanced cancer have described feeling hopeless and a wish to die (Coyle & Sculco, 2004; Mak et al., 2005). Additionally, settings where the research took place and as described above the severity of suffering they were experiencing influenced this response to advanced cancer. The Davies & Sque (2002) study took place in an inpatient hospice unit in Hong Kong. This inpatient setting and the patients' advanced disease state influenced the feelings of lack of future and social isolation and the changes in how they identified themselves. A second study by Kuhl (2011), although it is not highly appraised for the quality of its research technique, included patients' words describing similar feelings related to unrelieved symptoms, feelings of isolation, and also the spiritual impact on coping during those times. Kuhl's study participants included AIDS patients and those patients may also experience emotions

similar to the cultural experiences described by the Chinese and Pakistani studies, where isolation and stigma of having a cancer diagnosis or fear of communicable disease caused increased suffering for people experiencing advanced cancer recurrence (Banning & Tanzeem, 2013; Kuhl, 2011; Mak et al., 2005).

Pineros et al. (2015) described advanced colorectal patients' feeling less hopeful for remission or stable disease based on their symptoms. In this population, improved symptoms brought an increase of hope, whereas worsened symptoms, such as unrelieved pain, brought feelings of hopelessness and a sense of worsening prognosis. Participants in this grounded theory study did not discuss symptoms as a major factor in the interviews, possibly because their disease had only recently recurred and symptoms had not become a major concern.

These responses were not seen in my study's model, but this may be due to the timing of my study. These participants were within two weeks to one year of recurrence, and only one participant was dealing with symptoms that were primarily skin changes and fatigue; otherwise they were independent and able to live their lives without inconveniences at this time. This allowed them to maintain a hopeful and positive attitude.

4.15.10 Conclusion and influence of hope on the conceptual model of Reluctant Acceptance of Living with Advanced Cancer Recurrence.

The concept of hope as described in this conceptual model is reflected in the perspectives of the reviewed literature (Elliott & Olver, 2007; MacArtney et al.,

2015). The perspectives of hope across studies were similar in participants who were experiencing advanced cancer nearing end of life and those who had been receiving care in inpatient hospices and palliative care units (Mak, 2002; Pineros et al., 2015). Hope in people experiencing advanced recurrent cancer provided resilience and energy to cope with their uncertain future (Brown & de Graaf, 2013; Daneault et al., 2016; Duggleby & Wright, 2004; Garcia-Rueda et al., 2016). Participants in the reviewed literature were disinterested in talking about end of life, especially when treatment options were available (Gibson et al., 2016; Lewis, Willis, Yee, & Kilbreath, 2016). The meaning of hope remains a complex concept that provides a means of coping with advanced recurrent cancer from initial recurrence and focus on seeking treatment and supporting the transition to the end of life. Hope becomes focused toward a peaceful, symptom-free, good death (Daneault et al., 2016; Reynolds, 2008; Robinson, 2012). Hope has been shown to be a complex emotion described by participants experiencing advanced cancer recurrence and seeking survival.

4.16 Discussion

The three concepts constructed through the CGT method and the narrative synthesis literature review has shown that these concepts are consistent with other research on advanced cancer recurrence. This review substantiates the inclusion of the three concepts of Reluctant Acceptance, Seeking Life Through Continuous Treatment, and Hope in the Face of an Uncertain Future as they pertain to people acknowledging and living with advanced cancer recurrence in the context of improved treatment options for advanced-stage cancers. The reviewed literature substantiates the relationship between Reluctant

Acceptance and treatment providing hope; other research as described above has shown the relationship between hope and treatment and the need for acceptance of the recurrence as a catalyst to seek living through treatment. This newly developed conceptual model captures a moment in the time immediately after diagnosis with advanced recurrence, after participants had experienced two or more years of cancer free time and considered themselves to be cured at a time where improved treatment options are changing the paradigm of care for people with advanced-stage cancer. The systematically developed narrative synthesis review allowed the concepts to be compared to other qualitative literature related to these three concepts in people experiencing advanced cancer recurrence. The literature syntheses further supported the theoretical development of this research and did not alter the conceptual model but did reinforce what this experience of advanced cancer recurrence is and the unique experience of these participants transitioning from considering themselves as free of cancer to now living with cancer at a time when more people are living with advanced-stage cancers.

4.17 Limitations

This literature synthesis is limited by having been performed by only one reviewer. The lack of multiple reviewers may have limited objectivity and provided opportunity for error. Thesis supervisors did provide some level of review, but detailed discussions of categories and concepts from the reviewed literature were limited.

The narrative synthesis approach was chosen because it provided a framework that closely fit the constant comparison and inductive process of

constructivist grounded theory. The literature review was focused on evaluating this newly developed conceptual model when there are limited numbers of studies that directly relate to the specific population. Therefore, the framework of a review aimed at contributing to the interpretation of the review findings and flexible enough to allow the iterative approach necessary to compare and contrast literature to this point in time was important (Barnett-Page & Thomas, 2009; Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Lucas et al., 2007; Popay et al., 2006).

As per CGT, the purpose of the delayed literature review is to 'claim, locate and evaluate literature to defend the constructed findings' (Charmaz, 2014, p. 305). This literature review allows the synthesis of multiple studies to help define the experience of people seeking to live with a newly diagnosed advanced cancer recurrence. Although the delayed completion of the literature review remains controversial, it is a recognized approach for constructivist grounded theory. Continually asking the question, 'what is happening in the data?' was not only part of the original interview analysis, but it was a part of the literature review and synthesis, as it pertained to the development of the conceptual model (Chiovitti & Piran, 2003, p. 429). My understanding of the participants' perspective contributes to the constructivist results and therefore a limitation to the results is in reference to the specific period of time of this research study and the meanings developed for this moment in time (Charmaz, 2014; Chiovitti & Piran, 2003). This literature synthesis has added to the methodological literature in identifying this period of disease recurrence as unique and distinct from later stages in recurrence where people have increased symptoms, unendurable suffering, and are focused on end of life as

was seen in the literature (Chen et al., 2015; Coyle & Sculco, 2004; Mak, 2002; Mak et al., 2005).

4.18 Strengths

The delaying of the literature review was central to performing this study, and understanding the participants' experience with advanced cancer recurrence within the context of evolving treatment options. By following this method, I was cautious to not be influenced by other theoretical concepts that could have altered or biased the results of this study (Charmaz, 2014; Giles et al., 2013). This literature review synthesis fit well within the CGT, allowing the theoretical development to be evaluated and situated within the defined period of the cancer trajectory. This narrative synthesis literature review allowed the findings to be compared, and substantiated and sustained the inclusion of these important concepts of advanced cancer recurrence in my study's conceptual model of Reluctant Acceptance of Living with Advanced Cancer Recurrence. The descriptions of the participants describing their experience with advanced cancer recurrence were supported by this current research study and supported this newly developed conceptual model. It also reinforces the transferability or fittingness of the model.

4.19 Summary

In summary, this specific approach to the narrative synthesis literature review allowed the use of other findings to support the conceptual model generated by this research through context and characteristics comparisons (Barnett-Page & Thomas, 2009; Dixon-Woods et al., 2005; Popay et al., 2006). The three main concepts defined in the model stand as (a) Reluctant Acceptance,

(b) Seeking Life through Continuous Treatment, and (c) Hope in the Face of an Uncertain Future. The context of this conceptual model is based on a specific time in the trajectory of the participants' recurrence of cancer, in those participants having lived two or more years without evidence of disease, having believed themselves to be cancer free. Within this context of evolving treatment options, the phases of survivorship no longer rest at extended survival-disease free, but now also include extended survival-advanced disease.

Chapter 5:

Discussion: Seeking Life With Advanced Cancer Recurrence

5.1 Introduction

The final conceptual model of Reluctant Acceptance of Living With Advanced Cancer Recurrence is presented in this chapter. The chapter reflects the process of conceptual development of the model, it critically considers my study's findings in reference to the previous literature discussed in Chapter 4 and, it outlines the key findings and the evidence drawn from the data collection. Strengths and limitations of the study, as well as implications and recommendations for future research, are included. Final considerations related to this study's contributions to the fields of palliative care and cancer survivorship are discussed in the conclusion.

5.2 Conceptual Model of Reluctant Acceptance of Living With Advanced Cancer Recurrence: Process of Development

A conceptual model provides 'a set of highly abstract, related constructs that broadly explains phenomena of interest, expresses assumptions, and reflects a philosophical stance' (Burns & Grove, 2001, p. 793). The conceptual model, Reluctant Acceptance of Living with Advanced Cancer Recurrence is empirically grounded in the experience of people with cancer who, for a minimum of two years, perceived themselves to be cured of their disease and then subsequently experience a recurrence with incurable stage III or IV disease. The model depicts the relationship between the theoretical concepts that have been constructed from the data describing the experience of living with advanced cancer recurrence. The three concepts constructed through the grounded theory method are: Reluctant Acceptance, Hope in the Face of an

Uncertain Future, and Seeking Survival Through Continuous Treatment. The literature review in Chapter 4 substantiates the final constructed concepts of the conceptual model and provides the background for this discussion. This model describes the interrelationship of the three concepts (Reluctant Acceptance, Seeking Survival Through Continuous Treatment, and Hope in the Face of an Uncertain Future) to the experience of living with advanced cancer recurrence in the changing context of evolving treatment options such as immunotherapy and focused treatments. This model of living with advanced cancer recurrence is an important contribution to the field of cancer survivorship and focuses on a subpopulation of people living with advanced-stage cancer who now have treatment options that have been specifically designed to include people with advanced cancer. The population of this study views their advanced cancer recurrence as incurable but not terminal. This is a perspective that in the past was different for people diagnosed with stage IV advanced cancers who were told there was nothing more that could be done (Couzin-Frankel, 2013).

5.3 The Conceptual Model of Reluctant Acceptance of Living with Advanced Cancer Recurrence: Steps in the Development of the Model

The concepts were constructed through the understanding of the abstract meanings of the codes conceptualised from the interviews. The model illustrates the progression from diagnosis with advanced cancer recurrence to treatment. As such it reflects the experience of participants from the moment of diagnosis with advanced cancer recurrence and the subsequent infinite movement from treatment to remission and back again. Figure 8 illustrates the

initial description of the conceptualisation of the experience of advanced cancer recurrence as the infinity symbol.

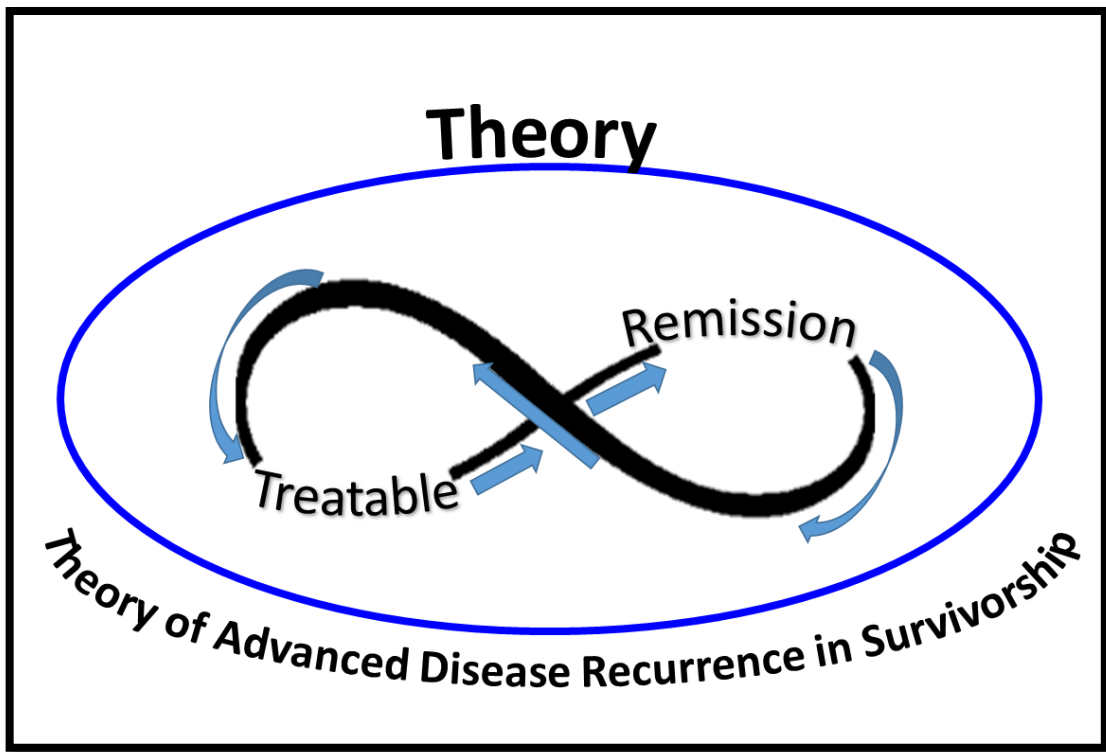


Figure 8. Infinity model.

This continuous motion was described by participants receiving treatment and either had stable disease or sought new treatment with recurrence. Newer treatment options require continuous dosing to support stable disease. In an effort to illustrate the significance of maintaining stability of the disease, a revised model (Figure 9 below) was used to capture the relationship seen between treatment and remission to maintain stable disease. The circular diagram came closer to clarifying the interrelationship between treatment without curable intent and maintaining stable disease. At this point, the process was conceptualised as continuous until death and therefore included two options that might describe what happens when treatment is either no longer available or they return to remission. This model was revised as my

research is not longitudinal and therefore it cannot be assumed that this is the case without further research (Figure 9).

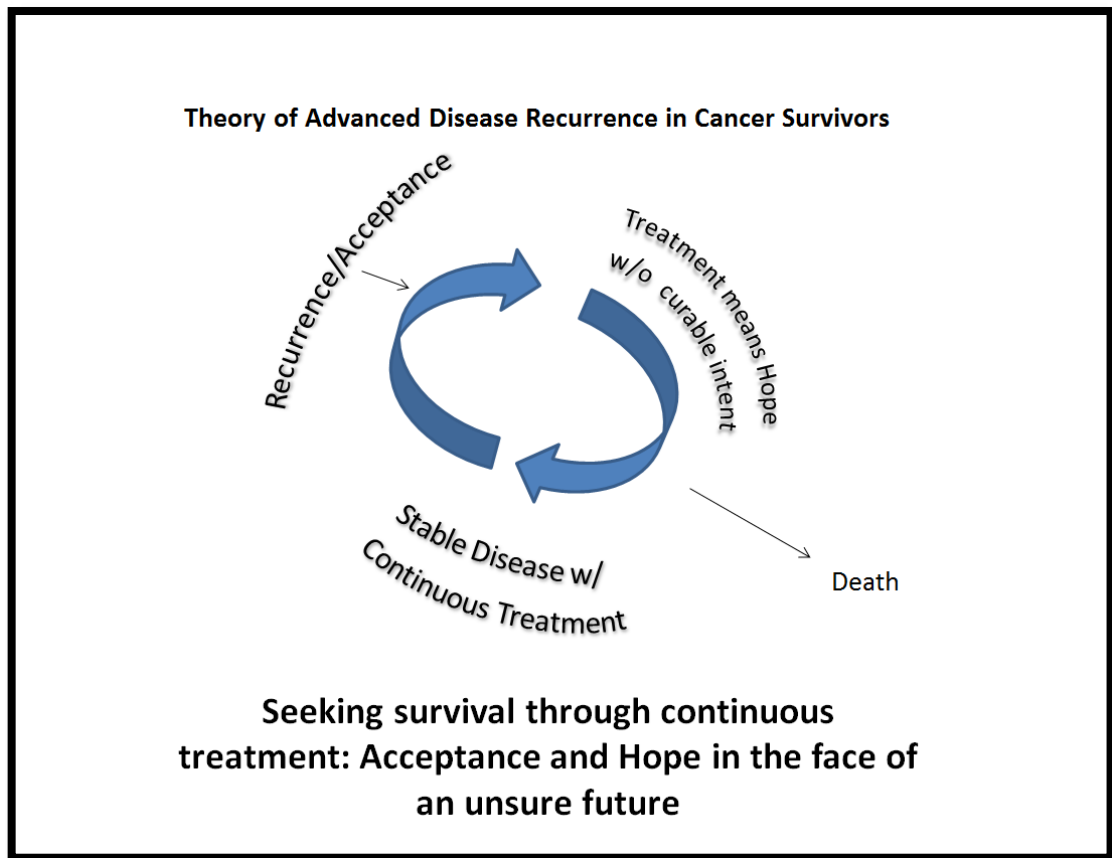


Figure 9. Circle transition.

The concepts of Reluctant Acceptance, Seeking Life Through Continuous Treatment, and Hope in the Face of an Uncertain Future were constructed from the participants' experience of advanced recurrence as detailed in Chapter 3. Figure 10 attempts to describe the interrelationship between the three separate concepts and describe the experience of advanced recurrence. Treatment is the force that moves participants in this study from reluctant acceptance to hope; therefore, the treatment cog was the largest and initial acceptance supported the treatment circle with hope moving between the two concepts.

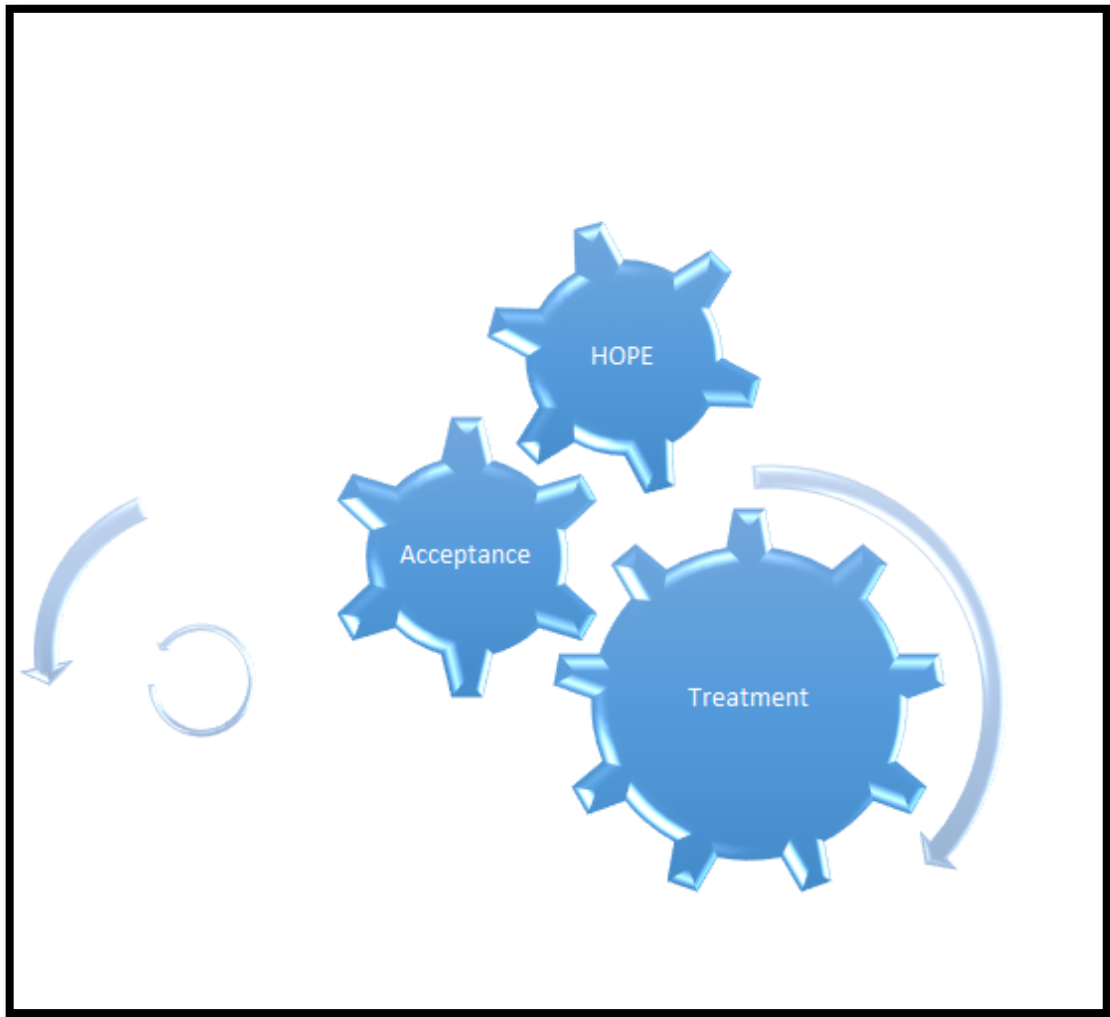


Figure 10. Gears model.

This figure still did not capture the hope for treatment and the treatment encouraging hope that were central to the experience of this population. There was a clear movement from initial diagnosis of advanced cancer to reluctant acceptance and moving into this process of hoping for treatment that was mixed with the uncertainty of treatment options and hope for living a longer life. Those two concepts—Seeking Life Through Continuous Treatment and Hope in the Face of an Uncertain Future—supported one another, depending on the ability to receive treatment. Therefore, because all of these participants were seeking treatment and receiving treatment, this model captures this

looping transition between advanced cancer recurrence and treatment. But it was important to establish the point of the cancer trajectory this research is describing. Figure 11 illustrates the conceptualisation of these interrelating concepts as they circled treatment and hope. Hope increased, as seeking treatment and the ability to receive treatment increased hope as participants lived this experience of advanced cancer recurrence after believing they had been cancer free. But this concept was still not visible in the model.

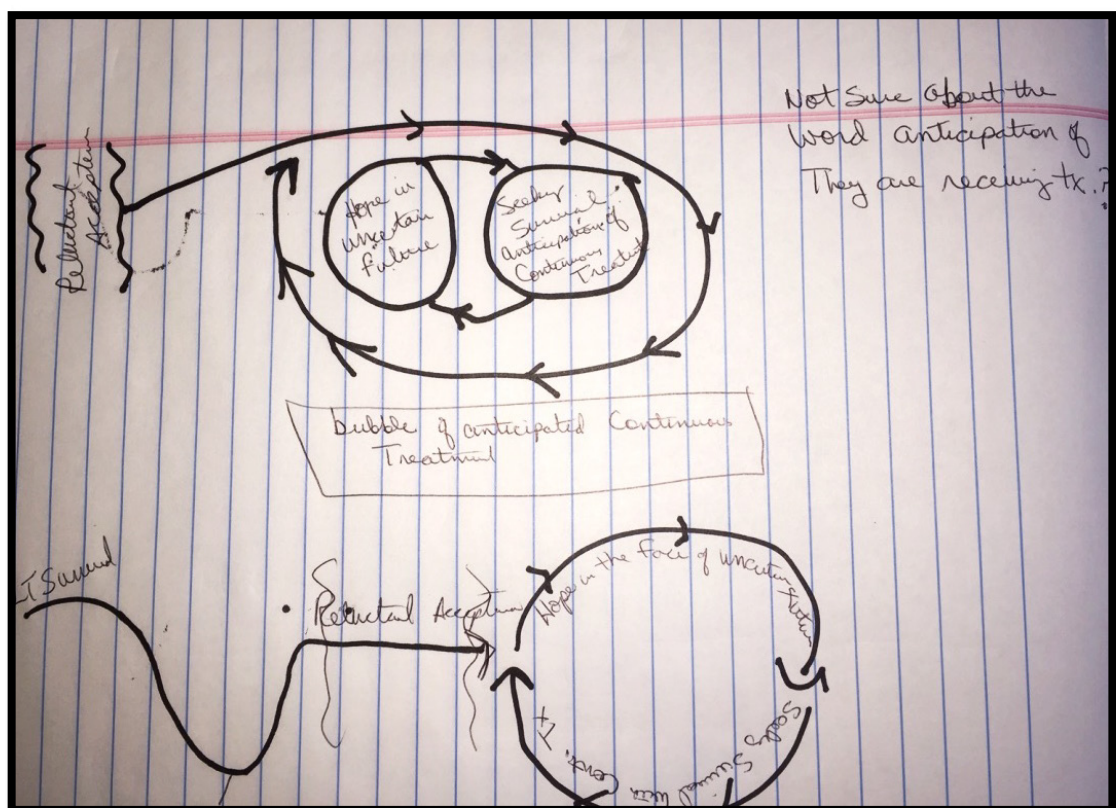


Figure 11. Developing circle of 3 concepts together.

Therefore with further review of the models and re-examining the data, Figure 12 shows how the conceptualisation developed into the final model as the interrelationship and impact of the three concepts were constructed.

As identified in Figure 12 the emerged conceptual model of Reluctant Acceptance of Living with Advanced Cancer Recurrence includes the circle of treatment and hope, which remains an important piece of the final model as the focus of the experience at that particular time in the trajectory from diagnosis. The significance of reluctant acceptance is clearer in this final model. The direction of the movement from diagnosis through anger and sadness to reluctant acceptance as the catalyst that encourages seeking life through continuous treatment and creates hope in the face of an uncertain future.

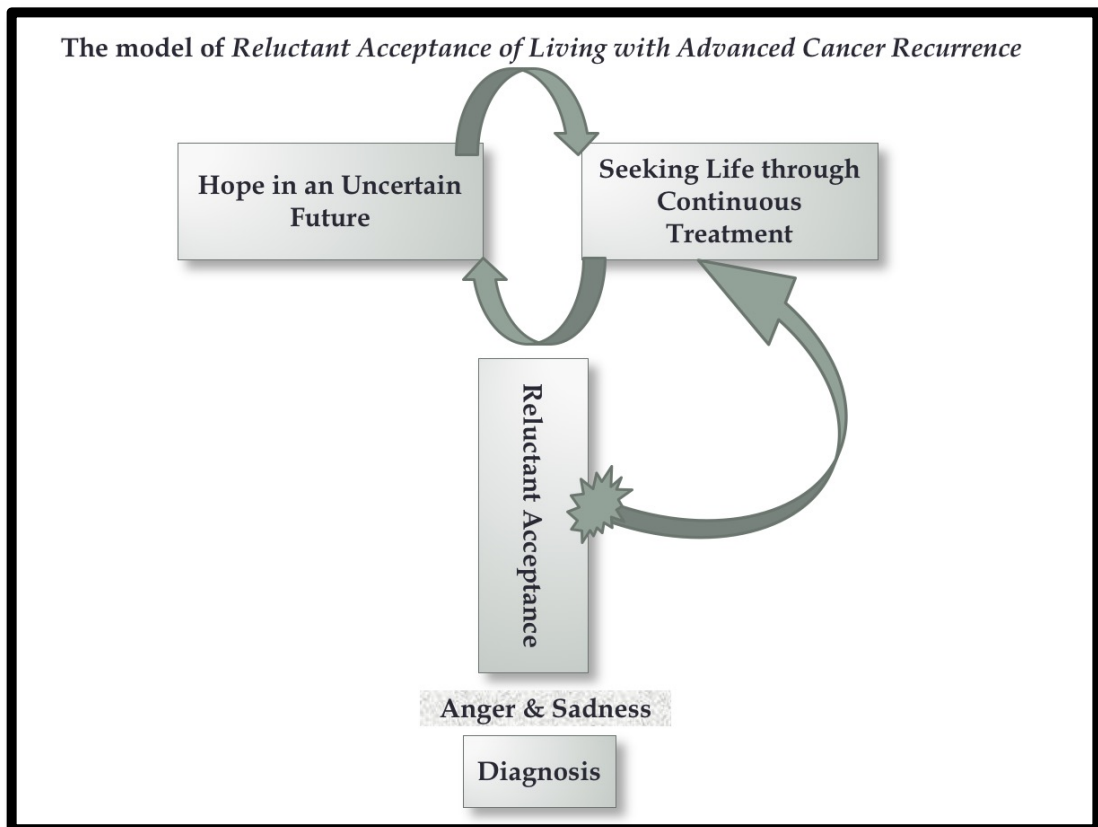


Figure 12. Conceptual model: Reluctant Acceptance of Living with Advanced Cancer Recurrence.

5.4 The Conceptual Model of Reluctant Acceptance of Living with Advanced Cancer Recurrence

Figure 12 presents the final developed conceptual model illustrating the key concepts, and capturing their interrelationship and impact during this distinct phase of the cancer trajectory, set within the phase of transition. The person with advanced cancer recurrence experiences extended disease-free survival to advanced cancer recurrence (Miller et al., 2008; Mullan, 1985). The concept of Reluctant Acceptance is the coming to terms with the change in disease status and the individual's appraisal of the situation and motivation to move forward in an effort to cope with this new phenomenon. Seeking Life Through Continuous Treatment is a coping strategy that promotes hope and provides a plan to manage this phenomenon that allows the person experiencing advanced cancer recurrence to reduce stress by feeling they are in control and have a plan to regain their, which in this case is remission of their disease (Clayton et al., 2005b).

The conceptual model of Reluctant Acceptance of Living with Advanced Cancer Recurrence illustrates the relationship between the availability of treatment and the increase in the level of hope for continued life. This hope–treatment cycle has a psychological impact on people living with advanced recurrent cancer in that it creates an energy that allows them, upon diagnosis of recurrence, to choose to think positively, gather knowledge, and reluctantly accept their disease status and face it by seeking treatment (Mahon & Casperson, 1997; McCarthy & Dowling, 2009; McTiernan, 2013).

The model of Reluctant Acceptance of Living with Advanced Cancer Recurrence is situated within the cancer survivor trajectory that describes individuals who have been living in 'extended survivorship as cancer free' (Miller et al., 2008, p. 372) but now recur with advanced cancer. In this trajectory, the decision to reluctantly accept the diagnosis of cancer recurrence and relinquish the belief of having been cured acts as a catalyst toward becoming optimistic in the search for treatment to continue living. As discussed earlier, the current context of treatment for people with advanced-stage cancers—particularly people with solid tumour cancers such as breast cancer, non-small cell lung cancer, and melanoma cancer—has impacted the understanding of palliative care as applied to the end-of-life trajectory (Miller et al., 2016). This concept has also been described by Couzin-Frankel (2013) as a paradigm shift as treatment options are now available for people with advanced cancer. Instead of accepting advanced incurable cancer as terminal, this study's population sought treatment to prolong their life and they were offered clinical trials and treatment options that had not been available for this population in the past. This current research was able to document this experience and newly occurring paradigm shift.

5.4.1 Reluctant acceptance of advanced recurrent cancer.

For people recurring with advanced cancer after perceiving themselves to be cancer free, the concept of Reluctant Acceptance motivated the action to move forward towards treatment. A key component of this conceptualisation was how the news of recurrence was understood by the participant and opportunities that were offered to the participant for treatment at the diagnosis

of advanced cancer recurrence. Unlike what has been described in previous literature, this population accepts the illness as incurable but persists in hoping for prolonged life despite their advanced cancer diagnosis. Within this context of evolving cancer treatment options, this population's response to the diagnosis is different from the populations discussed in the literature prior to these immunotherapy and focused treatment options (Brown, Levy, Rosberger, & Edgar, 2003; Chen, Haley, Robinson, & Schonwetter, 2003; Coyle et al., 2015). Rather than merely accepting the illness as incurable and reconciling that death may be soon, this population accepts the diagnosis but turns to treatment in the hope of prolonging life with advanced cancer recurrence.

The model of Reluctant Acceptance of Living with Advanced Cancer Recurrence describes the experience of adapting to this specific period of advanced cancer recurrence. Here it is useful to briefly turn to the work of Naus, Ishler, Parrott, & Kovacs (2009) who describe a Cancer Survivor Adaptation Model related to a chronic illness model (Figure 13). This adaptation model included three general components: (a) personal context, (b) adaptation process, and (c) quality of life outcomes. It uses the adaptation process as the central mechanism of change that is continual and yet ever-changing throughout the cancer experience. Although the Naus model does not describe the process of adaptation related to recurrence as is instead provided in the newly developed conceptual model Reluctant Acceptance of Living with Advanced Cancer Recurrence, it provides a basic framework or overview of the adaptation of cancer survivors.

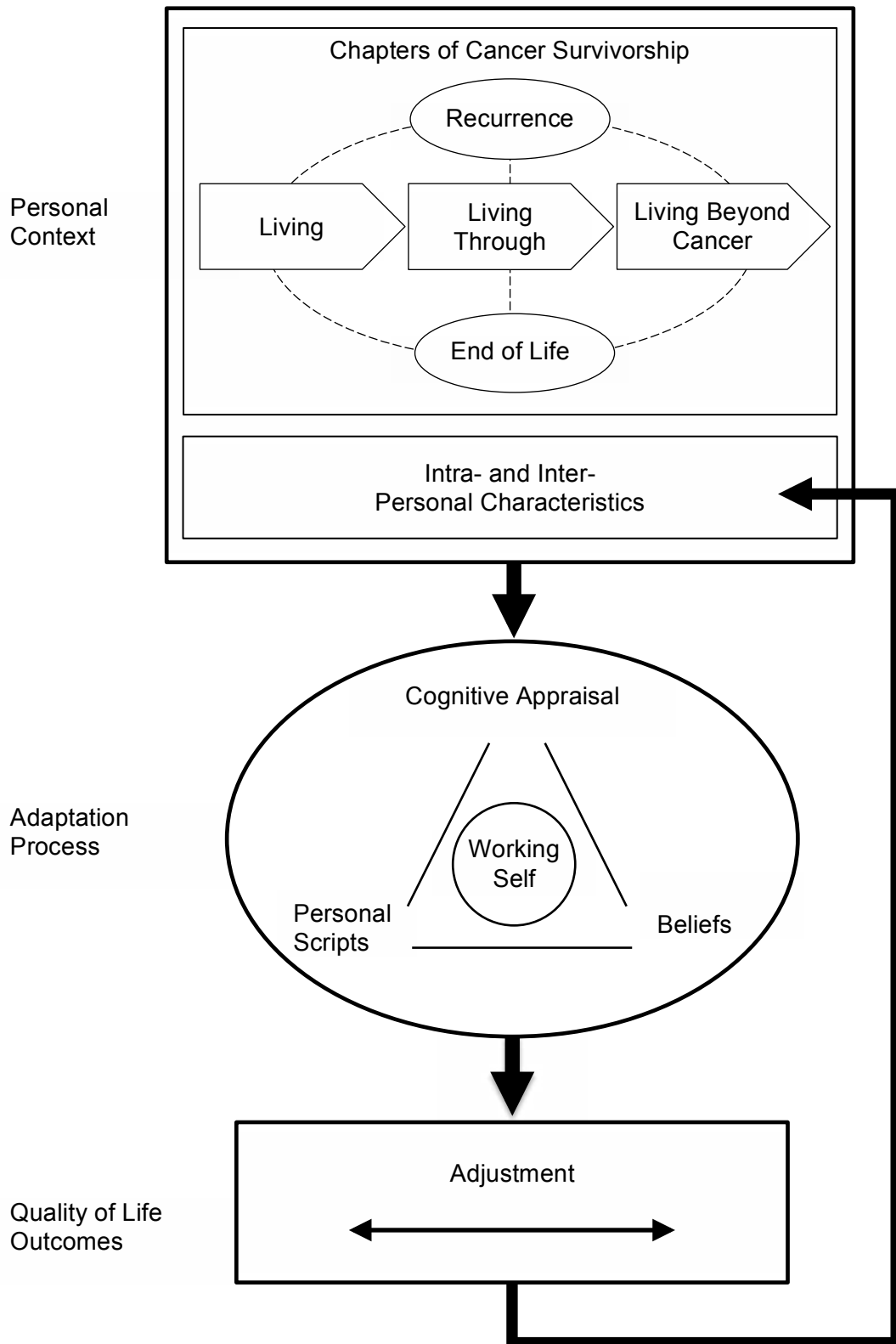


Figure 13. Cancer survivor adaptation model. Adapted from 'Cancer Survivor Adaptation Model: Conceptualizing Cancer as a Chronic Illness', by M. J. Naus, M. D. Ishler, C. E. Parrott, & S. A. Kovacs, 2009, *Journal of Clinical Psychology*, 65(12), 1350-1359, <https://onlinelibrary.wiley.com/doi/10974679>. Reproduced with permission.

Naus' et al.'s (2009) Cancer Survivor Adaptation Model reveals adaptation in the cancer survivor and includes the phases of cancer survivorship and the personal context that leads to cognitive appraisal and the adaptation process as a combined model that is dynamic but does not isolate the specifics of advanced cancer recurrence. My research addressed one section of the cancer survivorship trajectory, mainly the section that illustrates recurrence within the 'chapters of cancer survivorship' as shown in the Naus' model. My research, as described in Chapter 2, aims to answer the questions of how and what the participants' experience of advanced cancer recurrence is. Although the model speaks to adaptation process and quality of life outcomes my study did not focus on the why, and therefore these sections did not apply. As such, seeking treatment could be understood as a form of adaptation, given my study's focus on how and what the participants' experience, appraisal and outcome of this experience is not of relevance to this study.

The timing of this research captured this experience at a time of evolving treatment options for people with advanced cancer recurrence. This study's conceptual model can be situated within an area described in the Miller, Merry, & Miller (2008) model following 'Extended survivorship cancer free' (p. xx) to 'Permanent survivorship second cancers' and 'secondary cancers' (Figure 14). This research provides an empirical understanding of what the experience is for this specific population as they reluctantly accept advanced cancer recurrence.

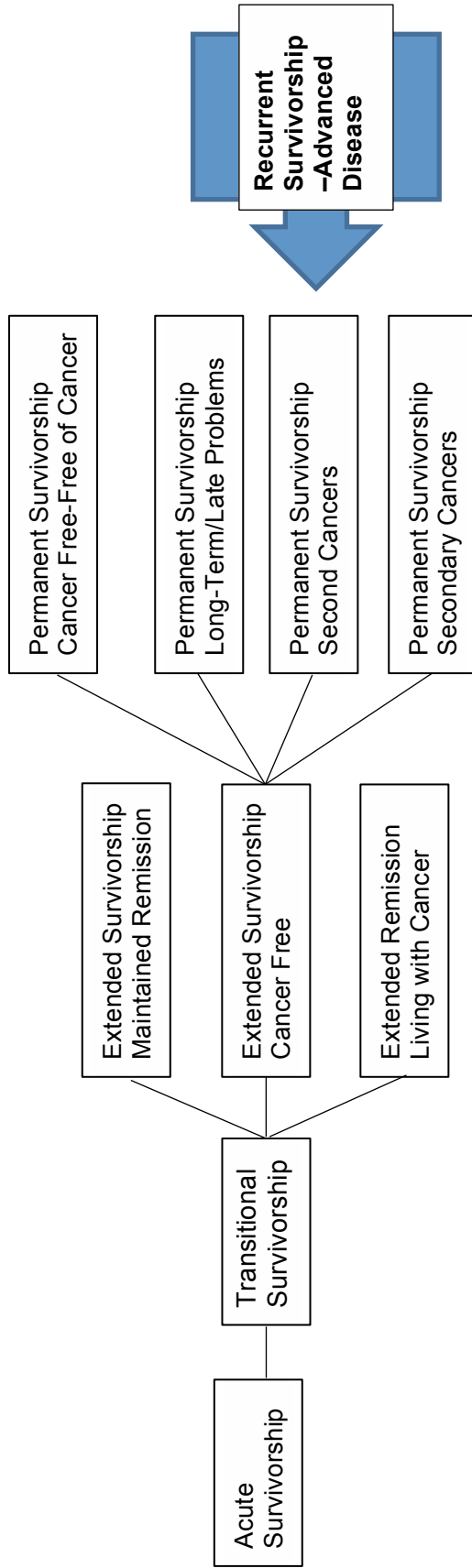


Figure 14. Proposed model for the seasons of survivorship. Adapted from 'Seasons of Survivorship Revisited,' by K. D. Miller, B. Merry, & J. Miller, 2008, *Cancer Journal*, 14(6), 369–374, <https://journals.lww.com/journalppo/pages/default.aspx>. Reproduced with permission.

Even though both Naus et al.'s (2009) and Miller et al.'s (2008) models provided for greater insight into the development of my model, neither model provides a framework for advanced cancer recurrence in light of this new paradigm shift of evolving treatment options.

5.4.2 Seeking Life Through Continuous Treatment motivated by hope in an uncertain future.

As reluctant acceptance was seen as the catalyst to seek treatment, hope revealed itself to be the driver towards seeking treatment as well as a buffer or insulator from worry (Dufault & Martocchio, 1985; Hicks & Conner, 2014; McClement & Chochinov, 2008; Nierop-Van Baalen et al., 2016; Rowland & Baker, 2005). As Elliott & Olver (2007) note, treatment is sought after when there is hope in for the successful outcome of the treatment. Similarly, the population of my study revealed a commitment to seeking and completing treatment because of their hope for a successful outcome. As the model shows, this population is willing to stay in this state of treatment for as long as possible, as this period allowed participants to believe that life could continue, and that their quality of life could be maintained in this 'normal' state. As indicated in the depiction of concepts in the model, advanced cancer participants in this circle of treatment and hope are able to maintain an acceptable quality of life. This study found in an effort to maintain a personal equilibrium people with advanced cancer recurrence are willing to stay in treatment for as long as it is effective. The model of Reluctant Acceptance of Living with Advanced Cancer Recurrence is not about a linear progression from diagnosis to treatment to end-of-life as Miller et al. (2008) and Mullan

(1985) described earlier in the field of cancer survivorship. This study's newly developed conceptual model provides a better understanding of this evolving population where treatment is available. The motivation to regain a personal equilibrium and control of advanced cancer recurrence influences this population into seeking survival through continuous treatment which then creates hope as described in this conceptual model of Reluctant Acceptance of Living with Advanced Cancer Recurrence. Sanders, Seda, & Kardinal (2012) describe the 'hope trajectory' (p. 241) that patients move through with advanced cancer. The phases of hope change throughout the course of disease, from diagnosis and a hope for cure, and fluctuate around the stages of the disease. This is the dynamic meaning of hope. Hope in the Face of an Uncertain Future is also conceptualised through Herth & Cutcliffe's (2002) work and also described in Wonghongkul, Moore, Musil, Schneider, & Deimling (2000). The definition of hope related to the concepts of this model is a multidimensional belief that a positive result can occur. Hope is both a connection between an individual and others and between self and the spiritual or existential. Hope is ever-changing depending on the object of what is being hoped for (Dufault & Martocchio, 1985; Herth & Cutcliffe, 2002; Wonghongkul et al., 2000, p. 423).

The availability of treatment provides hope for extended life (Elliott & Olver, 2007). Within today's context of increased treatment options, options which were previously not available to people with advanced recurrent cancer, acceptance of the disease manifests itself in the pursuit of Seeking Live Through Continuous Treatment (Brown et al., 2003; Karlsson et al., 2014; McCarthy, Jenn, Leng, & Hamzah, 2016).

Figure 12 portrays the circular action for which Reluctant Acceptance of the diagnosis is the catalyst that influences the need to seek treatment and creates hope in an uncertain future. Working to prolong life through treatment gave these participants something to work for while at the same time reconciling the reality that death was possible (Chen et al., 2015; Coyle et al., 2015).

Studies have shown that hope can positively impact physical and mental well-being in patients, and a positive attitude and belief in a future (Brown & de Graaf, 2013; Farran, Herth, & Popovich, 1995; Gottschalk, Fronczek, & Buchsbaum, 1993). These constructed concepts work together to maintain hope but when treatment is no longer an option; the person with cancer will re-evaluate their future and the meaning of hope. This becomes a multidimensional and dynamic process of hope (Clayton et al., 2005b; Daneault et al., 2016; Penson et al., 2007; Robinson, 2012).

5.5 Similarities and Differences Between Previous Literatures on Recurrence

As discussed above, this conceptual model illustrates the experience of advanced recurrence within the context of treatments now available to this population of people with advanced recurrent cancer.

A number of previous studies have focused on the topic of cancer recurrence (Andersen, Shapiro, Farrar, Crespino, & Wells-Digregorio, 2005; Brown & de Graaf, 2013; Cella, Mahon, & Donovan, 1990; Lobb et al., 2015; Mahon & Casperson, 1997; Northouse, Laten, & Reddy, 1995). Research on the relationship of hope and cancer recurrence has also been examined (Brown &

de Graaf, 2013; Duggleby, Holtslander, Steeves, Duggleby-Wenzel, & Cunningham, 2010; Sanders, Seda, & Kardinal, 2012). However, unlike these prior studies, this particular study developed within a context of much greater access to different treatment options (Couzin-Frankel, 2013; Early Breast Cancer Trialists' Collaborative Group, 2005; Lobb et al., 2015; Welch, Schwartz, & Woloshin, 2000). Therefore, this changing paradigm has shaped the relationship between hope, treatment, and cancer recurrence. In other words, the context of the prior studies differed from this study's context in that, for the most part, treatment options at the time of these earlier studies were not available to people with advanced-stage cancer recurrence other than in palliative or end of life care as discussed in Chapter 4: Literature Review. Anderson, Shapiro, Farrar, Crespin, & Wells-Digregorio (2005), Brown & de Graaf (2013), and Lobb et al. (2015) emphasised the impact of newly available treatments for participants dealing with advanced cancer recurrence.

In an effort to put the changing paradigm of advanced cancer recurrence into perspective, literature is examined in chronologic order to illustrate the impact of evolving treatment options on recurrence research (Couzin-Frankel, 2013). Cella et al. (1990) described cancer recurrence as a traumatic event and found there was more adjustment needed for recurrence than for initial disease diagnosis. Their participants were all diagnosed with incurable disease and they described the importance of not including participants with a life expectancy of 6 months or less as it may 'contaminate the issues related to a traumatic event versus issues related to terminal illness' (p. 16).

Prior to 2013, research looked at the question of cancer recurrence from a particular point of view, one that does not include the access to more treatment options for people with advanced cancer. This was likely because the context and the outlook for survival were different. The availability of treatment options has an impact on the type of questions examined by research. Cella et al. (1990) identified concerns about dying and a higher level of distress with recurrence over the initial diagnosis (Cella et al., 1990; Donovan & Glackin, 2012; Mahon & Casperson, 1997). Northouse et al. (1995) compared the response to recurrence of breast cancer between spouses. She found that the women had more emotional distress and more symptom distress with recurrence. Using the conceptual framework of Lazarus & Folkman's (1984) theory of stress, appraisal and coping, the Mahon & Casperson (1997) study evaluated two areas of how a person experiences a phenomenon to understand cognitive appraisal and coping related to the meaning of recurrence of cancer and whether the person perceived the initial diagnosis to be different than recurrence (Mahon & Casperson, 1997).

Mahon, Cella, & Donovan's (1990) study described avoidant coping strategies that decreased their overall response to recurrence. They suggested that longer periods of remission may have supported their avoidant coping and temporal uncertainty relating to forgoing follow-up with medical tests as recommended. This response was somewhat different in my study as participants had followed up as recommended, but they shared the concept of hope in the face of uncertainty. Having experienced cancer before and maintaining a longer remission, they believed that they could achieve remission again, *'I did it once, I can do it again'* (P3:27). Mahon & Casperson

(1997) described their participants as discussing death and dying easily, unlike within my population. My study population did not consider forgoing treatment; this may be a limitation of the study and is discussed in Section 5.9 Limitations.

Andersen et al. (2005) found the psychological response to a recurrent cancer caused more stress than what was found in this population. Their study describes how stress from the cancer is compartmentalized to decrease emotional distress and the resilience patients exhibit when dealing with recurrence. This perception of resilience was also described in Rowland & Baker (2005) related to diagnosis of cancer and experiencing 'catastrophic events' (p. 2543). Through compartmentalising the distress of cancer recurrence, people in this phase of advanced cancer recurrence display resilience in coping during the early weeks after diagnosis (Andersen et al., 2005). Choosing to accept the situation and maintain a positive outlook with a plan for treatment promotes hope and the illusion of having control over cancer (Rowland & Baker, 2005; Taylor & Armor, 1996). This finding was similar in my study as well, as participants responded to their diagnosis and moved into seeking treatment as they had done before with initial diagnosis. Unlike Anderson et al. my study did not measure stress which arguably may have been offset by increased availability of treatment options. Receiving treatment was interrelated with supporting hope, and acceptance of a new normal of continuous treatment to continue living. For patients with an advanced cancer recurrence after perceiving themselves to be cancer free, beginning treatment is the first step toward regaining a sense of control after the advanced cancer recurrence diagnosis. This population, as seen in others'

work (e.g., Brown & de Graaf, 2013), is eager to participate in clinical trials and hopeful that they will provide benefit to others and prolong their lives.

This research and resulting conceptual model describes the response to recurrence as the context of treatment and improvements in outcomes is growing. When compared to early research on recurrence, the concepts of hope, acceptance, and treatment remain important concepts in this population. The response to recurrence seems universal regardless of treatment options or stage of disease at recurrence. Andersen et al. (2005) and others recognized the different findings related to stress reactions to recurrence being seen as greater than at initial diagnosis (Cella et al., 1990; Mahon & Casperson, 1997). Vivar, Whyte, & Mcqueen (2010) work found people with recurrent cancer were less hopeful, although participants were in hospital or in palliative care settings in their work. Possibly the context of where they were influenced this response.

My research has identified differences in response to recurrence in comparison to recurrence before immunotherapy and genomics medicine. This study was the first step toward understanding how this population describes their experiences to develop future research directions.

5.6 Elements of the Conceptual Model Reluctant Acceptance of Living with Advanced Cancer Recurrence

As described above, this phase of advanced cancer recurrence has seen improved survival and quality of life related to improved detection and targeted treatment options (Brown & de Graaf, 2013; Lobb et al., 2015; Maher, Velikova, & Betteley, 2015). Although multiple studies have addressed living

with advanced disease, these have often focused on people who have discontinued disease-focused therapies and who are receiving palliative care only, or those living at the end of life (Chen et al., 2015; Garcia-Rueda et al., 2016; Mak, 2002). In this study, participants had options for continued disease focused treatment despite advanced recurrent cancer as found in other studies (Brown & de Graaf, 2013).

Although the evolving treatment options available such as genomics and focused therapy are mostly life prolonging, with most patients dying as a result of their cancer, some will live and die of other causes. I describe this new group as *'not curable but treatable'* (P10:66), and focused on the options of treatment for as long as remission can be possible (Maher et al., 2015). They recognise their disease status as incurable but do not see themselves as terminal.

This population is ambulatory, experiencing minimal symptoms and living with a sense of normalcy (Garcia-Rueda et al., 2016). This concept of seeking normalcy has been described in the literature related to post-treatment survivors of cancer who are working toward returning to a new 'normal' (Walker, Szanton, & Wenzel, 2015), but not in people with advanced cancer who are seeking survival through continuous treatment. Since new treatments such as oral agents often consist of targeted therapies and are less invasive, this population may experience minimal symptoms and are not limited in their daily lives (Lobb et al., 2015; Payne et al., 2007). This higher level of quality of life may make it easier to believe their lives can reach a level of normalcy even with advanced cancer (Marker, 2015; Payne et al., 2007). Their

prognosis, although incurable and unpredictable, may range from months to years (Lobb et al., 2015). These factors explain their perceptions of seeing their lives as 'normal' and being 'otherwise healthy' (McCarthy & Dowling, 2009; Nissim, Freeman, et al., 2012). Feeling well, despite their diagnosis, adds to their hope and to the cyclical nature of the model of Reluctant Acceptance of Living with Advanced Cancer Recurrence. This new population has been given treatment options; they are focused on continuing to live and maintaining their quality of life for as long as possible and they remain hopeful. These study findings are an important contribution that add to the understanding of the experience of this specific population who have an opportunity to live a longer life with advanced recurrent cancer in ways that was not possible for this population of people with cancer in the past (Brown & de Graaf, 2013).

5.6.1 Focusing on survival.

The need to survive is an inherent goal for any group of human beings (Bauman, 1992). As a social construct, human survival has been discussed as the human inability to reconcile the power of the mind and reason with the 'time-bound fleshy casing' (p. 1). The constant struggle for survival and avoidance of serious illness or death is experienced by all human beings. The desire to adapt to the transitions experienced between the diagnosis of cancer, stable disease, and recurrence to end of life are described above. Facing the reality that death is inevitable, and yet the desire is to delay it, this current study suggests that stabilising the cancer remains the constant goal. This desire to maintain life at the highest quality possible for as long as

possible is seen as allowing the participant to live until a possible cure is found or allowing them to ignore the inevitable (Clavarino et al., 2003; Karlsson et al., 2014; McCarthy & Dowling, 2009). Participants in this research study were not in a state of denial; they understood that their cancer had not only recurred, but that it was also advanced. They did express an understanding that this recurrence would lead to the end of their life. They maintained a belief in the possibility of stable disease, even if a cure was not possible. Seeking to live with cancer through access to continuous treatment in this population was the goal, despite the realisation that their initial treatment did not cure them.

5.6.2 Avoidance of death.

This population, described in my study as 'not curable but treatable' avoids consciously or unconsciously the possibility of dying from this disease. As other studies examined advanced recurrence and describe the experience related to palliative care and hospice, this population is not focused on end of life. These participants were receiving tumour-directed therapies and the benefit of supportive drugs that build bone, decrease side effects, and decrease discomfort. They also have access to multiple clinical trials aimed at stage IV advanced disease participants, unlike in past clinical trials where advanced disease participants were specifically excluded (Brown & de Graaf, 2013; Couzin-Frankel, 2013; Lobb et al., 2015).

In 1996, an editorial by Sledge titled 'Should We Dream the Impossible Dream?' discussed the future of long-term survival in metastatic breast cancer patients. This was the beginning of the understanding of hormone receptor importance in breast cancer disease management, and the idea that possible

changes in treatment could lead to longer survival. Twenty-one years later, targeted therapies have grown beyond hormone receptors to genetic indicators and provide focused treatments that are extending survival of cancer. Unlike the chemotherapy treatments of the past, new therapies have reduced toxicity profiles, making them more tolerable. Yet as the future of cancer care is rapidly changing, patients still live with the liminal reality of having cancer and the reality that it can recur (Little, Jordens, Paul, Montgomery, & Philipson, 1998; McKenzie & Crouch, 2004).

Other studies related to initial recurrence with advanced cancer have also noted the lack of willingness to discuss death and dying in advanced cancer patients (Lobb et al., 2015). It is important to note that all of the participants in this thesis study were receiving a treatment regimen post diagnosis of their advanced cancer recurrence.

This avoidance of death described in this research relates to the pertinent context of increased hope, even in an uncertain future as this population has opportunities for treatment to stabilise disease (Brown & de Graaf, 2013). This allows them to focus on living and maintaining a sense of a normal life (Lobb et al., 2015; Periyakoil, Neri, & Kraemer, 2016). Despite social and professional advances through hospice and palliative care over the past 30 years, it is not normal in Western society to talk about death and dying and there is sometimes a sense that talking or thinking about death can make it happen (Periyakoil et al., 2016).

In many cultures, there are superstitions or culturally-based beliefs about discussing death and dying, as well as religious beliefs influencing perceptions

of illness and death (Periyakoil et al., 2016). Additionally for this population receiving treatment and experiencing good quality of life, their focus was on remission and therefore, they believed it was not necessary to talk about end of life at this time. The participants remained hopeful about the prospect of new treatments in the future that could lead to stable disease. As long as their cancer and symptoms are controlled, they maintain hope for a future. Others have also described this sense of living until they die or have unacceptable quality of life (Ryan, 2005). The lack of symptoms or side effects from newer treatments and oral agents reinforced their sense of wellness and normalcy as well as the ability to avoid thinking about the possibility of death. The ability to maintain quality of life within the conceptual model of treatment and hope allows avoidance of the possibility of dying soon from advanced cancer and maintains their desire to live and hope for continual response to treatment.

5.7 Liminality in Cancer Survivors

Liminality as a process of being in a life transition that early literature referred to as a 'rite of passage' has been described in cancer survivors and people with chronic disease (Blows, Bird, Seymour, & Cox, 2012; Froggatt, 1997; Hockey, 2002; Little et al., 1998; Thompson, 2007). A cancer diagnosis labels the person with cancer for life (Little et al., 1998; Thompson, 2007). People with cancer have a sense of always being a 'cancer patient' with or without active disease or in liminality terms, always being on the threshold of cancer (Little et al., 1998).

Secondly, people with cancer often had an inability to communicate the meaning of the experience of cancer and its treatment and a sense of life

related to the boundaries of cancer and the awareness of the loss of time, loss of control, and uncertainty for their future (Little et al., 1998). This concept of liminality for this population who are no longer cancer survivors but have crossed a threshold and are now people living with advanced cancer recurrence remains a reality, but how this concept is imagined in light of improved survival rates with recent advanced treatment options is yet to be understood. These participants have transitioned from someone who had been cured of cancer to having advanced recurrent cancer.

Thus the concept of liminality is applied to the cancer survivor as being a person with cancer, but now advanced cancer that is incurable but treatable. Froggatt (1997) described the concept of liminality related to a person transitioning to hospice and eventual death. This provides for a culture in which the transition will lead to death, in light of the context of advanced cancer and the hope to continue living overrides the willingness to transition towards death or dying in this new population.

Hockey (2002) describes the pattern identified by Van Gennep as a tripartite structure where the rites of passage are aggregated to '1) passage out of a previous phase or social status; 2) an ambiguous time and space betwixt and between fixed positions; and 3) re-entry into a new social position or period' (p. 212). People living in a liminal stage of this 'in-between' re-enter society at a higher social status or different place (p. 212). This newly growing population who go from no cancer to advanced cancer are in a place that in the past had meant transitioning to end of life. This population is in a new phase of life, living longer after an advanced cancer recurrence with new

treatments that prolong survival beyond days to months or years (Brown & de Graaf, 2013; Miller et al., 2016).

From the sociological sense of avoiding death and the realisation of the limited life they now face, these participants sought continued life through treatment and have a greater opportunity to actually have a prolonged life. Seeking to maintain autonomy and normality in their lives was the primary concern for this emerging population in a way that has never before been an option. This changing reality has prolonged survival; therefore the realisation of the potential for improved survival has also impacted participants' responses to advanced cancer. Despite treatment options, the outcomes remain uncertain and patients seek hope and believe in a future (Little et al., 1998; Maher et al., 2015; Thompson, 2007). The liminality was very much a part of this study due to the context and methodology. By restricting the study inclusion to people who had recently been diagnosed with advanced recurrent cancer, the study captured this liminal experience of being at the threshold of a new phase of life.

5.8 Summary of the Conceptual Model of Reluctant Acceptance of Living with Advanced Cancer Recurrence

This final chapter has described the process of conceptual development of the final model, Reluctant Acceptance of Living with Advanced Cancer Recurrence, and discussed this process of development in relation to the evidence drawn on from the qualitative data collected. Using constructivist grounded theory the process of development was illustrated through the different model conceptions as the final model concepts were constructed and

meanings were developed. What is demonstrated in this conceptual model of Reluctant Acceptance of Living with Advanced Cancer Recurrence is that after the initial shock of diagnosis for participants recurring with cancer after perceiving themselves to be cancer free, there is a shift to a state of reluctant acceptance which then as a result of new treatment options moves participants to seeking survival through treatment in the hope of an uncertain future.

Reluctant Acceptance as the initial concept motivated the action to move forward toward treatment. The conceptualisation of the appraisal of the transition from cancer free to advanced cancer recurrence identified that personal context and characteristics of the person experiencing recurrence were important indicators to how a person accepts and chooses treatments. This was compared to the Naus et al. (2009) CSA model and the Miller et al. (2008) model to illustrate this specific population and how this new information can contribute to the explanation of their experience. My study differs from Naus et al. and Miller et al. in that their respective models do not isolate recurrence as separate from survivorship.

Hope in the Face of an Uncertain Future as defined for this population includes the multidimensional aspect of hoping for treatment, hoping for a future, and recognizing the significance hope provides toward seeking treatment even in this era of uncertainty. Mullan (1985) described an area of 'uncharted middle ground' (p. 273) resulting from the rapid growth of survivors seen from 1965, where the 5-year survivorship had been 25% and in 1985 rose to almost 50% (p. 273). This is where this population of people with

advanced cancer recurrence stand today, within this gap of understanding what the future holds. In the absence of available treatment options in the past, this population was considered untreatable. Research focused on people who have been diagnosed with advanced cancer recurrence may include a whole new experience. Benefits and long-term outcomes of new treatment regimens are uncharted and additional research is needed to understand the patient experience.

It is difficult to identify where the changing paradigm begins. Literature usually includes data collected one to two years before publication. The American Society of Clinical Oncology [ASCO] (2012) provides yearly annual reports on clinical cancer advances that started in 2011. Record numbers of survivors were documented in 2010 and the U.S. Food and Drug Administration began to approve multiple anticancer agents between 2011 and 2012. With notable advances in immunotherapy treatment of cancers such as for lung and melanoma with Anti PD-1 and Car-T therapies, this trend of improving survivorship is continuing (Couzin-Frankel, 2013).

The boundaries of this research as described above are not entirely clear. Comparing the understanding of treatment advances for people with advanced cancer recurrence to recurrence literature in the past will provide meaningful information to improve our understanding of this paradigm and whether it is different and in what ways. Death avoidance and the concept of liminality appear to be described by people with cancer or advanced cancer recurrence, but again what this means for this new era of cancer treatment is just now beginning to evolve.

5.9 Strengths and Limitations of the Study

There are both limitations and strengths in this study of advanced cancer recurrence in this growing population. Participants in this study were predominately Caucasian and were primarily women. Future research should broaden the sample and include more men and greater representation of various ethnicities, as these factors could influence the response to advanced cancer recurrence and therefore the model. Although the sampling approach attempted to include more solid tumour types, the participants were primarily breast cancer patients. This population has been researched heavily and also has benefited from great success in current treatment opportunities (DeSantis, Ma, Goding Sauer, Newman, & Jemal, 2017).

As the site of this study is a free-standing cancer research and treatment centre it must be noted that participants may have been biased to seek treatment and therefore may not have been willing to consider options that may have included no treatment or seeking hospice care. As one of 49 comprehensive cancer centres in the U.S. (as designated by the U.S. Cancer Institute) it has a focus on treatment as well as research and care. It is possible that the population from which the sample was recruited had particular expectations about treatment. As such future research with the conceptual model should encompass a variety of settings to explore beyond The City of Hope, with commercial advertising offering 'The Miracle of Science with Soul'.

The positive attitude surrounding these participants may have contributed to their treatment choices and attitudes about treatment. These participants are

focused on achieving a response to advanced cancer recurrence after a period of believing they were cancer free; therefore the timing of the interviews and the fact that the participants were all in active treatment may have contributed to the interrelatedness of hope and treatment. Other studies in advanced cancer recurrence in different settings and in additional tumour sites have also identified similar concepts related to hope and treatment (Brown & de Graaf, 2013; Duggleby et al., 2012; Penson et al., 2007).

The strengths of this research include that this is a new era of cancer treatment options in a population who in the past were referred to hospice for end-of-life care. Describing this experience of advanced recurrence in a person who has been cancer free for two or more years in light of these advances, will also provide empirical data to compare with past recurrence literature. This new research provides a theoretically based, qualitative approach to provide focused information from the participants' experience.

The use of constructivist grounded theory as a method allowed me to be part of this research and was found to be an acceptable method that allowed the participant voices of this newly evolving population to guide the development of this model. Constructivist grounded theory allowed the flexible gathering of the participants' experience to be individually described yet compared iteratively to build a co-constructed understanding of the experience of advanced cancer recurrence in people who perceived themselves to be cancer free. Phenomenology would have also been an appropriate method for this study and may have shortened the length of time to complete this study without the initial focus on theory development (Charmaz, 2014; Hussein, Hirst, Salyers, & Osuji, 2014).

This study has resulted in a conceptual model to describe the experience early after the diagnosis of advanced recurrence in cancer survivors in the context of available treatments and clinical trials provided for advanced cancer, late-stage participants and thus add to a critical new area of scholarship. The cancer survivorship movement in the U.S. was a patient advocacy effort borne out of experiences of people living with cancer. The National Coalition for Cancer Survivorship (NCCS) has advocated for better care of this patient population (National Coalition of Cancer Survivorship (NCCS), 2013). This study's findings and new model can be used as a means of advocacy to share the experiences of people facing advanced cancer recurrence as this paradigm shift is occurring.

This research will allow the next step comparison to the experience of advanced cancer recurrence prior to 2012, where access to clinical trials for stage IV cancers—especially in lung, pancreatic and melanoma cancer patients—was not an option (Roth et al., 2012). Therefore evaluating the conceptual model and concept links described in this model will lead to theory development and build the knowledge base needed to manage care in this population for the future.

Constructivist methodology allowed the constructed knowledge of the experience within this newly evolving context of improved treatment and survival in advanced-stage cancer patients. As CGT is meant to include the context of the phenomenon being studied it also includes the timing and details of the inquiry; this was the most appropriate method to capture an experience that may be different in light of this new context. CGT allows for

broad open coding and conceptual development to capture an unknown experience. Charmaz (2014) describes a concept-indicator model as 'a method of theory construction in which the researcher constructs concepts that account for relationships defined in the empirical data and each concept rests on empirical indicators, thus the concept is grounded in data' (p. 342). Therefore this research will direct the next steps in understanding this population that will continue to grow.

5.10 Implications for Clinicians and Policymakers

The conceptual model of Reluctant Acceptance of Living with Advanced Cancer Recurrence has important implications for clinicians and policymakers. Clinicians must understand the priorities of this population of long-term cancer survivors who are now living with advanced cancer with treatment options and symptom control not seen in the past. Minimal research that describes the experience of this population with advanced cancer and treatment options needs to be better understood so that clinicians can be prepared to provide a realistic treatment plan. Clinicians thus need to be well prepared to discuss treatment options while also communicating the reality of progressive disease.

Communication has become a very important area of research in cancer care, as researchers evaluate how communication is occurring between clinicians, patients, and family members (Thorne et al., 2014). Communication research would be especially important in this population facing recurrent cancer and responding to this incurable prognosis. There is a growing body of knowledge related to barriers in communication between patients and physicians and the impact of poor communication on satisfaction with cancer care, symptom

management, lower rates of compliance with medical recommendations, reduced trust in physicians, and reduced hope (Brandes, Linn, Smit, & Van Weert, 2016; Chawla et al., 2016; Thorne et al., 2014). The inability of clinicians and patients to communicate effectively leads to misunderstandings, promotes uncertainty, and inhibits patients from making informed decisions (Brandes et al., 2016; Chawla et al., 2016; Clayton et al., 2005b; Thorne et al., 2014). The impact on decision-making would be especially important as these participants deal with continuous treatment and the potential for treatment failure and transition to hospice and end-of-life care. The limited communication noted within this research was an indicator of avoidance of the possibility of death from this advanced cancer recurrence either from the clinician or participant.

Palliative care was only discussed by one participant who was dealing with side effects related to her multiple treatments, despite the importance of palliative care interventions and potential benefits. This is a consideration that is important for clinicians and policymakers alike. Research related to the benefit of the early introduction of palliative care to advanced-stage cancer patients requires this consideration (Temel et al., 2010).

Advanced cancer patients who are continuing to receive cancer-focused treatment may experience multiple comorbidities. The mean age for this population was 71 years-of-age, and the age range was between 61 and 80 years. The older age of this population of advanced recurrence is related to cancer incidence increasing with aging. The majority of advanced cancer survivors will be older; this is especially true as the population ages (American

Society of Clinical Oncology [ASCO], 2018). Clinicians will need to also consider how older adults are impacted with these newer treatments. Coordination of care among multiple disciplines sharing their expertise will be important to manage comorbidities.

A change in definition of palliative care can strengthen the impact for this new population. The important factors described in this research as well as throughout the literature identify the factors that remain important throughout the trajectory of recurrence. These factors include family, spiritual and social support, finding meaning, maintaining hope, and positive thinking. Palliative care provides support to patients and families who are facing issues related to life-threatening illness, yet patients living with cancer have not previously been a targeted population for palliative care (Smith et al., 2012). Both the patient and family are coping with recurrence, reinitiating cancer treatment, and facing an uncertain future. Managing complex psychosocial issues that may arise such as anxiety and existential distress is an area where palliative care interventions can help improve patient experiences.

This population of cancer patients with advanced recurrent cancer described the importance of family and spiritual support to help them cope with this new recurrence. Palliative care research has supported the importance of spiritual care and its impact on quality of life, survival, and coping (Puchalski, Ferrell, & O'Donnell, 2016). This population of people living with cancer described the importance of their spiritual beliefs to help them during this process of maintaining hope and seeking meaning in their life and bringing stability to their feelings of uncertainty. The importance of family support must also be

recognised as an essential part of the care needed by people experiencing advanced recurrence.

This study revealed that the social connectedness and relationships of family and friends was an important sub-category of the construct of hope. Supporting the family caregiver will improve the quality of care experienced by this population (Northouse, Williams, Given, & McCorkle, 2012). Palliative care provides resources and understanding for the special needs of these family caregivers. This period of advanced recurrence after believing their family member was cured is especially stressful for caregivers: Supporting their loved one through treatment, with the realisation that cure is not the goal of care and the future is uncertain, can cause feelings of anger and suffering for loved ones (Borneman & Brown-Saltzman, 2016; Vivar et al., 2010). Palliative care involvement provides support for families through these emotions or changed plans as well as supporting them through bereavement in the future.

5.10.1 Impact of continued treatment options of cost of care in the U.S.

The population of advanced cancer patients seeking continued treatment will have a major impact for health policy in the U.S. Cancer care is known to be extremely costly and one study found that 79% of cancer patients experienced extreme financial burden (Zafar et al., 2013). An additional study found that cancer patients declare bankruptcy 2.7 times more often than people without cancer (Ramsey et al., 2013). In the United States, health insurance provides support to a majority of the population but these plans include patient co-pays

that may be as high as 20% of their health care costs. Even patients covered under government-supported Medicare may experience out-of-pocket expenses that are as much as 24% of their household income (Narang & Nicholas, 2016). Thus, although advanced cancer patients have access to new anti-cancer therapies, they are expensive and the long-term benefits are often unknown (Goldstein, 2017).

This model should inform policymakers of the potential impact for the person with advanced recurrent cancer seeking expensive treatments, despite advancing disease. Financial coverage for healthcare in the United States allows for either individual self-payments or insurance coverage that supports second- and third-line treatments if desired by the participant; thus, seeking continuous treatment is possible (Smith & Medalia, 2014). These opportunities are rapidly changing in the United States; it is unclear at this time how long this type of insurance coverage will be possible (American Society of Clinical Oncology [ASCO], 2018). Regardless of future policy changes, there will remain important health policy implications given the more than 14 million cancer survivors in the United States (Hewitt et al., 2006).

The option to participate in clinical trials as described by Brown & de Graaf (2013) recognises this changing paradigm for end-of-life treatment. This study documented that cancer survivors hope to access clinical trials as new treatment options become available. Clinicians and policymakers will need to consider the population of people with advanced cancer recurrences who continue to seek treatment and the need to coordinate palliative care in an effort to provide guidance when needed for end of life care.

5.10.2 Palliative care versus hospice care in the U.S.

An important aspect of palliative care when compared to hospice or end-of-life care in the U.S. is the ability for palliative care to be provided to patients receiving anti-cancer therapies while dealing with advanced recurrence that is allowed by most health insurance coverage. Hospice care in the United States is only covered for patients with a prognosis of 6 months or less and does not allow anti-cancer therapies to be provided or any other disease-focused treatments other than comfort-focused care (Zerzan, Stearns, & Hanson, 2000). Therefore, this population of cancer survivors—whose priorities as described in this research are focused on maintaining survival and promoting life at all costs—are not willing to transition their care to hospice. This study and the evolving model have captured the unique experiences and perspectives of cancer survivors, which have many implications for developing, delivering, and reimbursing care. The benefits of palliative care interventions will provide physical symptom management, psychosocial and spiritual support during this phase of seeking life in an uncertain future. Providing access to palliative care will support participants' goals of care as well as support them during future transitions of care providing coordination of services for the benefit of both participants and their family caregivers.

5.11 Implications for Future Research

The importance of research within this population goes beyond the discussion in the section above. Policymakers in the U.S. need information regarding expectations of people with advanced cancer recurrence, including defining what palliative chemotherapy means, treatment options, and prognosis.

Evaluating the model of living with advanced cancer recurrence in different settings may provide additional insight into this period of advanced cancer recurrence that has not been specifically researched in the past. The needs of a population that transitions from the status of free of cancer to being a person with cancer living with advanced disease with improved treatment options is a new area of research. A longitudinal study would allow a better understanding of the transition through these experiences. It may also give insights about any shift away from treatment and or to end of life care. Applying the newly developed model to types other than solid tumours may yield different experiences, which will be valuable in extending the model. Different tumour types have different options for advanced-stage treatments (Brown & de Graaf, 2013).

Community hospital settings and physician practices may also be providing continuous treatment to this population of advanced recurrent cancer patients seeking survival. Settings have access to different resources and clinicians in each setting should be prepared to support people with advanced cancer in comparing treatment options and transitions of care to insure that equitable and quality care are provided. Research is needed to evaluate outcomes of new care models across settings.

Applying this conceptual model in different populations would also provide additional insight into the application of this model across age groups, genders, and disease types and provide a framework for the future development of a theory to describe this population. The population of this study was primarily women with breast cancer and responses to advanced

recurrence by other populations would serve to further inform this model and future theory development. Understanding the patient experience through the grounded theory approach can inform future theoretical research to insure that the interventions reflect true patient needs.

Based on this growing population of people living with cancer, further longitudinal research about newer treatment options for advanced cancer and toxicity profiles would help describe long-term effects of these treatments on this population living with advanced cancer and continuous treatment. Additional qualitative research applying this conceptual model could be undertaken concurrently with clinical trials and triangulation methodology could include quantitative measures of the concepts in the model such as hope and uncertainty. Longitudinal studies that follow participants when cancer treatment is no longer tolerable or available would provide much-needed insight into how to prepare and support this population through that transition of care to end of life or how that transition occurs. This study consisted of a one-time interview soon after recurrent disease was diagnosed, but longitudinal studies could aid in theory development by testing relationship between concepts described within this conceptual model.

This conceptual model provides insight into this specific phase of advanced cancer recurrence that has not been described in other models (Miller et al., 2008; Mullan, 1985). As discussed in Chapter 1, Mullan (1985) and Miller et al. (2008) described phases of living with cancer related to diagnosis, treatment, and cancer free status but this model describes a specific phase that follows the period of being cancer free with a diagnosis of advanced

recurrence. This conceptual model extends the knowledge-based understanding of what this specific phase of living with advanced cancer recurrence means within this new paradigm of available treatment for advanced-stage cancer (Brown & de Graaf, 2013; Couzin-Frankel, 2013).

5.12 Conclusion

This study and the conceptual model constructed from the findings have made an important contribution to the literature addressing a growing population of people living with advanced recurrent cancer after a period of being cancer free. The conceptual model Reluctant Acceptance of Living with Advanced Cancer Recurrence illustrates the key constructed concepts of the experience of people living with advanced recurrent cancer: Reluctant Acceptance, Seeking Survival Through Continuous Treatment, and Hope in the Face of an Uncertain Future. This model puts into context this specific population that has moved beyond the stage of Extended Survivorship Cancer-Free described by Miller et al. (2008) and now recurs with advanced incurable cancer. Future research to study the conceptualised relationships towards theory development is needed.

The term cancer survivor does not adequately describe this group of people who experience advanced recurrence. Although the U.S. Institute of Medicine definition of a cancer survivor includes all people who are diagnosed with cancer from initial diagnosis throughout life, this population is different (Hewitt et al., 2006). They have an increased risk of dying from their advanced cancer but by living longer, other age-related comorbidities may also lead to death. They no longer look at a future in terms of being cancer free but focus on

survival, as in living with advanced cancer for as long as possible. These people seek cancer treatment and are willing to participate in clinical trials and any treatments that will prolong their lives with the hope of reaching remission or stable disease (Brown & de Graaf, 2013; Ferrell et al., 2017).

There are important implications for future health needs of this population as they receive multiple treatments and risk multiple co-morbidities associated with continued treatment. Cancer risk increases with age and as this population includes a significant number of older adults; co-morbidities of aging and extensive cancer treatments mean that this population could benefit from palliative care support. This study has broad clinical and policy implications and should serve as a guide to advancing practice and the focus for future research.

Generic terms such as survivor or survivorship to describe a group of people who have experienced a cancer diagnosis limits the understanding of the clinical and research needs for this population. This conceptual model provides a starting place for future researchers to build knowledge and interventions to improve care for this population and describes a newly developing population of people with cancer along the continuum of the cancer experience who have not been described before. This population is growing at a time when improvements in the understanding of the biology and treatment of cancer have led to new and innovative treatments that can improve and stabilise advanced cancers.

The growing recognition that people with advanced cancer recurrence can hold on to treatment as hope for longer life with acceptable quality, rather than

merely treat their disease as incurable or terminal, in invaluable. Within this new context of advancing treatment opportunities, this study's model aims to illustrate the experience of this specific population. This model contributes to future research which is needed to build evidence based oncology and palliative care practice.

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Appendix A – Research Consent and Patient Bill of Rights

Principal Investigator: Denice Economou RN, MN

Department/Division: Population Sciences/Department of Nursing Research & Education

Telephone number: 626-256-4673 X63477



INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES

Exploring the Recurrence with Advanced Disease of Long Term Cancer Free Survivors

- I. **PURPOSE OF THIS RESEARCH STUDY:** You have been asked to participate in this research study because you are a long term cancer survivor who has recurred. The purpose of this study is to understand better what your specific needs are and how best to provide support to you and your family. Your participation in this study is expected to last for a one to one and a half hour interview.
- II. **BACKGROUND:** As a cancer survivor you have experienced a time of disease free survival. Providing efficient coordinated care is important for cancer survivors. Understanding what your cancer recurrence means will help us to better meet your needs.
- III. **WHAT WILL BE DONE:** This study will require a one-time detailed interview that may take up to one and a half hours. This interview will be audio taped and information will be used by the researcher to attempt to describe specific concerns of long term cancer survivors who recur.
- IV. **POSSIBLE BENEFITS:** You may benefit from participation in this study by describing your thoughts and concerns related to your recurrence after a long period of disease free survival.
- V. **POSSIBLE RISKS:** The risks and discomforts of this study are possible distress related to discussing your emotions and concerns over cancer recurrence.

You may become tired from the amount of time needed to complete the interview. The interview will focus on life issues that could cause you to

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become emotionally upset. If this occurs, you will be referred to your physician to determine how best to handle the concerns and issues. Support and counseling will be available from social workers and psychologists as needed.

- VI. **ALTERNATIVES TO PARTICIPATION**: Your alternative is to choose not to participate in this study. Choosing not to participate will not interfere with any future treatment, *or* any relationship with your physicians or health care team here at City of Hope.
- VII. **CONFIDENTIALITY OF INFORMATION**: Any information learned from this study in which you might be identified will be confidential and disclosed only with your permission. By signing this form, however, you allow the researchers to make your information available to City of Hope Institutional Review Board (IRB) Office, the Cancer Protocol Review and Monitoring Committee (CPRMC) *or* Protocol Review and Monitoring Committee (PRMC)], the Office for Human Research Protections (OHRP), the National Cancer Institute (NCI), and the PhD supervisors at Lancaster University, Lancaster, England and other regulatory agencies as required by law. If information learned from this study is published, you will not be identified by name.
- VIII. **OFFER TO ANSWER QUESTIONS**: The principal investigator, Denice Economou, has offered to and has answered any and all questions regarding your participation in this research study. If you have any further questions, you can contact Denice Economou at (626) 256-HOPE (4673) ext. 63477.
- IX. **COST TO THE RESEARCH PARTICIPANT FOR PARTICIPATION**: Neither you nor your insurance carrier will be charged for your participation in this study.
- X. **VOLUNTARY PARTICIPATION WITH RIGHT OF REFUSAL**: You have been informed that your participation in this research study is voluntary. You are free to withdraw your consent for participation in this study without any loss of benefits, penalty, or interference with any future treatment at, *or* any relationship with, City of Hope.
- XI. **IRB REVIEW AND IMPARTIAL THIRD PARTY**: This study has been reviewed and approved by the Institutional Review Board (IRB). A representative of that Board, from the Office of Human Research Subjects Protection, is available to discuss the review process or your rights as a research subject. The telephone number of the Office of Human Research Subjects Protection is (626) 256-HOPE (4673) ext. 62700.

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XII. **FINDINGS RELATING TO WILLINGNESS TO CONTINUE PARTICIPATION**: The person consenting you to this study has explained to you that you will be informed of any significant new findings related to this study which might affect your willingness to continue to participate.

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EXPERIMENTAL SUBJECT'S BILL OF RIGHTS FOR PSYCHOSOCIAL STUDIES

The rights below are the rights of every person who is asked to be in a research study. As a research subject in a psychosocial or quality of life study, you have the following rights:

1. To be told what the research study is trying to find out,
2. To be told what will happen to you and whether any of the study procedures to be used are different from what would be used in standard practice,
3. To be told about the risks, side effects, or discomforts of the things that will happen to you as part of the research study,
4. To be told if you can expect any benefit from participating in the research study, and, if so, what the benefit might be,
5. To be told of the other choices you have and how they may be better or worse than being in the research study,
6. To be allowed to ask any questions concerning the research study, both before agreeing to be in the study and during the course of the study,
7. To be told what support or treatment is available if any complications arise,
8. To refuse to participate in the research study or to change your mind about participation after the study is started. To be informed that this decision will not affect your right to receive the care you would receive if you were not in the study,
9. To receive a copy of the signed and dated research study consent form,
10. To be free of pressure when considering whether you wish to agree to be in the research study.

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SIGNATURE FOR CONSENT: By signing this consent form, you are making a decision to participate in this research study. Your signature on this informed consent form indicates that you:

1. Have read and understood the information in this form.
2. Have had the information in this form explained to you.
3. Have had a chance to ask questions and these questions were answered to your satisfaction.
4. Have been informed that you will receive a copy of this signed consent form, which includes the "Experimental Subject's Bill of Rights."

I hereby agree to be a research participant in this research study:

Research Participant's Signature: _____ Date: _____
Time _____
(date and time must be in research participant's handwriting)

Print Research Participant's Name: _____

Investigator's Signature: _____ Date: _____
Time _____

Print Investigator's Name: _____

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**Exploring the Recurrence with Advanced Disease
of Long Term Cancer Free Survivors**

**AUTHORIZATION TO USE AND DISCLOSE YOUR PROTECTED
HEALTH INFORMATION (PHI) FOR PURPOSES OF THIS STUDY**

- I. Purpose of this Authorization:** The information about your health is something that is protected by law and cannot, except for certain purposes, be disclosed (shared) without your permission. As part of this research, you are agreeing to allow City of Hope National Medical Center (City of Hope) to use and share with others your personal health information (PHI), as needed for the research. If you agree to participate in the study named above (called the “Study”), you must sign this consent form in addition to the Study Consent Form.
- II. The Information About You that is Covered By this Authorization:** PHI refers to information that we maintain about you that identifies you and includes the information contained in your medical record. Your medical record consists of information related to your health and the treatment we provide to you, such as your medical history, the results of physical exams, blood tests, x-rays and other diagnostic and medical procedures. If you sign this form, you are allowing City of Hope and the individuals indicated below to use and share any PHI we maintain about you that is required for your participation in the Study.
- III. Purposes for Uses and Sharing of your PHI; Who Will Use, Share and Receive your PHI:** Your PHI will be used and shared with others for the purpose of doing this research as described in the Study Consent Form. Your PHI will also be used to keep the research sponsor informed about this Study, for reporting to those individuals and authorities responsible for overseeing our research activities to make sure that the activities are properly conducted, and to report to regulatory agencies as required by the Study.

The people authorized to use and share your PHI for purposes of the Study include the Principal Investigator and the research staff supporting the Study; your City of Hope physicians and the health care team; and the Health Information Management Services Department (Medical Records Department). This also includes any agents or contractors used by these individuals or groups for purposes of conducting or managing this Study. At City of Hope, the Institutional Review Board (IRB) and other City of Hope research regulatory committees will have access to your PHI as necessary to

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monitor research. In addition, at City of Hope, the Cancer Protocol Review and Monitoring Committee (“CPRMC”)

You are also allowing your PHI to be shared with the Office for Human Research Protections (OHRP) and with any person or agency as required by law.

*

[***Include as applicable:*** Also certain other groups and institutions, including, ***insert name of cooperative group***; researchers at ***insert name of collaborating institution(s)***; ***insert name of CRO***, a contract research organization (“CRO”), will also have access to your PHI as necessary for research purposes and to conduct the Study.]

By signing this consent form, you also authorize disclosure of your PHI by other health care providers outside City of Hope to be given to City of Hope investigator and/or the City of Hope research team for follow-up purposes. This follow-up information may include results of laboratory tests, physical examination, radiological tests, and other information about you.

This authorization will allow us to use and share your PHI for the Study. No other additional uses and disclosures other than for the purposes of the Study are included in this authorization. City of Hope’s Notice of Privacy Practices will continue to protect your non-Study information. If necessary, another separate permission will be obtained from you for any non-Study uses or sharing of your PHI.

- IV. Expiration of this Authorization:** This authorization to use and share your PHI will expire twenty-five (25) years from the date that you sign this authorization.
- V. Further Sharing of Your PHI:** Your privacy is important, and this is the reason for having rules which control who can use or see your PHI. City of Hope maintains control over your PHI at present, but once we share this information with a third party (for example, an individual or agency outside of City of Hope), then it is no longer possible to maintain the same level of protection. The persons outside our control may not be governed by federal or state privacy laws, and it is possible that they could share your PHI with others for whom you have not given permission.

The information from this Study may be published in scientific journals or presented at scientific meetings, but your identity will be kept confidential.

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VI. Your Rights Under this Authorization: You may cancel this permission to use and share your PHI at any time by contacting City of Hope's Privacy Officer at (626) 256-HOPE (4673) ext. 64025. You should ask for the **Revocation (Cancellation) of Authorization for Use of Protected Health Information for Research.** Fill this form out and return it as the form instructs. Your cancellation begins when the Health Information Management Department of City of Hope receives this form. If you cancel this authorization to use and share your PHI, you will no longer be able to participate in the Study. This is because the research under this Study cannot be conducted without your PHI.

Once you cancel your permission to use and share your PHI, the researchers and others involved in conducting the Study will no longer be able to use or share your PHI for this research. PHI already used and shared up to this point as part of this Study will continue to be used for purposes of this research. This means that any uses of your PHI and any PHI shared about you by City of Hope prior to receiving your cancellation (revocation) form cannot be taken back. While no further PHI about you will be shared for the Study, your PHI already shared will continue to be used in the overall Study.

VII. Signing this Authorization is Your Choice: Your ability to obtain care at City of Hope will not be affected by your decision to sign this authorization form. You will be able to continue to receive health care at City of Hope if you choose not to sign this authorization form or if you sign this form and later cancel your permission to use and share your PHI.

If you agree to the use and sharing of your PHI, please sign below. You will be given a copy of this authorization form.

Research Participant's Signature: _____ Date: _____
Time: _____
(date and time must be in research participant's handwriting)

Print Research Participant's Name: _____

Investigator's Signature: _____ Date: _____
Time: _____

Print Investigator's Name: _____

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Appendix B: Research Protocol U.S.

**CITY OF HOPE NATIONAL MEDICAL CENTER
1500 E. DUARTE ROAD
DUARTE, CA 91010**

DEPARTMENT OF POPULATION SCIENCES- NURSING RESEARCH and EDUCATION

TITLE: EXPLORING THE EXPERIENCE OF ADVANCED RECURRENCE IN SURVIVORS WHO PERCEIVED THEMSELVES AS CANCER FREE: A QUALITATIVE STUDY

CITY OF HOPE PROTOCOL NUMBER: 14082 **VERSION:**3 01

DATE(S) OF AMENDMENT(S)/REVISION(S): COH Amendment Dated

SPONSOR/IND NUMBER: N/A

DISEASE SITE: Lung, Colon, Rectum, Ovarian, Breast

STAGE (if applicable): III, IV, Recurrence

MODALITY: Survey, Interview

PHASE/TYPE: Behavioral

PRINCIPAL INVESTIGATOR:

Denice Economou, RN, MN

This is a dissertation research project

COLLABORATING INVESTIGATOR(S):

Dr. Sarah Brearley
Lecturer/Director of Studies PhD in Palliative Care-International Observatory on End of Life Care-Faculty of Health and Medicine
0049 Furness College
Lancaster University
Lancaster, LA1 4YG, England

Dr. Catherine Walshe
Senior Lecturer of PhD in Palliative Care-International Observatory on End of Life Care. Division of Health Research
C52 Furness College
Lancaster University
Lancaster, LA1 4 YG, England

PARTICIPATING CLINICIANS:

N/A

PARTICIPATING SITES:

N/A

STUDY SPONSOR AND MONITOR:

City of Hope

Experimental Design Schema

Qualitative Study Design

To describe the experience of recurrence of advanced cancer in people with solid tumors who consider themselves disease free two or more years post –treatment a qualitative approach guided by Grounded Theory will be used. A qualitative design is appropriate for this type of question and allows for the patient experiencing this recurrence with advanced cancer to inform us on the meaning of this experience.

In-depth interviews will be conducted with people with a diagnosis of cancer recurrence (solid tumors) following two or more years post treatment where they had perceived themselves to be disease free. Participants will be recruited to the study until saturation of themes is achieved. The objective is to develop a theory of the experience of this transition which will facilitate better care in the future.

Sample Size

Estimated sample size is between 12 to 15 people with advanced cancer (each to be interviewed once). This is a typical sample size for a grounded theory study. The final sample size will be iteratively determined by the saturation of themes. Interviews will be transcribed and coded after each interview using the techniques of constant comparative analysis (Glaser, 1967; Charmaz, 2006) .

Protocol Synopsis

Protocol Title:
EXPLORING THE EXPERIENCE OF ADVANCED RECURRENCE IN SURVIVORS WHO PERCEIVED THEMSELVES AS CANCER FREE: A QUALITATIVE STUDY
Brief Protocol Title for the Lay Public (if applicable):
N/A
Study Phase:
Behavioral
Participating Sites:
N/A
Rationale for this Study:
<p>Although advances in diagnosis and treatment have improved cancer survival, it is anticipated that about 1.2 million cancer survivors will have a recurrence of their cancer (1 in 6), and 50 percent of those will recur with advanced cancer that leads to death (Jemal et al., 2008, Ng and Travis, 2008). There is limited research on the experience of advanced recurrence in patients who have been disease free for 2 or more years. (Ferrell, 2011, Burnet and Robinson, 2000). Care needs for people who experience this transition from perception of disease free survival to recurrence with advanced cancer may be different from that provided to patients who have never experienced extended disease-free survival (Mahon and Casperson, 1997, Vivar et al., 2009). There is recognition that long-term social and psychological needs of patients who have a recurrence of their disease with advanced cancer have been understudied (Ferrell, 2011, Jarrett et al., 2013). Understanding the impact of recurrence of advanced cancer in someone who perceived themselves to be living disease free for 2 or more years since completing treatment will add much needed new information (Vivar et al., 2010).</p>
Objectives:
<p>The objective of this research is to explore the experience of transition from the perception of being a disease free cancer survivor to someone with a diagnosis of advanced cancer. A grounded-theory approach will be used to gather the meaning of this transition for the cancer survivor. A substantive theory will be developed related to the transition from perception of being cancer free to that of having advanced cancer.</p>
Study Design:
<p>A qualitative approach will be used, based on a Grounded Theory method. Approximately 12 to 15 in-depth interviews will be conducted with people experiencing the transition from perceiving themselves to be disease free to having advanced cancer. Interviews will be transcribed and categorized after each interview using constant comparative analysis (Glaser & Strauss).</p>
Endpoints:
N/A
Sample Size:
<p>It is anticipated that approximately 12 to 15 people with advanced cancer may be required. The final number will be determined iteratively when themes are saturated.</p>

Estimated Duration of the Study
24 months
Summary of Subject Eligibility Criteria:
<u>Inclusion Criteria</u> <ul style="list-style-type: none"> • People with a diagnosis of lung, colon, rectum, ovarian or breast cancer (solid tumors) who have had 2 or more years of perceived disease-free survival and recur with stage III or IV advanced cancer without potential for cure. • English speaking • Age 18 or older • Able to complete a 1 to 2 hour in-depth interview • Ability to read and/or understand the study protocol requirements and provide written informed consent. <u>Exclusion Criteria</u> <ul style="list-style-type: none"> • Under age 18 • Non-English speaking
Investigational Product Dosage and Administration:
N/A
Clinical Observations and Tests to be Performed:
N/A
Statistical Considerations:
N/A
Sponsor/Licensee:
City of Hope
Case Report Forms
N/A

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Abbreviations

Abbreviation	Meaning
AE	Adverse Event
ASCO	American Society of Clinical Oncology
COH	City of Hope
DSMC	Data Safety Monitoring Committee
IOM	Institute of Medicine
IRB	Institutional Review Board
NCI	National Cancer Institute
NCCS	National Coalition of Cancer Survivors
PI	Principal Investigator

Definition of Terms

Grounded Theory	Qualitative research used to study social situations by creating conceptual frameworks or theories through inductive analysis of the data.
Constant Comparative Analysis	A method of analysis that successively compares concepts or theories from inductively gathered data with data, data with category, category with category, and category to concept. (Bryant & Charmaz, 2007)
Saturation of Themes	When no new categories or themes are generated from interview data

1.0 Goals and Objectives (Scientific Aims)

1.1 Goals and Objectives

The purpose of this study is to describe the experience of the transition from being a person who perceives themselves to be cancer free (two or more years post treatment) and experiences a recurrence with advanced cancer. This study will adopt a grounded theory approach to gather the meaning of the experience of this transition from the person with advanced cancer. For this study, someone who perceives themselves to be cancer free is someone who has lived 2 or more years since completing cancer treatment and perceives themselves as disease free. We define recurrence with advanced cancer as someone who now has advanced stage III or IV cancer without a possibility of cure.

Aim: To explore the lived experience of advanced cancer recurrence in perceived disease free survivors.

1.1 Introduction/Rationale for Development

The Institute of Medicine (IOM) in the United States defines an individual as a cancer survivor from diagnosis until death and includes caregivers and significant others (Hewitt, 2006). The IOM report, "From Cancer Patient to Cancer Survivor-Lost in Transition", identified the gap in cancer treatment between active treatment, and transitioning to cancer survivor (Hewitt, 2006).

The term survivor was established by the National Coalition of Cancer Survivors (NCCS) in 1986, which was meant to support patients in making informed treatment decisions and promote research focused on cancer survivors to improve their care and move from cancer victim to cancer survivor (Clark and Stovall, 1996, Khan et al., 2012, NCCS, 2013). The term survivor has been accepted by most researchers as it has become an identifier for this population of people diagnosed with cancer and throughout the trajectory of their life until end of life (Hewitt, 2006). This final trajectory has been referred to as the "final phase of survivorship", leading to end of life (Ferrell, 2011). The term survivorship includes a patient's experience from diagnosis through treatment, post treatment, remission and recurrence on until death (Mullan, 1985). In this study, cancer survivors in the final phase of survivorship are defined by advanced disease recurrence.

In the United Kingdom, the number of cancer survivors is growing rapidly as in the United States. By 2030 it is anticipated that there will be between 3 million and 18 million people living with cancer in both countries (O'Dowd, 2010, American Cancer Society). The last 20 years have seen improvements over survival rates for many diseases (American Society of Clinical Oncology, 2012, Ganz, 2009). Lung cancer, pancreatic cancer, melanoma, breast cancer, and prostate cancer have seen significant improvements in survival rates (American Society of Clinical Oncology, 2012, O'Dowd, 2010). Changes in chemotherapy and radiation treatments have reduced side effects and improved survival (American Society of Clinical Oncology, 2012, American Cancer Society). Early stage breast cancer patients have a 99 percent chance of 5-year survival (American Cancer Society). Improved use of genomic profiling has allowed cell lines to be tested with different chemotherapy treatments in an effort to personalize treatments to allow for better response and less side effects (American Society of Clinical Oncology, 2012). Further genetic studies have decreased patient morbidity from chemotherapy and have been responsible for improved treatment response and survival (American Society of Clinical Oncology, 2012). Patients continue to believe that long periods of time without recurrence means cure of their disease.

Survivors are not a homogeneous group of patients (Feuerstein, 2007). Advances in cancer diagnosis and treatment have been made, but it is anticipated that about 1.2 million patients will have a recurrence of their cancer (1 in 6), and 50 percent of those will recur with rapidly progressing disease that leads to death (Jemal et al., 2008, Ng and Travis, 2008). Little research is available to describe the meaning of this experience of transitioning from the belief you are cured of your cancer to recurrence with advanced

cancer and probable death (Ferrell, 2011, Burnet and Robinson, 2000). Care needs in this population of those who experience this transition from the expectation that they are cured of their cancer to advanced cancer recurrence may be different from that provided to patients who have never experienced the concept of being disease-free (Mahon and Casperson, 1997, Vivar et al., 2009). There is recognition that long-term social and psychological needs of patients who recur have been understudied (Ferrell, 2011, Jarrett et al., 2013). Understanding the impact of recurrence with advanced cancer for those who perceived themselves to be cancer free will add much needed new information (Vivar et al., 2010).

We have learned that barriers still exist to full integration of survivorship care into the cancer care trajectory. Communication and consistent messages related to future risks of recurrence and potential late effects of treatment continue. Programs are focused on survivorship in such a way that patients who recur and do not fall into the trajectory of retreatment and cure are outside of the eligibility for most programs and therefore may be undertreated or not directed to appropriate palliative care interventions that may improve the quality of their life for whatever time they have left. This will be an opportunity to hear from this patient population directly regarding their experience of advanced recurrence.

1.2 Overview of Proposed Study

This study will require a one-time detailed interview with people with cancer (solid tumor) who perceived themselves to be disease free for two or more years post-treatment prior to the diagnosis of advanced cancer. Interviews will be conducted and will be digitally audio recorded. Qualitative data analysis will use grounded theory techniques. Interviews will be transcribed and then themed and categorized using the technique of constant comparison. Themes will be inductively identified and through the process of comparison will be used to develop a mid-level theory describing the meaning of recurrence with advanced cancer for those who perceived themselves to be disease free. A memo-journal will be maintained by the researcher for each interview participant to record the insights, feelings or thematic ideas related to the research.

Patient Eligibility

1.3 Inclusion Criteria

Eligibility Criteria:

- Patients with solid tumor (lung, colorectal, ovarian, and breast) cancers who have perceived 2 or more years of cancer-free survival and recur with stage III or IV disease without potential for cure,
- English speaking,
- Age 18 or older,
- Able to complete a 1 to 2 hour in-depth interview,
- Ability to read and/or understand the study protocol requirements and provide written informed consent.

1.3.1 Disease Status

Patient has recurrence with stage III or IV disease without potential for cure.

1.3.2 Age Criteria, Performance Status and Life Expectancy

Children or adults under 18 years are excluded because occurrence of target cancer types and recurrence is rare.

1.3.3 Protocol-Specific Criteria

The sample will include patients with stage III or IV disease recurrence following 2 or more years of perceived cancer-free survival.

1.4 **Exclusion Criteria**

- Patients with active malignancies other than lung, colorectal, ovarian, and breast cancers are ineligible for this study.

1.4.1 Non-Compliance

Subjects, who in the opinion of the investigator, may not be able to comply with the safety monitoring requirements of the study.

2.0 **Grounded Theory strategies**

2.1 **Qualitative Sampling**

Grounded Theory research are not focused on a representative sample. Recruitment is focused on patients who meet the eligibility criteria. Constant Comparative Analysis allows exploration of emerging issues from the analysis through theoretical sampling. Sampling is focused on building a theory from the emerging data to explain the meaning of advanced recurrence for long term cancer free survivors (Charmaz, 2006). Minorities will be limited to English speaking since the investigator speaks only English and would be unable to interview non English speaking patients. No exclusion will be made on the basis of race. Theoretical sampling will allow for patients who meet the inclusion criteria to provide additional information to explore emerging issues from the analysis. An attempt will be made to include non white participants if available. Grounded Theory does not seek to provide a representative sample (Charmaz, 2006). The goal is to develop theoretical categories using the patients words to identify the concepts. Screening and Registration Procedures

2.2 **Screening Procedures**

Patients who have recurred with Stage III or Stage IV disease after 2 or more years of completion of their treatment will be referred to the PI by the oncologist team. The PI will discuss the patients perspective to their perception of their disease status during the years post treatment. The research project will be introduced and the patient will be consented and the interview will be scheduled at their convenience. Demographic data will be gathered from the medical record to identify disease status and time of treatment and completion of treatment. Clinical documentation will be evaluated for concurrence with the patients perspective but patient perception of disease free is the primary inclusive condition.

2.3 **Informed Consent**

The investigational nature and objectives of the trial will be carefully explained by the researcher once the physician or nurse practitioner have identified them as potential participants, and a signed informed consent will be obtained. Informed consent will be kept in the PI's office in locked drawers. A copy of the signed consent will be given to the participant before the interview begins.

3.0 Reporting/Protocol Deviations

3.1 Data Reporting

3.1.1 Confidentiality and Storage of Records

The original hard copy transcriptions will be stored in a locked office in the Population Sciences building in the division of Nursing Research and Education office, room 181. Digital audio interviews will be coded and identification numbers applied. All identifiers will be removed. Digital audio data will be encrypted and saved onto a Seagate Backup Plus Portable Drive and kept in the PI's locked office as described above and HIPAA requirements. When results of this study are reported in medical journals or at meetings, identification of those taking part will not be disclosed. Medical records of subjects will be securely maintained in the strictest confidence, according to current legal requirements. They will be made available for review, as required by the FDA, HHS, or other authorized users such as the NCI, under the guidelines established by the Federal Privacy Act and rules for the protection of human subjects. Data may be shared with dissertation supervisors at Lancaster University maintaining confidentiality.

4.0 Statistical Considerations

4.1 Study Design

In-depth interviews will be conducted with between 15 and 25 participants but recruitment of participants will continue until saturation of themes is achieved. Grounded Theory methods will be used which require simultaneous data collection and constant comparative analysis of themes or categories of data. The theoretical framework of this study uses Constant Comparative Analysis (CCA) but the word comparative has no meaning for statistical comparison. Memo writing will be part of the analysis process and used to analyze ideas related to codes and themes. The development of a substantive theory will be defined related to the transition from the perception of being cancer free to experience of being diagnosed with recurrent advanced cancer.

4.2 Sample Size Accrual Rate

It is anticipated that 12 to 15 patients will be recruited; however the final sample size is related to when theme saturation occurs. The study duration is anticipated to be 24 months. Purposeful sampling will be used at the beginning of the study with theoretical sampling used after initial interview analysis .allows refinement of sampling based on emerging concepts that need further investigation.

4.3 Statistical Analysis Plan

Interviews will be analyzed using a rigorous process of constant comparative analysis where interviews and analysis occur simultaneously. Interviews will be transcribed and themed and results used to select future participants until saturation of themes occurs. Atlas Ti data management program will be used.

5.0 Human Subject Issues

5.1 Institutional Review Board

In accordance with City of Hope policies, an Institutional Review Board (IRB) that complies with the federal regulations at 45 CFR 46 and 21 CFR 50, 56 and State of California Health and Safety code, Title 17, must review and approve this protocol and the informed consent form prior to initiation of the study. All institutional, NCI, Federal, and State of California regulations must be fulfilled.

5.2 Study location and Performance Sites

This study will be performed at COH.

5.3 Confidentiality

This research will be conducted in compliance with federal and state of California requirements relating to protected health information (PHI). The PHI that will be recorded includes name and medical record number and diagnosis date and recurrence date. This information will be contained in a password protected Access study database.

Financial Obligations and Compensation

5.4 Informed Consent Processes

The Principal Investigator will explain the nature, duration, purpose of the study, potential risks, alternatives and potential benefits, and all other information contained in the informed consent document. In addition, they will review the experimental subject's bill of rights and the HIPAA research authorization form. Research subjects will be informed that they may withdraw from the study at any time and for any reason without prejudice, including as applicable, their current or future care or employment at City of Hope or any relationship they have with City of Hope. Research subjects will be afforded sufficient time ranging from immediately to 4 weeks to consider whether or not to participate in the research.

6.0 References

- American Cancer Society. *Cancer Facts & Figures* [Online]. American Cancer Society. Available: <http://www.cancer.org/cancer/news/news/facts-and-figures-report-declines-in-cancer-deaths-reach-milestone?awid=6598989681723518903-572> [Accessed June 10 2013].
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Appendix C – FHMREC Application



Faculty of Health and Medicine Research Ethics Committee (FHMREC) Lancaster University

Application for Ethical Approval for Research

Instructions

1. Apply to the committee by submitting
 - ✓ The University's Stage 1 Self-Assessment Form (standard form or student form) **and** the Project Information & Ethics questionnaire. These are available on the Research Support Office website: [LU Ethics](#)
 - ✓ The completed FHMREC application form
 - ✓ Your full research proposal (background, literature review, methodology/methods, ethical considerations)
 - ✓ All accompanying research materials such as, but not limited to,
 - 1) Advertising materials (posters, e-mails)
 - 2) Letters of invitation to participate
 - 3) Participant information sheets
 - 4) Consent forms
 - 5) Questionnaires, surveys, demographic sheets
 - 6) Interview schedules, interview question guides, focus group scripts
 - 7) Debriefing sheets, resource lists
2. Submit all the materials electronically as a **SINGLE** email attachment in PDF format. Instructions for creating such a document are available on the FHMREC website (<http://www.lancs.ac.uk/shm/research/ethics/>).
3. Submit one collated and signed paper copy of the full application materials. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
4. Committee meeting dates and application submission dates are listed on the research ethics committee website <http://www.lancs.ac.uk/shm/research/ethics>. Applications must be submitted by the deadline stated on the website, to:

Diane Hopkins
Faculty of Health & Medicine
B03, Furness College
Lancaster University, LA1 4YG
d.hopkins@lancaster.ac.uk
5. Attend the committee meeting on the day that the application is considered.

<p>1. Title of Project: Exploring the Experience of Advanced Recurrence with Advanced Disease of Long Term Cancer Free Survivors</p>
<p>2. If this is a student project, please indicate what type of project by ticking the relevant box:</p> <p><input type="checkbox"/> PG Diploma <input type="checkbox"/> Masters dissertation <input type="checkbox"/> MRes <input type="checkbox"/> MSc <input type="checkbox"/> DClInPsy SRP</p> <p><input type="checkbox"/> PhD Thesis <input checked="" type="checkbox"/> PhD Pall. Care/Pub. Hlth/Org. Hlth & Well Being <input type="checkbox"/> MD <input type="checkbox"/> DClInPsy Thesis</p> <p><input type="checkbox"/> Special Study Module (3rd year medical student)</p>
<p>3. Type of study</p> <p><input checked="" type="checkbox"/> Involves direct involvement by human subjects</p> <p><input type="checkbox"/> Involves existing documents/data only. Contact the Chair of FHMREC before continuing.</p>

<p>Applicant information</p>
<p>4. Name of applicant/researcher: Denice Economou</p>
<p>5. Appointment/position held by applicant and Division within FHM PhD Student in Palliative Care</p>
<p>6. Contact information for applicant:</p> <p>E-mail: <u>deconomou@coh.org</u> Telephone: <u>310-729-0960</u></p> <p>Address: <u>1798 Michael Lane, Pacific Palisades, California 90272</u></p>
<p>7. Project supervisor(s), if different from applicant:</p> <p>Name(s): <u>Dr. Sarah Brearley and Dr. Catherine Walshe</u></p> <p>E-mail(s): sarah.brearley@lancaster.ac.uk C.Walshe@lancaster.ac.uk</p>
<p>8. Appointment held by supervisor(s) and institution(s) where based (if applicable): Director of Studies PhD in Palliative Care, International Observatory on End of Life Care Senior Lecturer in Palliative Care, International Observatory on End of Life Care</p>
<p>9. Names and appointments of all members of the research team (including degree where applicable) No others</p>

<p>The Project</p> <p>NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.</p>
<p>10. Summary of research protocol in lay terms (maximum length 150 words).</p>

There are currently 13.7 million cancer survivors in the United States. The numbers are expected to reach 18 million by 2020 (American Cancer Society). Of those survivors, it is anticipated that about 1.2 million will have a recurrence of their cancer (1 in 6) and 50% of those will recur with rapidly progressing disease that leads to death. The purpose of this study is to describe what terminal cancer recurrence means to long term cancer survivors after 2 or more years of disease free survival. Using a grounded theory approach, a qualitative study will be conducted using in-depth interviews to describe what advanced recurrence means to patients after 2 or more years of disease free survival. The meaning identified through this study will provide a baseline understanding of the concerns of this population of late stage recurrence of disease and will help guide palliative care planning and coordination of care.

11. Anticipated project dates

Start date: _03 March 2014_____ End date: 12 December 2015_____

12. Please describe the sample of participants to be studied (including number, age, gender):

Eligibility Criteria:

- solid tumour patients: lung cancer, colorectal cancer, ovarian cancer, and breast cancer who have had 2 or more years of cancer free survival and recur with Stage III or IV disease without potential for cure.
- English speaking
- Age 21 or older
- Able to complete a 1 to 2 hour in depth interview
- Ability to read and/or understand the study protocol requirements, and provide written informed consent.

As a grounded theory qualitative research methodology-anticipate up to 20 interviews but will interview until saturation of themes.

13. How will participants be recruited and from where? Be as specific as possible.

Solid tumor patients will be recruited from lung cancer, colorectal cancer, ovarian cancer, and breast cancer who have had 2 or more years of cancer free survival and recur with Stage III or IV disease without potential for cure. Physicians and their nurse practitioners from each disease specialty will be advised on the criteria for eligibility by the PI and contact information shared. The palliative care team will also be informed should they be referred appropriate patients.

14. What procedure is proposed for obtaining consent?

Recruitment and Informed Consent – Potential subjects will have their first contact with the PI through identification by the treating oncologist or their nurse practitioner. The PI and oncologists will ascertain patient interest in the study. The PI and oncologists will verify eligibility. The PI will inform the patient about the nature of their participation and the duration of the study. The PI will inform patients of all data collection methods, the time required, and potential risks. Patients will have the

opportunity to ask questions, and are free to withdraw from the study at any time. Patients may also refuse to answer any specific questions within the interview. The PI will obtain written consent, approved by COH's CPRMC and IRB, from all subjects.

15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

Potential Risks – All contacts with the patient will be arranged at the patient's convenience and in the setting preferred (face-to-face, telephone or in-home). The potential risk is the possibility of emotional distress by discussing their long-term or end-of-life concerns. The time required for data collection is approximately 60 – 90 minutes. In any situation where a patient is experiencing uncontrolled symptoms, the PI will contact the treating oncologist immediately and referral to social work and the Biller Center will be provided per oncologists recommendations.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

The primary concerns for the researcher are related to discussing palliative and end-of-life plans with patients. In-person in the cancer center or telephone interviews will be the primary sites for conducting interviews. If in-home interviews are needed the time will be coordinated and telephone contact with the nursing research & education secretary will occur at the start and at completion of the interview.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

Includes recognition of survivorship needs for advanced stage patients without potential for cure.

Importance of the Knowledge to be gained – Knowledge to be gained from this study may potentially benefit present and future late stage patients by addressing their concerns.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

There will be no incentives or payments made to any participants.

19. Briefly describe your data collection and analysis methods, and the rationale for their use

Using a grounded theory methodology in depth interviews will be conducted with up to 20 participants but will continue until saturation of themes is achieved. Interviews will be transcribed and categorized after each interview using constant comparative analysis (Glaser & Strauss). The development of a substantive theory will be defined related to the transition from cancer free to a terminal cancer diagnosis.

20. Describe the involvement of users/service users in the design and conduct of your research. If you have not involved users/service users in developing your research protocol, please indicate this and provide a brief rationale/explanation.

I have had experience with patients diagnosed with advanced recurrence as part of my palliative care practice in the past. I have queried palliative care specialists through

Project Supervisor* (if applicable):

.....

Date:

.....

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

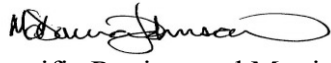
Appendix D – CPRMC Approval Letter

CITY OF HOPE NATIONAL MEDICAL CENTER CANCER PROTOCOL

REVIEW & MONITORING COMMITTEE

ACTION NOTICE

TO: Denice Economou, R.N., M.N.

FROM: MaDonna Johnson 
Manager, Protocol Scientific Review and Monitoring Office

DATE: April 30, 2014

PROTOCOL: 14082 - EXPLORING ADVANCED RECURRENCE IN SURVIVORS WHO
PERCEIVED THEMSELVES AS CANCER FREE: A QUALITATIVE STUDY

The Cancer Protocol Review & Monitoring Committee (CPRMC) took the following action on the protocol referenced above:

APPROVED

The response and revised documents submitted on 04/17/14 for the conditions issued on 04/03/14 have been reviewed by the committee. The concerns have been adequately addressed and the new protocol (version dated 04/17/14) was approved on 04/29/14.

If you have any questions, please contact Gwen Jorgensen at extension

63034. Thank you. cc: IRB

Appendix E – IRB Approval Letter



INSTITUTIONAL REVIEW BOARD (IRB) ACTION NOTICE

TO: Betty Ferrell, Ph.D., Principal Investigator
Denice Economou, R.N., M.N., Co-
Investigator City of Hope - Nursing
Research MC

FROM: Christine Hui, MPH, IRB Director *Christine Hui*
Office of Human Research
Subjects Protection

DATE: May 15, 2014

STUDY TITLE: Exploring Advanced Recurrence In Survivors Who
Perceived Themselves As Cancer Free: A Qualitative
Study

IRB#/REF#: 14082 / 106791

SUBMISSION: Submission Response for

Initial Review Submission REVIEW PROCESS:

Expedite

Conditions set by the Institutional Review Board for approval of the protocol
submission referenced above have been met and the following action is in effect:

APPROVAL FROM 05/14/2014 UNTIL 05/11/2015

COMMENT(S):

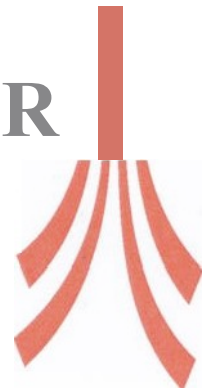
I. **City of Hope (COH) PROTOCOL DATED 5/13/14 APPROVED AS COH
VERSION 00.**

NOTE: DURING THE PERIOD COVERED BY IRB APPROVAL ANY CHANGES IN THE PROTOCOL, OR ANY UNEXPECTED PROBLEMS INVOLVING HUMAN SUBJECTS, MUST BE SUBMITTED TO THE IRB VIA iRIS FOR REVIEW. NO STUDY CHANGES CAN BE INITIATED UNTIL APPROVAL HAS BEEN OBTAINED FROM THE IRB.

If you have questions or concerns about this submission, please contact Suzanne Kelly.

Appendix F – FHMREC Approval Letter

LANCASTER
UNIVERSITY



Applicant: Denice Economou Supervisor: Dr Sarah Brearley
Department: OHR

27 June 2014

Dear Denice and Sarah,

Re: Exploring the lived experience of advanced recurrence in survivors who perceive themselves as cancer free: a qualitative study

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);

submitting details of proposed substantive amendments
to the protocol to the Research Ethics Officer for
approval.

Please contact the Research Ethics Officer, Debbie Knight (01542
592605 ethics@lancaster.ac.uk) if you have any queries or require
further information.

Yours sincerely,



Sarah Taylor
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, (Chair, UREC); Professor Paul Bates (Chair,
FHMREC)

**Research Support Office
Research and Enterprise Services**

Lancaster University Bowland Main
Lancaster LA1 4YT United Kingdom

Tel: +44 (0) 1524 592002
Fax: +44 (0) 1524 593229
Web: <http://www.lancs.ac.uk>

Appendix G – IRB Renewal Letter



INSTITUTIONAL REVIEW BOARD (IRB) ACTION NOTICE

TO: Betty Ferrell, Ph.D., Principal
Investigator City of Hope -
Nursing Research MC

FROM: Diana Shycoff, BS, IRB Operations
Diana Shycoff
Manager Office of
Human Research Subjects Protection

DATE: April 10, 2015

STUDY TITLE: Exploring Advanced Recurrence In Survivors Who
Perceived Themselves As Cancer Free: A Qualitative
Study

IRB#/REF#: 14082 / 115677

SUBMISSION: Continuation REVIEW PROCESS: Expedite IRB ACTION
DATE: 04/10/2015 IRB ACTION:

APPROVAL FROM 04/10/2015 UNTIL 04/09/2016

**NOTE: DURING THE PERIOD COVERED BY IRB APPROVAL
ANY CHANGES IN THE PROTOCOL, OR ANY
UNEXPECTED PROBLEMS INVOLVING HUMAN SUBJECTS,
MUST BE SUBMITTED TO THE IRB VIA IRIS FOR REVIEW.
NO STUDY CHANGES CAN BE INITIATED UNTIL
APPROVAL HAS BEEN OBTAINED FROM THE IRB.**

If you have questions or concerns about this submission, please contact Suzanne Kelly.

Appendix H – IRB Accrual Closure Letter



INSTITUTIONAL REVIEW BOARD (IRB) ACTION NOTICE

TO: Betty Ferrell, Ph.D., Principal
Investigator City of Hope -
Nursing Research MC

FROM: Diana Shycoff, BS, IRB Operations
Manager Office of Human
Research Subjects Protection

A handwritten signature in black ink that reads "Diana Shycoff".

DATE: July 11, 2016

STUDY TITLE: Exploring Advanced Recurrence In Survivors Who
Perceived Themselves As Cancer Free: A Qualitative
Study

IRB#/REF#: 14082 / 130040

SUBMISSION: Amendment

REVIEW PROCESS: Administrative Review

IRB ACTION DATE: 07/11/2016

IRB ACTION:

SUBMISSION RECEIVED IN IRB OFFICE ON 05/12/2016 01:26:08
PM PDT ACCEPTED AS INFORMATIONAL

COMMENT(S):

- I. This amendment changes the accrual status of this study at City of Hope and does not affect the protocol versioning.
- II. This protocol is open to analysis of previously collected data only.

NOTE: DURING THE PERIOD COVERED BY IRB APPROVAL ANY CHANGES IN THE PROTOCOL, OR ANY UNEXPECTED PROBLEMS INVOLVING HUMAN SUBJECTS, MUST BE SUBMITTED TO THE IRB VIA iRIS FOR REVIEW. NO STUDY CHANGES CAN BE INITIATED UNTIL APPROVAL HAS BEEN OBTAINED FROM THE IRB.

If you have questions or concerns about this submission, please contact Suzanne Kelly.

Appendix I – Interview Guide

Areas to be examined	Rationale for inclusion	Example questions
Introduction	General discussion about original diagnosis	Please tell me briefly about your initial diagnosis and what that entailed?
Concept of cure or living with “no disease”	Attempt to verify their perception of being cured	<ol style="list-style-type: none"> 1. How did you end your initial treatment? 2. What did you understand about your prognosis? 3. What was this time of “no disease” like for you?
Understanding what this recurrence means	Aim of study is to understand what recurrence means after perceiving self to be cured. Need to explore those feelings and what recurrence means for them	<ol style="list-style-type: none"> 1. What do you understand about your recurrence? 2. Did you expect to have your cancer return? 3. What does this recurrence mean to you?
Exploring what the participants wishes are now that they have recurred	<p>Opportunity to hear what the participant’s plans are and what is important to them now.</p> <p>Using strategies to verify meaning and build theoretical confirmation of newly evolving theory</p>	<ol style="list-style-type: none"> 1. What are your concerns now? 2. What is most important to you now? 3. Explore in depth beliefs around theory constructs to further clarify evolving theory.
Wrap up	<p>Explore any additional thoughts the participant might like to discuss</p> <p>Thank them for their participation and provide the researchers contact information should they have any further questions.</p>	<ol style="list-style-type: none"> 1. Are there any other thoughts or concerns you have about this advanced recurrence? 2. Thank you for participating

Appendix J: Transcript Coding Sample

Date: 12/14/2015

P10: Dissertation Interview patient 9.txt

Page: 1/6

- 001 Dissertation Interviews
002
- 003 DE: Thank you for agreeing to do this with me. Um, I'm interested in hearing about your recurrence and what it has been like, but we'll start with what it was like the first time you were diagnosed with Ovarian cancer.
- 004 Speaker 1: Ok, the first time I was diagnosed with Ovarian Cancer was in 2005. And I had gone out to lunch with my daughter and my daughter said something to the effect, 'Mom what's wrong with your stomach?' I said I'm just chubby. She said, 'no there's something wrong.' So she took me that day to her doctor and he said, 'I think you have Ovarian Cancer.'
- 005 DE: Wow.
- 006 Speaker 1: Now I had never heard of Ovarian Cancer. I wasn't even aware of what that was all about. And when I did I thought old women got this. (laughs) But anyway, then I went to my regular doctor. He diagnosed me. He said, 'yes, definitely Ovarian Cancer. Right away we're gonna do CAT Scan.' Did that then he said, 'absolutely it's Ovarian Cancer.' Then my...I had a hysterectomy and then my daughter did some research and decided the best place for me to go would be XXXX. That's how I ended up at XXXXXX.
- 007 DE: So what did you think about that? You said...
- 008 Speaker 1: I was scared. Uh, when I had gone to my Internist, uh, he said, 'usually women are not very successful with this.' And I thought oh my gosh that's like a death sentence. And I got very upset. Not so much that he was telling that it was the fact that he was accepting that decision and I said well I will fight this tooth and nail because I am not going to die. (laugh) And so then, um, then I went on from there to XXXXXXX. XXXXXXX was a complete opposite viewpoints. 'You definitely will survive. You do exactly what we tell you, you will survive.' And from the moment I came in the door of XXXXXX and the very first doctor I saw everybody continued with this positive attitude and never once did I think this wasn't going to work out.
- 009 DE: That's great. That's great. So you then went on...you completed your treatment and went on to do...to be in remission? We're you...
- 010 Speaker 1: I had chemo...
- 011 DE: And then after all that was done...
- 012 Speaker 1: Then I was in remission for 10 years.
- 013 DE: So no cancer?
- 014 Speaker 1: No. None at all.
- 015 DE: And what was that like?
- 016 Speaker 1: Um, it was kind of like I guess I think...I never thought I was gonna get cancer again. I knew there was that possibility, but I've been told that from the very beginning. So I knew you were in remission, you're not completely healed. Um, and I accepted that. But I think in my mind in a way I didn't because I never really thought I was gonna get...I was never afraid, I never thought about it. And I found out really accidentally that the cancer had returned because I as a result of having the hysterectomy I had a, um, hernia.
- 017 DE: Mhm.

unaware of initial diagnosis no uncertainty

laurens didn't think of herself as a

feeling knowledge that others had

Acknowledging feeling fearful
Asserting need to fight tooth + nail
asserting need to fight tooth + nail
laughing / humor 'Not going to die'
faith in Physician
Positive Attitude encouraged feeling Positive

Believing cancer free

Remission 10 years

Believing she wouldn't get it again
Recognizing not completely healed
Believed was C

I accepted possibly it could recur
but didn't believe it

018 Speaker 1: And the hernia was getting larger and now it was becoming painful. And so the last year or so I had been telling my internist, you know, I'm really thinking I should have the surgery to, you know, have the hernia healed whatever because it's causing me a lot of pain. And it was. Every day I'd go to bend down, I'd go to get into the car, I'd twist a certain way and there would be a problem with the hernia. So at that particular time that was December of last year he said, 'yes I think that's an excellent idea. I think you should definitely have this taken care of.' So he did some lab work, which he had been doing every three months, but he noticed that my cancer marker was rising. And he said, 'I want you to come back in a week and we're gonna redo this check...this test because I'm not certain this is correct.' So I came back in a week and it had risen a couple more. And so he said, 'ok were gonna definitely do a CAT Scan because you have this history of cancer.' And so he did the CAT scan and then at that point I said, you know, I want to go to XXXXXXX. I want to make sure my Oncologist who had released me the year before saying I was cancer free, I wanted her to be up-to-date on this and so I went to see her. She said, 'ok we got the CAT scan we're going to do a biopsy now.' And then that's when they told me for sure, 'yes there is cancer present and we have to go in an remove that.'

Describing physical symptoms/ops

verifying occurrence of cancer

verifying recurrence of cancer

019 DE: So what did you think? I mean...

020 Speaker 1: Once again I wasn't really scared. I just I never really thought of this as like oh this could be a death sentence because it's Ovarian Cancer. I never thought that way. I thought XXXXXX took care of this the first time and they're gonna take care of it again, you know. That's the way I thought. Ok what are we going to do? Let's move on.

Didn't feel like I was going to die

They took care of it the first time. They will do it again.

Have a Plan Move Forward

021 DE: So what did they say about this diagnosis? What did the doctor tell you about it?

022 Speaker 1: Um, they thought it was very unusual to have gone 10 years before the cancer returned. They thought that was not the norm. That was a very unusual situation. And they just said that they actually thought it was going to be a little easier this time. I don't know if that's the correct word, but they wouldn't have to be quite as aggressive as the first time around because my cancer marker was a lot lower this time around and we're already on top of this, you know, we already see there's a problem and we gonna go in and take care of this. So I just had complete faith in them.

Believing recurrence is unusual

Believing recurrence is unusual

Minimize Stage of Disease

023 DE: So they've been very positive with this one as well.

024 Speaker 1: Oh yes. Absolutely.

025 DE: You're starting chemo again.

026 Speaker 1: Start chemo today mmhm and I think I go through six cycles once a month for the next six months.

chemotherapy again

Chemotherapy -

027 DE: And you're idea of the prognosis is that...

028 Speaker 1: That I'm...

029 DE: ...that you're gonna go back into remission.

030 Speaker 1: It's gonna be gone, you know. Right, yeah.

031 DE: Ok.

Believing will or have remission one

believing it will go into Remission "gone"

032 Speaker 1: I think there's very little if any cancer present at the moment. I think this is their way of being aggressive and were gonna be on top of this. And were gonna be sure there isn't any cancer in there, but

Minimizing disease

I feel quite positive about it.

033 DE: So what do you think about the fact that this, this...finding this was kind of incidental. I mean as you think about if you thought about what others or what that means...

034 Speaker 1: Mmhm.

035 DE: ...on how they found it?

036 Speaker 1: In a way I don't think it was incidental because my Internist had been taking my CA125 so even...

037 DE: So how many years has that been happening? For 10 years?

038 Speaker 1: Oh yes, all along. Well up until last year I was still a patient of XXXXXX as far as the cancer, but once they found out that I was cancer free then I went to my internist and said ok when...because I'm a diabetic. So we were already checking my blood sugar every three months. So I said will you do the CA 125? 'Oh sure, I'll do that fine.' So he would have been aware of it even if I hadn't had the problem with a hernia in the process of going there for the three month exam he would have picked up on that and notice. 'Oh by the way this is starting to climb.'

039 DE: So you, your...I'm just trying to understand. So you really didn't watch yourself so much, you knew...you trusted the physician's were watching.

040 Speaker 1: Well yes because I would have no way of knowing about the cancer, you know.

041 DE: Yes.

042 Speaker 1: It's not like you'd feel anything.

043 DE: Yes it's very different.

044 Speaker 1: No. It's very different. So...

045 DE: Silent.

046 Speaker 1: ...I just relied on that cancer marker number to be told what that was.

047 DE: So you were pretty on it. So during that time 10 years of no disease, um, did you think about it? Did you live your life?

048 Speaker 1: I thought I was cancer free and I was gonna be cancer free the rest of my life. I never ever, ever thought, you know, this could come back. Even though I was aware of the possibility I knew that, but it was just like no I feel too good. I'm very active and I'm doing things. I'm not having problems. You know, so no I never really considered having cancer again. I really didn't.

049 DE: That's...so do you have any grandchildren or any...

050 Speaker 1: Yes I have three grandchildren. Mmhm. They're all adults. They're all healthy. There's not any problems with cancer with anybody in my family. No one in my family had cancer before.

051 DE: And you live up in the mountains?

052 Speaker 1: I live up with my daughter and my son-in-law. Yes, I love it.

053 DE: Great. Great that's so wonderful. So if you think about having dealt with cancer and this is there anything that is important to you? Or is there something you focus on? Or did it...did it do anything about your outlook on the future?

054 Speaker 1: Absolutely. Um, immediately life becomes a lot more

U Feel Positive

believed they were watching

acknowledging no family history of c

Believing she wouldn't do it again

never thought I would have cancer again.

acknowledging no family history of c

realizing life after cancer become

precious. And you I think you have a tendency to take life more seriously than you did before. And to enjoy your life more seriously than you did before. Uh, most of my life I think I've been a pretty positive person. So that wasn't a big change, but what was a big change to me was to learn as much about Ovarian Cancer as I could...

Evaluating life - more precious

Positive
acknowledging positive outcome
Becky Knowledge about Disease

055 DE: Mmhm.

056 Speaker 1: ...be aware of what knowledge was out there, but basically within my own personal philosophy is to be positive. Everyday be positive because I learned to fight better than I ever have in my life. I realized there was gonna be days when you get and you think I don't really feel like doing this today. I don't feel like fighting. I'm very tired. And then you think no, no I'm gonna be a survivor. I'm a survivor. I have to fight every day. I have to think positive. I have to find something to laugh at whatever, you know.

learn to fight better than ever have
learning to fight better than I ever

Be Positive

Positive. Find a way to laugh every day.

057 DE: Mmhm.

058 Speaker 1: So yes that made me more aware.

059 DE: So that word survivor does it mean something...you said earlier you didn't expect to get it back.

060 Speaker 1: No I didn't. To me to be a survivor is to be never giving up. Never giving up. Just doing everything that you possibly can to better your situation. Whatever you're in charge of yourself, what you can do about it, you know, that's basically what I've tried to do. Mmhm.

Being a survivor means never giving

061 DE: That's wonderful. That's wonderful. That seems to have worked for you. Now as you look into having chemo. Now you had chemo before.

062 Speaker 1: Yes, right.

063 DE: You remember the side effects.

064 Speaker 1: Right.

065 DE: What are you anticipating with this chemo. Are you concerned about your energy level to handle it or is it seem...

066 Speaker 1: The only negative factor I think I have at the moment is the fact that I'm 10 years older. So I realize that, but the fact that I've been through chemo before I kind of know what to anticipate, you know. What are possibilities of side effects. I'm not gonna lose my hair. That's very positive. I think it has a lot to do with your mental outlook too. Um, the main problems I had before with the chemo were mouth sores ok? And my doctors already prescribed the different types of medicine I need to deal with these problems hopefully. And the other problem I had was one of the drugs they used would cause pains in my legs. Um, but they're not gonna use that drug this time around. So that's kind of like taken of my little list. So I just take it as it comes. And like I said I'm kind of prepared with the medicines and everything so I think I'll have an answer for it, you know.

Acknowledging older Age
acknowledging that older age is

anticipate symptoms
anticipating symptoms and plan
Planning for Side Effect

067 DE: Good. It's interesting that you've said that 10 years older. I've had other patients who are doing...facing recurrence like this and that's been their concern too is, 'I'm a lot older than I was the first time.' So...

068 Speaker 1: Right.

069 DE: Yes.

070 Speaker 1: And you have to deal with that. You have to realize, you know, I was 10 years younger then, you know, but I don't believe that's going to be a problem. I think I'm gonna get tired. That's kind of a given. I

Believe
Age won't effect

know that's gonna cause I get tired now so...

071 DE: Yeah.

072 Speaker 1: ...but I thought ok fine. You take a nap, you rest and then you get up and do what you want to do, you know.

073 DE: So you've got a real positive attitude at this recurrence...

074 Speaker 1: Yeah. I think so.

075 DE: ...and what it's gonna do and the chemotherapy again.

076 Speaker 1: Right, yeah. I'm ready.

077 DE: That's good. Any, any final comments of thoughts about this experience of cancer?

078 Speaker : Uh no, I just I kind of like to reach out when I can when I need someone who's going through something similar to this. And I, I tried to reinforce the idea you know what you gotta be really strong. Not only physically, but mentally you got to really kind of prepare yourself and be as positive as you can and you'll get through it.

079 DE: So do you ever think about what would happen if it didn't go away or?

080 Speaker 1: No.

081 DE: Stay positive.

082 Speaker 1: I don't really address that. (laughs) I mean I know that could happen, you know, and if it does well, you know, that's the way it is, but, uh, I'm not going to do anything to discourage myself, you know. And I don't like to think things like that cause I think ok let's don't go there. We don't know that's a possibility you know. Just take today, you know. That's what we got.

083 DE: Live for today.

084 Speaker 1: Right.

085 DE: Good for you. That's wonderful. Thank you for this. This was a lot faster than.

086 Speaker 1: Yeah well you're very welcome. I hope this helps somebody or your research. Whatever.

087

088 END OF AUDIO PART 1

089 DE: I'm sorry we're going to add to this, to this patient nine interview. Um, so for coping for handling it what is something you do use.

090 Speaker 1: Ok my very first place I go to is my faith. My family, my friend and my medical who are of course always there, but my faith is with me when I'm by myself or not by myself it's with me all the time. And if I get down, and I do once in awhile, I think hey god is right here, you know. He's not going to leave me. So whatever I have to face he's still going to be there. So...

091 DE: So that does give you strength?

092 Speaker 1: Absolutely, yes.

093 DE: The strength to keep going, good. It helps with your attitude of the future?

094 Speaker 1: Mmhm. It's going to be very positive because I know I'm with him. You know whatever way he wants it to be that's the way it's gonna be, you know. And I don't worry about that, you know.

095 DE: Is there a reason you didn't mention your faith before?

096 Speaker 1: Yeah. I didn't think you would want to hear about that.

U

responding in doubtful way
Positive Attitude

believer that being strong improve

Displaying fatalistic attitude toward
refusing to consider that treatment

Tried to get her to talk about
Potential for end of life -
I don't Address that (husband)
Believe talking about it discourages
one day at a time

Acknowledging Spiritual Support

Belief in God, faith he will
be there.

Displaying fatalistic attitude toward
fatalistic / Faith in God

Displaying fatalistic attitude toward

097 DE: No I want to hear about everything that effects your cancer and
it's recurrence.

098 Speaker 1: Well my faith does help me through all of this. It gives
me strength and keeps me positive.

099 DE: Thank you for adding that in. Is there anything else I should
know are think about?

100 Speaker 1: No, I will call you if I think of something else. You're
very welcome.

101 DE: I'm glad we were able to do that. Thank you. End this now and
turn it off again. We'll add that in.

102 END OF AUDIO PART 2

103

104

Appendix K – Atlas Ti Training Tools & Resource List



Atlas-Ti Training Tools and Resources

Atlas Ti Training modules on line:

<http://atlasti.com/product/features/>

<http://atlasti.com/training/>

Atlas Ti Resource book- Friese, S. (2014) Qualitative Data Analysis with ATLAS.ti Second edition. Los Angeles, Ca. Sage Publishers.

Atlas Ti Introduction Seminar- UCLA December 18, 2014

Researchtalk.com - On line support for Atlas Ti users working with consultant: Alison Hamilton

Appendix L – Synthesis of Final Codes to Categories

Initial codes collapsed into categories	30 Categories – Subcategories	15 Categories – Subcategories	Concepts
<p>2nd cancer - 2nd code used to verify second diagnosis comments</p>	<p>1. Continuous treatment-treatment</p> <ul style="list-style-type: none"> • Need to fight again • Not curable but treatable 	<p>1. Continuous treatment-treatment</p> <ul style="list-style-type: none"> • Need to fight again • Not curable but treatable 	<p>1. Seeking Life Through Continuous Treatment</p> <ul style="list-style-type: none"> • Need to fight again • Not curable but treatable • Fearing recurrence-death • Focus on new chemotherapy-less toxic-imp of plan • Alternative treatment • Questioning initial tx. - mismanaged?
<p>Acceptance/accepting diagnosis</p>	<p>2. Positive focus-Hopeful for future</p> <ul style="list-style-type: none"> • Hopeful for future 	<p>2. Coping-Working-Existential. Positive focus-Hopeful for future</p> <ul style="list-style-type: none"> • Hopeful for future • Faith in Doctor • Importance of having a plan • Importance of Spiritual support • Live each day be grateful 	<p>2. Hope in the Face of an Uncertain Future</p> <ul style="list-style-type: none"> • Hopeful for future • Faith in Doctor • Importance of having a plan • Importance of Spiritual support • Live each day be grateful • Meaning & Purpose-cancer changed their life • Meaning • Self sacrifice-others first

Initial codes collapsed into categories	30 Categories – Subcategories	15 Categories – Subcategories	Concepts
3. Seeking knowledge about cancer and its cause <ul style="list-style-type: none"> • Alternative Treatment • Questioning initial tx. 	3. Seeking knowledge about cancer and its cause <ul style="list-style-type: none"> • Alternative Treatment • Questioning initial tx.- mismanaged? • Genetic impact 	<ul style="list-style-type: none"> • Not liking use of word survivor or patient-sounds like victim • Realizing not curable • Importance of family support • .masking feelings with humor • Humor as a coping mechanism 	Seeking knowledge about cancer and its cause-how to live <ul style="list-style-type: none"> • Genetically determined • Promoting self health • Self Advocacy

Initial codes collapsed into categories	30 Categories – Subcategories	15 Categories – Subcategories	Concepts
Age - All codes related to age	4. Acceptance-accepting diagnosis <ul style="list-style-type: none"> • Age-impact on cancer 	4. Behaviour & Attitude Toward Recurrence. Acceptance-reluctantly accepting diagnosis <ul style="list-style-type: none"> • Age-impact on cancer • Coping denial-ignoring • Minimising cancer-relating to other diseases 	3. Reluctant Acceptance <ul style="list-style-type: none"> • Age-impact on cancer • Coping denial-ignoring • Minimising cancer-relating to other diseases • Unsure future • Anger/sadness –Just deal with it • Sadness-Loss related to cancer
Alternative treatment - codes related to seeking alternative treatments	5. Meaning & purpose-cancer changed their life <ul style="list-style-type: none"> • Meaning • Self sacrifice-others first • Sadness-Loss related to cancer • Not liking use of word survivor or patient-sounds like victim 	5. Meaning & Purpose-cancer changed their life <ul style="list-style-type: none"> • Meaning • Self sacrifice-others first • Sadness-Loss related to cancer • Not liking use of word survivor or patient-sounds like victim • Realizing not curable 	Insurance Issues dropped-not acknowledged in theoretical sampling.
Anger - codes related to anger at recurrence	6. Anger/sadness focused codes	6. Anger/sadness focused codes	

Initial codes collapsed into categories	30 Categories – Subcategories	15 Categories – Subcategories	Concepts
Believed cured - code related to verification of preceived disease free	7. Family-support-importance	7. Family-support-importance	
Meaning - related to seeking meaning or describing the meaning of their diagnosis	8. Believing cured	8. Believing cured	
Seeking knowledge - codes related to trying to understand how cancer recurred, how to maintain health, treatment options	9. Promoting self health <ul style="list-style-type: none"> • Self Advocacy 	9. Promoting self health <ul style="list-style-type: none"> • Self Advocacy 	
City of Hope - second code for comments related to treatment site	10. Unsure future	10. Uncertain future	
Minimize - general codes for statements made that minimize seriousness of disease and or consequences	11. Masking feelings with humor <ul style="list-style-type: none"> • Humor as a coping mechanism 	11. Masking feelings with humor <ul style="list-style-type: none"> • Humor as a coping mechanism 	
Continuous treatment - codes related to continuous treatment choice	12. Fearing recurrence/death	12. Fearing recurrence/death	

Initial codes collapsed into categories	30 Categories – Subcategories	15 Categories – Subcategories	Concepts
Coping mechanisms - codes related to coping-denial, stress reduction, externalizing by comparing to others (it could be worse)	13. Focus on new chemotherapy-less toxic	13. Focus on new chemotherapy-less toxic	
Faith in doctor - believing in physician and treatment plan	14. Insurance issues	14. Insurance issues	
Family support - all codes related to positive family support including children and grandchildren	15. Anger at recurrence	15. Anger at recurrence	
Fatigue - 2nd code for specific symptom acknowledgement	16. Faith in doctor		
Fear-dying - beyond fear of recurrence-that has happened	17. Coping-denial-ignoring <ul style="list-style-type: none"> • Focusing on day to day 		
Helpless/hopeless - codes for feelings acknowledged by participant	18. Importance of having a plan		

Initial codes collapsed into categories	30 Categories – Subcategories	15 Categories – Subcategories	Concepts
Fight again - codes described by participant as "again"	19. Spiritual support important	Dropped	
Chemotherapy-new treatments - codes related to new treatment and feelings that new treatments less toxic	20. Realizing not curable	Self blame-failure - not verified through theoretical interviews	
Genetics - codes related to genetic evaluation or known BRCA involvement	21. Hopeful for future	Believing cured - code used to verify perceived as cured before recurrence	
Meaning - codes related to describing meaning of their disease, impact on future, change	22. Mismanaged care with initial tx-prior to recurrence		
Having a plan - reduce fear and anxiety-acknowledging importance of having a plan	23. Fatigue		
Health promotion - codes related to promoting self health	24. Self blame/failure		

Initial codes collapsed into categories	30 Categories – Subcategories	15 Categories – Subcategories	Concepts
Hopeful for future - codes related to hope or acknowledgement of a future	25. Live each day-be grateful		
Humour for coping - codes of laughter or humor used for coping-minimising fear	26. Minimising cancer related to other diseases-fear-		
Insurance - codes related to lack of insurance or insurance coverage	27. Fight-again-need to fight		
Day to day - coping by daily focus to minimise fear of future	28. Self-advocacy		
Not curable-treatable - codes describing state of disease as incurable but treatable	29. Genetic involvement		
Positive-hopeful outlook - describing outlook for future	30. Not curable but treatable		
Self advocacy - codes related to advocating for self related to seeking care			

Initial codes collapsed into categories	30 Categories – Subcategories	15 Categories – Subcategories	Concepts
Self blame/failure - codes related to participants stating recurrence was their fault-recurrence seen as failure	DROPPED CODES-2nd Cancer, City of Hope, fatigue, pain-used for 2nd coding for families		
Spiritual support - codes where participants described importance of spiritual support to their coping with their recurrence	Hopelessness/Helplessness – not acknowledged by majority of participants in theoretical coding process		
Self sacrifice-others first - caring about others first	Non compliant with recommended tx. For 1 st . DX-not significant for this study.		
Mismanaged care with initial tx - prior to recurrence			
Non compliant with recommended tx. For 1st DX			
Pain-symptom Sadness-Loss related to cancer - emotions experienced with recurrent cancer			

Initial codes collapsed into categories	30 Categories – Subcategories	15 Categories – Subcategories	Concepts
<p>Uncontrollable/unsure future - realization not curable-maintaining hope</p> <p>Not liking use of word survivor or patient-sounds like victim</p> <p>Coping through denial</p>			

Appendix M – PubMed Database Search Results

Concept	Controlled vocabulary terms (MeSH or other)	Text keywords	Search strategy-PubMed 9-28-2016 N = 3576 N = 3721
Advanced	'palliative care'[mh] 'hospice care'[mh] 'palliative medicine'[mh]	Palliative Hospice 'end of life'	('palliative care'[mh] OR 'hospice care'[mh] OR 'palliative medicine'[mh] OR Palliative[tw] OR Hospice[tw] OR 'end of life'[tw])
Cancer	Neoplasms[mh] Metastatic [mh] 'Neoplasm metastasis'[mh]	Cancer Oncology Carcinoma Neoplasms Metastasis Metastatic	(Neoplasms[mh] OR Cancer[tw] OR Oncology[tw] OR Carcinoma[tw] OR neoplasms[tw])

Concept	Controlled vocabulary terms (MeSH or other)	Text keywords	Search strategy-PubMed
Identifying meaning	Attitude[mh]	Experience* Feel* view* voice* attitude* perspective* understand* believe belief* meaning significance hope	9-28-2016 N = 3576 N = 3721 (Attitude[mh] OR Experience*[tw] OR feel*[tw] OR view*[tw] OR voice*[tw] OR attitude*[tw] OR perspective*[tw] OR understand*[tw] OR believe[tw] OR belief*[tw] OR meaning[tw] OR significance[tw] OR hope[tw])
Qualitative	'Surveys and Questionnaires'[mh] 'interviews as topic'[mh] Narration[mh] 'focus groups'[mh] 'qualitative research'[mh] 'personal narratives'[publication type]	Survey Questionnaire Interview 'focus group' case study qualitative narrative ethnology ethnograph*	('Surveys and Questionnaires'[mh] OR 'interviews as topic'[mh] OR Narration[mh] OR 'focus groups'[mh] OR 'qualitative research'[mh] OR 'personal narratives'[publication type] OR Survey*[tw] OR Questionnaire*[tw] OR Interview*[tw] OR 'focus group'[tw] OR 'case study'[tw] OR qualitative[tw] OR narrative[tw] OR ethnology[tw] OR ethnograph*[tw])

Note. ('Neoplasm metastasis' [mh] OR Metastatic [tw] OR 'palliative care' [mh] OR 'hospice care' [mh] OR 'palliative medicine' [mh] OR Palliative [tw] OR Hospice [tw] OR 'end of life' [tw]) AND (Neoplasms [mh] OR Cancer [tw] OR Oncology [tw] OR Carcinoma [tw] OR neoplasms [tw]) AND (Attitude [mh] OR Experience [tw] OR feel* [tw] OR view* [tw] OR voice* [tw] OR attitude* [tw] OR perspective* [tw] OR understand* [tw] OR believe [tw] OR belief* [tw] OR meaning [tw] OR significance [tw] OR hope [tw]) AND ('Surveys and Questionnaires' [mh] OR 'interviews as topic' [mh] OR Narration [mh] OR 'focus groups' [mh] OR 'qualitative research' [mh] OR 'personal narratives' [publication type] OR Survey* [tw] OR Questionnaire* [tw] OR Interview* [tw] OR 'focus group' [tw] OR 'case study' [tw] OR qualitative [tw] OR narrative [tw] OR ethnology [tw] OR ethnograph* [tw]).

Key papers:

- 27098887 – comes up in search
- 20920031 – part of hand search
- 26224137 – part of hand search

Appendix N – Database Search: Metastatic

Concept	Controlled vocabulary terms	Text keywords	Search strategy Web of Science 9-28-2016 N = 4157 N = 5519
Advanced		Palliative Hospice 'end of life' Metastatic Metastasis	(Palliative OR Hospice OR 'end of life')
Cancer		Cancer Oncology Carcinoma neoplasms	(Cancer OR Oncology OR Carcinoma OR neoplasms)
Identifying meaning		Experience* Feel* view* voice* attitude* perspective* understand* believe belief* meaning significance hope	(Experience* OR feel* OR view* OR voice* OR attitude* OR perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope)
Qualitative		Survey Questionnaire Interview 'focus group' case study qualitative narrative ethnology ethnograph*	(Survey* OR Questionnaire* OR Interview* OR 'focus group' OR 'case study' OR qualitative OR narrative OR ethnology OR ethnograph*)

Note. Copy and paste: (Palliative OR Hospice OR 'end of life' OR metastatic OR metastasis) AND (Cancer OR Oncology OR Carcinoma OR neoplasms) AND (Experience* OR feel* OR view* OR voice* OR attitude* OR perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope) AND (Survey* OR Questionnaire* OR Interview* OR 'focus group' OR 'case study' OR qualitative OR narrative OR ethnology OR ethnograph*)

Publish: TS=((Palliative OR Hospice OR 'end of life') AND (Cancer OR Oncology OR Carcinoma OR neoplasms) AND (Experience* OR feel* OR view* OR voice* OR attitude* OR perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope) AND (Survey* OR

Questionnaire* OR Interview* OR 'focus group' OR 'case study' OR qualitative
OR narrative OR ethnology OR ethnograph*))

Key papers:

27098887 – comes up in search

20920031 – part of hand search

26224137 – part of hand search

Appendix O – CINAHL Database Search: Strategy

Concept	Controlled vocabulary terms	Text keywords	Search strategy CINAHL 9-28-2016 N = 1992
Advanced	(MH 'Palliative Care') (MH 'Hospice Care') (MH 'Hospice and Palliative Nursing')	Palliative Hospice 'end of life'	((MH 'Palliative Care') OR (MH 'Hospice Care') OR (MH 'Hospice and Palliative Nursing')) OR TI(Palliative OR Hospice OR 'end of life') OR AB(Palliative OR Hospice OR 'end of life'))
Cancer	(MH 'Neoplasms+') (MH 'Cancer Patients')	Cancer Oncology Carcinoma neoplasms	((MH 'Neoplasms+') OR (MH 'Cancer Patients') OR TI(Cancer OR Oncology OR Carcinoma OR neoplasms) OR AB(Cancer OR Oncology OR Carcinoma OR neoplasms))
Identifying meaning	(MH 'Attitude+') (MH 'Psychosocial Aspects of Illness+') (MH 'Adaptation, Psychological+')	Experience* Feel* view* voice* attitude* perspective* understand* believe belief* meaning significance hope	((MH 'Attitude+') OR (MH 'Psychosocial Aspects of Illness+') OR (MH 'Adaptation, Psychological+') OR TI(Experience* OR feel* OR view* OR voice* OR attitude* OR perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope) OR AB(Experience* OR feel* OR view* OR voice* OR attitude* OR perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope))

Concept	Controlled vocabulary terms	Text keywords	Search strategy CINAHL 9-28-2016 N = 1992
Qualitative	(MH 'Qualitative Studies+')	Survey Questionnaire Interview 'focus group' case study qualitative narrative ethnology ethnograph*	((MH 'Qualitative Studies+') OR TI(Survey* OR Questionnaire* OR Interview* OR 'focus group' OR 'case study' OR qualitative OR narrative OR ethnology OR ethnograph*)) OR AB(Survey* OR Questionnaire* OR Interview* OR 'focus group' OR 'case study' OR qualitative OR narrative OR ethnology OR ethnograph*))
<p><i>Note.</i> ((MH 'Palliative Care') OR (MH 'Hospice Care') OR (MH 'Hospice and Palliative Nursing') OR TI(Palliative OR Hospice OR 'end of life') OR AB(Palliative OR Hospice OR 'end of life')) AND ((MH 'Neoplasms+') OR (MH 'Cancer Patients') OR TI(Cancer OR Oncology OR Carcinoma OR neoplasms) OR AB(Cancer OR Oncology OR Carcinoma OR neoplasms)) AND ((MH 'Attitude+') OR (MH 'Psychosocial Aspects of Illness+') OR (MH 'Adaptation, Psychological+') OR TI(Experience* OR feel* OR view* OR voice* OR attitude* OR perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope) OR AB(Experience* OR feel* OR view* OR voice* OR attitude* OR perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope)) AND ((MH 'Qualitative Studies+') OR TI(Survey* OR Questionnaire* OR Interview* OR 'focus group' OR 'case study' OR qualitative OR narrative OR ethnology OR ethnograph*)) OR AB(Survey* OR Questionnaire* OR Interview* OR 'focus group' OR 'case study' OR qualitative OR narrative OR ethnology OR ethnograph*))</p>			

Appendix P – PsychINFO Database Search: Strategy

Concept	Controlled vocabulary terms	Text keywords	Search strategy PsychINFO 9-28-2016 N = 1273
Advanced	SU.EXACT('Hospice') SU.EXACT('Terminally Ill Patients') SU.EXACT('Palliative Care')	Palliative Hospice 'end of life'	(SU.EXACT('Hospice') OR SU.EXACT('Terminally Ill Patients') OR SU.EXACT('Palliative Care')) TI(Palliative OR Hospice OR 'end of life') OR AB(Palliative OR Hospice OR 'end of life')
Cancer	SU.EXACT.EXPLODE('Neoplasms')	Cancer Oncology Carcinoma neoplasms	(SU.EXACT.EXPLODE('Neoplasms') OR TI(Cancer OR Oncology OR Carcinoma OR neoplasms) OR AB(Cancer OR Oncology OR Carcinoma OR neoplasms))
Identifying meaning	SU.EXACT('Health Attitudes') OR SU.EXACT('Death Attitudes') SU.EXACT.EXPLODE('Emotional Adjustment') SU.EXACT.EXPLODE('Meaning') SU.EXACT('Meaningfulness')	Experience* Feel* view* voice* attitude* perspective* understand* believe belief* meaning significance hope	(SU.EXACT('Health Attitudes') OR SU.EXACT('Death Attitudes') OR SU.EXACT.EXPLODE('Emotional Adjustment') OR SU.EXACT.EXPLODE('Meaning') OR SU.EXACT('Meaningfulness') OR TI(Experience* OR feel* OR view* OR voice* OR attitude* OR perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope) OR AB(Experience* OR feel* OR view* OR voice* OR attitude* OR

Concept	Controlled vocabulary terms	Text keywords	Search strategy PsycINFO 9-28-2016 N = 1273
Qualitative	SU.EXACT.EXPLODE('Qualitative Research') ME('Focus Group') ME('Interview') ME('Qualitative Study') ME('Clinical Case Study')	Survey Questionnaire Interview 'focus group' case study qualitative narrative ethnology ethnograph*	perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope)) (SU.EXACT.EXPLODE('Qualitative Research') OR ME('Focus Group') OR ME('Interview') OR ME('Qualitative Study') OR ME('Clinical Case Study') OR TI(Survey* OR Questionnaire* OR Interview* OR 'focus group' OR 'case study' OR qualitative OR narrative OR ethnology OR ethnograph*) OR AB(Survey* OR Questionnaire* OR Interview* OR 'focus group' OR 'case study' OR qualitative OR narrative OR ethnology OR ethnograph*))

Note. (SU.EXACT('Hospice') OR SU.EXACT('Terminally Ill Patients') OR SU.EXACT('Palliative Care') TI(Palliative OR Hospice OR 'end of life') OR AB(Palliative OR Hospice OR 'end of life')) AND (SU.EXACT.EXPLODE('Neoplasms') OR TI(Cancer OR Oncology OR Carcinoma OR neoplasms) OR AB(Cancer OR Oncology OR Carcinoma OR neoplasms)) AND (SU.EXACT('Health Attitudes') OR SU.EXACT('Death Attitudes') OR SU.EXACT.EXPLODE('Emotional Adjustment') OR SU.EXACT.EXPLODE('Meaning') OR SU.EXACT('Meaningfulness') OR TI(Experience* OR feel* OR view* OR voice* OR attitude* OR perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope) OR AB(Experience* OR feel* OR view* OR voice* OR attitude* OR perspective* OR understand* OR believe OR belief* OR meaning OR significance OR hope)) AND (SU.EXACT.EXPLODE('Qualitative Research') OR ME('Focus Group') OR ME('Interview') OR ME('Qualitative Study') OR

ME('Clinical Case Study') OR TI(Survey* OR Questionnaire* OR Interview* OR 'focus group' OR 'case study' OR qualitative OR narrative OR ethnology OR ethnograph*) OR AB(Survey* OR Questionnaire* OR Interview* OR 'focus group' OR 'case study' OR qualitative OR narrative OR ethnology OR ethnograph*))

Key papers:

- 27098887 – comes up in search
- 20920031 – part of hand search
- 26224137 – part of hand search

Appendix Q – Excluded Literature Grid With Reasons for Exclusion

Manuscript evaluations for inclusion in literature review	Response to inclusion/exclusion with reason for decision	Reasons	Numbers
Aabom, B., & Pfeiffer, P. (2009). Why are some patients in treatment for advanced cancer reluctant to consult their GP? <i>Scand J Prim Health Care</i> , 27(1), 58–62. doi: 10.1080/02813430802677817	exclude related to consulting GP NOT FOCUSED ON PT PERCEPTION OF ADV. RECURRENCE	NOT FOCUSED ON PT PERCEPTION OF ADV RECURRENCE	11
Ando, M., Morita, T., Akechi, T., & Takashi, K. (2012). Factors in narratives to questions in the Short-Term Life Review interviews of terminally ill cancer patients and utility of the questions. <i>Palliat Support Care</i> , 10(2), 83–90. doi: 10.1017/s1478951511000708	exclude data related to Short-Term Life Review tool NOT QUALITATIVE	NOT QUALITATIVE	5
Ando, M., Morita, T., Lee, V., & Okamoto, T. (2008). A pilot study of transformation, attributed meanings to the illness, and spiritual well-being for terminally ill cancer patients. <i>Palliat Support Care</i> , 6(4), 335–340. doi: 10.1017/s1478951508000539	exclude related to spiritual transformation to illness FOCUSED ON UNRELATED CONCEPT	FOCUSED ON UNRELATED CONCEPT	13
Arman, M., Rehnsfeldt, A. (2002) Living with breast cancer- a challenge to expansive and creative forces	exclude only one of the participants was 2 or more years before recurrence. Data not separate		

Manuscript evaluations for inclusion in literature review	Response to inclusion/exclusion with reason for decision	Reasons	Numbers
Arman, M., Rehnfeldt, A., Lindholm, L., Hamrin, E. (2002) The face of suffering among women with breast cancer-Being in a field of forces	excluded as focus of interviews was to describe suffering experience of breast cancer. Focus not on defined concepts or perception of advanced recurrence. Population combined with different stages of disease.		
Asgeirsdottir, G. H., Sigurbjornsson, E., Traustadottir, R., Sigurdardottir, V., Gunnarsdottir, S., & Kelly, E. (2014). In the shadow of death: existential and spiritual concerns among persons receiving palliative care. <i>J Pastoral Care Counsel</i> , 68(1-2), 4.	exclude-related to cancer nurses FOCUSED ON PROF. OR CAREGIVER	FOCUSED ON PROF OR CAREGIVER	5
Beaumont, T. (2013). HOW DO WOMEN WITH METASTATIC BREAST CANCER VIEW PALLIATIVE CARE? A QUALITATIVE STUDY USING A GROUNDED THEORY APPROACH TO ENABLE THE VIEWS OF WOMEN TO BE SOUGHT. <i>Breast</i> , 22, S29-S29.	exclude-related to view of palliative care FOCUSED ON UNRELATED CONCEPT	NOT INTERVIEWS	4
Clarke, G., Johnston, S., Corrie, P., Kuhn, I., & Barclay, S. (2015). Withdrawal of anticancer therapy in advanced disease: a systematic literature review. <i>BMC Cancer</i> , 15. doi: 10.1186/s12885-015-1862-0	Exclude-systematic literature review NOT INTERVIEWS	FOCUSED ON INTERVENTION	4
De Faye, B. J., Wilson, K. G., Chater, S., Viola, R. A., & Hall, P. (2006). Stress and coping with advanced cancer. <i>Palliat Support Care</i> , 4(3), 239-249.	Excluded-no interview data apparent in the manuscript-verified with CW NOT INTERVIEWS	NOT FOCUSED ON ADULT POPULATION	8

Manuscript evaluations for inclusion in literature review	Response to inclusion/exclusion with reason for decision	Reasons	Numbers
De Lima, L. (2014). Lucy. <i>J Palliat Med</i> , 17(2), 243. doi: 10.1089/jpm.2013.0322	Excluded-not specific to advanced disease or recurrence NOT FOCUSED ON PT PERCEPTION OF ADV RECURRENCE	REPRINT OF EARLIER MANUSCRIPT	1
Duggleby, W., & Wright, K. (2009). Transforming hope: how elderly palliative patients live with hope. <i>Canadian Journal of Nursing Research</i> , 41(1), 204–217.	Reprint of 2005 article Excluded	REPRINT OF EARLIER MANUSCRIPT	51
Gonzaga, M. A. (2013). Listening to the voices: an exploratory study of the experiences of women diagnosed and living with breast cancer in Uganda. <i>Pan Afr Med J</i> , 16, 60. doi: 10.11604/pamj.2013.16.60.2431	Excluded -focused on living not advanced cancer-incurable NOT FOCUSED ON PT PERCEPTION OF ADV RECURRENCE		
Herth, K. A., & Cutcliffe, J. R. (2002). The concept of hope in nursing 3: hope and palliative care nursing. <i>Br J Nurs</i> , 11(14), 977–983. doi: 10.12968/bjon.2002.11.14.10470	Excluded-related to nurses perspective not patients FOCUSED ON PROF OR CAREGIVER		
Jones, L., Fitzgerald, G., Leurent, B., Round, J., Eades, J., Davis, S., . . . Tookman, A. (2013). Rehabilitation in advanced, progressive, recurrent cancer: a randomized controlled trial. <i>J Pain Symptom Manage</i> , 46(3), 315–325 e313. doi: 10.1016/j.jpainsymman.2012.08.017	Excluded-testing a rehabilitation intervention FOCUSED ON INTERVENTION		

Manuscript evaluations for inclusion in literature review	Response to inclusion/exclusion with reason for decision	Reasons	Numbers
Kendall, M., Murray, S. A., Carduff, E., Worth, A., Harris, F., Lloyd, A., . . . Sheikh, A. (2009). Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. <i>British Medical Journal</i> , 339. doi: 10.1136/bmj.b4122	Excluded- related to carer's and patients' beliefs of cancer not terminal illness FOCUSED ON PROF. OR CAREGIVER		
Maloney, C., Lyons, K. D., Li, Z. Z., Hegel, M., Ahles, T. A., & Bakitas, M. (2013). Patient perspectives on participation in the ENABLE II randomized controlled trial of a concurrent oncology palliative care intervention: Benefits and burdens. <i>Palliative Medicine</i> , 27(4), 375–383. doi: 10.1177/0269216312445188	Excluded -focused on response to ENABLE study FOCUSED ON INTERVENTIONS		
Miccinesi, G., Bianchi, E., Brunelli, C., & Borreani, C. (2012). End-of-life preferences in advanced cancer patients willing to discuss issues surrounding their terminal condition. <i>Eur J Cancer Care (Engl)</i> , 21(5), 623–633. doi: 10.1111/j.1365-2354.2012.01347.x	Excluded-related to patients specifically at end of life and their preferences. FOCUSED ON NON RELATED CONCEPT		
Muzzin, L. J., Anderson, N. J., Figueredo, A. T., & Gudelis, S. O. (1994). The experience of cancer. <i>Soc Sci Med</i> , 38(9), 1201–1208.	Excluded-not specific to advanced disease or recurrence NOT FOCUSED ON PT PERCEPTION OF ADV RECURRENCE		
Nelson, W. A. (2004). Patient adaptation to terminal situations through a life reflection process. Retrieved from http://search.proquest.com/docview/620631538?accountid=14512	Excluded-related to a specific process or intervention FOCUSED ON AN INTERVENTION		

Manuscript evaluations for inclusion in literature review	Response to inclusion/exclusion with reason for decision	Reasons	Numbers
Nilmanat, K., Chailungka, P., Temsak, P., Promnoi, C., Tulathamkit, K., Noo-urai, P., & Phattaranavig, S. (2010). Living with suffering as voiced by Thai patients with terminal advanced cancer. <i>Int J Palliat Nurs</i> , 16(8), 393–399. doi: 10.12968/ijpn.2010.16.8.393	Excluded focused on suffering-interviews FOCUSED ON NON RELATED CONCEPT		
Noot, T., Tassanee, T., Forrester, D. A., & Pimpan, S. (2016). Experiences of People with Advanced Cancer in Home-Based Palliative Care. <i>Pacific Rim International Journal of Nursing Research</i> , 20(3), 238–251.	Excluded-related to satisfaction with home based palliative care-not the experience of living with advanced cancer. NOT FOCUSED ON PT PERCEPTION OF ADV RECURRENCE		
Olsson, L., Östlund, G., Grassman, E. J., Friedrichsen, M., & Strang, P. (2010). Maintaining hope when close to death: insight from cancer patients in palliative home care. <i>Int J Palliat Nurs</i> , 16(12), 607–612.	Excluded-focus on hope when close to death in palliative home care service NOT FOCUSED ON PT PERCEPTION OF ADV RECURRENCE		
Olsson, L., Östlund, G., Strang, P., Grassman, E. J., & Friedrichsen, M. (2011). The glimmering embers: experiences of hope among cancer patients in palliative home care. <i>Palliat Support Care</i> , 9(1), 43–54. doi: 10.1017/S1478951510000532	Excluded-same data again focused on end of life NOT FOCUSED ON PT PERCEPTION OF ADV RECURRENCE		

Manuscript evaluations for inclusion in literature review	Response to inclusion/exclusion with reason for decision	Reasons	Numbers
O'Sullivan, E. M., & Higginson, I. J. (2016). 'I'll continue as long as I can, and die when I can't help it': a qualitative exploration of the views of end-of-life care by those affected by head and neck cancer (HNC). <i>BMJ Support Palliat Care</i> , 6(1), 43–51. doi: 10.1136/bmjspcare-2014-000664	Excluded-focused on end of life care and preferences for place of death FOCUSED ON NON RELATED CONCEPT		
Parker Olver, D. (2013). When worlds collide: when research becomes reality. <i>J Palliat Med</i> , 16(2), 208–210. doi: 10.1089/jpm.2012.0309	Excluded-related to parents fear of childhood brain tumour recurrence NOT FOCUSED ON ADULT POPULATION		
Parker Olver, D. (2014). Bittersweet waiting: blessings and burdens. <i>J Palliat Med</i> , 17(11), 1282–1283. doi: 10.1089/jpm.2013.0662	Excluded-related to above data again parents perspective and pediatric patient NOT FOCUSED ON ADULT POPULATION		
Payne, S. A. (1992). A study of quality of life in cancer patients receiving palliative chemotherapy. <i>Soc Sci Med</i> , 35(12), 1505–1509.	Excluded-data pertinent to this study unclear		
Penman, J., & Ellis, B. (2015). Palliative care clients' and caregivers' notion of fear and their strategies for overcoming it. <i>Palliat Support Care</i> , 13(3), 777–785. doi: 10.1017/s1478951514000571	Excluded-focused of fear of death and strategies to overcome it. Not related to this studies theory FOCUSED ON INTERVENTIONS		

Manuscript evaluations for inclusion in literature review	Response to inclusion/exclusion with reason for decision	Reasons	Numbers
Perkins, H. S., Cortez, J. D., & Hazuda, H. P. (2012). Patients' diverse beliefs about what happens at the time of death. <i>J Hosp Med, 7</i> (2), 110–116. doi: 10.1002/jhm.947	Excluded -focused on time of death FOCUSED ON NON RELATED CONCEPT		
Pestinger, M., Stiel, S., Elsner, F., Widdershoven, G., Voltz, R., Nauck, F., & Radbruch, L. (2015). The desire to hasten death: Using Grounded Theory for a better understanding 'When perception of time tends to be a slippery slope'. <i>Palliative Medicine, 29</i> (8), 711–719. doi: 10.1177/0269216315577748	Excluded- focused on hastening death FOCUSED ON NON RELATED CONCEPT		
Phipps, E., True, G., Harris, D., Chong, U., Tester, W., Chavin, S., Braitman, L. (2003). Approaching the end of life: attitudes, preferences, and behaviors of African-American and White patients and their family caregivers. <i>Journal of Clinical Oncology, 21</i> (3), 549–554. doi 10.1200/JCO.2003.12.080	Excluded-focused on autonomy and advanced directives FOCUSED ON NON RELATED CONCEPT		
Refsgaard, B., & Frederiksen, K. (2013). Illness-related emotional experiences of patients living with incurable lung cancer: a qualitative metasynthesis. <i>Cancer Nurs, 36</i> (3), 221–228. doi: 10.1097/NCC.0b013e318268f983	Excluded-meta synthesis NOT INTERVIEWS		
Richardson, A., Wagland, R., Foster, R., Symons, J., Davis, C., Boyland, L., . . . Addington-Hall, J. (2015). Uncertainty and anxiety in the cancer of unknown primary patient journey: a multiperspective qualitative study. <i>BMJ Support Palliat Care, 5</i> (4), 366–372. doi: 10.1136/bmjspcare-2013-000482	Excluded- unknown primary NOT FOCUSED ON PT PERCEPTION OF ADVANCED RECURRENCE		

Manuscript evaluations for inclusion in literature review	Response to inclusion/exclusion with reason for decision	Reasons	Numbers
Rugno, F. C., Ribeiro Paiva, B. S., Nunes, J. S., & Paiva, C. E. (2014). 'There won't be anything else...it's over': Perceptions of women referred to palliative care only. <i>European Journal of Oncology Nursing</i> , 18(3), 261–266. http://dx.doi.org/10.1016/j.ejon.2014.01.003	Excluded-focused on referral to palliative care in general FOCUSED ON PROF OR CAREGIVER		
Sinclair, S., Beamer, K., Hack, T. F., McClement, S., Raffin Bouchal, S., Chochinov, H. M., & Hagen, N. A. (2016). Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences. <i>Palliat Med</i> . doi: 10.1177/0269216316663499	Excluded- methodology was confusing-initial interviews-then specific interviews related to sympathy, empathy and compassion. Discussed need for 53 participants to meet data saturation?? Qualitative gt study???	NOT QUALITATIVE	
Smith, C., Bosanquet, N., Riley, J., & Koffman, J. (2016). Loss, transition and trust: perspectives of terminally ill patients and their oncologists when transferring care from the hospital into the community at the end of life. <i>BMJ Support Palliat Care</i> . doi: 10.1136/bmjspcare-2015-001075	Excluded-focused interviews primarily related to patient-physician relationship FOCUSED ON PROF OR CAREGIVER		
Thompson, G. N., Chochinov, H. M., Wilson, K. G., McPherson, C. J., Chary, S., O'Shea, F. M., . . . Macmillan, K. A. (2009). Prognostic acceptance and the well-being of patients receiving palliative care for cancer. <i>J Clin Oncol</i> , 27(34), 5757–5762. doi: 10.1200/jco.2009.22.9799	Excluded-focused on transition from hospital to palliative care FOCUSED ON NON RELATED CONCEPT		

Manuscript evaluations for inclusion in literature review	Response to inclusion/exclusion with reason for decision	Reasons	Numbers
Tipseankhum, N., Tongprateep, T., Forrester, D. A., & Silpasuwun, P. (2016). Experiences of People with Advanced Cancer in Home-Based Palliative Care. <i>Pacific Rim International Journal of Nursing Research</i> , 20(3), 238–251.	Excluded related to data in above study 'Noot,T.'? Focused on home palliative care	FOCUSED ON NON RELATED CONCEPT	
Trevor, T. (2014). Prepping for the day you hope never arrives: facing recurrence. <i>Narrat Inq Bioeth</i> , 4(1), 27–30. doi: 10.1353/nib.2014.0025	Excluded-parents perception of cancer recurrence in their child	NOT FOCUSED ON ADULT POPULATION	
Warren, M. (2009). Metastatic breast cancer recurrence: a literature review of themes and issues arising from diagnosis. <i>Int J Palliat Nurs</i> , 15(5), 222–225. doi: 10.12968/ijpn.2009.15.5.42347	Excluded -literature review	NOT QUALITATIVE	
White, C. D., Hardy, J. R., Gilshenan, K. S., Charles, M. A., & Pinkerton, C. R. (2008). Randomised controlled trials of palliative care -- a survey of the views of advanced cancer patients and their relatives. <i>European Journal of Cancer</i> , 44(13), 1820–1828.	Excluded-questionnaire-not qualitative	NOT QUALITATIVE	
Worden, J. W. (1989). The Experience of Recurrent Cancer. <i>Ca-a Cancer Journal for Clinicians</i> , 39(5), 305–310. doi: DOI 10.3322/canjclin.39.5.305	Excluded-not qualitative	NOT QUALITATIVE	
Zimmermann, C. (2004). Denial of impending death: a discourse analysis of the palliative care literature. <i>Social Science & Medicine</i> , 59(8), 1769–1780. doi: 10.1016/j.socscimed.2004.02.012	Excluded-analysis of end of life literature	NOT INTERVIEWS	

Manuscript evaluations for inclusion in literature review	Response to inclusion/exclusion with reason for decision	Reasons	Numbers
Zimmermann, C. (2012). Acceptance of dying: A discourse analysis of palliative care literature. <i>Social Science & Medicine</i> , 75(1), 217–224. doi: 10.1016/j.socscimed.2012.02.047	Excluded-discourse analysis of pc literature NOT FOCUSED ON PT PERCEPTION OF ADV RECURRENCE		
Zimmermann, C., Swami, N., Krzyzanowska, M., Leighl, N., Rycall, A., Rodin, G., . . . Hannon, B. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. <i>CMAJ</i> , 188(10), E217–227. doi: 10.1503/cmaj.151171	Excluded-perceptions of palliative care FOCUSED ON NON RELATED CONCEPT		
42 = excluded			

Appendix R – Included Literature: No CASP

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Banning, M., Tanzeem, T. SAT	2013	Managing the illness experience of women with advanced breast cancer: hopes and fears of cancer-related insecurity	Lahore, Pakistan	European Journal of Cancer Care	Qualitative. Semi-structured Interview	Pakistani women with advanced breast cancer. Time since diagnosis varied from 1 yr to 11 years. N=21	Pakistani women being treated at Shaukat Khanum Memorial Cancer Hospital in Lahore for advanced breast cancer	Semi-structured interviews in Urdu transcripts were translated into English then back translated into Urdu to assure quality of translation.	“When person is alive she is hopeful”	More discuss on about “knowing I will die” more with advanced disease.4 hopelessness. More focus on marital relations hips. Cultural discrimin-ation- stigma of cancer and fear of contagio us disease.	Unclear if this was recurrence with advanced disease or initial diagnosis with advanced disease.4 themes- insecurity of health, resistance to cancer, marital relationships, impact on physical and emotional well-being with sub-theme of cultural discrimination Previously sought spiritual scholars rather than medical	

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support hope	Theses that support acceptance	Theses that support continuous Tx	Data not found in my work	Key points
Best, M., Butow, P., Olver, I. SAT	2014	Spiritual support of cancer patients and the role of the doctor	Sydney, Australia	Supportive Care in Cancer	GT- qualitative analysis- semi structure d face to face interviews	Advanced cancer- stage IV disease- Onc and PC hospitals in 4 hospitals around Sydney N=15	location of choice- home or hospital.	Semi-structured face to face interviews by same palliative care physician. Recorded and transcribed verbatim	Spiritual wellbeing contributes to ability to cope. Supportive relationships between self, family and God were intrinsic to quality of life and sense of wholeness	Describe sources of spiritual support that provides strength and courage to go forward. Describe importance of physician awareness of their spiritual beliefs to support communi	Theses that support acceptance	Lack of support. Disease at diagnosis.	Spirituality effects ability to cope. Identified 3 types of relationships that support relationships- self, family and God- NOT environment. Themes identified related to spiritual support- improve coping and meet spiritual needs, 2-facilitators of spiritual support- enhance pt.

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Brown, Patrick, de Graaf, Sabine KP	2013	Considering a future which may not exist: the construction of time and expectations amidst	The Netherlands	Health Risk & Society	Qualitative Study- In-depth- Narrative Interview s- IPA	people with advanced stage cancer. Participating in a clinical trial. Poor prognosis N=13 Primary Ca-Kidney, Pancreatic, CRC, Mult	Regional Hospital and city based academic hospital. Recent or currently participating in phase 2 or 3 clinical trial	In-depth interviews. 1-4 hours. Coding done by two researchers. CCA.	Hope and uncertainty a precautionary approach, future led. Hope defined and focused by future opportunities which	Accept illness that cannot be cured. Think positively .“feel obliged to interpret this and consider how to	Hope for a future through pharmaceuticals Consider how pharmaceutical products could change the progress	describe some with collapse of patients “lifeworlds inducing “severe suffering and anguish”	access to sources of strength in their spiritual path and 3-role of doctor in spiritual support- engagement of spirituality in the medical consultation.

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
		advance d-stage cancer				Myeloma			enable action and coping in the present.	live within the likelihood of this newly confined future" pg 544	on and prognoses of their illness. Pg545		within those coping methods at one time or concurrently. This seems paradoxical. Can plan for a future yet "bracket" away the future. Live with a short focus on future and experience the day. "synthesizes" concepts allowed them to cope with the uncertainty of the experience. Impacted by medical information and social contexts of themselves. "habitus" . 3

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in found in my work	Key points
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themes: 1)
 Uncertain quantity and quality of life;
 2) bracketing away future; 3) tensions between these constructions.
 Need to have self-control to live within these constructions.
 Conscious effort to think positively. Time is co-constructed between human (self-control) and non-human (clock time).
 Patients experienced paradoxes in some way or

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Chen, H., Komaromy, C., Valentin, C., SAT	2015	From hope to hope: The experience of older Chinese people with advanced cancer	UK	Health	Qualitative "embedded case study" and qualitative interview s.	Older Chinese patients with advanced cancer in palliative care settings- N=25	3 settings- committee, hospice and ward	Varied settings to provide different perspective s of care. 1 family member and doctor in charge were also interviewed . Patients were observed and interviewed	all pts. Expressed desire for cure or remission as their best hope. Otherwise hope for more life. All described worst was preparing for death. Concept of living for today don't think about	Hope for the best, prepare for the worst. Reconciled with death as acceptance of their state. Mental preparation involved confronting then reconciling the	trying to treat disease gave hope to participants. "if it doesn't work there is nothing else I can do"		other. Some pts. Found the inconsistencies easier to live with than others.
													"When days cannot be added to life, add life to days" p 161. Point out that living longer is not the only goal they also wanted to enjoy life as a social experience with significant others a meaningful and valued existence. Discussed the "hope work"

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
									<p>tomorrow. Interconnectedness drove desire to live longer and gave energy to sustain it.</p>	<p>prospect of death</p>			<p>described by others. Help to maintain hope through relationships and care-provided by health care workers and families. Taking food and drink had two meanings hope to stay alive and reinforced communication from family and others that there is hope. Interesting in light of the different culture the use of hope is the same as seen in my work</p>

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support hope	Theses that support acceptance	Theses that support continuous Tx	Data not found in my work	Key points
Clavarino, A., Najman, J., Beadle, G. SAT	2003	The Impact of will to live and belief in curability on the subjective well-being of patients with advanced cancer	Queensland and Australia	Mortality	Mixed methods. Interview between oncologists and patients informing them of prognosis and questionnaire 2 weeks after interview and 3 months during course of disease.	N=100 pts. With WHO performance score between 0-2. More than 50% waking hours locally recurrent or metastatic cancer with > 3 mo but <2 yrs life expectancy .	Newly referred outpatients attending one of several tx. Centres in south-east Queensland.	Initial interviews at referral to palliative care. Recorded as physicians informed them that cancer is incurable. 69/100 patients returned tapes. Only this piece reviewed for inclusion here.	78.3% said their Dr. told them cancer was incurable. 25 pts though believed that they did not believe what the doctor told them. 14 believed curable and 11 unknown.	74% receiving chemo at T1 and RT or Surgery. At T3 interview 65% had chemo w/in 2 weeks of interview and 9% RT and 7% surgery. This was w/in 8 weeks of death.	Quantitative piece – will to live, curability and subjective well-being measure.	The mixed methods piece is important	
Clayton, J., Butow, P., Fosterin and nurturin	2005	Fostering coping and nurturin	Sydney, Australia	Cancer	Focus groups and telephone	N=19 cancer pts. With incurable	3 PC services in Sydney, Australia.	Focus groups with 4-8 pts, supplement as disease	Spectrum of hope changes			PC provider's feelings	Hope was not specifically asked about but discussed

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Arnold, R., Tattersal I, M. SAT		g hope when discussing the future with terminally ill cancer patients and their caregivers.			semi-structured interviews	disease, 24 Caregivers and 22 PC providers.		<p>conducted by individual interviews with pts. Unable to attend a focus group.</p>	<p>progressive disease. Hope for miracle cure or spontaneous remission, hope of living longer than expected, hope for every day living</p>	<p>Theses that support-acceptance</p>	<p>Theses that support-continuous Tx</p>	<p>about hope from participants and caregivers differed from HC providers in that Hope for healing relationships and special times with family and friends was not discussed nor hope for finding spiritual meaning. This may still be issues considered too personal to discuss with the PC provider. Also the realization that all Participants</p>	<p>by the participants. Interestingly patients and caregivers differed from HC providers in that Hope for healing relationships and special times with family and friends was not discussed nor hope for finding spiritual meaning. This may still be issues considered too personal to discuss with the PC provider. Also the realization that all Participants</p>

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Coyle, N. SAT	2004	Expressed Desire for Hastened Death in 7 patients living with advanced	US	Onc. Nsg. Forum	qualitative phenomenologic study	N=7 terminally ill pts with cancer who had expressed a desire for hastened death	Urban cancer research hospital	semistructured interviews, audiotaped, transcribed, coded and themed				participants did not express desire to hasten death in fact the opposite	Participants in pain and palliative care program in the US are primarily focused on symptom management. Referral to PC programs are usually due to
													were being cared for by the PC provider so may be different than patients not being cared for by PC providers in PC units. "temper our honesty with compassion (Robinson)"

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in found in my work	Key points
		cancer: A phenom enologic Inquiry											uncontrollable symptoms. Attitude towards hastening death may be effected by uncontrolled symptoms and a feeling of helplessness and hopelessness.
Coyle, N. SAT	2006	The Hard Work of Living in the Face of Death	Pain & Palliative Care pts in Urban Cancer Research Center	Journal of Pain & Symptom Management	Qualitative Study- In-depth Narrative Interview s- IPA	N=7 pts. Advanced cancer who at one time talked about hastening death. Small number of pts.	Urban cancer research hospital	30-60 minute interviews. 1 – 6 times- median 3 at initial	Fighters trying to make sense of what was happening to them.	Accepted illness	Palliative chemo and RT. Hope for tx in the future	Wish for hastened death at least once the same time preparing for death” Active participants with a sense of urgency to accomplish something with	“creating a tenable existence with something to offer while at the same time preparing for death” Active participants with a sense of urgency to accomplish something with

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support hope	Theses that support acceptance	Theses that support continuous Tx	Data not found in my work	Key points
Dale, M., Johnston, B., SAT	2011	An exploration of the concerns of patients with inoperable lung cancer	Scotland	Int. J. of Pall. Nsg.	Qualitative Study- interpretive constructive approach. Did thematic analysis.	Purposive sampling – Inoperable lung cancer patients. N=6	specialist palliative care nursing setting in rural community in Scotland.	Semi-structured exploratory interviews		stoicism- get on with living life for as long as possible. Trust in physician s.			an unknown time frame. They work to prolong life. 3 main themes 1) steadfast living life, 2) family support important and 3) professional support. Also they found no real focus on death and dying similar to my population.
Daneault, S., Lussier, V., Mongeau, S., Yelle, L., Cote, A., Sicotte,	2016	Ultimate journey of the terminally ill- ways and pathways of	Canada	Canadian Family Physician	Qualitative analysis- interview until saturation occurred	patients with life expectancy of 12 mo. Or less, loved ones and treating physicians	tertiary specialized cancer centre in Canada	pts underwent up to 3 interviews –aim to better understand the role of hope	Hope akin to human reflex. People denying what they have been told and maintain				Described aim related to multiple noncurative treatments now offered to cancer patients and how that effects hope for

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
C., Paille, P., Doin, D., Coulombe, M. SAT		hope				N=12 each total 36 interviews		among terminally ill cancer patients.	g self-preserving illusions. Hope for a miracle. Envisioned a miraculous cure. Hope changes over time with progression of illness, Hope for a prolonged life and good quality of life.				people faced with terminal illness. Because their aim was to understand hope and changes over course of illness they interviewed loved one and physician treating incurable cancer as well. Found similar meanings of hope as I found in my terminally ill patients. Help to show that marketing model for my institution is not promoting the concept of "miracle". Other

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Davies, M., Sque, M. SAT	2002	Living on the outside looking in: a theory of living with advanced breast cancer	Southampton, UK	International Journal of Palliative Nursing	Qualitative approach. Semi structured interviews	10 pts. Hospice woman living with advanced breast cancer	Single hospice. Patients with advanced breast cancer in palliative stage of their disease	Semi Structured interviews using GT methodology and CCA	sense of hope important.	Process of adaptation and coping during survival – trying to restore old identities	Theses that support-continuous Tx	The concept of reconciling a different me. The referral to fear of recurrence as in	terminally ill patients go there without the marketing statement. The model in this paper related to hope alone but also tries to illustrate the circular or continuous aspect of the themes around hope. These findings show a different perspective than findings in my study. The idea of social isolation, need to find others with breast cancer as a

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									Theses that support-hope	but with realization that not possible accepted and shifted to living with the disease.	Theses that support-continuous Tx	a time bomb, declining relations hips with professionals. Not seen if my work. Also the concept of rescuers . My participants did not focus on others. Also the concept of "change d identity". My particip	"Lifeline" is different than what I saw in my population. Media effect was not pronounced in my study. Patient choice and empowerment was an overriding principle stated in the study. That remained true. The statements about breast cancer woman building a new identity did not fit with mine. Clearly the experiences for these women in this hospice were different

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nts saw than those I
 themselves saw in an
 es as outpatient
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Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
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n and patient due to frustration with difficulty in diagnosing recurrence, led to change in feelings towards doctor. Not seen in my work. My participants adored their physicians and believed they

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were the reason they were alive.

Duggleb y, W., Wright, K.	2004	Elderly Palliative care cancer patients' descriptions of hope-fostering strategies	Canada	int. j. of Palliative Care Nsg.	Qualitative interviews and data tools Herth Hope Index and ESAS	older palliative home care cancer patients. > 65 N=10	Receiving palliative home care services. Rural Canadian health region.	Broad open-ended questions. Interviewed twice if possible. To clarify interpretations.	Hope fostering strategy-leaving a legacy, short-term goals, supportive family & Friends and faith.				The hope fostering strategies found in this article exhibit similar sub categories found in my work. The focus on nature as a symbol of hope, positive thoughts, turning your mind off as similar to focus on day to day and limiting far reaching future thoughts. Faith that provides
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													<p>comfort and hope. Leaving a legacy related to thinking about what you appreciate about in this life and its support of hope for a future.</p> <p>Background of paper describes the experience of a tension between hope for a cure and reconciliation with life and death. Also a comment by Kagan, 1997 about elderly cancer patients coping with their experience by</p>

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Duggleb y, W., Wright, K. SAT	2005	Transfor ming Hope: How elderly palliativ e patients live with hope	Canada	Canada n Journal of nursing research									integrating it into a "life mostly lived". Pertinent to my study since population is older.
Eliott, J., Olver, I. SAT	2009	Hope, Life, and death: a qualitati ve analysis of dying	Australia	Death Studies	qualitativ e	cancer pts within 3 mo of death being treated in cancer hospital N=28	cancer setting.	Face to face interviews.	Multiple aspects of hope as seen in my data. Paradoxical hope for	acceptan ce of death but hopeful for life	If appropriate they wanted options if available	focused on how hope is perceived and constructed. Interesting approach to encourage spontaneous	

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		cancer patients' talk about hope							more life but also realization of hope for good death if life not an option				hope talk without specifically asking direct questions until end of interview. Paradoxical aspect of hope. Appreciated the social constructionism of the data analysis and discussion. Dual aspect-"buffered against challenges to hope", "buffered against adversity, and as buffering against adversity". Found hope for cure or hope

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Ekwall, E., Ternstedt, B. M., Sorbe, B.	2007	Recurrence of Ovarian Cancer-Living in Limbo	Orebro, Sweden	Cancer Nursing	Qualitative Phenomenological method	Women who had lived at least 1 yr post initial completion of primary treatment clinically free of disease and recurred with Ovarian Cancer Stages 1C-3C N=12	Location of interviews dependent on participant's choice.	Semi-structured interviews- 10 in participant's homes and 2 conducted at the hospital.	Living in limbo was about knowing this was not curable but hoping to delay disease progression to live longer	Describe understanding the extent of their disease. Similar to my study focusing on positive attitude and how to keep living. Increased hope despite despair of disease.	Feeling in-between wellness and illness- "existenti al homeles sness" this lonelines s was not describe d in my study. Suffering and changes in body	Shared key points of knowing disease is extensive but wanting to live longer. Living with uncertainty. Also talked about self-advocacy healthy diets and exercise. These patients were having traditional chemotherapy. My population were not receiving	

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Esteves, A., Roxo, J., da Conceicao Saraiva, M. SAT	2015	The lived experience of people with progressive advanced cancer	Coimbra	Brit. J. of Nsg.	Qualitative-phenomenologic	Woman with advanced cancer	Acute oncology ward.	Semi structured-interviews-chosen who would present a dense, fully detailed description" t ?	Hope seen as a sub constituent of Emotional Reactions (essential constituent)			Part of emotional support included "affectio n shown by nurses when providin	Advanced cancer care in Portugal only done in acute hospital. These were all woman with advanced disease and highly educated. They used Giorgi's
												image seen based on surgical interventions. More side effects experienced in my population	standard chemotherapy and therefore fewer side effects and not necessary to come into the center weekly for treatment or follow up.

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g care
 helped them cope"
 This was seen as part of establishing a sense of trust.
 four step method to evaluate the data and arrived at 6 major "constituents".
 Limited explanation on how they arrived at those 6 constituents.
 More fear noted from my participants.
 More stress on loss of independence.
 (these were all in-patient with adv. disease and symptoms).
 Shared similar concerns to my population related to importance of

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Flemming, K. SAT	1997	The meaning of hope to palliative care cancer patients	Oxford, England	Int. Journal of palliative nursing	Qualitative phenomenological study	Patients receiving palliative care. With advanced disease N=4	In-patient interviews for 2 and out-patient interviews for 2	Aim was to understand meaning of hope. 3 factors that influenced hope-disease process and treatment, social influence of family and friends and professional influence nurses and					family, desire to stay positive. There was a sadness over the loss of meaning in one's life that I did not see.
													These processes of maintaining or inspiring hope were seen in my research as well. Control over circumstances, religious faiths influence on hope as well as evaluating life and hope for present continuation of life.

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Garcia-Rueda, N., Valcarce I, A.C., Saracibar-Razquin, M., Solabarrieta, M.A. KP	2016	The experience of living with advanced-stage cancer: a thematic synthesis of the literature	Spain	Eur J Cancer Care	Qualitative meta-synthesis	adults living with advanced-stage cancer 13 studies included	multiple settings including hospital's-urban and rural communities, oncology day unit and home	original studies describing the experience of living with advanced-stage cancer. Patients own perspective -mult. Qual. Methodologies. ID papers, coded line by line then code bank, then thematic synthesis and analysis of themes.	Hope through treatment. Hope for normalcy. Hope as a motivation provides courage to face their present reality and see a future.	Consider death a natural part of life but not ready to die. Person re-evaluates acceptable parameters of qol. Adapting to change in search of "normalcy". Acceptance depends on the context	treatment as a strategy to endorse living. Desire to live longer motivates synthesis of txs. Tx. Seen as a source of hope.	Focus on suffering related to sympto ms. Only seen in 2 patients. For the most part my population was doing very well. Possibly biased as they were seeking treatment and	4 sub themes: suffering during the experience, inner workings of the person, living with new meaning, and impact of the disease on family dynamics. Different from the exp of recurrence of adv disease in survivors in that all patients in my study were in treatment. Common theme "desire to live normally while being aware of the

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										and the individual .		willing themselves to be well.	proximity of death" shared theme with my work. Many shared themes, seeking information to understand their situation, finding meaning in their life, positive comparison to feel more grateful for what they have, recognition of limited time and setting realistic goals. Maintain hope for being cured unspoken word in my population but hoped for
										P 556			

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Gibson, A., Cruz, L., Janda, M., Beesley,	2016	Beyond survivorship? A discursive analysis	Brisbane, Australia	Journal of Health Psychology	Qualitative thematic discourse analysis	Pancreatic cancer patients transitioning from active	Sub-sample of a larger study were asked to	Interviewed by Skype N=14 and 6? Home (=20?)	Interesting that this population looking at active tx. To end of	Minimize uncertainty and focus on treatment table". Looking	No treatment is "unacceptable". Looking	The focus on active treatment to end of life	2 areas described- well to ill transition and transition to end of life. My work only
													anyway. Spiritual support and religious support imp. As well as family and friends. Also seeking a healthy lifestyle. Similar to adv. recurrence as well. Model developed "The experience of the person living with advanced-stage cancer" pg 563

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V., Neale, R., Rowland s, I. SAT		of how people with pancreatic cancer negotiate identity transitions in their health				treatment to end of life care N=19	be interviewed about their experience following diagnosis		life care shared similar responses around positive attitude and hope to cope with cancer and treatment. "construct ed" approach to extend their lives. Ignoring prognosis. g time"	at statistics and believe in future. "constructing themselves as accepting the seriousness of their cancer and making the most of their remainin	for experime ntal tx.	care found similar concepts as describe d by my participa nt who did not consider their treatment as end of life care-being positive, treatment t to extend lives. Clinical trials.	focuses on the first well to ill. Similar to my work focus on healthy lifestyle. This provided a sense of control. Hoping for return to pre cancer life style. (normalcy). Flexibility between active tx. And palliative care important for adv. Disease. *Good points around how survivorship and fighting or conquering cancer can prevent discussions about death

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Karlsson, M., Friberg, F., Wallengren, C., Ohlen, J. SAT	2014	Meanings of existential uncertainty and certainty for people diagnosed with cancer and receiving palliative treatment: a life-world phenomenologic	Sweden	BMC Palliative Care	secondary analysis of larger study. Qualitative interviews.	Adv. GI cancer pts. N=14	receiving palliative care in oncology outpatient clinic.	Narrative analysis of interviews. Hermeneutic interpretive principles of Ricoeur's theory of interpretation on 3 steps: naïve reading, structural analysis and interpreted whole. Interviewed over 2 ½ years	describing meaning of existential uncertainty. Hope for a cure or making a full recovery to live a few more years.	Trust increased certainty.	New tx. Methods provided hope for a cure or ability to live long enough for time to develop a cure		and constructing their narrative. Although the focus of this paper is focused on a specific population shared themes were supported. Sub themes seen in this work related to trust in the physician supporting hope, the need to focus on day to day living to provide hope and reduce uncertainty and finding hope in companionship with friends

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al study

and family also shared in this adv. recurrence research. The focus on reducing the fear of existential uncertainty related to unpredictable reality. There was a similar attitude related to positive thinking as important to benefit their quality of life now. Dealing with the uncertainty-struggle promoted personal growth. This realization of

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Krigel, S., Myers, J., Befort, C., Krebill, H., Klemp, J. SAT	2014	Cancer changes everything! Exploring the lived experiences of women with metastatic breast cancer	Kansas, USA	Int. Journal of Palliative Nursing	Qualitative methodology of focus groups- semi-structured interviews	4 focus groups N=15 Met. Bst. Ca	2 groups in academic medical centre and 1 in each of 2 rural cancer centres. 5 metastatic at diagnosis. Months since diagnosis ranged from 4 mo.- 11.7yrs	Semi-structured group interviews. Participants encouraged to express their thoughts and divergent ideas.	Focus on positive attitude-being strong 'there is always hope'.	'Put on big girl pants and keep going'.	Decline in overall quality of life 2 nd to fatigue effecting phy. And social relationships, and emotion and dealing with functional. Dec in sexual functioning and body image. (different tx. Older age of participant) role	Decline in overall quality of life 2 nd to fatigue effecting phy. And social relationships, and communication , self-image and dealing with functional. Dec in sexual functioning and body image. (different tx. Older age of participant) role	death was also a shared theme.

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Kuhl, D SAT/FF	2011	What is the lived experience of having a terminal illness?	Canada	J of Palliative Care	Existential Phenomenological	Adv CA and AIDS N=21 (14 CA, 7 AIDS) Reported here on 8 (5 CA, 3 AIDS)	PC Unit or home	Qualitative Interviews				effects? *rural settings more pragmatic	Not focused on disease but dying This was not a well done paper. Unable to identify AIDS versus Cancer patients and think that some of the feeling of loneliness and suffering related to living what one called a "duplicious life". There was a shared theme in participants who were spiritual and grew stronger from their

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Lewis, S., Willis, K., Yee, J., Kilbreath, S., SAT	2016	Living Well? Strategies used by women living with metastases	New South Wales, Australia	Qualitative Health Research	Qualitative Social constructionist	Recruited from a cross-sectional research study looking at levels of physical	On-line breast cancer research volunteers . Asked to participate in an exit interview	Exit interview of first study asked to extend interview to include additional information	Described hope as maintaining positive, hopeful, and strong attitude. Seeking some	Focused on attitude towards living and quality of life. Focus on strategies	Initial study focus on physical activity and exercise responses related to	Interesting when women asked to describe their diagnosis with met. Disease similar responses related to	illness. He called the participants "co-researchers" then in the limitations section talked about their difficulty describing their experience making developing themes difficult?? Not very well done.

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Lin, HR SAT	2008	Searchi ng for Meanin g- narrativ es and analysis of US- Residen	U.S. resident s of Chinese immigra nts from China or Taiwan *author	Cancer Nursing	Qualitativ e Narrative analysis	Metastatic Cancer patients recruited from Massachus etts, New York, and New Jersey . N=12	Interviews were held in homes or in communit y as desired by participant . N=12	3 part interviews – life history, present life experience, and meaning	Hope and faith was described as a theme. As motivating an individual and giving	Readjust ment and Transcen dence. This allowed them to live with meaning	Continue d to receive tx. After they were notified of incurable	Very interesting study related to my research. Culturally different and yet like other Chinese research the focus on	
		fic breast cancer				activity and physical fitness in women with met. Breast cancer. N=18	and added questions to this interview if consented . Audio recorded and transcribe d. 6 open ended questions used to elicit further discussion	on their health. Looking at strategies used to stay healthy.	control of the uncertain ty of this disease. Avoid negativity	to improve life		finding normality. Being positive, hopeful and strong. Focused on strategies used to manage feelings experienced as uncertainty, anxiety, and fear.	

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		Chinese immigrants with metastatic cancer	affiliated with Taipei College of Nursing in Taiwan			through professional healthcare providers and chairpersons in Chinese organizations.		Audio-recorded in Mandarin or Taiwanese then transcribed, translated and interpreted.	courage to face present and future. Living itself gives hope.	when they were able to transcend the situation.	cancer. Treatment gave them hope.		continuing to live is still there.* this is a human response
MacArtney, J., Broom, A., Kirby, E., Good, P., Wootton, J., Yates, P., Adams, J.	2014	On resilience and acceptance in the transition to palliative care at the end of life	Australia	Health	Qualitative	palliative care inpatients within last few weeks of life.	In patient specialist palliative care unit within a sub-acute care hospital	in depth interviews	focused on transition to palliative care and stopping life prolonging treatments. Hope was related to help for relief of symptoms	acceptance was related to accepting change in plans and transition to palliative care (Hospice ?)	no see continuous tx as counter-productive and prolonging the inevitable.	Focused on meaning of palliative care. PC here was focused on end of life "you don't come out"	Described the down side of resilience and a positive attitude and not giving up seen as disruptive at end of life and counter-productive to maintaining or enhancing participant's quality of life. This was related to

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patients seeking more treatment that was seen as futile.

Mahon, S., Casperson, D. KP	1997	Exploring the psychosocial meaning of recurrent cancer: a descriptive study	U.S.	Cancer Nursing	Descriptive Study, Qualitative Interview, Summary of findings presented to 3 subjects for feedback.	N=20 Adv Cancer, mult. Sites	Inpatient and outpatient community hospital	theoretical sampling. Inc 6mo N.E.D. and Exc. If < 6mo to live. Semi structured interviews	17 of 20 believed they would have a stronger appreciation of life this time and it would last longer then first dx. (hope)	Hope for remission was strong. Believed it worked once before it will work again.	Easily discussed related issues related to death and dying "with little or no probing". Not so in my group.	Good points related to patients concerns with recurrence 1) subjects more aware of meaning of cancer recurrence-potential tx, uncertainty for future. Similar stages of initial shock of dx. And of attributing vague symptom prior to dx. As normal aches
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and pains. Did not anticipate cancer recurrence. Unaware of surveillance needs. Trying to find the "cause" for recurrence. Anticipated their outcomes related to knowledge of others who had experienced a recurrence that they knew. Interestingly even in 1997 with recurrence commented on changes in tx. Since the initial diagnosis.

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Mak, M. SAT	2002	Accepting the timing of one's death: An experience of Chinese hospice patients	Hong Kong, China	OMEGA	Qualitative. Cons. Comp. Method	Chinese pts. With terminal CA N=33	In-Patients in Chinese hospice	Semi-Structured In-depth Interviews	Hope in hospice is around a good death	aspects of acceptance of death related to 1) complete role in life, 2) Old Age (good & natural), 3) Religious faiths facilitated (eternal life & Hope) and 4) meaningful lives (sustained Hope & Control)	NA-these pts. On hospice but comment on when no treatment available they knew it was the end.	My data not focused on hospice but many shared themes related to dying. Not similar in discussions on suicide.	Chinese focus on death and dying around religious faiths is somewhat different but faith beliefs are similar if shared faith regardless of nationality. Chinese culture has a strong sense of social obligation "Law of Kinship". 5 cardinal relations: emperor (or government)-people, parent-child (filial), spouses, siblings, and friends. So relationships are assessed and provide

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value to their life. Completing these roles contributes to accepting time of death. Focus on dying in old age as appropriate, simple, and gradual. That is regarded as "good" death. So death has a personal meaning, socio-cultural meaning, seeking meaning for life. Even based on religious faith not all accepted death as part of life and die peacefully. I

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found this paper very telling-Chinese culture or not these seem to be "Human" responses to dying regardless of their culture. These concerns are shared by many cultures.

Mak, Y. 2005 Voices of the terminally ill: uncovering the meaning of desire for euthanasia
 SAT Hong Kong, China Palliative Medicine Qualitative N=6 Chinese pts. With advanced terminal cancer
 Bradbury Hospice, Hong Kong
 Purposive sampling, Chinese pts. Wishing for euthanasia.

Hopeless believing nothing can be done. Suffering, believe no miracles
 Described the voices of terminally ill in China. Progressive disease believed to mean inevitable death. Inadequate knowledge

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about prognosis and what to expect leads to uncertainty. Desire to die well. Describes overt and Covert depth of desire for euthanasia. Proposed framework for dealing with pts. Desiring death. Multiple reasons for seeking euthanasia. Fear of being a burden, loss of personhood and feeling hopeless.

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McCarthy, I., Dowling, M. SAT	2009	Living with a diagnosis of non-small cell lung cancer: patients' lived experience	Ireland	Inter. Journal of Palliative Nursing	Qualitative-phenomenological study	NSCLC pts. N=6.	Pts being seen in hospitals oncology day unit	invited with met. NSCLC. Exc. Pts. Unfit to be interviewed and not fluent in English	Maintaining life. Hope is a motivator	Maintainin g life. Hope is a motivator	"staying on the train" fear of stopping treatment	Loss of job was not describe d by my participa nts probably due to older age.	The importance of understanding the experience of this population is growing. Living with NSCLC is now related to biological agents. Similar themes reports such as maintaining as normal a life as possible, also importance of family and maintaining independence. Also describing a change in toxicity profile related to new synthesize. This is an important aspect to be

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McKech nie, R., MacLea od, R., Keeling, S. SAT	2007	Facing uncertai nty: The lived experie nce of palliati ve care	New Zealand	Palliati ve and Supporti ve Care	qualitati ve inter views	N=7 terminal cancer	Receiving PC at Communit y Hospice	semi- structured interviews face to face.			All pts. Actively being treated in hospice		researched in the future. The theme of uncertainty is seen in other research related to hospice patients experience of dying.
McTiern an, K., O'Conne ll, M. SAT	2015	An interpret ative phenom enologic al analysis explorin g 342ynth esiz experie nce of individu	Ireland	Palliati ve and Supporti ve Care	IPA- convenie nce sampling	N=8 terminal cancer	Receiving PC in Ireland	audio recorded public interviews- semi structured interviews. Hospice or residential settings from 2006- 2011	Hope as individual coping. Found in family support, continuing or alternative treatment. Concept of uncertain y seen	Continue d treatment desired to increase lifespan.	All pts. On hospice and taking care of sympto ms	Interesting model would like more information on how the interviews were conducted and what questions were asked. Found many similar results to other studies and shared in mine. Starting	

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		als dying from terminal cancer in Ireland							and living while dying.				with lengthened time between diagnosis and death from medical advances. Positive thinking, social support of family, importance of physician input, humor and hope. Most importantly it is living with uncertainty seen throughout with the meaning of hope. Helps to protect against death anxiety. Described importance of understanding that each

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in found in my work	Key points
McWilliams, C., Ward-Griffin, C., Oudshoorn	2008	Living while dying/dying while living	Ontario, Canada	Journal of Hospice and Palliative Care	qualitative-interview design. Ethnographic	N=4. Participants in-home palliative care with terminal	In-home palliative care	4-6 interviews per client.		Accepting life's circumstances. Living in the	Theses that support-continuous Tx	talk about dying and death. Active in	Focused on what participants thought was important about Palliative care.
									Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in found in my work	participant's dying experience is unique. Participants discuss a need to know how to handle a terminal illness. Others have found participants wanting to have more information on what to expect and finding hospice very helpful and supportive.

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
orn, A., Krestick, E. SAT				Nursing	design. Older clients	cancer >65.			Theses that support-hope	moment but wishing to live longer	Theses that support-continuous Tx	social management of their dying.	Also included family caregivers and providers. Also focused on living while dying. Circle of dying moving beyond and holding on.
Mok, E., Lam, W., Chan, L., Lau, K., Ng, J., Chan, K. SAT	2010	The meaning of hope from the perspective of Chinese advanced cancer patients in Hong Kong	Hong Kong, China	Int. Journal of Palliative Nursing	qualitative	N=17 Chinese adv cancer pts. In PC hospital	Haven of Hope Hospital, Hong Kong	Semi-structured interviews. General questions	hope was focus of these interviews. 5 meanings found: living a normal life, social support, actively letting go of control, reconciliati on	acceptance in avoidance of death	focus on Chinese culture found Chinese more acceptin g of letting go of control "to remain harmoni ous with nature"	focus on Chinese culture found Chinese more acceptin g of letting go of control "to remain harmoni ous with nature"	The idea of Chinese maintaining control by letting go even though the researcher did compare to Western thought may not be completely accurate. It might be said that my population "let

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
n, C., Schmidt-RioValle, J., Gomez-Chica, A., Marti-Garcia, C., Cruz-Quintan a, F.		ncing sufferin g: A qualitati ve study							pessimisti c	ty- Religious influence on accepting gods plan.	they are losing and leaving unresolv ed	of my data related to suffering???	Balance between threat and helplessness against the threat. My pop. Had hope in treatment options. The non onc perspective was helpful. Noted differences could be related to the onset of chronic disease versus oncology. A noted change in physical abilities more acute in onc. Less insidious
SAT													

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
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as in chronic disease.
 Chronic sees changes usually in gradual way and learn to change routines to cope etc. similar "live each day" and focus on life with a different perspective when realize have adv disease. Trying not to focus on uncertainty of future. Gender diff related to women more religious men more optimistic even with inc. uncertainty (?).
 Spain very

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Nierop-Van Baalen, C., Grypdonck, M., Van Hecke, A., Verhaeghe, S. KP	2016	Hope dies last...A qualitative study into the meaning of hope for people with cancer in the palliative phase	The Netherlands and Flanders	European Journal of Cancer Care	Secondary analysis of qualitative research. 6 separate studies	Advanced cancer pts with 3-12 month life expectancy. No curative options were left. No longer being treated. N=76 interviews evaluated	6 sites-4 hospitals and 2 At Home. Data collection period between 2000-2007	All studies included interviews that looked at broader illness experience where hope was discussed. Each study was IRB approved. Used amplified sampling	aimed to understand the meaning and function of hope.				Catholic country influence on accepting death as "gods will" "have to"
													Found similar responses related to hope: Hope for recovery, Hope aided coping by reducing stress and increasing resilience. Hope for peaceful death as well as recovery. Hope gives energy and takes energy. Hope that with prolonged survival a new

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Nissim, R., Gagliese, L., Rodin, G.	2009	The desire for hastened death in individuals	Canada	Death Studies	Longitudinal qualitative study	N=54 advanced lung or GI cancer	O/P clinic in CCC	Interviews at baseline and at intervals and 3 months prior to			Did talk about using chemotherapy to stay alive	This was focused on wish for death. This was used as	3 findings as a hypothetical exit plan, an expression of despair and manifestation of letting go
													medicine will come along that will cure them. Reduction of symptoms equated with improved disease (strengthened hope) described similar thought seen in Coyle's work related to the work associated with maintaining hope

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
SAT		als with advanced cancer: A longitudinal qualitative study						death. 5 pts died within 4 weeks of death			longer	a way to cope with controlling their end of life and wishing not to be a burden and die with dignity. Although it was hypothetical plan and not necessary a suicide plan.	this was a type of acceptance of advanced disease. This population of patients was used to follow up with additional interviews used in another study looking at feelings associated with dying from advanced cancer without a focus on desiring to hasten death.
Nissim, R., Rennie,	2012	Goals set in the land	Canada	Death Studies	Longitudinal qualitative	N=27 adv lung or gi cancer.	O/P clinic in CCC	Interviews as baseline and 1 mo –	Hope around medical	in the sense of the 3 pt	seek cont. treatment	None of my participa	many similarities to my findings

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
D., Fleming, S., Hales, S., Gagliese, L., Rodin, G. SAT		of the living/dying: A longitudinal study of patients living with advanced cancer			case study	Exp survival of up to 2 years		3 yrs post first interview	hope for prolongation of life	goals controlling dying, valuing life in present, creating a living legacy	to prevent dying.	nts had dependent children or needed to work to support family	although maybe labeled differently. Key that population is similar to mine-active independent patients. Also not in palliative or hospice care. Similar population all in outpatient cancer center. Although considered a longitudinal study it was not clear how the additional interviews were timed? Talked about interviewing 5 week of death. No discussion seen on how they were

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Penson, R., Gu, F., Harris, S., Thiel, M.M., Lawton, N., Fuller, A., Lynch, T.	2007	Hope as part of Medical Ethics: Schwartz Center Rounds	Boston Mass	The Oncologist	Documented Schwartz rounds related to Hope	N=1 pt. with recurrent ovarian cancer-12 yr. remission after recurrence.	Schwartz Center Rounds-Mass. General Hospital-Boston USA	Transcript of rounds of discussion-published in the Oncologist verbatim	Hope at the core of what sustains cancer pts and provides resilience. Discussed concerns about false hope, unrealistic expectations. In pt's words "It never occurred to me not to have hope."	Acceptance of disease stage but maintains acceptance of the diagnosis and hope for continued remission	recurrence not seen as a failure for anyone. It just doesn't work for one reason or another		different or not??
SAT						Surgeon, SW, Med Onc, Rabbi and psychiatrist							Interesting to have the perspectives of so many health care providers along with the patient and the opportunity to see how the patient responds to the physician and other providers feelings about her status and journey with her disease. Appreciated the discussion of hope as a fluid thing that "transcends resources, and reality." It is

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international and universal. "one and the same time both an anticipation of something positive and a positive acceptance of the inevitable." Patients are desperate to keep hope alive. They also discuss the importance of caregivers maintaining hope. Not a good example of a research paper but provides the words of all involved. Analysis based on other resources for

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Pineros, C., Saldarria ga Fourth, M., Davalos, D. SAT	2015	Cancer of the colon and rectum in palliative care: a look from the meanings of the patient	Colombia	Advances in psychology Latin America	qualitative-phenomenology	N=3 d with adv CRC in Palliative Care	private clinic in Colombia	In-depth interviews	not using the word hope but found peace, well being and projected towards future when symptoms were decreasing or relieved	Used adaptation as a coping mechanism that allowed them to integrate the experience and move on with their lives	All were receiving palliative chemotherapy prior to interview s.	Multiple symptoms especially pain. Body image issues related to colostomy	Many similar responses to adv patients in my study. All found that they were aware of the incurability of their disease but still thought they could be cured. This population shared the trust in God seen in my population as well as faith
													comparison. In Robinson talk about this article providing thought about "no such thing as false hope, there is just hope".

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in found in my work	Key points
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in medical treatments and positive thinking. Also importance of family support. Even palliative treatments seen as potential for cure (God has the power). Real belief that minimal symptoms and reduced pain meant cure of disease. This study also showed the significance of the family caregiver and barriers seen due to colostomy. Also promotes communication

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuos Tx	Data not found in my work	Key points
Reynolds, M. & SAT	2008	Hope in adults, ages 20-59, with advanced stage cancer	Idaho, USA	Palliative and Supportive Care	descriptive longitudinal qualitative research	N=12 Advanced stage cancer-6 palliative care, 6 active treatment	local hospice and cancer centers in northern Utah and central Washington	3 interviews once a month x 3 months.	Interviews were meant to elicit feelings about hope and influence as well as hope goals 100% said they had hope	6 were in active treatment	Focused on maintaining hope and 3 strategies – hope for the best plan for the worst. Join with family's hopes and introduce the discussion of preferences for end of life care with a hypothetical question. "if	between patient and physician. (this articles translation is not perfect. Some words were difficult to ascertain what they meant)	

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in found in my work	Key points
Robinson, C.	2012	Our best hope is a cure. Hope in the context	Canada	Palliative and Supportive Care	qualitative interpretive study	N=18 Advanced Lung cancer and sign other	1 and 1/2 hour drive from study site.	In depth interviews with patient and 1 sign. Other	Hope described related to advance care planning. Found		Hope for cure reinforced commitment to challenge		Multiple themes shared with other work on Hope and also in my findings recently. Hope
SAT													things do not go as we hope and you experience complications, can you see that it might be a good idea to talk about what would happen and their relationships with people and family critical to sustaining hope. Very much like my findings.

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
		of advanced care planning							hope for cure unanimous among participants. Hope is resilient and persistent and Hope is multifaceted.		ng tx. Regimens		in advanced recurrence is seen as a "counter balance" to suffering. Hoping keeps a person positive and engaged in their life. Recognize disease is incurable but still hope for the best as they prepare for the worst.
Saetere n, B., Linstrom, U., Naden, D. SAT	2010	Latching onto life: living in the area of tension between the possibilities	Norway	Journal of Clinical Nursing	qualitative – ontological hermeneutics	N=15 Advanced cancer	in hospital palliative care	In person interviews	Hope like others hope for a miracle, hope for cure. Seen as the greatest	Acceptance may have been defined as reconciliation. Once	Admission to ward to be evaluated for more tx. Opened possibility of	openness to talking about their own death. Also pain and	More discussion on pts. Wanting to talk about death and feeling lack of respect or that they were not taken seriously.

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
		ty of life and the necessity of death							value for the pt.	reconciled with no cure and advanced disease. Said to allow them to move between awareness of dying and hope.	prolonged life. Gave renewed hope	symptoms. Not seen in my population but these were in-patient. palliative care. More thoughts on loneliness and despair not seen in my pts. Population and timing were different.	Similar themes related to wanting to live a normal life, appreciating life more with the diagnosis and hope. Also wanting to seek health. Interesting notes- stmt. About unspoken suffering as a means to cope and protect themselves. Also the idea that the increased need for respect seemed to correlate with their vulnerability.

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Sarenmalm, E., Thoren-Jonsson, A., Gaston-Johansson, F., Ohlen, J. SAT	2009	Making sense of living under the shadow of death: Adjusting to a recurrent breast cancer illness	Sweden	Qualitative Health Research	Qualitative GT	N=20 or N=12?? Recurrent breast cancer 17 dist mets, 3 locoregional	Home or Hospital	Interviews-baseline and 12 participants between 2 weeks and 24 mo. Than 6 part. Interviewed late stage	importance of hope described by participants s-hope to survive, hope tx. Works, accept it.	inner strength, view themselves as survivors. You just have to accept it.	Don't want to hear there is nothing to do.	Participants experience same themes. Hope and knowing it is incurable same also desire to live life like they had been prior to recurrence. Experiencing a "life threat" makes you see things differently. Also desire to maintain a cheerful attitude and using humour to hide sadness and nausea or body image concern s not seen in opportunity to	Interesting many of the same themes. Hope and knowing it is incurable same also desire to live life like they had been prior to recurrence. Experiencing a "life threat" makes you see things differently. Also desire to maintain a cheerful attitude and using humour to hide sadness and nausea or body image concern s not seen in opportunity to

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in my work	Key points
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									Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in my work	Key points
												my population.	talk about dying and what it means. This was not seen as my population were actively seeking treatment and had options. Found over time these women adjusted by making sense of their new situation and repatterning and finding new ways to interact with others. Ongoing personal transition. Her model showed the transcending

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Schildmann, J., Ritter, P., Salloch, S., Uhl, W., Vollmann, J.	2013	One also needs a bit of trust in the doctor... : a qualitative interview study with pancreatic	Germany	Annals of Oncology	Qualitative	N=12 pancreatic cancer pts	Hospital	Semi-Structured interviews	Hope for cure even with advanced cancer	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	piece of "creating wellness" with the inner circle showing the dichotomy of easing distress and struggling with fear. The circular pattern of emotions.
SAT									Perceive choice but to be treated				Similar responses of hope as seen in other studies. Regardless of the awareness of advanced status of cancer still held hope for cure. Interesting recognition that initially in this advanced

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cancer patients about their perceptions and views on information and treatment decision-making

population total support "no choice and trust in the physician" but later as has more experience with treatments more interested in more information and making a decision about what treatments would be. Hope for improvement in combination with clinical uncertainty a challenge for pts.

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support hope	Theses that support acceptance	Theses that support continuous Tx	Data not found in my work	Key points
Svensson, H., Brandberg, Y., Einbeigi, Z., Hattis, K., T., Ahlberg, K.	2009	Psychological reaction to progression of metastatic breast cancer: an interview study	Sweden	Cancer Nursing	Qualitative interviews	Metastatic breast cancer women who were participating in the TEX trial and failed this first-line chemotherapy for met. Ca. N=20	2 clinics in Sweden where the TEX trial was taking place.	Semi-structured interviews in outpatient clinic in private room. Recorded and transcribed	Being hopeful and maintaining a fighting spirit to keep hope alive was shared. Hope for a future. Hope for new medicine for treatment	Acceptance was also seen quickly. Associated with previous experiences of coping with negative information.	Hope for new medicine for treatment. The overlap of themes also seen.	In this study most of the women had suspected disease progression.	The main themes future perspective, need for support, coping and hope also seen in my study. Spiritual support, family support and coping strategies similar. Living in the present.
Vivar, C., Whyte, D., McQueen, A., KP	2009	Again: the impact of recurrence on survivors of cancer	Spain	Journal of Clinical Nursing	Qualitative	N=15 Advanced cancer	4 cancer units in two hospitals in Spain	Semi-Structured interviews with family members & nurses	Found less hopeful with recurrence. Less hope for cure	Less hope not seen in my pop. But mine were all in active treatment	Less hope not seen in my pop. But mine were all in active treatment	Nicely done to describe the psychosocial meaning of recurrence. Thoughtful description of the aim of the study. Variation	

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
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and family members

sampling was helpful. Shared themes related to Age of recurrence and amount of time in remission prior to recurrence. *One of only 2 papers that focused on this population specifically beyond just recurrence. Asked specifically what it was like from first dx. To second dx. Especially of family members. Also saw the living with "fear of relapse" during remission. But

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similarly not overwhelmed with it. This population not so clear that it is incurable. But many did focus on "control" of disease. Also found hope for repeated length of time in remission was greater if they had experienced a long remission with first cancer. Length of survival and age influenced their response to recurrence.

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Volker, D., Kahn, D., Penticuff, J., SAT	2004	Patient control and end-of-life care Part II: The patient perspective	Texas, USA	Oncology Nursing Forum	Qualitative	N=7 advanced cancer	community dwellings	semi-structured interviews				different priorities probably related to stage of disease-end of life. Openly discussing dying	Six themes identified as: Protection of dignity, Control of pain and other symptoms associated with disease, Management of treatment, Management of how remaining time is spent, Management of impact on family and Control over the dying process. These themes might have been seen in my population at a later time point. These patients were clear that they were not

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support hope	Theses that support acceptance	Theses that support continuous Tx	Data not found in my work	Key points
Wanat, m., Boulton, M., Watson, E. KP	2016	Patients , experie nce with cancer recurren ce: a meta-ethno graphy	Oxford, UK	Psycho- Oncology	Qualitativ e synthesis regarding patients' exp. Of cancer recurrence	17 articles included pub. Between 1997-2014	2 nd order constructs form data for meta-eth. – concepts and themes and their interpretati on by authors	Qualitative interviews- focus groups- details search strategy.	Theses that support hope	“balancin g hope with acceptance that a cure may not be possible”	“Threat of mortality magnifie d for those not eligible for surgery- seen as only route to a cure”	Data not found in my work	receiving curative intent treatment. Six-third order concepts developed from synthesis- correlate with this research but diagnosis site and stage of disease not clear in synthesis.
Warmen hoven, F., Lucasse n, P., Vermandere, M., Aertgeer ts, B.,	2016	Life is still worth living: a pilot explorati on of self-reported	Belgium	BMC Family Practice	Qualitativ e – secondary analysis of original study assessin g	N=15 Advanced cancer	outpatient- ambulant pts- academic oncology unit-O/P PC and different family	face to face interviews.					This was focused on psychological response to end of life needs as they progressed. The interviews were between

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Van Weel, C., Vissers, K., Prins, J. SAT		resources of palliative care patients			depressive disorder. BDI questionnaire 1/2 >16 and 1/2 <16		practices-interviews took place in their homes						1 month to 115 months from dx with advanced disease. So a long interval between dx of "incurable illness" and interview. Coping strategies were similar. Attitude-optimisim, acceptance or surrender, fighting spirit, humour, seeing positive side of things, actively solving problems, engaging in activities, not thinking about the future (living in the day), effective

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in found in my work	Key points
Weeks, J., Catalano, P., Cronin, A., Finkelm	2012	Patients' expectations about effects of	Boston Mass USA	New England Journal of Medicine	Qualitative using computer generated interviews	N=1193 advanced lung or CRC Opted to receive chemotherapy	5 geographic regions- Northern California, Southern California,	telephone computer generated interviews					<p>Interesting study to help understand patients' understanding of chemotherapy</p> <p>Focus of interview was on beliefs on effectiveness of chemo.</p>
													<p>coping skills from the past, self-care, spirituality- religious rituals, attitude towards life, family connections and support, health care professionals actively caring for pt. All themes shared with my specific population as well.</p>

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in found in my work	Key points
an, M., Mack, J., Keating, N., Schrag, D.		chemotherapy for advanced cancer					North Carolina, Iowa and Alabama-large health maintenance org. and 15 VA hospitals		Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in found in my work	for advanced disease. Trying to understand how physician communication affects pts. Understanding of the treatment plan. Higher physician communication also higher risk for inaccurate expectations. Especially higher in lung cancer pts versus CRC. Offers a question as to whether we should worry about pts. Holding inaccurate understanding
SAT											69%lung and 81% CRC had inaccurate expectations about curative potential of chemo.		

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
Yedia, M., MacGrogan, B.	2001	Confronting the prospect of dying:	New York, USA	Journal of Pain and Symptom	qualitative interviewing	N=30 advanced disease-life threatening	Hospital and palliative care units-interviews	serial interviews					related to informed consent to their treatment??? Is "possibility" enough. Disclosure alone does not lead to understanding. This study does not discuss the patients need to live and effect on coping my maintaining belief in chemo. (Hope???)
													important information from patients dying about what the

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not found in my work	Key points
SAT		reports of terminally ill patients		Management			hospital and home						<p>experience is like.</p> <p>Reinforced that patients die like they live.</p> <p>Seven Motif's described different personalities including Living and Dying is a struggle,</p> <p>Dissonance: dying is not living,</p> <p>Endurance-triumph of inner strength,</p> <p>Incorporation-belief system accommodates death and Coping</p> <p>=working to find a new balance,</p> <p>Quest-seeking</p>

Authors & grade*	Year	Title	Country	Journal	Design	Population	Setting	Data collection method	Theses that support-hope	Theses that support-acceptance	Theses that support-continuous Tx	Data not in found in my work	Key points
													<p>meaning in dying and Volatile-unresolved and un-resigned. Trajectories of life stories.</p>

Note. * KP = key paper providing rich conceptual insights; SAT = satisfactory paper; FF = fatally flawed.

Appendix S – CASP Analysis for Included Literature

Authors	Clear aims CASP	Is qualitative approp.	Is research design approp. for aims	Is recruitment strategy approp. for aims	Were data collected in way to address research issue	Has relationship between researcher and particip. been considered	Ethical issues considered	Was data analysis sufficient & rigourous	Is there a clear stmt. of findings	How valuable is the research?
Banning, M., Tanzeem, T.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Cultural impact described & important. Translated from Urdu into English
Best, M., Butow, P., Olver, I.	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Helpful to provide insight into patients desires related to spiritual communication and impact on doctor-patient relationship
Brown, Patrick, de Graaf, Sabine	Yes	Yes	Yes	Yes	Yes	Yes				
Chen, H., Komaromy, C., Valentine, C.	Yes	Yes	?	?	yes	yes	yes	not sure	yes	Adds to literature on hope. Also Chinese culture perspective

Authors	Clear aims CASP	Is qualitative approp.	Is research design approp. for aims	Is recruitment strategy approp. for aims	Were data collected in way to address research issue	Has relationship between researcher and particip. been considered	Ethical issues considered	Was data analysis sufficient & rigorous	Is there a clear stmt. of findings	How valuable is the research?
Clavarino, A., Najman, J., Beadle, G.	Yes	Yes	No	Yes	Yes	No	No	Yes	Yes	Mixed methods is useful but would have liked more interview data reported. Concept of subjective well-being and effect on will to live
Clayton, J., Butow, P., Arnold, R., Tattersall, M.	Yes	Yes	yes but combine d groups pt and caregiver may have impacted results.	Yes	yes and no. pt perspective not sole focus.	no	partially. Realization that pts in a pc unit may not be the same as non pc pts.	yes compared and difference s discussed	yes	Important for understanding types of hope experienced by incurable cancer patients, caregivers and PC providers.
Coyle, N.	Yes	Yes	Yes	Yes	yes	Yes	Yes	Yes	Yes	Important to help reduce suffering by understanding early vulnerability markers.

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Coyle, N.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Rigorous approach. Themes related to my theory as living in sight of death.
Dale, M., Johnston, B.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Mod adds to literature on advanced lung cancer
Daneault, S., Lussier, V., Mongeau, S., Yelle, L., Cote, A., Sicotte, C., Paille, P., Doin, D., Coulombe, M.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Very important for the understanding of hope in terminally ill
Davies, M., Sque, M.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	A different perspective
Duggleby, W., Wright, K.	Yes	Yes	Yes	Yes	Yes	no	?	Yes	Yes	Moderate. Reinforces additional studies in hope strategies
Duggleby, W., Wright, K.										

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Elliott, J., Oliver, I.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Very valuable. Clear description of hope changing over the course of illness and interesting aspect of how hope used as noun or verb
Ekwall, E., Ternestedt, BM., Sorbe, B.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Supportive of concepts
Esteves, A., Roxo, J., da Conceicao Saraiva, M.	Yes	Yes	Yes	No	Yes	Yes	not clear	Yes	Yes	Not sure, since recruitment was so purposeful related to ability to communicate "dense" rich interviews
Flemming, K.	Yes	Yes	Yes	Yes	Yes	Yes	somewhat	Yes	Yes	Concept of hope and related themes described.

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Garcia-Rueda, N., Valcarcel, A.C., Saracibar-Razquin, M., Solabarrieta, M.A.	Yes	Yes	Yes	Yes	Yes	Yes	not clear	Yes	Yes	Important to help analyze research results at a higher level of abstraction of knowledge. Aimed to reduce findings as a mere summary
Gibson, A., D'Cruz, L., Janda, M., Beesley, V., Neale, R., Rowlands, I.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Insight into expectation to maintain hope
Karlsson, M, Friberg, F., Wallengren, C., Ohlen, J.	Yes	Yes	Yes	not sure how original was done	Yes	not sure in original work	Yes	Yes	Yes	Valuable and supports similar themes
Krigel, S., Myers, J., Befort, C., Krebill, H., Klomp, J.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Supports similar themes
Lewis, S., Willis, K., Yee, J., Kilbreath, S.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Context focused on health strategies
Lin, HR	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Supports themes. Also readjustment & transcendence

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MacArtney, J., Broom, A., Kirby, E., Good, P., Wootton, J., Yates, P., Adams, J.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Relates to the phase of transitioning to end of life. Also supports palliative care and impact on symptom management
Mahon, S., Casperson, D.	Yes	Yes	Yes	Yes	Yes	Yes	not clear	Yes	Yes	This was early work on recurrence. Good discussion of initial concerns with recurrence
Mak, M.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Building literature on Chinese culture and feelings related to dying in light of different cultural aspects of diff. faiths
Mak, Y.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Documents desire for euthanasia in China.
McCarthy, I., Dowling, M.	Yes	Yes	Yes	Yes	Yes	Yes	Researcher known by pts??	Yes	Yes	This is a growing population who are benefitting from new tx. options.

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McKechnie, R., MacLeod, R., Keeling, S.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	not sure	Yes	Reinforces what others have said about the dying exp
McTiernan, K., O'Connell, M.	Yes	Yes	not sure no detailed informati on on partici pants	not sure how original was done	Yes	not sure if known	Yes	not detailed	Yes	Nothing new; reinforces other findings
McWilliams, C., Ward-Griffin, C., Oudshoorn, A., Krestick, E.	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Nice discussion of participants' views of PC
Mok, E., Lam, W., Chan, L., Lau, K., Ng, J., Chan, K.	yes	yes	yes	not sure- recruitment by researchers who worked in site with patients already	yes	yes/no	not sure did get ethical approval	yes	yes	Interesting to have Chinese focused response to hope

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Montoya-Juarez, R., Garcia-Caro, M., Campos-Calderon, C., Schmidt-RioValle, J., Gomez-Chica, A., Marti-Garcia, C., Cruz-Quintana, F.	yes	yes	yes	yes	yes	Yes	Yes	yes	yes	Allows some comparison between chronic dis and ca.
Nierop-Van Baalen, C., Grypdonck, M., Van Hecke, A., Verhaeghe, S.	Yes	yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Very valuable concept of hope possible with uncertainty. Ontological security difficult in this situation.
Nissim, R., Gagliese, L., Rodin, G.	yes	Yes	yes	yes	yes	not sure	Yes	not sure	yes	Reinforces what others have said about the dying exp
Nissim, R., Rennie, D., Fleming, S., Hales, S., Gagliese, L., Rodin, G.	Yes	Yes	Yes	Yes	Yes	No	Yes	not sure	yes	Important and relates to my findings.

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Penson, R., Gu, F., Harris, S., Thiel, M.M., Lawton, N., Fuller, A., Lynch, T.	Yes	Yes	related to one pt	NA	NA	NA	Yes	NA	Yes	Helpful insights in hope for advanced cancer pt
Pineros, C., Saldarriaga Fourth, M., Davalos, D.	Yes	Yes	Yes	Yes	Yes	not sure	Yes	not sure	Yes	Helpful for Latin perspective
Reynolds, M.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable and supports similar themes associated in other studies related to hope
Robinson, C.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Further reinforces meaning of hope related to advanced disease
Saeteren, B., Linstrom, U., Naden, D.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	More end of life than my population but reinforced themes seen in many other works

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Sarenmalm, E., Thoren-Jonsson, A., Gaston-Johansson, F., Ohlen, J.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Focused bst. population. Different attitude than my population
Schildmann, J., Ritter, P., Salloch, S., Uhl, W., Vollmann, J.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Helpful for pancreatic pts
Svensson, H., Brandberg, Y., Einbeigi, Z., Hatschek, T., Ahlberg, K.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Supported similar themes
Vivar, C., Whyte, D., Mcqueen, A.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Very nicely done. Including aspect of family and nurse important
Volker, D., Kahn, D., Penticuff, J.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Thematic description of pt. concerns at end of life
Wanat, M., Boulton, M., Watson, E.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Meta-ethnography around aim of this study

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Warmenhoven, F., Lucassen, P., Vermandere, M., Aertgeerts, B., Van Weel, C., Vissers, K., Prins, J.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Focused on how cope with pc at end of life
Weeks, J., Catalano, P., Cronin, A., Finkelman, M., Mack, J., Keating, N., Schrag, D.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes important to help understand pts. beliefs of chemotherapy intent.
Yedidia, M., MacGregor, B.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Imp. insight from dying pts.