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THE EXPERIENCE OF SCANXIETY IN SURVIVORS OF PANCREATIC CANCER:  
A PHENOMENOLOGICAL STUDY

By

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B.A., Indiana University, 2001  
A.D.N., Jefferson Community College, 2008  
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A Dissertation  
Submitted to the Faculty of the  
School of Nursing of the University of Louisville  
In Partial Fulfillment of the Requirements  
For the Degree of

Doctor of Philosophy in Nursing

School of Nursing  
University of Louisville  
Louisville, Kentucky

May 2022

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A Dissertation Approved on

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## DEDICATION

*“Apprehension, uncertainty, waiting, expectation, fear of surprise, do a patient more harm than any exertion. Remember, he is face to face with his enemy all the time.”*

*Florence Nightingale, Notes on Nursing, 1860*

This dissertation is dedicated to survivors of cancer everywhere who wake up each day in a continuous state of uncertainty. May you find the courage and strength to keep going.

And to eighteen courageous individuals who graciously unveiled their suffering and pain for the purpose of this dissertation.

Thank you for entrusting me with your experiences.

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countless hours of friendship, laughter, and encouragement throughout our journey.

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Most of all, I give ultimate thanks and praise to God Almighty, whose grace has guided me from the very inception of this project to research completion. May His enduring love and faithfulness continue to guide me throughout my career and beyond.



## ABSTRACT

### THE EXPERIENCE OF SCANXIETY IN SURVIVORS OF PANCREATIC CANCER: A PHENOMENOLOGICAL STUDY

Susan Winebrenner

March 1, 2022

Surveillance scans can signify a crisis point in a cancer patient's life, provoking fear and anxiety that negatively impact quality of life. Scan-related anxiety or *scanxiety* has been briefly discussed in the literature among lung cancer and lymphoma populations, but relatively few investigations have studied the psychological impact of routine surveillance scans during cancer survivorship. The purpose of this study was to illuminate the lived experience of scanxiety in survivors of pancreatic cancer who have undergone curative surgical resection. Hermeneutic phenomenology as applied by Heidegger provided the philosophical underpinnings for this study and van Manen's methodological approach was used to guide the research process. Semi-structured interviews, observations, and field notes from 18 participants were collected and analyzed to provide an in-depth understanding of the scanxiety experience. Additional sources of data using art and poetry were used to further illuminate the true essence of the experience. Thematic analysis uncovered two essential themes: the recurring cycle of scanxiety and hope for lifelong remission. *The recurring cycle of scanxiety* was introduced as a four-stage process and described the complex sequence of events participants experienced during the time surrounding their surveillance scans. *Hope for*

*lifelong remission* served as the primary objective of survivorship, offering a glimmering chance of a cure and keeping survivors engaged throughout the cycle.

This study illuminates the intricate relationship between the pancreatic cancer survivor and their surveillance scan and highlights the complex way in which survivors experience their scans. The results of this study highlight the need for heightened awareness among oncology providers to help guide the development of interventions and improve outcomes across cancer patient populations.

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## CHAPTER I

### INTRODUCTION

*“Scans are like revolving doors, emotional roulette wheels that spin us around for a few days and spit us out on the other side. Land on red, we're in for another trip to Cancerland; land on black, we have a few more months of freedom.” (Feiler, 2011).*

#### **Background and Significance**

For individuals with cancer, the rapid growth in medical imaging performed to screen, diagnose, and monitor disease has significantly improved rates of survival, yet the exams themselves can provoke fear and anxiety that negatively impact quality of life (Grilo et al., 2017; Bui et al., 2022). In a 2011 *Time* magazine article, cancer survivor Bruce Feiler introduced the term “scanxiety” to describe the fear and anxiety cancer patients experience when anticipating upcoming scans and waiting on the results. Scanxiety is widely reported among healthy individuals undergoing cancer screenings, (Kitano et al., 2015; Rasmussen et al., 2015), and is briefly discussed in the literature among lung cancer and lymphoma populations (Bauml et al., 2016; Thompson et al., 2010), but relatively few researchers have explored the psychological impact of routine surveillance scans during cancer survivorship. A possible explanation may stem from the lack of recognition of scanxiety as a legitimate comorbidity in cancer survivorship. Among non-scholarly sources, scanxiety is widely accepted as a common and distressing concern for cancer survivors (Alexander, 2020; Patel, 2021). A Google search of the term yielded over 50,000 hits, and numerous international cancer institutions and cancer-



support networks acknowledge the concept (Bhargava, 2020; Kaplan, 2021; Mulcahy, 2017; Portman, 2019). Despite the term's popularity, "scanxiety" is not yet part of the medical lexicon and subsequently is not sufficiently defined, explored, or measured in published research studies (Bui et al., 2021b; Mulcahy, 2017).

Frequent scanning of cancers associated with a poor prognosis, such as pancreatic cancer, may provoke more severe symptoms of anxiety and distress. Individuals with pancreatic cancer experience increased psychological distress, primarily because pancreatic cancer is largely considered an incurable disease (American Cancer Society [ACS], 2021b; McGuigan et al., 2018). Only 20% of patients survive the first year after diagnosis and across all stages of disease, less than 10% will live beyond five years. The only curative treatment is surgical resection, yet even after surgery, pancreatic cancer will recur in over 75% of patients. To date, there is no consistently effective treatment for recurrent pancreatic cancer (Moletta et al., 2019). The National Comprehensive Cancer Network (NCCN, 2021) guidelines for the management of pancreatic cancer recommend frequent surveillance scan imaging with Computed Tomography (CT) or Magnetic Resonance Imaging (MRI) for at least five years following curative surgery. Given the high rate of disease recurrence, pancreatic cancer survivors are at a high risk for scanxiety which can significantly impair overall quality of life. To date, there are no published data on the psychological impact of surveillance CT scans in survivors of pancreatic cancer.

### **Gaps in the Literature**

In the oncology literature, very few studies examine psychological distress during the diagnostic phases of cancer survivorship. There are only nine published empirical

studies to date, and pancreatic cancer populations are not included in any of the studies (see Appendix A). The absence of pancreatic cancer data is concerning and highlights a knowledge gap in the literature. Individuals with pancreatic cancer have the lowest survival rates of any other cancer and have extremely high rates of recurrence, yet the psychological impact of surveillance scans remains unknown in this population. Another limitation in the existing literature involves the lack of consistency in existing study findings. While all nine studies support the existence of scan-related anxiety in cancer populations, the source of the anxiety is a subject of debate. For example, in two separate studies using a similar pretest-posttest design, Grilo et al. (2017) and Abreu et al. (2017) measured anxiety levels immediately before and after routine PET scans in samples of mixed cancer populations. Grilo et al. found higher levels of anxiety post-scan which suggests the anticipation of scan results is the primary source of anxiety. In contrast, patients in the study of Abreu et al. had lower anxiety levels post-scan and identified scan-specific concerns (e.g., fear of radiation, claustrophobia, etc.) as the main sources of scan-related anxiety. Research on the clinical and sociodemographic risk factors associated with scan-related anxiety is even less consistent, as there are contradictory findings related to age, race, gender, and stage of disease (Bauml et al., 2016; Grilo et al., 2017; Heyer et al., 2015; LoRe et al., 2016).

A final limitation of the existing literature involves the overuse of cross-sectional study designs. Six of the nine studies captured levels of anxiety at a single point in time, generally in the radiology waiting room immediately before an upcoming scan. This single point in time approach fails to explore the temporal factors that may modulate the severity of anxiety over the survivorship trajectory. With only three longitudinal studies

published to date, the impact of time on scan-related anxiety is not well described. There are no prior studies of anxiety levels for a duration longer than two months nor over a series of consecutive surveillance scans. Further research is needed to explore the prevalence and stability of scan-related anxiety over time.

### **Purpose of the Study**

The purpose of this study was to illuminate the lived experiences of scanxiety in survivors of pancreatic cancer who have undergone curative surgical resection. There is limited understanding of patient experiences during the diagnostic phases of cancer survivorship. The goal was to provide an in-depth understanding of the psychological impact of frequent surveillance scans in survivors of pancreatic cancer. This study expanded the knowledge of scanxiety from the patient's perspective and provided insight into the key factors that exacerbate scan-related anxiety and distress. The knowledge gained from this study informs future research and provides critical information to oncology providers, nurses, and mental health professionals to help create targeted interventions to improve the quality of life across cancer survivorship.

A hermeneutic phenomenological approach provided both the philosophical framework and methodology underpinning this research (Heidegger, 1962; Husserl 1931; van Manen, 1990). Participants were asked questions related to their personal experiences with cancer surveillance scans. Themes and essences that emerged from the data provided insight into how cancer survivors endure frequent scanning procedures.

### **Research Question**

The research question guiding this study was, "What is the lived experience of

survivors of pancreatic cancer undergoing cancer surveillance scans after curative cancer surgery?”

### **Summary of Chapters**

This dissertation is comprised of five chapters. Chapter One presents an introductory overview of the phenomenon of interest and describes the research problem in the context of the patient population. This chapter also identifies the gaps in the existing literature, a justification for the study, and the overall study objectives.

Chapter Two provides an overview of the state of the science related to scan-related anxiety with an emphasis on individuals with a cancer diagnosis. Key variables closely related to scan-related anxiety in the literature are discussed. Additional variables such as cancer-related distress, anxiety in cancer, and fear of cancer recurrence are examined in the context of a pancreatic cancer diagnosis.

Chapter Three provides an overview of the philosophical framework of phenomenology, the evolution of hermeneutic phenomenological inquiry, and the application of phenomenology using van Manen’s (1990) methodological approach. A detailed description of the research methodology is provided along with a description of specific study components including the sample, setting, interview guide, procedure, data analysis plan, protection of human subjects, and trustworthiness of the data.

Chapter Four presents the findings of the thematic analysis from the phenomenological study. The socio-demographic data of each participant is provided. Essential themes and corresponding subthemes are defined and discussed. Illustrative quotes from participants are offered to support the existence of the themes. Alternative sources of expression using art and poetry are used to illuminate the true essence of the

themes and to uncover the lived quality of the experience in a fuller and deeper manner. Finally, a conceptual model of the study themes is presented.

Chapter Five summarizes the key findings derived from the study and compares and contrasts themes with the current literature. The findings are discussed in the context of Lee-Jones's Cancer Recurrence Model (1997) and a modified framework is presented. The study limitations, significance to nursing, and implications for future research are presented.

## CHAPTER TWO

### LITERATURE REVIEW

*“Once I get the [scan] paperwork in the mail, it’s all right there in my mind. And from that point forward it’s always there gnawing in my mind. It’s like waiting to go in front of a judge that has a sentence for you. Somebody’s making a decision that’s going to affect your life forever. It’s a feeling that your life is completely out of your hands.” (Jake, p. 7, lines 288-306).*

#### **Psychological Distress in Cancer**

Individuals with cancer suffer significant psychological burdens related to both their cancer diagnosis and the uncertainty of their disease. The period following a cancer diagnosis is fraught with uncertainty about the future. Patients must learn to adapt quickly to a life full of multiple threats and novel experiences while struggling to resolve the series of consequential decisions that confront them. Not surprisingly, psychological distress is common across the cancer trajectory, beginning at diagnosis and extending into late-stage survivorship (Carlson et al., 2018; Tonsing & Vungkhanching, 2018). The National Comprehensive Cancer Network (NCCN, 2022) defines psychological distress as, "a multifactorial unpleasant emotional experience of a psychological (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment" (pg. 1).

Distress exists along a continuum and can range from normal feelings of sadness and uncertainty to debilitating problems impacting daily life (NCCN, Distress Management, 2022). Psychological distress frequently coexists with other debilitating symptoms such as the presence of pain, insomnia, irritable mood, fatigue, and impaired concentration. The negative impact of psychological distress is well-documented in the oncology literature. Higher levels of distress are associated with non-adherence to treatments, reduced patient satisfaction, increased functional impairments, inability to work, and reduced quality of life (Batty et al., 2017; Carlson et al., 2018; Chad-Friedman et al., 2017; Hellstadius et al., 2017; Lotfi-Jam et al., 2019).

Nearly all patients experience distress at some point throughout their cancer journey and approximately 50% of patients reach significantly high levels impacting their daily life (Carlson et al., 2018; Oechsle et al., 2020). The prevalence and severity of distress can vary according to the sociodemographic, clinical, and treatment-related factors of the individual. Higher levels of distress occur among individuals who are female, younger in age, of lower socioeconomic status, have increased symptom burden, and are receiving aggressive cancer therapies (Lavelle et al., 2017; McMullen et al., 2018; Syrowatka et al., 2017). Certain cancers with poor prognoses and a high symptom burden, such as pancreatic and lung cancers, are associated with higher levels of distress (Saad et al., 2019). The experience of distress can create a considerable comorbidity for cancer patients and warrant the need for routine screening during key time points to identify individuals most in need of supportive interventions.

### **Anxiety in Cancer**

For survivors of cancer, psychological distress can manifest as debilitating

disorders such as anxiety, depression, panic, social isolation, and spiritual crisis (NCCN, 2022). Of these, anxiety is the most prevalent in the clinical setting; over 40% of all cancer patients meet the diagnostic criteria for anxiety disorder (Berihun, 2017; Nikbakhsh et al., 2014; Oechsle et al., 2020). Anxiety is defined as an adaptive emotional reaction characterized by an overwhelming sense of worry, apprehension, or fear over an impending or anticipated event with an uncertain outcome (Merriam-Webster, 2022). For a majority of patients, a diagnosis of cancer represents a frightening and stressful event, filled with anticipatory threats with uncertain outcomes. It is therefore not surprising that anxiety is a common reaction in individuals with cancer. Anxiety can be linked to a patient's psychological reactions to a cancer diagnosis, treatments, possible side effects, and the uncertainty of the course of the disease (Oechsle et al., 2020). Worries and fears about disease progression and recurrence are highly prevalent, as up to 87% of patients report ongoing fears of cancer recurrence (Simard et al., 2013). Even after the cancer is stabilized, cancer-related anxiety can continue. In fact, anxiety disorders in cancer are highest in patients who have lived with cancer for more than two years (Götze et al., 2019; Niedzwiedz et al., 2019).

### **Fear of Cancer Recurrence**

Fear of cancer recurrence (FCR) is a relatively new concept in the literature but has quickly emerged as an important research topic in the field of psycho-oncology. Broadly defined as the fear, worry, or concern that cancer will respond poorly to treatment, progress, or recur elsewhere in the body (Simard et al., 2013; Vickberg, 2003), FCR is a complex, multidimensional experience that involves numerous cancer-related concerns including fears of death and further treatments, loss of autonomy, increased pain



and physical suffering, and becoming a burden to one's family (Şengün İnan & Üstün, 2019). Fears of recurrence are ubiquitous across various subtypes and stages of malignancy. The research documented that most cancer survivors experience at least some degree of FCR (Kim et al., 2020). Some of the highest rates are reported in breast (Fang et al., 2018; Rocque et al., 2021), lung (Lee et al., 2020), ovarian (Ozga et al., 2015), pancreatic (Petzel et al., 2012), prostate (Friedenreich et al., 2017), and colorectal cancers (Dang et al., 2019). Recurrence fears can affect individuals at any point during their cancer trajectory and can last several years after successful cancer treatments (Custers et al., 2017; Simard et al., 2013).

A fear of cancer recurrence is a well-founded concern, as nearly one-third of individuals with a cancer diagnosis die of cancer within a 5-year period (ACS, 2021a). While some degree of FCR is adaptive, (e.g., maintaining routine medical appointments, vigilance to body symptoms, engaging in a healthy lifestyle), FCR in excess can be debilitating and is widely known to worsen quality of life (Butow et al., 2018; Dang et al., 2019; Hall et al., 2019; Tsai et al., 2018). A large and growing body of literature on the relationship between FCR and quality of life consistently revealed high FCR is associated with poor functional status (Hedman et al., 2017; Tran et al., 2021), heightened anxiety (Chen et al., 2018; Tsai et al., 2018; van Eck et al., 2021), intrusive thoughts (Mutsaers et al., 2016; Zhang et al., 2021), severe depressive symptoms (Liu et al., 2018), and post-traumatic stress (Moschopoulou et al., 2018). Elevated fears of cancer recurrence are linked to higher utilization of health care services, i.e., increased consultations with health care providers, increased emergency room visits, and higher use of psychotropic medications (Champagne et al., 2018; Lebel et al., 2016).

Research investigating the severity of FCR over time is limited since a large number of studies used cross-sectional designs. Of the few longitudinal studies, most are limited to two years post-diagnosis and demonstrate FCR remains relatively stable over time (Crist & Grunfeld, 2013; McGinity et al., 2016; Simard et al., 2013). These research findings are not consistent in the literature, as more recent studies reported significant decreases in FCR severity over time (Götze et al., 2019, 2020; Leclair et al., 2019; Wu et al., 2019). The discrepancies in the longitudinal literature may be explained by the chosen time intervals in which FCR is measured in each study's design. Most studies assessed FCR at arbitrary intervals (e.g., 1-month after treatment, 1-year after diagnosis) and not during key medical time points such as during times of cancer surveillance scans. A thorough review of the literature revealed only one longitudinal study that investigated FCR during the time surrounding a cancer surveillance scan. McGinty et al. found significant changes in FCR during the time surrounding mammograms, with FCR scores that increased before the mammogram, decreased immediately following receipt of negative mammogram results, and increased in the month following the mammogram. Heightened FCR during times of cancer surveillance scans is known to exist anecdotally (Feiler, 2011), but has been only briefly explored in the medical literature. Given the limited longitudinal studies exploring FCR during key time points, additional studies are needed to examine FCR trajectories over time.

### **Scan-Related Anxiety**

Diagnostic imaging is a critical component to screen, diagnose, and follow-up disease but the exams themselves can provoke fear and anxiety that can significantly impair quality of life (Lo Re et al., 2016). Among healthy patients undergoing cancer

screenings, scan-related anxiety is well-documented. For example, in a study exploring the psychological impact of breast cancer screening in routine mammography, Kitano et al. (2015) measured anxiety and depression of 312 healthy women who received call-back notifications after inconclusive mammographic findings. Significant anxiety and psychological distress were reported by over 70% of women undergoing routine screening mammography (Kitano et al., 2015). The reported psychological harms caused by screening mammography is not a new finding and similar results have been reported in other cancer screening populations (Loving et al., 2021; Zhang et al., 2020).

Individuals undergoing CT imaging for lung cancer screenings are among the most widely reported cases of scan-related anxiety. For example, in a study exploring anxiety, fear of cancer, and perceived risk of cancer among individuals at high risk for developing lung cancer, Byrne et al. (2008) examined 400 patients undergoing lung cancer screening CT scans. Individuals with indeterminate and suspicious CT findings suffered significant long-term psychological distress including increased anxiety, fear of cancer, and perceived risk of cancer. In another study, van den Bergh et al. (2008) measured anxiety, discomfort levels, and health-related quality of life in 351 high-risk patients who were undergoing CT screening for lung cancer. Participants were given surveys at three distinct time points: 1-day before the scan, 1-day after the scan, and 6-months after the scan. Although participants reported no specific discomfort related to the CT scan (e.g., feelings of claustrophobia, lying still without breathing), there was a significant amount of distress reported while waiting for the scan results (van den Bergh et al., 2008).

### ***Scan-Related Anxiety in Cancer Populations***

In cancer populations, surveillance scans provide a unique opportunity to study temporal fluctuations in fear of cancer recurrence and psychological distress. Although there is a paucity of research investigating the relationship between anxiety and diagnostic imaging among oncology populations, scan-related anxiety is reported in the literature (Abreu et al., 2017; Bauml et al., 2016; Grilo et al., 2017; LoRe et al., 2016; Thompson et al., 2010). Using a convergent mixed-methods approach, Thompson et al. assessed the psychological impact of surveillance CT scans in 70 long-term lymphoma survivors. Despite participants representing a largely cured population, 37% of patients experienced clinically significant anxiety levels at the time of their routine surveillance scans. The CT scans exacerbated underlying anxiety symptoms, and both a history of relapse and worse patient-physician relationships were associated with higher anxiety scores. Subsequent qualitative interviews revealed a fear of cancer recurrence was the primary source of patient anxiety (Thompson et al., 2010). Similarly, in a study exploring scan-associated distress among patients with recurrent or metastatic lung cancer, Bauml et al. measured levels of distress and quality of life in participants who were undergoing routine surveillance scan imaging. Among 103 lung cancer patients, 83% reported scan-associated distress before the imaging studies. Bauml et al. also noted that scan distress was associated with impaired quality of life. Interestingly, the severity of scan-associated distress was not related to the receipt of the scan results, indicating that *scanxiety* may exist well beyond the scan itself; thus, being told “good news” may not be as reassuring as once assumed (Bauml et al., 2016.).

Scan-related anxiety may be more prevalent in cancers with known steep, downward disease trajectories such as pancreatic cancer. Individuals with pancreatic cancer have the worst prognosis of individuals with any other cancer; they have high rates of disease recurrence, high symptom burden, and debilitating psychological distress (Janda et al., 2017; NCCN, 2022; Petzel et al., 2012).

### **Pancreatic Cancer**

Pancreatic ductal adenocarcinoma is the deadliest malignancy and the third leading cause of cancer-related death in the United States (ACS, 2021b). With an overall 5-year survival rate of 10% across all stages of disease, surgical resection remains the only curative option and even after surgery, pancreatic cancer will recur in over 75% of patients (Gordon-Dseagu et al., 2018). For most patients, surgery is not an option. Pancreatic cancer is most often diagnosed in advanced stages and less than 20% of all malignancies are surgically resectable at the time of diagnosis. Many factors contribute to late-stage diagnoses. Because pancreatic cancer has a relatively low incidence, it is not commonly seen in the primary care setting. As a result, early symptoms which are often vague and non-specific often go unnoticed by the patient's primary care provider (Schmidt-Hansen et al., 2016). In addition, there are no screening tests for pancreatic cancer and any investigation involves diagnostic tests that are expensive and invasive to the patient. Consequently, patients often undergo multiple office visits and consultations before a diagnosis can be made (ACS, 2021b; McGuigan et al., 2018).

### ***Psychological Distress in Pancreatic Cancer***

Compared with other cancers, psychological distress is much more prevalent in

pancreatic cancer survivors with nearly 60% of all patients reporting clinically significant levels of distress at some point throughout their cancer trajectory (Carlson et al., 2018; Mehnert et al., 2018). The poor prognosis coupled with the high symptom burden has been reported as a major contributing factor to the higher rates of psychological distress (Bettison et al., 2018; Pijnappel et al., 2021). Symptoms of anxiety often coexist with clinical depression and can have a detrimental effect on patient outcomes, including increased morbidity and mortality and impaired quality of life (Beesley et al., 2016; Janda et al., 2017; Lewis et al., 2018). In a recent landmark report evaluating the suicide rates among individuals with newly diagnosed cancers, Saad et al. (2019) reviewed Surveillance, Epidemiology, and End Results (SEER) data from over 4.6 million patients within their first year of a cancer diagnosis. Higher rates of suicide were associated with poorer disease prognoses, and individuals with pancreatic cancer had the highest rate of suicide when compared with all other cancer sites (Saad et al., 2019). These findings are consistent with the previously reported cancer suicide literature (Henson et al., 2019), and underscore the need for frequent distress screening and psychosocial interventions in this population.

Pancreatic cancer survivors who have undergone curative surgical resection may be faced with additional fears and worries of cancer recurrence. Although only a few studies have examined psychological distress in pancreatic cancer patients following curative resections, high rates of FCR have been reported. Using a cross-sectional design, Petzel et al. (2012) explored FCR in a sample of 240 pancreatic cancer survivors following curative pancreatectomy. Despite survivors being on average nearly four years out from their surgery, more than one-third of the patients suffered high levels of FCR.

Post-operative fears of recurrence were associated with high levels of anxiety including frequent fearful thoughts, emotional disturbances, and functional impairments which negatively impacted quality of life (Petzel et al., 2012). The study findings are understandable given the high rates of relapse and the high likelihood of death from the disease. For post-operative survivors the stakes are high. There is currently no effective treatment for recurrent pancreatic cancer and a recurrence would invariably indicate a fatal prognosis, with a median survival time of around 9 months (ACS, 2020; Moletta et al., 2019). Although a recurrence typically occurs within the first two years following surgery, it may develop as late as seven years post-pancreatectomy (Akabori et al., 2014; Feng et al., 2019). Consequently, FCR is a significant and realistic concern for this population and represents a primary source of psychological distress (Bettison et al., 2018).

### **Summary**

Pancreatic cancer has the highest mortality rate of all other major cancers and is the third leading cause of cancer-related death in the United States (ACS, 2021b). Surgical removal of the tumor offers patients a slim chance of cure, yet more than 75% of patients will develop recurrent, incurable disease generally within the first two years following surgery. The high likelihood of recurrent pancreatic cancer requires individuals to undergo frequent CT surveillance scans every three to six months following curative surgery. These scans can provoke severe and debilitating anxiety and distress, as they frequently signal the transition from curable to an incurable disease. Very few studies have examined the psychological impact of surveillance scans in individuals with cancer and to date, no study has explored the concept in survivors of pancreatic cancer.

Untreated anxiety and psychological distress are widely known to worsen quality of life in survivors of cancer, yet the patient experiences during diagnostic phases of survivorship remain largely unknown.

The exploration of the lived experience of undergoing a CT surveillance scan following curative pancreatic cancer surgery will remedy the inadequacies in the literature and advance understanding of the emotional strain and consequences surveillance scans may have across cancer survivorship. The knowledge gained from this study informs future research and provides critical information to oncology health professionals to help create targeted interventions to improve the quality of life of cancer survivors.



## CHAPTER THREE

### METHODS

*“About a week out I start getting really nervous. Wondering what it’s going to show. Is this it? I obsess over the what-ifs. Will this be the [scan] where my luck runs out? Over and over – I just can’t get it out of my head.” (Leah, p. 11, lines 313 - 316)*

The purpose of this study was to illuminate the lived experiences of scanxiety in survivors of pancreatic cancer who have undergone curative surgical resection.

Hermeneutic phenomenology as applied by Heidegger (1962) provided the philosophical foundation for this study, and van Manen’s methodological approach (1990) was used to guide the research process. This chapter provides an overview of the philosophical framework of phenomenology, the evolution of hermeneutic phenomenological inquiry, and the application of phenomenology using van Manen’s methodological approach. A description of the research methodology is provided along with a description of specific study components including the sample, setting, procedure, data analysis plan, protection of human subjects, and trustworthiness of the data.

#### **Hermeneutic Phenomenology in Human Science Research**

Little is known about the personal experiences of undergoing surveillance scans following curative pancreatic cancer surgery. For this reason, a qualitative study using a

hermeneutic phenomenological approach was chosen. Qualitative research provides an in-depth understanding of phenomena by exploring personal experiences through the lens of human subjectivity (Munhall, 2012). Phenomenology is a form of qualitative research that focuses on the study of an individual's lived experience within the world (Neubauer et al., 2019). It is an appropriate method to use when attempting to understand the essence of an experience or phenomenon that is not fully understood (Munhall, 2012; Richards & Morse, 2013). Hermeneutical phenomenology uncovers meaning within human subjectivity. In this methodology, knowledge comes into being through language and interpretation (Van Manen, 1990). Understanding is viewed as an evolving and dynamic process and through continual reflection, writing, and rewriting, the researcher may come to interpret and describe the essence or meaning of the lived experience (Heidegger, 1962).

When conducting hermeneutic phenomenological research, there are diverse approaches to inquiry, each with its own assumptions, methodologies, and distinct characteristics to guide the research process (Errasti-Ibarrondo, 2018). The researcher is responsible for selecting a phenomenological approach that is congruent with their own worldview, their professional discipline, and the phenomenon under study. For the purpose of this study, van Manen's methodological approach was used as it combines the descriptive features of Husserlian's transcendental phenomenology with the interpretative features of Heidegger's hermeneutic phenomenology to create a blended framework that regards phenomenology as, "always descriptive, interpretative, linguistic, and hermeneutic" (van Manen, 2014, p. 26). The use of a hermeneutic phenomenological approach allowed the researcher to uncover the reality from the cancer survivors'

perspective so that in-depth, pathic descriptions of the essence of the phenomenon could be gleaned from the data. The methodology chosen is compatible with the researcher's personal worldview, is congruent with the phenomenon under study, and is wholly consistent with the discipline of nursing.

### **Phenomenology as a Philosophy**

Phenomenology is the philosophical study of the structures of consciousness, or *essences* of experiences (Husserl, 1931). The term phenomenology is derived from the Greek "phaenesthai," which means "to appear," and is based on constructivist philosophy which describes all phenomena as cognitive constructions formulated by the human being (Kant et al., 2011). In the twentieth century, Edmund Husserl (1859-1938) founded the philosophical movement of phenomenology as a protest to positivism which was the dominant philosophical movement of the time (Reiners, 2012). The positivistic paradigm asserts all knowledge is based upon observed facts and phenomena that are ordered, rational, and logical. Reality is the same for every person and can be objectively measured independent of human interaction (Comte, 1856; Reiners, 2012). Although widely popular, positivism failed to describe essential phenomena of the human world such as values, feelings, intentions, and the life experiences of human beings. Husserl rejected the positive approach and attempted to restore the reality of humans in their lifeworlds or "lived experiences" by introducing a philosophical framework that sought to uncover the pure essence of a phenomenon (Quotoshi, 2018). Husserl described phenomena as what appears in the consciousness and asserted the world is knowable only through cognitive awareness. All one can ever know and understand must present itself to consciousness, and anything outside of consciousness is unknowable and therefore

outside the bounds of a lived experience (van Manen, 1990). Husserl adopted the concept of intentionality which asserted that every act of consciousness (e.g., thinking, perceiving, remembering) is related to some object and is always intentional. One becomes aware of something because it intentionally enters their consciousness, and the goal of phenomenology is to seek the essence of consciousness (Husserl, 1931).

Husserl described essence as the universal quality or qualities that are essential to the phenomenon and make something what it is. To understand the essence of a phenomenon one must intentionally bracket all prior knowledge, judgments, and presuppositions, and objectively describe the phenomenon under study. Bracketing or phenomenological reduction is a key assumption in Husserlian phenomenology. Only by intentionally suspending one's preunderstandings can one investigate, describe, and understand the core components of the phenomenon under study (Husserl, 1931). This philosophical framework is known as transcendental phenomenology and was eventually expanded on by Husserl's student and protégé Martin Heidegger (1889 – 1976).

While Husserl developed an eidetic descriptive form of phenomenology, Heidegger expanded the phenomenological movement by moving beyond description and giving priority to interpretation. Heidegger believed all knowledge is interpretation and one's understanding of the everyday world is derived from one's own perception of it. Heidegger developed interpretative phenomenology by incorporating hermeneutics, the study of interpretation, into his phenomenological approach. In hermeneutic phenomenology, knowledge comes into being through interpreting and describing human experience (Polit & Beck, 2017). Whereas descriptive phenomenology focuses on uncovering the *essence* of an individual's lived experience, hermeneutic phenomenology

focuses on interpreting the *meaning* an individual gives to their experience. Heidegger rejected the idea of completely bracketing the subjectivity of the researcher, believing it impossible to rid the mind of all prior knowledge and preconceived awareness of a phenomenon. He asserted that prior understandings impact one's own interpretations of the world and personal awareness is intrinsic to the hermeneutic phenomenological approach (Reiners, 2012). Meaning is always interpretative and presupposes prior understandings. Knowledge comes into being through language, history, culture, and social practices and it is only through one's placement in the world or *Dasein*, that accurate interpretation and understanding can occur (Heidegger, 1962).

A central theme of hermeneutic phenomenology is the belief that understanding and interpretation are intertwined in a circular process known as the *Hermeneutic Circle*. This process posits that during an interpretative understanding of new knowledge, the knowledge obtained serves to inform one's prior knowledge (e.g., presuppositions, biases, judgments) which in turn presupposes the new knowledge obtained. In hermeneutic phenomenology, understanding is a continuous revisionary process by which one's preconceived knowledge is repeatedly broken down and revised as new knowledge is obtained. Knowledge development is described as an evolving process and through continual awareness, reflection, and interpretation one may come to understand the essence or meaning of the lived experience (Heidegger, 1962).

### **Phenomenology as a Research Methodology**

As a method of inquiry, hermeneutic phenomenology seeks to uncover a phenomenon as it is experienced subjectively, through the lifeworld or lived experience of the individual (Munhall, 2012). The researcher does not merely ask, "How do cancer

survivors prepare for their surveillance scans?" but asks instead, "How do cancer survivors *experience* their surveillance scans?" Perceptions originate through an individual's lifeworld, and it is through the lifeworld that knowledge and understanding of the world are created. Using this methodology, the consciousness of the individual experiencing the phenomenon must be explored to understand how life is perceived through the experience and to discern the meaning the individual attributes to experience. An individual's perception, interpretation, and meaning of an experience are informed by their background or unique life experiences which are a culmination of numerous factors including their social, cultural, historical, and family influences. Human beings are embodied in their own worlds and only understandable in their own contexts (Richards & Morse, 2013). The lived experience is the point of arrival and departure in phenomenological research; transforming the experience into a textual expression of its essence is the primary research goal (van Manen, 1990).

### **Max van Manen's Phenomenology of Practice**

Van Manen's (1990) phenomenology of practice is an integrated phenomenological approach that blends several philosophical sources to create a descriptive and interpretative method of inquiry that can inform and guide the research process. For van Manen, phenomenology is fundamentally a writing activity with a primary goal of creating text that can uncover the essential structures or essences of an experience (van Manen, 2014). Building on the work of Husserl and Heidegger, van Manen introduced six methodological themes to guide researchers in conducting hermeneutic phenomenological research. For this study, van Manen's approach was used as a framework, and each step is described in detail below.

## **Van Manen's Six-Step Research Activities**

### *1. Turning to a phenomenon that seriously interests us and commits us to the world.*

The first step requires the researcher to identify a phenomenon of profound interest and formulate the research question. The phenomenon of interest in this study was developed through the researcher's clinical experiences caring for individuals with cancer who were undergoing repeated surveillance scans to monitor for disease recurrence. This led the researcher to question, "What is it like to endure these scans every few months?" In caring for patients who had survived poor prognosis cancers with high rates of recurrence, and in which recurrent disease would invariably indicate a terminal prognosis, the researcher wondered, "What is it like to survive one of the deadliest forms of cancer and undergo frequent surveillance scans knowing a cancer recurrence would mean incurable disease?" Reflection on this question led the researcher to reflect on survivors of pancreatic cancer, a deadly malignancy with extremely high rates of recurrence and a mortality rate over 90%. Among those diagnosed, only a very small minority of patients will be eligible for a potential cure that involves aggressive, neoadjuvant chemotherapy, followed by an extensive surgical resection and then at least three additional months of adjuvant chemotherapy. Despite the treatments, more than 75% of patients develop recurrent disease and eventually die from their cancer. Understanding the trajectory of this disease led the researcher to formulate the research question.

Van Manen's (1990) first step also requires the researcher to use reflexivity to explicate their assumptions, preunderstandings, and existing bodies of knowledge that may predispose the researcher to interpret the nature of the phenomenon before the

research study. To reduce the subjectivity of the researcher, all prior knowledge, awareness, and presuppositions of the phenomenon were documented a priori in a research notebook and continually reflected upon throughout the study.

*2. Investigating experience as we live it rather than as we conceptualize it.*

The second research activity is the process of gathering experiential data from participants who have experienced the phenomenon. Data are chiefly obtained by in-depth dialogue between the researcher and participant. Van Manen emphasized the importance of communication between the researcher and participant and conceptualized the researcher as the *instrument* through which participants tell their stories. Experiential data consist primarily of observations and in-depth interviews, but oftentimes other secondary sources are used to augment understanding. Secondary data sources can include supplementary texts, artwork, poetry, novels, or other artistic expressions which add insight and clarity to the phenomenon of interest. The researcher in this study used in-depth participant interviews as the primary source of data. Additional data from non-scholarly literature, poetry, and artwork were used to contribute to the essential nature of the participant experiences.

*3. Reflecting on essential themes that characterize the phenomenon.*

Hermeneutic phenomenological reflection is van Manen's third research process and involves analyzing the study data and identifying the essential themes which characterize the phenomenon. Analysis of the data involves immersion in which the researcher reads through field text numerous times to arrive at an initial interpretation that can guide the coding process and help to uncover thematic aspects hidden in the participant's lifeworld descriptions. Using phenomenological reflection, researchers select



thematic statements and obtain thematic artistic expressions and reflect on the meaning of the lived experience. Four lifeworld existential themes can be used as guides for reflection: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality). These four existentials pervade the lifeworlds of all human beings and can be used during thematic analyses to bring different perspectives of the lived experience. For this study, immersion and thematic analyses were performed following van Manen's research process. Specific details describing the remaining steps of data analyses are reported under the Data Analysis section.

#### *4. Describing the phenomenon through the art of writing and rewriting.*

The fourth research activity describes the creation of phenomenological text. This activity is achieved when the researcher begins to organize the essential themes as a way of describing the experiential meanings of the phenomenon. The text created from phenomenological inquiry contains meaning in a way that differs from other forms of text. Phenomenological text evokes emotion and enables the reader to reflect on their own prior experiences, feelings, perceptions, relationships, and self-image. This type of text fosters *pathic* forms of knowledge that cannot be conveyed by any other means. Some experiences are ineffable or beyond one's linguistic competency. For example, the experience of love, which is difficult to describe, may be better reflected in a song or a painting. These indescribable experiences may be better illustrated through artistic sources of text such as poetry or anecdotal narratives.

Consistent with the process of the Hermeneutic Circle, data collection and analysis occur simultaneously as a circular process in which text is read through as a whole, broken down into smaller parts (codes or themes), then synthesized again as a

whole. This process occurs repeatedly until a new understanding emerges. In this way, understanding increases by moving from an understanding of the parts to an understanding of the whole, and again back to the parts, continually changing as new data are introduced. Knowledge is an evolving process and through continual reflection, writing, and rewriting, one may come to uncover the essence or meaning of phenomena.

*5. Maintain a strong and oriented relation to the phenomenon.*

This research process requires the researcher to remain strongly focused at all times on the ultimate purpose of the study. Van Manen describes phenomenological research as a demanding and onerous process in which the researcher can easily lose interest and indulge in speculation or settle for preconceived opinions of the phenomenon under study. To be strong and oriented to the phenomenon requires the researcher to maintain an intense focus on the research question.

*6. Balancing the research context by considering the parts as a whole.*

The final research activity requires the researcher to remain focused on the methodological approach by engaging in continuous evaluation of the emerging text as a whole to ensure all elements of the text are presented. The text should be strong, rich, and deep, and evoke understandings through language that seems to be non-cognitive and intuitive in nature. As van Manen notes, the essence of an experience has been adequately described through language if the description reveals the lived quality and significance of the experience in a fuller and deeper manner (van Manen, 1990; 2014).

For this research, van Manen's approach offered a descriptive, reflective, interpretative, and engaging mode of inquiry from which the essence of experiencing a pancreatic cancer surveillance scan was elicited.

## **Study Design**

This qualitative study used a hermeneutic phenomenological methodology to address the research question, "What is the lived experience of undergoing a pancreatic cancer surveillance scan following curative surgical resection?" Data were collected during interviews conducted over 23 months from August 2019 to July 2021. The research was guided by van Manen's (1990) hermeneutic phenomenological approach.

## **Setting**

This study was conducted in two separate multidisciplinary cancer centers in the Southeastern United States. All in-person study visits and study-related procedures took place at one of the two specified study sites. These institutions were chosen as they receive a high volume of patients with pancreatic cancer -- more than 100 patients annually. In addition, both institutions employ board-certified medical oncologists, surgical oncologists, advanced practice oncology nurses, certified oncology nurses, oncology physician residents and fellows, and social workers specializing in oncology care.

## **Sample**

The target population for this study was individuals who underwent curative surgery for pancreatic cancer and were undergoing frequent CT imaging to monitor for disease recurrence. A purposive criterion sample of 18 survivors of pancreatic cancer was recruited to participate in this study. Purposive sampling is a qualitative sampling technique in which researchers select specific participants who may be able to provide information-rich data to help illuminate the questions under the study (Patton, 1990). Criterion sampling is a form of purposive sampling in which participant selection is

based on meeting pre-determined criteria of importance (Moser & Korstjens, 2018). Eighteen eligible participants were approached in-person by the investigator and given details about the purpose and procedure of the research study. Each individual was asked two questions to determine eligibility for the study. The questions were:

- When you have an upcoming surveillance scan, do you find yourself thinking about the scan more than twice a day?
- Are you comfortable sharing your personal experiences with your scans?

All eighteen individuals answered “yes” to both questions and were deemed eligible to participate. The use of this type of selective sampling procedure allowed the researcher to decide whether the potential participant could provide rich informative data that would yield meaningful insight into the study questions (Patton, 1990).

The final determination of the sample size was directed by the emerging analysis of the data. In qualitative inquiry, data must be collected until theoretical saturation is achieved. Data saturation is achieved when the information provided by the participants is rich and thick and is replicated. For this study, the data saturation occurred when the existing data offered no new insight or direction into the research question. Saturation provided the researcher with certainty and confidence that the analysis is strong, and the conclusions are accurate (Richards & Morse, 2013).

### **Eligibility Criteria**

Participants were selected using the following inclusion criteria: (a) age 18 or older, (b) diagnosed with pancreatic adenocarcinoma, (c) status post curative pancreatectomy with no radiologic evidence of disease, and (d) undergoing routine CT imaging at intervals no greater than every six months for disease surveillance. Although

CT and MRI are the two recommended imaging methods for pancreatic cancer disease surveillance (NCCN, 2021), previous findings revealed MRI-related anxiety secondary to patient fears of confinement and claustrophobia-related distress (Heyer et al., 2015; Lo Re et al., 2016). For this reason, only participants undergoing CT imaging as a primary method of surveillance were included. Potential participants were excluded if they had: (a) radiologic evidence of disease recurrence or progression or (b) impaired cognitive ability that would render them unable to complete the questionnaires.

## **Procedure**

### ***Recruitment***

Study recruitment took place in-person, in one of the two designated study sites and proceeded through the following mechanisms. To identify potential participants, the researcher electronically reviewed oncology clinic schedules and identified patients with upcoming medical visits who met the eligibility criteria. Patients who met the eligibility criteria were approached by the researcher during their routine office visit. After their medical visit while still in the private exam room, patients were given information about the study including study purpose, procedure, types of data collected, risks and benefits of participation, and confidentiality and privacy. Each person was given a copy of the informed consent (Appendix B) and was allowed adequate time to read through and ask questions. Individuals who agreed to participate were asked to sign the informed consent form and were given a copy of their signed form. Prior to giving written consent, the researcher asked each participant the established criterion sampling questions to determine suitability for the study. Participants who answered "yes" to both questions were eligible to participate.

### ***Data Collection***

Primary data sources collected for this study included transcripts and audiotapes of in-depth semi-structured interviews, the researcher's field notes, analytic memos, and observations, and baseline demographic data. Secondary data sources included poetry, art, and literary works. The use of secondary data sources such as art, literature, theatre, photography, poetry, or other aesthetic works is congruent with hermeneutic phenomenological inquiry as they have the potential to further illuminate the essence of the phenomenon under study (Munhall, 2012; van Manen, 1990). In choosing appropriate artistic sources of data, the researcher explored a variety of literary websites and databases and examined countless sources of visual and literary artworks in the forms of paintings, sketches, photographs, film, poetry, novels, internet blog sites, and cancer support groups. All secondary data sources were chosen for their relevance to the emerging themes and their ability to further illustrate the essence of the phenomenon.

Baseline demographic data for each participant were collected by the investigator through a review of the participant's medical chart. Demographic data were collected on a case report form (see Appendix C) and included name, age, gender, date of diagnosis, cancer staging, date of surgery, date of most recent scan, and any comorbid conditions.

Upon enrollment in the study, participants were given the option of either an in-person or telephone interview. Interviews were scheduled for a time most convenient for the participant. Interviews took place over 23 months, in one session; each interview lasted between 60 – 90 minutes. Initial interviews were conducted using a semi-structured guide which was developed from the review of the literature. Additional

follow-up interviews were initially considered; however, changes in participant disease status limited the opportunity for follow-up interviews.

### ***Interview Guide***

Interviews were informal and conversational allowing each participant to tell their story in their own way. An interview guide (see Appendix D) was used and consisted of open-ended questions with the ability for follow-up probes. The preliminary interview questions included: Can you tell me what it's like to have a diagnosis of pancreatic cancer? What is it like to receive the date of your next scheduled CT scan? Can you describe the days leading up to your scan? How do you experience the wait time before you get the results? This type of reflective interviewing is common in qualitative inquiry as it provides the researcher with general overview questions and allows deeper exploration of relevant issues (Munhall, 2012).

The interviews were audio-recorded and transcribed verbatim by the researcher. Field notes were taken by the researcher throughout each interview and included the researcher's observations of details such as the participant's body language, non-verbal cues such as gaze, gesture, and action, and their emotional response to questions. Following each interview analytic notes were created to record the researcher's reflective thoughts about the interview, including initial impressions, interpretations, speculations, preliminary codes, and emerging themes.

### **Data Analysis**

Data were analyzed continuously throughout the duration of the study to allow for emerging analysis of the data (Corbin & Strauss, 1990). After each participant interview, the researcher transcribed the audio recorded interview and read through it several times

in its entirety to understand the whole account of the experience. Following van Manen's methodological approach, dynamic thematic data analysis was performed which included reflexive reading and writing and re-writing of the data to identify relevant concepts and phrases threaded throughout each interview. Each line of text was read and reflected upon to identify recurring statements or phrases that seemed to reflect essential components of the experience. Next, the researcher created preliminary units of meaning which seemed to characterize the phenomenon and categorized them separately in an Excel worksheet. Grouped meaning units from each interview were then compiled in an aggregated worksheet and regrouped to search for any concept linkages or connections between emerging themes (see Appendix E). Thematic descriptions were also gleaned from non-scholarly literature, artwork, poetry, and the researcher's field notes and compiled together with thematic statements from the interviews so that groupings were inclusive of the full data set. Thematic statements were then analyzed individually and compared with each transcribed interview as a whole to check for consistency in emerging themes and to identify the essence of each theme. Categories of meaning units, preliminary codes, and the final themes chosen were reflected upon as a whole to ensure textual meaning was accurately reflected in the context of the experience. This required the researcher to critically review themes while maintaining focus on the study design and central aim of the study. In hermeneutic phenomenology, this process ensures themes are not only descriptive in nature but are also interpretative in that they reflect the underlying meaning and true essence of the experience (Heidegger, 1962).

Once essential themes and meanings were established, a final stage of analysis was performed in which final themes were reflected upon using van Manen's (1990) four



existentials of lived space, lived body, lived time, and lived relation. These four fundamental existentials form the underlying structure in which human beings experience their lifeworlds. During this stage, secondary sources of data in the forms of poetry and artwork were used to symbolize the final themes and to provide the reader with an alternative understanding of the scanxiety experience. This final step of analysis provided the researcher with an additional process of phenomenological writing and re-writing and helped to enhance the researcher's understanding of the existential lived experience of the phenomenon.

### **Trustworthiness**

Trustworthiness in qualitative research can be determined from the researcher's ability to account for the specific processes which lead to the outcomes of the study (Richards & Morse, 2013). Using criteria established by Lincoln and Guba (1985), several strategies were used to ensure methodological rigor and trustworthiness of the research findings. Lincoln and Guba suggested the following four criteria are needed to establish rigor in qualitative research: credibility, dependability, confirmability, and transferability. These four criteria were established to mirror the positivists' criteria of internal validity, reliability, objectivity, and external validity, respectively. Since its development, the Lincoln and Guba framework has been used extensively as a benchmark to ensure rigor during the conduct of qualitative research (Richards & Morse, 2013). Each of these four criteria was used in this study and is described in detail below.

Credibility refers to the accurate and truthful depiction of the participant's lived experience and the confidence in the truth of the study findings. To ensure study findings were credible, member checking, prolonged engagement, and persistent observation were

used. Member checking is a qualitative technique used to establish the accuracy and truthfulness of the data. Throughout each interview, participants were asked to clarify, elaborate, and expand on their experiences. As initial themes began to emerge, participants were asked to reflect on each theme to ensure the emerging data analysis was congruent with the participant's lived experience. Prolonged engagement and persistent observation are highly interdependent methods and refer to the researcher spending sufficient time in the field, culture, or social setting to thoroughly observe the phenomenon in order to identify what is relevant to the study. Both as a registered nurse and as an advanced practice nurse, the researcher has spent nearly two decades in outpatient cancer care settings working with cancer survivors during times of their surveillance scans. Throughout the study, she continued to work in the oncology healthcare clinic where diagnostic imaging was performed and where scan results were communicated to patients. Although she did not enroll any of her own patients for this study, she is very familiar with the study setting, the social and cultural context, and the patient population.

Triangulation was also used to establish credibility and involved using multiple sources of data to reduce bias and augment understanding. For this study, data were collected through participant interviews and observations, the researcher's field notes and analytic memos, social media sources, and online cancer blogs in which patients candidly discussed their feelings regarding their upcoming scans. Quantitative data measuring levels of anxiety and fear of cancer recurrence in pancreatic cancer survivors was collected in a separate study by the researcher and findings were used to provide an

additional data source to further establish credibility and enhance understanding of the phenomenon (Winebrenner, 2022).

Dependability refers to the reliability of data over time and in other contexts. In this study, all raw data, audio recordings, written transcripts, analytic memos, and coding notes were maintained to create a clear audit trail of study findings. In addition, an external audit was conducted by an independent nurse researcher on data from the first nine participants. The independent researcher was able to review the process and study findings and confirm that the researcher's thematic analyses were supported by the data.

Transferability is a form of external validity and refers to the potential for findings to be applicable in other settings or groups. This can be achieved by providing sufficient details and descriptions of data so that others can evaluate the applicability to other contexts. Thick, rich, and meaningful descriptions of data were used to document the lived experiences of each participant. Specific details about study settings, eligibility criteria, sample characteristics, and data collection and analysis methods were provided so the reader can evaluate the extent to which findings are transferable to other populations.

Confirmability refers to the objectivity of the researcher and is concerned with establishing that the findings and interpretations are clearly derived from the data (Nowell et al., 2017). Lincoln and Guba (1985) state that confirmability is established when credibility, transferability, and dependability are all achieved. In addition to establishing these three criteria, the researcher kept a reflective notebook to demonstrate the research process and how study interpretations and conclusions were made. The

researcher also maintained self-awareness during the study by continuously reflecting on prior knowledge, perceptions, and presuppositions throughout data analysis.

### **Protection of Human Subjects**

This study was approved by the University of Louisville Biomedical Institutional Review Board. No study-related procedures were performed prior to institutional approval.

### **Ethical Conduct of the Study**

The proposed study was conducted according to the standards of ethical conduct in research outlined in the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). The main ethical principles of the Belmont Report include beneficence, respect for persons, and justice. These principles were considered throughout the conduct of the study and specific protections taken are described below.

#### ***Beneficence***

Beneficence imposes a duty on researchers to minimize harm and maximize benefits (DHHS, 1979). In psychosocial oncology trials, research participants are often asked to complete multi-item questionnaires that may contain sensitive questions and may be burdensome for a fatigued patient receiving cancer treatments (Dellson et al., 2018). This study used lengthy interviews with sensitive questions which could have potentially caused harm to the study participants. All attempts were made to minimize harm to study participants. In an effort to reduce participant burden and minimize distress, participants selected the time and place for each interview. Participants were be

informed of their right to decline participation at any time and refuse any questions which may increase discomfort or distress.

### ***Respect for persons***

"Respect for persons requires that subjects, to the degree which they are capable, be given the opportunity to choose what shall or shall not happen to them" (DHHS, 1979). This principle is firmly implemented when a comprehensive informed consent process is completed. The informed consent process was conducted by the investigator in a private exam room. Before informed consent was sought, the investigator gave specific details about the nature of the study and explained the risks and benefits of participation. All potential participants were provided with an IRB-approved consent form that described the nature of the study and provide sufficient information to make an informed decision about participation. Participants were informed that their participation was voluntary and that declining to participate would not impact their care in any way. Written informed consent was obtained before conducting any research activities and all participants met eligibility criteria. While there were no conflicts of interest to be disclosed, participants were informed of their right to be notified of any conflicts of interest if any arose during the study.

### ***Justice***

In human subjects research, justice refers to a participant's right to fair treatment and privacy (Polit & Beck, 2017). Several key measures were used to protect participants' privacy and anonymity. Subject transcripts and case report forms did not contain any identifying information. Upon enrollment, all participants were assigned a unique subject identifier beginning with "001". The unique identifier helped de-identify

participant data and maintain participant anonymity. Only research team members had access to the data which included transcripts, case report forms, and participants' demographic information were stored in a securely locked file cabinet at the University of Louisville School of Nursing. The office containing the study materials was always locked and only the researcher had access. All electronic materials used to transcribe or store data were secured on a password-protected computer on a University of Louisville shared and encrypted drive.

## **Minority and Children Participation**

### ***Participation of Minorities***

Historically, minorities are underrepresented in healthcare research (Erves et al., 2017). Pancreatic carcinoma is a cancer that affects men and women from all racial and ethnic groups. Participants from all racial and ethnic groups were eligible if they met the eligibility criteria. This study used two distinct study sites to increase the potential for ethnic diversity in the sample. Every attempt was made to enroll representative proportions of minorities in this study.

### ***Participation of Children***

The occurrence of primary pancreatic cancer of any histology in persons less than 18 years of age is extremely rare (Gordon-Dseagu et al., 2018). In consideration of this, children were not included in this study.

## CHAPTER FOUR

### FINDINGS

*"My life is broken up into three-month increments, living scan-to-scan. This last scan was good so I can breathe a sigh of relief, but there's another one coming. So, it's hard to appreciate the good results of today when you know the next one could kill you." (Luke, p. 14, lines 282 – 285).*

The purpose of this study was to illuminate the lived experiences of scanxiety in survivors of pancreatic cancer who have undergone curative surgical resection.

The participants provided vivid, in-depth descriptions of their experiences. Two essential themes emerged from the data: the recurrent cycle of scanxiety and the hope for lifelong remission.

#### **Sample Characteristics**

Eighteen survivors of pancreatic cancer participated in this study. Interviews took place from July 2019 through May 2021 and were either in-person or by phone, lasting from 45 to 120 minutes. All participants were Caucasian and non-Latino; ten females and eight males composed the study sample. Participant ages ranged from 51 to 73 years; their mean age was 63.7 years of age ( $SD = 6.3$ ). All 18 participants had undergone curative surgical resection of pancreatic adenocarcinoma; the median time since surgical resection was 17.5 months. Most of the participants (61.1%) had received neoadjuvant

chemotherapy and every participant received adjuvant chemotherapy, although two participants had to discontinue treatment early due to poor tolerance to therapy. The overall cancer stage of participants was determined following surgical resection and ranged from stage IA to III. At the time of data analysis, five participants (27.8%) had died of disease (DOD), three participants (16.7%) had developed progression of disease (POD) and were either receiving palliative treatments or under hospice care, and 10 participants (55.6%) had no evidence of disease (NED). Table 1 displays additional characteristics of the study sample.

### **Participant Characteristics**

Table 2 displays the characteristics of each participant. At the time of each interview, participants had undergone curative surgical resection of their pancreatic cancer, were in complete remission from their cancer, and had recently received computed tomography (CT) scan results revealing no evidence of recurrent disease. Interviews took place either in-person in the oncologist's office after the participant received their scan results or by phone within two days of the participant receiving their scan results. Pseudonyms were assigned to protect the identity of each participant. A brief description of each participant is provided to describe background information and the historical context of each participant's lifeworld.

**Anne** was a 72-year-old retired school teacher with stage IIB pancreatic cancer who underwent surgery eight months before her interview. Anne's interview took place by phone one day after she received her scan results.

**Naomi** was a 57-year-old homemaker with stage III pancreatic cancer who underwent surgery 10 months prior to her interview. Naomi was interviewed in-person at



Table 1

*Sociodemographic Characteristics of the Study Sample (N = 18)*

| Characteristics             | <i>n</i> (%) |
|-----------------------------|--------------|
| Gender                      |              |
| Male                        | 8 (44.4)     |
| Female                      | 10 (56.6)    |
| Race                        |              |
| Non-Hispanic White          | 18 (100.0)   |
| Marital Status              |              |
| Married living with spouse  | 12 (66.7)    |
| Widowed                     | 1 (5.6)      |
| Divorced                    | 4 (22.2)     |
| Separated                   | 1 (5.6)      |
| Education                   |              |
| High school diploma         | 9 (50.0)     |
| College graduate            | 9 (50.0)     |
| Stage of pancreatic cancer  |              |
| Stage IA                    | 3 (16.7)     |
| Stage IIA                   | 3 (16.7)     |
| Stage IIB                   | 4 (22.2)     |
| Stage III                   | 8 (44.4)     |
| Neoadjuvant chemotherapy?   |              |
| Yes                         | 11 (61.1)    |
| No                          | 7 (38.9)     |
| Adjuvant chemotherapy?      |              |
| Yes                         | 16 (88.9)    |
| Yes, but discontinued early | 2 (11.1)     |
| Time interval between scans |              |
| Every 3 months              | 16 (88.8)    |
| Every 6 months              | 1 (5.6)      |
| Annually                    | 1 (5.6)      |

Table 2

*Characteristics of the Participants (N = 18)*

| Assigned Pseudonym | Gender | Age | Stage of Cancer | Time since Surgery (months) | Current Status |
|--------------------|--------|-----|-----------------|-----------------------------|----------------|
| Anne               | F      | 72  | IIB             | 19                          | DOD            |
| Naomi              | F      | 57  | III             | 10                          | DOD            |
| Hannah             | F      | 51  | IIA             | 75                          | NED            |
| Mike               | M      | 65  | III             | 5                           | POD            |
| Deborah            | F      | 62  | IIA             | 7                           | NED            |
| Miriam             | F      | 56  | IIA             | 16                          | NED            |
| Mark               | M      | 69  | IIB             | 9                           | DOD            |
| Steve              | M      | 63  | IIB             | 17                          | DOD            |
| Luke               | M      | 68  | III             | 11                          | POD            |
| Jake               | M      | 69  | III             | 39                          | POD            |
| Tom                | M      | 57  | III             | 8                           | DOD            |
| Sarah              | F      | 58  | III             | 18                          | NED            |
| Ruth               | F      | 58  | III             | 18                          | NED            |
| Matt               | M      | 68  | IIB             | 16                          | NED            |
| Ethan              | M      | 73  | III             | 21                          | NED            |
| Paula              | F      | 64  | IA              | 35                          | NED            |
| Carolyn            | F      | 66  | IA              | 33                          | NED            |
| Leah               | F      | 70  | IA              | 18                          | NED            |

Note. DOD = died of disease; NED = no evidence of disease; POD = progression of disease.

her oncologist's office after she received her scan results. She was accompanied by her husband.

**Hannah** was a 51-year-old registered nurse who underwent surgery for a stage IIA pancreatic cancer six years prior to her interview. She was interviewed by phone two days after she received her scan results.

**Mike** was a 65-year-old repairman who underwent surgical resection of stage III pancreatic cancer six months prior to his interview. He was interviewed in-person in his oncologist's office shortly after receiving his scan results. He was accompanied by his wife.

**Deborah** was a 62-year-old college admissions officer who underwent surgical resection for a stage IIA pancreatic cancer seven months prior to the interview. She was interviewed by phone one day after receiving her scan results.

**Miriam** was a 56-year-old administrative assistant who underwent surgery for stage IIA pancreatic cancer 16 months prior to her interview. She was interviewed by phone one day after she received her scan results.

**Mark** was a 69-year-old cattle farmer who underwent surgical resection for a stage IIB pancreatic cancer nine months prior to his interview. He was interviewed in person in his oncologist's office after he received his scan results. He was accompanied by his wife and adult daughter.

**Steve** was a 63-year-old corporate executive who underwent surgery for stage IIB pancreatic cancer 17 months before the interview. He was interviewed by phone two days after he received his scan results.

**Luke** was a 68-year-old retired physician who underwent surgery for stage III pancreatic cancer 11 months prior to his interview. He was interviewed by phone one day after he received his scan results.

**Jake** was a 69-year-old owner of a trucking company who underwent surgical resection for stage III pancreatic cancer three years prior to his interview. His interview took place in person in the oncologist's office after he received his scan results. He was accompanied by his sister.

**Tom** was a 57-year-old auto mechanic and car enthusiast who underwent surgery for stage III pancreatic cancer six months prior to his interview. Tom was interviewed by phone one day after receiving his scan results.

**Sarah** was a 58-year-old retired insurance adjuster who underwent surgery for stage III pancreatic cancer 14 months prior to her interview. Sarah was interviewed by phone two days after receiving her scan results.

**Ruth** was a 58-year-old retired administrative assistant who underwent surgery for stage III pancreatic cancer 14 months prior to her interview. She was interviewed by phone one day after receiving her scan results.

**Matt** was a 68-year-old financial analyst who underwent surgical resection for stage IIB pancreatic cancer eight months prior to his interview. He was interviewed by phone two days after receiving his scan results.

**Ethan** was a 73-year-old retired army veteran who underwent surgical resection for stage IIB pancreatic cancer two years prior to his interview. Ethan's phone interview was conducted one day after he received his scan results.

**Paula** was a 64-year-old female who underwent surgical resection for stage IA pancreatic cancer three years prior to her interview. She was interviewed by phone two days after receiving her scan results.

**Carolyn** was a 64-year-old oncology nurse who underwent surgical resection for stage IA pancreatic cancer 22 months prior to her interview. Her interview took place by phone two days after she received her scan results.

**Leah** was a 70-year-old editor who underwent surgical resection for a stage IA pancreatic cancer eight months prior to her interview. Leah's interview was by phone two days after she received her scan results.

### **Summary**

Each study participant was in complete radiologic remission from pancreatic cancer and underwent at least one surveillance CT scan to determine if recurrent disease was present. All participants were interviewed within two days of receipt of their CT scan. In the remainder of this chapter, the essential themes of the phenomenon of undergoing surveillance scans after curative pancreatic cancer surgery are discussed.

### **Research Findings**

The phenomenological analysis of 18 interviews revealed two essential themes: *the recurring cycle of scanxiety* and *hope for lifelong remission*. The recurring cycle of scanxiety describes the complex sequence of events survivors experienced during the time surrounding their surveillance scans. Hope for lifelong remission describes the distinct hope and belief that lasting remission is possible. The uncovering of these themes reveals the essential meaning structure and true essence of pancreatic cancer survivors' lived experience of undergoing surveillance scans. Table 3 describes the essential themes

and subthemes uncovered in the data. In the following sections, each essential theme and corresponding subthemes are defined and discussed. Illustrative quotes from participants are offered to support the existence of the themes.

### **The Recurring Cycle of Scanxiety**

The first theme is *the recurring cycle of scanxiety* which is a complex repetitive pattern of behavioral and emotional responses manifested by pancreatic cancer survivors during the time surrounding their surveillance scans. Scanxiety or scan-related anxiety describes the anxiety and distress before, during, and after a cancer-related scan. The cycle of scanxiety identifies the universal experiences participants described in the time interval starting from the days leading up to the scan and following the receipt of the scan result. This essential theme is composed of five overlapping subthemes: the fear of cancer recurrence, mental preparation, proof of life, waiting to exhale, and resetting the clock.

### ***The Fear of Cancer Recurrence***

Regardless of participant demographics, cancer stage, or age of survivorship, every participant experienced a persistent and underlying fear of cancer recurrence. This was described as a deep-seated permanent fixture in the lives of participants and was described by several survivors as being "always in the back of my mind." During non-scan times, recurrence fears were generally manageable, and although negative thoughts could "creep in" at any time, survivors were able to suspend their fears and continue performing their normal daily activities. Upon notification of an upcoming scan, or generally about one week prior to the scan, participants experienced a heightened fear of cancer recurrence that increased in strength and magnitude as the scan date approached. The words used to describe the emotion included "worry," "fear," "dread," "scared,"

Table 3

*Essential Themes and Subthemes of the Lived Experience of Scanxiety*

| Theme and Description   | Subthemes   |
|---|---|
| <p>Recurring cycle of scanxiety</p> <p>A complex repetitive pattern of behavioral and emotional responses manifested by survivors during the time surrounding their surveillance scans.</p> | <p>Fear of cancer recurrence</p> <p>Mental preparation</p> <p>Proof of life</p> <p>Waiting to exhale</p> <p>Resetting the clock</p> |
| <p>Hope for lifelong remission</p> <p>The intense desire for a complete recovery and a return to normal life.</p>   | <p>Balancing fatalism and optimism</p> <p>Reframing hope</p>  |

"frightened," and "terrified." Fears of recurrence took the form of daily recurring and intrusive thoughts of the cancer returning, interpretation of unrelated body symptoms as a sign of recurrence, and an inability to plan for the future. One participant described a panic-type fear of recurrence that induced a post-traumatic stress response causing her to flashback to her original cancer diagnosis. Heightened cancer fears caused significant psychological distress including disturbances in mood, sleep, and daily functioning. The upcoming scan served as an external trigger, an approaching reminder of the looming threat to life. Matt described how his fear of cancer recurrence increased in the days prior to the scan.

I'm on a three-month schedule for scans so for probably two months before the scan I'm doing ok. I mean I'm always thinking about the cancer coming back. It's always there in the back of my mind but I'm not dwelling on it. And then maybe one week to 10 days before the scan, [the oncologist's office] will call me with the [scan] date and from that point,

I'll be thinking about it pretty much every day. I mean constantly. I can't put it out of my mind. It's just wondering what it's going to show and if [the cancer has] come back. I'll watch the calendar and mark off the days, beforehand. As the date gets closer, I get more tense, and by the time it's here, well let's just say I'm wound pretty tight (p. 3, lines 69-81).

The date of the approaching scan created a foreboding sense of unease, which prompted several participants to unintentionally lock the scan date into their working memory. Naomi described how her upcoming scan date was imprinted in her mind.

As soon as it gets scheduled, I put it in my phone and just dwell on it. The date is in my brain constantly. It gets locked in my brain. It's always there just like looming over me. And I'm always looking at the calendar and doing the countdown (p. 1, lines 27-29).

As fears of cancer recurrence increased in the days leading up to the scan, the participants experienced physical and psychological manifestations which affected their daily lives. Psychological manifestations included mood changes such as depression, anxiety, irritability, feelings of powerlessness and dread, fatigue, daily ruminations of death and dying, fear of being a burden to one's family, and impaired memory and concentration. Physical manifestations of recurrence fears involved increased pain, disruptions in the gastrointestinal system, and disorders in sleep.

**Psychological Manifestations.** Intolerance for uncertainty was described by nearly every participant (16/18). The high likelihood of recurrent disease was made known to the participants by their medical oncologists, leaving many to wonder how a disease recurrence would impact their survival status. A majority (14/18) assumed



recurrent disease was not curable and this awareness heightened fears of recurrence and generated a growing sense of powerlessness. The belief that cancer could recur at any time was among the most difficult concepts for the participants to accept. The seemingly arbitrary nature of a cancer recurrence frustrated the participants who wanted to retake some control of their lives. The participants had endured aggressive chemotherapies and a difficult surgical resection to achieve full remission of their cancer. The idea that cancer could return randomly, at any time without warning, left the participants feeling vulnerable and defenseless. Anne described the sense of powerlessness she experienced during times of her surveillance scans.

It's hard knowing there's nothing you can do to change it or make it better. Especially after all that. You get through the chemo and the Whipple and then they give you more chemo and it makes you so sick. But you do it, everything they throw at you – you do. And you get through it all. And now you have to wait to see if anything comes back. And there's nothing you can do. There's nothing that improves your odds. You just have to wait (p. 1, lines 38-44).

Miriam vividly described the feeling of powerlessness using a metaphor to help the researcher better understand her perspective.

I know there's nothing I can do to affect the outcome. I don't have any control over any of it. It's kinda like a feeling of free fall with no idea if there's a net down there to catch you (p. 5, lines 186-189).

Survivors who described themselves as having a high internal locus of control appeared to have the most difficulty tolerating uncertainty. Leah described herself as a

“control freak” and someone who took responsibility for her life and her circumstances. She described her struggle in coping with the uncertainty.

I think it’s so hard for me because I need to feel in control. I have to feel like I am contributing to the decision in this. And it’s very frustrating to know that you cannot control it. I can do certain things. I can follow a treatment plan. I can get surgery. But other than that, there’s really nothing I can do. And that is probably the hardest aspect of this (p. 16, lines 637-645).

The increased feeling of powerlessness was accompanied by the dread of having to undergo the scan. The anticipation of the upcoming scan was one of the most difficult features of the scan period. Anticipating the scan often involved an endless series of negative thoughts, focused on the worst possible outcomes. Several participants described their feelings of powerlessness and dread vividly using analogies to help the researcher understand.

Once I get the [scan] paperwork in the mail, it’s all right there in my mind. And from that point forward it’s always there gnawing in my mind. It doesn’t completely incapacitate me or anything, but it’s something that you would be in a group somewhere with friends, having a good laugh or something, and then it would hit you, “Oh shit. I got to go do that on Monday.” It gives you a little gut check or something. So yeah, it gnaws at you. It's like waiting to go in front of a judge that has a sentence for you. Somebody’s making a decision that’s going to affect your life forever. It’s

a feeling that your life is completely out of your hands (Jake, p. 7, lines 288-306).

The feeling of not being in control is something that's always in the back of my mind. Sometimes it doesn't dominate as much but it seems like when you get closer to having the scan done you feel it more. And then just thinking of having to have the scan, it's like, ugh, I gotta take a test. And you're thinking, I wonder how well I'm going to do on my test? Let's hurry and get it over with. Can the teacher hurry up and grade it right away and give me back my results?! Sort of like that, I guess (Luke, p. 5, lines 163-174).

It's kind of like going to the dentist. You know you have to do it. It's not the doctor making you do it, but you have to do it for yourself to make sure that you're okay. And as that time gets shorter, you just dread it. You hate it. Just the thought of having it done and that [the cancer] could come back. And then your whole life would change (Miriam, p. 3, lines 100-110).

The feelings of dread provoked by an upcoming scan were not associated with the scan itself. The participants considered scans a normal part of cancer care and a majority reported a sense of familiarity with the scan procedure, as most had undergone numerous CT scans throughout their survivorship period. The dread provoked by the upcoming scan was primarily associated with the potential consequences of a positive scan result indicating a cancer recurrence. Participants acknowledged their understanding of the

serious nature of a pancreatic cancer recurrence, and this awareness heightened fears of recurrence and generated fears of death.

It's not the scan. I mean I've had several scans at the hospital so that doesn't bother me. It's the results. I'm afraid of the results. If the cancer came back, I mean I wish someone would just tell me that it's not inevitable that I'm going to die. Which I mean I'm smart enough to know that that's probably what's going to happen (Anne, p. 5, lines 181-187).

Steve was accustomed to having a working plan for circumstances in his professional life. Since his diagnosis, he struggled to cope with the uncertainty of his pancreatic cancer and believed if he was given the strategy for managing a recurrence, this might alleviate some of his fears.

The scan is not bad. I mean it's not my first rodeo so I don't have any concerns about that. I think I worry about the dying part. I mean nobody has ever talked to me at any level about what would come next. You know 'If it comes back, we'll try this' or 'If it comes back, we'll do this'. It's just out there. And I think that would help me. Just knowing what the next steps would be (p. 4, lines 168-175).

Steve was only one of four survivors who preferred to know the treatment strategy for a cancer recurrence. Most participants (11/18) assumed recurrent disease would be fatal and actually preferred uncertainty or "not knowing" how the disease would be managed, rather than the certainty of knowing their fate in the context of an incurable disease.

In the days before an upcoming scan, mood changes were reported by 15 out of 18 participants. Irritability was described by six participants and occurred primarily among the females (5/6). Depression, anxiety, isolation, fatigue, and impaired concentration also were reported. Naomi described how her mood changes affected her husband. "Right before [my scans] I get hateful. I do, I get bitchy, I lose sleep. I take it out on him a lot (pointing to husband). Especially the weekend before. It's really rough on him." (p. 6, lines 250-254).

Similar experiences were described by other survivors. Hannah, who was six years out from her pancreatic surgery at the time of her interview, recalled her scan experiences the first two years after her surgery. She experienced debilitating symptoms in the week leading up to her scan.

For that whole week before the scan, I was a mess. And it got worse the closer it got to the scan date. I couldn't sleep. I had trouble focusing and concentrating on things. I couldn't work. I mean I'd go to work but I wasn't really doing anything. I just couldn't get out of my own head. It was really hard on my family. The kids just knew to keep their distance (p. 1, lines 16-22).

Sleep disturbance (15/18) was one of the most commonly reported manifestations experienced by the participants as they anticipated their upcoming scan. Leah described her inability to sleep on the eve of her CT scan.

The night before [the scan] I'm wired. Making sure everything is out and ready. I'm kind of OC there. Just making sure everything is nice and arranged. And I think, 'OK I'm going to go to bed early.' And then I lay

there wide awake. And then you start doing the countdown, ‘If I go to sleep now, I can get 4 hours of sleep. If I go to sleep now, then I can still get 2 hours.’ And I keep doing this until it’s time to get up (p. 9, lines 386-394).

**Physical Manifestations.** About half of the participants (8/18) described an increased incidence of somatic symptoms in the days leading up to their scan. Symptoms such as diarrhea, nausea, abdominal pain, and incisional discomfort were commonly reported and perceived by the participants as a possible sign of cancer recurrence. Deborah described how her physical symptoms affected her anxiety about her scans.

I can usually manage my anxiety pretty well. I try not to get too worked up but this last [scan] I had was different. I had these weird symptoms about two days before the scan. I started feeling weak, my blood sugars were running high, and I just didn’t feel good. I got sort of depressed. I’d never felt like this before and I figured this was some new cancer symptom presenting itself (p. 1, lines 38-46).

Five participants recognized their physical symptoms were psychosomatic in nature, primarily because symptoms consistently appeared in the days leading up to the scan. Miriam described the “mind games” her body played on her when a scan date was approaching. Although she recognized symptoms were likely anxiety-provoked, she still experienced exacerbated fears and anxieties of cancer recurrence.

Once you get scheduled for the scan then that’s when your mind just starts playing games with you. You know you don't feel good, and this bothers you or that bothers you, or maybe you have diarrhea, or you know, kind of

all of the above. And I think it's really just that your mind is playing games with you. You're thinking, 'Oh, you're going to have this cat scan and they're going to find something' (p. 1, lines 23-32).

Luke experienced physical symptoms of abdominal pain near the site of his surgical incision. He recalled how the pain induced a flashback to the time of his original diagnosis.

Yesterday [the day before the scan] I started to feel a little discomfort over here in my abdomen. And I thought, 'Uh oh, what is this? What's going on here? Is this something else?' It takes me back to when I got diagnosed. Maybe it's not the same type of symptoms but just a little discomfort. And it makes you wonder if the cancer's back (p. 12, lines 441- 463).

Although only half (8/16) of the survivors experienced physical symptoms in the days leading up to the scan, every participant experienced some type of psychological change. It was important for survivors to continue to do their normal everyday activities despite their psychological impairments. More than two-thirds of the participants (13/18) described separating their emotions from their actions to perform their normal daily routines. Jake described how he used compartmentalization to cope in the week leading up to his last scan.

I don't know if my routine changed. I mean on the outside I still went to Kroger and got the car washed but those are just outside functions. The inside functions were bad. I don't want to say I was having a pity party inside, but I may have been a little woe is me. Externally my routines were pretty much the same, but internally I'm balled up inside. It's inside me. It

gives me perspective when those scans come up. I realize that it may not be so important to get my shoes shined or whatever, you know? But I keep everything inside. I just tell people at work I have a doctor's appointment. I don't tell them all what's going on (p. 8, lines 310- 323).

Fear of cancer recurrence is the primary source of scan-related anxiety and the antecedent to the cycle of scanxiety. Fluctuating recurrence fears drive each phase of the cycle and shape the emotional and behavioral responses survivors manifest throughout their scan period.

### ***Mental Preparation***

Mental preparation for a cancer surveillance scan is a highly complex and emotional process for which survivors must ready themselves for their upcoming scan. This is the first phase in the recurrent cycle of scanxiety and begins one to two weeks before the upcoming scan. As fears of cancer recurrence increased, the participants needed to prepare themselves for all possible outcomes of the scan, while also continuing to function in their normal daily life. The participants used two simultaneous coping processes to prepare themselves for the scan: contingency planning and distraction.

**Contingency Planning.** Contingency planning is a profoundly emotional and distressing process requiring participants to deeply reflect upon worst-case scenarios in the days leading up to their cancer scan. It was important for participants to conceive the impact recurrent disease would have on those around them and contemplate alternative plans if a recurrence was identified on their upcoming scan. Planning for contingencies allowed the participants to gain some control over their life and mitigate the damage a cancer recurrence would have on those around them. Fifteen participants described a



process of envisioning the possibility of a cancer recurrence. Each reflected on how recurrent cancer would impact their lives and the lives of others and created introspective interim plans to prepare for all possibilities. Ruth took care of her young grandchildren during the day while her daughter-in-law worked. She worried about the care of her grandchildren and who could take her place if cancer returned.

My mind just starts thinking, what if I do have cancer? And my daughter-in-law is still working. So, what will we do now? Who is going to be there during the day to watch the grandkids? You know, how can we adjust things so it's not too disruptive for [the grandkids]? So, I just try to think it through and make plans in my head, just in case (p. 7, lines 282 – 288).

Miriam and her husband had full custody of her three grandchildren. As the primary caregiver in the home, Miriam worried how a recurrence would impact the family. She described the difficulty of making backup plans when she is unsure how a cancer recurrence would be managed.

I start thinking about what would happen if [the cancer] came back. How we would handle it, you know as a family? Who's going to get the kids off to school? And then what about pick-up? And homework? I mean all of these things. These are things we need to prepare for. And it's hard because I don't really know what would happen [if the cancer recurred]. If it comes back in my pancreas, I mean would they still be able to take it out? Would I go back through and do all the chemo treatments? Or will I do radiation? I mean just exactly what would happen? And I mean if I did all that stuff am I still just going to die? And again, who would take care

of the kids? I mean I guess it's just all that [rolled] into one (p. 8, lines 344 – 351).

Contingency planning for a cancer recurrence was an inner-directed, thoughtful process. Participants did not record or document alternative plans nor did they seek support or assistance from others. The introspective process was a mental reflection of possible strategies that could be used to mitigate the family life disruptions a cancer recurrence would produce. Paula's contingency planning consisted of identifying bills that would need to be paid and considering alternative caregivers for her mother.

I try to think about what I'd do if it comes back. If everybody's going to be able to find everything they need. Would they be able to do this, or would they know where to pay this? And I take care of my mom, she lives with me. What would happen to her, you know? (p. 7, lines 248 – 253).

Planning for contingencies often involved delaying major decisions or postponing plans until after the participant received their scan result. As a mother with young children, Hannah described the difficulty making future plans before her upcoming scan.

I always have to look ahead at what's going on in the weeks after my scan and I say to myself, 'Oh my gosh, if my cancer comes back, I can't do this, or this, or this.' Because I'll be back in treatment. So, for me, I can never plan for the future. I can never plan vacations. I can never volunteer to go on my daughter's field trip in a month. I can't contribute to anything because I don't know if I'll be dead or if I'll be in treatment (p. 1, lines 24-29).

Contingency planning was distressing and tightly intertwined with rising fears of cancer recurrence. Although anxiety often increased during times of planning, three survivors described increased feelings of control and a sense of fulfilling their obligations to others, which in turn lessened uncertainty and generated some peace of mind. Steve, 63, was asked to describe how planning for contingencies impacted his scan-related fears.

I'm not sure it affects it at all. I mean it doesn't take [the anxiety] away that's for sure. It's still there. But I think it helps to know we have something in place. And that everyone would be all right and know how to manage. And then knowing that I could do that for [my wife]. She doesn't need to worry about all of that (p. 3, lines 111 – 115).

**Distractions.** Planning for contingencies required participants to acknowledge the high likelihood of incurable disease and to confront the serious threat to survival that faced them. Prolonged ruminations of death were common and emotionally taxing to patients in the week leading up to their scan. Participants often found ways to temporarily dismiss negative thoughts with various distraction techniques. Distractions allowed the participant to mitigate the threat of the upcoming scan to continue normal routines, maintain social relationships, and participate in daily activities. Nearly every participant (16/18) reported some form of distraction as a way of coping with their upcoming scan. Distraction techniques were primarily in the form of staying active and keeping busy. Mike described how he kept his mind occupied.

I like to stay pretty busy just to keep my mind occupied. Like this morning [before my scan] I went down to the bank, came home, watered some

flowers, was just looking for things to do. Just to stay busy (p. 12, lines 494 – 497).

Ruth also looked for tasks around the house to keep herself from thinking about her upcoming scan.

I have to keep really busy. For this last [scan], I knew [my anxiety] was going to be bad, so this weekend I volunteered to sell raffle tickets for our bike club and I kept really busy. And then I came home and got my shower and got ready and cooked dinner for my husband. Monday was a little awkward because I was home alone, so I cleaned the house and that occupied my time. I did the laundry. I vacuumed. I gave my dogs a bath. I found things to do. I was able to occupy my time this weekend because I knew what was coming. And that helped (p. 10, lines 397 – 406).

Luke acknowledged the emotional burden of trying to think through worst-case scenarios for extended periods. He described alternating his contingency planning with distraction techniques.

I have to plan all scenarios, try to figure out what I would do if the scan doesn't go my way. How the family would handle everything. When I start to think about it too much, I get down a little. My wife will say to me, "I know you're getting this way because we're getting ready to go for a scan." And I'm just thinking about all the options. But you can only do that for so long. Then I have to go out and actually do something, you know? So, I go out and walk. Because if I were to sit at home in a chair all

day, well I'm sure I would dwell on that. And being active really helps keep my mind occupied (p. 4, lines 47 – 158).

Every distraction technique reported involved the use of physical or mental activities to redirect threatening thoughts and decrease awareness of the upcoming scan. Hannah described an alternative method of distraction involving the use of medication to induce sleep when she was unable to effectively distract herself from thinking about her scan.

I try to avoid all idle time about 1 week before my scan. I can't watch TV because I can't concentrate. I just need to be active and when I'm not busy doing something then I just want to sleep. I still have some Phenergan left over so I'll take that or something just to let me sleep. I mean I'd prefer to stay busy but when I can't then I'll take some pills and take a nap. I never want to have idle time. Just so I don't think about it (p. 1, lines 34 – 40).

Distractions helped temporarily lessen fears of cancer recurrence, although not all distraction techniques were successful. Many attempts of distraction were impeded by triggering events that redirected the participants' thoughts back to their cancer and subsequently back to thoughts of their upcoming scan. These triggers included receiving notifications from cancer providers, watching television shows or movies about someone with cancer, seeing cancer-related social media postings, watching television commercials about cancer-directed therapies, and attending funerals. Fearful thoughts of upcoming scans triggered by these events were described as insidious in nature, subtly "creeping" into the participant's conscious mind and dismantling the peace of

unawareness. Sarah described the impact television commercials had in the days leading up to her scan.

I really try not to think about [the upcoming scan] but so many times it just creeps in. My mind wanders or I'll see a commercial about a certain chemotherapy for lung cancer and then it makes me think, 'Do I have that? Has the cancer spread to my lungs?' (p. 10, lines 411 – 414).

Over one-third (7/18) of the participants identified the television show *Jeopardy* with host Alex Trebek as a trigger for fear of cancer recurrence. These participants avoided the show during the time surrounding their surveillance scans. Although *Jeopardy!* was one of Matt's favorite television programs, he described his emotional reaction to the show.

I know this sounds strange, but I can't watch Jeopardy before [my scan]. And it's one of my favorite shows. I just don't want to see Alex Trebek. I just don't want to see him and then knowing what he went through. It just makes me think about it more than I already am (p. 7, lines 290 – 293).

### ***Waiting to Exhale***

In the cycle of scanxiety, the second phase is "waiting to exhale" and describes the participants' experiences in the interval of time between the scan procedure and receipt of the scan result. This period was the most difficult juncture for many participants and elicited the highest levels of anxiety and distress. Most participants (15/18) reported fears of cancer recurrence were at their highest point immediately before receiving the results of their scan. Factors influencing participants' perception of the scan result experience were affected by numerous external stimuli including the length of time

waiting for the result, the method of scan result notification, social relationships, and the perceived congruence between members of the multidisciplinary care team. Both the patient-provider relationship and the duration of the waiting period were important variables influencing how the participants experienced their scan results. Most of the participants (15/18) received their scan results in person, in their oncologist's office, although three learned of their results by self-viewing the report from the patient portal, *My Chart*.

**The Wait.** The length of time between the scan procedure and receipt of the result was identified by every participant (18/18) as the single most important factor influencing fears of recurrence and distress. Participants preferred to receive their scan results in person, from their medical or surgical oncologist, and within one to two days of the scan procedure. Several participants reported same-day or next-day scan results which provided comfort and helped lessen uncertainty and fears of recurrence. Luke described the effects of shortened waiting periods.

I usually get the scan in the morning and see the doctor right after. So, I always know I'll find out the results within hours. That really helps. If I had to wait more than a day or two, well that would be horrible. That uncertainty. You know your mind will take over. And for me, I just want to know. If I had to wait longer it would make my anxiety so much worse (p. 2, lines 55 – 60).

Three participants experienced an extended wait time of at least one week between their scan and receipt of the results. The negative psychological impact of the prolonged wait time was described and identified as a key factor in exacerbating anxiety

symptoms. Miriam described an increase in psychosomatic symptoms during the week between her scan procedure and receipt of the scan result.

I had to wait a full week [to get the results] this time. It was horrible. I felt sick the whole week. My incision bothered me, I felt sick to my stomach. I just didn't feel good. And then finally going in [to the oncologist's office] to get the results. My blood pressure was way up, and they mentioned that to me. Then they take you back to that little room, and that's when it really gets bad. In my head I'm like, 'Come on, come on' and it could only be like 10 minutes until Dr. X comes in, but you feel like it's been 30 or 40 minutes since you've been back there. You can't see him soon enough to be told what the results are (p. 4, lines 140 – 145).

Three participants who frequently experienced prolonged wait times described a bimodal distribution of scanxiety that peaked before the scan procedure and again before receiving the results. Sarah described her experience with bimodal scanxiety.

About a week before the scan is when my anxiety really gets started. It gets really high right before the scan, but then goes down a little because the scans are over with. But then you have to wait another week and you think, 'Okay well now what?' and my anxiety starts to go back up, and by the time you go to the doctor that anxiety has come back and is probably one of the worst times (p. 7, lines 158 – 163).

Increased waiting times often occurred on the day the survivor received their scan results. Several participants experienced unanticipated delays in the clinic setting while waiting for the provider to give them their results. Although delays are not uncommon in



healthcare settings, the unexpected delays exacerbated symptoms of anxiety, and in some participants, caused significant psychological distress. Jake described his experience when his oncologist was running late during clinic.

Waiting for the results, that's when I'm most anxious. Sitting in that room waiting for the doctor to come in. And this last time Dr. X was running late. I think he was called into surgery or something, so I had to wait longer than usual. It was after 2:00 and I'd been up since 4:00 am for my scan, and I hadn't eaten anything. But at that point, I couldn't eat anyway. My stomach was churning like a milk truck just waiting for him to come into the room. I almost got sick right there in the room. I mean you're waiting for the news to find out what the rest of your life is going to be like (p. 6, lines 246 – 258).

Ruth described how she showed up at her oncologist's office to receive the scan results, but her scan report was not ready. She had to wait in the doctor's office for nearly 90 minutes until the results were available.

It was hard. Just sitting in [the oncologist's] office in one of those little rooms. I tried to keep calm, but it was really hard. My husband was with me. I finally told him I was going to close my eyes for a little bit, and I rested my head on his shoulder. And I closed my eyes for a little while and just waited. It seemed like forever. And [the office staff] told me I didn't have to wait, and they'd call me with the result, but I didn't want to leave. I just wanted to get it over with (p. 12, lines 452 – 464).

Carolyn experienced an unexpected delay receiving her scan results and assumed the delay was related to a cancer recurrence. She described her catastrophizing thoughts of recurrent disease and her emotional reaction to her oncologist who appeared indifferent to her angst.

For this last scan, I felt like I had to wait longer for the doctor to come in and give me the results. I sat there in the office and kept fidgeting. I was praying, 'Oh my God, Please God let it be clear, let it be clear. And it was getting later, and he still hadn't come. And I thought, "Oh my God. My scans are not okay. And that's why they haven't come into the room yet. Because they're dreading coming into the room to tell me. And when (the oncologist) finally came in the room, he just started chit-chatting about random things. And I was like, "Are my scans okay?" And he goes, " Oh yeah they're clear. They're fine" And I said, "Well that needs to be the first thing you tell me because I'm a wreck!" (p. 7, lines 234 – 242).

**Time since Diagnosis.** Most participants (16/18) described stable scan-related fears of cancer recurrence, with scan-related anxiety that had not changed in frequency or intensity since their pancreatic cancer surgery. Two participants, however, reported a decrease in their scan-related fears over time. Hannah, who was six years post-surgery, and Carolyn, who was nearly three years post-surgery, both reported a notable decrease in levels of anxiety as time passed. Hannah described the impact of time on her scanxiety.

For the first two years, it was awful. I'd have so much anxiety before [my scans]. Then probably about three years after my diagnosis, I sort of relaxed a little bit before my scan. This is when I realized, 'Hey, I might

not die from this right away'. So then, I became a little more relaxed with a little more time under my belt. And at my four-year mark, I had this kind of inner peace come over me with my scans. I still got nervous and had trouble sleeping. Even now, I always get worried and still take something the night before my scan to help me sleep, but I just didn't worry as much. After four years the scan stopped being in the forefront of my mind. I mean, I always knew it was there, and I was waiting for my results, but at least I could function (p. 2, lines 67 – 80).

**Notification Method.** During the study, federal legislation was passed which altered the way in which participants received their scan results. The 21<sup>st</sup> Century Cures Act (2020) is a federal law requiring health care organizations to provide patients with immediate and unfettered access to their electronic health information, thereby eliminating wait times for test results and allowing patients to receive their entire medical record, including office notes and scan reports in real-time, often before their health care provider has viewed them. This legislation was enacted after 11 participants had completed their interviews. Prior to this policy change, participants received their scan results in-person, from their oncologist. The in-person method occasionally involved prolonged wait times which influenced and exacerbated scanxiety symptoms. Seven participant interviews occurred after the passage of this law. Although all seven participants were eligible to view their results online, only three participants regularly used their My Chart account and received text notifications of available scan results. Upon receiving the notification, all three participants chose to view their scan results using the patient portal. The participants described heightened recurrence fears similar to

fears described by participants receiving in-person scan results; however, the self-viewing participants reported different experiences in the way they prepared themselves for their results. For example, when receiving in-person results, most participants (15/18) preferred to have someone accompany them to their oncologist's office. The support person predominately chosen by married participants was a spouse. Unmarried participants chose close friends to accompany them. Interestingly, when using a patient portal, all three participants preferred to view their scan results alone, isolated from family and friends. The self-viewing participants did not tell anyone of their available scan results, describing a need to view their results at their own pace. Leah explained her experience viewing her results online. "I was alone, and I actually prefer that. I need to have time to process my feelings before sharing them with anybody."

Overall, patient portals were viewed as both positive and negative. Although a majority of participants (15/18) did not use the patient portal in place of receiving in-person scan results from their oncologist, numerous participants (11/18) appreciated having the option to use the portal to reduce scan-result wait time, if they could not receive their scan results in a timely manner. Matt described the temptation of receiving immediate scan results using the patient portal.

Ugh... My Chart is the devil. But I hate the waiting time between the scan and getting the results, so whenever I get the text [notification of scan result], I have to pull it up. There are times when I'm afraid to look at it but it's hard not to once you get that text. And this last time, I actually saw the result before Dr. X and Dr. Y saw it. So, I already knew the result was

good news. Thank God. Because I don't like doing that. I really don't like to see the results until I've seen the doctor (p. 1, lines 27 – 31).

The appeal of using the patient portal enabled participants to gain immediate access to their scan results to reduce uncertainty. As an oncology nurse, Carolyn recognized the emotional risk associated with accessing potentially devastating results without an oncology provider present.

My anxiety has actually been getting better as time has gone on. But now [the hospital] has passed some new law or regulation where they release all your scans in My Chart. So now you can see the scans even before you see the doctor. And that freaks me out. So, like I got the text message that I had a new result and I'm like, Oh my God. Do I look at it? Do I not look at it? I don't know what to do. What if I look at it and it's not okay? And then I've got to sit here and wait a day or two before I see the doctor. And I ended up opening it up and looking at it. And thank God it was ok. But what if it wasn't? (p. 10, lines 402 – 414).

**Social Support.** During times of an upcoming scan, several participants (8/18) avoided discussing their scan-related worries and fears of recurrence with family and friends. Limiting these emotional conversations was an important method of coping in the days leading up to the scan and allowed participants to control triggering discussions that could increase scan-related anxiety. An unsolicited conversation about the upcoming scan had the potential to antagonize recurrence fears, provoking further anxiety and distress. For example, two participants described the counterproductive effect of a well-intentioned spouse or coworker who initiated scan conversations to allay fears but instead

disrupted the distraction techniques survivors had put in place. It was important for survivors to control the negative intrusive thoughts as much as possible. Paula chose not to discuss her upcoming scans with her husband or her mother.

I don't tell anyone [of upcoming scan] because there's nothing they can do.

And just talking about it makes me feel worse. This is mine to deal with.

And it's not like they can say anything to make it better. My husband would just want to talk about it and I don't want to talk about it. That's the last thing I want to do (p. 4, lines 224- 227).

Social support was an important factor mitigating the participants' anxiety when receiving in-person scan results. As described earlier, most participants preferred to have someone accompany them to their oncologist's office to receive the news. Social support was not as important to participants who viewed their results using the patient portal, as all three participants preferred to view their results alone and isolated from others.

**Patient-Provider Relationships.** The patient-physician relationship was described by nearly all participants (16/18) as an important factor influencing the severity of scan-related anxiety. Survivors acknowledged the importance of perceiving their oncologists as highly skilled and competent. All 16 participants believed their oncologists were well-equipped to handle recurrent disease and this lessened their fears of their cancer returning. Ethan described his relationship with his medical and surgical oncologist and how these relationships impact his scan-related anxiety.

I just feel like I'm in the best hands. I feel like Dr. X is the best surgeon and I think Dr. Y has been really impressive. They're both tried and proven. Everyone has told me how great they both are. And they both

have a good trusting relationship and that keeps my anxiety in check (p. 10, lines 363 – 372).

As a physician, Luke had the resources to travel outside his home state to obtain his medical care from one of the largest cancer centers in the country. After several recommendations, he eventually decided to use a local surgical oncologist because of his confidence in the skill of the surgeon. He described the importance of trusting his provider and how this affected his emotional reaction to his upcoming scan.

I'm grateful that I was able to find Dr. X because in the beginning, we were like, where do I go? Do I go to Johns Hopkins? Do I go to MD Anderson? And we were setting up all of these things. And then several colleagues helped me realize that we have one of the best surgeons here in Louisville with Dr. X. I have 100% confidence in him. And so yeah, I still get anxious [around scan times] but just having him on my team brings me comfort (p.16, lines 611 – 618).

***Incongruence among Providers.*** The participants were followed by both their medical oncologist and surgical oncologist, and most (17/18) had separate provider visits to discuss their scan results. It was important for participants to view both oncology providers as a cohesive partnership, working together for the patient's best interests. Of the 18 participants, nearly three-fourths (13/18) perceived some form of disconnect between their medical oncologist and surgical oncologist. Provider discrepancies included poor communication between providers (e.g., lack of sharing medical records) provider disagreements over treatment plans or conflicting advice from providers. The

incongruences increased the participants' uncertainty of care and often left patients feeling "stuck in the middle" and uncertain about whose advice to follow.

Provider disagreements over treatment plans were frequent sources of scan-related distress. Several survivors witnessed instances in which one provider raised doubt about another provider's plan of care. Anne described the disconnect she perceived between members of her oncology care team.

I'm not sure my two doctors are always on the same page. They disagreed over when I should start chemo [after surgery], then they disagreed over when I should stop. Dr. X wanted me to have another cycle but Dr. Y said I didn't need that much. So, I only got three cycles instead of four. And I don't think that made Dr. Y very happy. So, I don't know what to think. I already have high anxiety from being ill and this makes it so much worse.

I just wish there was better communication (p. 9, lines 376 – 387).

Survivors described instances in which they interpreted casual, even offhand provider inquiries as evidence their oncology team members were not in communication with one another. These perceptions increased patient uncertainty and exacerbated fears of cancer recurrence. Matt described the anxiety he experienced when he was asked about another provider's opinion of his recent scans. Matt's angst was further increased when he was asked to serve as an intermediary between his medical oncologist and surgical oncologist.

I don't know if Dr. X and Dr. Y talk to each other about my treatments.

Dr. Y is always asking me what Dr. X thinks about my scans. And this last time Dr. X asked if Dr. Y was planning to give me more chemo. I mean



don't they talk to each other? So now I'm supposed to ask Dr. Y about the chemo. It's nerve-racking to think that I'm playing the go-between. I don't have any medical training or knowledge. It's scary to be in that position (p. 3, lines 114 – 120).

Mike also experienced a significant increase in fear when one provider questioned the other provider's plan of care.

I think they should be able to communicate with one another. Even through email or whatever just so everyone's on the same page. I don't think Dr. X thinks Dr. Y gave me strong enough chemo to make sure it won't come back. I mean Dr. X told me I needed the stronger stuff like I had before surgery, but Dr. Y only offered me the pill. And don't get me wrong, I liked taking the pill instead of having that pump on all the time. But does that mean the cancer's going to come back because we didn't do the pump? So that makes me more nervous with my CAT scan because I'm thinking I didn't get the right stuff so now it's going to come back. I just wished they would've talked to each other (p. 2, lines 76-81).

Discrepancies also occurred when two providers required different types of scans. For example, every participant underwent a CT scan of the abdomen and pelvis as part of their surveillance plan. Three participants described the medical oncologist's additional need for a CT of the chest which was not always performed when the surgical oncologist ordered the scan. This resulted in the participant having to undergo an additional CT scan of the chest which often spawned an additional cycle of scanxiety.

There's a level of disconnect between Dr. X's office and Dr. Y's office. With this last scan, Dr. X scheduled me to have a scan of my abdomen and pancreas area. After I had the scan, I went to see Dr. Y who wanted to know why they didn't scan my lungs, too. Well, I don't know. I don't schedule the scans. I guess Dr. X isn't worried about what's going on in my lungs. So now I have to go in next week for another scan of my lungs and it's a whole other procedure. I guess it's not really a big deal but it's inconvenient. And now I have something else to worry about (p. 10, lines 404 – 414).

One participant experienced increased distress when her provider misinterpreted the results of her scan. Sarah described an embarrassing experience when she received negative scan results from one provider and significantly different results from her other provider.

Dr. X (medical oncologist) ordered the scan but I had an appointment with Dr. Y (surgeon) the next day and he was able to pull up my results. So, Dr. Y came in the room smiling and he said, "You're good!" and I'm like, "Really? Are you sure? Because Dr. X had thought he saw something in my lung on the last scan." And Dr. Y told me, "No, everything looks great. Go live a good life. You're good!" And I was so relieved. I was crying when I left [his office]. And I came home and posted on Facebook how surprised I was that [the lung lesion] had disappeared. And that if you've ever prayed for me thank you because I got this great news from my surgeon. But when I went to see Dr. X the

next day, he told me it wasn't a good scan and the spot on my lung had actually grown. So that was hard to hear. I just wish I hadn't posted all of that. I felt embarrassed that I posted how great my scan was because it wasn't good news at all (p. 19, lines 804 – 821).

Although Sarah's scan showed a slight increase in the size of her pulmonary nodule, the lesion remained too small for biopsy, and disease progression could not be confirmed. At the time of the interview, Sarah was still considered to be in full radiologic remission of her pancreatic cancer. Sarah told the researcher, "I'm in limbo. We don't know what [the lung nodule] is. But I know it's too little to biopsy and too small to show up on a PET scan. So, I just have to have patience and wait for the next scan and see if anything shows up. And there's a lot more anxiety with that." (p. 9, lines 370- 373).

### ***Proof of Life***

Except for Sarah, every participant received a negative scan result indicating no evidence of recurrent disease. The receipt of "good news" was a pivot point in the cycle of scanxiety and the phase in which participants experienced reassurance and a significant drop in scan-related anxiety. This third phase of the scanxiety cycle is the *anxiety nadir* and was labeled "proof of life" to describe the underlying meaning pancreatic cancer survivors assigned to their scans. In hostage situations, a proof of life is a form of communication provided by the hostage-taker as indisputable evidence the kidnapped victim is alive. Often in the form of photographs or videos, proof of life evidence is typically the first indication of the condition of the victim and provides reassurance and hope to the victims' families by reducing the uncertainty of their loved one's fate (Giebels et al., 2005; Rossin et al., 2018). For study participants, the

surveillance scans offered a *radiologic proof of life*, indisputable evidence that survivors were still “okay” and in complete remission. The proof of life evidenced by the negative scan provided a permission slip of sorts for participants to resume some aspects of their normal life. Although no physical changes had occurred, numerous participants (9/18) described feeling strong and healthy after receiving negative scan results. They were able to resume their normal roles in the family and in work. They could attend upcoming family functions and holidays and start to make plans for future events. The negative scan reduced the uncertainty of the participants’ fate and allowed them to hold on to hope, despite the high likelihood of recurrent disease. Ruth was interviewed one day after receiving her scan result and described the overwhelming joy she experienced after hearing she was still in remission. She became tearful as she tried to put her feelings into words:

It’s just a wonderful feeling that I want to cry. I want to cry every time. I made it through another scan. And I can sit here and cry right now. And I’m sorry (voice cracking, crying softly) I apologize. I made it through another scan. Nothing showed up. My blood work was superb. I feel healthy. I don’t feel like a little weakling anymore (p. 12, lines 483 – 490).

### ***Resetting the Clock***

The feelings of relief and reassurance following receipt of a negative scan were ubiquitous across all participants; however, the reassuring effect of the scan result was often short-lived. The final phase “resetting the clock” describes the temporary reassurance the negative scan provided and uncovers the participants’ experience living

with uncertainty during non-scan times. This final stage completes the recurrent cycle of scanxiety and serves as a pivotal juncture for the cycle to start again.

**Temporary Reassurances.** The lasting effects of reassurance from a negative scan varied widely among participants. A minority of participants (4/18) accepted their scan as evidence of ongoing remission and were able to keep underlying fears of recurrence in check until the next scan date approached. However, for most survivors (14/18), the comfort of receiving a negative scan was quickly overshadowed by the continuous uncertainty of the disease and the ongoing need for future scans. Survivors described how their “good news” was quickly eclipsed by the need to restart the countdown to their next scan. Anne described the momentary relief she experienced after receiving the results of her negative scan.

The scan that I just had came back and they didn't see any cancer cells. I mean that's a tremendous relief. But the closer that it gets to the next 3 months, then the greater the anxiety. The clock just starts all over again (p.1, lines 46 – 54).

Matt described a similar experience.

So even though I got good news from the scans, It's still always in the back of your head, what if there's something there they didn't see. Or what if it's going to come back 3 months from now? It's always in the back of your mind (p.8, lines 312 – 318).

Several participants expressed uncertainty over the radiologist's ability to accurately interpret the scan and detect a possible cancer recurrence. Naomi was

interviewed in her oncologist's office less than one hour after receiving her "good news" scan results. Despite the scan showing no evidence of cancer, she continued to doubt.

I mean even now, Dr. X just told me everything looks great. I'm doing great. But there's still a little bit of anxiety thinking, did they read it correctly? Are they going to call me back later with something they missed? (p. 5, lines 188 – 192).

All three participants who worked in health care reported a lack of confidence in the medical technology used to detect a cancer recurrence. As a physician, Luke understood the limitations of computed tomography.

And what's always in the back of my mind is that I realize the scans are not definitive. I mean in order to detect something at that resolution, well there's only a certain size in millimeters before you can even detect it. So that is always there. And it only takes one cell to make trouble (p. 9, lines 323 – 327).

**Uncertainty During Non-Scan Times.** Living with the uncertainty of a cancer diagnosis was a pervasive and distressing feeling discussed by every participant. During times outside of the surveillance scan period, the ruminating and intrusive fears of cancer recurrence were less frequent. Although underlying fears of recurrence persisted, a majority of participants (14/18) were able to temporarily dismiss worries and continue performing their normal daily activities. Leah described her fears of cancer recurrence in the months following a negative cancer scan.

The fear is still there, but not to the degree as it was previously. It's not an everyday thinking about it and dwelling about it event. It may pop up in

my head, but for the first couple of months [after a good scan] it's easy to push it back down and say, damnit [Leah], get on with living your life (p. 18, lines 723 – 734).

Participants described a dependence on their surveillance scans and recognized the unintentional focal point scans had become in their lives. One participant described her scan as being “the root of my being.” Another phrase, “living scan to scan” was described by several participants (6/18) as living a life in a constant state of uncertainty. Carolyn described her life as existing in 3-month increments to reflect the interval of time between her surveillance scans.

Whenever I get a good scan report, I'm relieved. And I guess I'm okay for a bit. It's kind of like you live in blocks of time that are three or four months long. It's like okay, I can relax for about two and a half months. And then my anxiety starts building again (p. 4, lines 214 – 218).

Living with the uncertainty of a life-threatening illness was described as a life priority for Luke. He recognized the need to change his outlook to accommodate the uncertainty in his life. He described a deliberate form of self-transformation as he transitioned from physician to patient.

Yeah. I get that relief. But then like I said, I look into the future and think, okay what's next? What's the next scan going to show? For now, I'm just living scan to scan, you know? It's good that the report was good, but it's still always in the back of your mind. It's not ever going to go away. It's like a friend of mine said, “This is your new job.” And he was right. I mean I was a doctor, but now I'm on the other side. And this is my new

job. Now I just have to take the time and realize this is my job to do (p. 15, lines 570 – 579).

Most participants (16/18) envisioned ongoing fears of cancer recurrence for the rest of their lives. Jake owned and operated a successful business and could not envision a day when his fear and anxiety over a cancer recurrence would end. He recognized how cancer had changed him and acknowledged he is not the same person he was before his cancer diagnosis.

I mean my anxiety gets really high, and after I hear the negative results, it goes way down but it never goes away. And I don't think it will ever go away. I think I'll always live with anxiety now. I'm never going to be what I was before my cancer. The best I can do is find a level where I can operate at my best in the face of my anxiety (p. 6, lines 220 – 224).

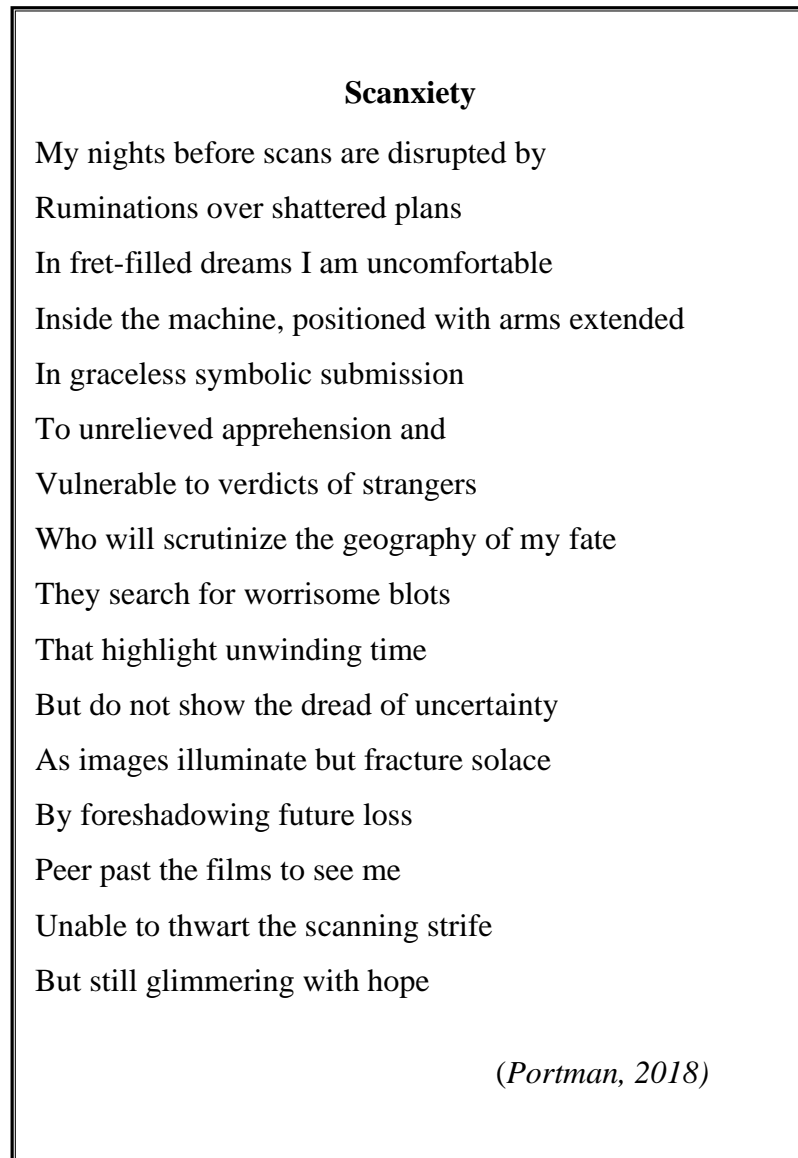
Resetting the clock after a cancer scan describes the short-lived peace of mind a negative scan produces and the instinctive apprehension and dread of the next upcoming scan.

Every participant described a process of sequential phases of emotional and behavioral responses during times of their cancer scans. A recurring cycle of scanxiety consisting of four phases was identified: mental preparation, waiting to exhale, proof of life, and resetting the clock. Fear of cancer recurrence was the primary source of scanxiety and was the impetus shaping the survivor's responses through each phase of the cycle. The cycle of scanxiety was experienced as a deeply personal and at times painful process. The essential quality of this experience can be illuminated further using the language of poetry (see Figure 1).



Figure 1

*Poetry Depicting the Essence of the Theme Recurring Cycle of Scanxiety*



***The Essence of Scanxiety Depicted in Poetry***

Some phenomenological experiences are so emotionally powerful they are considered ineffable, or too great for words. In phenomenological research, alternative sources of expression including fine arts, music, poetry, and cinematography are often used to illuminate the true essence of the phenomenon being described (van Manen,

1990). In depicting the essential quality of the scanxiety experience, the true essence can be further illuminated using the language of poetry. The poem, *Scanxiety* (Portman, 2018), uncovers the lived quality of the experience in a fuller and deeper manner.

### **Hope for Lifelong Remission**

Hope for lifelong remission is the second essential theme uncovered, and it describes the underlying hope survivors maintained despite the high likelihood of recurrent, incurable disease. The word "hope" was used by every participant and was endorsed as the belief that a cure for pancreatic cancer was possible. Hope was inherent and central in each participant's narrative. The primary object of hope was to live cancer-free and regain some aspects of life before cancer. The phrase, "I just want my life back" was used by two participants and supported in several participants' narratives. A secondary object of hope involved the hope for scan-related anxieties to lessen over time. Survivors generally assumed anxiety surrounding cancer scans would be a permanent fixture in their lives yet continued to hope their scans would get easier in the future. When asked if she believed her scan-related anxiety would get better over time, Sarah expressed doubt.

Interviewer: Do you think your anxiety concerning your scans will lessen over time?

Sarah: (Long pause with an audible sigh) Probably not. I mean I've already had like four of them and it hasn't gotten better. So, I doubt it. But I hope so. I really do. I hope this gets better because I don't like this feeling. Just always feeling like something's wrong when it's really not. I don't want to keep going on like this (p. 12, lines 507 – 512).

Hope was used intuitively as a form of coping, and lessened fears of cancer recurrence during times of surveillance scans. Other secondary objects of hope included the hope to avoid further treatments, to live pain-free, and to reduce the distressing side effects from chemotherapy and surgery such as diarrhea, nausea, and dyspepsia.

### ***Balancing Fatalism and Optimism***

Participants hoped for a full recovery from cancer, but many were cautious to endorse this goal, acknowledging the notion of not wanting to "tempt fate." The belief that a full recovery was possible in the face of a pancreatic cancer diagnosis was a difficult concept to accept. Many participants tried to remain hopeful while balancing their fatalistic views of the disease. Leah found it difficult to find hope considering the high likelihood of recurrent disease. She had performed an extensive online search examining the statistics of pancreatic cancer and found discouraging results. She described trying to offset her fatalistic view of pancreatic cancer with an optimistic outlook in which she could live out her life cancer-free. She frequently had to remind herself to live in the moment and not in a future state.

You have to be realistic. You have people who want to deal with things directly and others who want to bury their heads in the sand. I like to confront things head-on. So, what I have to do is balance being a realist with kicking myself in the butt. I have to remind myself, keep on - you're not dead yet! You know like Monte Python? (laughing) You're not dead yet! (p. 18, lines 767 – 784).

Hope for lifelong remission was at the heart of the cancer scan experience and provided the means that made it possible for survivors to continue on the recurring cycle

of scanxiety. The belief that a cure was possible was often unspoken yet corroborated throughout each participant's story. Hope was the center of the scanxiety cycle, and all things revolved around hope. When Luke was asked to summarize his overall scan experience, he made the focus of hope explicit in his response.

It's hanging on to hope. That's what I keep thinking. Just hang on to that hope that one day this will all be behind you. I've made it one year, and that's great, but we need to get further down the road. I ran into a friend the other day. He'd gone through some leukemia treatments, and he was like 12 or 13 years in remission. And I was like wow, wouldn't I like to say that? (p. 15, lines 584 – 590).

**Reframing Hope.** The time surrounding a surveillance scan was described by many (12/18) as a way to prioritize what matters most. The typical daily stressors of life seemed trivial to those facing a life-threatening disease. One participant described the scan period as a time to “retake stock of your life” and figure out what really matters. As perspectives shifted, survivorship goals were often revised. Several participants (6/18) described an adaptive process of reframing hope in relation to the ongoing uncertainty of cancer survivorship. Ruth was interviewed 18 months after her pancreatic cancer surgery. Although she desperately wanted to live as long as she could, she learned to hope in new ways that allowed her to confront the uncertainty facing her. She described a process of reframing hope, from an initial desire for long-term survival to the hope of surviving to live one more day. Ruth learned to appreciate every day as a gift and live life in the present. She described the importance of not sweating the small stuff, a sentiment she reinforced with a sign on her front porch.

I think I've already reached my hope stage. Just to be here. When I first heard the words pancreatic cancer, I thought it was a death sentence - because I never heard of anyone surviving. And I did. So, I think my hope is already here. And I think I've been blessed. It's a blessing to be here. It's a blessing to be around my family. To watch my grandkids graduate. I watched my oldest grandson graduate in Florida last week, and it was the best thing in the world. I watched my granddaughter win a mathematics award, and it was great to be there. And that's what I'm thankful for. And if I'm not here tomorrow well that's ok. Because I'm here today (p. 19, lines 855 – 863).

### ***The Essence of Hope Depicted in Art***

Maintaining hope for long-term survival despite overwhelming rates of recurrence was difficult for survivors undergoing pancreatic cancer surveillance scans. The dynamic nature of holding out hope was multifaceted and may not be completely uncovered by the power of language. The painting of *Hope* (Figure 2) completed by George Frederic Watts (1886) captures the true quality of this theme and illustrates the deliberate act of maintaining hope in the face of a deadly disease.

**Hope in Art.** In the painting *Hope* artist George Frederic Watts (1817 - 1904) portrayed hope as a blindfolded female who sits alone on an unstable world, floating in water. The woman appears to be on the brink of despair; she appears overcome yet not defeated. She remains deeply seated on her world. She huddles over a lyre with only one string. All other strings are broken, yet she is determined to play. She bends her ear to hear the soft sound of her music. There is a single small star in the sky that she

Figure 2

*Painting to Illuminate the Essential Quality of the Hope for Lifelong Remission*



cannot see. Her circumstances appear dismal, and her efforts seem in vain, yet she is not deterred. She must find her hope from within. Hope is her instrument to play.

Similar to the symbolic representation of hope in the painting, the participants held on to a distinct hope and belief in lifelong remission, despite the high likelihood of

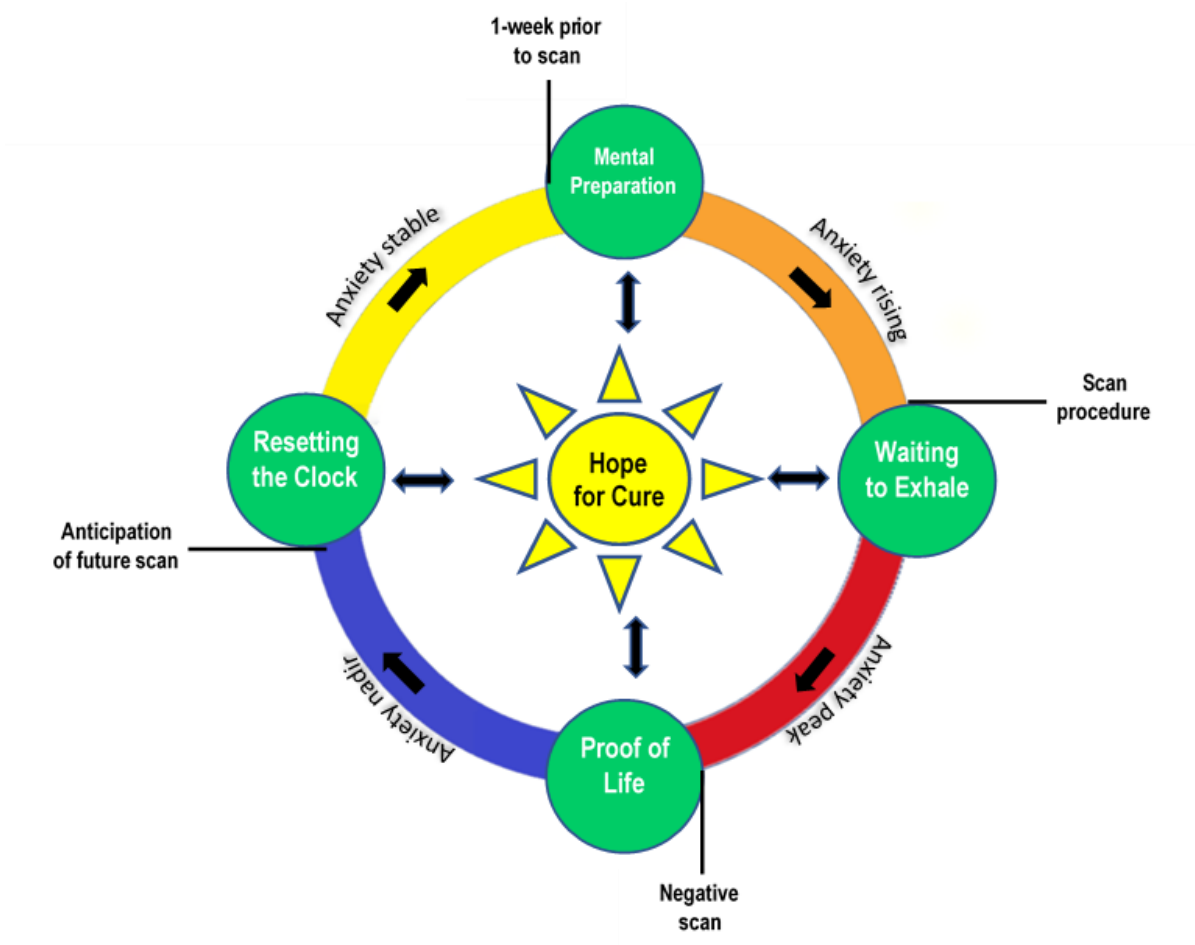
recurrent, incurable disease. Leaving room for hope enhanced coping strategies and empowered survivors to keep going, as they continuously endured their surveillance scans throughout their survivorship period.

### **Conceptual Framework**

The essential themes uncovered in this research were: the recurring cycle of scanxiety and the hope for lifelong remission. A conceptual model of the study themes is presented in Figure 3. As shown in the model, the recurring cycle of scanxiety is a four-stage process initiated about one week prior to an upcoming scan. Scan awareness triggers increased anxiety and fears of cancer recurrence which influence the individual's emotional and behavioral responses. Mental preparation is the first stage of the cycle and describes the preparations survivors make to ready themselves for their scan. Anxiety and recurrence fears continue to rise and intensify in the interval between the scan procedure and receipt of the scan result. Waiting to exhale describes the anxiety peak as survivors anticipate their scan results. Following notification of a negative scan, anxiety and recurrence fears nadir, and survivors are reassured their cancer has not returned. Proof of life describes the evidentiary proof survivors require to decrease fears and resume normal activities of daily life. The relief generated from the scan is short-lived, as survivors recognize their need for future scans. Resetting the clock describes the reflexive rise and stabilization of anxiety as survivors anticipate their next upcoming scan. The cycle is centered around the survivors' hope for continued remission. Hope allows survivors to conceptualize a return to their pre-cancer life, which in turn motivates individuals to carry on throughout each phase of the cycle.

Figure 3

*Conceptual Framework of the Recurrent Cycle of Scanxiety*



### Summary

Although the participants described vastly different experiences, the recurring cycle of scanxiety and the hope for lifelong remission were etched into every participant's narrative. The cycle of scanxiety describes the complex repetitive sequence of behavioral and emotional responses manifested by pancreatic cancer survivors during times of their surveillance scans. Fear of cancer recurrence provides the backdrop for the



cycle and shaped the participants' responses as they moved through each phase of the cycle. Finally, hope for lifelong remission describes the underlying driving force propelling participants during diagnostic phases of survivorship. Maintaining hope allowed the participants to hold on to the most positive outcome of complete and lasting remission, often prompting a deliberate change in mindset which allowed for positive growth throughout the cancer journey.

## CHAPTER FIVE

### DISCUSSION

*“I live with fear pretty much on a daily basis. Sometimes it’s in the back of my mind and sometimes it’s in the forefront, but it’s always there. It’s frightening. It’s the unknown. It’s waiting for the other shoe to drop.” (Leah, p. 16, lines 446 – 450).*

The purpose of this study was to illuminate the lived experiences of scanxiety in survivors of pancreatic cancer who have undergone curative surgical resection. Eighteen survivors of pancreatic cancer participated and shared their personal experiences as they underwent a CT scan. Participant interviews were digitally recorded and transcribed verbatim. Hermeneutic phenomenology as applied by Heidegger (1962) provided the philosophical foundation for this study, and van Manen’s phenomenological approach (1990) was used to guide the research process. Thematic analysis uncovered two essential themes: the recurring cycle of scanxiety and hope for lifelong remission. *The recurring cycle of scanxiety* was introduced as a four-stage process describing the complex sequence of events participants experienced during the time surrounding their surveillance scans. Fear of cancer recurrence (FCR) was the primary source of scanxiety. Continuous fluctuations in FCR were common and shaped the participants’ responses throughout each phase of the cycle. *Hope for lifelong remission* served as the primary objective of survivorship, offering a glimmering chance of a cure and keeping survivors engaged throughout the cycle. A conceptual model was developed to provide a

framework for understanding the participants' reactions to their scans. This chapter summarizes the key findings derived from the study and compares and contrasts themes with the current literature. The findings are discussed in the context of the Cancer Recurrence Model (Lee-Jones,1997). The study limitations, implications, and directions for future research are presented.

### **The Recurring Cycle of Scanxiety**

During times surrounding a surveillance scan, the participants experienced significant psychological distress that affected their physical and mental health, impaired their social functioning, and reduced the quality of their lives. Heightened fears of cancer recurrence and scan-related anxiety were extremely distressing and were reported by all participants. Despite the debilitating nature of distress due to scanxiety, patient fears seem to go unnoticed by oncology providers. The lack of recognition by healthcare providers is not surprising. Scanxiety is a relatively new concept in the cancer literature and is not uniformly recognized or measured in published studies (Bui et al., 2022). What little is known about scanxiety is largely based on investigations evaluating the psychological impact of cancer screening scans in healthy patient populations. Among these studies, cancer screening scans have been linked to negative psychosocial consequences in patients at high risk for developing breast, colon, lung, and pancreatic cancers (Bui et al., 2021b; Overbeek et al., 2020; Rasmussen et al., 2015). In the few studies where scan-related anxiety was explored in oncology populations, scanxiety was reported in populations with lymphoma, breast, and lung cancers (Abreu et al., 2017; Bauml et al., 2016; LoRe et al., 2016; Thompson et al., 2010). The prevalence of scanxiety varies greatly, ranging from 37% in long-term lymphoma survivors (Thompson

et al., 2010) to 86% in solid tumors of the lung, breast, and prostate (Grilo et al., 2017). In a recent scoping review on the prevalence and contributing factors associated with scanxiety, Bui et al. (2021a) identified several factors contributing to the increased severity of scanxiety. Variables such as lower education, history of smoking, higher perceived risk of cancer, and higher levels of pain were associated with higher scanxiety severity. Interestingly, the prevalence or severity of scanxiety was not related to age, gender, income, or marital status (Bui et al., 2021a).

There is a general lack of research on the impact of surveillance scans among the pancreatic cancer population. To date, no published studies have explored the concept, despite the debilitating psychological distress known to exist among persons with pancreatic cancer (Watson et al., 2019). The exclusion of pancreatic cancer in the scanxiety literature is discouraging, yet not surprising. Pancreatic cancer is largely under-represented in psychosocial oncology literature, and further research is needed to address the psychological needs of this patient population.

### ***Fear of Cancer Recurrence***

For study participants, the lived experience of undergoing a pancreatic cancer surveillance scan began with fear. Fears of death, pain, further treatments, increased toxicities, and being a burden to one's family were symptoms of a deep-rooted primary fear of the cancer returning. In the literature, fears of recurrence are highly prevalent among cancer survivors regardless of cancer type or stage of the disease. There is a considerable amount of literature demonstrating that most cancer survivors experience at least some degree of FCR (Sharpe et al., 2018), especially among those with breast (Schapira et al., 2021), lung (Lee et al., 2020), ovarian (Ozga et al., 2015), pancreatic

(Petzel et al., 2012), prostate (Meissner et al., 2021) and colorectal cancers (Dang et al., 2019). In the current study, increased FCR was commonly associated with increased physical symptoms which survivors interpreted as signs of recurrence, creating a positive feedback loop that further increased FCR. Misrepresentation of normal body symptoms is a known consequence of FCR and often leads to continuous somatization which further increases FCR and cancer-related distress (Tuman et al., 2021).

### ***Influencing Factors***

**Impact of Wait Times.** The time spent waiting for a scan result was described by every participant as the single most important factor influencing anxiety around times of scans. Survivors described increased anxiety, depression, and somatization during extended wait times for scan results. These findings mirror those observed in earlier studies which reported increased anxiety and emotional distress among patients who waited longer than two days to receive radiology results (Woolen et al., 2018). Conversely, several participants experienced shortened wait times and received their results on the same day as their CT scan. This rapid diagnostic pathway not only decreased anxiety while waiting for the scan result but also reduced anxiety and distress in the days leading up to the scan. Survivors reported just "knowing" they would receive the results immediately after their scan provided comfort and reduced pre-scan anxieties. Wait time research in the oncology literature is limited, as research is primarily focused on the diagnosis-to-treatment pathway and not on the length of time waiting on a surveillance scan; however, in non-cancer populations, the negative psychological impact of wait times has been reported. Extended wait times for medical test results are known to induce physical and psychological distress and impair quality of life (Howell & Sweeny,

2016). In some cases, anticipating bad news may provoke more anxiety and distress than actually receiving bad news itself (Sweeny & Falkenstein, 2015).

**Impact of Time since Diagnosis.** Research examining the trajectories of FCR over time has not been consistent. Many studies have reported moderate to severe FCR that lessens over time (Götze et al., Mulcahy 2019, 2020; Leclair et al., 2019; Wu et al., 2019), whereas other studies report FCR is stable over the course of survivorship or even worsens five years out from diagnosis (McGinity et al., 2016; Schapira et al., 2021). The findings from this study indicate the age of survivorship may impact the severity of scanxiety over time. Two participants reported experiencing decreased scan-related anxiety as their age of survivorship increased. As noted in the literature review, very little is known about the course of scan-related anxiety over time. Research examining the concept is limited since most studies used a cross-sectional design. The single-point in time approach fails to explore temporal factors that may influence the prevalence and severity of scanxiety over the survivorship trajectory.

**Impact of Relationships.** Social support is strongly linked to a better quality of life during cancer survivorship (Aydın Sayılan & Demir Doğan, 2020). Surprisingly, in the days leading up to the scan, the support of family and friends was not described as an essential element to assuage scan-related fears. Preparing for an upcoming cancer scan was largely described as a solitary experience, as many participants chose to keep scan-related fears and concerns to themselves. This type of emotional withdrawal allowed participants to limit triggering conversations that could increase scan-related anxiety. The use of avoidance behaviors such as social isolation and emotional withdrawal was

reported in the cancer literature and are maladaptive, leading to poorer health outcomes (Hall et al., 2018; Jeong et al., 2016; Leung et al., 2021).

A critical finding in this study was the influence of the patient-provider relationship on psychological wellbeing. It was important for survivors to perceive their oncologists as trustworthy, knowledgeable, and highly skilled in the management of pancreatic cancer. These factors helped lessen fears of recurrence and decreased scan-related distress. This finding is not surprising and is strongly supported in the literature (Blödt et al., 2021; Niranjana et al., 2020; Torbit et al., 2016; Truong et al., 2019). A therapeutic patient-provider relationship is a critical component of high-quality, patient-centered care. Within the context of cancer, the relationship between the patient and the oncologist is particularly important. Ongoing advancements and breakthroughs in cancer research continue to yield more targeted drug therapies and multidisciplinary treatment modalities which can overwhelm and unsettle patients and their families. Patients need to perceive their provider as up to date with the latest advancements and as having the primary goal of improving the quality and quantity of their life (Heuser et al., 2020; Kelly et al., 2019). Participants who trusted their oncologist's ability to handle recurrent disease believed having faith in their provider lessened their anxieties around the time of their scan. Conversely, differing opinions and lack of communication among oncology providers increased scan-related anxiety and uncertainty. Participants expected their oncology providers to be in direct communication with one another and always "on the same page". Several participants perceived some form of disconnect between their medical and surgical oncologists. Often the perceived discrepancy stemmed from a casual, off-hand comment made by one provider about another. Questions such as, "What

did Doctor X think of your scan?" were perceived by the patient as a lack of communication among providers and increased anxiety. A small number (2/18) of those interviewed described provider disagreements over type and duration of adjuvant chemotherapy, in which one oncologist expressed doubt over the other oncologist's treatment plan. In these cases, participants worried their chemotherapy may not be effective and experienced significant fears of recurrence and psychological distress that lasted well beyond the interval of time surrounding the scan.

**The Impact of Scan Procedure.** Interestingly, the scanxiety experience largely centered around the days leading up to the scan rather than the scan procedure itself. In the participants' descriptions of their scan experiences, they often left out the experience of undergoing the scan procedure. Although many participants reported the unpleasantness of drinking the oral contrast and the discomfort of being "stuck" by the needle for the intravenous contrast, these discomforts were accepted as routine events that are a normal part of cancer care. Bui et al. (2021a) reported similar study findings in qualitative interviews among solid tumor cancer survivors in late-stage survivorship. These findings are also supported in the quantitative literature (Abreu et al., 2017; Bauml et al., 2016; LoRe et al., 2016) and indicate the source scanxiety may be entirely related to the anticipation of scan result rather than the fear of the scan procedure.

### ***Uncertainty in Illness***

A key source of scanxiety stemmed from the uncertainty and unpredictability of the disease. Most of the participants understood the incurable nature of a pancreatic cancer recurrence, and this knowledge heightened a sense of uncertainty and provoked a fear of cancer recurrence that shaped their response to the upcoming scan. Participants in



the study exhibited distinctly different psychological and behavioral responses to their scan with varying levels of severity. Participants who described themselves as needing to be in control appeared to have more difficulty accepting the uncertainty surrounding the surveillance scan period. Rotter's Locus of Control (LOC) Theory (1966) describes how individuals discern the external influences impacting their lives. Individuals with an internal LOC tend to see themselves as in control of their own circumstances and believe their health outcomes are determined by their own actions. In contrast, individuals with an external LOC view themselves as having little control over their circumstances and believe their health outcomes are determined by external influences, outside of their control. In persons with cancer, someone with an external LOC may be able to tolerate uncertainty better than someone with an internal locus of control. Brown et al. (2017) explored locus of control, mental health, and quality of life among terminal cancer patients and found higher levels of LOC were associated with increased depression and anxiety and decreased peace, faith, and hope. This finding is consistent with previous uncertainty literature in which uncertainty in cancer is a known predictor of poor health outcomes including increased physical and psychological morbidities (Ghodraty Jabloo et al., 2017; Guan et al., 2020a, 2020b).

One unanticipated finding was the participants' inconsistent preference for certainty over uncertainty. Nearly every participant described an intolerance for the uncertainty associated with a pancreatic cancer diagnosis, yet most (14/18) preferred "not knowing" how recurrent disease would be managed. Only four participants preferred to know the treatment strategy if a cancer recurrence was detected. This rather contradictory finding may be explained by Mishel's Uncertainty in Illness Theory (1988, 1990). Mishel

describes the concept of “illness uncertainty” as a cognitive state which represents the person’s inability to interpret illness-related events. Initially, illness uncertainty is viewed as a neutral event. A person will appraise the uncertainty based on their own knowledge and experience and will decide if the uncertainty represents a threat or an opportunity. If an individual views the uncertainty as a threat or danger, they may seek ways to minimize the uncertainty in order to gain control over the illness. If the individual appraises the uncertainty as an opportunity, they may attempt to maintain the uncertainty by perpetuating the ambiguity of their illness. The latter often occurs when the alternative to uncertainty is negative certainty. For example, a patient with an extensive smoking history and a new development of hemoptysis may refuse to seek care, preferring uncertainty or *not knowing* to a possible diagnosis of lung cancer. Mishel’s theory may explain why participants in this study feared uncertainty when there was hope for a positive outcome, (i.e., negative CT scan indicating continued remission), but preferred uncertainty in the context of a cancer recurrence, when the inevitable outcome would be death from disease (Mishel, 1988, 1990).

### ***Coping***

Several coping strategies were described by participants as they prepared themselves for their upcoming scan. Most of the participants described a process of contingency planning which involved contemplating life plans if a cancer recurrence was detected on their scan. This finding corroborates the qualitative research findings of Latella et al. (2020) which described mental planning as an important coping mechanism used to reduce FCR in lymphoma survivors. In the current study, participants alternated contingency planning with the use of avoidant coping strategies aimed at distracting

themselves from thinking about their upcoming scan. These results agree with the findings in other studies in which avoidant-coping strategies were reported as a primary method of reducing anxiety-provoking thoughts (Cohee et al., 2021; Inan & Ustun, 2018; Latella et al., 2020).

Participants reported numerous external stimuli which disrupted distraction-coping methods and increased FCR. The host of the television show *Jeopardy*, Alex Trebek, who died from pancreatic cancer during this study, was a commonly reported trigger of FCR. Other reported triggers included watching a commercial for cancer-related therapies, reading cancer-related postings on social media, and receiving notifications from healthcare providers. The negative psychological impact of cancer-related media on the well-being of cancer survivors is well-documented in the literature. Numerous studies have reported similar findings among survivors of breast, lung, colon, and prostate cancers (Cohee et al., 2021; Latella et al., 2020; Luo et al., 2020; Şengün İnan & Üstün İnan, 2018).

### **Hope for Lifelong Remission**

The participants in this study experienced a distinct hope and belief in complete, long-term remission and this hope made it possible to endure scan-related distress in the days leading up to the scan. The hope for a complete recovery was implicit, and often unspoken, yet was nurtured by every participant in the study. The surveillance scan served as a mechanism to keep hope alive. Participants wanted to believe they could be cured of their pancreatic cancer, and the surveillance scan provided a way to foster that belief.

Hope is an important coping strategy during a life-threatening illness and is known to enhance coping skills and a sense of well-being (Corn et al., 2020). In cancer populations, hope is widely reported as a protective factor against cancer-related distress and is linked to positive mental health outcomes including decreased anxiety and depression and increased quality of life (Baczewska, 2020; Grealish et al., 2019). Although no previous study has investigated the concept of hope in survivors of pancreatic cancer, there has been a considerable amount of literature published on the benefits of hope in other cancer subtypes and throughout all stages of survivorship. In quantitative studies, hope is positively associated with psychological resilience, a sense of well-being, and enhanced adjustment to illness in breast, colorectal, and lung cancer populations (Baczewska, 2019; Nieron-van Baalen et al., 2016, 2020; Y. Zhang et al., 2020). Hope is a highly prevalent coping strategy in patients with advanced-stage cancers; research has shown palliative care patients can have hope equally as strong as curative patients (Baczewska, 2019, 2020; Nieron-van Baalen et al., 2016; Wang & Ling, 2016).

**Factors Influencing Hope.** Factors influencing hope were explored in several studies. In a systematic review examining factors associated with hope during cancer treatment, hope was positively associated with quality of life, social support, and spiritual well-being and negatively associated with symptom burden, psychological distress, and depression (Nierop-van Baalen et al., 2020). In a systematic review of the biopsychosocial correlates of hope in Asian cancer populations, hope was positively associated with income, performance status, and having an early-stage cancer diagnosis,

and was negatively associated with fatigue, pain, and feelings of uncertainty (Mahendran et al., 2016).

The primary object of hope for participants in the study was the expectation of complete recovery from their cancer. Secondary objects of hope included the hope to reach family milestones (e.g., weddings, the birth of a grandchild, etc.), to avoid further treatments, and to recover from pain and toxicities of chemotherapy. Six participants described a process of reframing hope in which the focus of hope was expanded to include other more attainable outcomes such as the hope to live “one more day.” Quantitative research has reported similar findings. In a cross-sectional study examining the role of hope in persons with advanced cancer, Peh et al. (2017) reported on reappraisals of hope throughout the cancer trajectory. Hope reappraisal was positively associated with life satisfaction and inversely associated with affect. The hope experienced by participants in the study was fragile and fluid; it was in constant flux in response to several factors. Hope could be diminished by external stimuli such as hearing about a cancer death in the news or unsolicited advice from a well-intentioned loved one. This finding is consistent with the literature where hope is described as a multidimensional and ever-changing process (Nierop-van Baalen et al., 2016, 2020; Petri & Berthelsen, 2015). In a study of hope and healing in patients living with advanced non-small cell lung cancer, Eustache et al. (2014) described a process where hope was diminished or lost entirely, regained, and reshaped as patients learned to live with their advanced-stage diagnoses. Similarly, participants in this study experienced a continuous change in levels of hope. Hope was maintained by a conscious effort on the part of the participant. As the scan date approached, participants worked harder to keep hope alive.

The surveillance scan served as a threat to hope before the procedure, but interestingly became a source of hope afterward.

Participants described their surveillance scan as paradoxical in nature, on one hand causing increased anxiety and fears of recurrence and on the other providing reassurance and hope for a long-term cure. Surveillance scans were terrifying, yet they offered survivors the chance of freedom from life-threatening illness and a path to reclaim their pre-cancer lives. Contrary to previous literature in which patients perceived their cancer scan as a “necessary evil” (Bui et al., 2021; Thompson et al., 2010), the participants viewed their scan as a lifeline. The scans were symbolic of future birthdays, graduations, Christmases, and vacations. When facing a disease with extremely low rates of survival, surveillance scans provided passage out of the hopelessness of incurable illness and into a life filled with the possibility of rebirth.

### **Conceptual Model of Research Findings**

This research is the first to offer a conceptual framework to guide our understanding of the lived experience of scanxiety. The comprehensive conceptual model of scanxiety provides insight into how cancer survivors are affected by post-treatment surveillance scans. The framework can be used as a resource to educate clinicians about the critical time points surrounding a scan and to facilitate early recognition and intervention for psychological distress.

### **Relevant Theoretical Framework**

Each survivor’s experience of facing a surveillance scan was centered around a fear of the cancer returning. The fear of cancer recurring was visceral and shaped the survivor’s emotional and behavioral response throughout the scan period. The Fear of

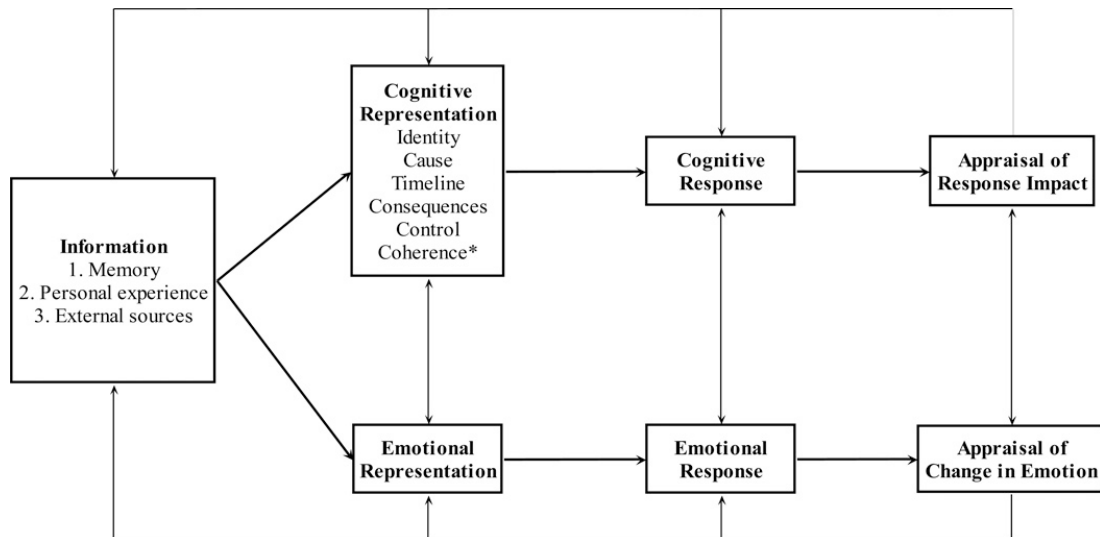
Cancer Recurrence Model (Lee-Jones et al., 1997) can be used as a framework to understand how internal and external cues, cognitions, and emotions can impact how pancreatic cancer survivors experience and respond to their surveillance scans.

### ***Lee-Jones's Fear of Cancer Recurrence Model***

Theory provides a contextual framework for examining a specific phenomenon through varying lenses. While there is not a conceptual model specific to scan-related anxiety in cancer populations, the Self-Regulation Model of Illness (SRM) developed by Leventhal et al. (1992) and later expanded by Lee-Jones et al. (1997) provides a useful framework. As shown in Figure 4, the SRM describes the processes by which individuals become aware of a health threat, navigate affective responses to the threat, and develop coping strategies to manage the threat. The model posits that when individuals are confronted with a health threat, an illness representation of two motivational processing systems (cognitive and emotional) is constructed which act simultaneously to inform a person's response to the threat. The illness representation reflects the individual's common sense understanding of the health threat and is influenced by one's memory and personal experiences, and external sources of information. The individual's illness representation is then used to guide health-related decisions and behaviors. In this model, the individual is viewed as an active problem-solver who must interpret two phenomena simultaneously: (a) the perceived reality of the health threat and (b) the emotional response to that threat (Leventhal et al.). Fear of cancer recurrence was later added to the model by Lee-Jones et al. to explain how cancer-related fears and worries are processed by cancer survivors.

Figure 4

*Leventhal's Self-Regulation Model of Illness*



In the expanded model, FCR is central and is influenced by an individual's internal cues such as physical symptoms and external cues such as follow-up office visits and media sources of information. Cognitions include an individual's perceived risk of recurrence and are influenced by one's personal knowledge of cancer (e.g., cure and survival rates), past experiences of cancer and its treatments, and beliefs about the eradication of initial cancer. Emotions are associated with concerns about cancer returning, general anxiety over the cancer diagnosis, and regret over past treatment decisions. An important contribution of this model is its ability to explain the psychological and behavioral consequences of FCR. The psychological consequences may include symptom misrepresentation (e.g., attributing neutral body symptoms as evidence of cancer recurrence), increased somatic anxiety, or increased propensity to panic attacks. Behavioral consequences can include excessive body checking (e.g.,

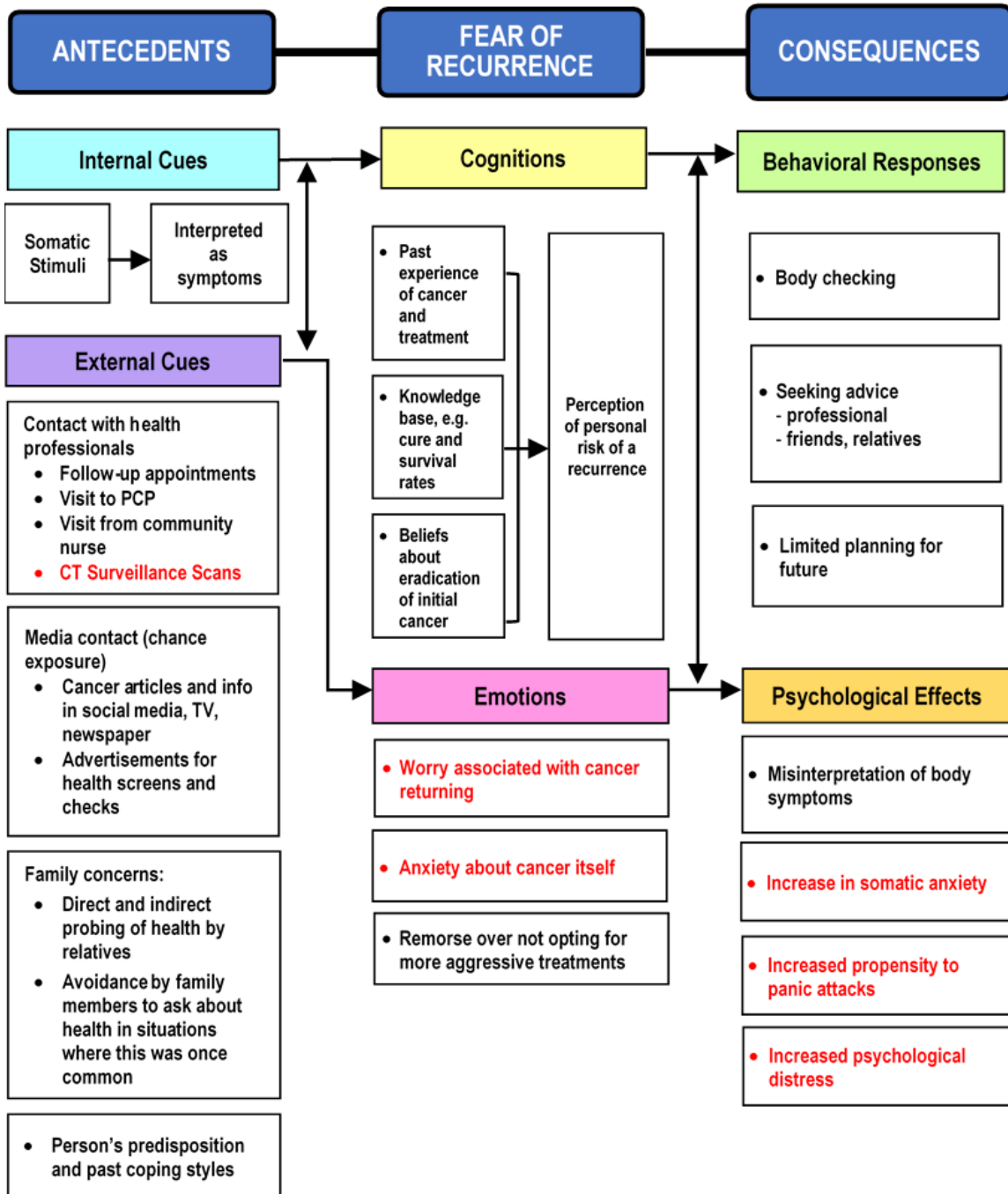


anxious preoccupation with checking for signs and symptoms of cancer), overutilization of the health care system (e.g., increased doctor visits, requesting scans), and limited planning for the future. The Fear of Cancer Recurrence model describes how antecedents, cognitions, and emotions can influence an individual's perceived personal risk for recurrence, and how this perception can lead to behavioral and psychological consequences (Lee-Jones et al., 1997).

As shown in Figure 5, the findings from the current study were mapped onto the Lee-Jones et al. (1997) FCR model to evaluate its applicability to pancreatic cancer survivors during times of surveillance imaging. Existing variables of the model that were supported by the study findings are shown in red. Additional variables identified in this study were added to the model and are highlighted in yellow. The adapted model highlights the internal cues triggering FCR that were supported in this study which include the presence of somatic symptoms, follow-up oncology appointments, and exposure to cancer-related media such as television shows or social media postings. Surveillance scans were incorporated into the model as an additional external cue triggering FCR. Relevant cognitions supported by the qualitative interviews include the patient's knowledge of pancreatic cancer survival rates, understanding of the risk of cancer recurrence, and perception of what a recurrence might indicate (i.e., incurable disease). Finally, the addition of avoidant coping and planning contingencies as behavioral consequences and increased psychological distress as a psychological consequence were supported by the study findings and incorporated into the model. The resulting refined framework supports the applicability of the FCR model during times of cancer surveillance scan imaging. The revised model increases our understanding of the

**Figure 5**

*Modified Fear of Cancer Recurrence Conceptual Model*



numerous factors influencing scan-related anxiety and can guide research in this underexplored area.

### **Limitations**

As with all qualitative research, the small sample size makes the findings less generalizable to larger patient populations. In addition, the participant pool was limited to a specific cancer population that received definitive treatment and had no evidence of disease. The narrow scope of participants further limits generalizability to other cancer populations. Pancreatic adenocarcinoma bears the distinction of being one of the deadliest malignancies worldwide, with a high risk for recurrent disease and a low overall survival rate. Other cancer populations with more favorable prognoses may not experience their surveillance scans in the same way. Because the study was limited to participants with no evidence of disease, it is unknown if similar scanxiety levels would be reported in patients with advanced stages of the disease.

A second limitation is the lack of additional follow-up interviews with the participants. Follow-up interviews were initially planned at the outset of the study; however, changes in participant disease status limited subsequent interviews for many of the participants. For example, throughout the study, nearly half of the participants (8/18) either developed a recurrence of pancreatic cancer or died from the disease. For this reason, the researcher chose to perform one-time interviews with each participant.

A third limitation was the lack of racial diversity in the sample. Although attempts were made to increase the diversity of the sample, all 18 participants were Caucasian. Consequently, this study cannot address whether the lived experience of pancreatic cancer survivors undergoing cancer surveillance scans differs by race of the participants.

A final study limitation involved the unexpected passage of the 21<sup>st</sup> Century Cures Act (2020) on April 5, 2021. This legislation was enacted during study enrollment after 11 participants had completed their interviews. This policy change enabled three participants to view their scan results immediately, using the patient portal My Chart. Passage of this federal law during the study altered the way participants received their scan results and possibly influenced the results obtained. The time spent waiting for a scan result was described by every participant as the single most important factor influencing anxiety around times of scans. Patient portals eliminate prolonged wait times which can exacerbate scanxiety symptoms. The three self-viewing participants received their scan results immediately, which eliminated a prolonged wait time and gave rise to a different scan experience. Further research is needed to explore the implications of the 21<sup>st</sup> Century Cures Act and the impact patient portals have on individuals undergoing cancer surveillance scans.

## **Implications**

### ***Implications for Nursing Practice and Policy***

The findings of this study have important implications for advancing nursing knowledge of scanxiety in cancer populations. Scan-related anxiety can have a profound impact on patients with cancer, as it affects their physical, psychological, and emotional well-being, and subsequently decreases overall quality of life (Janda et al., 2017). In the clinical setting, untreated anxiety interferes with a patient's cognitive functioning by disrupting the processing of new information, impairing memory storage and recall, and interfering with decision-making abilities (Kemp et al., 2020; Woolen et al., 2018). Cancer surveillance scans provide important information regarding the patient's response

to therapy and overall prognosis. Patients with untreated anxiety may not be able to accurately understand or interpret their scan results, thereby limiting their ability to engage in shared medical decision-making with their provider (Derry et al., 2019; Nguyen et al., 2019).

In the clinic setting, there is little understanding of the potential for psychological harm during cancer surveillance scans; thus, patient concerns are not assessed. Cancer distress screening is widely recognized as the sixth vital sign in routine cancer care (Andersen et al., 2015) and was mandated for national cancer center accreditation in 2015 (American College of Surgeons Commission on Cancer [CoC], 2015). Despite these guidelines, distress screening is not routinely performed during key times of cancer survivorship. The current mandate requires cancer centers to screen individuals at least one time during a "pivotal medical visit" which is defined as one of three time points when patients are: (a) starting their initial cancer treatment; (b) transitioning to new treatments (e.g., switching from chemotherapy to radiation therapy); or (c) transitioning off treatments (CoC, 2016; CoC, 2020). The visits surrounding the time for surveillance scans are not mentioned as possible high-distress visits and thus are not recommended time points to evaluate for distress. Nursing is a key discipline within the healthcare system to address this inadequacy. In the clinic setting, oncology nurses are well-positioned to ask patients about any fears or concerns they may have about their upcoming scans and to implement cancer-distress screenings to identify patients who may be at risk. By helping to promote the use of routine distress screening during times of diagnostic scans, nurses can recognize symptoms of distress early and provide the supportive measures needed to improve quality of life across cancer patient populations.

### ***Implications for Research***

The findings of this study add to a growing body of literature highlighting the critical need for distress screenings during the diagnostic phases of cancer survivorship. Post-treatment surveillance scans are an essential component to monitor for disease recurrence, yet the psychological burden of these scans is underexplored in the cancer literature. Scanxiety is a common clinical phenomenon and has been anecdotally observed by oncology clinicians, widely reported in social media, and recognized among many national cancer organizations (Ennis-O'Connor, 2018; Hillard, 2016; Portman, 2019), yet the term “scanxiety” is not part of the medical lexicon and subsequently is not sufficiently defined, explored, or measured in published research studies (Bui et al., 2021; Mulcachy, 2017). Some cancer populations may be at higher risk for psychological harm from surveillance scans. Individuals with cancers associated with a poor prognosis and high symptom burden such as pancreatic and lung cancers may be more likely to develop scanxiety and require early psychological interventions during times of surveillance imaging. Individuals with advanced-stage cancers represent a vulnerable high-risk population and may also need additional support to effectively cope with upcoming scans.

This study uncovered many questions in need of further investigation. A considerable amount of research is needed to better understand the defining features and contributing factors associated with scanxiety. Currently, there is no clear definition or characterization of the term. Establishing a universal definition would provide a foundation for future research and facilitate the development of a scanxiety measure that could be used in empirical investigations and support the development of psychosocial

interventions. Additional research is needed to explore the clinical significance of scanxiety and to help clinicians recognize when scanxiety levels are clinically relevant and require immediate psychosocial interventions. Further research is also needed to identify high-risk populations and to understand the impact of scanxiety over time.

## **Conclusions**

The purpose of this study was to explore the lived experience of survivors of pancreatic cancer who underwent a surveillance scan to monitor for disease recurrence. A recurring cycle of scanxiety and hope for lifelong remission were revealed as the essence of living through a surveillance scan in the face of a pancreatic cancer diagnosis. The results of this study enhance our understanding of the cancer-scan experience and highlight the need for heightened awareness of scanxiety among oncology providers. There is a fundamental need to improve our understanding of the psychological impact of cancer surveillance scans to help guide the development of interventions and improve outcomes across cancer patient populations.

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APPENDIX A

*Summary of Studies Investigating Scanxiety in Cancer*

| <b>Author / Year</b> | <b>Study design</b>                | <b>Sample</b>                                     | <b>Methodological considerations</b>   | <b>Study findings</b>  | <b>Comments</b>  |
|----------------------|------------------------------------|---|--|--|--|
| Abreu et al., 2017   | Longitudinal Pre / posttest design | n = 232<br>Mixed cancer population                | -Anxiety measured immediately pre- and post-PET scan   | -Higher anxiety scores prior to scan<br>-Anxiety higher in men and patients without metastatic disease<br>-No significant differences found in age or education  | No validated instruments used                            |
| Bauml et al., 2016   | Cross-sectional                    | n = 103<br>Recurrent or metastatic lung cancer    | -Distress (IES6) and QOL (FACT-L) measured immediately prior to CT scan  | Scan-distress reported in 83% of patients and significantly impairs QOL ( $p < .004$ )<br>-Distress not associated with time since diagnosis or results of prior scan<br>-No sociodemographic variables associated with severity of distress |  |
| Grilo et al., 2017   | Longitudinal Pre / posttest design | n = 81<br>Lung, breast, prostate, and lymphoma    | Anxiety (STAI) and scan experience questionnaire (SEQ) immediately pre- and post-PET scan  | -Higher anxiety scores post-scan<br>-Scan results are primary source of anxiety<br>-No significant differences between patients undergoing first-time scan   |  |
| Heyer et al., 2015   | Cross-sectional                    | n = 825<br>Mixed cancer and non-cancer population | Anxiety (STAI-S) measured immediately prior to CT scan.<br>10 additional questions given to measure concerns specific to CT scan procedure | -Scan anxiety exists and related to fears of contrast agents, radiation exposure and claustrophobia<br>- Anxiety higher in women, first time scanners, patients receiving IV contrast and patients with solid tumors                         |  |
| LoRe et al., 2016    | Cross-sectional                    | n = 260<br>Mixed cancer and non-cancer population | Anxiety (STAI) measured immediately prior to CT, mammography, MRI, US, X-ray   | -Anxiety present in 91% of patients<br>-Anxiety higher in women, non-cancer patients and patients undergoing US  | Anxiety in US possibly related to immediate test results |

| <b>Author/<br/>Year</b> | <b>Study<br/>design</b>                           | <b>Sample</b>   | <b>Methodological<br/>considerations</b>  | <b>Study findings</b>   | <b>Comments</b>   |
|-------------------------|---|---|---|---|---|
| McGinty et al., 2016;   | Longitudinal<br>7 time points<br>over 2<br>months | n = 161<br><br>Breast cancer,<br>Stage 0-3A, within<br>3 years following<br>primary treatment | Fear of recurrence (FCRI, CWS) and anxiety (VAS1, VAS2) measured at various time points before and after routine mammography  | - Severity of FCR and anxiety significantly change over time<br>- Scores increase prior mammogram, decreased after mammogram and increased again 1 month after.   |   |
| Pifarre et al., 2011.   | Cross-sectional                                   | n = 200<br><br>Mixed cancer population  | Anxiety (STAI) measured immediately prior to PET-CT scan.   | - Anxiety present in 67.5% of patients undergoing PET-CT<br>-Higher anxiety in men, initial cancer staging, and if staging for metastatic disease   | Lower anxiety in patients with known mets and receiving treatment |
| Thompson et al., 2010   | Cross-sectional, mixed methods                    | n= 70 Quant/ n=30 qual Adult lymphoma survivors > 2 years out from cancer treatment           | -Anxiety (STAI) and patient provider relationship measured in outpatient oncology setting<br>-Subset of patients qualitatively interviewed and asked to describe personal experiences with scan | - Clinically significant anxiety in 37% patients<br>-Anxiety positively associated with worse provider relationship and history of relapse<br>- Qualitative interviews found anxiety peaks prior to scan, resolves after scan and related to FCR<br>- No clinical or sociodemographic variables associated with anxiety | Data collection not related to timing of upcoming scan            |
| Yu et al., 2011.        | Cross-sectional                                   | n = 398<br><br>Mixed cancer population  | Anxiety (STAI and HADS) given immediately prior to CT, mammography, MRI, US, X-ray  | Anxiety present in 46% of patients undergoing diagnostic imaging<br>-Anxiety higher in women, younger patients and lower SES  |   |

## APPENDIX B

**STUDY TITLE:** Exploring the Patient Experience of Undergoing Surveillance Scans in Survivors of Pancreatic Cancer

UofL Institutional Review Boards  
UofL Institutional Review Boards  
IRB NUMBER: 19.0454  
IRB NUMBER: 19.0454  
IRB APPROVAL DATE: 05/29/2021  
IRB APPROVAL DATE: 05/16/2019

### Informed Consent and Research Authorization

#### Exploring the Patient Experience of Undergoing Surveillance Scans in Survivors of Pancreatic Cancer

|                       |   |  |
|-----------------------|---|--|
| <b>Investigators:</b> | <b>Robert Martin, MD, PhD</b><br><b>University of Louisville</b><br><b>Division of Surgical Oncology</b><br><b>315 E. Broadway</b><br><b>Louisville, KY 40202</b> | <b>Susan Winebrenner, APRN</b><br><b>University of Louisville</b><br><b>School of Nursing</b><br><b>555 S. Floyd Street</b><br><b>Louisville, KY 40202</b> |
|-----------------------|---|--|

#### Key Summary Information

The purpose of this study is to understand the patient experience of undergoing routine scans to monitor their pancreatic cancer. Participants in this study will agree to be interviewed in 1-2 sessions, lasting approximately 15-30 minutes in length. Interview questions will be open-ended, and will ask participants to describe their own personal experiences of undergoing a scan to monitor their pancreatic cancer. There are no risks associated with this study and no other commitments are required. If you are interested in learning more about this study, please continue to read below.

#### Introduction and Background Information

You are invited to take part in a research study because you have a diagnosis of pancreatic cancer and are undergoing routine scans to monitor your disease. The study is being conducted under the direction of Dr. Robert Martin, MD and Susan Winebrenner, APRN at the University of Louisville. About 10 - 20 local subjects will be invited to take part in this research.

#### Purpose

The purpose of this study is to understand the patient experience of undergoing routine scans to monitor pancreatic cancer.

#### Procedures

Your participation in this study will include an interview that will last approximately 15-30 minutes, in 1 to 2 sessions. The interview will take place in-person, in a private room in your physician's office or over the telephone. The interview questions will be open-ended, meaning they will require more than a "yes" or "no" answer and will encourage you to describe your own personal experiences and feelings about scans that monitor your pancreatic cancer. You do not have to answer any questions that make you feel uncomfortable. Your interview will be recorded and transcribed at a later date. After your initial interview, there may be additional questions the investigator has and if so, you may be asked to answer a few more interview questions. If a follow-up interview is needed, the investigator will contact you and will ask you the questions over the phone. You will not need to come back to the office at any time for this study. After two interviews, no other study interviews or procedures will take place.

#### Potential Risks

There are no foreseeable risks, although there may be unforeseen risks.

#### Benefits

The information collected may not benefit you directly, but may be helpful to others.

IRB Number: 19.0454  
ICF Version 3: 5/24/21  
IRB Expiration Date: 5/15/22

**STUDY TITLE:** Exploring the Patient Experience of Undergoing Surveillance Scans in Survivors of Pancreatic Cancer

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IRB APPROVAL DATE: 05/29/2021  
IRB APPROVAL DATE: 05/16/2019

**Payment**

You will not be compensated for your time, inconvenience or expenses while you are in this study.

**Costs**

There will be no additional cost to you for participating.

**HIPAA Research Authorization**

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides federal safeguards for your protected health information (PHI). State and federal privacy laws also may also require your health information to be protected. By signing this form you provide your permission, called your “authorization,” for the use and disclosure of PHI.

If you sign this form, the research team working on this study will use and share your health information to answer the research questions described in this document, and to make sure that the research was done correctly. This includes things learned from the interviews described in this consent form. The PHI that will be collected, used and shared in this study are your name, date of birth, medical history and the transcripts from the interview(s). Those persons who receive your health information may not be required by Federal privacy laws (such as the HIPAA Privacy Rule) to protect it and may share your information with others without your permission, if permitted by laws governing them.

In most cases, the health information that identifies you can be used or shared by the research team only if you give your permission by signing this form. Your health information may be shared with a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, and conducting public health surveillance, investigations or interventions.

The time period when information can be used or shared ends when all activities related to this study are completed. You do not have to sign this form. If you do not sign this form, you may not participate in the study and health information that identifies you will not be shared for research purposes.

**Revocation of Research Authorization**

You may withdraw the authorization you have given to use and share your protected health information at any time. This means you can tell us to stop using and sharing your protected health information. If you withdraw/revoke your authorization:

- We will stop collecting information about you.
- You may not withdraw information that we had before you told us to stop.
  - We may already have used it or shared it.
  - We may need it to complete the research.
  - We may need it to search records that are available to the public.
- Staff may ask your permission to follow-up with you if there is a medical reason to do so.

To withdraw your authorization, you will be requested to complete a written “Revocation of Research Authorization” form located at the end of this document. You may also obtain a copy from your study doctor, designated personnel or from the Human Subjects Protections Program Office website (<https://louisville.edu/research/humansubjects/templates/biomedical-forms>).

IRB Number: 19.0454  
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**STUDY TITLE:** Exploring the Patient Experience of Undergoing Surveillance Scans in Survivors of Pancreatic Cancer

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### **Confidentiality**

Total privacy cannot be guaranteed. We will protect your privacy to the extent permitted by law. If the results from this study are published, your name will not be made public. Once your information leaves our institution, we cannot promise that others will keep it private.

Your information may be shared with the following:

- Organizations that provide funding at any time for the conduct of the research.
- The University of Louisville Institutional Review Board, Human Subjects Protection Program Office, Privacy Office, others involved in research administration and research and legal compliance at the University, and others contracted by the University for ensuring human subjects safety or research and legal compliance
- The local research team
- People who are responsible for research, compliance and HIPAA/privacy oversight at the institutions where the research is conducted
- People responsible for billing, sending and receiving payments related to your participation in the study
- Applicable government agencies, such as:
  - Office for Human Research Protections
  - Office of Civil Rights
  - Food and Drug Administration
- Those responsible for data safety monitoring related to the study

### **Security**

Your information will be kept private by placing it in a secure, locked cabinet and a password protected computer in a locked office at the University of Louisville School of Nursing.

### **Conflict of Interest**

There is no conflict of interest associated with this study.

### **Voluntary Participation**

Taking part in this study is completely voluntary. You may choose not to take part at all. If you decide not to be in this study, you won't be penalized or lose any benefits for which you qualify. If you decide to be in this study, you may change your mind and stop taking part at any time. If you decide to stop taking part, you won't be penalized or lose any benefits for which you qualify. You will be told about any new information learned during the study that could affect your decision to continue in the study.

### **Termination**

Your study doctor has the right to stop this study at any point. Your study doctor may take you out of this study with or without your okay, if he/she believes it is in your best interest.

### **Participation in Other Research Studies**

You may take part in this study if you are currently in another research study. It is important to let your doctor know if you are in another research study.

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**STUDY TITLE:** Exploring the Patient Experience of Undergoing Surveillance Scans in Survivors of Pancreatic Cancer

UofL Institutional Review Boards  
UofL Institutional Review Boards  
IRB NUMBER: 19.0454  
IRB APPROVAL DATE: 05/29/2021  
IRB APPROVAL DATE: 05/16/2019

### Research Subject's Rights

If you have any questions about your rights as a research subject, you may call the Human Subjects Protection Program Office at (502) 852-5188. You may discuss any questions about your rights as a research subject, in private, with a member of the Institutional Review Board (IRB). You may also call this number if you have other questions about the research, and you cannot reach the study doctor, or want to talk to someone else. The IRB is an independent committee made up of people from the University community, staff of the institutions, as well as people from the community not connected with these institutions. The IRB has approved the participation of human subjects in this research study.

### Questions, Concerns and Complaints

If you have any questions or concerns about the research study, please contact Dr. Robert Martin, 502-583-8303 or Susan Winebrenner, 502-718-0149.

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call the toll free number 1-877-852-1167. This is a 24 hour hot line answered by people who do not work at the University of Louisville.

### Acknowledgment and Signatures

This document tells you what will happen during the study if you choose to take part. Your signature and date indicates that this study has been explained to you, that your questions have been answered, and that you agree to take part in the study. You are not giving up any legal rights to which you are entitled by signing this informed consent document though you are providing your authorization as outlined in this informed consent document. You will be given a copy of this consent form to keep for your records.

\_\_\_\_\_  
Subject Name (Please Print)

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Date Signed

\_\_\_\_\_  
Printed Name of Person Explaining Consent Form

\_\_\_\_\_  
Signature of Person Explaining  
Consent Form (if other than the Investigator)

\_\_\_\_\_  
Date Signed

\_\_\_\_\_  
Printed Name of Investigator (PI, Sub-I, or Co-I)

\_\_\_\_\_  
Signature of Investigator (PI, Sub-I, or Co-I) Date Signed

Investigators: Robert Martin, MD, PhD  
Surgical Oncology  
315 E. Broadway  
Louisville, KY 40202  
502-583-8303 (24 hour)

Susan Winebrenner, APRN  
School of Nursing  
555 S. Floyd Street  
Louisville, KY 40202  
(502) 718-0149

Site(s) where study is to be conducted: University of Louisville Physicians, PSC

IRB Number: 19.0454  
ICF Version 3: 5/24/21  
IRB Expiration Date: 5/15/22

APPENDIX C

Subject Initials    Subject ID      Date:   /   /    
Month Day Year

**Data Collection Form**

|   |  |
|---|--|
| <b>Gender*:</b><br><input type="checkbox"/> Male<br><input type="checkbox"/> Female<br><input type="checkbox"/> Unknown or Not Reported | <b>Ethnicity*:</b><br><input type="checkbox"/> Hispanic<br><input type="checkbox"/> Non-Hispanic<br><input type="checkbox"/> Unknown or Not Reported |
|---|--|

|  |   |
|--|---|
| <b>Race*:</b><br><input type="checkbox"/> American Indian or Alaska Native<br><input type="checkbox"/> Asian<br><input type="checkbox"/> Black or African American | <input type="checkbox"/> Native Hawaiian or Other Pacific Islander<br><input type="checkbox"/> White or Caucasian<br><input type="checkbox"/> Unknown or Not Reported |
|--|---|

**Marital Status\*:**  Single  Married/Partner  Divorced  Widowed  Separated

**Education:**  Some high school  Diploma/GED  Some college  College Degree

**Date of Cancer Diagnosis:** \_\_\_\_\_

**Date of Pancreatic Cancer Surgery:** \_\_\_\_\_

**Pancreatic Cancer Histology:** \_\_\_\_\_

**Cancer Stage:**  IA  IB  IIA  IIB  III  IV

**Received Neoadjuvant Therapy?**  Yes  No  Yes, but discontinued early

**Received Adjuvant Therapy?**  Yes  No  Yes, but discontinued early

**Interval of Time Between Scans:**  3 months  6 months  9 months  12 months

**Date of Signed Consent:** \_\_\_\_\_

**Date of Interview:** \_\_\_\_\_  In-person  By phone

**Form Completed By:** \_\_\_\_\_ **Date:** \_\_\_\_\_



## APPENDIX D

### **Interview Guide--Lived Experience of Surveillance Scans**

Preliminary questions:

“When you have an upcoming surveillance scan, do you find yourself thinking about the scan more than twice a day?”

“Are you comfortable sharing your personal experiences with your scans?”

#### **Interview Questions:**

1. Since receiving your diagnosis, tell me about your experience as a survivor of pancreatic cancer.

#### **DAYS LEADING UP TO SCAN**

2. Can you describe the days leading up to your scan?
  - How do you generally know when it’s time to have your scan?
  - Who orders this scan?
  - How do you remember the date?
  - Experience with medical staff?
  - Do you tell others about your upcoming scan?
  - How do you **pass the time** in days leading up to your scan? \*Physical / Behavioral changes prior to scan
  - Do you find yourself thinking about your scan often?
  - Do you notice any changes in your emotions before your scan?
  - Does your family notice any changes in you prior to your scan?
  - Any coping strategies used

#### **THE SCAN**

3. Describe the day of your scan.
4. Transportation to scan
5. Alone or accompanied?
6. Describe the scan procedure
  - Do you do ok with IV and contrast?
  - Radiology Dept staff demeanor?
  - Radiology staff competency?
  - What do you think about when you are in the CT scanner?
  - What is your emotional reaction to scan procedure?

## **RESULTS**

7. How do you get your scan results?
  - How long do you have to wait?
  - How do you pass the time while you wait?
  - Do you prefer to be with people or alone?
  - How do you react emotionally to the wait?
  - What things do you think about?
8. Have you ever found out results from patient portal?
  - If so, describe this experience?
  - Would you rather know immediately or wait until Dr can tell you and hear his impression / recommendations?
9. What information was given to you when you received your results?
10. What was your emotional reaction to the results?
  - Physical / behavioral reaction? (holding someone's hand, clenching fist?)
11. How did the staff treat you in the Dr's office?
  - Were you treated any different from other non-scan visits?
12. After leaving the Dr.'s office, did you feel like you properly understood your results?
13. Afterward, what did you do after receiving your scan results?

## **OVERALL EXPERIENCE**

14. Are there any factors that influence your experience with your scans?
15. Tell me about your experience during *non-scan times*.
16. Do your scans hold any meaning for you?
17. Describe what things may help you cope?
18. Is there any aspect of the scan experience you find most difficult?
19. Is there anything you do to help yourself (emotionally or physically) prepare for your upcoming scans?
20. Are there any factors that hinder your coping during this period?

APPENDIX E

| Themes                                     | P1 | P2 | P3 | P4 | P5 | P6 | P7 | P8 | P9 | P10 | P11 | P12 | P13 | P14 | P15 | P16 | P17 | P18 |
|--|----|----|----|----|----|----|----|----|----|-----|-----|-----|-----|-----|-----|-----|-----|-----|
| Fear of cancer returning                   | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | x   | x   | x   | x   | x   | x   | x   | x   |
| Recurring cycle of Scanxiety               | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | x   | x   | x   | x   |     | x   | x   | x   |
| Anxiety rises 1-2 weeks prior scan         | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | x   | x   | x   | x   |     | x   | x   | x   |
| Limits discussions of upcoming scans       | x  |    | x  |    |    | x  |    |    |    | x   |     |     | x   |     |     | x   | x   | x   |
| Scan Peak prior to results                 | x  | x  |    | x  | x  | x  |    |    | x  | x   | x   | x   | x   | x   | x   | x   | x   | x   |
| Anxiety increased w incr wait time         | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | x   | x   | x   | x   | x   | x   | x   | x   |
| Bi-Modal anxiety                           |    | x  | x  |    |    | x  |    |    |    |     |     |     |     |     |     |     |     |     |
| Incongruence among providers               | x  | x  |    |    | x  | x  |    |    | x  | x   | x   | x   | x   | x   |     | x   | x   | x   |
| Relationship w provider impacts anxiety    | x  | x  | x  | x  | x  | x  |    | x  |    | x   | x   | x   | x   | x   | x   | x   | x   | x   |
| Sleep disturbances                         | x  | x  | x  | x  | x  | x  | x  |    |    | x   | x   | x   |     | x   | x   | x   | x   | x   |
| Assume recurrence is fatal                 | x  | x  | x  | x  |    |    | x  | x  |    | x   |     | x   | x   |     |     |     | x   | x   |
| Negative interaction with med/rad staff    | x  | x  |    |    | x  |    |    |    | x  | x   |     | x   |     | x   |     |     | x   | x   |
| Assuming Death from PC/Fatalism            | x  | x  | x  |    |    |    |    |    | x  | x   |     | x   | x   | x   |     | x   | x   | x   |
| Scanxiety has decreased over time          |    |    | x  |    |    |    |    |    |    |     |     |     |     |     |     |     |     | x   |
| Believe anxiety is lifelong                | x  | x  | x  |    |    | x  | x  | x  | x  | x   | x   | x   | x   | x   | x   | x   | x   | x   |
| Distractions as coping                     | x  | x  | x  | x  | x  | x  |    |    | x  | x   | x   | x   | x   | x   | x   | x   | x   | x   |
| Scan is good and valuable                  | x  | x  | x  | x  | x  | x  |    | x  | x  | x   | x   | x   | x   | x   | x   | x   | x   | x   |
| Refocusing on what is important            |    |    | x  | x  | x  | x  |    |    | x  | x   | x   | x   | x   | x   |     |     |     | x   |
| Mentioned alex trebek / Jeopardy           |    |    | x  | x  | x  |    |    |    |    | x   |     |     |     | x   |     |     | x   | x   |
| Scan discrepancy with scheduling           |    |    |    |    |    |    |    |    | x  |     | x   |     |     | x   |     |     |     |     |
| Continuous anxiety all the time            | x  | x  | x  | x  | x  | x  |    | x  | x  | x   | x   | x   | x   | x   | x   | x   | x   | x   |
| Symptoms increase anxiety                  |    | x  | x  |    | x  | x  |    |    | x  |     |     | x   |     |     |     |     | x   | x   |
| Want to bring someone to result visit      | x  | x  | x  | x  |    | x  |    | x  | x  | x   | x   | x   | x   | x   | x   | x   | x   |     |
| Kids in Household incr anxiety             |    |    | x  |    |    | x  |    |    |    |     |     |     | x   |     |     |     |     |     |
| Understand dismal stats in PC dx           | x  | x  | x  |    |    |    |    | x  | x  | x   |     | x   | x   | x   |     | x   | x   | x   |
| Reframing hope                             |    |    | x  |    | x  | x  |    |    | x  |     |     |     | x   |     |     |     | x   |     |
| Compartmentalization as coping             | x  |    | x  | x  |    | x  | x  |    |    | x   | x   | x   | x   | x   |     | x   | x   | x   |
| Living scan to scan/one day at time        | x  | x  | x  |    |    | x  | x  | x  | x  | x   | x   | x   | x   | x   | x   | x   | x   | x   |
| Describes self as high locus of control    |    |    |    |    |    |    |    |    | x  | x   |     |     |     | x   |     |     | x   | x   |
| Feeling healthier after receiving neg scan |    |    | x  |    | x  | x  |    |    | x  | x   |     | x   | x   |     |     |     | x   | x   |
| Patient portal reduces anxiety             |    |    | x  |    | x  | x  |    | x  | x  | x   | x   | x   |     | x   |     |     | x   | x   |
| Assume delays r/t cancer recurrence        | x  | x  | x  |    |    | x  |    |    | x  | x   |     | x   | x   | x   |     |     | x   | x   |
| Trying live in present                     |    |    | x  | x  |    | x  |    |    | x  | x   | x   | x   |     |     |     | x   | x   | x   |
| Psychological manifestations               | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | x   | x   | x   | x   | x   | x   | x   | x   |

| <b>Themes</b>                       | <b>P1</b> | <b>P2</b> | <b>P3</b> | <b>P4</b> | <b>P5</b> | <b>P6</b> | <b>P7</b> | <b>P8</b> | <b>P9</b> | <b>P10</b> | <b>P11</b> | <b>P12</b> | <b>P13</b> | <b>P14</b> | <b>P15</b> | <b>P16</b> | <b>P17</b> | <b>P18</b> |
|-------------------------------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|------------|------------|------------|------------|------------|------------|------------|------------|------------|
| Contingency planning                | x         | x         | x         | x         |           | x         |           |           | x         | x          | x          | x          | x          | x          | x          | x          | x          | x          |
| Intolerance for Uncertainty         | x         | x         | x         | x         | x         | x         | x         | x         |           | x          | x          | x          | x          | x          |            | x          | x          | x          |
| Changes in mood prior to scan       | x         | x         | x         |           | x         | x         |           |           | x         | x          | x          | x          | x          | x          | x          | x          | x          | x          |
| Irritability/ Anger prior to scan   | x         | x         | x         |           |           | x         |           |           |           |            |            |            | x          | x          |            |            |            |            |
| Psychosomatic symptoms              |           |           | x         |           | x         | x         |           |           | x         |            |            |            |            |            |            |            | x          |            |
| Control r/t contingency planning    |           |           |           |           |           |           |           |           |           | x          |            |            |            |            | x          |            |            | x          |
| Received scan results from My Chart |           |           |           |           |           |           |           |           |           |            | x          |            |            | x          |            |            | x          | x          |
| Waited > 1 week for scan results    |           |           | x         |           |           | x         |           |           |           |            |            |            |            |            |            | x          |            |            |
| Short lived reassurances            | x         | x         | x         | x         |           | x         |           |           | x         | x          | x          | x          | x          | x          | x          |            | x          | x          |
| Mentioned phrase scan to scan       | x         |           | x         | x         |           |           |           |           | x         |            |            |            |            |            |            |            | x          | x          |

APPENDIX F



Human Subjects Protection Program Office
MedCenter One – Suite 200
501 E. Broadway
Louisville, KY 40202-1798
Office: 502.852.5188 Fax: 502.852.2164

DATE: May 24, 2019
TO: Carla P Hermann
FROM: The University of Louisville Institutional Review Board
IRB NUMBER: 19.0454
STUDY TITLE: Exploring Scan-Related Anxiety in Pancreatic Cancer: A Qualitative Study
REFERENCE #: 683655
IRB STAFF CONTACT: Sherry Block 852-2163 slbloc04@louisville.edu

This study was reviewed on 05/13/2019 by the Chair/Vice Chair of the Institutional Review Board and approved with changes through Expedited Review Procedure, according to 45 CFR 46.110(b), since this study falls under Category 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

The changes were reviewed and approved by HSPPPO staff on 05/16/2019.

This study now has final IRB approval from 05/16/2019 through 05/15/2022.

The following items have been approved:

Table with 4 columns: Submission Components, Title, Version #, Version Date, Outcome. Rows include Interview Guide - Appendix B, Study Protocol, Data Collection Form, ICF Revision 5-15-19 Clean, and HIPAA Partial Waiver.

Your study does not require annual continuing review. Your study has been set with a three year expiration date. If your study is still ongoing you will receive IRIS automated reminders to submit a request to continue your study prior to the expiration date above.

All other IRB requirements are still applicable. You are still required to submit amendments, personnel changes, deviations, etc... to the IRB for review. Please submit a closure amendment to close out your study with the IRB if it ends prior to the three year expiration date.

Human Subjects & HIPAA Research training are required for all study personnel. It is the responsibility of the investigator to ensure that all study personnel maintain current Human Subjects & HIPAA Research training while the study is ongoing.

For guidance on using IRIS, including finding your approved stamped documents, please follow the instructions at <https://louisville.edu/research/humansubjects/iRISSubmissionManual.pdf>

**Please note:** Consent and assent forms no longer have an expiration date stamped on them. The consent/assents expire if the study lapses in IRB approval. Enrollment cannot take place if a study lapses in approval. For additional information view [Guide 038](#).

#### **Site Approval**

If this study will take place at an affiliated research institution, such as KentuckyOne Health, Norton Healthcare or University of Louisville Hospital/James Graham Brown Cancer Center, permission to use the site of the affiliated institution is necessary before the research may begin. If this study will take place outside of the University of Louisville Campuses, permission from the organization must be obtained before the research may begin (e.g. Jefferson County Public Schools). Failure to obtain this permission may result in a delay in the start of your research.

#### **Privacy & Encryption Statement**

The University of Louisville's Privacy and Encryption Policy requires such information as identifiable medical and health records: credit card, bank account and other personal financial information; social security numbers; proprietary research data; dates of birth (when combined with name, address and/or phone numbers) to be encrypted. For additional information: <http://security.louisville.edu/PolStds/ISO/PS018.htm>.

#### **Implementation of Changes to Previously Approved Research**

Prior to the implementation of any changes in the approved research, the investigator will submit any modifications to the IRB and await approval before implementing the changes, unless the change is being made to ensure the safety and welfare of the subjects enrolled in the research. If such occurs, a Protocol Deviation/Violation should be submitted within five days of the occurrence indicating what safety measures were taken, along with an amendment to revise the protocol.

#### **Unanticipated Problems Involving Risks to Subjects or Others (UPIRTSOs)**

In general, these may include any incident, experience, or outcome, which has been associated with an unexpected event(s), related or possibly related to participation in the research, and suggests that the research places subjects or others at a greater risk of harm than was previously known or suspected. UPIRTSOs may or may not require suspension of the research. Each incident is evaluated on a case by case basis to make this determination. The IRB may require remedial action or education as deemed necessary for the investigator or any other key personnel. The investigator is responsible for reporting UPIRTSOs to the IRB within 5 working days. Use the UPIRTSO form located within the iRIS system to report any UPIRTSOs.

#### **Payments to Subjects**

As a reminder, in compliance with University policies and Internal Revenue Service code, all payments (including checks, pre-paid cards, and gift certificates) to research subjects must be reported to the University Controller's Office. For additional information, please contact the Controller's Office at 852-8237 or [controll@louisville.edu](mailto:controll@louisville.edu). For additional information: <http://louisville.edu/research/humansubjects/policies/PayingHumanSubjectsPolicy201412.pdf>

Full Accreditation since June 2005 by the Association for the Accreditation of Human Research Protection Programs, Inc.

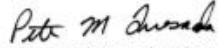


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The committee will be advised of this action at a regularly scheduled meeting.

If you have any questions, please contact the IRB analyst listed above or the Human Subjects Protection Program office at [hspofc@louisville.edu](mailto:hspofc@louisville.edu).

Sincerely,



Peter M. Quesada, Ph.D., Chair  
Social/Behavioral/Educational Institutional Review Board

We value your feedback. Please let us know how you think we are doing:  
<https://www.surveymonkey.com/r/CCLHXP>

Full Accreditation since June 2005 by the Association for the Accreditation of Human Research Protection Programs, Inc.



## APPENDIX G

### *Essential Themes and Subthemes of the Lived Experience of Scanxiety*

| <b>Theme and Description</b>   | <b>Subthemes</b>   |
|--|--|
| Recurring cycle of scanxiety<br>A complex repetitive pattern of behavioral and emotional responses manifested by survivors during the time surrounding their surveillance scans. | Fear of cancer recurrence<br>Mental preparation<br>Proof of life<br>Waiting to exhale<br>Resetting the clock |
| Hope for lifelong remission<br>The intense desire for a complete recovery and a return to normal life.   | Balancing fatalism and optimism<br>Reframing hope  |



## CURRICULUM VITA

Susan Ellis Winebrenner, MSN, APRN, AGNP-BC, OCN

1906 Mount Sterling Drive, Sellersburg, Indiana 47172  
susan.winebrenner@gmail.com Phone: (502) 718-0149

### Education

- 2018 – Present      **University of Louisville**  
PhD Candidate – School of Nursing
- 2016                    **University of Louisville**  
Adult-Gerontology Primary Care Nurse Practitioner Program  
Master of Science in Nursing, Summa Cum Laude
- 2012                    **University of Louisville**  
Bachelor of Science in Nursing, Summa Cum Laude
- 2008                    **Jefferson Community College**  
Associate Degree in Nursing, President’s Scholar
- 2001                    **Indiana University**  
Bachelor of Arts, Biology with Chemistry Minor, Magna Cum  
Laude

### Licensure

- Advanced Practice Registered Nurse, Commonwealth of Kentucky  
License # 3010325
- Registered Nurse, Commonwealth of Kentucky License # 1117788
- Advanced Practice Registered Nurse, Indiana # 71006386A
- Registered Nurse, Indiana License # 28226500A

### Certifications

- Adult-Gerontology Nurse Practitioner (AGNP) - AANP
- Oncology Certified Nurse (OCN®)

Chemotherapy Biotherapy Certified, ONS

Certified Clinical End-of-Life Nursing Education Consortium (ELNEC) Geriatrics – Core Trainer **Awards**

2019 Research! Louisville Nursing Graduate Student Award  
Outstanding Poster Presentation

2016 Leadership in Service Award – MSN  
Excellence in academic achievement and service

2012 Outstanding Community Health Student Award – BSN  
Excellence in undergraduate community health nursing

### **Experience**

2018 – Present Graduate Research Assistant  
University of Louisville, School of Nursing

2017 – Present Oncology Nurse Practitioner  
Norton Cancer Institute

2016 –2017 Primary Care Nurse Practitioner  
MD2U

2008 – 2015 Oncology Registered Nurse  
University of Louisville – Surgical Oncology

2003 – 2008 Research Coordinator – Oncology  
University of Louisville – Surgical Oncology

2002 – 2003 Research Technologist II  
University of Louisville – Neurological Surgery

### **Funding Support**

2021 Ruth Craddock Research Grant (*Internal grant*) \$570.35

2019 Graduate Student Research Council Award (*Internal grant*) \$350

2019 Ruth Craddock Funding Award (*Internal grant*) \$600

2019 Graduate Student Research Council Award (*Internal grant*) \$500

2019 Oncology Nursing Foundation Research Doctoral Scholarship \$5,000

## Publications

Martin, R., Cannon, R., Brown, R., **Ellis, S.**, Williams, S., Scoggins, C. R., & Abbas, A. E. (2014). Evaluation of quality of life following placement of self-expanding plastic stents as a bridge to surgery in patients receiving neoadjuvant therapy for esophageal cancer. *The Oncologist*, *19*(3), 259 – 265. doi: 10.1634/theoncologist.2013-0344

Cannon, R. M., **Ellis, S.**, Hayes, D., Narayanan, G., & Martin, R. C. G. (2013). Safety and efficacy of irreversible electroporation for hepatic tumors in proximity to vital structures. *Journal of Surgical Oncology*, *107*(5), 544-549. doi: 10.1002/jso.23280

Bower, M. R., **Ellis, S. F.**, Scoggins, C. R., McMasters, K. M., & Martin, R. C. G. (2011). Phase II comparison study of intraoperative autotransfusion for major oncologic procedures. *Annals of Surgical Oncology*, *18*(1), 166-173. doi: 10.1245/s10434-010-1228-4

Brown, R. E., Abbas, A. E., **Ellis, S.**, Williams, S., Scoggins, C. R., McMasters, K. M., & Martin, R. C. G., 2nd. (2011). A prospective phase II evaluation of esophageal stenting for neoadjuvant therapy for esophageal cancer: Optimal performance and surgical safety. *Journal of the American College of Surgeons*, *212*(4), 582-589. doi: 10.1016/j.jamcollsurg.2010.12.026.

Martin, R. C. G., McFarland, K., **Ellis, S.**, & Velanovich, V. (2012). Irreversible electroporation in the management of locally advanced pancreatic adenocarcinoma. *Journal of the American College of Surgeons*, *215*(3), 361-369. doi: 10.1016/j.jamcollsurg.2012.05.021.

Martin, R. C., Philips, P., **Ellis, S.**, Hayes, D., & Bagla, S. (2014). Irreversible electroporation of unresectable soft tissue tumors with vascular invasion: Effective palliation. *BMC Cancer*, *14*, 540. doi: <http://org/10.1186/1471-2407-14-540>

Miller, A., Brown, R., St Hill, C., Roach, B. A., **Ellis, S. E.**, Scoggins, C. R., McMasters, K. M., & Martin, R. C. G. (2013). Health-related quality of life changes following major hepatic resection: The impact of complications and post-operative anemia. *The American Journal of Surgery*, *206*(4), 443-450. doi: 10.1016/j.amjsurg.2013.02.011.

Mbah, N., Brown, R. E., St Hill, C. R., Bower, M. R., **Ellis, S. E.**, Scoggins, C. R., McMasters, K. M., & Martin, R. C. G. (2012) Impact of post-operative complications on quality of life after pancreaticoduodenectomy. *Journal of Pancreas*, *13*(4), 387-393. doi: 10.6092/1590-8577/617

Whitney, R., Tatum, C., Hahl, M., **Ellis, S.**, Scoggins, C. R., McMasters, K., & Martin, R. C. G. (2011). Safety of hepatic resection in metastatic disease to the liver after yttrium-90 therapy. *Journal of Surgical Research*, *166*(2), 236-240. doi: 10.1016/j.jss.2009.05.021.

Martin, R., Duvall, R., **Ellis, S.**, & Scoggins, C. R. (2009). The use of self-expanding silicone stents in esophageal cancer care: Optimal pre-, peri-, and postoperative care. *Surgical Endoscopy*, 23(3), 615-621. doi: 10.1007/s00464-008-9851-x.

Woodall, C. E., Scoggins, C. R., **Ellis, S. F.**, Tatum, C. M., Hahl, M. J., Ravindra, K. V., & Martin, R. C. G., 2nd. (2009). Is selective internal radioembolization safe and effective for patients with inoperable hepatocellular carcinoma and venous thrombosis? *Journal of American College of Surgeons*, 208(3), 375-382. doi: 10.1016/j.jamcollsurg.2008.12.009.

Martin, R., Duvall, R., **Ellis, S.**, & Scoggins, C. R. (2008). The use of self-expanding silicone stents in esophageal strictures: Less cost and more efficiency. *Annals of Thoracic Surgery*, 86(2), 436-440.

Eid, S., Stromberg, A. J., Ames, S., **Ellis, S.**, McMasters, K. M., & Martin, R. C. G. (2006). Assessment of symptom experience in patients undergoing hepatic resection or ablation. *Cancer*, 107(11), 2715-2722.

Li, Y., Wo, J. M., **Ellis, S.**, Ray, M. B., Jones, W., & Martin, R. C. (2006). A novel external esophageal perfusion model for reflux esophageal injury. *Digestive Diseases & Sciences*, 51(3), 527-532.

Li, Y., Wo, J. M., **Ellis, S.**, Ray, M. B., Jones, W., & Martin, R. C. G. (2006). Morphological transformation in esophageal submucosa by bone marrow cells: Esophageal implantation under external esophageal perfusion. *Stem Cells & Development*, 15(5), 697-705.

Li, Y., Wo, J. M., Ray, M. B., Jones, W., Su, R. R., **Ellis, S.**, & Martin, R. C. G. (2006). Cyclooxygenase-2 and epithelial growth factor receptor up-regulation during progression of Barrett's esophagus to adenocarcinoma. *World Journal of Gastroenterology*, 12(6), 928-934.

### **Oral Presentations**

**Winebrenner, S.**, Hermann, C., Christian, B. J., and Martin, R. (2021). Waiting to exhale: A pilot study examining scan-related anxiety in survivors of pancreatic cancer. *Graduate Student Regional Research Conference*, Louisville, Kentucky.

**Winebrenner, S.**, Hermann, C., Christian, B. J., and Martin, R. (2020). Exploring 'scanxiety' in pancreatic cancer survivors: A qualitative study. *Spring Research Assembly*, University of Louisville, Louisville, Kentucky.

### **Poster Presentations**

**Winebrenner, S.**, Hermann, C., Christian, B. J., and Martin, R. (2021). Waiting to exhale: A pilot study examining scan-related anxiety in survivors of pancreatic cancer. *Graduate Student Regional Research Conference*, Louisville, Kentucky.

**Winebrenner, S.,** Hermann, C., Christian, B. J., and Martin, R. (2020). Exploring ‘scanxiety’ in pancreatic cancer survivors: A qualitative study. *Midwest Nursing Research Conference*, Schaumburg, Illinois.

**Winebrenner, S.,** Hermann, C., Christian, B. J., and Martin, R. (2019). Waiting to exhale: A pilot study examining scan-related anxiety in survivors of pancreatic cancer. *Research! Louisville*, Louisville, Kentucky. *Winner Nursing Graduate Student Poster Award*

**Winebrenner, S.,** Hermann, C., and Christian, B. J. (2019). Fear of cancer recurrence: A concept analysis. *Graduate Research Student Research Conference*, Louisville, Kentucky.

### **Professional Memberships**

American Academy of Nurse Practitioners  
American Society of Clinical Oncology  
Coalition of Advanced Practice Nurses of Indiana  
Kentucky Coalition of Nurse Practitioners and Midwives  
Oncology Nursing Society  
Sigma Theta Tau International

### **Volunteerism**

Hospirus of Southern Indiana  
Norton Cancer Institute