

A QUALITATIVE DESCRIPTIVE STUDY OF THE NEEDS OF OLDER ADULTS  
RECENTLY DIAGNOSED WITH CANCER

By

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## Abstract

Adults aged 65 years and older are the population most often diagnosed with cancer. Although much research has been conducted on a person's adjustment to a cancer diagnosis, there has not been a direct focus on older adults' perceptions of their needs following a cancer diagnosis. The significance of the problem of inattention to the unique needs of older adults at their time of cancer diagnosis relates to a number of national organizational missions and goals, including Healthy People 2020, the Agency for Healthcare Research and Quality, the Institute of Medicine, the Oncology Nursing Society, and the Geriatric Oncology Consortium.

This research used naturalistic inquiry within the constructivist paradigm. The goal was to explore the needs experienced by older adults (65 years and older) diagnosed with cancer within the past four months using a descriptive qualitative design. The intent of this research is to explore the needs of older adults, thereby discovering opportunities to enhance the access to comprehensive care in the older population.

Literature findings related to maintaining independence, coping with the diagnosis, social support, and financial concerns provided the context for exploring factors associated with the experience of the older adult diagnosed with cancer. This research involved 14 Midwestern older adult participants, with an average age of 69 and who were an average of 9 weeks from cancer diagnosis. The participants completed semi-structured interviews, and data from the interviews and researcher field notes were analyzed using qualitative content analysis. It is from this process that the themes and categories of the study emerged. The study's three themes include: (a) The Cancer Health Care Experience: Interactions with providers that are generally positive but not without disappointments, (b) Challenges in Managing the Cancer Experience: Barriers to feeling normal and hurdles to overcome, and (c) Coping with the Cancer Experience:

Handling the cancer journey with mental adaptation and external support. These themes covered twelve categories including: Excellent Care, Trusting and Respecting Providers, Disappointments in Healthcare, A New Experience, What the Patient Brings to the Table, Desire for Control, Physical Limitations, Emotional Strain, Positive Outlook, Thinking of Others, Support and Encouragement, and Reflection. Implications include using these findings: (a) to meet the needs of older adults who recently have been diagnosed with cancer; (b) to integrate health care delivery teams; (c) to facilitate the maintenance of self-identity and control among older adults; (d) to improve training for healthcare providers on patient financial and workforce concerns; and (e) to explore further research with additional perspectives and broader samples.

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## CHAPTER ONE

### Introduction

Sixty percent of newly diagnosed cancer patients are 65 years and older (Howlader et al., 2011). This percentage is likely to increase in the years to come as the U.S. population ages. U.S. Census Bureau (2008) estimates suggest that in the next 30 years, the proportion of adults aged 65 years and older in the population will reach 20% from its current proportion of less than 13%. As this segment of the population continues to grow, there is an increasing concern for cancer diagnoses in this segment of older adults. Older adults can have different physical and psychosocial cancer needs, such as advanced symptom management, pharmacologic issues, and different life cycle experiences, than younger adults (Cope & Reb, 2006), and a general lack of awareness or understanding of these needs may affect older adults' access to comprehensive, quality care.

Ageism in cancer care has long been cited (Derby, 1991; Miller, 1999; Kagan, 2008) as a nursing concern. Decisions regarding cancer treatment and quality of life for those age 65 and older are highly informed by historical attitudes about the elderly (Derby, 1991) and health professionals' own value-laden experiences (Miller, 1999). Kagan, who cites these earlier works, acknowledges that little has changed. Older adults with cancer are still subject to ageism, despite efforts in the arenas of public policy and clinical trials over the last three decades. Kagan describes the current nature of ageism in cancer care as beneficent ageism. This ageism stems from compassionate discrimination coupled with misunderstandings about the capacities, goals, and needs of older adults. The older adult's wishes and desires are neglected in the name of a desire to protect the older adult or older adults in general. Though beneficent ageism is driven by positive intentions, its practice is restricting the standard of cancer care available to older

adults. This research explores the needs of older adults (65 and older) who recently have been diagnosed with cancer and their perceptions of their providers' abilities to meet those needs, thereby identifying opportunities to enhance access to comprehensive care for this population.

## **Background**

### **Older Adults Receiving Cancer Diagnoses**

Receiving a cancer diagnosis begins a transitional stage in a person's life; many decisions must be made and many changes may occur in a short period of time. For the vulnerable population of older adults receiving cancer diagnoses, the experience may be complicated by numerous emotional and practical issues related to their advanced age (Oncology Nursing Society, 2010). Additionally, the concern driving this research is the lack of literature on the unique needs of older adults with new cancer diagnoses. Without an understanding of the needs of older adults with new cancer diagnoses, the problem is significant to health care because we cannot ensure that we are providing comprehensive, quality health care, and inadvertently may be creating barriers to care.

The proposed research aims to illuminate older adults' perceived needs following a cancer diagnosis. Discovering such needs may help to highlight ways in which their comprehensive and quality care may be enhanced, as well as provide information that could help reduce delays in care and preventable hospitalizations in the older population.

### **The Multi-faceted Needs of Older Adults with Recent Cancer Diagnoses**

The American Society of Clinical Oncology [ASCO] (2010) outlines several factors that impact the cancer experiences of adults aged 65 years and older. The first is maintaining independence. An older person's ability to cope with his or her new cancer diagnosis is affected by the degree to which the older person feels it impacts his or her self-identity and ability to

maintain activities of daily living. Focusing on those 65 years and older (a bureaucratic definition of old age in the U. S.), Hillier and Barrow (2007) acknowledge a wide range of sociological issues for older adults, including those with cancer. Like the ASCO, their work highlights the importance among older adults to preserve their sense of self and maintain a sense of control.

Another issue for older adults diagnosed with cancer can be lack of support (ASCO, 2010). By virtue of their age, older adults are more likely than younger adults to have gone through or to be going through other transitions such as relocation or loss of family members and close friends. These losses and changes may result in better coping skills, or on the other hand, a weaker support system and an increased sense of isolation.

Financial concerns, an issue for many people, may have greater prominence for older adults due to their often limited incomes and costly medical care. Evidence in a population younger than 65 years of age (Ward et al., 2008) suggests that financial barriers to care negatively impact cancer care use and outcomes including poorer participation in cancer prevention and screening, delayed care and therefore worse prognosis at the time of diagnosis, and significantly worse five-year survival rates. The financial needs of older adults recently diagnosed with cancer have not been explored.

In conjunction with cancer care, cognitive and physical comorbidities in adults aged 65 years and older also can result in greater functional limitations in the areas of mobility, communication and interpersonal skills, and self-direction and self-care (Repetto et al., 1997). The areas of concern including the psychological, social, financial, physical etc., are those faced by older adults recently diagnosed with cancer. Researching the needs in these areas will allow us better to understand and meet them, thus providing greater comprehensive and quality care.

Hercinger (2007) explored the experiences of decision making among adults over 50 newly-diagnosed with cancer. The five major themes that emerged from the findings reflect broad factors that included the importance of positive coping, spirituality, relationships, communication, and powerlessness. Hercinger was not the first to examine the cancer experiences of older adults with recent diagnoses. Biley, Robbe, and Langharne (2001) examined a sample of cancer patients aged 56 years and older in a study on sources of health information. They found that these cancer patients mainly rely on methods such as word of mouth and leaflets for their health information, but they report an eagerness to develop computer and internet skills to enhance their cancer knowledge needs. This study highlights a need for nurses to be considerate of their older patients' desires for knowledge sources that may be non-traditional or different than what is anticipated.

Maly, Leake, and Silliman (2004) studied the impact of patient-physician interactions in newly diagnosed, 65 years and older breast cancer patients. In a follow-up study Maly, Stein, Umezawa, Leake, and Anglin (2008) examined racial disparities in quality of life and treatment modalities among newly diagnosed, 55 years and older, breast cancer patients. Both of these studies provide insight into mitigating disparities in the older population, but leave room for speculation that increased and improved physician communication may effectively increase cancer knowledge and provide empowerment to these patients. However, with the studies that have emerged in the past ten years, there are very few studies that focus on older adults (65 years and older) who recently have been diagnosed with cancer, despite the fact that that this population receives the most new cancer diagnoses.

Jansen et al. (2007) conducted a literature review on the specific needs of older patients in the treatment phase of their cancer. The authors found no studies that specifically addressed

meeting the treatment-related needs of cancer patients aged 65 years and older. From other studies that investigated the relationship between age and needs, the authors identified that informational needs were the most prevalent in the “older” groups, with categories ranging from 50 years and older to 70 years and older.

Greene and Adelman (2003) acknowledge that improved provider communication is of great importance in understanding the needs of cancer patients aged 65 years and older. Having grown up in an era when cancer was a taboo topic, older adults may have many misperceptions about cancer. Careful communication is therefore of great importance in examining older adults’ perceptions of their needs.

### **Impact of Needs on Access to Care**

Although the Healthy People 2020 data indicate that 96.3% of persons aged 65 years and older have access to care, this measure is defined as having a self-reported (non-emergency room) source where respondents usually go when they are ill or in need of health advice (U.S. Department of Health and Human Services, 2011). According to Bierman et al. (1998), quality health care access for the older adult goes further than having a regular source of care. It entails three steps: (a) gaining entry to the health care system, (b) getting access to sites of care, and (c) finding a provider who meets their individual needs and with whom they can develop mutual communication and trust. Given this third step in the definition of quality health care access, research and experience suggest that it is likely that the cited 96.3% of older adults with access to care truly are not receiving quality health care access. Finding providers who meet their individual needs and with whom they can develop mutual communication and trust is suspected to be a problem area in access to quality care for older adults.

Improving access to comprehensive, quality health care services is a national goal of Healthy People 2020 (U.S. Department of Health & Human Services, 2011). Furthermore, the Agency for Healthcare Research and Quality's (AHRQ) 2008 National Healthcare Disparities Report identifies that the lack of access to health care disproportionately affects underserved, vulnerable populations such as minorities, people of low socioeconomic status, and the older adult.

## **Significance**

### **Significance of Research**

The significance of the gap in knowledge regarding the unique needs of adults 65 years and older at the time of cancer diagnosis relates to a number of national organizational missions and goals. The Institute of Medicine (IOM, 2008) recognizes adults age 65 and older as a vulnerable population with regard to cancer care. The Oncology Nursing Society [ONS] and the Geriatric Oncology Consortium [GOC] have issued a joint position on cancer care in adults 65 years or older (ONS, 2007). In this position statement, the limited evidence available in geriatric oncology is emphasized as a hindrance to best practice. The ONS and GOC recognize that psychosocial, behavioral, and socioeconomic factors are not sufficiently addressed in current geriatric oncology research, and that these must be explored in order to advance science. The research problem for this study focuses on such factors and therefore matches this identified need.

The IOM (2003) also has laid out a set of five competencies required for all health care professionals. First and foremost is the need for all disciplines, including nursing, to provide patient-centered care. This includes identifying and respecting the individual differences, needs, and values of all patients. With the vulnerable older adult population, this competency is

unquestionably important. Initiating research that strives to identify the unique needs of older adults at their time of cancer diagnosis will help nurses to provide better patient-centered care to this vulnerable population. The IOM (2008) additionally advocates for holistic care specifically targeted toward cancer patients and, in its recommendations for research priorities on holistic cancer care, addresses older adults as a target for research.

### **Significance to Nursing**

Within the nursing and allied health professions literature, there is no apparent focus on the holistic needs of older adults recently diagnosed with cancer. There are various pieces that are foundational (e.g., needs of new cancer patients in general, select needs of older adults) to the overall state of the science in this topical area, but further focused study is needed to synthesize and solidify the foundation. New research in the area of needs assessment in a population of older adults recently diagnosed with cancer can begin to fill the gaps in this foundation, creating possibilities for greater access to quality and comprehensive health care in the older population of cancer patients.

Facilitating the best possible transitions for older adults to their cancer diagnoses should be a growing nursing concern regardless of the persons' conditions or their decisions regarding care. Study in this area could lead to outcomes such as clearer identification of the unique needs of older adults at the time of diagnosis, better understanding of the relationships of these needs to patient outcomes, and design and testing of interventions to improve older adults' cancer transitions. Such research would have the potential to advance nursing science by creating additional research questions, influencing nursing practice and policy, and possibly spurring the development or refinement of nursing theory.



### **Study Purpose and Research Questions**

The purpose of this qualitative study was to explore the needs of older adults recently diagnosed with cancer. The specific aims of the study were to assess the needs that older adults experience after receiving a cancer diagnosis using a holistic approach and explore the older adults' perceptions of their health care provider's abilities to meet those needs.

The problem at hand is the lack of understanding of the unique needs of older adults at the time following a cancer diagnosis. Without this understanding, providers cannot sufficiently meet older adults' needs and build mutually satisfying communication and trust. The research questions that were formulated to address the aims of this study were:

1. What needs are experienced by older adults following a recent cancer diagnosis?
2. What are the perceptions of older adults about their health care providers' abilities to identify and meet their needs?

### **Philosophical Approach**

The philosophical approach for this research was naturalistic inquiry within the constructivist paradigm. This philosophy holds that all reality is interpreted or constructed differently by different individuals (Patton, 2002). In other words, human perception creates reality. Qualitative description served as the method to carry out this approach. Sandelowski (2000, 2010) describes this approach as one that provides a comprehensive summary in everyday, "data-near" terms; though it is not without interpretation, it is less interpretive than methods such as phenomenology or grounded theory. Phenomenology is a philosophical approach seeking an understanding of the participant's lived experience and the goal of grounded theory is to move beyond description and develop a theoretical explanation of concepts (Munhall, 2012). In qualitative description, the interpretation of findings leads to thematically

clustering and detailing rather than transforming into, for instance, theory (Sandelowski, 2010). Researchers stay closer to the surface of their data in an effort to clearly understand the meanings given them by the participants. Because this study proposed to explore the answer to very minimally theorized questions, qualitative description is a well-suited approach. In this study, the use of open-ended interview questions and field observation within a natural setting was intended to illicit individual perceptions of reality and the collective data viewed as a unique consensus representation of the perceptions of the participants involved rather than as facts or truth which can be broadly generalized.

### **Assumptions of the Study**

This study includes several assumptions. First, adults 65 years and older perceive new needs in the period following a cancer diagnosis. Second, older adults see those needs as something healthcare providers can assist in meeting. Third, older adults are able to adequately recall their experiences and needs since their diagnosis. Fourth, older adults share an honest account of their experiences and needs since their diagnosis. Last, older adults, when compared to younger adults, have more needs that remain unmet by their providers, and because of these needs may experience decreased access to the comprehensive healthcare they are seeking.

### **Definitions of Key Terms**

This section provides clarification on the definitions of terms as they are used for this particular study.

*Access to healthcare:* A three part process that entails gaining entry to the health care system, getting access to sites of care, and finding a provider who meets the individual's needs and with whom they can develop mutual communication and trust (Bierman et al., 1998).

*Cancer:* A malignant disease of any part of the body.

*Older adult:* Based on the definition of older adult by Healthy People 2020, an older adult is an individual of 65 years of age or older (U.S. Department of Health and Human Services, 2011).

*Healthcare provider (treatment team member):* Any individual from whom the older adult receives healthcare related to his or her cancer such as a physician, nurse, radiologist, social worker, etc.

*Holistic approach:* That which emphasizes the interconnectedness of all parts (e.g. physical, social, spiritual, etc) as a whole

*Nurse navigator:* A key member of the multidisciplinary team functioning as an advocate, educator and facilitator of care. Responsible for ensuring all referred patients receive quality and comprehensive services throughout the continuum.

*Recent cancer diagnosis:* An individual has received his or her first diagnosis of cancer within the past four months. (Based on this definition, cancer survivors who are recently diagnosed with a cancer recurrence, new metastases, or a new primary form of cancer will be excluded from this study).

*Transition:* The passage from one life phase, condition, or status to another, which embraces the elements of process, time span, and perception (Chick & Meleis, 1986).

### **Summary**

As the proportion of cancer cases in older adults continues to rise in the U.S., it is imperative that nurses and other members of the health care team come to a better understanding of the needs older adults have after receiving the diagnosis of cancer. Previous research indicates that older adults have a variety of needs following cancer diagnosis. However, there is a paucity of literature focused on the period immediately following diagnosis or regarding how well older

adults feel that their needs are being met by their health care team. This study was framed by the literature-guided belief that quality healthcare for older adults involves finding providers who meet their individual needs and with whom they can develop mutual communication and trust. In doing so, this study explores the needs of older adults following a cancer diagnosis using a qualitative descriptive approach.

## CHAPTER TWO

Chapter Two provides a literature review that explores the needs of older adults with cancer. Older adults who are diagnosed with cancer may have different needs based on their age and situation in life. Research is explored around the needs related to: (a) quality of life, (b) coping, (c) sexual issues, (d) social support, and (e) disenfranchised grief. This chapter also explores the literature surrounding communication between older adults recently diagnosed with cancer and their health providers.

### Needs of Older Adults with Cancer

#### Older Adults

Related research, cited in this paper, uses a variety of definitions for the term “older adult”, varying from 50 and older (Hercinger, 2007) to 75 and older (Bungay & Capello, 2009). Healthy People 2020, does define an older adult as an individual of 65 years of age or older (U.S. Department of Health and Human Services, 2011).

As identified in Chapter 1, there have been a few studies (Hillier & Barrow, 2007; Repetto et al., 1997; Greene & Adelman, 2003) that included the 65 years and older adult to identify their needs (i.e., sociological issues, functional limitations, provider communication, respectively). Additionally, unmet needs of cancer patients have been researched (Foot & Sanson-Fisher, 1995; Sanson-Fisher, et al., 2000), but the focus has not been on either cancer patients or those who are of older age and recently diagnosed. Consequently, the age of 65 years was selected as the cut-off for this research as it was: (a) deemed feasible for participant recruitment, (b) and was slightly more prevalent than other definitions in the literature, and (c) is the definition used by Healthy People 2020.

## Quality of Life

Nussbaum, Baringer, and Kundrat (2003) highlight the interpersonal and relationship issues that affect quality of life for older adults with cancer. Discussing Carstensen's socio-emotional selectivity theory, the authors emphasize the equal importance of understanding the psychosocial as well as the biological components of cancer care in the older population. They call for more interpersonal theories to be translated into the lives of cancer patients.

Following with a longitudinal study on the topic of quality of life in older adults diagnosed with cancer, Esbensen, Osterlind, Roer, and Hallberg (2004) found that risk for low quality of life in the older adult population was associated with lung cancer diagnoses, lower finances, lower levels of hope, higher rates of dependency, and higher perceived seriousness of the cancer. Esbensen, Osterlind, and Hallberg (2006, 2007) followed these patients at three and six months. They found little overall change in the older adults' quality of life at three months, but 30% had significantly decreased quality of life at six months; the same factors remained associated with low quality of life. These results called for further research that may reveal useful interventions to increase quality of life, particularly related to finances, increased physical dependency on others, and maintaining hope at diagnosis and through the months that follow.

In an analysis of the development of gero-oncology research, Kagan (2004) suggests a different conceptualization of quality of life for the older adult: quality of daily living. She writes about the gradual recognition of the field of gero-oncology and the shifts that have occurred and continue to occur in language and perspective. Kagan's introduction of the phrase, quality of daily living, is part of this changing language of gero-oncology. She argues that the longitudinal undertones of quality of life are not especially relevant for older adults whose quality of life is evaluated on a day-to-day basis. This is supported by the earlier qualitative work of Kagan

(1997) on older adults that were integrating cancer into a life mostly lived, as well as by more recent qualitative work of Kagan (2009) on the blessings and battles of cancer in the lives of older Americans. Consistent with the call of Nussbaum et al. (2003), Kagan's body of work also calls for better theoretical and methodological models to guide research and practice in the field of gero-oncology.

### **Coping**

Perhaps closely tied to the issue of quality of life, the literature also revealed qualitative studies centered on older adults coping with cancer diagnoses. Pentz (2005) investigated the psychosocial experiences of older adults with cancer and found resilience to be a prominent characteristic among the study participants. The main themes in Pentz's work were social support, spirituality, positive attitude, positive coping, and loss. The overall tones of the interviews with these older adults diagnosed with cancer primarily were positive and suggestive of the idea that older adults cope with cancer diagnoses quite successfully. Pentz provides one glimpse into the cancer coping experience for older adults. However, considering the difficulty in generalizing qualitative research, further work is needed to better understand this phenomenon of concern.

Dutch researchers, Ranchor et al. (2010), examined older adults' coping from the perspective of perceptions of control, specifically looking to the stability of these perceptions before and after cancer diagnoses. The authors found that perceptions of control declined in their prospective study sample across the pre-diagnosis and post-diagnosis assessments. The authors questioned this loss of control, wondering about the adaptive differences in maintaining or relinquishing control. Thus they additionally explored the older adults' levels of distress. They found that those with greater maintenance of control had lower distress six and twelve months

following cancer diagnosis. In order to seek ways to lower the distress of older adult, there is a need for further exploration of the experiences of maintaining or losing control in the lives of older adults diagnosed with cancer.

### **Sexual Issues**

Dealing with breast cancer as well as other cancers raises questions of sexual concerns. Coping with changes in sexuality brought on by treatment is seldom addressed with older adults. Kagan, Holland, and Chalian (2008) provide an overview of sexuality in older adult cancer survivors; they provide an eye-opening vignette and introduction to the wide variety of issues along with the impact of insensitivity and ageist assumptions regarding sexuality. Kagan, Holland, and Chalian discuss the effects of cancer-related surgery and pharmacological treatments on body concerns, intimacy, and connectedness. These issues further are complicated by normal aging changes in sexual desire, capacity, and behavior as well as decreased partner availability in late life. Further work focused on older adults coping with sexuality issues related to their cancer does not exist.

### **Social Support**

Research on social support among older adults diagnosed with cancer adds another dimension of understanding to the work on quality of life and coping. Edwards and Clarke (2004) studied the impact of cancer diagnosis on Australian families to determine the dimensions of family function associated with lower levels of depression and anxiety. They found that family functioning aspects of problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control affected the depression and anxiety levels of patients as well as their families. Such family dynamics accounted for 21% of the variance in depression and 15% of the variance in anxiety for the newly diagnosed cancer patients. With regard to



cancer treatment in older adults, Given and Given (2009) describe current areas in need of psychosocial research; family support is one such area.

Guided by the principles of symbolic interactionism, Gardner (2008) studied not the entire family dynamics but the dyadic context of cancer. The author explored the relationship of support and communication among older couples where one partner had advanced or terminal cancer. Interviewing the partner dyads together and separately, Gardner found the strong presence of both individual and dyadic voices throughout the interviews. Participants shifted seamlessly between first person singular and plural voices, giving the partner dyad a voice of solidarity. Three themes dominated the study: (a) living with uncertainty, (b) search for shared meanings, and (c) illness and death trajectories. In negotiating the ambiguity and search for shared meaning at the end of life, caregiving partners provided an excellent source of support for older adults with cancer. These results provide a view of the positive effects that the social support of a partner can have on older adults with cancer. In contrast, the work of Edwards and Clark (2004) illuminated some of the negative effects that a family source of social support can have on older adults with cancer. Specifically, the result was anxiety and depression for patients and family members when the family has higher levels of dysfunctional problem solving and communication.

### **Disenfranchised Grief**

Disenfranchised grief is the emotion that individuals feel when they experience a loss that is not or cannot be socially sanctioned, openly acknowledged, or publicly mourned (Doka, 1989). It is a loss that often must remain hidden due to unwritten societal “rules” about when, where, how, how long, and for what or for whom to grieve.

Due to the unacknowledged nature of disenfranchised grief, it is difficult to identify the prevalence among older adults. However, a review of the nursing and allied health literature revealed the wide scope of the issue, and gives some idea of just how many older adults are at risk of experiencing disenfranchised grief. Doka (2002) highlights the impact of ageism on societal support and recognition of an older adult's loss of a sexual or intimate relationship. Thus, grief reactions to such losses among older adults may be even less supported than such losses among younger people.

A study by Thupayagale-Tshweneagae (2008) found disenfranchised grief to be a common experience among grandmothers in rural Botswana who were raising their grandchildren after the loss of the children's parents. In many instances, the loss was due to incarceration or death due to AIDS. The grandmothers felt unable to grieve their own losses due to their community's focus on the children's loss and the stigmatized nature of the loss. Hayslip and White (2008) also found disenfranchised grief among custodial grandparents.

Carr (2008) listed many losses more commonly experienced in older age: the loss of spouses, friends, and siblings, and more ambiguous losses such as cognitive and physical decline, financial strain, and the loss of employment. It should be noted that these ambiguous losses may be brought about by cancer or cancer treatment. Carr (2008) also reported differences in older adults' expressions of grief. Having a greater capacity to regulate their emotional states, older adults typically experience less extreme and less variable emotional responses. These responses could be misinterpreted by others as a lack of grief.

Each of these examples has highlighted categories of disenfranchised grief into which older adults may fall: unrecognized relationships, unacknowledged losses, circumstances which contribute to stigma, and expressions of grief that are not accepted. In addition to these

categories, the category of excluded griever is very applicable to older adults. Doka (2008) names older adults, along with young children, as a group often excluded from discussions and rituals surrounding death due to a lack of social recognition of their comprehension, reaction, and their need to mourn. Given these examples, it is possible to see that virtually every older adult faces a significant chance of experiencing disenfranchised grief.

The “costs” of disenfranchised grief in older adults occur on both an individual and a societal level. Kauffman (1989) addressed the fact that the source of disenfranchisement may be society, or it may be from one’s self, or it may be from both. He stated that the distinction between psychological and sociological sources of disenfranchised grief is not always clear, but that self-disenfranchised grievers are fueled by shame. This shame surrounds the individual’s emotions and could be linked to consequences such as relationship conflicts, self-destruction, anger, helplessness, decreased self-esteem, self-alienation, and future self-disenfranchisement. Kauffman also addressed the weakening effect of disenfranchisement on communities – whether they be families, friends, neighborhoods, or colleagues. Community ties are weakened when individuals in them are weakened by disenfranchised grief.

Though a sociological concept, the phenomenon of disenfranchised grief among older adults is one very significant to nursing. It is widely known that, given their percentage of the population, older adults access a disproportionately large amount of healthcare. As nurses, we are most often on the front lines of that health care. Armed with an awareness of the situations from which disenfranchised grief stems as well as an understanding of its personal and societal impact, nurses can adequately assess for disenfranchised grief in their older adult clients and intervene with support, education, and referrals.

Nurses are socially mandated to diagnose and treat human health responses (Omery, Kasper, & Page, 1995). Such responses include not only physiological responses, but also social, spiritual, and psychological responses. Older adults experiencing disenfranchised grief due to a recent cancer diagnosis may respond in all of these ways and must be supported in their unique needs.

### **Communication and Trust with Health Care Providers**

#### **Communication**

Recently, several studies that focus on communication between the patient and the health care providers during the cancer diagnostic period have been published. Amalraj, Starkweather, Nguyen, and Naeim (2009) reviewed the literature on health literacy, communication, and treatment decision making among older cancer patients. This review highlights that there is a high risk for poor health literacy and poor communication in this population. Coupled with complex decision making for the patient and the mixed effects that older adults' caregivers and companions can have on their decision making, the issues can negatively impact self-efficacy, risk perception, and older adults' degree of shared decision making.

Repetto, Piselli, Raffaele, and Locatelli (2009) conducted a study to investigate clinical communication patterns with a sample of older Italian adults. Not surprisingly, patients reported their family as the main support, and they desired family involvement in the consultations with oncologists. The degree of nondisclosure that some patients reported receiving and being satisfied with was more surprising. Giacalone et al. (2007) studied the information needs of older cancer patients and found consistent results; the older patients newly diagnosed with cancer desired information, but the degree of information they desired was considerably less than that of their younger counterparts. Although consistent with each other, these results may in part reflect

the cultural influence of their Italian samples and may be inconsistent with results in the United States.

In an American study, Elkin, Kim, Casper, Kissane, and Schrag (2007) studied older cancer patients' desire for information and involvement in treatment decisions as well as physician's perceptions of such preferences. The authors found that 52% of the patients desired a passive role as opposed to an active or collaborative one, perhaps reflecting a degree of consistency with the work of Repetto et al. (2009) and Giacalone et al. (2007). Also notable in the study of Elkin and colleagues was the finding that older patients' preferences for prognostic information and active decision-making roles are not predictable by physicians, whose perceptions often were incongruent with the patient preferences. Instead of making assumptions regarding the preferences of older adults, this study leaves room to speculate that perhaps we should ask more directly their preferences for prognostics and decision making. White and Cohen (2008) support such advocacy through the provision of comprehensive geriatric assessment and tailored treatment.

Figg et al. (2010) investigated the process of disclosure of cancer diagnoses and the subsequent impact on patient satisfaction. The sample was not limited to older adults, and there were no remarks given on age-related differences in receipt of diagnosis or satisfaction. However, the main finding was that greater satisfaction was associated with: (a) greater time spent discussing the news, (b) disclosure that occurred in a personal setting, and (c) the inclusion of an initial discussion of treatment options.

Step, Siminoff, and Rose (2009) also examined physician communication, with a focus on age-related differences and the resultant decision-making outcomes. The findings reflected that oncologists were more fluent and direct with older patients, and also they expressed their

own preferences more often than with younger patients. If older adults do in fact desire a more passive decision-making role this may be ideal, but these accommodations by the oncologists also may hamper patient participation. The findings raise the concern that intergenerational communication patterns and stereotypes may be a problem for some older cancer patients while they may be ideal for others. We must work to determine in which cases these patterns should be modified.

Although not strictly with a sample of older adults, Thorne et al. (2009) explored the patients' perspectives of provider communications across the cancer trajectory. After one year, patients were very consistent in the recollections of difficult communications with the provider, although most issues had been resolved. A main problem in the communications was that of insufficient hopefulness in the communication from the provider. This communication pattern is significant because as Esbensen et al. (2004) discovered, lower levels of hope can be associated with lower quality of life.

### **Trust**

Research into patient-provider trust is limited for older cancer patients, but a few studies highlight the presence of trust, its relation to needs, and its importance in this population. Bungay and Cappello (2009) interviewed a sample of men aged 75 and over with prostate cancer to determine their information and support needs. The researchers found that trust in health professionals was a major factor in their informational needs. Though a number of men did not understand their treatment or its impact on their quality of life, their trust in their health professionals and satisfaction with their care left them with no need for further information. However, the research did not address the basis of this trust. Is it earned through health care

providers' outstanding performance, or is it freely given by a group of ambivalent individuals who are accustomed to deferring to health professionals?

Kowalski and colleagues (2009), a German research team, found that trust between physicians and breast cancer patients was associated with the patient's perception of the physician's accessibility and communication behaviors and also with the perceived quality of the hospital organizational climate. Although this cross-sectional study was not restricted to older adults, the results may hold some truth for older adults recently diagnosed with breast cancer. This proposed research entails various cancer clinics that are associated with the same hospital that may allow the perceived quality of the organizational climate to come through during participant interviews.

Dale and Johnston (2011), in an attempt to uncover the concerns of older patients with inoperable lung cancer, found trust in professionals to be a main theme of their qualitative study. Many aspects played a role in this trust, including feeling listened to and cared about, being given understandable information, and having concerns followed up. The authors found that this element of trust was crucial in allowing patients to have a voice. The authors' discussion leads to the conclusion that a patient whose voice is permitted to be heard is a patient whose needs are better recognized and who receives better quality and comprehensive care. Thus, trust is critical in this process.

In a qualitative study by Hillen, Onderwater, van Zwieten, de Haes, and Smets (2012), the authors questioned whether our attempts to measure cancer patients' trust are accurate. The findings of this study highlighted the power imbalance between cancer patients and their providers and the *need*, the *determination*, and the *intention* to trust rather than actual trust among cancer patients. In the sample, which it should be noted was neither restricted to older

adults nor those who were recently diagnosed with cancer; competence-based trust was a necessity due to the life-threatening nature of their cancer. Emotional bonds of trust developed after repeated interactions and were based on the interpersonal skills of the provider. In addition to competence, aspects of fidelity, honesty, and caring were strongly reflected as contributors to trust in the participant interviews.

### **Summary**

A clear understanding of the experience of a cancer diagnosis for the older adult is missing. Particularly lacking is an understanding of the older American adult's cancer experience. Much of the work in this area is European, though Australia and Canada also are represented. Although older adults diagnosed with cancer in the Western nations may have experiences similar to those older adults diagnosed with cancer in the United States, various differences in the history, culture, and economics of these nations may create important differences in the cancer experiences for these older adults. The foreign results, while illuminating important human experiences, leave us to question the actual needs of older adults experiencing cancer diagnoses here in the United States. Without such an understanding, providers lack the information necessary to adequately assess older adults' needs, meet those needs, and establish mutual communication and trust.

Though the nursing and allied health literature contains information on the general needs of new cancer patients and select needs of older adults, there is no apparent focus on the holistic needs of older adults who have been recently diagnosed with cancer. Further focused study is needed to synthesize and solidify this foundation. Additionally, the extent to which this older population perceives its needs being adequately met is a relatively unstudied area. Exploring these issues alongside the topic of provider communication and trust will provide a more



complete picture of the older adult's cancer transition, providing knowledge that may lead to possibilities for greater access to quality and comprehensive health care in the older population of cancer patients.

## CHAPTER THREE

This chapter includes an overview of the methodology that includes the research design, participants, setting, recruitment and data collection procedures, data analysis plan, researcher as instrument, trustworthiness and methodological rigor, and ethical considerations. Study limitations also will be discussed.

### Research Design

The purpose of this qualitative study was to explore the needs of older adults recently diagnosed with cancer. This study used a qualitative descriptive design to gain a better understanding of the needs that older adults experience after receiving a cancer diagnosis as well as the older adults' perceptions of their relationship with their health care providers. Congruent with this purpose, the research questions included:

1. What are the needs that older adults experience following a recent cancer diagnosis?
2. What are older adults' perceptions about their health care providers' ability to identify and meet their needs?

Sandelowski (2000, 2010) describes this qualitative descriptive method as one that provides a comprehensive summary in everyday terms; it is less transformational than methods such as phenomenology or grounded theory. Researchers stay closer to the surface of their data in an effort to get the facts, and the meanings given them by the participants, straight. Because this study was preliminary in nature and explored the answer to a very minimally theorized question, "*How do older adults recently diagnosed with cancer describe the meeting of their needs by their providers?*" this was the most appropriate approach.

## Participants

As sampling adequacy in qualitative research is determined by the appropriateness of the data rather than by the number of participants (O'Reilly & Parker, 2013), this predicted sample size for this study was an informed estimation. Magilvy and Thomas (2009) support the use of as few as three to five participants in qualitative descriptive research and as many as 20. In other qualitative research studies with similar purpose, as few as seven participants (Meenaghan & Dowling, 2010) and as many as 19 participants (Bungay & Cappello, 2009) have been deemed adequate. The estimated sample size was therefore set at 16-20 with adequate breadth and depth of data in mind, though there was an understanding that informational redundancy or saturation may occur with a smaller number of participants. For this research, saturation was based on repeated identification of similar major needs by recently diagnosed participants. To enhance quality, decisions about the achievement of saturation are made transparent in the discussion of study findings.

Participants were recruited with the assistance of staff members from the community hospital cancer center described below. The participants consisted of older adults (age 65 and older) with a recent (four months or less) cancer diagnosis; the final sample size of 14 was determined based on detailed analysis and saturation of data and theme construction.

The selection of a "new diagnosis" time frame is variable with related studies using periods ranging from three weeks (Esbensen et. al, 2004) to 16 weeks (Elkin et. al, 2007). Despite the range in timeframes, both of these studies illuminated topics such as finances, information and decision making needs, and changes in physical function and sense of control. Given these findings and after consultation with staff at the recruitment sites and adjustments

made to expedite recruitment, four months or less was determined to be the most feasible time frame.

With regard to the type of cancer diagnosis, the literature review yielded studies which focus specifically on older adults with a particular diagnosis (i.e. breast, prostate, or colon cancer) as well as those with any cancer diagnosis. The research question for this study was not guided toward any particular diagnosis by the literature; therefore, it is intentionally broad. However, variations in the diagnoses of participants are somewhat limited based on the recruitment sites that are detailed below.

Criteria for inclusion included individuals who were: (a) age 65 or older, (b) English speaking, (c) able to give informed consent, and (d) diagnosed with cancer for the first time within the four months prior to their recruitment. Participants were excluded if their recent cancer diagnosis was a cancer recurrence, new metastases, or a new primary form of cancer.

### **Setting**

The regional setting in which the research took place was metropolitan West Michigan. According to the 2010 U.S. Census, this metropolitan region has a population of 774,160. Of these residents, 11.7% are 65 years and over. Roughly 83% of the population in this area is White, 8% is Black, 3% is of two or more races, 2% is Asian, less than 1% is Native American and 4% is some other race. Roughly 8% of the population is Hispanic or Latino. The percentage of adults who have completed high school is roughly 88% and the percentage with a bachelor's degree or higher is 26%. As of 2010, unemployment was at 9.6% and 13.9% lived below the poverty level (U.S. Census Bureau, 2010). It should be noted that the demographics for the metro area are easiest to report but may vary from the demographic profile of the participants in this

research because participants living in surrounding rural areas who receive health care within the metropolitan area also took part in the study.

Participants were recruited from a Midwestern community-based hospital cancer center. The community hospital cancer center is a National Cancer Institute (NCI) Community Cancer Center program that provides funding for research and clinical trials in community-based settings. The center is part of a 344-bed hospital and houses the following areas that were used for recruitment: (a) an inpatient cancer unit, (b) an infusion clinic, and (c) several multidisciplinary clinics. The clinics focus on the four areas of surgical oncology, breast surgical oncology, thoracic oncology, and gynecologic oncology. Flyers were also placed at a support group site in the community, but this yielded no recruitment.

## **Procedures**

### **Recruitment**

The researcher obtained IRB approval from the Midwestern community-based hospital and the Midwestern academic medical center where she was a student. The researcher relied upon convenience sampling, as participants volunteered based on advertising and word-of-mouth via the researcher and nurses in the hospital. Following orientation to the study purpose and procedures, the nurse researcher and hospital staff used standardized flyers (Appendix A) to introduce the study to potential participants.

Potential participants were contacted initially by the researcher, after consultation with a staff nurse or a nurse navigator. The first contact was in person or by telephone to introduce the study, share details of informed consent, and set up a follow up contact time. Follow up contact confirmed the participants' interest in the study and schedule an interview. The researcher obtained consent from the participant at the time of the scheduled interview.

## **Data Collection**

Data collection began by establishing contact with cancer patients with the assistance of the aforementioned hospital staff. Each participant completed a consent form (Appendix B) designed to explain the rights of the participant as a research subject, to obtain consent for study participation and audio-recording, and for the use of direct quotes. All participants were given a copy of the consent for their records. Each participant was coded with a pseudonym that was used throughout the study to protect the anonymity and confidentiality of the participant. The researcher conducted all interviews; the interviews were completely voluntary; and the participants were not be paid or reimbursed in any way for their time. As part of the consent process, participants were informed that they have the option of refusing to answer any question or discontinuing the interview at any time. Each participant also was assured that all identifying data, including names of health care providers or facilities, would be eliminated.

Following recruitment, data were collected using semi-structured individual audio-recorded interviews and field notes. Because this study used face-to-face, one-on-one interviews, each participant was encouraged to select a location for the interview that provided a private environment that afforded comfort and convenience. Possible sites suggested were the participant's home or place of worship. Interviews did not take place in the researcher's home or while the participant was hospitalized.

Prior to the interview questions, the researcher completed a demographic sheet (Appendix C) with each participant for purposes of sample description. A code was assigned to match the demographic information with the interview data. The researcher kept the code information in a locked cabinet, and this information was only known to the researchers. This demographic portion of the interview was not audio-recorded.

Interviews were projected to last approximately one hour each and were guided by a semi-structured interview guide that consisted of broad, opened-ended questions to allow the participant to share experiences in a naturalistic manner (Appendix D). The interview was audio-recorded for transcription, and notes were taken by the researcher. The tapes will be destroyed upon completion of the study and written records kept securely for the duration required by the institutional review boards. In addition to the interview transcriptions, the researcher also completed field notes following each interview. These field notes captured the overall interview context including participant affect, nonverbal interchange, and any interruptions or other factors which affected the interview session. As qualitative analysis occurs concurrently with data collection, once data saturation was achieved by mutual agreement of the research interviewer and research advisors, additional interviews were not conducted.

### **Interview Guide**

A semi-structured interview guide (Appendix D) served as the primary data collection tool in this study. The interview guide was created for this research study and was based on: a) the literature reviewed for this research, and (b) the clinical expertise of the primary researcher who has worked with this population over nine years.

Prior to use, the interview guide was modified for improved clarity and flow by the researcher following consultation with a group of peers. Each interview session began with a dialogue and a review of the purpose and expectations of the interview and was followed by completion of the demographic form. The interview guide began with the researcher asking the participant to talk about his or her cancer experience in more general terms before moving on to questions about personal conditions, holistic needs, and provider relationships. The questions of the interview guide shifted after the first four interviews. A new question was added at the

beginning, asking participants to speak about what led to their cancer diagnoses. This not only provided better background for the researcher and a smoother start for participants' narratives, but it also had the unexpected effect of illuminating some needs that the participants experienced. The first several participants struggled when presented with the third interview question, "Since receiving your cancer diagnosis, what kinds of needs have you experienced?" This question was found to not elicit the response desired, and in fact often brought the interview flow to a halt as participants did not feel that they had any needs. The responses gleaned from the addition of the initial question helped to tailor the third question to the participants' unique experiences, and the replacement of "needs" with words like troubles, concerns, complications, and stumbling blocks helped keep the interview moving. The final question was open ended, asking for any other information related to his or her cancer diagnosis that the participant would like to share. The researcher provided clarification of the questions as well as probes for deeper meaning and detail as necessary. As is common in qualitative research, the interview questions evolved after initial interviews so as to better understand the experiences and perceptions of the participants.

The questions in the interview guide potentially could be obtained through written responses rather than through interviews as this would save research time and resources. However, the use of interviews for qualitative data collection was selected for several reasons. First, the personal interaction of interviews allows the opportunity for on-the-spot probing and clarification of the interview questions. This leads to richer responses than written prompts. Secondly, interviews reduce a number of sources of error that could be introduced through written responses: missing or incomplete responses and false interpretations of grammar, spelling, and penmanship. With the use of the interview, higher response rates are achieved,



clarity and depth are increased, missing data is reduced, and sensitivity to slight impairments in vision and literacy that may hamper written responses are afforded.

All interviews were audio-recorded and transcribed verbatim by a transcriptionist with training in protection of Human Subject confidentiality. For accuracy, the recordings also were compared to the transcriptions by the researcher. Any identifying information (i.e. addresses, names) was removed from the transcription by the researcher. All physical data for this study was secured in a locked file cabinet only accessible to the primary researcher. Secure and encrypted email was used for all correspondence with other researchers regarding study data.

### **Qualitative Data Analysis**

Qualitative content analysis--specifically, conventional content analysis (Hsieh & Shannon, 2005)--provided organization and interpretation of the interview data by generating patterns of meanings and overarching themes from the data. The process of inductive qualitative analysis was used to create a larger generalization from the specific examples given by the participants (Patton, 2002). The analytic procedure included seven phases: organization of the data, immersion of the data, coding the data, generating themes and categories, offering data interpretations, searching for alternative understandings, and generating the final findings (Marshall & Rossman, 2010).

Data analysis began following the audio recording and verbatim transcription of each interview. Appropriate to qualitative research, the researcher was immersed in the data through interviews, checking and reading interview transcripts, coding of data, and ongoing meetings with advisors to discuss the data analysis and emerging themes. Inclusion of interview data, observations, and literature review were used to search for alternative meanings and emerging themes throughout the data collection process.

### **Researcher as Instrument**

In qualitative inquiry, the researcher may be viewed as the instrument, a measuring tool to be administered in a standardized and credible manner (Patton, 2002). With regard to credibility of the researcher as instrument in this study, the researcher engaged in reflexive journaling beginning before data collection and continuing throughout the research process to maintain awareness and set aside any personal experiences, biases, or expectations. The researcher also has been trained in qualitative methods, including doctoral-level courses and additional seminars in qualitative research methods, and has been instructed and mentored by experienced qualitative researchers at a Midwestern academic medical center university as well as the Midwestern hospital. The researcher also successfully completed training prior to the collection of data as required by the university and the hospital review boards.

### **Trustworthiness and Methodological Rigor**

To satisfy the rigor for trustworthiness, Lincoln and Guba (1985) proposed that the criteria of credibility, transferability, dependability and confirmability be used as guidelines. These criteria were used to ensure the trustworthiness and methodological rigor of this study. Credibility was achieved by prolonged engagement with both the participants in the study and the data they provided. Fourteen participants were interviewed to provide saturation of dominant themes. The researcher analyzed the interview transcripts and conducted multiple debriefings with advisors in order to maintain close contact with the data. Member checking of interview findings was accomplished immediately following each interview by summarizing the interviewer's understanding of the participant's responses to interview questions.

Transferability is accomplished through careful data collection that allows for a thick description of the phenomenon under study (Lincoln & Guba, 1985). Careful selection of

interview questions, follow-up prompts and a close collaboration with advisors helped to ensure that the interviews captured information that satisfies the requirement of “thick description” of the data. To assure dependability, the researcher worked closely with advisors in the development of a process design to provide for consistency in interviewing and management of data in the field. Interviews were transcribed verbatim by a trained transcriptionist and verified by the researcher to ensure accuracy in the transcription process. Confirmability of the data to support objectivity was attained by maintenance of an audit trail. The audit trail includes maintenance of all raw data, the staged products of data reduction and analysis including meaning units, codes, categories and major themes, and all communications made between the researcher and advisors.

Authenticity of this study was established through the principle of fairness (Guba & Lincoln, 1989). Because fairness is characterized by balance, deliberate attempts were made in recruitment to include the widest variety of voices possible under the exclusion criteria of this study. Additionally, the findings of this research underwent various possible constructions to maximize the balance of the experiences, feelings, and perceptions of all participants being represented in the text.

### **Ethical Considerations**

Several ethical considerations have been taken into account in this study. The researcher sought approval from the institutional review board of the Midwestern academic medical center as well as the review board overseeing the Midwestern community hospital prior to the start of research. Informed consent was required of all participants, and all were reminded that if talking about the cancer diagnosis became upsetting to the individual, the interview would be stopped and the participant would have the option to withdraw at any time. The researcher maintained

confidentiality throughout the study as participant pseudonyms were used in data collection and sharing among the research advisors as well as in research dissemination. Any identifying information (e.g. addresses, provider names) was omitted from the interview transcriptions, and their recordings were deleted at the completion of the study. The transcriptions of the interviews will be maintained in a secure file for 15 years, as required by the University.

### **Study Limitations**

The following methodology limitations of the study are outlined below:

1. Given the recruitment procedures and relatively small sample size, the final sample for this study is fairly homogenous in terms of age, gender, race, and/or cancer diagnosis. The findings and implications are therefore more specific and less relevant for a general population of older adults recently diagnosed with cancer.
2. Those older adults who volunteered to participate in the study may have been those with the strongest altruistic motives and/or strong positive or negative opinions regarding the study aims, leading to participant bias.
3. The exclusion criteria, though providing practical limits for the purpose of this research, may have excluded important elements of the experiences of older adults recently diagnosed with cancer.

### **Summary**

In this section, the research design of the proposed study was described. An overview of the participants was given along with the inclusion/exclusion criteria. Information pertaining to the setting and recruitment procedures also was provided as well as the procedures for data collection, data analysis, and establishing the trustworthiness of the study. Additionally, sections on ethical considerations and study limitations were included.

## CHAPTER FOUR

### Introduction

The purpose of this study was to explore the needs of older adults recently diagnosed with cancer. Data collection occurred May through September of 2015. Data were collected from 14 participants. When looking to define the emerging categories among the data, it was evident that saturation was obtained by the thirteenth interview if not sooner. The categorizing of the codes in the fourteenth interview revealed no outliers and data collection ended.

Chapter four presents the results of the study. The chapter is organized by presentation of the sample characteristics, an overview of the participants, and the presentation of findings that includes a discussion on the coding, the development of categories with similar patterns, and the creation of study themes. All findings are summarized at the end of the chapter.

### Sample Characteristics

Table 1 contains a demographic summary of the participants. The 14 participants ranged in age from 65 to 78, and the average was 69. There were nine male participants (64%) and five female participants (36%). All participants, except for one Black participant, were White. Six participants (43%) had completed at least a Bachelor's degree, and six (43%) had completed high school. The average distance that the participants lived from the cancer center from which they were recruited was 22 miles, (*range* = 2 - 90 miles). Prostate cancer was the most common cancer diagnosis among this group, followed by pancreatic and lung. Other diagnoses included ovarian, breast, esophageal, and colon cancer. Among these participants, the time between the diagnosis and interview dates ranged from four weeks to eighteen weeks; the average was nine weeks.

Table 1

*Demographic descriptors ( N = 14)*

	<i>N</i>	<i>%*</i>	<i>Mean (Range)</i>
Gender			NA
Female	5	36	
Male	9	65	
Age			69 (65-78)
65-69	10	71	
70-75	3	21	
75-80	1	7	
Race			NA
Black	1	7	
White	13	93	
Formal education completed			NA
Less than High School	2	14	
High School	6	43	
College degree	6	43	
Miles from home to cancer center			22 (2-90)
0-10	7	50	
11-20	2	14	
21-30	3	21	
81-90	2	14	
Type of cancer			NA
Breast	1	7	
Colon	1	7	
Esophageal	1	7	
Lung	3	21	
Ovarian	1	7	
Pancreatic	2	14	
Prostate	5	36	
Weeks from diagnosis to interview			9 (4-18)
0-4	2	14	
5-9	7	50	
10-14	4	29	
15-19	1	7	

\* Percentages do not add to 100 due to rounding

Three of the participants were referred by two of the nurse navigators at the cancer center. The remaining participants were approached by the investigator, following consultation with a Registered Nurse (RN), who provided their inpatient care at the cancer center. Those participants were contacted at home at an agreed-upon later date to set up an interview. The interviews ranged from 33 to 98 minutes. Most interviews were conducted in the participants' homes, often with a family member nearby. Exceptions included: (a) one interview that was conducted, at the participant's request and with permission of the staff, in an empty private infusion room at the clinic, and (b) one that was conducted in the participant's workplace.

### **Overview of Participants**

A detailed description of each participant follows. Pseudonyms are provided to protect the confidentiality of the participants.

Diana, a 67 year old Caucasian woman, had been diagnosed with pancreatic cancer six weeks prior to her interview and was undergoing palliative chemotherapy. Diana requested to be interviewed during an infusion. Diana was a little restless due to pain and her daughter encouraged her to take some pain medicine. As a recently retired nurse, Diana admitted feeling “naughty” taking narcotics in public, but she did so after calling home to her husband to confirm that it was time for a dose. Diana and her daughter met with the doctor prior to the infusion and received news that Diana’s platelets were too low for an infusion. Diana still was interested in giving an interview since she wanted to wait to talk to the palliative care nurse and financial coordinator. The interview took place in an unused private infusion room, and Diana was eager to share her story. As the caretaker for her disabled husband, one of Diana’s main concerns was getting him situated before her passing. Diana’s daughter sat with us during the interview and was tearful at times. The interview lasted just over an hour.

Barbara, a 68 year old Caucasian woman, was the most recently diagnosed in the sample; her interview was four weeks after her diagnosis of ovarian cancer. Barbara was college-educated and lived in a rural area about 20 miles from the city with her husband, one daughter, and grandchildren. Barbara already had surgery and had been re-hospitalized for bowel issues by the time of the interview in her home. She was looking forward to starting chemotherapy and getting back to life with her grandchildren. Barbara's cancer experience was complicated by concurrent shingles and a daughter's illness; despite this, she was optimistic and strengthened by her faith. Barbara was tearful throughout the interview just as she had been during her recruitment. Her tears did not keep her from talking, but they fairly often did flow freely down her face as she shared her responses. One of Barbara's daughters arrived during the interview and did some cleaning in another part of the house. The interview lasted about 50 minutes.

Bruce, a 66 year old Caucasian man, had been diagnosed with prostate cancer eighteen weeks prior to his interview. Though home alone during the interview, Bruce lived on a farm about 25 miles outside the city with his wife. Bruce's eyes were misty as he described his diagnosis as "like being hit by a train" and making him a "two time loser" after his experience with Agent Orange exposure in Vietnam. His cancer story had several setbacks, complications, and disappointments including being re-hospitalized after surgery for pain control and several serious family health issues. Bruce expressed frustration that his case didn't "go by the book."

Bruce soon was to return to his work driving handicapped people to doctor's appointments. The interview lasted about 50 minutes.

Jean, a 65 year old Caucasian woman, had been diagnosed with lung cancer five weeks prior to her interview. Jean had some college education, and lived about 25 miles from the city with her husband. Her husband was golfing during our interview, a hobby that she greatly



missed during her surgical recovery. Jean's cancer was diagnosed in Stage I, and she felt very grateful and lucky. She found her diagnosis unbelievable at first, since she had never been a smoker. For Jean, her cancer treatment just entailed surgery, to which she was no stranger, having had 10 surgeries in her 65 years. Since surgery, Jean had been feeling exhausted and bothered by the fact that her incision kept her from wearing a bra. Jean's interview was just over 30 minutes, and more than once she mentioned that her interview was probably not very useful. Her Stage I diagnosis was different than others' but she was reassured that her perspective was still an important one.

Peter was a 74 year old Caucasian man diagnosed with non-small cell lung cancer eight weeks prior to his interview. He was one of two participants who had not completed high school, and he was now retired. Peter lived with his wife nearly 90 miles north of the city in a very rural location. His wife was, in fact, cleaning up the yard from the mess some bears had made just prior to the interview. The interview was arranged via Peter's wife who was very vocal regarding his care and needs, even from the time of recruitment. Peter, his wife, and their puppy were all present during the interview that took place on the patio on a cool summer evening. Peter was a bit emotional at the start of the interview when he talked about a stranger who had been supporting him via a prayer chain. Peter's surgery had been aborted when the surgeon found the lung cancer had spread to his heart. Since then, Peter and his wife were both feeling in the dark about his cancer plan. Chemotherapy would be taking place at a rural satellite clinic but had not yet started. Peter's interview lasted about 70 minutes.

Helena was a 65 year old Caucasian woman diagnosed with breast cancer ten weeks prior to her interview. Helena was college educated and still working as a teacher. The location of Helena's home, 90 miles away, was not a rural one and she had many closer options for her

cancer care. Helena spoke highly of the practice of seeking a second opinion, although she was not entirely pleased with how that had played out for her. She had liked the idea of having just one surgery, a partnership between the breast surgeon and plastic surgeon, but then her breast implant became infected and required additional surgery. She had summed up her experience with some profanity during her recruitment and was probably the most critical and cynical of the participants. Helena admitted to being a private person and that few people knew of her diagnosis. She kept her emotions mostly closed off with just a glimmer of emotion when she spoke of thinking of leaving her grandchildren behind. Helena's interview lasted about 75 minutes.

Clark, a 72 year old Caucasian man, was diagnosed with prostate cancer eighteen weeks prior to his interview. The interview took place at his general store; his daughter and grandson were also present and an occasional customer came in for snacks or cigarettes. The interview was arranged via Clark's daughter who emphasized over the phone that her father denies his cancer. She reported that Clark is a Vietnam veteran with post traumatic stress disorder and that he uses denial as a coping mechanism. The strategy of not being insistent about his cancer and mimicking his own wording (e.g. "there were indications of two spots turning into cancer") worked well during the interview. With regard to his slow physical healing, Clark at one point stated that he is "not Superman". At the end of the interview, Clark mentioned that he only recently is getting better at talking about things. His family has wanted him to go to the VA for years, but he won't go because "you have to talk about things" in order to get in. The interview lasted about 35 minutes.

Barry, a 73 year old Caucasian man, was diagnosed with stage IV esophageal cancer eleven weeks prior to his interview and undergoing chemotherapy. Barry was Masters educated,

retired, and lived with his wife in a nice suburb twenty miles from the city. Barry's wife also was present during most of the interview and spoke up from time to time. Barry's faith in God and the firmly held belief that God is healing him of his cancer were very prominent during the interview. He was thankful for a stage IV diagnosis because it provides a better opportunity to show the healing power of God. Like many others, Barry veered off topic, but he seemed to do it with purpose. He was good at bringing himself back to the point he was making. Barry was teary eyed a couple of times talking about an acquaintance who prayed for his healing and talking about hope. Barry seemed to enjoy sharing his story, and talked at length about various aspects of his life once the interview was complete. Barry's interview lasted about an hour and 40 minutes.

Felicia was a 68 year old Caucasian woman diagnosed with pancreatic cancer nine weeks prior to her interview. A divorced and retired teacher, Felicia was the only participant who lived alone. Her home was in the city, only two miles from the cancer center. Her home was, perhaps surprisingly, the only one to smell of cigarettes. Felicia also perhaps most "looked the part" of a cancer patient with her turban and loose fitting clothing. Felicia spoke freely and seemed comfortable during the interview, occasionally referencing her notebook of medical details at the dining table. Her interpretation of her prognosis seemed favorable; after chemotherapy, radiation, more chemotherapy, and then surgery, she should be cured of cancer at the price of gaining diabetes. Like most others, Felicia often referenced her faith and belief in prayer.

Felicia spoke especially highly of the clinic's oncology social worker and the help she provided Felicia in sharing her diagnosis with her young grandson. The interview lasted just over one hour.

Dick was a 65 year old Caucasian man diagnosed with prostate cancer thirteen weeks prior to his interview. Dick was high school educated, retired, and lived with his wife in a suburb just a few miles outside of the city. Dick's interview was challenging because his wife, who mentioned at the outset that she was recently diagnosed with a cognitive impairment, did a lot of talking. Dick showed signs of quiet frustration as she put words in his mouth or monopolized the interview. Dick's wife brought up sexual side effect of his surgery, which none of the other participants discussed. His wife said this was the reason he was crying and emotional before surgery. Dick had previously discussed crying but gave different reasoning for it. During the interview, Dick seemed on the verge of tears when he spoke about not being able to fulfill his traditional role as a husband in taking care of his wife and supporting her own health issues. It also had been hard for him to give up caring for his lawn since his surgery. His interview lasted just short of one hour.

Steve, a 69 year old Caucasian man, was diagnosed with prostate cancer nine weeks prior to his interview. Steve was college educated and retired, but working a "fun" job in his retirement. He lived with his wife in a suburb just a few miles outside the city. Steve's wife was home during the interview but mostly cleaning and cooking elsewhere in the house. At the start of the interview, Steve mentioned that he might not have a lot to offer because his faith had made his cancer journey such an easy process. During the interview he frequently referenced his faith as a driving force in coping with his diagnosis and his healing process. He mentioned that his support system of family and friends has the same strong faith, and this made sharing his diagnosis with them easy. When it came to the care he received, Steve held the hospital nurses in very high regard but had some frustration with "administrative things" on the outpatient side. He said, however, that he is more tolerant of miscommunications and inconsistencies in that

arena; it is when he is uncertain and vulnerable in the hospital that everything should exceed expectations. Steve's interview lasted approximately 50 minutes.

Matthew was a 68 year old Caucasian man and the most highly educated. A retired business executive, Matthew was diagnosed with prostate cancer eight weeks prior to his interview. He lived in a condo about ten miles from the city with his wife, who was home but kept her distance during the interview. During the interview, Matthew spoke very highly of his family's support and of the outstanding experience with the doctors and nurses. He seemed candid and comfortable and was not emotional at any point during the interview. He also spoke of God and faith but less so than others. Matthew knew many others with cancer, including several former coworkers and his sister. He expressed gratitude to be cured from his cancer after surgery, and left the impression that he would prefer to downplay his diagnosis while others are going through so much suffering with their cancers. Matthew's interview lasted just over an hour.

Hal, a 78 year old Caucasian man, was the only widowed participant. Hal was diagnosed with small cell lung cancer eight weeks prior to his interview. He lived with his son, who moved in with him several months prior after Hal's wife died, in a suburb just outside the city. Hal was very emotional during the interview. He was first teary when he talked about how cancer has changed his life: he's tired and can't do anything. He also was teary talking about the tremendous level of support he receives from his son. Discussing his financial difficulty also made Hal emotional. He was the only participant to discuss financial trouble. Even at 78, Hal still relied on his part time income -- especially after the loss of his wife and her income -- to pay the bills, and he had been unable to work since his diagnosis. Hal was especially teary talking

about how the hardest part for him is not having his wife. Hal's interview lasted just over an hour.

Arthur, a 65 year old man, was the only African American participant. He was diagnosed with colon cancer eight weeks prior to his interview. Arthur lived with his wife in an apartment two miles from the cancer center, and he had not completed grade school. His wife, who arranged the interview on his behalf, also was present but mostly sat quietly by until the interview was complete. Arthur had both a different racial as well as different religious background than the other participants, but his overall responses were not different than those of the others. He gave perhaps fewer medical details but expressed, like others, concern for his grandchildren, appreciation for nurses, and struggle with physical symptoms. Arthur's interview lasted about an hour and twenty minutes.

## **Findings**

### **Interpretive Process**

Data analysis began in July. The codes from the first six interviews were compiled, and the researcher began to cluster them together by hand into subcategories. The clustering for interviews seven through thirteen then followed, using and refining the pattern of subcategories developed with interviews one through six. The field notes supported the emerging structure.

As previously mentioned, the clustering of codes from interview fourteen came last and served to confirm the data saturation achieved in the prior interviews. From the 1,618 codes, a structure of 32 subcategories was developed. After a few iterations, the 32 subcategories that held similar patterns of meanings were group together to form 12 categories. These 12 categories with similar patterns of meanings were then placed under three overarching themes. Each of the

themes was represented in every interview, as were most of the individual categories. Table 2 contains a diagram of this structure.

Table 2

*Final Themes, Categories, and Subcategories*

<b>Themes</b>	<b>Categories</b>	<b>Subcategories</b>
The Cancer Health Care Experience	Excellent Care	Excellent Care
	Trusting and Respecting Providers	Listening/Obedying Reading Providers Trusting Providers
	Disappointments in Healthcare	Healthcare Communication Problems In the Dark Inferior Care
	A New Experience	Moving Quickly New Experience Surprised
Challenges in Managing the Cancer Experience	What the Patient Brings to the Table	Other Coexisting Problems\ Poor History with Doctors
	Desire for Control	Desire for Control Hasn't Changed Let's Go
	Physical Limitations	Physical Limitations
	Emotional Strain	Denial/Avoidance Emotional Struggle Hands Tied Regrets Reluctance for Help Skepticism Worry
Coping with the Cancer Experience	Positive Outlook	Contentedness Having Hope Positive Outlook Power of Faith
	Thinking of Others	Social Impact Thinking of Others
	Support and Encouragement	Support and Encouragement
	Reflection	Be Accountable Reflection

## Study Themes

The three themes derived from the data reflect the participants' views on their needs as newly diagnosed cancer patients. The themes are:

- I. *The Cancer Health Care Experience*
- II. *Challenges in Managing the Cancer Experience*
- III. *Coping with the Cancer Experience*

The following sections will provide participant quotes that illustrate each of the categories within these three themes.

### **Theme I: The Cancer Health Care Experience**

Theme I is defined as the interaction with providers that is generally positive but not without disappointment. Theme I is comprised of four categories: (a) excellent care; (b) trusting and respecting providers; (c) disappointments in healthcare; and (d) a new experience.

**Excellent care.** The category of excellent care is defined as *the compassion, attentiveness, and overall superior quality of the care delivered across the entire spectrum of providers*. The participant responses in this category dealt with physicians and physician assistants, nurses and nurse aides, laboratory and radiology staff, and the entire hospital in general. The participants described compassion that made them feel important, explanations that really helped them understand, and attentiveness from staff who were gracious, candid, and personable. Matthew spoke of the numerous times his doctor called just to check in on him, but his doctor was not the only one who he thought went above and beyond:

And, uh, the other people that stand out in my mind were the two nurses and two assistants who took care of me at [cancer center]. In fact, on my to-do list is to write them a thank you note. I am convinced, having been in management, that they had to have gone through some special interviews to be placed on that floor. I mean they didn't know it and when I asked them the question they kind of looked at each other like...but I am convinced that not just everybody serves as a nurse at [cancer center].



Matthew was consistently impressed by and appreciative of the genuine attention and care he received. He said, “Excuse the vernacular, but I can see through a lot of B.S. The care in the hospital was genuine, and I would underscore genuine. I mean there’s nobody who walked in the door, put on a smiling face and, you know, walked out with a frown.”

Dick gave similar support of the excellent and genuine care he received:

But as far as care, it’s there. Now I don’t want to hear somebody saying it’s not there, cause I’d have to...I think I’d have to say something. Everybody is so nice. They come in to check on you and I mean they’re doing their job and the care is there. They ask you if you’re okay and anything they can do for you. And it’s just...they care about you. They try to treat you like you’re part of the family. Like it...I would say it is a family hospital.

Felicia also described feeling like her care was special; it was personalized and she didn’t feel like a number:

And I was there a little bit early on this past Friday, because thanks to [social worker] I now have a will and estate planning and whatever all that stuff is. And I was meeting the lawyers in the library upstairs at 9:30 but I really didn’t have an appointment till 10:30 but I told them I was there and they said okay. And between that time and 10:30 I had my appointment with [oncologist]. So it was, you know, I just...I don’t know, I guess maybe because it’s small enough I’ve had the same nurse every single time I’ve had chemo. And it’s probably that way all over, but I don’t have experience with them. But I am just really pleased with everything there.

Arthur, on the other hand who was not pleased with everything still reported that he experienced moments of excellent care:

But at the end I met some good nurses. The one that took...when I went down that floor that night after they gave me some kind of medicine, she was a tall nurse. You could just feel kindness from her. I don’t know if it was the way she was talking or how pretty she was, but she was just kind. She was just kind nurse. And she put...no pain with the IVs. And I had been there maybe two days in and I had a little must odor on me, she came and asked me, ‘Would you like to be washed up? You can’t be in the hospital with a little must on you like that.’ Washed me, you know, sponge. And I thought that was so nice.

This participant was touched by this nurse's kindness toward him, as well as another nurse's kindness and attention toward his wife. In a field of disappointing experiences, to be later addressed, these still comprised a significant part of his cancer health care experience.

**Trusting and respecting providers.** This category is defined as *having a provider relationship characterized by mutual listening and understanding*. Responses in this category mainly dealt with having comfort with and confidence in providers based on the trust and respect that often grew from mutually listening to and understanding each other - patient and provider. Participants also described reading their providers, interpreting their words and actions.

Helena described a nurse and a doctor putting her at ease about her surgical healing and how their positive feedback created greater confidence and trust in the providers:

And in the meantime my nurse navigator heard that I was there and I had never met her and she came down and gave me a big hug and she looked at it and she said, 'Helena, it looks really good.' I would think they wouldn't tell me that it didn't look good, you know. She would have told me that there was something wrong with it. And in the meantime I had also gone to my oncologist and he said it looks really good. So I really felt confident that since [plastic surgeon] thought that I didn't need to come for six weeks, three doctors or two doctors and a nurse is pretty good.

Helena cited many examples of reading her providers. Their hugs, their tears, and their ways of trying not to alarm her all fed into her trust, respect, and understanding.

Dick, who had immense trust for his primary care physician [PCP], states: "Cause you hear a lot of people saying they don't trust their doctor, you know, and I don't know,...it's a family...you're coming there as a patient and once you're there they treat you like family and that means a lot." Dick went on to describe how his trust of his PCP bled over to the urologist:

[Urologist] asked me, he says, 'Do you want a second opinion?' I said, 'I don't need it.' He said, 'Well, you can have it.' I says, 'No.' But I said, 'You're the best there is and the best I know; let's go for it.' Yep, because [PCP] he said...he took me down and set to me about fifteen minutes to a half hour when I first found out I had cancer, he sent all the nurses out of the room and he said that [urologist] is the top notch in his field and that's the way I feel. And [PCP] don't say something like that unless he means it. It's gold.

Clark also echoed Dick's thoughts on knowing others who don't trust their doctors. He said, "I've known several people that, I don't know, 'I don't go to doctors.' Well, suit yourself. I go to doctors, hopefully they know what they're doing. The ones I found do....They just seem to know what they're doing.." Having found doctors who he was comfortable with, Clark described having respect for doctors' knowledge and expertise, trusting them, and following their restrictions.

Steve's perspective differed slightly from others. Though he described instances of respect and understanding between him and his doctor, his general trust in providers was more an extension of his trust in God. He described telling his family about his diagnosis as, "And you know, their reaction was the same. And you trust in God in these situations and, you know, trust in the medical profession to do the best they can and so there wasn't shock or distrust within the family either." Steve and his family trusted that God would get them through by way of the medical professionals who would do the best they could.

**Disappointments in healthcare.** The category of disappointments in healthcare is defined as *being on the receiving end of miscommunications, lack of answers, and inferior care*. The responses in this category dealt primarily with an assortment of healthcare communication problems, care that lacked adequate quality or inferior care, and participants being 'in the dark' when it came to their care plans.

Barbara experienced disappointments right off the bat, in the process leading up to her cancer diagnosis and struggles for months to get healthcare providers to actually hear what her problem was:

I would have like to have had the one problem solved a lot sooner. I think they may have found the cancer a lot sooner had they taken me seriously about the bowel problem. Because I couldn't get anybody to listen for a long time about that. And I said, 'Look I

know there's something wrong, I know my body.' And finally I called for a referral from my doctor's office. I mean I called just to get a referral to a specialist that could handle that then and they got me in to see my doctor. I had been trying for two months to get in to see her...They just didn't...it was just like they were hearing or listening to what I was saying, but they weren't actually hearing what the problem was. But I know they kept putting me off as far as getting an appointment with a doctor.

Helena waited 'in the dark' for hours for biopsy results that didn't exist:

And so my husband went with me and we sat there for an hour before we were called back and then we sat another forty-five minutes in the room. And then I was very...was upset with the doctor because I said, "Is it bad?" and he goes, "Yes, it's very bad."...But I was disappointed that he did not know anything at all except that I had breast cancer. He did not have my records or my files from the hospital. That was, to me, very disappointing and I probably am not going to go back to him...They need to let the patients know right away, you know, if something's not there.

Steve had a disappointing miscommunication that occurred on the day of his surgery.

Having recently started a new medication for a tremor, he communicated with his family doctor and the urologist to make sure it wouldn't pose a problem for his upcoming prostatectomy:

And it was early morning schedule and I was in the room with an IV hooked up and a nurse practitioner said, 'Let's quickly go over the medications that you've been taking.' And, you know, I'm not on that much, multivitamins and stuff like that, cod liver oil. Anyway I said Selegiline. He said, 'Ooh,' he said, 'I don't know about that one.' The anesthesiologist came in a short while later and they printed off a report and on the front page it was 'You've got to be off of this for ten days prior to' and so unplugged and went home.

This participant was very bothered by the fact that he had raised the red flag prior to surgery and the work hadn't been done ahead of time. He and his family got "all geared up" and then had to reschedule and do the preoperative prep again two and a half weeks later.

Arthur had disappointments with inferior care that came about when he was in the hospital while he was recovering from surgery. One nurse in particular treated him poorly and he sought desperate measures to get better care:

Like when I was up on that first floor I kept telling the nurse something...all she wanted to do was give me pain medicine. And I'm telling you I'm not in pain, it's just like an agonizing feeling. You know, everytime I call for her, she come up with the same

medicine and stand up and look at me with a needle, you know, like you're an animal or something and give you that there and I'm telling her, I don't need that. I need something...I need something else. So that son told me, said the only way you're going to get off from up here is you're going to do something. So I throwed up, got sick, I put my finger down my mouth and throwed up. It hurted, but I had to get them up here.

Thus, the cancer healthcare experience is not one entirely characterized by excellent care and trust with providers. Rather it is a complicated experience of ups and downs.

**A new experience.** The category of a new experience is defined as *a surprising and quickly moving cancer journey*. Responses within this category dealt with participant experiences happening quickly, and things playing out differently than they were expected.

Bruce, who expected to “buzz right through” his surgery and recovery based on a coworker’s prior experience with prostate cancer spoke of a different experience that was more troublesome than he expected:

They give you all these percentages, 1% of the people might have this, you know, they got those percentages. But I never heard the one about the... if the prostate's large you're going to get beat up and it will take a long time to come back. I never heard that one before...yeah, I always said they have to write a different book on this one.

On the other hand, Felicia’s new health care experience was one that impressed her:

When I look at this paper and think that on April 1 I called my doctor and said ‘I’m losing weight, what do you think?’ and here it is the end of July I’m going to have my last phase 1 chemo treatment. April, May, June, July, I mean I don’t know, but to me that’s kind of fast...that first day meeting with all five of those people it was like holy cow I’ve got a whole cancer library here...and I just so appreciate that, you know. I mean I didn’t know what was going on.

Similar to Felicia, Barry also noted the speed of the process, saying, “It was amazing how fast it all took place once things got in place. So we started chemo and we’ve done eight weeks chemo now. Actually four times, but it’s every two weeks.”

Clark’s explanation of his new experience was neither negative nor positive, just simply new:

I've got some friends of mine that have been through this. I was kidding them, I said you got used to this, you know they've been in and out of hospitals for health things, heart attack...I had a heart attack. But I said anyway, you guys have been doing this for a long time, I'm new to the game. I'm new to the pill thing and getting all your prescriptions. I just don't...I've never had to do it.

The notable newness of the cancer experience was a factor discussed by all of the participants in relation to the needs they were experiencing as recently diagnosed cancer patients.

## **Theme II: Challenges in Managing the Cancer Experience**

Theme II is defined as barriers to feeling normal and hurdles to overcome. Theme II is comprised of four categories: (a) what the patient brings to the table; (b) desire for control; (c) physical limitations; and (d) emotional strain.

**What the patient brings to the table.** This category is defined as *relevant issues including patient identity and characteristics, concurrent family or co-existing medical problems, or history with the health care system or the providers*. Within the theme of Challenges in Managing the Cancer Experience, all but one participant gave responses that fell within this category.

Barbara provided an excellent example:

I'm not one to go to the doctor to start with... So I've not had a lot of confidence...there's been a lot of incidences through the years with doctors. It took them four years to diagnose my brain tumor. Both times, four years. And I knew it was there. My chiropractor knew it was there. Nobody would diagnose it. They didn't do the right tests or didn't focus on the right areas. And I went through, I think six or eight doctors before I finally got somebody to diagnose it. So I just don't have...didn't have a lot of faith in them.

Here Barbara outlines a relevant issue that she brings to the table, one that falls within this category's definition of poor history with doctors. Barbara's historical lack of faith in doctors served as a challenge for her to overcome in her cancer experience.

Bruce also struggled with his doctor visits. Identifying as a person who doesn't tend to go to the doctor, or at least one who doesn't enjoy it, the volume of appointments was a challenge for Bruce to overcome:

I hate going to doctors. Doctor's appointments drive me crazy. I'm not the type of person to go to the doctor a lot. You know, I go at normal ones and stuff like that, but everything seems to be you go here, you go there... I had like between the first of January and by the time I had my surgery, 18 doctor appointments, you know, which is a lot.

Hal provided an example of a different concurrent issue with his cancer struggle, "Well between house payment and bills, so no, I'm...we're trying to do something with the house, but...see if we can get a reverse mortgage or something on it. Yeah. Financial's been a struggle." The coexisting financial troubles related to the loss of his wife and his inability to work that he brought to the table were only complicated by his cancer diagnosis and treatment.

Helena summarized a prime example of the myriad issues that older adults bring to the table:

And then my husband had radiation and we know about that because his prostate level rose more than it should, so he went in for the radiation treatments and all of this happening at the same time, it was unreal. And then the deaths. And he had three close friends that passed away and then two...it's like goodness sakes, when it rains it pours, cause we've been really healthy. It's like oh I get on Medicare and boom (laughter). Shit hits the fan, I guess. I don't know.

Her spouse's medical treatment, death of close friends, and changes in finances/insurance all on top of Helena's complicated post-operative course provides a final example of just how many complicating factors some of these older adults recently diagnosed with cancer carry with them.

**Desire for control.** The category of desire for control is defined as *an interest in getting it over with, striving to maintain or return to normal, and managing matters such as time and money*. Responses in this category dealt with desires to take action and to return to normalcy

(i.e., let's go) as well as discussions of controlling elements such as time, money, and diet at a period in life when so much is outside of the participant's control.

Diana, who was obtaining palliative chemotherapy for pancreatic cancer, spoke of money management, using retirement money to replace the windows in her home to raise the resale value for her husband. She also reflected on her identity as a "doer" which had not been changed by the cancer diagnosis. She very much wanted to feel like the same person:

So actually on so many levels it hasn't and I don't even want...want it...I want it to feel the same. As a matter of fact, I've been waiting for a sunshiny nice day where I can wipe the chairs out back and sit and look out...just sit out back, look at the creek, the ducks.

A quote from Helena demonstrates the desire for action or "let's go" when discussing the infection in her breast implant, "I didn't know really what I had, but anyway I really wanted it out and they put me on antibiotics for three days and then they ended up taking it out, because it wasn't going away." Helena really wanted the implant removal over and done with once it started causing problems and was frustrated with the wait and see approach of the doctors. Though she later expressed a desire to "feel like a whole person" and eventually have an implant placed again, she remained undecided due to the risk of an uncontrolled infection reoccurring.

Barry was very focused on controlling his diet, having read a lot about nutrition and cancer. He and his wife were taking control of his diet very seriously:

I don't think [oncologist] necessarily agrees with our diet, because he wants me to beef up, but in reading and studying, cancer eats off of glucose and so we took all the things, the starches and all that out of my diet. Okay. Cause I have no desire to feed that thing that I don't have. Okay. Cause I haven't claimed it either. I don't claim it. I've been diagnosed, but it's not mine. I don't own it. I refuse to own it.

Barry goes on to detail some of the dietary plans he and his wife have tried and how the modified recipes "don't taste as good as the real stuff, but at the same time you at least get to have eggs and pancakes and you get to have muffins and you get to have things that are similar and you're



not like depriving yourself of anything.” Barry alluded to the fact that his diet, and subsequently his weight, has always been something he tightly controlled, thus also hinting at how cancer “hasn’t changed” his lifelong desire for weight control.

Matthew spoke of the impact that his diagnosis had on his financial priorities and his newfound desires to manage his money differently:

[Wife] and I have a bucket list that we’ve started working on and I know one thing that she would like to do very badly is a Mediterranean cruise, so I’m going to try to get that set up for next year, the right time of the year. Um, probably going to sell the condominium in Charlotte...the reality is that what I pay in taxes, HOA fees and insurance would more than pay for three or four months in a condominium on a beach at Gulf Shores...And, you know, I think I’d rather do a total family cruise or do a total family getaway and use money that way as opposed to sitting in a building.

Although not everyone owned second homes or had money for cruises, all of the participants expressed desire for control in some form or another.

**Physical limitations.** The category of physical limitations is defined as *experiencing symptoms and feeling tired, slow, sedentary, or suddenly old*. This was a fairly broad category in which participant responses dealt with limitations such as pain, gastrointestinal symptoms, weakness, and exhaustion. Physical limitations were second only to emotional strain when it came to participants’ challenges in dealing with the cancer experience.

Jean stated, “Every room I go in I keep thinking, ‘Well, you need to clean this room,’ but I just don’t have the energy. I mean I’m doing laundry and cooking a few meals...just trying to do a little bit more every day.” Jean was not alone in this. In fact, many of the women struggled with the physical limitations that kept them from the housekeeping needs they saw building up around them.

Similarly Clark, who ran a business, was frustrated by the surprisingly rapid loss of strength he experienced. He was not accustomed to feeling weak and trying his best to be patient while relying on others to do the lifting required in his line of work:

Can't do anything. I'm usually very active, you know, like even at my age I do a lot of physical work. And because of the two surgeries that I had at one time, well basically at one time, pretty much immobilized physically. I can't lift anything above 10 pounds. So it's boring...you can't do nothing.

Arthur discussed having decreased taste sensation and appetite as a result of his chemo. Arthur also experienced physical trouble eating and drinking, usually a source of enjoyment for him, because of mouth pain after he finishes his chemo treatments.

Then when I come off it my taste buds don't be...they feel like I done, you know, when you take something too hot and how it make your gums, I mean the upper feel like that. And I can't drink no ice water. Nothing cold. And I came home the other day and drunk...I had some cold...cold juice up there, apple juice and forgot I had that...and drunk it. And I thought I had drunk...felt like I was drinking toothpicks.

Hal was perhaps the most emotional when discussing his physical limitations brought on by fatigue:

I can't do nothing. I get too tired. See that's what I miss. I mean I used to like to...excuse me (crying). I can't work in the yard. Can't walk much. You're just limited to what you can do (crying). It's just, I don't know, when you're used to doing something then all of a sudden you can't do it no more it makes a big difference, you know.

Hal went on to discuss how his physical limitations lead to boredom and then more fatigue. Though he did small yard work tasks, his physical limitations from fatigue and discomfort at the port site created a significant challenge in his overall cancer experience.

**Emotional strain.** The final category in Challenges in Managing the Cancer Experience is emotional strain. This category is defined as *struggle with a variety of emotions including fear, worry, shock, and reluctance*. This category was comprised of issues such as anxiety,

apprehension, being overwhelmed, stress, and uncertainty that came up repeatedly among participants.

Jean said of her diagnosis, “It just didn’t feel real. Because I’m a non-smoker and you just kind of associate lung cancer with smoking.” Not only did her unbelievable diagnosis admittedly surprise and scare her, but she also dealt with a degree of worry despite her very early stage disease saying, “I wonder, if I had it once, what’s to stop it from coming back?”

Another lung cancer patient, Peter, frequently expressed apprehension over the disease course lying ahead of him:

And you cannot tell a lie, I don’t care who it is and how spiritual you are, when you have something like this that you’re told that you have, you’ve got to be apprehensive. You’d be telling a fib if you wasn’t apprehensive...I think anyone is going to be apprehensive on it. No matter what their faith and how strong their spirituality is, they’re going to have a little apprehension. You have to have, you’re only human.

Peter often defended his feelings of apprehension, making the point that they could coexist with his strong faith.

Barry spoke of many coping mechanisms that he used to keep him from an emotional struggle, including speaking with positivity and not taking ownership of his cancer. However, even he had his struggles, “And so I try not to claim anything that I don’t want. I try to be positive in what I say. It’s hard sometimes. You’ll find your old self slide in. You know, as I call it, my first thoughts.” Barry’s old self and his first thoughts crept in from time to time, particularly in the face of daily weight loss.

In contrast to much of Barry’s emotional struggle centering on his battle with weight management, much of Diana’s struggles revolved around her husband. Her ailing health caused her disabled husband to show greater independence which in turn caused Diana some feelings of regret over the years she spent feeling burdened or impatient with him:

I mean not that I would have changed anything, but maybe I would have done it with...instead of so many heavy groans and (heavy sighs). Maybe I would have been a little bit nicer about it if I'd known that he could, but I was just doing it out of choice. But there were some times when I felt a little put out. And I think I expected him to read my mind a little bit sometimes too.

In addition to the regrets she reflected on, Diana also described feeling overwhelmed by the stress of trying to solve their issues with insurance coverage. Speaking about the idea of financial resource support for bereaved spouses, she said:

But how helpful that would be to people who just feel so overwhelmed. And maybe there are a lot of people who don't. Maybe it's just because [husband] and my situation is a little unusual that it feels a little much sometimes. I'm starting to get to the point almost with some of this that I don't care...and I don't think that's a real good place to be.

Diana was not happy with the apathy she felt creeping in because she was also still worried about leaving the work undone. Recalling a conversation she had with the insurance company, she said, "I said 'This is the thing that worries me.' I said, 'I have an incurable type of cancer.' This is where I used my cancer card. 'I have an incurable type of cancer that is probably going to...at this rate it's going to take me long before the paperwork gets done.'" Diana's examples of emotional strain show just how intense the emotional strain can be when it comes to the challenges of managing the cancer experience.

### **Theme III: Coping with the Cancer Experience**

Theme III is defined as handling the cancer journey with mental adaptation and external support. Theme III is comprised of four categories: (a) positive outlook; (b) thinking of others; (c) support and encouragement; and (d) reflection.

**Positive outlook.** The category of positive outlook is defined as *being driven in one's cancer journey by faith, gratitude, and hope*. This is the category representing the largest amount of participant responses. Responses in this category dealt with contentment,

thankfulness, happiness, hopefulness, and positivity. For many, but not all, participants, these responses were tied to power of faith and God.

Jean's positive outlook was revealed early in the interview as she described being diagnosed with a surprising stage I lung cancer:

So when they found mine the very earliest stage...so I consider myself very fortunate. Now that I'm healing, I don't think about it anymore. I guess that's the way it was meant to be and the Lord wasn't ready for me to leave yet, so He allowed me to find out about it so soon.

Jean's trust in the Lord's plans for her helped her to see the fortunate timing of her cancer diagnosis.

Peter was another participant who often spoke of the positive outlook inspired by his faith. He described how scripture readings helped him shape his mindset, "I'm trying to stay positive. I have my faith in our Father in Heaven and I basically leave myself in his hands and what will be, will be. And I know it can be taken care of if I get myself in the right frame of mind."

Barbara was another participant whose positivity was tied to her faith. She first described using Jesus' suffering to put her own in perspective and later recalled her struggle with shingles to do the same:

And actually I've come to appreciate [the shingles] in a way, because I...I think I would have been terrified if I hadn't already gone through the horrible ordeal and struggle. And so it made me appreciate, 'Oh it's only cancer,' you know (laughter)... I mean you just get to where you think it through and you get a grip on it and you think, well this is doable. And if you just bite it off a little bit at a time it's not so surmountable, or insurmountable, you just...that way you can handle it. So back when my shingles pain was bad I said, 'I don't think I can handle chemo right now' and then shingles pain started getting better and I said, 'Okay, let's do this.'...Whatever comes into our lives we grow from. Now you can either let it turn you sour and bitter or you can look for the positive and see the good that can come from it.

Barbara's positive attitude was matched only by Dick, who had a sense of hope and positivity about nearly everything...including his doctors, his medical bills, his prognosis, and his recovery. Dick spoke about his postoperative urinary symptoms and his hope for their improvement:

It's coming. It's temporary. I know it's temporary because I can see a big difference in my water today. I didn't hardly go to the bathroom at all. This morning and this afternoon I went a little bit. But, you know, I can see...I can see it coming. I'd rather have it come gradually instead of all at once and say, 'What's going on?'

Dick, like many others, expressed thankfulness for aspects of his situation, even though most would agree that the big picture of a cancer diagnosis is not a desirable one.

**Thinking of others.** The category of thinking of others is defined as *concern for their loved ones and understanding of others amidst a life of reduced social interaction*. Responses in this category dealt with the social impact cancer played in participant's lives. Participants spoke of issues such as worrying about the loved ones they will leave behind, becoming more socially isolated, not knowing what to say to people, and trying to allow others to help them. They also acknowledged their families' struggles with the process, expressed empathy for others with cancer, and some shared desires to give back to the cancer community.

Diana was keeping very busy in what she knew would be her final months. Despite her own health issues, Diana was very focused on others at this point in her life. She spoke of spending time dividing her jewelry collection to give away and of making many arrangements for her husband:

He will be going eventually on Meals on Wheels. Well I was the one that called and talked to them to make sure that he qualifies for that. I was the one that called Healthcare Associates and had them come over, that's who he had after his stroke. That's who we're going to continue with after I'm gone. And so I had them...you know, I made an appointment and we sat down, did a care plan, got that all renewed and set for him.

Peter was another participant focused on others. He spoke of trying to forgive and forget his daughter's past offenses toward him, guilt over cancelling plans for archery with his grandson, and he especially spoke of his wife:

And I told her and she agreed, I don't want a funeral either. I thought very much about it. I cannot see her spending \$6000, \$7000 or more to have people come and stare at me in a casket. My biggest worry is her...This old house is over 100 years old, we did a lot of work on it, rewired and dry walled and everything and I've got a lot of equipment out there. And I dwell on this a lot. Maybe I should make arrangements for an auction sale to get rid of this right now so she don't have to deal with it.

Unlike Diana and Peter, Felicia had a rather favorable prognosis. Yet she still did share a significant amount about her thinking of others, especially her grandchildren. Felicia had been very worried about telling her seven year old grandson, a bright shining star in her life, about her diagnosis. Though it went well, she was missing her interaction with him and his sister, and the oncologist recommended seeing them more. Felicia then struggled with her need for the interaction and trying not to intrude on her daughter's schedule:

But [oncologist] also said that I should see the grandbabies as often as possible. She said I really think you're missing them and [daughter] just has to make time to come see you. Well then for like two weeks my sister-in-law was like, 'Did [daughter] come by with the kids today?' Well, no. Oh. '[Daughter] come by with the kids today? Do I have to call her and tell her?' I said, 'Look, she's not ignoring me, she has a life with kids and a job. You know [grandson] is on ball teams and he's got practice. There's just times when she can and times when she can't.' So, no I was not going to let her call and I don't think she did.

Matthew was another participant whose coping with cancer involved thinking of others. He spoke a bit about his concern that his wife was becoming too socially isolated along with him during his recovery, but he also spoke very thoughtfully about sharing his diagnosis as it related to his sister:

I then eventually communicated with my siblings. But there was a reluctance there and I can't explain why, because I'm a pretty open person. I guess, you know, I just wanted to get it over and done with. I have a sister who's dying of cancer. I mean she will never be cured and kind of in the way my mind works, it was far more appropriate that she continue getting the attention from my siblings. I mean she goes for chemo treatments

every two weeks and she's fighting for her life to extend her period with her husband and her children. So mine is kind of nothing in relationship to that...you know, I just wanted the focus to remain where it belonged.

Matthew later shared that his cancer experience had given him the opportunity to tell his sister what a good role model she was to him. For all of the participants but one, thinking of others came up as a part of their process of coping with their diagnoses and treatments.

**Support and encouragement.** The category of support and encouragement is defined as *the assistance, kindness, and thoughtfulness of family, friends, community resources, and even strangers*. Responses in this category dealt with recollections of friendliness and help that the participants received in many forms. Hal made clear just how supportive his son had been to him:

I don't know what I would have done if he wasn't here. He, uh...no I don't know what I would have done if he hadn't been here, I really don't. Well, he takes me every place, cause I don't drive half the time. Especially after I had that stroke I couldn't...And, uh, you know, he does most of the cooking. One thing I didn't do was ever cook much (laughter). And he likes to cook, so. He does most of the cooking and what not. It's just, you know, and having somebody here. Makes a big difference.

Family was also helpful to Bruce, whose nephew was a doctor and therefore was able to help give him extra explanations and coach him about the questions to ask his doctor. Bruce also highlighted the assistance of friends and neighbors:

Other people they'll come back and they'll do more for you, stand behind you and stuff, even though they don't understand it. Then we've got other friends over here that she's had cancer quite a bit and they come through very...quite a bit for me and stuff and someone you can talk to.

Felicia had found much support from resources in her community; she discussed her happiness with meal delivery and free salon/boutique services. She also spoke very fondly of the support and encouragement from the friends in her church community:

There are just so many beautiful people that first of all gave me this huge hug and then before church was done our pastor said, 'Felicia can you like walk up here because we



would like to pray over you.' I said, 'Yeah, I can do that.' So I did and was anointed with oil...But yeah, they have been great, visiting, bringing their leftovers...so yeah, it's really been really good. And everybody at church too said, 'Praying for you every day.'...And I don't know if they're here or not [looking around papers on table] but the kids...the kids made me and came and marched them up to me, but all these little cards. Yeah. Not this past Sunday, but the pastor's wife had the kids just you know make little cards for Ms. Felicia. Yeah. So that was really sweet too.

Similarly, Peter cited spiritual support from his church community and also from a complete stranger:

I got a phone call from Alaska from a gentleman I've never met before in my life, he gave me encouragement. MK put me on the prayer chain at their church in Alaska and J called me, he'd went through cancer. He'd been ten years cancer free, he said it's come back now, Peter, and he's going to be 86 here shortly. And he says, I'm not going to beat this one, but I want you to know there is hope. And the next day he called me again and he said, Peter, I want you to know it's going to be okay. He says whatever happens it's going to be okay. You've got your faith, there's a brighter side to everything. Yep, very special [crying]. Excuse me. That's how special it was.

Support and encouragement was a large category, playing a role in the coping experience of all of the study participants.

**Reflection.** The category of reflection is defined as *considering one's own situation with advice to give*. Reflection was represented among the responses of all but one participant.

Responses in this category dealt with participants' reflections on their own habits, mindsets, and situations.

Bruce, for example, discussed his process of learning to open up to others about his cancer by saying, "But I've found out it's...well first of all you don't want to say anything to anybody, you know, you just want to kind of keep it to yourself and then I found out it was better to talk about it." Clark shared his mindset on the inevitability of his situation in saying, "Well yeah, you just know that at my age, 72, the good run was bound to come to an end sometime. You're going to have to start paying your dues."

Participants also gave advice to hypothetical others such as the need to be accountable and involved in one's own healthcare. Steve, who experienced a frustrating rescheduling of his surgery despite his effort at self advocacy, spoke often about being one's own advocate. Hal discussed a need for simply sticking around and having patience in the hospital:

It's just like I tell my one son, he was in the hospital for a while, I said you've got to calm down. He just wants to get in and get out, you know. Well yeah, I've learned that with age (laughter). Well, a little bit, yeah, as far as that goes. There's other things I don't have much patience. But as far as the hospital, I've been in the hospital enough times to know that you've got to wait a bit here and there.

These examples illustrate a sampling of the category of *reflection* present in the participant's discussion of the needs surrounding their cancer experiences, the final element in the theme of Coping with the Cancer Experience.

### **Summary**

Chapter four presented the results of the study. The chapter gave a summary of the demographics of the participants as well as an overview of each of the participants. The presentation of findings included a brief discussion on the undertaking of the process described in Chapter 3. Finally, the three themes and twelve categories into which the data were organized were presented and illustrated through quotes from the study participants.

## CHAPTER FIVE

### Introduction

The purpose of this study was to gain a richer understanding of the needs of older adults recently diagnosed with cancer through qualitative analysis of interviews with fourteen participants. The first section of this chapter reviews each of the study themes as they relate to the research questions. The second section of this chapter presents implications for practice, education, and research. The third section of this chapter covers strengths and limitations of the research along with recommendations for future research.

### Discussion

Three themes emerged from the data describing the cancer care experience of adults recently diagnosed with cancer. The themes were: (a) the cancer health care experience, (b) challenges in managing the cancer experience, and (c) coping with the cancer experience.

#### **Theme I: The Cancer Health Care Experience**

Theme I identifies how participants described their experiences with cancer health care providers and the health care system. The responses, like the participants themselves, were not homogenous. In response to the first research question of the study, "*What needs are experienced by older adults following a recent cancer diagnosis*", the participants illuminated several needs.

Thus far for the participants, some needs had been met. Met needs included being listened to and understood by health providers and, likewise, being able to listen to and understand their healthcare providers. Participants often described this need being met with compassion and attentiveness. Additionally their needs to be treated well were met. This is an important point to be made. This study of fourteen participants is far from generalizable to an

entire population of older adults recently diagnosed with cancer. Thus, some needs that were identified as being met in this sample may not be met among individuals in other groups or areas of the county. This may be specific to the type of care delivery that is provided in this cancer center.

Participants often reported about the newness of the experience. It was all happening so quickly for them and many elements were surprising. Their needs for support resulted from new information along with confusion regarding expectations related to their diagnosis and treatment. This finding is reflected in a study by Holt, Hansen, and Mogensen (2014) where supportive needs during the quickly moving cancer pre-diagnostic period were explored. Study participants experienced needs in managing new information and making decisions, and the authors concluded that readily-accessible information and the support of relatives were helpful in meeting these needs. This study examining the cancer pre-diagnostic period is relevant to the current study since the majority of participants experienced needs that arose during the pre-diagnostic period and continued into their early diagnosis period. In retrospect, identifying some of these very early needs in the experience of the patient with a new cancer diagnosis is very important for health care providers.

Although participants in general spoke highly of their experiences with providers and the healthcare system, each also had disappointments to share. The disappointments centered on additional unexpected illness complications and inadequate communication by health care providers, reflecting needs for better organization of health care delivery, better listening on the part of providers, and better general communication. Listening and communication skills are required for health care providers to ensure that the cancer patient knows and understands what to expect as they face their diagnosis and treatment. Understanding that the message is not

always heard during the initial stages of diagnosis makes it imperative that information is communicated more than once and understanding is sought. Additionally, misperceiving the capacities and neglecting the goals of older adults in the name of beneficent ageism needs to be seen for the discrimination that it is, and efforts need to be made to ensure the same standard of care is delivered to older adults with cancer.

In looking at the second research question of the study, “*What are the perceptions of older adults about their health care providers’ abilities to identify and meet their needs,*” participants provided additional understanding of the importance of the relationship between patients and providers. As previously mentioned, the participants identified listening and understanding between themselves and their healthcare providers as important. Participants identified very few needs when directly asked for them in the research interview. This may have been in part related to the ability of the providers to anticipate, identify and meet those needs before participants registered the needs themselves. The findings about participant perceptions of their health care providers suggest a consistent appreciation for the providers’ abilities such as listening, knowledge, and compassion. Despite a belief in providers’ abilities, there were instances in which needs were not identified or met. The participants often attributed the unmet needs as accounts of failures in the overall healthcare system—communication breakdowns, “too many cooks”, or time constraints—rather than incompetence on the part of a particular health care provider. It may be easier to blame the system rather than the provider with whom they have established a relationship for their care.

## **Theme II: Challenges in Managing the Cancer Experience**

Within Theme II the barriers to feeling normal that were experienced by participants as well as the hurdles they described needing to overcome were identified. In focusing on the

*“needs experienced by older adults following a recent cancer diagnosis,”* the desire to maintain a sense of self-identity was prominent. Participants wanted control and they wanted sameness; if these weren't immediately possible, they wanted to get moving as quickly as possible to the resumption of normal. While the need for maintaining self-identity and way of life is not unique to older adults, its presence is prominent in this study. The participants in the study faced many recent life changes: (a) death and illness of family and close friends, (b) changes in employment, and (c) concurrent health issues are just a few. Rather than take the cancer diagnosis in stride, accepting it as just another change to which to adapt, all participants to some degree fought to return to their “sameness and control”.

Financial needs were prominent for a few participants, while others admitted ignorance on the topic. This reveals another major recommendation from this study--a need for financial counselors or navigators. With the delays in billing seen in our health care system, many of the participants did not know what financial burden their cancer care would bring and at the time of this study simply hoped for the best. They relied on what family and friends told them to expect in their bills as well as what their insurance covered for other care in the past. Based on care payment models surrounding health care costs in our country, it is baffling as the care is most often delivered and received without either party having an awareness of the final cost to the patient. It does beg the question of how much patients would like to be informed of the cost of their care up front. Perhaps knowing would impact the decisions of those in financial difficulty or spur them to seek financial assistance sooner. On the other hand, when dealing with a cancer diagnosis, perhaps, patients prefer not to know and do not want to have to make a financially-based decision about how much treatment to seek based on costs.

Although sexual concerns were identified as an issue for patients in the literature review (Doka (2002); Kagan, Holland, & Chalian (2008)), rarely were they discussed by participants in this study. One participant with breast cancer mentioned only in passing of her husband's shock at the doctor's recommendation for a total mastectomy. She subsequently mentioned having an aversion to looking at her scarred chest since surgery. Gentle probing revealed her disinterest in talking about her body image concerns, but she later did discuss her appreciation for the cancer center providing a breast prosthetic to her. Her needs related to her body image were at least partially identified and met through the provision of the prosthetic, though her acceptance of her scarring as well as her husband's acceptance of her changed body may not have been identified or addressed by providers.

Another participant with prostate cancer denied being bothered by the likelihood of sexual side effects when his wife offered that explanation for his pre-operative worries. In his case, there seemed to have been education about sexual side effects for men and their partners after prostate surgery, but the participant was not comfortable discussing the issue during the interview. Thus, while the general need may have been identified by his provider it cannot be said whether or not the participant and his wife had adequate education or support to adapt to changes in their sexual intimacy. It is difficult to assess sensitive topics such as sexual concerns, which often are considered very private, when the participant and interviewer do not have any previously established rapport. However, it raises the question of whether or not these issues are addressed or adequately discussed by providers with whom the participants have established a trusting relationship.

### **Theme III: Coping with the Cancer Experience**

Coping with the cancer experience encompasses the support and adaptation that participants utilized in handling their cancer journeys. The participants identified needs for hope, support, and encouragement that were prominent throughout the interviews; these areas were tied to trust. Hope was accepted from those who were trusted, and support and encouragement enhanced trust in those who gave them. There was an interesting distinction among participants related to the finding that hope and trust were identified as needs in the cancer coping experience. Some participants awarded their trust to providers who had proven time and again to deliver truly excellent care while others seemed to simply give automatic trust to health care providers. No matter the origin of the trust, trust was prominent. This is consistent with Bierman and colleague's work (1998) and the premise that quality health care for the older adult goes further than having a regular source of care and entails three steps: (a) gaining entry to the health care system, (b) getting access to sites of care, and (c) finding a provider who meets their individual needs and with whom they can develop mutual communication and trust. The findings of this study suggest that this third step in access is not a problem area, at least among the participants in this study.

In talking about their experiences of coping with the cancer experience, the participants provided additional perceptions. First and foremost there was a confirmation of the first assumption of this study: that older adults perceive themselves as having new needs after being diagnosed with cancer. As previously mentioned, it was discovered early in the course of interviews that participants struggled to name their needs even while general discussion of their experiences drew out various needs both met and unmet. So many of the participants relied heavily on a positive outlook and religious faith to help them cope with the cancer experience



that needs, though present, were often not the focus of their experience. Hope for their future, gratitude for their support and care, and strong faith overshadowed their narratives and left little room to express needs. It could be interpreted that providers did a poor job identifying and meeting needs; however, this would be more a function of the participants' failure to recognize their own needs, perhaps not being socialized within their generation to know they have a right to express their needs, rather than incompetence on the part of the providers.

### **Implications for Practice, Training, and Research**

Implications include using these findings better to meet the needs of older adults who have recently been diagnosed with cancer, to integrate health care delivery teams, to facilitate the maintenance of self-identity and control among older adults, to improve training for healthcare providers on patient financial and workforce concerns, and to explore further research with additional perspectives and broader samples. Implications will be discussed for practice, training, and research.

#### **Practice**

The team of Browne et al. (2013) identified a need for primary care offices to be more involved in cancer care. After playing a role in establishing a diagnosis, care frequently shifted away from the general practitioner. There was a noted absence of the primary care provider in complications that arose from disease and treatment. This finding corresponds with information from the participants of the current study. The older adults described close involvement with their primary care doctors with whom they were more familiar, and the transition to various cancer specialists was at times disjointed and things fell through the cracks. Though the role of nurse navigator strives to avoid such issues by assuming responsibility for the patient's story and ensuring integration and communication among the interdisciplinary team, there is room for

improvement in current clinical practice. In order to better serve older adults in their transitions to cancer patients, efforts to communicate and include the primary care team are warranted.

Vieira, Burke, and Marks-Maran (2003) raised the issue of patient preferences in follow-up care. In the drive for cost-effective care, delivery models are in a near constant state of change. As patients transition from acute to chronic care for their cancer, follow-up becomes more remote and episodic. Vieira and associates found that this is very relevant for the older adult population. They generally want to maintain more frequent face to face contact with their providers as they move through their cancer survivorship, but that is not the most economically feasible option when compared to telephone and web-based monitoring. However, older adults need to feel they have ready access to expert advice and support. Nurses can play a tremendous role in designing care models that meet patients' needs for access and advice while still respecting the financial burden on the health care system.

Other practice issues important to address include older adults' desire to maintain self-identity, to cope in healthy ways, and to have some control over their treatment. All of these areas can be nurse driven. Nurses can help older adults, one-on-one or in group settings, focus on the ways in which they are still maintaining their identities despite the myriad changes cancer may be bringing to their lives. Nurses can also emphasize healthy coping behaviors and work among their interdisciplinary teams to connect older adults with resources that will help them bolster their positive coping behaviors. Facilitating a sense of control over treatment can be brought about by working with older adults and the rest of the health care team to discover the communication and information gaps in care and leading initiatives to give older adults more transparency and choice in their cancer care.

## **Training**

Of the young-older adult population interviewed in this study, a high proportion was still active in the workforce. It is important to note that employed patients beyond the age of 65 may have needs for symptom accommodation at work, legal support, and more. Murphy et al. (2013) conducted a study exploring the employment-related needs of cancer patients still in the workforce and found that neither employers nor health care providers were perceived as good sources of information about employment related concerns for cancer patients. The development of training resources for providers, patients, and even employers could help to alleviate the struggles met by older adults juggling cancer and work. As for other training opportunities to impact older adults, including those no longer in the workforce, training for providers in areas such as helping older adults with financial navigation or learning ways to address sexual concerns is warranted.

## **Research**

There are limited previous studies regarding the needs of older adults recently diagnosed with cancer. Additional qualitative studies are needed with more participants. Additional research using mixed method designs could elucidate more comprehensive data, exploring issues identified here such as self-identity or financial need from a more objective perspective. Participants also could be further segregated into more homogenous groups with similar needs such as categories based on age, gender, diagnosis, prognosis, or time since diagnosis.

Future research also should explore the perspectives of health care providers and family members. A recommendation for future research includes the advance preparation of consent forms for caregivers wishing to participate in the participant interview. In this research, it was found that caregivers at times had valuable information to add to the interview, but it could not

be coded and included in analysis. Another option for future research is to purposefully interview patient and caregiver dyads in order to obtain more complete data.

This research was limited to those older adults who have and use their access to a health care system and have generally consistent providers whom the older adults have grown to trust and respect. There remains the question of what needs older adults with limited financial, educational, or mental health resources impairing their health care access would have. Broadening the scope of this study in terms of geographic regions and ethnic or cultural communities would also provide a better understanding of older adults' needs.

### **Strengths and Limitations in Methodology**

The findings of this study should be interpreted in the context of its strengths and limitations. The following are strengths of the study that benefitted from the rich data that a qualitative approach provides. Such rich description allowed for the development of detailed categories and themes. Additionally, the use of fist level member checking following each interview enhanced the reliability of the data interpretations. The single interviewer assured relative consistency in the interview techniques and data collection. Moreover, regular review of data collection and analysis between the novice researcher and experienced faculty provided valuable guidance in considering other viewpoints and alternatives. These consultations allowed a faculty advisor to serve as a second researcher to validate interview technique, coding, and interpretation. Phone and email communication facilitated the sharing of the first three interview transcripts and coding sheets as well as the transcript and coding for the tenth participant.

Perhaps both a strength and a limitation was the semi-structured interview guide. As a strength, the interview questions shifted after initial interviews to elicit more in-depth perceptions and experiences of the participants in gaining a greater understanding of their needs after a cancer diagnosis.

While the interview guide directed the interview process, naturally no two interviews were the same and a limitation was variety in how well all of the interview questions were answered by the participants.

There are several limitations of this study. First, as with most qualitative research, the sample is not representative of the population, with little demographic variation with regard to age, race, diagnosis, and geographic location. It is unknown how the responses would differ from a sample of participants in their 80s or 90s, from different racial or ethnic backgrounds, with more varied diagnoses, or living in different geographical regions. Another related factor is the limits imposed by the inclusion and exclusion criteria of the study. The circumstances of one patient encountered during recruitment efforts as a possible participant illuminates this well. She was a bit different from the recruited participants, in her nineties and only seeking palliation. However, the patient did not, and would not, receive an actual cancer diagnosis. Metastatic cancer was presumed, but the patient did not desire a biopsy and was content to proceed with hospice care. The perspective of older adults such as this patient would be very interesting in a study with looser inclusion criteria, as would the perspectives of those with language barriers or dementia. Additionally, incorporating final member checking of the overall study findings was not completed in this study due to the expected burden on participants, but this is a limitation that could be resolved with the final member checking of a few participants in future research.

Selection bias is another limitation of this study. The participants who self-selected to participate in the study may be different from: (a) those who were approached but declined participation, (b) those who the staff nurses discouraged approaching because of their own perceptions of the individuals' willingness to participate, (c) those who were not engaged with the health care system, and (d) those who were interested but were lost to follow up or expired

before participating. The sample in this study is skewed toward young-older adults who were experiencing their first cancer diagnosis, since the old-older adults approached during recruitment were often experiencing their second or third cancer diagnosis or recurrence of a cancer earlier in life. There was also a strong representation of prostate cancer in this sample. This was perhaps due to: (a) the researcher's interest and bias with this population after early success with them, or (b) a higher proportion of prostate cancer patients in the recruitment pool. It also could be that these patients, who were generally younger and in relatively good health, were more willing to participate when approached by the researcher.

Another limitation of the study is the use of only self-reported data. While the approach of naturalistic inquiry seeks individual perceptions of reality, these perceptions may be viewed as only a part of the puzzle. Without saying that participants were untruthful, their self-reported interview responses may have been colored by an unintentional desire to say what they thought wanted to be heard, particularly as it pertains to the interviews in which a family member was present or within earshot. Various data from additional sources including family members or health care providers could provide a broader picture of the needs experienced by older adults recently diagnosed with cancer.

### **Conclusion**

This research contributes to an understanding of the needs experienced by older adults diagnosed with cancer. The narratives presented illustrate three themes: The Cancer Health Care Experience, Challenges in Managing the Cancer Experience, and Coping with the Cancer Experience. These themes, and the corresponding categories of which they are comprised, suggest that healthcare team members have an incomplete understanding of the self-identified needs of older adults diagnosed with cancer. Further research and commitment to the older

adult's cancer experience is needed in order to better understand and alleviate the needs of older adults diagnosed with cancer.

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## Appendix A

### Participant Recruitment Flyer

If you are age 65 or older, English speaking, able to give informed consent, and diagnosed with any form of cancer for the first time within the past four months, then you are invited to participate in a voluntary research study conducted by Genevieve Barrett, BSN, RN, OCN, a University of Kansas doctoral student researcher.

The purpose of this study is to explore the needs of older adults who have recently been diagnosed with cancer. If you are eligible and decide to participate in this study, your participation will last approximately one hour for an interview and possibly up to another hour for follow-up contact and verification of interview findings.

There is no cost for being in the study. There is no payment for the study. If you are interested in participating, please contact Genevieve Barrett to discuss eligibility, the nature of the research, issues related to confidentiality and anonymity, possible dates and locations to conduct the interview, or any other questions or concerns you may have about the research.

Genevieve can be reached by phone at 616-406-7988 or by email at [gbarrett@kumc.edu](mailto:gbarrett@kumc.edu).

## Appendix B

### Research Informed Consent Form

**Study Title:** A Qualitative Descriptive Study of the Experiences and Perceptions of Older Adults Recently Diagnosed with Cancer

**Principal Investigator:** Genevieve Barrett, BSN, RN, OCN

“You” refers to the subject. “We” refers to Mercy Health.

#### 1. Introduction

You are being asked to participate in a clinical research study. Clinical research is the study of human diseases in an attempt to improve diagnosis and treatment. In order to decide whether or not you should agree to be part of this research study, you should receive enough information about its risks and benefits to make a judgment. This process is called informed consent.

This consent form gives detailed information about the research study, which will be discussed with you. If you wish to participate in this study you will be asked to sign this form.

#### 2. Purpose of This Research Study

The purpose of this study is to explore the experience and impressions of older adults recently diagnosed with cancer. The specific aims of the study are to assess the needs that older adults experience after receiving a cancer diagnosis, explore the older adults’ perceptions of their health care provider’s abilities to meet those needs, and examine the older adults’ sense of mutual communication and trust with their providers.

With this study, the researcher hopes to gain a better understanding of the unique needs of older adults following a cancer diagnosis and how well these needs are met by health care providers.

Criteria for inclusion in this study include age 65 or older, English speaking, able to give informed consent, and diagnosed with any form of cancer for the first time within the four months prior to their recruitment. Participants will be excluded if their recent cancer diagnosis is a cancer recurrence, new metastases, or a new primary form of cancer.

You are being asked to take part in this study because you are an older adult who has recently been diagnosed with cancer.

### **3. Length of Your Participation**

If you are eligible and decide to participate in this study, your participation will last approximately 1 hour for the interview and possibly another hour for a follow-up contact.

### **4. Where the Study is Being Done and Number of People Participating**

The research study will take place in the West Michigan community. A total of approximately 16 older adults, recruited from Mercy Health, will be interviewed for the study.

### **5. Study Procedures**

Your participation will involve:

- An interview with the researcher with the researcher asking questions regarding your cancer experience.
- A follow-up interview may be asked of you to verify the meaning of information you provided, seek further information, and review the transcribed information.
- The interviews will be recorded and transcribed by the research team. Your identity will be held in confidence by using a pseudonym as the identity marker for your transcribed interview comments and only known to the researchers.
- All recordings will be destroyed after the analysis of the data is completed.
- You will be asked a short series of demographic questions such as age, gender, ethnic background, education level, type of cancer, and approximate date of diagnosis.

### **6. Possible Risks or Side Effects of Taking Part in this Study**

You may feel uncomfortable discussing your experiences. If at any point you are not comfortable you may skip a question or stop participating. The treatment of the information will be confidential although there is some risk that the information might be released. In order to minimize these risks, your information will be kept confidential. You are free to give only the information you choose.

Participation may involve unforeseeable risks. You will be told about anything new that might change your decision to be in this study. You may be provided with a new consent form if this occurs.

### **7. Costs for Taking Part in this Study**

There is no cost for being in this study.

### **8. Payment for Taking Part in this Study**

There is no payment for this study.

## **9. Possible Benefits to You for Taking Part in the Study**

You will not directly benefit from participating in this research study. However, your participation may contribute to the understanding of the issues faced by older adults who are diagnosed with cancer.

## **10. About Participating in this Study**

Your participation in this study is voluntary. You may stop participating in this study at any time. Your decision not to take part in this study or to stop your participation, will not affect your medical care or any benefits to which you are entitled. If you decide to stop taking part in this study, you should tell the investigator so that your information can be removed from the study records.

Your doctor, the investigator and/or the Sponsor may stop your participation in the study at any time if they decide that it is in your best interest. They may also do this if you do not follow instructions. If you have other medical problems or side effects, the doctor and/or nurse will decide if you may continue in the research study.

If you wish to take part in this study, we expect that you will:

- Keep your study appointments. If you cannot keep an appointment, contact the investigator or research study staff to reschedule as soon as you know that you will miss the appointment.
- Tell the investigator or research study staff about any side effects, doctor visits, or hospitalization that you may have whether or not you think they are related to the study therapy.

## **11. Compensation for Injury**

If you are injured as a result of your participation in this research project, medical care and/or hospitalization will be provided, if necessary. If you have health insurance, your insurance carrier will be billed in the ordinary manner. As with any health insurance, any costs that are not covered or are in excess of what is paid by your insurance, including deductibles, will be your responsibility. No funds have been set aside to pay you in the event of a study related injury. By signing this consent form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.

## **12. Confidentiality of Study Records and Medical Records**

The researcher will protect your information, as required by law. Both physical and electronic information, including your coded pseudonym, will be stored securely. Absolute confidentiality cannot be guaranteed because persons outside the study team, including delegated representatives of the Mercy Health Institutional Review Board (IRB), as well as the Food and Drug Administration (FDA) and other government agencies involved in keeping research safe for people may look at your medical records when necessary, either in person, by mail, fax or electronically. Additionally, your personal information may be

disclosed if required by law. The study team may publish the results of the study. If they do, they will only discuss group results. Your name will not be used in any publication or scientific presentation about the study.

### **13. Release of Personal Information**

We will do our best to ensure that your personal information is kept confidential and private to the maximum extent required by law. Although secure measures will be used to share your identifiable data with the faculty advisors on the study team, Dr. Marjorie Bott and Dr. Elaine Williams Domian at the University of Kansas School of Nursing, we cannot guarantee absolute confidentiality and privacy. Your personal information may be disclosed if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

### **14. HIPAA Authorization**

As part of this research study, you are being asked to release your health information. The Health Insurance Portability and Accountability Act (HIPAA) permits a hospital or doctor's office to use or release protected health information (PHI) for the purposes of treatment, payment or health care operations. A HIPAA authorization gives permission from you to use or release PHI for research purposes, and is in addition to your consent to participate in this research study.

In working with the sponsor, the investigator, Genevieve Barrett, will use and share personal health information about you. *This is information about your health that may also include your name, address, telephone number or other facts that could identify the health information as yours.* This includes information in your medical record and information created or collected during the study. This information may include your medical history, physical exam and laboratory test results. Some of these tests may have been done as part of your regular care. The investigator will use this information about you to complete this research.

In most cases, the investigator will use your initials and assign a code number to your information that is shared with the sponsor. The sponsor and its representative may review or copy your personal health information at the study site. Regulatory authorities and the Mercy Health's Institutional Review Board may also review or copy your information to make sure that the study is done properly or for other purposes required by law.

By signing this Authorization, you allow the investigator to use your personal health information to carry out and evaluate this study. You also allow the investigator to share your personal health information with:

- the sponsor and its representatives
- the Mercy Health Institutional Review Board
- the U.S. Food and Drug Administration (FDA)

- Other regulatory agencies - e.g. National Institutes of Health (NIH) and Department of Health and Human Services (DHHS)

Your personal health information may be further shared by the groups above. If shared by them, the information will no longer be covered by the Privacy Rule. However, these groups are committed to keeping your personal health confidential.

You have the right to see and get a copy of your records related to the study for as long as the investigator has this information. However, by signing this Authorization you agree that you might not be able to review or receive some of your records related to the study until after the study has been completed.

You may choose to withdraw this Authorization at any time, but you must notify the investigator in writing. Send your written withdrawal notice to Genevieve Barrett at 200 Jefferson Ave SE, Grand Rapids, MI 49503. If you withdraw from the study and withdraw your Authorization, no new information will be collected for study purposes unless the information concerns an adverse event (a bad effect) related to the study. If an adverse event occurs, your entire medical records may be reviewed. All information that has already been collected for study purposes, and any new information about an adverse event to the study, will be sent to the study sponsor.

If you withdraw from the study but do not withdraw your Authorization, new personal health information may be collected until this study ends. This authorization does not have an expiration date.

If you do not sign this Authorization, you cannot participate in this research study or receive study-related treatment. If you withdraw this Authorization in the future, you will no longer be able to participate in this study. Your decision to withdraw your Authorization or not to participate will not involve any penalty or loss of access to treatment or other benefits to which you are entitled.

## **17. Names of Contacts for Questions about the Study**

If you have any questions about taking part in this study, or in the event of a research related illness or injury, contact Genevieve Barrett at 616-406-7988. If you have any questions about your rights as a research participant, you may contact:

Brenda Hoffman, Mercy Health Institutional Review Board (IRB) Chairperson

200 Jefferson Ave. SE – Grand Rapids, MI 49503

Telephone: 616-685-6198

## DOCUMENTATION OF INFORMED CONSENT

By signing this consent form and HIPAA authorization and by initialing each page, you certify you have read this form, you have had the opportunity to ask questions about this study and this form, and you have received answers that fully satisfy those questions. You are voluntarily signing this consent form and HIPAA authorization as evidence of your decision to participate in this research study and you are giving authorization for release of all your protected health information relative to this research.

You are aware you may withdraw your consent and HIPAA authorization in writing at any time without harming my future medical care or losing any benefits to which you might be otherwise entitled. You have been advised that the investigator in charge of this study may discontinue your participation in this study if it is felt to be in your best interest, if you do not follow the study requirements or if the study is stopped.

You will receive a signed copy of this Research Informed Consent Form and HIPAA Authorization.

By signing this consent form, you have not waived any of your legal rights or released the parties involved in this study from liability for negligence.

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Signature of Study Participant

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Date

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Printed Name of Study Participant

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Signature of Person Obtaining Consent

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Date

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Signature of Principal Investigator

---

Date



Appendix C  
Demographic Sheet

1. Age \_\_\_\_\_

2. Gender: Female \_\_\_ Male \_\_\_

3. Race (select all that apply)

\_\_\_ African American/Black

\_\_\_ Hispanic/Latino

\_\_\_ Asian

\_\_\_ Native American

\_\_\_ Caucasian/White

\_\_\_ Other (Please specify) \_\_\_\_\_

4. Education

\_\_\_ Less than high school

\_\_\_ High school

\_\_\_ Bachelor's degree or higher

5. Distance (in miles) from home to clinic \_\_\_\_\_

6. Type of cancer

\_\_\_ Breast

\_\_\_ Lung

\_\_\_ Cervical

\_\_\_ Ovarian

\_\_\_ Colon/rectal

\_\_\_ Pancreatic

\_\_\_ Endometrial

\_\_\_ Other (Please specify) \_\_\_\_\_

7. Approximate date of diagnosis \_\_\_\_\_

## Appendix D

### Interview Guide

1. On the day you got your diagnosis, how did you feel when they told you that you had cancer?
2. What has it been like since your cancer diagnosis?
  - a. Can you tell me how cancer has affected your life? Can you tell me more about that?
  - b. Has having cancer changed what you do every day?
  - c. Has it changed how you relate to your family or friends?
  - d. Has it changed what is important in your life?
3. Since receiving your cancer diagnosis, what kinds of needs have you experienced?  
(Give examples of needs such as transportation, insurance information, etc. to help participants if they are having difficulty answering question)
  - a. What types of XXX needs do you have?
  - b. Who is helping you with this need?
  - c. How do you feel about asking for help with XXX, etc.?
  - d. Have you had needs that surprised you? Did you ever expect to have these needs in your life?
4. What has gone well for you during this time?
5. What has not gone so well during this time?
6. What health care providers have you worked with since your cancer diagnosis?
7. Can you tell me how you feel about these health care providers?
8. How have these health care providers spent time helping answer your concerns and addressing the needs you discussed above?
9. How could your health care providers better serve you?
10. Is there anything else that I have not asked you that you think would be beneficial for researchers, health care providers, or older adults to know?