

THE IMPACT OF CANCER CAREGIVING ON CANCER CAREGIVERS:  
STORIES OF LIVES IN TRANSITION

By

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## ABSTRACT

### THE IMPACT OF CAREGIVING ON CANCER CAREGIVERS: STORIES OF LIVES IN TRANSITION

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Under the Supervision of Dr. Patricia Stevens

The purpose of the study was to examine the impact of cancer caregiving on primary caregivers, exploring their personal narratives looking back on the entire experience from diagnosis, through treatment, and beyond. Caregiving is associated with exacerbation of stress-related disorders such as hypertension and heart disease and may also be associated with increased mortality rates. Transitions theory served as the conceptual framework for the study. Eleven adult caregivers, pre-retirement age, each participated in two semi-structured interviews. Caregivers were recruited from a community cancer resource center and were purposively selected to achieve maximum variation in terms of outcome of cancer treatment. The sample included 8 females and 3 males; there were 3 husbands, 6 wives, and 2 daughters. Caregivers provided care for patients with a variety of cancer types and a variety of treatment outcomes, from cancer free with sequelae to deceased. Each caregiver interview recording was transcribed, and preliminary examination of each transcript helped guide subsequent interviews. NVivo9 software was used to assist with data management. Data saturation was achieved. Narrative within-case analyses as well as thematic analysis were used to address research

questions. Thematic analysis resulted in seven themes: Burden: The Load that Never Ends; Disconnectedness and Isolation: The Invisible Person; Helplessness and Loss of Control: Tied to This Ride; Dealing with the Healthcare System; Role Disruption: Spinning the Plates; Loss, Change, and Grief: Reaction to the Whole; and Carrying Forward with Scars: New Priorities and Permanent Change. All of the caregivers changed their employment or social responsibilities due to the demands of caregiving. Themes were present in different parts of the cancer trajectory and in differing intensities in all interviews. Findings included disconnectedness and isolation as a central feature of cancer caregiving, plus significant grief present through the cancer trajectory, especially in the post-treatment phase. Furthermore, the experience of cancer caregiving remained one of significant impact years after treatment had ended. Successful transitioning requires connectedness and mastery, but participants in this study identified that their caregiving trajectories were full of isolation, grief, burden, and helplessness. Many suggested the need for support, even though they tended to deny their own physical and emotional needs while caregiving. Healthcare professionals can help by providing information, support, listening, and grief counselling. Research is needed on interventions that may reduce isolation, helplessness, and burden for caregivers.

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## DEDICATION

I dedicate this work to my husband John, without whose support and patience this would not have been completed.

I thank God for helping me to remain steadfast as I experienced other life events while I worked on the coursework and dissertation. He had other learning for me to pursue in addition to doctoral studies.

I thank my Major Professor, Dr. Patricia Stevens, who encouraged me and held me to high standards as I traveled this journey. I am thankful also to the other members of my committee: Drs. Sarah Morgan, Barbara Daley, Jane Leske, and Laura Joesse. Their time and efforts on my behalf were invaluable. In addition, I wish to thank Jennifer at the Cancer Center for Healthy Living, who believed in my study and encouraged me. Finally, I wish to thank and acknowledge the participants in my study. Theirs are stories that should be heard and heeded. I deeply appreciate their contributions of time, tears, and travel so that they could help me to understand what was so important to them.

Soli Deo Gloria

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## CHAPTER ONE: INTRODUCTION TO THE STUDY

Cancer as a disease occurs in patients, but cancer as an experience happens to families and social networks as well. Cancer treatment is costly, time-consuming, and fraught with side effects, many of which are serious and long lasting. Cancer survivors - and indirectly their primary caregivers - may need to cope with surgical wounds and alterations, incomplete eradication of the cancer, chemotherapy effects, radiotherapy effects, fatigue, role strain, psychosocial sequelae, financial burden, and lifestyle changes. Cancer caregiving is a stressful experience and is associated with increased morbidity and mortality in caregivers (Boyle, 2004; Capiello, Cunningham, Knobf, & Erdos, 2007; Carter & Chang, 2000; Clark, 2002; Edwards & Clark, 2004; Glajchen, 2004; Grunfeld, et. al., 2004; Hodgkinson, Butow, Hobbs, & Wain, 2007; Mellon, 2002; Mellon, Northouse & Weiss, 2006; Morris, Grant, & Lynch, 2007; Morse & Fife, 1998).

The purpose of the study was to examine the impact of cancer caregiving on primary caregivers, exploring their personal narratives of the cancer experience looking back on the entire experience from diagnosis, through treatment, and beyond. Eleven adult caregivers, self-identified as pre-retirement age, each participated in two semi-structured interviews. To qualify, the cancer patient for whom they cared must have completed at least one round of active cancer treatment and had been diagnosed within the prior 10 years. Transitions Theory (Meleis, 2010) served as the theoretical framework for the study. This chapter introduces the reader to the problems faced by caregivers of patients with cancer. Background, purpose of the study, research questions, research approach, assumptions, significance, and researcher perspective are also described.

## The Problem

Cancer is a disruption in one's life. People who experience cancer become cancer patients, and their significant others may be called upon to become caregivers. Caregivers act to support patients, facilitate treatment, and supplement roles that cancer patients are unable to fulfill due to cancer and its treatment. Indeed, cancer happens to families and social networks, not just to individuals.

The outlook for cancer has changed over the past few decades. Thanks to advances in medical science, cancer is no longer seen as inevitably fatal, but neither is cancer without its after-effects. In fact, cancer survivorship may take several forms. Patients may be cancer free and free of the effects of cancer and its treatment if, for example, the cancer was *in situ* and successfully excised or otherwise eradicated without sequelae. However, patients may also be cancer free but left with serious physical and psychosocial effects of cancer that may cause permanent changes in patients' lives. This may be called being cancer free but not free of cancer (Miller, Merry, & Miller, 2008). Patients may also be left in remission after cancer treatment, and sometimes this remission requires periodic therapy to avoid exacerbation of the disease. Finally, some patients are left with a chronic cancer that is not in remission and which may be a permanent and potentially fatal disease. Therefore, there are a number of different faces to cancer survivorship. One common element, however, is that almost all patients with cancer need help from a caregiver at some point along the way during cancer treatment and afterwards.

Caregiving can be a long-term activity, since patients often need to cope with significant challenges inherent in the aftermath of cancer and its treatment. However,

even though the effects of cancer and its treatment often persist for a long time, there are few healthcare resources for cancer survivors and survivors of cancer caregiving in the transition period after initial cancer treatment. When reimbursement ends, then services from healthcare providers tend to end as well. A study of 37 National Cancer Institute comprehensive cancer care centers found that few programs exist for family support, especially after active cancer treatment ends (Tesauro, Rowland, & Lustig, 2002). A growing number of oncology nurse authors, therefore, are calling for more family-centered cancer care, both during treatment and afterward (Boyle, 2004; Mellon, Northouse, & Weiss, 2006; Mellon, 2002; Lewis, 2004). Within the current healthcare system, unless there is a formal diagnosis of depression or other psychological disorder that requires medical care, the costs of providing psychosocial support for families are not covered by standard reimbursement plans. In addition, the experiences of cancer caregivers are not fully understood.

Nearly 10 million caregivers provide approximately 8.5 billion hours of unpaid healthcare each year in the United States (American Cancer Society, 2011) for an estimated value of \$45 billion in healthcare services (Institute of Medicine of the National Academies, 2008). However, this common and valuable activity of caregiving is hazardous for cancer caregivers. The caregiving experience is related to the onset or worsening of depression, reduced immune function, slow wound healing, new diagnoses of hypertension, and coronary artery disease for caregivers (Carter, 2006; Kiecolt-Glaser, Preacher, MacCallum, Atkinson, Malarkey, & Glaser, 2003; Vitaliano, Zhang, & Scanlan, 2003). Cancer patient caregivers who report role strain due to supporting a spouse during cancer treatment have been found to be 63 percent more likely to die

within 4 years than others their age (Schulz & Beach, 1999). There seems to be something about the experience of cancer caregiving that is hazardous for cancer caregivers.

### **Background, Context, and Significance of the Problem**

Cancer is a life-changing, values-clarifying, meaning-making experience for both cancer survivors and their caregivers. Cancer happens to individuals, but individuals exist within social networks, dyads, families, and contexts. Cancer, as all significant life experiences, leaves those who are touched by the disease forever changed.

Approximately 1.3 million people are diagnosed with cancer each year, and more patients are surviving cancer for longer periods of time than ever before. The National Coalition for Cancer Survivorship ([www.canceradvocacy.org](http://www.canceradvocacy.org)) estimates that there are approximately 12 to 14 million cancer survivors in the United States, and the number is rising. Survivorship, especially post-treatment survivorship, has been identified as a research priority by the Oncology Nursing Society (ONS, 2009). The key term in the ONS research agenda is “post-treatment.” That is when reimbursement stops for healthcare providers. Cancer survivors often live as integral parts of families, and family members experience cancer and its treatment along with cancer survivors. This means that family networks may share a complicated future that has been modified by cancer (Northouse, Mellon, Harden, & Schafenacker, 2009).

The good news about cancer survivorship is that the definition of the term has changed. A cancer survivor was once defined as the person left behind after a patient with cancer had lost the battle, since death was considered inevitable. Years ago, a diagnosis of cancer meant that a patient would go home, take pain medications, get his or

her “affairs in order,” and wait to die. Now, however, with medical advances in treatment, improved early detection, and more accurate diagnosis, an estimated 11.4 million people with a history of cancer were alive in 2006 (American Cancer Society, 2011). Moreover, the 5-year survival rate for all cancers diagnosed from 1999 to 2005 is 68%, up from 50% in the mid-1970s (American Cancer Society, 2011). With almost 12 million people in the U.S. – or about one in 20 - living with a history of cancer, survivorship has become an issue for healthcare professionals, employers, families, patients, and society as a whole.

As medical treatments for cancer improved, cancer survivors were defined as people who had been treated for cancer and had survived the magic number of five years after diagnosis and remained cancer-free. However, terminology has changed in recent years. Currently, the term “cancer survivor” is applied to anyone who lives beyond the diagnosis of cancer (Mellon, 2002; Clark & Stovall, 1996). This means that cancer survivorship includes the period of time immediately after diagnosis, during active treatment, during the post-treatment phase, and throughout any recurring episodes or diagnoses of new cancers and their treatments. Survivors of cancer are defined by the National Cancer Institute (NCI) as both cancer patients and caregivers. The NCI identifies survivors as follows: “An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition” (National Cancer Institute, n.d.b.). This broad definition, while accurate, is almost too inclusive since so very many people have had cancer or have been impacted by the disease and its treatment. Nevertheless, the point is well made that cancer is a

significant life experience for all who are touched by the effects of the disease and its treatment.

From the moment of diagnosis, there is an emphasis on survival for both cancer survivor and caregiver. Initially, the cancer survivor hopes to survive the treatment and the active disease. Once treatment is completed, the normal reaction is to rejoice and to attempt to define a new normality for the cancer survivor and the caregiver (Alfano & Rowland, 2009). This is not a simple project, however, given some enormous after-effects of cancer and its treatment.

Medical complications from cancer and cancer treatment can include chronic pain, physical fatigue, limitations on physical performance, osteoporosis, premature cardiovascular disease, obesity, and secondary cancers (American Institute for Cancer Research, 2003; Mellon, Northouse, & Weiss, 2006; Ness, Mertens, Hudson, Wall, Leisenring, Oeffinger, Sklar, Robison, & Gurney, 2005; Lyne & Coyne, 2002; Bennet & Winters-Sloan, 2006). Although pain is most typically considered to be a component of the acute phase of cancer treatment, there are also a number of chronic pain conditions which can affect cancer survivors after initial treatment ends. These include proctitis, obstruction, plexopathy, and neuropathy (Dow, 2003).

Newer findings have documented defects in cognition in adults resulting from chemotherapy (Dow, 2003). The phenomenon, sometimes called “chemo brain,” is potentially permanent (Alfano & Rowland, 2009). The cognitive deficits caused by chemotherapy are often quite distressing to adults, who may view the deficits as developmental challenges or even “going downhill.” In terms of adult development, an integrative model proposed by Magnusson (1995 and 1999) assumes that individuals

function and develop as total, integrated organisms in interaction with their environment. Cognitive deficits interfere with effective interaction with others and with environmental entities (Magnusson, 1995).

Cancer survivors and their families also face psychosocial sequelae of cancer and its treatments; these sequelae may include depression, post-traumatic stress symptoms, and financial stress (Tesauro, Rowland, & Lustig, 2002). There are significant effects on quality of life in general and on relationships within families as well as with others due to cancer treatment (Northouse, Mood, Templin, Mellon, & George, 2000; Mellon, et. al., 2006). A history of cancer affects the ability of survivors to find and maintain employment (Ness, Wall, Oakes, Robison, & Gurney, 2006; Pryce, Munir, & Haslam., 2007; Feuerstein, 2005). Changes in employment and income can seriously affect social status, self-concept, and other sociocultural aspects of development.

Once initial cancer treatment ends, there is often limited contact between healthcare providers and caregivers, so the experience of caregivers in the post-treatment phase of the cancer experience is not well understood (Hodgkinson, et al., 2007). Patient survivors must adjust to the sense of loss of medical monitoring and the support of healthcare professionals (Allen, Savadatti, & Levy, 2008). For both patients and families, life after cancer treatment includes the after-effects of both the cancer disease and its treatment, and these after-effects often last much longer than the treatment itself (Northouse, et al., 2009).

Findings from one study of posttraumatic stress disorder in breast cancer survivors has indicated that symptoms such as depression, anxiety attacks, and functional impairment may persist for an indefinite length of time, up to twelve months

(Andrykowski, Cordova, McGrath, Sloan, & Kenady, 2000). Dow, Ferrel, Haberman, & Eaton (1999) conducted a qualitative study of cancer survivors with a mean time after diagnosis of 6.7 years. The researchers found that survivors were still coping with issues of independence, balance, coping with losses, expectations of health, and purpose even after so many years.

Indeed, cancer directly impacts all members of the family unit. In a prospective study of the effects of cancer diagnosis on depression and anxiety in families during cancer treatment, Edwards and Clarke (2004) found that levels of depression and anxiety were similar for patients and caregivers. Mellon (2002) compared cancer survivors and their caregivers in a qualitative study of families between 1 and 6 years post-treatment and found that caregivers had more fear of cancer recurrence than did the cancer survivors and that women feared cancer recurrence more than did the men. These findings may have serious implications for female caregivers of cancer patients. Still other researchers have found that some sequelae of cancer may impact family relationships and functioning, including intimacy, role changes and strain, financial health, spiritual health, employment issues, and psychoemotional health of couples (IOM, 2008; Kitrungrrote & Cohen, 2006).

Cancer caregivers experience significant risks of depression, adverse health effects, and uncertainty about the future (IOM, 2008). Moreover, stress in caregivers has been noted to decrease optimal outcomes for both family members and cancer survivors (IOM, 2008). Jensen and Given (1993) studied 248 caregivers with regard to fatigue and found that almost all of them reported at least mild fatigue, with 28% reporting severe fatigue. Given that most cancer survivors are over the age of 65 at diagnosis, family

members may well have chronic diseases of their own, which could add to family distress (Northouse, et al., 2009). Only rarely have studies examined physical well-being in cancer caregivers during the post-treatment phase.

### **Purpose of the Study and Research Questions**

The general problem addressed by the study was the need to understand the experience of cancer caregiving. Specifically, the purpose of the study was to examine the impact of cancer caregiving on caregivers, exploring their personal narratives of the cancer experience looking back on the entire experience from diagnosis, through initial treatment, and beyond. Eleven adult caregivers, self-identified as pre-retirement age, participated in two semi-structured interviews. To qualify, the cancer patients for whom they cared must have completed at least one round of active cancer treatment and must have been diagnosed within the prior 10 years. Transitions theory is the theoretical framework for the study, since that theory takes into account the element of time as well as context when examining the health/illness transitions caused by cancer and cancer treatment.

Three research questions were:

1. What are the circumstances (contexts and conditions) with which caregivers contend over the full trajectory of their significant other's cancer, from the time they noticed something was amiss to diagnosis and then through active cancer treatment and post-treatment?
2. How do caregivers describe the impact of cancer on their own lives over the course of their caregiving experiences?

3. How do the narratives of caregivers illustrate and give meaning to transitions that the caregivers have undergone?

### **Research Approach**

A holistic approach afforded by a qualitative inquiry allowed the researcher to capture context, complexity, and nuances of meaning. The specific qualitative design of narrative inquiry was appropriate for the study of cancer caregiving survivors because this design allowed the stories, or narratives, of participants to be recorded and analyzed while keeping the narratives intact. Keeping the narratives intact allowed the researcher to analyze themes in context and allowed participants to tell their stories as they perceived them, keeping the details together in a meaningful whole.

The study was a narrative analysis of interviews with caregivers of cancer survivors who were between one and ten years post-diagnosis. Caregivers were each interviewed twice in order to ascertain their perceptions of what they had lived through as caregivers as well as to pursue emergent analytic areas based upon concurrent thematic analysis of data as they were collected. The goal was to focus on details of narratives in order to understand the stories of these caregivers. The aim was to understand each caregiver's story, the narrative, which Reissman describes as a disruption, rupture, or disturbance in one's normal course of events (Reissman, 2008). Furthermore, narrative inquiry is used to understand a story as more than a series of events; rather, as Pinnegar and Daynes note, "narrative inquiry embraces narrative as both the method and phenomena of study... Narrative inquiry begins in experience as expressed in lived and told stories" (Pinnegar & Daynes, 2007, p.5). Within-case narrative analysis was used to

examine narratives of participants for epiphanies, turning points, chronological events, situations, and significant people within the stories.

### **Theoretical Framework Introduction**

There is no single conceptual framework that has been widely used for studies of cancer caregivers. Those that have been used tend to be based upon the work of Lazarus and Folkman (1984) and their theory of stress, appraisal, and coping. While this seminal body of research is important in the understanding of how families and individuals react to and cope with stressors, it assumes that coping is the instrumental means for adaptation. This may be more useful as a conceptual framework in short-term, crisis events as opposed to long-term living with the aftermath of cancer and its treatment.

Transitions theory was chosen as the conceptual framework for this study. Transitions are periods of time that occur between relatively stable states (Chick & Meleis, 1986). Transitions are caused by disruptions in one's story, and they occur over time and within the context of one's experiences, one's personal development, and one's social milieu. The rationales for using Transitions Theory in this study were:

- a) It takes into account the dynamic and changing nature of cancer caregiving experiences along the trajectory from diagnosis to treatment and beyond;
- b) It takes into account the concepts of physical and socioemotional contexts;
- c) It adequately describes the process of successfully transitioning over time from one stable state to a new stable state;
- d) It allows for simultaneous transitions, both expected and unexpected, of various types. (Meleis, Sawyer, Im, Messias, & Schumacher, 2000; Meleis, 2010).

Transitions theory provides a conceptual framework that is dynamic, that takes into account the contexts (physical and psychosocial) of cancer survivorship, and that relates well to changes in the context of time.

### **Assumptions and Definitions**

Assumptions that undergird the study are:

- Caregivers are truthful in their reporting narratives of their experiences with cancer, its treatment, and its aftermath. That is, they are accurate in terms of their recall of the experience and able to convey their feelings and perceptions as they experienced them.
- Life-threatening illness impacts caregivers as well as patients.
- Cancer caregivers are able to recall their experiences well enough to construct a narrative.
- Transitions theory is an adequate theoretical lens through which to view the data because transitions theory takes into consideration the dynamic and changing nature of the trajectory of cancer caregiving.

#### *Definitions*

It is important to identify relevant terms for complete understanding of the phenomena of interest.

CANCER SURVIVORS are those individuals who have survived beyond the initial diagnosis of cancer. That may include patients in the initial phases of treatment, after treatment has ended, during periods of recurrence, or in hospice care at end of life (IOM, 2008; Mellon, 2002; National Cancer Institute, 2008; Oncology Nursing Society, 2009; National Coalition for Cancer Survivorship, 2011).

PRIMARY CAREGIVER is defined as one who contributes significant assistance and support to the cancer survivor during and after cancer treatment (Mellon, 2002; Oncology Nursing Society, 2009a and 2009b; National Coalition for Cancer Survivorship, 2011). Primary caregivers normally share the same residence with the cancer patient, thereby interacting on a daily basis.

TRANSITIONS are defined as periods of time between fairly stable states (Chick & Meleis, 1986). Transition is not the same as simple change; rather, it is both a process and an outcome. Along the way from one state to another, the complex process of a person's transition takes place within context, over time, and often as a result of some event or condition (Meleis, 2010).

ACTIVE CANCER TREATMENT is the time during which medical therapy is being planned and implemented for the medical treatment of newly diagnosed or recurrent cancer. This may include diagnostic testing and review of test results, chemotherapy, radiotherapy (radiation therapy), surgical procedures, and medical care of complications. Active cancer treatment does not include surveillance for cancer at follow-up appointments. The diagnosis of existing cancer does not necessarily mean that a person is in active cancer treatment, since some cancers (such as some forms of prostate cancer) may not be treated other than a course of watchful waiting and surveillance.

### **About Writing Style**

I will use the first person from time to time throughout this work, which is less formal and not unusual for qualitative research. According to APA format (American Psychological Association, 2008), first person may be used when describing research steps and when referring to self as the researcher. I use the first person throughout.

## CHAPTER 2: REVIEW OF LITERATURE

The purpose of study was to examine the impact of cancer caregiving on caregivers, exploring their personal narratives of the cancer experience looking back on the entire experience from diagnosis, through treatment, and beyond. Eleven adult caregivers, self-identified as pre-retirement age were sought to participate in a minimum of two semi-structured interviews. To qualify, their family members had to have completed at least one round of active cancer treatment and must have been diagnosed with a new cancer or serious aftereffect of cancer within the prior 10 years.

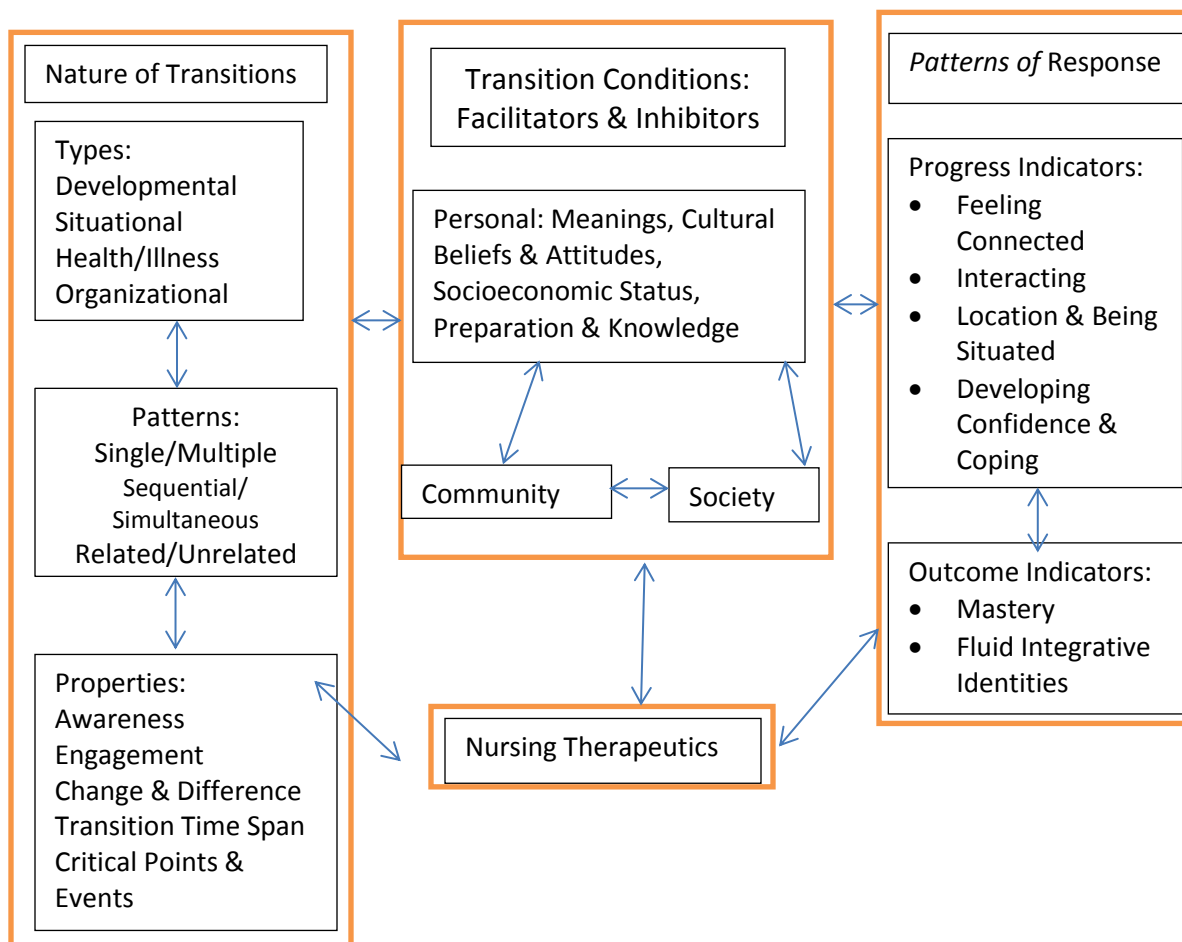
Transitions Theory (Meleis, 2010) served as the theoretical framework for the study and is reviewed first in this chapter. A critical review of empirical literature on cancer survivorship and caregiving is presented second. Next, I discuss how the empirical evidence on cancer survivorship and caregiving relates to transitions theory and then how applying transition theory gives added meaning to what we know about cancer survivorship and cancer caregiving. Following this, I review theoretical literature about adult development and how this impacts the experience of cancer caregiving for caregivers. It is relevant to consider the developmental stage of caregivers and patients as part of the context for cancer caregiving. Finally, I discuss how extant research informs the study and how the study addresses gaps in the literature.

### **Transitions Theory**

Prior to examining literature on cancer survivorship and cancer caregiving, it is helpful to identify, explicate, and define the components of the theoretical framework for the study. The study is based upon Transitions Theory as a conceptual framework. Figure 1, a theoretical model of transitions (Meleis, Sawyer, Im, Messias, & Schumacher,

2010, p. 56) is the compilation of decades of research and thinking regarding transitions as they affect the human condition, over time, and within context.

Figure 1. The Middle Range Theory of Transitions



Source: Meleis, A. I., Sawyer, L.M., Im, E., Messias, D.K.H., & Schumacher, K. (2010). Experiencing transitions: An emerging middle-range theory. In *Transitions Theory: Middle-Range and Situation-Specific Theories in Nursing Research and Practice*, A. I. Meleis (Ed.). New York: Springer Publishing Company, pages 52-65. The figure is found on p. 56. See Appendix D for information about permissions from Springer Publishing Company.

Transitions Theory is a middle-range theory that is useful as an overarching concept for nursing practice and for the study. It may be helpful for the reader to refer to Figure 1 while reading the following discussion. First, I will discuss the concept of

transitions, followed by a discussion of the model, then the implications of transitions theory for interpersonal roles, then how the model helps to explain the transitions in the cancer experience and the usefulness of the model for the study of other phenomena.

### **Conceptual Work on Transitions**

Transitions are defined as periods of time between fairly stable states (Chick & Meleis, 1986). However, transition is not the same as simple change; rather, it is both a process and an outcome. Along the way from one state to another, the complex process of a person's transition takes place within context, over time, and often as a result of some event or condition (Meleis, 2010). Changes, however, cause people to recognize that things are not the same. They disrupt one's story and require a response in order to re-establish a stable state. In that way, changes cause transitions. On the other hand, transitions also cause changes because the experiences of multiple transitions create a history of events, skills, and experiences that become part of personal identities. Examples of transitions include changes in health, changes in situations, developmental changes, and organizational changes (Meleis, 2010). Defining characteristics of transition include the concepts of "process, disconnectedness perception, and patterns of response" (Chick & Meleis, 1986, p.240). These concepts are discussed later.

The defining characteristics can be used to drive theory-based qualitative inquiry and can serve as the basis for questions to cancer caregivers about process, perceptions of disconnectedness, and responses. Furthermore, transitions theory is appropriate for narrative qualitative inquiry because narratives, or stories, are born from disruptions in living.

Transitions happen over time. Bridges (1980, 2010) identified three phases of transitions. First, there is the ending phase in which there is an end to what was. This may be accompanied by disenchantment or very often grief (Meleis, 2010) due to losses of the past. Second, there is a neutral phase, which is not aptly named, since it is characterized by disorganization, uncertainty, disintegration, and disequilibrium. Finally, there is a beginning phase, the beginning of a new stable state with new roles and anticipation of new ways of being. Each phase requires different coping strategies (Meleis, 2010).

Some of the early investigations into the meaning and nature of transitions were done by Afaf Meleis, who was an immigrant to the United States from Egypt and was intrigued by the nature of transitions experienced by immigrants as they adjust to and reorient to a new country. In addition, she was interested in theory development in nursing.

Chick and Meleis (1986) presented a concept analysis of transitions using six components or activities. First, they defined antecedents and consequences of transitions. Next, they examined congruence of the concept of transitions with other extant nursing theories. Third, they developed, described, and analyzed exemplars of the concept of transitions. Fourth, they compared transitions to other similar concepts to establish boundaries for the concept and dimensions to transitions. Fifth, they sought contrary cases among borderline areas. Finally, they examined the concept of transitions for research potential (Chick & Meleis, 1986). Their work was significant in that they established the concept of transitions in such a systematic manner.

In defining the concept of transitions, Chick and Meleis (1986) noted that defining characteristics of transitions include process, disconnectedness, perception, awareness, and patterns of response. Process as a defining characteristic of transitions means that there is movement over time, whether the transition is expected or unexpected, short-term or long-term, or originating from internal or external changes. Disconnectedness as a characteristic of transitions implies disruption of familiar linkages and the recognition that former roles, expectations, and means of satisfying needs are no longer in place as they had been prior to the transition (Chick, et al., 1986). Perception as a defining characteristic of transitions implies that people undergoing transitions attach meaning to the experience, and closely allied with perception is the necessity that people undergoing transitions be aware of the changes. Chick and Meleis went as far as to say that if people were either unaware of changes or denying those changes then they could not be in transition and could not therefore successfully transition. Finally, patterns of response to transitions were said to include behaviors that reflect inner transition work; these patterns of response are described as disorientation, distress, irritability, anxiety, depression, and changes in self-image and role perceptions (Chick & Meleis, 1986). What all of this means is that Chick and Meleis established an orderly description of the many facets and implications of transitions in the human experience.

In terms of dimensions of transitions, Chick and Meleis (1986) noted that there are general patterns to transitions that are similar from one person to another in that they adhere to a three-phase sequence of two stable states separated by a transition period. However, they noted that transition phases may vary in duration and may blend into one another. Therefore, dimensions of transitions may be described in such terms as scope,

duration, reversibility, and magnitude (Chick & Meleis, 1986). Furthermore, Chick and Meleis identified congruence between the domains of transitions and current nursing theories. Their description of nursing theories as sharing a commonality of change set the foundation for placing a future middle-range theory of transitions within the tradition of major nursing theories. For example, transition is compatible with the Roy Adaptation Model of nursing as well as the patterns involved in the evolution of the unitary being of Rogers (Chick & Meleis, 1986).

Later, in 2006, Kralik, Visentin, & van Loon (2006) presented a comprehensive review of how the concept of “transitions” is used in health literature and what the concept informs. They found that the concept called transition has been used to describe different aspects of the phenomenon over the past three decades. First, they noted that transitions involve a passage from one point to another. Next, they noted that there is a transformation or other type of alteration in people as they experience transitions. Finally, they noted that the arrival of people from one stable state to another involves a reorientation of some sort to the new stable state on the other side of the intermediate period of disorganization (Kralik, et al., 2006). Their review of literature produced evidence that along the way people who undergo transitions also undergo challenges to their self-identities, which in turn may impact their relationships with significant others (Kralik, et al., 2006). These relationships may include those in employment, families, partnerships, and other meaningful social structures in life. As Kralik and colleagues noted, much of the literature on transitions points to the importance of transitions to one’s ability to internally reorient the self. They noted also that the establishment of a

meaningful and successful self-identity after transitioning is of critical importance to the transition outcome (Kralik, et al., 2006).

### **The Nature, Conditions, and Patterns of Response to Transitions: The Model**

The model (Figure 1) of the middle-range theory of transitions put forth by Meleis and colleagues (2010) consists of three main sections. First, the nature of transitions is examined, and facets of the transition experience are identified in terms of types of transitions, patterns of transitions, and properties of transitions. Secondly, conditions of transitions occur in the middle section. These conditions of transitions are societal, community, and personal conditions that may be either facilitators or inhibitors of transitioning. Finally, patterns of response include progress indicators and outcome indicators. All of the three parts of the model are amenable to nursing therapeutics, since nurses have a role and interact with individuals experiencing all phases and aspects of transitions, especially health/illness transitions.

#### **Nature of transitions: types, patterns, and properties.**

According to Figure 1, transitions are multifaceted in terms of types, patterns, and properties. Four basic types of transitions include those caused by developmental events, situational events, changes in health and illness, and organizational changes (Meleis, 2010; Chick & Meleis, 1986; Schumacher & Meleis, 1994; Meleis, et al., 2000). Transitions may be occurring simultaneously and in multiples, just as we all have multiple roles that occur simultaneously. For example, the developmental transition of retirement may occur at the same time as the health/illness transition of cancer. Therefore, the nature of transitions includes four basic types that may occur in various

patterns, including single/multiple, sequential/simultaneous, and related/unrelated (Meleis, et al., 2000).

The substantive material of transitions can be described as properties (Meleis et al., 2000; Figure 1). As mentioned earlier, transitions occur over time, and the time of transition is between two relatively stable states. The middle phase is the most disorganized and challenging of the three phases of transitioning, and the properties (lower left in Figure 1) refer to the nature of the middle transitioning phase: awareness, engagement, change and difference, transition time span, and critical points and events (Meleis, et al., 2000). Each property is best defined and then described using the example of a health/illness transition for the purposes of this study.

Awareness of a transition is related to “perception, knowledge, and recognition of a transition experience. Level of awareness is often reflected in the degree of congruency between what is known about processes and responses and what constitutes an expected set of responses and perceptions” (Meleis, et al., 2000, p. 26). In other words, in order for someone to recognize that they are entering a sick role that person needs to be aware of changes that are occurring. For example, diagnostic signs and symptoms would draw one’s attention to the impending transition.

Engagement refers to “the degree to which a person demonstrates involvement in the processes inherent in the transition” (Meleis, et al., 2000, p. 26). In the example of a person becoming ill, the initial signs and symptoms may have prompted the person to pay attention to his or her health, seek the help of a healthcare professional, and perhaps cancel some activities.

Change and difference are essential properties of transitions. Sometimes the changes are not related to the transition, even though all transitions involve change of some sort. For example, a long-term transition may be initiated by a serious diagnosis of a chronic disease, but there may be an abrupt change in the focus of a dyad that is not involved in the actual transition. Changes initiate transitions, and it is important to fully understand the meaning and effects of those changes in order to properly understand the transition. Changes may be due to disruption of processes, ideas, and identities (Meleis, et al., 2000). Differences are a related concept to change, but not quite the same. People undergoing transitions confront differences in the way they see their situation, the world, expectations, and how things are. Changes may happen and cause things to be different, and these differences must be acknowledged and processed.

Time span is another property of transitions in that transitions occur over time. As Bridges (1980, 2010) noted, transitions take time to develop and resolve in terms of the three stages of ending, transition/disorganization, and new beginning. In the example of a health/illness transition, it takes time for a person to assume the role of patient, convalesce, and resume normal or optimally normal activities again.

The final property of transitions is that of critical events. These are turning points or some event that is associated with the recognition that something has changed and that impact has been experienced. Critical periods in the health/illness transition of cancer might include receiving the diagnosis, surgery, beginning and ending chemotherapy, losing hair, changes in body image and structure, or being unable for the first time to fulfill a normal role.

**Transition conditions: facilitators and inhibitors.**

Moving to the middle of Figure 1, transitions occur in the context of various conditions, and these conditions exist within persons, communities, and society. These conditions may facilitate successful transitioning or they may inhibit one's ability to successfully transition (and these outcomes will be defined shortly). Personal conditions are most influential on the individual's role attainment and transition outcome, since these conditions include the meaning one attaches to the transition, cultural beliefs and attitudes, socioeconomic status (resources and challenges), and preparation and knowledge needed to deal with the transition period (Meleis, et al., 2000).

To follow with the example given previously, if someone is retiring and has just been diagnosed with cancer, then it is helpful to understand the meaning of cancer, cultural beliefs about health and illness, the individual's financial and social resources, as well as the individual's knowledge and past experiences when assessing the impact of the cancer diagnosis on that individual. Obviously, these personal conditions may facilitate the transition to altered health state (belief that cancer is curable, health beliefs of compliance with medical regimen is helpful and good, adequate financial resources and insurance, and a positive experience with cancer in a friend, for example) or they may inhibit the transition.

Community conditions may include social networks and supports for the individual, information available to enhance preparation and role attainment, and ready availability of healthcare resources at reasonable cost, for example. Examples of society conditions may include health resources within driving distance, societal provisions for the sick role, and the like. There may be overlapping of conditions that inhibit or

facilitate transitions. For example, cultural beliefs may be personal as well as societal. An example of a cultural belief that inhibits transitions may be a person whose social and cultural beliefs attach stigma to a certain disease or condition that they have, such as diseases that are sexually transmitted.

**Patterns of response to transitions: progress and outcome indicators.**

Patterns of response to transitions include progress and outcome indicators, to which I referred earlier as indicators of successful transitioning. In other words, how does one identify progress as one experiences transition between one stable state (health, for example) and another (recovery and return to function, for example)? Progress indicators include feeling connected, interacting, location and being situated, and developing confidence and coping. These indicators are prominent themes in transitions narratives.

Feeling connected is the opposite of feeling disconnected and isolated. As such, it is a positive indicator that enables one who is undergoing transitions to interact with helpful others. For example, feeling connected to a healthcare person is a prelude to being able to ask questions and gain information needed to feel prepared and able to fulfill necessary roles. Interacting is important in terms of role theory in that roles are interactionally determined, clarified, and given meaning (Meleis, et al., 2010). In fact, without interaction the individual is back to being disconnected and isolated. In a positive direction, however, interaction is a lifeline for information, suggestions, instruction, clarification, acknowledgement, and assistance, so interaction is a positive pattern of response and indicates progress in the midst of transition. Location and being situated refers to identifying where one is now that things have changed. In the example

of immigration, the location and being situated indicator is rather obvious (a new country), but in the example of a cancer diagnosis a new location may be the new situation in life with new meanings, new perceptions, and new comparisons with the former life before transition. Developing confidence and coping is an indicator of transitions because demonstrating confidence and coping indicates an adequate understanding of conditions, roles, and information needed to make adjustments. For example, in the person who is diagnosed with cancer, confidence and coping would indicate that there is sufficient information and support to progress towards making necessary role changes to cope with chemotherapy, travel limitations, dietary implications of treatment, and the like.

Outcome indicators of transitions include mastery and fluid, integrative identities (Meleis, 2010). The presence of these outcome indicators indicate that transition has been traversed and a new stable state has been reached. Of course, a new transition may present itself at any time, heralded by awareness of a new condition, engagement, recognition of changes over time, and the acknowledgement of critical points and events (Meleis, 2010). In terms of the cancer story, outcome indicators may signal that a transition has been experienced, but the new stable state may be fraught with difficulties and changes that may necessitate new transitions. Cancer patients may be unable to return to work, unable to perform their customary roles due to fatigue or cognitive effects of therapy, and unable to engage in their former relationships due to alterations in body image, self-concept, and other sequelae of cancer therapy (Mellon, 2002).

Healthy transitions occur every day when individuals and groups of people achieve mastery of the behaviors, sentiments, cues, and symbols associated with new

roles and identities (Meleis, 2010). However, even healthy transitions may marginalize people as they move from one state to another; change is the problem as well as the opportunity. Even healthy-outcome transitions require coping with the multidimensional process that is transitioning. When patients and caregivers feel marginalized by cancer, they may also, in accordance with transitions theory, experience disconnectedness and loss of social support.

Unhealthy and ineffective transitions may result in negative outcomes, including role insufficiency (Meleis, 2010). Meleis notes further, “During transitions, there are losses of networks, social supports, meaningful objects, and changes in familiar objects. There are also periods of uncertainty requiring different skills and competencies” (Meleis, 2010, p.5). Thus, transition theory would suggest that periods of transitioning, such as the transition from caregiving during cancer treatment to post-cancer living, may produce stress, negative outcomes, reactions to losses, and uncertainty. For the caregiver, the post-treatment phase of cancer survivorship is largely unexplored in terms of the roles of uncertainty, grief (reaction to losses), and coping. This is part of the focus of the proposed qualitative research.

### **Roles and Transitions**

As early as 1975, Meleis published a conceptual framework of role insufficiency and role supplementation (Meleis, 1975). Taking an interactional perspective, she noted that roles are socially determined and validated through interactions with other people and that changes in one person’s roles necessitate changes in the roles of significant others (Meleis, 1975). Following this line of thinking, she noted that when a person or their significant others perceived that there is an incongruence or disparity between role

expectations and the ability of one to perform that role, then there is role insufficiency (Meleis, 1975). Role insufficiency may entail feelings of inadequacy and may produce anxiety, depression, apathy, frustration, grief (reaction to losses), powerlessness, and aggression and irritability (Meleis, 1975).

Meleis also discusses the concept and strategies for role supplementation. Historically, literature identified role supplementation as something that entails the deliberate identification of role insufficiency, role clarification, and role taking on behalf of another person in order to prevent or decrease role insufficiency (Meleis, 1975). Components of role supplementation are role clarification and role taking. Role clarification involves clear communication of the demands of a role and the information a person would need to perform that function to meet the role demands. Roles are learned, and by lessening ambiguity of a role one can assist another person to enact that role well (Meleis, 1975). Role taking involves assuming the position of another person either literally or vicariously (Meleis, 1975) and thereby assisting the person to learn a role.

More recently, Meleis identified that roles are important in transitions, since we use our role performances to navigate the tasks of daily living. When something about living changes and transition occurs, then roles change. Meleis recognized that transitions are often the context for role changes and potential role insufficiencies. Transitions are heralded by changes in terms of situations, health/illness, developmental phases, and organizational changes (Meleis, 2010). Changes mean the old and familiar is lost, and people may grieve the loss of the familiar and at the same time may see themselves or be seen by others as needing different skills and knowledge to perform new roles. If the individual is not prepared or equipped for new roles, then role insufficiency

occurs and the negative effects of role insufficiency are experienced by the person undergoing transitions.

### **Application of Transitions Theory to the Cancer Story**

So how does the cancer survivorship and cancer caregiving look through the lens of transitions theory? Cancer patients and their caregivers may encounter transitions as they go through the cancer experience. Meleis (2010) writes of nurses and patients in general, “What makes their transition a nursing concern is the potential risk that the transitional experience may place on them. Preventing these risks, enhancing well-being, maximizing functioning, and mastering self-care activities are outcomes that nurses strive for in their interventions” (p.xv). Seeing cancer caregiving as part of a transition is immensely helpful for understanding the dynamic story of cancer caregiving over time, holistically, and within context.

Cancer is a disruption in the lives of those touched by cancer. The disruption caused by a cancer diagnosis initiates a family into significant changes in health, roles, functioning, and identities. Changes cause people to enter periods of transitions, and transitions theory can be helpful in understanding the nature, conditions, and patterns of responses to the experience of cancer as a transition.

### **Usefulness of Transitions Theory for Nursing Research Other than Cancer**

Transitions theory has been used a number of times for research in nursing and for research that is relevant to nursing. For example, researchers have used the theory as a basis for understanding patient discharge (Weiss, Piacentine, Lokken, Ancona, Archer, Gresser, et al., 2007; Rittman, Boylstein, Hinojosa, Hinojosa, & Haun, 2007; Rossen, 2007), relocation to different living situations (Rossen & Knafl, 2007; Davies, 2005),

immigration (Samarasinghe, Fridlund, & Arvidsson, 2006; Messias, 2002; Meleis, Douglas, Eribes, Shih, & Messias, 1996), socialization in education (Brennan & McSherry, 2007; Wieland, Altmiller, Dorr, & Wolf, 2007; Sharoff, 2006), transitional care models of nursing care (Naylor, Brooten, Campbell, Maislin, McCauley, & Schwartz, 2004; Visentin, Koch, & Kralik, 2006; McCauley, Bixby, & Naylor, 2006), and developmental transitions such as parenthood (Mercer, 2004; Shin & White-Traut, 2007), menopause (Im & Meleis, 1999), and retirement (Schumacher, Jones, & Meleis, 1999). In addition, transitions theory continues to have currency and is suggested for the study of trajectories. A special-theme issue of *Nursing Research* included a study of the trajectory of chronic diseases for which the authors used the transitions theory model shown in Figure 1 (Gaugler, Roth, Haley, & Mittelman, 2011). That study was a secondary analysis of data from the New York University Caregiver Intervention, a study included 406 caregivers of patients with Alzheimer's Disease who were placing the persons with dementia into nursing homes. The authors found that "the inclusion of transitions and health trajectories, in a randomized controlled trial, offers an intriguing picture of how comprehensive psychosocial interventions can help families navigate the challenges of chronic disease care" (Gaugler, et al., 2011, p. S28).

### **The Review Process: Empirical Literature**

To access the empirical literature on cancer survivorship and cancer caregiving, I used online database search engines CINAHL, Medline, and PsychInfo. Key words used to search the databases included such terms as: *cancer, survivors, survivorship, quality of life, caregiving, caregivers – psychosocial factors, caregiving burden, family functioning, family, sequelae, caregiver, coping, transition, uncertainty, fatigue, fear of recurrence,*

*hardiness, social support, cancer worries, long-term survivorship, family distress, adjustment, spouse-support, resources, grief, loss, adult development, adult learning, and others.* In addition, I searched for specialty organizations on the internet, including such websites as the National Cancer Institute, Oncology Nursing Society, American Cancer Society, the Lance Armstrong Foundation, Susan G. Komen Foundation for the Cure, and various websites for cancer survivors and survivorship for additional evidence.

### **Cancer Survivorship and Caregiving: Empirical Literature**

Literature on cancer survivorship is especially strong in terms of what we know about physical survivorship and its effects on cancer patients. However, recently more researchers are conducting studies on the psychosocial aspects of the cancer experience. There is emerging evidence that cancer caregiving is hazardous to caregivers, so caregivers, as well as patients, have attracted the attention of researchers.

From the moment of diagnosis, there is an emphasis on survival for the cancer patient and – vicariously – for his or her family. Initially, the cancer survivor hopes to survive the treatment and eradicate the disease. Once treatment is completed, the usual reaction is to rejoice and to attempt to define a new path forward for both cancer survivor and caregiver (Alfano & Rowland, 2009). This is not a simple project, however, given some enormous after-effects of cancer and its treatment.

### **Physical Aftereffects of Cancer and Its Treatment**

In order to understand why there are psychosocial effects of cancer on patients and their caregivers, it helps to establish that there are significant physical impairments that affect cancer patients. Essentially all organ systems can be affected by cancer (Miller, Merry, & Miller, 2008). Moreover, significant physical impairments, whether

temporary or permanent, can affect one's ability to function in a life role such as mother, employee, or household maintainer, resulting in role insufficiency. What affects one person in a dyad affects both people in the dyad (McCubbin & McCubbin, 1991), so the effects on cancer caregivers begin with the effects on cancer survivors.

The long-term physical consequences of cancer and its treatment can be severe and even incapacitating. Living with the physical after-effects of both the cancer disease and its treatment means understanding that the after-effects often last much longer than the treatment itself (Northouse, Mellon, Harden, & Schafenacker, 2009). Medical complications from cancer and cancer treatment can include chronic pain, physical fatigue, limitations on physical performance, osteoporosis, premature cardiovascular disease, obesity, and second cancers (American Institute for Cancer Research, 2003; Mellon, Northouse, & Weiss, 2006; Ness, Mertens, Hudson, Wall, Leisenring, Oeffinger, Sklar, Robison, & Gurney, 2005; Lyne, Coyne, & Watson, 2002; Bennett & Winters-Sloan, 2006). Although pain is typically considered to be a component of the acute phase of cancer treatment, there are a number of chronic pain conditions which can affect cancer survivors after the acute phase of treatment. These include proctitis, obstruction, plexopathy, and neuropathy (Dow, 2003). Newer findings have documented defects in cognition in adults resulting from chemotherapy (Dow, 2003). The phenomenon, sometimes called "chemo brain," is a common after-effect of chemotherapy. Cognitive changes have been documented in patients with a wide variety of cancers, are potentially permanent, and are significantly related to chemotherapy dosage and duration (Ahles & Saykin, 2002, Meyers, 2000; Ganz, 2001; Ganz, Desmond, Leedham, Rowland, Meyerowitz, & Belin, 2002).

Cancer survivors may exhibit physical limitations long after cancer treatment ends. In one epidemiological study of 279 recent and 434 long-term cancer survivors, researchers compared these survivors to 9370 persons with no history of cancer (Ness, Wall, Oakes, Robison, & Gurney, 2006). They found that cancer survivors were more likely to have physical performance limitations and to have participation restrictions than their cancer-free controls, with the majority of cancer survivors exhibiting some limitations to physical performance (Ness, et al., 2006). The most intriguing finding from this study was that the most striking difference was in the age group 40 to 49, which are peak earning years for most people in terms of their careers. Thus, there is evidence that socioeconomic status may be affected indirectly by the effects of cancer and its treatment outside of the direct impact of financial costs of the treatment itself.

One particularly valuable qualitative study explored the experiences of 58 cancer survivors who were at least 15 years post-diagnosis for cancer (Foley, Farmer, Petronis, Mith, McGraw, Smith, Carver, & Avis, 2006). The researchers compared the cancer experiences of these long-term survivors by cancer type, ethnicity, gender, and age. The researchers found four conditions of survivorship, and they termed these conditions “That’s Life,” “Personal Growth,” “Relinquishing Control,” and “Resentment” (Foley, et al., 2006, p. 248). They found that quality of life was highest for cancer survivors who viewed the cancer more or less as just an occurrence in their lives (“That’s Life”) and lowest in survivors who resented what the cancer had done to them and to their families. Not surprisingly, the group who reported the highest quality of life had fewer sequelae from cancer than did those who resented the experience, but it is interesting to note that

even 15 years or more post-diagnosis some survivors reported that pain, physical deformities, and social isolation had decreased their quality of life (Foley, et al., 2006).

### **Fatigue.**

A subgroup of literature on cancer survivorship concerns the physical phenomenon of fatigue caused by cancer treatment. This intense feeling of utter tiredness, unrelieved by rest or sleep, is a common experience for cancer patients undergoing treatment and afterward. Fatigue is often accompanied by pain, sleep disturbances, nausea, difficulty concentrating, and depression (Byar, Berger, Bakken, & Cetak, 2006; Lavdaniti, Patiraki, Dafni, Katapodi, Papathanasoglou, & Sotiropoulou, 2006; Mast, 1998; Payne, Piper, Rabinowitz, & Zimmerman, 2006). Barbara Piper developed a program of research to address the problem of cancer treatment-induced fatigue and developed an instrument to measure subjective fatigue intensity (Piper, Lindsey, Dodd, 1987; Piper, Dibble, Dodd, Weiss, Slaughter, & Paul, 1998).

Psychometric evaluation of the Revised Piper Fatigue Scale was conducted with 382 women with breast cancer (Piper, et al., 1998), and the researchers found that the scale and its four subscales adequately measured chemotherapy-induced fatigue in that population (Piper, et al., 1998). One group of researchers conducted a factor analysis of the Piper Fatigue Scale and its use with caregivers, but the instrument has not been widely used for that population (Clark, Ashford, Burt, Aycok, & Kimble, 2006). Clark and colleagues studied 132 cancer caregivers and found that the Piper Fatigue Scale, when used with caregivers, exhibited strong internal consistency. However, their data suggested that the caregivers may experience fatigue somewhat differently than do cancer patients (Clark, et al., 2006). Their findings support the need for research focusing on

the experiences of caregivers, since they may have different perspectives than do cancer patients.

Fatigue, however, remains a significant part of cancer survivorship, especially during active treatment; the fatigue is of sufficient intensity that it makes role performance all but impossible. This may be a significant stressor for patients and families, and it may alter the transition experience of patients and caregivers by altering role performance and socioeconomic aspects of the cancer journey (if employment role is affected or if others must be hired to do homemaking roles). Fatigue associated with cancer and its treatment has been found to have an impact on patient employment patterns (Poirier, 2006). Specifically, high fatigue levels have been found to be associated with radiation sites in the chest, pelvis, head, and neck (Poirier, 2006), and significant fatigue was found to seriously decrease the ability of patients to maintain their employment patterns while in treatment and for months after treatment.

Research in the area of the impact of fatigue remains primarily exploratory. For example, researchers have found that chemotherapy dosage as well as anxiety, fear of recurrence, and health beliefs contribute to the severity of fatigue, while level of activity or rest does not contribute to the severity of fatigue (Thompson, 2007; Byar, et al., 2006; Young & White, 2006).

There is evidence that fatigue from cancer treatment is associated with both radiation therapy and chemotherapy treatments. A correlational, repeated measures study of 106 Greek women with breast cancer examined fatigue during radiation therapy and the impact of that fatigue on health status (Lavdaniti, et al., 2006). The researchers found that all subjects experienced an increase in fatigue during radiation therapy, and

this fatigue was indeed associated with deterioration of health status (Lavdaniti et al., 2006). Dosages of chemotherapy were studied in a pilot study of 15 women receiving chemotherapy for breast cancer. The longitudinal, repeated measures study of 8 women receiving dose dense chemotherapy for breast cancer and 7 women receiving standard chemotherapy compared fatigue between the two groups (Sura, Murphy, & Gonzales, 2006). The researchers found significantly greater fatigue in subjects undergoing dose-dense chemotherapy than those subjects undergoing standard chemotherapy (Sura et al., 2006).

There is evidence that fatigue from cancer treatment persists long after active treatment has ended, however. Young and White (2006) studied 69 disease-free survivors of breast cancer who were at least 6 months post-treatment. They found that 19% of their sample met the ICD-9 diagnostic criteria for cancer-related fatigue, no matter what their activity level. In fact, they found that a major contributor to cancer-related fatigue appeared to be psychological distress, including fear of recurrence (Young & White, 2006).

### **Psychosocial Challenges of Cancer Survivorship for Survivors and Caregivers**

Psychosocial challenges of cancer survivorship are no less daunting than the physical challenges. The impact of cancer on a cancer survivor directly impacts all members of the family. In a prospective study of the effects of cancer diagnosis on depression and anxiety in families during cancer treatment, Edwards and Clarke (2004) found that levels of depression and anxiety were similar for patients and caregivers.

**Research programs of Northouse and Mellon: psychosocial survivorship.**

Two prominent researchers in the area of cancer family caregiving are Laurel Northouse and Suzanne Mellon, who conducted a number of research studies focused on psychosocial impact of cancer on caregivers. In 2000, Northouse, Mood, Templin, Mellon, and George published the results of a longitudinal study based loosely on Lazarus and Folkman's (1984) theory of stress, appraisal, and coping and later on theories of families in crisis by McCubbin and McCubbin (1991). Northouse and colleagues were replicating a similar study done by Northouse of breast cancer patients and their husbands, but in the 2000 study they examined more closely the issues of gender differences and roles in 56 patients with colon cancer and their spouses. The researchers found that women were more likely to report distress, role problems, and marital dissatisfaction than were men. While both partners reported decreased family functioning due to the cancer experience, they differed in terms of predictors. The strongest predictors of patient role adjustment problems were hopelessness and role problems in spouses; on the other hand, the spouses' role problems were most significantly predicted by their own baseline role problems and the level of marital satisfaction (Northouse, et al., 2000).

The next year, Mellon and Northouse published the results of Mellon's study of 123 family dyads to examine quality of life and to test a model of predictors of family quality of life from 1 to 5 years after treatment for various types of cancer (Mellon & Northouse, 2001). Their model, based on the McCubbin and McCubbin (1991) family stress model used previously by Northouse, was found to explain 63% of the variance in family quality of life. They found examined illness survival stressors (concurrent stresses

for the family, fear of recurrence, and somatic concerns), family resources (hardiness and social support), and the ensuing meaning of cancer as an illness as all impacting overall quality of family life. Their work provided support for the need to address cancer-related stressors for families, family resources, and the meaning of cancer to family members as important to family quality of life (Mellon & Northouse, 2001).

In 2002, Northouse and colleagues reported on a program evaluation of an intervention to improve family involvement, optimistic attitudes, coping effectiveness, reduction of uncertainty, and management of symptoms for 400 breast cancer patients and their caregivers (Northouse, Walker, Schafenacker, Mood, Mellon, Galvin, Harden, & Freeman-Gibb, 2002). This study was evaluated only in terms of patient and family satisfaction of the intervention group compared with a control group, but the intervention was rated highly by the intervention group in each of the five areas (Northouse, et al., 2002a).

Also that year, Mellon reported the results of the qualitative portion of the 2001 study, in which caregivers and cancer survivors were asked two open-ended questions about the meaning of cancer as an illness and family quality of life (Mellon, 2002). Data were analyzed for content, and she found that there were both negative and positive dimensions to meaning of illness and quality of life, that meaning of illness was related closely with family quality of life, and that cancer survivors and their caregivers differed in their views of support from others. Cancer survivors identified that receiving support from others was important, while family members were more focused on how to give support to cancer survivors (Mellon, 2002).

Also in 2002, Northouse and her colleagues published the results of a study of 189 dyads of breast cancer patients and their family members to identify quality of life within one month after cancer recurrence (Northouse, Mood, Kershaw, Schafenacker, Mellon, Walker, Galvin, & Decker, 2002b). They found that patients reported significant impairments in physical, functional, and emotional well-being. Family members reported impaired emotional well-being. A structural equation modeling analysis identified variables that had positive and negative effects on quality of life. The overall impact of this study was to establish the need for patients and family members who experience the recurrence of breast cancer to have mental health support (Northouse, et al., 2002b).

In 2006, Mellon and colleagues published another analysis of their study of 123 dyads of patients with various types of cancers and their family members, but this time they examined the differences between cancer survivors and family members in terms of predictors of quality of life (Mellon, Northouse, & Weiss, 2006). They found significant differences between family members and cancer survivors at a point between 1 and 6 years after diagnosis of cancer. Interestingly, cancer survivors reported significantly higher quality of life, less fear of cancer recurrence, and more support than their family members. Mellon and colleagues provided evidence for the need of family members to be included in care (Mellon, et al., 2006).

The next year, Mellon and colleagues examined fear of recurrence among cancer survivors and their family members with emphasis on identifying factors associated with fear of recurrence, using the data from the 123 dyads in the 2001 study (Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007). They found that family members had higher fear of recurrence than cancer survivors and that they influenced each other's fear

of recurrence. Additionally, they found that family stressors, a negative meaning attached to the illness, and older age were related to higher fears of cancer recurrence for both groups (Mellon, et al., 2007).

Northouse joined other colleagues (Kershaw, Mood, Newth, Ronis, Sanda, Vaishampayan, & Northouse, 2008) in examining predictors of quality of life in patients with prostate cancer and their spouses. They conducted a study of 121 dyads and found that a stress-coping model accounted for between 24 % and 43% of quality of physical and mental quality of life for patients and their spouses. They identified the need for programs to assist patients and their spouses to manage the effects of prostate cancer and its treatment (Kershaw, et al., 2008).

The work of Northouse and Mellon has propelled the study of cancer caregiving and quality of life issues. Their contributions to the study of psychosocial aspects of cancer and cancer caregiving remain significant.

#### **Other psychosocial aspects of cancer survivorship and caregiving.**

A number of other researchers have studied various psychosocial aspects of cancer survivorship. These areas include : family stress and coping, quality of life, physical functioning, advocacy of nurses, research of minorities and medically underserved groups, family issues, post-treatment employment, and pain management (Lyne, Coyne, & Watson, 2002; Dow, 2003; Ness, et. al., 2006; Aziz & Rowland, 2002; Drouin, 2004; Feuerstein, 2005; Mellon, 2002; Northouse, et. al., 2002a and 2002b). As noted above, a few studies have proposed models of some aspect of cancer survivorship (Mellon, et al., 2006; Mellon, et al., 2007; O'Hair & Villagran, 2003; Farmer & Smith,

2002), primarily models based on the stress/appraisal/coping model of Lazarus and Folkman (1984) and family theories based on that (McCubbin & McCubbin, 1991).

One group of researchers examined survivorship from active cancer treatment to post-treatment using a qualitative focus group study of women with breast cancer (Allen, Savadatti, & Levy, 2008). While this study included only female cancer survivors, primarily Caucasian survivors, it was a significant step towards understanding the impact of completing cancer treatment on cancer survivors. Study participants associated the end of active cancer treatment with feelings of being left without support and without the vigilance of the healthcare community. The study did not address losses or active transitioning, developmental issues, or the family context (Allen, et al., 2008). However, the study was significant in that it examined the phenomenon of leaving the constant surveillance of active cancer treatment and the effect this change has on cancer patients. Farmer and Smith (2002) applied Rodger's (2000) evolutionary view of concept analysis to the term "cancer survivorship" as it applied to breast cancer and African American women. They concluded that, based upon literature, cancer survivorship as a concept can be defined as "the process of living through the cancer experience beyond a breast cancer diagnosis" (Farmer & Smith, 2002, p. 786). Moreover, they asserted that there was a need to explore the meaning of cancer survivorship among African American women in order for nurses to be culturally competent in their care of these patients (Farmer & Smith, 2002). Furthermore, they concluded that the concept of cancer survivorship is indeed changing over time as survival rates improve and treatments change for cancer. However, they noted that each person who travels the cancer journey does so

individually, so it behooves nurses to understand each person's meaning of the journey in order to provide culturally competent care. Farmer and Smith (2002, p. 779) wrote:

Cancer survivorship is an evolutionary, dynamic, and multifaceted process that is unique, personal, and complex and involves people with cancer as well as those who support or care for them. Cancer survivorship is an individualized journey. The first step in providing culturally competent care is for nurses and other healthcare professionals to understand the meaning of this journey to cancer survivors.

Changes in the meaning of cancer as an illness may, according to transitions theory, either inhibit or facilitate transitioning through the cancer experience. For example, if a cancer survivor is old enough to remember cancer as basically incurable, then the meaning of cancer for that patient might be different from the meaning of cancer for a younger survivor who may have always thought of cancer as survivable. Historical developments in the successful treatment of cancer, therefore, may interact with developmental issues to facilitate or inhibit successful transitioning to life after cancer treatment.

O'Hair and colleagues (2003) examined the concept of cancer survivorship and the agency model in their study of communication with cancer survivors after diagnosis. Their purpose was to apply effective communication theory to the study of cancer survivors in order to empower clients and enable them to become agents for themselves in terms of decision making and self-efficacy. They did not identify specific interventions, but the ultimate outcome of the study was to highlight the importance of communication in surviving and living with cancer, its treatment, and its aftermath. Examining this finding in light of transitions theory, it becomes clear that communication is a key to knowledge acquisition and preparation for various phases of cancer treatment and as a personal facilitator of transitioning through the cancer experience. It makes

sense that effective communication may also promote a realistic appraisal of the experience of cancer and can promote role sufficiency by equipping the cancer survivor and caregiver with the information needed to successfully fulfill new roles and demands.

### **Grief.**

One intriguing aspect of cancer survivorship for both survivors and caregivers is the concept of grief. Marwit and colleagues, defining grief as reaction to loss, developed a pre-death grief inventory for caregivers of patients with dementia and successfully tested the inventory, the Marwit-Meuser Caregiver Grief Inventory (MM-CGI) with cancer caregivers (Marwit, Chibnall, Dougherty, Jenkins, & Shawgo, 2008). When using the MM-CGI with cancer caregivers they found that cancer caregivers do experience significant loss, and therefore grief, during the process of caring for someone who undergoes cancer treatment. Indeed, grief is emerging as a part of the cancer caregiving picture.

### **Fear of recurrence.**

As identified above, research indicates that many cancer survivors and their family members are burdened by fears that the cancer will return. In terms of Transitions Theory, fear of recurrence may be related to a person's cultural beliefs and attitudes and possibly the meaning one attaches to cancer. If fear is incapacitating then it can affect family functioning by affecting role performance. Fear of recurrence may be related to having a realistic or unrealistic view of cancer, and this perception of cancer may be affected by one's preparation and knowledge level. No one is truly prepared for the experience of cancer, but knowledge may facilitate or inhibit one's ability to transition to life after cancer treatment.

Foundational research on fear of cancer recurrence was conducted by Vickberg (2001, 2003), who developed the Concerns About Recurrence Scale (CARS). Vickberg studied 160 women with breast cancer and found that survivors are concerned about cancer recurring, but specifically they are concerned about the possibilities of death; further treatment; health threats; and threats to roles, femininity, and body image (Vickberg, 2003). Mellon and colleagues (2006) took this a step further in their mixed-methods study of 123 African-American and Caucasian cancer survivors and their caregivers. Participants were contacted from one to six years after the end of active cancer treatment for this study of quality of life. Results indicated that cancer survivors reported significantly higher quality of life, less fear of recurrence of the cancer, and more support than did the caregivers (Mellon, Northouse, & Weiss, 2006).

The finding that caregivers had more fear of cancer recurrence than did the cancer patients themselves may be indicative of the depth of psychosocial trauma and the unmet needs of caregivers of patients with cancer. This is an important finding for the current study. Mellon and colleagues also found that fear of recurrence was higher in females than in males (Mellon, et al, 2006). The findings from this study may have serious implications for caregivers who are female in terms of heightened fear of recurrence of cancer.

One final study that illustrated the physiological effects of fear of cancer recurrence was conducted by Porter and colleagues in 2003. They examined the effects of mammography screening on salivary cortisol levels of 33 breast cancer survivors in a repeated measures study. They found that breast cancer survivors have elevated baseline and response cortisol levels in response to mammography even years after breast cancer

treatment has ended (Porter, Mishel, Neelon, Belyea, Pisano, & Soo, 2003). The study is significant in that it points out the important role of chronic stress in physiologic functioning for cancer survivors.

### **Quality of Life.**

Concepts such as fear of recurrence and grief, as well as other psychosocial aspects of the cancer experience can affect the quality of life for cancer survivors and their family members. Quality of life as a concept involves emotional well-being, social well-being, physical well-being, and spiritual well-being (Northouse, et al., 2009). As noted earlier, the theoretical framework used to study families and quality of life is often a variation of family stress theory (H. I. McCubbin, Thompson, & McCubbin, 1996; M.A. McCubbin & McCubbin, 1991). Family stress theory includes the proposition that families are a reverberating system of impact; what impacts one member also affects the others within the family. Furthermore, a buildup of stressful stimuli can exceed a family's resources for coping and may therefore be counter-productive in producing adaptation; indeed, family members may adopt maladaptive behaviors when stress-fighting resources are overwhelmed (M.A. McCubbin & McCubbin, 1991). Similarly, family stress theory is based upon general stress and coping theory, since both individuals and families attempt to cope with illness and its treatment as a stressor (Lazarus & Folkman, 1984).

Research on family quality of life in terms of emotional well-being has indicated that emotional adjustment problems in both cancer survivors and their family members persist over time in the post-treatment phase of survivorship. It is unclear how long emotional distress persists for families, although Mellon noted that family members

reported slightly less emotional distress after approximately 3 years (Mellon, 2002). Of interest is the finding that emotional adjustment of cancer survivors and family members are interdependent and that adjustment of family members has a significant effect on adjustment of cancer survivors one year after diagnosis (Northouse, Mood, Templin, Mellon, & George, 2000). Furthermore, dealing with uncertainty on a long-term basis is identified as a significant source of stress for family members (Mellon, 2002). Finally, Mellon and Northouse (2001) found that fear of recurrence was a strong negative predictor of family members' quality of life in the post-treatment phase of cancer survivorship.

Research on family quality of life concerning social well-being indicates that cancer impacts the quality of family life. Most research in this area has examined the effects of cancer on marital adjustment and the general quality of marital relationships. Northouse, et al. (2009) report that most studies indicate that marital relationships remain basically unchanged by cancer over the long term. However, there were some areas of strain in marriages impacted by cancer, and open communication was found to help with role functioning and marital strain (Edwards & Clarke, 2004). Regarding sexuality in marriages after cancer, almost all of the research in this area concerns cancer survivors rather than family members or spouses, and most of that concerns cancer survivors after breast cancer and colon cancer (Edwards & Clarke, 2004).

Dow, Ferrell, Haberman, & Eaton (1999) conducted a qualitative study of cancer survivors with a mean time after diagnosis of 6.7 years. Themes that emerged relative to the meaning of quality of life for these survivors included balancing independence and dependence, purposeful life, reclaiming their lives, coping with multiple losses, having

control, changes in the meaning of health, and permanent challenges to survival as families (Dow, et al., 1999). Some of these sequelae may impact family relationships and functioning, including intimacy, role changes and strain, financial health, spiritual health, employment issues, and psychoemotional health of couples (IOM, 2008; Kitrungrote & Cohen, 2006). Studies of cancer survivors' quality of life generally conclude that cancer alters lives in almost innumerable ways.

### **Overall psychosocial impact of cancer.**

The overall impact of the experience of cancer and cancer treatment is a disruption in one's story, which can threaten one's personal identity (Little, Paul, Jordens, & Sayers, 2002). Little and colleagues conducted qualitative research interviews with 13 Australian cancer patients and noted that while cancer patients are treated with acceptance and understanding during treatment for the cancer, the same cannot always be said about conditions of post-treatment survivorship (Little, et al., 2002). The result of extreme circumstances threatening continuity of life is often a threat to personal identity, so survivors of cancer and other serious circumstances are faced with a major task of restoring or preserving that continuity in order to preserve their self-identities. They noted that "A satisfactory discourse of survival has yet to enter the public domain" (Little, et al., 2002, p. 170). The proposed research would complement the work of Little and colleagues by examining the transitions of caregivers who had also experienced disruption within dyads, family groups, or other significant relationships.

One longitudinal study of 46 breast cancer survivors produced data that post-traumatic stress disorder (PTSD) symptoms were present in this population and did not diminish over the year-long course of the study (Andrykowski, Cordova, McGrath,

Sloan, & Kenady, 1999). Black and White (2005) took these findings further in their correlational study of 48 patients with hematologic cancers. They found significant relationships between participants' fears of recurrence and PTSD (Black & White, 2005), supporting the important negative impact of fear of recurrence for cancer survivors and their caregivers.

### **Literature Specific to Cancer Caregiving**

Some researchers have focused their studies exclusively on cancer caregivers, and this body of literature has helped to identify and explicate the experiences of caregivers as distinct from cancer survivors. The following review of literature includes studies that have advanced the science regarding the experiences of cancer caregivers.

Physical sequelae of the cancer experience are not limited to cancer patients. Family members and significant others who care for patients undergoing treatment for serious disease pay a price in terms of biopsychosocial sequelae. Caregiving is emotionally draining, intellectually challenging, and sometimes physically demanding. Families in which a member has been diagnosed with cancer experience role changes, sometimes permanently, and these role changes may be fatiguing and burdensome to caregivers (Wagner, Bigatti, & Storniolo, 2005; Rivera, 2009; Ponto & Barton, 2008; Morris, Grant & Lynch, 2007; Mellon & Northouse, 2001; Jensen & Given, 1991). Positive aspects of caregiving, on the other hand, include gaining esteem and making meaning through caregiving (Mellon, 2002; Germino, Fife, & Funk, 1995).

One informative study of what caregivers do for patients with cancer was a qualitative study (part of a larger study) by Schumacher and colleagues, who examined the concept of family caregiving skill (Schumacher, Stewart, Archbold, Dodd, & Dibble,

2000). They used grounded theory to examine interview transcripts from caregivers recruited through medical oncology practices. Most of the caregivers in the study were described as women, Caucasian, and spouses. Most of the cancer patients in the study were undergoing initial treatment for lymphomas. Investigators asked how caregivers managed various caring problems and procedures, and the analysis produced concepts related to caregiving skills. The researchers found 63 indicators of caregiving skills that were grouped into nine categories or processes: monitoring, interpreting, making decisions, taking action, providing hands-on care, making adjustments, accessing needed resources, working with patients to provide individualized care, and negotiating with the healthcare system to meet needs (Schumacher, et al., 2000).

Schumacher and colleagues also tested a model of family caregiving based upon interactionist approaches to role theory in a descriptive, correlational study of 87 caregivers of patients being treated for solid tumors or lymphoma (Schumacher, Stewart, Archbold, Caparro, Mutale, & Agrawal, 2008). Their hypothesis was that there are three variables related to the caregiving role that would predict outcomes of caregiving: demand of caregiving, mutuality between patients and caregivers, and how well-prepared caregivers were for the job of caregiving. They examined caregiving demand in terms of time spent and number of tasks involved in caregiving, mutuality in terms of positive quality of the relationship between cancer patients and caregivers, and preparedness in terms of how well caregivers perceived that they were ready to perform caregiving roles. Outcome variables were role strain and caregiver mood (including tension, depression, anger, and total mood disturbance). They found that perception of caregiving as highly demanding was associated with global role strain and difficulty giving care. High levels

of mutuality were negatively associated with caregiver anger. Preparedness was unexpectedly more strongly associated with mood disturbances than with the variables of caregiving difficulty and strain. The researchers concluded that the three independent variables did indeed predict multiple caregiving outcomes for caregivers and that clinical assessment of the three independent variables (demand, mutuality, and preparedness) could provide a basis for the development of interventions for caregivers (Schumacher, et al., 2008). This model, tested by Schumacher and colleagues, however, was developed with data from caregivers who were coping with the effects of active cancer treatment of significant others. The current study examined the experiences of caregivers after active treatment had ended.

The cancer experience may be different for caregivers than for cancer survivors. As early as 1992, Clipp and George conducted a qualitative study of thirty dyads to determine whether cancer patients and their caregivers perceive the illness experience similarly. They found that cancer patients and caregivers differed in their subjective assessments of the illness experience, quality of marriage, patient symptoms, and patients' functioning (Clipp & George, 1992). Their findings suggest that caregivers and cancer patients may perceive things differently.

Jensen and Given (1991) studied 248 caregivers of cancer patients as part of a larger study to examine the role of fatigue and role attainment in caregiving. They found a significant relationship between fatigue of caregivers and the impact of care on the daily schedule; the more caregivers' daily schedule was impacted by cancer caregiving the greater the fatigue (Jensen & Given, 1991). Shortly after that study was published, Davis-Ali and colleagues published a study of worries and support as reported by 91

adults with cancer and 78 spouses (Davis-Ali, Chesler, & Chesney, 1993). While they found that patients and spouses worry equally about their own health status, the caregivers tended to worry more about the cancer patients' futures than did the cancer patients themselves (Davis-Ali, et al., 1993). This was consistent with the findings of Mellon and colleagues (2006), who found that caregivers in their study of 123 dyads (cancer patients and their significant caregivers) were more fearful of cancer recurrence than were the patients themselves. In fact, they noted that fear of recurrence and social support most strongly predicted caregivers' quality of life (Mellon, Northouse, & Weiss, 2006). Similarly, Edwards and Clarke (2004) conducted a study of 48 newly diagnosed cancer patients and 99 of their adult relatives and found that family members had higher levels of depression and anxiety than did the cancer patients.

There are several other published studies that indicate that cancer caregiving has negative psychosocial consequences for caregivers. These studies indicate that caregiving affects quality of life, burden, and family distress levels (Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle, et al., 2004; Edwards & Clarke, 2004; Downe-Wamboldt, Butler, & Coulter, 2006; Wagner, et al., 2006, Morris, et al., 2007). Moreover, problems persist long after the cancer treatment ends. Hodgkinson and colleagues conducted a qualitative study utilizing telephone interviews with 25 cancer survivors and their partners. They found that long after cancer treatment ended, there remained significant needs in the areas of information, health care, physical functioning, interpersonal relationships, emotions, and socio-economic issues (Hodgkinson, Butow, Hobbs, & Wain, 2007).

The problems for caregivers may be severe enough to contribute to morbidity and even mortality (Schulz & Beach, 1999). Schulz and Beach conducted an epidemiological study of family caregiving as a risk factor for mortality and found that caregivers who describe the experience as stressful have a 63% higher mortality rate over the following four years as compared with other people their age.

There is evidence that there are gender differences in the impact of cancer caregiving on caregivers. Hagedoorn and colleagues studied 173 couples facing various forms of cancer and compared them with a control group of 80 couples (Hagedoorn, Buunk, Juijter, Wobbles, & Sanderman, 2000). They found that women – both female cancer patients and female caregivers – were more susceptible to depression, psychological distress, and lower quality of life than were males in the study. This was true for the control group as well as the cancer group. However, they found that men were more affected than women by role attainment and performance difficulties (Hagedoorn, et al., 2000). The other study of gender in relationship to caregiving was conducted by Allen and colleagues (1999). They investigated gender differences in spousal caregiving in a sample of 353 married couples facing outpatient treatment for cancer. She found that husbands were less likely than wives to assist with household tasks but were more likely to seek other helpers; wives, on the other hand, were more likely to be the sole caregiver (Allen, Goldschneider, & Ciambone, 1999). This finding may help explain the higher level of morbidity in the female caregivers compared to husbands. Finally, the wives in Allen's study were more likely to report unmet needs than were the husbands. Since most caregivers in this country are women it would

appear that female caregivers may be especially in need of assessment, intervention, and support.

### **The Importance of Developmental Transitions as Context for Cancer**

When one considers that most cancer is diagnosed in adults, a theoretical framework of developmental transitions is immensely useful in identifying potential needs of adults with cancer and their caregivers. Adult caregivers have histories. They have developed to a certain point in life in which they have achieved life skills and have attached meanings to experiences such as cancer and the transitions that it engenders in a family. As mentioned earlier in the section on transitions theory, transitions may be expected as well as unexpected, and developmental transitions are expected for adults. Cancer, on the other hand, is an unexpected change in health status and would be considered a source of unexpected transition for an adult who has established other life goals and developmental accomplishments, especially in those adults who are pre-retirement age. As Meleis (2010) noted, the dimensions of transition include scope, duration, reversibility, and magnitude; cancer in the family is a disruption in family life that can be broad in scope, indeterminate in duration, partially irreversible, and enormous in magnitude and therefore causes a significant transition that is unexpected. Adults rarely plan for this sort of life disruption.

Furthermore, developmental transitions are pre-existing and underlying in adults. The importance of developmental transitions for the study is that they provide a simultaneous and contextual transition experience that occurs concurrently with transitions surrounding the cancer experience. As such, they could be identified and acknowledged as concurrent transitions.

Adult development theory is relevant to the understanding of cancer survivorship and caregiving because of the enormity of the impact of cancer upon individual and family life of adults; cancer affects and is affected by adult development. In addition, cancer is a foreign experience to most people, and there is an intersection of one's developmental characteristics and status that are developed over time and one's ability and motivation to learn coping and other new skills in order to successfully transition to life after cancer treatment. Adults develop as they age, and adult development is a context for coping, learning, and adopting new roles such as caregiving. The study at hand examines ways in which pre-retirement-age caregivers cope with and transition through the cancer experience, so it is beneficial to examine principles of adult development in light of what has been presented. Several areas of adult development are presented here and examined in terms of how they contribute to the understanding of adult development and cancer.

The field of adult development is relatively new, having arisen in the twentieth century (Clark & Caffarella, 1999). Development is a process, the definition of which is based upon value judgments (Reeves, 1999). Knowledge of adult development helps us understand age-related characteristics of adults in the healthcare setting and in the community. Adult development literature is relevant to the stories of caregivers of patients with cancer because they are adults and have a history of role attainment, coping habits, information seeking or avoidance, and tolerance of uncertainty.

Coping with cancer is not a universal, normal developmental task of adult development, so the stages perspective (Erickson, 1963; Levinson, 1986) may be of limited application to cancer caregiving. However, developmental stages can help us to

understand the impact of losses caused by cancer on the individual and the dyad. For example, Erickson's stage of generativity versus stagnation in middle adults may help explain depressive symptoms in a cancer caregiver who is unable to contribute in a meaningful way to his or her volunteer or occupation activities due to the demands of caregiving. This person, who is working towards outcomes of usefulness and accomplishment, may view the demands of caregiving as threatening to meaningful, productive living.

Sociocultural perspective theorists provide an understanding of adult development in terms of social and cultural roles and how society defines them for us. This perspective on adult development would include the examination of the roles of race, gender, ethnicity, social class, and sexual orientation on adult development (Clark & Caffarella, 1999). This perspective is useful for understanding how roles – within families as well as external – are impacted by cancer and its treatment. For example, men who have experienced impotence resulting from prostate cancer surgery may be challenged by the inability to fulfill the socially-defined role of intimacy with a partner. Nurses have an opportunity to assist with this challenge to intimacy by providing information regarding remedies available as well as other creative ways to express intimacy. Another example of a challenge to sociocultural adult development would be sudden and severe financial losses due to the costs associated with cancer treatment as well as employment changes necessitated by caregiving. These changes may include temporary or permanent loss of employment ability for the caregiver. Social class may be affected, and caregivers may find it difficult to keep up appearances of their former lifestyles, no matter what they were.

A third perspective on adult development - the integrative perspective - provides us with the intersection of all of the above perspectives by studying the impact of life events and transitions between those events (Clark & Caffarella, 1999). This perspective is pertinent to the study of transitioning between relatively stable states of health and illness, and transitioning between role phases. The perspective of life events and transitions allows a more holistic and individualized understanding of people as they transition, incorporates the environmental influences on adult development, and allows the understanding of life events as both milestones and processes (Reeves, 1999). Of course, no one individual has exactly the same trajectory through life as another individual, so adults may experience a variety of routine events (such as retirement or becoming a parent), unexpected events (such as cancer), and non-events (such as failure to become employed as expected) throughout life. The total of these events will affect how a person develops and will present developmental transitions for the person to traverse. Prior development and transitioning equips the individual with resources and weaknesses that will affect how the person successfully or unsuccessfully transitions (Reeves, 1999). Thus, the experience associated with a cancer diagnosis in the family impacts the developmental characteristics of each individual in the family. In addition, how caregivers adapt to and cope with cancer caregiving is in part a function of adult development. Schlossberg (1987) noted that resources and deficits may be clustered into the categories of situation, self, supports, and strategies. This idea has obvious implications for developing nursing interventions in these four areas. Cancer family caregiving may impact adult development, and adult development may impact satisfactory family caregiving.

Development continues to occur throughout life, and this is significant when addressing the transitions of cancer survivors as well as cancer caregiving survivors. Fisher (1993) conducted a qualitative study of 74 older adults in order to identify their experiences along the trajectory towards older adulthood. Using grounded theory, he identified a framework for describing five age-independent periods of change which occur in later adulthood: continuity with middle age, early transition, revised lifestyle, later transition, and a final period of life (Fisher, 1993). These phases are not dependent on age, but rather upon life's conditions and the needs of older individuals.

### **Where the Study Fits**

It is notable that, with the exception of larger studies such as the ones by Mellon (2002) and Mellon and Northouse (2001), many studies of cancer survivorship have examined only the survivors of one type of cancer. Perhaps this is indicative of funding sources for research, but there is a large body of literature on survivors of breast cancer, and to a much lesser extent prostate cancer, colon cancer, and hematologic cancers. Hematologic cancers, moreover, are primarily studied in children rather than in adults. However, what may be a gap in the literature may be related to issues of funding, social support, and advocacy impetus. Therefore, the complicated group of diseases called cancer creates problems for researchers.

The current study, on the other hand, examined the stories of caregivers of patients with a variety of cancers and found common patterns and themes. Of course, different cancers have different prognoses, sequelae, body image effects, functional impairments, and social acceptability that would affect lives in different ways. For example, sensory impairment due to cancer of eyes, ears, and brain may be isolating to

the cancer survivor and may impair one's ability to communicate. Social acceptability and body image may be impaired by radical facial, head, throat, and neck surgery for cancer. Cancer survivors who have had surgical alterations such as colostomies, ileostomies, and prostatectomies may have body image disturbances and problems with the roles of intimacy that those patients with leukemias may not have. These are all examples of how different cancer sites can impact patients differently.

However, just as there are differences in physical impact of cancer, there are also commonalities in terms of the caregiving experience. The current study explored the commonalities among very different individuals experiencing cancer and cancer caregiving, identifying patterns and themes in the individual caregivers.

### **Cancer Survivorship, Caregiving, and Transitions Theory: Summary**

The evidence on cancer survivorship and caregiving can be viewed through the lens of transitions theory, beginning with the cancer experience. Moreover, the three phases of transition offer different opportunities for nursing therapeutics for cancer caregivers. In the first phase (ending of the old), the losses may include health of a family member, roles, former identities, and financial assets, among others. The reaction to loss is grief, and grief reactions in caregivers may be present and may require assistance from nursing; at the very least, the nurse should be aware that caregivers suffer losses and grieve them.

The second phase of transitioning involves disintegration, disequilibrium, uncertainty, and a general upheaval, the challenges of which the caregiver may have inadequate experience and resources to meet. Role inadequacy on the part of the transitioning person may be meaningfully addressed by acquiring knowledge, informing

the meaning of illness for the family, and by social and socioeconomic supports, according to the transitions theory model (Figure 1).

In the third phase of transitioning, there is a re-establishment of a relatively stable state, and this can be compared to the adjustments that are made after cancer treatment has ended. However, the patterns of response include progress indicators and outcome indicators, some of which are a problem for cancer caregivers, especially if adequate social supports are missing or if there is disconnectedness.

In summary, transitions theory is a most useful and appropriate theoretical framework for a study of the transition narratives of cancer caregivers. Transitions theory takes into account the dynamic nature of the experience of cancer caregivers, over time, from pre-diagnosis through treatment and beyond. It encompasses physical and social contexts of individuals, dyads, and extended family units. An integral part of transitions theory is that there are changes over time. I identified numerous ways in which the cancer and cancer caregiving experience may be viewed through the lens of transitions theory (Figure 1). Cancer and its treatment cause a health/illness type of transition that is simultaneous with other developmental transitions being experienced by cancer survivors and their caregivers. Earlier in this chapter I noted that the properties of awareness and engagement in the early phases of illness and diagnosis and starting treatment. Along the way there are changes and differences, although these may be perceived in different ways by different caregivers.

Critical points and events in the cancer experience include the obvious events of diagnosis, beginning and ending treatment, role changes, and other more subjectively important events for caregivers. Literature provides evidence to help explain and explore

transition conditions, which are facilitators and inhibitors of transitioning through cancer, its treatment, and its aftermath. I noted earlier that community services tend to disappear after active cancer treatment ends, but social supports for cancer caregivers have not been well-explored. Applying transitions theory gives added meaning to what we know about cancer survivorship and caregiving by examining and exploring the transition narratives of caregivers. Specifically, transition theory can enrich our understanding of the stories of cancer caregivers as they look back on the cancer experience with a significant other's illness. Transitions theory provides the framework for research in order to understand the caregiving experience and to give voice to cancer caregivers.

Literature informs the study by identifying the hazards and effects of cancer and its treatment on caregivers. The need to care for caregivers is well-supported by literature. Literature also tells us that adult development affects how cancer impacts families and caregivers, especially caregivers who are older adult females, which describes most caregivers.

The current study gives voice to the caregivers of cancer patients in those long years after diagnosis and initial treatment. If nursing is a caring profession, then we need to reach out to cancer caregivers, understand them, and intervene intelligently and compassionately. But first there is a need to understand and to listen.

### **CHAPTER THREE: METHODOLOGY AND SAMPLE**

The purpose of the study was to examine the impact of cancer caregiving on caregivers, exploring their personal narratives of the cancer experience looking back on the entire experience from diagnosis, through treatment, and beyond. Eleven adult caregivers, self-identified as pre-retirement age, participated in two semi-structured interviews per participant. To qualify as a caregiver for the study, each participant reported that they had provided primary support for a cancer patient who had completed at least one round of active cancer treatment and had been diagnosed with cancer within the prior 10 years. Transitions Theory (Meleis, 2010) served as the theoretical framework and guided the interview questions for this qualitative study. Specific concepts from Transitions Theory were used in data analysis, so these concepts are presented in the analysis section of this chapter.

#### **Sampling Principles**

Sampling for this qualitative study was purposive; that is, participants were recruited intentionally from a major oncology center by way of an associated local cancer support center. The overall goal for sampling was to be able to address the research questions for the study by recruiting caregivers who had been caregivers throughout the whole cancer experience from start to present and who had been fully involved with diagnosis, treatment, and post-treatment aftermath of cancer caregiving. In addition, the caregivers had to reside with the cancer patients; in this way I could gain a full picture of the contexts and conditions of caregiving, and the caregivers would have experienced significant impact on their lives.

Data analysis began as soon as interview transcripts became available, usually within days of the interviews, and concurrent data collection and preliminary analysis allowed me to adjust participant recruitment in the manner of emergent design. As data collection progressed, I began to seek variety in the sample (spouses, adult children, different cancer outcomes and status of cancers), and this purposive sampling was based upon themes and issues that began to emerge as important to the participants. For example, I found that there was a different emotional tone of the interviews depending on the present cancer status and outcome for the patient, so I sought caregivers who had different experiences with cancer and different outcomes of cancer caregiving. Miles and Huberman described this sampling method as stratified purposeful sampling and stated that this method “illustrates subgroups and facilitates comparisons” (1994, p. 28). I intended to see if there were similarities or differences in emerging patterns of relationships based upon different outcomes of cancer for each caregiving dyad.

Two interviews were required for each participant because a second interview allowed me to clarify, explore, probe, and otherwise develop data from what participants had said in the first interviews. Also, the second interviews all began with a question about any reactions or things that participants had thought of after we spoke the first time, and the responses to this beginning question was often quite lengthy; that information would not have been available if only one interview had been conducted. In addition, I was able to spend sufficient time with each participant using two interviews of up to two hours each; these interviews allowed me enough time to make detailed observations, to explore details of narratives, and to allow participants time to fully explicate their stories. Most of the participants did not tell their narratives in strictly chronological order, since

they occasionally would return to a previous topic of discussion with additional information or insights from time to time. Spending unhurried and lengthy periods of time with participants allowed them to think, explain, enrich, and develop their narratives. The use of a semi-structured interview guide, plus two thorough interviews per participant, provided sufficient depth and richness of data that allowed a full exploration of narratives and data saturation with eight or nine participants, but I allowed two additional participants who had already been scheduled for interviews to participate so that I could confirm that no new types of responses were going to emerge from the data.

Approximately three weeks were allowed between interviews. The rationale for this was to allow time for transcription and review of the initial interview transcripts prior to second interviews. In addition, the participants would have time to think about what we had discussed in the first interviews and could form impressions and reactions. Longer than three weeks might have been too long for the impressions and reactions to seem fresh in the minds of participants, however, so I kept the intervals as close to three weeks as possible.

### **Inclusion criteria**

Cancer caregivers were conceptually defined as people who contributed significant assistance and support to cancer survivors during and after cancer treatment (Mellon, 2002; Oncology Nursing Society, 2009b; National Coalition for Cancer Survivorship, 2011). For this study the operational definition of a caregiver was a person who self-identified that he or she was the person who contributed such significant assistance and support to a cancer survivor through diagnosis and then during and after

cancer treatment. The sample included husbands, wives, and daughters of cancer patients. In order to confirm the caregiver status I initially asked potential participants to describe briefly their support activities for the cancer survivor during diagnosis, treatment, and after at least one round of active treatment for cancer. I did this to screen potential participants prior to arranging an appointment for our initial interview.

Specific inclusion criteria for the study included the following:

- Participants were self-identified as pre-retirement age, whether employed or unemployed. The rationale for this criterion is that the typical caregiver in the United States is a woman in her forties who is fully employed and who spends an average of 20 hours per week outside her employment on caregiving activities (National Caregiving Alliance, 2012). Furthermore, caregiving is complicated when caregivers have their own careers, family responsibilities, and goals. For this reason I wanted to explore the narratives of caregivers who experienced the impact of caregiving that was in addition to their other time demands.
- Primary caregivers shared a household with the cancer patient so that the two were in daily contact with each other. The rationale for this inclusion criterion is that Transitions Theory includes engagement as part of the nature of transitions, and engagement requires contact and shared events.
- Participants were self-identified as caregivers who provided significant assistance and support to cancer patients who:
  - had completed at least one round of active treatment (chemotherapy, radiation therapy, surgery, or other invasive therapy such as stem cell transplantation),

- were between one and 10 years post-diagnosis (enough time to develop the whole narrative but not long enough to impair recall of details of the diagnostic phase of the narrative), and
- may or may not be cancer-free at the time of interviews.
- Participants were conversant in English.

Originally, I had planned to limit the time since diagnosis to six years because several studies in my literature review had limited the time since diagnosis to six years. My other rationale for limiting the time since diagnosis to six years was to avoid problems with caregiver participants being able to recall details of the experience. However, I found that the first rationale – that of emulating other literature – was not evidence-based, and I also found that participants were able to recall vividly their whole caregiving experience “as if it was yesterday” (Shirley). Therefore, I decided to expand the six year limit to ten years. Beyond ten years there may have been enough progress in terms of medical treatment advances that could have created a markedly different caregiving experience from what is experienced in more recent years. This is why I included participants who were up to ten years post diagnosis for their cancer patient for whom they were caregivers.

None of the participants had sensory impairments, so accommodations were not needed to enhance communication. The inclusion criteria were broad enough to allow diversity of the sample but structured enough to allow me to address the purpose of the research and to address the research questions.

## **Sample Size**

Narrative qualitative research normally requires a small number of participants whose interviews yield large amounts of rich, detailed data. My goal for the study was to interview at least ten participants, and eleven participants were included in the final study sample. Data saturation was achieved at around nine participants, but two other participants had been already scheduled for interviews at that point, so they were included in the sample as well as the first nine. There were no participants who dropped out of the study. All participants were successfully interviewed twice.

A sample size of eleven participants is consistent with the narrative tradition of qualitative study. Small sample sizes are expected when data are rich and deep and when the research scope is narrow (Morse, 2000). In addition to the sample of eleven participants, one additional potential participant was ready to participate in the study, but she called me just prior to the arranged date of our first interview to tell me that her husband had received bad news from his yearly PET scan, that he was “full of cancer,” and that he was going to be in hospice care. She was willing to participate at a later date, but I felt that she was into a new caregiving experience and seemed to be in emotional turmoil, so I determined that it would be best if she would not participate. My rationale was that she would be influenced by the demands of the present time and would lose the trajectory perspective, which was the focus of the study. She told me that I could contact her in the future if needed for any reason related to my line of research.

## **Diversity**

The study was open to participants from all ethnic and socioeconomic groups that were present in our community, although I did not include strategies specifically

designed to recruit diverse participants. While I believed that my recruitment strategies provided me with possible diversity in terms of ethnic, socioeconomic, and cultural backgrounds in the sample, the primary goal of recruitment was to address the research questions rather than to provide diversity. The sample did include people who were somewhat diverse in terms of socioeconomic characteristics, medical insurance coverage status, ages (while still pre-retirement age), family development stage (some with grown children and others with young children in the home), occupations, educational levels, marital status, and religious backgrounds. I did not, however, obtain an ethnically diverse sample, since all of the participants were Caucasian.

### **Procedures**

Procedures for the study included Institutional Review Board approval, recruitment, data collection, data management and analysis. Ethical and scientific considerations were important to the conduct of the study, and procedures were implemented and followed in order to comply with the best accepted research practices and the highest standards of research behavior throughout the conduct of the study. Ethical considerations are more fully explained at the end of this chapter. Study procedures are described below.

### **Recruitment and Retention**

After obtaining study approval by the Institutional Review Board at the University of Wisconsin at Milwaukee, I contacted the director of the Cancer Center for Healthy Living (CCHL) for help in recruiting participants for the study. I inquired about IRB approval for the Cancer Center for Healthy Living, and she told me that they would not allow me access to client information, but as long as I followed the procedure of

having caregivers voluntarily and privately contact me (rather than having me contact caregivers) there would be no need for IRB approval at the center. In other words, the CCHL would serve as a conduit for me to publicize the study, but it would be up to potential participants to voluntarily contact me. Potential participants took the initiative to contact me through self-referrals, referrals from the CCHL or the oncology center, or through personal referrals. Most of the participants contacted me as a result of reading the notice published in the CCHL newsletter for January of 2012. (Appendix E).

I provided the CCHL with several copies of informational flyers (Appendix B), which they posted in the Center. Caregivers who indicated an interest in participating in the study were given a copy of the flyer with my contact information, including email address and telephone number, so that they could contact me for more information about the study. If they contacted me by email I arranged a time for a phone call, but sometimes participants asked for more information via email before they agreed to a phone conversation. During the initial contact phone call with each potential participant, I clarified the purposes of the research, the role of participants in the study, the requirements of the study, the compensation of gift cards for participation in the study, and the assurances of confidentiality and voluntary participation. If that was agreeable to the caregiver, we then arranged a suitable location for our initial interview at a mutually agreed upon time.

I had other potential recruitment sites available, but they were not needed. Other potential recruitment sites included physician offices, American Cancer Society newsletter for our local branch office, and community health publications. I reached my target number of participants through the methods described above, and I was able to

achieve data saturation with that number of participants and their interviews. Therefore, the Cancer Center for Healthy Living was the primary recruitment site for the study.

**The cancer center.**

The Cancer Center for Healthy Living (CCHL) is a community cancer resource center at which there are two support groups for cancer patients and their caregivers currently underway. Patients and family members who make use of the CCHL are from all walks of life and are members of most ethnic groups which are present in this region of the state. The CCHL recently became formally affiliated with the major oncology center in this area as well as a local community health education center.

This facility serves cancer survivors and their families; in 2010 they provided 11,106 units of service of all types to 2207 different clients in central Illinois. They receive referrals from all central Illinois oncology offices and centers. Their mission is to provide adjunct services and counseling to patients and caregivers throughout the cancer process as a complement to the medical oncology care. They provide counseling, nutrition information tailored to individual needs, relaxation/yoga/aromatherapy classes, support groups, and all types of healthy living activities and information. They serve the needs of cancer survivors (59%), caregivers (16%), bereaved families (2%), general public (12%), and professionals (11%). The clients of the center are mostly female, but 23% are male (personal communication with CCHL office manager – figures are for 2010). They serve primarily Caucasian individuals, but their clients also include people from African American, Hispanic, and Asian communities. Included in the Caucasian group is a significant Lebanese population in the Central Illinois area. Included in the Hispanic population are people who are migrant farm workers as well as full-time central

Illinois residents. I believe that the CCHL was a good starting place for snowball recruitment and sampling methodology. In addition, the staff at the CCHL is interested in becoming more helpful for caregivers, so they were quite interested in helping with this study.

The counselor of the CCHL was willing to recruit caregivers as potential participants in the study. She posted the notice of the study (Appendix B) in the center as well as in the affiliated major oncology center. She is employed by both entities, and she is a gatekeeper for access to both sites. I gave her recruitment flyers with my contact information on them for her to give to potential caregiver participants. She identified potential caregiver participants for me, contacted them on my behalf when they came to the center, and gave them copies of the recruitment flyer. Interested caregivers were asked to contact me by phone or by email. Most contacted who initiated contact with me did so by email.

In addition, the CCHL media director placed a notice in the CCHL monthly newsletter briefly describing my study and providing my contact information (Appendix E). The CCHL newsletter notice contained an abbreviated form of the same information as the on-site recruitment flyer (Appendix B). The notice indicated that potential study participants were to contact me if they were interested in participating. The advertisement also provided my contact information in case readers were not caregivers themselves but knew of someone who may be interested in the study. The newsletter was most effective in generating study participants, either directly or by word of mouth. I knew this because a number of participants volunteered the information that they had either seen the notice in the newsletter or had been told about it. Publication of

information about the study was aimed at cancer caregivers rather than cancer survivors. The CCHL serves patients who have a wide variety of types of cancer, so it was not difficult to obtain participants who were caregivers for patients with several types of cancer.

### **Initial Contact**

During my initial conversation with caregivers who were potential participants, I discussed the purpose of the study, verified that the caregiver met the inclusion criteria, described the nature of participation by describing the two recorded interview sessions, and made an appointment at a place of the caregiver's choosing for our initial interview. I left other demographic information to be covered in the "getting to know you" portion at the beginning of the first interview. At the time of the first interview I identified such demographics as type of cancer, types of treatment experienced, demographics of the dyad (including ethnicity and age), caregiver relationship to cancer survivor, and current treatment (if any) that was ongoing or recurring for the cancer survivor.

### **Sample Description**

Participants were recruited for variation in terms of relationship to cancer patients and also in terms of outcome of the cancer treatment experience. Table 1 provides a summary of the sample over all.

Table 1. Characteristics of the Sample

Gender (number)	Relationship to Cancer Patient (number)	Age at Time of Cancer Diagnosed (mean)	Residence Related to Cancer Patient (number)
Male (3)	Husbands (3)	34-57 (48.7) years	Live with Patient (3)
Female (8)	Wife (6), Daughter (2)	31-56 (48.6) years	Live with Patient (8)

Note that the male participants were all husbands; no other male friends or relatives participated. Ages of males ranged from 37 to 60 years, with a mean age of 51.7 years at the time of interviews. However, ages at time of their wives' diagnoses ranged from 34 to 57 with a mean age of 48.7 years.

Female participants included six wives and two daughters. The wives ranged in age from 33 to 64 years at time of interviews, with a mean age of 53.5 years. Their ages at time of cancer diagnosis in the family member ranged from 31 to 56 years, with a mean age at diagnosis of 48.6 years. Two daughters in the study were 43 and 36 years old at the time of interviews and were 41 and 31 years old at the time their parents were diagnosed with cancer.

Tables 2 and 3 provide descriptions of individual participants and the cancer patients for whom they cared. As noted in the tables, participant caregivers came from a variety of occupations and were of various pre-retirement ages. They suggested a variety of interview sites, so I conducted interviews in offices, coffee shops, libraries, homes, and hospital cafeterias. All of the interview sites worked well, but some sites such as hospital cafeterias were not as quiet as we would have liked, depending on the time of day. However, the quality of all recordings was good, and transcriptionists were able to provide accurate transcripts. Table 2 summarized some of the characteristics of participant caregivers, while Table 3 summarizes salient characteristics of the cancer survivors for whom they provided support.

Table 2. Summary of Participant Caregivers

<b>Participant Pseudonym</b>	<b>Gender</b>	<b>Age</b>	<b>Relationship to Cancer Survivor</b>	<b>Yrs. since Diagnosis</b>	<b>Occupation of Participant at Diagnosis</b>	<b>Site of Interview</b>	<b>Minor Child at Home at Diagnosis</b>
Mike	Male	37	Husband	3	electrical engineer	his office	2
Rose	Female	43	Daughter	2	respiratory therapist	hospital cafeteria	none
Robert	Male	58	Husband	3	executive of major corporation	coffee shop	0 but one in college
Phyllis	Female	64	Wife	9	homemaker	Home	2
Shirley	Female	54	Wife	6	Admin. Assistant	coffee shop	None
April	Female	33	Wife	18 mo.	homemaker	Library	1
Rachel	Female	36	Daughter	5	Outpatient Admin. Assistant	coffee shop, restaurant	2
Sharon	Female	59	Wife	2	Legal Office Worker	legal office conference room	None
Diane	Female	58	Wife	6	dancer, special education teacher	Library	None
David	Male	60	Husband	3	chiropractor	coffee shop	none
Lucy	Female	58	Wife	1.5	retired LPN	Library	None

Participant Pseudonym	Type of Cancer	Age at Diagnosis	Cancer Patient Occupation	Treatment for Most Recent Cancer	Cancer Treatment Outcome	Prognosis
Mike (wife)	Breast	28	Graphic Designer, self-employed	surgery, chemotherapy, radiation	Metastasis to bone, brain	Ultimately fatal.
Rose (father)	Lung	72	Retired railroad worker	chemotherapy, then maintenance chemotherapy	Cancer persists; ongoing intermittent chemotherapy	Cancer is ongoing and may be fatal
Robert (wife)	multiple myeloma	52	Information technology specialist	chemotherapy and stem cell transplant	Cancer persists; episodic chemotherapy	Ultimately fatal
Phyllis (husband)	Brain	56	University Professor	Surgery, chemotherapy and radiation	Cancer free; radiation necrosis of brain	Progressive neuro deterioration
Shirley (husband)	nodular lymphoma	60	Executive for corporation	Intermittent maintenance chemotherapy	Cancer recurrence	Uncertain Prognosis
April (husband)	Oligo-astrocytoma (brain)	32	Diesel Mechanic	surgery x 2, radiation	Cancer persists	Ultimately fatal
Rachel (mother)	Ovarian	52	Office worker	Surgery, chemotherapy.	Hospice care	Deceased
Sharon (husband)	base of tongue, neck	59	Factory Worker	Inoperable. Radiation and chemotherapy.	Recurrence	Deceased
Diane (husband)	colon and prostate	58	Laboratory Scientist	Surgeries, chemotherapy and radiation	Cancer Free with aftereffects of treatment	Good Prognosis
David (wife)	Breast	55	Nurse, neonatal	surgery and chemotherapy	Cancer free, lymphedema	Good Prognosis
Lucy (husband)	tonsil and neck	59	Executive for corporation	Surgeries, chemotherapy and radiation	Cancer Free with aftereffects of treatment	Good Prognosis

As shown in Table 3, sample variation was achieved in terms of types of cancer.

Participants cared for patients with breast, ovarian, brain, lymphatic, colon, prostate, lung, and head and neck cancers.

The caregiver sample consisted of eight women and three men, all of whom participated in two full interviews, with interviews lasting from one hour five minutes to one hour 55 minutes. None of the participants withdrew from the study once they began, but one husband needed to delay the second interview for three weeks because his wife had to be hospitalized for chemotherapy. I realized that I had begun to reach data saturation after 9 participants, but I continued to collect data because I had already set up the interviews and because I wanted to interview a few more different types of caregivers dealing with different cancer outcomes in an effort to confirm that what I was finding was stable and trustworthy.

Of the male study participants, all were husbands of cancer survivors and all were employed at the time cancer was diagnosed in their wives. All, however, changed their employment in some way and attributed that change to the demands of living with cancer and cancer treatment: one retired early to care for his wife; one changed jobs for more flexibility; and another changed the hours of his chiropractic practice to allow him to care for his wife at lunch time.

Of the female study participants, six were wives and two were daughters. The two daughters were fully employed and single when their parents were diagnosed with cancer (one father and one mother). One of the daughters had to quit her job partly due to the demands of cancer caregiving, and the other took an occasional extensive leave of absence to care for her father. The six wives who participated in the study also reported

changing their employment or cutting back on other activity commitments due to cancer caregiving. Four of the wives took leaves of absence and two quit their jobs to care for their husbands.

One interesting thing that happened during the study was that two of the female caregivers – a wife and a daughter – found that they themselves had cancer, diagnosed during the time between our first and second interviews. One was diagnosed with lung cancer that was subsequently removed surgically, and the other was diagnosed with breast cancer and was planning to undergo bilateral mastectomies and chemotherapy after our second interview was completed. The latter participant chose to follow aggressive treatment partly due to her young age of 36 years and mostly due to her fear of dying of cancer. Her mother had died of ovarian cancer.

As noted earlier, I conducted purposeful sampling to obtain variation in the cancer status of the cancer survivors in each dyad. As a result, there was a variety of cancer treatment outcomes represented in the sample, as follows:

- Two outcomes in which the cancer patient is now deceased
- Four outcomes in which cancer is permanent, but they were now in between cancer treatment episodes and in surveillance mode (One of these re-entered cancer treatment during the study and one shortly after the second interview.)
- Two outcomes in which the survivors are cancer free but with serious sequelae (radiation necrosis of the brain and severe lymphedema)
- One outcome in which the cancer patient continues to have permanent cancer and no treatment, just surveillance

- Two outcomes in which the patients are cancer free but have minor aftereffects of cancer and its treatment.

I decided to sample with the intention of including caregivers who were coping with a variety of outcomes because the first two participants I interviewed seemed to be dealing with very different situations post-treatment, since one was in between treatments for his wife's permanent cancer and the other was dealing with grief after losing her mother. They each had common perspectives on the caregiving experience but had experienced different trajectories, and I wanted to capture that variation.

In terms of other sample characteristics, the sample included participants in pre-retirement age groups, from young adult to middle-aged adults. Both daughters in the study were unmarried, and one had two small children. Of the wives, five had adult children who no longer lived at home, and one wife had a small child at home.

Of the husband caregivers, one husband's wife re-entered cancer treatment between our first and second interview. Another husband's wife has required chemotherapy since the second interview. The third husband's wife remains cancer free with significant sequelae in terms of lymphedema, fatigue, and cognitive impairment.

### **Data Collection**

Data were collected from participants using recorded interviews and field notes. In addition to the study data, I kept a research journal to record my reflections, observations, reactions, and other methodological musings. The primary source of data was recorded interviews with caregivers. The community within which I conducted interviews was located in a mid-sized city in the Midwest. I took steps to provide

research sites and other data collection conditions that were comfortable for participants by soliciting their preferences regarding times and locations of interviews.

### **Data Collection Sites**

Research sites needed to be comfortable for participants, both physically and emotionally. Reissman (2008, p. 26) noted, “Working ethnographically with participants in their settings over time offers the best conditions for storytelling.” I believe that ensuring participant comfort facilitated rich data, detailed stories as well as ease of communication for the study participants. For this reason interviews were never conducted at the oncology or other treatment centers.

In addition, participants were more comfortable sharing and would be better able to focus on their narratives without distraction, so a measure of privacy was a characteristic of all interview locations. Within those parameters, I asked participants to choose a location and time for data collection; I offered to meet with caregivers to conduct interviews in homes, hospital lounges, coffee shops, quiet restaurants, and the Cancer Center for Healthy Living (CCHL). All of the interviews were done either in homes, business private offices, hospital cafeterias, coffee shops, or libraries. None of the participants chose to use the CCHL for our interview locations. This makes sense, considering that the CCHL is associated with the oncology center, which is in turn associated with cancer diagnosis and treatment. I conducted some interviews in hospital cafeterias because one participant was a hospital employee and another participant was there because her husband had just had successful back surgery that was unrelated to cancer. The libraries where I conducted interviews provided us with quiet rooms for

conversation where we would not bother other patrons or be bothered during the interview.

### **Data Collection Conditions**

I needed to conduct data collection in comfort and privacy for study participants in one other respect. It was my experience in working with cancer caregivers that they tended to de-emphasize the negative aspects of caregiving in the presence of the cancer patient in order to lessen the burden on the cancer patient. Therefore, I felt it necessary to conduct the interviews privately, outside the range of hearing of other people, including the cancer patients. I made it clear that the interviews were about the experiences of the caregivers, so on no occasion was the cancer patient present during the interview or within earshot of our conversations. I provided a private and nonjudgmental atmosphere psychologically for participants in order to allow them to express their honest feelings and recollections rather than saying what they thought might be socially acceptable. Indeed, sometimes caregivers had negative things to say about healthcare professionals and sometimes even about their significant others with cancer, and I wanted them to be able to speak freely and without pressure from me.

In addition, I noted that sometimes participants had meaningful things to say at the very end of our time together, so I found it valuable to keep the recorder operating until right before I left the interview site. I was in no hurry to leave after the main interviews were completed, and sometimes participants would reopen something meaningful to them for purposes of emphasis, clarification, or further narration.

**Data Collection: Interviews**

Data collection took place at convenient and acceptable times as designated by participants, but I made every attempt to reserve adequate time for each interview so that participants would not feel rushed or pressured. Interviews lasted from one hour 5 minutes to a maximum of about two hours. At each initial interview I established the details of the caregiver's cancer narrative as he or she had cared for a significant other with cancer. Interview questions were mostly open-ended and were guided by the suggested sequence of questions contained in the interview guide (Appendix C) which had been developed prior to data collection. Interviews were recorded digitally, and each digital recording was sent to the transcriptionist within 24 hours of the interview. Digital recordings were sent via encrypted uploading electronically to a secure, password-protected site. I received the transcripts within four days of each interview, and I reviewed each initial interview prior to conducting the second interview for each participant. I conducted all the interviews myself and wore modest and unobtrusive attire in order to comply with recommended practice to facilitate participant comfort, blend in with participants, and not draw attention to myself (Riessman, 2008). The transcription service was HIPAA certified for confidentiality. In addition, participants were identified only by number and my last name when the recordings were sent to the transcriptionist. Participants were identified only by number in the field journal, audio recording, and transcript for purposes of anonymity. The transcriptionist did not have access to identifying or contact information for participants. I keep participant identities by number in a separate and securely encrypted, password-protected electronic format in

order to ensure confidentiality. I will keep the participant identities securely for 15 years, at which time I will destroy the files.

**Feedback about the interview process.**

The implications of having cancer affecting a significant other is an emotional as well as a medical situation, so it was not difficult for participants to remember the entire trajectory of their caregiving experiences. They tended to provide rich details of pivotal moments such as diagnosis, treatment, and how they experienced the outcome of cancer in a significant other.

When people ask about the study and I tell them that the topic is the impact of caregiving on caregivers of people who have been through cancer treatment, almost everyone seems to have a story to tell, and most of those stories are emotional and heartfelt. Similarly, all of the participants in the study were at times tearful and otherwise emotional during each of the interviews. All 22 interviews contained tearful moments, and many of the participants – both men and women – verbalized that they were surprised at how raw their emotions still were when speaking about these intense experiences that they had undergone. Some even said they were emotionally drained after having completed the first interview. As Lucy noted,

I was a little surprised how it kind of drained me afterwards, talking about it. I guess I really haven't sat down and talked to somebody about it in that length of time, bits and pieces. That was kind of like – I had some errands to do and I thought, "I don't really feel like doing this. I'm just going to go home."  
[Laughter] That was kind of surprising to me.

Lucy's reaction to the first interview was echoed by other participants as well.

**First interview.**

As noted earlier, during the first interview I established the caregivers' narratives of their experiences from the time they noticed something amiss to diagnosis, treatment, and post-treatment. At the first interview I did a lot of listening and expected to hear about details such as cancer types and sites, types of treatments experienced, demographics, current status of the patients' cancers and treatments, and initial information about the caregivers' perspectives regarding the impact of cancer. For example, in the first interview I asked about life during treatment and asked participants to describe a typical day during that time. I followed a generally chronological pathway unless the participant wished to digress to another time. We ended the first interviews with some reflections about where things were going in the future, the meaning of cancer and caregiving, and participants' reflections on their roles as caregivers. At the end of those interviews I asked an open ended question regarding anything else the participant would like me to know, and then we made the appointment for our next interview. I gave participants a \$15 store gift card at the conclusion of each data collection session.

**Between interviews.**

Between the two interview dates, I conducted a preliminary review of the data in order to identify potential areas in need of clarification, potential themes in need of further inquiry, and areas of inquiry that had arisen and which would be good to address. For this reason the prompt transcription proved to be both advantageous and necessary. Because I had the transcripts back well before our second interviews I was able to proof the transcripts with the audio recordings and also add such non-verbal information to the transcripts as sighs, tearfulness, and long pauses. In reviewing the initial interviews I was

able to identify areas in need of clarification and further exploration. Approximately two to four weeks elapsed between interviews, although one participant had to delay the second interview for five weeks after the first interview due to his wife's health.

Rationales for the spacing the interviews included the need to conduct the preliminary review of initial data, a way to provide courtesy towards the participants in terms of time burden, and an opportunity to allow participants sufficient time to ruminate on the narratives. Interviews were not spaced too far apart so that participants would remember the first interviews, but interviews were spaced far enough apart to allow participant reactions and thoughts to surface. At the end of first interviews I told participants that I would like them to remember any reactions and keep track of any further thoughts that may emerge from the first interview so that they could share those ideas at the beginning of the second interviews. In this way, participants were given some perspective on and expectations for the second interview format and content. This provided us with an agreeable way to start the second interviews, and it was not uncommon to find that participants had given much thought to the content of the first interviews.

I began data analysis with the first participant's first interview by reviewing, proofing, and editing the transcripts as soon as they were available as well as by entering information into my field journal, which was in the form of an evidence table. I recorded initial impressions, ideas about further exploration of narratives, and connections of narratives with transition theory concepts. In analyzing data from the interviews, I found I needed to slightly adjust future interview questions in order to enhance clarity and to fully illuminate issues related to the research questions. For example, I found that participants emphasized that they felt a sense of disconnectedness during their caregiving

experience, so I included questions in subsequent interviews related to this phenomenon. Another example was when, for those caregivers who identified information seeking as a huge issue during diagnosis, I placed increased emphasis on this topic in future interviews. After each initial interview, I adapted the interview guide for the second interview to begin with my findings from the first interview. The interview guide (Appendix C) for second interviews contains a reference to this method of beginning the second sessions.

### **Second interview.**

I allowed some intentional content overlap between first and second interviews in order to provide continuity for participants and to enhance clarity of narratives as a whole. I began the second interviews with a question allowing the participants to reflect upon the previous interview and our interactions during that first interview. For example, I would ask “How did you feel during our first conversation? Did it bring up any reactions for you or things you would like to discuss today?” I intended to listen to their reactions and responses from the first interview before I initiated my exploratory and clarifying questions from what we had discussed. That way I did not bias the participants and allowed them the freedom they needed to express their reactions and responses without feeling that there was a predetermined format or listing of topics. In other words, I wanted to find out what was important to them before I asked clarification for myself. In this way, I often found that participants addressed the very same topics that I had planned to address, but they did it in their own way and in their own time with their own emphasis and narrative context. In this way they were able to enrich the data, explain

their perspectives, and identify areas of importance to them. This initial portion of the second interviews often lasted for 20 to 30 minutes.

As the second interviews progressed, I asked participants to think about what we had discussed so far and asked open-ended questions about impact, meaning of caregiving, and outcomes. For example, I often asked, “What does cancer mean to you? In your family? In the community?” or “How did cancer caregiving affect you personally?” or “How do you look to the future?” The interviews ended with open-ended opportunities for participants to add anything they would like to add. I was prepared to offer referrals for counseling when appropriate, so I did make one referral to a young wife whose husband has permanent cancer and who was distressed about how to put her life “back on track.” Before terminating the second interview sessions, I reminded participants about how to contact me if needed and assured them once again of confidentiality. Finally, I gave each participant another small stipend in the form of a gift card. Several of the participants asked for a summary of the results of the study when they become available, and all participants were willing to be contacted again for further study in years to come. Those who wish to have a summary of results have provided me with a way to send the summary to them.

#### **Data Collection: Field Notes**

I used a field journal to record details about the interview settings, the participants, and other observations that I believed to be valuable for a complete understanding of the data.

Field notes included:

- Site of interview

- Age of caregiver
- Occupation of caregiver
- Gender
- Relationship to cancer patient
- Type(s) of cancer
- Methods of cancer treatment
- Length of time since diagnosis
- General health status of the caregiver, including significant co-morbidities
- Significant details about the psychological affect, attitudes, or dress of the caregiver
- Any other pertinent observations that I thought may enhance data analysis.

Data collection is intimately connected with credibility of results, both in method as well as quantity of data collected. Data in qualitative studies are analyzed as they are collected so that interview questions may reflect what is emerging from the data and so that interviews may clarify, illumine, and explain what is emerging from early data.

### **Data Management**

Following interview data collection and initial review, the interviews were transcribed and entered into NVivo9 software for coding and data management. In preparation for data management, I participated in learning programs sponsored by the software developer, QSR International, to enhance my competence and accuracy in the utilization of the software for data management. Whole transcripts remain preserved electronically in the NVivo9 software, and the preserved transcripts have been highlighted and coded into themes within the software. Using the software I was able to

identify stories that related to parts of the Transitions Theory model as well as to the research questions.

In addition to using NVivo9 for transcript management and coding, I used the software to record field notes, which were connected electronically with each transcript, thereby keeping the data for each participant together. I also have my field journal in the form of a spreadsheet stored electronically within NVivo9. A research journal provides an audit trail for transparency of my methodological decisions as well as a record of my reactions and impressions as they occurred during the study. Prior to entering transcripts into the software, I proof-read each transcript for accuracy by reading along with the transcript as the audio recording was played. At that time I was able to add nonverbal data at appropriate points in the transcript. Nonverbal sounds included data such as sighs, repetitions, pauses, drastic changes in voice volume (such as shouting or suddenly whispering), and tearfulness. These notations added to the richness of data and were helpful to me in understanding the narratives and the meanings that participants attached to their experiences. I added the nonverbal information because transcription is taken very seriously by qualitative researchers due to the limitations of language in conveying meaning. As Riessman noted, "Thoughtful investigators no longer assume the transparency of language" (Riessman, 2002, p. 225). Mishler noted that transcription is like photography, which purports to represent reality but which in actuality is affected by lenses, technique, lighting, and other procedural factors (Mishler, 1991). As much detail as possible, then, was added to the interview records.

## Data Analysis

Initial identification of narratives – stories – helps to keep stories intact, and this is a hallmark of the narrative method of study. The focus of narrative analysis is to explore life stories of individuals and was therefore appropriate for the study of transitions and impact of cancer caregiving over time. Data were also analyzed according to principles of thematic narrative analysis, which is an iterative process of coding, categorizing, and theme-recognizing as the analyst goes back and forth from data to analysis and around again (Riessman, 2008). Stories are operationalized as events described by participants, and each event had a beginning, a middle, and an end. There were often several stories within each overall narrative, which is operationalized as the overall trajectory of cancer caregiving from diagnosis through treatment and beyond.

Data analysis is summarized in the Table 4 and described more explicitly in the text following the table. Table 4 identifies the steps of data analysis in relation to collecting data, specifically at the first and second interviews. In this way the reader can identify how the analysis was related temporally to data collection activities.

Table 4. Steps of Analysis in Relation to Data Collection

Data Collection: Interview #1 conducted	
1	Close reading of interview #1 transcript, highlighting and marking areas for clarification and focus
Data Collection: Interview #2 conducted	
2	Proofreading of both interview transcripts while listening to audio recordings, adding nonverbal comments
3	Multiple readings and memoing of entire dataset (Data collection completed)
4	Structural Analysis using matrices
5	Restorying into Individual Narrative Summaries
6	Use of NVivo9 software to manage data while coding
7	Comparison of codes within and across participants, using grids
8	Identification of larger themes and selection of excerpts

**Step 1: Close Reading of Interview #1**

I wanted to familiarize myself with each of the transcripts of first interviews prior to conducting the second interviews for each participant because part of the preparation for second interviews was to identify areas for further probing and clarification. To do this I read through the initial interview transcripts, highlighting and marking areas for clarification and focus. At this time also I added some of the nonverbal information that I remembered from the first interview, but I did not listen to the audio recording while reading along until after the second interview was completed.

The purpose of this reading of the transcript was to enhance the interview guide for the second interview. Each of the second interviews began with an open-ended question about participants' reactions to their first interviews, followed by clarification and probing questions based on the first interviews, so I needed to review each initial interview transcript.

**Step 2: Proofreading of Both Interviews**

Upon the completion of the second interview for each participant, I listened to both audio recordings and followed along on the printed transcript, adding notes and nonverbal information from the field notes and from the audio recording. I found it valuable to do a thorough proofreading of both interviews along with the audio because it provided me with an overall sense of what each participant had experienced along the trajectory of caregiving and beyond.

In addition, I was able to add nonverbal elements to the transcripts and correct the very few errors that I found in the transcripts while listening to the audio recordings. Nonverbal elements included sighs, tearfulness, long silences, dramatic changes in

volume, sound effects, and visual elements that I had recorded in the field journal that corresponded with particular topics of discussions. I found that errors in transcription were limited to minor spelling of proper nouns (primarily names of places and physicians that would be unknown to the transcriptionists) as well as commonly used figures of speech that were misinterpreted by the transcriptionists.

By proofreading both transcripts from each participant I was able to create an accurate record of what had been communicated, but the immersion in each participant's transcripts and audio recordings enabled me to become familiar with the details of their narratives as well as the general tone of our interviews. I found that all of the participants were consistent in how they told their stories from one interview to the next. For example, Mike was particularly terse at times, even when tearful, as if he found it difficult to elaborate on the details of his story, and this habit continued in our second interview as it had been in the first. Therefore, when Mike spoke at length about a topic, I tended to recognize that topic as significant to him, and I made a note of that in my field journal. By staying close to the data and by working from the data to conclusions I was able to follow an inductive methodology.

Another example of a pattern in the interviews that was characteristic of one participant was April's use of certain words to emphasize parts of her story. She used the word "huge" when describing something that was intensely meaningful to her, such as when neighbors dropped by with food or gasoline gift cards for her family. She would describe something like that and then say, "That was huge" or "I mean, it was huge." I made note of those times when she emphasized certain events.

Overall, the proofreading step provided a better overview of each participant's interview than I had gained from my review of first interviews, but perhaps this was because the purpose had changed. In the first step, when I reviewed the first interview transcript I was doing so in order to identify areas to pursue and clarify in the second interviews. In contrast, the proofreading of both transcripts for each individual allowed me to gain a closer relationship to the data because I was no longer looking forward to the second interviews. Rather, I was focused on immersing myself in the data that were there and bringing together the interview transcript and the field notes and the audio components into a rich, thick documentation of the whole from each participant.

### **Step 3: Multiple Readings and Memoing of Entire Dataset**

Following a comprehensive review of each participant's two interviews, the next step was to read through all of the transcripts once again without the audio for an overview of the data and to familiarize myself with the feel of what was there. The emphasis at this step was to gain a better understanding of the dataset as a whole, so I read and re-read every interview multiple times while memoing. I avoided coming to conclusions, however, at this early stage of analysis. As Riessman (2002) noted, responses to interview questions may include lengthy narratives, and for me to jump into dissection and analysis of these stories would be to lose the whole of them.

Repeated readings of whole interviews allowed stories to emerge from the data and enabled me to become quite familiar with the data. I was also able to make notes about what each participant emphasized, getting a feel for what was important to each of them and what they had in common. For example, the participants did not mention uncertainty as a stressor or as an outcome, although I had expected them to do so. On the

other hand, what came through clearly from multiple readings of the data was a sense of feeling disconnected and isolated from the world around them and from their own needs as well. Without reading through the dataset multiple times it is doubtful whether I would have identified these concepts or derived these impressions. During the initial reading of all of the transcripts, I made notes and formed an impression of initial coding to address the research questions. This step is called reading and memoing (Creswell, 2007) and was included in the initial reading of the whole body of data as well as in subsequent analysis.

Riessman noted that “Respondents narrativize particular experiences in their lives, often where there has been a breach between the ideal and real, self and society” (Riessman, 2002, p. 219). There were indeed many breaches of the type described by Riessman, since the cancer experience is far from ideal, and the sense of disconnectedness was how I described the breach between self and society. Given that cancer was a serious disruption in the expectations of living for the participants, I found that there were sometimes multiple smaller narratives within each participant’s overall narrative of the disruption of cancer and how that played out in the lives of participants. For example, there would be the overall trajectory of symptoms, diagnosis, treatment, and after treatment. At the same time, each participant seemed to have rehearsed a narrative about how they were told the diagnosis and how that event was received by them and the cancer patient for whom they cared.

#### **Step 4: Structural Analysis Using Matrices**

It was in reviewing and studying the whole body of data that I came to recognize the poignancy, intensity, and depth of the data at hand. My personal reaction was awe

that caregivers were willing to share so much with me about their experiences, the personal meaning of those experiences, and their reactions to what had happened. I became determined to honor that trust and sharing with a faithful analysis of their stories.

Therefore, in the fourth step, I conducted a structural analysis in order to identify elements of each participant's overall narrative chronologically. I found it helpful to use an expanded version of the research journal spreadsheet in which I had recorded common elements of all the narratives so that I would not omit important parts. I had developed the original spreadsheet to identify and systematically assemble common demographic characteristics of participants, important story elements, and elements of the narratives that would pertain to transitions. The spreadsheet allowed me to organize data so that I could adequately describe the sample, differentiating participants from each other, and provided background for each participant's narrative.

Labov and Waletzky (1967) identified the overall structure of narratives as being composed of four main parts: orientation, complications (time-ordered), evaluation, and resolution. The orientation of a narrative sets the stage and provides background for what is to come. Complications are where we often think of stories as beginning, where things begin to become abnormal and some events or conditions interrupt life as previously planned. Resolution may be seen as results and how things turn out in the end. The three parts of orientation, complications, and results describe what happens and how things turn out, but for the people involved there is a crucial step after time-ordered complications and before the resolution of the narrative in which the participant comes to attach meaning to what has happened and to evaluate what is happening as important. As Labov and Waletzky noted:

A simple sequence of complication and result does not indicate to the listener the relative importance of these events or help him distinguish complication from resolution. We also find that in narratives without a point it is difficult to distinguish the complicating action from the result. Therefore it is necessary for the narrator to delineate the structure of the narrative by emphasizing the point where the complication has reached a maximum: the break between the complication and the result. Most narratives contain an evaluation section which carries out this function (Labov & Waletzky, 1967, pp. 34-35).

The expanded version of the journal spreadsheet became a matrix that I used for structural analysis. I analyzed each participant's transcripts according to the four elements of narratives described above: orientation, time-ordered complications, evaluation, and resolution. The matrices were a series of large poster boards with the four elements (or categories of data) at the top in heavy marker. The poster board categories became a large canvas of sorts for me to write down significant quotes and detailed elements of each narrative into the proper narrative element categories. The poster boards became organizational and analytical helps for me to identify each participant's perspective; the structural analysis poster board method allowed the participant's thoughts and feelings to come through, since I limited the data on the poster boards to information that I found in the data rather than my own interpretations. The poster boards, therefore, became the format for restorying matrices that enabled me to employ structural analysis of each participant's story.

Participants did not perform their narratives in chronological order, but restorying the narratives in a parallel fashion allowed me to see commonalities as well as distinct differences in the narrative data. The narratives were assembled in chronological order with similar content areas coming in similar order so that the within-case structural analysis would be parallel and systematic for all of the narratives. As noted earlier, the content areas were consistent with phases or elements of narratives (Creswell, 2007;

Riessman, 2002; Labov & Waletzky, 1967). Each narrative was arranged into four elements: orientation, time-ordered complications, evaluation of the complications as the participants saw them, and resolutions (Labov & Waletzky, 1967; Stevens, 1998). For example, all of the re-storied narratives begin with the orientation phase, including life before the diagnosis of cancer and a description of the history of each dyad in order to set the stage for the life disruption of symptoms leading up to a cancer diagnosis. This step of within-case data analysis became quite detailed, since it was obvious that the data were rich with thick descriptions, numerous details, and poignant stories. Since narratives are a way in which people commonly express and describe their significant events of living, one advantage of restorying analysis was that I could analyze the data while staying true to the format in which the data were obtained, including context (Reissman, 2002).

There were several advantages to using the large structural analysis boards for restorying the narratives. For example, since participants rarely presented their narratives in chronological order, the handwritten matrix-on-poster-board format allowed me to organize elements of the narratives chronologically. A second advantage to using this method was that it allowed me to combine information about the same topic from two interviews into one coherent whole for each participant, since participants often returned to important events repeatedly if they had more to share. Since we spent the initial minutes of all of the second interviews revisiting the first interviews, the matrices allowed me to gather related information in one spot. For example, narrative details related to diagnosis were organized in chronological order to facilitate a restorying of that experience; the notes I made on the poster board enabled my description of each

participant's diagnosis experience to be richer and more detailed because I had collected all of the details and stories into that section of the matrix.

This portion of data analysis was done by hand so that I could spread out the details of stories in matrix format on large sheets of poster paper. While NVivo9 can also be used to do some of this, it was helpful to see the data as a physical whole as it was spread out and visible rather than viewing portions of the whole on a computer screen. I believe the manual method of analysis allowed me to stay closer to the transcripts and the organized data, plus it allowed me to gain a better sense of the whole for each participant's narrative. Finally, the matrix format also facilitated comparisons, checking of story details, and other manual tasks. I referred constantly to the printed versions of transcripts while I conducted this analysis, and sometimes I played the audio of the interviews while I read the transcript sections so that I could enrich the details.

The use of the matrices in breaking down the data and organizing each participant's information into the elements of narratives facilitated the next step, which was to reassemble the narratives – to restory them – into more understandable wholes with parallel structures.

### **Step 5: Restorying into Individual Narrative Summaries**

Once the matrices were completed for each participant, the data were combined into an integrated whole to summarize the narrative of each participant in terms of orientation, time-ordered (chronological) disruptions, evaluation of those disruptions, and resolutions. These narrative summaries are presented in parallel fashion in Chapter 4 and represent what authors describe as “restorying” in order to set forth the chronology of each participant's narrative (Creswell, 2007, p.56). Creswell defines “restorying” as “the

process of reorganizing the stories into some general type of framework” (2007, p. 56). In this case, the framework was chronology, since a chronological organization of the narratives enabled the emergence of the sense of trajectory of the cancer caregiving experience.

Paying attention to the common elements of narratives was helpful in making sense of the data in order to re-story the events into a coherent whole. Furthermore, the resulting re-storied narratives consisted of many detailed excerpts that I used to illustrate and to give meaning to each participant’s detailed narrative as they described their caregiving trajectories. The narratives of the participants illustrated the complexity of their cancer caregiving experiences. At this point in data analysis, however, I was careful to stay close to the raw data and to avoid coming to premature conclusions. The narrative summaries, then, are simply that: summaries of the data organized into parallel structures. No interpretation or conclusions were presented within the narrative summaries; this allowed the summaries to be close representations of the data. In a sense, the participants were the authors of the narrative summaries and I just organized them chronologically and according to elements of narratives.

The fourth and fifth steps of data analysis were therefore integrally related in that the matrices formed an organizing framework for analyzing the data and the restorying process produced narrative summaries that were rich with detail and organized into the framework of narratives. The narrative summaries give a sense of what was in the data, a sense of the whole, and they set the tone for each participant’s contribution to the study.

### **Step 6: Using NVivo9 Software to Manage Data While Coding**

In the sixth step I used NVivo9 software to manage the data as I identified codes in the transcripts. Within each person's narrative were many details about diagnosis, chemotherapy, dealing with the healthcare system, dealing with family and friends, and facing the future. I coded the transcripts in NVivo9, keeping stories intact as much as possible in order to ensure that the coded material would be preserved in context. Story is operationalized as a distinct event described by participants. Stories contain "recognizable beginnings, middles, and ends. They include the events that occurred and the interpretations placed on them by the teller" (Stevens, 1998, p.82). The inductive process of coding from data helped to ensure that emerging themes were informed by raw data and were credible.

Coding was an iterative process of comparing codes with excerpts and going back again to codes. Initial coding was broad and often related to elements of transitions theory or narrative structure. Examples of broad codes were "disconnectedness" and things related to the process of "diagnosis" of cancer. Subsequently, I looked at the data using the NVivo9 coding search function to see what excerpts were coded according to each code, and I was able to return to the coding process to subdivide the more general codes into more detailed codes, depending on the data. Following the example of "disconnectedness" and "diagnosis" as broad codes, the more detailed codes that emerged from these two broader codes included "feelings of invisibility" and "feelings of isolation" within the broad code of "disconnectedness." Similarly, the detailed codes of "information overload" and "being left adrift" emerged from the data within the broader code of "diagnosis." In other words, I began with larger codes and allowed the detailed

codes that emerged to provide rich detail, emphasis, and facets of the complete picture within the larger codes.

I kept returning to the data and coding in a back and forth, iterative process as I went along until it was apparent that all parts of the data were coded and that all excerpts for each code were identified. NVivo9 software was helpful for organizing and managing coded excerpts, since with the code searching function of the software I was able to print out excerpts that had been coded for each code. There were approximately six hundred pages of data, but there were more pages of codes and excerpts, since many of the excerpts were coded for more than one code. I used this phenomenon when I clustered the coded excerpts together, since the same passage in the data being coded in multiple codes tended to be evidence that the codes were similar or related in some way. The full listing of all codes is provided in Appendix F.

### **Step 7: Comparing Codes Within and Across Participants**

The seventh step I used to analyze the data was to compare the codes within participants and across participants. I examined the codes within each transcript as well as excerpts from all participants for each code. During this process, I interrogated the data from the perspective of Transitions Theory. I examined the data for information about typical types of transitions, conditions of transitions (personal, social, and community), as well as patterns of response as noted in the model of the theory (Figure 1). Transitions theory provided me with an organizing framework as well as a theoretical perspective on what the data revealed. Eventually I had fifty-six individual codes (Appendix F). Analysis of those codes revealed that there was some overlap, some duplication (using similar labels), and definite clustering. I examined the codes for common elements

within the data and found that there were some codes that were important to all of the participants, while there were other codes mentioned by only a few participants. In order to identify common codes, I created a large grid on a large sheet of paper that included each participant across the top and each of the 56 codes along the vertical axis. Then I filled in the grid, placing a check mark under the participants' names for each code that I had found within their data. In this manner I could determine which participants were represented in which codes. This grid became a basis for identifying larger themes that were mentioned by all of the caregiver participants in the study.

I transferred the grid to an electronic spreadsheet format so that I could sort codes according to different characteristics of the participants. For example, I could color code the spreadsheets according to different criteria, so I could see which codes were mentioned by men and which by women, or I could see which codes were mentioned by people whose cancer patient was deceased and which were mentioned by people who were still giving intermittent care for their cancer survivors. I was surprised to find, for example, that grief and loss was mentioned by all of the caregivers, not just the ones who had lost their cancer patient significant others. I was also surprised to find that uncertainty was not emphasized by any of the participants and was only mentioned by a few of them.

This electronic spreadsheet grid was also valuable for analysis of within-case as well as across-case codes. I could identify when they mentioned each code and what part of the cancer caregiving trajectory was represented by which of the codes for each participant by looking at the excerpts. The two-fold analysis of data included, first, the within-case analysis: restorying of the narrative summaries chronologically in order to

arrive at the trajectory for each participant. The second analytical strategy was across-case analysis of the data, comparing sections of the trajectories of the participants as a group and determining which themes were emphasized by participants at each of the elements of the trajectory of cancer caregiving. The elements of the cancer caregiving trajectory include pre-diagnosis orientation, diagnostic process, active cancer treatment, and life after initial treatment. Thus, it was imperative for me to arrange the narrative summaries chronologically for each participant caregiver so that I could compare the cancer caregivers to one another at the same element or stage in the trajectory.

The electronic spreadsheet grid allowed me to identify which codes were mentioned by all of the participants; there were 17 codes mentioned by all participants. These codes are identified in Appendix F by an asterisk next to the codes. I gave serious attention to the codes mentioned by all of the participants. For example, “disconnectedness,” “feelings of being a non-person,” and “denial of self” were all codes that were prominently represented in the transcripts of all of the participants. Moreover, these themes of disconnectedness, non-personhood, and self-denial were not mentioned until active cancer treatments were underway. Up until that time, the caregivers were in urgency mode, and they did not reflect on how they felt about themselves. However, when active treatment was underway, the caregivers became increasingly aware of their sense of disconnection with the world about them. Those who tried to access support services found themselves feeling unwelcome, disenfranchised, and even a bit guilty about wanting some attention for their own needs. Chapter 5 will present more detail about these patterns of themes among the participants.

I clustered similar codes using the code/participant grid and printed out the excerpts for each of those code clusters using the coding query function in NVivo9. In order to cluster the codes, I first examined the codes to see which of them seemed to be conceptually similar. I checked my impressions for accuracy by looking at printouts of the data excerpts that were coded for similar codes, and I accepted that the codes were similar if many of the same excerpts appeared in the printouts of the codes. In this way I was able to cluster the codes, identifying which of the codes were more general and which were facets of the general codes (more specific) to create an organized framework of coding. For example, some of the caregivers were quite distressed at the reaction to diagnosis exhibited by the cancer patients. Upon receiving the diagnosis of cancer, some of the cancer patients immediately responded with the request that the caregiver not talk about the diagnosis with other people. Caregivers who reported this problem were all quite distressed at having to keep the whole thing quiet because that cut the caregivers off from social support from other people who were not the cancer patient. In fact, some of the cancer patients persisted in not allowing the caregivers to speak about the cancer for months and sometimes years, and caregivers found this to be a very stressful, isolating, and unhappy experience. The excerpts for this code of “hiding the cancer” were also, therefore, sometimes assigned the codes of denial of self, disconnectedness, burden, or helplessness/loss of control. In this manner I was able to identify code clusters that were associated with this phenomenon of having to keep quiet about the cancer because the cancer survivors did not want to have to cope with people knowing about the diagnosis. Describing various aspects of the “hiding cancer” experience from different viewpoints

of various codes provided a more precise and scientifically rigorous explication of the experience from the perspective of caregivers.

**Step 8: Identification of Themes, Applied to the Cancer Trajectory, and Excerpts**

Finally, I identified themes, addressed my research questions, and looked for clarification through the lens of Transitions Theory. The research questions were:

1. What are the circumstances (contexts and conditions) with which caregivers contend over the full trajectory of their significant other's cancer, from the time they noticed something was amiss to diagnosis and then through active cancer treatment and post-treatment?
2. How do caregivers describe the impact of cancer on their own lives over the course of their caregiving experiences?
3. How do the narratives of caregivers illustrate and give meaning to transitions that the caregivers have undergone?

Concepts and terms from the research questions were presented as part of the explanation of Transition Theory in Chapter 2 and are further explicated here.

The entire cancer caregiving trajectory was defined in the first research question as “from the time they noticed something was amiss to diagnosis and then through active cancer treatment and post-treatment.” However, I operationalized these concepts in order to conduct the across-case analysis of data. Specifically, the cancer trajectory components are associated with the four elements of narratives, as shown in Table 5:

Table 5. Narrative Elements and Components of the Cancer Trajectory

<u>Narrative Element and Phase of Cancer Caregiving Trajectory</u>	<u>Operational Definition</u>
Orientation: Life before Cancer	This was the initial context for cancer caregiving prior to the recognition of cancer symptoms.
Time-Ordered Complications: Emergence of Symptoms through Diagnosis	This was the diagnostic process, from recognizing that all is not well to seeking medical help, through diagnostic testing and including the delivery of the diagnosis and presentation of treatment options.
Making Meaning of Complications: Life during Initial Active Cancer Treatment	This included surgery, chemotherapy, radiation therapy, stem cell transplants, or any combination of these therapies. Initial Active Cancer Treatment ended when the cancer patient had completed a final course of treatment and was placed into a surveillance program or was no longer receiving the active treatments for a period of time.
Resolution: Aftermath of Initial Course of Treatment	This phase began when active treatment ended and continued until the time of interviews. It included a variety of outcomes of cancer treatment, from patients being free of cancer to being deceased.

Within the above components of the cancer trajectory, I categorized the codes that I found related to each component and made notes through memoing to describe how intensely present each code was expressed at that time of the cancer trajectory. For example, feelings of disconnectedness were present once they were drawn into the diagnostic process, but those feelings were not felt acutely by most caregivers until well into active cancer treatment. At first, caregivers were almost overwhelmed with new connectedness – with the healthcare system, with large numbers of people who reached out to them, and with other cancer patients. On the other hand, they felt mildly disconnected from their normal lives, but the disconnectedness was not noticeable

because of the emergent nature of the cancer diagnostic process. However, once active treatment began and cancer patients became increasingly subject to side effects of treatment, caregivers began to feel acutely disconnected from normal life. At this point, the many people who had been helpful at the beginning began to drop away. Also at this point, the caregivers began to feel a need for increased social support, but since the cancer patients were not feeling up to attending the support group sessions the caregivers were reluctant to go alone. This is an example of a code (disconnectedness) that was not evenly present throughout the trajectory of cancer caregiving, as recalled by participant caregivers.

#### **Association of codes with concepts of Transitions Theory.**

Transitions Theory was the conceptual framework for this study. In order to identify data related to components of Transitions Theory, I operationalized the concepts in accordance with Meleis' (2000) exposition of the theoretical framework. In this way, there is both a deductive as well as an inductive approach to the study. Inductive reasoning was used in developing conclusions from the specific data; deductive reasoning was used to help interpret the findings. The first research question is "What are the circumstances (contexts and conditions) with which caregivers contend over the full trajectory of their significant other's cancer, from the time they noticed something was amiss to diagnosis and then through active cancer treatment and post-treatment?" Circumstances, then, would include conditions of transitions that are both related to the caregiving role and outside the caregiving role. According to Transitions Theory (Figure 1), conditions of transitions include contexts in that conditions are all of the facilitators and inhibitors – personal, societal, and community – that affect one's ability to

successfully transition. Therefore, contexts and conditions are related in that conditions include contexts.

Impact, moreover, relates to the Transitions theory as patterns of response (Figure 1). All of these concepts of Transitions Theory are conceptually defined in Chapter 2, but the concepts of “contexts,” “conditions,” and “impact” are specifically operationalized here in Table 6:

Table 6. Conceptual and Operational Definitions of Contexts, Conditions, and Impacts

Term	Conceptual Definition	Operational Definition
Contexts	The nature of life other than cancer caregiving, within which the cancer caregiving trajectory occurs	Setting, family composition, employment, community and societal characteristics not associated with caregiving. Note that community and societal contexts are included in “Transition Conditions: Facilitators and Inhibitors: in Transitions Theory (Figure 1).
Conditions	Facilitators and Inhibitors affecting the cancer caregiving experience, as identified in the Transitions Theory model (Figure 1)	Personal: meanings, cultural belief and attitudes, socioeconomic status, expressions of preparation and knowledge about cancer caregiving as adequate or inadequate. Society: Social supports from friends, family, and other individuals as expressed by caregiver participants Community: Help or hindrance from healthcare professionals, structural supports (such as organizations) in place.
Impacts	How caregivers are affected by the experience of cancer caregiving and the transition process over time, looking back on the entire trajectory	Patterns of Response (Meleis, et al., 2000): Progress indicators of feeling connected, interacting with others, location and being situated within acceptable relationships, and expressing confidence and coping success. Outcome Indicators of expressing feelings of mastery and perceptions of self as a caregiver in terms of

		successful identity. Expressions of the above by caregivers throughout trajectory
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The codes found in the data were related to contexts, conditions, and impact of transitions (the main concepts mentioned in the research questions) in the lives of participant caregivers. Transitions theory elements were present all along the trajectory, with some at certain points more than at others. For example, none of the participant caregivers expressed feelings of mastery of the caregiving role at the time of diagnosis, even those caregivers with medical backgrounds. However, several of them expressed a sense of accomplishment that they realized after active treatment had ended. Their feelings of mastery developed over time as they experienced the trajectory of active cancer treatment and the aftermath of treatment; their perspective of looking back at the trajectory was valuable in distinguishing their transitions over time along the course of their narratives.

#### **Conceptual common ground: Themes.**

In order to develop themes from coded material, I examined my grid that I developed in Step 7. I looked at code clusters and identified conceptual common ground for the clusters. Then I examined the excerpts for similarities. For example, the codes of “burden,” “changes in caregiver employment,” and “role problems for caregivers” tended to include the same excerpts around similar times in the narratives for these caregiver participants, so I developed the code clusters into themes and renamed them to include the aspects of the codes included in each theme. The theme of Burden included the codes mentioned above. In some cases, such as with the theme of Burden, the names of the themes were amalgams of the codes that gave rise to the themes. For other themes

– such as the theme of Moving Forward with Scars – I had to summarize the meaning of the codes that were associated with the theme. I checked the themes with two of the participants (Mike and April) to see if they agreed that my theme labels accurately represented what they had tried to convey to me. This member-checking activity enhanced scientific rigor of the study.

In order to capture the full essence of each participant's excerpts in each code, I coded the data by lengthy excerpts. Since these excerpts were often rambling and multifaceted, I found it necessary when presenting illustrative excerpts to use ellipses (...) when appropriate in order to present only the relevant portions of each story to illustrate and substantiate the codes. The raw coding contained full length excerpts without omissions, but I used ellipses when presenting the results in order to omit irrelevant details and to provide focus so that readers would not become lost in lengthy quotes.

Data analysis commenced with the first interview, since emerging themes and codes reinforced and sometimes slightly redirected the direction of my interview questions in subsequent interviews. In this way, narrative analysis is typical of qualitative research in terms of an emerging design (Riessman, 2008).

### **Ensuring Scientific Adequacy**

As Creswell (2007) stated, "Qualitative researchers strive for 'understanding,' that deep structure of knowledge that comes from visiting personally with participants, spending extensive time in the field, and probing to obtain detailed meanings. During or after a study, qualitative researchers ask, 'Did we get it right?'" (Creswell, 2007, p. 201). This is an important question to ask, since one does not conduct qualitative research for

personal voyeurism or to please one's self. Qualitative research is not conducted with generalizability or testing of hypotheses in mind, as is the case with quantitative research in the logical positivist paradigm. Rather, instead of generalizability the qualitative researcher seeks *credibility, transferability, dependability, trustworthiness, and transparency*. To this end, the qualitative researcher must keep meticulous records in a journal of methodological decisions, personal reactions and insights that may affect data interpretation, and data from more than one source (such as verbal and nonverbal) to verify the story if possible. This is termed "thick description" (Chase, 2005). Creswell (2007) looks for the following aspects of an acceptable narrative study:

- Collects stories about a significant issue related to an individual's life
- Develops a chronology that connects different phases or aspects of a story
- Tells a story that re-stories the story of the participant in the study
- Tells a persuasive story told in a literary way
- Possibly reports themes that build from the story to tell a broader analysis
- Reflexively brings himself or herself into the study (pp. 214-215)

### **Ensuring Scientific Adequacy: The Research Journal**

The research journal was kept for purposes of scientific rigor in terms of transparency and dependability. I kept a journal of my personal reflections as the study progressed in order to enhance reflexivity and to identify why and how decisions were made along the way. I understand that researchers tend to study things in which they are interested, and sometimes this interest comes from personal experience. Through my personal experience observing family caregiving for a relative who died of cancer, I became interested in the toll that cancer takes on family members, especially caregivers. It was entirely appropriate and supportive of trustworthiness of the study that I kept a research journal that documented my methodological and analytical decisions as well as my personal reactions to the data. I found that data collection was surprisingly draining

for me, emotionally, so I needed to limit myself to no more than two interviews per day and no more than four per week. Even with this schedule, I found it necessary to have several hours of time elapse between interviews so that I could refresh myself and prepare for the next interview.

My research journal documented my methodological decisions and rationales as well as providing evidence of my reflexivity as I conducted the interviews and data analysis. The journal is one method that I used to demonstrate transparency, but an additional method was to outline the steps of my data analysis in detail so that my analytical steps were open to scrutiny.

### **Ensuring Scientific Adequacy: Multiple Sources of Data; Multiple Analyses**

Trustworthiness was addressed through the use of multiple sources of data collected as well as multiple methods of data analysis and arriving at conclusions through multiple lenses and illustrations. Meticulous attention to details, noting nuances of nonverbal data, creating field notes to enhance the verbal transcript data, and repeated review of the interview transcripts enhanced trustworthiness by collecting data by as many modes as possible to enrich the data. In addition, using two basic approaches to data analysis – within-case narrative analysis and across-case thematic analysis – provided insights into the participants' experiences of cancer caregiving across the trajectory from two complementary viewpoints. These methods of analysis added to trustworthiness of the findings.

### **Ensuring Scientific Adequacy: Credibility in Data Collection**

Data were collected and managed in such a way as to ensure credibility. Interviews were entirely voluntary, comfortable as much as possible, and gently probing.

The assurance of privacy of surroundings as well as confidentiality of data collection and anonymity of data management and analysis enhanced participants' willingness to respond completely and honestly to open-ended interview questions. I was quite surprised and humbled by participants' willingness to be quite open with me and to talk to me about what had to have been a stressful experience in their lives. Moreover, several of the participants actually thanked me for doing the study, expressed surprise at how emotional it had been for them, and asked me for a summary of the findings when they become available. With their permission, I discussed my preliminary findings with two of the participants to ascertain that I was understanding their narratives correctly and that I was seeing the details as they presented them. This enhanced the credibility of the study results.

### **Ensuring Other Aspects of Scientific Adequacy**

Scientific rigor is integrally related to methodological soundness. The study must be scientifically adequate for the results to be transferable to other settings, populations, and possibly situations. The methodology heretofore described was developed to create a study that was scientifically adequate.

Methodological rigor for this study centered on issues of rigor as identified by Hall and Stevens (1991). Hall and Stevens (1991) emphasized the need for adequacy of inquiry for scientific rigor. They described adequacy as the quality of research processes that are "well-grounded, cogent, justifiable, relevant, and meaningful" (Hall & Stevens, 1991, p. 20). Adequacy is at the heart of scientific rigor and implies that the researcher has identified the necessity of reflexivity, credibility, rapport with participants,

consensus, relevance, honesty, mutuality, naming, and relationality (Hall & Stevens, 1991).

Reflexivity was addressed through the use of the research journal and my personal reflections and reactions as I progressed through data collection. I am aware of the issues surrounding my personal history with cancer caregiving as well as my personal assumptions as noted earlier in this chapter. Some of my reactions to the poignant details of participant interviews were surprising to me in terms of how emotionally draining it was to stay focused, to implement the semi-structured interviews, and to maintain therapeutic communication techniques. I used the research journal writing to reflect on how participants' stories affected me and to reflect on any potential patterns of association, implications for future interviews, exceptionally vivid statements by participants, and any other details that I wanted to record about each interview.

Credibility was supported through the presentation of rich data, thick descriptions, and lengthy excerpts to support themes and to answer research questions. Once again, multiple sources of data and rich detail enhanced the depth of the data and scientific adequacy by supporting credibility of the results.

Rapport with participants was enhanced by the personal referral process as well as the two-step interview methodology. I found that participant comfort and rapport was enhanced by my allowing them to become familiar with me in a first interview, with the later interview going into more depth and detail once rapport was established. I utilized techniques of therapeutic communication and principles of active listening to clarify and promote good communication with participants. Rapport was also enhanced by the fact that I began all of the second interviews by listening to participants. I began the second

interviews by asking each participant if they had any reflections, any details to add, or any reactions to our previous interviews. Sometimes this listening session was quite lengthy and lasted the better part of one hour.

Coherence was addressed through the use of transcripts, field notes, and details of conversations and participant responses to repeated topics. I examined responses to individual questions and topics of discussion within interviews to compare them for coherence and consistency. It was important that participants be consistent in how they responded to similar questions about similar topics. In this way I could be more assured that I understood their responses clearly and that they understood my questions. I did not find that any of the participants varied their narratives in any way; the data were coherent and consistent within the transcripts from each participant. Lack of coherence would have been detected when I conducted the within-case narrative analysis because I would have noticed if the participant had been incoherent or lacking in clarity.

Similarly, consensus was enhanced by the presentation of responses of different individuals responding to similar interview topics. This was achieved by the across-case analysis, since in that analytical step I compared codes between participants. I was surprised at how much the participants in the study agreed on several topics. These patterns of response across participants were significant in establishing scientifically defensible statements of thematic analysis and comparisons between participants.

Complexity was self-evident by the fact that responses to my interview questions and cues produced rich, thick data with details and illustrations. In addition, a comprehensive review of literature, presented in Chapter 2, allowed me to hint at the complexity of the caregiving experience and the distinct differences that I found to be

present, depending on cancer conditions of survivorship. Transitions theory conditions of transitions enhanced the analysis of data by informing the complex issues related to nature of transitions, conditions (especially personal) of facilitators and inhibitors, and patterns of response to transitions. Similarly, the relevance has hopefully been established by my review of literature and significance of the issue of cancer caregiving.

Caregiving is complex in and of itself, and the role issues alone make this an important topic for research. Honesty, mutuality, and relationality are all qualities of the interview and interaction process with study participants. I was able to interact with participants and to help them to clarify and express or construct their narratives with honesty and understanding within the umbrella of our short-term relationship. Once again, privacy, comfort, and therapeutic communication techniques enhanced the quality of data.

Throughout this chapter, sufficient details are provided so that the reader can determine the steps of study planning, data collection, and data analysis. This transparency of methodology could enable the reader to conduct a similar study in a different location or with different caregivers, following the methodological plan outlined here. In addition, methodological decisions were discussed and rationales provided so that readers could understand the thinking behind what was done, what was perhaps changed, and how the study was implemented. Transparency enhances scientific rigor.

It was my intention to conduct a study that was scientifically rigorous and to provide information that may be used in other settings with cancer caregivers. This property of transferability is enhanced by conducting strong quality interviews, making methodological decisions that are transparent and verifiable and providing evidence to

support themes, exemplars, and conclusions. With the above efforts to conduct a study that is scientifically rigorous, transferability, credibility, dependability, and trustworthiness were supported.

### **Ethical Considerations**

Ethical issues are always involved in human subject research. For this reason, it is imperative to assure participants that no identifying information will be retained and that identifying details will be kept confidential. Interview conditions were established by ground rules that were reviewed with each participant prior to interviews. It was important that interviews be conducted in privacy and with comfort in mind for the participants. Therefore, I made it clear that each interview was to be kept confidential and that as researcher I would respect the confidentiality of the each person's interview content.

Prior to contacting potential participants, approval was obtained from the Institutional Review Board (IRB) of the University of Wisconsin at Milwaukee. Informed consent (Appendix A) was obtained from all participants prior to interviews. Participation was entirely voluntary, and participants were free to stop the interviews or withdraw from the study at any time. None of the participants withdrew from the study once they began to participate, but one potential participant had to cancel her participation prior to the first interview because her husband was found to have an unexpected recurrence of his cancer and she did not feel up to participating. Wherever appropriate, I made every effort to de-identify stories, details, and conditions so that no one would be revealed to public scrutiny. This included names of healthcare professionals, hospitals and facilities (with the exception of the CCHL), and spouse

names. All participants were given pseudonyms and ID numbers for confidentiality. Confidentiality was maintained throughout the study. The transcriptionist did not know the identities of participants, only ID numbers and whether it was interview part A or part B. The NVivo9 software was set to be password protected, but no identifying information was entered into the software, so that is perhaps a moot point. The only storage of participants' contact information was done using a locked storage cabinet which was available only to the researcher.

One potential hazard for participants in the study was possible psychological distress due to telling stories about life-disrupting events, difficult times, and fearful scenarios. Participants sometimes expressed surprise at the emotional nature of their reactions our discussions, saying things like "I didn't realize I would still be this emotional about what happened." However, only one participant was referred for counseling after our interviews. She was unable to make life decisions and wanted to find someone who could help her to move forward with her education and support that she would need to succeed in that regard. I referred her back to the counselor at the CCHL, who made appropriate referrals from that point. I also had the approval from a local psychologist who works with patients with post-traumatic stress disorder and who was willing to take referrals from me from the study had that been needed.

Another possible hazard for participants in the study was the amount of time it took out of their schedules to gather data. Interviews lasted from one hour 5 minutes to almost two hours. Since two interviews were conducted with each study participant, consideration was made for the physical and emotional comfort of each participant in the study. Interviews were conducted at a convenient time of day, and interviews could have

been paused or ended as needed if participants become overly fatigued. This was not needed, however. Interviews were conducted at locations that were convenient to participants, and these locations included homes, coffee shops, hospital cafeterias, and libraries. For emotional and psychological comfort of participants, I wore appropriate attire of street clothes without a lab coat and observed courtesies as a guest of the participant caregiver. I thanked the participants for their participation and gave each participant a \$15 store gift card. One participant, an early-retired executive, refused the gift card, so I gave the extra cards to the participant who received the social services referral.

Safety was of utmost importance during the conduct of this research. If there had been any complications encountered in the interview process, they would have been addressed. For example, no participant voiced a plan for self-harm, and no significant medical needs emerged, so it was not necessary for me to make referrals for those situations.

The next chapter will present the narrative summaries. Details were altered in order to de-identify people and specific agencies mentioned by participants, but the rest of the data are original.

## **CHAPTER 4: NARRATIVES AND WITHIN-CASE ANALYSES**

Eleven caregivers participated in the study. Each caregiver was interviewed twice, following the semi-structured interview guides (Appendix A). The interviews were recorded, transcribed, proofed, annotated with field notes, and coded. I recorded field notes after each interview to provide additional information about participant demeanor, body language, and any other observations that I could make. The field notes were added to transcripts as part of the proofing process as I listened to the audio recordings and corrected the transcripts as needed.

Sampling was purposeful so that the research questions could be addressed. To review, the research questions were:

1. What are the circumstances (contexts and conditions) with which caregivers contend over the full trajectory of their significant other's cancer, from the time they noticed something was amiss to diagnosis and then through active cancer treatment and post-treatment?
2. How do caregivers describe the impact of cancer on their own lives over the course of their caregiving experiences?
3. How do the narratives of caregivers illustrate and give meaning to transitions that the caregivers have undergone?

These research questions guided the sampling as well as the interview questions for the study.

### **Narrative Summaries**

Each caregiver was asked to tell his or her narrative about the trajectory of cancer caregiving, from the time of pre-diagnosis, through treatment and beyond the first course

of active treatments. Active treatments included surgery, radiation therapy, chemotherapy, and stem cell transplants. Many times, the caregivers digressed from chronological order in telling their narratives, preferring to illustrate or to give background information for what they were discussing at the time. These digressions were often in themselves stories with beginning disruptions, middle engagement, and ending resolutions, so there were smaller stories within all of the narratives. I refer to the narratives as the whole trajectory, the overall sequence of events within which there are stories – stories of diagnosis, telling the family, coping with employment issues, and the like. The narratives have been constructed from transcripts of interviews and re-storied chronologically in order to provide clarity and a sense of the trajectories experienced by each of the caregivers. All participants are referred to by pseudonyms to ensure confidentiality.

These within-case narrative analyses are presented in order to give the reader a sense of the experience of each participant, each interview, and to allow the reader to experience some of what I experienced when talking with these exceptional individuals. Presenting the narrative summaries in a systematic and parallel manner will allow me to address the research question regarding what were the contexts and conditions under which the caregivers experienced their personal cancer caregiving trajectories.

Narrative summaries are presented in the order of narratives in general: orientation, time ordered complications, evaluations of those complications, and resolution (Labov & Waletzky, 1967, Stevens, 1998). Accordingly, the narrative summaries are introduced with an orientation to the caregiver participants, their circumstances, their relationships to the cancer patients, and other demographic details.

This provides a setting for the disruption that becomes the focus of the narrative: cancer diagnosis and treatment. Following the introduction, orientation, and demographics, the narratives are presented in chronological order. Every effort has been made to provide key dates, details, and insights into the caregiving experience. I will focus on key events and turning points as emphasized by each caregiver. The chronologies end with information related to life at the time of the interviews and how things have become resolved or continue to change. The narrative summaries provide a detailed within-case analysis of each caregiver's experience as told by the caregiver.

The order of presentation of caregiver narratives is thoughtful and purposive. Early in the study I decided that it would be valuable to obtain data on the trajectories of caregivers who had experienced different outcomes of cancer treatment for their significant other. I did this because I found some intense emotions being expressed by the first two participants, each of whom was a husband who would eventually lose his wife to cancer. I wanted to determine if the intensity and nature of the emotional aspect of caregiving would be different in participants whose significant others were cancer free, continuing in treatment indefinitely, or deceased. While it was surprising that the experiences were remarkably similar no matter how effective initial cancer treatment had been, there were small differences in outlook for the future for the different caregivers. For this reason the narrative re-story summaries are presented in order according to cancer treatment outcome and current status of cancer survivor patients, from the most positive outcomes to the least positive outcomes. All of the narrative summaries are the result of structural analysis using the grid as described in Chapter Three.

### **Cancer-Free with Sequelae: Narrative Summaries**

The first group of caregivers to be presented is composed of those whose cancer patients are currently cancer free. None of the cancer patients or former patients in the study was free of both cancer and its after-effects, so this was the most positive outcome of cancer treatment represented by caregivers in the sample. Sequelae ranged from dry mouth, dental issues, cognitive defects, and fatigue after head and neck cancer treatment to debilitating radiation necrosis of the brain after radiation for a mixed glioma of the brain. For the latter patient, the radiation necrosis is progressively debilitating and will ultimately cause him to enter a nursing home and will likely be the cause of his death, although there is no sign of cancer and has not been for years.

#### **Narrative summary: Lucy.**

Lucy is a 58 year-old retired Licensed Practical Nurse who worked for years in cardiac rehabilitation before retiring several years ago to spend more time with family. Her husband is a successful information technology specialist with a major corporation. She and her husband have both been married before and have adult children from their prior marriages, but they have none from the current marriage. Before they were married she had gynecologic surgery that left her with surgical menopause. More recently, her healthcare provider has suggested that she wean herself from the hormonal supplements that she has been taking for years, considering the fact that now that she is past the natural age of menopause. She has mixed emotions about doing this because in the past she has tried to slowly discontinue the use of hormonal replacements and has been unhappy with the side effects, so she returned to using them.

Lucy's daughter and her husband had moved to Georgia in 2010, but their adolescent daughter wished to finish her senior year of high school locally. Therefore, at the time that Lucy's husband was diagnosed with cancer they had her granddaughter living with them. The granddaughter went to live with her parents shortly after Lucy's husband was diagnosed with cancer, so the granddaughter was neither a burden nor a help during the cancer treatment experience.

Lucy's husband Greg was 59 years old in 2010 when he was diagnosed with HPV-related squamous cell carcinoma of the neck; the cancer had originated in his right tonsil. He was shaving one morning and noticed a lump on the side of his neck, so he sought medical advice and was referred to the otolaryngologist for a biopsy. Two years prior to that event, he had noticed a similar lump, which was found to be an infection, so Lucy and her husband were not alarmed. They went to the otolaryngologist's office and were seen by a physician's assistant, who biopsied the lump and endoscopically examined Greg's throat. The physician's assistant did not find obvious signs of cancer in Greg's throat.

Two nights after the biopsy, Greg awoke at home during the night with swelling in his neck and fever, so he called the emergency department of the hospital. They told him to come right in, so he told Lucy, "Don't worry. I'm going. You stay home." Lucy explained that her husband is very private, somewhat introverted, and sometimes anxious. She found it odd that he wanted to go to the emergency department alone, but he was insistent that she stay at home, promising that he would call her if there was a problem.

While Lucy's husband was at the emergency department, the physician there told him that he had checked on the biopsy results and told Greg that the biopsy had revealed

a malignancy. Greg did not call Lucy, nor did anyone at the hospital contact her, so it was not until the morning when Greg arrived home that he told Lucy the diagnosis. Greg told her bluntly that he had cancer and that he needed her to call the otolaryngologist's office for an appointment, but he was frustrated about getting in to see the physician there. He said, "They can't seem to get me in for an appointment. Can you try to get me in to the ENT to do a follow-up on this? I'm off to work." Then he went to work. Lucy related that moment as the moment that her husband "just shut down," as if he could not cope with the diagnosis. Lucy reported that after that point he seemed to expect her to keep this news very private, and he seemed to relinquish control over everything – information, interactions with the healthcare system, implementation of adjunct treatment, and assessment activities - to her. There was no discussion of who would help with caregiving; Lucy just slipped into the role because Greg immediately began to depend on Lucy as soon as he knew the diagnosis.

For weeks, Greg expected Lucy to not tell anyone about the diagnosis, in spite of the fact that Lucy felt that she needed to discuss it with family. When Lucy's granddaughter mentioned something about Greg's cancer, he became angry with Lucy for discussing it with the granddaughter. Lucy replied that the granddaughter was home at the time he came home from the emergency department, announced he had cancer, and asked Lucy to make an appointment, so it was unavoidable that the granddaughter was aware of the situation. Lucy noted that Greg took almost five weeks to tell his family about the diagnosis, and even after that time she was limited in how many people she was allowed tell about the cancer. This keeping silence was a burden for Lucy, who then had no one upon whom to rely for emotional support, information, and assistance. Her

husband was “shut down” and dependent on Lucy for everything related to cancer care. Lucy indicated that their marriage before cancer intruded was satisfactory, but she also noted that he was a very quiet person, and the cancer diagnosis made this characteristic more pronounced.

It did not take long before Lucy became disappointed with the pace of care for her husband in their community. She called the otolaryngologist’s office the morning that her husband had found out that he had cancer, and she found that none of the physicians in the group could possibly see her husband for another three weeks. She suggested that perhaps a PET scan could be done in the meantime, and they agreed that this could be done. She did research on the internet about cancer of the head and neck and was shocked to find that treatment should begin as soon as possible after diagnosis for the best outcome; she became concerned about waiting, so she asked for more testing while they waited for the appointment date to arrive. When they finally went to see the otolaryngologist, he referred them to an oncologist but the otolaryngologist refused to attempt to find the source of the cancer, stating that the physician’s assistant had looked into the throat and found no abnormal lesions. However, the physician did note that the PET scan showed a spot on her husband’s right lung, and he told Lucy and Greg that he was “90-some percent sure that it’s metastasized.” Unfortunately, the oncologist could not see them for another week and a half, and Lucy became more concerned by the day.

While awaiting the date of the oncology appointment, Lucy contacted her daughter in Savannah, Georgia, whose oncologist friend recommended going to Chicago for treatment and speeding up the timetable. When Lucy and her husband saw the local oncologist and the oncologist outlined a course of chemotherapy, she asked for a second

opinion. This oncologist facilitated their referral to the oncology team in Chicago, and that was on a Friday. Their appointment in Chicago was the very next Monday. Lucy was impressed at the speed with which the oncology team in Chicago was able to get her husband in to see them, and she began to feel better. It had now been approximately five weeks since her husband's biopsy, and Lucy was eager to find out what needed to be done and how soon they could begin treatment. Greg, on the other hand, remained quiet about the diagnosis and his disease and refused to discuss it, preferring to leave everything to Lucy. As Lucy stated, "I was leading him around like a six year old, or maybe a three year old. I wanted him to make the decisions..." Lucy took over the duties of interacting with the team in Chicago and gathered all the reports, including cytological slides of her husband's biopsy, for the trip.

Lucy and Greg arrived in Chicago on Sunday, ready to see the oncology team on Monday morning. After that, Lucy reported that everything went almost too rapidly for her to handle. On Wednesday they saw the surgeon in Chicago, and on Friday her husband had radical neck dissection surgery to remove as much of the tumor as possible. Meanwhile, the oncology team members had repeated the endoscopic examination of Greg's oropharynx and had found that the primary site of the cancer was the right tonsil. After the radical neck dissection surgery Greg was expected to have a tonsillectomy and also a thoracotomy to remove part of the right lung, and this was scheduled for the Tuesday after the neck dissection. The lung lesion was found to be benign, so that was a source of relief to Lucy. Her husband's surgeries in Chicago were followed by two courses of chemotherapy and then radiation therapy. Each course of chemotherapy lasted two months, with radiation therapy lasting for over one month. Initial chemotherapy was

done locally, and this enabled Lucy to avoid the three hours each way of driving to and from the city for Greg's treatment. The treatments began in late summer of 2010, so they were in treatment through the holidays until the end of December.

In order to be in Chicago for the surgeries and later for the second round of chemotherapy and also for radiation therapy, Lucy rented an apartment near the hospital, which is located "in an unsavory part of Chicago." She was there only for a few weeks when Greg had his surgeries, but because the surgeries were closely spaced there was a lot of wound care for Lucy to do. She and later Greg lived in the apartment for his postoperative period. During the second round of chemotherapy and radiation therapy Lucy spent months living there for most of each week, returning home only for one night over the weekend because Greg wanted to be home whenever possible and Lucy wanted to do what she could to keep things running at home.

In order to be home on Saturday nights and still be ready for treatment to resume on Monday morning, Lucy had to transport a heavily-medicated Greg along with all of his wound care supplies, intravenous fluids, intravenous pumps and stands, and other equipment each Friday night to return home and each Saturday evening or Sunday morning to be at the hospital again by noon. Along the way, she also gave her husband erythropoietin injections for neutropenia, managed his pain medications, and assisted with his feedings. Feedings were quite a chore, since he lost his ability to swallow effectively during radiation treatment and she had to administer tube feedings for a period of time. All in all, Lucy stated that she kept busy but was very lonely, being far from home and isolated from friends. She said she felt that she was "back at full time work again" and that it was an "autopilot" feeling. As Lucy stated,

We had to be back there on Sunday by noon, so a lot of times... we'd end up going back on Saturday because it was just too hard for me to get him all ready to do, and of course I had IV bags, IV poles, his medications, his dressings for his neck, that I was hauling in the car. There was no way... he would even be able to take directions. He would, but this was somebody that was so doped up that you'd say take this to the car. Well, the next thing I'd turn around and he'd just be sitting there.

As Greg's cancer treatment progressed he became more and more dependent on Lucy and less and less communicative due to sedation, discomfort, fatigue, functional side effects of treatment, and communication difficulties. Lucy's daughter tried to visit with them while they were in Chicago, but the daughter brought her small son and a dog along at a time when Greg was immunosuppressed and could not be around animals or children, so the daughter stayed with Lucy's elderly parents in a Chicago suburb. At one time, close to Thanksgiving holiday, Lucy was feeling especially alone and abandoned by friends and family, so she phoned her parents' home. Her mother answered the phone and told her that they were "having a party" with her daughter and some other people. Lucy reported that the phone conversation was stunning in terms of the lack of consideration for her feelings and the lack of any perceptible desire to help Greg and Lucy. That was a turning point for Lucy in terms of feeling unable to call upon family members whom she had assumed she would be able to call upon for help. She stated, "That's when I knew I was on my own with this thing. My husband wasn't going to help; my family wasn't going to help; and I was alone in Chicago... I just kept going and didn't look back."

Lucy emphasized repeatedly that she felt deserted by friends and family, and this was both shocking and disappointing to her. She now feels that her relationship with family members has been irrevocably changed because of that experience. Whenever she

discussed this issue during the interviews, she became tearful and appeared grief-stricken. Lucy stated, “It’s just different when it comes to – I mean, my relationship with my daughter. It just was – some friends that weren’t there for me. Not that I’m angry or, it’s just, maybe a little sad to think that some of that happened.”

Her husband currently has esophageal strictures, xerostomia, dental problems, loss of taste, anxiety, radiation burns of the skin, and cognitive impairment, but he appears to be cancer free. Unfortunately, there were additional unrelated medical problems that occurred during the time he underwent cancer treatment. In the 13 months since her husband’s cancer diagnosis, he has also had a laparoscopic cholecystectomy and a herniorrhaphy. They currently are in a program of medical surveillance for recurrence of the cancer, and he is taking medication for depression.

Lucy stated she slept fairly well while Greg was in treatment “due to exhaustion” but she has experienced new medical problems of her own in the aftermath of the caregiving. She has developed a heart murmur and hypertension. She also currently reports having sleep difficulties. Her relationship with her husband has deteriorated due to his cognitive impairment and what she describes as his “taking his introverted nature to a new level.” She is hoping things become more normal soon, noting that “we are 13 months out now.”

**Narrative summary: David.**

David is a 60 year-old chiropractor who is married and the father of three grown children. David and his 56 year-old wife have been married only once and to each other. They are active in their church and are very involved with their careers. David has been practicing chiropractic in one location as a sole proprietor for his entire career, and last

year he celebrated his 25<sup>th</sup> anniversary of being cancer-free from a brain tumor, which was surgically resected. His cancer did not require any chemotherapy or radiation therapy, since it was entirely removed at an early stage by way of surgery. His only after-effect from that surgery was some mild facial paralysis on the left side of his face, but he counts himself “blessed” to be free of cancer. He has a strong family history of cancer, since his mother had a rare form of breast cancer when he was in his twenties. She, too, was treated surgically and lived another three decades past her diagnosis. He has a sister who has is a breast cancer survivor as well.

David’s wife Carol is a 56 year-old nurse who works with a neonatal research team and implements clinical protocols for the neonatologists. She does data collection, so her work is not physically demanding. David also has three sisters who are nurses, and the couple’s daughter is a nurse, so he feels surrounded by nurses. In 2008, Carol noticed a lump in her breast in April, but she went through diagnostic testing and it was determined to be “nothing to worry about.” However, after she had a mammogram in June of that year, she found a lump again in July, and this time they were on vacation. They decided to wait awhile to see if it would go away, since Carol had a history of fibrocystic breast tissue and was sensitive to caffeine. She took herself off coffee and waited for a month. In August, she decided to make an appointment to see her physician, and by the end of the month she was having testing. The biopsy result came back malignant on September 6, and David stated that it was a rather abrupt process, receiving the diagnosis:

They did the ... ultrasound and the biopsy about the same time. They did that like on a Thursday and then [we] got the news on Friday... Went back to the cancer center. The radiologist met with us and hit us in the face. Boom... She did that, and it’s hard to take [becomes tearful]. Then there was more testing.

After the initial diagnosis, however, David recalled that the surgeon and other healthcare personnel took time with them and helped them through the process. David related that Carol was stressed by the experience, as he was also, but they managed to find some humorous moments in true-to-personality form. For example, David and Carol have two unmarried sons. When they met with the “pathfinder” supplied by the oncology office, they found themselves spending a lot of time with her, making sense of the whole situation prior to deciding on surgery and treatment for Carol. As David tells it, Carol was not totally focused on what was going on for the entire afternoon:

[Carol] being the consummate mother with unmarried sons. After she got the diagnosis of cancer and stuff and before we left, this [nurse] said, ‘Are you [name of son]’s parents? We go, ‘Yeah.’ She said, “Well, I... went to homecoming with him our junior year in high school. Carol says, ‘Are you married?’ [laughs] I said, ‘For crying out loud, you just got the worst diagnosis you could ever get and you’re still trying to find a bride.’ ‘Well, she’s a nice girl.’ ... I thought it was kind of funny. She’s cute. She’s here. She’s got a profession. They won’t starve.

David recalled that after they found out the diagnosis they immediately needed to tell their children, two sons and a daughter. This was a very emotional task for them, especially since their older son lived out of state and was not able to be there. They went to their daughter’s home and told her the news personally, and then they went to their younger son’s home and told him the news. However, David recalls that it was especially painful to tell his older son the news by telephone. David said that during Carol’s treatment the children were very attentive and tentative, always calling to ask permission to send things or to visit.

David recalls that Carol’s care “was on the fast track” after her diagnosis because of her friendships in the hospital where she worked, so they took advantage of it. He noted that when people need help with a dental emergency or a sprained ankle they are

seen and treated within a day or two. However, he bemoaned the fact that with cancer things seemed to take a long time to move, even considering the fact that Carol was given priority. He did not seem to think that was appropriate and questioned if it was necessary for people to have to wait so long before being treated.

Carol's surgery was a mastectomy on October 1 of 2008. They opted for a mastectomy because the MRI had shown a large lymph node. Carol had the surgery on a Tuesday and returned home from the hospital on Thursday. Then, he said, copious amounts of food began to appear, courtesy of Carol's co-workers and friends. Carol's parents were present for the postoperative day in the hospital and the first day she was home, but the next day Carol needed to rest so they did not come. After that, David recalled, they "disappeared." He stated:

You get the extremes. Either people are extremely helpful or gone. It can be heartfelt and it can be surprising...Her parents were gone. I mean literally gone. They live here and we did not see them for four months. [chuckles] It just shocked the hell out of me is the thing. They were there... They were there for the surgery. They're good, good people. God bless them. They're good... and I don't know if they couldn't handle it or what the deal was.

Carol's surgery went well and she recovered enough for the couple to go to Hawaii five weeks later. This was a vacation that had been planned before diagnosis, and they decided to go and have some relaxation and "just heal." He said this vacation prior to chemotherapy was a wonderful break for them. They returned just in time for Thanksgiving, and she began her chemotherapy the day after Thanksgiving in 2008. She would have chemotherapy every three weeks for six times and then would have four months off prior to starting radiation therapy.

Through all of Carol's treatment, David went to all doctor appointments when he could arrange his schedule to do so. When asked if there had been a discussion of what

his role would be or how he would help Carol, David stated that he never really gave it much thought, just that he did what he had to do. He mentioned that the disease of cancer is one over which people feel little control, so doing things for Carol allowed him to do something to improve her care and thereby maintain a little control in the situation. He also said he felt it was natural for him to assume the caregiver role because that was how things were done in his family. He told a story about his high school friend's father, whom David said had always been "the ultimate gentleman," and David had seen him opening the car door for his wife. He said he decided then that he wanted to be like that man, and the caregiver role was in keeping with that aspiration. David stated that he just did what he had to do, and he noted that there was no one else he would allow to be a caregiver for his wife. He seemed to accept it as a part of marriage that he would be the one to do what had to be done so that she could get the treatment and the rest that she needed.

Chemotherapy produced the usual effects for Carol: nausea, fatigue, weight loss, and lots of sleep. I asked David to recall a typical day during Carol's chemotherapy, and he did what most of the caregivers did, responding in terms of the experience for Carol. On each day of chemotherapy Carol was tired but felt rather well. However, the nausea was severe for two days after chemotherapy, and she felt a severe fatigue that caused her to sleep most of the time for several days after chemotherapy. Actually, this fatigue became worse as time went on, as if it had a cumulative nature, and she found herself unable to do much other than sleep and – if possible – to eat. David's days were burdensome, since he took on the job of house cleaning, laundry, cooking, shopping, and transporting. He reduced his office schedule to allow him to have two-hour lunch periods

each day so that he could go home and care for Carol; this schedule has remained until the present day.

David found that meal planning for someone on chemotherapy was a challenge. He stated that the day after receiving chemotherapy Carol was deeply asleep most of the day. He went on:

The big thing of course was the nausea and stuff. I got to the point where I just would go ... to work. I'd call her and see what she felt like eating. Then go to [grocery store] and get that. Then, go home and fix her lunch. Then, she'd go back to bed and then I'd go back to work. Then, the same thing for the evening, too, to see what she felt like eating. I got to the point where I was going to [the grocery store] twice a day. It was just easier because I was throwing so much food away before that.

He found that there were some surprises and some battles as he and his wife went through the cancer treatment experience. For example, David found that he "needed to be a jerk sometimes" because he found that his wife needed an advocate so that she could rest, recover, and care for her needs. He described a time when he argued with a friend about interrupting Carol's sleep after a session of chemotherapy. The friend wanted to come in and visit while Carol was asleep, and David had a particularly difficult time getting the visitor to leave.

He also pointed out that people sometimes are "industrial strength stupid" when it comes to making comments and caring for people with cancer. A friend at church came up to his wife and told her that she was looking good. He followed that with the statement "So was my sister. Then she died." As David put it, he found himself trying to protect his wife from interactions such as that one. He was also one of the caregiver participants in the study who had some strong opinions about what is helpful and what is not helpful in terms of caring behaviors from others.

Currently, it appears that David's wife is cancer-free, but she has significant lymphedema from the mastectomy and lymph node removals. He continues to do lymphatic massage for her on a daily basis. She wears a heavy compression sleeve at night and a lighter one during the day. He noted that she continues to be quite fatigued at times, but he is positive about the future and looks forward to retirement someday. He adjusted his practice hours and daily schedule at first while she was in treatment, but he has permanently changed his lunch hour to be two hours long so that he can go home to make his wife's lunch or prepare for dinner. We met for our interviews in a restaurant, and he said "this place has fed us many a night and day over the past few years."

At the time of the interview, David reflected on how the experience had changed him. He noted with a sense of humor that he had become a "great cook," but "this laundry thing sucks." He also felt that he had changed the way in which he relates to people who are going through similar life experiences. He noted that after this experience he felt that he was more compassionate and was more likely to send cards and go out of his way to reach out, instead of just thinking about doing so. This outreach included those patients in his chiropractic practice who experience similar health-related disruptions. He stated that his perspective had changed, and caring for his wife had caused him to reevaluate his priorities in life.

David reports that his wife has returned to work on a part-time basis, but her hours necessarily remain flexible. He reports that she still tires easily and has cognitive impairment as well as the physical effect of lymphedema. David reports that his own health is "as well as can be expected, with all that I am doing" and says he is hoping that his wife and he will be able to retire and rest someday.

**Narrative summary: Diane.**

Diane is a dynamic, educated, compassionate, and interesting lady. She is a 58 year-old retired dancer and later a special education teacher. She is currently a hospice volunteer and has been active for many years with Al-Anon, a program for people who live with people who struggle with alcoholism. Diane's current husband Charles is a second husband, since her first marriage ended in divorce after her first husband's struggle with alcoholism became unbearable. Diane and Charles met after he had begun his scientific career.

I interviewed Diane first in a library conference room, but the second interview was in a hospital cafeteria because Charles had just had back surgery unrelated to cancer. Diane is a very elegant lady, who began life as a dancer and has a master's degree in dance. She is a native Californian, but she came to the Midwest after her husband decided to move closer to his family after his retirement from his career as a scientist working on physics research at a government laboratory in California. In addition to her master's degree in dance, Diane has a master's degree in special education, so when she developed cervical spine problems and was unable to continue dancing after her neck surgery about 13 years ago, she taught special education. She misses life with her family and friends in California, but she has made friends and social contacts in the Midwest as well.

One reason they moved the Midwest was because Charles' father was living alone and in failing health. "Dad" was in his nineties and refused to move to California, so when Charles retired and when Diane found that she was no longer able to teach due to her neck problems they moved to the Midwest. Sometime later, Dad fell down the stairs

backwards and broke some ribs and punctured a lung, so after that hospitalization Diane and Charles welcomed Dad into their home. Diane was caring for Dad when her husband was diagnosed with cancer. Also, at that time they lived in a home in a rural setting with a large amount of landscaping. Charles had been a runner and had kept in shape for decades, so once he was retired he spent a lot of time and energy working on the landscaping for their beautiful country home. Later, their daughter moved with them as well, and the resulting household had three generations under one roof. The daughter has since moved out, married a man from a nearby town, and started a family, so now Diane is happy to live near her grandchildren. However, when Charles was diagnosed with cancer in 2008 they were living in the country with three generations in the same home and a significant landscaping burden.

In October of 2007, Charles attempted to donate blood and was refused due to low hemoglobin; the blood donation personnel recommended that he see his physician about possible anemia. However, he decided to delay seeing his physician until his December regular health examination, which was on his 67<sup>th</sup> birthday. Diane noted that “if he’d gone sooner it would have been a lot easier because in the end it was only a millimeter from being in his body.” The physician scheduled Charles for a colonoscopy in January of 2008. They found two cancerous lesions in the colon on January 2 and decided to remove them surgically soon after that.

When Charles was diagnosed with cancer, they still had Dad living with them, and the job of caring for Dad fell to Diane. She was sad when she reported that she had decided that she could not care for both Charles and his father, so they had to make the difficult decision to place her father-in-law into assisted living, at least temporarily. She

said, “I think he forgave me, because we moved him back with us later on, and he died at home.” Meanwhile, the Diane was unable to do the landscaping that her property required, so she hired someone to do that. Unfortunately, this was quite costly, so they had to move to a house in town while Charles was in between cancer treatments later that year.

Three weeks before he was to have surgery in March of 2008, Charles was diagnosed with an aggressive form of prostate cancer that had invaded tissue outside his prostate, and this was in addition to the colon cancer. The couple and their physicians had to decide which cancer to treat first, since the two forms could not be treated concurrently. The outcome of that decision was that her husband had surgery for colon cancer, chemotherapy for colon cancer, and later surgery for prostate cancer, followed by radiation for prostate cancer. During 2008, he had surgery for colon cancer, two types of chemotherapy, and in December he had surgery for his prostate cancer. He had an appointment to continue with radiation treatment for his prostate cancer early in 2009, but Diane reported that her husband...

decided, not cognitively, but he took 2009 off and didn't do any other treatments [sigh], which wasn't such a good thing because they determined that the prostate cancer was fairly aggressive... He had an appointment with his radiologist in March of 2009, which he didn't go to, and so they rescheduled and he didn't go to that either. He didn't have the treatment with radiation until a whole year later. That's when we found it was outside in the body.

Diane attempted to support her husband's autonomy. As she noted, “It was really hard, but it was his disease and I had to let him manage it. It was very difficult for me.” She found herself faced with well-meaning friends who recommended foods and other wellness approaches to cancer care, but she was not in control of her husband's eating or decision-making, so the help was more stressful than helpful for her. She explained that

Charles is a “typical scientist” and that “he’s German,” indicating that these characteristics meant that Charles was rather autonomous.

During her husband’s chemotherapy, Diane noted that her husband continued to be quite independent and liked to have full information in order to make his own decisions. For most of his treatment, however, Diane found that Charles was not given the depth of information that he needed to cope with the disease or its treatment. For example, she reported that, as a scientist, he knew that there were margins of error on lab tests, but he could never get that information about the tests they were doing for him. She explained that he needed that level of detail to maintain control over his treatments, and she felt that the fact that he was not allowed to have detailed information was disrespectful to her husband. Finally, however, when he went for radiation therapy for the prostate cancer, the medical physicist answered all of her husband’s questions, and this satisfied him. She said, “then he knew what damage it would do and why.”

One thing that made her life of caregiving difficult was what Diane called her husband’s stubbornness. She attributed it to his German heritage and how he grew up, but she said the same culture that made him strong also made him difficult at times. For example, her husband refused cancer treatment for all of 2009, and she reported that looking back at the whole experience she thought her husband had not been able to cope with the loss of control, the insufficient information, and what he felt were assaults on his autonomy imposed by the cancer experience. Late in 2008, while he was still in chemotherapy, she once overruled her husband’s decision not to seek medical care when he became acutely ill at home. He did not wish to go to the emergency room, and when

she called for an ambulance he agreed to go, but she said “he was quite angry at me for that for a long time afterward.” The next year, 2009, was when he refused all treatment.

After 2009, Diane’s husband resumed caring for his remaining prostate cancer and resumed surveillance care. Of the year-long absence, Diane said, “he got by with it. He’s fine.” She just shook her head and chuckled when she said that.

Diane reported that whenever her husband was in treatment he would sleep for days at a time, so she had to take over the entire burden of the household as well as ancillary tasks related to his care at home. She reported that she had a strong faith life, which helped a great deal. She reported feeling quite lonely and isolated during this time, but she credited the skills she learned in Al-Anon for helping her to get through 2008 and beyond. She found that there was a “total transference” between Al-Anon principles and the skills she needed to cope with her husband’s reaction to cancer and cancer treatment. She found that she had to recognize what she could and could not control, to set limits for herself, and find a way to reconnect with other people once his cancer treatment was completed in 2009. However, for the year of 2008 and early 2009 she felt that she shouldered the entire burden of caring for her husband, while being partially disabled due to her cervical spine condition.

One thing that Diane reported as a great help during her times of frustration, burden, and loneliness was her dog. She had been a hospice volunteer for about two years when her husband was diagnosed with cancer. One of her clients in hospice care had a dog, and as the client neared the end of his life he became increasingly abusive to the dog, so the hospice personnel got the client’s permission to offer the dog for adoption. Diane felt sorry for the dog and adopted him about six months before her husband’s

cancer diagnosis, so she and the dog “were good buddies” when Charles became ill. Diane stated she and the dog “sort of rescued each other in that manner” and gave credit to God for providing the dog for her before she would need the support during Charles’ cancer experience.

Diane is looking forward to retirement with her husband and is accepting of the sequelae of cancer treatment, especially prostate treatment after-effects. She said they lost “100% of our intimacy” due to cancer, and she added that her husband is plagued with cognitive impairment, especially related to word retrieval and remembering things. She finds that she becomes frustrated with him at times, saying “he was never very good at remembering minor things anyway, but now it’s almost hopeless.” On the other hand, Diane expressed the belief that she is more connected again since his treatment has ended and is more confident about the future than she had been for the past few years. She is quite philosophical about the meaning of cancer for family members and likes to “work through the difficulty of the past.” When I asked her what she meant by that she replied that she understood that sometimes people do not intend to be hurtful but they “cope with things in their own way, and this includes family and friends.”

**Narrative summary: Phyllis.**

Phyllis is a 64 year-old female, a retired teacher, who has cared for her husband since he was diagnosed with brain cancer nine years ago. I selected Phyllis for the study because her husband is cancer free but is slowly losing his life due to radiation necrosis of the brain. Prior to her husband’s illness, she had been a teacher, and he had taught college level computer science. They had both worked to manage a number of rental properties. They had been active travelers and certified scuba divers for many years prior

to his diagnosis, and the walls of their home are adorned with underwater photographs that Phyllis and her husband Frank had taken.

Phyllis and Frank have been married only to each other, and their two children were in their later teens and early adulthood when he was diagnosed with cancer in 2002. This turned out to be unfortunate timing, according to Phyllis, because the children began to experiment with drugs and even criminal behavior as Frank's condition deteriorated.

I interviewed Phyllis in their home. Her husband was napping, and I did not meet him. In addition to photos of underwater scenes, there were photos of children and a couple of grandchildren that filled the living room. They also had a piano and a guitar in the living room because Phyllis once had a business of playing guitar and singing for children's groups. She had been active in her church choir and had always been very involved with her children's schools. Phyllis and her husband had been an active couple. They were proficient at scuba diving – and Frank was a certified instructor – and had dived in places such as Grand Cayman, Belize, and Bonaire. They loved to travel extensively, camp with the family, and ride their motorcycles across the country.

When Frank was diagnosed with cancer at age 56, he and Phyllis had a number of businesses – the music entertainment business and rental property ownership and management – in addition to Frank's career teaching computer science. Phyllis had retired from teaching high school home economics because those courses were eliminated from the public schools due to budgetary constraints. She used the extra time for their other businesses and enjoyed spending more time with her children, her church, and her volunteer activities whenever she and Frank were not traveling. In short, as

Phyllis stated, they were “very busy, very normal, and very much not aware of what was about to hit... Not only the cancer thing, but the children were getting into trouble.”

Shortly before Frank was diagnosed with cancer, Phyllis noticed that he had become forgetful and had difficulty lifting his foot high enough to clear a book on the floor of their living room. He was unable to go upstairs without dropping his foot, and he was worried about possibly having a damaged nerve in his leg from some household remodeling that he had been doing. He sought medical advice, and within a few days MRI imaging revealed that he had a brain lesion. The physicians wanted to treat him conservatively because he was diagnosed with a *glioblastoma multiforme*, which is a grade four astrocytoma and almost always fatal. Phyllis reported that the doctors told him to “get his affairs in order.” She sought information about the cancer, but she was not adept at using the internet, so she called resource places to which she had been referred and received paper reports and documents about the disease.

Her husband, however, was not interested in conservative treatment and wanted to see what other options were available. He decided to travel out of state to Texas in order to get a second opinion, and it was there that they diagnosed a mixed glioma rather than the more lethal cancer that was diagnosed initially. He had surgery for the mixed glioma while they were in Texas, and Phyllis reported that they were told that he would not have been treatable if they had agreed to have the treatment initially proposed as conservative. Following Frank’s successful brain surgery, the next course of treatment was chemotherapy for one year, to be followed by radiation therapy. The physicians in Texas told Phyllis and her husband that the cancer was almost surely gone after the chemotherapy, but they still recommended follow-up radiation therapy to ensure success.

They mentioned briefly that radiation therapy can be damaging to the brain, but the thinking was that it was worth the possible harm. Phyllis stated that she did not remember being told what damage could ensue from radiation therapy, but she remembered clearly that she questioned the need for radiation, since everyone thought the cancer was gone after surgery. As she stated, “I should have put my foot down and insisted about that. But we wanted the insurance that the cancer wouldn’t return... The first year I was horribly grieved because, well, it just hits you so hard.” After all three treatment modalities – surgery, chemotherapy, and radiation therapy – Frank was able to return to his teaching position with a brace on his leg, since the tumor had affected his motor function on the right side of his body.

Phyllis returned to the workforce for financial reasons during the year that Frank received chemotherapy. They had sold their businesses, curtailed their spending and travel, and had dipped into their savings to pay medical expenses. At that time, Phyllis found it useful that her college minor was in English, so she was able to obtain employment teaching middle school English. As she noted, “I was only two pages ahead of the students. It was hard!” Phyllis returned to work full-time while she also found herself picking up more and more of the household duties that her husband had done. In addition, she provided physical care to Frank as needed. For example, she helped with dressings and wound care and administered injections as needed.

Two years after Frank’s successful surgery and radiation therapy, Frank was still receiving medical surveillance that involved periodic MRI evaluation of his brain. In 2005, his routine MRI imaging showed a “spot on the MRI again in the brain, and it kept getting bigger and bigger” according to Phyllis. They returned to Texas hopeful that they

would have a good report from Frank's biopsy, and they were encouraged to find that the cancer had not returned. However, they were told that Frank had an unusual side effect of radiation therapy and that he would continue to suffer progressive neurological deterioration due to radiation necrosis of the brain. He was to have hyperbaric treatment and anticoagulant injections, which Phyllis administered. Unfortunately, Frank's condition continued to deteriorate, with the most rapid deterioration in the first two years, through 2007. His motor ability, speech, and memory were all rapidly deteriorating. Their friends became intolerant of conducting one-sided conversations, so the couple became less able to maintain their social contacts. At the time of our interview which occurred approximately six years after Frank was diagnosed with radiation necrosis of the brain, Phyllis reported that Frank was unable to walk up stairs, unable to speak, unable to toilet himself, and unable to participate in daily functions. Phyllis dropped out of her church choir.

While Frank's condition was deteriorating, their children were "getting into trouble" of a serious nature. Phyllis found that both younger children were involved in drug addiction and were engaging in criminal activities. Their daughter went away to college but dropped out and did not tell her parents. They only found out about this when the daughter had a medical injury and the insurance company refused to cover her because she was no longer a full-time student. Phyllis was upset that they then had the cost of the daughter's knee surgery in addition to expenses related to Frank's care. Meanwhile, their son dropped out of community college, refused to look for employment, and refused to leave home until Phyllis finally removed the son's belongings from their home and had the locks changed.

Eventually, Phyllis had to quit her employment due to increasing demands of caregiving for her husband. While she counts her blessings and meditates daily, she also reports that she has episodes of anger and frustration that she directs towards her husband. She demands that he do what he can to help with his own care and believes that he has maintained more function because she has not done things for him that he can do himself.

In our second interview, Phyllis talked about how she sometimes feels guilty that she wants to leave the house and do things and has to leave him with a caregiving situation. She said she sometimes takes him to a caregiver respite program so that she can leave and enjoy some social life or do errands, and she knows that he would like to come along but he cannot. She talked about experiencing “guilt when I want to do something or I have to leave him because it’s inaccessible or he is unable to do it. I feel really guilty.” At times, Phyllis admitted that she had even wished that her husband would die. When I asked her about the future, she stated, “Sometimes I really worry about it...Yes, there’s been many times that I wished that he would drop dead, when I’ve been depressed or overwhelmed. I remember saying that to my sister once. I said, ‘God, I just wish he would drop dead.’” When I asked her if she still loved him, she said, “Yeah, it’s different though. It’s different.”

At this point however, Phyllis’s life revolves around caregiving for her husband. She does what she can to take him out of the house, since he seems to enjoy that, but she has to be careful where they go because “it’s all about the bathroom.” She explained that she has to plan outings that are handicapped accessible.

Phyllis also voiced some frustration because she felt she does not seem to fit in with support groups and services. Her husband's cancer is long gone, but he has not had a brain injury of the normal sort. Her husband's brain injury was iatrogenic, and his course is one of deterioration rather than recovery. She stated that she finds the most common ground with a local brain injury group, so that is where she goes for some support. She also finds that her faith and church have been a great source of strength for her, although she is no longer able to sing in the choir as she did in the past. From time to time during our interviews Phyllis seemed bitter, angry, and depressed and stated that she felt that way. However, she seemed to take a practical approach to everything that has happened.

#### **Cancer Persists: Intermittent Maintenance Treatment**

The above three participants in the study were each primary caregiver for someone who no longer has cancer, but they each found themselves still living with the after-effects of cancer and its treatment. The following participants were caregivers for cancer patients who still required intermittent treatment for persistent cancer. At the time of our first interviews, these participants reported that their family member was not undergoing active chemotherapy or radiation therapy but may have been taking some medications.

##### **Narrative summary: Mike.**

Mike was a 37 year-old husband and father whose wife Beth was diagnosed with breast cancer three months after their second child was born. Mike and Beth had been high school sweethearts while growing up in Missouri. Mike was educated in electrical engineering at the U.S. Naval Nuclear School in Maryland and has moved to the Midwest

to pursue his employment opportunities. He has a sister in Missouri, and Beth has three sisters in Southern Illinois, Saint Louis, and Texas; neither of them have family close by. Mike and his wife are both strong Christians and are actively involved in their church and the children's Christian school. They have two children – a daughter and a younger son – who keep them both busy. Mike's wife was self-employed as a graphics designer prior to her diagnosis of cancer but has needed to stop working, even from home, since being on cancer treatments.

In 2005, Mike's wife Beth had just given birth to their son and was happily caring for their young daughter and the new infant boy. When the baby was about three months old she felt a breast lump and thought she had a plugged milk duct, so she went to her nurse midwife, who sent her for a mammogram. Neither Mike nor Beth expected this to be anything serious and were surprised to find that it was cancer of the breast. Neither of them had a history of cancer in the family, and Beth did not have any identifiable risk factors, so this diagnosis was overwhelming as well as shocking to them. Mike was working for an electrical firm in which there was little flexibility in terms of working hours and time off, so he found that he was unable to go to many of the appointments with his wife. Her mother came to be with the family during this process, and it was Mike's mother-in-law who coordinated the care of their small children and transporting Beth to many of the diagnostic testing appointments. Mike reported that he received the news about Beth's diagnosis over the phone, and this was bothersome to him, but he took a rather practical view of it after so many other events had passed.

Beth's treatment included bilateral mastectomy followed by chemotherapy with ovarian suppression for five years following. Five years later, in 2010, Beth was

pronounced cancer free and was placed on medical surveillance. Not quite one year after that, however, Beth developed numbness in her face and tongue, so she once again sought medical advice. A Positron Emission Tomogram (PET Scan) revealed stage 4 metastatic carcinoma of the breast involving the bones of her head, shoulder, ribs, pelvis, and legs. As Mike puts it, the cancer “came back with a vengeance” and is “treatable but not curable.” Beth’s options were to return to chemotherapy, trying new medications for that, and then follow chemotherapy with a course of radiation treatment. Mike reported that Beth is a “picky eater anyway,” but the radiation therapy caused her to have esophageal problems and digestive issues that still persist. When I interviewed Mike the family was learning to live with permanent cancer and hoping to do well on the maintenance medications in order to postpone chemotherapy as long as possible. It was Mike’s expectation that there would be the need for intermittent chemotherapy from time to time, but that the cancer would eventually take Beth from them.

I interviewed Mike at his office building. When his wife was diagnosed with cancer he had been employed as an electrical engineer in a factory situation which allowed him little flexibility of work hours. At that time, it was understood that once he was at work he was expected to work the entire shift, so he found his employment incompatible with his caregiving activities, especially when the children needed him to be home due to Beth’s illness and treatment effects. His employer at that time also required him to travel extensively, so that became a problem as well. Mike was forced to look for other employment, and he reported that he followed a series of leads, only to reject job offers if the insurance was not good or if there was no cancer center nearby. He also noted that at least one potential employer never called him back after he had been

honest about his wife's medical condition, and this seemed to be a source of pain for him. As he put it, "That's not legal, but I can't really make a case that it happened."

Mike eventually found employment as an electrical engineer with an out-of-state company that allowed him to telecommute and required little travel. He stated that when Beth would need to have chemotherapy again he would probably need to make adjustments in his work schedule accordingly, but he felt optimistic that this employer would allow that flexibility that he so valued. In addition, he had begun a self-employment situation just before his wife's cancer returned, so he decided to maintain that activity "just in case."

Mike's experiences with Beth's diagnosis and re-diagnosis were problematic for him. He found out his wife's cancer had returned via phone call, since they were not expecting the cancer to reoccur and he had gone to work that evening. His mother-in-law had accompanied his wife to the doctor's office and phoned him with the bad news. Mike was also emotionally unable to stay at the hospital during his wife's mastectomy surgery, which he stated was "problematic" for the medical personnel. When I asked him why this was his approach, he replied that "I don't wait well, and you would not like me around if I am waiting for something important." He went on to say, "The doctor was not very happy with me. Her parents were there, though."

Mike reported that his wife tried to be as independent as she could be during her treatments and beyond, so he found himself trying to focus on "paying the bills and keeping things together" for the family. He had difficulty managing the competing demands of two very small children, a demanding job, and his worry for his wife's cancer treatment, side effects, and outcomes.

Mike voiced concerns that his wife's care could have been better if perhaps the medical community would have tried alternative and complementary therapies initially, but he said he did not want to ask the oncologist if he would have done things differently, looking back on things. Mike said his wife was happy with her care, but he always wondered if any advances had been made in breast cancer treatment that might have made a difference in the outcome for Beth. I asked him if he had brought this up to the oncologist, and he replied, "I'm not sure I could handle his answer." He was not willing to elaborate on that.

Turning points for Mike were when he was forced to look for other employment, when he found acceptable other employment, and when they received the second diagnosis of cancer. While he identified his faith as primary in "keeping me going," he also said that the diagnoses were some of the toughest times he could imagine. He stated, "I really wasn't prepared for any of the initial news... You have to adapt and keep expectations low."

One thing that Mike discussed at length was his need to make all plans for himself and the family tentative, pending Beth's health. For example, the previous Christmas holiday they had opened presents and then taken Beth to the emergency room. She was diagnosed with pneumonia that day. Mike said he would make other plans, thinking that Beth's symptoms and side effects would allow her to participate, only to find that the symptoms of cancer treatment would last much longer than they anticipated.

I asked Mike if he had enough information to meet his needs, and he responded that he was unable to focus on the details of cancer information and found himself avoiding that topic. On the other hand, he noted that Beth would "arrive home after a

doctor visit and get on the internet to look things up,” so he felt that she would find out what they needed to know. In that way Mike would not have to look for the information himself.

When I asked Mike about how he and Beth discuss her illness, he said he often comes home and is unable to cope with discussions about cancer, but he finds it helpful to read Beth’s blog online later in the evening. Beth had begun a blog to provide her thoughts, updates, and advice online so that someday when she was gone the children could read, listen, and see. As Mike put it, “The children aren’t really much in the loop right now because they are so young, so she does this to show them later on how much she loved them.” Mike also finds the blog helpful, since he reads the updates that are emailed to him and can process the updates in depth and in privacy. He can also revisit Beth’s blog and finds the posts of love and support from others immensely helpful. He noted that their church family members have been incredibly supportive, especially in meeting the needs of Beth and the children, and for that he expressed heartfelt thanks.

Mike discussed his insights and reflections on the healthcare community at some length. He expressed a “new appreciation for the profession of nursing” looking back on all of the nurses who had helped him so much. However, he was not quite as enthusiastic when speaking about the medical community. For one thing, there were times when he felt that the physicians were focused on the cancer and not on people. He expressed a desire to have a physician with “a human quality – a sensitivity to how people are going to react to what you’re presenting... We’re not animals to just siphon through and get the check list done.” Mike declined to discuss this matter further.

Mike's body language during our interview was rather tense and closed at times, but relaxed and pleasant at others. He looked around a lot and lowered his voice to almost a whisper from time to time as if thinking aloud to himself. In addition, there were some topics that he was firmly not willing to discuss. For example, he was not willing to discuss the future. He stated that his goal and hope is simply "to keep her around for as long as possible." He went on to say, "I don't make plans long term. I just don't try to make a definite 5 to 10 year plan... and just avoid looking farther [became tearful at that point]...Everything that I do has an asterisk note on it that says, pending [Beth's] health." He noted that he was finally in a good place in terms of his career goals, but "now... I gotta remember priorities, and realize that that's not who I am, I guess."

Mike is intensely protective and quite devoted to his wife and family. I noticed that when I asked him how he was doing, he would always reply something like, "Well, she's..." When I pointed out that he always answered the question "How are you?" with a reply about his wife, he responded, "Well, I am however she is."

As for his own health, Mike admitted that the stress "gets to me sometimes." On the other hand, he stated that it was important for him to find ways to handle his stress through wellness behaviors because "I have to stay healthy for the sake of the kids." His conversation at the end of our interviews was focused on his philosophical thinking. He noted "I have had to grow up. I have to be a dad, taking on responsibilities and changing my priorities... So we're a lot more cautious as a family. We keep planning to a minimum."

Since our interviews, Mike's wife has had bad news on her PET scan and has returned to chemotherapy. The cancer has spread to her brain, liver, and near her ureter. Their church friends recently held a community benefit for the family because Beth would like to know that her medical bills will be paid and the children will be able to go to college someday.

**Narrative summary: Rose.**

Rose is a 43 year-old respiratory therapist whose father was diagnosed with lung cancer in 2009 as he underwent routine preoperative testing for carpal tunnel surgery. Rose has two brothers who live out of state, but they are both married and have families. Rose was living in the Midwest near her elderly parents, but when they began to suffer failing health she had them both move in with her so that she could someday provide the care that they needed. Rose has practiced at a local medical center for over 20 years as a respiratory therapist and was never married, so she has always worked full time. Her mother was having difficulties with early dementia when she had her parents move in with her, but her father had been in fairly good health. She has aunts who live within driving distance, but they are quite elderly.

In 2009, Rose's father became aware of some pain in his hands and arms, so he sought medical care. He was diagnosed with carpal tunnel syndrome, so he saw a surgeon and prepared to have surgery. Rose applied for and received approval for Family Medical Leave Act (FMLA) leave from her job so she could care for both of her parents when her father had carpal tunnel surgery, one wrist at a time. In preparation for this surgery, Rose's father had a chest x-ray imaging done, and "that showed something." One referral led to another, and each healthcare specialist ordered imaging. Finally, the

oncologist ordered a PET scan and found a suspicious mass. There was still no confirmed diagnosis because the biopsy was not definitive, so Rose took her father to a thoracic surgeon who performed a thoracotomy and made the diagnosis of Stage IIIB lung cancer. All of the medical care for the lungs had to be done at the same time as Rose's father was having his carpal tunnel surgeries because she only had six weeks of leave available from her job. Therefore, Rose's father had one surgery every two weeks: a right wrist carpal tunnel surgery, the thoracotomy, and then the left wrist carpal tunnel surgery. She returned to work two weeks after the second wrist surgery. These things all happened in spring of 2010.

When Rose's father returned to the oncologist they received the diagnosis of a spiculated malignancy, non-small cell type. Her father evidently had done some research on the topic, and he was apparently greatly relieved when he found out that the cancer was not small cell, and he "simply deflated and relaxed." Rose said it was difficult to see him develop cancer of the lung because she had tried to convince him to quit smoking for several decades. He had smoked all of his life.

Rose vividly described the diagnostic process and the effect that it had on her and on her father. She reported that she was a fastidious note-taker, and she found herself immediately overwhelmed and unable to process all of the detailed information that the oncologist gave them along with the diagnosis. She said that she and her father evidently appeared to be in "overload," so the oncologist said they could go home to think about things for a while and return in two weeks to discuss their options and to find out more about what was happening. Rose was grateful for that reprieve, but she said her father did not want to talk about the cancer and could not bring himself to even say that he had

cancer, even to his siblings. Rose said that her mother was completely overwhelmed and seemed unable to cope with the situation, so Rose said it was “up to me to take over the task of navigating us through what was ahead.” Rose was also quite concerned about her mother’s failing health, and she was reluctant to burden her mother with anything related to caring for her father. Meanwhile, Rose’s employer – a large, tertiary care medical center – were quite tentative in allowing her to miss work or to change her schedule to accommodate her parents’ needs. She stated, “After all, their perspective was that I had just been off for six weeks and that needed to come to an end.”

Rose found it helpful in terms of coping and staying on top of things to keep copious notes about her father’s condition. She immediately began to keep detailed logs of all of his tests, imaging, treatments, side effects, and responses to care. After they returned to the oncologist’s office, they found that the cancer was inoperable, but her father would require ongoing intermittent chemotherapy for the rest of his life, and chemotherapy was initiated in June of 2010. The oncologist would provide him with chemotherapy of a certain type as long as the tumor did not grow in size. Once the imaging showed growth in the tumors they would need to change to a different drug for chemotherapy. Since chemotherapy is every three weeks, Rose reported that at the time of our interview her father had just completed chemotherapy session number 21.

Rose reported that her father was quite symptomatic after each chemotherapy session with diarrhea, nausea, fatigue, sensations of coldness, inability to keep his feet still, and symptoms of peripheral neuropathy. She found that he responded to ginger brew for the nausea, but his alternating diarrhea and constipation was challenging for her

to manage with her full-time employment, especially when the hospital changed her working hours to twelve-hour shifts in 2011.

From the beginning, Rose found that her greatest supporters were her “church family.” They brought in meals, sat with her father if needed, and were otherwise supportive, but they did not provide the level of physical care that Rose provided. Rose found it necessary to arrange her work schedule around chemotherapy days and the days when she knew her father would need her help the most, and at that time she would be off work at the hospital and very much at work caring for her father’s physical, emotional, and psychological needs. She found this regimen quite “isolating.”

Rose was becoming very concerned about the competing demands of her mother, her father, and her employment when a tragedy relieved at least some of her burden. Her mother suffered a stroke in early 2011 and died a week later. While this was incredibly painful for Rose and her father, Rose admitted that it meant that she would not need to worry about her mother’s care for the future. Rose and her father experienced grief together after her mother died. They found that the things her mother had been doing around the house were no longer being done, and Rose noticed that her father was no longer interested in his appearance, cooking, or eating other than very simple meals.

Around the same time that Rose’s mother died, her father developed an incapacitating cough, so she called the physician. The cough was from a pleural effusion, and her father required a thoracentesis to drain two liters of fluid from his chest. As a result of the events of winter of 2011, Rose reported that she has been planning for the loss of her father, “for the time when he is no longer here to advise me.” She told about having him identify people in old photographs of family members, having him write

down the schedules for home maintenance tasks, and having him discuss decide what he would like to do with the rest of his life. She wistfully discussed the planning that would be required, for example, to take her father on a train trip across Canada.

Rose stated that everything – even the most simple things – takes planning and effort. She discussed the fact that her father will not accept oxygen at home, a feeding tube, a breathing tube, or other life-extending measures when the time comes to decide those things. She became tearful when discussing the future and also when discussing happier times in the past.

During our interviews, Rose sometimes seemed to forget that her mother had passed away and would speak about her as if she were still alive. She talked about caring for her “mother and father” on several occasions. Rose also seemed to be intimately connected with her father’s cancer treatment, and would say things like “we” began chemo and “we were tired.” She talked about her meticulous planning that was required to make sure her father had what he needed when she went to work, and she reported that she had changed her work hours to better care for her father. However, she seemed to be disappointed in her co-workers, who “had the attitude of ‘hasn’t he died yet?’” It seems that at first when her father was diagnosed and treated there were plenty of people who understood and cared, but lately that well of understanding and kindness “has sort of dried up.”

Indeed, Rose’s employment has not been a positive force in her life throughout her father’s illness. At first, the people at work were supportive, but now that she is working 12-hour shifts things have become more burdensome than ever, and Rose reported finding herself in a position of having to refuse to work overtime. She said she

tried to explain her situation to her supervisor, but they are no longer sympathetic or helpful. She said the attitude is, "I ask you and you say yes. That's how it is supposed to go." Several of her co-workers and supervisors have made comments that she is using her father's illness as an excuse to not work extra when needed, even though she tried to explain the planning it took for her to leave her father even for a day. She also noted that she is unable to do social activities such as going out with co-workers after work, and there is some resentment for that as well.

Nevertheless, Rose remains a staunch advocate for her father. For example, at one time she found that she was unable to return to work after another family leave because he was not making adequate progress in his physical therapy. She reported that the supervisor's response was "Well, you need to be here to care for our patients" but she pointed out that she also had priorities at home. All of this seemed to be stressful to her.

Looking ahead, Rose seemed interested in trying to make her father's last days as happy as possible. She would like to have taken him on a train trip because he likes trains, but that seems to be impractical. She said she often wondered aloud if it would have made a difference if she would have had children and a husband to support her and to provide her with diversion through all of the caregiving experience. Nevertheless, she is determined to provide care for her father and to anticipate what is needed. Her only worry at the time we talked was the fact that she had experienced a large tax bill and it had decimated her savings that she had set aside for her father's funeral. However, she is organized and dedicated and has confidence that she will be ready when the time comes.

Rose voiced the fear that she could become ill and everything would fall apart. She was determined to provide her father's care, but she was also aware that her situation

at work has been at times precarious, so she is worried about that. She voiced concern that the isolation feelings would continue and even worsen, and she felt that at the same time she had fewer and fewer options for herself. For example, she said she would like to move away from the area to either return to school or to further her career in a different location, but she believes this is not feasible while her father still needs her to care for him. She said she felt she had to stay where she was working, but she also felt that her life circumstances were keeping her from being able to do what her employers wanted her to do. She said she did not want to think about what might happen if she should become ill and need care herself, both in terms of her employment and in terms of her father's care.

**Narrative summary: Robert.**

Robert was a 58 year-old executive with a major multi-national corporation whose wife Lois was diagnosed with multiple myeloma three years ago at age 53. This marriage is Robert's second marriage, but they had been married almost 25 years when we spoke. Robert had a son from his previous marriage, and he and his wife had two daughters. One daughter was about to graduate from college in California, and the other daughter was a psychologist in Colorado and was expecting their first grandchild in a few months, right after her sister's graduation.

Robert had an emotional burden from the sudden and traumatic death of his young son 15 years ago from an all-terrain vehicle (ATV) accident. Robert blamed himself for the death of his son because he had allowed him to ride on the ATV without a helmet, since there was no helmet small enough to fit. Ten minutes into the ride, his son was thrown from the ATV and hit his head. The son spent a little over a week in

intensive care before being taken off life support due to brain death. Following the death of his son, Robert experienced bouts of heavy drinking, faith crises, depression, and marital problems. He attributed the survival of his marriage to his wife's steadfastness and strength, plus the fact that he decided he had to be a father to his two daughters even after the loss of his son. Robert has also been supporting his mother, who has a gambling addiction and has lost everything she had twice due to her gambling. Robert and Lois provided a financial safety net for Robert's mother and restored her financial stability twice during the past ten years.

Robert and his wife had been looking forward to a retirement together. Robert reported that "everyone on my side of the family is dead from cancer" but he said his wife's family history is negative for cancer. Therefore, all of their retirement plans had been predicated on the idea of Robert dying before his wife, and he and she had planned things so that she would be in a good position after his passing. It was ironic, then, that Robert was in a position to care for his wife with cancer, especially since this type of cancer is atypical in a middle aged, Caucasian female.

In July of 2009, Robert's wife fell while walking their dog and hurt her hip. A few weeks later the hip was still painful, so she sought medical care. She was referred to an orthopedic specialist after muscle relaxants were ineffective. The orthopedic specialist ordered an MRI of the hip, and the technician saw something that drew his attention at the edge of the imaging field and asked to have further imaging done. The extra images revealed that Robert's wife had multiple lesions in her hip area as well as the spine. Her only symptom was hip pain. Robert expressed dismay and amazement that Lois had

become so very ill, since he described her as “very healthy, she took excellent care of herself.”

With his family history background and the guilt he felt after his son’s death, Robert “did not want to make any mistakes. I needed to care for my wife and not leave it to someone else.” Therefore, he insisted on being the person to take Lois to doctor visits, to care for her during her medical treatments, and advocate for her as an active member of her medical team. When he and I spoke I found him to be extremely knowledgeable about multiple myeloma, its treatments, and medical tests and imaging. For example, he knew his wife’s history of Kappa light chain protein levels before, during, and after her treatments. In short, Robert became an intense participant and a determined advocate for Lois in her illness.

Lois was referred to an oncology team, who administered intensive chemotherapy in conjunction with Mayo Clinic protocols. Robert and Lois went to Mayo Clinic on several occasions in order to update her treatment, since their local oncologist had done his oncology medical residency there. After intensive chemotherapy, Lois was monitored for her response. Unfortunately, she did not respond to the chemotherapy regimen as they had hoped, so changes were made and another round of chemotherapy was begun. After some time it became apparent that Lois’ response to the new chemotherapy was less than stellar, and she underwent an autologous stem cell transplant in 2010 at the local hospital facility. Robert reported that this treatment was incredibly hard on Lois and required her to stay in the hospital for three weeks.

Meanwhile, Robert found that he was unable to work at an acceptable level in his job and do all the caregiving activities, so he made the decision to retire early so he could

help his wife through stem cell transplant therapy. He wanted to “be the one” to give her injections, take her to her medical appointments, monitor her health and safety, and help her with her medications. He was a full-service caregiver and even gave her baths when she was in the hospital.

After the stem cell transplant, Lois enjoyed a partial remission of the cancer, so the couple traveled a lot. As Robert noted, “We spent the last year stuffing in everything we planned to do in retirement.” He said they had spent the travel budget “six times over” the previous year, traveling to Mexico, California, Colorado, and other places. Robert explained, “Realistically all that money we set aside for retirement, she’s not going to be around to enjoy [tearful, bouncing a coffee cup lid nervously], so let’s enjoy it as much as we can now... The plans that we had for 15 years from now aren’t going to happen, ten years from now, five years from now.”

Unfortunately, right before our first interview in late 2011 the cancer “returned full-blown” with tumors in her spine and a large tumor in her hip that was growing fast. This meant that between our two interviews the couple would be traveling to Mayo Clinic once again for treatment planning.

Through all of her treatment, Lois tried her best to hide her illness and to minimize the severity of her situation. However, Robert disagreed about the wisdom and efficacy of that approach. For example, Robert noted that he found out from his son’s death that he needed to open up more to people, to accept the support of others, and to lean on his support systems. At the time of our interviews Robert reported that she was very, very ill and did not acknowledge this to family or friends. Robert did, however, receive support from the oncology team, his pastor, and his close friends.

Robert thought the medical care for his wife was sometimes “wonderful and sometimes not so wonderful.” He had a close relationship with the oncology team, but there were times when Lois was in the hospital that he felt her life was in danger because of incompetent medical care. One significant event occurred when she had been on immunosuppressants due to the stem cell transplant. She was admitted to the hospital because she had a significant fever and sepsis. She was admitted to the oncology unit, but when her blood pressure became unstable they needed a critical care bed for her. For some reason she was transferred to neurological intensive care. During the night, however, Robert found out that her blood pressure was around 70 to 80 systolic, and he became worried about why the pressor medications were not working. The neurological intensive care unit staff told him she was on no medication for her blood pressure “because they were not ordered.” He advocated for his wife, and the next move was to the Medical ICU of that hospital, where they began to treat her hypotension as well as the fever and sepsis. After about four days in that unit she was still running fevers and still on pressor medication, but things were improving. An unfamiliar physician came into the room and told Robert that they would be transferring Lois out of the ICU because her blood pressure had been stable for three days (when it had not been stable), her temperature had been down for 24 hours (when it had not been down), and because they thought her fevers were from a medication that Robert knew Lois was not receiving. He refused to allow her to be transferred out, and the attending physician became angry. Meanwhile, Robert found out later that the nurse manager of the oncology unit had been arguing with the medical ICU that Lois was not stable enough to be transferred out of intensive care. The end result of this confrontation between Robert and the medical staff

was that Lois was packed up and prepared to move to the oncology unit, which was on the other side of the hospital. By the time Lois was ready to leave, however, she showed signs that her fever was up, so they took her temperature and it was 105.5 degrees Fahrenheit. Therefore, Lois was allowed to stay in the medical intensive care unit and was placed on a cooling blanket. As Robert stated, “They almost killed her.” Robert had high praise to say for many members of the medical team and for nurses, but there were some notable exceptions in among the medical staff.

All of the advocacy, the monitoring, the vigilance, the worry, and the caregiving took a heavy toll on Robert. As he stated:

The more in depth you get into being a care giver the less you are really looking at yourself... then all of a sudden it's like a tsunami hitting you... all at once. That can be debilitating for you as a care giver, and you can become ineffective. It's a tough tightrope to walk... You feel like anything you are feeling is insignificant in comparison to what the person you're caring for is, so you start looking at yourself as being insignificant.

When we met for the second interview, Robert looked as if he had not been sleeping or eating well. His eyes were bloodshot, and he was more intense than he had been before. He reported that he was having trouble due to the fact that his wife had minimized the extent of her disease, and now even family members didn't realize how truly sick she was and how close to death she had come recently. He was feeling alone and worried. His two daughters live out of state. One is pregnant and expecting a child in a few months and cannot understand why her mother is not able to come to be with her for a few months. The younger daughter is graduating from college several thousand miles away, and she is expressing concern that her parents will not be able to attend graduation. This was all weighing heavily on Robert.

In addition, Robert occasionally coughed and then winced while we spoke. During the first interview, he had a text message on his phone to remind him that he had a CT scan scheduled for the next day. He explained that he had pain in his abdomen and a mass to go along with the pain. The physicians thought at first that it was a hernia, but it was not a hernia, so the CT imaging was planned. As Robert said, however, “I can’t be sick now. This will have to wait.”

Robert voiced a sense of urgency about things. He felt that exercise helped him to cope with Lois’ illness, but he was not able to exercise most recently due to the abdominal pain. I asked him about his goals. He replied that his goal was “to make it through this without hating God, hating each other, and setting an example for others, especially for our children.” I asked him if he found out some things about himself through this experience, and he replied, “I found that I am as strong as I thought I was, but not as insulated as I thought I was. This hurts.” He went on to state that he felt he was a “better, kinder – but sadder – person.”

I saw Robert elsewhere in the community about six months after our last interview. He told me that Lois had recently died, having held the grandchild and having gone to their daughter’s graduation.

**Narrative summary: Shirley.**

Shirley is a 54 year-old female whose husband was diagnosed with nodular lymphoma five years ago. Her husband had chemotherapy for the lymphoma, but they knew that her husband would experience a return of the lymphoma that would require repeated chemotherapy. The lymphoma returned in 2010, and Shirley’s husband underwent a year of chemotherapy, ending in July of 2011. Unfortunately, she reported

that her husband was experiencing hip pain again, which had been a sign of his lymphoma, and this time if this is what is going on the lymphoma would have returned earlier than expected. When we talked, Shirley noted that her husband's CT scan was not remarkable, but he was to have another CT scan the next month, and they worried about what that one would show.

Shirley is 17 years younger than her husband, who is 71, and the marriage is a second marriage for each of them. She reported that she and her husband were both divorced when they met, but she no longer had contact with her former husband because he had "abandoned" her. They have one adult daughter, who lives in Texas, and Shirley's husband has three adult children who live closer to them but are estranged from their father. This is a matter of some emotional pain for Shirley, who cared for her stepson when he became a quadriplegic after an automobile accident when he was in his teens. Today he is able to dress himself, drive, and live independently.

Shirley and her husband have several grandchildren of their own, plus there are several grandchildren from Shirley's stepchildren. She reported that she makes an effort to keep in touch with all of the grandchildren, but it is easier to communicate with the family in Texas than it is to communicate with her stepchildren and their families because of their estrangement with their father.

Shirley reported that she had cared for other family members through the years, so she felt somewhat prepared for caregiving. Shirley had three brothers, each of whom had hemophilia. Two of the brothers contracted HIV/AIDS infections from infected blood products, and one of the brothers had a wife who became infected from the husband and died before he did. Shirley's third brother did not contract the HIV infection, so he

remains living and in another part of the country. Shirley's father had vertebral stenosis, which was quite severe and caused him a lot of pain. He was self-employed in the restaurant business, and he delayed treatment for his cervical spinal stenosis until he suddenly had a spinal fracture which left him with severe quadriplegia. Shirley helped care for her father for many years. Finally, Shirley cared for her mother-in-law in her home for 6 years before the mother-in-law died of Alzheimer's disease. Shirley remarked that her mother-in-law was very pleasant but severely impaired when she lived with Shirley and her husband. In short, Shirley felt that she was prepared for caregiving.

Shirley's main concern regarding caregiving, however, was that she did not feel physically able to provide much care of the physical sort because she had chronic spinal problems similar to her father's condition. She had had neck surgery to relieve pain on several occasions, and this was why she was not employed when her husband was first diagnosed with lymphoma. In addition, Shirley was diagnosed with lung cancer and had a thoracotomy shortly after our first interview. She was in the library with her granddaughter shortly after the biopsy, and received the diagnosis by way of a phone call to her cellular phone. She said she was stunned and went right home. She stated, "I just needed to sit down and process that news for a bit." She had to delay our second interview so she could recover from the surgery to remove a small part of her lung, but she was happy to report that she was expected to have no further problems with cancer and expected to require no further treatment past surgical removal of the encapsulated malignant lesion. Her only other medical problem was asthma.

When Shirley thought back about her husband's diagnosis and early treatment, she did not elaborate about the symptoms, other than to say that the malignancy was

found after a routine examination that her husband had with his family physician. Her husband had complained of hip pain, and then as Shirley noted, “one thing just led to another.” At first they thought her husband had bursitis, so he received cortisone injections. However, when he was referred to the orthopedic specialist and had imaging done they found the lesions in his bones, which turned out to be malignant lesions. When Shirley’s husband was diagnosed she was on medical leave from her job as an administrative assistant due to her cervical spine surgery to relieve pain. She returned to work “for a short time” afterward, but she soon realized that her husband needed her more at home than she needed to work, so she quit her job. She had fully intended to return to work after his chemotherapy course was completed, but at that time they both decided that they wanted to spend more time together. Shirley remained active, however, by volunteering with her church, doing things with friends, and being very active in a Christian women’s group. She stated that what kept her going were her faith life and her friends and social contacts, saying that they are very important to her. She reported that she has always valued her independence and her friends.

Shirley stated that the diagnosis of cancer in her husband meant that “I was on my own, more or less, with my own problems.” Moreover, she noted that when her husband had chemotherapy treatments he would become irritable and taciturn for days after each treatment. She said she had “to walk on eggshells... You have to be careful of how your body language is when he gets like that.” She said when he was in treatment she was required to be at home with him to help him with meals and symptom management, but she said other people would avoid being there because he was so irritable. She said that his chemotherapy treatments lasted all day, during which someone would sit with him at

the chemotherapy center. On the day after chemotherapy he mostly rested and slept, and the third day he would have more chemotherapy. When her husband would be in treatment she would go out by herself when he was able to be left alone because she felt she had to get away and because he was “fatigued and sleeping a lot anyway.”

In general, Shirley believed that the diagnosis and treatment of her husband’s cancer had impaired their relationship with each other. She stated that they had always had a good time, going out and taking trips from time to time, and all of that tended to change after his diagnosis, even when he was not in treatment. At the time we spoke, she was wistfully discussing the possibility of taking a trip to Texas to see her daughter and grandchildren. The trip had been planned on numerous occasions but had always been cancelled due to her husband’s fatigue level or treatment. She noted that a year ago they had paid for her daughter and grandchildren to visit them at her home, but she said it was not the same as seeing the grandchildren where they lived.

Shirley reported that her husband had always avoided using the services of the Cancer Center for Healthy Living, but she enjoyed the support she gained from talking with the staff there. She stated that the second diagnosis of lymphoma had been a turning point for her husband and for her. She said, “Well, life is still good, but you... realize that life is shorter and you just enjoy the little things more instead of going places and doing things.” She said that since his most recent treatments for cancer her husband had become “possessive,” not wanting her to go places. She stated that she was unhappy about this, but she believed that it was due to the fact that he had become increasingly preoccupied with his death and the idea that he may not live much longer.

Shirley, on the other hand, has other worries. She stated that she is worried about how she would be able to care for him if he became less able to do things for himself and would need more physical care than her cervical spine condition would allow her to do. She voiced concerns that she would be unable to help him with heavy physical activities, but if he needed a nursing home she worried that she would not be able to afford that living arrangement for him.

Shirley repeatedly voiced concerns about what she called her husband's possessive nature. She stated:

He's becoming more possessive, not wanting me to go places and wanting us to stay together more. I still have a lot of things I like to do... I told him I would cut back on going places... so that I can stay with him more.

She noted, however, that her friends were not happy with the situation either:

You need to let [friends] know, it's fine but you're not in the situation. You don't have to live there and deal with it if there's anger issues and things... It wasn't this way in the beginning. It's just been this last... year and a half he's becoming more possessive.

Shirley stated that her husband "keeps talking about death... it gets me down."

She stated that she wants to get by in the short term. She noted that people think that cancer is a death sentence, "that you're not going to be around long." She preferred to take life one treatment at a time, one episode at a time, and not look too far into the future. As Shirley summed it up, "I miss my grandkids. I miss the health. I miss the travel. Those are some of the things that we've lost... We just live in the moment." At the time of our interviews, Shirley was hopeful for a good report from their CT scans the next month, hopeful that they would be able to travel to Texas, and hopeful that she would continue to be adequate for the task of caring for her husband as they traveled the uncertain future.

**Narrative summary: April.**

April is a 33 year-old mother of a 9 year-old daughter. Her husband was diagnosed with an oligoastrocytoma in his brain a little less than two years prior to our interviews. April and her husband Cole were high school sweethearts, having met when April was 15 years old. When Cole graduated April quit high school and married Cole shortly thereafter. They had planned a small family, with April's role being mother and home maker and with Cole's role being that of employed husband and father. They had a daughter a few years after they married, and the family was happy, according to April. About two years before Cole's diagnosis, Cole lost his employment as a diesel truck mechanic, and they found that it was difficult to pay expenses while there was only unemployment money coming into the home. Their savings account was drained by living expenses, and they had to live with Cole's mother. Cole eventually found other employment, but at a lower salary, so they decided that it would be advantageous to move to a small community where the cost of housing was less than it had been where they were living before Cole lost his job. April reported that they had "just gotten back on our feet again financially" and were planning to begin insurance coverage in a few months when her husband became ill.

April reported that she had grown up in a household in which there was domestic abuse, so she was determined to make a peaceful childhood for her daughter. At the time Cole became ill, both April and Cole had mothers who lived within driving distance, but neither of the mothers was especially supportive of April. Occasionally April could rely on her mother to watch her daughter, but that was the extent of the support from family

members. Cole's mother was employed as a medical office assistant for a large oncology group, but April reported that "she made it all about herself" when Cole became ill.

Cole was diagnosed in 2010 at age 32 when he suffered a grand mal seizure at home and was taken by ambulance from their small-town home to a large medical center. Their daughter was 8 years old at that time. The family was awakened in the middle of the night when Cole fell out of bed and began to have a seizure. April told their daughter to remain in her room until she came to get her. Then April called the ambulance team for their small community. The ambulance service was staffed by volunteers who were unable to render significant help, but they were able to transport April's husband to the local small hospital, where the emergency room staff did a CT scan and told April "there was something in his head." Cole was transported to a larger medical center in a neighboring city, where an MRI revealed a mass in the right brain area. On the second day, April met the neurologist, who told her that surgery was needed as soon as possible. They put Cole on anti-seizure medication and sent the family home to wait for a few days prior to surgery. April reported that she was "numb" and that they were "pretty naïve" about what would happen, and they had no idea what to expect from the surgery. She reported that the house was filled with people visiting and bringing food.

A few days after the initial seizure, Cole had 8 hours of surgery and was able to recognize and speak to April when he awoke. When he spoke to her, she reported that she broke down in tears and went into the hallway. April's mother-in-law followed her to the hallway and told her to "suck it up because he needs you." Two days after surgery they were able to go home, but other than a follow-up appointment with the surgeon there was no information for April about what to expect. When her husband began to have

recurrent seizures at home, April called the surgeon's office and was told "Well, this is his surgeon; we don't take care of his medicine." She did some internet research and decided that she should contact the neurologist. She was told by the neurologist's office staff that her husband should expect to have seizures because he had undergone surgery. They also mentioned that he may need to go to the epilepsy clinic.

April did not meet the oncologist until one month after her husband was diagnosed and weeks after his surgery. She reported that the tumor was a mixed glioma (glioblastoma) that could not be entirely removed with surgery, but the surgeon had been able to remove a sizeable portion of the tumor. April reported that she did not know what to expect after Cole's surgery:

He didn't have any balance... He had headaches, but it was mostly from the brain swelling... They sent us home and that was it. He was on anti-seizure medication. He wasn't working anymore. I had to call his job, and it was scary because we didn't know how much to tell them because we didn't know what was going to happen at all... They didn't send us home with any kind of information. They said to watch his wound... and if we have any problems to call them, but no one told us about his antibiotics. No one told us about his medicine... I had no idea what to do.

Six weeks after Cole's surgery, he had another MRI and began thirty days of radiation treatment, which made the daily seizures worse. Through all of this, the neurologists had added to Cole's anti-seizure medications until he was taking three different medications. April reported:

They switched to a neurologist that was a lot more, I don't know, caring and acted like he didn't want [Cole] to have seizures. Because the other doctor was like, oh yeah, this is normal... We're thinking okay, brain cancer's one thing, but having seizures every day... like he had no quality of life... it was ridiculous.

April reported one particularly unpleasant incident when Cole was in the bathroom while she was making breakfast for the family. April heard a noise from the bathroom, and Cole had fallen in the bathroom:

It was a nightmare. He was stuck in the bathroom because our bathroom is so little. I couldn't get in to him. He was convulsing on the floor. I mean a mess. He hit his mouth and there was blood. You know, when they slobber so much with the seizure it made it look ten times worse... That was one of the hardest days. The seizures were the worse, by far. It was the scariest thing.

Finally, about one year after diagnosis Cole's seizures were under control, and he was able to drive a few months before April's interviews early in 2012. April did not, however, have total confidence in Cole's ability to remain seizure free, so she would not allow their daughter to ride with her father when he was driving. She reported that she remained on edge:

I had come to the point like we, I started making all these rules up. Like I can't leave him alone. I can't leave him alone with my daughter. I can't do this. You know, he's got to be with someone at all times. I would get someone to sit with him so I could go get groceries and medicine, and that's literally all I did. I didn't do anything. I didn't go anywhere. I mean I didn't do anything at the school, which I used to do with my daughter... It took him actually being seizure-free for a while to breathe again.

April reported that there were ongoing financial concerns that weighed heavily on her. She stated that they had no health insurance when her husband was diagnosed, and it took one month to begin to receive Medicaid assistance. She reported that they received approval for Medicaid only because they had a young daughter. Six months after Cole was diagnosed they were approved for disability payments through Cole's former employer, and Cole had not been able to return to work at the time of April's interviews. Cole's cancer is expected to become more active at some point, and it will be fatal eventually, but April does not know if that will be in a year or in 15 years. The future is

undetermined for them, so she voiced the need to make some plans to be able to support herself and her daughter at some time in the future.

Another major concern for April was their daughter's well-being, especially her fears of losing her father and of being left alone with him in case he had a seizure. Their daughter was on summer vacation from school when her father's cancer was diagnosed, but she returned to school and began third grade one week after his surgery. April voiced concerns about her daughter's ability to focus on school, stating that she could not believe the daughter had been able to make it through that school year at all. April and her daughter were afraid of what would happen much of the time, especially during the first year when Cole had repeated trips to the emergency room for management of seizures. April reported that sometimes her mother would take care of her daughter and sometimes the mother of her daughter's friend at school had been willing to take care of her daughter in the middle of the night.

At the time of April's interviews, she noted that she felt like a "co-survivor." She felt a need for support from people who were going through the same thing that she and her family were experiencing, but she did not feel that she had access to any support of that type. She joined a local brain tumor group and helped with their annual walk to raise money, but she did not feel supported as a family member. She noted, "I've never felt this way in my life. Like, I've always kind of been an outsider, but if you don't have brain cancer you kind of feel like they don't want you to be a part of their group." Her husband, she said, wants to move on, but she noted, "I'm still grieving and I can't move beyond it sometimes. I need someone who knows what I am going through."

April reported that she had always had problems with anxiety, but the experience made those difficulties worse. When we spoke, she was on anti-anxiety medication as well as medications for blood pressure. She reported that she sometimes had panic attack, vertigo, migraine headaches, and trouble sleeping. She reported that she felt she had lost her dreams as well as the support of her husband. She felt that she had nothing on which she could depend for support and help.

April is now in a small community with a husband who is disabled, a daughter who needs her, and no education or job for herself. When we spoke last, her family was on public assistance, and because they had a daughter they were receiving Social Security payments, but April was worried about losing the assistance if she tried to go to school for a GED or if she tried to work.

After our first interview, April commented that she felt better by “opening up about everything” again, and later in an email to me she stated that she had not realized how “dark and deep” her sadness had been through all of this. I met April at a library for both of our interviews, and we used a very quiet conference room for our discussion. For the second interview I thought to bring along a small package of tissues so that she would feel more comfortable and would not have to ask for some from the librarian. Our second interview yielded data about her reaction to “all the emotions that had been stirred up” by the first interview. She said she felt angry, depressed, and a little hopeless about the prospect of keeping herself “moving forward” and caring for her daughter through the uncertain future. She said she knows her husband’s cancer will return and will end his life, and in the meantime he will be unable to work, so this puts her into a difficult situation with little in the way of family or social support, according to April.

April was the only study participant who accepted my offer of a referral. I offered to refer her to the free counseling at the CCHL or to a private psychologist who had agreed to see my study participants, and she said she had not met the new counselor at CCHL and would start there. She followed up with the counselor and had some of her questions answered about how to return to school and resources available to help her care for her daughter and husband while she pursued her education. In addition, Robert had refused his \$15 store gift card, saying that I should use it for someone who really needs it. I offered the extra cards to April, and she began to cry, saying that it was two days until her daughter's birthday and this meant she could get her "something really nice."

### **Cancer Patient Is Deceased**

The previous five participants were dealing with persistent cancer in their significant others as well as ongoing or intermittent cancer treatment. The last two participants whose narratives will be presented are caregivers who have lost their significant others to cancer. The first, Rachel, is the daughter of a woman who died of ovarian cancer, and the second, Sharon, is a wife whose husband died of cancer at the base of his tongue. Both of these participants lost their significant others within the six months prior to our first interviews, so their grief process is ongoing.

#### **Narrative summary: Rachel.**

Rachel is a 36 year-old, divorced mother of two daughters, ages 9 and 14. Rachel's mother died from ovarian cancer 3 months prior to Rachel's participation in the study. When Rachel's mother was diagnosed in 2007 at age 63, Rachel was employed full-time as an administrative assistant at a substance abuse clinic at a local hospital. When Rachel's mother was in treatment, Rachel obtained counseling at the clinic, but

later she lost that job and had to change employment. Rachel regretted the loss of the hospital position because it allowed her to have ready access to counseling and stress management help. Rachel left her employment at the second firm, a public relations firm, due to stress of dealing with the job and her mother's illness, plus the fact that there was litigation in progress against the firm where she worked for alleged sexual harassment of a former co-worker who had been Rachel's friend. There was simply too much stress associated with that employment for her to continue working there, so she quit the job and moved herself and her two daughters into her mother's house to care for her mother for the last two months of her mother's life. Her mother was already on hospice care when Rachel quit her job to care for her mother.

Rachel reported that she has two older brothers, but only one lives in the area. Her mother was from Arkansas and had strong family ties there but no relatives in the state where she lived her last days. Rachel reported that her brothers were not helpful to her during her mother's illness, except for one brother who would help her with things at the end."

Following her mother's diagnosis, Rachel was not aware that her mother had cancer because her mother was very private and did not wish to share details with anyone. This was a matter of some surprise to Rachel because they had what Rachel described as a very close relationship in which she told her mother "everything." Rachel's mother told Rachel that she needed to have a hysterectomy, but no one knew that her mother had cancer until the surgeon told Rachel in his postoperative report to the family. Rachel was shocked by her mother's diagnosis of cancer because her mother gave no indication that the surgery was anything but a routine hysterectomy. The

surgeon went on to say that the cancer had metastasized “all over her insides” and that it would eventually be a fatal disease.

After the surgery and two weeks in the hospital, Rachel’s mother recovered enough to return home, and Rachel assumed the role of caregiver for her mother, who required little assistance except for meals and transportation. Rachel noted that her mother did not want to have chemotherapy, but “the doctor talked her into having it.” Rachel’s mother did not want anyone to know that she was ill, and she repeatedly voiced the intention to “not be a burden on anyone.” Her mother was quite independent, quite private, and quite adamant about not being a burden, and Rachel found these characteristics to be challenging when it came to giving her mother care. Even though Rachel and her mother had been very close, her mother resisted Rachel’s efforts to provide care. At the same time, Rachel was very upset when she was at work and found herself crying and calling her mother from time to time to see how she was doing. Rachel eventually required medications for anxiety and depression in addition to counseling for her stress.

Rachel’s daughters were helpful whenever possible, since they seemed to worry about their grandmother a lot and wanted to be part of the caregiving team. One day, Rachel came home from work to find her oldest daughter in the bathroom, dressed in a swimsuit and helping Grandma take a shower. On the other hand, Rachel reported that the girls needed her at times when she could not be there for them because of the demands of caring for their grandmother. Rachel said, “I missed a lot of things with them, and I can’t get that back... There were times when I felt like a piece of meat – like being pulled in all different directions.”

There were emotional and psychosocial aspects of caregiving that Rachel found quite challenging. Her mother seemed to single her out for verbal expressions of anger and discontent. Rachel reported being unable to please her mother; this was a shock to Rachel because of their previously close relationship. Rachel's mother also hid information from Rachel: information from the hospice team about the dying process as well as other details of what to expect from the cancer. Rachel found some of the printed literature on dying after her mother was deceased, and she said when she read it she thought it would have been very helpful information to have had months before.

When Rachel's mother neared the end of her life, she tried repeatedly to talk to Rachel about dying, but Rachel was unable to cope with having the conversation. Later, Rachel stated that she had a lot of regrets that she was unable to talk to her mother when her mother wanted to do so. Rachel reported, "I would just kind of blow it off." She had regrets about not having these conversations with her mother and also regrets about not staying in counseling, which she felt would have enabled her to cope with the caregiving role more effectively. It seemed to be painful for Rachel that her mother would be "angry and mean" at times, but later on Rachel found out from the hospice nurse that this behavior is sometimes seen between dying patients and those who are closest to them.

Rachel's opinion of the healthcare system was mixed. She appreciated the nurses and one physician assistant who took time with them and seemed to be compassionate. She disliked the oncologist, who she said was "totally lacking in compassion." The summer before her mother died, Rachel took her mother to the emergency room for treatment of diarrhea and vomiting. The emergency room physician broke the news to them that the tumor was very large and was obstructing the bowel. Rachel said they were

all shocked to hear that the cancer was so far advanced, and her mother was upset that “it was going to be so soon.” Later, when Rachel’s mother was in the hospital room, the oncologist visited and said, “Well, your time is up.”

That was when Rachel’s mother entered home hospice care. At that time Rachel was still employed, and she experienced a lot of job stress and difficulties with role conflicts between her employment and the caregiving role that she had assumed. Rachel has a brother who helped from time to time, but overall it was Rachel who cared for her mother until the end. Hospice nurses visited from time to time, but Rachel’s caregiving role expanded until she finally quit her job and gave total care to her mother, including bathing and toileting. She found that through the caregiving experience she was “able to do things I never would have imagined I could do” for her mother. In the final months of caregiving, Rachel’s boyfriend helped her to care for her mother. The boyfriend was a self-employed musician with a music school for stringed and fretted instruments, so he was able to make his time flexible to help Rachel care for her mother. Rachel’s daughters also helped, as did her brother when he was able to do so.

One day when her mother was still able to ride in the car, Rachel took her to a discount store that was having a holiday sale. Rachel’s mother insisted on purchasing all of the artificial flowers that were in the store, saying she wanted Rachel to take the flowers to the family grave site in Arkansas the next year for the traditional grave clean-up and “dinner on the ground.” Rachel explained that this tradition is when families clean and decorate family graves, and since it takes all day to do the work they have a picnic lunch. Rachel’s mother knew that she would be in her own grave the next year, but she asked Rachel to have her remains cremated and to take those remains to the

family grave site along with all of the flowers. Rachel said the flowers that her mother purchased filled the whole back seat of the car, almost to overflowing, but she intended to do what her mother had asked her to do. She showed me photos of the family grave site in Arkansas along with photos of her mother and her daughters. The memories and the photos are precious to her now, she explained. She also said she still listens to voicemails that she has stored on her telephone, just so she can hear her mother's voice again from time to time.

Between our first and second interviews Rachel was diagnosed with breast cancer. She knew there was a possibility of the diagnosis when we met for our first interview, but she told me the news when we met the second time. She said that she and her daughters are so traumatized by what cancer could do that she said she planned to have a double mastectomy and the chemotherapy that she had been offered in order to aggressively treat the cancer. She also reported that she had a job offer at a restaurant in her home town, and the employers there were willing to wait until she was recovered to have her begin working. She also voiced her intention to return to community college in the fall to pursue her career goals.

I met Rachel in the community about 8 months after she had participated in the study. She told me that she had undergone the mastectomy as well as chemotherapy. She had also married her boyfriend who had been so helpful when her mother was dying. She said she had discovered recently that she was pregnant with twins, so she did not plan to return to work or school for the foreseeable future. However, she said she was happy now, still missing her mother, and that her daughters were looking forward to having new little siblings.

**Narrative Summary: Sharon**

Sharon is a 59 year-old woman whose husband Jacob was diagnosed with cancer at the base of his tongue and neck in April of 2010 at age 69 and died in August of 2011. Sharon is a legal administrative assistant, and both of our interviews took place in a conference room at the legal office where she worked. Sharon and her husband had been happily married in the only marriage for each of them for decades, and they had a married daughter and grandson. Sharon and Jacob liked to travel in their motor home, so each summer they traveled north to watch a major NASCAR race in Michigan and then camp out with family members. They liked to socialize with friends, and they often would meet for a drink after Sharon left work for the day. Jacob was 14 years older than Sharon, so he was retired when he was diagnosed with cancer, although she was still working. The only other time Sharon had been a caregiver was in 2000 when Jacob fell and had a head injury followed by months of rehabilitation. He returned to work within the year, but he retired in 2006. Sharon reported that her employment was a good situation for her, and she was allowed to take medical leave when she needed to care for her husband. At one point, Sharon reported that she left work early one day and “cried all the way home. I was so angry and scared.” She said her co-workers and others in the office were very supportive and helped when they could do so.

In fall of 2009, Sharon and her husband had just purchased a home and were renovating it so they could have a place for his sports memorabilia in the basement and so that they could have the decorating colors that they preferred. Jacob complained of being tired easily, but Sharon thought it was just that he was getting older. Then Jacob complained “all winter” that he had a sore throat and difficulty swallowing. Sharon

reported that he had required repeated esophageal dilations after his prolonged endotracheal intubation when he had the head injury, so they assumed that he was in need of another “stretching.” Before they could make the appointment, however, Jacob became quite ill in April of 2011, passing out and feeling “very, very sick.” They took him to the emergency department, where physicians ruled out a myocardial infarction. However, since he had been fainting they studied his carotids and found a “shadow on one side.” The diagnosis was made of a tumor at the base of his tongue.

Sharon’s husband was told that his cancer was inoperable from the beginning, but the oncology team offered him radiation and chemotherapy. She found it to be surprising that Jacob agreed to have treatment, since he had always said he would never do that, but Sharon reported that “They dangle this little carrot.”

Sharon’s husband received three courses of chemotherapy over the next nine weeks, which was to be followed by 35 radiation treatments. However, after only a week and a half of chemotherapy Jacob was hospitalized with sepsis from an infected intravenous port, and Sharon thought that the infection was “the beginning of the end” for him, since he began to lose weight and was so very weak after the infection at the very beginning of his cancer treatment. He was able to complete the chemotherapy and radiation treatments, but he went from 175 pounds to 130 pounds over the next six months and was very weak. He required a feeding tube because of his drastic weight loss during chemotherapy, and they made the feeding tube permanent because they felt Jacob would have difficulty swallowing during radiation treatment.

After the completion of chemotherapy, Sharon questioned whether he needed to immediately proceed with radiation, since the tumor was “almost gone” and Jacob was so

weak. She said the doctor explained that the chemotherapy had shrunken the tumor, but the radiation therapy would kill surrounding cancer cells. Sharon reported that they were told that there might be some difficulty with swallowing due to radiation to the throat, but she felt that this was “massively understated,” since he would lose all of his ability to swallow. While Jacob was undergoing treatments, Sharon tried to continue to work, using a pump to infuse his tube feedings at night. In the morning she would discontinue the feedings and then use another pump to infuse a liter of saline into his PICC line for hydration. Then she would leave for work. She said that he was supposed to relax and try to rest during the day, but he was still tired by the time she returned home in the evenings and was in bed and asleep by 7:00 p.m. each night.

At the completion of radiation treatments, Jacob was totally unable to swallow, even his saliva. His PET scan showed no indication of cancer, but he was suffering from being unable to swallow. Sharon reported that “he spit into a Kleenex for the rest of his life.” He went to physical therapists, speech therapists, and other physicians to try to improve his swallowing ability, but nothing worked. Finally, one physician suggested that her husband try to swallow some water, and that was a failure. Three days later her husband was in the hospital with aspiration pneumonia. The second PET scan in June of 2011 showed spots on his lungs, and the biopsy revealed cancer metastasis. The physician said it would do no good to try the endoscopic examination of his throat, and Sharon reported that at that moment “they knew he would never be able to swallow again.” They had planned a July vacation, so they decided to see family and to travel as planned, but they did not go to the race in Michigan. Instead, they went to a beach near

Lake Michigan and allowed Jacob to rest and visit with family. They had a wonderful week, but Jacob became very ill the day they left for home.

When they returned home, they discussed further treatment options that were offered to them. Sharon stated that Jacob would never have survived the treatments, so he decided to end treatments. They visited their family physician and initiated hospice care at their home, where he died within a week.

Sharon became quite tearful several times during our interviews, but the conference room was very private and I allowed her to take the time she needed to use her tissues and recover her composure. Overall, Sharon was tearful, contemplative, and sad. She said that after her husband's chemotherapy and radiation he was unable to eat or swallow, so he took a box of tissues with him wherever he went in order to catch saliva. She said he was not willing to go out any longer or to socialize in that condition and she identified the inability to swallow as the main thing that "robbed him of his quality of life and aged him so much."

Sharon brought some photos to our first interview. Both photos were of the two of them, and one photo was from about 6 years ago while the other was later in his illness shortly before his death. She said, "See how much he aged!" I saw that indeed he had aged, but I was stunned to see how much more she herself had aged compared to her husband. The first photo showed her looking almost decades younger than she did in the second photo, while her husband appeared merely thinner and tired. I did not tell her that my impression was that she had "aged" more than her husband had aged. At times she expressed anger about her husband's suffering that she felt could have been better

alleviated by the oncology team. She expressed the opinion that some of the oncologists “had no heart” and that “they only want to treat the cancer, not the person.”

She tells an unexpectedly funny story about the hospice conditions. They apparently moved a hospital bed into their home for her husband to use, but he refused to use it because he said “people die in those things.” She, however, found the hospital bed to be quite comfortable, so she slept in the hospital bed until he passed away. After that, her daughter purchased a new bed for her mother, redecorated the bedroom, and painted the walls. Her daughter explained that Jacob had instructed her to do those things.

In terms of the healthcare team, Sharon was favorably impressed by the nurses she met throughout the caregiving journey. She said the nurses “seemed to care, seemed to just get it.” She said that the hospice nurse was the first person to suggest medication to dry up her husband’s oral secretions that he could not swallow, and that made her husband much more comfortable. Sharon said, “Why didn’t they suggest that while he was still in treatment?”

Sharon stated that she still enjoys her work, but at the end of the day she says “there is nothing to go home to.” She expressed the wish that someone would ask if she would like to go for a drink after work sometime, “because a lady really shouldn’t be drinking alone.” She looks to the future with hopefulness and looks to the past with a feeling of accomplishment. She felt that she did her best to care for her husband, and she knows she gave him her best efforts.

Sharon expressed the fear that moving forward would be painful. For example, the lower level of her home is still unfinished and still has Jacob’s sports memorabilia in it. She worries about what it will feel like to sell the motor home, that it will feel like

“letting go again.” Finally, she expressed concern that she should not have supported Jacob’s decision to end treatment, even though she knew it would not end well in any case.

Sharon was sad and thoughtful, especially in the second interview. She stated that she had been changed by the caregiving experience. She felt that she was more compassionate, less tolerant of “petty things,” and unwilling to take things for granted compared to how she had been before Jacob’s illness. She stated that her priorities had changed, that she found it more important to sit on the floor and play with her grandson than to deep-clean the house. She reported that caregiving was an all-consuming experience, and she felt that she was just beginning to “care about things” four months after Jacob’s death.

Sharon recommended that people be more “pushy” with caregivers, since she recognized that she had been one of those caregivers who were unwilling to take help, to get away for a few hours, to care for herself from time to time. She stated that it is important that caregivers get relief and refreshment, but she acknowledged that she was less than cooperative with the efforts of others to relieve her when she was caring for Jacob. Her response to that situation was that she has become more willing to reach out to others who are overburdened and caring for someone else.

Finally, Sharon expressed some hope for the future. She found that she enjoys her family and her job, but she would like adult social interaction once again, to “feel alive again.” She does not intend to marry again, but, as she said, “you never know about things like that.”

### **Chapter Summary**

As the narrative restorying within-case analyses indicate, cancer caregiving is a significant experience in the lives of caregivers. Each caregiver told a different narrative, but all of the narratives were heartfelt. All of the participants discussed the emotional release that they experienced when telling me their stories. All of the stories were at times tearful, at times humorous, and at times painful to hear. They had experienced a significant disruption in their lives, and my goal was to honor their efforts by listening and by caring about what they had to say.

## CHAPTER 5: RESULTS OF THEMATIC NARRATIVE ANALYSIS

The purpose of this chapter is to present the findings of the across-case analysis of data. In keeping with the trajectory perspective offered by participants in the interviews, I identified common themes in the data across cases and strove to locate those themes along the trajectory. Once I identified themes, I examined the transcripts to ascertain where in the trajectory they were emphasized most clearly and strongly by participants in telling their stories. For example, a common theme of “grief” was not emphasized in the pre-diagnosis phase of the cancer trajectory since nothing had changed due to cancer at that point, but the theme of “grief” was strongly emphasized during treatment and post-treatment portions of the trajectories. It is important to remember that the narratives were all elicited from participants in the post-treatment phase of the cancer experience because I wanted to have the benefit of their perspective looking back at the whole trajectory of each person. In this way participants could express their insights and thoughts from a more informed stance as compared with viewpoints that they may have expressed while experiencing the cancer trajectory with their significant other.

Research questions were as follows:

1. What are the circumstances (contexts and conditions) with which caregivers contend over the full trajectory of their significant other’s cancer, from the time they noticed something was amiss to diagnosis and then through active cancer treatment and post-treatment?
2. How do caregivers describe the impact of cancer on their own lives over the course of their caregiving experiences?

3. How do the narratives of caregivers illustrate and give meaning to transitions that the caregivers have undergone?

### **Circumstances and Impacts**

The narrative summaries presented in Chapter 4 described the chronological, time-ordered disruptions in participants' lives along the cancer trajectory. There were both similarities and differences in the contexts, conditions, and impacts for caregivers over the cancer caregiving trajectories as described by caregivers. The purpose of Chapter 4 was to present the within-case analysis, the narrative summaries that were created by structural analysis of data into narrative elements and then restorying the categorized data into synopses with excerpts. Each narrative summary was presented in parallel fashion with the others so that similarities and differences would become apparent as the narratives were read and so the trajectories would be followed chronologically.

The purpose of this chapter is to present the results of the across-case analysis, in which I compared the narratives across individuals and found common conditions, contexts, and impacts of the caregiving experiences along the trajectory of cancer. Since a major focus of this study was the perspective of trajectory – experiences over time – the across-case analysis results are presented here in terms of the trajectory of cancer caregiving, that is, chronologically.

### **Themes Present in All Transcripts: Impacts**

Seven themes were significantly present in transcripts of interviews from every one of the participants. The major themes are presented in detail as they occur along the cancer caregiving trajectory as described by the participant caregivers. Not all of the

themes appear at all parts of the trajectory, and not all of the themes are present with equal emphasis in various portions of the cancer trajectory, so these differences are noted as presented. The format for presentation of the themes is time-ordered, or chronological, according to major sections of the cancer trajectory: pre-diagnosis, diagnostic process, active treatment, and current post-treatment phases.

The themes were:

- Burden: The Load that Never Ends
- Disconnectedness and Isolation: The Invisible Person
- Helplessness and Loss of Control: Tied to This Ride
- Dealing with the Healthcare System
- Role Disruption: Spinning the Plates
- Loss, Change, and Grief: Reaction to the Whole
- Carrying Forward with Scars: New Priorities and Permanent Change

Locations of themes within the trajectories were quite consistent and similar from one participant to another. This finding provides strength for the conclusion that the themes were associated with certain portions of the cancer caregiving experience. Implications of these findings will be explored in Chapter 6.

Not all of the themes were present with equal intensity at all phases of the cancer caregiving trajectory. Table 6 identifies which themes were present at which phases of the trajectory. Themes that are presented next to asterisks (\*\*) in the table were represented with significant intensity during that phase.

Table 7. Phases of Caregiving Trajectory and Associated Themes

Pre-Diagnosis	No themes
Diagnostic Phase	Burden: The Load that Never Ends Disconnectedness and Isolation: The Invisible Person **Dealing with the Healthcare System **Helplessness and Loss of Control: Tied to This Ride
Treatment Phase	**Burden: The Load that Never Ends **Role Disruption: Spinning the Plates **Disconnectedness and Isolation: The Invisible Person **Dealing with the Healthcare System **Helplessness and Loss of Control: Tied to This Ride Loss, Change, and Grief: Reaction to the Whole
Post-Treatment Phase	Burden: The Load that Never Ends Helplessness and Loss of Control: Tied to This Ride **Loss, Change, and Grief: Reaction to the Whole **Carrying Forward with Scars: New Priorities, Permanent Change

### Pre-Diagnosis Across-Case Analysis

The pre-diagnosis phases of participants' cancer caregiving trajectories were the most diverse portion of the cancer caregiving narratives, as one would expect. Of course, caregivers did not know at that time that they would soon be caring for a family member with cancer, so they did not realize any impact from the effects of cancer caregiving. Nevertheless, the pre-diagnostic phase of each participant's caregiving experience was important in terms of preexisting contexts for the transition to cancer caregiving as well as conditions (personal attributes, social structures, and community resources) that would affect how they would soon view cancer caregiving. Since transitions are periods of disorganization and change between two relatively stable states (Meleis, 2010), the pre-diagnosis portion of each caregiver's cancer trajectory would relate to the first relatively stable state that would soon end, ushering in the transition period. Therefore, themes of impact were not found within the data related to this portion of the trajectory. What I describe here is what participants told me about how things were before cancer invaded

their lives. I present this information from their perspective of looking back, knowing what they knew and had experienced at the times of our interviews.

### **Pre-Diagnosis: Circumstances (Contexts and Conditions)**

Most of the caregivers were employed prior to their family member's diagnosis, and those who were not employed had significant non-employment responsibilities and activities within the community. Occupations of caregivers are summarized in Table 3 located in Chapter 3, but the main point is that these were all pre-retirement age individuals who were actively contributing to their families, social networks, communities, and in most cases to their formal employments. At this stage of adult development, it is natural to assume that pre-retirement age people would be involved in highly productive and meaningful responsibilities. The important contextual idea was that these caregivers were busy doing productive things, even those who were partially disabled and unable to work. For example, Diane was no longer able to be a dancer or a special education teacher due to her neck condition, but she was in a leadership role in her local Al-Anon program. Shirley was unable to work due to her spinal stenosis, which had required surgery, but she was in a leadership role in her church group, a faith-related community women's group, and a community service organization. Therefore, each participant would experience a disruption of their life activities due to cancer in a family member. There is no easy time for cancer to impact a family, but these caregivers were all occupied with significant demands on their time prior to the diagnosis of cancer in a significant other.

As I asked participants to look back and reflect upon the pre-diagnosis time, all of them – even those who were familiar with healthcare – voiced the opinion that they had a

certain level of ignorance, naiveté, and “blissful lack of awareness of what was about to happen” (Lucy). They had different opinions about cancer, but most of them shared what they still felt was the prevailing social opinion that cancer was a life-threatening disease and that it meant that someone who was diagnosed with cancer might die. Participants stated that their knowledge about cancer and its treatment had grown through the caregiving experience, but they were still of the opinion that cancer was life-threatening.

No themes emerged regarding the conditions of transitioning prior to cancer diagnosis, since the transition had not yet begun with the disruption in their former state. However, they expressed various levels of awareness of community resources available to them. They were also of varying social backgrounds and had varying levels of social support prior to their significant other’s diagnosis of cancer. For example, April and her husband had just relocated to a new community when her husband was diagnosed with brain cancer, so she had few friends and little social network upon which she could depend for help. On the other hand, David’s wife was a nurse in a neonatal care unit, and she had friends, especially in the healthcare community. David noted that her friendships resulted in her “case being fast-tracked” and given priority from the beginning. Therefore, he voiced the opinion that he had better social resources upon which to depend than did most caregivers.

However, looking back on this part of the trajectory from their current perspectives, all participants seemed to dismiss the social supports that had been in place prior to their cancer experiences. When I asked some of them if they had been in a good situation with adequate social support prior to cancer caregiving, they responded that what had been there for them prior to cancer did not necessarily carry through the cancer

experience. From their perspectives of looking back, they all voiced the opinion that some of the people they had expected to be able to depend upon had shown themselves to be undependable, for whatever reason, while other people had “stepped up to the plate” (Lucy). They almost dismissed my questions about their social supports that were in place prior to cancer diagnosis.

### **Pre-Diagnosis: Impacts**

As noted earlier, there would be no impacts of cancer caregiving emerging from the data related to pre-diagnosis. Therefore, there is no section presented here on impacts during this stage of the cancer trajectory.

### **Diagnostic Phase Across-Case Analysis**

The diagnostic process began when each of the caregivers or their significant others began to sense that something was amiss. This means, according to Transitions Theory, that there was an awareness of something wrong. The diagnostic phase ended when active treatment began. Active treatment included surgery, chemotherapy, radiation therapy, and stem cell transplantation. Any of those treatment modalities signaled the end of the diagnostic phase of the cancer caregiving trajectory.

### **Diagnostic Phase: Circumstances (Contexts and Conditions)**

The early signs of cancer sometimes absent or are not unlike signs of less serious, non-malignant medical conditions, so some of the cancer patients found out their diagnoses by “accident” and had no idea that there was something wrong prior to being diagnosed with cancer. For those caregivers the first awareness of the cancer being present was an alarming and unexpected finding that emerged from otherwise routine healthcare delivery or screening. For example, Rose’s father was diagnosed with lung

cancer as a result of a screening chest x-ray film taken as part of preoperative testing for his carpal tunnel surgery. Diane's husband found that he had both colon cancer and (separately) prostate cancer, and both of these were detected through the same annual routine physical examination. Others in the sample told stories of their significant other's cancer being initially misdiagnosed as something else. Robert's wife received cortisone injections for a sore hip that was later found to be due to multiple myeloma. Lucy's husband was initially told that his tonsil and neck cancer was an infected lymph node. Phyllis' husband was diagnosed with brain cancer, but not the correct type, after his initial evaluation for motor problems.

However, most of the cancer patients were diagnosed due to a symptom or several symptoms and were diagnosed correctly from the onset of the trajectory. Mike's wife thought she had a plugged milk duct and went to her nurse midwife; the nurse midwife immediately sent her to have a diagnostic mammogram, which led to a diagnosis of breast cancer. David's wife was correctly diagnosed with breast cancer after she found a lump upon breast self-examination.

Regardless of the course of the diagnosis, all of the caregivers voice feelings of shock and upheaval when the diagnosis was communicated. As David noted, "We went back to the cancer center. The radiologist met with us and hit us in the face. Boom... [Becomes tearful] Then there was more testing... I think my wife kind of expected it, a little, but you still don't want it. Then, you're just numb."

The contexts of trajectories at the beginning of the diagnostic processes were as varied as the contexts of pre-diagnosis, but as the caregivers told their narratives of the diagnostic process the narratives began to become increasingly uniform. There was a

difference in location of treatment and speed of follow-up, but generally patients were referred to oncologists and at that point found out their treatment options. The beginning of active treatment signaled the end of the diagnostic phase and the onset of the next phase – active treatment – of the cancer caregiving trajectory.

### **Diagnostic Phase: Impacts**

Major concerns voiced by caregivers about the diagnostic phase had to do with facing or avoiding the reactions of others, the burden of coping with this new disruption in their family lives, the importance of information being available in appropriate amounts and at appropriate times, and dealing with healthcare professionals at this critical time of diagnosis. As a result, the impact on caregivers was multi-faceted. Themes began to emerge in the data at this part of the cancer caregiving trajectory.

#### **A special situational condition: Hiding the diagnosis.**

None of the caregivers described any major difficulties caused by having to deal with negative reactions of others during the diagnostic process, but some of the caregivers mentioned that their significant others with cancer were concerned about the potential difficulty of dealing with the reactions of others and wanted to keep the diagnosis a secret. This phenomenon of hiding the cancer diagnosis at the request of the cancer patient was a condition of cancer caregiving experienced by six of the eleven participant caregivers, and all of them found it to be extremely burdensome for them. This special condition of caregiving impacted several themes, especially during the diagnostic phase. Although not all caregivers experienced this condition of caregiving, it was so painful for the caregivers who experienced it that it warranted extra consideration in this chapter. The phenomenon of hiding the cancer diagnosis would be

related to several of the themes, such as burden to caregivers; disconnectedness and isolation; and helplessness and loss of control. In this way, hiding the cancer diagnosis was a condition that cut across several themes.

In several cases, this experience of hiding the diagnosis went on for months, and the burden of not being able to tell even family members was identified as a significant difficulty by the affected caregivers. They felt the burden of having to help the person with cancer, but they were not able or allowed to reach out to others for support, advice, or assistance – with the exception of the healthcare team treating the cancer.

Paradoxically, this social isolation of the caregivers that cut them off from outside support actually provided respite for the cancer patients, who then did not have to deal with the responses of other people to the diagnosis while they themselves were becoming accustomed to the notion of having cancer in their lives. The caregivers who experienced this understood why it was comfortable for the cancer patient to keep quiet about the diagnosis, but the caregivers reported that it made life difficult for them.

Robert's wife, who had malignant lymphoma, hid her disease from as many people as possible and for as long as possible. In addition, she tended to take measures to minimize the appearance of illness so that even those who knew she had cancer did not realize how serious her condition had become:

Even with 25 pounds off, people look at her and say, "You look great. You can't be sick." That's one of the things about this particular disease. You don't have to look sick, and she doesn't. She looks great even without hair... She wears scarves or hats or something... I don't think her sisters have grasped it yet... The one just wrote something in an email last week, and I looked at [my wife] and said, "This worries me. She said 'And now you've beaten cancer.' Honey, your sister writes that, and she is a very smart woman."

The interview in which Robert made the above comment was approximately 6 months before his wife died. Robert had the prior experience of his young son dying from trauma, and he had suffered from that experience. He found that in his current situation as caregiver for his wife he was able to draw upon the lessons learned from his prior experience, and he tried to encourage his wife to be more open about her diagnosis:

We've had this discussion a couple of times. ...She had gotten to the point for a while to where she would actually almost lie about the [medical] results we were getting so people wouldn't know and I said I can't do that. That's not fair to you and it's not fair to our friends. It's not fair to our family. They need to know what's happening and we need to be able to talk about it openly. I need to be able to talk about it openly. That was something, like I said, I learned after my son's death. I learned that I had to talk.

Hiding the cancer diagnosis had several effects on caregivers. First, caregivers saw it as a stressor and a burden when they were not allowed by the cancer patients to speak about the cancer to others, especially since it was always on their minds. Secondly, the fact that they could not speak to others about the cancer diagnosis caused caregivers to feel isolated from social supports. Thirdly, not speaking about the cancer diagnosis took a certain measure of control away from caregivers and was related to caregivers verbalizing feelings of helplessness. Therefore, the situation of having to hide the cancer diagnosis from others created the impacts of feelings of burden, isolation, and helplessness in caregivers. Those caregivers who were faced with the burden of not being able to tell people about the diagnosis identified this condition as a particularly stressful condition of caregiving. Other themes related to the diagnostic phase of the cancer trajectory are identified here.

**Theme of Burden: The Load that Never Ends.**

Caregivers noted that one contextual situation that occurred during the diagnostic phase of the cancer trajectory was their automatic sense of duty to care for the significant other with cancer. Caregivers assumed the heavy burdens associated with caregiving with an unquestioning sense of duty. They often voiced an almost deontological sense of doing the right thing because it was the right thing to do, no matter what. They saw themselves as advocates for the patients with cancer. None of the caregivers reported that there was any discussion about whether they would assume the role of caregiver. On the contrary, they all assumed the role from the beginning and carried through to the time of our interviews. Sometimes there was a sense of grim determination to stay the course and persevere through the experience of caregiving over the cancer trajectory. As Robert said, "I want to get this right; I need to do this right." Robert lost his wife to cancer about six months after our second interview. I saw him in the community after his wife's death, and he said that he had done his best, but he still worried about whether he had gotten it "right."

**Theme of Dealing with the Healthcare System.**

The diagnosis of cancer in a family member automatically placed caregivers into an important relationship with the healthcare system, so the theme of "Dealing with the Healthcare System" was a prominent one during the diagnostic phase of cancer caregiving. For some of the caregivers this was basically a positive experience with a few negative events, but for most of the caregivers the need to deal with the healthcare system was a stressor in itself. Caregivers stated that they needed certain things from healthcare professionals: information, support, direction, and recommendations. What

they sometimes received was fragmented information that depended on caregivers knowing the right questions to ask in order to get the help they needed for their family member. Having to generate the right questions to ask was seen as stressful.

During the diagnostic phase of the cancer caregiving trajectory, caregivers found that they needed to process information in an appropriate amount at appropriate times. This became difficult, however, when they were adjusting to the implications of cancer intruding upon their lives. They voiced concerns during our interviews that they were thrust into an unfamiliar and serious world of cancer and its treatments, but they could only absorb so much information at a time. Therefore, almost all of the caregivers spoke of receiving information in a manner and amount that either overloaded them or else left their families wondering about their next steps.

For example, April was sent home from the hospital with her husband who had just had brain surgery to remove some of his mixed glioma, and she had no idea of assessment signs for which to watch, when to call the healthcare provider, and what to expect. Her husband had been diagnosed with a brain tumor in the Emergency Department and stayed in the hospital for the surgery, which was done a few days later. She felt left adrift and concerned for the welfare of herself and her nine-year-old daughter. In contrast, when Lucy arrived with her husband at the clinic in Chicago she found that things went almost too rapidly for her to digest, and she was given copious amounts of information from various sources as her husband was taken from diagnosis to surgery and subsequent cancer treatment within a week. She reported that she felt overwhelmed at times with all of the information and decisions that she needed to make. Her husband had “shut down” in response to the enormity of the situation for him and

was leaning on her for everything, so she felt the need for someone else to take control. She eventually found that the clinic personnel in Chicago were up to the task and would lead the way for both her husband and herself.

All of the caregivers voiced concerns regarding their experiences with the healthcare system, beginning with diagnosis, and their concerns were not limited to how well their informational needs were met. For some caregivers, there was a problem with making the healthcare system responsive in a timely manner. Lucy's husband found a lump in his neck while he was shaving, and he had a biopsy done. However, before the biopsy results were back, her husband had an emergency room visit:

A few days after the biopsy he was at home, and he woke up at 2 or 3 in the morning. It was like his neck was huge, and he ran a high temp... Of course the release sheets from the hospital said if this happens call the hospital right away, so he did call. They said to come back in. He's kind of a high strung kind of guy, so he said, "Don't worry. I'm going. You stay home." He went and he was there for hours and hours in the emergency room, and they did, it must have been another CT. He was there by himself, and the doctor came in and said, "Well, you have cancer." That was it. He drove home and he told me, he said, "They can't seem to get me in for an appointment. Can you try to get me into the ENT to do a follow-up on this? I'm off to work." So I called, and they wouldn't see us for three weeks.

Fortunately, Lucy found another medical healthcare provider who was more readily available and who was more informative. She related the difference in how she felt about the second healthcare facility:

The moment we talked to the doctor there, that very first appointment, I just felt like something had lifted off of me because it was like finally they are the ones that are saying, "Okay, we need to do this test. We need to do that. You need to see this ENT. She's going to scope you. She'll do these biopsies here, there, and we need to get this lung thing straight." I mean, it was like bang, bang, bang, bang, bang. Of course, I know my husband was overwhelmed, and I had had a bunch of notes then about what I wanted to be done to the best of my knowledge... I just felt totally, I mean, relieved. It was the strangest feeling that he's in the right place. If he lives or dies, he's in the right place and I could sit back.

**Theme of Helplessness and Loss of Control: Tied to This ride.**

The major theme of “Helplessness and Loss of Control: Tied to This Ride” began in the diagnostic phase of the cancer trajectory as caregivers found themselves plucked from their daily routines and thrown into a world over which they had less than adequate control. All of the caregivers in the study identified feelings of helplessness and loss of control at times during the trajectory of cancer caregiving, and these impacts began during the diagnostic phase and became more acute during the treatment phase of cancer caregiving. Loss of control and feelings of helplessness were related to dealing with the healthcare system during the diagnostic phase. The enormity of a cancer diagnosis was a major event that was out of their control.

**Theme of Disconnectedness and Isolation: The Invisible Person.**

The theme of “Disconnectedness and Isolation: The Invisible Person” also began during the diagnostic phase, especially for those caregivers who were not allowed by the cancer patient to speak to others about the diagnosis. When this was the condition of caregiving – being quiet about the diagnosis – then they were unable to reach out to others for support, advice, or assistance with the exception of the healthcare team treating the cancer. However, during the diagnostic phase caregivers had not yet developed a relationship with the healthcare team on an emotional level, so caregivers felt adrift and out of control. The healthcare team was their lifeline, but they were not yet comfortable with the healthcare team during the diagnosis phase.

For those caregivers whose cancer patients had chosen to hide the diagnosis, there was the impact of being cut off from their usual sources of support. Since the significant other with cancer had expressed the need and desire that no one should know about the

diagnosis, caregivers were unable to reach out to others for support, advice, and assistance. These circumstances created social isolation for caregivers. Paradoxically, while hiding the diagnosis of cancer caused social isolation of caregivers, the effect on cancer patients was one of respite, since they did not have to deal with the reactions of other people at that time. Therefore, the cancer patients who chose to hid their diagnosis created a situation of isolation for their caregivers, a situation which caregivers uniformly found to be quite burdensome and stressful.

On the other hand, those caregivers whose cancer patients allowed them to discuss cancer with others also experienced isolation due to the misunderstandings of others. It was sometimes difficult for caregivers to deal with the reactions of other people to the idea that a family member had cancer, especially if the other people did not quite understand cancer as a disease. Caregivers noted that most people did not seem to understand that cancer is not a uniform and consistent experience for all people. Misconceptions of those around the caregivers added to their feelings of being alone and disconnected. April addressed the cultural meaning of cancer in her small Midwestern community:

I think honestly people think you're going to die. If you say brain cancer people think you are going to die in like a week... They don't understand treatment. They don't understand how much research that there isn't... Then they also think that if you are upright and walking around that you must be in remission or cancer free... For my husband there is no remission. He will always have cancer, and people don't understand that... They all think he had chemo. They don't understand at all. Like what radiation does, and how it affects people for years... I think they do probably judge him and think he's mentally not there... I know people are scared when they hear that word. Also, you can almost see the relief in their eyes, that it's not them having to deal with it.

Caregivers viewed the diagnosis of cancer in a significant other as a huge event in their lives, and it was an event over which they had little or no control. Even if they were able

to discuss cancer with others in their social circles, they were not immune to feelings of isolation caused by misunderstandings of others related to cancer and its treatment.

Conditions of caregiving during the diagnostic phase of cancer set the stage for caregivers to become increasingly disconnected as the trajectory progressed, as caregiving would become more demanding during cancer treatment.

### **Treatment Phase Across-Case Analysis**

During the treatment phase of cancer caregiving, the enormity of dealing with the disease became clear for cancer caregivers. The circumstances – contexts and conditions – of caregiving were such that caregivers were well into the caregiving experiences almost before they had a chance to assess the demands of caregiving as an activity. During the treatment phase they were involved in providing support for a significant other who was experiencing the effects of the disease as well as its treatment. In most cases, by the time patients were in treatment the diagnosis had been made public, although some of the cancer patients persisted in minimizing the diagnosis if not hiding it from those outside the family. Caregivers tended to minimize their own needs and burdens even as the burdens became acute: they did not want to complain since they felt that their burdens could not compare to the severity of having cancer. In addition, the treatment phase of cancer caregiving required caregivers to become intimately familiar with the healthcare delivery system. Six of the seven major themes were prominent in the treatment phase of cancer caregiving: Burden, Disconnectedness and Isolation, Helplessness and Loss of Control, Dealing with the Healthcare System, Role Disruption, and Loss and Grief. What follows is a presentation first of the circumstances (contexts and conditions) experienced by caregivers during this phase, followed by the major

themes that represented the impacts that the circumstances had produced in the lives of participant caregivers.

### **Treatment Phase: Circumstances (Contexts and Conditions)**

For most of the cancer patients, treatment meant surgery first, followed by chemotherapy and later radiation therapy. Several of the cancer patients did not have one of the three treatment modalities, but all of them had experienced at least two of the three. Cancer treatment, then, was a disruptive and unpleasant phase in the lives of both patients and caregivers. One thing that was incredibly clear when reading participant descriptions of treatment for cancer and the circumstances treatment created for caregivers was the fact that caregivers faced significant stresses and disruptions to normal living that had multiple impacts on their lives.

One major context for caregivers in the treatment phase was working with the healthcare delivery system. Caregivers most often provided transportation for significant others and often accompanied them to major medical office visits, although most of them did not go to every treatment or stay with their significant others for the entire time they were at the treatment center. However, all of the caregivers were intimately aware of and in contact with oncologists, radiologists, surgeons, and nurses as they helped to manage their significant others' effects of cancer treatment.

A corollary of working with the healthcare system was the cost of treatment and the financial effect it had on families. Most of the caregivers voiced concerns with the expense of cancer treatment, even when it was covered by public assistance (April and Rachel's situations) or insurance. Diane noted that her husband received three chemotherapy drugs each time he went for treatment every three weeks, and one of the

drugs was quite costly, at \$18,000 per dose. Other caregivers noted that there were costs not covered by any type of insurance: lost hours of work, travel expenses, meals on the run, comfort items, and having to hire jobs to be done because no one was able to do them. Diane and her husband had just moved to a home with acres of landscaping when he was diagnosed with colon and prostate cancers. She did not wish to burden her husband with the details of maintaining the landscaping, but she could not do the work herself due to being disabled from a recent neck surgery. Therefore, she paid a landscaping assistant almost seven hundred dollars each month in spring, summer, and fall to do the work needed for their property.

Another major context for caregivers in the treatment phase was extended family and relationships with family and friends. It was during treatment that positive and negative surprises occurred frequently, causing caregivers to wonder if they could count on significant relationships while finding new sources of support. The effect of dealing with family and friends while treatment was underway was both a burden and a blessing to most of the caregivers. Contexts of caregiving during treatment included family intrusions or help, competing demands of employment and community responsibilities, losses of normal patterns of living, having to learn new skills related to household duties, and financial issues.

Conditions of caregiving during cancer treatment included caregivers' perceptions of the meaning of cancer, social supports, access to community and social resources for medical care and respite, and the changing needs of cancer patients. It was during the treatment phase of cancer caregiving that all of the caregivers made changes to their employment or social responsibilities due to the demands of cancer caregiving. Mike

changed jobs. Rose adjusted her work hours and took medical leave. Shirley resigned from several of her community service groups. Diane found that she had no further time for Al-Anon (but resumed this activity in post-treatment). Robert retired from his executive position to care for her wife during her stem cell transplant. Phyllis returned to work for financial reasons, then changed her employment so that she would qualify for retirement benefits that she thought she would need when her husband would no longer be able to work. April quit her activities with her daughter's school and after-school activities because of her husband's daily seizures and personality changes after brain surgery. Sharon took leave from her employment and then returned to work part-time until her husband's death. Rachel quit her job and moved in with her dying mother. All of these changes added to social isolation for caregivers because of the disconnection that ensued from changes in and losses of normal life activities.

The normal order of cancer treatment (surgery, chemotherapy, and then radiation) seemed to be arranged in escalating order when it came to physical impact on patients and caregivers. Surgery was a fairly common experience, and recovery from surgery was significant and serious, but there was still some sort of recovery and healing aspect to the after-effects that took place relatively rapidly. Rose's father, for example, was able to fit his thoracotomy for lung cancer in between two carpal tunnel surgeries so she could be off work and on family medical leave from her employment as a respiratory therapist. Mike's wife healed rapidly from her mastectomies, as did David's wife from hers. Other caregivers told stories of disfiguring surgeries for head and neck cancer or brain cancer that left permanent disabilities in the cancer patients, but even these surgeries had recovery aspects.

Chemotherapy seemed to be an escalation of in terms of the effects of cancer on caregivers' lives. Chemotherapy was associated with serious nausea and fatigue which Mike described as "fatigue from the cells on out." At this point caregivers became role supports or substitutes for their significant others because of the inability of patients on chemotherapy to maintain their full normal roles in the family or outside the home. David, for example, changed his working hours while his wife was on chemotherapy so he could go home and make lunch for her and return to his chiropractic practice. He reported that he would go to the grocery store twice daily because he never knew what she felt like eating and he did not wish to waste food. Caregivers became more involved than previously with activities such as cooking meals, cleaning homes, caring for children, providing transportation, and other activities that had formerly been performed mostly by their significant others. In addition to performing more of the routine activities, caregivers learned new activities directly related to patient care: dressing changes, administering injections, working with feeding tubes, assessing for signs of complications, safeguarding patients during seizures, and other activities.

Radiation therapy typically followed chemotherapy, if both were appropriate modes of treatment. Those caregivers whose significant others experienced radiation therapy identified that treatment modality as the most burdensome and the one which caused the most serious side-effects for their significant others. Radiation therapy often damaged healthy tissues that were near the targeted treatment region, and several of the cancer patients experienced serious quality of life issues and losses as a result of radiation therapy. One prominent result of radiation therapy was difficulty with swallowing, or in the case of Sharon's husband the total inability to swallow even saliva for the remainder

of his life. Swallowing was a serious issue because of the nutritional needs of cancer patients, and most of the caregivers reported that there was little or no improvement in swallowing as time went on. Phyllis' husband was cured of his brain cancer after radiation therapy, but he experienced significant deterioration of his motor and mental status from radiation necrosis of the brain. He was not incapacitated by cancer; he was incapacitated by radiation therapy.

When I asked caregivers to describe how they got through the treatment phase of caregiving, they all responded that they would have liked to attend a support group for the duration of treatment. I noted that several of them had attended a support group at the cancer center, but they responded that most support groups were for cancer patients and their families, not just for cancer caregivers without cancer patients being present.

Unfortunately, cancer patients often stopped attending support group meetings shortly after beginning treatment because they were not feeling well enough to go. On the other hand, caregivers reported that it was at that time when the burden became most intense that they most wished to attend, most needed the support, when their caregiver roles were the most demanding. Once again, what was helpful for cancer patients – staying home and resting – was burdensome for caregivers, because without the cancer patients along the caregivers did not feel welcome to attend support group meetings. As Dorothy noted:

I guess I would have felt like I didn't have the right to be there, which isn't true, I'm sure. But [long pause] without him there I couldn't really talk about it because it would be like talking behind his back. I wouldn't do that... There was a predominance of the patients and of a room of twenty people, there were only three of us caregivers – hardy souls, I guess. But I couldn't come without him.

These were the circumstances of caregiving during active cancer treatment for their significant others. Caregivers were immersed into a world of changes, losses, burdens, and pressures without any assurance of healthy outcome. As we spoke during the interviews, when caregivers looked back on the days of active treatment, they often became tearful; their voices became quite soft – almost to a whisper – as they described the events of that time in their lives. When I listened to those sections of the interview recordings I was struck by the uniformly quiet nature of these discussions, as if the caregivers were reliving the experience and were focusing on how it had been rather than on my presence there with them.

### **Treatment Phase: Impacts**

During the treatment phase of the cancer caregiving trajectory, caregivers became personally identified with however their cancer patient was doing at the time. As Mike noted, “I am however she is doing.” Caregiving during cancer treatment was intensely consuming and mentally all-encompassing. During treatment, caregivers often put aside their own needs and began to evaluate how their own days were going according to however their significant other was doing that day. As Lucy explained, “How he was reacting to treatment determined how my life was going to go at that point, so my own existence was immaterial... I was just too busy to look at myself for those months.”

### **Theme of Burden: The Load that Never Ends.**

One theme expressed with intensity by caregivers when speaking of the treatment phase had to do with burden. The burden of cancer caregiving was multi-faceted and pervasive, and caregivers expressed the unanimous opinion that the burden that began during the diagnostic phase actually peaked during active cancer treatment. During

diagnosis, caregivers took time from work and other activities to accompany their significant others to testing and medical appointments of all types, as a sort of emergency or urgent family responsibility. However, as time wore on and treatment commenced, the full impact of what unfolded as the cancer experience began to create heavy burdens that were more chronic in nature and required more depth of stamina, resources, and patience than most of the caregivers had expected, even when all went well. The nature of caregiving burden during treatment included the burden of financial stress, the burden of coping with side effects of cancer and cancer treatment, the sense of duty felt by caregivers, and the burden of honoring the wishes of some cancer patients to not discuss their cancer diagnosis with others. In some cases, cancer patients continued to hide their cancer from others, and this continued to place the burden of isolation on their caregivers. However, caregivers tended to shoulder the burden of caregiving even to the point of denying their own needs and wishes. In that respect, they were sometimes accomplices in their own neglect.

All of the caregivers noted that they felt an automatic sense of duty and commitment to the caregiving role, especially when their significant other needed them most, and this was a sentiment felt keenly during active treatment for cancer. April described her dedication to caring for her husband as something built on their history together as a couple:

He's always been there for me. Always. And I've always kind of been like this emotional mess sometimes, and he has always been there for me. I don't care what I was going through or what I was doing... He's the best human being. I'm not just saying that because he has cancer. He will always be like the best person I've ever known... It's nobody's fault and nobody wants this, but I was definitely handed these cards and I have to make the best of them.

All of the caregivers mentioned the burden of coping with the serious side effects of cancer and its treatment. They all seemed to be stunned by the severity of the side effects of cancer treatment. As David noted, he had to become the family cook when his wife was going through treatment for breast cancer and retained some of that responsibility due to her ongoing fatigue level, even at the time of our interviews:

I got to the point where I just would go in and go to work [as a chiropractor]. I'd call her and see what she felt like eating. Then go to the grocery store and get that. Then go home and fix her lunch or something. Then she'd go back to bed and I'd go back to work. Then the same thing for the evening too, to see what she felt like eating. I got to the point where I was going to [the grocery store] twice a day. It was easier because I was throwing so much food away.

Those caregivers who cared for cancer patients who were treated far from home had the burden of travel as well as the burden of managing physical and psychological side effects of treatment. Lucy's husband was treated for head and neck cancer, and most of his treatment was done at a facility in Chicago, which was about two and a half hours away from their home. She stated that her husband became very dependent on her from the time of diagnosis. Lucy was a retired Licensed Practical Nurse, so she was able to manage wound care, intravenous poles and fluids, injections for neutropenia, as well as the logistics of caring for her husband as she lived in an apartment near the treatment center but far from home and friends. However, she reported that she had difficulty getting her husband to resume taking responsibility for his activities and care as he was able to do so, and this situation became apparent to the oncologist in a humorous way:

We were up there at the doctor's in Chicago, this was after he was released [after surgery], and of course he was on so much pain medication at that time. He was on some type of codeine... He was constipated. I remember the oncologist said, "Well, are you having bowel movements?" He looked at me and he said, "Did I this morning?" The oncologist looked at me and she said, "Do you do that for him too?" I thought, okay, it's time. He's got to start, even though he's still on the pain medication.

Financial burdens were mentioned by 9 of the 11 caregivers in the study, as noted earlier. Many of the caregivers mentioned how thankful they were to have insurance coverage through the cancer trajectory. Others noted that insurance did not cover all of the expenses of living through cancer treatment, such as the costs of living out of town during treatment or reductions in salary from reducing employment. Two of the caregivers noted that the cancer patient was uninsured at the time of the cancer diagnosis, and this was reported as a stressor. April's husband had just been called back to work after being unemployed for a period of time when he was diagnosed with a brain tumor. She said:

Our small town gathered together and would drop off food and money and gas cards. I mean it was amazing. My family had a benefit for [her husband], and it was huge ... I mean we had nothing. We didn't have anything to begin with, so we kind of were used to living that way. But literally when you have no income it's a lot different, and it took like six months to get okayed for him for disability. That was not certain, and it still isn't because he's so young. They had to go through different channels and different people to check off. He's always worked, but since he was only 32 they were like, "Well, you know." I'm like, "Well, we didn't ask for brain cancer either."

Sometimes family members, however well-intentioned, became a problem for cancer patients who underwent treatment, and caregivers found themselves having to shoulder the burden of being advocates for their significant others within the context of family dynamics. For example, David described his experience of being an advocate for his wife against the will of well-meaning but misguided relatives:

One of her aunts came over one day in the afternoon and came into the house and said, "Well, I'm gonna go up and see her." I said, "No you are not. She is asleep." "Well, she will want to see me." I said, "No, she needs her sleep. You can talk to me and if she wakes up, she will see you. But you are not going up there." "Well, I brought dinner." "Well, thank you [chuckles]" They [the cancer patients] have to come first, is the thing... and if they need their rest or they need their quiet, that's the kind of jerk you have to be. And sometimes I put notes on the door saying no visitors and we are out of food. Feed yourself.

Participant caregivers reported that they were quite protective of their significant others, to the point of becoming assertive as patient advocates. All of the caregivers mentioned their sense of duty and dedication to this role, and they all took it quite seriously, even to the point of verbalizing that they believed they were preserving life, or at least quality of life, for the cancer patient.

All of the caregivers emphasized that caregiving during the active treatment phase of cancer was burdensome, and it was a heavier burden during treatment than it had been during diagnosis. Caregivers especially noted that it was burdensome to cope with the side effects of treatment, the financial aspects of cancer care, and the burden of well-intentioned but burdensome family members and acquaintances. The burdens experienced by caregivers were heavy and unrelenting, but caregivers persevered in their commitment to provide care to a significant other in need.

**Theme of Role Disruption: Spinning the Plates.**

As noted earlier, all of the caregivers in the study changed their employment and other roles and responsibilities in order to meet the demands of cancer caregiving. While the diagnosis phase of cancer care made it necessary for caregivers to adjust their schedules and perhaps take time off from responsibilities, those changes were episodic in nature and not intended to be permanent. However, during the active treatment phase all of the caregivers took a hard look at their responsibilities and the demands of caregiving as well as the implications of cancer in the family and made changes to employment and other commitments. Some of these changes were potentially permanent in nature. Those who were employed rearranged their hours, cut back on work, retired early, changed employers, or took family leave in order to make things work well for them and for their

families. All of the caregivers were pre-retirement age at the time of cancer diagnosis, even though some of them were not employed at that time. Those who were not employed, however, reported making drastic changes in their level of commitment to other life activities to free up more time and energy for caregiving.

Role disruption and subsequent changes were reported by Shirley and Lucy, who were not employed outside the home when their husbands were diagnosed with cancer but who drastically reduced and eliminated their social and service activities in order to care for the person with cancer. Shirley had been active in various community service organizations, and she had to curtail those responsibilities to care for her husband. Lucy had to cut back on the hours she spent in a leadership position with Al-Anon and found that she was unable to care for her father-in-law, who had moved in with them when he became old and frail. As a result, Lucy's father-in-law had to move to an assisted living facility until her husband's cancer treatments had ended.

For those caregivers who were employed at the time of their significant other's diagnosis and who had to remain employed, things sometimes became difficult. Rose, an unmarried respiratory therapist, reported that she felt trapped in her job due to her father's cancer because she did not believe she could move from the area to pursue further education or other employment. At the time of our interviews she was facing difficulties with her employer because of the demands of caregiving:

I had to call work and say, "This is what's going on. My Dad's in the hospital now; I'm going to need more time off." "Oh, that!" was the reply. The silence then at the end of the phone was deafening. [sigh] So it, it wasn't a great experience. But I guess they really couldn't say no because that would have become a human resources kind of issue... I had some [co-workers] who, I think they came across very cold, very like, "You're just trying to get out of working an extra shift."

Sometimes caregivers changed employers to allow for more flexibility that they needed to meet the demands of caregiving. Mike changed his employment as an electrical engineer and found a job with a company out of state for which he could telecommute. His previous employer had not been flexible, so he could not care for his two small children if needed when his wife was very ill. When he was seeking other employment he found that it became important to him to have oncology care available for his wife, good insurance coverage, and also flexible hours so that he could make things work for his family.

Robert reported that he had to retire from his employment earlier than planned when his wife needed a stem cell transplant for multiple myeloma:

When it became apparent and we understood fully what was going on, when we understood fully what her treatment was going to be, when it came time to prepare for the transplants she needed to have shots every day... I didn't want anybody else doing this. I wanted to be the one, so I tried juggling work for a while and doing all this, but I wasn't giving my job... I'm a perfectionist and I was not as good at work as I used to be and so it was time. I had 37 ½ years in. It's not like we need money, so it wasn't you know, greedy... Well, I finally said that's crazy... So I called my boss on my cell phone and said I'm retiring February 1. Said I cannot do the job justice and do what I want to do for her.

While some of the caregivers had employment difficulties or made changes in employment, almost all of them experienced the added role difficulties of role strain and changes in their roles in the home and within the family. April had many events that she missed with her young daughter's school. Rachel missed family events due to working and the simultaneous demands of parenting two young daughters while caring for her mother:

As a parent you're concerned or you're working with seeing how they're doing and making sure that their needs are met and that sort of thing too. You're kind of between caring for your mom and taking care of the girls and making sure they

have the attention they need. There were times that I felt like I was a piece of meat – like being pulled in all different directions.

Indeed, all of the caregivers found that they needed to re-prioritize, adjust their schedules and responsibilities, and find new ways of meeting the needs of everyone while their significant others underwent cancer treatment. This meant adjusting their roles both in the home and outside the home.

### **Theme of Dealing with the Healthcare System**

Caregivers found that their relationships with healthcare professionals that had begun during the diagnostic phase were more intense during active treatment. Active cancer treatment required that patients and caregivers interact with healthcare professionals on a regular basis, so a relationship had deepened by the time diagnosis was completed and treatment was underway. The theme of “Dealing with the Healthcare System” was voiced by all of the participant caregivers during the diagnosis phase of cancer caregiving, but this theme became more pronounced, with significant emphasis, during the active treatment phase of cancer caregiving. All of the caregivers wanted and expected to be given respect for what they were doing, for the care they had for their significant others, and they all expected to be included in the healthcare team. They wanted to be informed about treatment options and plans of care.

All of the caregivers mentioned that they considered patient advocacy to be part of their caregiver roles during cancer treatment, and this included advocacy within the healthcare situation. For example, Robert considered the advocacy role to be crucial to his wife’s survival during treatment:

You have to be assertive... You need to be able to... let the doctor know that you’re not just some – I’m not just sitting here and you tell me what to do and I’m going to accept it. I’m part of this... You want to be part of the team that’s

working on the solution and not just some innocent bystander who's waiting for them to tell you what to do next. You have to be prepared that things are going to change constantly. You have to accept change. I mean, change in mood, change in plans, change in everything.

After Robert's wife had nearly been transferred out of Intensive Care by a resident who was unaware of her medical situation, he wrote on his wife's blog "Do not ever go to a doctor or hospital when there may be something more serious than a splinter without having an advocate with you that can listen and hear what is going on and be your advocate if you are not able to be your own."

Several of the caregivers had been particularly disappointed in the level of care – or perhaps caring – provided by physicians. They expressed the opinion that they had experienced a lack of compassion and caring from the medical community. Sharon expressed her opinion that perhaps healthcare professionals cannot understand the caregiving experience unless they have been through the same thing:

I don't think anybody can understand caregiving until you are in it. I could have understood it was hard, but until you are in it, there are no words to describe just how lost you become, how overwhelmed you become, how you just go about things automatically. You do what you have to do when you have to do it. No, I don't think doctors understand that...I don't think there is any way they can. I know that they deal with sick people every day, but – and I am sure there are some people that they take home with them in their hearts, but no. No. [long pause, and quiet] Not to the extent that it needs to be understood. If they did understand they would be more proactive. Do I think that they are bad people? No. Do I think that most of them are doing the best they can? Yes. Do I realize that not everything has a happy ending? Yes. They're only human. Sh\*\* happens.

Professionals in emergency departments earned special mention from caregivers because of some of the interactions that became difficult within that milieu. April related a difficult medical encounter with her 32 year-old husband during one of their

many visits to the emergency department in the aftermath of her husband's surgery for brain cancer:

Resident doctors gave him a prognosis one time... I mean when that resident came in and [my husband] was depressed, and they were talking to him about seeing a counselor at the hospital. She said, "Well you don't want to be depressed for like – you could live four to six years. You don't want to be depressed the whole time, do you?" I have read stuff on line, but I have never told him. He has specifically said, "If there was a prognosis, I don't want it." And she did that, and he just looked at me. I mean I could have physically hurt somebody. I was like, how am I supposed to deal with this now? He's looking at me like, did you know?

Rachel described the lack of information from healthcare providers as very upsetting when it came to her mother's last days. Her mother withheld information from her about how close she was to death, but the medical staff also did not seem to communicate well with either Rachel or her mother. Rachel described an incident when they went to the emergency department to see about some abdominal pain, vomiting, and diarrhea from the ovarian cancer that her mother had:

I was the only one for them to call to give information to. But they never called me, ever. Like when she was sick and I took her to the ER... It was kind of a shock because the ER doctor told me, "I'm not an oncologist, but it seems like she doesn't have very long." I've always known that... but when it comes down to it, like we had no idea. And my Mom didn't even know. My mom said, "Well you knew I was going to die, but I didn't know I was going to die this soon... Yep, she [the physician] walked in and said "now, your time is up."

Caregivers acknowledged that they were not entirely knowledgeable about the oncology specialty, even though many of them had investigated various topics on the internet. Therefore, they expected healthcare professionals to think of things that the caregivers had not thought to ask, to be proactive, and to address all the needs of the cancer patients. In addition, caregivers especially disliked fragmentation of medical care. Sometimes the fragmented nature of care and what was perceived as a lack of

coordinated care was a stressor for caregivers and contributed to their feelings of anger and frustration. For example, Sharon's husband died of head and neck cancer, and he had been without his ability to swallow even saliva for the last few months of his life.

She had some thoughts on the topic of coordinated care:

When Hospice came in, there were medicines that they were able to give [her husband] to dry up his secretions. I was so angry. I said, "Now that he's going to die? Now they are going to give him something to dry up his secretions, so that he's not spitting all the time? Doesn't have all that ropey junk in his throat all the time?" Come to find out that Dr. [oncologist] had been a hospice doctor before he was a radiation oncologist. And I said that was one of the things that made me the maddest. I said, "You know some of this could have been relieved... I swore to everybody that would listen that I was going to bring that up.

She went on to describe the lack of holistic caring of some of the medical community:

I had to call and tell them that he was getting worse. But like I said, the cancer doctors look at just healing the cancer. If they are seeing the cancer go away they've done their job. It needs to be an all-over approach. It needs to be yes, we are curing cancer, but we are going to take care of your body and your mind and your spirit at the same time. It's holistic, I know, but you know what? I say to this day that cancer doctors have one thing. They want to cure the cancer and to hell with how they have to do it or what it does to you. It's not like this is their first rodeo.

Mike also argued for a more holistic, humane interface with the healthcare system, which he said was technically good but a bit lacking, especially the caring component of medicine:

I can't describe it very well except for just the human relation quality. Um, a sensitivity to how people are going to react to what you are presenting, or what's going on in their lives, rather than just the things that need to get done, I guess. We're not animals to just siphon through and get the checklist done... I sometimes go back to what the radiologist said, his list of treatments that are set from day one without criteria of if the person is really sick from the treatments, you know, should we really go through with this. I think that would have given me at least a level of comfort to say that, you know, is the cure more detrimental than the cancer? I don't think, sometimes, with the doctors, I don't necessarily see that as being on their radar or list of concerns.

Caregivers were concerned about what they saw as difficulties with communication, holistic care, and coordination of care in dealing with the healthcare system. Most of them, however, were not angry about their experiences; they were saddened by what they saw as preventable distress.

**Theme of Helplessness and Loss of Control: Tied to This Ride.**

The theme of “Helplessness and Loss of Control: Tied to This Ride” was a natural accompaniment to the reactions of caregivers to dealing with the healthcare system and dealing with side effects of cancer treatment for their significant others. During the diagnostic phase of the cancer experience, caregivers noted that they felt quite helpless and out of control, but they had expected this to lessen during treatment, after a period of adjustment and the acquisition of mastery of certain skills. Generally, helplessness and loss of control were usually attributed to the cancer as well as the impact of cancer treatment.

Nothing, however, prepared Diane for the feeling of helplessness that she experienced because of her husband’s sudden refusal to accept treatment. She reported that he “decided to take 2009 off” from treatment. Initially, Diane’s husband was found to have both colon cancer and prostate cancer in January of 2008, and the two diagnoses were made within three weeks of each other. The medical team had to decide which cancer to treat first, and they treated the colon cancer first. After his treatment was completed for colon cancer, however, Diane’s husband delayed treating his prostate cancer, and people did not seem to understand that she was not somehow in control of the course of events in her husband’s care:

He decided, not cognitively, but he took 2009 off and didn’t do any other treatments. [sigh] Which wasn’t such a good thing because they determined that

the prostate cancer was fairly aggressive... He had an appointment with his radiologist in March of 2009, which he didn't go to, and so they rescheduled and he didn't go to that either. He didn't have the radiation treatment for the prostate until a whole year later. That's when we found it was outside in the body... It was hard. It was really hard, but it was his disease and I had to let him manage it. It was very difficult for me. One of the frustrating things was people try to help you and say here are these great meals you can use. They prevent the cancer growth, blah, blah, blah. Well, it doesn't matter if I fix them. He's got to eat them. People don't understand.

She noted later in our conversation that her husband was trying to remain in control of his disease and accept treatments only as he felt he was able. However, the actions – or inaction – her husband took to cope with his disease increased her feelings of helplessness, since she found that she could not only not control his cancer, but she could not control his response to medical advice.

Sometimes caregivers were frustrated with their significant others, sometimes with the people around them, and often with the healthcare system. Mike noted that it was frustrating when healthcare professionals did not know how to use the implanted intravenous central line port that his wife had:

She does have a port, for medicine and other things, which a lot of people aren't trained on. Her veins were never really good to stick anyway, and after the chemo that she's been on, you know; her veins are now very brittle and hurt a lot whenever they use those. I wish that more people were trained on how to use that port rather than, uh, well, sorry. I don't have training on that. We're going to have to use your arms. Oh well, can't find it on this arm. Gotta go to the other side. That's one thing that's been really hard on her. And there it sits, the port. She has to take that into consideration when she chooses wardrobes because it's always right there. And they can't always use it.

In all, helplessness and loss of control was less of a problem for caregivers after the diagnosis phase of cancer care, once caregivers became more knowledgeable and gained experience in caring for their significant others. However, helplessness remained

a problem for them from time to time when something unexpected would happen, something for which they were unprepared or unsupported.

**Theme of Disconnectedness and Isolation: The Invisible Person.**

Caregivers described the phase of active cancer treatment as primarily burdensome in such a way that it took over most of their time and energy. They were preoccupied with cancer caregiving and with being available for their significant others while juggling the other demands of roles and responsibilities. As a result, there was little time or energy left for themselves, and they began to feel increasingly isolated and disconnected from the world about them.

All eleven of the participant caregivers verbalized a sense of being disconnected, isolated, and detached from the world around them that was most acute during the active treatment phase of cancer care. The disconnectedness felt by participant caregivers seemed to be associated with a sense of selflessness. Caregivers in the study were a selfless group of people in that they were so devoted to caring for someone with cancer that they tended to deny their own needs and even delayed medical care for themselves. It was as though they were accomplices in the neglect of their own needs. For example, Robert had a painful mass in his abdomen, and it caused him discomfort when he coughed during our first interview. He said it had been determined that the mass was not a hernia, but “they don’t know what it is. I don’t have time to be sick, so this will just have to wait.” At the time of our second interview Robert had still not been treated for the pain in his abdomen. Another example was that Lucy delayed her needed treatment for hormonal problems until after her husband’s treatment for throat cancer. The feelings of selflessness expressed by caregivers seemed to be due to their need to focus

on caregiving, as Robert noted. Several of the caregivers discussed the impact of this selflessness:

Sharon: You spend so much time – the time that you are a caregiver – you essentially give everything up. You give yourself up. You give your family up. You give everybody up, and you concentrate on trying to take care of the person that you love and hoping it makes their life better and encourage them to get well when you know darn well what the outcome's probably going to be.

Diane: I end up setting all of my concerns and needs aside because of him, which is appropriate; but then it would be real easy to slip into being a non-person and not taking care of myself and my responsibilities because I am so focused on him. So I think that is where the detachment has to come in. Yes, it's really important and I have all of these responsibilities, but I'm no good to him if I don't watch out for myself.

Robert: You feel like anything that you're feeling is insignificant in comparison to what the person you're caring for is, so you start looking at yourself as being insignificant. So you don't want other people helping you because you should be helping her. No, I'm fine. I gotta be fine because I am taking care of her. You realize fairly quickly whether it's conscious or not, but pretty soon you start thinking I shouldn't say anything about anything I am feeling because it is insignificant compared to the person that may be dying of cancer. I don't know how to deal with that one very well yet... The more in depth you get into being a caregiver, the less you are really looking at yourself and you have missed the fact that you need something until all of a sudden you are feeling wiped out... It's like a tsunami hitting you because you haven't been staying cognizant of it along the way and all of a sudden it hits you all at once. That can be debilitating for you as a caregiver than then you can become ineffective. That's a tough tightrope to walk.

Many of the caregivers felt disconnected from their surroundings and their social contacts. The overwhelming nature of cancer caregiving (the "tsunami" noted above) seemed to consume much of their time and attention, causing them to withdraw into a world of caregiving demands. They found themselves disconnected from their usual social supports, unable to focus on their employment demands at times and sometimes even abandoned by friends and family members. They found that people reacted in different ways to their situations, and all of the participant caregivers voiced surprise at

how various people had either gone out of their way to help them or else did not help them as they had expected.

On the positive side, all of the caregivers reported that they had been surprised by people who unexpectedly reached out in kindness when they had needed it the most. As Lucy noted:

My neighbors across the street were great. She came in and took care of the house. We have an outdoor cat that came as a stray, so that was all taken care of by her, so I had that. She brought over food a couple of times... I thought it was great. I mean, it really kind of boosted my feelings, especially those days when – the days that we did come back home. Well, they even called us in Chicago.

However, the caregivers also reported that there were also surprises of a negative nature. They reported that some people whom the caregivers had expected to help did not help, even as other people had surprised them with their thoughtfulness and acts of support and kindness. David's story was typical of the negative and hurtful reactions of close relatives:

You get the extremes. Either people are extremely helpful or gone. It can be heartfelt, and it can be surprising. Her parents were gone. I mean literally gone. They live here and we did not see them for four months. [chuckles] It just shocked the hell out of me, is the thing. They came for the surgery... They are good, good people. God bless them. I don't know if they couldn't handle it or what the deal was... Her parents were at the hospital. They came over on Friday at noon because we had all this food so they ate. Then, they were there Saturday and I couldn't get rid of them. She needed to rest... Then, we didn't see them. We saw them at Christmas for a few hours and then didn't see them until Easter and they called like three times. I mean, that's an extreme example, but it's just like God d\*\*\* it.

All of the caregivers had family members and other people whom they had expected to help in a significant way but who had not done so. This seemed to be a major source of disappointment and even emotional pain for some of the caregivers. There were parents, siblings, co-workers, and others who had been a source of major

disappointment due to the unexpected lack of support. In some cases, relationships remained strained at the time of our interviews, and the pain was still there. Lucy reported that she was quite grieved by her daughter's failure to help and by her parents' unwillingness to provide compassion:

I've talked to other people that have gone through this. This is where things start to happen. It's complicated. Everybody's feelings start to get involved... My daughter from Georgia brought her son and her dog. They ended up...when my husband came for clinic that day before we were to come back home, found out that he had to wear the mask. His blood count was down, so he could not be around any children, could not be around dogs... plants, the whole big thing. And...it was pretty traumatic because she ended up staying at my parents'... He was running high temps and all this kind of stuff that goes along with all this. So that was very hurtful not to have anybody... Then I remember calling over to my parents' because my daughter was over there, and I said to my dad, "What's going on?" and he said, "Well, we're having a party."

The disconnectedness and isolation seemed to be exacerbated by expectations that had been dashed. People whom caregivers had most expected to be supportive had failed them in some ways. The failure of support seemed to add to caregivers' feelings of being alone, disconnected, and isolated from normal life.

Several of the caregivers noted that there were some awkward times when people said or did things that were insensitive, hurtful, or simply ignorant. David had some examples to share:

Some people are just, they say "Let me know if I can help," or "I will pray for you," or "You're in our thoughts." Then, other people will say some of the stupidest... You know, industrial strength ridiculous things. Such as a guy that has an office two doors down from me, insurance financial planning type of guy. He came and he was giving me grief about something. We're in a condo association. I said, "Listen. My wife just got diagnosed with breast cancer. I don't have time for this. You deal with it." I said, "It's very severe. She's stage three plus, and it came on fast." He replied, "Well, that means it's fatal." [pauses, sighing, and shakes his head] Thank you for your input... Even at church one time it ended up, a friend you know. He came up, and his sister had unfortunately died of some type of cancer. He said, Oh you're looking good, [David's wife's name]. So was my sister. And then she died." God.

While caregivers described their feelings of disconnectedness and isolation, they also voiced concern that the disconnectedness that they felt was not healthy for them. They verbalized the wish that there could have been more social support, and that the social support would have been more caregiver-focused rather than patient-focused, even to the point of breaking through their own defenses. Unfortunately, participant caregivers noted that there were few support resources of this sort available for caregivers. Some of them tried to attend support groups in which there were cancer patients, but they often found that they felt unwelcome or that they just did not fit in with those groups, even if they were supposed to be for both caregivers and patients. Diane noted that she felt disconnectedness when she was at a cancer support group meeting:

The support groups that were held at the cancer center were helpful to some degree, but my husband finally just got fed up with it and left because there was one person that was outspoken who was not a medical person who margined on giving medical advice. My husband couldn't take that because he was, after all, a scientist. We had to leave, which was too bad. It would have been nice for me to stay, but without him I was a non-person, so it didn't matter. I felt like a non-person lots of times except for my support network and my family... The caregiver has no reason to be at the support group... How do they survive after their spouse or person dies of cancer? I have no idea what happened to those people. I'd like to know, and I think we could have – I'd still be friends with them, I think, because we would have been through such a big experience together. I think we'd still be friends... There were very few of us caregivers who had the nerve to show up. There were like three of us.

Some of the caregivers tried to access resources from the community to help with their need for support. For example, Lucy tried to call different organizations to find if there was a support group for caregiver or someone to talk to about family issues during cancer treatment. She said she was referred from one phone number to another, and she got a voice mailbox at the phone numbers. She finally gave up when she became too busy caring for her husband to pursue caregiver-focused support group activities.

While social support was identified as valuable by the caregivers, none of them reported that they had adequate social support of the right type to really help with the job of caregiving. On the other hand, some of them also voiced the recognition that they had been less than willing to accept help when it was needed, fearing that they would be less than effective at shouldering their advocacy and burden-bearing roles. Sharon, whose husband had died of head and neck cancer, put it this way:

You just kind of have to be pushy with people that are going through that, I think. You have to just kind of say, “I know I can’t do it as well as you, but you’re going to be a much better person, or better able to take care of him if you let me do this for a couple hours and you just go someplace. If you want to just go someplace and read. Go to the park. Sit out in the sun. Go shopping. Go have dinner. Go to a movie. Do something other than being around a sick person. It takes its toll.

Aspects of disconnectedness and isolation that were expressed by the participant caregivers included feelings of being socially invisible, surprises (both positive and negative) when dealing with others, dealing with misconceptions of others regarding cancer and treatment, and their expressed need – even a longing – for better social and emotional support. They all expressed the opinion that the “tsunami” of cancer caregiving had taken over their lives and caused them to feel disconnected from life around them during active cancer treatment, no matter what the treatment was and no matter how the treatment was implemented.

### **Theme of Loss, Change, and Grief: Reaction to the Whole.**

As noted in Chapter 2, grief is a natural reaction to loss, and there is loss associated with changes. When things change, there is a loss of what once was. All of the caregivers – no matter what the status was of the significant other at the time of our interviews – expressed the theme of grief. As noted in Chapter 3, this came as a surprise to me when I first began to analyze the data in response to the first few interviews. I

noted that there seemed to be sadness and grief being expressed, so I purposefully sampled caregivers with maximum variation in terms of the outcome of cancer treatment for the significant others. Regardless of the outcome of cancer treatment (how the cancer survivor was doing at the times of our interviews), all caregivers expressed painful losses and grief. In some cases, there was a loss of the person who had died from cancer. In other cases, there was a loss of the future, loss of life as it had been, loss of family relationships, or loss of employment and financial security. Losses and grief reactions were indeed a major theme in the data.

Even though Robert did not have a bleak financial situation, he and his wife had planned to retire later than they did and then to travel. He reported that all of their retirement plans had been made with the idea that he would die first, since he noted that “all of the men in my family die young of cancer.” Instead, he was facing the loss of his wife at her early age:

Well, I'm kind of one of those that wants to know what's happening. I want to know what we are facing. I want to figure out how to fix this. Well, one day we were sitting there talking with the doctor, and I finally looked at my wife and asked, “so will she be here in five years?” [shakes his head] That's all he did, just shook his head and said no. With this, because you are on chemo constantly, if the disease doesn't get you the drugs will, because of what they do to your body. [Robert became tearful at this point.]

While most of the grief and loss was experienced by caregivers during the post-treatment phase of the cancer trajectory, losses during the treatment phase tended to revolve around losses of income due to employment changes, losses of relationships that were affected by people who did not help when they were expected to help, and losses of functions experienced by the significant others as a result of cancer or cancer treatment. The losses of functions were recognized more strongly in post-treatment than in

treatment because during post-treatment the cancer survivors and their caregivers were focused not on getting through the next round of treatment but rather on taking inventory of what had changed and how long the change was likely to last. Therefore, the theme of “Loss, Change, and Grief: Reaction to the Whole” began during the diagnostic phase of the trajectory, intensified during treatment, and was most keenly felt and expressed by caregivers from their perspective of looking back from the post-treatment phase of the cancer trajectory.

During the treatment phase of the cancer trajectory, themes that emerged from the data were “Burden: The Load that Never Ends,” “Role Disruption: Spinning the Plates,” “Dealing with the Healthcare System,” “Disconnectedness and Isolation: The Invisible Person,” and “Loss, Change, and Grief: Reaction to the Whole.” However, the most keenly felt – and most intensely expressed – themes during this phase of the cancer trajectory were those of burden, dealing with the healthcare system, and disconnectedness. It was not until caregivers had time and energy to reflect upon what had changed and what they had lost that they began to be aware of intense grief. The only major theme that was not present during the treatment phase of the cancer trajectory was “Carrying Forward with Scars: New Priorities and Permanent Change,” which emerged strongly during the post-treatment phase of the cancer caregiving trajectory.

### **Post-Treatment Phase Across-Case Analysis**

Once active treatment or initial active treatment ended, caregivers and cancer survivors expected to regain their sense of normalcy, but that was not their experience. None of the cancer survivors were cancer free and without physical sequelae at the time of caregiver interviews. Perhaps the fact that I was unable to find a participant caregiver

whose cancer survivor had emerged unscathed by the cancer trajectory was predictive of the finding that all of the caregivers and their significant others were changed by the cancer experience.

### **Post-Treatment Phase: Circumstances (Contexts and Conditions)**

After the end of active cancer treatment or the initial cancer treatment, caregivers expected to return to their normal activities and families expected to adjust to a new type of family life in which they would return to a more normal stress level than they had experienced during cancer treatment. However, if cancer can aptly be described as a “tsunami,” then there is little chance that nothing will remain changed by such an experience.

The majority of caregivers experienced the context of post-treatment as an effort to return to pre-cancer normalcy, since that was the most familiar way to live when cancer was not in the daily routines. Contexts for post-treatment caregiving included changes in family structures that had arisen from disappointments during treatment when family members or close friends had not been as supportive as expected. The other major context for caregiving in the post-treatment phase of cancer trajectory was ongoing changes in employment and other responsibilities that caregivers experienced in response to demands of caregiving during cancer treatment. Sometimes these changes in employment and other activities persisted into the post-treatment phase. For example, Robert retired early in order to care for his wife, and he remained retired at the time of our interviews because he expected to have to care for her again soon and wanted to travel with her as long as she could do so. Rose continued to have little extra time for working additional shifts in her role as a respiratory therapist because her father’s

condition had deteriorated and he still needed care. Mike continued to work as a telecommuter for a company out of state so that he can have the flexibility that he needed for his family as his wife's condition deteriorated. David's wife was able to return to work on a limited basis, but her fatigue and lymphedema continued and were expected to be permanent. Therefore, David continued to have two hours for lunch at his chiropractic office so that he could care for her if needed during the day at lunch time or go home to do laundry or cleaning. None of the caregivers returned to the full scope of their roles in employment or social responsibilities once their significant others had completed cancer treatment.

In addition, two of the caregivers experienced further changes in employment that were initiated in the post-treatment phase of the cancer trajectory. April found that she needed to consider the fact that her husband would never again be able to provide for her or their daughter financially and that she would lose her husband when his brain cancer inevitably returned. Therefore, she was exploring ways to finish her high school education, obtain a GED certificate, and potentially return to the workforce when she loses her husband.

Another caregiver who changed employment in the post-treatment phase was Phyllis. She found that her husband was deteriorating not due to his brain cancer but due to the after-effect of brain radiation necrosis, so she wanted to ensure her retirement income. She returned to work as a teacher in order to qualify for her personal retirement funding. However, at the time of our interviews she had left that employment because of her husband's deterioration. However, she had worked long enough to qualify for her own retirement plan and was focusing on her husband's increasingly demanding care.

Conditions of caregiving in the post-treatment phase of the cancer trajectory included coping with residual effects of cancer and treatment, the outcomes of treatment in terms of the effects on cancer, and changes in the meaning of cancer and living with cancer for those affected by it. As noted earlier, all of the cancer survivors had sequelae of treatment or cancer, so all of the caregivers were still caregiving at least in some small way, unless they had lost their cancer patients. Conditions of caregiving post-treatment were greatly affected by how successful treatment efforts had been in terms of eradicating or controlling the cancer, and this was the focus of my maximum variation purposive sampling efforts. Finally, the meaning of cancer had changed for all of the caregivers and provided a change of outlook post-treatment that had been informed by what they had learned and experienced during the preceding trajectory.

#### **Post-Treatment Phase: Impacts**

Themes expressed by caregivers related to life after cancer treatment were different from those expressed in relation to earlier phases because the overall impact of cancer on their lives was resolving. In this respect, the trajectory of cancer caregiving as a large narrative was entering resolution (Labov & Waltezky, 1967). Therefore, there was less mention of disconnectedness and role disruption after the end of cancer treatment, but since none of the cancer patients had an absence of sequelae of cancer there was still some burden and role change present. Some of the caregivers were adjusting to the loss of their significant other, and that was different from life during treatment, too. In addition, disconnectedness was less emphasized by caregivers in relation to life after treatment, since the burden was less isolating and life was more normal at that time.

However, since the outcomes of cancer treatment differed somewhat from one person to the next that meant there were differences in the impact of post-treatment caregiving on the lives of caregivers. As noted earlier in this chapter, caregivers had relatively little in common pre-diagnosis, but the diagnostic phase and treatment phase of cancer caregiving produced relatively homogeneous impacts on caregivers. Once treatment ended and outcomes were different, the experiences of caregivers differed somewhat from each other and the impact of caregiving during post-treatment was less than identical for the participant caregivers. Therefore, what is presented here is primarily what caregivers described consistently, and what is not consistent among the participants is identified as such.

The new theme expressed in relation to the post-treatment phase of cancer was that of “Carrying Forward with Scars: New Priorities and Permanent Change.” The other major theme that was significantly present post-treatment was “Loss, Change, and Grief: Reaction to the Whole.” Themes that emerged from the data but which were not emphasized were “Helplessness and Loss of Control: Tied to This Ride” and the theme of “Burden: The Load that Never Ends.” The theme of burden was significant for Phyllis and to a lesser extent all of the other caregivers who still had roles and responsibilities that they had assumed during cancer treatment. The four major themes – two significant and two less than significant – related to post-treatment caregiving will be discussed in order of emphasis, from least to greatest.

#### **Theme of Burden: The Load that Never Ends.**

Burden was quite variable in the post-treatment phase of the cancer trajectory, since it depended on the physical condition of cancer survivors after treatment. While

all of the cancer survivors had sequelae, some had more than others. For the most part, burden had become something more specific, such as grief or changes in priorities. However, Phyllis noted that her husband was free of cancer and had been for years, and yet her burden was increasing daily.

Her husband, once a college professor of computer science, had brain cancer years ago, and the cancer had been successfully treated with surgery and radiation. However, she found out later that he had developed progressive radiation necrosis of the brain. This after-effect of the treatment has debilitated her husband, both mentally and physically, to the point that he was nonverbal and almost immobile at the times of our interviews. She noted that they tried to use a variety of assistive devices, but those efforts were not always successful in dealing with his losses due to the side effects of the radiation:

He can't add. It's just difficult. You're dealing with the physical limitations, but also the mental limitations of not being able to read. In fact, we went with a communication device... It's one of those big computer-like things that you can type into. But he can't type. Okay, it took him a year to learn how to do this at [the rehabilitation institute]. Okay, so we need to go with pictures instead of the words... Let's say where do you want to go tonight? Do you want to go out for food? Okay. You've got to figure out the path of the food and then what do you want to eat, and all of this. By that time, I had to do it and it wasn't any good to him. He couldn't even carry the device. So that went out the window.

Phyllis also noted that her husband's motor and cognitive impairments contribute to his loss of basic daily functions. She emphasized that everything had become frustratingly slow and tedious, even simple activities such as moving about. She was quite frank in explaining how angry, frustrated, and overwhelmed she felt:

Some days his hand just falls off the walker and I have to walk right along. The brain injury group gave us a scooter, which is just wonderful. So we have two wide steps that I had built to get to the garage. And it takes him ten minutes to get from the threshold to the bottom of the floor of the garage going down these two

steps. A lot of times he would get tired and just fall down, so I would yell at him and cuss, and say “Get up. Don’t you dare fall down.” Then I would have to pull him up or I would get my neighbor to help get him up...He couldn’t walk out that door and turn around and close the door. I mean, it might have some bad consequences. That’s what is horribly scary, that I – it gets overwhelming how much responsibility I have.

Other caregivers had burdens related to cancer caregiving during the post-treatment phase, but Phyllis was atypical in that her post-treatment caregiving role was much more demanding than her caregiving role was during treatment for her husband’s cancer.

**Theme of Helplessness and Loss of Control: Tied to This Ride.**

The theme of helplessness and loss of control was significantly less prominent during the post-treatment phase of cancer caregiving than it had been during diagnosis and active treatment. However, some of the caregivers still expressed helplessness or loss of control that was not associated with another theme (such as grief). For example, some of the caregivers felt that they had no control over the cancer and when it would return to their significant other. April, whose husband had completed treatment for an oligoastrocytoma of the brain, was still caring for her disabled husband on a daily basis at the time of our interviews because he experienced frequent seizures, cognitive impairment, personality changes, and other side effects from his radiation treatments and the cancer. She noted that the physician told her that it was normal for her husband to have the seizures long after the end of cancer treatment:

Like this is something he’s going to have to live with for the rest of his life. We’re thinking like, “Okay, brain cancer’s one thing, but having seizures every day?” He had no quality of life. He would have a seizure and even if it was like a thirty second one, just frozen, he would just freeze and stop what he was doing. He would literally sleep most of the day after that. So it was ridiculous... Like I was going to stop it from happening [chuckles] or protect him at all times.

Fortunately, not all of the caregivers were faced with caring for such serious and unpredictable needs. April was unable to travel far from home due to the unpredictability of her husband's seizures. Moreover, her nine-year-old daughter was afraid to stay with her father because of the seizures, so April voiced the need to protect her daughter from being alone at home with Dad. They expect the cancer to take her husband's life in a few years, and she worries about how she will cope in the meantime. As April noted:

That was like the biggest lesson I've ever learned. It's a huge joke that people walk around thinking that they have control over life. I'm like the biggest planner, controlling. [chuckles] You know what I mean? Like this is the way I want my life to be. I worked really hard to make my family, and keep a marriage. I mean all of it. When it comes down to it you have no say-so. I mean you have say-so in parts of it, but overall the big, I mean you don't. It's just going to happen, whatever you are doing.

Once again, hopelessness and loss of control issues were not dominant major themes for the post-treatment caregiving trajectories of participant caregivers. They all had residual concerns about things over which they had no control, but compared to how things had been during diagnosis and treatment they all felt that the situation was better after treatment ended.

### **Theme of Loss, Change and Grief: Reaction to the Whole**

Two themes that were emphasized quite intensely by all of the caregivers in relation to post-treatment caregiving were the themes of "Loss, Change, and Grief: Reaction to the Whole" and "Carrying Forward with Scars: New Priorities and Permanent Change." The first of these, loss and grief, was present during diagnosis and treatment phases of the cancer trajectory, but it became most prominent in relation to the post-treatment phase. After active treatment, caregivers had time to reflect on what they had lost, what had changed, and what would never be the same again.

As might be expected, those caregivers who were younger were more likely to mention the loss of future dreams and possibilities than were the older caregivers. However, all of the caregivers were pre-retirement age, so many of them had sacrificed either full or partial employment prospects so that they could fulfill their caregiving roles. Losses of all types caused grief responses and pain for caregivers. For example, several of the caregivers mentioned that they had lost their future plans, and this was quite painful for them. April noted that she had lost her future with her husband as well as her ability to trust in the future:

I definitely feel like I could become that person that never trusts anybody again and never wants to be vulnerable again. Because in the end, you only can rely on yourself. I mean, for one second I let go and relied on him. [Sobs] It is huge... I don't know how to move on. I don't know how to fix things... Like, as a family we are all lost... Like we always knew he was going to work. I was going to take care of our family... To feel like I may have to live without him someday and [sobs] raise my daughter, and financially take care of her and myself. I was so naïve. Cancer wasn't in the plans. Now I'm 32, uneducated, and feel like I don't trust living off the government... You know, basically it's just like you lost your dreams. We married so young. We had our daughter, and we gave everything to her. When she grew up it was going to be our time. We were going to do what we wanted to do. We've always talked about having grandkids and just growing old together. [cries]

Several of the caregivers discussed at length their feelings about how their relationships had changed. Some of them were sad about the loss of relationships with other family members. Lucy was especially sad about the loss of her relationship with her friends and family who had not helped her when Lucy had needed them:

I think the hardest thing for me was the disappointment in family and friends. I think that was the worst. Not having the support that I thought I would get from some people... I've talked to others and it's been similar for them. I don't know how to articulate this. It's just different when it comes to my relationship with my daughter. It was just – some friends that weren't there. It's just a different – not that I am angry – it's just, I don't know, maybe a little sad to think that some of that happened.

Other caregivers were quite frank about the loss of certain qualities of their relationships with the cancer survivors for whom they cared. Those caregivers who described a loss in their relationship with their significant others often described the loss of physical functions, especially intimacy. April noted that her husband had changed so much after his surgery and radiation therapy for brain cancer that he was unable to manage intimacy, and she was not willing or able to discuss it with him:

No intimacy, like physically he couldn't. Then it's just hard because it took a long time for me to get mental pictures out. You know men don't feel like men unless they are, you know – so that part is huge. It's a huge part of our marriage. Then, if I had a problem I would go to him. I can't go to him about this.

Diane's husband had physical limitations after his prostate cancer treatments that left him with impotence. She explained it this way:

Most people would not be as comfortable, and he knew how humongous the radiation doses were [for the prostate cancer]. I had him write it down once so I could tell the friend of ours that was a chemist, and he knew that there would be long term ramifications from the doses he got, and there were. There's no sex life left for him, and that was a big adjustment even at his age.

In addition, Diane's husband had significant cognitive impairment due to his chemotherapy and other treatments. Diane, a retired special education teacher, was acutely aware of his language deficits, and this affected their relationship:

It's really bad, what his word retrieval is down to, he has very little word retrieval right now. He wasn't that great with words before. He's a scientist and he's all in his head. But his word retrieval – I was a teacher, so it was kind of hard. I could identify what was happening. I worked with troubled kids. I was a resource specialist... After chemotherapy he would go to bed for four days. I was very lonely.

Diane eventually discussed the possibility that her husband could eventually die from cancer, although he was cancer-free at the time of our interviews. She did consider the possibility that she could lose him if his either of his two types of cancer would return.

This troubled her a great deal, but she found support from a member of their cancer support group who was dying of cancer:

One of our first meetings this really wonderful guy said, “Well, it’s time for me to stop doing the dance.” That’s what he said. There were no other options left to him, and I bless that man because today my husband has no other options. He’s done every treatment he can possibly do for either cancer, and we know that peace can come after that because this man showed us that sometimes we just have to stop doing the dance.

Finally, Sharon described the loss of her husband and her feeling that she had lost a part of herself through the cancer experience. Fortunately, her daughter had been helpful with her grieving process, but Sharon was still working through her grief at the time of our interviews:

This was a year and a half that we went through this. It wasn’t just the last six months when he couldn’t do anything, but it’s been a long time. My daughter said, “I want you to be able to feel alive again.” I don’t know. That part of me wants to go out and try to live again, but just not quite ready for it. But I [pause] hope that I get over that hump, because I don’t want to just be me until I die. I want to – I had such a good marriage with [him]. We had so much fun! [cries] He told my daughter not to let me sit in the house, so I know that he would not want me to just sit around but... [long pause, tearful] I think your self starts coming back. I lost myself for a bit.

There were a number of other excerpts of grief and loss that were equally poignant. For example, Mike became tearful when he said that what he hoped for at the time of the interview was “to keep her around as long as possible.” His children are now 10 and 7, and their mother returned to chemotherapy since the second interview occurred because she has metastases to bones, liver, and brain from the original breast cancer. It became apparent when listening to the caregivers that the impact of caregiving was not only on the caregivers but on the family units.

### **Theme of Carrying Forward with Scars: New Priorities, Permanent Change.**

The new theme that emerged in relation to post-treatment caregiving for all of the caregivers was “Carrying Forward with Scars: New Priorities, Permanent Change.” To continue the metaphor, after the “tsunami” had left, the destruction remained and the landscape remained unstable. None of the caregivers were at peace with the aftermath of cancer. April described it as a tornado that had gone through their lives:

It’s just like a tornado comes into your life and tears it all up. I mean that actually would be easier because you could rebuild a home and buy new things. Right now we just have this huge mess, and I don’t know how to fix, don’t know how to rebuild. It’s almost like why bother?

The major theme of “Carrying Forward with Scars,” however, had less to do with what had happened to them than with how they had changed as people by enduring, persevering, and experiencing cancer caregiving. Something significant had happened to them while they were focused on someone else. Caregivers had changed as employees, as family members, and as individuals. Some of the changes were positive, and some were negative, but none of them were left unchanged by the cancer caregiving trajectory.

The caregivers have found ways to live and to do normal things in the aftermath of cancer caregiving. Shirley tries to make time for her friends and church activities.

Phyllis tries to get out more individually, but she ends up feeling guilty:

One of the things that really bothers me, and I don’t know how to handle it, is my feeling of guilt when I want to do something or I have to leave him because it’s inaccessible, or he is unable to do it, and then I feel really guilty.

April, who was not employed outside the home when her husband was diagnosed, reported that she was trying to find a way to return to school for a GED so that she could support herself and her daughter when her husband’s brain cancer eventually leads to his death. Susan was looking forward to resuming some of her social and community

activities, within the restrictions that her husband had requested: no evening meetings and no all-day absences from their home.

Several of the caregivers noted that they were not the same as employees as they had been before they experienced cancer caregiving. Rose noted she had changed as a respiratory therapist in terms of how she felt about her job and how well she was able to cope with the demands of her employment. She described the change as being more task oriented and less comforting to her patients:

The weight of it kind of wears you down. I'm weary all the time, kind of fatigued... I'm more task-focused. You know, I want to make sure I'm ... taking care of the patients. But am I spending that extra second with them? Probably not. Am I gripping their hand, taking that extra second to hold their hand or smile at the family member, the spouse? Probably not like I used to. I just want to get the job done, because I have things to do at home that need to get done. I am more task-focused rather than seeing the big picture. There's not really a big picture anymore. Just focus on the small tasks and get through it all.

Most of the data related to the theme of "Carrying Forward with Scars: New Priorities and Permanent Change" was the result of personal changes that caregivers saw in themselves due to their experiences with cancer caregiving. For example, they often kept changes in roles that they had learned and assumed along the trajectory. They also found that they had changed as people, sometimes for the better and other times in a more negative way.

David had experienced role issues with some of the duties he had assumed at home due to his wife's persistent fatigue from chemotherapy. She had worked as a nurse researcher in a neonatal center at a local hospital, but she had always done most of the home activities herself, while David had worked long hours in his chiropractic practice prior to his wife's diagnosis. However, after she was diagnosed with breast cancer things changed for David. He cut back his hours of the practice and made his

lunch hours two hours long so he could help her at home with lunch, and this change persisted into the post-treatment phase. He had a humorous outlook on the changes in himself that he saw because of cancer caregiving:

You find out there's a lot of stuff to do here. This laundry sucks. [laughs] Can't we hire that out? Aren't there these trucks that come and pick this up? I always cooked on the grill, but just threw the meat on and then you'd have chips or something like that. I have actually become a really good cook. Got a lot of cookbooks and a lot of utensils and so I do all the cooking, and she likes it that way. When she comes home tired, she sits and then she gets a plate. Then, she's good to go. That I think we appreciate our time together, which you think you do anyway, but you just try to enjoy it a little more.

David stated that he still does the cooking and much of the cleaning because his wife continues to have serious lymphedema and fatigue problems. He is self-employed as a chiropractor, and he has permanently adjusted his schedule to accommodate his home and family responsibilities.

Most of the caregivers reported that their outlooks and priorities had changed as a result of cancer caregiving. Phyllis reported that her outlook had changed because she had become more self-reliant than she had been in the past:

I don't mean to disrespect my sister or anything, but she will say – her husband's name is David. She will say "David, I can't get this door open." I thought, "Oh, sh\*\*. My God, do it yourself" or bring in the luggage – whatever, do it yourself. I think about how much I have learned and it is good. I used to hate fixing anything because my husband used to do it all... We used to own apartments and he and I did it together... You have to grow up, or you just have to face reality. You've got to live with it.

Caregiver participants reported that their lives were no longer the way they were before cancer happened to their families, even if the cancer was gone at the time of the interviews. Participants reported that there was fallout in terms of changed and changing relationships, changes in priorities of living, and almost post-traumatic feelings about what they had experienced as caregivers. Several of them were in uncertain situations at

the time of our interviews. April was looking for a way to return to school so that she could support herself and her nine-year-old daughter when she would lose her husband. Sharon was working through the grief of losing her husband and trying to pick up the pieces of her life. Rachel was grieving the loss of her mother while worrying about her own future with newly-diagnosed breast cancer. Mike was wondering when the eventual return to chemotherapy would occur for his wife and trying to keep their family running with two young children. David was hoping that his wife's lymphedema and fatigue would lessen so that they could return to their normal activities and begin to travel again. Diane was trying to cope with her husband's cognitive difficulties and the loss of their physical relationship. Phyllis was trying to postpone the eventual move to the nursing home for her husband's care. Shirley was wondering about the return of her own newly-diagnosed cancer as well as when her husband's cancer would return. Rose was hoping to be prepared for the eventual loss of her father and worrying about her employment demands as her father's condition would eventually decline even further. Robert was still trying to "get this right" and provide the best care for his wife, whose cancer exacerbated between our first and second interviews.

Carrying forward required some transitioning. It required caregivers to draw upon their previous experiences and other personal resources in order to make it through the cancer caregiving experience. Robert, for example, had expected to find that he was easily able to step into the caregiver role for his wife because of his traumatic experience of losing his young son. However, he reported that this was only partially the case:

I've learned how strong I am through this, but I am not as insulated from pain as I thought I was. I thought I had myself really insulated well, and I am finding out that nope, this proved that wrong... It probably is healthier that I feel it so much,

but it's scarier, too. The thought of life without her is – I realize it's painful. [tearfully] It's more painful than I thought it was going to be.

All of the caregivers reported that cancer caregiving had changed them personally, including reordering their priorities and making them more compassionate, more willing and likely to reach out to other people. As Diane put it, "I think it's upped my compassion meter." As Sharon noted:

We all get so caught up in our own little lives that we don't take a moment to reach out a helping hand like we should. It's not because we don't want to. It's just that we don't think we have the time to do it. You know what? What's five minutes out of your day to say a kind word to somebody or give them a hug or just say "I care. I can't know what you are experiencing, but I want you to know that I am thinking about you."

Rose reported that she has changed, but she seemed sad about the changes that she saw in herself:

I don't laugh as much as I used to. I actually have to stop to enjoy the spring when the flowers are in bloom. Sometimes it takes somebody else to point it out to me because I don't notice it. I have to actually stop and take a deep breath, and look at the beauty of the new flowers, of the blooming trees, of ice forming on a pond in winter... [long pause] Well, I guess it's just back to you don't seem to laugh as much as you used to. Your sense of humor is kind of gone.

Diane noted that she had been supported by her friends and family, but not all of them had been as supportive as she had hoped. She stated that there was a positive side to her experience, however:

I think a relationship can get much stronger when you fight the cancer whether it's with just the patient or your family members... You find out who's really a friend, and who's kind of afraid of being a friend and that's okay, they can go their way and I won't hold it against them, because it's a scary thing.

All of the caregivers reported that they had seen various changes in themselves as the result of their experiences with cancer caregiving. One change that seemed to be almost universal among the participant caregivers, however, was a change in worldview,

a new paradigm with new and different priorities for living. All of the participant caregivers noted that their priorities had changed in that they felt more strongly than ever before about the need for human connection, reaching out to others with compassion. Several of the caregivers illustrated and described what they saw as the changes that had occurred in their priorities. Sharon was one of the caregivers who found that she had become more aware of what was important to her:

I have a lot less tolerance for the petty things in life when people get bogged down...It's not nice to say that everybody needs to go through this in order to learn, but unless it hits you smack in the head, I don't think you think about it. Who would want to think about it? Yes, it changed me. It made me more aware, made me slow down, made me more tolerant. Made me realize that having my house clean all the time isn't one of the most important things in life.

Similarly, David stated that he had begun to reach out to others more often than he had in the past. As he put it, "It only takes a few minutes to drop a card or note in the mail, to make a phone call, to give a hug... and it means so much, so very much." He stated that it was not enough to merely intend to reach out, since only actions would be received.

Mike and Robert illustrated a time element to their priorities. Mike did not know when his wife's cancer would return and require treatment, and he did not know how long his wife would live, so he experienced changes in his approach to the future:

Priorities – I just approach things from a different perspective. I don't make plans long term, I don't try to make a definite five to ten year plan on what we are going to be doing; probably just shorter term plans and just avoid looking farther into the future...

He went on to say that he would not contemplate the long-term future but preferred – and even insisted on – keeping his focus on the immediate and short-term needs and plans for his family.

Robert, on the other hand, looked at his and his wife's long-term plans and attempted to accelerate some of them into the present. As reported in Chapter 4, he stated that he and his wife had tried to do all of the traveling that they had planned for retirement in a short time frame. He explained it this way:

I have a sense of urgency about everything. We have this discussion every now and then. She's not – we're not always on the same page when it comes to how to deal with this which, gee, it's not surprising, married couples not always being on the same page. To me, I can't plan for tomorrow. I don't know if there's going to be a tomorrow, so if there is something that needs to be done let's do it today. If there's something we want to do, let's do it today. We don't know. Life expectancy for what she has with her genetic abnormalities was less than 26 months and we are into the third year now.

His wife died about six months after our second interview.

### **Chapter Summary**

Data from caregiver participants provided information about the experiences of cancer caregiving as caregivers looked back on the whole trajectory of their experiences. During the pre-diagnosis phase of the cancer caregiving trajectory, the circumstances of participant caregivers were varied, but caregivers-to-be were all pre-retirement age and engaged in what was to them meaningful work. They were maximally productive and had a variety of life experiences through which they had developed as productive individuals. They had goals and were working to meet them. When cancer was diagnosed, the experiences of participant caregivers became more uniform. They were converted from being a varied group to being a group of people with something significant in common: cancer in a significant other. The impact of cancer diagnosis included the emergence of burden, but mostly the need to deal with the healthcare system, feelings of helplessness and loss of control, and a sense of disconnectedness and isolation. As caregivers automatically assumed their roles as caregivers, they were

sometimes faced with the burden of having to hide the cancer diagnosis for the comfort and at the insistence of their significant other. This phenomenon – hiding the diagnosis – was a significant stressor to caregivers, since it isolated them from social support and created a burden of keeping silent.

During cancer treatment, caregivers uniformly expressed themes of significant burden, role disruption, dealing with the healthcare system, disconnectedness and isolation, and helplessness and loss of control over their world. They were isolated by the burden of caregiving; the intensity of the burden and the emotional energy that was draining from them created a sense of focus. They focused on what they needed to do and eliminated other activities and responsibilities as much as possible. They were so focused that sometimes they put their own needs aside and participated in their own neglect. They mentioned the need for social support, but they felt none was available for them as caregivers, so it was easiest to just allow that need to be unmet. During treatment a theme of loss, change, and grief emerged as small changes and losses became evident and caregivers began to realize that some of these changes and losses would become permanent.

After initial cancer treatment had ended, caregivers allowed themselves time and emotional space to reflect on what had happened to them and to their significant others. They found that they had varying degrees of burden, depending on the post-treatment status of their significant others. Helplessness and loss of control was a theme expressed by most of the caregivers related to post-treatment, but the helplessness and loss of control was more reflective in nature. They were no longer feeling helpless to cope with the demands of caregiving as much as they were feeling that they no longer could count

on a future that they had planned. Two themes emerged from data related to post-treatment cancer caregiving: loss, change, and grief as well as carrying forward with scars. Caregivers pondered what they considered to be an enormous and significant event in their lives and in the lives of their families. They found that they had lost much, and they grieved their losses. They found that they had also changed much as people, sometimes for the better and sometimes in a more negative way. They found that they would change their approach to friends whose significant others were going through cancer treatment to become more active. They reordered their priorities and resolved to be more self-reliant and caring. They would become what they had needed along the way.

These are stories from the trenches of cancer caregiving, from diagnosis through treatment and into the post-treatment phase of cancer care. Things change after cancer, and the new state is not necessarily stable for caregivers or for their families. None of the caregivers emerged unscathed. All of them reported changes in priorities and in themselves. Implications of the study findings are presented in Chapter 6.

## CHAPTER 6: DISCUSSION

The purpose of this narrative, qualitative study was to examine the impact of cancer caregiving on caregivers, exploring their personal narratives of the cancer experience looking back on the entire experience from diagnosis, through initial treatment, and beyond. Eleven participants participated in two semi-structured interviews, which were transcribed and analyzed using within-case and across-case narrative analysis. In this chapter I present a synopsis of major thematic findings from the study, provide conclusions, describe limitations, and suggest implications.

### **Synopsis of Themes: Findings**

Themes characterizing cancer caregiving across the trajectory of the illness were:

- Burden: The Load that Never Ends
- Disconnectedness and Isolation: The Invisible Person
- Helplessness and Loss of Control: Tied to This Ride
- Dealing with the Healthcare System
- Role Disruption: Spinning the Plates
- Loss, Change, and Grief: Reaction to the Whole
- Carrying Forward with Scars: New Priorities and Permanent Change

The theme of burden was most prominently emphasized by caregivers who participated in this study as they discussed their lives during the treatment phase of the cancer trajectory. Caregivers assumed the burdens of caregiving willingly, with strength and perseverance, as they came to grips with the demands of the cancer experience for their significant others. The burden associated with cancer caregiving was all-encompassing and pervasive in their lives and in the lives of their family members. The

burdens were most intense during treatment, but after treatment ended all of the caregivers noted that residual burdens remained indefinitely.

The issue of caregiving burden contributed to the development of feelings of disconnectedness and isolation, which was another major theme. As caregivers became increasingly consumed by the demands of caregiving, they began to disconnect from familiar things in order to meet the demands of caregiving and absorb the enormity of what was happening. They became knowledgeable about what was needed for their significant others and less interested in the mundane aspects of life around them. In addition, they noted that interaction with others sometimes became awkward, and the effort of interacting with casual acquaintances, and sometimes even family members, became costly in terms of precious energy and time. Therefore, they subjugated their own needs for social connection and buried themselves in the most important priority for them at the time – cancer caregiving.

Once they began the caregiving journey, none of the caregivers were willing to give it up, especially after they became knowledgeable about the needs of their significant others. They were tied to the role of caregiving, but they did not feel that they were in control of the situation, often feeling helpless. In this way they were tied to the ride, so to speak, since they were holding to their commitments and yet not in charge of where things were going. Cancer, as they said, was an unpredictable and harsh driver.

Throughout the caregiving journey, caregivers maintained a changing relationship with the healthcare system. At first, the healthcare professionals were their lifeline to information, options, and treatment decisions. During treatment, however, the relationship with the healthcare system became more intimate as they dealt with the

effects of both cancer and cancer treatments in their significant others. The healthcare system became a necessary partner in care, but not everything about the healthcare system was seen as positive and caring, especially when it came to interactions with physicians.

The theme of role disruption was an inevitable consequence of burden and disconnectedness with cancer caregiving, a job that was both intensely connected with healthcare and yet not within their own control. Therefore, they found that they were stretched to a point that all of the caregivers had to prioritize their time and energy. They were caught in a situation of trying to meet all of their responsibilities and failing to do so. One participant vividly described the experience as being much like the old variety show act in which the performer would keep several plates spinning atop sticks. No sooner had the performer given one plate a spin to keep it going than one or two other plates would begin to falter. The result was that eventually if the performer lost concentration there would be a crash of plates. As a result, all of the caregivers made changes in employment and social responsibilities and commitments. They found themselves unable to continue as usual in their normal productive lives while at the same time assuming new roles and responsibilities related to cancer caregiving and family needs.

Through the experience of cancer caregiving, caregivers experienced losses and changes. They lost or experienced changes in roles, relationships, finances, employment, their future plans, and a myriad of other smaller changes in living, and they grieved these losses. While none of the caregivers could describe only one type of loss, they all agreed

that the whole of the experience was aptly described as one of loss, and their normal reaction was to grieve.

Finally, the theme of carrying forward with scars was one of permanent change, but not static change. Caregivers came to grips with the fact that they, in addition to their significant others, had been through a significant experience, but they did not have a feeling of closure or settlement about the aftermath. They were less than certain about the future, but there was some variation in how far into the future the caregivers looked. For some, the future was uncertain, with possible perils and pitfalls. For others, the future was grim; they knew that their significant others would experience recurrence of cancer and would possibly die from the disease. Therefore, the scars from their past caregiving combined with the permanent change to which they looked ahead often caused them to look at life differently, with changed priorities, compared to their lives before cancer. For example, they all noted that they were more compelled to reach out to other caregivers now that they had been through caregiving than they had been in the past.

There were no themes that emerged from the data that were positive, such as personal growth or joy in living. In fact, when I mentioned these concepts to the first few participants in the study they were all adamant about their perspective that there was nothing positive about the cancer experience or anything related to cancer.

### **Conclusions**

The findings of the study indicate that cancer caregiving is fraught with disconnectedness, associated with grief and loss, dynamic over the trajectory of the cancer experience, and enduring in terms of impact upon caregivers. The first conclusion based on these findings is that the *conditions of cancer caregiving impair*

*healthy transitioning through the trajectory.* Transitions Theory (Figure 1) identifies conditions of transitioning as those personal, societal, and community characteristics that facilitate or inhibit successful transitioning. The burden and isolation reported by participant caregivers served to inhibit transitioning by overwhelming the energy of caregivers and by severing their ties to sources of potential support. All of the participants in the study expressed the need for more support that was targeted just for caregivers, even though they admitted that they had been less than willing at times to accept help that was just for them. Furthermore, literature on Transitions Theory and the theoretical framework model (Figure 1) indicate that healthy patterns of response to transitions include the progress indicators of feeling connected, interacting, location and being situated, and developing confidence and coping (Meleis, et al.,2010). Connectedness is a progress indicator of healthy transitioning and indicates positive progress in the midst of transition. In contrast, participant caregivers experienced disconnectedness rather than feeling connected, feelings of isolation rather than interacting, feelings of being voluntarily tied to an unavoidable burden rather than being situated in their position of choice, and loss of control rather than developing confidence and coping. The struggles experienced by the participant caregivers illustrated their efforts to persevere in spite of the difficulties involved. Prior to this study, transitioning of caregivers over the trajectory of cancer caregiving was largely unexplored. Meleis noted that unhealthy and ineffective transitions can result in negative outcomes, including role insufficiency (Meleis, 2010).

The second conclusion is that *family caregivers are part of the client unit and require application of the nursing process: assessment, diagnosis, planning,*

*intervention, and evaluation.* Caregivers are in close contact with healthcare professionals as they learn how to help their significant others with cancer, so it would behoove healthcare professionals to turn more attention specifically to this other part of the client unit. The findings that caregiving is a major event for caregivers and that intense grief may occur after the end of their significant other's cancer treatment means that caregivers have needs of their own that are unique to them. The finding that caregivers tend to feel almost "invisible" from their isolation and disconnectedness indicates that healthcare professionals are less than effective at reaching out to caregivers other than to train them to help the cancer patients. Caregivers require and deserve their own nursing process (including assessment), support, and care and should be monitored for cardiovascular health, psychosocial health, and grief reactions to losses.

The third conclusion from the study is that *care for caregivers should not be tied to medical treatment of cancer in their significant others; rather, the needs of caregivers change over the trajectory of caregiving.* The caregiving experience is not the same as the cancer experience, even though it is affected by the trajectory of cancer diagnosis, treatment, and post-treatment. Medical needs of cancer patients require a significant investment of time, energy, and mental processes from caregivers, but the impact of this cancer caregiving creates needs in caregivers that are individual and related to their own conditions of caregiving (facilitators and inhibitors of transitioning). Therefore, efforts to help caregivers that are tied to medical treatment for cancer patients will not be effective in breaking through the reluctance of caregivers to accept interventions at a time when they are almost overwhelmed with the demands of caregiving. Finally, the timing of caregiver needs is not the same as the timing of medical needs of cancer patients. For

example, normal grief reactions in caregivers become most intense after cancer treatment ends for their significant others.

The presence of grief in cancer caregivers was vividly expressed and almost palpable even years after their cancer caregiving journeys had begun, well into the post-treatment phase of cancer. All of the caregivers were able to recall their experiences in vivid details, and most of them were stunned and surprised at the impact of reliving those experiences and discussing them in the interviews. Some reported that they had been unable to function after the first interview and had to go home to rest. They reported that they were surprised that they had become tearful after so much time had passed since cancer was diagnosed in their significant others. All of the caregivers reported that they had no difficulty remembering or expressing the details of cancer caregiving, no matter how much time had passed since their significant others were diagnosed. Considering that grief is a normal reaction to loss, the presence of grief was not surprising. However, the fact that all of the caregivers spoke of intense feelings of grief, no matter what the outcomes had been of their significant others' cancer treatments, was surprising. It was not surprising to hear feelings of grief expressed by caregivers who had lost their cancer patients. The fact that similar feelings of loss and grief were expressed by caregivers whose significant others were cancer-free, however, was perhaps due to caregivers reflecting on what had been lost and what had changed along the way of the cancer trajectory.

### **Discussion of Findings**

The findings of this study are well-suited to move the science forward in terms of what is known about the conditions and impacts of cancer caregiving for caregivers over

the trajectory of the cancer experience. Thematic findings revealed the impact of caregiving on cancer caregivers as significant, burdensome, and stressful. Furthermore, the intensity and nature of themes changes over the cancer trajectory, so the perspective of looking back over the whole cancer caregiving experience was valuable in terms of adding to the knowledge base about the dynamic nature of cancer caregiving over time.

Another new finding from the study was the caregivers expressed grief, no matter what the outcome of cancer treatment, and the expressions of grief were most intense after the end of cancer treatment. This impact, plus the finding of intense disconnectedness, burden, and isolation during active treatment may help to explain the serious psychosocial and emotional impact of cancer caregiving on caregivers, impact that persisted for years after cancer treatment had ended for their significant others. Moreover, all of the caregivers expressed the need for support targeted specifically for caregivers, although they noted that most caregivers are somewhat reluctant to accept help if they have subjugated their needs to those of the cancer patients.

### **Relationship of the Study to Existing Literature**

Prior studies presented earlier were partially validated and in some cases challenged by the findings of this study. For example, several researchers noted that cancer patients were affected differently than were their caregivers by cancer. Mellon and colleagues (2006) noted that cancer survivors reported significantly higher quality of life, less fear of cancer recurrence, and more support than did their family members at 1 to 6 years post-diagnosis. The findings of this study did not contradict that conclusion. Furthermore, Foley and colleagues (2006) noted that most cancer survivors used the cancer treatment experience to make positive changes in their lives and to move past the

experience in a positive way. In contrast, none of the caregiver participants in this study seemed to find anything positive about cancer, and some even vehemently opposed the suggestion that there was anything positive about the experience.

Other studies were validated by the findings of this study. The thematic findings of isolation, hopelessness, loss of control, burden, grief, and disconnectedness did not contradict the findings of Edwards and Clarke (2004), who noted that depression and anxiety were lower for cancer patients than for their caregivers during cancer treatment. Mellon (2002) studied 123 family dyads to test a model of predictors of family quality of life, and she found that cancer survivors identified that receiving support from others was important, while family caregivers were more focused on how to give support to cancer survivors. These studies can be explained by the findings of this study that caregivers subordinated their own needs to the needs of cancer patients for whom they provided care and support.

More recently, researchers have examined the caregiving experience and impacts, but not from the perspective of the trajectory over time. Wagner, Das, Bigatti, and Sterniolo (2011) studied 119 husbands of breast cancer patients during treatment and one year after treatment to characterize caregiving activities and to examine which activities predicted psychological distress. They found that at 1 year after treatment caregiver role strains improved in the social domain but worsened in the domestic domain. Further, they found that domestic role strains were most predictive of distress at 1 year. This finding can be explained by the current study, which revealed that the effects of caregiving persist after cancer treatment, especially grief and struggles with a new, unstable future.

Another study of men involved 15 caregivers of women with breast and gynecologic cancer up to 12 months after diagnosis (Lopez, Copp, & Molassiotis, 2012). The researchers found that cognitive, physical, and psychological impacts were experienced by caregivers at 12 months and that the caregivers were reluctant to seek support for themselves. The findings of Lopez and colleagues would suggest that more needs to be known about gender and the caregiving experience of cancer.

Similarly, Martin and colleagues (Martin, et al., 2012) examined racial variation in cancer caregiving and found that African American caregivers spent more time caregiving and performed more caregiving tasks than did white caregivers. This would suggest that more needs to be known about racial differences in cancer caregiving.

Recent studies comparing cancer survivors to caregivers within the dyad have included a study of 100 cancer patients and 100 caregivers, comparing perceptions of each regarding the psychosocial aspects of caregiving (Desields, Rihanek, Potter, Zhang, Kuhrik, and O'Neill, 2012). The researchers found that cancer patients underestimated how difficult caregivers perceived the psychosocial aspects of caregiving to be. This finding would be consistent with the finding of the current study that showed isolation and burden along with disconnectedness to be prominent issues for caregivers, especially during active cancer treatment. Other studies have provided evidence that coping and social support is very important for caregivers (Epiphaniou, et. al., 2012; Fitzell & Pakenham, 2009).

Finally, the issue of detrimental effects of caregiving on caregivers seems to be essentially unchanged since the study by Schulz and Beach (1999) in which researchers found a 63% higher mortality rate in caregivers over the following four years compared

to others their age. A recent study of 218 caregivers at two years and five years post-diagnosis provided evidence that there is long-term negative impact on caregivers (Kim, Spillers, & Hall, 2010), but the study did not examine specific elements of the cancer caregiving trajectory. More recently, a study of 91 caregivers of patients with lung cancer was conducted to describe the physical health, mental health, and life changes among family caregivers of patients with lung cancer during treatment (Mosher, Bakas, & Champion, 2013). They found that the majority of caregivers reported negative emotional effects, and about one-third reported physical health effects of caregiving.

It would appear from the current study that there is a dynamic experience of cancer caregiving over the whole trajectory, that there are enduring impacts on cancer caregivers, and that the experience of cancer caregiving was remarkably similar regardless of outcome of cancer treatment. The major conclusions of the study based on these findings contribute to the scientific literature on cancer caregiving.

### **Methodological Limitations**

The sample was Caucasian and lacked participants of other cultural groups, even though the cancer center from which I recruited participants served individuals of a variety of cultures and ethnicities. This homogeneity may limit the transferability of the study findings to individuals of other ethnicities. Similarly, the participants were all residents of central Illinois, and perhaps that regionality could have influenced the findings. Ethnicity and regionality might have influenced participants' cultural and personal meanings attached to cancer or caregiving in general.

Because the study was descriptive and qualitative, no inferences may be made regarding causality. In addition, the study participants were all in some way connected

with the Cancer Center for Healthy Living, so cancer caregivers who do not utilize the services of such centers may be different in many ways from those who do. The application of themes to cancer caregivers in general may be limited in terms of transferability. In addition, caregiver participants had a very emotional reaction to the interviews, and they were able to recall details of the cancer experience with clarity, but it is possible that some of them could have been affected by some other perspective that they had at the time of the interview.

The limitation of using a process theory as a theoretical framework for the study is that there is the implication that a linear process exists in cancer caregiving. While it is true that the sequence of events of cancer diagnosis, treatment, and post-treatment are linear, it is human nature to revisit those events psycho-emotionally and thereby go back and forth – at least mentally – once caregivers are in the post-treatment phase of cancer care. However, the trajectory of cancer and its treatment is linear, and the retrospective views of caregivers were vital to answer the research questions.

### **Methodological Strengths**

Qualitative methods served a unique and vital purpose in the investigation of the impact of cancer caregiving on caregivers over the cancer trajectory. One reason the study was conducted using narrative, qualitative methodology was because the relationships between variables – and even the identities of relevant variables – were unclear at best. Using narrative qualitative inquiry allowed a holistic view of the whole caregiving experience without excluding any potential issues that could become variables in a subsequent quantitative or mixed methods study. The narrative aspect of the inquiry kept stories of participants intact and allowed the stories to span the cancer

trajectory while not losing the thoughtful, retrospective view of participants who had had time to ruminate and to think about what had happened to them. Furthermore, without narrative within-case and across-case analysis, it is doubtful that the changing nature of the experience would have emerged, since some of the themes were present more or less at different times along the trajectory.

One main advantage of using narrative inquiry for the study was that it allowed a better understanding of the interaction of impacts on caregivers and how those impacts led to others. For example, the mounting burden associated with cancer caregiving during active treatment served to deepen feelings of isolation and disconnectedness in caregivers. Another example is the finding that caregivers entered into the caregiving role enthusiastically and determined to succeed and ended up putting their own needs aside due to the demands of caregiving. Narrative inquiry, keeping stories intact, and especially across-case analysis combined with the chronological within-case analyses, served well to identify the complex interactive nature of the impacts of cancer caregiving on caregivers as they transitioned through cancer treatment and beyond.

In moving the science forward, narrative inquiry would be useful on its own or as a part of a mixed methods study that would focus on grief, trajectory changes, disconnectedness, and interventions to help caregivers of patients going through cancer treatment and beyond. Qualitative methods may serve to illustrate and deepen the understanding of cancer caregiving as an exemplar for transitions theory as well, since the data obtained through qualitative inquiry are rich and deep.

### **Implications of the Study**

The study findings and conclusions provide implications for practice, theory, social policy, research, and education. Cancer caregivers are increasing in number as cancer survivors are increasing in number, with approximately twelve million cancer survivors alive in the United States today (American Cancer Society, 2011). It behooves theorists, policy makers, researchers, and educators to discover more about how to assist caregivers in their roles as caregivers while supporting them as people with personal needs as well.

#### **Implications for Practice: Through the Trajectory of Cancer Caregiving**

Implications for practice are different at the various phases of the cancer caregiving trajectory, since the needs of caregivers vary from phase to phase just as themes varied. Caregivers were a resilient lot, but they were almost too good at hiding their needs and subordinating their needs to the needs of the persons with cancer for whom they cared.

##### **Practice implications during diagnosis.**

Caring for caregivers who are going through cancer diagnosis with a significant other may be challenging because few people have a pre-developed relationship with the oncology community prior to entering it for care. Therefore, it behooves those working in diagnostic areas and oncology offices to recognize that information is critical. Moreover, it is important to recognize the ability of patients and family members to absorb information. It would help to do a needs assessment in terms of informational need, recognizing that the time of diagnosis is emotionally challenging.

Caregivers in the study were all pre-retirement age, so the implication for healthcare professionals is to recognize each family caregiver's stage of adult development and the implications for those caregivers. If caregivers are pre-retirement age, then the impact of unexpected cancer caregiving on their careers or other family and social responsibilities is significant and may be overwhelming. They will need anticipatory information so that they can better manage the competing demands of families, employment, and vocational responsibilities while carrying the burdens of cancer caregiving.

In addition, healthcare professionals could offer to meet with other family members and assist with meeting informational needs, provide support, and help explain the diagnosis and treatment. Perhaps role playing could be useful to help equip cancer patients and caregivers to "break the bad news" to significant others in their social and family networks while maintaining the level of confidentiality and privacy that is necessary. With creative planning and clear communication, the phenomenon of not disclosing the cancer diagnosis can be less burdensome for caregivers.

#### **Practice implications during treatment.**

During active cancer treatment, caregivers experienced the peak levels of burden, role disruption, disconnectedness, helplessness and loss of control, and interaction with the healthcare system. In addition, they experienced to a lesser extent some recognition of what the various losses and changes would mean to them and to their significant others, so grief reactions began to emerge from the data at this phase. These impacts on caregivers suggest practice implications for healthcare professionals.

Caregivers stated that they wanted certain things from healthcare professionals. They wanted information without having to know what questions to ask. They did not find supports in place for caregivers alone, distinct from cancer patient support services. As a result of their sense of duty and experience with the burden of caregiving, caregivers came to the point of putting their own needs last. Therefore, it would behoove healthcare professionals to shift their practice paradigm to include caregivers as “co-patients.” Healthcare professionals often utilize the services of family caregivers as we teach them how to give injections, do wound care, assess for signs of complications, and set limits on patient activity. Therefore, since we are interacting with caregivers in such a meaningful way it makes sense to use preexisting interactions to offer support, anticipatory information, and guidance. Shifting the paradigm from utilizing caregivers to treating them as part of the patient unit and care team would provide a framework for supporting caregivers in their caregiving and assessing their needs.

For example, a friend was going out of town for her husband’s stem cell transplant therapy. She knew of the study of family caregivers of patients with cancer, and she was excited to tell me that she had gone to a “caregiver’s class” in preparation for the new treatment. When I asked about the content of the caregiver class, she replied that the entire content had been focused on the needs of the cancer patient: what he would need to eat, avoiding plants and children, avoiding animals, staying within a certain distance from the medical center for 100 days, side effects to be managed, and the like. There was nothing in the content of the class for this caregiver, for herself. She saw nothing wrong with that, since she had long since subordinated her own needs to those of

her husband because of his cancer diagnosis. That was a missed opportunity for healthcare professionals to reach out to caregivers.

During cancer treatment, demands on caregivers are high and their time is at a premium. Therefore, it is essential to identify needs and meet them using a minimum of time and trouble for caregivers. Collaboration and information sharing should be the norm on the supportive healthcare team so that caregivers do not have to repeatedly tell healthcare providers important information. Caregivers were distrustful of healthcare providers who did not seem to be knowledgeable about the patient's medical history.

All of the participant caregivers identified that they had needed more support than they had received, especially during cancer treatment for their significant others. Particularly, they identified that looking back over the whole trajectory they had needed targeted support for caregivers in terms of someone to contact for information, someone to contact them to offer specific respite services and household help (meals, cleaning, laundry, transportation for children), someone to refer them to community resources, and someone who could offer suggestions for getting through various modalities of treatment. These types of social support should be available for caregivers as individuals, distinct from support offered to cancer patients alone or to dyads. Several of the caregivers noted that they felt unwelcome in support groups if their cancer patient was too fatigued or ill to attend. In addition, most of the caregivers noted that they had not been very receptive to help during the treatment phase; nevertheless, they all suggested that someone should actively reach out with offers of assistance as noted above rather than having caregivers initiate the process.

Several of the caregivers in the study mentioned the need to find someone else “who had been through this and who knew what I was going through.” This is also a possible implication for practice during active treatment, especially since it would enhance feelings of connectedness as well as support. Caregivers noted that they felt that they had been hindered from reaching out to other caregivers due to federal privacy laws and limits on how much information the Cancer Center could make available to clients about other clients.

Caregiving during active cancer treatment was the most burdensome and disconnected portion of the cancer trajectory for caregivers. Moreover, participant caregivers stated that, although they had needed more social support and help, they acknowledged that they had been less than willing to accept support for themselves, preferring to focus on the patient with cancer. They all stated that caregivers should be more willing to accept support and help, and that people who offer support need to be gently persistent.

#### **Practice implications during the post-treatment phase.**

There is a paucity of support available even in National Cancer Institute certified oncology centers for both patients and caregivers after active cancer treatment ends (Tessauro, Rowland, & Lustig, 2002). When active medical treatment for cancer ends, even temporarily, compensation ends as well. However, that does not mean that needs do not continue. It is important to recognize that grief reactions to losses and changes become most intense for caregivers when the burden of physical caregiving begins to ease and when they have time in the post-treatment phase to focus on their losses. The finding that the theme of “Loss, Change, and Grief” is most intense in the post-treatment

phase means that healthcare providers need to actively facilitate connections with caregivers, to follow up with families, and to be alert for signs of dysfunctional or severe grief reactions. Follow-up care may include phone calls, emails, and home visits if needed.

Caregivers may find themselves emotionally drained by grief and other emotions and may find it difficult to resume their normal activities, even though others expect them to do so once cancer treatment has ended for their significant other. They may not feel up to participating in their employment or social activities. They may need time to process what has happened, to work through their grief, and to return to normal gradually. Healthcare providers can help by offering anticipatory assistance and resources to caregivers near the end of active treatment so they are prepared for the possible emotional changes ahead and plan accordingly. Resources such as grief counselors need to be available in case caregivers find that they need them, and perhaps healthcare professionals should reach out in a follow-up manner to see how caregivers adjust to life after cancer treatment. Once again, caregivers are likely to be resistant to outreach, since they will have been in the mode of caregiving and subjugating their own needs during cancer treatment for their significant others.

Unfortunately, unless a caregiver qualifies for a specific medical diagnosis, such as depression, supportive care for a caregiver is not likely to be covered by insurance. It behooves healthcare professionals, therefore, to anticipate potential caregiver needs and to facilitate connections between caregivers and free or low-cost community resources prior to the end of active cancer treatment. Such a “hand-off” would allow caregivers to feel connected with support systems in a seamless fashion.

Implications for practice vary throughout the cancer caregiving trajectory, but connectedness may be the key element that facilitates successful caring for caregivers. Several ways to facilitate connectedness include targeting caregivers with support services, involving them in planning care, supporting them with an informed healthcare team, shifting the paradigm to include caregivers as co-patients, and anticipating changes throughout the trajectory and providing supports appropriate to each individual at each stage of the caregiving trajectory. Referrals may be needed in situations of profound and dysfunctional grief, employment or social service needs, assisting with management of information about diagnosis, counseling to help with coping, and spiritual distress.

### **Implications for Theory: An Exemplar for Transitions**

The findings of this study support the use of cancer caregiving as an exemplar for Transitions Theory (Figure 1). Specifically, Transitions Theory is useful in understanding the phenomenon of cancer caregiving and identifying ways to assist caregivers and cancer patients.

Using the language of Transitions Theory, the nature of cancer caregiving as a transition experience can easily be viewed as a health/illness transition that occurs simultaneously with other life transitions (developmental transitions and perhaps situational transitions, depending on the events). Furthermore, cancer caregiving as a narrative has certain properties that are easily identified in terms of the transition properties of awareness, engagement, change/difference, time span, and critical points and events (Meleis, 2010). Chapter 4 presented the narrative summaries of participants in parallel fashion, using the four elements of narrative of orientation, time-ordered complications, making meaning of the complications, and resolution (Labov & Waletzky,

1967; Stevens, 1998). The orientation portion of the narrative summary is the relatively stable state that occurs prior to the disruption of cancer in the lives of patients and caregivers. In terms of the theory of transitions, cancer awareness begins at the point of symptom development or, if no symptoms were present, at the moment of unexpected diagnosis. Engagement occurs when there is attention drawn to the fact that something needs to be done about the symptoms or to treat the newly-diagnosed disease.

All along the cancer trajectory are the transition properties of change and difference. Cancer changes things; it changes one's medical history, body image, relationships, outlook, priorities, and other facets of the life story. The cancer experience is not short-term in nature, so the time element is critical to how individuals work through the transitions. Finally, along the way there are critical points and events that mark the divisions between chapters in the cancer story for both patients and caregivers. Such critical events may include surgery, chemotherapy, radiation therapy, aftereffects of cancer treatment, loss of employment, return to work or normal activities, and a host of other milestones along the way. These properties of transitions – awareness, engagement, change and difference, transition time span, and critical points and events – are consistent with the nature of transitions as identified in Transitions Theory.

Study findings related to transitions included personal, societal, and community facilitators and inhibitors that affected how caregivers were able to successfully or unsuccessfully transition to the post-transition relatively stable state of post-treatment cancer. For the purposes of the study, however, I divided transitions conditions into contexts and conditions, with contexts being those conditions not related to cancer caregiving and conditions being related to caregiving. Both contexts and conditions

together I termed circumstances of cancer caregiving. For example, in terms of Transition Theory (Figure 1), personal contexts would include previously-held cultural beliefs and attitudes, socioeconomic status prior to caregiving, family structure, employment, and history of caregiving in other settings or with other people. Contexts were the setting of caregiving, especially related to the orientation elements of caregiving narratives. Conditions included meaning of caregiving for the current situation, changes in employment and new skills and information that affected caregiving directly.

Patterns of response to transitions include progress indicators and outcome indicators. Progress indicators include feeling connected, interacting, location and being situated, and developing confidence and coping. Findings of the study supported the idea that cancer caregivers experienced serious impact in the area of progress indicators, possibly suggesting that assistance is needed for caregivers to successfully transition through the cancer caregiving experience. Most importantly, the progress indicator of feeling connected was universally impacted by caregiving in that caregivers experienced serious issues of disconnectedness and isolation. They were hindered in their interactions with others who did not understand what they were experiencing, and they felt repeatedly challenged by new and different conditions of caregiving that affected their feelings of confidence and their ability to cope with the competing demands of living with cancer in a significant other. Outcome indicators of mastery and acceptable fluid integrative identities were only partially expressed by participant caregivers, even years after active treatment had ended. However, most of the caregivers identified that they had been changed as people by the caregiving experience, that they had altered their priorities and had learned new skills. In this way, the outcome indicators were illustrated in the data.

The model of Transitions Theory (Figure 1) shows the concept of Nursing Therapeutics engaging and being engaged by other parts of the model. Nursing therapeutics can target the nature of transitions, transition conditions, and patterns of response in terms of the implications for nursing practice as noted above. However, the findings of the study are mostly supportive of assessment efforts; further research is needed to identify nursing interventions to assist caregivers through successful transitioning.

One part of the nature of transitions is the category of types of transitions: developmental, situational, health/illness, and organizational. Cancer caregiving is initiated by a health/illness transition, but the pattern of transition is multiple and simultaneous with unrelated developmental transitions in the pre-retirement age adult caregiver. As noted in Chapter 2, adult development is less uniform than child development, because adults have a history of role attainment and coping habits. Erickson (1963) noted that adults in their pre-retirement years have a developmental task of generativity versus stagnation, and it is within this developmental stage that cancer caregiving disrupted the lives of participant caregivers. Furthermore, as noted by Clark and Caffarella (1999), the integrative perspective of adult development includes the total of life experiences that caregivers have had prior to cancer caregiving, and these life experiences serve to shape caregivers' coping habits, preparation level, knowledge level, socioeconomic status, and beliefs about cancer and what cancer means. In other words, prior life experiences contribute to transition conditions (facilitators and inhibitors) of Transitions Theory. Considering that pre-retirement age adults have attained life goals

and are situated at a high level of productivity, the impact of cancer caregiving may be permanent in terms of socioeconomic status, employment, and social relationships.

### **Implications for Social Policy**

Implications of the study for social policy include the need to acknowledge cancer caregiving as a source of vital healthcare for cancer patients, and this acknowledgement should occur at local, regional, state, and national levels. Since many caregivers are female, perhaps this is a women's issue, but it really does not matter who is giving care to cancer patients. This study did not find a difference in themes between male and female caregivers, so it seems more important to individualize and reach out with acknowledgement of caregiving as a personal activity than to identify the role with one gender or the other.

Since cancer caregiving is a vital healthcare service in cancer care, it seems logical that caregivers should be included in the healthcare team. Locally, this would mean that family caregivers should be part of planning sessions, interdisciplinary discussions, and treatment decisions. However, caregivers require more than being involved in the care of their significant others; they need care themselves and they need care in a phase-appropriate manner. When the burden level is high, caregivers often resist help and isolate themselves, disconnecting from normal living around them. At that time, it is important to reach out in a purposeful way to assist caregivers in doing their jobs and also in caring for their own needs, which they tend to subjugate to the job of caregiving. A mechanism for respite care would be appreciated by most of the caregivers in the study, although most of them admitted that they would need serious encouragement to take advantage of such a service.

Centers such as the Cancer Center for Healthy Living (CCHL) should understand that the need for social support for caregivers peaks at the time when cancer patients do not feel up to attending support group meetings during treatment. Therefore, social support and help groups should be established for caregivers only so that they can attend without having to fit in with a patient-focused group without their patient accompanying them. An alternative to this activity would be a mentoring type of relationship for caregivers to help other caregivers who are new to the caregiving trajectory. In short, services specifically and exclusively meant for caregivers would be appropriate and needed. This would require a change in how programs are set up and implemented.

Another important issue for caregivers is employment, since all of the caregivers in the study changed their employment due to cancer caregiving. Several of them were able to do so rather easily, but for most there was a significant upheaval in their professional lives as a result of caring for someone with cancer. Perhaps state and federal policy makers could assist companies by allowing them to hire temporary replacements for workers who are caring for significant others without facing unemployment taxes when the temporary workers finish their term of employment.

Some of the participants in the study noted that it would have been helpful to have help with expenses related to costs of caregiving that are not normally covered by insurance: travel, parking, meals away, lost overtime, certain medical supplies, and the like. Perhaps federal and state policy makers could allow tax deductions or tax credits for those expenses.

In order for these policy changes to take place, however, there would need to be a paradigm shift in social consciousness, a shift to include caregivers in the category of

people in need rather than simply people who can help care for cancer patients. Studies such as this one could contribute to the information the public and policy makers need to accomplish such a paradigm shift. Cancer happens to patients, but it also happens to families and social networks.

### **Implications for Research**

Further research is needed to extend the study to include a more diverse sample in terms of ethnicity and regions. In order to do this, recruitment should be aimed at a larger community and at an entire community rather than a cancer resource center affiliated with the regional oncology network. The entire oncology network would provide an improvement in this aspect of research participant recruitment.

In addition, research is needed with dyads, expanding data collection to include cancer patients individually and in combination with caregivers. In the pilot interview that I conducted prior to this study, I interviewed a husband caregiver in his home. About half way through the interview, he called to his wife to join us, and I noted that his demeanor was different once his wife entered the room. He became unwilling to acknowledge his burden or any difficulties with caregiving or needs as a caregiver. He became intensely protective of his wife, sometimes answering for her. For this reason, I decided to study caregivers without their significant others present, but it would further the science to conduct a series of interviews that would be individual at first and then with the dyads.

Further research is needed to explore different types of caregiving structures: non-family dyads, non-cohabiting dyads, partner dyads, and dyads in which caregivers are

neighbors or friends. It would be interesting to note similarities and different patterns of relationships and themes, if any, among caregivers.

Mixed methods research can be structured by identifying variables among some of the themes expressed by participants in this study. For example, the Marwit-Meuser Caregiver Grief Inventory – Short Form (Marwit, Chibnall, Dougherty, Jenkins, & Shawgo, 2008) has been used successfully to identify grief in cancer caregivers. The instrument has established reliability and validity with three subscales. The subscales include “heartfelt sadness and longing,” “burden and personal sacrifice,” and “worry and felt isolation.” These subscales could be used to measure variables based on the themes of burden, isolation, and grief that emerged from the data in this study. In addition, perhaps the concept of post-traumatic stress disorder should be investigated within the caregiver population. Mixed method research may be a useful means to identify predictors of successful and troublesome transition outcomes in cancer caregivers or in dyads.

Finally, research is needed to identify and test nursing interventions to minimize feelings of disconnectedness and isolation in caregivers, to increase support, and to help caregivers manage information from their healthcare providers. Interventions can be based on the nursing therapeutics portion of the model of Transitions Theory, and outcome measures of dependent variables could be identified using successful transition outcome in the theoretical framework.

### **Implications for Education: Equipping Professionals**

Implications of the study findings for nursing education involve paradigm shifting from focusing on individuals to emphasizing families and significant others as part of the

client unit. Caregivers may sometimes be seen by nursing students as appendages of patients: useful at times, in the way at times, and informative at times. Nursing education should include transitions theory and its application to client care. Particularly, the inclusion of caregivers in the client unit and the recognition that caregivers go through transitions along with patients would assist students to understand that caregivers have needs and that those needs are distinct from patient needs. In addition, educators can and should instruct students to apply the nursing process to caregivers as well as to patients, and this process should always begin with an accurate assessment.

Findings from the study can shed light on how caregivers transition through the cancer caregiving experience, and educators have a responsibility to assist and to teach students to recognize the different needs of caregivers along the cancer caregiving trajectory. Moreover, the inclusion of transition theory in nursing education would assist students in learning how disconnectedness, grief, isolation, and needs for social support can detract from healthy transitioning.

Nursing education should include information on nursing interventions to enhance social support for caregivers. It is a natural extension of the holistic focus in nursing education to include assessment, diagnosis, planning, intervention, and evaluation – the nursing process – for caregivers as well as for individual patients. Caregivers may experience distress, disconnectedness, disregard for their own needs, inability to meet competing role demands, ineffective coping, and inability to perform various aspects of self-care; students need to be taught to recognize this and provide nursing care as needed.

### **Reflections**

This study was a labor of love and determination, but not on the part of the researcher. My work and compassion paled in comparison to the love and determination of the participants as they tried to explain what was in their hearts. They genuinely had an interest in making sure that their efforts were not in vain and that I would have an adequate understanding of what it meant to them to go through cancer diagnosis, treatment, and post-treatment with a significant other. Some of the participants are still in the caregiving role. Others have lost their significant others to cancer. Still others anticipate a return of cancer in their midst, while yet others are hoping for a cancer-free future. All of them have spent time and effort on my behalf so that their stories are understood. To this end, I hope I have lived up to their expectations.

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## Appendix A: IRB Information

### Informed Consent

My name is Cynthia Steinwedel, and I am a doctoral student in nursing at the University of Wisconsin at Milwaukee. You are being asked to participate in a research study entitled, “The Impact of Cancer Caregiving on Cancer Caregivers: Stories of Lives in Transition.” Your participation is completely voluntary, and you may withdraw from the study at any time.

The purpose of this study is to examine the impact of cancer caregiving on caregivers. Caregiving can be a challenging time for caregivers, and I would like to hear your story about how the caregiving impacted you and your family. The goals of the study are to study transitions that caregivers go through as they care for someone who is diagnosed and treated, as well as to study the caregivers’ stories of how cancer has impacted their lives over the long term since the cancer diagnosis.

I will conduct the study personally and will meet with up to 20 caregivers who have provided significant care to someone with cancer. Each participant will meet with me for two interviews approximately 2 to 4 weeks apart. Names will not be associated with the interviews in order to provide privacy and confidentiality for participants. At the end of each interview, participants will be compensated for their time with a \$15 Target store gift card as a token of appreciation. Even if you do not complete an interview you will still be provided the gift card.

You are under no obligation to participate in the study and may withdraw from the study at any time. If you agree to participate, you will be asked to arrange a convenient time for each of the interviews. A total of two interviews will take place in a location of your choice that is comfortable for you. Each interview will last approximately 90 minutes with a maximum of 2 hours. Recorded interviews are necessary for me to hear your cancer caregiving story and to do my analysis of the stories of caregivers who participate in the study. I will analyze the interviews without your name attached and will keep your information confidential. I want to study the recordings so that I can fully understand the details of your story and so that I can compare them with the stories of other cancer caregivers in the study. If you refuse to have your interview recorded I will not be able to use your interview for the study.

The only foreseeable risk that you will face by participating in this study is the possibility that the interviews could be somewhat emotional, since we will be discussing a time in your life that may have been challenging for you. However, I have a list of support resources for you that may help you if you decide that is something you might need.

There are no benefits to you other than to further research and to help nurses understand what caregivers of people with cancer experience. I appreciate your time and efforts on behalf of the study.

You will not be responsible for any costs from taking part in this research study.

You will receive a \$15 Target store gift card at the completion of each interview in appreciation for your time.

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. We may decide to present what I find to

others, or publish our results in scientific journals or at scientific conferences. No information that identifies you personally will be attached to the data, and your contact information will not be released. Your recorded interview and your contact information will be stored in separate locked cabinets, accessible only by myself (the researcher) and the doctoral dissertation major professor. However, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study's records.

Following the study, your contact information will be kept in the locked cabinet – if you give permission to do so – for 10 years in case of a follow-up study. The interview information will also be kept for 10 years in a secure computer. After 10 years have passed all of the data and contact information will be destroyed.

Your participation in the study is entirely voluntary. You may choose not to take part in this study. If you decide to take part, you can change your mind later and withdraw from the study. You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with the Cancer Center for Healthy Living or with the University of Wisconsin at Milwaukee. If you decide to withdraw from the study early I will use the information that I have collected about you to that point, including any interviews that were recorded, unless you tell me that you do not want your data included in the study.

For more information about the study or the study procedures or treatments, or to withdraw from the study, please contact:

Cynthia Steinwedel, MS, RN, CNE  
College of Nursing, University of Wisconsin – Milwaukee  
1921 E. Hartford Street  
Milwaukee, WI 53201

My phone number is 309-472-8877. I live in Peoria, but I am a UWM doctoral student.

If you have questions about your rights or complaints regarding your treatment as a research participant you may contact the Institutional Review Board of UWM. They may ask your name, but all complaints are kept in confidence.

Please do not hesitate to ask if you have any questions about this research study. You may contact me at 309-472-8877. My faculty advisor, Dr. Patricia Stevens, may be reached at 414-229-5817.

This study has been approved ( #12.123) by the Institutional Review Board of the University of Wisconsin at Milwaukee for a period of one year, until October 28, 2012. You may contact the Institutional Review Board at:

Institutional Review Board, Human Research Protection Program  
University of Wisconsin – Milwaukee  
P.O. Box 413  
Milwaukee, WI 53201  
(414) 229-3173

**Research Subject's Consent to Participate in Research:**

*To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study, you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read or had read to you this entire consent form, including the risks and benefits, and have had all of your questions answered, and that you are 18 years of age or older.*

\_\_\_\_\_  
Printed Name of Subject/ Legally Authorized Representative

\_\_\_\_\_  
Signature of Subject/Legally Authorized Representative

\_\_\_\_\_  
Date

**Research Subject's Consent to Audio/Video/Photo Recording:**

It is okay to audio-record me while I am in this study and use my audio-recorded data in the research.

Please initial: \_\_\_\_\_ Yes \_\_\_\_\_ No

**Principal Investigator (or Designee)**

*I have given this research subject information on the study that is accurate and sufficient for the subject to fully understand the nature, risks and benefits of the study.*

\_\_\_\_\_  
Printed Name of Person Obtaining Consent

\_\_\_\_\_  
Study Role

\_\_\_\_\_  
Signature of Person Obtaining Consent

\_\_\_\_\_  
Date

Thank you for your participation.

## APPENDIX B: NOTICE FOR RECRUITMENT

A local nurse researcher is interested in learning about the experiences of cancer from the perspective of caregivers of people who have been treated for cancer. Volunteers of all ethnic and gender groups are welcome. Participation in the study consists of two interviews to be arranged at the convenience of participants. To qualify for the study, caregivers must have provided care for someone with cancer who is between one and 5 years post-diagnosis of any type of cancer. I would be happy to answer any questions you have about the study. If you or anyone you know might be interested in participating, please contact:

Cynthia Steinwedel, MS, RN, CNE

(309) 693-0148 or email [csteinwedel@bradley.edu](mailto:csteinwedel@bradley.edu)

You may leave a message and I will return your call or email as soon as possible.

Participation is entirely voluntary and confidential. Participants will not be identified in the study results.

This study has been approved by the Institutional Review Board of the University of Wisconsin at Milwaukee.

## APPENDIX C: INTERVIEW GUIDES

## First Interview

- I. Introduction
  - a. Consent: Verify that informed consent is granted and have participant sign the consent form. This includes the fact that interviews are recorded and will be kept confidential. Participants will be told that they may end the interviews at any time and will be asked if it is permissible to continue.
  - b. Purpose: The purpose of our interviews is to give you an opportunity to tell your story as a caregiver of someone who has had cancer. I would most like to understand your story as a caregiver, from your perspective.
- II. Background: (The basic narrative, which I will keep moving with therapeutic communication and active listening techniques)
  - a. How was the cancer found and how did that process go for you and for \_\_\_\_\_ (name of cancer survivor)?
  - b. How did you happen to become the support person for \_\_\_\_\_?
  - c. Tell me about life during treatment. What was a typical day like at that time?
  - d. How did things change along the way?
  - e. What has it been like since treatment ended?
  - f. Thinking back on things, what does cancer mean to you at this point?
  - g. How did the cancer and caregiving affect you?
- III. Conclusion (lighter topics)
  - a. What else would you like me to know?

- b. Thank you so much for your time.
- c. Make next appointment

### Second Interview

- I. Introduction and re-connecting
  - a. How are things going this week?
  - b. How did you feel during our first conversation? Did it bring up any reactions or things you would like to discuss today?
- II. In-depth interview
  - a. Bring up any areas that need clarification from last time. Ask for explanation, examples, and reactions to those areas. Try to elude meanings that participant attaches to the narrative. Also cultural beliefs and attitudes. This may take some time. This portion of the interview will depend largely on preliminary impressions and analysis of data from the first interview.
  - b. What does cancer mean in your family and community?
  - c. How did cancer affect you personally? Emotional health?
  - d. How are things now as compared to before cancer?
  - e. How have things changed for you? (And how do you look to the future?)
  - f. How well did you feel that your life prepared you for caregiving?
  - g. How do you see the future at this point?
- III. Conclusion

- a. Is there anything else you have thought of that you would like me to know about the cancer caregiving story?
- b. If you could say something to the healthcare system about caregiving or caregivers, what would that be?
- c. Thank you so very much

IV. Handling closure activities

- a. Referrals as needed – offer?
- b. How to contact me
- c. Assurance of confidentiality
- d. Stipend gift

#### APPENDIX D: SPRINGER PUBLISHING POLICY ON PERMISSIONS

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## APPENDIX E: RECRUITMENT NOTICE IN CCHL NEWSLETTER

The following recruitment notice appeared in the January, 2012 edition of the newsletter of the Cancer Center for Healthy Living:

## Seeking Caregiver Study Participants

Cynthia Steinwedel, MS, RN, CNE, is a PhD candidate who is seeking volunteers for a study on caregivers of cancer patients. To qualify for the study, caregivers must have provided care for someone with cancer who is between 1 and 10 years post-diagnosis of any type of cancer. Participation is voluntary and confidential. Participants will be compensated for their time with Target store gift cards. If you are interested in participating in the study, please call Cynthia at 693-0148 or by email at [csteinwedel@bradley.edu](mailto:csteinwedel@bradley.edu).

The notice appeared only once and was not needed again.

## APPENDIX F: LIST OF INITIAL CODES IDENTIFIED WITHIN DATA

The following is the listing of individual codes that emerged from the analysis of data. These initial codes provided the basis for organizing and grouping clusters of codes into identifiable themes.

Advice  
Anger  
Break from it all  
\*Burden  
\*Cancer meaning to others  
\*Changes  
Comorbidities in caregiver  
\*Control/helpless  
Coping  
Dedication  
\*Deny self  
\*Diagnosis situation  
Differently, would have done  
Difficult  
Disconnectedness  
Draining to talk  
\*Duty and dedication  
\*Caregiver employment  
\*Family members  
Fear of losing cancer survivor  
Fear of recurrence  
Finances  
Future  
Gems  
Giving up  
Guilty  
\*Healthcare system  
Hiding cancer  
\*Information  
Initial treatment  
Keeps you going  
Life stage disruption  
Life with cancer  
\*Loss and grief  
Meaning search  
Moving forward  
Outsider  
Overwhelming

Patient advocate role  
Positives about cancer  
Post-treatment adjustment  
Preparation for caregiving role  
\*Priorities changed  
Protection  
Patient employment  
\*Relationships  
\*Role issues with caregiver  
Side effects of cancer  
\*Side effects of treatment  
\*Social support  
Stress in caregiver  
Numb (transition conditions)  
Abrupt and unexpected (transitions nature)  
Withdrawal of patient (transitions pattern of response)  
Treatment decisions  
Treatment life  
Uncertainty  
Vigilance  
Worry

These codes were examined to see if some of them were essentially the same (evidenced by the same excerpts being contained in each one) or could be subsumed under each other.

## CURRICULUM VITAE

Cynthia M. Steinwedel

Place of Birth: St. Louis, Missouri

Education:

B.S., Bradley University, May 1974 (Summa cum Laude)

Major: Nursing

M.S., University of Illinois – Chicago, June 1986

Major: Medical-Surgical Nursing

Dissertation Title: The Impact of Cancer Caregiving on Cancer Caregivers: Stories of Lives in Transition

Teaching Experience:

Graduate Program Lecturer, Medical-Surgical Nursing graduate program,  
University of Illinois at Chicago

Undergraduate nursing clinical instructor, Bradley University

Assistant Professor in Nursing, Bradley University, Peoria, Illinois

Certifications:

Certified Nurse Educator, National League for Nursing, 2010

CCRN certification in critical care nursing, American Association of Critical-Care  
Nurses, 1981-1987

Professional Organizations

International Family Nursing Association

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Education Committee Chairperson

Sigma Theta Tau International, Epsilon Epsilon and Eta Nu Chapters

Nurse Leader Application reviewer

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Awards and Honors

Phi Kappa Phi honor society

Sigma Theta Tau International honor society in nursing  
 Research Award, Epsilon Epsilon Chapter, STTI  
 Research Award, Academy of Medical-Surgical Nurses  
 Golden Key International Honour Society, University of Wisconsin at Milwaukee  
 Chancellor's Graduate Award, University of Wisconsin at Milwaukee  
 Chancellor's Graduate Scholarship, University of Wisconsin at Milwaukee  
 Harriet Werley Doctoral Fellowship, University of Wisconsin at Milwaukee  
 Milton & Joan Morris Doctoral Scholarship, University of Wisconsin at  
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 Graduate Peer Award for Outstanding Leadership, Scholarship, and Community  
 Service, University of Illinois at Chicago

Presentations:

"Adult Child and Spouse Caregivers of Persons with Dementia: Reactions to  
 Loss," International Conference on Alzheimer's Disease, American  
 Alzheimer Association  
 "Designing and Implementing Clinical Research for Dental Clinicians,"  
 Piper/McKee Dental Study Group  
 "A Closer Look at Medsurg Nursing as a Specialty," (Interview for publication).  
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Research Field Work:

Knowledge Developer for the Aurora-Cerner-Wisconsin Knowledge-Based  
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Publications:

Steinwedel, C. (2012). You are a nurse, right? (editorial). *MEDSURG Nursing  
 Journal*, 21(6), 333-334.  
 Bridgeland, H., Hartenberger, K., Poppen, A., Zobrist, K. (In press). Polytrauma  
 and veterans: what does this mean for the med surg nurse? *MEDSURG  
 Nursing*. Publication date July, 2014.