

Cancer's Impact on Spousal Caregiver Health: A Qualitative Analysis in Grounded Theory

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Abstract The purpose of this qualitative study is to examine the impact cancer has on a spouse/partner caregiver. The psychological effects of caregiving are well documented, but information related to the physical outcomes of the caregiver of a partner with cancer is lacking. This is a qualitative study based in grounded theory and explores themes from transcribed interviews of eight spousal caregivers and four widowers. The caregiver is often the “silent sufferer.” Caregivers that experience compounding hardships and have multiple caregiving responsibilities tend to have paradoxical feelings about their experience and report higher levels of emotional and physical distress. Current caregivers report lower quality of physical health, as compared to widowers who report being in better health after the death of their spouse.

Keywords Family therapy · Cancer · Caregiver · Health · Qualitative research · Death/dying

Introduction

An estimated 1.6 million individuals in the US will be diagnosed with cancer in 2012 (American Cancer Society 2010). With this number expected to rise annually, it is not surprising that three out of four families have a member who is a cancer survivor (American Cancer Society 2010). Cancer imposes challenges not only for the individual diagnosed, but also for their family members. This is particularly significant given the increasing awareness that cancer is a family and relational illness rather than an individual illness. (Kim et al. 2006; Lethborg et al. 2003; Manne and Badr 2010; Northouse et al. 2005). The challenges

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associated with providing care to cancer survivors may weigh most heavily on their spouses, as they are typically the primary caregivers to adult patients (Kim et al. 2008; Lantz and Gregoire 2000). A caregiver is the person who most often helps the patient with cancer and is not paid to do so. In most cases, the main or primary caregiver is a spouse, partner, or an adult child. When an individual is diagnosed with cancer, life changes for the patient, immediate family, and for the caregiver who will primarily help the patient through the experience of cancer (CancerCare 2008). American Cancer Society (2010) reports a 5-year relative survival rate of 67 % for those diagnosed between the years of 2001 and 2007. With advances in medical care, and the progression toward a lower mortality rate, cancer has turned from an acute disease resulting in death, to a chronic illness leading to a need for long-term care.

This shift of cancer becoming a chronic illness has taken the responsibility from medical care professionals and placed it upon informal caregivers such as partners or spouses (Jacobs 2012; Nijober et al. 2001). For the purpose of this study the terms “spouse” and “partner” will be used interchangeably. Partner refers to the same role as spousal caregiver holds; it applies to someone who is in a close relationship to the patient with cancer, and also applies to the caregiver who has multiple roles such as full or part-time employment, caretaker for children, or other responsibilities outside of being an informal caregiver.

Quality of life (QOL)—a term used to evaluate the overall well being of individuals—is a measure that is used in various studies and one that is the focus of cancer research. Standard indicators of the quality of life include wealth and employment, but also the environment, physical and mental health, education, recreation, leisure time, and social belonging (National Cancer Institute 2010). Compared to other informal caregivers, spousal caregivers and partners are identified as the most vulnerable group of caregivers, and report lower QOL (Manne and Badr 2010; Oberst et al. 1989, as cited in Nijober et al. 1998). Partners as compared to other caregivers, are likely to experience more strain; they may become ill themselves (Schultz et al. 1987, as cited in Nijober et al. 1998; Colgrove et al. 2007), and may experience higher levels of psychiatric symptoms (George and Gwyther 1986, as cited in Nijober et al. 1998; Manne and Badr 2010; Wagner et al. 2006). Psychologically, depression and anxiety are the top mental disorders among patients diagnosed with cancer and their primary caregivers. Several studies have shown that patients and their partners reported higher levels of psychological distress as compared to the general population, with little or no variance in the level and intensity of the patient/partner distress (Nijober et al. 1998; Pinqart and Duberstein 2005).

Oberst and James (1985) observed spouses of cancer patients undergoing treatment expressing high levels of anger and resentment about the disruption to their lives caused by their partners' disease. They reported fatigue, multiple physical problems such as aches, pains, indigestion, exacerbation of preexisting conditions, and upper respiratory tract infections. Generalized fatigue and a wide variety of physical problems have been reported by partners of cancer patients, such as food intolerance, exacerbation of medical conditions, exhaustion and indigestion (Oberst et al. 1989 as cited in Nijober et al. 1998). Health deterioration may be attributable to the stressors of caregiving, while health improvements may result from a decrease of caregiving stressor or adaptation of caregiver over time (Nijober et al. 2001).

Caregiver burden, strain, or role strain, are terms generally used to refer to the physical, psychological, social and/or financial reactions that can be experienced in giving care (Given et al. as cited in Nijober et al. 1998; Manne and Badr 2010). For the purpose of this study burden was not evaluated so much as the specific stresses on the caregiver and the changes to their health. Pinqart and Duberstein (2005) suggest that although caregivers

report higher levels of psychological distress, there is a great deal of variability in the responses. (Jacobs 2012) The factors of burden and health are related to each other (Stuckey et al. 1996 as cited in Nijober et al. 1998). Whether the impact of caregiving burden leads to an effect on health or whether health leads to an effect on burden is unclear. The longitudinal studies of the outcomes of caregivers and causal relations in the field of oncology seem to be scarce (Nijober et al. 1998). As pointed out by Canavaro and Dattilio (2011) much of the professional literature has been from the perspective of the individual with the diagnosis rather than the impact it has on spousal or family dynamics. Spousal feelings of depression and anger tend to remain after the acute stages of illness, along with guilt for having these feelings and for wanting to take care of their own needs (Doherty and Campbell 1988). This study attests to the significant stress experienced by the caretaking spouse/partner during the period following cancer treatment.

Nijober et al. (2001) found that as of 2001, no longitudinal research had been conducted that examines physical, mental and social dimensions of health all at once in caregivers of patients with cancer. It has also been recently noted the gap in literature that explores the process of spouses or partners of women with breast cancer (Burwell et al. 2008). Although the research findings indicated that patient's dependency and need for assistance may influence caregiver's health over time, little is known about the pattern of caregivers' health and predictors of health following the course of a cancer diagnosis.

Our nation increasingly relies on family members or friends for needed care and support as we age. Caregivers typically assume their caregiving role willingly and reap personal fulfillment from helping a family member (Brehaut et al. 2009). However, partners often assume this new and complex role with little advance notice and training, which has the possibility to cause disarray in their existing role (Kim et al. 2006). Caregivers often inadvertently sacrifice their own health and well-being. For example, depression, anxiety, use of psychoactive medications, poor physical health, and compromised immune function are more common among family caregivers (Nijober et al. 2000; Oslund et al. 2010; Klassen et al. 2007; Wagner et al. 2006).

Rationale/Purpose of Current Study

As elaborated in the previous section, the impact cancer has on a significant other is considerable and is an individual, relational, and a family issue. Therefore, it is important to understand the perspective of the caregiver with their health as the focus (Oslund et al. 2010). In addition, there needs to be awareness that declining health of caregivers can compromise their ability to provide care to others.

The benefit of bringing a family systems and biopsychosocial lens to oncology is the focus of familial strengths versus pathology. Behaviors of the patient and the family are viewed as well-intended efforts to solve problems (Kazak et al. 2002). A family systems lens provides an inclusive understanding of change for family members that allowed us to focus on patterns that are sustainable versus individual behavior changes. Suggested research in oncology is toward the direction of exploring many spectrums of a family's biopsychosocial and systemic processes. Attention should be paid to the influences of family structures, roles, rules, backgrounds, phases of disease, medical context, medical team dynamics, patient and family members relationship, developmental phases of family members, and beliefs. All of this research is being used to inform application of evidence based family therapy models within an oncology setting (Hodgson et al. 2011). The ideal situation proposed by Doherty and Campbell (1988) would include the close involvement of a family therapist in a variety of medical settings to work alongside clinicians (p. 131).

Theoretical Framework

The framework that guided this research and the literature review were general systems theory and biopsychosocial theory. General systems theory, introduced largely by Ludwig von Bertalanffy in 1968, takes into consideration that a system is a set of independent and interactive parts (Doherty and Campbell 1988). Systems thinkers have stressed that a family's present behavior cannot be adequately understood apart from its history (Rolland 1994). Multigenerational legacies and patterns of adaptation shape myths, beliefs, and expectations that strongly influence how families perceive a current health crisis and guide the kinds of systems they develop in the face of adversity. In relation to cancer and caregiving, this theory implies that the process of illness cannot be understood without taking into account all the interactions between the patient, caregiver, clinicians, children, and family. These interdependencies play a role in prognosis. Factors such as strained relationships, unspoken rules, and rigid belief systems that are in place prior to the diagnosis of cancer will only be exacerbated by the course of the disease and treatment. As in any systems theory perspective, you cannot treat one person without taking into account all the people that comprise the world they live in. What this translates into for medical/cancer settings is that the cancer patient and the medical staff cannot tackle the complexities of treatment alone. Special attention to the health of the family, especially the spousal/partner caregiver suggests the collaborative effort in caring for the whole person.

The second theory proposed by George Engel (1977) is the biopsychosocial theory which states that biological factors must be understood as occurring in an individual who is an integrated mind–body organism. The body affects the mind and the mind affects the body in such a way that neither notion makes sense alone (Doherty and Campbell 1988). To further this concept, an individual exists within their families and other social groups. These families and social contexts then provide the context for understanding that individual. The family affects the individuals' health, and the individuals' health affects the family. This is the basis for the theoretical approach of the biopsychosocial model (Kazak et al. 2002; Rolland 1994; Hodgson et al. 2011). When used in the context of a cancer caregiver's experience, mental stressors have an impact on the physical body, the same way that the stress upon the physical body will have an impact on mental processes. This study attempts to examine the connection between the adverse psychological impact of stressors of caregiving and the physical health of the caregiver. By utilizing a qualitative design the nuances of each caregivers experience could be explored in an attempt to identify similarities and differences. The study was guided by the question, 'Does stress from caregiving have an impact on the biopsychosocial health of the caregiver?'

Research Question

Do partner or spousal caregivers with multiple roles have a higher risk for developing a physical illness, particularly a chronic illness, throughout the course of their caregiving experience?

Method

This research is a descriptive study, using a qualitative approach. Qualitative research is used when little is known about the topic or when a phenomenon needs to be explored. "This approach is interactive: context dependant; holistic; flexible; evolving; inductive and

descriptive. It has as its foci, perspectives, meanings, uniqueness, and subjective live experiences. Its aim is to provide understanding.” By constructing a model guided by two theoretical frameworks, systems theory and biopsychosocial; the authors are able to make their assumptions and biases overt. The authors used coding techniques specific to guidelines of Strauss and Corbin (1990), including open, axial, and selective coding as a way to look at the thematic analysis in an open ended, systematic way to generate a theoretical model. This study is framework based while identifying themes and phenomenon. A grounded theory approach is a style of inductive analysis, which “is based on the systematic generating of theory from data, theory is both a process and an outcome” (Glaser 1978, p. 2). Grounded theory was chosen for this project in an attempt to develop a theoretical model out of emerging themes from participants in order to give meaning and outcome to a cancer caregiver’s experience. Qualitative methods with biopsychosocial framework are recommended to be purposefully chosen according to each researcher’s aims, scope, timeframe, and resources (Mendenhall et al. 2012). Grounded theory is often used in health and sociological research when one wants to develop or generate a theory derived from the empirical data to explain a social phenomenon or psychological process (Green and Thorogood 2009, p. 31).

The qualitative design allowed for many variables to be included into the all-encompassing word of ‘health’. Qualitative design has been suggested in recent years by researchers when looking at the caregiver’s experience. Health care practitioners, managers, and policy-makers have increasingly turned to the qualitative methods of social inquiry used within the social sciences to enhance understanding of health, and health behavior. When attempting to define the word ‘health’, it may be more useful to use the language of the people experiencing the phenomenon. The most basic way of characterizing qualitative studies is to describe their aims as seeking answers to questions about ‘how’ or ‘why’ of a phenomenon, rather than questions about ‘how many’ or ‘how much’ (Green and Thorogood 2009, p. 5). Grounded theory is suggested to be of use in situations where little is known about a phenomenon; in this research the little known phenomenon is the physical health of the caregiver. The ‘why’ in this research is aimed toward use the caregiver’s language, understanding, and meaning making processes in how they connect their caregiving experience to the outcomes in their health since becoming a caregiver. In using a health research paradigm integrated with concepts from Strauss and Corbin (1990), systematic observation and induction processes were used to move from specific instances to general patterns. The strongest motive for employing a grounded theory methodology was the curiosity to discover knowledge about the facets of a caregiving experience and the desire to seek connection in their experiences. The method searches for that which is true for a specific person, in a given situation; statements are formed from the persons’ interpretations and meanings (Glaser and Strauss 1967).

Participants

Participants for this research were recruited based on the purpose of the study, which required the participant to be a spouse and a caregiver for a patient with cancer. The sample was located and recruited from a local cancer center using a convenience and snowball sampling method. Cancer/caregiver dyads were recruited from a rural Minnesota cancer center. Brochures, flyers, and notifications of the study recruited participants internally by oncology staff. A presentation was given by this researcher to medical oncology staff informing them of the proposed research and the inclusion criteria for participation. Acceptance was given to the researchers to conduct interviews using clinic resources by

the hospital's internal review board. Once recruitment was approved and underway, interested participants contacted the researcher individually to determine eligibility. Inclusion criteria included: older than 18 years of age, being the spouse or long-term committed partner of a cancer patient, and being the patients' primary informal caregiver. The researchers recruited spousal/partner caregivers who were current caregivers. There was an expressed interest from four widowers to participate, bringing the total sample size to 12 (eight married, four widowed). The sample included four male and four female caregivers, and two male and two female widows. Of the 12 participants, all were Caucasian with a mean age of 61.5, 50 % were employed, 29.8 was the mean number of years married, and 4.5 was the mean number of years caregiving (Table 1).

Instruments

Review of Systems Checklist (ROS) was used to allow the participants to indicate any physical changes in their health that had come about since they have begun caregiving for their spouse. The Review of Systems is a checklist of all major body systems, including psychological stress. It is a measure that is commonly used in medical practice to evaluate overall changes in health. For the purpose of this study, stress and anxiety were observed in the same manner. Since the ROS does not have an indication of anxiety, participants were asked how they described their stress, and if it was stated as anxiety it was included in the data. In this study the term stress was noted if the participants stated having stress or stated having anxiety.

A *demographic questionnaire* gathered the following information: age, gender, educational background, number of household members, years married or length of time in

Table 1 Demographic information

Variables		(N = 12) Percent
Age	Mean = 61.5	SD = 8.7
Number of years married	Mean = 29.8 Range (11–53)	SD = 12.3
Employment status	Employed	6 (50.0)
	Unemployed	2 (16.6)
	Retired	4 (33.3)
Time caregiving (years)	Mean = 4.5	SD = 3.9
	Range (1–12)	
Time since spouse death (years)	Mean = 4.5	SD = 5.0
	Range (2–12)	
Spouse stage of cancer	Stage I	1 (8.3)
	Stage II	0 (0)
	Stage III	1 (8.3)
	Stage IV	6 (50.0)
	Death	4 (33.3)
Spouse type of cancer	Leukemia	4 (33.3)
	Breast	4 (33.3)
	Lung	3 (25.0)
	Head/neck	1 (8.3)

committed relationship, type and stage of partners cancer, length of time since diagnosis, and whether the patient is currently receiving treatment or is in remission.

In-depth semi-structured interview. Semi-structured interview format with open-ended questions were used to facilitate the development of the participants' story. Questions were used to "open up" the participants' language, and to stimulate more specific and related questions in order to assist in the development of categories, properties, and dimensions (Strauss and Corbin 1990). After each participant completed the ROS and the demographic questionnaire, they were asked to begin narrating their story of from the moment their spouse received the diagnosis of cancer. Other questions dealt with daily routine and tasks of the caregiver to changes in health, emotions, routine and relationships. All interviews ranged between 60 and 150 min, which were audio recorded, transcribed, and included extensive post-interview memos. The following open-ended questions were used to explore specifics to the caregiver's experience.

When did your spouse or partner receive a diagnosis of cancer?	Have you had to miss any work? Have there been changes to your work schedule or responsibilities?
How long had they been sick prior to diagnosis?	Have you incurred any financial difficulties?
What was going on in your families' life at the time of diagnosis?	Do you receive support from any other areas? If yes, in what areas?
What were your care tasks right after diagnosis?	Approximately how much time per week do you dedicate to the act of caregiving?
How have those tasks changed over time?	Do you have children or other people that you are also currently caring for?
Describe your emotional reactions at the time of diagnosis	If family support groups, couples therapy, or family therapy were an option (Family-Centered Services) would you have utilized those services? Why or why not
Describe your emotional state at the present time	Is there anything that we haven't discussed about your experience that you would like to bring up now?
Have any aspects of your health changed since the diagnosis?	
Have there been any changes to your eating/sleeping/exercising patterns?	
Have you sought help from therapists or support groups, friends or family? Did you find them helpful? Why or why not	

Data Collection and Analysis

In the words of Corbin and Strauss (2008), grounded theory's purpose is to "build rather than test theory" and to "identify, develop, and relate the concepts that are the building blocks of theory" (p. 13). In this study, by using a grounded theory method the researchers were able to start with an open ended question of: Do partner or spousal caregivers with have a higher risk for developing a physical illness, particularly a chronic illness, throughout the course of their caregiving experience? Will spouses who are caregivers for a cancer patient retrospectively report having poorer health outcomes than they had before their spouse was diagnosed? The open-ended question was based on the primary researchers own observations in clinical and social life. The question was also a link

between systems and biopsychosocial framework that was used to guide the formation of a grounded theory conceptual model. Basic social processes, theoretical sampling, saturation, open, axial, and selective coding are original to grounded theory and will serve as the basis of data analysis for this research (Glaser and Strauss 1967).

Transcripts were crosschecked with the audio recordings of each participant for word-for-word accuracy. Line by line or open coding, was conducted as the first stage of analysis. The data were analyzed step by step first using open coding to explore the data in a detailed way; in this research the recorded audio was transcribed verbatim, coded line by line where core concepts began to emerge, this is considered the processes of fracturing the data. During the interview process emerging themes were noted in field notes or memos. For example, when the caregivers would recall the initial diagnosis of their spouse they would speak to feeling emotions such as “shock”, “disbelief”, and “disillusionment”. As phenomenon emerged in the later interviews, the participants were contacted to confirm the data as relevant. The same procedure was done as patterns emerged early in the interview process, subsequent participants were asked to confirm emergent themes. Theoretical saturation was reached when once it appeared no new data was emerging, it was also an indication that clear phenomenon were being developed and relationships were being made between concepts. Following the saturation of data and the commencement of the interviews, transcripts were read and re-read as the second phase of the coding process began to take place. The second process is considered a categorization process that includes putting the data back together. This is the dimension of axial coding where there is the attempt to connect the category or the phenomenon of the situations and interactions between statements (Strauss and Corbin 1990). This creates the context of the properties that are being described in the deductive recognition of a phenomenon. The phenomenon were named and written in the margin of the codes. Statements such as “immediately you wonder if it means a death sentence”, “I feel so out of control”, “the rug as been pulled from under us”, “we’ve been doing everything right, how could she have cancer”; these were categorized under “the emotions of diagnosis”. Selective coding is the last step in a grounded theory process which involved choosing the core categories; this aided in the confirmation of the relationships that were developing in the axial coding process. Once substantive themes were developed the data were re-read to confirm or to pull more verifying data. Following the above example, the category of “emotions of diagnosis” were included along with other categories that dealt with emotions but included varying emotions that were felt further in the trajectory of the illness process. The core theme “an emotional journey” was chosen to encompass the emotions that were present upon diagnosis through experiences in palliative care.

Member-checking processes were conducted throughout the research. Emerging themes, categories, and quotations were allowed to be read for validation of the participants’ spoken word in order to increase validity, credibility, and rigor of the research. Field notes were used before each interview to process potential biases prior to meeting with participant, and were written after each interview in order to track researchers’ impressions, biases, and thoughts; these field notes were not included in the analysis of the data. During the interview process participants were observed for non-verbal gestures, changes in tone of voice, and instances of emoting. These observations were noted and included in the documentation and analysis. Memos in the form of code notes and diagrams were recorded at the initiation of the research through the final stages of analysis and development the theoretical model. Memos and diagrams were constantly checked and re-checked inductively test out phenomenon and themes that were emerging during the interview process.

Results

The original design of this study was to recruit current caregivers for a spouse or partner who has cancer, but with the expressed interest of 4 widowers, the sample changed. With the change in sample, so was the change in the narratives. In this section the similarities between the population of caregiver and widower will be discussed. The differences between the current caregivers and the widowers will be discussed in the conclusion. The 12 spouses who had been a cancer caregiver describe consistent themes they used to narrate their experiences. Table 2 discuss the 12 most frequent themes: an emotional journey; compounding hardships; caregiving career; silent communicator; needs of caregiver; caregiver coping; protective factors; the marriage; the unknown; perspective; cancer as a dictator; and the paradox of illness.

An Emotional Journey

This study examined the impact of being a caregiver to a partner or spouse with cancer. Such impact is often led by an emotional reaction when they first learn about their partner's diagnosis with cancer. Most common was the response of "being in shock" while others described feeling terrified, out of control, scared, and thinking as though "*we were in some strange reality, this was not our life.*" The first thoughts that often accompanied the news was, "*how bad is it*", "*are they going to die*", along with "*this cannot be happening to us.*"

As one male participant recalled, "*You just find yourself in the most incredible circumstances, it was as if we began a mad scramble for survival.*" Along with the initial shock of diagnosis, came the unthinkable of their spouse dying. "*It blindsided us, it blindsided the whole community, she did not fit the profile for cancer.*" "*The word terminal was the first to come to mind, but I could not say it.*"

Most talked about how they immediately went into action mode, that although they were thinking the worst, they tried to push through those thoughts in order to move onto the next step of "*what do we do next.*" Some described it as being in crisis mode, almost a state of disillusionment. The first few weeks were blurry; they were running on little to no sleep, accompanied by feelings of terror and loss of control. Participants made comments such as, "*We began a mad scramble for survival*", "*You do what you have to do, what choice do you have?*" and "*The number one concern was her welfare, I had to trust that the rest would work out.*"

Treatment marked a state of hopefulness paralleled with hopelessness. The hopefulness emerged from something being done, their spouse was receiving treatment, and it was providing a sense of control. The hopelessness appeared to be a lack of control; there was nothing to fight, there was nothing they could "do" to help. Noted by Holtstlander and Duggleby (2009) current scientific knowledge of hope and the hope experience remains descriptive and leaves gaps in our knowledge about the processes and meaning ascribed to them.

Over time many of the caregivers felt isolated, and the constant state of anxiety took a toll on their emotional state. They described it as being exhausted, overwhelmed, disconnected, lonely, and isolated. Various caregivers remarked, "*I felt guilty for wanting to take a break, if I was not there for him, who was going to be?*" "*Sitting for hours on end, day after day was just draining.*"

Table 2 Results of thematic analysis

An emotional journey	The force by which emotion is felt immediately upon diagnosis. Common reactions of fear, anxiety, shock, out of control at diagnosis, followed by reactions of feeling overwhelmed, isolated, exhausted, and disconnected
Compounding hardships	Caregivers reported higher stress levels when there were multiple complications in treatment and multiple hospitalizations, and setbacks
Caregiving career	A spousal caregiver is generally the one who is silently delegated to the task of primary caregiver. This is a job that is taken on by the spouse with little questions, and minimal experience. Becoming caregiver was a second full-time career
Silent communicator	An overarching theme when the participants spoke of how they communicated about cancer was that they did not verbally process the experiences of cancer and its impacts
Needs of caregiver	The congruent message from the current caregivers and the widowers was the need for connection. There was a desire for connection from their spouse, friends, community, and medical staff. Also, the need to be cared for, the need to feel essential, and the need to be connected to those that “get it”
Caregiver coping	Three main types of coping were discussed by caregivers: not coping (throwing themselves into caregiving); positive coping (journaling, exercise, prayer); negative coping (smoking, drinking, overeating)
Protective factors	What participants described as strengths that were deemed most helpful were, having a flexible job, being retired, no financial stress, having a strong faith that things would just “work out,” a medical background, and a good relationship with the medical staff
The marriage	Participants discussed mixed perceptions of the marriage post-diagnosis. Some stated that it was a chance to define their life before cancer as the old marriage, and now after diagnosis as the new marriage. Some discussed stuffing their own emotions and putting on a positive front in order to keep stress levels low, to appease their spouse and keep the marriage stable
The unknown	The sudden shift from known situations seen as life experiences before diagnosis, to the unknowns dictated by cancer is a devastating reality for the caregiver as well as the patient. With the perception of less control, caregivers often feel at loss in comparison to challenges in their life prior to cancer
Perspective	In searching for meaning through their process, caregivers and widowers discussed finding perspective as a way to cope. Sometimes conscious decisions are made between partners that influence their personal narratives during the cancer process
Cancer as a dictator	Participants discussed the unpredictability of cancer as having control their life, including aspects of their health. Caring for one’s physical self requires time, reflection, preparation, and routine. This is something the caregivers stated as not having. Current cancer caregivers discussed having to put themselves last, having no energy even to address their own health concerns as they were too exhausted by day’s end
The paradox of illness	Many of the participants, current caregivers and widowers reported feeling two opposing thoughts most of the time. While they mentally entertained an idea, they were also often fighting off another in their head. Some paradoxical feelings were directed toward spouses care, but most of the paradoxical feelings were ones about themselves, as a spousal caregiver

Compounding Hardships

Compounding hardships in this sample included multiple doctors’ visits to different clinics, numerous hospitalizations for seemingly minor infections and fevers. Fifty percent of the caregivers were employed part or full-time, and 25 % also had children under the age of 18 at home. Thirty percent of the caregivers reported job loss or other serious financial strain. Four of the 12 participants filed for medical bankruptcy due to the immense financial strain

placed on their family, and the inability to keep up with the medical expenses. All of the caregivers reported doing what they had to do at any cost in order to get the care their spouse needed. Similar to the pile up effect of stressors, most of the caregivers explained encountering many difficulties when it seemed as though they could not “*catch a break.*” Multiple demands were being placed on the caregivers, and the pile up effects of the treatment added up quickly. Caregivers reported higher stress levels when there were multiple complications in treatment and multiple hospitalizations. Some caregivers were able to view these setbacks as “*bumps in the road,*” and accepted them as part of the treatment regimen. While others reported wanting for “*things to stop happening, so I can catch my breath.*” One participant recalled “*feeling like we are always waiting for the other shoe to drop.*” “*Just when things are calm, you begin to wonder, what is next,*” and “*After each visit with our oncologist, I wanted to scream, enough already!*”

Caregiving Career

A male widower reflected, “*I did everything from meals to wheels, everything pivoted around her care that became central.*” A spousal caregiver is generally the one who is silently delegated to the task of primary caregiver. This is a job that is taken on by the spouse with little questions, and minimal experience. In previous research the most frequently the stated concerns of the caregiver was the survival of their spouse. The best way to ensure that was to devote themselves completely to the task of caregiving, this research confirms those findings as current caregivers appeared to be more committed to their time caregiving for their spouse than taking care of themselves. (Gotay 1984 as cited in Scott et al. 2004) Caregivers spoke in detail about the vast array of tasks performed, outside of their daily tasks of the home that needed to continue. They became an advocate for their spouse; they were note-takers at oncology visits, navigators of the insurance system, medication distributors, appointment schedulers, and spokesperson to family and friends regarding their spouses’ health. A female participant stated, “*when you are married, you just do what you have to do when your spouse gets sick. Nobody asks you to, its not talked about, you just do it.*”

In three instances, the spouse had been in the caregiving position first. A female recalled, “*I would do anything for him, he was the one who took care of me when I was sick, this is one way that I can repay him*”, another stated, “*I feel like I can now repay my spouse for all the wonderful things they did for me over the years.*”

Silent Communicator

An overarching theme when the participants spoke of how they communicated about cancer was that they did not verbally process the experiences of cancer and its impacts. “*We don’t discuss the ‘C’ word.*” Manne et al. (1999) discussed less adaptive cognitive processing in the spouses of cancer patients who felt strained in communicating their worries to their spouse.

Most of the caregivers admitted to not bringing up emotions related to cancer when talking to their spouse. One female participant talked about how she would stuff her own emotions for the sake of not upsetting her spouse. “*Since he has been diagnosed we have never said the ‘C’ word in conversation.*” “*I don’t want to think about the outcomes, and he does not seem to want to discuss them.*” Sixteen percent of the caregivers stated they had talked to their spouse about death. The caregivers that did talk about death stated that they were able to talk end of life decisions and wishes when death was imminent. Both

caregivers stated the conversation gave them more peace around the topic of death, and were able to bring more openness and communication to the marriage. *“We actually do talk to each other, we are closer now than we have ever been.”* One of the widowers recalled a conversation he and his wife had about death, and said that he was able to give her the kind of death she wanted. *“It was very peaceful and the way she wanted, she said I wanted to die in my sleep with you holding me, so....”*

Needs of the Caregiver

The congruent message from the current caregivers and the widowers was the need for connection. There was a desire for connection from their spouse, friends, community, and medical staff. The needs from the medical staff included more information, wanting more time explaining treatments and procedures, more time spent discussing and connecting with the family, and more options of care. As one woman explained, *“We needed an interpreter when he was diagnosed, all of this was a foreign language, and we were not hearing anything. That was stressful, when family asked me questions, I didn’t know what to tell them, because I didn’t know what was said, all I kept thinking was, is he going to die?”*

Another facet of connection was to the need of the caregivers themselves to feel connected. As one male stated, *“nobody cares for the caregiver.”* *“There is lots of support for the patient, but nothing for the caregiver.”* Another stated, *“no one should do this alone; one person may have cancer, but the spouse is also dealing with it.”* A female caregiver recalled, *“I felt like a second-rate citizen.”* Other reported needs of the caregiver included wanting validation, respect, feeling needed, valued, and to have some sense of control. *“I wanted to hear that I was appreciated, that was all, I wanted to be a good caregiver.”* When interviewed and asked what it was they most needed, one caregiver stated, *“a break, I just need a break.”* Another said, *“I want someone to tell me to take care of myself, go, get out of the house.”*

Along with the need for connection was the need for people who “get” it. Participants talked about being the go-to person in the family, the one who has all the information, they were now a recorder, researcher, and reporter. What they also wanted was someone to talk to that understood what they were going through. For instance, *“It seemed all I was doing was taking care of everyone else’s uncomfortableness, I had to deal with everyone else’s emotions ... I never had time for mine.”* *“What I’ve seen is that others can be clumsy with their words, I just want your presence, just sit there, put your arm around me, hold my hand, you don’t have to say anything, your friendship, your love is all that is conveyed, your words don’t matter, its just the being there for somebody, be my friend and love me, that is good enough.”* One of the widowers discussed the connection she had to a widowers support group, *“it was great to find this group I was able to talk with; none of my other friends understood the gruesome details of what we go through.”*

Caregiver Coping

Caregivers had a variety of ways in which they coped during the experience of their spouses’ cancer. Throwing themselves into the caregiving role as a means of coping was an overarching theme for the participants. Additionally, being able to attend most clinic appointments, and acting as record keeper etc., were also means of effective coping. All of the participants stated that they had to stay busy, it was when their thoughts were still and things were quiet that their anxiety was the highest. Caregivers used positive coping means

such as journaling, therapy, prayer, self-reflection, hobbies, and exercise. As one participant said, *“I just told myself, that I couldn’t afford to be sick now.”* *“Cancer has forced me to re-examine my own life.”* Others found ways of coping that could be seen as less positive means of coping, such as drinking, overeating, smoking, denial, and overworking. One of the widowers reflected on the one thing that helped him cope and that was having a hobby. He stated that if he had to tell another man how to cope if their spouse died, was to *“make damn sure you have a life.”* He reflected on the deep love in his marriage and how they always made the decision together that they *“would not put all of our eggs in each others’ baskets.”* He also stated that *“if you are lucky to be married long enough, one of you is going to die first.”*

Supports/Protective Factors/Strengths

All of the participants stated having very good support systems. They reported having family, friends, church, and community support at all stages of the diagnosis. Most of the participants were from rural communities where there is a community culture that pulls together in support of its members. Other areas the caregivers mentioned as the largest support was their place of employment. Having a secure job with good health insurance, with the flexibility to be a caregiver, and an employee who was as one stated, *“a God send.”*

Participants discussed making a conscious decision that they were going to *“do what they had to do, no matter the cost.”* *“This is something you cannot walk away from, so you find you own way to cope.”* *“As a family you just find out what you have to do and you just stick to it, all the while you search for normalcy.”* One participant recalled a nurse telling him that he is going to get sick of hearing the statement *“one day at a time”*, but realized how true it was. *“I would hear people say that all you can do it take it one day at a time, and it used to annoy me, but then I realized how real that was, if you look too far ahead it gets too overwhelming.”*

What participants described as strengths that were deemed most helpful were, having a flexible job, being retired, no financial stress, having a strong faith that things would just *“work out,”* a medical background, and a good relationship with the medical staff. These were seen as factors that facilitated strength during their journey.

The Marriage

Participants discussed their mixed perceptions of the marriage post-diagnosis. Some stated that it was a chance to define their life before cancer as the old marriage, and now after diagnosis as the new marriage. They were able to take this as a chance to start new, to open new means of communication, and to change patterns that had not been working. For instance, one male stated, *“our marriage has changed for the better, we have a new marriage now, it is like a renewal.”* Another stated, *“We are closer now that we have ever been.”* Others talked about the strength of their marriage; their ability to use humor, and connect through conversation was one of the things that made the process more bearable.

On the other hand, participants discussed stuffing their own emotions and putting on a positive front in order to keep stress levels low, and appease their spouse. One participant stated that they live separate lives in the same home, *“we don’t sleep together, we don’t have the same schedule, we don’t eat the same foods, we don’t even like the house to be the same temperature.”*

One of the major differences between the current caregivers and the widowers is their narrative about their marriage. The widowers recall a more positive experience and discuss the richness of their marriage in the final months. They all described their marriage as the best it had ever been. These differences will be further explored in the conclusion.

The Unknown

The sudden shift from known situations seen as life experiences before diagnosis, to the unknowns dictated by cancer is a devastating reality for the caregiver as well as the patient. With the perception of less control, caregivers often feel at loss in comparison to challenges in their life prior to cancer. Statements like, *“I can’t physically fight this”*, *“Don’t know what to do”*, and *“There are no answers with cancer”*... are all examples of the “unknown” phenomenon of cancer had contributed to their outlook toward the challenges they faced. Many participants spoke to the unknown trajectory of the illness, with quotes such as, *“Does cancer have to equal death?”*, *“The big C word is terrible, you think that it is an immediate death sentence”*, and *“I don’t believe that cancer ever goes away”* speak to the ambiguity of cancer. As evidenced through the interviews, what is often effectively managed is the facts about cancer but rarely addressed is the process of cancer in family life. One participant commented on an unknown relational phenomenon by saying *“I’m unsure how much to push my spouse, how much should I try to motivate her to be active, or to change?”* One caregiver recognized their spouses’ declining health and stated, *“I don’t believe that cancer ever goes away”, “We were fighting an un-fightable thing.”*

Perspective

In searching for meaning through their process, caregivers and widowers discussed finding perspective as a way to cope. Participants stated, *“I feel fortunate, others have it way worse than we do”*, *“We really are lucky if you look at the big picture”*, and *“We have had so many good years.”* Sometimes conscious decisions are made between partners that influence their personal narratives during the cancer process. As one participant reflected on a conversation with his wife, *“There are so many ways that cancer has not changed us, I have become more intensely aware of her, but we made the decision right away that cancer was not going to ruin our lives.”* One widower discussed the narrative of his wife’s life, *“She lived life twice as fast, so really she did live to be 106, she lived a good life.”*

Cancer as a Dictator

Participants discussed cancer as having control their life, including aspects of their health. The course of cancer is so unpredictable, as one participant explained, *“it does not have a plan, so as much as you try it is difficult to find routine.”* Caring for one’s physical self requires time, reflection, preparation, and routine. This is something the caregivers stated as not having. Current cancer caregivers discussed having to put themselves last, having no energy even to address their own health concerns as they were too exhausted by day’s end. Statement such as, *“Waiting for a break, so I can care for myself”*, *“My body is screaming at me”*, *“I’m choosing to put my health on hold until he gets better”*, and *“To hell with myself, I will do anything for him, even if that means putting myself last”* speak to the chosen neglect of their own health. Sixteen percent of the participants reported making positive changes to their health; they quit smoking, started eating better, and realized that

self-care was just as important as the care of their spouse. Additionally, all of the widowers who participated discussed making major life changes after the death of their spouse. They began taking care of themselves; lost all the weight they gained while caregiving, and made healthier life choices. When asking a female widower if she could have made healthier choices during her caregiving time, she stated, *“I knew the benefits of exercise, I just didn’t do it. Could I have found time? sure I could have, I just didn’t do it.”*

Table 3 shows the reported symptomatology of the 8 caregivers (participant A–H), and the four widowers (participant I–L). One male caregiver and one male widower reported no changes to their health during the time of caregiving for their spouse. While these results cannot be generalized to the entire population of caregivers, it is important to note the impact of caregiving for a spouse with cancer and the health outcomes. Seventy-five percent of the sample reported generalized stress and anxiety. Sixty-seven percent reported weight gain and fatigue, 58 % reported insomnia, 50 % self-reported depressive symptoms, and 50 % stated having multiple gastrointestinal issues. Thirty-three percent of the participants reported chest pain, and neck/back pain; 17 % reported headaches and weight loss. Ninety-two percent (N = 11) stated being on some types of medication to control health issues like lowering blood pressure, decreasing symptoms of depression and anxiety and for insomnia.

The Paradox of Illness

Many of the participants, current caregivers and widowers reported feeling two opposing thoughts most of the time. While they mentally entertained an idea, they were also often fighting off another in their head. Some of the paradoxical feelings were directed toward their spouse, as seen in statements such as, *“I feel like I enabled my spouse to be helpless, and I don’t want to be resentful, but I wonder if I would make him do more for himself if he would”, “I get mad sometimes that he is not doing anything to get better, if I had cancer I would change all my bad habits. I know that he is sick, that is why I feel bad saying that”,* and *“Sometimes I am so lonely, even when I am right next to him, I am lonely.”*

Other feelings were directed toward their spouses’ care; *“I never feel like I can be really excited about anything, I want to be excited for good news from the doctor, but I seem to always anticipate the other shoe will drop soon”, “After my spouse died, I had a lot of regret, did we do enough? Should we have gone to another clinic in the end, would she still be here? But then I know that is not realistic to think like that, we did all that we could.”*

Most of the paradoxical feelings were ones about themselves, as a spousal caregiver. Participants made statements such as, *“I feel that if I am negative in my thoughts I will not be able to take care of him, so I have to fake being happy”, “There are times that I think, how can I actually be happy right now, I can’t be this happy if I don’t have my spouse anymore”, “There are things that I want to do for myself, but I feel guilty for even wanting to do them”, “I have gotten good at faking it, I can really fake it on the outside, but I am just dying inside”*. In reflecting on her role as necessary, a female stated, *“I feel unessential, yet I know that I am the most essential.”* Another discussed her health by saying, *“I want to take better care of myself, but I feel selfish for doing so, I mean, I have my health.”*

Discussion

Cancer’s impact is far reaching into the lives of the patients as well as the spousal caregivers. Difficulty in relationships can be a result of the multitude of changes brought on by

Table 3 Results of review of systems checklist

Participant	Weight gain	Weight loss	Fatigue	Insomnia	Neck/back pain	GI issues	Chest pain	Headaches	Fibromyalgia	Cancer	Stress	Depression
A	x	0	x	x	x	x	0	0	x	0	x	x
B	x	0	x	x	0	0	0	0	0	0	x	x
C	x	0	x	x	x	x	0	0	0	0	x	0
D	0	0	0	0	0	0	0	0	0	0	0	0
E	0	0	0	0	0	x	0	0	0	0	x	0
F	x	0	x	0	0	0	x	0	0	0	x	x
G	x	0	x	x	x	0	x	x	0	x	x	x
H	0	0	x	x	0	x	x	0	0	0	x	0
I	0	0	0	0	0	0	0	0	0	0	0	0
J	x	x	x	x	x	x	0	x	0	0	x	x
K	x	x	x	x	0	x	0	0	0	0	x	x
L	x	0	0	0	0	0	x	0	0	x	0	0

a spouse's illness (Forbat et al. 2012). Analysis of the participants' interviews included coding the responses of the current caregivers and widowers together. As themes began to emerge there were many similarities between the two groups, but also some notable differences. In the analysis process, the current caregivers and the widowers were coded together. After the themes were developed it was apparent that there were differences between aspects of the widower's narratives and physical health that should be noted in this study. Since the sample was 4 widowers the results cannot be generalized, but to be taken as a description of an experience.

The narratives of the widowers spoke to a different perceived caregiving experience than those reported by current caregivers. Upon reflection, the widowers discussed the emotional toll of the experience while caregiving, but spoke to a more positive overall experience. The second difference was the health outcomes between the caregivers and the widowers. The narratives of the widowers' retrospectively recall a more positive experience, and openly discuss the richness in their marriage in the final months. They were able to acknowledge that although their caregiving experience was difficult, they would go through the whole process again, just to have more time with their spouse. The widowers being more than a year removed from the death of their spouse do not describe their experience as one of being negative or burdensome. As one male widower stated "*I would do it all over again, just to have 30 more seconds with her.*"

The other difference between the current caregivers and the widowers was the recollection of their marriage. All of the widowers discussed a richness in their marriage during the last years. They describe how the experience brought them closer together, and the love felt in those final months was unparalleled to any other love they had experienced. As a female participant stated, "*we had a better marriage, it was the best we had ever been.*"

The last difference between the current caregivers and the widowers were the reported health outcomes. All widowers stated being in better health currently than when they were in the caregiving role. They reported being in better health two years post spousal death. They stated making major life changes and health decisions in order to better care for themselves. This is opposite from the narratives of the current caregivers, where the majority put themselves and their health last and stated poorer health outcomes.

Figure 1 explains the hypothesized process of health outcomes for current spousal caregivers. Caregivers stated feeling impending loss, the fear of the unknown and a loss of control. Increased fear and a constant state of anxiety accompanied those feelings. Anger was the primary emotion that was stated most amongst the current caregivers and was most described as being directed at the cancer itself. This anger toward cancer and the process of their spouse having cancer propelled the current caregivers to channel their anger toward "fighting" for their spouse. They would throw themselves into the role of caregiving in order to "do" something, which in Fig. 1 is referred to as the "action phase". This action phase gave the caregivers a sense of control. This action phase marked a time where the caregivers appeared to neglect themselves and neglect their health as their time and energy was being directed to the ultimate care of their partner. The more time and energy invested to the care of their spouse, the less time was directed to their own health, therefore drawing the association that the caregivers reported poorer health outcomes, resulting in illness, and more symptoms on the review of systems checklist.

In contrast, Fig. 2 is the hypothesized process of health outcomes for the widowers. The death of a spouse created an apparent numb period that is termed "inaction phase". Widowers reported this phase as time for reflective processing, during which they began movement into a stage of peace and acceptance. During the reported calm period they began the process of meaning making, during which time widowers reported an



Fig. 1 Process of health outcomes for current spousal caregiver

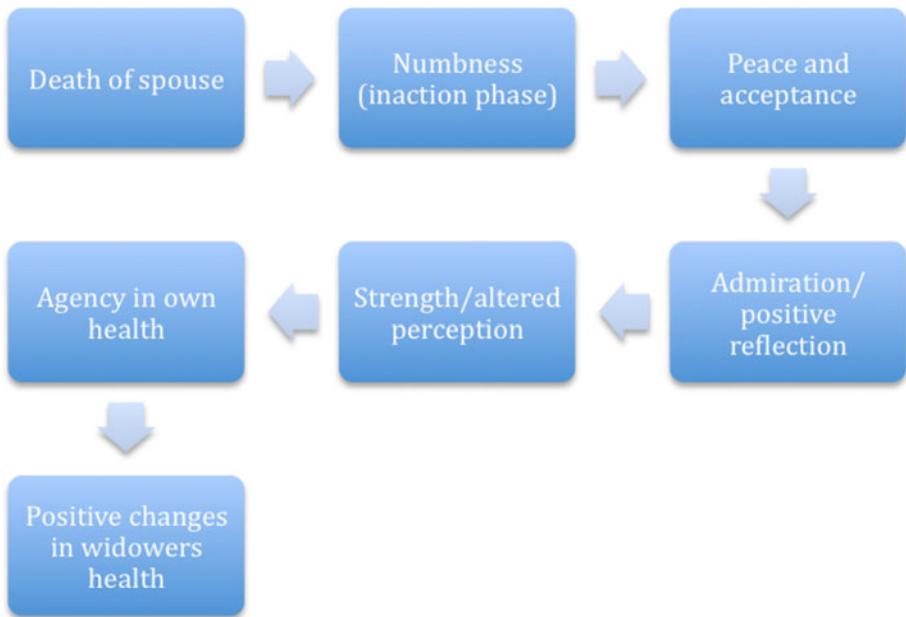


Fig. 2 Process of health outcomes for widowers

overwhelming admiration for what their spouse had gone through during his/her illness. This admiration gave them strength and initiative to promote agency in their own health outcomes. The term agency as described by McDaniel et al. (1992), is an involvement and commitment to personal choices that influences one's own health. In accompanying a biopsychosocial framework, agency in one's health can lead to decisions of care that can improve overall health outcomes. Such characteristic appeared to be missing in the narratives of the current caregivers. Agency inspired the widowers to create and make changes in their physical health. Outcomes of the widowers' health as positive 2 years post spousal death included reported loss of weight, initiation of a consistent exercise regimen, and healthier food choices. As one participant stated, "*I am in the best shape of my life, I have changed many things about my old habits, I feel healthy,*" this demonstrates the desire to take control of their own health outcomes. Limits to these results are recognition that all of the widowers were over the age of 50, were no longer in a caregiving position, and did not have children living at home.

Recommendations and Implications for Practice

Research focusing exclusively on the caregiving process involving cancer patients and their caregivers is scarce (Nijober et al. 1998). The authors of multiple studies recognize the scarcity of research in this area (Klassen et al. 2007; Kim et al. 2008; Northouse et al. 2005; Doherty and Campbell 1988; Rolland 1994). Future research can lead to examination of the caregiver process over time. Also, examining the relational dynamics as a variable to further explore what is occurring in the groups of caregivers that report more physical illness is beneficial. A larger and more representative sample and longitudinal data collection would be helpful in order to understand caregiver process, relational dynamics during cancer, and physical outcomes of caregivers. Also, a sample of self-reported healthy caregivers should be examined to further understand their protective factors, coping mechanisms, and relational dynamics. Health outcomes and self-reported physical symptoms would be better understood by a larger sample with the inclusion of caregivers and widowers who are currently in parent capacity who are also caretaking for children. Since this research was grounded in a systems and biopsychosocial framework it aligns with the guiding tenants of Medical Family Therapy. Family therapists grounded in a systemic and relational lens are well positioned attend to the sensitivities of families who have a member diagnosed with illness (Hodgson et al. 2012). This research adds to the growing literature that provides insight into the spousal caregiver process. It also adds a unique glimpse into the emotional and health perspectives of widowers who were once caregiver for a spouse with cancer. The contributions of this study can assist in the development of interventions aimed toward the specific needs of spousal caregivers using a relational, systemic, and biopsychosocial framework. Keeping in mind that the emotional and psychological health of a spousal caregiver is an importance aspect to the cancer patient's experience.

Limitations of the Study

Despite some limitations, the findings of this research are important for understanding the emotional and physical impact cancer has on spousal caregiver. Although the results of this study cannot be generalized to the population of spousal cancer caregivers, it is reasonable to believe that there could be an influence on the overall emotional as well as physical health of the caregiver. The results of this study can only be generalized to the present sample. There is no variance in geographical location, race, and socioeconomic status of

the participants. There was no screening process in place to determine healthy versus non-healthy caregivers prior to the study. The recruitment process was geared toward patients who were currently receiving care in a cancer setting. This leaves out entire populations who are in remission, or nearing the end of their treatment and not present in the clinic as often as those that are receiving weekly treatment. Lastly, the limitations of a qualitative study is that of inter subjectivity. Analysis from the researcher can be subject to bias and mistakes. Themes were confirmed with participants, and quotes used in writing were presented for feedback to determine correct interpretation from the researcher.

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