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Exploring Experiences, Support, And Growth With Advanced Cancer Caregivers From Rural Communities

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EXPLORING EXPERIENCES, SUPPORT, AND GROWTH WITH ADVANCED CANCER CAREGIVERS FROM RURAL COMMUNITIES

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by

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ABSTRACT

This study is an exploratory, qualitative research study of nonpaid caregivers for advanced cancer patients. Fifteen caregiver participants completed semi-structured interviews. The patients for whom they provided care lived at home and were diagnosed with advanced (stage 3 or 4) cancer. The original site of cancer and involvement in treatment was not important for the study. Research recruitment prioritized caregivers residing in rural settings, knowing these areas often lack resources.

During the semi-structured interviews, caregivers discussed their perceived challenges and rewards, discussed their stressors and how they managed stress, and discussed their supports. Caregivers addressed the impact of caregiving on each domain of quality of life (social, physical, emotional/psychological, and spiritual). Caregivers discussed positive and negative impacts of living in a rural area while caregiving. Once the interview questions were addressed, the participants were invited to contribute any closing thoughts they would like to add.

Interview data was analyzed to determine codes, themes, and present theory grounded in the data of the caregiver experience. Themes of the study include caregiver multi-faceted experience of loss, medicine as a foreign language, unexpected strength in community, significant impact of the caregiving role on caregiver quality of life, and the balance of forced mindfulness (staying in the moment) versus anticipating grief and loss (being future-oriented). Results indicate that caregiving has significant impacts on caregiver quality of life, which mutually impacts the patient experience and the status of health and wellness of both parties.

The results concluded with presentation of the theory, which indicates caregiver use of negative social comparisons to cope with their challenging circumstances in the tone of “it could be worse.” This method of coping minimizes the caregivers experience of stress and loss by downplaying the effects of their experiences and level of hardship. It is of note that the caregiver experience of stress and emotional response was nearly always maintained privately from the patient, except in one experience of long-term caregiving (14 years) in a spousal relationship. However, even in this patient caregiver dyad, there was still some protection of information from the caregiver to the patient.

ACKNOWLEDGEMENTS

It is interesting where a professional career path may lead us over time. Ten years after completing a Master's Degree, I stumbled upon an opportunity to teach as an adjunct faculty in a BSW program. A couple of years later, I was hired as a faculty member and discussing a return to graduate school to complete a doctoral degree. Having access to tuition waiver opened that door without creating financial burden. I would have only had these opportunities because of the ability to engage in so many different experiences in my career as a social worker, first. This career has allowed me to garnish a true passion in the work that I do every day, whether serving clients, supervising staff, and now teaching students to join this career that I love.

My daughter, Charlotte Taylor Griffin, had recently turned two years old when I began coursework for the DHSc program. We learned many things together throughout this process. Both of us have made sacrifices so that I could complete this degree, including hours away from her as a young one to attend classes, missing sick visits to urgent care, an abundance of time working on assignments and dissertation while she had to learn to play independently, among other experiences. My hope is that she will use this process as a path toward her own education and can build the persistence, stamina, and growth that one must demonstrate to successfully complete any degree. I am truly grateful to be able to demonstrate these values to her at such a young age.

My dissertation committee, chaired by Dr. Matthew Hutchins and including Dr. Renee Bauer and Dr. Whitney Nesser, were a dream. They breathed air and life into me just when I needed the extra oxygen. They were supportive and timely. I am grateful for their guidance, direction, and time. Further, Dr. Bauer spent countless hours supporting the qualitative processes of this study. I am thankful to call her a mentor and friend. Her expertise in health care and personal experiences tied to this study made her the perfect addition to the team.

The faculty in the DHSc program have become inspirations within my career in higher education. Being a part of this program has helped me to learn and grow in many ways. I am most thankful that it paved the scholarly and professional path I need to be successful as a professor in higher education. Finally, the number of my predecessors who have graduated from the DHSc program have been true advocates and supports. I now call them my friends and colleagues, and I'm grateful that this program allowed me to build these relationships.

Finally, if it wasn't for my past employment as a hospice social worker and current work in the Cancer Center at Terre Haute Regional Hospital, my interest for this project would have never developed. Working in oncology has been one of the most challenging, but also rewarding practice areas in my professional experience. I am a member of an amazing medical team of providers who have helped me sustain my passion and involvement. I also was able to partner with Visiting Hospice Association and Hospice of the Wabash Valley to assist with recruitment, which also allowed me see true examples of the excellent care they give to our community. I'm thankful to the staff, patients, and families I have met over the years. I remember the many, many patients we have also lost to this terrible disease, some of which are even represented in this study. I regularly pray that we find a cure to this disease that affects the lives of so many.

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CHAPTER 1

INTRODUCTION

According to the National Cancer Institute at the National Institute for Health, 2016 yielded 1,685,210 new cancer diagnoses across the United States (2017). The World Health Organization (WHO) predicts the number of new cancer cases to rise by approximately 70% over the next twenty years (2017). National Cancer Institute (NCI) shares 2010-2012 data indicating approximately 39.6% of men and women will be diagnosed with cancer at some point during their lifetimes (2017).

While this information indicates the incidence of cancer overall, advanced cancer patients have more prominent needs among those diagnosed with this disease. Ferrell et al., (2017), describe patients with advanced cancer as “those with distant metastases, late-stage disease, cancer that is life limiting, and/or with prognosis of 6 to 24 months” (p. 96). Because their cancer is not considered curable, aspects of treatment to these patients and families include end-of-life planning, family support, and preparation for the intensification of care needs as physical health status declines with time.

In-home caregivers often provide physical care support that may be outside of their scope and range of both professional and personal experience, leading potentially to caregiver burden, physical fatigue, and need for emotional support. Eifert, Adams, Morrison, and Strack (2016) describe family caregivers as “relatives, friends, or loved ones who provide any unpaid help to an individual over the age of 18,” including assistance with finances, household management, physical health care, or accessing health care (p. 178). It is of note that this was the specific definition of the family caregiver used for the purpose of this study. As utilization and length of stay in inpatient facilities is shortened due to changes in health care reimbursement and funding, the role of family caregiving within home and community-based settings is now of greater importance (American Association of Retired Persons [AARP] and NCI, 2015). According to the AARP and NCI Public Policy Institute’s 2015 report, more than 34 million people have provided unpaid care to adults above the age of 50 years in the past 12 months. In 2009, the annual economic value of informal, unpaid caregiving was estimated to be more than $450 billion; this figure increased from a figure in 2007 of $375 billion (Feinberg, Reinhard, Houser, & Choula, 2011). Family caregivers fulfill a critical role in the management of cancer; “enlisting their cooperation and including them as the unit of care from the outset are considered critical ingredients to effective cancer management” (PDQ Supportive and Palliative Care Editorial Board, 2016, para. 3).

Caregiving for the oncology patient encompasses numerous roles and demands upon the loved ones providing care. Those in an unpaid caregiving role risk stress, physical demands, and economic hardship, which promote vulnerabilities to negative health outcomes (Feinberg et al., 2011). Caregivers are affected physically due to demands of the caregiving role. They are also affected emotionally and psychologically as the role is stressful; they are often juggling other responsibilities, leading them to neglect their own self-care. These factors can combine to contribute to poor caregiver quality of life (Grant et al., 2013).

Caregiver quality of life is described as encompassing four domains: physical, psychological, social, and spiritual (Grant et al., 2013). Physical health can be impacted because caregivers have the potential to live with their own chronic illness(es) while providing care to their loved one living with advanced cancer. The physical demands and stressors of the caregiving role may exacerbate presentation and symptoms of their own health issues.

Caregivers become increasingly busy with the tasks and duties of caregiving, leading them to ignore their own health needs and to engage in negative lifestyle choices (Fujinami, Otis-Green, Klein, Sidhu, & Ferrell, 2012). Additionally, fatigue may become a regular experience within the caregiving role. As the disease progresses, it may be necessary for family caregivers to support daily living needs and provide physical care to their loved one (Fujinami et al., 2012). Caregiving tasks may include transportation, home supports such as cleaning and meal preparation, laundry, support of the patient's finances, and physical health care (de Moor et al., 2017). Physical aspects of care can even mimic those a nurse or nurse's assistant may complete, including bathing, toileting, medication organization and delivery, and special care based on any complication from treatment or other medical issues (de Moor et al., 2017).

Caregiving becomes demanding on psychological well-being. While caregiving is associated with both positive and negative psychological outcomes, the level of a support system that a family caregiver has becomes a critical factor related to psychological outcomes (Fujinami et al., 2012). A strained relationship with the patient and a lacking support system contributes to higher caregiver burden, which also puts the family caregiver at higher risk of anxiety and depression (Fujinami et al., 2012). The caregiving role adds additional stress and strain, especially when caregivers are balancing other needs. Fujinami et al. (2012) report that patients and family caregivers experience similar worries and uncertainties at the time of cancer diagnosis, during treatment decisions, when experiencing symptoms and side effects, and throughout the overall impact of the disease on functioning; this process is overwhelming for both parties. Caregivers with a prior history of mental health and substance use needs may be at greater risk for development of negative psychological outcomes.

Caregivers need adequate social support to succeed in the caregiving role. However, many caregivers do not have access to a necessary level of social support. Social relationships are impacted when caregivers are overwhelmed and cannot engage in this aspect of life, which is a stress reliever. As the illness worsens, family caregivers become increasingly fatigued and have lesser time available to engage in social activities and relationships (Fujinami et al., 2012). When caregivers lose a support network, they can easily feel isolated, which contributes to worsened psychological well-being (Fujinami et al., 2012). Spousal caregivers can be at higher risk when the physical demands of care impact their sexual health and activities (Fujinami et al., 2012). Communication becomes increasingly important in reducing the risk of these dynamics on the intimate relationship between a patient and a spousal caregiver.

Spiritual well-being may encompass the hope or meaning one has in life. According to Fujinami et al., “for both patients and caregivers, hope evolves in time and each may find that they are hoping for different things” (2012, p. 212). Faith and spirituality of the patient and family caregiver changes over time, from hope that the diagnosis is wrong, that treatment will be effective, and later for a peaceful death (Fujinami et al., 2012). A family caregiver is even at risk of feeling guilty that their loved one is ill while he/she remains in good health. Spiritual care can be instrumental in supporting family caregivers within aspects of anticipatory grief and bereavement support.

Background of the Problem

Oncology caregivers are significantly impacted by the stressors of the caregiving role, which affects their emotional and physical wellness. Becoming a cancer caregiver for a family member is not an anticipated or desired role (Kim, Baker, Spillers, & Wellisch, 2006). Caregivers are challenged by the need to balance multiple responsibilities within their own family, marriage, and employment, while simultaneously providing care, which leads to role overload and strain (Sumner, Wellisch, Youngmee, & Spillers, 2015). Hudson et al. (2015) indicate that family caregivers can be described as “hidden patients” (p. 19). The authors explain this phenomenon as significant, as the focus of medical attention and intervention is on the patient, but caregivers are also prone to physical, psychological, social, and financial issues due to caregiving (Hudson et al., 2015). These caregivers need attention and support to alleviate burdens and function effectively within the caregiver role. The level of distress incurred by family members providing care can be as high as or higher than distress experienced by the patient (Wozniak & Izycki, 2014).

When advanced cancer patients and caregivers reside in rural settings, challenges experienced by patients and caregivers can be exacerbated. Rural areas are defined as all populations, housing, and territory not included within an urbanized area or urban cluster (US Census Bureau, 2016). Stemming from this definition, the rural aspects of the United States include a variety of areas that display differing characteristics, from densely settled small towns and housing subdivisions on the fringes of urban areas, to more sparsely populated and remote areas. In comparison, the Census Bureau defines urban areas as those having a population of 50,000 or more, thus those with smaller populations fall into their classification as rural (2016).

Compared to their urban counterparts, rural health care has limitations. According to the National Rural Health Association (NRHA, 2018), health care providers and patients in rural areas differ greatly from those in urban areas. Primary areas of difference lie in cultural and social traits, economic needs, educational and employment limitations, overall isolation, and a lack of recognition and priority by policymakers to address barriers in rural areas (NRHA, 2018). Urban areas have greater access to physicians and dentists. People living in rural areas earn an average of $9842 less per capita than those in urban settings, are more likely to live in poverty, and more frequently rely on public assistance programs (NRHA, 2018). Further, rural settings have more limitations in overall access to healthcare due to higher unemployment, leading more people to live without health insurance.

Rural settings have difficulty with access to qualified providers because they have insufficient numbers of social service workers and health care providers in these areas are overworked (Goodridge & Dubbleby, 2010). Gaps remain in the availability of literature regarding the needs of patients and families in rural communities. Relatively few studies have examined the barriers to quality care experienced by terminally ill patients and their families in rural areas, especially at the end of life (Brazil, Kaasalainen, Williams, & Rodriguez, 2013). Barriers to quality care in rural settings can include the recruitment and retention of necessary, qualified healthcare workforce to care for patients, as well as a general lack in resources and funding.

Brazil et al. (2013) suggests that due to the lack of medical providers in rural areas, family caregivers often take on additional responsibilities and roles in caring for patients at home and in the community setting versus their urban counterparts. These researchers report that little is known about the caregiving experience for terminally ill patients, especially near the end of life, thus further exploration is needed to better understand caregiver needs and barriers to having them met. Within their research, Brazil and colleagues noted that sampling was likely difficult due to the likelihood that family caregivers were “so busy completing daily caregiving tasks that participation in a study may have been viewed as too time-consuming in comparison to the numerous demands already placed on their time" (2013, p. 5).

Need for the Study

The WHO predicts the number of new cancer cases to rise by approximately 70% over the next twenty years (2017). In 2015, the Commission on Cancer (COC) included psychosocial and behavioral healthcare as required components of accredited cancer care programs (American College of Surgeons, 2020). As a result, psychosocial needs in patients and caregivers, such as social and emotional functioning, coping skills, and potential mental health issues, are now more closely monitored and evaluated. This ensures potential needs are identified and addressed in areas of patient and family psychosocial functioning. Advanced cancer patients have more prominent needs among those who are diagnosed. Because they are not considered curable, aspects of treatment to these patients and families include end of life planning, family support, and preparation for the intensification of the care needs as patients physically decline with time (NCI, 2014).

More than 34 million people have provided unpaid care to adults above the age of 50 years in the past 12 months (AARP & NCI, 2015). In 2009, the annual economic value of informal, unpaid caregiving was estimated to be more than $450 billion; this figure increased from a figure in 2007 of $375 billion (Feinberg et al., 2011). AARP describes a caregiving cliff, noting that in the next several years caregiving needs of the population will increase; there will only be one caregiver available for every three people needing care (AARP & NCI, 2015). Having a better understanding of effective support services and working to implement these services is a strong plan to maintain the longevity and ability of these highly demanded caregivers.

Family caregivers fulfill a critical role in the management of cancer (PDQ Supportive and Palliative Care Editorial Board, 2016). Despite the growing volume of caregiving, recognizing and addressing the needs of family caregivers to oncology patients remains an area riddled with limitations. Access to supportive care for the caregiver is crucial to mitigate the risk of caregiver burnout and promote wellness within the dyad composed of the patient and caregiver. Prior studies have found that use of formal services (spiritual care, support groups, social work) by caregivers occurs less than 25% of the time when these services are offered (Grant et al., 2013). With a better understanding of the reasons that support services are used or declined, a more effective method to intervene and offer support may be developed and available to this population.

Recent research has begun to explore the family caregiving role, the challenges within, means to provide support and assistance, and impact of the caregiver role on the patient. Participation and involvement in support services remains restricted without understanding of the best ways to serve this vulnerable dyad (van Ryn et al., 2011). Prior studies recommend interventions to target the complex emotional experience of caregiving (Ostlund, Wennman-Larsen, Persson, Gustavsson, and Wengström, 2010).

Exploring the experience of advanced cancer family caregivers provided further understanding of how to support this specific population. This study examined stressors and opportunities for personal growth that caregivers experienced. The data provided further understanding of the caregiving experience as well as further depth of understanding of stressors and positive aspects of caregiving, specific to rural communities. These outcomes could improve clinical practice and care for both oncology patients and their caregivers. Results provided further evidence of support needs and stressors that may be used to create evidence-based interventions to support both the patient and caregiver.

The long-term goal of the proposed study may enhance quality of life and support specific to oncology caregivers; in accordance with literature, improving the quality of care and quality of life of oncology patients affects both the patient and the caregiver. The enhancement of supportive services for caregivers reduces experience of burnout within family caregivers. A better understanding of caregiver needs and experiences prepares a basis for effective caregiver services to alleviate stress and role overload experienced in rural settings. These support services should be grounded in evidence to ensure effectiveness.

Previous studies often carry a limited focus to caregivers of a specific type of cancer (i.e. non-small cell lung cancer). This study did not limit to a certain focus of oncology diagnosis, but included any nonpaid caregiver providing care to an advanced cancer patient regardless of type of cancer. The study targeted advanced cancer caregivers living within rural settings, recognizing that rural areas often have more limited finances and resources.

Purpose of the Study

The purpose of the study was to examine the experiences of family caregivers of advanced cancer patients in rural communities. In this study, caregivers were relatives, friends, or loved ones who provide unpaid help to an advanced cancer patient. Caregiving assistance addressed finances, household management, physical care, or accessing health care. The research used a grounded theory approach to examine the caregiving experience, explore stressors, and inquire upon benefits of the caregiving experience. Grounded theory works to create a theory developed from data collection based in participant experience (Creswell & Creswell, 2018). The study focused on rural communities, knowing that these areas tend to be limited in resources.

Research Questions:

1. What does the process of caregiving entail for those who provide unpaid care for loved ones with advanced cancer?
2. How do these unpaid caregivers manage stressors and challenges within their role?
3. Does the process of advanced cancer caregiving lead to an experience of growth and meaning for the unpaid caregiver? If so, in what way?
4. How does advanced cancer caregiving affect each of the domains of quality of life (physical, psychological, social, and spiritual)?
5. What is the impact of living in a rural community when caregiving for an advanced cancer patient?

Assumptions

The following assumptions within this research project should be acknowledged:

1. The questions asked within the interview protocol within this qualitative study are valid and reliable;

2. Participants will answer the interview questions in an honest and candid manner based on their personal experiences;

3. The sample is representative of other advanced cancer caregivers living in rural settings;

4. The inclusion criteria of the sample are appropriate;

5. The numbers of participants will reach a level at which saturation of the data is achieved, or when no new data or meaningful units are discovered.

Limitations

The following limitations within this research project should be recognized:

1. The study is generalizable only to similar populations.

Delimitations

Delimitations for this study are:

1. Participants will consist of nonpaid caregivers;
2. Caregivers will be at least 18 years of age;
3. The study will include interviews with a minimum of fifteen caregivers and will continue interviews until reaching saturation of data;
4. Caregivers will be recruited from home health care, hospice, hospital, and outpatient oncology offices providing care for patients in and around Terre Haute, Indiana (a rural community situated one hour west of Indianapolis);
5. Caregivers will be providing care to a patient living with advanced cancer (noncurative in nature and does not respond significantly to treatment);
6. The patient and/or caregiver will be living within rural areas surrounding Terre Haute, Indiana.

Operational Definitions

Operational definitions will help in understanding the execution of the study.

1. Advanced cancer: According to the American Cancer Society, advanced cancer is considered to be noncurative in nature and does not respond significantly to treatment (2016). Advanced cancers may or may not be metastatic, or have spread to other areas of the body from the original tumor site.

2. Family Caregiver: A family caregiver is identified as someone responsible for the daily needs of another person. In this study, caregivers will be “relatives, friends, or loved ones who provide any unpaid help to an individual over the age of 18,” including assistance with

finances, household management, physical health care, or accessing health care (Eifert et al., 2016 p. 178). These caregivers can be members of a family of origin or can be a member of a family of choice. In either case, family caregivers are not considered professionals (although some may have medical training) and provide care to their loved ones without compensation.

3. Quality of Life: Grant et al. (2013) describe caregiver quality of life as encompassing four domains: physical, psychological, social, and spiritual domains are included. To comprehensively address the needs of patients and caregivers, all four aspects should be considered. This consideration can be of particular importance when considering assessment and intervention methods.

4. Rural Settings: Rural areas are defined as all populations, housing, and territory not included within an urbanized area or urban cluster (US Census Bureau, 2016). The Census Bureau defines urban areas as those having a population of 50,000 or more, thus those with smaller populations fall into their classification as rural (2016).

5. Supportive Oncology Care: The National Comprehensive Cancer Network has established Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Supportive Care. These are the standards identified by the American College of Surgeon’s Commission on Cancer. The standards indicate supportive oncology services to include palliative care, psychosocial distress screening, and survivorship care planning (2017). Additionally, supportive services in oncology care may include those offered by an oncology nurse navigator, social worker, and/or pastoral counselor and in settings of individual, family, and group counseling.

6. Positive aspects of caregiving: The extent to which caregiving enhances and becomes enriching to an individual (Li & Loke, 2013).

7. Meaning within the caregiving role: Caregiver perspective of the value of caregiving

when life for the patient and caregiver was maintained in as normal of a way as possible, allowing a positive view of the experience (Li & Loke, 2013). In other studies, caregivers report that they become more accepting overall, learn to prioritize life challenges, and view negative experiences from the perspective of the growth and meaning created as a result of them. This creates a sense of purpose and appreciation as a result of the caregiving experience (Li & Loke, 2013).

Research Design

This inductive systems study was qualitative and exploratory in nature and utilized a constructivist worldview. The theoretical orientation forming this study was grounded theory. Grounded theory uses examination of data to work toward development of a theory (Creswell & Creswell, 2018). In-depth recorded, semi-structured interviews were conducted with caregivers and utilized to form generalizations and ultimately a theory as an end point. This theory can later be used to inform best practices for supporting oncology caregivers for advanced cancer patients.

Expected Impact and Significance of Study

The knowledge acquired from this study provides information to the medical community serving oncology patients, including oncology social workers, nurses, radiation therapists, medical oncologists, chaplains, providers offering complementary and alternative approaches, home health and hospice agencies, among others. Results provide additional understanding of the positive aspects of nonpaid caregiving for advanced cancer patients. Results provide further information about ideas to support the needs of advanced cancer caregivers living in rural areas of Indiana and the Midwest. Results of this study may be used to inform more effective interventions to this population, which also will improve care received by advanced cancer patients from their nonpaid caregivers.

Summary

While prior studies have addressed many areas of psychosocial needs for oncology patients, their family members, and their caregivers, gaps remain in understanding the best ways to serve this complex group. Caregivers for the advanced cancer population have been determined to have physical, emotional, social, and spiritual needs, yet current interventions are not effective to address their burden and alleviate these challenges. Using a focus on oncology caregivers of advanced cancer patients addressed a population that is often vulnerable to the extent of both the disease and the weight of caregiving burden. Additionally, residing in a rural community can further complicate circumstances, as these individuals are more isolated, lack resources, and have less access to qualified health care providers. Rural communities are also much more likely than urban communities to be medically underserved.

Research has become more expansive to focus on the challenges of the caregiving experience. Literature has begun to explore the positive aspects of caregiving and the meaning and value one can gain from the experience. Improving understanding of these dynamics may allow a more effective focus of support services that can be implemented for caregivers. This research can be useful in designing evidence-based supportive services for these caregivers, may empower caregiver abilities to provide the best quality care to those patients they serve, and may contribute to improvement in patient outcomes.

CHAPTER 2

LITERATURE REVIEW

Introduction

The literature review for this study will focus on the incidence of advanced cancer and its impact on rural communities, the role of the cancer caregiver and its impact on health, support services for the caregiving population, and exploration of grounded theory and its use in this population.

Purpose of the Study

The purpose of the study was to examine the experiences of family caregivers of advanced cancer patients in rural communities. In this study, caregivers were relatives, friends, or loved ones who provide unpaid help to an advanced cancer patient. Caregiving assistance addressed finances, household management, physical care, or accessing health care. The research used a grounded theory approach to examine the caregiving experience, explore stressors, and inquire upon benefits of the caregiving experience. Grounded theory works to create a theory developed from data collection based in participant experience (Creswell & Creswell, 2018). The study focused on rural communities, knowing that these areas tend to be limited in resources.

Research Questions:

1. What does the process of caregiving encompass for those who provide unpaid care for loved ones with advanced cancer?
2. How do these unpaid caregivers manage stressors and challenges within their role?

3. Does the process of advanced cancer caregiving lead to an experience of growth and meaning for the unpaid caregiver? If so, in what way?
4. How does advanced cancer caregiving affect each of the domains of quality of life (physical, psychological, social, and spiritual)?
5. What is the impact of living in a rural community when caregiving for an advanced cancer patient?

Advanced Cancer

The field of oncology is constantly changing, which impacts those who live with and those who care for others living with the disease. Advanced cancer is described as “those with distant metastases, late-stage disease, cancer that is life limiting, and/or with prognosis of six to 24 months” (Ferrell et al., 2017, p. 9). Receiving an advanced cancer diagnosis is a perplexing life event, both for patients and their family members and caregivers (Ellis, 2017).

Advanced cancer patients have more prominent needs among those who are diagnosed with this disease. Because they are not considered curable, aspects of treatment to these patients and families include end of life planning, family support, and preparation for the intensification of the care needs as patients physically decline with time (NCI, 2014). Advanced cancer patients do have opportunities to pursue various means of support and preparation once treatment is no longer an option for them. There may even be options for a new treatment or clinical trial that could be feasible. Once treatment is no longer an option, advanced cancer patients may choose to enroll in hospice services to transition care to home, which can support quality of life and access to loved ones in the final days and weeks of life (NCI, 2014). Palliative care (including palliative radiation and chemotherapy) is also an option, however this can be offered much earlier in a cancer diagnosis and treatment. Palliative care should be accessed by patients earlier in the cancer experience versus when cancer is in advanced stages.

Patients affected by advanced cancer often have increased needs for emotional support from family, loved ones, and/or professionals to prepare for end-of-life decisions. This becomes a period when patients may be facing mortality but feel they lack the internal strength to be able to do so. Within home care and hospice settings, a medical team is involved in supporting the patient, family, and caregivers as the patient advances toward the end of life. These professionals can be an effective resource in providing information for end of life planning, including funeral arrangements, living wills, power of attorney, and choices about resuscitation. This can occur alongside of the medical care provided to monitor and support the patient’s overall medical functioning while at home.

Advanced Cancer Caregivers

The importance of recognition of caregiving as a public health concern is expanding, “given the burdens of the healthcare system, the chronically ill,” and the aging population within the United States (Grant et al., 2013, p. 339). In 2009, the annual economic value of informal, unpaid caregiving was estimated to be more than $450 billion; this figure is increased from a figure in 2007 of $375 billion (Feinberg et al., 2011). Feinberg et al. (2011) notes that in 2009, approximately “42.1 million family caregivers in the United States provided care for an adult with limitations in daily activities at any given point in time, and about 61.6 million provided care at some point during the year” (p. 1).

As the American population ages, the profile of the average family caregiver is also changing (National Alliance for Caregiving and AARP, 2015). The typical American family caregiver is a 49 year old woman providing care for a relative; however, caregivers are becoming more diverse with time (National Alliance for Caregiving & AARP, 2015). Historically, female caregivers have been more commonly involved than male. The National Alliance for Caregiving reports that in 2015, three in five caregivers were female; two in five were male. The vast majority of nonpaid caregivers provide care to a family member; the National Alliance for Caregiving and AARP (2015) report this percentage to be near 85%, with half of those providing care for a parent or parent-in-law. Leow and Chan (2017) note that due to increasing dual-income households and women managing full-time employment, men are becoming more involved in caregiving than in the past. Ockerby, Livingston, O'Connell, and Gaskin (2016) found that men typically receive caregiving from their spouse or partner, while women are most likely to receive care from family and friends outside of their home. de Moor et al. (2017) note that caregiver demand is expected to increase; as oral and outpatient-delivered chemotherapy regimens are more commonly used, the roles of in-home care will expand. This will increase demand in both the number of caregivers and the function of their role, as populations are living longer and are managing chronic medical conditions over lengthier periods of time.

The literature has addressed caregiving roles and needs for some time, with primary focus on caregiving within specific types of cancer diagnosis, different stages of the illness, or to caregivers who are offering palliative care. Because diagnoses of cancer can vary immensely, the current study captured caregiving needs more specifically versus broadly to those caring for patients living with advanced cancer. As a result, this study will focus on caregiving experience of family caregivers of advanced cancer patients without specific cancer site or stage as a factor

Expanded Role of Caregivers

Decreased length of stay in hospitals, increased use of medical technology in the home, and limitations in hospital discharge planning have exacerbated the caregiving role at home;

family caregivers are more regularly involved in completing complicated medical procedures in the home setting (Feinberg et al., 2011). Additionally, length of time in the caregiving role is extending. This results from advances in cancer treatments that have also lengthened timelines of survivorship (Ferrell, Hanson, & Grant, 2013). The National Alliance for Caregiving collaborated with the AARP Public Policy Institute to compile a report on caregiving in the United States during the year 2015. In this period, seven percent of caregivers in the United States cared for an adult living with some type of cancer (AARP Public Policy Institute & National Alliance for Caregiving, 2015).

Caregiving for the oncology patient encompasses numerous roles and demands upon the loved ones providing care. Those in an unpaid caregiving role risk stress, physical demands, and economic hardship, promoting vulnerabilities (Feinberg et al., 2011).There can be high incidence of caregivers living in poverty who have minimal access to financial and concrete resources (which meet basic needs such as food, clothing, and shelter) despite the demand for these within the caregiving role (van Ryn et al., 2011). Caregiving tasks may include transportation, home supports, such as cleaning and meal preparation, laundry, support of the patient’s finances, and physical health care (de Moor et al., 2017). Physical aspects of care can even mimic those a nurse or nurse’s aide may complete, including bathing, toileting, medication organization and delivery, and special care based on any complication from treatment or other medical issues (de Moor et al., 2017). Special care could include specific medication regimens, home infusions, massage, relaxation, or anything directly related to that patient’s treatment regimen or management of side effects. Family caregivers work “valiantly amidst difficult circumstances of inadequate knowledge, inadequate support, and competing priorities” (Robinson, Pesut, and Bottorff, 2012, p. 480). While caregiving can lead to a strengthened relationship with the patient, it can also create tension with other family members; this results when family members choose not to become involved in caregiving, when there are disagreements with the care provided, or when family members have different expectations of caregiving (Ng, Griva, Lim, Tan, & Mahendran, 2016).

Previous research has demonstrated that family caregivers believe “they could provide the best kind of care for someone they loved who was dying” (Robinson et al., 2012, p. 474). They are compelled to fulfill this role as the person best suited for it regardless of the burden involved. In their qualitative study of caregiving for advanced cancer patients in Singapore, Leow & Chan (2017) state that “when (caregivers) saw the patient suffer, they perceived themselves as having not done enough to care for the patient,” generating need for caregivers to be educated at the reality of physical decline in patients with disease progression (p. 28). In studies of palliative caregiving, family caregivers were even motivated to engage in the caregiving role by the short length of time the loved one had to live and the implication of this brevity within the relationship (Robinson et al., 2012). It is recognized that cultural practices may differ between Singapore and the United States; these differences could impact the perception and experience of caregiving.

Caregiver Challenges and Needs

Caregiving needs are noted to change over time based on the type and trajectory of the disease. There are critical periods within caregiving when patients and families may have increased needs. Family caregivers “face multiple challenges throughout the illness trajectory, evolving over time from the initial diagnosis of a life-threatening illness, throughout treatment, to living with the potential for disease progression and end-of-life care” (Fujinami et al., p. 210). Demiralp et al. (2010) found that at the time of diagnosis of malignant musculoskeletal tumor, caregivers experienced feelings of “fear, despair, a huge shock, and hopelessness” (p. 89). In this time, caregivers experienced an acute stress reaction; this may be a period early on in the disease trajectory when caregiver needs are great and they could benefit from targeted support to address their feelings and stressors surrounding the initial cancer diagnosis and quick movement into the role of a caregiver (Demiralp et al., 2010).

Dougherty (2010) completed a study of patients and family caregivers during an inpatient stay for oncology treatment. Her research notes that when patients and families are admitted to the hospital related to diagnosis or treatment of cancer, they often experience uncertainty and fears related to prognosis, which contributes to patients and family experience of a significant demand (Dougherty, 2010). Sherwood et al. (2011) completed a qualitative study of family caregivers of patients living with a primary malignant brain tumor. Themes discovered in the results indicate that caregivers needs change over time as the patient’s physical function declines. They also found that the need exists for families to address end of life issues. Furthermore, the research highlighted the burden of caregiving. Caregiving was found to limit the available free time of the caregiver extensively which prevented the ability to access supportive resources (Sherwood et al., 2011).

Emotional needs of patients and caregivers intensify as advanced cancer progresses and patients approach the end of the life. Caregivers might feel guilty about their own good health status while their loved one is weakening and approaches death (Fujinami et al., 2012). As death approaches, the burden of caregiving increases as advanced cancer patients require additional care in this phase of transition (Lee, Yiin, & Chao, 2016).

Barriers to Receiving Support

The literature identifies that several barriers exist which limit caregiver access to supportive services. These supports can fulfill a variety of needs, including caregiver self-care, emotional/physical/psychological health needs, and even education regarding care needs for the patient and how to fulfill them (i.e. medical training). Primary barriers to receipt of support services include misunderstanding or lacking attention to caregivers by medical providers, specific focus of caregivers on patient needs versus their own, burden of the disease that causes hesitation of the caregiver to separate from the patient, and communication limitations between the patient and caregiver.

In the history of oncology care, patients have been the primary focus of treatment by the oncology medical team. As time progresses and home care becomes more actively used and needed, caregivers are being more recognized as targets for support and information. Recognizing, anticipating, understanding, and implementing solutions to address caregiving challenges are a critical component to adequately caring for the patient (Fujinami et al., 2012). Robinson et al. found that when addressing caregiver self-care of palliative care patients, caregivers often avoided discussion of their own personal needs, noting that care to their dying loved one was of greater importance; family caregivers "were aware of the importance of self-care but dismissed it as a reasonable possibility" (2012, p. 475). The literature notes that this becomes further complicated when caregivers are simultaneously attempting to manage their own chronic illness while caregiving.

Caregivers can be hesitant to take time from their loved one when they are ill. "Some individuals bear the entire burden of this responsibility alone and do not leave the patient for even a short time"; this can vary based on familial, cultural, and religious beliefs (Hashemi-

Ghasemabadi, Taleghani, Yousefy, Kohan, 2016, p. 1272). In their research about accuracy of caregiver reporting of needs, Libert, Merckaert, Slachmuylder, and Razavi (2013) found that patients and caregivers may be reluctant to discuss problems and challenges due to perceived disruption it may cause in the relationship. There is delicacy in this relationship that may include effort to prevent further stress initiated not only from the patient toward the caregiver, but also vice versa. Interventions should encourage patients and caregivers to engage in open dialogue about emotions, experiences, thoughts, and concerns instead of avoiding distressing emotions (Milbury, Badr, & Carmack, 2012). These communication dynamics may even prevent the family from receiving supportive intervention as the patient and caregiver hesitate to openly discuss negative topics in order to protect one another and themselves (Ammari, Hendriksen, & Rydahl-Hansen, 2015).

Caregivers are hesitant to engage in support through traditional mental health services. Mosher, Bakas, and Champion (2013) found that the majority of caregivers experiencing distress will not seek emotional support or assistance through formal mental health services. Mosher, Given, and Ostroff (2015) more specifically found that oncology caregivers will only use mental health services as a last resort, citing that both cost and caregiver desire to manage these issues independently are contributing factors. Mosher et al. (2015) even found a negative perception of mental health services by this group of lung cancer caregivers. This encouraged these caregivers to access mental health services only of their emotional needs became too great to manage or if they had severe psychiatric symptoms (i.e. suicidal ideation) (Mosher et al., 2015). These caregivers indicated that accessing professional support was a sign of weakness that would lead to a negative perception by others (Mosher et al., 2015).

Adjustment to the Caregiver Role

The caregiving role has become more complex resulting from improved survival rates of disabling chronic conditions (Abendroth, Lutz, & Young, 2012). Relative caregivers require support to manage the role of caregiving but are often hesitant to seek assistance and help (Ammari et al., 2015). Families can find it difficult to discuss feelings and emotions, especially in the tenuous and fragile period of management of chronic illness, furthermore when the illness is life-threatening (Ammari et al., 2015).

Many caregivers operate with too little social support, yet do not engage in offerings of support groups or other supportive services (van Ryn et al., 2011). Caregivers are more likely to utilize family and friends as a source of support versus accessing this within a professional arena (Grant et al., 2013). Caregivers may locate a family or friend with a healthcare background to fill in gaps of training by medical providers; in this role, these supports can help direct the caregiver to resources, assist with problem solving, and help to anticipate needs as the caregiving burden increases (Robinson et al., 2012). A study by Mosher et al. (2013) found that a number of caregivers for patients with lung cancer were receptive to utilizing professional help with psychosocial and practical needs but did not follow through in doing so. Grant et al. (2013) found that caregiver use of formal services (spiritual care, support group, social work) occurred at an incidence of below 25% despite that the need is greater.

Upon the time of cancer diagnosis, a complex process of adjustment of the caregiver to the caregiving role can result in both positive and negative outcomes (Mosher, Bakas, & Champion, 2013). Caregiver priorities may include employment and care for their own children or other family members; they must shift these priorities immediately to accommodate the time required for caregiving of the patient as well. In a mixed method study regarding palliative caregiving burden in rural settings in British Columbia, caregivers were found to have had little opportunity to discuss the transition to the caregiving role with the patient or any support system; there was little time for adjustment to the quick change into these roles and responsibilities once the patient became ill and the demand for intense care arose (Robinson, et al., 2012). Furthermore, the qualitative interviews in this study found little evidence of discussion between patient, caregiving, and someone from the medical team regarding the changing role of caregiving (Robinson et al., 2012). Of note is that the role of the caregiver, responsibilities included within this role, and that patient and caregiving needs will increase with time; this left gaps in knowledge and understanding of the caregiving process (Robinson et al., 2012).

Impact of Caregiving on Health

Caregivers often experience unmet needs as they fulfill the caregiving role, which can impact their own emotional and physical wellness. “Caregiver burden is influenced by characteristics of the patient, caregivers, and the care environment” (Grant et al., 2013, p. 338). Caregivers are affected physically due to demands of the caregiving role, emotionally and mentally as the role is stressful and they are often juggling other responsibilities, and caregivers often tend to neglect their own self-care; these factors can combine to contribute to poor caregiver quality of life (Grant et al., 2013).

Fatigue becomes a regular experience within the caregiving role. Caregivers often feel pressured to complete tasks versus just spending time with a loved one, which drives the feeling for them that the work is never done and there is always more that can be done (Robinson et al., 2012). Rural palliative caregivers noted regret that caregiving tasks could easily get in the way of just being with their family member at the crucial moment at the end of life. As the illness worsens, caregiving burden increases and can exacerbate fatigue, which also limits time available for caregivers to engage with a support system, putting them at risk for isolation (Fujinami et al., 2012).

Caregivers have potential to live with their own chronic health issues while providing care to their loved one. Kim, Carver, Shaffer, Gansler, and Cannady (2015) studied the relationship between the perceived stress related to cancer caregiving and caregiver chronic health conditions (specifically arthritis, chronic back pain, and heart disease). Kim et al. (2015) discovered it was “the caregivers’ subjective appraisal of their caregiving role as overwhelming, rather than the care recipient’s objective disease severity, that was associated with impairments to caregiver health and wellness (p. 308). This indicates a relationship between perceived stress of caregiving and caregiver resistance to addressing their own physical health needs, which should both be monitored and supported within supportive services. Caregiver physical health needs also were more inclined to worsen as they provided care in preparation for a patient’s death (Kim et al., 2015). Recommendations from this study also included health care providers reminding caregivers to maintain contact with their own medical professionals while serving the patient in the home.

Specific relationship between early caregiving stresses demonstrated a link to chronic heart disease, which echoes previous understanding of the relationship between stress and cardiac issues (Kim et al., 2015). An overall summation of this study from Kim et al. (2015) is that “feeling overwhelmed by the caregiver role, yet feeling guilty when engaging in activities for self-care, are both likely to lead caregivers to disengage from healthy lifestyle behaviors” (p. 308). It is also important to provide continuous education and support to caregivers to manage the physical strain of the role; healthcare providers can assist family caregivers in accessing different solutions to manage the physical environment, distribute the caregiving workload with other family supports, and to access available community resources as needed to manage the caregiving load (Kim et al., 2015).

Social support for caregivers is of importance, as distress in one partner is found to intensify distress in the other *(*Fujinami et al., 2015). Anxiety demonstrated by patients is a contributory factor that influences overall functioning, health care service needs and use, and both interpersonal and emotional needs of both patients and their caregivers (Chen et al., 2016). Mental health of caregivers can be negatively impacted by the demands of caregiving, especially in close proximity of the time to the death of the patient (Ostlund et al., 2010). Emotional strength and sustainability can be an expectation of the caregiving role; thus to access formal care may cause others to view the caregiver as unable to cope, promoting stigma related to accessing support that deters use of help (Ostlund et al., 2010).

Anxiety, worries, and fears occur when caregivers do not feel that they have received adequate training to meet the medical needs of their loved one (Robinson et al., 2012). Caregiver elevated anxiety and depression have found to be strongly associated with unmet needs for information related to the medical condition of the patient or the necessary function of the caregiver role (Oberoi et al., 2016). Fear of disease progression can also contribute to emotional needs of caregivers. In their study of caregivers caring for advanced lung cancer patients, Chen et al. (2016) found that caregivers fear disease progression more than patients; they recommended medical providers provide more information regarding disease progression to alleviate these concerns and provide more accurate and responsive care as needs become more complex with time.

Additionally, caregivers of patients with advanced cancer are susceptible to intense phases of grief (Duggleby et al., 2014). Hashemi-Ghasemabadi et al. (2016) indicate that even the transition into the caregiving role is accompanied by intense loss. At the time of diagnosis, these losses can include “self-sacrifice, loss of normal life, loss of former identity in the relationship with the patient, and loss of positive emotions and health” (Hashemi-Ghasemabadi et al., 2016, p.1272). Caregivers even lose their identity and sense of self when they step away from previous roles and responsibilities to accommodate the requirements of caregiving (Hashemi-Ghasemabadi et al., 2016). Caregiver losses can build related to the loss of time with the dying loved one, loss of interpersonal relationships and connections, and loss of health functioning; these combined losses can lead to a sense of being overwhelmed and intense grieving (Duggleby et al., 2014).

When caregivers are providing care for a spouse or other intimate partner, the caregiving role and present physical health concerns can impact intimacy and sexuality within that relationship. Partners are challenged to maintain a typical level of intimacy when engaged in the daily medical interventions that can be required in the caregiving role. There also can be concerns regarding causing pain or discomfort that may be caused as a result of sexual activity (Fujinami et al., 2012).

Importance of Self-Care

Components of caregiver self-care can include a variety of areas; basic health maintenance, obtaining regular medical care, exercise, good nutritional habits, and having access to social support are important areas of self-care for caregivers to consider (Grant et al., 2013). Fujinami et al. (2012) tie caregiver self-care to quality of life; “the demands of the family caregiver role, as well as bearing witness to the patient’s suffering, impact the caregiver’s quality of life and ability to function” (p. 210). Dionne-Odom et al. (2017) completed the first research study that addressed the habits and practices tying to self-care of family caregivers caring for patients with advanced cancers with poor prognosis. In this research, it was determined that caregivers who demonstrated lower scores in every self-care practice (such as basic health maintenance, obtaining regular medical care, exercise, good nutritional habits, having access to social support) demonstrated worse caregiver well-being related to anxiety, depression, and overall mental health (Dionne-Odom et al., 2017). The study also found worse performance in caregiving practices and activities when caregivers did not engage in self-care practices related to “health responsibility, spiritual growth, interpersonal relation, and stress management” (Dionne-Odom et al., 2017, p. 5). In a meta-analysis of interventions for family caregivers of advanced cancer patients, Northouse, Katapodi, Song, Zhang, & Mood (2010) determined that support services for caregivers did not primarily address self-care needs, but instead focused psychoeducational needs and skills training. There is an indicated need and benefit for interventions to directly address self-care.

Meaning-Based Coping

Much of the literature on caregiving for oncology patients focuses on the negative impact of this extensive responsibility by addressing the stressors and hardships involved. Expanding available literature addresses the perspective of oncology caregiving to also include the positive aspects of fulfillment of this role. Li and Loke (2013) counterbalanced the vast majority of prior studies that explore the negative aspects of caregiving, but instead focused on the positive aspects and benefits. The “lack of acknowledgment of the positive aspects of caregiving seriously skews perceptions of the caregiving experience and limits the ability to acquire a full understanding of caregiving” (Li and Loke, 2013, p. 2399). Their research notes that the positive aspects of caregiving involve the extent to which caregiving enhances and becomes enriching to an individual. They include and explain concepts of post-traumatic growth, benefit finding, optimism, positive effects, hope, and meaning in life, which they note contributes toward a perspective of meaning-based coping (Li and Loke, 2013). Spirituality and religious beliefs may facilitate success and progress toward coping and finding meaning.

Emphasizing the negative aspects of caregiving can limit understanding of the mechanism to support caregivers (Li & Loke, 2013). Personal growth can occur as a result of fulfilling this role on behalf of a loved one, especially in a time of dire need. Positive impacts of caregiving experienced by caregivers can be “an enhanced relationship with the care-receiver, the feeling of being rewarded, a sense of personal growth, and a perception of personal satisfaction” (Li & Loke, 2013, p. 2399). It was found that looking for meaning in the experience could foster a deeper relationship between the patient and caregiver and could assist in more effective coping with the stressors, a process that can be referred to as meaning-based coping. Additionally, Leow and Chan (2017) learned in their qualitative study of 19 caregivers that they not only felt a deepened connection with the patient, but also with other family members as well. Li and Loke (2013) describe caregiver benefits related to accomplishment such as such as “feeling rewarded, discovering personal growth, perceiving personal satisfaction, feeling needed, and receiving respect and appreciation from their care-receivers” (p. 2402). It is recognized that because this study occurred in Singapore, cultural differences are likely present that may impact the related experience in the United States.

Robinson et al. (2012) found that rural palliative caregivers engaged in their own internal resources to cope with caregiving challenges despite the limited resources and mismatch between needed medical services and what was actually received. Caregivers in rural communities need specific services, but based on lacking available to resources and options, the services needed were not those received. These researchers found that family caregivers “drew heavily on their own inner strength, resolve, and common sense, and were proud of their accomplishments" (p. 482). When asked, these caregivers voiced that they would do it again. They were found to use acceptance despite the difficult and complicated circumstances of their role (Robinson et al., 2012).

Demiralp et al. (2010) identified a theme in their qualitative research of family caregivers caring for loved ones with malignant musculoskeletal tumors. This theme focused on the benefit of thinking positively and finding meaning through caregiving. It was summarized with the caregiver impression that "positive thinking made caregiving easier and generally gave them renewed hope" (Demiralp et al., 2010, p. 89). Spirituality and its impact was a contributing factor, but these caregivers also noted that family relationships were strengthened as a result of the experience and the caregiving role. Therefore, having a focus on the positive aspects of caregiving may help support and build family relationships versus causing more strain within them. Additionally, the impact of social supports was critical to provide support and encouragement, which in turn led to improved emotional strength to fulfill the caregiving role. Visits from a support system "were pleasant and lifted their spirits" (Demiralp et al., 2010, p. 89). The majority of available literature focuses on the burden and stressors of caregiving. Few studies do exist that tailor responses to growth and development that occur out of the caregiving experiences, but not specific to rural advanced cancer caregivers. This further warrants the need for this study.

Available Support Services and Interventions

Limited research has addressed use of specific interventions to address caregiving needs. Interventions should be tailored to the specific level of caregiver burden, resources, and demands to be most effective in addressing these needs. Interventions for family caregivers of advanced cancer patients have impact on their appraisal of illness, ability to cope with the caregiving role, and overall quality of life (Northouse et al., 2010*).* Structured psychoeducational support that incorporates information and tools toward emotional wellness assists in mitigating the stress experienced when caregivers experience the death of their loved ones (Hudson et al., 2015). Holm et al. (2016) researched effectiveness of a short-term psychoeducational intervention with palliative family caregivers; their results indicated significant improvement in preparedness for caregiving as well as improvement in competence.

Health care professionals should be more directly involved in thorough assessment and offering of care programs specific to identified need. Based on the assessment of patients and their family caregivers, early intervention to address identified caregiver needs "in areas of greatest vulnerability" is needed to support and expand caregiver of life (Fujinami et al., 2012, p. 215). These needs could be financial, physical, emotional/psychological, and could be exacerbated due to the onset and impact of their loved one's illness or they may be preexisting. Specific interventions should target the complex emotional experience of caregiving (Ostlund et al., 2010). Because the caregiving experience affects patients and caregivers across all dimensions of life experience, "an interdisciplinary, team-based approach to providing biopsychosocial spiritual care is critical" to their support (Fujinami et al., 2012, p. 212). Their recommendations for interdisciplinary team members include oncology nurses, physicians, spiritual care providers, and social workers.

Preparedness for caregiving can modulate the distress experienced when caregivers quickly move into this complex role; this becomes a critical time for support, education, and resources to promote caregivers feeling ready for the challenge (Fujinami et al., 2015). Literature suggests that the perceived skill level and ability of caregivers are associated with higher caregiver burden, as the medical community tends to assume that caregivers are prepared for the role when in actuality, they are not (Grant et al., 2013). Rural caregivers have described the tedious medical responsibilities included in the caregiving role. These can include specific feeding regimens, medication management, pain control, and management of increasing needs at the end of life (Robinson et al., 2012). They experience discomfort in being forced to complete these more medically-driven components of caregiving and despite this feeling, often eventually giving in to do so due to having no other option for this care. Adding further complication is the fact that needs of the patient will change over the course of the disease, meaning that caregivers will need to acquire new skills to address physical care as the patient's physical status changes and later declines with time (Grant et al., 2013). This indicates the need for continued education, training, and support throughout the disease and when it progresses.

Belgacem et al. (2013) completed a clinical trial of an educational program in France that was offered in an inpatient oncology setting. This was a face-to-face program that included medical staff offering education to family caregivers for application in both the inpatient and home settings. The intervention included information regarding skills in feeding, nursing and physical care, massage for comfort and pain management, and symptom management. This educational program improved caregiver quality of life and alleviated caregiver burden (Belgacem et al., 2013). It highlighted the impact of a "triangular relationship" including the patient, family caregiver, and medical professionals (Belgacem et al., 2013, p. 876). It also highlighted a need to better train medical professionals in the content and context of teaching to improve their comfort level and confidence in this role, which will improve effectiveness in their education of caregivers.

Patient and caregiver partnerships can be affected by lack of communication regarding needs; the patient does not want to burden the caregiver and vice versa (Ammari et al., 2015). Fujinami et al. (2012) note that lacking openness and honesty in communication about needs and concerns can impair the relationship creating distance, isolation, and loneliness to both parties. Additionally, “conversations regarding advanced disease and end-of-life decisions are essential to provide quality care and facilitate sound choices at the end of life” (Goldsmith, Wittenberg, Platt, Iannarino, & Reno, 2016, p. 469). Patient and caregivers who engage in minimal communication about the disease do not have the opportunity to address plans, identify goals for treatment, and develop a shared vision to improve quality of life for both partners (Goldsmith et al., 2016). Intervention by medical professionals can allow an opportunity to solicit communication from all parties involved to encourage openness in emotional expression of needs and stressors (Fujinami et al., 2012). These discussions can then move toward cooperative planning of goals for care and addressing any needs identified by the patient, caregiver and family.

Support groups can become an element of effective intervention and support for caregivers. Caregivers can benefit from the shared knowledge and experience of other caregivers who have currently or have previously been in similar circumstances; the caregiving experience is also normalized (Fujinami et al., 2012). Tehrani, Farajzadegan, Rajabi, and Zamani (2011) studied support group participation within breast cancer patients. Tehrani et al. (2011) included use of social comparison theory, acknowledging that “by expressing personal experiences to people who have gone through the same experiences and making new opportunities to help similar people would normalize patient's experience …, reinforce (augment) health-promoting behaviors, and enhance self-confidence” in participants (2011, p. 659). Their experiment yielded primarily positive results of a six week psychoeducational and social intervention that affected quality of life, mental health, and even pain management (Tehrani et al., 2011). Support groups can provide many benefits to patients and caregivers affected by advanced cancer, but not all who may benefit are comfortable with engagement in type of setting. It requires that participants, should they choose to disclose in a group setting, demonstrate some vulnerability in sharing stories and struggles.

Family caregivers are found to benefit from the break that respite care can offer to allow some time to focus on their own personal needs or tasks that may not be fulfilled during caregiving. Respite care involved the patient staying away from the caregiver for a brief period of time (typically 5 days or fewer) in a skilled nursing facility to give the family caregiver some time off of care. Respite can allow family caregivers to have time to tend to their own personal and self-care needs and offer the space and time to do so (Fujinami et al., 2015). However, respite care can be viewed in different ways; some caregivers may approach a break of a few hours while others may pursue a few days in a skilled nursing facility. Robinson et al. (2012) found that rural palliative caregivers would appreciate a break of a couple to a few hours, but medical caregivers often assumed the need was greater and would push the need for institutionalization, creating a rift between the caregiver and provider that promotes further strain, isolation, and distress. From their study and literature review, respite care was more socially acceptable in urban versus rural settings. Chen et al. (2016) found in a study of advanced lung cancer patients that “caregivers have limited access to information on how to access respite care service to help them manage their caregiver strain” (p. 3006).

In their study of the impact of aging baby boomers on the caregiving workforce, Eifert et al. (2016) note that access to and use of technology will impact the engagement of caregivers.

The current baby boomers will have the advantage of increased knowledge and comfort level toward and access to technology versus any prior generations (Eifert et al., 2016). Family caregivers report that technology saves time, brings greater logistical ease, alleviates physical demands, and decreases depression and stress (Eifert et al., 2016). Technology can affect the caregiver role in many ways, including increased access to supports through online support groups and social media, providing apps that can organize medical care, and accessing telemedicine to facilitate access to more specialized practitioners in smaller areas.

Self-efficacy, or the caregiver's perception of ability and skill to complete the caregiving role, has shown to play an impact on overall wellness and success in caregiving. Lee et al. (2016) offered a caregiver intervention to advanced cancer caregivers within the last three months of the patient's life; theirs was the first of its kind to focus specifically in this period of time. This intervention provided a hospital-based educational and supportive program that addressed coping, caregiver assistance, resources, and education related to patient needs. A specific component of this intervention was access to support, communication, and negotiation during periods of difficult decision-making, such as advanced care planning, hospice care, and choosing/accessing the desired location for the patient's death (Lee et al., 2016). In their study, they found that caregiver self-efficacy minimized appraisal of the stressor and experience of burden (Lee et al., 2016). Caregiver interventions that address educational needs and problem-solving skills have demonstrated improvement in caregiver objective and subjective self-efficacy (Lee et al., 2016). The intervention provided was successful in significantly decreasing caregiver burden at the fragile stage of the final three months of the life of the patient (Lee et al., 2016). It also was significant to note that having access to a medical team 24 hours a day was effective in allowing caregivers to feel supported.

Recommended Interventions

Effective interventions will support the caregiving role of the caregiver to spend more time with the patient, or to support the concrete needs of the patient or caregiver to strengthen the caregiving role. Robinson et al. notes that caregivers “desired interventions that supported their direct caregiving and that gave them time to ‘be’ with their loved ones” (2012, p. 485). Mosher, Bakas, and Champion (2013) recommend interventions to focus on the relational benefits of caregiving so that the relationships between the caregiver, the patient, and their support system are enhanced within the process. Dionne-Odom et al. (2017) addressed caregiver self-care practices and corresponding mental health functioning and performance within caregiving practices. Recommendations based on their results indicate the need for programs that support caregiver interpersonal connections and support with spiritual growth while simultaneously addressing education, training, and support to fulfill the caregiving role.

Lee et al. (2016) delivered the first research-based caregiver intervention to advanced cancer caregivers within the last three months of the patient’s life (2016). The focus was on the interplay of caregiver self-efficacy and problem-solving, education, and communication needs (Lee et al., 2016). A specific component of this individualized, face-to-face intervention was access to support, communication, and negotiation during periods of difficult decision-making, such as advanced care planning, hospice care, and the desired location for the patient’s death (Lee et al., 2016). Caregivers had access to 24-hour support via telephone, assessment of and referrals to address physical/emotional health needs, referral to resources, and concrete skills regarding to patient care and needed information (Lee et al., 2016). Lee et al. (2016) incorporated ongoing assessment throughout the intervention which led to responsive adjustments to better serve patients and caregivers based on emergent needs. The intervention provided was successful in significantly decreasing caregiver burden at the fragile stage of the final three months of the life of the patient (Lee et al., 2016). Targeted intervention, responsiveness of health care providers, and access to professional support proved effective to management of the complex needs of patients and families during this critical period.

The Veterans Administration has compiled a caregiver support arena of services to address family caregivers who are providing care for Veterans at home (United States Department of Veterans Affairs, 2017). These supports are available to caregivers for any type of disease. Comprehensive services are available within the clinic setting and in the home. Programs include options to access a caregiver support line, peer support and mentoring (caregiver to caregiver), access to a caregiver support coordinator, home care, telehealth services at home, and respite care (U.S. Department of Veterans Affairs, 2017). Comprehensive service availability may offer caregivers several options to seek services that are most suited to address needs, interest, and comfort level.

Rural Heath and Caregiving Needs

The needs of family caregivers to advanced cancer patients are poorly understood, and even more so with rural caregivers (Robinson et al., 2012). Within their mixed methods study, they found that family caregivers had knowledge and awareness of the need for them to care for themselves while caring for their family member, but felt that there was no possibility to do so (Robinson et al., 2012). Rural caregivers may more heavily rely on family members or friends with healthcare backgrounds to assist with navigation of caregiving needs, especially as medical communities are often a further distance from the patient and caregiver home (Robinson et al., 2012). Because a continuum of several different types of health care and support services are not available in rural communities, these caregivers are more likely to rely on their own informal support networks. At the balance of this, rural palliative care patients and families in rural settings also seek independence as their care needs intensify; this may prevent them from seeking help outside of the context of those immediately and imminently involved (Duggleby et al., 2011). Duggleby et al. (2011) note that participants in their research "experienced a tension between wanting to be independent and, yet becoming more dependent" (p. 8).

When patients, caregivers, and families do not have additional supports, a risk of living in rural communities is isolation. Isolation is characterized by limitations in resources and in contact with others; resource limitations can include access to health care (Duggleby et al., 2011). Isolation can be further exacerbated as patients and families in rural communities approach end of life (Duggleby et al., 2011). In their qualitative study interviewing advanced cancer patients receiving palliative care, bereaved family caregivers, and healthcare professionals in rural Canada, Duggleby et al. (2011) identified themes of "community connectedness/isolation, lack of accessibility to care, communication/information issues, and independence/dependence" (p. 5). The study notes that patients, family caregivers, and healthcare professionals report feeling isolated in social, physical, geographical contexts where there was limited access to resources due to the distance involved (Duggleby et al., 2011). "Family caregivers felt completely alone in providing the physical care needed as the palliative patient's illness progressed" (Duggleby et al., 2011, p. 8).

Residence within a rural community can also increase the burden of travel to larger communities to access healthcare. There appear to be mixed reviews regarding impacts of commuting. Although the cost of commuting is high, Lockie, Bottorff, Robinson, and Pesut (2010) indicate it brings significant benefits to patients affecting quality of life and promoting supportive relationships. Time spent in travel allows the patient and caregiver an opportunity to be together and to engage in communication. In contrast, Robinson et al. (2012) note that the demands of preparing for travel can increase caregiver distress and adverse health outcomes (anxiety, fatigue, negative impacts on eating and sleeping, poor management of own health needs). There can be several areas of consideration with commuting, especially with advanced cancer or palliative patients, which includes crisis management and pain control while traveling long distances for medical care. Lockie et al. (2010) discussed the need for caregivers to assess for patient tolerance of travel, which becomes increasingly difficult as the disease progresses and the patient is increasingly affected by pain, fatigue, and other side effects of either treatment or the disease.

Brazil et al. (2013) acknowledge a “growing concern regarding the adequacy of care that is provided (in rural areas), particularly for patients who are terminally ill living within these regions” (p. 2). Brazil et al. (2013) note that the caregiving burden for rural caregivers suggest their burden is different versus those providing care in an urban setting. Their study found that rural caregivers more often rely on hospital services (such as inpatient stays) while urban caregivers are more likely to use respite care services (such as a brief stay in a skilled nursing facility or adult day care program), which may be due to lacking availability of respite care in more remote areas which lack substantial resources.

Because care can be limited and fragmented in rural settings, patients and families are affected by disruptions in continuity of care (Duggleby et al., 2011). In their qualitative study of palliative care patients, caregivers, and medical providers, Duggleby et al. (2011) found that fragmented care was characterized by further drives to seek medical assistance, changes in medical providers, long waits in emergency rooms, and limitations in the decision of setting for medical care and even death. Further, family caregivers in rural communities have found that when health care professionals and medical services are needed, they cannot always be relied upon (Robinson et al., 2012). Within a context of limited resources, this can be devastating, as there may be nowhere else to turn.

However, Duggleby et al. (2011) also noted that rural palliative patients and families are often closely bonded with healthcare professionals, especially those who live close to their home communities. There is often a sense of interconnectedness and family orientation, as they tend to have a long history and sense of bond around the mutual community of residence; they are considered "as integral parts of their community network" (Duggleby et al., 2011, p. 8).
Living with advanced cancer in rural communities brings a delicate web to balance. Patients and families struggle between having close connections to feeling isolated, especially closer to end of life as care needs intensify. This population would benefit from additional research and understanding of experiences, stressors, and support needs to better inform effective interventions to alleviate burden.

Grounded Theory

Grounded theory is an inductive methodology that can be used in various disciplines (Grounded Theory Institute, 2014). Originally derived by sociologists Glaser and Strauss in the 1960s with the purpose "to construct theory grounded in data" (Corbin & Strauss, 2015, p. 4), grounded theory has become one of the most well-known approaches to qualitative research (Padgett, 2008; Glaser & Strauss, 1967). The original study that developed grounded theory research studied experiences of patients dying from cancer in six hospitals within the San Francisco Bay area (Glaser & Strauss, 1967). In the process of this field study, the researchers completed intensive field work via both observations and interviews. They followed medical providers, engaged in daily routines within the hospital, interviewed patients, and observed interactions of patients, families, and medical staff in order to understand the experience of living with terminal cancer at the end of life. While Glaser and Strauss researched together for many years, Strauss eventually developed his own style of grounded theory and the two came to an eventual variation in approach used (Corbin & Strauss, 2015).

Grounded theory "allows for identification of general concepts, the development of theoretical explanations that reach beyond the known, and offers new insights into a variety of experiences and phenomena" (Corbin & Strauss, 2015, p. 6). The concepts included within the theory develop through the collection of data instead of being chosen prior to the research (Corbin & Strauss, 2015). In grounded theory research, the researcher works towards theory developed tied to the perspective of the participants; the theory can involve process, action, or interaction (Creswell & Creswell, 2018). This process uses multiple stages of data collection; furthermore, data is refined to interrelate and make meaning of categories of information (Creswell & Creswell, 2018; Charmaz, 2006; Corbin & Strauss, 2015). In grounded theory approaches, there is a continuous process of collection and analysis of data throughout the research (Corbin & Strauss, 2015).

Data collection in grounded theory can be gathered by a variety of means, most often by interviews and observations (Corbin & Strauss, 2015). In grounded theory approaches, nearly any type of written, observed, or recorded data can be used as a type of data. This research focused on semi-structured interviews as the primary source of data and interviewed fifteen participants (advanced cancer caregivers). Semi-structured interviews promote some structure during the interview process; interview topics and questions are selected prior to the research based on literature (Corbin & Strauss, 2015). However, during each interview, the interview content can vary based on each participant and their direction of discussion. In the process of semi-structured interviews, each interview topic is covered but participants are also able to contribute additional content that they may deem relevant (Corbin & Strauss, 2015). Within this study, written materials were also utilized as data from the research journal (Corbin & Strauss, 2015) which can also be a means of triangulation (Creswell & Creswell, 2018), both of which are attempts to validate findings in grounded theory research.

Within the process of grounded theory research, the researcher "cycles between data collection and analysis" (Padgett, 2008, p. 32). Senden et al. (2015) describe a "cyclic process of data collection and analysis with a constant forward–backward movement … in order to check findings and adjust sampling based on gained insights" (p. 199). The analysis of data begins with review and open coding with interview transcripts. This process continues with completion of each interview, thus the data set and coding process grows substantially with time (Padgett, 2008). Corbin and Strauss (2015) identify the process as "constant comparisons" whereby data are separated into small, manageable pieces and are compared for similarities and differences (p. 7). Data that is similar are then grouped together under a heading that represents the identified, similar concept (Corbin & Strauss, 2015). As the data continues to be analyzed and builds, concepts are linked together to former a greater unit of data through categories. Categories are developed and organized related to properties and dimensions and are eventually built to surround a core category (Corbin & Strauss, 2015). All of these components eventual combine to develop the structure of the theory.

Qualitative computer software programs, such as NVivo 12, are available to assist in organizing and managing the extensive data received. NVivo 12 will be used within this study. Creswell and Creswell (2018) note that these programs "help researchers organize, sort, and search for information in text or image databases" (p. 192). Computer use can assist with efficiency in storing, organizing, and locating qualitative data; however, the researcher is still obligated to review each line of text and assign codes (Creswell & Creswell, 2018). There are an expanding number of programs available that operate with similar and accessible features.

Literature involving oncology caregiving and advanced cancer patients has previously used qualitative methodology and grounded theory approaches. While there are some studies that have occurred with similar populations, there is difference in the participants, the focus of the context of this study on rural settings, and the overall areas explored within the interview and study. However, despite these differences, there is comparative literature available to guide this grounded theory research.

Senden et al. (2015) completed a qualitative study exploring the lived experiences of older cancer patients and their family caregivers. These patients ranged in age from 70 to 86 years old; the study gauged how the experience of diagnosis and treatment mutually influenced one another. The aim of this study was to understand methods for meaningfully supporting both the older patient and the family caregiver. Semi-structured interviews were given with 32 older patients and 19 family caregivers. The researchers found a mutual interaction and influence within the relationship between the oncology patient and family caregiver (Senden et al., 2015). “The cyclic process of ‘struggling with the truth and searching for hope’ is the overriding theme of older people living with cancer” (Senden et al., 2015, p. 203). The researchers recommend that active listening be an integral component to understanding the experiences of older oncology patients and to offer them support and attention, which also supports the premise of family-centered care (Senden et al., 2015).

Leow and Chan (2017) conducted a qualitative study on family caregivers of advanced cancer patients in Singapore. Their study explored challenges, emotions, coping, and gains experienced during caregiving with a purposive sample of 19 family caregivers recruited from home hospice services; because they were all hospice patients, this sample focused on the stage of end of life caregiving (Leow & Chan, 2017). The researchers used a four-step process of data analysis that involved two members. Upon receipt of interview transcripts, each researcher individually read the completed transcript several times, paying careful attention to the aspects of the transcription that related to the overall research question of the study (Leow & Chan, 2017). Coding for each unit was formed; codes were then interpreted and grouped in to categories specific to similarities or differences present in each (Leow & Chan, 2017). These categories were then eventually built into greater themes. Once the themes were developed, they were compared between both researchers, with the aim to agree on the major themes developed via discussion. Four themes emerged within this study: “caregiving challenges, negative emotions, cope with caregiving, and positive gains of caregiving” (Leow & Chan, 2017, p. 24). It is recognized that because this study occurred in Singapore, cultural differences were likely involved. Should the study be replicated in the United States, there may be differences in results based on the impacts of the cultural experiences.

CHAPTER 3

METHODS

Introduction

The methods section reviews the purpose for the study, research questions, and research design. It describes participant selection, data collection, and data analysis. It closes with details regarding the worldview and theoretical orientation of the study, as well as the process to strengthen the reliability and validity within the research.

Purpose of the Study

The purpose of the study was to examine the experiences of family caregivers of advanced cancer patients in rural communities. In this study, caregivers were relatives, friends, or loved ones who provide unpaid help to an advanced cancer patient. Caregiving assistance addressed finances, household management, physical care, or accessing health care. The research used a grounded theory approach to examine the caregiving experience, explore stressors, and inquire upon benefits of the caregiving experience. Grounded theory works to create a theory developed from data collection based in participant experience (Creswell & Creswell, 2018). The study focused on rural communities, knowing that these areas tend to be limited in resources.

Research Questions:

1. What does the process of caregiving encompass for those who provide unpaid care for loved ones with advanced cancer?
2. How do these unpaid caregivers manage stressors and challenges within their role?

3. Does the process of advanced cancer caregiving lead to an experience of growth and meaning for the unpaid caregiver? If so, in what way?
4. How does advanced cancer caregiving affect each of the domains of quality of life (physical, psychological, social, and spiritual)?
5. What is the impact of living in a rural community when caregiving for an advanced cancer patient?

Participants

The participants for this study were a purposeful sample of fifteen nonpaid family or friend caregivers providing care to advanced cancer patients. Participants were utilized regardless of site of the initial cancer location or stage of disease of the patient at the time of diagnosis. However, all caregivers participating in the study provided nonpaid care to a patient living with advanced cancer. Patients lived in home settings and caregivers provided care there. Caregivers were unpaid family and friends who elected to function in this caregiving capacity. Potential participants were identified through local health care providers in communities served for this research.

Recruitment for the study occurred directly via communication of the researcher with local oncology providers and health care organizations caring for oncology patients. These relationships were established due to clinical experience of the researcher in oncology settings in the same community. Recruitment also included posting of flyers regarding the study that include information about eligibility criteria and contact information of the researcher. These flyers were posted in a local hospice care agency and in a local mental health counseling organization; consent to post flyers was approved by these organizations (see Appendix D).

Recruitment flyers remained posted until the desired number of willing participants was obtained. The targeted number of participants was a minimum of fifteen; interviews continued until saturation of data was reached.

Secondarily, snowball sampling was also used as a method of recruitment in this study. In this method, caregivers who participated in the study could refer other caregivers interested and eligible for study participation. Flyers were available to caregivers participating in the study to disseminate if they knew of any others in similar caregiving roles who may be interested in participation. This allowed the option for caregivers to share with one another the opportunity for participation in this study and to contact the researcher if they were interested.

To begin recruitment of participants, the researcher notified the sites that approved assistance and agreed to post recruitment flyers; they were notified that participant recruitment could actively begin. The providers within these practices were informed of the study and the criteria for participants (unpaid family caregiver of any age or type of advanced cancer patient). Flyers were provided sharing details about the study, participant criteria and eligibility, and contact information for the researcher. These involved practices were asked to provide contact information for any prospective caregiver participant who is willing to discuss the study.

While it was not a requirement of the study, some nonpaid caregivers may have medical experience which supports the caregiving role. Confidentiality and anonymity was used to share as little information as needed (name and contact information only) to ensure that information about potential participants remained confidential and was only shared between the referring provider and the researcher. All information related to the study was kept secure and locked throughout the course of the study. It will remain secure and locked for a minimum of three years, per expectation of the Institutional Review Board (IRB).

Data Collection

Once potential participants were identified, the researcher contacted them via phone to explain the study and determine if he/she would be willing to participate. Potential participants were contacted to determine their interest and willingness to participate in the research study. Within the phone call, the researcher secured the participant's contact information to receive the letter explaining the study (Appendix A) and the informed consent form (Appendix B). Informed consent forms were signed by the participant at the first face-to-face meeting but prior to beginning the interview.

It was the aim of the researcher to complete in-depth semi-structured interviews on a face-to-face basis. Personal interviews completed on a face-to-face basis are considered the most respected method of interviewing (Polit & Beck, 2017). This method, while demanding in terms of the time involved, yields higher quality information and have lowered rates of refusal of participants (Polit & Beck, 2017). All interviews were recorded as indicated in the informed consent form. Interviews were scheduled for up to 75 minutes; it was assumed that they would be 60 minutes in length. All fifteen interviews were completed in a single session. The longest interview capped at 70 minutes.

The interview protocol and questions included (see Appendix C) were used as a pilot prior to beginning participant interviews. This pilot did not include participants that met the specific eligibility criteria for the study. It instead involved four caregivers who have experience providing caregiving for a cancer patient in the past, but caregiving was not currently happening. The pilot interviews allowed for feedback from these pilot testing participants related to the interview questions used. When there were suggestions or revisions made within the pilot process, the interview questions were revised prior to submission of the interview questions to the IRB. In order to develop the interview protocol, literature similar to this study was used to access related qualitative interview protocols used in related research.

Although an interview protocol that poses the exact questions captured within this research was not available, there were similar interview procedures that explore comparable topics but with different populations. This supports the need for this research. Hashemi-Ghasemabadi et al. (2016) completed a qualitative study that posed questions about the experiences of caregivers of advanced breast cancer patients living in Iran. Their interview questions explored the value caregiving has brought the lives of the caregivers, the health effects of caregiving, and the methods by which these caregivers managed their challenges. Additionally, Demiralp et al. (2010) completed a qualitative study exploring the caregiving role for patients with malignant musculoskeletal tumors in Turkey. This study included exploration of the response at the time of diagnosis and the early phases of orienting to the caregiving role. The questions available from the study by Demiralp et al. (2010) were also considered for basis of interview questions in this study. For the purpose of this study, an interview protocol was developed and was used within the initial interview for testing. As is the nature with semi-structured interviews, questions included in the interview protocol could be modified as each interview was completed.

Once the interviews were complete, each interview recording was transcribed into a Microsoft Word document by a transcriptionist service through the Rev Recorder Application. Some of the cost of transcription was paid by the researcher; the rest was paid through a supplemental research grant awarded through the College of Graduate and Professional Studies at Indiana State University. The interviews were each transcribed as quickly as was feasible upon completion. The researcher did not complete the interview transcription.

Each completed transcription was then uploaded into NVivo 12 software. This software assists with coding, data analysis, and theory development. Once the transcripts were complete, the caregiver was offered an opportunity to review the transcript for the purpose of member checking and verification of accuracy of what was documented from the interview. Any recommended changes were then corrected by the researcher. Once these corrections were made, the caregiver was offered another opportunity for review and verification. Furthermore, the final results of the study were made available to the participants for their review. Participants will be notified of completion of the study and will be given an opportunity to receive study results via email or postal mail (based on access to email).

A research journal and a recording device were utilized as a means of debrief for each interview. The debrief occurred at the completion of each interview to allow the process to occur immediately to depict the experience of the interview with as much accuracy as possible. As suggested by the literature, the researcher journaled key words and comments during interviews for use in data checking (Corbin & Strauss, 2015). These data from the debrief journal data were also uploaded to NVivo 12. Audio recordings of each debrief session after interviews and any additional notes from the written research journal were uploaded into NVivo 12 for coding and data analysis.

Data for the study were stored electronically in a password protected file on a computer with access restricted to the researcher. Informed consent forms, interview transcriptions, the researcher’s debrief journal, and any other materials used in the study were scanned for electronic storage. The original paper documents were stored in a locked file cabinet. Once transcriptions were verified and stored, digital recording files used during the interviews were deleted. In order to protect participant identity, participants were assigned a Participant Number, sequential by interview (i.e. Participant 101, Participant, 102…). The Participant Number was documented on the Informed Consent Form, and all other documents only utilized the assigned Participant Number.

Upon completion of each transcription, the data was reviewed by the researcher to determine initial thoughts regarding codes once it was uploaded to NVivo 12. A research colleague reviewer completed an independent review of each transcription to note codes and contribute toward development of theory. Upon completion of the independent reviews, the researcher and the research colleague collectively reviewed these results and developed consensus regarding emerging codes. This process continued until each interview was completed and the transcripts were reviewed and coded.

At the time the interviews and any other identified documents had been gathered and were uploaded in NVivo 12, the full data set was explored to determine findings. The researcher studied the complete data set with a goal to develop theory through the process of connecting related information, constant comparison, and connecting codes from each interview. Additionally, the full data set was treated in a similar fashion as each transcript of two independent (the researcher and a research colleague) and then a collaborative review including the two. Finally, a completed report of results was developed. When there was a discrepancy regarding the determination of codes, codes were revised based on the feedback from the colleague reviewer. Upon these steps being complete, the final results report was written.

Data Analysis

Grounded theory uses a process in which a researcher “derives a general, abstract theory of a process, action, or interaction grounded in the views of the participants” (Creswell & Creswell, 2018, p. 13). This process uses multiple stages of data collection; furthermore, data is refined to interrelate and make meaning of categories of information (Creswell & Creswell, 2018; Charmaz, 2006; Corbin & Strauss, 2015). Corbin and Strauss (2015) identify the process as “constant comparisons” whereby data are separated into small, manageable pieces and are compared for similarities and differences (p. 7). Data that are similar are then grouped together under a heading that represents the identified, similar concept (Corbin & Strauss, 2015). As the data continue to be analyzed and built, concepts are linked together to form a greater unit of data through categories. Categories are developed and organized related to properties and dimensions and are eventually built to surround a core category (Corbin & Strauss, 2015). All of these components eventual combine to develop the structure of the theory.

Creswell and Creswell (2018) describe the process of coding as falling into three categories. They describe expected codes, which would be expected based on the knowledge of the literature and some common sense used related to the area of research. Next, Creswell and Creswell (2018) describe surprising codes as those that would not be expected before the research begins. Codes of unusual or conceptual interest are codes that include unusual ideas; these bring conceptual interest to readers in and of themselves and can become important within analysis (Creswell & Creswell, 2018). Additionally, coding toward development of grounded theory is described to have several systematic steps (Creswell & Creswell, 2018; Corbin & Strauss, 2015). Creswell and Creswell (2018) describe steps of open, axial, and selective coding. Open coding involves generating overall categories of information, while axial and selective coding become more specific (Creswell & Creswell, 2018). Axial coding involves using one of the selected categories and using it within a theoretical model, while selective coding takes this further to development of a story within the interconnection of categories and codes (Creswell & Creswell, 2018). These various codes contribute to the development of the final theory.

The process of coding is the premise to understand and link data in grounded theory. Computer software, specifically NVivo 12, was used in this study to organize data and assist with coding and categorizing. The organization and structure provided through NVivo 12 contributes toward the overall theory development. Questions and topics discussed during the interviews were adapted via information yielded from prior interviews. After each interview was completed, all recorded and transcribed interviews and any other written data were added to the comprehensive data set and processed for identification of categories. Finally, the complete data set was reviewed for development the theories and checked for bias and validity; these final reviews of the complete data set included both the researcher and a research colleague reviewer experienced with publishing and teaching qualitative research.

Research Design

Worldview

According to Creswell and Creswell (2018), a constructivist worldview involves individuals seeking “understanding of the world in which they live and work” (p. 8). As people have different experiences, they develop subjective meanings of them. Meanings can vary from person to person and there may be many of them; in the constructivist worldview, researchers seek out complexities instead of simplifying meanings into a more basic categories or ideas (Creswell & Creswell, 2018). In constructivist research, the participant perspective of the situation is the main focus of study. Questions are more broad, general, and open-ended in order to allow the participant the option to expand upon experience and develop their own construction of meaning tied to the event or circumstance (Creswell & Creswell, 2018). This is a similar structure and process to that of semi-structured interviewing. Constructivist worldview also considers the social lens where participants live and the impact of the surrounding context where they live and work. A theory is generated or inductively developed based on patterns of meaning (Creswell & Creswell, 2018).

Grounded Theory

Grounded theory is an inductive methodology that can be used in various disciplines (Grounded Theory Institute, 2014). Originally derived by sociologists Glaser and Strauss in the 1960s with the purpose “to construct theory grounded in data” (Corbin & Strauss, 2015, p. 4), grounded theory has become one of the most well-known approaches to qualitative research (Padgett, 2008; Glaser & Strauss, 1967). Grounded theory derives a theory based in participant experience; theory is developed through multiple reviews of data collected to link related information (Creswell & Creswell, 2018).

The study utilized purposive sampling to ensure that participants met the guidelines intended for the research study. In this case, the participants for this study were a purposive sample of a minimum of fifteen nonpaid family or friend caregivers providing care to advanced cancer patients. Interviews continued until saturation of data occurs, which was completed by the fifteenth interview. As the process of constant comparison and coding begins, codes may begin to repeat one another without contributing additional new information, at which case, saturation has occurred (Corbin & Strauss, 2015). Data collection for this study was primarily interviews with some written documents available via field notes and the research journal.

Based on the desire for the interview process to be flexible and follow the lead of the participant, semi-structured interviews were best suited to this research. While an interview protocol (see Appendix C) was used to provide structure, there was less emphasis on the exact order and specific methods in which questions are asked. There was also opportunity for the participant to contribute additional feedback or information that was not addressed within the interview protocol. Each interview closed with a statement that the specified questions were complete, but asked the participant to contribute any additional thoughts or experience that may not have been previously discussed during the interview. This promoted the option of the participant to share any further thoughts and feelings related to the caregiving experience, adding richness to results.

Validating Findings

Qualitative research expects several steps and process to ensure validation of the research findings. According to Creswell and Creswell (2018), these steps are a means to "check for the accuracy and the credibility of … findings" (pg. 199). Even the choice to interview in a natural setting can contribute to validity; "giving the participants the opportunity to choose a safe environment for the interview" contributes to credibility (Senden et al., 2015, p. 199). The process to validate findings in this study included member checking, use of a research journal, saturation, colleague debrief and review of coding, and triangulation.

Member Checking

After completion of each interview, the recording was transcribed. Once transcription was completed, the Microsoft Word document will be uploaded into the NVivo 12 software, the data was coded and identified. This transcription and the identified codes was provided to the caregiver for review and feedback, which validates each interview (Creswell & Creswell, 2018). Upon final approval by each participant, each interview was incorporated into the complete data set. Interviews were summarized by the researcher and the research colleague for inclusion in the research results; participants had the opportunity to review and verify accuracy of these summaries, if they were willing to doing so. Participants were provided via email with the transcriptions of the interviews. Participants were also provided an option to schedule an additional face-to-face meeting for transcription review based on preference and accessibility of the participant. Further, using participant review of findings from the completed research study is another mechanism of member checking that promotes accuracy and validation of the completed research findings reported (Senden et al., 2015).

Research Journal

Corbin and Strauss (2015) note the importance of use of a research journal for researchers to document the activities that develop and occur within the process of a qualitative research study. This could include notes during the development of the research, notes of discussions in development, and basis for decisions made during the development of the research study. Corbin and Strauss (2015) note that the research journal becomes valuable because it "enables a researcher to become more self-aware, not only of his or her biases and assumptions but also of the reason for making certain decisions" (p. 37).

Reflexivity becomes a necessary aspect of this process in qualitative research. As described by Polit and Beck (2017), reflexivity is the understanding and awareness of the researcher as having a unique background, set of values and believes, and a social and professional identify that can affect the process of the research. A research journal can be of assistance in identifying and processing the effects of the researcher on data collection, analysis, and development of results (Polit & Beck, 2017). Memos included in a research journal may include self-reflections on various topics related to the research. These may include the impact of interviews and observations on the researcher, the impact of the researcher within interviews, the impacts of these dynamics on the study, and the personal intent of the researcher in completing the study (Krathwohl, 2009).

The research journal was elemental as a means of note-taking post interview. This documented challenges that occurred within caregiver interviews and indicated how issues or challenges were addressed. Upon completion of the research journal, these written materials were uploaded to NVivo 12 and included in the full data set.

Saturation

The researcher included the process of saturation within the data collection process. After the researcher completed an interview and the session was transcribed and member-checked, the researcher coded the data using the NVivo 12 Software. When no new categories emerge from data, the data was evaluated for saturation. Saturation is a concept from grounded theory whereby data collection stops when the categories are saturated; “when gathering fresh data no longer sparks new insights or reveals new properties…you have an adequate sample” (Creswell & Creswell, 2018, p. 186; Charmaz, 2006). Initial participant interviews were set at a minimum of fifteen. Should this number of participants did not reach saturation of data within the codes identified, additional participants would be recruited until saturation was reached. However, data saturation was achieved within fifteen interviews, so no further interviews were required after. Termination of interviewing and data collection ended when saturation occurred within the emerging categories of codes, themes, and development of the grounded theory.

Colleague Debrief and Review of Coding

Padgett (2008) recommends that qualitative researchers have access to peer debriefing within the process of the research. Debriefing allows researchers the opportunity to receive and give feedback, offer ideas and input, and access support to what can be an emotionally taxing research process (Padgett, 2008). Peer debriefing also promotes researcher integrity and assists to manage bias within the research, which promotes rigor within qualitative research (Padgett, 2008). This research did not incorporate access to a peer debriefing group, but did access debriefing on a one-to-one basis through a research colleague experienced in qualitative research methods. A research colleague was available via phone or face-to-face meetings for discussion post participant interviews or for question and answer during coding.

Furthermore, a research colleague experienced in qualitative research was involved in review of codes within each interview transcript building to the full data set. The researcher reviewed codes developed with assistance from the NVivo 12 Software. At conclusion of each interview, the interview was immediately transcribed and uploaded into the NVivo 12 software. A research colleague reviewer with qualitative research experience reviewed transcripts and specific areas of data to verify codes. These reviews were not completed collaboratively, but occurred independently; the research colleague and the researcher reviewer identified codes together to ensure consistency. At the time all data was collected and the collective data was available, they reviewed final codes and progression toward the theory. Within these processes of review, any recommended adaptations were incorporated through completion of data analysis and final reporting.

Previous related qualitative research has established a four-step process for review of codes. Leow and Chan (2017) conducted a qualitative study on family caregivers of advanced cancer patients in Singapore; the study explored challenges, emotions, coping, and gains experienced during caregiving with a purposive sample of 19 family caregivers recruited from home hospice services; their study focused on the stage of end of life caregiving (Leow & Chan, 2017). The researchers used a four-step process of data analysis that involved two members. Upon receipt of interview transcripts, each researcher individually read the completed transcript several times, paying careful attention to the aspects of the transcription that related to the overall research question of the study (Leow & Chan, 2017). Coding for each unit was formed; codes were then interpreted and grouped in to categories specific to similarities or differences present in each (Leow & Chan, 2017). These categories were then eventually built into greater concepts. Once these concepts were developed, they were compared between both researchers, with the aim to agree on the major themes developed via discussion.

This study will model this established structure; it will begin with a basis of individual reviews, then cross-checking between the research colleague to ensure consensus on coding that will build toward development of the grounded theory. Padgett (2008) describes that no pair of co-coders will have consensus on each area. It requires flexibility and openness to direct a co-coding process of independent review and later work toward agreement to a goal that best fits the data (Padgett, 2008).

Triangulation

Triangulation is a process using various data sources to examine evidence within and across them to build "coherent justification" for codes (Creswell & Creswell, 2018, p. 200). When codes are established due to convergence in multiple sources of data or reports from participants, validity is added to the study (Creswell & Creswell, 2018). Within the context of this research study, triangulation occurred in multiple ways. These included collecting data via semi-structured interviews flexibly and editing the interview protocol as needed based on prior interviews, having participants verify content of transcribed interviews via member checking, and use of a research journal and peer debrief process to develop awareness of potential bias and manage it through the process. Additionally, the transcriptions and included codes developed within the research were reviewed by a research colleague reviewer with experience in qualitative research to verify accuracy and allow the opportunity for feedback. Revisions were made as suggested.

Summary

This study used qualitative inquiry to explore the caregiving experiences, stressors, and opportunities for growth and meaning found in the caregiving role with advanced cancer patients. A minimum of fifteen participants were identified from rural communities surrounding Terre Haute, Indiana. Interviews continued until saturation of data was achieved. Semi-structured interviews were used with each participant. Face-to-face interviews lasted no longer than 75 minutes; all interviews were completed in the first interview sessions. Interviews were recorded, transcribed, and uploaded into NVivo 12 for use in organization of the data and development of codes that built into the theory. Interviews continued until saturation was reached, meaning no additional or new content was identified. Building categories, codes, and theories within the data were them used to develop a grounded theory, founded in the caregiving experiences of these participants.

CHAPTER 4

FINDINGS

Introduction

The findings section reviews the purpose of the study, the research questions, and describes the sample. It reviews the research methodology applied to data analysis, summarizes the data, and presents results of analysis. The findings close with discussion of the overall themes derived from the data, as well as explains the grounded theory emerging through this research study.

Purpose of the Study

The purpose of the study was to examine the experiences of family caregivers of advanced cancer patients in rural communities. In this study, caregivers were relatives, friends, or loved ones who provide unpaid help to an advanced cancer patient. Caregiving assistance addressed finances, household management, physical care, or accessing health care. The research used a grounded theory approach to examine the caregiving experience, explore stressors, and inquire upon benefits of the caregiving experience. Grounded theory works to create a theory developed from data collection based in participant experience (Creswell & Creswell, 2018). The study focused on rural communities, knowing that these areas tend to be limited in resources.

Research Questions:

1. What does the process of caregiving encompass for those who provide unpaid care for loved ones with advanced cancer?

2. How do these unpaid caregivers manage stressors and challenges within their role?

3. Does the process of advanced cancer caregiving lead to an experience of growth and meaning for the unpaid caregiver? If so, in what way?

4. How does advanced cancer caregiving affect each of the domains of quality of life (physical, psychological, social, and spiritual)?

5. What is the impact of living in a rural community when caregiving for an advanced cancer patient?

Description of the Sample

Fifteen caregivers were interviewed for this study. Of these caregivers, the majority were female (14, 93.3%), with one (6.7%) being male. Ages of caregiver participants ranged from 34 to 72 years old. Ethnicities represented by caregivers were majority white (12, 80%), two caregivers were black (13.3%), and one caregiver was biracial (white and Filipino, 6.7%). Educational levels of caregivers included completed eighth grade (1, 6.7%), completed high school (3, 20%), completed some college (4, 26.7%), completed an undergraduate degree (3, 20%), completed a graduate degree (2, 13.3%), and completed a doctorate (2, 13.3%).

The majority of caregiver participants experienced impacts of caregiving on their employment status. Near half of the caregivers interviewed were not employed (7, 46.7%), one caregiver had stopped working within the family business as a result of caregiving tasks (1, 6.7%), and some caregivers had to rearrange their employment duties or time spent at work to accommodate completion of caregiving tasks (6, 40%). One caregiver was not working outside of the home to raise her two young children, ages 1 and 3 (6.7%). Of the seven caregivers who maintained employment or owned a business, their employment settings varied as well, ranging from manual labor (2, 13.3%), business owners (1, 6.7%), medical professionals (2, 13.3%), and educators (2, 13.3%).

Caregivers were caring for a variety of family members and friends, including their spouse (6, 40%), significant other (1, 6.7%), mother (4, 26.7%), father (1, 6.7%), son (1, 6.7%), sister (1, 6.7%), and friend (2, 13.3%). One caregiver respondent was providing simultaneous care to two advanced cancer patients, her son and a friend. The time dedicated to caregiving varied between each caregiver and patient, but four caregivers (26.7%) considered their caregiving role to be continuous by the time of interview (24 hours per day, 7 days per week). The minimum amount of weekly time caregiving noted by a caregiver interviewed for this study was 10 hours per week. Five caregivers were simultaneously raising minor children during the time of advanced cancer caregiving; they spoke extensively of the demands of managing caregiving tasks with those required of their parental obligations and expectations. Table 1 summarizes aspects of the descriptive information about the sample.

Table 1

Caregiver Demographic Data

Caregiver	Age	Gender	Ethnicity	Education	Caring For	Origin	Minor Children
101	59	M	White	High School	Spouse	Lung	
102	63	F	White	Bachelors	Mother	Breast	
103	49	F	White	High School	Significant Other	Rectal	
104	63	F	Black	High School	Spouse	Lung	
105	72	F	White	Some College	Son & Friend	Lung	
106	58	F	White	Some College	Friend	Lung	
107	47	F	Black	Some College	Mother	Breast	
108	49	F	Biracial	Graduate Degree	Spouse	Pancreatic	Ages 13 &16
cc109	42	F	White	Doctorate	Father	Brain	Ages 10 $ 13
110	60	F	White	Doctorate	Mother	Unknown	
111	50	F	White	Graduate Degree	Mother	Breast	Age 15
112	38	F	White	Eighth Grade	Spouse	Lung	Ages 16 & 18
113	59	F	White	Some College	Spouse	Lung	
114	64	F	White	Bachelors	Spouse	Prostate	
115	34	F	White	Graduate Degree	Sister	Breast	Ages 1 & 3

Research Methodology applied to the Data Analysis

Each caregiver was interviewed after reviewing and signing the informed consent form. The interviews were documented by audio recording via a recording application called Rev Recorder. Rev allows the capability of interview transcription, so each interview was transcribed using their service. Each caregiver was offered the opportunity to review and verify accuracy of the transcribed interview to complete the process of member checking. Member checking promotes accuracy and validation of each interview and the full data set of research findings (Senden et al., 2015). After member checking, the transcribed interviews were uploaded by the researcher to NVivo 12. NVivo 12 was used to organize the interview data, categorize the content of interview transcriptions, and work to develop themes and codes from this research.

Creswell and Creswell (2018) describe steps of open, axial, and selective coding. Open coding involves generating overall categories of information, while axial and selective coding become more specific (Creswell & Creswell, 2018). Axial coding involves using one of the selected categories within a theoretical model, while selective coding takes this further to development of a story within the interconnection of categories and codes (Creswell & Creswell, 2018). These various codes contribute to the development of the final theory.

Through the use of NVivo 12, each caregiver response to interview questions was categorized into specific areas. Open codes were developed to include responses to the research questions, including: caregiving tasks, challenges, rewards, stress management activities, supports, ideal resources, relationship impact of caregiving, personal growth, quality of life, and rural impact. Interview content, themes, and direct quotes from each caregiver were organized into each of these open codes. As interview details were reviewed and compared, the open codes became more specific. Axial codes emerged from the overlapping areas of open codes to build research themes within the data. Then, selective codes developed the story emerging from the data into the final themes, summarizing the caregiver experience represented within this study. These final selective codes expanded upon related open and axial codes across interview questions. For instance, selective codes represent information from all interview topics (positive and negative) included in the open codes.

As interviews continued to be completed and described, the research colleague reviewer participated in review of initial open codes and collaborated with the researcher to develop axial and selective codes. This collaboration built the themes within the data. Structure for the final research themes and development of a grounded theory were built with collaboration and direction from the research colleague reviewer. As interviews were finalized, the research colleague reviewer assisted to refine the final codes, themes, and theory that considered additions of final interview data.

Presentation of Data (Organized by Research Questions)

The data gathered during caregiver interviews will first be presented. The data will be organized by each of the five research questions included in the caregiver interviews. After presenting the data summary categorized by the research questions, the findings will then report the themes. The findings section will close with discussion of the grounded theory emerging from the caregiver experience.

Caregiving Tasks Completed by Advanced Cancer Caregivers

Research question one asked the following: What does the process of caregiving encompass for those who provide unpaid care for loved ones with advanced cancer? Advanced cancer caregivers completed a number of tasks on behalf of their designated patient(s). The following tasks are listed based on the highest percentage of caregivers who completed them as represented in this study.

- 93.3% of caregivers (14) assisted with household tasks, such as cooking, cleaning, laundry, running errands, and other related tasks.
- 93.3% of caregivers (14) attended medical appointments with the patient, which often includes transportation of the patient to/from the appointment. The time involved often includes time spent waiting for chemotherapy infusions or other medical appointments to be complete.
- 60% of caregivers (9) offered some assistance with medication management, such as preparing medications, monitoring patient compliance with taking medications, ensuring medication lists are accurate during appointments and hospital stays, and obtaining prescription refill orders from prescribers.
- 53.3% of caregivers (8) assisted with management of financial circumstances or addressed financial issues.
- 46.7% of caregivers (7) provided extensive personal care for patients, including cleaning or bathing, assisting with toileting, dressing, wound care, ambulating or repositioning, and other daily hygiene or care tasks.
- 46.7% of caregivers (7) offered emotional support to patients, including conversations face-to-face, over the phone, and online mechanisms.

Other caregiving tasks represented by caregiver participants included on a less frequent basis included:

- navigating health or life insurance (40%, 6 caregivers),
- completing modifications of the home (13.3%, 2 caregivers),

- obtaining needed supplies on behalf of the patient, such as durable medical equipment such as a walker or a wheelchair or wound care supplies (13.3%, 2 caregivers),
- assisting with advanced directives (6.7%, 1 caregiver),
- and supporting the patient in completion of tasks related to work (6.7%, 1 caregiver). This employment position required travel and the caregiver drove the patient when he was not physically able to tolerate driving after chemotherapy treatments.

The time included and number of each of these tasks completed varied to each caregiver. Four caregivers completed every one of these tasks and considered their caregiving role to be continuous (24 hours per day, 7 days per week). The minimum amount of weekly time caregiving noted by the caregivers interviewed for this study was approximately 10 hours per week. Caregivers did have some difficulty answering this question, especially if they lived a distance from the patient. In that arrangement, the number of hours caregiving per week would drastically increase if the patient had medical appointments and the caregiver attended, the patient had chemotherapy or a medical emergency, and if the caregiver was simply visiting and staying with the patient. Accordingly, the amount of hours completing caregiving raised from a smaller total over the phone to nearly continuous, in some cases. When comparing time spent in caregiving, hours spent per day or week vary immensely based on scheduled medical appointments or unanticipated time spent in the hospital during an unexpected inpatient hospital admission.

Caregiver Management of Stressors and Challenges

Research question two asked the following: How do these unpaid caregivers manage stressors and challenges within their role? This set of interview questions addressed a number of areas tied to the cancer caregiving experience, including caregiver challenges and rewards. Caregivers were asked about their activities and efforts to manage stress and if they were able to manage stress without impacts on caregiving. Caregiver participants discussed unmet needs, current supports in place, and their ideas surrounding ideal caregiving resources.

Caregiver challenges. Each caregiver interviewed spoke at length regarding their own personal caregiving challenges. These challenges did overlap and are presented below based on open codes identified through the data analysis. Overlapping challenges were eventually collapsed to develop axial and selective codes. Axial and open codes became the themes of the study, which will be discussed later in this chapter. In this section, each of the 23 caregiving challenges are presented based on frequency each specific challenge was identified by caregiver participants. The challenges indicated will follow, as well as quoted examples from interviews to demonstrate each challenge.

- Manage finances, especially when the ability to work is impacted by caregiving requirements (8 participants)

"I'm carrying a financial role for both of us. I think that upsets him because he feels that I'm taking care of him, and so it has...I think finances have put a little bit of strain on us." (103)

"I've racked up thousands of dollars of credit card debt just from staying in hotels. When he's at the hospital we stay at the hotel and it's $250 a night. And I've stayed there probably 20 nights, so I've put that all on a credit card, so a little bit, a lot a bit of financial stress there too." (109)

"I worry about of course how our bills are going to get paid. How I'm going to feed the kids, making sure you've got gas to go back and forth to his appointments, trying to make sure to have the out of money pocket expenses for the cough medicines and the diarrhea medicines and the things that are not covered by the insurance." (112)

- Keep emotions private so as to not negatively affect the patient (8 participants)

"It's very hard to just be like a third party. It's hard to not get my head wrapped into it too, because I wouldn't be able to provide the care and provide the hope. I wouldn't be able to be supportive if I put all my emotions into it." (108)

"When I'm there, I feel like I'm able to sort of put on a façade that okay, I'm here. Everything's okay. And I was sort of always the peacemaker in the family anyway, and then when I get home to my own immediate family, that's sort of when they feel the impact." (109)

"Sometimes I think we may not speak as openly or honestly about our fears. Because we don't want the other one to...we want to both cheer the other one up." (114)

- Prepare for end-of-life (7 participants)

"Another challenge is just understanding the prognosis. Trying to be positive and keep... How do I explain it? How to do it, and give him hope." (108)

"Because the idea of thinking that I could actually lose my husband. I mean, I know people pass away every day. You never know what's going to happen, but just the thought of actually losing him. And I mean, it's still there in the back of my mind. But I mean, I try not to think about it as much or if I do, I try not to do it when he's around." (112)

"Well, I was worried about him all the time… And then it would scare me when he couldn't breathe. And wondering if I was going to wake up in the morning and he was going to be gone." (113)

- Ignore own physical health needs to prioritize those of the patient instead (6 participants)

"I've been really exhausted, and now I've lost like 27 pounds, and I don't know why." (107)

"I've been sick with my own problems. I was supposed to have surgery back in July. Of course, it's very hard for me to have surgery when I know I have to be around for them." (108)

"I've had health issues like migraines and different skin issues and things like that I know are 100% related to stress." (109)

- Neglect to engage in typical self-care habits or activities (6 participants)

"Take care of yourself, I'm not real good at taking my own advice, but I mean if I told someone else, eat right and get rest and you got to take care of yourself so you can take care of that person." (106)

"I know I don't take care of myself, and I feel like at the same time, you know, I want to help my mom, but I feel like life is short, and I really don't have time to be bitter all the time." (107)

"There's no time. Basically, it consumes every minute of my day. There's no extra time anymore for me. For my own, you know, just for me." (108)

- Experience a loss of prior relationships due to a number of factors (5 participants)

"I decided last week to quit checking on people that I normally check on just because I wanted to see if anybody really, I guess in my aspect, was taking for granted what I did do. I haven't heard from these people. If I don't call them, then they don't reach out." (103)

"So, people just don't want to deal with…they don't want to deal with cancer even though it's not them that's dealing with it, that it's almost like they're going to catch it if they come over to your house." (103)

"So we've kind of been, stopped being invited to as many things because of it, or we've had to miss things because the priority is on my family right now." (109)

- Operate as the source of the patient's venting (4 participants)

"I guess the sounding board is a negative because he takes all of his aggression out verbally normally to me, so that gets frustrating and challenging…yeah, sometimes I would not want to be his safe place." (103)

"Right now I'm having a hard time with her mood changes and sometimes she gets very, very grouchy and upset at stuff. My son does too. And they yell at me and then I get to where I don't feel right and I feel like I've done something wrong." (105)

- Cope with changes in intimacy (4 participants)

"We have become closer, but due to his circumstances, there's no intimacy. Very little contact, because...I'm afraid to touch him right now because he has chemo pump attached to him and a needle in his chest. So, that becoming more of the finance person, the bill payer, the grocery shopper, sometimes you feel more like, almost like Mom or the maid instead of a spouse. So, emotionally, that is challenging to get over." (103)

- Prioritize caregiving time over parenting time, leading to time away from children at home (4 participants)

"I feel like I have not been there for the kids at all. I do feel like they really emotionally suffer because I put so much into trying to make (their) *dad's life good that they definitely have suffered."* (108)

"I have two boys myself. One of which has some special needs. And so that has probably honestly been the most stressful. I mean, aside from knowing I'm going to lose my dad, but having the day-to-day stress of when I'm away helping take care of him. My youngest son that has some special needs, knowing that I really need to be there for him as well is really stressful on me." (109)

- Navigate difficulties with health insurance (4 participants)

“So those types of things are really critical, and insurance really needs to get their head out of the clouds. Look at the people. The patient. (Get a) *real close look on this insurance controlling your life. It's just gotten out of control. The insurance people have.”* (101)

“I didn't know all the system and I didn't know what it was all out there. And from my job as a nurse, I'm removed from what a lot of programs exist. So not having the time to look up all of that.” (110)

- Experience changes in employment based on caregiving burden or task (3 participants)

“I only live eight minutes from work, so that's not a big thing. But I normally start my day off and go out to the barn until 8:00. Yeah, I go out to our farm at 8:00, and then I start wrapping up between 12:00 and 12:30 so I can be back at the house cleaned up and ready to go to his appointments here no later than 1:30. Then, if I didn't get done what I need to do, we come to appointments, and then I go back to work at the end of when we go back to town.” (103)

- Learn medical tasks of patient care without medical training to complete those tasks (3 participants)

“She has to be changed every four hours. Sometimes it goes through on the bed. I just learned a trick the other day on how to do the sheet underneath her. Physically, taking care of her has been the worst thing. Just knowing what to do. Because I have no nursing background.” (102)

“And then with him being weak, when he would get those fever spikes because he never did get over the pneumonia, I had to put ice packs under his armpits and on the back of his neck and on his belly. And then I'd put ice in water and put cold washcloths on his head to drop his fever because he was too weak to get in the bathtub. And then he did get those bedsores, and I cleared them up in 25 days with MediHoney and got them all cleared up. And we had to take him to ICU, and they put Band-Aids on him. And when they ripped them off, they tore it all back open.” (113)

- Operate as a caregiver while living a physical distance from the patient (3 participants)

“I think it's also hard on me not being in town because there has been probably five or six instances, he had a blood clot, so I was called at 2:00 in the morning that they were concerned that he could possibly die immediately. So, I packed up my bag and I got in my car and I drove at 2:00 in the morning four hours, so I got there at 6:00, and the whole time I was scared that he was going to pass away on my drive. And so, sometimes it makes it...you're away, so you don't have that daily burden, but then the distance creates a different kind of stress.” (109)

- Encourage patient compliance with medical recommendations (3 participants)

"You know what's best for someone (due to employment as a nurse), *but they want to keep being independent, but you know it's not always safe. Like driving when you're fuzzy and just making choices that you know aren't going to be good."* (108)

"I think it's still pretty bad, because he's still smoking. Because there for a while, he had slowed down a lot when he first found out (about his cancer)*, but now I've been noticing an increase in it again. And of course, I've been saying something, but he's going to do what he wants to do."* (112)

- Learn medical jargon (2 participants)

"I think that sometimes the medical staff, they will use such words and not everybody will say, 'You're speaking Greek. I don't know what you just said.'" (101)

- Adjust to the new normal (2 participants)

"Life is different now. It will be forever. And so, we don't even know what the new normal is going to be. It's a daily adjustment." (101)

- Implement and maintain boundaries with visitors (2 participants)

*"Our house was always, has always kind of been Grand Central Station. And, that's fine, but we had to tell people, 'Look, you need to knock before you come in. Call before you come to see if it's a good time.' We did, and there were some people that just randomly said, 'Hey, that's fine, don't wake her up.' But there was a person who became offended, and has dropped off our radar. And that's okay." (*101)

"There's constantly company coming in to see him, which is wonderful that he has so many friends but I'm constantly entertaining. My house is like a bed and breakfast now, there's always company. Which, once again, means the kids come last and the company comes first and it's hard to maintain any normalcy." (108)

- Experience physical demands and burden of the patient's care due to transferring, lifting, bathing and other personal care tasks (2 participant)

"It's just taking a toll on me. I do what I can, it's hard. And then with my aches and pains that ain't doing me no good, and he's around here hurting." (104)

*"Well, he's a lot bigger than me. So it was really hard getting him...At first, it was okay. He wasn't quite as weak, but when he started getting weaker, for me to help him get to the bathroom and things was really hard because I'm 5'4", and he's 6'4". I had got him in the bathtub to begin with, but then he got so weak. The last time I put him in the bathtub, it took everything I had to get him out." (*113)

- Observe the physical health and strength of the patient decline with treatment (2 participants)

"The hardest part is just seeing him so weak and get so wore out so easy. Because I mean, he's used to being on the go, moving, lifting, and all the heavy things. So just seeing him not being able to do everyday tasks as not even walking to the bathroom without getting out of breath, that for me, the hardest part is just seeing him not be the man that he always was used to being." (112)

"Yeah, and people don't realize how much chemo makes them tired. And then the last week, or I mean the radiation, and the last week he was doing radiation, he also started the chemo. So, between radiation and chemo, he was completely exhausted, and then the chemo made him not have an appetite." (113)

- Manage insurance requirements to access the patient's medications (1 participant)

"If you're talking about pharmacies, the insurance and the Indiana law, and this pre-authorization, needs to be re-looked at when people ...people actually need their medicines without having to go through all the hoops. We got caught a couple of times with no pre-authorization and no pain medicine after all of her (the patient's) *amputations. We all got pretty rough with the insurance."* (101)

- Spend limited time in the caregiver's own home because of moving into the home of the patient to provide care (1 participant)

"It's just easier to stay here. I just go home a couple of days a week, close my eyes and hold my breath, and walk in. Hopefully if the house is still standing." (102)

- Encourage the patient to stop drinking alcohol and smoking due to the cancer diagnosis and treatment (1 participant)

"He (the patient) *did quit the drinking. Because doctor told him, "Either you want to drink or you want to live." So he quit that…but I mean, of course I worry that he'll go back afterwards."* (112)

- Stay on the same page to fight the cancer, not each other (1 participant)

"It's kind of like communication together to be sure we're on the same page…Sometimes I'll think something is... I'll have a different memory of something than he does. So we have to work through that. And I think there is such a thing as chemo brain. So sometimes it's a matter of us seeing the cancer as the enemy and being sure that we're on the same page fighting the cancer, not each other." (114)

The rewards of caregiving. Each caregiver interviewed could identify at least one reward experienced as a result of the caregiving experience. Rewards were repetitive across caregiver interviews. Some caregivers also could discuss multiple rewards they experience as a result of caregiving. In this section, each of the rewards caregivers identified are presented based on the frequency they were mentioned. The rewards indicated will follow, as well as quoted examples from interviews to demonstrate them.

- Provide high quality care for the patient (5 participants)

"Knowing that I do have the patience to do it, and that, yeah, I may go cry. But at the end of the day, to know that he's comfortable and that he's taken care of and that he's still got the…oh, he's still willing to fight the battle. Because I do want to make sure he gets the best care and that he's safe, and that he's eating, and he feels okay." (103)

"Helping him out. Just being there." (104)

"I enjoy being with patients. I enjoy being with them and listening to their stories." (105)

"I just want to see joy in life as much as I can and help them." (106)

"The wound care lady, she told me, she said, 'usually when they're having chemo and radiation, you can't get these (open wounds) *healed.' And she was really proud of me that I got them healed up."* (113)

"I know other people try to take care of him, but they can't take care of him as good as I can because I listened to everything the doctor said. And I tried to do everything that he would allow me to do. And so I felt like I gave him the best treatment that he could get." (113)

- Fulfill the caregiver's personality as a nurturing person (3 participants)

"I know being a caregiver's hard, but it is rewarding. But it's got to be something that a person's wanting to do, not having to do because they have to do it. They're going to find it as a burden and not as a...I guess in some aspects, I feel it fulfills me." (103)

"But it makes me feel like I'm needed. I enjoy doing it. I feel like I'm helping somebody and everything. I've always wanted to help people in life. I've always been told it takes a special person to become caregiver but I've always enjoyed it and everything. It's just, I enjoy meeting people, talking to people and stuff. So I enjoy it." (105)

"I just always like to help people. It just makes me feel good." (106)

- Reciprocate care for a family member, often a child caring for a parent, who previously cared for them (2 participants)

"She took care of me for years. She watched my kids when I worked, she'd pick up the kids at school for me and take them to dance, and music, and tutoring or whatever I needed. So I said,

'You've taken care of me for all these years,' now I can be paying her back and take care of her. I don't know sometimes that I'm doing the best job, but I'm trying." (102)

"I get to help my mom, and she's still, and I'm just so grateful that she's still here with me you know…so it's rewarding to see my mom happy." (107)

- Celebrate when the patient goes into remission or has improvement in their physical health (2 participants)

"When you find out that their cancer has been treated and they're getting over it and everything. I am as happy as the patient because I feel like I'm part of it." (107)

"I guess the reward is that he might be here tomorrow. I guess that's it, just the fact that he might be here tomorrow." (108)

- Motivate the patient for treatment (2 participants)

"He's still willing to fight the battle. Because if he doesn't want to fight the battle, then you can't fight it for him…that's the biggest thing is to make sure he tries to stay positive." (103)

"Just not letting him lay in bed all the time. I try to get him to play a game with me or something, or just take a little walk around the block, when it hasn't been so cold outside or rainy or something." (112)

- Fulfill the patient wishes (2 participants)

"And it made me feel good that I could bring him home to let him pass away because that's what he wanted." (113)

- Have the opportunity to spend more quality time with the patient (1 participant)

"But I love the time to be able to spend with him, and joke around with him and try to keep him active, you know?...Just the extra time with him, I think is the best reward for me." (112)

Managing stress as an advanced cancer caregiver. Additionally, caregivers were asked about their own use of coping strategies to manage stressors. Questions asked if how they were managing stress, if they had unmet needs, and about the supports they were using or would be willing to use to assist with stress. Specific interview questions asked if they felt the stress of caregiving impacted the ability to care for the patient. It is significant to note that each caregiver interviewed responded to this question with "no" and discussed how they could manage their own stress without affecting the patient. Caregivers would then discuss examples of how their emotions fell secondary to those of the patient. The ways in which caregivers reported managing stress and examples of their coping strategies follow.

- Access support system (7 participants)

“I've actually leaned on some friends that, at the beginning, I'm like "I'm fine, I'm fine" and now I will go for walks and I talk to people I don't usually open up to. At work, I've developed some close relationships with people because I'm able to talk to them about it. There's one person who's been through it.” (108)

“I am fortunate to have great friends, a great husband. I have great in-laws that my husband would really be mindful of what I was going through and would be very supportive to me. Maybe do some things in the house for me, help me with our own, you know, cleaning or meals or things like that.” (111)

One caregiver facilitated access to treatment for her husband through a specialty medical hospital across the country from where they live. During his five week treatment time there, they stayed in an onsite lodge sponsored by the American Cancer Society. She described the experience.

“And so you're there, you are on the same floor with a group of people that all share the same kitchen…And so you're eating meals together and you're with spouses who are caregivers, or children or whoever, and so you just sort of naturally have some conversation. And you share the meals, you share the cooking, you share the shopping, you maybe workout together, you whatever. Then we've kept up. I've kept...I had everybody sign a...Put your name and address and contact information. So we keep that up. When somebody has something hard, or whatever, or they're going back and maybe we, ‘Oh, I'm going to be back (at the hospital). *Are you going to be there then?’ We can see if somebody else is going to be there and we can get together…Yeah, that's been a good thing. And that has helped us all talk a bit more. It also is sad at times because three of our friends have died.”* (114)

- Use faith (6 participants)

“The best thing to do is pray about it.” (101)

“I go to hear the word of God. Listen to the music, the choir sing, and when the pastor preaches.” (104)

“We would all pray for her to have healing and comfort and peace. I think that it strengthened my spiritual life and my spiritual walk because she truly believes that she is here today by the grace of God.” (111)

"I also I read the Bible regularly." (114)

- Take a break (4 participants)

"I take my break and I go home, and I clean houses…I do take time for myself. I go do my nails." (102)

"I can deal with it for a certain amount of time and then I have to get away from everybody and just kind of be by myself and stress out. But I like doing crafts and stuff, so that kind of calms me down." (105)

"If I could sneak in like a manicure or pedicure or you know, get my hair done or something like that. Just to sort of lift me up. Then it would also, interestingly enough, my mother would actually see that, and she would be so thankful and so happy that I actually took time to go." (111)

- Engage in health behaviors, such as sleep, exercise, and purposely refraining from substance use (specifically alcohol) as a method to manage stress (4 participants)

"I know some people have turned to drinking or substances…So I purposely try not to have anything like that when I'm feeling stressed because I never want to lean on it because I also know how that can be. Especially when you're stressed out, you could develop an addiction. I don't do that, and I think I'm managing it okay." (108)

"I try to exercise. That is an immediate stress reliever for me." (109)
"Because you can get out a lot of stress just walking. I walk seven miles a day five days a week, and it helps to just get that out and then I can talk and I can read while I'm on the treadmill and I can watch Jeopardy." (114)

- Engage in work as an outlet or distraction (4 participants)

"I do have a tendency of wrapping myself up into my work just so I don't have to think about it all the time." (103)

"Burying myself in work is a way that I manage it, although I'm not sure if that's effective or not… I almost feel like I don't want to admit how stressed I am, because then it just becomes so real. You know? If I can just keep plugging away, plugging away, then I'll get through it." (109)

"Work was really therapeutic because I could go to work and just turn it off and it would come back at times, but work was very therapeutic." (110)

"Honestly, the thing that helps me the most, and I think this was really weird for a lot of people, was working. Because I could go to work and do therapy with all of my families and listen to their problems and help them with their problems and I didn't have to worry about or think about my own…And when I was working, I worked too much longer hours than I normally okay was working. I was working 12 hours a day just so, basically just so I wouldn't have to, not because I didn't want to be at home, but so that I didn't have to come home and just think about it." (115)

- Maintain a positive outlook (3 participants)

"Maybe to just know…that not all battles do get lost." (103)

"But I've also tried to keep an upbeat and let people know that there's still hope." (105)

- Let things go (3 participants)

"You have to let it go. You ignore it because there's no time to deal with that. Have stress, of my stress, it's the comfort of the patient. And that is the first and foremost." (101)

"At first I struggled, but now I'm thinking, well, you know, she (the patient) *is just that way so I might as well just accept it. So it seems like when I got to that point, even though she's angry and she says a lot of things, I just don't lash back at her because it doesn't work. So I just leave her alone, and just, you know, it, it makes me feel a lot better."* (107)

- Practice patience (1 participant)

"What my answer to her (the patient) *is just 'slow and steady wins the race.' And we don't know what we're going to be able to do because we haven't got there yet. One lady told her, 'your story's still being written so we don't know what the outcome's going to be.'"* (101)

Caregiver supports. Caregivers spoke about their supports used within the caregiving process. These supports were already in place at the time of the interview. Some of the areas overlap with their coping strategies to manage stress. The supports discussed by caregivers follow with examples of their ideas about them.

- Access to a support system that was in place prior to the time of the cancer diagnosis (7 participants)

"Because they understand more than anything, they've been through it, they've been through the cancer, a lot of them have been to the caregiving. So you know, they know what it's like from both sides." (106)

"Even like, our hairstylist was a support because mom, when she chose her wig, she couldn't find a hairstyle that she liked. So she found one that was similar, and we have gone to our hairstylists for years, and so we kind of had a hair party, and she went to our hair stylists and

she actually did shave her head and then did put her wig on, and actually did cut the wig, and did some different things to the wig. So it actually looked like her hair, and it was her hairstyle. So you know, even that was a support for us, and not maybe this kind of support that you would think. But you know, and we had great family support, great support from friends, and I know that the hospital actually offered wigs. They offered support. They have a support group that they offered as well. Mom was not ready to go to the support group and never has, but she always knows that that's an option." (111)

"So they're very intentional about saying, 'No really, how are you?' And then you kind of come to grips with it and you say how you are, and then all of a sudden you end up with a meal on your door." (114)

- The community reached out to help with meals, transportation, donations, etc. To note, this was also regularly discussed as a benefit of the rural community. (6 participants)

"Yeah, even the garbage man. He's dropped in, and I forget which family member...he had had his aunt crochet a little bear…He goes, 'I've carried it with me. I've carried it with me for a few days,' he said. 'Probably smells like that trash truck,' he said, 'But you know I carry it with me, and I can say a prayer for you when I see that.' These are people out of their heart. And it's like, wow, wow. That just amazes me. It's just life-changing." (101)

"I just look around and I am appreciative of everything we have and the people that we know and I never realized like certain people that have been there for us…I'm like, "Wow I never would have expected that from them.'" (108)

"The community, everyone knows my dad, everyone knows my mom. So I mean, people are constantly sending cards. People have actually gave so much money. I didn't know that people did that, and we open cards in their mail, and there's $200 in a card which is just so generous." (109)

- Faith or a faith community (6 participants)

"We have a few people from church to stop by and stuff. That helps too." (102)

- Utilizing home health or hospice care providers to assist with patient care (4 participants)

"Well, we're just thankful for the visiting nurses, like you said, to start with. Any type of those organizations that are able to come out and offer services, they are very well appreciated. We wouldn't have made it without the visiting nurses and the physical therapy, occupational therapy, and, it's all those things. Because, it'd have been too hard to go into town." (101)

- Insurance coverage was excellent and facilitated access to care (2 participants)

"He had everything set up before he died. He had a supplemental set up for her that I bet she hasn't paid $1,000 in 20 years. It's paid almost every... I had to pay $100 the other day on a medical bill for her. It was a shock. That was all taken care of. She was in regional when she was diagnosed. She went to regional willingly because she hadn't been feeling good and we thought that it was a combination of things…They moved her to rehab at (a deidentified skilled nursing facility). *She wouldn't get up, couldn't get out of bed, so we got in with hospice. Through all of this, I bet we paid $100."* (102)

- Being physically healthy or in good shape ameliorated caregiver burden (2 participants)

"You've got to be in pretty good physical strength when you're a caregiver to be able to make sure you got yourself plus your patient, and you can get them up over the threshold, up over the step on the ramp, in the wheelchair. And a lot of times the other spouse is not quite that physically fit to do that. And that could create a very big problem for people in a rural area. I can manage that." (101)

"Not that I'm in the best shape of all, but I wasn't as strong as I am now. I have to pull her up, I have to turn it over a little bit." (102)

- Hiring additional help for completion of tasks, such as cooking and cleaning (2 participants)

"(Hired caregiver's name) *comes in eight hours a week and helps with mom and stuff around the house."* (102)

"Some things we just, that are kind of in his expertise, we either let them slip, or we have paid people occasionally to do things." (114)

Perceptions of idea resources and supports for caregivers. The final question in this section of the interviews asked about the perceptions of an ideal resource or support for each caregiver to which they could not or did not presently access due to a number of factors (such as lack of available time or money). The caregivers mentioned several ideas for supports that could help with some of their largest perceived challenges. The ideal resources indicated are as follows:

- Networking opportunities with other caregivers who have been in similar circumstances (5 participants)
- In-home supports to assist with meal preparation, cleaning, personal care for the patient, and other miscellaneous tasks (3 participants)
- Respite care to allow for a break at periods of caregiver exhaustion (2 participants)
- Reliable transportation that would allow for caregivers to accompany the patient to medical appointments and chemotherapy treatments (2 participants)
- Inexpensive or free lodging that would prevent long-distance travel for appointments (2 participants)
- System navigation, especially tailored to address financial support, programs, and advanced directives (2 participants)
- Access to telemedicine or phone consultation with physicians that could prevent or mitigate some of the long-distance traveling for appointments (1 participant)
- More discussion about what to expect toward the end of life to know how better to prepare for it (1 participant)

It is of note that most of these ideal resources involve system navigation related to the healthcare system, interaction with the treatment process, and engaging with insurance. Furthermore, ideal resources supported lacking finances and time available due to the burden of advanced cancer caregiving. Every ideal resource supported these specific barriers and challenges in caregiving. This observation will be discussed more extensively when the themes of the study are presented later in this chapter (see page 105).

Personal Growth Experienced by Advanced Cancer Caregivers

Research question three asked the following: Does the process of advanced cancer caregiving lead to an experience of growth and meaning for the unpaid caregiver? If so, in what way? It is significant to note that every caregiver interviewed recognized their own personal growth as a result of the caregiving experience. In this section, each of the areas of personal growth is presented based on frequency of each type of growth was discussed by the caregivers. The main themes of discussion about positive growth include having a growing awareness to support others (6 participants), the development of appreciation (6 participants), the importance of caregiving (5 participants), and recognition of survival (4 participants). Also mentioned were strengthening of faith (2 participants), development and use of advocacy skills (2 participants), and recognition of the desire to raise a family as a result of the caregiving experience (1 participant).

Becoming more aware of the need to support others. There was a recurrent discussion related to personal growth from caregiving that recognized challenges we all can have in life. In this theme, it was clear that the caregiving experience led these participants to recognize there is no room for judgment when others are experiencing difficulty. Caregivers discussed the importance of being nonjudgmental, and a need to step up to support others in times of need.

"Yeah, it changes your perspective on life, no questions asked. Judgmental about a person? Never again, ever. It doesn't matter. It is a human being that needs help…how can you be happy when you're this sick? But I'm like, I mean, it's not wonderful to be sick, but just, it's been so wonderful. It's just eye-opening, it's heart-opening. It opens your compassion for people and recognizing it, actually, where we wouldn't have recognized it before, I don't think." (101)

"But, you know, and just try to help people, that's what we're here for, to help each other. Don't go in there saying things if you don't have a clue what you're talking about or, watch what you say around the person so you don't say something mean to them. Just understand and support them." (106)

"And I think it's helped us all to not judge a book by its cover. They know how sick he is and behind closed doors how he's never out of the bathtub and he's in bed all the time and he has bad days. But you know everybody else sees him as looking fantastic. So we've all kind of learned how to be less judgmental of people." (108)

Development of appreciation overall. Similar to the concept of finding the silver lining, some caregivers discussed their growth in appreciation. They now look for the positive aspects of their life circumstances. Caregivers also discussed a focus on optimism.

"I've actually learned to appreciate everybody a little bit more. You really do realize there won't be a tomorrow. I think that you look at things that bothered you before and you say 'Hey. It doesn't really matter.' I say far more, I realize 'oh, why am I causing a fight?' I think that even with my kids, we all just have learned to appreciate each other a little bit more, appreciate what we have more." (108)

"It allows me to see how supportive my immediate family is, my kids and my husband have been extremely supportive of really holding down the fort. Sometimes I think they can't survive without me, but that's really not true, because they manage." (109)

"So I'm definitely trying to be more mindful. I'm trying to appreciate my days and these moments and all of these things." (109)

"We all did grow and you realize the brevity of life and how nothing just lasts. I mean, it's just a moment in time." (110)

"Well, yeah, probably. I mean, it taught me to not take a lot of things for granted and enjoy them while you got them…just the little things mean a lot." (113)

"And I definitely, getting conversation going and not taking each day for granted. You don't know how many you have, and we never do, but sometimes we just pretend we do I guess…Yeah, to me, it's made me appreciate a lot of life for sure and how fragile it is, and yet how sometimes you can be pretty resilient too." (114)

The importance of caregiving. Caregivers recognize the importance of taking the action to be the caregiver, not only in the life of their designated patient, but to encompass this role for people and society overall. There was also a sense of accomplishment in completing the caregiving role effectively and to "help out" (caregiver 104) their patient (and others). The experience of advanced cancer caregiving, which included taking treatment for some caregiver and affiliated patients, exposed them to how often caregiving is taking place and how necessary caregiving is to support the health and needs of others.

"I realize how much care people take." (102)

"More people need to have somebody that cares. I've had a lot of hospice nurses. I've had a lot of home-health nurses in my home, and you hear conversations, but you really only hear one side. There's a lot of people that sons and daughters put them in a nursing home or leave them there and expect somebody else to attend to them because they don't want to do it. They're a burden. I never want (patient name) *to feel like he's a burden."* (103)

"Well, when I was married I was told I was nothing. I couldn't do nothing. I was not smart enough to do nothing. And I have proved that I can get up and I can go and I can take care of people and I can do. And I think it's made me feel more younger because I'm active…it has made me realize, you know, that there was a lot of people that needs to just talk or just have somebody that they can call when they need somebody." (105)

Recognition of survival. Caregivers discussed that their own perception of survival and strength. Caregivers, patients, and family members were able to survive and overcome the emotional challenges faced in this period, often at a greater capacity than they expected. There was recognition of internal strength and survival mentioned discussed by caregivers, and they mentioned that watching the patient survive was also motivating.

"I know all of us are strong, stronger than maybe we gave ourselves credit for." (109)

"I saw what she went through…and how emotionally strong and physically strong that she was. I grew through her strength, as silly as that might seem, but just seeing how strong she was, and she wasn't going to let this get her, that she wasn't going to let the disease process get her certainly helped me to grow as a person too and helped strengthen our bond." (111)

"But I do always think that people should see how they can grow through situations. So I think that... I don't know, I think one thing I've learned with cancer though is that even though you walk with somebody through it, it's still primarily their struggle, and I think that's hard because... Cue the tears. Because as a caregiver, you want to make it all right, you know?

I'm just grateful that the Lord's given him this long. His oncologist said, 'I don't have people with prostate cancer sitting in front of me after 13 years.' And that's unusual to make it that long. So that's kind of neat, but it's also kind of a warning in a way, you know?" (114)

Strengthening of faith. Caregivers discussed their experience of cancer diagnosis and treatment, as well as caregiving, led faith and spirituality to become more of a priority. This may have been achieved by the caregiver (and family) engaging more frequently in a faith community. Caregivers also could recognize the patient preparing spiritually for the end-of-life and his/her perspective of the afterlife.

One caregiver cared for a patient who was on life support and was in a coma for several days after experiencing a collapsed lung. She was not expected to survive, which was confirmed in discussion by several physicians involved in her care. Her caregiver stated:

"It definitely makes you realize that God is in control because from what she has had and been through, there's zero survivor chance. So, it's a true miracle from God." (101)

Caregivers could notice when their loved ones were engaged in spiritual preparation for end of life. This may include discussion of people who had passed away and may not have been mentioned for an extended period of time.

"So you noticed even some of the content of her conversation changing, like she was preparing to be reunited with those people at the end of her life and after she died." (110)

Some caregivers reengaged in a faith community, some alongside a patient. It was discussed that these spiritual practices became a higher priority than they had been prior to the cancer diagnosis and caregiving experience.

"As far as spiritually we are back at church. It's been two years since we went to church and we're now all back at church. My husband left the Catholic church a long time ago and he just started going back a little bit but we all kind of put God back in our lives." (108)

"I think that it strengthened my spiritual life and my spiritual walk because she truly believes that she is here today by the grace of God. She would tell you the same." (111)

Development and use of advocacy skills on behalf of the patient. Two caregivers discussed the importance of using advocacy skills that have been learned to support the patient's needs during her treatment process. Advocacy assisted the caregiver in meeting patient needs as they arose and was directed toward the medical team treating the patient. Further, advocacy skills were required within the insurance system to ensure that she could have access to care and services.

"When she was in her coma, or whatever your state that was in, I wouldn't allow the doctor to even say that word (cancer) *around her. I would say, 'Stop, go out in the hallway.' 'Well, she can't hear you.' I said, 'I guarantee you she's hearing every word we say, because I know how she is. Whether she's awake or not, she is listening to everything we said.' And she was, because she said some things I know she heard."* (101)

"And so, like I say the insurance controlling all those issues, they need to get a little closer look at the patients. What is really required? Are we doing an injustice to the patients? They've had so many stories to talk about. Insurance wouldn't pay for it." (101)

"Early on I did a fair amount of research about what treatments were available and talked to different people who had gone different directions with treatment, and then so that we could make some decisions about what to do. Partway through, when we had a pretty inept urologist, I demanded some studies." (114)

Confirmed desire to raise a family as a result of caregiving. The youngest caregiver interviewed was caring for her younger sister, who was diagnosed with metastatic breast cancer before the age of 30. At the start of treatment, the patient had two young children. They did not live in the same area, but the caregiver would come to stay for one to two weeks during rounds of chemotherapy to care for her sister's children so that she could make it through treatment and had the time she needed to rest. She spoke of her reward as having this process confirm her desire to eventually have children of her own, and now she does.

"I would say that I did as far as, I don't even know how to explain it as far as taking care of children and knowing what their needs are and basically they helped me decide that I wanted to have my own kids." (115)

Impact of Caregiving on the Relationship between Caregiver and Patient

Another set of questions asked about the impact of the caregiving role on relationships, first on the relationship with the patient. The majority of caregivers discussed that the relationship between the patient and caregiver grew closer once in the caregiving role. While some caregivers expected this to be the case, others expected that the change in roles may drive them apart but were surprised instead to have grown closer. It is of note that no caregiver perceived their relationship grew apart as a result of the caregiving relationship.

"It's changed as far as I think that it's made us...it has made us a little bit closer, which surprised me because I honestly thought it would possibly drive us apart because he's not a needy person, and I have a tendency to over-help him." (103)

"Well I think he does appreciate me more, even though I said at the beginning that lately not so much. But I think he does appreciate me more and before he used to say 'I do everything' and lately I think he's seeing that I contributed. I don't even know. You know, we talk more. We spend more time together." (108)

"I'm not like that with everyone in my life. There's things I regret or things that I wish I would have said. But with him, he's probably the one person in my life that I just feel everything is kind of at peace. And so, I guess that's a reward, knowing that. And I think for him too, knowing that he can pass knowing that at least, him and I are very much at peace." (109)

"I've not seen him very vulnerable during his lifetime and so I think when we see people in a vulnerable state, at least for me, it makes them more relatable and more lovable almost, because you know okay, they need me. And everybody likes to feel needed. I wish he didn't need me in this way, but so seeing him vulnerable and needing me has made us closer. We've had a lot of one-on-one time to talk about really deep things." (109)

"During those times just to try to help her focus on something else, we would just talk about memories is me as a child and some of the things that we would do, and fun things that I remembered, and that seemed to bring joy to her. So I would say that it's, you know, a difficult situation actually brought us even closer together." (111)

Impact of Caregiving on Other Relationships within the Family

Caregivers noted impacts of the caregiving role on relationships with other family members. Some caregivers described experiences of the role allowing relationships to grow closer together, even when the relationship before cancer was distant or strained. On the opposite end, other caregivers discussed conflict resulting from the family's experience of cancer that led to estrangement. The estrangement was viewed as permanent in some of these discussions.

When caregiving enhances family relationships. At times, the cancer diagnosis improved relationships with extended family members that were once distant or even estranged.

"Yeah so he has an older son and two granddaughters out in California, and a daughter in law. And he used to be so disappointed that they never called or came to visit, they never did much. And actually, back when the melanoma started they came out with the girls, with their daughters, and the kids are three and six. And ever since then, it was like their relationship has grown with all of us, and they come out here probably every other month now. And this summer they came up for two and a half weeks, they were out last month, they're coming for a week at Thanksgiving but they're just always visiting now. The kids write cards, probably every three days he gets a card in the mail from the little girls so he's really been close to them." (108)

"My sister and I have definitely gotten closer. She's nine years older than me and so I think just age wise and distance wise, because we've always lived in different towns, we just didn't really have a connection. But I think through this process, we've honestly become best friends. So I think that that is certainly a reward and my dad would be happy about that." (109)

When caregiving leads to family conflict. Caregivers described dynamics when caregiving intensified relationship conflict. One caregiver interviewed discussed that caring for her father caused negative impacts on the relationship with her brother. She then supported her father when dealing with the fallout of the relationship.

"I saw him just break down into like a sobbing, crying fit because he thinks it's his fault that my brother won't come. He thinks that he did something wrong as a father, that my brother will not dedicate the time to spend with him, even though he's dying. And so, it just really pissed me off, because my dad is such a great dad and I mean, to be honest, my brother is just a very selfish person. And so it really has nothing to do with my dad, but yet, it just tore me up to know that he feels this way. So I kind of, I said some pretty nasty things to my brother. So I'm pretty much sure that relationship is severed, and part of me doesn't really care. Just because I feel like I was defending my dad, and so that relationship's not been improved by the situation." (109)

Furthermore, another caregiver discussed challenges between longstanding conflict between her sister and the patient, her mother. In the caregiving role, she was thrown between the two and became involved.

“I tell my sister but she doesn't really listen to me, she just lives her life…they were going to stress me out the other day, and I had to shut them down because they were getting mad that I don't tell them anything, but I don't have time to play phone tag with them. If I tried to call you one time, and you don't answer your phone or call me back then I don't care. You know because you guys don't get along.” (107)

Caregiving when parenting minor children. Five caregivers interviewed were actively balancing parental tasks of child-rearing simultaneously with caregiving. It was explicitly discussed by them that caregiving prioritized parenting at times. These caregivers also discussed the negative impact that caregiving had on their children.

“I will say the kids kind of suffer. We wouldn't normally leave them alone 'til ten at night, but when we go up to the hospital, the kids are alone, basically, from the time they wake up until they go to bed, so it does allow that to also get into bad habits and make bad choices. They've been getting into a little bit of trouble.” (108)

“So I feel like I have not been there for the kids at all. I do feel like they really emotionally suffer because I put so much into trying to make dad's life good that they definitely have suffered. My 13 year old is basically just out around town on his bike all afternoon, I don't even know what he's doing any more. And the other guy, my 16 year old he'll go away with dad or have to go away with us just because we know it might be dad's last this or dad's last that so we do what dad wants but basically they're like, ‘But what about us? We don't want to do that.’ It's like they've been put last and they're feeling like they're last, I think. So I think that that's really bad. I think emotionally, that's the one thing. We actually just started getting help yesterday for my older son because I think it's really starting to, he's starting to act out because as much as he's sad that this could not go in the right direction I think he's also feeling like his feelings aren't respected.” (108)

“I have two boys myself. One of which has some special needs. And so that has probably honestly been the most stressful. I mean, aside from knowing I'm going to lose my dad, but having the day-to-day stress of when I'm away either at the hospital or at my parents’ helping take care of him. My youngest son that has some special needs, knowing that I really need to be there for him as well is really stressful on me.” (109)

Impact of Caregiving on the Caregiver’s Perspective of Health

Caregivers were asked for their thoughts on being an advanced cancer caregiver and how this role his contributed to their overall perspective of health. Not every caregiver had a specific response to this question. Others discussed how watching their loved one dealing with cancer changed their perspective and behaviors related to their own health.

“I've always thought, watch out about my heart. Now I'm thinking cancer. I've already looked at some of the things. Some of the cancer things, I can't help. I had my first child at 30. I am trying to lose some weight because I know weight gain is one of the things that can do that. I haven't had my mammogram this year, but I'm going to get it. It made me more conscious of what could happen to me.” (102)

“I know that it has certainly made me become more aware of my body and be almost hypervigilant about self-care and about doctor's appointments and follow-ups. Because I know that mom is here today, and she is a survivor because of early detection…It certainly lets you know that life is precious and life is not promised tomorrow, and you have to live each day to the fullest and make memories, as many memories as you can, because you never know when you look back that that might be all that's left.” (111)

“He probably should have had more screenings, but we didn't have a lot of insurance…so I mean, if he had had better insurance or had insurance, than maybe we could have caught this a little quicker than what we did…definitely go get your checkups and go to the doctor like you're supposed to. Because he has never been a check-up kind of guy, or a doctor kind of guy. But now with all these things, and it's like, I have to be more out looking and make sure, ‘Yes, you got to get to this. Yes, we've got to make this appointment.’ So that's just my biggest thing, is making sure. Now he's at every check-up.” (112)

Effects of Advanced Cancer Caregiving on the Domains of Quality of Life

Research question four asked the following: How does advanced cancer caregiving affect each of the domains of quality of life (physical, psychological, social, and spiritual)? Every participant from the study indicated impacts of caregiving on at least one of the domains of quality of life (physical, psychological, social, and spiritual). Each of these areas will be explored further in the section to follow (see page 119). Further, impacts of caregiving on the quality of life of caregivers are of significance and have a theme developed to the topic.

Impact of the Rural Setting

The fifth and final research question asked the following: What is the impact of living in a rural community when caregiving for an advanced cancer patient? Caregiving within rural environments contributed positive and negative aspects to the experience. The most frequently mentioned positive impact of the rural community were the neighborly actions experienced when at the time of and subsequent to the cancer diagnosis. On the opposite end, caregivers elaborated on the time and distance traveled to access medical care and treatments.

Positive impact of living in a rural community. Caregivers described the positive aspects of rural communities as being neighborly (8 participants), living in close proximity to people within their support systems (6 participants), and emphasized the safety of the community (2 participants).

“Small towns though they seem to help one another.” (105)

“I think the people. The community, everyone knows my dad, everyone knows my mom. So I mean, people are constantly sending cards. People have actually gave so much money. I didn't know that people did that, and we open cards in their mail, and there's $200 in a card which is just so generous. But I think the community support that you get in a small town is awesome.” (109)

“You get to see a lot of people that you grew up with and you know you're familiar with and you just reflect and you can reflect, you know, on all of those people and have visitors and it's close like that.” (110)

“Our family all lives in the community. My mother's father was living there. My father's parents were living there. My mother's sister was there, so she did have some other family support there.” (111)

“The church community, and then their bus driver even came to the church service the other day and she said that she was still praying for us and everything.” (112)

Negative impact of living in a rural community. The most frequently mentioned drawback of living in a rural community is the travel required to access medical care (8 participants).

“We traveled. It may not seem like a lot to anybody from (home area to location of hospital), *but when somebody is weak and tired, it's hard on them. So, if we lived closer to the facilities, it might've been a little easier…yeah, because you think about it, we'd spend, what, 45 minutes getting up there. Then you spend six or seven hours at chemo, then 45 minutes coming home. That got old pretty fast.”* (113)

“Even when we called an ambulance to come out, it took them an hour to get to our house.” (101)

“Those two places are where the leading specialists, leading neurologists in this type of brain cancer is. So if you want him to live longer than that, you have to go there. So we immediately took him there, and that's where all of our treatment is. But like I said, it's two and a half to three and a half hours from my parents' home. And they want to do everything, they want to do every lab, they want to do every MRI.” (109)

It was discussed that rural communities have more limited options for resources (5 participants). Further, caregivers discussed some negative impact of the lack of anonymity within small communities (2 participants).

“I think in a big city it'd be easier, because you'd have more resources around to go to. Hospice is good, but right now they only come in once a week. I don't know if they would come more if it was a bigger organization. They're doing what they think mom should do, and I think mom would just wish they didn't come at all. I just like some reassurance when they come.” (102)

“I think living in our area just does make it a little bit challenging…because there's not really any place to go.” (103)

“I mean, there are no resources. We have looked into sort of support groups, like I said, for my mom and things like that. Or like food type of situations, ‘Let's bring food out,’ or I mean, anything. And it's just so limited because of it being a small community.” (109)

“I think that in a rural community you're going to have kind of that small town mentality.” (111)

One caregiver also described the impact of loss of power and the time it takes to be restored, which became concerning when the patient had medications that require refrigeration.

“Some of the needs are very different than what you would think. I mean, when we are off the grid, if our electricity goes off, we are on...we've been told we're on a transformer unit that there's only three, maybe, or two other residents on there. If it's a major outage, and everybody's out, we continue to go down the list to be restored, because they do the most houses on a transformer first.” (101)

Results of Data Analysis

Upon organization of open codes corresponding to each of the research questions, axial and selective codes were then developed to add further detail, link open codes, and work to develop the themes of the study. The themes include the following: caregiver multi-faceted experience of loss, medicine is a foreign language, unexpected strength in community, significant impact of the caregiving role on caregiver quality of life, and the balance of forced mindfulness (staying in the moment) versus anticipating grief and loss (being future-oriented).

Caregiver Multi-faceted Experience of Loss

The caregiving role encompass a multidimensional experience of loss. Some losses are actual and occur instantly at the time of cancer diagnosis and shift into the caregiver role. These losses include the shifting in roles of relationship with the patient and employment or financial changes when caregiving tasks impact the caregiver’s ability to maintain employment at the same level. Some losses build over time, such as loss of self-care, loss of social relationships, and other impacts of caregiving on the quality of life of the patient. Further losses are anticipatory based on the terminal diagnosis of the patient and finality of the illness in death. It is of note that not all caregivers directly discussed the finality and terminality of the advanced cancer diagnosis.

Loss of Self. Several caregivers discussed that they know they should take better care of themselves in different ways, such as improving diet, exercising, and taking a break. However, due to the number of tasks required to be completed on a daily basis, they did not follow through with these activities.

"I know what to do and how to do it and I don't do it for myself." (105)

"I gained like an extra hundred pounds. I don't do as much as I used to. I go out, and do different things. Okay. It's bad. Like it's real bad. I just don't tell her (the patient)*."* (107)

"I know I don't take care of myself, and I feel like at the same time, you know, I want to help my mom, but I feel like life is short, and I really don't have time to be bitter all the time." (107)

"As far as me I don't work out any more, I don't walk, I don't go to yoga, I don't really exercise anymore that much. I might go for a walk with a friend just to talk but that's just a little walk. But I don't really do much as far as taking care of myself any more…there's no time. Basically, it consumes every minute of my day. There's no extra time anymore for me. For my own, you know, just for me." (108)

"I think it's definitely taken a toll physically, of not sleeping at all and definitely not practicing self-care. Probably drinking more than I should, or not exercising as much as I like to because that's my stress management tool, burying myself in work in order to sort of, when I'm away to sort of cope." (109)

Caregivers explicitly mentioned the emotional toll of this role. Depression was specifically mentioned in some interviews. Anxiety was also noted.

"I, I don't, I feel like I just exist and I don't live… But it's just, I don't know, I'm just being so angry sometimes. Initially I just feel like I'm not the person that I used to be, and it makes me sad." (107)

"So I am definitely depressed. Like definitely, absolutely, I know I am because when I'm depressed. When just everything bothers you, you know? I'm sure I'm depressed. And emotionally I look like I'm smiling all the time but really it's because I'm so close to crying all the time. So I think I'm so close to tears that I cover it up with a big smile." (108)

"I think I'm probably just a tad bit depressed. I don't feel like running out and hanging out with people." (109)

"I stopped doing anything. Just too depressed. If I would do something, I just wasn't there, so I just completely pretty much stopped doing things." (115)

One caregiver discussed that she recently began taking antidepressant medication since her spouse's cancer diagnosis to help her sleep and to manage stress better.

"Once again, it's gone from a normal amount of stress to like over the moon stress. I mean, even taking medicine, because they just prescribed me something, I've been on it for almost like a month now. And she (the prescriber) *said, 'Oh, in about a week or two, you'll be able to feel the*

difference.' Yeah, no…no. I mean, I'm still just as anxious and jumpy and everything's freaking me out and my mind's constantly just like…racing. All the time." (112)

Furthermore, caregivers could not attend to other physical health issues as a result of the time involved in caring for the patient. One caregiver discussed that prioritizing care for her mother meant there was a focus missed on growing medical issues of her spouse. She discussed her perception that these medical issues could be the focus at a later time.

"My husband, I'm pretty sure he's in early stages of dementia because of all the blockages in his brain, and we haven't been able to get some of the stuff done with him that we probably should have. We'll just catch that up when we can." (102)

Also, caregivers were limited to intervene in their own medical issues as a result of the time involved in going to medical appointments. One caregiver was experiencing extensive medical complications because of delaying a needed surgery, which was more of an issue when the surgery required a period of recovery afterward. Additionally, caregivers did not maintain preventative or primary health care based on prioritizing the needs of the patient instead.

"I've been sick with my own problems. I was supposed to have surgery back in July. Of course, it's very hard for me to have surgery when I know I have to be around for them. I actually need a hysterectomy. I'm just very uncomfortable. I'm keeping an eye on it every few months, but I thought the surgery you want to have for this, in the middle of something like this." (108)

Loss of relationships. Caregivers discussed that relationships with their friends and family members changed, sometimes immediately at the start of the caregiving role. One caregiver even described this phenomenon as "cancer is contagious" when discussing avoidance of her and the patient by some members of their support network.

"But there was a person who became offended, and has dropped off our radar. And that's okay." (101)

"So, people just don't want to deal with...they don't want to deal with cancer even though it's not them that's dealing with it, that it's almost like they're going to catch it if they come over to your house." (103)

“Like for instance, somebody just the other day told her that he didn't want to be around people with cancer.” (106)

“I tell my sister but she doesn't really listen to me, she just lives her life, and in her sisters saw if they were going to stress me out the other day, and I had to shut them down because they were getting mad that I don't tell them anything, but I don't have time to play phone tag with them.” (107)

“It's not really fun to hang out with the girl who has to like, ‘Oh, sorry. I have to cancel these plans, because I have to drive up and take care of my dad.’ It's like, they may be having a social function, and I just came back from taking care of my dad and I might not be in the right frame of mind to let loose and have fun. So we've kind of been, stopped being invited to as many things because of it, or we've had to miss things because the priority is on my family right now. So I think that's definitely taken a toll. And honestly, I'm tired. I don't want to do things.” (109)

Caregivers feelings are masked to focus on the patient’s needs. Several caregivers discussed neglect of their own feelings to focus on the emotional and physical care of the patient. Even though caregivers spend extensive time with the patient, they were very guarded to display any emotional reactions in the presence of the patient. Caregivers mentioned feelings of guilt about their true feelings that they kept from the patient.

“I'm scared that she's going to die any time, I'm just scared to death of it. And of course I can't say that to her, you know?” (107)

“I would come home and the only person that I would say that I was tired to or that I would actually admit how bad it sucked to have to continue to drive up there and stuff was my husband because I knew he was going to love me no matter what. But I would never admit that out loud to anybody else, because I would feel ashamed or guilty for feeling that way.” (109)

“I’d be strong in front of him, but then when I would leave, go outside and leave the room, I would just bawl. Because the idea of thinking that I could actually lose my husband…But I mean, I try not to think about it as much or if I do, I try not to do it when he's around. So I'll cry in the shower or if he doesn't feel like going for a walk, I'll still go for one and cry so that way he's not seeing.” (112)

“I never let him know…I just kept telling him everything was going to work out.” (113)

“But I would say, thinking about this a little bit, that if...sometimes I think we may not speak as openly or honestly about our fears. Because we don't want the other one to...we want to both cheer the other one up.” (114)

Furthermore, patients would emotionally act out toward the caregiver in their role of a sounding board, someone to whom the patient could ventilate feelings and stressors, or simply would be a target of frustration for some patients.

"I guess the sounding board is a negative because he takes all of his aggression out verbally normally to me, so that gets frustrating and challenging." (103)

"They yell at me and then I get to where I don't feel right and I feel like I've done something wrong." (105)

"I get frustrated with her because she's still smoking, and that really gets me. And I'm always trying to get her to quit, and encourage her to quit. And so that's probably the worst thing is she's just so stubborn…It's just, it's hard to, I try to stay positive, to keep (the patient) up, and sometimes it's really hard to do that, especially when I see what she's doing to herself, you know?" (106)

"We're pretty close, I would say, even though she's mean to me sometimes, but I know that's because she's so angry with, you know, she's not happy with how her life is." (107)

Loss or significant changes in employment or financial status. Changes in employment or financial status could be two-fold. Caregivers may not be able to work at all or as often due to caregiving burden. The household may have also lost income because the patient is not able to be employed or work as often due to medical status or side effects from treatments. In the case of patient employment being affected, caregivers often did not know how long those circumstances would last.

"And so, I find myself thinking, 'Well, we're in a pretty low income category, and we have some forever money.' But, it's scary to think, 'Well, how are we going to get through this?'" (101)

"It was going to cost additional thousand dollars a month to have the coverage that he needed for cancer. So, we have been taking cash withdrawals out on his credit cards to pay his premiums. The hospital here has a...they applied for Medicaid for him. I did get word yesterday that he has been approved." (103)

"So, it's a good thing that he's not needy as far as me needing to be home to take care of him in this time because I'm carrying a financial role for both of us. I think that upsets him because he feels that I'm taking care of him, and so it has...I think finances have put a little bit of strain on us." (103)

"We're paying basically just the deductibles and it's been just like a few thousand dollars as far as what we're paying out of pocket. There is a little hardship when it comes to lost work because,

you know, each time he goes for a test and he goes for chemo it is lost work. But, the bills have been manageable for us, so we're very, very lucky that we have good insurance." (108)

"Well, I want to shield her. Try to, so she won't get upset so I just started to deal with everything (financial)." (107)

"I've racked up thousands of dollars of credit card debt just from staying in hotels. When he's at the hospital, we stay at the hotel and it's $250 a night. And I've stayed there probably 20 nights, so I've put that all on a credit card, so a little bit, a lot a bit of financial stress there too." (109)

"I worry about of course how our bills are going to get paid. How I'm going to feed the kids, making sure you've got gas to go back and forth to his appointments, trying to make sure to have the out of money pocket expenses for the cough medicines and the diarrhea medicines and the things that are not covered by the insurance." (112)

Loss of intimacy. Caregivers discussed changes in the ability to be physically and sexually intimate as a result of the cancer treatment, side effects, or other aspects of physical health changes.

"We have become closer, but due to his circumstances, there's no intimacy. Very little contact, because ... I'm afraid to touch him right now because he has chemo pump attached to him and a needle in his chest." (103)

Intimacy changes also were discussed related to emotional intimacy and the challenges in supporting the patient when he/she was not inclined to discuss stressors or feelings about medical status.

"I don't know what he's going through, and I mean, he'll talk to me about it some but not a lot. I mean, just like if something's hurting him, then he'll tell me. But he hasn't ever really told me what he thinks about this diagnosis. Because he's never been that kind of a person, that was emotional or talk about what's going on. Yeah, if something hurts him, he'll tell me, 'Hey, this is hurting today.'...but I really don't know how he feels, so that's kind of... I wish I knew, but I mean, he has to deal with his things in his own way. So that I think is the hardest is, if he gets a bit snippy and I just try to... because I don't really understand what he's going through, because it's not me, so I don't know." (112)

Loss of typical roles and responsibilities. The caregiving role shifts the focus off of the prior relationship (spousal, parent-child) to focus on the needs of the patient. The following examples refer to specific roles that were held between the patient and the caregiver, as well as the surrounding family system.

“Life is different now. It will be forever. And so, we don't even know what the new normal is going to be.” (101)

“I just go home a couple of days a week, close my eyes and hold my breath, and walk in. Hopefully if the house is still standing. My son's home and he has Asperger's, so he doesn't have a full time job. He dog sits but, he doesn't have a full time job. He's here with my husband who has a multitude of health issues, and all of our animals, except for the one I've got here now…He (referring to the caregiver’s husband) is running the house, pretty much. Feeding our animals, and taking care of (husband) and he's had to do a lot more, so he's had to step up.” (102)

“It can be very stressful. It is very emotional because at some aspect, you become a caregiver and no longer a spouse, and that's hard…Becoming more of the finance person, the bill payer, the grocery shopper, sometimes you feel more like, almost like Mom or the maid instead of a spouse. So, emotionally, that is challenging to get over.” (103)

Anticipatory loss of the patient. Caregivers discussed the challenges of considering finality of life, especially in respect to their loved ones. It is interesting to note that many of these emotions are kept private from the patient. This further promoted the experience of masking emotions for the sake of the patient and the mutual worries that caregivers and patients have for one another.

“I don't know what I'm going to do when she is gone. I know it's coming, so I'll just deal with it until then.” (102)

“Watching someone die is one of the hardest things I have to do as a caregiver.” (105)
“I don't want to say pity, but you know, I feel sorry for so much, and I don't want to, I try not to talk about something like that. It's hard to keep her up, you know? But I've always had this, I'm scared that she's going to die any time, I'm just scared to death of it. And of course I can't say that to her, you know?” (106)

“So those are the challenges. Is being able to be there, being able to keep going with your own life when you don't know if there's going to be a tomorrow for him.” (108)
“I mean, we've always had a fantastic relationship. I think just, it's almost like being allowed to have closure. If someone dies in a car accident, I mean, seeing the suffering of cancer just sucks terribly bad. But someone dies in a car accident, it's like you don't get that like, ‘I just want to let you know how much I love you,’ kind of thing, but when someone is dying, you get that time and you get to prepare kind of for that.” (109)

One caregiver described this experience even before the loss to death, as she discussed the decline of her spouse's physical status due to the cancer treatment. She talked about how seeing him in his current physical status was a significant change from his typical self.

"Just seeing him not being able to do everyday tasks as not even walking to the bathroom without getting out of breath, that for me, the hardest part is just seeing him not be the man that he always was used to being." (112)

Medicine is a Foreign Language

At the time of advanced cancer diagnosis, patients and caregivers are instantly thrown into an often unfamiliar medical world. Many of the caregivers interviewed did not have any educational or personal experience with different aspects of insurance and the healthcare system prior to this time. Five caregivers were currently or previously employed in healthcare settings (nursing, social work, nursing assistant), so these caregivers discussed the benefits of their work histories on caregiving. Other than these examples, medicine and healthcare were foreign based on a number of factors, including the nature of relationships with medical professionals (specifically physicians treating cancer and its related issues), understanding medical jargon, navigating of health insurance and medical care, and requiring medical training to support caregiving.

Relationships with medical professionals. Caregivers manage complex relationships with medical providers. There were several related issues that built this theme. One specific instance involved authorization for pain medication, conversations with physicians related to questions and concerns, and a perception that the physician was not direct and clear about limited prognosis.

This initial example involved a caregiver who helped the patient access needed pain medications through the prior authorization process. During the circumstances, the patient and caregiver felt judged by their need for the medication (potentially viewed as medication seeking instead of having legitimate pain management needs).

"Professionalism in every step of the way needs to be emphasized. I am not here to be judged. I am here to be treated." (101)

"Now, if you see something that you want to talk to me about, that's wonderful, we can always have a conversation. But sometimes you do feel like, well, they think I'm saying that I hurt so I can get this medicine or something like that. Which, for us, couldn't be further from the truth. In fact, they had told me and I listened and I do it. They said, 'You have to stay on the medicine for the pain, or you won't heal.'" (101)

Another caregiver described hesitance of the patient to ask questions or upset the medical oncologist for fear the physician may become angry or irritated. In this example, there was even a discussion about how the physician had saved the patient's life before, so "let him do his work to do it again." In this circumstance, the patient did not know many details about the treatment being received and the caregiver was pushing her to ask more questions and get more information.

"She's like, 'No, no, no. Don't be, don't be asking him questions. Don't make him mad or anything.' And I said, you just, she's got this attitude like, it's Dr. (name removed for confidentiality). *And she said that he saved her life before, that's how she puts it. So she just expects that this time…"I said, 'You know, okay number one it* (the returned cancer) *is worse now.' And I said, 'Number two, he's not God.' And I said, 'You have to help too.' I said, 'It's your body, open your mouth, ask questions, tell him what's going on.' If she's hurting, she doesn't even tell him, you know? She doesn't know anything about her treatment or anything."* (106)

The final example was from a caregiver who very recently lost her spouse to his lung cancer. Looking back on their experience, she felt that there were gaps in information provided about his prognosis and some of the signs that his health and condition were worsening. The patient experienced specific challenges with some side effects; the caregiver felt that written information (pamphlets, brochures, educational materials) that was shared with them did not address their circumstances.

"If they would really actually talk to more people that's actually took care of a cancer patient and talked to cancer patients themselves and kind of get ideas of what they're actually going through and to give people a better idea of what they might go through, I think it might help them a little more." (113)

This patient had challenges with loss of appetite related to concurrent radiation and chemotherapy treatment. The caregiver felt pressure that she was not meeting his nutrition needs based on multiple conversations with providers. This was a definite contribution to her stress level.

"Well, like I told them, 'I can't make him eat it. And what do you want me to do? Get a funnel and pour it down him or what?' And they looked at me like I was plumb crazy, but like I told them, 'If he don't want to eat, I can't make him get more protein when he won't eat.' And they need to not make a caregiver feel like they're doing something wrong because they're not getting him to eat." (113)

As his health began to fail, the caregiver felt that despite having visits from multiple members of the medical team, no one was direct with them about the prognosis. They had several hospital stays in a short window of time. At his last admission, the patient and caregiver were surprised to hear that the cancer had become too aggressive and that a discharge home with hospice care was being recommended at that time.

"And even after he started having fluid, they kept being real optimistic because he got the fluid around his heart, and he got the fluid around his lung, and that's bad. And nobody really told me that was bad except for Dr. (name removed for confidentiality). *Everybody else kept saying, 'We're still on the right track.' And just the week before he went on hospice, Dr.* (name removed for confidentiality) *told me the tumor was shrinking, the lymph nodes was shrinking, we was right on track. So I thought, 'Okay, everything's good.' We go home on that Friday, come back on Sunday, and then Monday they put him on hospice and tell us it* (the cancer) *was too aggressive. I just felt like I was lied to because somebody should've told me this was worse."*

"Yeah, and I felt like they kept sugar-coating everything and pretty much lying to me until I confronted them. And I don't think they should do that to people. I don't think they should take a lot of hope away from him to begin with, but when they see things are getting a lot worse like they did with (the patient), *I think they should've said, 'Hey, you guys might want to prepare*

because this might not come out the way you're thinking because it's a lot more aggressive than we thought it was going to be. And you might want to prepare yourself for this not turning out the way we hoped to.'"

"Yeah, I think they should not do that. I think they should be more realistic with people because whether you realize it or not, people can take it." (113)

It is of note that there were two interviews completed shortly after the patient passed away. Other caregiver participants had not seen their loved ones experience this type of decline. There is not a comparison basis to how this may have looked within other cases.

Lack of medical training or background to support caregiving needs. Caregivers unfamiliar with provision of medical services felt that they lacked training for the care tasks they were completing. This seemed to be of greatest concern related to navigation of healthcare access and insurance issues, completing personal care tasks (especially positioning and dressing changes), and management of medications.

"I've told everybody this one, I had no medical background. None, zilch, zero. She has to be changed every four hours. Sometimes it goes through on the bed. I just learned a trick the other day on how to do the sheet underneath her. Physically, taking care of her has been the worst thing. Just knowing what to do. Because I have no nursing background." (102)

One caregiver had to complete daily dressing changes for wound care. While a home health care nurse did come out to show how to change the dressings, insurance only paid for one visit to do that.

"The insurance needs to get a little more personal with the patient before they say 'We're not going to pay for the visiting nurse to come out,' because they (home care nurse) *should have come out a lot more than what they did…they came when they could, but the wound care for my right foot amputation, which is not related to the cancer...and it paid for her to come and do a dressing change twice a week...I had to do the rest of it."* (101)

Medical jargon. Caregivers had challenges negotiating medical terminology. This impacted understanding of treatment process and recommendations when meeting with medical professionals to discuss plans. This was mentioned to be a larger challenge at the start of the diagnosis.

“Sometimes the medical staff, they will use such words and not everybody will say, ‘You're speaking Greek. I don't know what you just said.’” (101)

Navigation of health insurance and medical care. The complexities of the healthcare system became challenging for every caregiver in their own individual circumstances. A few caregivers expressed intense gratitude that their insurance was comprehensive and they did not have extensive out-of-pocket obligations, but this was not the norm. Others had extensive challenges and concerns with insurance and financial issues. Caregivers felt that that it was highly difficult to get information when requested and to have questions answered by insurance providers.

“The insurance needs to get a little more personal with the patient before they say, ‘We're not going to pay for the visiting nurse to come out,’ because they should have come out a lot more than what they did. I have had a coach or a case manager with my insurance. She's called to check on me. They're very good at evading questions.” (101)

“And so, like I say the insurance controlling all those issues, they need to get a little closer look at the patients. What is really required? Are we doing an injustice to the patients? They've had so many stories to talk about. Insurance wouldn't pay for it.” (101)

“I didn't know all the system and I didn't know what it was all out there. And from my job as a nurse, I'm removed from what a lot of programs exist. So not having the time to look up all of that.” (110)

Revisiting caregiver ideas related to ideal supports. Of significance in this theme of medicine as a foreign language was the discussion of ideal resources by caregivers. Ideal resources were repetitive throughout the interviews, and many of those ideas about resources involved navigation of the health care system or the treatment process. Additionally, ideal resources were focused around supports that would be helpful if the family had access to more financial resources. The most frequently mentioned ideal resource was to have networking opportunities with other experienced caregivers. Several caregivers discussed how much this would benefit them, but because their time was so limited, they weren't sure how they could facilitate access to that kind of support.

Many of these support ideas involved assistance in care for the patient or completion of household tasks that caregivers were challenged to accomplish on their own. Resources would assist with the daily tasks that caregivers were challenged to be able to complete due to time limitations, such as meal preparation, cleaning, and personal care for the patient. It is significant to note that caregivers discussed that in-home supports would primarily support the patient, but would also be used to support the health and nutrition of caregivers so that they could better sustain themselves.

The other theme in caregiver ideas of ideal resources revolve around system and treatment navigation. Caregivers discussed their need for reliable, free transportation that would allow for caregivers to accompany the patient to medical appointments and chemotherapy treatments. Due to the burden of gasoline costs and concerns related to traveling in periods of inclement weather, simply having more relief related to the stressors of transportation was perceived as significantly helpful. Further, caregivers discussed an idea for inexpensive or free lodging that would prevent long-distance travel for appointments. One caregiver related this to the resource of the Ronald McDonald House (RMHC, website, 2020). This organization offers living space for parents and families of children who are hospitalized for extended periods of time at little to no cost for the family.

One caregiver suggested having access to telemedicine or phone consultation with physicians that may limit long distance travel to the hospital or a medical office for an appointment. A need for overall medical system navigation was identified, especially tailored to address financial support, programs, and advanced directives, as well as discussion of expectations about end-of-life. Caregivers experienced anxiety and worries about planning for terminality, but were underprepared with information or resources that could help alleviate concerns.

Unexpected Strength in Community

While the experience of living with and caring for a patient with advanced cancer is clearly overwhelming and isolating, many of the interviews discussed the actions taken by their neighbors and community to support the patient and caregiver throughout their experience.

"My neighbors next door are real nice and I talk to them. They been over there maybe two years and if they need something that I got, they can get it. I'll go over there and talk to them. Every now and then she take her dogs out in the yard and I talk to her. They both know (patient) *got cancer and she said that her either her dad or her mom died from cancer a few years ago. So she related to what I'm going through."* (104)

"I think in a small community they respect you more. In a larger community, you don't see that many people. But here you're friends with just about everybody. Everybody knows everybody. Small towns though they seem to help one another." (105)

"After her chemo, she would have to get a Neulasta shot and a Neulasta injection. So the challenge was that she had her treatment in (urban area more than one hour away)*. So when she would come home, then her physician was in* (the next largest town to them)*. So that was a 30 minute drive, and she, you know, didn't feel like getting out to get that Neulasta injection. So that was a challenge because now what do we do? So we actually found a nurse practitioner in the rural area that we live in. If the physician in* (urban area more than one hour away) *gave her the script, they would go to our pharmacy and fill it. Then the nurse practitioner would actually come to my mother's home, and she would give the injection there."* (111)

"Something happens to somebody, the whole town kind of comes together. You know, neighbors were bringing, you know, some things, some food over. The church family was very important at that point in time. So that was certainly a benefit was the support in the community." (111)

Despite an assumption that living in a rural area and experiencing advanced cancer may bring many challenges, this experience of community appeared to mitigate the burden of travel requirements and lacking resources. It is interesting to note that the discussion of the impact of living in the rural community carried a more positive tone than a negative one in nearly every interview. One caregiver did have a negative perception of the rural community, but she and her family moved to a new area from a much larger urban area just two months before her husband was diagnosed with advanced lung cancer. Their family was not yet able to develop a support system (outside of their church home) prior to the cancer diagnosis.

Advanced Cancer Caregiving Significantly Impacts Caregiver Quality of Life

Every caregiver interviewed noted specific impacts on each of the four domain of quality of life (physical, psychological, social, and spiritual). From interviews with these caregivers, the most evident area of quality of life impacted was on the social domain. Nearly every caregiver also indicated concerns with the physical domain of quality of life, especially when considering the impacts on sleep and feelings of exhaustion. Caregivers also emphasized psychological/emotional impact. When addressing spiritual quality of life, some caregivers felt this area was either positively impacted, negatively impacted, or there was no effect.

Social quality of life. Caregivers discussed the impacts of caregiving on their social relationships. They had little time available to spend engaged socially with others. Others specifically stated that any social life was nonexistent due to the time spent caregiving while balancing other responsibilities. Caregiving was a distinct priority over social relationships and the time spent to maintain them.

"It's hard. I'll run home or if I'll run somewhere, but if I know I'm somewhere where, I'm too far away, it might be hard to get away. Not that I was ever that social, but I used to do transports every weekend and I don't do those now…I don't go out as much because I know, not that she's gonna need that much, but if she dropped something, or if she would need something and I can't get away fast, then usually the kids will come over. Sometimes that's not an option." (102)

"I don't do nothing but stay at home and watch TV. I couldn't change too much, it's just I got to help him out. I don't have company over to the house no more." (104)

"I don't have a social life. I have no social life." (106)

“Like sometimes I'm not happy because, and I know that I choose to take care of her, and do whatever I can for her, but as soon as like I never get away, it feels like I just exist…I don't live at all, and sometimes when people ask me to go do different things, and go like to concerts, and different things, I'm like I can't because I don't have anybody to take care of her.” (107)

“Because mom's needs came before any, you know, shopping or going out to eat, or having a drink with a friend, or any other relationships really. Even with my husband, which thank God, he was so understandable.” (111)

“Yeah, I didn't worry about what anybody else needed but him.” (113)

Another caregiver described her experience as not having the time and energy available to maintain her social relationships. She described this as a shift in what would typically be her personality. This change was perceived as negative.

“I think I've become more self-centered. I don't ask anybody how their day is anymore because I've got so much going on in mine that I think I've become more self-centered. It's all about me and my family. I think that's a bad thing. I don't think that's a good thing.” (108)

Another caregiver felt that her social relationships and friendships were impacted. She felt that she lost friendships due to having to change or cancel plans. This could happen because she felt fatigued or because responsibilities of caregiving were a priority if an issue arose in care for her father.

“I feel like I've actually lost my friends over it. Friends like, and I don't know how good of friends they were, but and we just moved to a new community and so these are friends that we've kind of just recently made, but they don't really want... It's not really fun to hang out with the girl who has to like, ‘Oh, sorry. I have to cancel these plans, because I have to drive up and take care of my dad.’ It's like, they may be having a social function, and I just came back from taking care of my dad and I might not be in the right frame of mind to let loose and have fun. So we've kind of been, stopped being invited to as many things because of it, or we've had to miss things because the priority is on my family right now.” (109)

Physical quality of life. Caregivers discussed the impacts of caregiving on physical health. There were several physical impacts, including physical demands, ignoring their own medical issues, impacts on sleep, and lack of proper nutrition. Some caregivers experienced a number of these varied impacts on physical quality of life.

Caregivers experience physical demands as a result of providing personal care to patients. They can experience strain due to transferring from furniture to the toilet and repositioning while in bed or in a chair. Some caregivers complete these tasks on regular basis as part of a daily routine.

"It's just taking a toll on me. I do what I can, it's hard. And then with my aches and pains that ain't doing me no good, and he's around here hurting…yeah it hurts to take care of him but I do it." (104)

Caregivers were affected physically to the point of developing their own medical issues. Caregivers discussed that their own health issues became of lesser priority than care for the patient. Caregivers openly discussed did not deal with those physical health issues at the level that was needed. One was putting off a recommended surgery for some time, due to the impacts of the recovery time on her availability to support her husband, who was undergoing treatment for pancreatic cancer.

"I've been sick with my own problems. I was supposed to have surgery back in July. Of course, it's very hard for me to have surgery when I know I have to be around for them. I actually need a hysterectomy. I'm just very uncomfortable. I'm keeping an eye on it every few months, but I thought the surgery you want to have for this, in the middle of something like this." (108)

Caregivers also openly discussed the impacts of caregiving and its burden on their sleep. They often discussed feeling exhausted and fatigued on a regular basis. Their ability to sleep, even during respite periods, was highly impacted.

"I'm just tired. It just took a toll on me, I ain't got that energy, I ain't got that stamina, I ain't got nothing no more. I ain't slept for 2 days, 2 days I'll go get in the bed. Because I'll sit and watch TV till about 1 o'clock, when I get into the bed I might nod off then I look at the clock I ain't been asleep at all. I ain't slept for 2 days." (104)

"I just don't, I feel like I'm being pulled… I can't remember when I've slept all night through." (105)

"Probably not getting as much sleep as I should I would say. We'll (patient and caregiver) *stay up and talk until three in the morning sometimes."* (106)

“So I'm exhausted. I didn't realize how much emotional exhaustion can make you feel physically sick. I feel like my adrenaline is always going, my heart is always beating in my throat. But you're always trying to look calm.” (108)

“And then, I would just say just constant fatigue from running back and forth…I've had health issues like migraines and different skin issues and things like that I know are 100% related to stress and it's like my body's way of saying, ‘You actually are really stressed out,’ even though my mind tells me that I'm not. So, I probably am not, like I said, I think I have some probably coping mechanisms that aren't as healthy instead of just sort of embracing it.” (109)

“He would be in that bed, and I'd sleep on the couch. And when I'd hear him move, I'd get up because I knew I had to go help him to the bathroom or whatever, you know?...so you just kind of catch catnaps here and there or sleep when they do. And I told them, I said, ‘Most of the time, I'm just exhausted,’ but you just get up and do it again. (113)

In some interviews, caregivers discussed that they were neglecting their own nutrition and overall care.

“I don't feed myself properly and because I'm on the go all the time so I grab a sandwich or something.” (105)

“And then I feel like I'm neglecting myself, and I'm thinking, Oh my gosh, I'm starting to go downhill even more so myself.” (107)

“I feel like I've been like that, I haven't been eating well, I haven't been planning meals or anything so, basically just eating take out and whatever food people brought us. Which is, you know, lots of cookies and baked goods.” (108)

Psychological/Emotional quality of life. Caregivers very readily discussed the emotional impact of this role. Their experiences were framed as stressful, emotional, and overwhelming. This became more of a burden when they were juggling other responsibilities in addition to the tasks of and time dedicated to caregiving.

“It is a stressor with everything else going on. It's just that on top of that. I know won't last forever, unfortunately. That's kind of the bad thing.” (102)

“It can be very stressful. It is very emotional because at some aspect, you become a caregiver and no longer a spouse, and that's hard.” (103)

“So when I'm really overwhelmed, I think my stress comes from being overwhelmed, basically. So I'm just not nice about it.” (108)

“I am definitely more emotional. I'm crabby to my family, I'm not as clear at work, I'm fatigued. So I'm definitely more negative. I have more of a negative mindset about things, but I think because of the physical toll it's taken, it's taken an emotional toll. But also just seeing the pain

that my dad's in and the emotional toll it's taken on my mom as well, it affects my emotions too." (109)

"As a daughter, it's difficult to see your parents because the parent has, even though I was an adult, you always look to your parent. They still are the ones that are kind of in control, and I mean, you just look to them for advice in different things, and when you see them and they're not able to do that, you know, then it affects you emotionally also." (111)

"I would just say that it's very stressful, obviously, and tiring because you're grieving yourself for someone and everything that you're watching them go through, it's very, very sad…And even though you are helping them because you're helping take care of whatever it is they need, you still feel really helpless, but that's all you can do and it doesn't feel like anything." (115)

Caregivers could speak about specific triggers to emotional suffering. One discussed a specific time when her mother had to go to the emergency room and could talk specifically of how she felt during this time. During that process, there was concern about new metastatic disease, leading to worry about terminality of the illness.

"I don't know how it could not affect your emotional wellbeing. I remember when mom was sick on Mother's Day weekend, and we had thought maybe she had some metastatic disease. We just really weren't sure what was going on. She came in, as I saw them roll her into the emergency room, she was gray and had a pink turban on. I just remember looking at her, and she just looked so sick. I think that that's when it finally hit me as I went into the other side of the ER room. So she couldn't see me, and just bawled because it was at that point in time I realized that my mom was a cancer patient, and that, you know, you can say it and you can see it, but it was something like that that really just took for me to actually just own it and know it, was seeing that, and that was tough." (111)

"I would worry about how much longer my mom had. I would worry about that she wasn't, that she would be out there alone and thank God she had visitors every day and sometimes twice." (110)

One caregiver openly discussed the impacts of her anxiety related to caregiving and how that was linked to some of her own physical health concerns.

"Well I would have anxiety attacks all the time. At first when it first started getting really bad, and that's when I started getting high blood pressure, and different things...Because I didn't want, it took me awhile to realize that I can't get everything done in one day, and then that is okay. Because I was really in a bad place for a while there because of it... But it's just, I don't know, I'm just being so angry sometimes. Initially I just feel like I'm not the person that I used to be, and it makes me sad…I feel like I'm getting tired and stressed. There's like so much going on, and I don't tell people she doesn't even know." (107)

Another caregiver was heavily involved in managing aspects of treatment related to her husband's lung cancer. Her regular and repetitive tasks to assist included giving him breathing treatments and medication management. She discussed her heavy burden of worry during that time, that even included worries that she may wake up to find that he had died overnight.

"Well, I was worried about him all the time. And a lot of times, I was just really, really nervous, you know?...Yeah,(I worried about) *making sure I was getting the medicine on time and the breathing treatments on time. And then it would scare me when he couldn't breathe. And wondering if I was going to wake up in the morning and he was going to be gone."* (113)

Spiritual quality of life. There was mixed feedback received on this domain of quality of life. While some caregivers felt experiences renewed and strengthened their faith, others felt the impacts of cancer caused strain in their perspective of faith and spirituality. Some caregivers felt that they prioritized church attendance or spiritual activities, like prayer. One caregiver felt no change in spiritual quality of life. Another chose to focus some time on trying to speak with her patient (a friend) about her spirituality and faith in hopes it would cause some interest in church attendance during this vulnerable time.

Some caregivers felt a renewed commitment to faith practices and attendance at church activities or services. While they felt that the experience of advanced cancer tested faith at times, overall they viewed spirituality as a positive support.

"Mom has always had as very strong spiritual faith. When she was sick, you know, our pastor would visit frequently, and we would all pray together, and we would all pray for her to have healing and comfort and peace. I think that it strengthened my spiritual life and my spiritual walk because she truly believes that she is here today by the grace of God. She would tell you the same." (111)

"But in a smaller group setting, like we're also in a small group and stuff, I don't know and I've... It's helped because I've met other people in similar... with cancer or who are caregivers and they kind of give you some encouragement as well about what they've learned from the Lord. So spiritually, yeah I think it's definitely... It's drawing us close to each other and closer to the Lord, even though I am pretty selfish, and pretty self-seeking, and I guess I've said that a few too many time." (114)

Additionally, caregivers discussed making more efforts to pray or reflect spiritually on the circumstances.

"I definitely do more reflecting because I'm alone a lot more than I used to be. I used to get together with friends a lot and now I'm often alone and he's sleeping or whatever. Or I'm driving. I definitely do a lot more thinking and a lot more praying, a lot more appreciating than I used to." (108)

"I try to always go to church and do all that, and granted, we didn't go like we were supposed to, and now I must say, I find myself do praying a lot more…I'll find myself watching church on TV, or praying a little bit more." (112)

"I prayed a lot…Well, a lot of people blame God when something like this happens. It's not God's fault. And just knowing (the patient is) *in a good place."* (113)

Other caregivers discussed feelings of anger toward their perceived higher power or a questioning of faith as a result of the circumstances with their loved one.

"They keep saying that God don't give you any more than what you can handle, and I really want to know what he thinks I can handle because I am at my...I mean, me and (patient) *are not married. But we've been together for 10 years, and there's a reason we're not married, because I would lose my insurance and everything with that…But as far as my spiritual belief, I would say probably on that aspect, getting cancer kind of makes me challenge it all because I just really just don't know what the hope, or if praying really works, or if God's mad at me, you know?"* (103)

"And the other thing is I'm having a hard time believing in Christ anymore, which has probably been the most upsetting thing. It's like an internal battle that I've been having that I'm trying to work through, and then it's probably been the biggest outlook change so I, you know?...I mean, it's hard for me to sort of wrap my mind around the why and how this happens. And I know I'm supposed to have faith, and I've asked our pastor and I sometimes, and I, I mean, I'll probably go to hell for this, but I sometimes think these answers are superficial. You know? 'Well, God has his plan.' Well, I think his plan is crap, because I'm seeing my dad suffer so terribly bad and he just, he's just such a great person that it just makes you question." (109)

Others were simply unable to incorporate faith practices into their schedule due to lack of available time.

"It's horrible. I used to go out the church, and even if I did work 12 hours, and I had to go before it got really bad, I would just go out, and go to church or go out with my friends." (107)

Furthermore, one caregiver felt no impact on spiritual quality of life, as the faith community actually broadcasts services online.

"There's definitely been no effect. They're video streaming the church service." (102)

One caregiver also made a regular practice of speaking to the patient about faith in hopes that she would engage in spirituality and attend church.

"I've been kind of, I won't say nagging, but you know, trying to talk to her about God and everything too because she just, she doesn't go to church, she doesn't. I don't even, all this time I really don't know what she believes because she just never talked about God or anything at all." (106)

Forced Mindfulness versus Anticipatory Grief

Caregivers often have to stay focused on being in the moment with the patient to meet current and present needs. This can cause future plans and future orientation to feel distant, which may delay focus and actions to plan for end-of-life issues. The perspective of patients and caregivers was not on distant issues or the future, but to instead stay focused on today. Furthermore, caregivers discussed the need to maintain hope and optimism. This became especially important as a motivating factor for patients to complete treatment successfully, to manage side effects, and to maintain compliance with medical recommendations

Stay focused on today to maintain optimism, motivation, and hope for the patient. Caregivers discussed various examples of how they focused on being in the moment. They often had to manage challenges and celebrate successes day by day. The mentioned the importance of maintaining optimism, motivation, and hope, both for themselves and for the patient. This was another way that their emotional experience was kept separate from that of the patient, because even if they did not feel optimistic and hopeful, they would present themselves to be in the presence of the patient.

"Knowing that I do have the patience to do it, and that, yeah, I may go cry. But at the end of the day, to know that he's comfortable and that he's taken care of and that he's still got the…oh, he's still willing to fight the battle. Because if he doesn't want to fight the battle, then you can't fight it for him…that's the biggest thing is to make sure he tries to stay positive." (103)
"Another challenge is just understanding the prognosis. Trying to be positive and keep... How do I explain it? How to do it, and give him hope." (108)

"Because of realizing as we're older that we don't know, we can't count our days, so let's make the most of them. And know that...yeah, otherwise we're going to be robbing each day of the joy that it could have really. And in fact, an example of that is one of our kids had been particularly difficult through high school…but that particular one is one that suggested that everybody write what they see in Dad and just the love they have him and stuff. Okay, now I'll cry. I cry on cue. And wrote such a beautiful, beautiful thing." (114)

Consideration of end of life planning. Caregivers often felt overwhelmed when thinking about end-of-life. Even though this was on the minds of many of the caregivers interviewed, it did not appear that they were attending to this aspect regularly or making active plans to address it. There was a tone of putting planning, management of details, and emotional considerations off until the time was necessary.

"I don't know what I'm going to do when she is gone. I know it's coming, so I'll just deal with it until then." (102)

"And I have a lot of, I don't want to say pity, but you know, I feel sorry for so much, and I don't want to, I try not to talk about something like that. It's hard to keep her up, you know? But I've always had this, I'm scared that she's going to die any time, I'm just scared to death of it. And of course I can't say that to her, you know?" (106)

"I think it's actually raised my anxiety level up a little bit, because I've just, the thought of something actually happening to him when he first got admitted to the hospital and found out all this, I mean, I couldn't... I'd be strong in front of him, but then when I would leave, go outside and leave the room, I would just bawl. Because the idea of thinking that I could actually lose my husband. I mean, I know people pass away every day. You never know what's going to happen, but just the thought of actually losing him. And I mean, its' still there in the back of my mind. But I mean, I try not to think about it as much or if I do, I try not to do it when he's around." (112)

Another caregiver discussed her need for life insurance to support her financially at the time of her spouse's death, but that they were unable to afford it.

"We don't have no kind of life insurance. I can't afford it. God forbid, if something happens to (patient) *I don't know what I'll do. Oh god, insurance is so expensive. It seems like the one I want*

> *to get, they want $100 a month. I ain't got $100 a month to give nobody for no insurance, and then you got to wait too, I pay insurance today somebody to get up tomorrow, two years that's what my bill says to me. Yeah because I'll be calling and I'll be on the internet finding out about all this different kind of insurance. The first thing I ask them I say 'Once I get this do I gotta two year wait period?'"* (104)

One caregiver could discuss that knowing the terminality of her father's illness allowed them to have open discussions about it. They were able to prepare for his death as a result. These discussions ensured there was no unfinished business.

> *"I know time is limited, so I'm almost jealous that my sister lives there, because she gets the daily interaction and I'm there a lot, but I don't... I know every hour is precious almost…I mean, we've always had a fantastic relationship. I think just, it's almost like being allowed to have closure. If someone dies in a car accident, I mean, seeing the suffering of cancer just sucks terribly bad. But someone dies in a car accident, it's like you don't get that like, 'I just want to let you know how much I love you,' kind of thing, but when someone is dying, you get that time and you get to prepare kind of for that."* (109)

Development and Presentation of the Theory

Coding of data from the caregiver interviews began upon completion of the initial interviews. Creswell and Creswell (2018) describe three steps of open, axial, and selective coding. Open codes, generated from the overall categories of information (Creswell & Creswell, 2018), were first developed. Open codes correlated with the research questions and included categories of caregiving tasks, challenges, rewards, stressors, supports, ideal resources, personal growth, quality of life, and rural impact. Creswell & Creswell (2018) describe axial coding as building categories to develop a theoretical model. As caregiver interviews continued, the content, themes, and direct quotes from each caregiver were next organized to build axial codes, which encompassed the areas of the positive and negative aspects of caregiving. The axial codes also wove across interview questions and caregiver interviews to more broadly include repeating responses to interview questions. The third stage of coding is selective coding; this stage moved further to develop the caregiver stories, interconnected among categories and codes, which build into the final theory (Creswell & Creswell, 2018). The final themes and theory were representative of the repetitive codes and themes, growing to build the story of the advanced cancer caregiving experience represented in these interviews. See Appendix D for a code map linking each of these levels of codes with the research questions and the grounded theory.

Grounded theory requires constant comparison of data to build these open, axial, and selective codes, as well as to develop the theory (Creswell & Creswell, 2018). As the final caregivers were interviewed, their responses to interview questions were included in the original open and axial codes where their data fit. When new information was identified, new open codes were built to ensure that any new categories of information were outlined and included.

Positive Aspects of Caregiving Mitigate the Negative Experiences

In development and consideration of grounded theory, the data obtained during caregiver interviews was overwhelmingly negative related caregiver experience. The strain of caregiving focused on multidimensional experience of loss affecting multiple life domains. The loss experience accumulates over time, culminating in the likely eventual death of the patient for whom the caregiver provided care, as the patients represented in these interviews were all diagnoses with a noncurative illness. Caregiver strain also was multifaceted to include every domain of quality of life (social, physical, psychological/emotional, and spiritual; for some caregivers, every domain of quality of life was negatively impacted by the caregiving experience.

However, the negative aspects of caregiving could be ameliorated when focused on the rewards of caregiving and the growth that developed as a result of the caregiving experience. Asking caregivers specific questions about rewards and growth allowed them to counterbalance challenges and stressors with positive aspects of the caregiving experience. The theory also indicates that there are surprising supports that develop and sustain the caregiver (and potentially the patient), most notably identified within this study in rural communities, who tend to look out for their own and take unrequested action to support those who are experiencing an advanced cancer diagnosis and treatment.

Every caregiver interviewed emphasized the need to shield patients from their concerns. Distress in one partner is found to intensify distress in the other *(*Fujinami et al., 2015); this dynamic was confirmed in every caregiver interviewed in this study. Caregivers masked their emotional needs and concerns extensively and viewed their own personal needs as secondary to those of the patients. Patients and caregivers were reluctant to discuss problems and challenges. It was discussed regularly that caregivers must help the patient maintain motivation for treatment and compliance, as well as optimism and hope that the treatment is working. While this self-sacrifice was made on behalf of the support and care needs of the patient, it perpetuated the significance of the caregiver multi-faceted experience of loss.

It is of note that for those caregivers who operate in this role for long-term windows of time, a continued, long-term loss experience could contribute to detrimental caregiver outcomes in a number of areas, including physical and emotional well-being. Most of the caregivers interviewed were adjusting to a newer cancer diagnosis, but one caregiver had been caring for her spouse for 14 years after his diagnosis of advanced prostate cancer. While it appeared their communication was more matured and they did address their emotional needs and thoughts of the cancer more so than other couples, they continued to have challenges of masking emotions even after many years of practice within this dynamic.

“It Could Always Be Worse”

Caregiver interview data saturated around a grounded theory demonstrative of a tone that “it could always be worse.” Caregiver circumstances and hardships were minimized based on distinct comparisons they could make to other circumstances they viewed as far worse than their own. Social comparisons have been found to be a method of coping used by advanced cancer patients and their caregivers (Starkings, Jenkins, & Shilling, 2019). These comparisons are used when a stressor and methods to cope are considered, especially in circumstances where the outcome is unlikely to be changed (Starkings et al., 2019). Social comparisons can be lateral, upward, or downward in nature. In this study, caregivers used downward social comparison as a source of optimism and hope to support the caregiving role, as a coping mechanism, and to motivate the patient.

For example, one spousal caregiver discussed her feelings of guilt resulting from the acts of kindness others were making toward her family. She compared her experience to that of a close friend who had just lost her husband very unexpectedly in a motorcycle accident. She viewed their family as contributing many selfless acts toward their family due to the caregiver’s husband’s cancer and medical status. However, the giving family of this friend actually experienced this terrible, unexpected loss before her husband died. She describes these conflicted feelings.

“Which is the one thing that bothers me the most about all of this--not the most, because the most is that he might not be here. But it's the guilt you feel when you're feeling sorry for yourself, but then people do really nice things for us, which they always do, you feel guilty like ‘but what if he's not dying?; And now you are giving me all of your time and you did all of these things for me and you know, he could be in better health than you. And you know, we just lost a friend in a motorcycle accident and I'm like ‘Oh my gosh, all the things they do for us, and he's the one gone.’...so there's a lot of guilt that goes along with it. That seems weird to say, I never ever thought in a million years that that could be associated with caregiving. And it's not the survival guilt, I shouldn't say not the survivor guilt. It's not the guilt of ‘oh he's alive and somebody else is

not,' but the guilt of like 'all the things people do for you, when what if he's in better health than them next year?'" (108)

The youngest caregiver interviewed in this study was 38 and caring for her husband. They have two teenage daughters still living at home. This caregiver described a downward social comparison of their circumstances to another family she knows who has a child battling a childhood cancer. She describes her perception of "it could be worse" within these circumstances; she even used that phrase verbatim.

"Like no matter how bad in life we've had things, there are people that have it worse. I mean, yes, I feel for my husband, I'm very sad that he has this. I wish that he didn't. But then when I see those commercials, or I've either got a really close friend of mine that my mom was best friends with when they were growing up, so we, all of us kids kind of grew up together. She has got a six-year-old daughter fighting cancer right now…I mean, so that one, it's like no, I'm not glad that he has it, but we knew eventually it could happen because of the things that he does in his life. But for these young children out here that aren't doing anything, they get all these diseases and then cancers and you're just, your heart breaks for them. ***It could always be worse****."* (112)

The downward social comparison was discussed when comparing the travel distance of a rural family to daily radiation treatments and weekly appointments for chemotherapy. Despite that this family traveled nearly one hour each direction for every treatment and medical appointment related to his lung cancer, the caregiver noted that the travel could be longer. She also used "it could be worse" to discuss that their driving distance could have been longer if they had to travel to a larger, urban area to access treatment.

"Besides, before that, we had done every day to radiation except for the weekends. And then, since he was as sick as he was, we spent a lot of time in the hospital in between times. So, yeah, if we had something closer to home, which that may sound like... because ***it could've been worse****, could've been trying to go to* (large urban area) *or something, you know?"* (113)

Additionally, when discussing the rewards of the caregiving experience, one caregiver mentioned the downward social comparison when viewing her bouts of personal challenges. She recognized that helping others brings her personal gain. She also could see that despite her own circumstances, there will always be others who have more difficult struggles than what she has in her own life.

"I just always like to help people. It just makes me feel good. And I like to see, I always figure, no matter what's going on, because I have all the bad luck in the world, but I figure no matter what's going on with me ***there's always somebody out there a lot worse than I am****."* (106)

The final verbatim example of this theory presented during discussion of the changing physical status of the patient during certain times of treatment. This particular patient and caregiver had lived in a communal living arrangement with other advanced cancer patients receiving longer-term care at a highly specialized facility far from their homes. The group built a strong comradery as a result of these circumstances. They shared contact information and continued to communicate with one another moving forward. The caregiver discussed the benefit of this group of people who all had shared experiences. Contrastingly, she also discussed that three of the patients in that group had since died as a result of cancer. She discussed the difficult of coping with losses from within this tight-knit group of people sharing similar life challenges and experiences.

"So when he's feeling better, it's like, 'Wow, man, I feel really good. I've got some real energy here.' And that can...that's a real boost. But then it also it gives you, gosh, a lot of perspective when you go and you see others that you're like, 'Whoa, I mean, ***it could get worse****,'* ***or 'they have it so much worse****,' or it just...there's a bond I think. It's sort of like if you're at the same college, you kind of cheer for the same thing. And if you have cancer, you kind of...everybody kind of has got the same jersey on kind of, but and you kind of support each other through that."* (114)

It appears that "it could be worse" shifts the caregiver perspective when some aspects of the burden of caregiving become too overwhelming. This negative social comparison allows the caregiver to minimize the extent of her experience to recognize that others have worse conditions than their own. Despite that this encourages appreciation for the current circumstances, it simultaneously dismisses the experiences and burden of the caregiver by overshadowing their own with what likely are horrible experiences of someone else in more dire circumstances. This negative social comparison was nearly quoted verbatim in five of fifteen interviews, 33.3% of the time. As the researcher reviews discussions by the other caregivers, similar tone can be found in nearly all of the interviews completed for the study. See Figure 1 for a visual image of the grounded theory compared to the themes that developed within the study.

Figure 1. Comparing Grounded Theory to the Themes of the Research

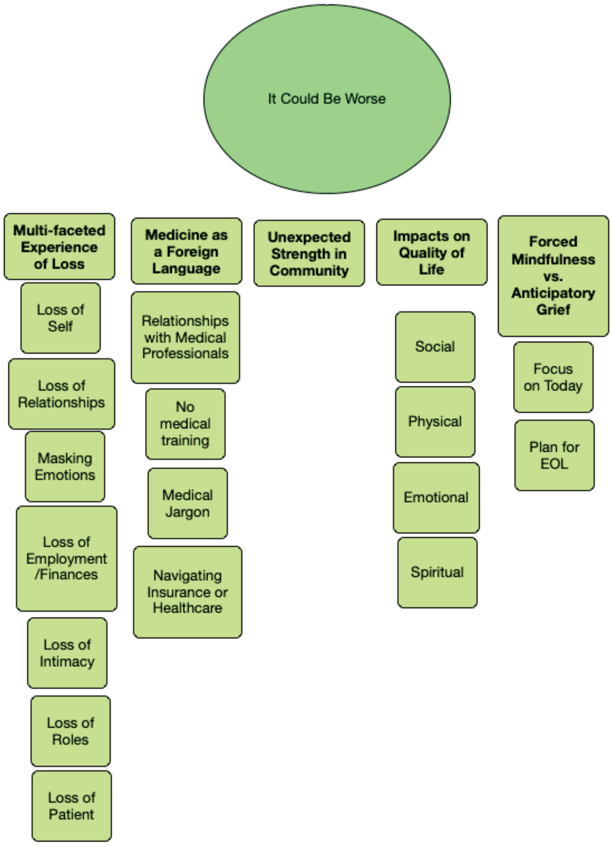

Figure 1. This figure compares the themes and their subthemes to the overall theory of caregiver coping through negative social comparisons. The phrase “it could be worse” was spoke verbatim in 33.3% of the caregiver interviews (n=5). There were tones of and dialogue using negative social comparisons, minimizing the burden of the experience, and masking emotions in every caregiver interview.

Summary

Fifteen advanced cancer caregivers were interviewed to review their caregiving tasks and experiences, emphasizing challenges and rewards. Interviews included discussion about their stressors, coping, and thoughts about ideal resources that may support caregiving. Caregivers discussed personal growth resulting from the caregiving experience including themes of the importance of caregiving, having a growing awareness to support others, and overall development of appreciation. Caregivers discussed the impact of caregiving on relationships with the patient, relationships with other family members, and on the caregiver's perspective of health. Finally, caregivers discussed the positive and negative impacts of living in the rural setting.

This chapter reviewed the description of the sample. It discussed the data analysis process, including steps to code interview data to work toward development of themes. The themes of the study include the following: caregiver multi-faceted experience of loss, medicine is a foreign language, significant impact of the caregiving role on caregiver quality of life, unexpected strength in community, and the balance of forced mindfulness (staying in the moment) versus anticipating grief and loss (being future-oriented). The results concluded with presentation of the theory derived from the data received from advanced cancer caregivers. This theory indicates the use of negative social comparisons to illustrate that advanced cancer caregivers cope with their circumstances in the tone of "it could be worse."

CHAPTER 5

DISCUSSION, CONCLUSIONS, LIMITATIONS, AND RECOMMENDATIONS

Introduction

The discussion, conclusions, limitations, and future recommendations section reviews the purpose of the study, the research questions, and provides a discussion of the relevance of the findings. It provides a conclusion to the research. This section closes with limitations of the study and recommendations for future research and practice development specific to this population.

Purpose of the Study

The purpose of the study was to examine the experiences of family caregivers of advanced cancer patients in rural communities. In this study, caregivers were relatives, friends, or loved ones who provide unpaid help to an advanced cancer patient. Caregiving assistance addressed finances, household management, physical care, or accessing health care. The research used a grounded theory approach to examine the caregiving experience, explore stressors, and inquire upon benefits of the caregiving experience. Grounded theory works to create a theory developed from data collection based in participant experience (Creswell & Creswell, 2018). The study focused on rural communities, knowing that these areas tend to be limited in resources.

Research Questions:

1. What does the process of caregiving encompass for those who provide unpaid care for loved ones with advanced cancer?

2. How do these unpaid caregivers manage stressors and challenges within their role?
3. Does the process of advanced cancer caregiving lead to an experience of growth and meaning for the unpaid caregiver? If so, in what way?
4. How does advanced cancer caregiving affect each of the domains of quality of life (physical, psychological, social, and spiritual)?
5. What is the impact of living in a rural community when caregiving for an advanced cancer patient?

Discussion

Caregiver interviews yielded a vast amount of information about caregiving to this specific population. Each of the interview questions created opportunities for caregivers to share details about their caregiving experiences. Because research questions focused on both negative and positive aspects of caregiving, participants could reflect upon these experiences in considering both views. This study confirmed the high level of needs for this specific population of caregivers. All domains of caregiver quality of life were significantly impacted due to the tasks and burden of the caregiving role.

Several of the ideal resources mentioned by caregivers involved information about resources and financial assistance. Despite that some of these resources do exist, there can include barriers to get services initiated, such as waitlists, being deemed ineligible for services, or simply not knowing what services are available. The ideal resources suggested by caregivers included in-home assistance with cleaning and meal preparation. Caregivers discussed supporting nutrition of the patient and the caregiver/family, as well as the tasks and time involved when grocery shopping. Trips to the grocery store involve leaving the patient for a window of time. Ideal resources also included respite care to prevent or intervene during periods of caregiver exhaustion. Furthermore, having access to navigation services was mentioned by a number of caregivers, which would assist them in identification of any of these types of resources (among others). Many of the ideal resources identified involved having time limitations; these resources would assist caregivers in having some of those time-intensive tasks completed that are difficult to accomplish when juggling caregiving as a priority. Another resource idea was lodging that would be free or inexpensive to prevent long hours of travel or be available after a long day of medical appointments.

Other resources identified included reliable transportation assistance that could include rides with the patient and caregiver from more rural communities requiring long travel distance for appointments. There has been recent news coverage discussing the difficulty of accessing reliable and timely transportation coverage through Medicaid across the state of Indiana (Glaven, 2019). A committee of legislators was formulated to address the state contract for medical transportation in November 2019. In 2018, the state of Indiana launched a $128 million dollar contract with a Georgia-based company called Southeasttrans for all medical transportation under the state's Medicaid system (Glaven, 2019). An independent review of the company is in the process due to a number of issues and complaints since that time (Glaven, 2019). Consumers indicate that there is high likelihood that scheduled rides do not show, but communication does not allow enough time for the patient to schedule another route of transportation. This impacts the ability of these patients to receive needed healthcare, even more so in the circumstances of managing chronic health conditions.

It is of note that many oncology treatment programs do offer navigation support through a role called an oncology nurse navigator, (Oncology Nursing Society, ONS, 2020). The role of oncology navigation is to "eliminate barriers to timely access to cancer care, which may be financial, psychological, logistic, or related to communication or the healthcare delivery system" (ONS, 2020, para. 1). Accreditation by Commission on Cancer (COC) does require accredited programs to have a patient navigation component and a process to address barriers to care (COC, 2020). These areas and all activities of the cancer program must have oversight by a cancer committee.

Many of the caregivers interviewed in this study did not discuss or identify access to patient navigation support personnel to meet or to problem-solve the extensive concrete challenges that were identified in their specific circumstances. It may be of concern that while these navigation services are available within some cancer programs, limited staffing prevents them from providing the extent of needed support services and face-to-face visits with patients and caregivers. As the status of the patient's condition worsens and needs intensify, it would be helpful to have additional supports to address care needs as they arise and to offer additional education and information. Caregivers often fear disease progression more than patients do (Chen et al., 2016). In their research with advanced lung cancer patients, Chen et al., (2016) recommend the medical team provide further information about expectations of disease progression to alleviate concerns and provide more accurate and responsive care become more complex over the course of the disease. More information is better than not enough during critical phases of disease progression.

Conclusions

It was of note that it became quite challenging to schedule interviews with this caregiving population. Despite several efforts to recruit and speak to many caregivers who were eligible for the study, the burden of caregiving often limited participation in interviews. Some of the caregivers who indicated interest in the study took time to schedule and coordinate interviews.

Some interviews were unable to be scheduled at all due to recurrent medical crises experiences by the patients for whom they received care, including several unplanned hospital stays or surgeries that limited caregiver time to be interviewed. One of these specific caregivers did complete an interview, but could not be involved until after her very ill spouse succumbed to his lung cancer and had passed away. This particular interview yielded some more specific information about caregiving experiences even after her husband had passed. She indicated her biggest challenge at that point to be to manage and fight with ongoing issues with health insurance and medical bills despite that her spouse had already died.

This study brings to light the layers and levels of stigma that are present throughout the process of being diagnosed with, treated for, and dying from advanced cancer. The stigma permeated through several different areas of the study. Physicians did not consistently have open and direct conversations with patients and caregivers related to prognosis. It causes the consideration of whether or not these direct discussions have to be pushed by the patient or family to occur. Referrals by physicians to hospice care occurred at times when the condition of the patient is so weak or frail that they live on hospice for a very short window of time.

It appeared that there was some resistance to dissemination of the study from partner research sites and other community members serving these oncology populations, which may demonstrate some of the stigma surrounding advanced cancer. The researcher speculates that using the descriptor of “advanced cancer caregiver” on recruitment flyers may have been a barrier to recruitment for the study. For example, one research participant mentioned in the interview that the home health provider approached with her with recruitment flyer because she thought she (the patient) and her spouse (the caregiver) may be interested in participation. The health care professional approached the study using the words of “no offense at showing this to you, but ...”.

Caregivers mentioned the notion of “cancer is contagious” to describe the phenomenon of some friends and family members becoming avoidant of them after the time of cancer diagnosis. This may have been an impacting phenomenon affecting recruitment for the study. People are dissuaded to openly talk about cancer and to label it “advanced” even after stage III or IV diagnoses. This can be linked avoidance of using other similar words such as “terminal” or “end-stage.” In some cases of hospice care, family members will even request that health care providers refrain from using the word “hospice” in the presence of the patient. However, to qualify for hospice care, a physician must certify that the current nature and course of the presenting illness would be terminal with a life expectancy of six months or less (Medicare, 2020). It is a challenge for a patient to prepare for terminality if their loved ones and hospice care providers are not openly discussing this short life expectancy, which promotes the stigma of more directly dealing with mortality.

Some caregivers discussed a desire for medical providers to be open and direct in their discussion with them about their family member’s needs, prognosis, and treatment. Caregivers feel more equipped to deal with problems they are facing when they have accurate information about what is happening. Furthermore, in the case of the interview with the caregiver who had a spouse pass away within the past three months from lung cancer, she very clearly felt that there was on only one physician on their treatment team (a surgeon) who had been honest to share that her spouse’s health was failing and his life expectancy was short. Otherwise, her perception was that even the oncologists directing care had given false hope and optimism to share his progress when in reality his overall health status was failing.

Communication must be of great emphasis when addressing advanced cancer. Caregivers and other family members can only make sound decisions about treatment options, medical procedures, and/or advanced directives when they have all available information. Goldsmith et al. (2016) emphasized that clear conversations about advancing disease and end-of-life decisions are critical to accessing quality care and to ensure that decision-making reflects the patient and family priorities. Having clear communication also promotes improved quality of life for both the patient and the caregiver (Goldsmith et al., 2016). Communication barriers can persist in multiple layers within the advanced cancer experience, starting at the base within the dynamic between the patient and caregiver. Because masking of emotions becomes so commonplace, as was viewed in these caregiver interviews, interventions need to clearly support open communication among and across all parties. These interventions should begin with the patient and caregiver and should include other family members, as well as the medical team.

The impact of the rural community and its characteristics of having neighborly care, kindness, and concern became an overwhelmingly positive factor of these geographic areas. This phenomenon, as well as the rural patients living in close proximity to family and friends, mitigated the challenges of rural living, the distance required for appointments, and limited availability of resources. Developing formal methods to utilize and build open the already-existing assets in these communities could develop into more available resources.

Limitations

The caregiver sample included in this exploratory study was focused on advanced cancer caregivers in rural areas in western central Indiana and Illinois. Generalizability of the study to other geographic locations is limited. Furthermore, three caregivers interviewed lived outside of that general catchment area, so their experiences may look different than the others in a more contained geographical vicinity. Regardless that these three caregivers did reside in a different area, their interview data aligned with the codes, themes, and grounded theory presented from the collective data including all fifteen interviews. Generalizability can only be focused on similar populations of advanced cancer caregivers.

An assumption of the study is also that the caregivers interviewed are representative of all advanced cancer caregivers living in rural areas; it is difficult to determine if their demographic characteristics demonstrate true representation of those in this role. The majority of caregivers interviewed are female (93.3%), which is consistent with the role of all unpaid caregivers to be predominantly female. The majority (80%) were also white. A larger sample in this area could draw comparison of gender and ethnicity variables in this study.

Furthermore, it is of note that caregivers interviewed for this study ranged significantly in level of education, as well as financial and employment circumstances. Future survey research with larger samples could determine if this distribution of education, finances/income, and employment is representative of advanced cancer caregivers in rural populations. It is of note that education levels ranged from completion of 8th grade to completion of a doctoral degree, indicating vast differences in level of education of those caregivers participating in this study. Cancer caregivers interviewed in this study could be caring for a patient with any type of advanced cancer and treatment plan; some patients tied to the interviewed caregivers were receiving treatment and some were not. Original sites of cancer varied. It is possible that generalizability of this information is limited based on the study choosing to focus generally on advanced cancer and not on a specific type of cancer. The most represented type of cancer in this study was lung cancer. Seven caregivers (46.7%) interviewed were caring for a patient with advanced lung cancer. Other types of cancer represented were breast (4, 26.7%), rectal (1, 6.7%), pancreatic (1, 6.7%), prostate (1, 6.7%), and an unknown primary site (1, 6.7%).

This study utilized an interview protocol that was developed and tested within this specific research project. The interview protocol was tested with four prior advanced cancer caregivers who have operated in this caregiver role. Their feedback was utilized to develop the interview protocol and revisions were made based on their discussion and recommendations. Information received from this pilot testing process was used to rearrange the order of questions asked to caregivers so that the interview made more logical sense within completion.

Two caregiver interviews completed within the study occurred in the presence of the patient, per the request of the caregiver participant. It is possible that the presence of the patient impacted the caregiver's participation in the interview and discussed responses. Based on the extensive data in the literature and observed in this study that caregivers mask emotions in front of the patient, it may have occurred that this also could occur during these interview discussions. It is of note that other caregivers assured privacy from the patient prior to interview completion to make sure their feedback was not overheard by the patient. To illustrate, when one caregiver was asked about sending the transcribed interviews for member checking, she declined this opportunity. She stated she did not want to take any risk of having her spouse (the patient) read what she had to say honestly about the caregiving experience.

Recommendations

Recommendations for future research.

Many needs remain to support oncology caregivers, specifically those who care for advanced cancer patients. While this study focuses on a highly specific geographic area, it would be interesting to understand more the caregiving experiences of advanced cancer caregivers in larger geographical areas. Future quantitative research could be used to survey large numbers of advanced cancer caregivers, for instance about quality of life or coping skills, to obtain a large number of responses and promote generalizability of research results.

The caregiving experience continues to worsen as the patient's physical health declines and the patient eventually dies resulting from the cancer or other medical complications tied to it. The needs of caregivers and family members related to bereavement beyond loss of the patient are extensive. Further mixed methods research in this population could yield critical information about how to support families specific to preparation for and grief after the loss of the patient.

Most of the caregiver participants included in this study had not been caregiving for an extensive period of time. Most of the cancer diagnoses were more recent, within the past 12 months. Most patients were actively involved in treatments. The needs of caregivers at distinct times after cancer diagnosis intensify. Certainly, there are other risks when caregivers are operating in this role for extended periods of time. Future research could look particularly at experiences of caregivers intentionally caregiving for specific windows of time, and how their experiences look different than those who have been caregiving for more brief periods of time.

Recommendations to enhance caregiving support practices.

Dissemination of the study results will begin with one of the partner research sites who assisted in recruiting caregivers for this study, Visiting Nurse Association and Hospice of the Wabash Valley (see Appendix D). Some of the caregivers interviewed requested a copy of the full research report. Further, completion of the caregiver study became a study of quality for the Commission on Cancer Certification and Cancer Committee at Terre Haute Regional Hospital in Terre Haute, Indiana. Dissemination of results will begin within these invested bodies.

A pilot caregiver training and support program should be developed and tested. The training and support program should address specific themes found within the research. Two main themes of this research includes caregiver loss of self and medicine as a foreign language. These two themes appeared to include several of the identified caregiver challenges and impacts on caregiver quality of life. Caregiver supports for these patients could address ways to alleviate the burden of the stress of advanced cancer caregiving, prevent or support multi-faceted caregiver loss and assist with navigation of the healthcare and insurance system.

Additionally, caregivers were very interested in networking with one another. Despite that time and geographic limitations may exist, there can be opportunity to develop and test a virtual support program that can be available online. This may reach advanced cancer caregivers when they have shorter available windows of time and cannot leave their patient to attend a face-to-face support group.

Caregiver needs are exacerbated as patients continue to worse, as care needs become more complex and physically demanding as patient health status declines. The role of the caregiver, responsibilities included within this role, and that patient and caregiving needs will increase with time as patient health fails and end of life approaches (Robison et al., 2012). Previous research found that there were gaps in caregiver knowledge and need for additional information at these transitions in care. Furthermore, caregivers mental health needs increase as anxiety is heightened when they do not have the information they need, which was confirmed throughout the caregiver interviews in this study. Previous research found that caregiver increasing anxiety and depression are strongly associated with unmet needs for information related to the medical condition of the patient or the necessary function of the caregiver role (Oberoi et al., 2016).

The multi-faceted caregiver loss of self includes several distinct, yet important losses. These losses include the shifting in roles of relationship with the patient and employment or financial changes when caregiving tasks impact the caregiver's ability to maintain working at the same level. Some losses build over time, such as loss of self-care, loss of social relationships, and other impacts of caregiving on the quality of life of the patient. Further losses are anticipatory based on the terminal diagnosis of the patient and finality of the illness in death.

The impact of stigma on the experience of living with and caring for someone with cancer continues to be immense. Stigma can only be addressed through education and communication about issues society may view as difficult to approach, discuss, and combat. This study yields a strong dynamic of keeping information quiet, the masking of emotions, and minimizing experience. Having further efforts to combat this stigma and to promote communication about experiences could alleviate negative outcomes for both caregivers and advanced cancer patients.

Summary

This study included a process of semi-structured interviews with fifteen nonpaid caregivers to advanced cancer patients. Caregivers discussed their experiences of challenges and rewards of caregiving, discussed stress and how they managed it, and addressed their supports. They discussed impact of caregiving on the domains of quality of life. Caregivers elaborated on the positive and negative impacts of living in a rural area and caregiving for an advanced cancer patient.

Caregiving has significant impacts on caregiver quality of life, which mutually impacts the patient experience. The themes of the study include caregiver multi-faceted experience of loss, medicine is a foreign language, significant impact of the caregiving role on caregiver quality of life, unexpected strength in community, and the balance of forced mindfulness (staying in the moment) versus anticipating grief and loss (being future-oriented). The results concluded with presentation of the theory, which indicates caregiver use of negative social comparisons to illustrate that advanced cancer caregivers cope with their circumstances in the tone of "it could be worse."

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APPENDIX A: LETTER EXPLAINING THE STUDY

To: Potential Participant (Caregiver) for the research study

From: Melissa Ketner, Principal Investigator

Date: (to be determined)

Subject: Informing and Recruiting Research Participants

I am writing to ask you to consider participating in a research study entitled “Exploring experiences, support, and meaning with advanced cancer caregivers from rural communities.” The research involves interviewing advanced cancer caregivers about their experience of nonpaid care for patients in rural communities. Caregivers involved in this study can be of any educational or employment background, any relationship assuming caregiving is unpaid, and can provide care for a patient living with advanced cancer, regardless of initial site or staging.

The purpose of the present study is to examine the experience of unpaid caregivers of advanced cancer patients. The research will use a grounded theory approach to examine the experience of caregiving, support needs, and opportunities for growth for caregivers in rural communities, knowing that these areas tend to be limited in resources.

I am contacting you because I learned from a referring hospital, oncologist office, home health care, or hospice organization that you may be a fit for the research.

Participation includes signing Informed Consent and one or two interviews. Each interview will last no longer than 75 minutes. Second interviews will be scheduled if the initial 75 minutes does not allow time to collect all the information the participant wants to share and only if the participant consents. Interviews will be completed in one or two face-to-face sessions. Additionally, participants will be request to review copies of the transcripts of the interview to verify accuracy. Total time participation will be limited to 3 hours; it is likely that participation will take less time than that. Participants will have access to review results of the study if they are interested.

The study utilizes a grounded theory qualitative research model, so the interviews are semi-structured and essentially involve open dialogue of topics. Interviews consist of five demographic and background questions and five content topics. Interviews will be recorded and transcribed. The written transcription and final research results will be provided back to the participant for verification of content and permission to advance the study.

The participant can provide as much or as little information as he/she chooses and interviews cease when the topics are covered or when the participant requests to stop or withdraw.

Participation is voluntary and there is no contact after transcripts are approved by the participant. Participants may withdraw at any time without penalty. Participation in this study is considered of minimal risk, yet the medical discipline of oncology may benefit from better understanding of the caregiving experience which could improve patient and family care.

Questions about the research may be directed to Melissa Ketner, MSW, Doctoral Candidate in Applied Health Science at Indiana State University, at ketnerm@uindy.edu or via phone at 317.777.9673. Faculty sponsor for this study is Matthew Hutchins, PhD, Associate Professor in Applied Health Science at Indiana State University, and he may be reached at Matthew.Hutchins@indstate.edu or via phone at 812.237.3299. Thank you for considering serving as a Participant in this study.

To participate, please reply to Melissa Ketner to complete the Informed Consent and schedule the interview.

IRB Approval date: 5/15/19
IRB Number: 870459-3

APPENDIX B: INFORMED CONSENT TO PARTICIPATE

The following will be used as the Informed Consent form to participate in this study. It will be collected via paper with signature. The Participant ID number will be assigned on this form and then the document will be scanned and stored electronically. The original document will be shredded once the electronic copy is confirmed.

CONSENT TO PARTICIPATE IN RESEARCH

EXPLORING EXPERIENCES, SUPPORT, AND MEANING WITH ADVANCED CANCER CAREGIVERS FROM RURAL COMMUNITIES

You are asked to participate in a research study conducted by Melissa Ketner, DHSc Candidate, under the faculty sponsorship of Matthew Hutchins, PhD, from the Department of Applied Health Science at Indiana State University. This study is being conducted as partial fulfillment of a doctoral dissertation. Your participation in this study is purely voluntary. Please read the information below and ask questions about anything you do not understand, before deciding whether or not to participate.

You are asked to participate in this study because of your role as a nonpaid caregiver for someone living with advanced cancer. The study has a particular focus on those living in rural areas.

PURPOSE OF THE STUDY

The purpose of the study is to examine the experiences of unpaid caregivers of advanced cancer patients. The research will use a grounded theory approach to examine receipt of support and development of growth and meaning within caregivers in rural communities, knowing that these areas tend to be limited in resources.

PROCEDURES

If you volunteer to participate in this study, you will be asked to do the following things:

Sign the Informed Consent and return the form to the Principal Investigator.

After signing the Informed Consent form, the Principal Investigator will contact you to schedule an interview. The semi-structured interview will last no longer than 75 minutes. If the interview is not completed in 75 minutes, you have the option to schedule a second interview. The interviews will be completed via face-to-face meeting when feasible, or by telephone. You will be asked to review the written transcript of your recorded interview to verify accuracy as well.

The study utilizes a grounded theory qualitative research model, so the interviews are semi-structured and essentially involve open dialogue of topics. Interviews consist of five demographic and background questions, as well as four content topics. Interviews will be recorded and transcribed. The written transcription will be provided back to you for verification of content and permission to advance with including the interview content in the study.

You can provide as much or as little information as you choose and interviews cease when the topics are covered or when you request to stop or withdraw.

Participation is voluntary and there is no study-related contact with you after approving the transcripts.

- **POTENTIAL RISKS AND DISCOMFORTS**

The interview questions and topics relate to your experience as an advanced cancer caregiver. As such, there are no to minimal foreseeable risks or discomforts including but not limited to, psychological, social, legal, or financial risks or harms. Should any psychological or emotional reaction occur during the discussion of the caregiving experience, interviews can be terminated by the participant.

Any participant who wishes to withdraw, for any reason and at any time, may do so. There are no foreseeable reasons for which the researcher may terminate the study.

- **POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

Participants will not benefit directly from participation in the study. It is hoped that the participants will receive a $15 gift card for participation in the study based on the time spent; this will be based on research funds available. The medical discipline of oncology may benefit from better understanding of the caregiving experience which could improve patient and family care.

- **CONFIDENTIALITY**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of recording responses with a sequential number, for example, Participant 1, or Participant 2. The results of the study will not reveal identifying information of any Participant. No one will be able to identify you or your answers, and no one will know whether or not you participated in the study.

The Informed Consent forms will be scanned and retained in the Principal Investigator's password protected computer. The original paper copies of Informed Consent forms will be destroyed by shredding once the electronic document is secured and verified. Transcriptions and Data Collection Tools will contain no Participant-specific identification. Audio-recordings will be used for transcription; upon approval by the Participant, the audio-recording will be destroyed/erased. All information related to the study will be kept secure and locked throughout the course of and after the study is completed.

- **PARTICIPATION AND WITHDRAWAL**

You can choose whether or not to be in this study. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer. There is no penalty if you withdraw from the study.

- **IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about this research, please contact Melissa Ketner, Principal Investigator, at 317.777.9673 or via email at maketner99@gmail.com or the Faculty Sponsor, Matthew Hutchins, PhD, at 812.237.3299 or via email at Matthew.Hutchins@indstate.edu.

Date of IRB Approval:
IRB Number:

- **RIGHTS OF RESEARCH SUBJECTS**

If you have any questions about your rights as a research subject, you may contact the Indiana State University Institutional Review Board (IRB) by mail at Indiana State University, Office of Sponsored Programs, Terre Haute, IN 47809, by phone at (812) 237-8217, or e-mail the IRB at irb@indstate.edu. You will be given the opportunity to discuss any questions about your rights as a research subject with a member of the IRB. The IRB is an independent committee composed of members of the University community, as well as lay members of the community not connected with ISU. The IRB has reviewed and approved this study.

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

____
Printed Name of Subject

______________________________________ ________________________
Signature of Subject Date

Research Participant Identification Number ___
(assigned after the participant agrees to participate)

APPENDIX C: SAMPLE INTRODUCTORY INTERVIEW

EXPLORING EXPERIENCES, SUPPORT, AND MEANING WITH ADVANCED CANCER CAREGIVERS FROM RURAL COMMUNITIES

Study Conducted by: Melissa Ketner

Research Conducted under the direction of: Matthew Hutchins

Background of the Caregiver:

- Name, Profession, Educational level, Gender, Age, and Race
- Please tell me about your role as a caregiver. What tasks do you complete in this role?
- How many hours per week do you spend caregiving?
- Please explain your relationship with the person for whom you provide care.
- If you are willing, please discuss circumstances regarding finances and insurance as related to your caregiving role.

Interview Questions:

1 Describe the experience of advanced cancer caregiving for your loved one.

- What challenges do you experience as a caregiver?

- What are the rewards of being a caregiver?

2 How well have you been or are you managing stress?

- How does stress impact or not impact your caregiving?

-What needs do you have that you are unable to meet?

-What support are you using?

-What supports are you willing to use?

-How do you think ideal supports for caregiving would look?

3 Have you grown or not grown as a result of this experience? In what way?

-How has caregiving impacted or not impacted your relationship with the patient?

-How has caregiving impacted or not impacted your relationship with other family members?

-How has caregiving changed or not changed your outlook on life?

-Has caregiving changed your perspective of health? If so, in what way?

4. How has caregiving affected your domains of quality of life?

-How has caregiving affected your physical quality of life?

-How has caregiving affected your psychological quality of life?

-How has caregiving affected your social quality of life?

-How has caregiving affected your spiritual quality of life?

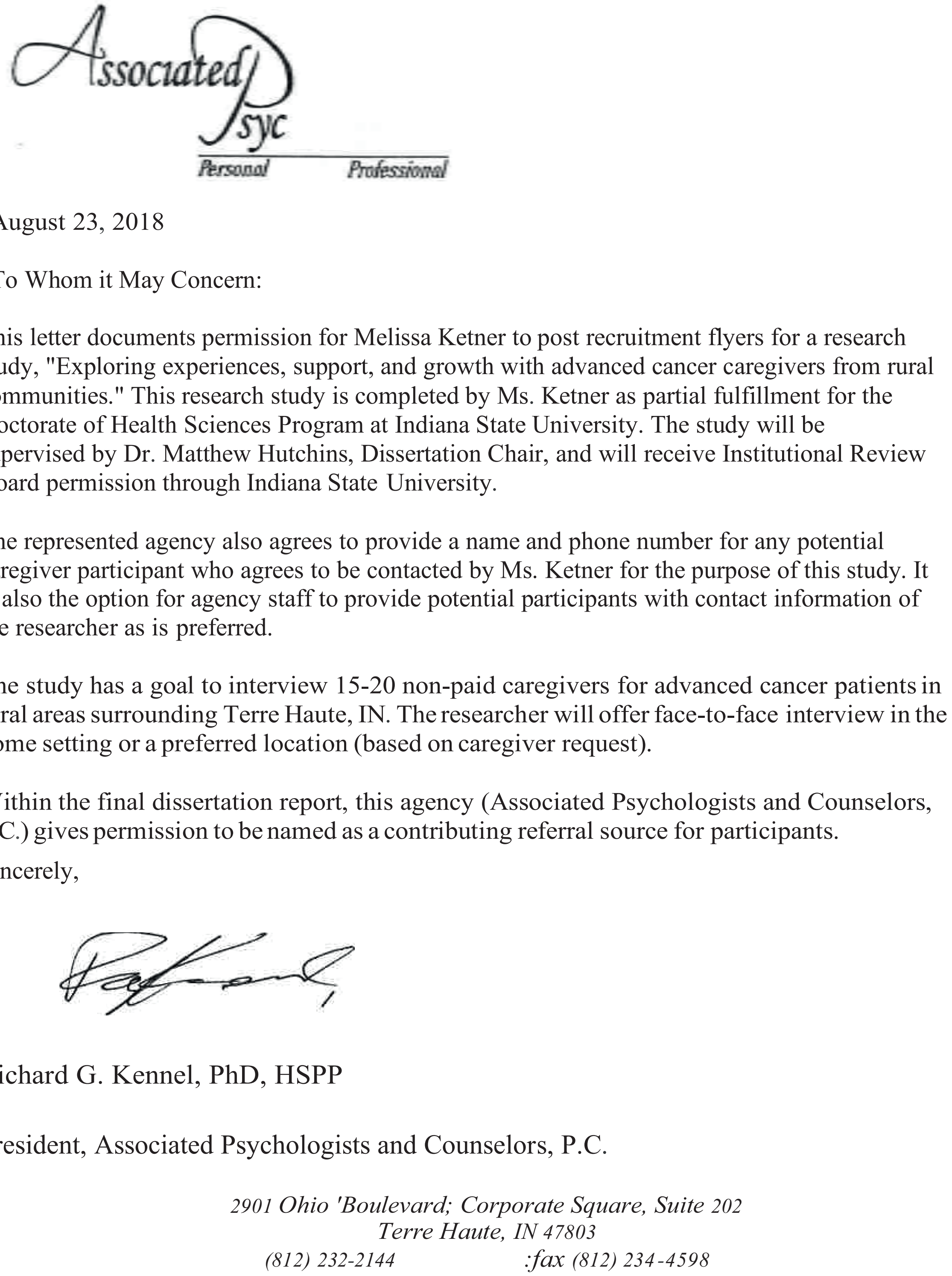
5 How does living in a rural community impact your caregiving?

-What challenges have you experienced?

-What benefits have you experienced?

6 What further comments would you like to add?

APPENDIX D: AGENCY APPROVAL LETTERS



Associated Psyc
Personal Professional

August 23, 2018

To Whom it May Concern:

This letter documents permission for Melissa Ketner to post recruitment flyers for a research study, "Exploring experiences, support, and growth with advanced cancer caregivers from rural communities." This research study is completed by Ms. Ketner as partial fulfillment for the Doctorate of Health Sciences Program at Indiana State University. The study will be supervised by Dr. Matthew Hutchins, Dissertation Chair, and will receive Institutional Review Board permission through Indiana State University.

The represented agency also agrees to provide a name and phone number for any potential caregiver participant who agrees to be contacted by Ms. Ketner for the purpose of this study. It is also the option for agency staff to provide potential participants with contact information of the researcher as is preferred.

The study has a goal to interview 15-20 non-paid caregivers for advanced cancer patients in rural areas surrounding Terre Haute, IN. The researcher will offer face-to-face interview in the home setting or a preferred location (based on caregiver request).

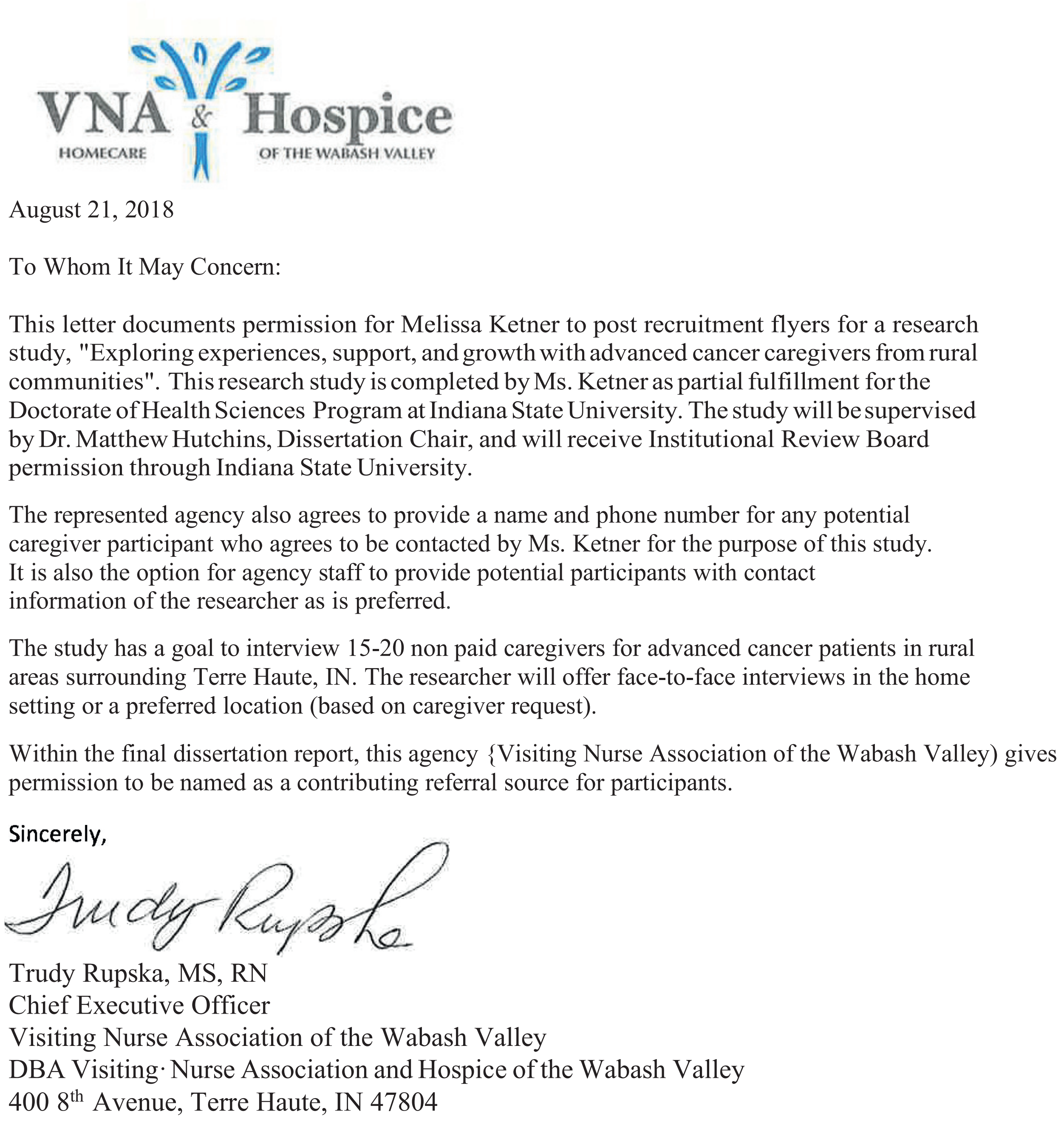
Within the final dissertation report, this agency (Associated Psychologists and Counselors, P.C.) gives permission to be named as a contributing referral source for participants.

Sincerely,

Richard G. Kennel, PhD, HSPP

President, Associated Psychologists and Counselors, P.C.

2901 Ohio 'Boulevard; Corporate Square, Suite 202
Terre Haute, IN 47803
(812) 232-2144 :fax (812) 234-4598



VNA & Hospice
HOMECARE OF THE WABASH VALLEY

August 21, 2018

To Whom It May Concern:

This letter documents permission for Melissa Ketner to post recruitment flyers for a research study, "Exploring experiences, support, and growth with advanced cancer caregivers from rural communities". This research study is completed by Ms. Ketner as partial fulfillment for the Doctorate of Health Sciences Program at Indiana State University. The study will be supervised by Dr. Matthew Hutchins, Dissertation Chair, and will receive Institutional Review Board permission through Indiana State University.

The represented agency also agrees to provide a name and phone number for any potential caregiver participant who agrees to be contacted by Ms. Ketner for the purpose of this study. It is also the option for agency staff to provide potential participants with contact information of the researcher as is preferred.

The study has a goal to interview 15-20 non paid caregivers for advanced cancer patients in rural areas surrounding Terre Haute, IN. The researcher will offer face-to-face interviews in the home setting or a preferred location (based on caregiver request).

Within the final dissertation report, this agency {Visiting Nurse Association of the Wabash Valley) gives permission to be named as a contributing referral source for participants.

Sincerely,

Trudy Rupska

Trudy Rupska, MS, RN
Chief Executive Officer
Visiting Nurse Association of the Wabash Valley
DBA Visiting· Nurse Association and Hospice of the Wabash Valley
400 8th Avenue, Terre Haute, IN 47804

APPENDIX E: CODE MAP

Table 2.

Map to Link Research Questions, Codes, Themes, and Grounded Theory

Research Questions	**Open Codes**	**Axial Codes**	**Selective Codes/Themes**	**Theory**
Tasks	C: Manage finances	**Related to the Patient:**	**Multifaceted Experience of Loss**	**Positive Mitigates Negative Aspects**
Challenges	C: Keep emotions private	-Physical needs	-Loss of self	-Loss Accumulates with Time
Stress management	C: Prepare for end of life	-Communication	-Loss of relationships	-Quality of Life impacts
Supports	C: Ignore physical health	-Health decline	-Feelings are masked	-Focus on rewards
Ideal resources	C: Neglect self-care	-Shifting roles	-Employment/financial loss	-Optimism & hope
Growth	C: Lose relationships	-Intimacy	-Loss of roles/responsibilities	-Masking emotions shields patient
Relationship changes	C: Patient source of venting	-Promote lifestyle changes	-Anticipatory loss of patient	**“It could always be worse”**
Quality of life	C: Intimacy changes	-Focus on wants/needs	**Medicine as a Foreign Language**	-Negative social comparisons
Rural	C: Parents falls second	**Health Care System:**	-Relationships with medical professionals	-Coping strategy
	C: Health insurance needs	-Insurance navigation	-Lack of medical training or medical background	-May manifest as guilt over help
	C: Employment changes	-Communication	-Medical jargon	-The (type/stage/treatment/progression) cancer could be worse
	C: No medical training	-Relationship with providers	-Insurance/health care navigation	-It could be a child instead of my husband
	C: Caregiving from distance	-Authorization process	-Caregiver ideas for supports	-Travel could be harder or more frequent
	C: Encourage patient compliance	-Medication needs	**Unexpected Strength in Community**	-My struggles aren’t as hard as others
	C: Learn medical jargon	-Understanding treatment	**Caregiver Quality of Life**	-Patient could have died already
	C: Adjust to new normal	**Rural Assets:**	-Social	
	C: Boundaries with visitors	-Feeling of community	-Physical	
	C: Physical demands	-Supports close proximity	-Emotional/psychological	
	C: Watch patient’s health decline	-Church involvement	-Spiritual	
	C: Access patient’s medications	-Creativity to meet needs	**Forced Mindfulness vs Anticipatory Grief**	
	C: Leave own home to live with patient	**Impact on Caregiver Quality of Life**	-Stay focused on today, optimism, hope	
	C: Encourage no drinking or smoking	**Caregiver Burden:**	-Consideration of end of life planning	
	C: Focus on cancer, not each other	-Ignoring needs		
	R: Provide high quality care	-Lack of self-care		

Research Questions	**Open Codes**	**Axial Codes**	**Selective Codes/Themes**	**Theory**
	R: Fulfill nurturing role	-Emotional needs		
	R: Reciprocate care for a parent	-Financial challenges		
	R: Celebrate remission or improvement	-Communication		
	R: Motivate patient for treatment	**Caregiver Coping:**		
	R: Fulfill patient’s wishes	-Stay focused on today		
	R: Quality time with patient	-Difficulty in managing future orientation		
	SM: Access support system	-Support system		
	SM: Use faith	-Health behaviors		
	SM: Take a break	-Use work as time away from caregiving burden		
	SM: Health behaviors	-Spirituality and faith		
	SM: Work as an outlet	-Optimism/Hope		
	SM: Positive outlook			
	SM: Let things go			
	SM: Practice patience			
	S: Support system			
	S: Help from the community			
	S: Spirituality & faith community			
	S: Home health/hospice care			
	S: Good insurance coverage			
	S: Good physical health			
	S: Hired additional help at home			
	IR: Network with other caregivers			
	IR: In-home supports for caregiving tasks			
	IR: Respite care			
	IR: Free, available transportation			
	IR: Inexpensive lodging when needed			
	IR: System navigation			
	IR: Telemedicine to help manage travel			
	IR: EOL Preparation & information			