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THE ROLE OF SOCIAL SUPPORTS ON THE FINANCIAL TOXICITY OF CANCER

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DEDICATION

"For from him and through him and to him all things. To him be the glory forever!

Amen." Romans 11:36

Scott & Madisen,
All things are possible when you have others who believe in you. Thank you for all the support and encouragement along the way.

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Thank you to all those who made this possible. I am extremely grateful for the guidance and mentorship from Dr. Karen Kayser. Your encouragement to THINK BIG and to question ‘why not’ pushed me to achieve more than I imagined. I am a better person and a better researcher because you believed in me and gave me the opportunity to succeed. I value your advice, opinion, and friendship.

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ABSTRACT

THE ROLE OF SOCIAL SUPPORTS ON THE FINANCIAL TOXICITY OF CANCER

Lisa C. Smith

April 10, 2019

Background It is evident that health care costs in the United States are astronomical and are expected to continue to rise. Cancer is one of the most expensive diseases to treat. As medical care costs continue to increase, so do insurance premiums, co-payments, and out-of-pocket health-related expenses. Consequently, the cancer experience can have a negative impact on an individual's financial stability. Although literature exists on the impact of cancer-related financial burden and its effects on quality of life, we do not have a full understanding of the nature of the financial burden on individuals and their families. Likewise, research on social supports has concentrated on social, emotional, functional, and physical well-being but not on the financial well-being of individuals with cancer.

The **purpose** of this study, driven by the theoretical frameworks of the Transactional Model of Stress and Coping Theory (Lazarus & Folkman, 1984), Stress-buffering Hypothesis (Cohen & Wills, 1985), and the Financial Toxicity Framework (Carrera & Zafar, 2018) is to understand the role of social support in the relationship between financial toxicity and quality of life of individuals living with cancer.

Methods This research project used a multiple methods approach composed of two studies. Study 1 was a secondary analysis of data from a study exploring the lived experiences of 26 cancer survivors who self-reported financial hardship due to the costs of their cancer experience. Interview transcripts were analyzed using a theory-based direct approach to Qualitative Content Analysis. Study 2 recruited 126 participants who had a diagnosis of blood (Leukemia, Lymphoma or Myeloma) or breast cancer within the past 5 years. Using the *Introduction to Mediation, Moderation, and Conditional Process Analysis* (PROCESS) macro for SPSS, moderator and mediator analyses were conducted to determine the specific path by which social support intervenes in and on the relationship between financial toxicity and quality of life.

Summary of Finding Findings confirm the existence, use and need for social support that addresses financial toxicity. Three categories were identified from the qualitative analyses of Study 1: Helpful Supports, Unhelpful Supports, and Gaps in Support. Although there was representation of several key aspects of social supports (emotional, informational, instrumental, and social constraint), barriers to accessing support and missing support emerged from the data analysis process. Further evidence from Study 2 provides empirical support for the importance of social support on the relations between financial toxicity of cancer and quality of life. Received social support moderated and perceived social support mediated the relationship between financial toxicity and quality of life.

Conclusions Social support plays a critical role in helping to protect patients from cancer-related financial toxicity. More needs to be done to address the financial needs of patients. Oncology social workers can play an essential role in assisting patients in averting financial toxicity.

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CHAPTER I: INTRODUCTION

"You treat a disease, you win, you lose. You treat a person, I guarantee you,
you'll win, no matter what the outcome."
– Patch Adams

While the systematic diagnosis and treatment of diseases such as cancer are obviously crucial in saving lives, they can impact a patient's life beyond their health and physical well-being. People do not simply separate their health and health care into silos; instead, their health is deeply intertwined with their overall well-being and quality of life. Physical, social, emotional, and economic aspects of life can all suffer health-related consequences. Subsequently, patient care needs to go beyond the medical treatment of the disease which requires a complex understanding of attitudes and beliefs, psychosocial needs, the financial impact, and preferences for communication and information. It compels the medical field to meet the patient where the patient is currently functioning emotionally, socially, economically, and physically. It necessitates treating the whole patient and not just a fraction thereof.

From a traditional standpoint, the goal of our medical system has been to identify, triage, and cure medical aliments. However, delivering a better experience leading to positive overall outcomes requires a multi-faceted design of patient care. Whole patient care, (i.e., patient-centered care) seeks to provide care that is responsive to each individual's needs and preferences. Transitioning from the traditional model to a patient-centered one, putting psychosocial needs on par with medical needs, has been an ongoing effort of the Institute of Medicine (IOM). Standards proposed for patient-centered care and distress screening brought attention to the importance of treating the whole patient, emphasizing the importance of addressing psychosocial needs and concerns in the treatment process. Of particular interest for this work, the IOM standards highlight identifying those patients at risk for financial hardship (Institute of Medicine, 2013), thus, recognizing the impact that financial distress can have on patients.

As the costs of medical care continue to rise, particular attention has been given to the financial burden and distress resulting from cancer care costs - so much so that it has been termed *financial toxicity.* The term *financial toxicity* encompasses both the objective burden and subjective distress brought on by the costs of cancer care. Objectively, patients face astronomical medical costs and unexpected out-of-pocket expenses. Subjectively, they experience overwhelming feelings of distress (Zafar et al., 2013). This septic situation can result in negative outcomes for patients and their families. (See the literature review in Chapter 2 and the framework proposed by Carrera and Zafar (2018) in Chapter 3 for a more detailed examination of financial toxicity.)

In this first Chapter, I provide the significance and purpose of conducting this research. This includes a brief overview of the study design as well as the specific aims, research questions and implications for healthcare professionals, patients and the field of social work.

Significance

In the United States, a staggering estimate of 1,735,350 new cases of cancer will be diagnosed this year (NCI, 2018). The exact number of those patients who will experience financial toxicity (objective burden and subjective distress) as a result of their cancer experience is difficult to surmise. However, a systematic review exploring the extent of financial burden concluded that a “substantial amount of cancer survivors” are affected by the objective financial burden of cancer care (Gorden, Merollini, Lowe, & Chan, 2017). More specifically, two nationwide surveys reported a third (Kent et al., 2013) to half (Pisu et al., 2015) of their participants experienced financial burden. This number is staggering and suggests that a substantial number of people may indeed face financial hardship as a result of their cancer experience.

While there is growing empirical evidence of the financial toxicity (objective burden and subjective distress) faced by many cancer patients, gaps in our understanding of the issue still remain. Studies have attempted to better understand and describe this issue, yet a thorough literature search found two studies that have attempted to intervene on the impact of financial toxicity through an influencing variable. In one study researchers attempted to address financial toxicity through the use of patient navigation (Shankaran et al., 2018). The second study implemented the Care Payment program which provided patients with 0% APR lines of credit (Lessard & Solomon, 2017). This is indicative of a gap in knowledge regarding influences of variables that may alleviate financial toxicity. Further knowledge is needed to develop interventions and standardized practice procedures for identifying and assisting those at risk of cancer-related financial toxicity. It is therefore the goal of this study to provide insight into the lived experiences of cancer patients by understanding their use of social support and the impact of social support on the patients’ experience with financial toxicity.

Purpose. The purpose of this project is to explore the role of social support in the context of cancer-related financial toxicity (objective burden and subjective distress).

This research project attempts to address the lack of information regarding factors that may alleviate or positively impact the experience of cancer patients and their families. The following overarching research question guided the development of this project:

> *What role does social support play in the experience of cancer-related financial toxicity?*

In order to answer this overarching question, the following two sub-questions were developed:

1. *For individuals who have had cancer, what is their experience with social support in the context of cancer-related financial toxicity?*
2. *How does social support influence cancer-related financial toxicity and patients' quality of life?*

Project Overview

To address these research questions, a multiple method paradigm was used. Multiple method designs are driven by an overarching question that is answered by two or more studies. The results of these studies are intricately intertwined to provide an in-depth understanding of the inquiry, yet each study remains relatively independent of the other (Morse, 2003). For this project the overarching question was addressed using two studies conducted sequentially but each had equal merit (see Figure 1.1 for the design overview). First, a study using qualitative methods was conducted identifying the existence, use, and need for social support in the given context. This study was followed by a quantitative study that sought to statistically identify the role social support played in the experience.

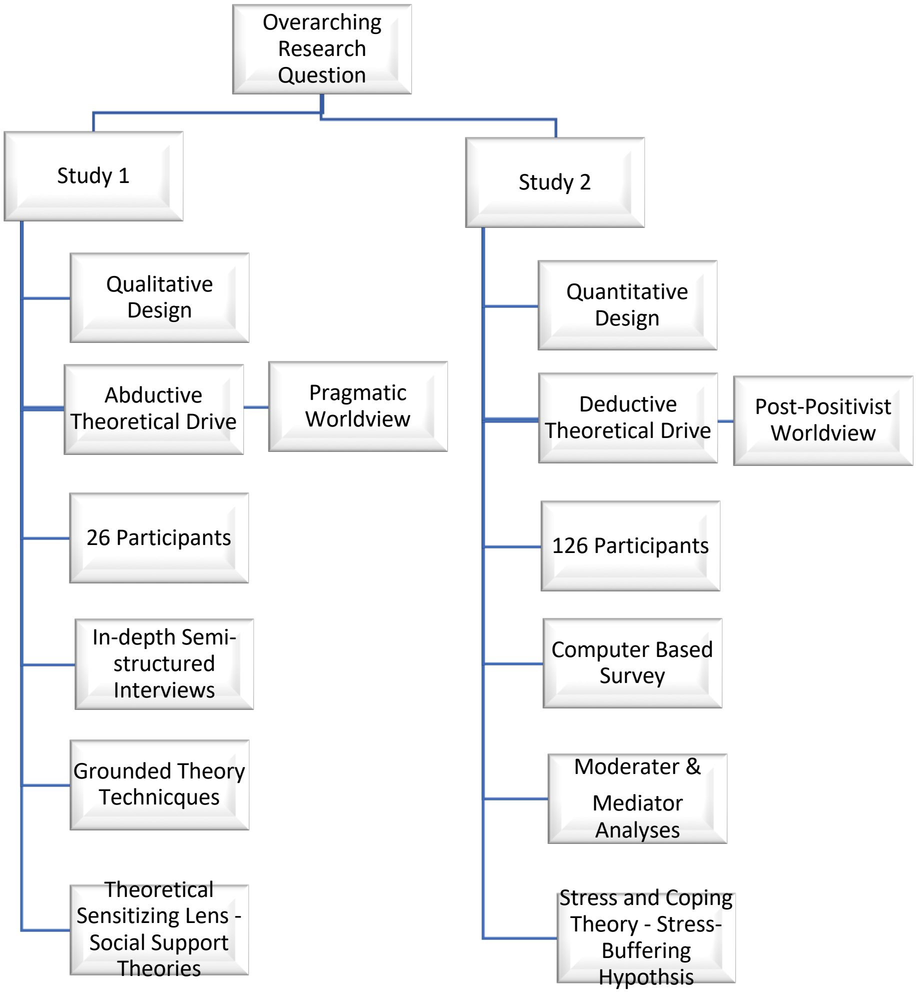


Figure 1. 1 Multiple Method Design

The data for Study 1 derived from a study that used a qualitative design involving semi-structured, in-depth interviews with 26 participants who reported to have experienced financial burden during their cancer experience. Interviews were audio recorded and transcribed verbatim. Transcripts were initially analyzed using constructivist grounded theory (CGT) techniques. From the findings, social support emerged as a primary theme.

For Study 1, a secondary data analysis used a generic qualitative approach (Caelli, Ray, & Mill, 2003). Theories of social support provided an analytic lens to view transcripts. Social supports were identified through the use of a theory-based direct approach to Qualitative Content Analysis. In-depth descriptions of types and uses of social support in the context of cancer-related financial toxicity were developed. (See Chapters 4 and 5 for Study 1 methods and results, respectively.)

Deriving from the preliminary findings of Study 1, Study 2 was created to further explain the presence of social support and patients' experiences statistically. Study 2 used a quantitative approach and relied on the theoretical foundations of the Transactional Model of Stress and Coping Theory (Lazarus & Folkman, 1984) and the Stress-buffering Hypothesis (Cohn & Wills, 1985). This study involved the development of a survey using reliable and valid scales as well as questions created from the qualitative study. Using an online platform, the survey was disseminated through several cancer-related organizations. A sample of 126 participants was obtained between July 2017 and December 2018. Moderator and mediator analyses were then performed using SPSS v25 statistical software with the Introduction to Mediation, Moderation, and Conditional Process Analysis (PROCESS) macro. The purpose of the analyses was to determine if social support played a statistically significant role in influencing the objective burden and subjective distress caused by cancer care and treatment costs. (See chapters 6 and 7 for Study 2 methods and results, respectively).

Multiple methods rationale. The multiple method design selected for this project is an equally weighted qualitative then quantitative approach. The approach is driven by an overarching inductive drive and is geared toward answering a descriptive overarching question. This design can be used to gain more insight into a topic and can eventually lead to the development of a framework or theory (Morse, 2003). Since little is known about cancer-related financial burden and social support, this approach provided a more comprehensive understanding of the role social support plays in the given context. Although the purpose of this project is not to create theory, it may inform and expand on the current framework of financial toxicity as described by Carrera et al. (2018) and social support theories. (See Chapter 3 for an in-depth discussion of these theories.)

Multiple method verses mixed method. Although they sound similar, few commonalities exist between mixed method and multiple method designs. According to Morse (2003), a mixed method design is when qualitative and quantitative methods are being used with-in a single project. The same question(s) is(are) being answered by both the qualitative and quantitative strand of the study. Important to the distinction between the two designs, the research in a mixed method design is driven by one theoretical assumption. Thus, one strand of the study is dependent on the other, neither being considered whole without the other. It is also the expectation that one set of data be used to complement and then build on the information obtained from another (Terrell, 2016).

Alternatively, multiple method designs contain relatively complete qualitative and/or quantitative studies within a larger project (Morse, 2003). Multiple method designs are defined as a series of studies that are interrelated by topic with an overarching question that defines the project goal. In order to answer this overarching question, each component of the project is driven by its own sub-questions and maintains its own worldview and assumptions. Unlike mixed method designs, multiple method designs are not limited to using one sample population. Using the multiple method designs allows for more flexibility in design allowing the researcher to obtain a broader perspective of the phenomena they are researching (Morse, 2003).

Implications

The overall aim for this study is to better understand the experience of cancer in regard to financial toxicity and social support. Through exploring this experience, we may be better able to identify and address financial issues that may result in unnecessary burden and distress. It is hoped that the results of this study will further inform patient-centered care, giving healthcare professionals insight into the influencing effects of social support on financial barriers faced by cancer patients. Social work practice is driven by ethical standards to ensure the use and implementation of services that will enhance and improve the lives of clients served. It is therefore my desire to inform social work practice on the impact social support may have on cancer-related financial toxicity to further assist in the development of effective and efficient interventions. Lastly, it is my hope that this work will inform healthcare research, practice, and policy by adding to the existing framework of Financial Toxicity.

Summary

This chapter provided a brief overview of this project which identifies the function social support plays in easing the impact cancer-related financial burden has on patients and their families. It first introduced the problem and purpose geared toward exploring the role of social support. Then, with justification for the use of a multiple method design, it briefly described the studies that were used to address the overarching question.

Chapter 2 presents the literature review on cancer-related financial burden explaining this multifaceted phenomenon. Then it provides a definition for social support relying on the operationalization of social support theories. This is followed by a brief literature review on social support in cancer care, thus pointing out the vast array of literature existing in this area. Lastly, it introduces the literature on social support as a moderator or mediator variable, providing support and justification for proposing that social support may play a similar role in cancer-related financial burden.

The outline for the remainder of this manuscript follows. Chapter 3 provides a more in-depth explanation of the Multiple Method Paradigm as well as introduces the theoretical perspectives relied on throughout this project. Chapter 4 provides a detailed description of the methods for Study 1 with the findings presented in Chapter 5. Then Chapter 6 details the methods for Study 2 with the results for Study 2 in Chapter 7. Finally, Chapter 8 brings the results from both studies together in an attempt to answer the overarching question. It concludes with a summary addressing the limitations of this project as well as offering suggestions for further research and implications for current social work and healthcare practices.

CHAPTER 2: LITERATURE REVIEW

‘Too many people are forced into a situation of whatever they do have, they bankrupt themselves with a medical disaster. It destroys every single cent that they have, because they have no resources or ability to counter balance the cost of good health.”
- Study 1 #26 (66-year-old man, Prostate & Bladder Cancer)

This chapter presents the literature as it relates to the overarching research questions: *What role does social support play in the experience of cancer-related financial toxicity?* Due to the multidimensional aspects of the variables used in this research, the chapter is divided into two separate parts. The first part examines cancer-related financial burden as a social problem due to the exorbitant and rising costs of medical care. It presents literature on cancer-related financial toxicity (i.e., objective burden and subjective distress), the resulting impact it has on patient care, and addresses who is at-risk. In the second part, the literature on social support in cancer research is reviewed, which is followed by a literature review of social support as a moderator or mediator variable as social support has been shown to have more than a direct effect in other situations.

Financial Toxicity of Cancer

The financial toxicity of cancer has been a hot topic over the last decade and related research has grown exponentially. The following literature review is extensive, but not exhaustive. The primary purpose is to provide a foundational understanding of this complex, multifaceted issue.

The Situation. In the United States, cancer is among the most expensive diseases to treat (American Cancer Society, 2012). Cancer patients can expect to pay thousands of dollars more in medical expenditures than those who have never had cancer. In 2007, the average yearly medical expenses for a newly diagnosed cancer patient was $16,910 with an out-of-pocket cost of $2,149 compared to $3,303 with $679 out-of-pocket expense for those without cancer (American Cancer Society, 2012). Furthermore, expenses associated with cancer continue into the survivorship phase. The post-treatment phase can be riddled with expensive follow-up tests, screenings, and costly medications that may last a lifetime. Cancer survivors pay $3,293 -$4,187 more per year for health care than those without a cancer history (Ekwueme et al., 2014). Consequently, the trajectory of cancer treatment-related expenditures may span years, thereby putting cancer patients at risk of experiencing long-term financial consequences.

Indeed, patients face high costs in care for in-patient/out-patient hospital and clinic visits, surgery, prescription drugs, medical treatments, lab tests, and home health services. These costs are alarmingly on the rise. One study suggests cancer treatment costs have nearly doubled in the past few decades (Tangka et al., 2010). A report on anticancer drug costs suggests a much greater increase. In 1995, the average cost of anticancer drugs for one extra year of life was $54,100; this jumped to $207,000 by 2013 (Howard, Bach, Berndt, & Conti, 2015). A second study reported similar increases in costs associated with treatment duration. Before 2000, treatment costs were less than $10,000; by 2012, these costs escalated to over $100,000 (Kantarjian, Steensma, Sanjuan, Eishaug, & Light, 2014). The costs associated with cancer are astronomical and are expected to continue to increase (Mariotto et al., 2011; Trogdon et al., 2010).

Several reasons have been suggested for the rise in costs. Advocates justifying higher drug prices indicate the high prices are due to free market demand, as well as research and development costs (Kantarjian et al., 2014). Increasing demand, improvements in cancer awareness, screenings, and treatment lead to increases in diagnoses and survival rates. Currently there are nearly 14.5 million cancer survivors (ACS-NCI, 2014). This number is expected to grow to nearly 18 million by 2020 (Weir, Thompson, Soman, Moller, & Leadbetter, 2015; Mariotto, Yabroff, Shao, Feuer, & Brown, 2011) and 19 million by 2024 (Simon, 2014). With the increase in diagnosis and survivorship the demand for oncology services is expected to escalate, taxing the healthcare system and resulting in a shortage of oncologists (Yang et al., 2014). This increased demand and lack of available services is suggestive of a supply-demand situation leading to rising costs of care.

Increases are also suggested to be due to research and development costs. The average cost of development for a new drug is estimated to be $802 million before approval and $900 million after approval (DiMasi, Hansen, & Grabowski, 2002). Improvements in current treatment, such as the development of targeted chemotherapies, are estimated to increase costs (Mariotto et al., 2011). As new drugs and improved treatments become available, these costs are passed down to patients (Howard, Back, Berndt, & Conti, 2016).

Regardless of the reason for higher costs, the costs are ultimately passed down to patients through higher cost-sharing insurance plans. Insurance providers shift the direct medical care costs to patients through higher premiums, deductibles, and copayments. Out-of-pocket caps for many insurance plans have been mandated through policy.

Although the cap is set for $7150 per individuals and $14,300 per family (ACS, 2017), this is still a hefty expense for many American families. In 2015, the Federal Reserve reported nearly half of Americans had to borrow or sell something in order to cover an unexpected $400 medical emergency (ACS, 2017).

Inadequate Insurance. Due to the astronomical costs of care, many cancer patients are faced with mounting bills. Even patients with insurance can expect to pay a significant amount for their cancer treatment. With the passage of the Patient Protection and Affordable Care Act (ACA), citizens in the United States were required to have insurance; however, this requirement was overturned by the following Presidential Administration. Still, the number of those who had insurance increased from before the ACA was passed. Nonetheless, possessing insurance does not necessarily equate to affordable cancer treatment. An 80/20-medical plan offers decent health coverage with the insurance company covering 80% of medical costs and the patient responsible for 20%. Yet for some cancer treatments, 20% can mean tens of thousands of dollars. Indeed 12 of the 13 new cancer drugs released in 2012 cost upwards of $100,000 per year (Light & Kantarjian, 2013). This could result in a $20,000 out of pocket expense for a patient with an 80/20-medical plan. Consequently, patients experience objective burden as the extreme costs of their health care are passed down to them through inadequate insurance policies.

Out-of-pocket expenses. In addition to high costs of care and inadequate insurance plans, cancer patients are often caught unaware of the out of pocket expenses (OOPE) that result from direct and indirect costs of treatment. Patients may experience increases in indirect costs such as insurance co-payments, monthly premiums and medications costs. In addition, indirect care costs can accumulate, including childcare, housekeeping, prosthetic, over-the-counter medications, and travel expenses (Lange et al., 2004; Darby, Davis, Likes, & Bell, 2009). These are costs that are not directly related to paying for medical expenses, but are expenses associated with having cancer. Patients can expect their OOPE to double what a person without cancer would pay for medical care (Short, Moran, & Punekar, 2011). OOPE have been found to augment the experience of related financial (objective) burden and lead to increased long-term financial debt (Lange et al., 2004; Finelstein et al., 2009; Markman & Luce, 2010; Pisu et al., 2010). In this respect, patients are experiencing objective burden as expenditures increase by way of increased insurance costs and unexpected out-of-pocket expenses.

Time away from work. To complicate the situation, patients may need to take time away from work to receive medical care resulting in lost wages (Chrikos, Russell-Jacobs, & Cantor, 2002; Lauzier, Maunsell, De Koninck, Drolet, & Robert, 2004; Bradley et al, 2007; Mehnert, 2010; Zajacova, Dowd, Schoeni, & Wallace, 2015). A national study reported that patients experience a decline in employment and income up to two years before their cancer diagnosis (Zajacova et al., 2015). This may be indicative of a patient's need to work less due to an impending diagnosis and needing to take time off for being sick. They also determined that the likelihood of being employed after a cancer diagnosis decreased for up to three years post-diagnosis. The study noted that it could take patients four to five years to recover from the financial effects and return to their pre-diagnosis economic state. Under these circumstances a family's income could decrease by 20-40% of their annual earnings (Zajacova et al., 2015). Additionally, some patients are unable to return to work after their cancer experience due to treatment effects and physical decline (Stepanikova, Powroznik, Cook, Tierney, & Laport, 2015).

Bankruptcy. Facing this financially toxic situation, patients may be forced to file bankruptcy in order to get out from under the accumulating medical bills (Amir, Wilson, Hennings, & Young, 2012). In 2007, medical debt attributed to 62% of bankruptcies. Most of these patients were middle-class, well educated, and owned their own home (Himmelstein, Thorne, Warren, & Woolhandler, 2007). Another study found that cancer patients are 2.65 times more likely to file for bankruptcy then those without cancer (Ramsey et al., 2013). Patients have also noted losing possessions including their homes as a result of their experience (Amir et al., 2012). Inevitably cancer can increase a person's risk of financial ruin that could take decades to overcome.

With costs of cancer treatment increasing, lack of adequate health insurance coverage, costs of OOPE, need for long-term follow-up care, and lost wages, many cancer patients are faced with astronomical medical expenses. It is undeniable that these costs can result in financial ruin for many individuals and their families. This toxic condition can then negatively impact patient's quality of life (QoL) and feelings of well-being.

Psychosocial impact. It is evident that the costs of cancer diagnosis, treatment, and follow-up care can cause subjective distress. Further review of the literature indicates the detrimental effects on patients' psychosocial well-being due to the costs of care. The following section reviews the psychosocial impact on patients as well as methods used by patients to offset cancer care expenses.

Effects of stress. It is well known in health-related research that chronic stress and depression can negatively affect a person's immune system, increase inflammation, impede the healing process (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002) and lead to more severe infections or chronic health conditions (Schneiderman, Ironson, & Siegel, 2005; Godbout & Glaser, 2006; Mohd, 2008). In particular, a study with breast cancer patients determined that chronic stress was associated with DNA repair, immune function, and tumor growth processes (McGregor, & Antoni, 2009). Furthermore, studies with cancer patients have found that patients who experience cancer-related financial burden are more likely to experience higher anxiety and depression levels then those who do not (Wong et al., 2010; Sharp, Carsin, & Timmons, 2013). As cancer-related financial burden increased so did anxiety and distress. Left unaddressed, cancer-related financial burden may lead to psychological distress, further health problems and slower recovery from cancer treatment.

Non-adherence. Another related issue affecting patient health and recovery is non-adherence to the treatment plan. It is estimated that more than 2 million Americans do not abide by recommended treatment due to costs (Weaver, Rowland, Bellizzi, & Azia, 2010). Non-adherence to medical treatment is defined as not taking prescribed medication, taking less medication than prescribed, or not filling or partially filling prescriptions. Many cancer patients reported that associated financial burden influenced their medical decision-making and treatment choices forcing them to make financial sacrifices to offset the costs of treatment (Wong et al., 2010). Patients have reported non-adherence with medical advice and treatment, further jeopardizing their health. In fact, a quarter of participants in a national study reported that they did not follow recommended treatment because of the costs associated with that treatment (Weaver, Rowland, Bellizzi, & Azia, 2010; Markman et al., 2015). Patients chose to skip medications or only partially fill prescriptions (Markman et al., 2015) and forgo other non-essential health care such as dental and eye care (Kent et. al., 2013; Bernard et al., 2011; Bullock, Hofstatter, Yushak, & Buss, 2012; Shankara et al., 2012; Zafar et al., 2013). Indeed, patients are being faced with difficult financial decisions that can adversely affect their general health, nutrition, and recovery, potentially affecting long-term survival.

Strategies to offset costs. Faced with financial burden, patients use a variety of strategies to offset the costs of treatment and defray expenses. To help pay for their medical expenditures, patients resort to using their savings, selling possessions, borrowing from others, and relying on credit cards (Bernard, Farr, & Fang, 2011). These efforts may result in the patient feeling indebted to others and/or trapped in increasing credit card or loan debt. Similarly, patients have sold stocks and investments, and withdrawn money from their retirement accounts (Shankara et al., 2012). Other strategies used involved cutting back on discretional spending such as decreased spending on leisure activities, food, and clothing (Bernard, Farr, & Fang, 2011; Wong et al., 2010; Zullig et al., 2013). Although these efforts may be financially beneficial, cutting out items an individual enjoys may negatively affect their emotional and social well-being. Consequentially, these methods may add to the experienced subjective distress.

Furthermore, financial toxicity (objective burden and subjective distress) has been shown to negatively affect a patient's psychosocial well-being and QoL (Ell et al., 2007; Meneses, Azuero, Hassey, McNeew, & Pisu, 2012; Gupta, Lis, & Grutsch, 2007; Fenn et al., 2014). Patients are forced to make sacrifices that can negatively affect themselves and their families. These compounding effects can negatively affect the overall experience and place patients under further stress, thereby complicating their general health and financial situation.

Who Is at Risk for Financial Hardship? Determining exactly which cancer patients are at risk for financial toxicity is challenging. The National Cancer Institute reports that the type of cancer, it's level of severity, and treatment type as well as age, race, income, job and insurance status can all make an individual susceptible to financial toxicity. More specifically, a recent systematic review of 25 peer-reviewed articles found that being female, younger aged, lower income, extended therapies and time since diagnosis were associated with financial toxicity (Gordon et al., 2017).

The literature reviewed for this chapter suggest other factors can put patients at risk as well. Insurance status showed those with private non-group insurance (Bernard, Farr, & Fang, 2011), Medicaid or lacking insurance coverage (Shankaran et al., 2012) were at risk. Being older middle-aged (55-64 years old) (Bernard el al., 2011) or older then 65 (Negut et al., 2011) put patients at risk. Shankaran et al. (2012) found other variables placed patients at higher risk. These included lower educational level, rural residency, multiple chronic health conditions, never married or widowed, and one or no children. In addition, Kent et al. (2013) reported risk was associated with a history of prior cancer treatment, and a shorter time since initial diagnosis. Furthermore, several studies agreed that individuals from minority racial groups were more likely to report financial burden as well as experience worse health outcomes (Bernard et al., 2011; Shankaran et al., 2012; Kent et al., 2013; Chirikos, Roetzheim, McCarthy, & Iezzoni, 2008). Two studies also reported that work-related status of disability, unemployment, or leaves of absence from work predicted financial burden (Bernard et al., 2011; Shankaran et al., 2012). Evidently, attempting to clearly define who is at risk of financial toxicity (objective burden and subjective distress) is complicated as few commonalities exist among studies. Conceivably the costs of cancer care can affect anyone depending on the type of cancer, treatment expenses, resources available, and personal circumstances.

Impact on family. It is generally accepted that cancer does not only affect the individual but can negatively impact the entire family (Bradley et al., 2007; Amir et al., 2012). Similarly, cancer-related financial toxicity can also plague the patient's family. Family members may need to quit their jobs or take time off to become caregivers (Carey et al., 2011). Individuals may need to give up outside employment to take care of their loved one. This can have a direct impact on the family member's financial well-being (Grunfeld et al., 2004). The family members may experience loss of access to resources. This has been shown to negatively affect a family member's health and access to health care as they may delay their own health concerns or general check-ups due to a lack of funds or insurance to access care (Grunfeld et al., 2004). The financial situation therefore contributes to the experience of caregiver burden.

Social Support in the Literature

Up to this point, I have cited the literature providing evidence for the impact of financial toxicity. The next half of this chapter will cover social support in cancer. The breadth and depth of literature on social support is vast and covers a plethora of situations. For the purposes of this part of the literature review, articles were retrieved that consider social support as a direct influence on health-related outcomes in cancer patients and survivors. Then another search was conducted to obtain articles that focused on social support as a moderator or mediator variable in both cancer studies and other health-related studies.

Social Support in Cancer. It is well known that adequate social support serves as a protective factor for people facing crisis or traumatic experiences (Cobb, 1976). The cancer experience is no exception to this. Several studies have identified social support as an important component having a direct relationship with health-related consequences over the cancer trajectory.

In the literature, low social support or lack of social support is associated with negative health-related outcomes. Social support has been shown to have a direct relationship on cancer disease progression in patients with breast cancer (Nausheen, Gidron, Peveler, & Moss-Morris, 2008) and acute myelogenous leukemia patients (Pinquart, Hoffken, Silbereisen, & Wedding, 2006). Lower levels of social support were found to predict patient mortality in acute myelogenous leukemia patients (Pinquart et.al., 2006). Furthermore, another study found that patients with lower social support at diagnosis were at risk of developing negative physical symptoms such as pain and inflammation (Hughes, 2014).

Social support has also been associated with the emotional well-being of patients. Those with lower levels of social support were more likely to experience higher depression (Uchitomi et al., 2000; Schroevers, Ranchor, & Sanderman, 2003; Eom, 2012; Hughes, 2014) and anxiety levels (Uchitomi et al., 2000). In a longitudinal study with cancer patients, those with lower levels of problem-focused emotional support displayed higher levels of depression (Schroevers, 2003). Moreover, perceived social support and a desire for social support were strong predictors of anxiety and depression symptoms in newly diagnosed cancer patients (Linden, 2009). For those patients with a lower desire for support, if support was not present, they experienced increased depression. These studies support that the lack of support can be detrimental to patient’s mental and emotional well-being.

Conversely, patients with higher levels of social support appear to gain health-related benefits. The more emotional support cancer patients had post diagnosis was a significant predictor of positive outcomes of treatment up to 8 years post treatment. (Schroevers, Helgeson, Sanderman, & Ranchor, 2010). Furthermore, social support has had a direct positive relationship with physical exercise and nutrition in cancer survivors (Barber, 2012; Coleman, 2014). More specifically, increased perceived social support positively influenced physical and mental health related QoL (Westby, 2016) and overall QoL (Eom, 2012). Emotional and information support have also been associated with increased social, emotional and functional well-being (Kroenke, 2013). In this same study, increased tangible supports were related to increased physical, and social well-being as well as overall QoL (Kroenke, 2013). Interestingly and in support of theory, the level of satisfaction with social support was found to be a predictor of patients’ QoL but the size of their social network was not (Cheng et al., 2013). This suggests that perceived or received social support is more important than the number of individuals available in one’s network to provide the support. Furthermore, although no study was found to determine the best types of social support, one study showed that received social support had a stronger influence and satisfaction than perceived (Schroevers et al., 2010)

Lastly, in a qualitative study of patients undergoing chemotherapy, several benefits of social support emerged in their data. Social support assisted patients in focusing on the bigger picture and adapting to living with cancer. It helped them steer from negative thoughts and aspects of cancer as it enabled them to engage in normal everyday activities. Furthermore, social support was instrumental in patients finding hope and support (Mattioli, 2008).

Social Support: An Influential Variable. For decades social support has been shown to have an influence on QoL by helping to maintain and promote emotional and physical well-being (Cobb, 1976; Cohen & Syme, 1985). To further this discussion the following section reviews the social support literature in the context of moderator or mediator variables. These articles are not specific to cancer although many of them are. The purpose of this review is to support the concept that social support can interact as an influential variable between the relationships of other variables.

Social support has been found to be a significant factor in coping with cancer-related stress. In the prior section social support was shown to have a direct effect on health and QoL but it also can moderate or mediate aspects within the cancer experience. In breast cancer patients, perceived social support was shown to moderate the effects of cancer-related negative thoughts on patient QoL (Lewis et al., 2001). In gynecological cancer patients, received social support was shown to moderate the effects of cancer-related traumatic stress on physical symptomatology; patients with greater perceived social supports reported fewer cancer-specific symptoms than those with poorer perceived social supports (Carpenter, Fowler, Maxwell, & Andersen, 2010). In a second study with breast cancer patients, social support mediated the negative association between optimism and distress (Trunzo, & Pinto, 2003). Perceived social support was found to mediate optimism and positive affect in non-cancer specific survivors, thus, social supports protected against negative psychological outcomes. This study also showed that social supports had a direct effect on positive affect (Hodges, & Winstanley, 2012).

Another study considered the impact of social constraint which occurs when social support is interpreted by the support received to be negative or non-help. In the literature reviewed social constraint was explored in breast and colon cancer patients. In this study, social constraint was seen as a mediator variable between optimism and patient affect. They also determined that patients who were more optimistic had fewer social constraints but did not necessarily have more social support (Lepore et al., 1999).

In studies focused on general health, received social support has been found to buffer the experience of financial stress on psychological well-being in general health research. Aslung, Larm, Starring and Nilsson (2014) examined the effects of financial stress on the psychological well-being and psychosomatic symptoms of individuals in the general population in Sweden. Although financial stress still had a substantial impact on emotional and physical well-being, those with more tangible social supports were significantly better off than those with less. Additionally, the level of stress increased significantly for those who had low social support (Aslung et. al., 2014). These findings are indicative of the buffering effect social support provided for the psychological well-being of those experiencing financial stress.

The literature reviewed discussed the importance and value of social support and how it can make an impact, both positive and negative, on an individual’s experience. We have also observed how social support can act as a direct or indirect variable which can interact as a moderator or mediator variable in different situations.

Gaps in the Literature

There have been several studies conducted on the financial burden of cancer. Although this is not an exhaustive review of the literature, it provides us with an intricate view of this complex issue. Still, there is much to be learned. There remains an inability to truly identify those at-risk. This lack of understanding may lead to unmet patient needs, and further exasperate the lack of access to financial assistance. Another issue is the lack of understanding of the process by which financial burden occurs. By better identifying key time periods in the cancer trajectory, interventions may be employed strategically. Another piece to the puzzle may be understanding help-seeking behaviors as they relate to financial aspects. Socially, taboo issues have long constrained people from talking about such issues as politics, religion, sex, and money. Furthermore, in my literature search, I was only able to identify two interventions that have been tested for effectiveness in addressing cancer-related financial burden.

It is apparent that more information is needed to fully understand this phenomenon and variables which may play a positive role in relieving the negative impact. As viewed through the literature on social support, it is apparent that it plays an important role in the cancer experience and has been shown to be a stress-buffer for financial strain in other contexts. In response to these findings, it is my intention to expand on the given literature by examining the role of social support in the context of cancer-related financial burden.

Summary

Despite awareness and efforts to improve patient care, little is being done to address the financial burden that cancer patients endure. Although literature exists on the impact of cancer-related financial toxicity and its effects on QoL, it is evident that we do not have a full understanding of the experience faced by many cancer patients. This research study strives to add to the literature by exploring the impact of social support as an influential factor in the lived experience of cancer. By gaining this knowledge, social work practice and research will be better informed to identify and work with those individuals at risk.

As presented in the literature reviewed, social support can have positive effects on health and wellness. Furthermore, it can act as a direct or indirect variable having a moderator or mediator effect. Nonetheless, there is a lack of knowledge regarding the influence of social support on experienced financial toxicity during and after cancer treatment. It is apparent that social support has a relationship with patient survival and QoL. In addition, social support has also been shown to have an impact on the perception of financial stress in another context. However, it is unclear how social support may impact an individual's experienced financial toxicity throughout the cancer trajectory.

The next chapter will present the theoretical perspectives and frameworks that support this project suggesting that social support may indeed play an important role. Chapters 4 and 5 provide the methods and results for Study 1 respectively. Likewise, chapters 6 and 7 provide the methods and results for Study 2. A final discussion bringing the results of both studies to address the overarching questions will conclude in Chapter 8.

CHAPTER 3: MULTIPLE METHOD APPROACH, RESEARCH PARADIGMS, AND THEORETICAL PERSPECTIVES

It is human nature to be inquisitive about the world that surrounds us. We have a strong desire to understand why, where, what, and how. We strive to comprehend a problem and find solutions. These questions and our desire to find answers to them is the driving force behind our research inquiry. In order to answer these questions researchers are faced with deciding how best to accomplish this task and are reliant on the philosophical and theoretical perspectives with which they align.

Research is deeply intertwined with these perspectives and the role they assume has been much debated with varying degrees of agreement. It has been my experience, in attempting to navigate this philosophical maze, there are multiple ways to philosophically approach a research question. This poses a task for the researcher to identify the best way to logically approach their question. Furthermore, they must be able to justify their decisions to align with a given design, philosophy, or theoretical perspective.

In order to address the overarching research question that drives this project: *What role does social support play in the experience of cancer-related financial toxicity (objective burden and subjective distress)?* I selected a multiple methods approach. This chapter will first present the Multiple Method design and justify its use. The Multiple Method approach is structured differently from other research designs as multiple independent studies are used to answer the overarching question. Therefore, it is important to understand the overall design of the project before presenting the philosophical assumptions for each study component.

Our philosophical assumptions consist of a basic set of beliefs used to approach a study. They suggest how we understand what reality is and dictates our role as a researcher to observe or interact intimately with the study. Philosophical assumptions guide our values and ethics suggesting an acknowledgement of presence or absence of bias. Furthermore, the philosophical alignment we take dictates the research methods we use (Guba & Lincoln, 2005). After presenting the foundational design of this Multiple Method project and the use of multiple studies, this chapter will cover the philosophical assumptions for each study component.

The final step in laying down the foundational pieces of this project will cover the theoretical perspectives and frameworks that gave steady footing to the project. Theories provide us with a way of understanding and explaining human behavior. They can serve multiple roles in the research process, such as, guiding the development, implementation, analysis procedures, and interpretation of a study (Bradbury-Jones et al., 2014). These theories and the work of Hayes (2017) give rise to a conceptual model which will be reviewed at the end of this chapter.

Multiple Method Design

Mixed Method and Multiple Method approaches are considered to be “in the middle of a boom” as an increasing number of researchers are relying on them (Seawright, 2016, p.42). Creswell and Clark (2011) suggest such methods are appropriate to further understand a phenomenon when using one data source is insufficient, if there is a desire to generalize findings, or a second method will further enhance the study’s findings. The use of multiple research strategies will help broaden the breadth and scope of understanding and provide a more complete picture of the phenomena (Morse, 2003). By combining different research strategies, it is suggested that the strengths of one method will compensate for the weaknesses of another leading to more credible outcomes (Hunter & Brewer, 2015). However, due to the novelty of this relatively emerging approach to research, terminology and methodological expectations are still murky. This section will attempt to provide clarification to the Multiple Method approach relied on for this project.

As presented in Chapter 1, Multiple Method approach begins with an overarching question and is composed of multiple individual studies that attempt to answer that question. Each study is considered to be interrelated with another in that they attempt to answer the same question, but they are separate and whole. Each study has its own sub-question and is guided by its own philosophical assumptions (Morse, 2003). For this project, two studies were conducted sequentially but had equal importance: first the qualitative and then the quantitative. From the qualitative study, social support was identified as an important concept. This led to a desire to understand more about the role social support played and informed the development of the quantitative study. More details about the methods of each study a presented in Chapter 4 (Study 1 Methods) and Chapter 6 (Study 2 Methods).

When designing a Multiple Method project each study component must be methodologically independent and executed separately. They must adhere to the specific methodological assumptions for each (Morse, 2003). Therefore, the qualitative will meet the assumptions consistent with qualitative research and likewise for the quantitative. In addition, the study samples are typically independent from one another adding to the concept that these studies are separate from one another. The final step of a Multiple Method design involves bridging the results to form a comprehensive understanding in response to the overarching question. (See Figure 3.1 for a depiction of the overall Multiple Method design showing the differences in methodology, and philosophical assumptions.)

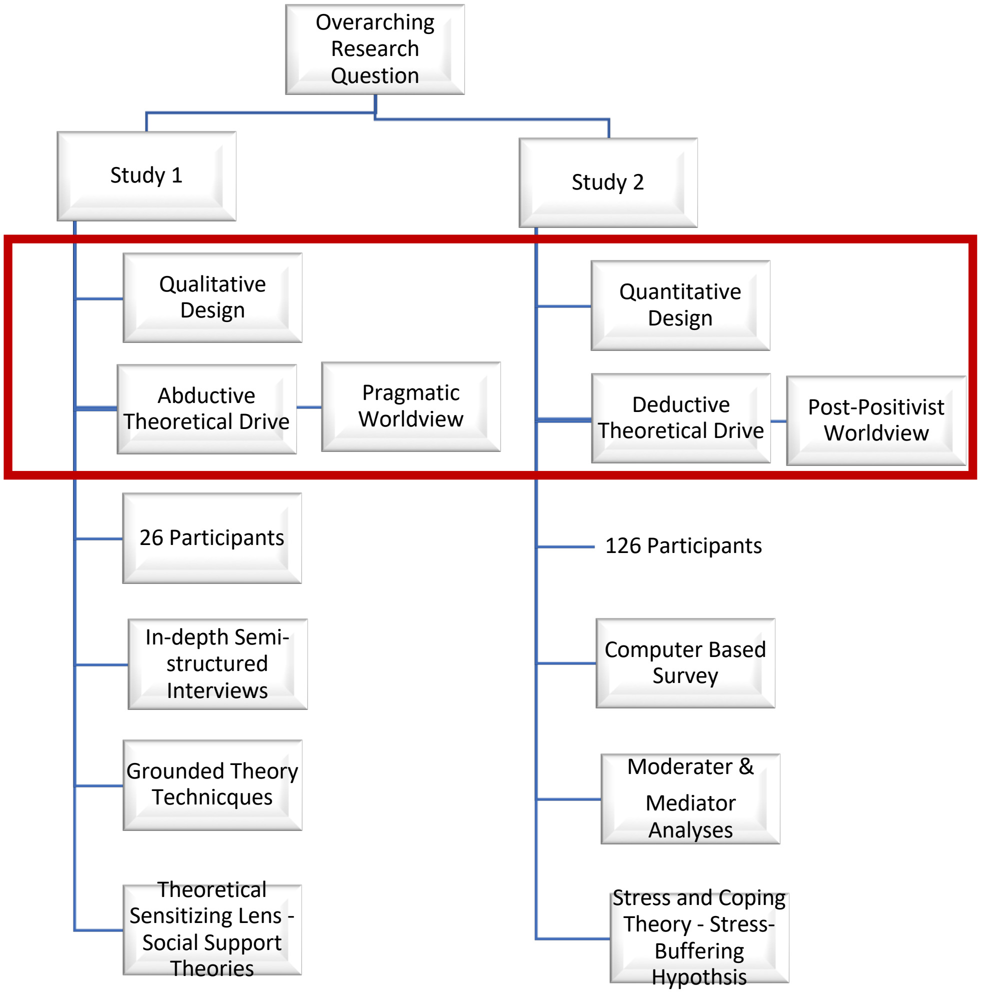


Figure 3. 1 Multiple Method Design Theoretical Focus

There are several benefits of using a multiple method approach. As stated earlier, multiple method approach allows for a comprehensive picture of the phenomenon that is under investigation. This approach allows for different perspectives on the topic by providing opportunities for the use of different theoretical lens and worldviews. By collecting multiple forms and different levels of data, a wider variety of conclusions can be ascertained. This approach will provide insight into the personal experiences of individuals exploring what types of social support helped them during their cancer experience. It will also provide statistical significance of social support in this context either by moderating or mediating the experience of financial toxicity on quality of life (QoL). In turn, this may inform and expand on the current framework of financial toxicity presented later in this chapter.

Weaknesses of the multiple method approach include the risk of placing too much credence or weighting to heavily on the results of the studies (Morse, 2003). Therefore, similar to other methods, the researcher should not overexaggerate the study finding but instead approach them modestly. In addition, Morse (2003) warns of the importance of being aware of the theoretical drive at all times in the process. This is dictated by the overarching question and design; however, each study component is driven by inductive or deductive reasoning depending on the particular aspect and sub-questions of each study. Specifically put, if using qualitative methods then inductive reasoning is the driving force; whereas, if using quantitative methods then deductive reasoning is relied on. In order to maintain methodological integrity each method must stay intact. It is important to not allow the studies to contaminate each other by ensuring their independence. Likewise, each study sample should be appropriate for the method used and adequate data analysis performed. Morse (2003) also stresses the importance of not violating assumptions.

In light of these warnings, each component of this project will be conducted separately and will align with each respective assumptions and theoretical lenses. Each will be driven by their separate theoretical drive and will address appropriate sub-question(s) for the given method. The qualitative study will use subjective data and an abductive theoretical drive involving iterative cycles of deductive and inductive reasoning (Graneheim, Lindgren, & Lundman, 2017). The quantitative will use objective data, deductive reasoning, standardized measures, and statistical analysis. The following section will present the philosophical assumptions relied on for each component of the project.

Philosophical Foundations

Philosophical assumptions are deeply rooted in the way we think about the world. They are ingrained in our thoughts and instilled in us through our education and training. Philosophical assumptions used depend on our approach to address a particular problem or social phenomenon. There are four philosophical assumptions used in the research process: ontology, axiology, methodology and epistemology. Ontology refers to reality and how it is the researcher knows and understands what reality is. Axiology conveys the role values and ethics play in the research process. This helps the researcher understand the use or hindrance of their biases. The stance the researcher takes in regard to Ontology and Axiology dictates the epistemology. The epistemology refers to the researcher's role and their understanding of the interaction between themselves and what is being studied. These philosophical assumptions lead to the way the research is conducted, namely the methodology and the specific methods used (Creswell et al., 2011). Each of these four elements (ontology, axiology, epistemology, and methodology) are woven together and provide a philosophical foundation referred to as an interpretive framework.

An interpretive framework conveys a basic set of philosophical assumptions. Heeding the warnings presented by Morse (2003) in the prior section, each study will be conducted separately using the interpretive framework that best serves the aims of each study. The overarching question and Study 1 will use a pragmatic interpretive framework and Study 2 will rely on the post-positivist stance. See Table 3.1 for an at-a-glance view of the philosophical assumption for each interpretive framework used.

Table 3. 1Philosophical Assumptions of Two Worldviews (adapted from Creswell et al., 2011).

	Ontology (what is real)	Axiology (values & ethics)	Epistemology (role)	Methodology (theoretical drive)
Pragmatism (Overarching Project, Study 1)	Both Single & Multiple Realities	Multiple Values & Perspectives	Focuses on Whatever Answers the Question	Dependent on the Question (Inductive or Deductive Reasoning)
Post-Positivism (Study 2)	Focused on Single Reality	Researcher Eliminates Biases	Quantitative Methods	Deductive Reasoning

Pragmatic Worldview. The pragmatic worldview is primarily focused on finding answers to the research question. In regard to Ontology, the pragmatist takes the view that reality can be both a single reality and/or multiple (Creswell et. al., 2011). Reality is a creation between what is in the world and how we react to it; therefore, what we know and understand of the world is based on what we have found to be proven useful (Ritzer & Stepnisky, 2013). Similarly, pragmatic axiology (role of values) proposes that an idea is neither good nor bad, but value depends instead on the success of its outcome (Hookway, 2016). The researcher can therefore use whichever epistemological design will answer the question. Methodologically a pragmatist is not limited to viewing a phenomenon one directionally but instead is open to the any possibility the data presents (Hookway, 2016). Essentially, the pragmatic worldview appears to be sitting on a proverbial fence selecting from either side of the continuum what will best help them answer their question.

Due to a seemingly flexible stance, the pragmatic approach works well for the Multiple Method design. The focus is therefore on the question being asked and the respective outcomes of the individual studies, not necessarily on the methods used to obtain them (Creswell et al., 2011). In this project the results from both the qualitative and quantitative studies are triangulated to answer the overarching question. The theoretical drive, methodological stance, is inductive which is in line with the overarching question format and conception of bringing the findings from both studies together to form an overall interpretation.

Pragmatism also informs the philosophical beliefs for Study 1. A generic qualitative approach allows for the use of varying epistemologies and methodologies. Caelli et al. (2003) propose that each qualitative approach be evaluated in congruence with its epistemological and methodological stance. Qualitative research should aim to address: 1) the theoretical position, 2) methodology and methods, 3) rigor and trustworthiness, and 4) the analytic lens used to examine the data (Caelli et al., 2003). A pragmatic perspective supports drawing from both deductive and inductive theoretical views using an abductive theoretical stance. Similarly, a pragmatism allows for multiple analyses methods and tool to be incorporated and used. Rigor and trustworthiness in a generic qualitative approach can be established by similar efforts used in other forms of qualitative approaches as well. Furthermore, a pragmatic worldview allows for the reliance on multiple theories informing the analytic lens.

Postpositivist Worldview. The post-positivistic worldview is a logical stance for quantitative research (Creswell et. al., 2013) and will be relied on for Study 2. It seeks to establish causal relationships by concentrating on established variables. The ontology is focused on a singular reality which can be derived through scientific methodology and driven by a deductive process (Creswell et al., 2013). Using measures that are proven reliable and valid helps the research to establish claim that a phenomenon does exist as a common, singular reality. Established measures also assist the researcher in eliminating biases (axiology) which can also be addressed through the study design and aspects of rigor. This, therefore, allows the research to remain impartial and allowing the presentation of the data to dictate the findings. Through the use of structured theoretical perspective/frameworks, this quantitative study relied on philosophical assumptions of Post-positivism: deductive reasoning, standardized measures, and statistical analysis.

Theoretical Perspectives

Theories are intimately interwoven into the research process. They serve as frameworks for understanding what we observe and how we make sense of it. They guide our research development leading us to ask important questions. They can postulate a basic concept and lead us in a common direction. Theories can also be created and emerge from our own research findings. The way theories are used in the research process is determined by the goals of the research project, and the methods used (Bradbury-Jones, Taylor, & Herber, 2014).

The theories I relied on can be classified as substantive and formal theories. Substantive theories are those that are specific to a given topic and based on empirical findings; whereas, formal theories are conceptually derived (Glaser, & Strauss, 1967). These theoretical perspectives were relied on to develop, implement, and interpret the findings of this project.

Financial Toxicity. The Financial Toxicity framework (Carrera & Zafar, 2018) was used in both studies of this project. In a recent publication, Carrrera et al. (2018) present their framework for the financial toxicity of cancer care. (See Figure 3.2 for a replication of Carrera's et al. (2018) interpretation of the financial toxicity framework.) This framework provides a conceptual understanding of the objective burden and subjective distress associated with the costs of cancer care. This framework served as a foundational piece for conceptualizing the problem and understanding how social supports fits into the process.

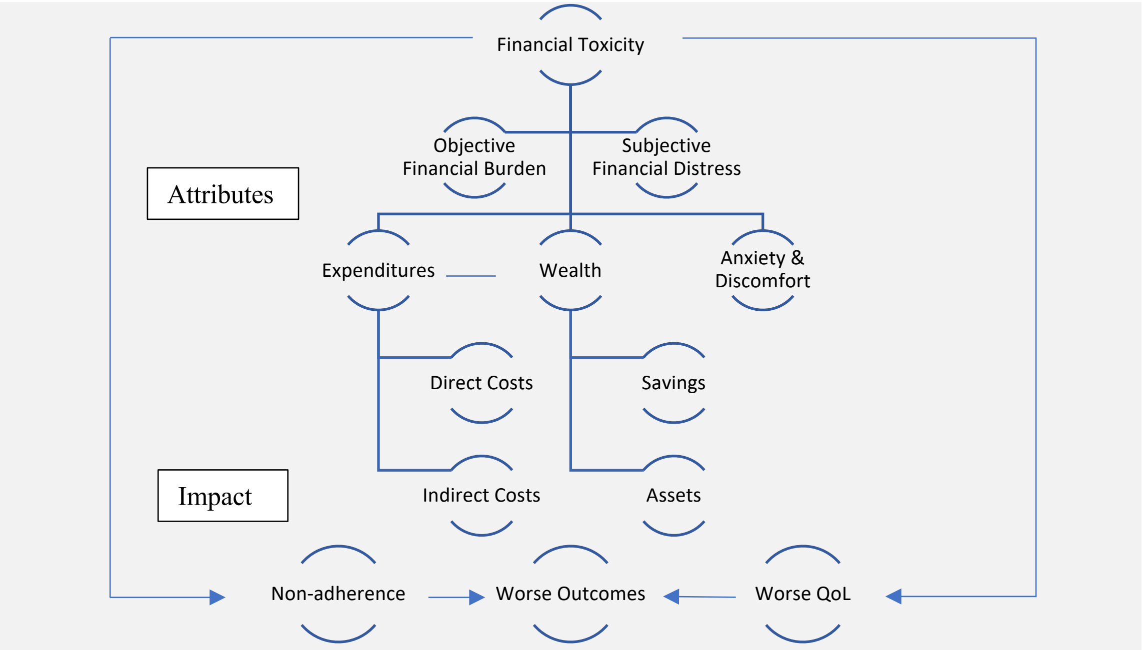


Figure 3. 2 Framework on Financial Toxicity (Carrera & Zafar, 2018).

Financial Toxicity refers to the financial objective burden and subjective distress experienced as a result of a cancer diagnosis and treatment. From an objective standpoint, patients face financial burden due to direct and indirect costs associated with their cancer care (Carrera et. al., 2018). As presented before, the costs of cancer care are astronomical, and many patients are faced with unexpected out-of-pocket expenses. Financial barriers exist such as being underinsured or uninsured which can be further complicated by forced changes in employment status. Patients make financial sacrifices such as selling belongings, reducing household spending and using savings. They may borrow money and use credit cards leading to increased financial debt which may result in bankruptcy. Subjectively the costs of care impact the patients experience and psycho-social well-being (Carrera et. al., 2018). Research has shown that patients report feelings of anxiety and distress. Furthermore, this multi-complex phenomenon (financial toxicity) not only impacts the patient, but it adversely effects the family as well.

These subjective and objective experiences of financial toxicity lead to potentially overall worse outcomes for patients and their families. As a result, a patient may choose to be non-adherence to medical treatment which may result in poorer health-related outcomes (Carrera et. al., 2018). Furthermore, financial toxicity can lead to worse quality of life. (Details on financial toxicity and supportive literature are presented in Chapter 2.)

Social Support Theories. Social support is a term used to describe the product of one's support network and interactions. It is well known in the cancer literature that social support plays a critical role in physical health, psychological well-being, social functioning and emotional adjustment among survivors and those living with cancer. For the purposes of this research project it is conceptualized as: the *emotional*, *informational*, and *instrumental* supports perceived and/or received from formal and informal support networks.

According to Sarason, Sarason, and Piece (1990) there are three models of social support: 1) network of support, 2) received supports, and 3) perceived supports. Each of these models describes important information about social support and helps to provide a more comprehensive conceptualization of the concept. The first model, network of support, often looks at the number of people who surround the individual and the types of those relationships. This is a laborious process for the study participant, time consuming for the researcher, and does not necessarily yield a connection between social support and health outcomes (Sarason et al., 1990). Given these concerns, I focus attention on the other two models: received and perceived supports. The extent to which networks are explored in this project is limited to whom the participant receives support from or perceives to be supported by.

A support network is made up of the social relationships that surround the individual and is composed of family, friends and community members (Laireiter, & Urs, 2013). This is composed of the people an individual interacts with. These relationships are considered formal or informal depending on the social role the network member plays. Formal support network members are typically from distant roles including individuals such as health care professionals and organizations. They typically perform more informational or instrumental support services (Cohen, 2013). Informal supports, on the other hand, are intimately close relationships consisting of family members and friends. They may provide informational, instrumental and emotional types of support.

Interestingly, whether or not a behavior is perceived as supportive is dependent on the provider of the support as well as the timing of when the support occurs (Cohen, 2013). It is important to be aware of the social role the supporter plays, the timing of the received social support and the support receiver's perception of the supportive act.

As noted, social support can be perceived or received. The perception that social support exists is based on the viewpoint of the receiver. In general, the receiver thinks or feels that support is available. Received support can be objectively measured either by self-report or reported by others (Laireiter et al., 2013). From the receiver's perspective these are social supports that are actually received. Both perceived and received supports can be in the form of emotional, informational, or instrumental.

Emotional support refers to the understanding that one is accepted, cared for and valued (Cohen & Syme, 1985). It can exist in the form of empathy, encouragement, reassurance, or feelings of being understood, accepted and loved (Langford, Bowsher, Maloney, & Lillis, 1997; Wong et al., 2016). Emotional supports may be received through others communicating support or having someone who is willing to listen and understand. It can also be a perception of knowing someone cares and would be available if needed.

Another category of support is *informational* support. This is defined by Cohen and Syme (1985) as one's ability to find knowledge and information to better understand the problematic event. Informational supports are most needed when a stressful event, such as a cancer diagnosis, exceeds the knowledge and problem-solving abilities of that individual. Therefore, the individual is required to seek advice, knowledge, and guidance from others. Examples of received informational support are problem-solving advice, receiving resource information and referrals. Informational support can be a perceived sense of support in the form of knowing that access to information or advice is available if requested (Langford et al., 1997; Wong et al., 2016). Ultimately, individuals need to know where to find the information or who to ask.

The final form of support that will be considered is *instrumental* support which consist of provided assistance with tasks, tangible, and material support (Cohen & Syme, 1985). Instrumental support for the issue of cancer-related financial toxicity may be in the form of financial assistance, providing material goods such as food and other daily-living necessities, or assistance with completing household chores. Similar to the other two forms of support, access to instrumental support can be a perception that this type of assistance and resource is available if needed, or it can be actually received.

Conditions of social support. To add another layer of complexity, certain conditions need to be met before social support is requested by the individual or provided by a network member. For a person to request assistance the request cannot be something that would potentially harm the relationship and the individual must feel comfortable in the relationship to make a request. The network member must know enough about the stressor, be capable of providing support and not overreact to the request being made. If the network member overreacts, the individual may feel embarrassed or ashamed of asking. The need for the request must be socially acceptable and perceived as a legitimate stressor. Socially taboo stressors may cause feelings of guilt or shame which may prevent the individual from requesting help or the network member from providing it. Additionally, if social norms dictate the necessity of providing support, then support will likely be provided. (Cohen, 2013). Therefore, the giver feels on obligation to provide support. Lastly, in order for social support to be most effective the support received must match the need (Cutrona & Russell, 1990). If the support does not match the need, the need will still remain leaving the individual feeling unsupported.

*Social constraints***.** Ideally, social support provides one with positive elements that help to provide feelings of comfort, encouragement, helpful information or usable items; however, social support can also be perceived or interpreted as negative (Lepore & Ituarte, 1997; Lepore & Revenson, 2007). Network members may say or do things that are interpreted by the individual as inappropriate, critical, or insensitive (Hobfoll, & Stephens, 1990; Cohen, 2013). They may attempt to minimize the stress-event or perhaps avoid and abandon the individual all together (Hobfoll et al., 1990; Veiel & Baumann, 2013). Life events such as having cancer may elicit avoidant or minimizing behaviors from network members (Veiel et al., 2013). This may complicate the situation further making it difficult for individuals to talk about their problem or ask for help.

Feeling socially constrained, patients keep their thoughts and feelings private. They become less likely to share or disclose their emotional and physical needs. They may feel they cannot talk to anyone about what is causing them distress (Veiel et al., 2013). This leads to the individuals feeling isolated and unsupported. Ultimately, the individual may experience mental health issues (Lepore et al., 2007) such as depression (Schroevers et al., 2003), increased distress and mood disturbances (Norton, 2005).

Stress and Coping Theory. The Transactional Model of Stress and Coping Theory (referred to as Stress and Coping Theory) developed by Lazarus and Folkman (1984) was designed to explain how individuals experience a stressful event, assess related risks, and select coping methods. This is a process-oriented approach for dealing with stress that involves cognitive assessment of a stressful event through the appraisal process and then selection of the best coping method. The effectiveness of the coping mechanism, in turn, dictates the outcome (Lazarus, & Folkman, 1984; Folkman, 1997; Folkman & Greer, 2000; Folkman, 2010). When new information is acquired, re-appraisal of the event occurs creating the reselection of coping mechanisms and potential effects on outcome (Folkman, 1997; Folkman, 2010). The following section will briefly review components of this theory within the context of cancer-related financial toxicity (objective burden and subjective distress). Refer to Figure 3.3 for a depiction of the Stress and Coping Theory in the context of cancer-related financial toxicity.

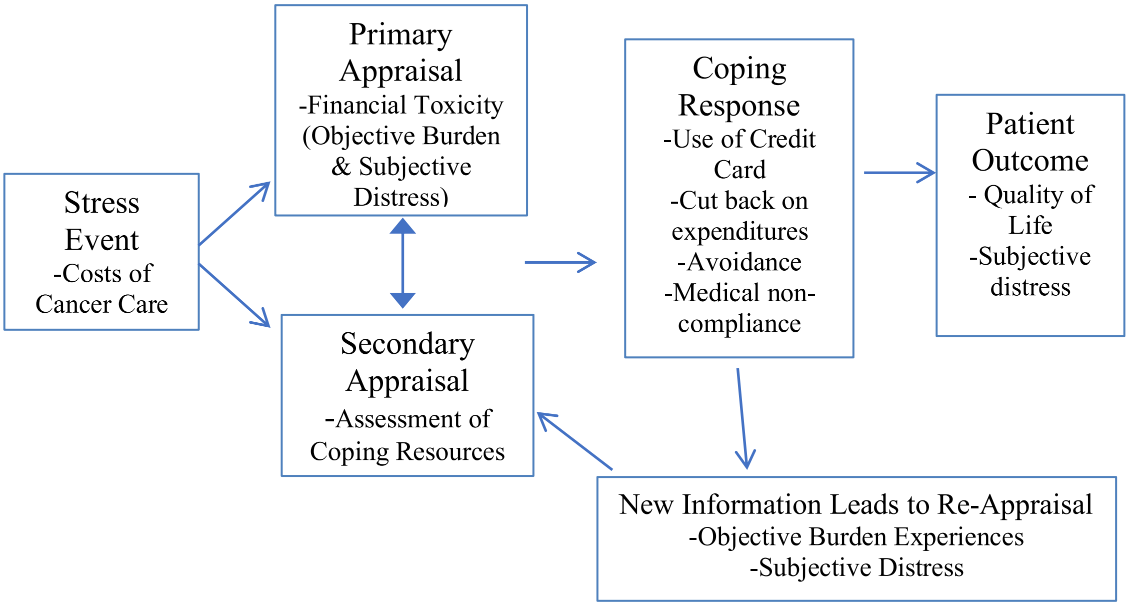


Figure 3. 3 Financial toxicity illustrated through the Stress and Coping Theory (Lazarus & Folkman 1984).

Stress event. According to Lazarus and Folkman (1984), stress is a response to a stimulus that induces a stressful physiological and behavioral response. It results when these demands overburden the individual, exceeding their available resources, and potentially risk the person’s sense of stability and well-being. For example, the stress-causing event may be a risk of harm, or unexpected demand placed on the individual. In the context of this study, the initial stress events are cancer and the costs of cancer care. Initially, patients experience increased expenditures related to their cancer care (objective burden). The actual costs or an anticipation of the costs of care may become overwhelming and result in effects on psycho-social well-being (subjective distress).

In time, the patient may experience a secondary stress event which occur through the feedback loop. Objectively, patients may be unable to work resulting in reduced income and potential job loss causing an additional stress event. Furthermore, a job loss could impact insurance availability and ability to cover medical and basic daily needs. Cancer patients may also face an accumulation of medical bills and related expenses. These stress events may then be interpreted to cause harm which in turn leads to use of coping mechanism resulting in an outcome.

In addition, the outcome can result in the subjective distress aspect of financial toxicity. The effects of stress on cancer patients have been well supported in the literature. As noted in Chapter I, research has shown that cancer patients who experience financial burden have increased anxiety, depression (Sharp et al., 2013) and distress (Markman et al., 2010; Lange et al., 2004). Patients have also reported long-term financial strain as a result of related OOPE (Darby, Davis, Likes, & Bell, 2009). The subjective distress could also lead back to the appraisal process through the feedback loop and becoming another stress event.

Appraisal. Once a person experiences a stress event, he/she engages in the appraisal processes. This is a cognitive process where the individual contemplates the stress event and desired outcome. During the appraisal process a person gains an understanding of a given situation and assesses whether the stress event is benign or threatening to their feelings of well-being (Lazarus et al., 1984; Folkman, Lazarus, Gruen, & DeLongis, 1986).

The appraisal of a stress event occurs during three phases: primary, secondary, and re-appraisal (Folkman, 1997). The primary and secondary appraisal processes can occur simultaneously. During the primary appraisal a person will assess if a situation is irrelevant, benign-positive or stressful. Then during the secondary appraisal, the individual determines what, if anything can be done. The individual assesses what coping options are available, and which will be effective. Then they determine if they have the ability to effectively execute that particular coping method. The final phase of appraisal occurs when the individual becomes aware of any new information that may affect the situation. This is referred to as the re-appraisal process since the individual re-assesses the situation through both the primary and secondary processes.

In the context of this study, individuals experience the stressor (initial cancer and cost, secondary objective burden and subjective distress) and then in the first appraisal process they assess the stress event as harmful or overwhelming. This may follow or occur simultaneously with the second appraisal process where the individual determines the best course of action to gain the best possible outcome given their available coping mechanisms and resources.

Coping. Once the stress event has been appraised, the individual engages in a coping response. Coping responses include anything a person thinks or does to manage the stress-event. Coping responses are influenced by the uniqueness of the individual and may be good or bad depending on the interaction between the individual and their environment (Lazarus et al., 1984; Folkman et al., 1986; Folkman and Greer, 2000; Folkman, 2010).

Coping responses for those experiencing cancer-related financial toxicity are well documented in the literature. Many of these responses are not beneficial to a patient's overall health and mental wellness. In one study, patients reported skipping or delaying medical treatments (Darby et al., 2009). Medical non-adherence is not uncommon among individuals who experience cancer-related financial toxicity. Patients will also base medical decisions based on the costs associated with the doctors' appointments and medical treatment (Markman et al., 2010; Wong et al., 2010; Shankaran et al., 2012). Other coping methods used by patients involved cutting back discretionary spending, selling possessions, using saving and retirement funds (Shankaran et al., 2012), borrowing money, and increasing debt (Bernard et al., 2011). Although these types of coping methods may temporarily alleviate the stress allowing the patient to get through the cancer experience, arguably they can result in negative outcomes impacting overall quality of life.

Outcome. The *outcome* is the result of the appraisal and coping processes (Lazarus et al., 1984). Depending on the effectiveness and the available coping resources, individuals may be able to carry on with their everyday activities or they may be immobilized and in a state of crisis. For the purpose of this proposed study, quality of life will be used as the outcome variable.

Understandably financial toxicity can impact multiple domains of quality of life: social, emotional, functional, physical and economical. For example, social well-being may be affected when individuals cut back on discretionary spending. They may not be able to afford to engage in social activities causing them to potentially lose social relationships. Likewise, this could affect their functional well-being. Individuals may not be able to afford to do things they once enjoyed doing. In the emotional domain, financial toxicity may cause an increase in sad or hopeless feelings when coping strategies are not effective. Individuals may feel powerless as their financial situation negatively affects their economic well-being.

Quality of life is often used as an outcome variable in research on cancer-related financial toxicity. Several articles have shown that cancer-related financial burden has a negative relationship with quality of life (Ell et al., 2007; Gupta, Lis, & Grutsch, 2007; Fenn et al., 2014). As patient financial strain increases, their quality of life decreases.

Stress, coping and financial toxicity. The stress and coping theory provides a basic model for understanding the effects and outcomes of cancer-related financial toxicity (objective burden and subjective distress). See Figure 3.3 (presented earlier) which illustrates how the initial stress events (cancer and cost of care) enacts the primary and secondary appraisal processes. Financial toxicity (the objective burden and subjective distress) is appraised and coping resources are assessed which leads to the coping response which in turn leads to patient outcomes and/or reassessment through the feedback loop.

Stress-Buffering Hypothesis. The stress-buffering hypothesis can be used to suggest that social support buffers the individual from adverse effects of a particular stress event. It builds upon the conceptualized framework of Stress and Coping Theory. (See Figure 3.4 for the addition of social support as a stress buffer to the Stress and

Coping Theory in the context of financial toxicity). According to Cohn and Wills (1985), social support may intervene with the stress and coping process during the appraisal process and/or the coping response.

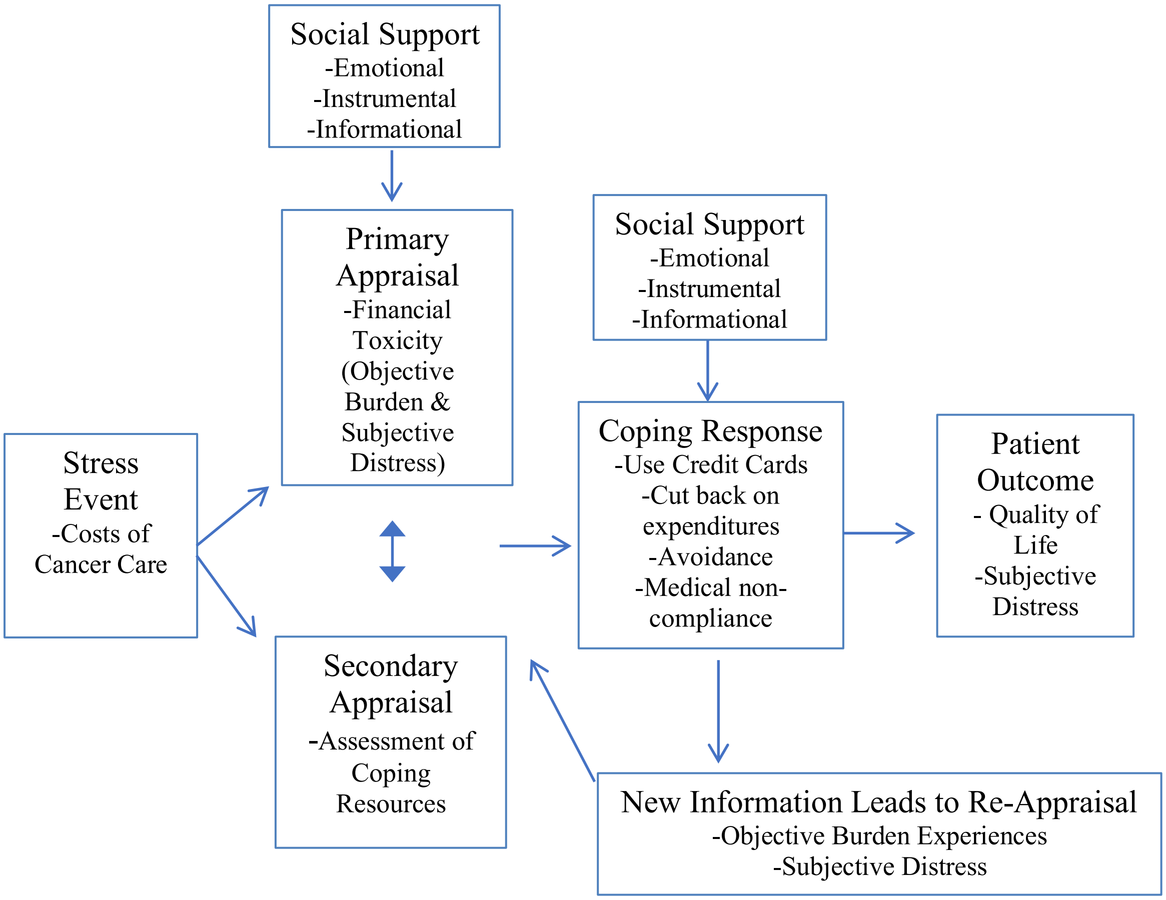


Figure 3. 4 Social support on financial toxicity interpreted by Stress and Coping Theory and Stress-buffering Hypothesis.

First, social supports may buffer the interaction between the stress event and the appraisal process (Cohen & Wills, 1985). Due to perceiving or receiving adequate support, individuals may not perceive the stress event to be as harmful or threatening as it would without those supports. A second point of support intervention may occur during the coping response process (Cohen & Wills, 1985). This may then cause the re-appraisal process to occur due to the acquisition of new information. This new information could be in the form of problem-solving advice, information or resources that may ease or eliminate the stress.

It is important to note that in order for the social support to be an effective buffer, the support provided must match the demands of the stress event (Cohen & Wills, 1985). Therefore, in the context of this proposed study, social support that helps to alleviate financial toxicity would act as a buffering agent. Currently there is no empirical support defining what this type of social support would be; however, the benefits of social support on health have long been established (see the literature review in Chapter 2 for more details).

Conceptual Model

There are two different ways a third variable can act as a buffer, either as a moderator or a mediator. A moderator variable will regulate the relationship between the independent variable and the dependent variable. The moderator variable may change the direction or the magnitude of the IV, maximizing or minimizing its effectiveness on the dependent variable. For study 2, social support will be examined to determine if it is a moderator variable regulating the relationship between financial toxicity and quality of life. Figure 3.5(a) displays the conceptual interpretation of social support as a moderator variable.

In addition to this framework, a moderated moderator model will further examine the moderator effects by adding social constraint to the model. Social constraint has been shown by the works of Lepore et al. (1999) to negatively impact the benefits of social support. See Figure 3.5(b) for social support as the moderated moderator model (Hayes, 2017). In this model, social constraint is conceptualized to regulate the interaction between financial toxicity and social support; therefore, the relationship between financial toxicity and QoL is moderated by social support which in turn is moderated by social constraint.

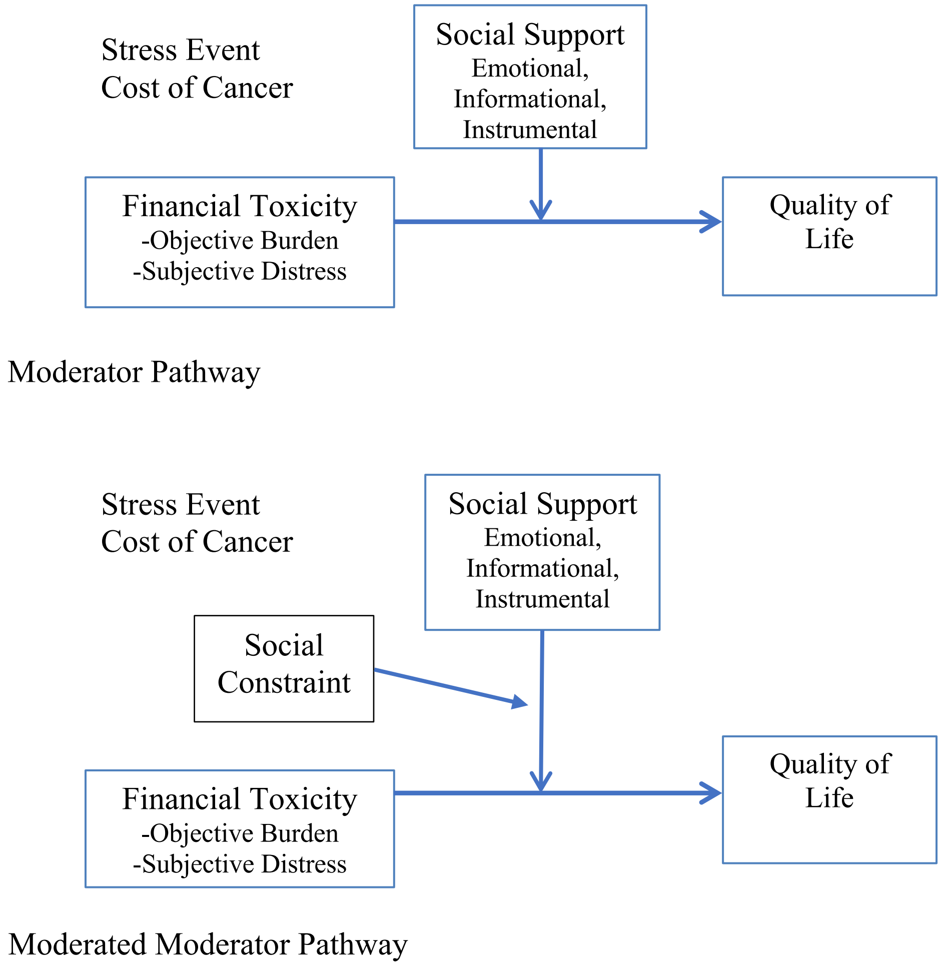
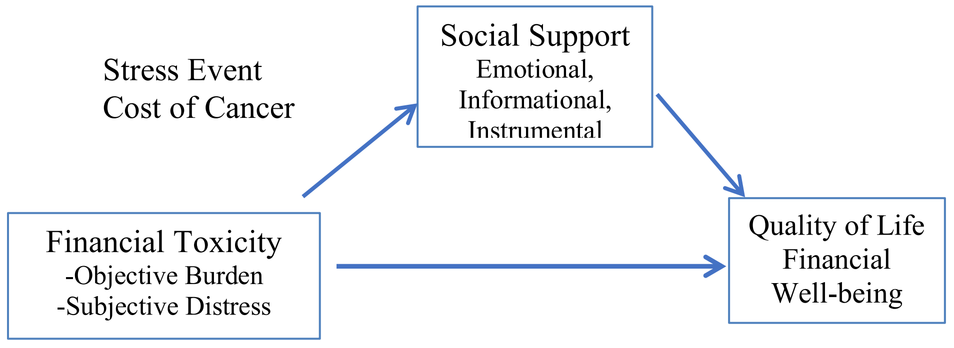
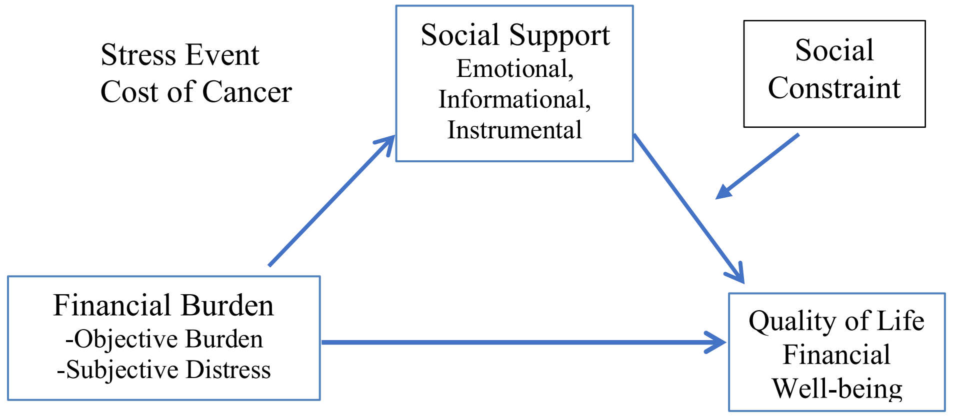


Figure 3. 5 Social support as a moderator variable, adapted from the work of Hayes (2017).

Alternatively, a mediator creates a mechanism through which the independent variable is able to influence the dependent variable. According to Hayes (2017), mediation offers a causal explanation for what is occurring in the phenomenon. It assumes the relationships in the analysis are causal. It therefore assumes financial toxicity has a direct causal relationship with QoL and an indirect effect on QoL through the mediator variable, social support. In this mediator relationship, financial toxicity leads to an increase in social support which in turn effects QoL. In this study, I will not be able to unequivocally establish causality due to the study design and the data available for this analysis. That will be noted as a limitation of this study; however, the analysis for a mediation variable will allow for some interpretation. (See figure 3.6 (a).)



Mediator Pathway



Moderated Mediator Pathway

Figure 3. 6 Social Support as a Mediator Pathways.

Furthermore, social constraint will be examined in the mediator analysis as well. This analysis will use a moderated mediator model (Hayes, 2018). It examines the impact of social constraint on the relationship between perceived social support and quality of life. (See Figure 3.6 (b).)

Summary

Researchers are tasked with identifying the best method to use to answer their research questions. For the purposes of answering the overarching question presented in Chapter 1, I chose to conduct a Multiple Method approach. This approach allowed me to draw conclusions from both qualitative and quantitative methods allowing for different perspectives and procedures to inform the discussion. As noted, there is a gap in the literature in regard to social support and cancer-related financial toxicity accordingly this multiple method approach will help to provide a broader perspective.

In addition, this chapter has addressed the foundational components underling the development of this project. The Multiple Method design requires that the individual studies be whole and complete. This requires the use of the appropriate philosophical and theoretical perspectives to answer the study questions. The assumptions, theoretical perspectives and frameworks for each study were presented, each providing the individualistic approach to each study component.

The next chapter provides detailed descriptions of the methods used. To remain true to the Multiple Method design as described by Morse (2003), each component of the project will be discussed as separate studies. The first part of Chapter 4 covers Study 1 (qualitative) followed by Study 1 results in Chapter 5. Chapter 6 and 7 presents the methods and results for Study 2. Then Chapter 8 presents a final discussion drawing on the finding from both studies to answer the overarching questions. This will also include concluding remarks and implications for social work practice.

CHAPTER 4: STUDY 1 METHODS

The overarching question that drives this research project is: *What role does social support play in the experience of cancer-related financial toxicity?* To answer this question a multiple method approach was used. Two studies were developed each answering an aspect of the overarching question. To stay true to the assumptions of the multiple method approach as presented in Chapter 3, each study was conducted separately and is considered to be solely complete by itself. Study 1 is presented first as it was the first study to be completed and aspects of the findings were used in the development of Study 2. The present chapter details the methods used for Study 1.

Study 1 - Qualitative

Study 1 was a secondary data analysis of a qualitative study that explored the lived experiences of 26 cancer survivors who self-reported experiencing financial burden and distress (financial toxicity) due to the costs of their care. Secondary data analysis of qualitative data is not a common practice but has been acknowledged in the literature as an acceptable method (Smith, Ayanian, Covinsky, Landon, McCarthy, Wee, and Steinman, 2011). I was involved with the original study (LEFT study) from its inception and participated in all aspects of the process. Social support emerged as a primary category, so the research team granted me permission to use this data.

Purpose

The specific aim of my analysis was to better understand the existence and use of social support within the lived experience of cancer-related financial burden. It specifically explored the research question: *For individuals who have had cancer, what is their experience with social support in the context of cancer-related financial toxicity?*

Pragmatism. Pragmatic philosophical assumptions were relied on in order to seek and understand this phenomenon. (Refer to Chapter 3 for in-depth details on the pragmatic worldview). The pragmatic worldview is focused on answering the research question through whatever tools or methods are most appropriate. This viewpoint allows for the use of multiple theories which not only provide the foundational support for the study but also informs the analysis and interpretation of the results.

From a pragmatic stance, I used a generic qualitative approach informed by Caelli et al. (2003). Since the generic qualitative approach does not align with any specific epistemology or methodology it is acceptable to use with pragmatism. Caelli et al. (2003) states that the epistemology and methodology used should be congruent. This leaves the researcher tasked with clearly identifying and substantiating their research according to four key issues: 1) a well-defined analytic lens, 2) a clear theoretical position, 3) congruence between epistemology, methodology and selected methods, and 4) establish rigor and trustworthiness (Caelli et al., 2003).

The analytic lens used for this study was social support theories. (For in-depth details on the conceptualization of these theories refer to Chapter 3.) This involved a back and forth process between social support theories and the data analysis process. Relying on a theoretical abductive drive, processes of deductive and inductive reasoning were incorporated (Graenheim et al., 2017). Through the analysis procedures, a primarily deductive approach was used to categorize the data. This process was followed with an inductive approach of developing in-depth definitions for each category. (Further explanation of these steps will be provided later in this chapter.) It is through this inductive process that a greater understanding can emerge (Charmaz, 2014). Calling on pragmatic roots, multiple methods of iterative processes that can occur through the data analysis phase. These iterative processes will highlight similarities and differences in the data (Miles and Huberman, 2014). Furthermore, the generic qualitative methodology allows for selecting methods which will inform and answer the study questions.

For this study, Qualitative Content Analysis (QCA) was the most appropriate method and remained congruent with the methodology (generic qualitative approach). Content analysis must be "systematic, methodologically based, and transparently reported" (Drisko & Maschi, 2016, p. 4). It can be used for secondary data analysis and can be driven by inductive and/or deductive coding approaches (Drisko & Maschi, 2016). Furthermore, it QCA uses deductive methods to organize data into categories and inductive methods to create definitions of those categories (Mayring, 2000).

Data in this study are organized into categories through a direct approach. The purpose of the direct approach is to validate or expand on a given theoretical framework. The direct approach uses a theory-based approach to coding where codes are informed or developed through using theory or relevant research findings (Hsiu-Fang & Shannon, 2005). These codes can remain manifested, meaning that they are grounded in the data staying true to the participants' words. On the other hand, the codes can be latent in nature allowing the researcher to immerse in the data and identify hidden, underlying meanings (Bengtsson, 2016).

Congruent with pragmatism, the generic qualitative approach and QCA, trustworthiness can be established through multiple methods. Results for the QCA can be displayed in a table format to give readers a quick glance at the material. In addition, quantification of sub-categories and categories can occur through counting occurrences of the identified unit of analysis (Bengtsson, 2016). Quantification can increase the magnitude of the phenomena being studied. However, according to Mayring (2000), QCA follows the rules of content analysis except it does not require the quantification of the data. Further efforts to establish trustworthiness can be borrowed from other qualitative methods such as those proposed by Lincoln and Guba (1985).

Study Sample. Sampling methods that were used to obtain participants include: criterion, snowballing and purposive. Initially, patients were obtained from a recruitment announcement posted in cancer centers, cancer support organizations, churches, and the University of Louisville daily e-news. It became clear that there was not much representation from the older adult population so purposive sampling was used to acquire more older adults. A total of 26 participants met the criteria and participated in the interviews.

Inclusion criteria. In order to participate, participants needed to be age 18 or older, had a cancer diagnosis and received treatment in the past 5 years. They also needed to perceive that they experienced financial hardship due to the cancer experience.

Data Saturation. Data collection was conducted until the research team determined saturation of data was reached. The process of determining data saturation involved multiple discussions regarding the data that had already been collected. The team of researchers conducted initial data analysis and identified common categories among all the interviews. Then conducted an assessment of the age ranges of the participants. It was determined that the sample was missing representation of older adults; therefore, the researchers purposely requested participation of individuals who were over 60 years old. Once an adequate representation of all age groups was achieved, the research team determined that the study had reached saturation.

Data Management. In order to ensure study integrity and confidentially for participants, data were carefully maintained. Audio files were transcribed and then destroyed. All identifiable information was removed from transcripts and data were kept in a password protected computer. The transcripts were also maintained in Dedoose^{TM} which is an online qualitative analysis program. Dedoose^{TM} provides a secure online platform for handling qualitative work.

Study Procedures. The following section begins by detailing the steps taken by the research team in the Origins section. It details how the initial categories of the larger qualitative study were determined using a theory-based approach and how Gaps in Support emerged from the analysis. This is followed by a description of my analysis process found in the Social Support Analysis section.

Origins. Financial burden associated with cancer treatment was identified as being a topic that dramatically affects patients and their families. After conducting a literature review, a research team was assembled to develop a study proposal. Once developed, study procedures were reviewed and approved by the Institutional Review Board. A call for study participation was sent out through various means: university system announcements, cancer related organization emails and area church correspondence. Interested participants responded by email or telephone and went through a screening process. Participants were asked a series of questions to determine if they met the study criteria (presented below). Those who met criteria were scheduled for an interview.

A team of researchers, consisting of three university professors, two doctoral students and a research assistant, conducted 26 one-on-one interviews. Interviews were conducted in a private setting convenient to the participant. Interviews took place over Skype if the participant was located in a different city than the interviewer. Other locations included participants' homes or their workplace offices, as well as offices located on the university campus.

Prior to each interview the participant was provided the consent preamble (see Appendix A for details). For those meeting over an online format, the preamble was emailed to them prior to the interview. Each interview began with a brief explanation of the study then participants were asked a series of semi-structured interview questions designed to elicit in-depth information regarding their related experience (see Appendix B for the interview schedule). Participants were asked about their cancer experience and when they first began to feel financial hardship. They were asked about their understanding of their medical expenses and insurance as well as how they coped with the financial stress. Interviews were recorded, professionally transcribed, and analyzed using qualitative data analysis software, Dedoose^{TM}.

After the completion of the interview, participants were asked to complete a questionnaire (see Appendix C). This questionnaire consisted of measures for sociodemographic information including age, gender, marital status, ethnicity/race, marital status, number of dependent children, income, job status before and after cancer, occupation, insurance status before and after cancer, and cancer disease characteristics. Other standardized measures were used as well and included quality of life, health literacy, and financial toxicity.

Using a constructivist grounded theory (CGT) approach as described by Charmaz (2014) and Corbin and Strauss (2008), data collection and analysis were conducted. Once a few interviews were conducted, data analysis began with line-by-line coding. Each member of the team assisted in this process initially. Focus codes were developed by grouping similar initial codes and then a codebook was established using the more frequent codes. The first ten interview transcripts were coded in Dedoose^{TM} using the codebook. After a discussion of the interview transcripts and coding process, a finalized codebook was established by the research team.

After each interview and coding session, the research team met to debrief, discussing the interviews and reflecting on the individuals' experiences. During each meeting, the research team would evaluate the questions and interview format to ensure that the interviews were obtaining the richest information possible.

All members of the research team engaged in the coding process for all of the interviews. Throughout this process, researchers engaged in inter-rater reliability checks to ensure rating consistency. A feature of Dedoose^{TM} analysis software assists researchers in building and maintaining inter-rater reliability (Sociocultural Research Consultants, LLC, 2014). Through this feature an initial pooled Cohen's kappa statistic of 92% was achieved. After differences were discussed and raters came to agreement on variances, a Cohen's kappa statistic of 100% was reached.

Moving beyond the coding process, themes were identified. The research team decided to divide the themes among the members of the team for further analysis. Social support was one of the themes identified and given my interest in social support as well as my active participation in the study, the research team provided me with the task of further exploring this component.

Social Support Analysis. The following section details the analysis of the data that I conducted for Study 1.

Overview. This section will provide a brief overview of the steps I carried out after receiving permission from the team to further analyze.

1. IRB approval was current for the original study; therefore, I did not need to request approval. The data were used in accordance with their oversight.

2. Interview transcripts were read multiple times and then uploaded to a new Dedoose^{TM} file for analysis.

3. Categories were informed and developed from social support theories using the theory-based direct approach of QCA (Hsiu-Fang & Shannon, 2005).

4. Using the theory-based categories, transcripts were first analyzed in Dedoose^{TM} and meaningful excerpts were identified (Mayring, 2000; Drisko & Maschi, 2016, Bengtsson, 2016).

5. Excerpts were extracted from the data and transferred into an Excel workbook. They were then analyzed using a Partially Ordered Meta-Matrix table for cross-case analysis (Miles, Huberman & Saldana, 2014).

6. I engaged in several forms of memo writing throughout the data analysis process (Charmaz, 2014; Corbin & Strauss, 2013; Miles et al., 2014).

7. Data interpretation and drawing conclusions involved developing links within and between subcategories based on social support theories (Creswell, 2013; Miles et al., 2013).

8. Subcategories were consolidated when appropriate and in-depth descriptions and definitions of each category and subcategory were created (Bengtsson, 2016; Hsiu-Fang & Shannon, 2005; Mayring, 2000).

9. Situational mapping (Clarke, 2005).

10. Development of Trustworthiness through the use of multiple techniques (Bengtsson, 2016; Creswell, 2013; Lincoln & Guba, 1985; Padgett, 1998).

Detailed analysis. I created a new project in Dedoose^{TM} and uploaded the 26 interview transcripts from the *LEFT* study. I decided to start with clean transcripts instead of going back to the ones originally used with all the prior codes. This allowed me a fresh, unhindered look at the data.

First, I started with reading and re-reading the transcripts. As I did, I began to recognize patterns that resembled social support theories. Participants clearly spoke about receiving information, emotional, and instrumental support as well as experiencing social constraints. Simultaneously, I recognized a clear distinction within the excerpts of who provided the support. In most situations, individuals spoke specifically about the person who provided the support. These excerpts were further organized on a system level by support provider: family, friends, medical professionals, work, and other organizations. In social support theories, whether or not an action is considered supportive is in part dependent on who the person is that provides the support. Therefore, it made sense to me to further delineate quotes into these network categories. In response to observing these patterns, I selected to use a theory-based direct approach to coding (Hsiu-Fang & Shannon, 2005). Therefore, the codebook was developed to reflect social support theories. (See codebook in Table 4.1). In addition to these theoretical codes, other codes were created to fully capture interviewees' experience.

Table 4. 1 Theory-based Codebook Used in Dedoose^{TM}

Category	Sub-category	Network Member Sub-category	Description
Helpful Support	Emotional Support		
		Family - Spouse	Emotional support from spouse that is helpful and supportive.
		Family - Parent	Emotional support received from a Parent that is considered to be helpful and supportive.
		Family - Sibling	Emotional support received from a Sibling that is considered to be helpful and supportive.
		Family - Child	Emotional support provided from the Child that is considered to be helpful and supportive.
		Family Member	Emotional social support from a Family Member Not Otherwise Specified that is considered to be helpful and supportive.
		Friends	Emotional support from Friends is considered to be helpful and supportive.
		Medical Professional - Nurses	Emotional support provided by Nurses that is helpful and supportive.
		Work/Employment	Emotional support provided by an employer, boss, work agency that is considered to be helpful and supportive.
		Organizations	Emotional support provided by a Professional Organization that is considered to be helpful and supportive.
	Informational Support		
		Family - Spouse	Information received from Spouse.
		Family - Parent	Information received from a Parent that is helpful and supportive.
		Family - Sibling	Information received from a Sibling that is considered to be helpful and supportive.
		Family - Child	Information provided by the Child that is helpful and supportive.
		Friends	Information received from Friends considered to be helpful and supportive.

		Medical Professional - Doctors	Information received from Doctors that is considered to be helpful and supportive.
		Medical Professional - Social Worker	Information received from a Social Worker that is considered to be helpful and supportive.
		Medical Professional - Hospitals/Cancer Centers	Information received from Hospital/Cancer Center is considered to be helpful and supportive.
		Organization	Information provided by a Professional Organization that is considered to be helpful and supportive.
	Instrumental Support		
		Family - Spouse	Instrumental support from a Spouse that is helpful and supportive.
		Family - Parent	Instrumental support from a parent that is considered to be helpful and supportive.
		Family - Sibling	Instrumental support from a Sibling that is considered to be helpful and supportive.
		Family - Child	Child provides an instrumental support that is helpful and supportive.
		Family Member	Instrumental support received from a family member that is not otherwise specified and is considered to be helpful and supportive.
		Friends	Instrumental support provided by Friends that is helpful and supportive.
		Medical Professional - Doctors	Instrumental support provided by Doctors that is considered to be helpful and supportive.
		Medical Professional - Financial Counselor	Instrumental support provided by a financial counselor that is considered to be helpful and supportive.
		Medical Professional - Nurses	Instrumental support provided by Nurses that is considered to be helpful and supportive.
		Medical Professional - Social Workers	Instrumental support provided by Social Workers considered to be helpful and supportive.
		Medical Professional - Hospitals/Cancer Centers	Instrumental support provided by the Hospital/Cancer Center that is considered to be helpful and supportive.
		Work/Employment	Instrumental support that is provided by an employer, boss, work agency that is considered to be helpful and supportive.
		Organization	Instrumental support provided by a Professional Organization that is considered to be helpful and supportive.
Non-helpful Supports	Social Constraint		
		Family - Spouse	Emotional support from a spouse that is not helpful or supportive.

		Family - Spouse	Instrumental support from a spouse that is not helpful or supportive.
		Family - Parent	Emotional support from a Parent that is not helpful or supportive.
		Family - Parent	Instrumental support from a Parent that is not helpful or supportive.
		Family - Sibling	Emotional support from a Sibling (brother/sister/in-laws) that is not helpful or supportive.
		Family - Sibling	Instrumental support from a sibling that is not helpful or supportive.
		Family - Child	Instrumental support from a child that is not helpful or supportive.
		Family - Child	Emotional social support from a Child that is not helpful or supportive.
		Family Member	Social support from family members that is not helpful or supportive.
		Friends	Social Support from Friends that is not helpful or supportive.
		Medical Professional - Doctors	Social support from Doctors that was not helpful or supportive.
		Medical Professional - Nurse	Social support from a Nurse is not helpful or supportive.
		Medical Professional - Social Workers	Social support from a Social Work is not helpful or supportive.
		Medical Professional - Financial Counselor	Social support from Financial Counselor/Navigator that is not helpful or supportive.
		Medical Professional - Hospital/Cancer Center	Social support from the Hospital or Cancer Center that is not helpful or supportive.
		Work/Employment	Social support from coworkers or employers that is not helpful or supportive.
		Organizations	Comments on social support from organizations that are not helpful or supportive.
Gaps in Support	Missing Support		
		Family	Expected social support from a family member is not available.
		Friend	Expected social support from a friend is not available.
		Medical Professional - Doctor	Social support that could have been provided by Doctors.
		Medical Professional -Nurse	Expected social support from a Nurse is not available.

	Medical Professional - Social Worker	Expected social support from a Social Worker is not available.
	Medical Professional - Financial Counselor	Expected social support from a Financial Counselor is not available.
	Medical Professional - Hospital/Cancer Center	Expected social support from a Hospital/Cancer Center is not available.
	Work/Employment	Social support that could have been provided by employers.
	Professional Organizations	Expected social support from Professional Organizations is not available.
Miscellaneous Categories		
	Desire for Help	Statement about wanting help, services, resources from any level of support.
	Difficulty Asking for Help	Expressed difficulty talking to others and asking for help.
	Embarrassing	Stated financial situation caused embarrassment.
	People don't want to talk about it	Expressed feelings that others did not want to talk about financial concerns.
	Supports Needed	The expressed desire for social support. Provided advice to improve services: Instrumental & Informational.

To ensure all excerpts of social support were captured by the analysis, I re-read all the transcripts once excerpts were selected. In addition, in order to maintain integrity with the original analysis, all excerpts of social support initially identified were compared to those identified in my analysis. There were only a few differences which were discussed with another research team member then included in the analysis.

The next analysis step was to create a partially ordered meta-matrix in Excel described by Miles and Huberman (2014). This heuristics technique, used for exploring qualitative data, assists the researcher by condensing large overwhelming amounts of data into a visual “at-a-glance” format. The process provided another method to use to reflect on the data and draw conclusions from them.

A partially ordered meta-matrix displays the participants case-by-case and in joining cells condenses relevant data. In order to do this, I downloaded excerpts from Dedoose^{TM} and compiled them into four different Excel workbooks organized by the type of person who provided the support (support provider). The four excel workbooks were each labeled: 1) Family, 2) Friends, 3) Medical Professionals, and 4) Organizations & Work. The first spreadsheet in each Excel workbooks provided an at-a-glance overview of the analysis using the sensitizing lens of social support. The first column contained a box for each participant code with demographic information. Then additional columns were created for each category of social support: instrumental, emotional, information, perceived, and negative support (social constraint). As I engaged in this analysis process a sixth column was created to include when social support was missing. For example, participant #1 indicated that she did not have anyone to talk to about her financial concerns. This was indicated in the sixth column. At this point, I systematically marked who provided that type of support by putting the person's role in the column of the type of support that was provided. (See Appendix D for visual examples of the partially ordered meta-matrix.)

To further help with the organization of the analysis, I created individual spreadsheets for the Family, Medical Professional, and Organization Excel workbooks breaking down each category further by support provider role. For example, spreadsheets in the Family Excel workbook included spouses, parents, children, siblings and other members. On these excel sheets, the participant and their specific quote about social support was inserted. I also used this form to provide additional thoughts on the quotes and shorten notation of what the quote was about. These processes and at-a-glance charts allowed for a deeper understanding of the what, who, and most importantly the gaps found within the experiences of these participants.

Through further reflection, I began to recognize commonalities between each of the support provider groups. The additional thoughts and shorten notations that I had made on each quote became concepts of which to collapse the data cohesively together. Using an inductive process, descriptions of each category and subcategory were created with the assistance of memo writing activities (Bengtsson, 2016; Hsiu-Fang & Shannon, 2005; Mayring, 2000). The outcomes that evolved through this process are discussed in the result section found in Chapter 5.

Memo writing. Charmaz (2014) emphasizes the importance of memo writing as it helps the researcher to remain active and stay engaged in the data. Memo writing serves several functions such as forcing the researcher to work conceptually and enabling them to work creatively giving insight into the data. Memos offer clarity, magnify important ideas and generate meaning (Corbin & Strauss, 2015). Memos can be done in different ways and serve numerous purposes. First and foremost, the memo writing that I engaged in throughout the data analysis and interpretive process was a methodological journal. This allowed me to keep an ongoing record of the analytical steps I was engaging in. It provided me with a safe space to explore fleeting thoughts and engage in reflexivity to maintain data integrity. Other memos took on a more structured purpose. For these types of memos, I followed direction and prompts provided by Charmaz (2014, p.183) and Corbin & Strauss (2015). See Appendix E for the outline used for memo writing activities and an example of one of my memos. The exercise of memo writing helped to provide connection and tease out distinctions within the data. Many of my memo writing excerpts were elaborated on and used in the results and interpretation section of this manuscript.

Data interpretation. Interpreting the findings of the data is an active process of making sense of the phenomenon. According to Creswell (2013), several forms of interpretation can evolve from the researcher's engagement and understanding of the data. Personal perspective as well as social constructs emerge from the data analysis and memo writing processes. Here the researcher is tasked with deciphering links within and between subcategories (Creswell, 2013; Miles et al., 2013). These links, according to Glaser (1978), are based on a deductive theoretical process. Charmaz (2014) takes this process deeper to state that it needs to emerge from the data; therefore, the focus is on the emerging theory or knowledge not on the imposing framework.

During the interpretation process of this study, I actively used social support theories as frameworks to understand the context and experiences of the study participants. This required building and constructing an understanding of the data informed by the categories and subcategories. This was accomplished through the memo writing processes as well as using situational mapping technique described by Clarke (2005). See Appendix F for examples. The process of using deductive and inductive reasoning to interpret the data was a useful way to show that social support theories exists in this context and allowed for other findings to emerge (see findings in Chapter 5).

Trustworthiness. In order to ensure the findings are valid and genuine I used several forms of trustworthiness. The development of trustworthiness for this study has been guided by criteria established by Lincoln and Guba (1985). Careful consideration was given to establishing these key concepts of trustworthiness: *credibility*, *transferability*, *dependability,* and *confirmability,* where possible (Cohen & Crabtree, 2006).

The concept of credibility is to have confidence in the outcomes of the analysis and to believe that these finds are indeed correct and true (Lincoln et al., 1985). Lincoln and Guba (1985) offer several ways to accomplish credibility in qualitative processes. Of these options, I engaged in *peer debriefing* and *negative case analysis*. The peer debriefing process requires the researcher to discuss research analysis procedures and findings with a peer. The peer listens and asks questions of the researcher, the findings, and the processes in an attempt to keep the researcher honest and true to the data (Creswell, 2013). Throughout the analysis process I met weekly with a colleague who was not involved in the original study. This was a mutually supportive process where we both provided feedback and guidance to each other in our analysis processes. This process assisted me in remaining true to the participants voices and gaining a clearer, deeper understanding of the data.

Another technique for credibility that was used is negative case analysis. I identified several cases that did not have excerpts of social support from specific people such as a spouse, family, and medical professional category. In addition, I documented instances of negative social support. These negative cases were pinnacle in the examination of social support in this context. These cases were reviewed for insight into why supports were deemed to either be missing or negative.

In addition to peer debriefing and negative case analysis, I compared the social support excerpts from the original analysis with the excerpts derived from my analysis.

Any discrepancies were reviewed and re-evaluated. They were then discussed with another member from the reach team and either included or excluded from the analysis.

Although the purpose of qualitative work is not to generalize the findings, Lincoln and Guba (1985) suggest that it is still possible to show that the outcomes of the study can be applicable in other contexts. Thick descriptions are a technique used by qualitative researchers to establish transferability (Lincoln, et al., 1985; Cohen & Crabtree, 2006). This allows for the researcher to understand the multiple dimensions of the phenomenon; therefore, lending itself to be transferable to other times, people, and setting (Cohen, et al., 2006). This was attempted through the multiple stages of the memo writing (Corbin, et al., 2015) where each additional memo on the specific topic was further thought about and elaborated on. Then a concise definition of each theme was created attempting to provide a thick and rich definition.

Another concept to establish trustworthiness is dependability. The purpose for this is to show that the findings of the study are consistent and repeatable. Lincoln and Guba (1985) suggest using what is called an external or inquiry audit. This process can be very time and labor intensive as it calls for an outside researcher not involved with the study to evaluate your work. I chose instead to take other steps to establish dependability. As noted earlier in the detailed analysis section, I re-analyzed the transcripts to ensure that all excerpts on social support were captured. When inconsistencies were found, I discussed these with a colleague to ensure what I was capturing was correct. In addition, all analysis work was provided as an audit trail.

The final concept of trustworthiness addressed by Lincoln and Guba (1985) and presented here is confirmability. This is the degree to which the findings arise from the interviewee and not a result of researcher bias. Three methods were used to establish confirmability: *triangulation, audit trail* and *reflexivity*. Triangulation can be used to establish a study's credibility and confirmability. It is the process of using multiple methods, theories, data, and analysis (Creswell, 2013). Triangulation occurred in this study at the theory level, forms of data analysis and methods used. Several theories led to the development and underlying understanding of financial toxicity and social support. In addition, I engaged in several techniques of data analysis as described earlier in the data analysis section. The second method used to establish confirmability is an audit trail. An audit trail allows for others to repeat and/or confirm the study findings (Lincoln & Guba, 1985; Padgett, 1998). To fulfill this technique, the steps and procedures used were closely documented and recorded. The final confirmability method, reflexivity, is an exercise a researcher engages in to identify any pre-conceptions, judgments or biases they may have prior to engaging in the analysis process. I engaged in this process by reflecting on me as a researcher, and my own personal experience with family members who have had cancer and their experiences with related financial concerns. I also reflected on my own perception on financial struggles. The product of this activity is presented in Appendix G.

Ethical Considerations. The University of Louisville Institutional Review Board (IRB) approved the larger qualitative study from which this study stemmed. I continued to work within the guidelines of that approval. Although I did not directly come in contact with human subjects during my analysis of the social support category, I was working with data that originated from human subjects. This required attention to confidentiality and sensitivity in the handling of this information. Steps were taken to insure confidentiality, as names and identifiers were removed or changed prior to my analysis. There were no risks for emotional distress or harm done.

Summary

Chapter 4 entailed an in-depth description of the qualitative methods, including a step-by-step description of the analysis procedures and memo writing exercises. It also covered issues of trustworthiness and a personal reflective exercise to establish study rigor. The results for study 1 can be found in Chapter 5 with examples of analysis materials located in the appendices referenced. Study 2 methods and results can be found in chapters 6 and 7. The final chapter 8, summarizes the overarching question, study implications and future research ideas.

CHAPTER 5: STUDY 1 RESULTS

"We had people go out and buy groceries and drop them off, making food and that kind of thing. That helped alleviate some of the cost as well as trying to figure out throwing together dinner when you're going through chemo and feeling awful and smells are making you sick. That was very helpful. Support of family and friends has really helped."
- Study 1 #23 (middle aged female, Multiple Myeloma)

"I didn't let anyone know I was sick, but it cost me mentally and emotionally."
-Study 1 #2 (65-year-old female, Breast Cancer)

Study 1 was used to gain perspective on what patients' experiences were in regard to social support and cancer-related financial toxicity (objective burden and subjective distress). It sought to answer the question: *For individuals who have had cancer, what is their experience with social support in the context of cancer-related financial toxicity?* Using data analysis techniques outlined in chapter 4, I took an in-depth look at social support expressed through the stories of 26 cancer survivors who experienced financial hardship due to their costs of care. Several categories, subcategories and dimensions were identified through the analysis. It revealed supportive issues that participants faced such as barriers to accessing and missing support. This chapter first presents the sample characteristic which is followed by the identified categories and subcategories. The chapter will end with a brief interpretation of the results.

Characteristics of Participants

A qualitative approach was used to explore the lived experiences of cancer survivors (N=26) who perceived financial hardship as a result of their cancer treatment. Tables for the demographic characteristics have been published in a prior article by Head, Harris, Kayser, Martin and Smith, (2018). These can be found in Tables 5.1 and 5.2 as well. Interviewees ranged from 30 to 67 years of age with a mean average of 50.6 years. Twenty were female (77%) and 6 were male (23%). The sample was primarily white (73%) and married (61%).

Table 5. 1 Demographics (Head et. al., 2018).

Characteristic	N (26)	%
Gender		
Male	6	23
Female	20	77
Race		
Black	5	19
White	19	73
Hispanic	2	8
Marital Status		
Single/Never Married	1	4
Single with Significant Other	1	4
Married	16	61
Separated/Divorced	6	23
Widowed	1	4
No Response	1	4
Income		
Less than $25,000	7	27
$25,001 – $40,000	5	19
$40,001 - $60,000	2	8
$60,001 - $80,000	4	15
Over $80,000	7	27
No Response	1	4

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Many interviewees experienced a job change from before and after their cancer experience. Prior to their cancer diagnosis 23 were employed full-time (88%), 2 were employed part-time (8%) and only 1 was unemployed (4%). After their cancer experience only 5 were employed full-time (19%), 6 worked part-time (23%), 8 were on disability assistance (31%), 2 retired (8%), and 2 were unemployed (8%). See Table 5.2 for more details on occupation and insurance status.

Table 5. 2 Job Status, Occupation, Insurance Status (Head et. al., 2018).

Characteristic	N (26)	%
Job Status Before Cancer		
Employed Full-Time	23	88
Employed Part-Time	2	8
Unemployed	1	4
Job Status After Cancer		
Employed Full-Time	5	19
Employed Part-Time	6	23
Unemployed	2	8
Homemaker	1	4
Disabled	8	31
Retired	2	8
No Response	2	8
Occupation		
Homemaker	4	15
Manager	2	8
Professional/Technical	11	43
Sales/Services	6	23
Manufacturing/Trade	2	8
No Response	1	4
Insurance Status at the Time of Diagnosis		
Through Employer	19	73
Self-Purchased	3	11
No Insurance	3	11
No Response	1	4
Insurance Status During Cancer		
No Changes - Same Insurance	13	50
No Changes – No Insurance	1	4
Lost Insurance Due to Job Loss	6	23
Eligible to Medicaid	1	4
Eligible for Medicare	2	8
Lost Insurance Due to Job Loss – Now Self-purchased	1	4
No Response	1	4

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Interviewees presented with several different types of cancer diagnosis. Two types of cancers were more prominent than the others: breast cancer n=8 (31%), and blood cancers n=6 (23%). Other cancer types that were represented include: Colorectal n=2 (8%), Head and Neck n= 2 (8%), and 1 each (4%) of appendiceal, brain, lung, ovarian, pancreatic, prostate/bladder, and synovial sarcoma. (Profiles on each participant can be viewed in Table 5.3.)

Table 5. 3 Characteristics by Participant Number (Head et. al., 2018).

Pt #	Age	Sex	Race	Marital Status	Education	Income @ diagnosis	Cancer Type
1	58	F	White	Married	Bachelor's	<$25,000	Breast
2	65	F	Black	Widow	Postgraduate	>$80,000	Breast Reoccurrence
3	54	M	White	Married	Bachelor's	$25,000-$40,000	Oropharynx
4	52	F	Black	Sep/div	Postgraduate	$25,000-$40,000	Hodgkin's Lymphoma
5	35	F	White	Married	Postgraduate	>$80,000	Breast
6	60	F	White	Sep/div	Postgraduate	$60,000-$80,000	NSCL
7	50	F	White	Married	Some College	>$80,000	Breast
8	67	F	White	Married	Postgraduate	$40,001-$60,000	Parotid Adenocytes
9	30	F	White	Married	Some College	>$80,000	Ovarian
10	35	F	No response	Single	Postgraduate	<$25,000	Leukemia
11	55	M	White	Married	High School/GED	$60,001-$80,000	Glioblastoma Brain
12	51	F	Black	Married	Some College	$25,001-$40,000	Breast
13	58	M	White	Married	Bachelor's	$40,001-$60,000	AML
14	64	F	White	Sep/div	Some College	<$25,000	Breast
15	56	M	White	Married	High School/GED	<$25,000	Synovial Sarcoma
16	55	F	Hispanic/ White	Sep/div	Some College	>$80,000	Colorectal
17	41	F	White	Sep/div	High School/GED	<$25,000	Rectal
18	*	F	Black	Single	*	*	*
19	37	F	White	Sign. other	Some College	$25,001-$40,000	Breast
20	53	F	Hispanic/ Black	Married	High School/GED	$40,001-$60,000	Pancreatic
21	36	M	White	Married	Some College	<$25,000	Lymphoma
22	62	F	White	Married	Postgraduate	>$80,000	Breast
23	*	F	White	Married	HS	$60,001-$80,000	Multiple Myeloma
24	49	F	White	Sep/div	Some college	<$25,000	Lymphoma
25	32	F	White	Married	Bachelor's	$25,001-$40,000	Appendiceal
26	66	M	White	Married	Bachelor's	>$80,000	Prostate & Bladder

*Not Reported

Qualitative Findings

All 26 interviewees commented on social support to some extent and the data reflected social support theories. Interviewees commented on received emotional, informational, and instrumental support. They also provided examples of social constraint and suggested missing supports. These findings fell into three major categories: Helpful Supports, Non-helpful Supports, and Gaps in Support. These categories contain subcategories which are further delineated into dimensions (see each section below for details).

Quantification occurred at the subcategory level. All excerpts were tabulated to display the magnitude of the social support discussed by interviewees. Refer to Table 5.4 to see a breakdown of the number of interviewees who commented on each type of support and how many comments were made throughout the interviews.

Table 5. 4 Social Support Comments by Social Network

	Helpful Supports							
	Received						Perceived	
	Emotional		Informational		Instrumental		Instrumental	
Social Network	Interviewees	Excerpts	Interviewees	Excerpts	Interviewees	Excerpts	Interviewees	Excerpts
Family	7	18	4	4	26	65	1	1
Friends	7	8	10	10	8	26	0	0
Med Prof	2	2	10	11	13	23	0	0
Organizations/Work	5	8	9	16	21	34	0	0
Total	21	36	33	41	68	148	1	1

	Non-Helpful Supports		Gaps in Support			
	Social Constraint		Missing Support		Barriers	
	Interviewees	Excerpts	Interviewees	Excerpts	Interviewees	Excerpts
Family	10	11	3	3	0	0
Friends	4	4	5	5	0	0
Med Prof	2	2	14	20	11	14
Organizations/Work	0	0	3	4	4	4
Total	16	17	25	32	15	18

The individuals who provided the support were categorized into five different social network categories: family, friends, medical professionals, work, and organizations. Refer to Table 5.5 for delineation of each social network category and the individual roles included in each network group.

Table 5. 5 Social Network Categories.

Social Network Category	Network Member
Family	Spouses Parents Siblings Adult Children Other Family
Friends	Church Members Co-workers Neighbors
Medical Professionals	Doctors Nurses Social Workers Financial Counselors Hospital System Staff Members
Work	Employer Agency/Company
Organizations	Non-profit Organizations Social Programs

Before presenting the themes of this analysis, it is important to note that when interviewees talked about social supports, they did not always make a clear distinction between financially-related social supports and those that were generally provided during their cancer experience. For example, in the below excerpt interviewee #9 (a 30-year-old female with ovarian cancer), discusses how her family members advocated for her.

> "My husband and sister were wonderful advocates for me, because I was totally unable to advocate for myself. And really pushing him to check why I was so sick in the hospital." #9 (30-year-old female, Ovarian Cancer)

The family members action was geared toward finding medical answers or solutions not specifically toward assisting her with the financial aspect. Although the interview script did not specifically ask about financial social support, these broad responses lead me to question the extent to which patients compartmentalize their experiences. Perhaps financial toxicity and social support overlap into all aspects of their lives.

Helpful Support

Helpful Support was the largest theme consisting of the three major categories found in the data. These included subcategories of received support (emotional, informational, and instrumental) and perceived (instrumental) support. Each subcategory is discussed providing thick descriptions of dimensions within each subcategory. Meaningful excerpts supporting these dimensions can be found in corresponding tables.

Received Emotional Support. As discussed in Chapter 3, emotional supports are supports that make a person feel or believe they are cared for and appreciated (Cohen et al., 1985). Some of the subcategories of emotional support intertwined with received informational and instrumental supports. Subcategories revolved around the concept of someone else taking control over part of the situation while others show emotional support being communicated through being presence during difficult events such as attending surgeries or treatments. By providing these other supports, the support provider reinforces the person's feelings of being loved, understood, and cared about. See Table 5.6 for a list of emotional support subcategories and example excerpts.

Table 5. 6 Received Emotional Support.

Dimensions	Excerpt
Acts of Service	"It was emotional support more so than financial. I didn't have to worry about him taking off work to take me to treatment, because my church members they were all there to do that, but I didn't let it be known that other things were going on." #12 (51-year-old female, Breast Cancer)
Reassurance	My husband said, "Give that bill to me. I will call them. I will take care of them. You don't worry about it. We can manage this… He just kept saying, "I'll handle this. This I can do something about.". #22 (62-year-old female, Breast Cancer)

	“My husband actually took over and he just told me to calm down and not worry.” #25 (32-year-old female, Appendiceal) “I didn’t realize how expensive, but I knew it was expensive because I would ask questions about how much a specific my chemo was or whatever. They would be like, ‘It’s not too bad.’ They try not to worry people. They really try to work with cancer patients. They don’t want people to be fretting.” #17 (41-year-old female, Rectal Cancer)
Someone to Talk To	“I feel like the women in the support group are like my new best friends because they get it, and they understand what is going on. Some of them have had money problems but some of them haven’t so they don’t, I don’t know if they quite understand that, but they understand the cancer stuff.” #1(58-year-old female, Breast Cancer) “My only source of socialization right after my diagnosis became [support group].” #6 (60-year-old female, Lung Cancer) “We would joke about it, especially like a [support group]. People would be like, ‘Oh, how do you handle all the bills?’ I'm like, ‘I have two filing systems, the kitchen garbage and the living room garbage.’ That's pretty much where the bills go when they come in. They're too overwhelming. There's no way I can pay them. I can't even feed my kids. I'm not going to pile them up somewhere and look at them every day, so I chucked them.” #21 (36-year-old male, Lymphoma)
Supportive Presence	“Then my other daughter, she doesn't have the money but she's the one that moved right in with me. Came home from Arizona, moved in with me. I told her and her fiancé could move in too and they were my caretakers.” #14 (64-year-old female, Breast Cancer) “My husband, he has also attempted to go to appointments with me and support me and be there when I needed him.” #22 (62-year-old female, Breast Cancer) “[My son] went to every doctor’s appointment with me b/c he was afraid for his mom and he took notes to make sure that if I didn’t get it, he got it.” #2 (65-year-old female, Breast Cancer) “My sister lives out of town in upstate New York. She came into town for my initial surgery and was here for two weeks, she’s flown back and forth several times.” #9 (30-year-old female, Ovarian Cancer) “She's been there every [time]. She went to the surgeon here with me.” #8 (67-year-old female, Parotid Adenoid Cystic)

Acts of Service. Acts of service are received instrumental or informational supports that when provided in turn have an emotional impact on the individual. The act of support can alleviate additional worry or concern relieving the patient from having to do one more thing. In providing this assistance, patients may feel supported and confident that someone else can take care of something for them while they focus on their treatment and survival. For example, one interviewee (#12) discussed how receiving transportation to and from her medical treatments alleviated the need for her husband to take time away from work to do so. She commented that the act of providing transportation was an emotion support.

Feeling understood. A few interviewees spoke about feeling understood by others. Having someone available who you can relate to and who understands what you are going through can be emotionally supportive. Most comments were associated with organizational social network members such as employment (employer, colleagues) and support groups. One interviewee (#19) spoke about her employer understanding her experience because she had had the same type of cancer. Another interviewee (22) shared how her colleagues did not make her feel bad and expressed sympathy for her situation. Additionally, support groups can provide a safe environment free from judgment where participants can share their experiences leading to feelings of acceptance and being understood. One interviewee (#1) commented that she did not talk to her friends about her financial concerns because she felt they would not understand; however, she could share them in a support group with others who were going through similar situations. The idea that other people do not understand or get the financial hardship experience because they have not experienced it is not a new concept in the context cancer. The loss or distancing of friends due to cancer has been well-known. In addition to this idea we see cancer-related financial toxicity as another component that may play a part in distancing cancer patients from others. (This idea is further discussed in Gaps in Support.)

Reassurance. In this subtheme, we see the support provider reinforcing the idea that things will be okay and that they (support provider) will take care of an additional stressor such as the medical bills or getting additional services. This in turn relieves the support receiver from concern or worry related to something other than their treatment.

Several interviewees spoke about family members reassuring them. This was often a behavior expressed by a spouse; however, for those who were single or lacked a supportive spouse/significant other, a family member would sometimes provide this support. One interviewee (#10) spoke about her mother assuming legal control to manage her financial responsibilities while she was in the hospital. Medical Professionals were also noted for attempting to provide assurance to patients to not worry about their costs of care. Although this final example was an attempt to reassure patients that things would be okay, it overlaps with the Non-helpful Support category: having good intentions that were ultimately not helpful. This may in turn lead to Gaps in Support as missing information or create barriers to patients seeking financial assistance.

Someone to talk to. Talking to other people about your concerns has long been known to provide a sense of support and well-being. It helps one to feel closer to other people and fosters relationship bonds. It can relieve stress and allow others to offer solutions or help. This can provide the support receiver with feelings of comfort and reassurance that things will be okay or that they are not alone in this situation.

Few participants commented on having someone to talk to about their financial concerns. One interviewee (#7) stated she talked to her sister, but it was followed by an expression of concern and desire to not want to burden her sister about her financial concerns. Alternatively, several interviewees found a safe place to talk about their financial concerns through organizations offering support opportunities. In these spaces, patients can talk about what they are going through without the fear of being stigmatized or judged. They can relate to the stories and experiences of others which allows them to feel part or a group and not isolated. Patients feel heard, understood and encouraged to keep going. Support groups, through organizations such as Gilda's Club and Cancer Support Community, provide opportunities for patients and caregivers to share these difficult experiences in a controlled and safe environment.

Supportive presence. Under this subcategory, interviewees explain ways in which family and friends were there for them. One interviewee (#14) directly commented that her daughter could not help her out financially, but she moved home and provided comfort in being present through the experience. Family and friends provided a supportive presence by attending medical appointments and taking notes. Some even traveled from out of town to be there for important surgeries and to help with caretaking during the healing process. Although these supports are not directly financially related, their presence within the data and the discussions offered by participants lends support to their importance within the total experience. In the context of experiencing cancer-related financial toxicity, receiving emotional support is not solely financially connected. Here participants received encouragement, assistance, and care from family and friends in other ways that brought comfort to their experience assuring patients that they were not alone in this experience.

Received Informational Support. Informational support occurs in response to a need for knowledge, advice or guidance. Throughout the analysis there were a few examples of informational support; although, not many. See table 5.7 for dimensions and excerpts. The missingness noted in this subcategory led to the development of one of the subcategories under the theme Gaps in Support which is explored later.

Table 5. 7 Received Informational Support

Dimensions	Excerpts
Financial Advice & Information	"My brother is a financial or wealth manager, so he told me that he wasn't going to let me touch your 401K if it came to that, so it didn't come to that. I was fortunate enough to not have to explore any of the other options." #3 (54-year-old male, Throat Cancer) "One of the ladies, when her husband had throat cancer, she said 'well what I did was once I got all of my EOBs, separated them all, I put them all, like, in an order and then when the bill came, I would line it up with that. Then she said don't pay anything until you make sure it's been through the insurance. They guide me on don't pay this, don't pay that. Kind of leading me and helping me along." #13 (58-year-old male, Leukemia) "They had a social worker come in and laid out everything that was available through them, through Medicaid, and through the Lymphoma/Leukemia Foundation." #24 (49-year-old female, Lymphoma) "They also connected me with the Leukemia/Lymphoma Society because they apparently have some programs for financial aid, too. We started the process for that, but we felt like we were in a position at that point that we didn't need to take that money away from somebody else that might need it." #23 (middle aged female, Multiple Myeloma) "Then when I went to the clinic in [location], they recommended doing the Livestrong prices for the clinic treatments, but they recommended the Walgreens grant for the medicine." #5 (35-year-old female, Breast Cancer) "I went to a doctor at [location], and one of his residents said, 'I think there might be a grant that helps pay for some of this,' but didn't know the details…so then I started researching." #5 (35-year-old female, Breast Cancer)
Navigating Systems	"I was talking to the social worker I said, 'I don't even know how much we have to pay.' So, she looked into it for me… [Someone at the cancer center] said I should probably know all that, but she [the social worker] looked into it." #15 (56-year-old male, Synovial Sarcoma) "It was really the oncology office who you know, calls you in and kind of explains to you this is what's covered, this is what's not covered, insurance will pay for this. They're the ones that kind of schooled me on what was going to be covered, and I'm thankful for that because at least I knew my chemotherapy was covered at a hundred percent." #15 (56-year-old male, Synovial Sarcoma) "My doctor, my orthopedic oncologist said to go ahead and put application in for disability." #15 (56-year-old male, Synovial Sarcoma) "The social worker is very helpful. She asks us to begin with if financially [we wanted assistance]. Did I want to consider going on disability for social security? I didn't want to do that unless I had to." #8 (67-year-old female, Parotid Adenoid Cystic)

Financial advice and information. Advice is defined as information that is provided for the purpose of providing guidance or recommendations. A few interviewees commented on receiving advice. Those that did received it from family, friends, and medical professionals. Having family members or friends with financial knowledge or insider information on navigating the healthcare system is a great resource that few may have access to. One interviewee (#3) had a brother who worked in finance. He was able to get guidance on how to manage his finances through this challenging experience. Another interviewee (#13) shared her confusion over managing her insurance and medical bills. She was not aware that she should wait for the insurance to cover their portion and needed help in understanding how to ensure that process had been properly completed. Fortunately, a friend told her when to make payments and when not. Receiving advice on navigating the insurance and medical billing process is basic information that patients may need. This sharing of ideas and providing guidance on how to navigate the system or just interpret the forms can be helpful as long as the advice is good, sound advice.

Medical professionals are positioned to provide accurate and timely information on medical billing and insurance processes as well as resource information. Some interviewees were fortunate and were provided a wealth of information at the time of their diagnosis. Although medical professionals do not have all the resources and information needed for every patient, they can offer direction on what might be available. For example, one interviewee (#5) shared how a doctor/resident was aware of a grant to assist with fertility treatment expenses. This information led her to seek out more information and find needed resources to assist with the high costs of fertility treatments.

Navigating systems. Medical professionals have a complex understanding of medical diagnosis and treatment, and a familiarity with the healthcare systems. One interviewee (#15) shared how she did not know what her deductible and was told by someone at the hospital that she should know that information. She asked a social worker who was able to quickly look into it and provided her the information. Finding this information may be fairly simple for people who know where to look or ask questions; however, to the average person, medical systems and insurance programs can be complicated and arduous.

Interviewees also shared stories about how medical professionals provide assistance regarding when to apply for government assistance programs like Medicare and Social Security Disability. One interviewee (#15) discussed receiving guidance and information from his doctor about applying for Medicaid. Another interviewee (#8) shared how a social worker offered assistance and information about social security disability. The participant was given the information needed to decide to apply or not.

The average individual is likely unaware of government assistance program qualifications; therefore, patients could benefit from having some guidance on when and how to apply for assistance. Medical Professionals may be able to provide that information. If a patient is advised to apply for disability when their diagnosis and treatment meet program requirements could potentially prevent undue financial hardship.

Received Instrumental Support. Instrumental support was the most abundantly discussed type of support. Supports in this category were tangible items and services. All types of support providers were commented on as providing instrumental supports. See Table 5.8 to view the dimensions of support and who provided those supports. Further detailed discussion on each of these themes are provided below.

Table 5. 8 Received Instrumental Support

Dimensions	**Excerpts**
Advocate	"She [mother] got it from calling around and asking, because she had to do the same thing for my father who is disabled. So, she kind of knew the avenues. For me she went in there." #10 (35-year-old, female, Leukemia)

	“She's really good at helping me advocate and encouraging me to use my voice because when you're in the middle of it's a whole different story. #6 (60-year-old female, Lung Cancer) “I felt like my healthcare system was an advocate.” #22 (62-year-old female, Breast Cancer) “Yes, she has become more of a friend and an advocate because she got on the phone and was talking to them and they paid attention to her. I can barely walk—but I can’t use a walker or a cane—but she got on the phone and made them pay attention about it like the wheelchair back in December. So that I can get around without being stuck in the house.” #2 (65-year-old female, Breast Cancer)
Childcare Assistance	“My dad's very supportive, he helps take care of our daughter when we're not having good days. He's very supportive.” #25 (32-year-old female, Appendiceal) “And my sister moved in with me to help take care of my daughter when I was in and out of the hospital. So, she’s okay.” #10 (35-year-old female, Leukemia)
Monetary Assistance	“I still have one in college, but my parents started [paying for grandchild’s tuition] just a couple of years ago, now that they have money. You know. Telling me now ‘we never paid for your college so let us pay tuition for the last one so.” #3 (54-year-old male, Throat Cancer) “She was feeding me, buying me food, paying [utilities] for me to be here.” #18 (middle-aged female, type of cancer not provided) “My daughter sings. She did a little singing one night, sang twice at night one night twice and the tips she gave to us, uh, one night it was $91.00 and, uh, one night it was, uh, like $107, so anyway she gave us her tips.” #13 (58-year-old male, Leukemia) “Then of course family would bring me food and give me 20 or 30 dollars here or $100 to help me out when they could. That was a help.” #4 (52-year-old female, Lymphoma) “We had had a couple of friends give us like, you know, $50 here or $50.” #20 (53-year-old female, Pancreatic Cancer) “We had a friend start a fundraiser for us that raised $19,000 that will cover my out of pocket max for last year and this year. My brother in law is one of the people who helped set up the fundraiser.” #9, (30-year-old female, married) “[A non-profit agency] did have a piece where you could fill out an application and on a monthly basis and get some reimbursement. I did utilize that for a while especially those times when I only got paid for two days.” #6 (60-year-old female, Lung Cancer) “I applied for their financial assistance regarding some of the out of pocket. I would say that they pretty much covered at least my hotel expenses when I was there. They paid for mine and they paid for our meals while we were there. That was nice.” #6 (60-year-old female, Lung Cancer) “One of the pharmaceuticals helped with the one shot--$500 a pop—something that I had to have for two weeks. I didn’t have $500 to shell out daily for 2 weeks.” #4 (52-year-old female, Lymphoma) “I was off work until July and I was able to tap into the shared leave program” #4 (52-year-old female, Lymphoma) “In fact, my office has been fabulous. When I ran out of sick days, they have donation sharing for sick days, so employees donated sick days, so that covered me, so I was able to maintain a full paycheck each time.” #5 (35-year-old female, Breast Cancer)
Managed Finances	“My husband said, ‘Give that bill to me. I will call them. I will take care of them. You don't worry about it. We can manage this." #22 (62-year-old female, Breast, Cancer)

	“'My husband actually took over and he just told me to calm down and not worry. We have very supportive family members that helped, too.” #25 (32-year-old female, Appendiceal) “I guess the second week when I was in the hospital … my mom really kind took over as a power of attorney so that she could go into my bank account and pay all my bills and get everything set up.” #10 (35-year-old female, Leukemia)
Resolving System Issues	“The insurance company put me in a panic. It was the social workers and the nurses at the cancer center that kept me from going over the edge. They were helpful. ‘Tell us what they said. OK, we will take care of it. Breathe and relax. We will take care of it.” #4 (52-year-old female, Lymphoma) “I got my first disability check. I was approved the first time. My doctors all helped push it, get it through.” #15 (56-year-old male, Synovial Sarcoma)
Small Stuff	“My husband had to do all the cooking, all the cleaning with the assistance of my parents, so for the first six weeks and then when I was going through chemo...” #5 (35-year-old female, Breast Cancer) “They gave the number to my daughter, the guy’s number, and my daughter helped me take care- she said, ‘mom don't worry about it, you take care of dad, I'll take care of the ramp.’" #13 (58-year-old male, Leukemia) “Then my other daughter, she doesn't have the money but she's the one that moved right in with me. Came home from Arizona, moved in with me. I told her and her fiancé could move in too and they were my caretakers” #14 (64-year-old female, Breast Cancer) “My friend, I called my friend who was a nurse and said, ‘Could you stay with me?’ She works 7 PM to 7 AM, so I said, ‘Could you stay with me for 3 days because I'm going to be.’ I didn't know how bad I was going to be. I really couldn't open my eyes. I couldn't do anything, and so she did.” #8 (67-year-old female, Parotid Adenoid Cystic) “We had people go out and buy groceries and drop them off, making food and that kind of thing. That helped alleviate some of the cost as well as trying to figure out throwing together dinner when you're going through chemo and feeling awful and smells are making you sick. That was very helpful. Support of family and friends has really helped.” #23 (middle-aged female, Multiple Myeloma) '"Oh, can we get you some groceries? Oh, let's cook dinner. Oh, can we help with the kids? Here's a little gas money." #21 (36-year-old male, Lymphoma) “My kids became my primary caregivers. At 17, it was hard with that. At 15, 17 years old, she’s buying groceries and paying bills and helping me get in and out of the shower. It changed her in that way. She had to grow up faster than she probably should have as a grown up.” #17 (41-year-old female, Rectal Cancer)
Transportation	“They would take me places where I couldn’t drive. For instance, we went to the ‘Look Good, Feel Better’.” #2 (65-year-old female, Breast Cancer) “I have two neighbors that are retired and another friend that's retired so they can give me rides and another neighbor doesn't go to work until two o'clock in the afternoon so if I needed something, she can help me out. Another neighbor offered to come you know, water my plants.” #16 (55-year-old female, Colorectal Cancer)
Work Allowances	“I had a period of time where I wasn't able to do any work due to my condition, and then when I was able to start gradually working from home on my laptop, my work allowed me to do that until I could come back to the office.” #5 (35-year-old, female Breast Cancer) “For the most part, when I was going through my treatments, I happened to have a great immediate manager. The president of our company had prostate cancer and was going through exactly the same treatments as I was. I was able, for 6 weeks, to have every afternoon off. I was going through radiation at that time,

> and working half days for 6 weeks, in a period which I don't know if most companies would ever have been patient enough to go through that process." #26 (66-year-old male, Prostate & Bladder)
>
> "My husband's work let him take an unlimited number of days off without charging him vacation time without docking his pay for it or anything like that…if I was in the hospital he was there. So, if I was in the hospital for 40 days, he missed 40 days of work." #9 (30-year-old female, Ovarian Cancer)
>
> "They've been very generous with him here at work in that they have allowed him to work from home when he needed to the first couple of days of my recovery." #22 (62-year-old female, Breast Cancer)

Advocate. Advocating is an act of service provided by the support provider to ensure the well-being and needs of the support receiver are met. A life threatening or severe disease, such as cancer, can cause a patient to feel vulnerable and physically exhausted due to the effects of the illness and treatment; therefore, patients could benefit from having someone to advocate for them. It allows them to take a step back and let another person have control over part of the situation. The patient can then focus on their health and well-being without having to spend time and energy on getting needed services. By advocating for the patient, support providers are a voice for the patient speaking up for their overall wellbeing, medical care, and needed health service.

In this instrumental support subcategory, we see that family members (spouses, parents, adult children, siblings) and medical professionals (nurses or other providers) served as advocates. Having another person available to attend appointments and assist in treatment decisions can alleviate some responsibility and burden from the patient. Several interviewees spoke about their spouse fulfilling this role. Other family members provided this support as well. One interviewee (#10) commented on how her mother's past life experiences with the medical system proved to be useful in getting her the services she needed. Knowing the avenues to take when seeking medical treatment or navigating the insurance world can provide valuable assistance and guidance. Another interviewee (#6) discussed how her adult child encouraged her to have a voice in her medical care and decision-making processes. From the perspective of social support theory, Medical Professionals are in the formal support provider categories and expected to provide information and instrumental supports. A few interviewees commented on their medical professionals advocating for them and helping them to get the services they needed.

Childcare assistance. For families of young children, childcare assistance is an important service. Parents care for the well-being of their child(ren) and want to make sure they are in good hands when they are unable to care for them. Paying for childcare is also noted in the literature as an often-unexpected expense that adds to the objective experience of financial toxicity. For some interviewees, childcare was provided as a support yet for others, it became a social constraint as seen in Good Intentions with Financial Consequences.

Monetary assistance. Several participants commented on receiving tangible financial assistance in the form of money or provided assistance that could lead to obtaining money. These instrumental supports were provided by family members (parents, adult child, siblings), friends, medical professionals and organizations. For some interviewees, their parents were in a financial position that allowed them to help financially. It is generally accepted that as you get older you have more financial means due to working longer and having more equity or investments. Other interviewees received assistance from their adult child(ren). One interviewee (#13) shared how his daughter gave what she could. Adult children are often still trying to financially establish themselves and often do not have access to the financial resources that older adults would have. No matter how small or big the monetary assistance was, interviewees commented on how helpful and supportive these acts were. Some family members and friends assisted in helping to organize fundraisers or benefit events to generate funds to help cover medical expenses. Interestingly, interviewees who talked about this type of support were typically younger adults and as discussed in Non-helpful Support, receiving supports of this nature were not always supported by others.

Applying for grants from organizations or financial assistance/forgiveness programs through the medical system appeared to be more widely commented on than other network categories. Several interviewees commented on organizations and programs offering assistance with food, paying small monthly bills and daily living expenses. A few received funding to pay for the cost of out-of-state travel for medical purposes. Yet another interviewee commented on receiving assistance with fertility treatment costs. Some interviewees found assistance through their medical centers which offered financial assistance program to help cover medical expenses. These provided a huge relief from the hefty medical expenditure. Medications assistance from pharmaceutical companies provided some financial relief as well. A few interviewees were also able to tap into programs provided through work. Some employers offered programs that provided financial assistance to their employees such as shared leave programs or donated sick time.

In this subcategory there are several examples of participants receiving financial assistance from all social network groups. Consequently, patients need to know about these programs in order to apply for assistance. This informed the development of the category Missing Information. Furthermore, seeking these resources can be time consuming and physically taxing on patients as noted in the Run Around subcategory of Barriers to Support.

Managed finances. This subcategory points to the importance of having a primary support person who can help manage the financial piece. Only a few participants commented on having someone who would take on the responsibility of managing the bills and household finances. This support was provided by spouses and parents. Taking on the responsibility of managing the finances appeared to be an attempt by the support provider to alleviate the worry or concern a support receiver had over their financial well-being. In this case, the instrumental support provided overlapped with the emotional support received. Ultimately, having this support can relieve a big burden from patients, allowing them to focus more on themselves and surviving cancer.

Resolving System Issues. Medical professionals are ideally positioned where they can provide needed assistance to patients when dealing with complicated systems such as insurance and disability. In this subcategory, support providers engage in action-oriented instrumental support in an attempt to resolve barriers. For example, one interviewee (#4) shared how a social worker and nurse were instrumental in resolving complications with the interviewee's insurance company. Another interviewee (#15) talked about how his doctor assisted him with applying for medically-related disability. Insurance companies and the social security disability system are notorious for having complicated and tedious systems often causing most people to struggle when dealing with them. Medical professionals can be instrumental in helping patients resolve complicated issues within each of these systems.

Small stuff. When facing a life-threatening disease, like cancer, patients can be overwhelmed with simple life tasks. In this subcategory, family and friends were noted for taking over the general organization and running of daily life activities. These activities can include cleaning, cooking, general caretaking activities, and managing medical care at home. Friends also provided assistance in caregiving and household management for short periods of time. One interviewee (#8) shared a story about her friend, who was a nurse, came and stayed with her for 3 days after her treatment. Tasks as simple as preparing meals, buying groceries or gas, and mowing the lawn or taking the garbage out, helped patients financially, physically and emotionally.

Sometimes these tasks and responsibilities are more time consuming and can have a negative effect on the family member providing the assistance. In the case of one interviewee (#17), her two teenaged children took on the primary caregiver roles in place of a significant other or other family member. She shared the negative impact her cancer had on her children.

Transportation. Research has shown that transportation causes a barrier to care for many patients due to the cost of paying for gas, taxi service or compounding travel expenses. Interviewees commented on family members and friends assisting them with getting to and from appointments or to other cancer-related events.

Work allowances. It is noted in the literature that many cancer patients experience a reduction in monthly income prior to diagnosis and during their cancer experience. This is likely due to the need for patients to take time off to address negative physical effects of their illness or treatment. Some interviewees commented on their employers being flexible with their work schedules and allowing them to work from home or maintain their positions at a part-time status. In additions, the employers of caregivers were also noted for being flexible with working hours. A few interviewees shared how their spouses' employers were lenient allowing the caregiver to take off time when needed so they could be present during treatment or recovery periods. Having an employer who understands (crossing over to emotional support) and is flexible to work with alternative schedules or work from home options (instrumental support) can make an impact on not only patients' financial outcomes but the overall experience as well.

Perceived Instrumental Support. The perception that emotional, informational or instrumental supports were available (which is considered different from the support received being told the resources were available), did not have a strong presence in the data. I came across one excerpt that eluded to perceived instrumental support. This was in response to a probing question about whether an interviewee's spouse or anyone else helped her manage the medical bills and other finances. The interviewee responded:

> "I'm sure he would have if I had needed his help, but I was able to keep track of all the finances myself." #5 (35-year-old female, Breast Cancer)

The absence of perceived support may have been due to the lack of a direct question or perhaps due to the post-experience design of the study.

Non-helpful Support

Non-helpful support is made up from the social constraint. Social support can be interpreted as a negative experience or as non-supportive action depending on the outcome or how that support is interpreted by the support receiver.

Social Constraint. Social constraint occurs when a support provider does something that they may believe is helpful, but the recipient does not interpret the action as supportive. See Table 5.9 to view the three dimensions of social constraint that and excerpts.

Table 5. 9 Social Constraint

Dimensions	**Excerpts**
Good Intentions with Financial Consequences	“She lives with me. When she first moved here, she didn’t have anything. She just started the job that she’s at now. This is the first time she has had a permanent job—it goes back about 3 years. Before she had temporary jobs, this was a permanent job, but she felt that she couldn’t take a lot of time off to help me, but she was able to contribute more to help me out with the rent and the phone, food and that sort of thing.” #4 (52-year-old female, Lymphoma) “It's been a big stress. Big stress. You know, I was having to feed him and for helping you know. I felt like it was my duty to feed him and not charge him anything to live here. He was helping me, but when the help stopped, that's when it was, became very, very, very stressful for me and then I just said you know, you know how I feel about drugs, you've got to go.” #16 (55-year-old female, Colorectal Cancer) “Even my own sister charged me to watch my kids … I would have to pay her to come pick the kids up or $20 in gas money to come 10 miles down the road and get the kids for me while I had him in the emergency room. It was always something. There were times when I just sat in the car and just cried. Overdraft fees, that was a big one. I was constantly over-drafting the bank account.” #21 (36-year-old male, Lymphoma)
Good Intentions Not Helpful	“My oldest daughter who's an LPN … I saw her interact with my doctor and I told her, ‘That's why you're not my medical power of attorney.’ It's that nurse thing that thinks the doctor is God or something. It's like no, you have to argue with the doctor sometimes.” #6 (60-year-old female, Lung Cancer) “I got a package from my sister in the mail and I opened it and there were pictures on top of when I was growing up and pictures of my mom, grandmother and family and then after all that there was a ribbon that I had given my mom and some of my mom’s belongings that were intimate belongings. So, I put that aside and I pulled out my mom’s cosmetic bag. For crying out loud, why did she send this to me? My mom’s make-up when she was in her end days. I opened it and in the top was her hairbrush and it still had her hair in it. I took a deep breath – it’s my mom. I lifted that out and mom’s prosthetic boobs were in the bottom. I thought oh my god what did she send these to me for.” #7 (50-year-old female, Breast Cancer) “We were all sitting around talking about it. My mom was very cynical and just not helpful. She's like, ‘Well nobody's going to donate to that. You're just wasting your time. You're just going to embarrass yourself.’ I was like, ‘You know what? It's my kids. It's his health. If it doesn't work, it doesn't work.’ What's the worst that can happen? It doesn't work." Really, the Go Fund Me is basically what got us through.” #21 (36-year-old male, Lymphoma) “It came back in September, and they started talking transplant, and I mentioned to his oncologist ‘well, maybe they can do it this year because we have already met our deductible.’ He was like ‘oh honey, it’s not going to matter what your deductible is because you’re going too far exceed it next year too.’ So, I was like oh, ok. Here we go again… I was like thanks.” #11 (55-year-old male, Glioblastoma)

	“I didn’t realize how expensive, but I knew it was expensive because I would ask questions about how much a specific my chemo was or whatever. They would be like, ‘It’s not too bad.’ They try not to worry people. They really try to work with cancer patients. They don’t want people to be fretting. You know what I mean? On top of trying to care of you. I would say how much is this costing or whatever and they would be like, ‘It’s not too bad. It’s not bad.’ I didn’t have any real clue what’s the real cost of some of this stuff was.” #17 (41-year-old female, Rectal Cancer)
Ineffective Support	“My husband at the time was theoretically also doing that, but I think that he was also like, ‘Oh, crap. My wife has cancer.” #19 (37-year-old female, Breast Cancer) “I moved out and I had to take a really - Like everyone who gets divorced, I think, I had to take a really hard look at finances.” #19 (37-year-old female, Breast Cancer)

Good intentions with financial consequences. This subcategory is characterized by a support provider engaging in an instrumental support such as childcare or attending treatment, but the supportive attempt was a financial expense for the patient. For example, one interviewee (#4) had her sibling move in with her under the expectation that she would provide caretaking and household assistance. Initially when the sibling moved in, she did not have any money and was financially dependent on the interviewee. This was a financial burden until the sibling was able to secure a permanent job. However, once the sibling secured a position, she was no longer available to assist around the house. In a second example, an interviewee’s (#16) son moved in with her when she was diagnosed with cancer. This was initially helpful but then he got involved with drugs. Ultimately, this caused more stress, both emotionally and financially. Eventually the interviewee had to send him out of town. Similarly, two other interviewees spoke about the financial consequences when family or friends helped them out during their cancer treatment by being present during or after treatment, or by providing childcare.

By providing acts of social supports, friends and family may feel they are being helpful; however, in these examples the helpful act came at a financial cost which further exacerbated the financial hardship.

Good intentions that are not helpful. There were several examples throughout the interviews of family, friends and medical professionals attempting to do something helpful, but those acts were not interpreted as helpful. For example, one interviewee (#7) shared that she had received a package from their sibling. The content of the package was disturbing for the interviewee as it contained items from when her mother had cancer. The sibling may have thought the recipient could use the items left after their mother had passed away; however, the receiver was baffled by the gesture. In another example, the interviewee (#21) was considering creating a Go-Fund-Me account to raise money to help pay for her treatment. The interviewee's parent made negative remarks about doing so. These comments were interpreted as negative and critical putting the patient on the defense; however, it is possible that the parent had intended to protect them from engaging in something she felt was socially taboo. This behavior may have been an attempt to prevented them from the embarrassment of asking others for financial help and crossing socially acceptable norms. Another interviewee (#6) had her daughter, with a medical background, attend her medical appointments. The interviewee, however, felt like the daughter was just agreeing with the doctor and not being an advocate for her. This is also an example of how the support that is provided needs to match the support that is needed. If the support provided does not match the needs of the support receiver, then the support receiver will not interpret the support provided as supportive. In this case the daughter is providing support by being present at the appointments; however, the interviewee wanted her daughter to advocate for her.

Interviewees shared experiences of social constraint from Medical Professionals as well. For example, one interviewee (#11) shared his story about getting a second diagnosis and treatment information from his doctor. The interviewee had already experienced tremendous financial hardship during the first cancer experience and had suggested they do the transplant before the year ended because he had already met their deductible. The doctor responded that it was not going to matter because they would most like meet the deductible the following year as well. The way in which this information was presented was interpreted by the interviewee as insensitive; however, that was likely not the doctor's intent. Furthermore, the medical industry is often criticized for being focused on curing the disease while neglecting to look beyond the recovery phase. Several interviewees commented on receiving reassurance from medical professionals, encouraging them to not worry about the costs even when they asked for the information. In the end these patients were left with a stack of medical bills and overwhelming feelings of financial hardship due to the costs they were encouraged to not worry about.

In these excerpts it is apparent that the topic of finances and financial struggles can evoke different reactions from patients and those around them. Acts meant to buffer the patient from stress or benign comments attempting to illicit humor are not meant to cause harm but can be interpreted as hurtful, insensitive and non-supportive.

Ineffective support. The act of receiving support is beneficial when the support is reliable and helpful; however, there were a few instances that interviewees shared where the support provided ended up putting the interviewee in a worse situation or provided them with unhelpful information or ideas. For one interviewee (#19), her husband was supposed to take care of the finances during her cancer experience; however, in her opinion, he did not do a very good job. The interviewee's statements appeared to be resentful toward how those finances were managed. This could be due to the fact that her marriage dissolved after her cancer experience, but before her medical debt was paid. The divorce further complicated her financial well-being. Another interviewee shared how she was advised to only take half the medication prescribed. Receiving inaccurate and unhelpful support can further complicate a person's situation.

Gaps in Support

The final theme is Gaps in Support. This theme is made from two categories: barriers to support or missing support. These categories evolved from direct comments, and interpretations of what was not said.

Barriers to Support. Several barriers to accessing supports were identified. See Table 5.10 for an overview of dimensions and interview excerpts.

Table 5. 10 Barriers to Support

Dimensions	**Excerpts**
Missing Timely Information	"I think I was in my second or third month before it clicked that there was financial assistance available. If they could bring that to the table right away that would be wonderful." #24 (49-year-old female, Lymphoma) "No one came out and said 'hey, you qualify for this'. I stumbled on that." #13 (58-year-old male, Leukemia)
Personal Barriers	"I can't say, 'Well, I don't have any lights today,' or 'Refrigerator's empty.' I can't do that. It's different for everybody." #12 (51-year-old female, Breast Cancer) "There's some places that can help you with assistance like food or electricity and things like that. You know, do I ever want to take advantage of that? I don't know, it's kind of like I don't know." #16 (55-year-old female, Colorectal Cancer) "Then I don't tell anyone about the money thing because to me it's like embarrassing." #1 (58-year-old female, Breast Cancer)

	“If you don’t have money or know how to navigate the system or know how to get the most of it paid. The ones who are supposed to be the advocates at the hospital, the ones who want to get most of it paid, they don’t care. It’s like you get flipped off. I had a question for someone, and they said, ‘I don’t have to deal with you anymore, you have Medicare.’ She said this in the hallway. I asked her to meet her in her office. She says this in the hallway in front of all of these people and she said, “I don’t have to see you anymore.” #2 (65- year-old female, Breast Cancer)
Support That is Not Needed	“When I ask about something, it's like, ‘Well, you can just go to the resource center.’ When I would say something, of course the nurse navigator just kind of disappears after the first visit or so. They told me that I could get a wig and they told me there were books and I could get all that at the resource center." #6 (60-year-old female, Lung Cancer) “The cancer centers, they always are like, ‘You can have free art therapy because you're a cancer survivor,’ and ‘You can have free massage and acupuncture.’ I'm like, ‘give me some free financial advice. Give me a free session with somebody that can tell me how to pick up these pieces and pay for all this stuff.’ That would be so much more useful, nothing against art therapy.” #19 (37-year-old female, Breast Cancer) “Here's the Resource Center. Go talk to them. Oh yeah, here you can get a massage every other month for free. Yeah, that was great, but at the end of the day it wasn't what was needed most. They didn't come out and tell you about the other stuff.” #21 (36-year-old male, Lymphoma) “I was told I could call a counselor and I did speak to [person’s name] on the phone and she said that she would send me forms, I could fill them out, and they probably would just write it all off, which would be wonderful. I'm telling you the truth, between filling out all these disability forms for ten hours while I was going through all this sickness and trying to move in the middle of chemotherapy, all I could do was sit in the floor and try to pack boxes. I was so no help. You're not allowed to lift, that's so awful. You're so sick with all those forms and then I filed my own divorce. That's fun forms about this thick. By the time I did all that I was wore out and I thought, you know when her forms came, I'm sorry, I apologize. I started filling them out, I never finished them.” #14 (64-year-old female, Breast Cancer)
The Run Around	“But I was paying them and when I inquired to see if I could get help, they said we are not funding breast cancer right now – we’re funding colorectal cancer or this cancer but not breast cancer right now. So, I did check with two resources given to me and it didn’t help.” #7 (50-year-old, female Breast Cancer) “I don't know who it was, but somebody gave me some pamphlet about this organization. They said, ‘Here, call them. They always help pay for prescriptions.’ I called them to try to get help. They were like, ‘Well, you don't qualify because you didn't have the right kind of cancer. After a while you burn out of resources because it doesn’t take very long to go through the few places that does offer the scholarships for people with this." #17 (41-year-old female, Rectal Cancer)

> "I've caught buses in the snow to get to [appointments] for these people from the United Way to the people for financial help in the hospitals. And I've waited and waited until they were finished with their lunches and chit chat to help me fill out forms that were foreign to me. One reason they were foreign to me was I expected one thing, they expected one thing and we never met in the middle. All because of a zip code. I expected you to talk to me like a person and you expected me to know the game and I don't know the game so consequently you didn't talk to me like a person. I would sit there and have a meltdown before anybody would look at me like a person." #2 (65-year-old female, Breast Cancer)
>
> "I've applied for grants. Nobody has any grants or anything for that drug. I called literally 20 different places to find assistance." #16 (55-year-old female, Colorectal Cancer)

Missing timely information. Receiving information when the information is needed and will benefit the patient is the premise of the next subcategory. Receiving information in a timely manner may make a difference in how patients manage their resources. One interviewee (#24) shared how she came upon information about financial resources that could have benefited her months earlier. It was not until the second or third month into her treatment that she realized financial assistance was available. Similarly, another interviewee (#13) several months into his treatment said that the day he was diagnosed he automatically qualified for Medicare and Social Security Benefits. He could have applied immediately for assistance. In both of these examples, these individuals had no idea they qualified for disability benefits. Instead they continued to tap the minimal resources they had and struggled financially. To complicate the matter further, it can take several months before a patient actually receives financial payments after they have been approved. This can further lead to more financial distress. Receiving information about financial resources and government assistance programs could benefit patients more if they made aware of these programs at the beginning of their diagnosis.

Personal barriers. Barriers to accessing financial resources and assistance can be due to personal barriers as well. A few interviewees expressed a sense of pride that prevented them from asking others for financial help and resources. Another interviewee (#1) expressed embarrassment about her financial struggles. These personal barriers can get in the way of patients talking with others and sharing their concerns. Patients may fear being judged by others. Our society is based on individualism and we pride ourselves on "picking ourselves up by our own bootstraps". It is not common place to openly talk about your financial situation. Talking about finances is considered to be one of the top socially inappropriate subjects to discuss in public. Due to this social stigma, patients may not feel comfortable admitting to others that they are struggling financially and need help.

Further complicating the situation, is that some individuals feel stigmatized when they ask for financial assistance. One interviewee (#2) shared how she attempted to get help but was treated poorly. Ultimately, she was unable to access the resources she needed and felt stigmatized because she was black and lived in the wrong neighborhood. Receiving messages such as these could negatively impact how patients proceed through the medical system and whether or not they seek further assistance. This could further lead to a state of learned helplessness.

Struggling with fears of stigma, embarrassment or pride can prevent patients from accessing and receiving needed financial assistance. These barriers can be further reinforced by issues of social constraint. Encouraging patients by normalizing their financial condition and providing a safe non-judgmental environment for them to express their financial concerns will help them to overcome these personal barriers.

Support that is not needed. According to social support theory, in order for a support to be interpreted as helpful it needs to reflect the support requested. That was true for participants in this study. Some interviewees who sought out resources and information received resources that were not what they needed or wanted. Not receiving the information and resources needed can further complicate their situation and frustrate patients as they are trying to seek help. As a result, the supports provided can be perceived as not supportive. Several interviewees commented on requesting financial assistance and guidance but were instead told about free monthly massages or art therapy, a wig, books or other services that were not what was needed. For one interviewee (#14), she shared how she needed assistance with completing the paperwork associated with getting financial assistance. She was overwhelmed with her cancer experience which was complicated by a divorce and having to move. She did not have the energy or capacity to complete the paperwork. Instead of applying for financial assistances she found it easier to file for bankruptcy. When patients are so overwhelmed with their financial situation, trying to survive cancer, and whatever else life has thrown at them, they may need help completing simple tasks such as filling out paperwork. This theme brings attention to the importance of providing resources and services that meet the requests of the patients. Not all patients need or want the same services. So those in the Medical Professional network should attempt to identify what those needs are and assist patients in locating requested resources or services.

The run around. Some participants who received assistance and information on resources reported to hit dead-ends. They spoke about receiving information and leads on where to find resources. However, for some, when they followed up with these resources, they were denied access. Some were told they did not have a specific type of cancer or did not live in the right zip code. Finding and accessing resources can be an exhausting and defeating process for patients further complicated when those resources are not accessible. The initial hope that aid and relief is available is quickly dashed by rejection after rejection becoming a defeating experience.

Missing Support. Dimensions in this section refer to lacking emotional, informational, and instrumental supports. Missing support was largely informed by participants stories, but these subcategories were also informed from the silences within the data. See Table 5.11 for a brief overview of subcategories and excerpts.

Table 5. 11 Missing Support

Dimensions	Excerpt
Diminishing Help	"Things settle off. Everybody else goes on and lives their life, yet this is our life. The help and the concern drift off, and then you're left with still all of these stressors and financial issues. You had so much help from people, you don't want to just say, 'I need more help,' or, 'Can you do this?" #21 (36-year-old male, Lymphoma)
Lacking a Confidant.	"It was emotional support more so than financial. I didn't have to worry about him taking off work to take me to treatment, because my church members they were all there to do that, but I didn't let it be known that other things were going on." #12 (51-year-old female, Breast Cancer) "I have a best friend that I have known her for over forty years and she's wonderful, but she has never had cancer and she just, she doesn't quite understand it. I don't want to scare her or burden her so there are things I hold back you know and the same way with my family, there are things that I hold back. I don't tell them all everything. Then I don't tell anyone about the money thing because to me it's like embarrassing." #1 (58-year-old female, Breast Cancer)
Missing Information	"I cut back some hours when I was in chemo. I took like three weeks off when I had surgery. If I had taken one more week off, I would have been able to qualify for short-term disability, but my HR person didn't know that. They didn't tell me that, so I just came back after three weeks, like, 'I'm just going to do my best.' People don't really know." #19 (37-year-old female, Breast Cancer) "I was kind of in a catch 22, because when I started the whole process, I had like fourteen weeks of sick time and vacation time banked up in my account. I thought, Oh, that's great because then it will cover any kind of short-term disability but didn't realize that people couldn't donate to me because I already had too much PTO. Once I got through those twelve weeks, I didn't have any PTO but then they couldn't donate to me because I wasn't on FMLA anymore. We were just in a bad spot I guess, timing wise." #23 (middle-aged female, Multiple Myeloma) "The last time when I had to take 6 weeks off during my school year time, I became aware of the program whereby school district employees can volunteer their sick days. I got like 23 sick days given to me and it covered everything I needed to make it through the last phase. But the first ones I didn't have anything. Nobody said anything." #7 (50-year-old female, Breast Cancer) "No and in fact I have made a few phone calls to see if there is anybody in their office to talk to me about it because I get online, and they say talk to the social worker at the hospital. There is no social worker at the hospital that will talk about that. At least not that I've heard." #1 (58-year-old female, Breast Cancer) "No, but that would have been helpful" [to have someone sit down and talk about costs… It would be really nice if there was some kind of counselor to help you figure it out." #1 (58-year-old female, Breast Cancer) "No, we are lucky they gave us side-effects of the drugs… So, there wasn't a lot of education, especially the financial part. No one ever even asked." #11 (55-year-old male, Glioblastoma) "I feel like nobody tells you that. I really can't remember talking to anybody in my cancer center about insurance filing or financial help or anything like that." #19 (37-year-old female, Breast Cancer) "I don't know that anyone ever sat down and went through the financial part of it with me and even being a financial professional it is not the first thing on your mind once you, you know. You think well you know I have insurance and you worry about the other stuff." #3 (54-year-old male, Throat Cancer) "They didn't go over pretty much anything with the cost of that." #23 (middle-aged female, Multiple Myeloma)

	"Finances have never been mentioned by any of my providers or social workers with the hospital or nurse navigators or anything… no one at any of the doctors or hospitals ever talked to me about finances or insurance." #5 (35-year-old woman, Breast Cancer) "We wanted to talk to someone…and all the social worker said was 'oh we have art therapy." #9 (30-year-old female, Ovarian Cancer) "when you go in and ask for information it wasn't specific. It's like, 'Well, here's a website.'" #6 (60-year-old female, Lung Cancer) "I didn't realize how expensive, but I knew it was expensive because I would ask questions about how much a specific, like, say, my chemo was or whatever. They would be like, "It's not too bad." They try not to worry people…They don't want people to be fretting. On top of trying to take care of you. I would say how much is this costing or whatever and they would be like, "It's not too bad. It's not bad." I didn't have any real clue what's the real cost of some of this stuff was." #17 (41-year-old female, Rectal Cancer) "Didn't understand the prognosis so didn't feel she needed the services. Then I was going through home care they suggested I apply for disability or contact a Social Worker. I opted not to because I figured I'd just go back to work by the time that any paperwork could be filed." #25 (32-year-old female, Appendiceal) "I was in my second or third month before it clicked that there was financial assistance available. If they could bring that to the table right away that would be wonderful." #24 (49-year-old woman, Lymphoma) "He was two years in before we even found out that they had a gas card program that could help us just with gas and getting back and forth to treatment." #21 (36-year-old male, Lymphoma) "When the bills started coming in, to be able to have that contact person to say, 'Okay, what can I do with this,' would have been really nice." #6 (60-year-old female, Lung Cancer)
Missed Opportunities	"I try not to say a whole lot about finances to people. In some ways, you have to because you don't have a normal life anymore. Other friends and people, even when he's feeling good, they're going out to dinner, going out to do things and we can't go simply because we can't afford to go like everybody else can." #21 (36-year-old male, Lymphoma) "Then I don't tell anyone about the money thing because to me it's like embarrassing." #1 (58-year-old female, Breast Cancer)

Diminishing Help. During the diagnosis and treatment phase patients may experience a lot of support from those around them; however, as time passes the help and assistance from others declines. Others may have been made aware of an initial need for support and are motivated to help where they can. For those who have cancers that require a lengthier treatment schedule or additional complications, help may decline and fade over time. This may be due to others being unaware of a need still existing. One interviewee (#21) commented on experiencing guilty over repeatedly asking for continued support and help. When a need for support is not expressed support diminishes potentially leaving needs unmet.

Lacking a confidant. Few interviewees made comments about sharing their financial concerns with others. For most of the interviewees there was silence regarding having someone to confide in about their financial struggles. One interviewee (#12) shared that she had other forms of support such as transportation to treatments, but she kept her financial concerns secret. A few participants provided insight into why they did not share their financial concerns with others. One interviewee (#7) explained that she did not share her financial concerns with her sister because she didn't want to worry her. Another interviewee (#1) stated she felt embarrassment over her situation and that is why she did not confide in others. This subcategory of missing a supportive confidant overlaps into the Barriers of Support as well. The embarrassment and desire to not worry others becomes a personal barrier for some people.

Missing information. A commonality among several of the interviews was that many lacked information that could have assisted in preparing them for the costs of their care or possibly taking steps to alleviate that impact. Several of the examples provided by interviewees were directly work related. Human Resource (HR) departments are key to explaining how policies and employee benefits work. Knowing what is available and timing the implementation of when to use these programs can possibly be tricky but could work in favor of the employee. One interviewee (#19) shared how she could have benefited from guidance from her HR on when to return to work. If she had stayed away from work another week, she could have tapped into her short-term disability benefits. Instead she returned to work even though she was not physically ready to do so. Another interviewee (#23) could have benefited from advice on how to navigate the use of her paid time off (PTO), Family Medical Leave Assistance (FMLA), and the agencies PTO donation program. Similarly, another interviewee (#7) was unaware of her employer's PTO donation program until her last treatment phase. Initially no one told her the program existed. For each of these interviewees, having access to information about these programs earlier and being given guidance on using them might have alleviated some of the financial hardship they experienced.

Interviewees also lacked information from their Medical Professionals. In response to a probing question about whether or not someone talked to them about their medical costs, many responded negatively. Not all patients are interested in knowing how much their medical treatment will cost, but some are. A few interviewees shared how they requested the information from several of their medical providers but were not given it. Some were told to not worry about it which, as discussed, overlaps into the Helpful and Non-helpful Support categories.

Receiving timely and accurate information could be beneficial to patients. It is important for patients to have an accurate understanding of their situation and what resources are available so they can make financial decisions or take actions that could soften the financial impact. For one interviewee (#6), the bills started to come in after treatment was completed, and she did not know who to ask for help. Knowing who to ask questions of when the bills are flooding in could perhaps help patients to cope with their financial situation by developing a plan for repayment.

Missed opportunities. As noted in the literature, financial toxicity can lead to changes in a person's social life as they cut back on entertainment and discretionary spending. One interviewee (#21) talked about cutting back on going out to dinner with friends because they could not afford it anymore. There friends still engaged in activities but without them. By not engaging in these activities' friendships are at risk of dissolving missing the potential opportunity to let others know that help is still needed. As noted earlier in this chapter, some patients do not disclose to others their financial concerns. Similarly, not talking about financial struggles can compound a patient's experience of being isolated and cut off from others who can and would provide help. Ultimately, they may miss out on social supports that could be available if others were aware of the need.

Brief Interpretation

In support of social support theories, cancer survivors in this study experienced received social support (emotional, informational, and instrumental) and social constraint. Emotional support was mostly provided by family members and friends; although, there were examples of emotional support from the medical professionals and organizations (mainly work). Emotional support is often seen intertwined or a result of a received instrumental support. Benefiting from acts of service or being relieved of a stressful responsibility can provide feelings of being cared about. Furthermore, having someone to talk with and share your financial concerns can provide feeling of being understood and can normalize the experience making cancer patients and survivors feel not so alone in their experiences.

In addition, informational supports were provided by family members, friends, and medical professionals. Cancer patients and survivors can benefit from advice on how to organize and understand their medical bills and insurance. Understanding medical and insurance forms and knowing when to pay medical bills or how to file appeals for insurance denials could give patients more control over their financial situation. Likewise, receiving timely information on accessing financial assistance or advice on when to apply for government assistance programs could ultimately have an impact on the financial outcomes for patients.

More noticeably, received instrumental support had a strong presence in the data and were provided by all social network members (family members, friends, medical professionals, and organizations). Monetary support or support that could have an economic value (childcare, transportation, food), no matter how small the assistance, can indeed provide some relief from the objective and subjective perspectives of financial toxicity.

As evident by the literature, cancer patients can be in a financially precarious situation due to their cancer costs. This condition can be further augmented by the presence and pressures of social constraint. Support providers may not take into consideration the financial implications of the support they offer. As was evident in the subcategory Good Intentions with Financial Implications where supportive efforts came at a financial expense for the cancer patient or when support was just bad support further complicated the patient’s financial well-being. Moreover, cancer patients are susceptible to receiving supports that are not helpful or otherwise not wanted. Receiving advice that is critical or not generally helpful, can put unwanted social pressure on patients and may prevent them from seeking help or talking to others about their financial concerns.

The third category, Gaps in Support, gave insight into areas where support is needed: missing support or barriers to accessing support. Cancer survivors in this study lacked timely and accurate information that could have helped them steer through some of the financial healthcare maze. Receiving information on how to balance employment related benefits to take the most advantage of those programs, or information on accessing agency or government assistance programs could have major financial benefits. Likewise, addressing personal barriers could alleviate patients' feelings of stigma or embarrassment about disclosing their financial concerns which in turn may improve their help-seeking and receiving behaviors.

In essence, this study brings to light that there are social supports that can and do benefit the financial well-being of cancer patients. Moreover, cancer patients and survivors may experience unmet needs and barriers to accessing support. This study opens up a discussion on ways to improve the system for future patients which will be addressed in the final chapter.

Summary

This chapter presented the findings for Study 1. It provided insight into the types of social support available and used by a sample of cancer survivors who self-reported cancer-related financial burden and distress. The next two chapters (6 and 7) will present the methods and findings for Study 2, respectively. This will allow further elaboration on how social support impacts the experience of financial toxicity. Chapter 8 will intertwine the interpretations from both studies for a final synopsis exploring implications for practice, research, and policy.

CHAPTER 6: STUDY 2 METHODS

This chapter presents the methods for the second study conducted to answer the overarching question: *What role does social support play in the experience of cancer-related financial toxicity?* Relying on quantitative methods, study 2 used a cross-sectional survey design. Similar to study 1, study 2 relied on the understanding of financial toxicity as presented in the Carrera et al. (2018) framework and social support theories as well as the by the Transactional Model of Stress and Coping Theory (Stress and Coping Theory) and the Stress Buffering hypothesis (see Chapter 3 for more details on these theories). These theories provided guidance and direction to determine if social support played a moderator or mediator role in the relationship between financial toxicity (objective burden and subjective distress) and quality of life (QoL). The present chapter details the methods used for study 2.

Purpose

Study 2 is the second study used in this multi-method project to gain a better understanding of the impact social support has on the financial toxicity of cancer care. The question that drives this study is: *How does social support influence cancer-related financial toxicity and patient's quality of life?* This question attempts to determine the path by which social support impacts the relationship between cancer-related financial toxicity and QoL, whether by mediating or moderating processes. The two specific aims and corresponding hypotheses are listed below.

Specific Aim 1: To determine if received and perceived social support moderates the relationship between cancer-related financial toxicity, and quality of life controlling for the effects of cancer treatment, education, employment, insurance status, marital status, and social constraint. (Quality of life will be considered under two conditions: 1) quality of life as determined by the FACT-G scale; and 2) quality of life with economic well-being using the FACT-G scale plus the Economic Well-being scale. Scales will be further explained in the Measures section below.)

Hypothesis 1.1: Received social support will moderate the relationship between financial toxicity and QoL.

Hypothesis 1.2: Perceived social support will moderate the relationship between financial toxicity and QoL.

Hypothesis 1.3: Received social support will moderate the relationship between financial toxicity and QoL including socio-economic well-being scale (Plus SEW).

Hypothesis 1.4: Perceived social support will moderate the relationship between financial toxicity and QoL Plus SEW.

Specific Aim 2: To determine if received and perceived social support mediates the relationship between cancer-related financial toxicity and QoL controlling for the effects of cancer treatment, education, employment, insurance status, marital status, and social constraint.

Hypothesis 2.1: Received social support mediates between financial toxicity and QoL.

Hypothesis 2.2: Perceived social support mediates between financial toxicity and QoL.

Hypothesis 2.3: Received social support mediates between financial toxicity and QoL Plus SEW.

Hypothesis 2.4: Perceived social support mediates between financial toxicity and QoL Plus SEW.

Baron, et al., (1986) comments that it is acceptable to begin with a moderator-oriented perspective that evolves into a mediator process; therefore, I first explored the moderator-oriented perspective (specific aim 1) and then the possibility of a mediator process as described in specific aim 2. The analysis procedure is outlined in the Data Analysis section below and results can be found in Chapter 6.

Study Design

Study 2 was a cross-sectional survey design as data was gathered at one time point for each participant. Cross-sectional study designs are appropriately used for measuring outcomes and determining associations between variables.

Human Subjects Protection. Study 2 was approved by the University of Louisville Institutional Review Board (IRB). The study required direct contact with human subjects; therefore, it needed to meet ethical standards. All participants were provided a consent preamble informing them of the purpose of the study and their rights to not participant in the study at any time. See Appendix H for the consent preamble.

Study sample. Participants were recruited using a convenience-sampling method. Multiple cancer-related agencies were asked and agreed to send out the call for participants through social media platforms, websites, emails and online monthly newsletters. See Table 6.1 for a complete list of agencies used, method of dissemination and number of participants obtained. If participants were interested in participating, they could follow the weblink provided in the correspondence. See Appendix I for the IRB approved call for participants.

Table 6. 1 Dissemination Methods and Responses by Agency.

Organizations	Method of Dissemination	Potential Exposure	Number Responses	Percent
Adelphi	Newsletter	~2000	1	.9
Atlanta Cancer Foundation	Newsletter	Unknown	1	.9
	Website	Unknown	1	.9
ACS-Cancer Support Network	Announcement Website	Unknown	3	2.8
Breast Friends	Email/Newsletter	~5000	56	52.8
Friends for Life	Email	~350	15	14.2
	Facebook	~2568	0	0
	Twitter	~6991	0	0
Komen Foundation Kansas City	Unknown	~8000	1	.9
	Facebook	~20,000	2	1.8
Research Match	Email	1324 Contacted 74 Initial Response	22	20.8
UofL Kent School	Website	Unknown	1	.9
Other: Referred by friend or agency that was not enlisted.	Unknown	Unknown	3	2.8

Inclusion criteria. Participation criteria required individuals to be 18 years and older, who had a breast or blood cancer diagnosis and/or treatment in the past 5 years.

Power consideration. Since a moderating variable may interact directly and/or indirectly with the outcome variable, it is difficult to detect an effect when statistical power is too low. The Sample Size application by Abu-bader (2014) was used to calculate required sample size for a multiple regression analysis. This application calculates the sample size necessary to achieve .80 statistical power for various statistical analysis. For a three-factor logistical regression, a sample size of 77 is required for an alpha level at .05 with a medium effect size. Three factors are consideration in a moderator analysis because there are two independent variables that interact, The interaction variable is considered to be the third factor. A sample size of at least 100 participants was sought to allow enough power to control variables that may have an influence on the relationship during the analysis.

After the sample was collected a second power analysis was conducted using G*Power (Faul, Erdfelder, Lang, & Buchner, 2007; Faul et al., 2009) to determine how many control variables may be used in the analyses to maintain a medium effect size. With the sample size obtained for this study at least 11 factors could be used (n=123).

Study Procedure

The survey was developed using initial data analysis from Study 1 as well as the theoretical frameworks of Lazarus et al. (1984), and Cohen et al. (1985). Standardized instruments were used to ensure validity and reliability of the measurement ofquality of life, financial toxicity and social support. In addition, questions pertaining to the use and type of social support, as well as demographic information, cancer type, and cancer treatment received were collected.

After receiving IRB approval, the survey was created in the Blue survey management system. The call for participants was sent out by participating cancer-related agencies (see Table 6.1). Participation was voluntary. If participants were interested in participating, they could follow the link to the questionnaire where they would first be presented with the consent preamble and then questions (see Appendix H for the consent preamble and Appendix J the survey questions). Surveys were collected through the Blue online survey platform between July 2017 to December 2018.

Data management. Data were initially collected in the Blue online survey system which is a password protected program licensed with the University of Louisville. After the data were collected, they were downloaded and transferred into an IBM SPSS v25 software file on a password protected and encrypted computer.

Measures. Variables were operationalized based on peer-reviewed literature and published books (see Appendix K). Standardized instruments were selected based on validity and reliability as well as their use in similar literature. Scales and questions were selected to gain the most accurate information with the least respondent toxicity. In addition, questions pertaining to the use and type of social support, as well as social constraints, demographic information, and disease specific information were collected. An overview of variables, measures, level of measurement and estimated time requirement can be viewed in Appendix K.

Clinical Questions. Questions were created to first gather cancer specific information about participants' diagnoses and treatments since these variables may be associated with other variables of interest.

Financial toxicity *– independent variable (IV).* Financial toxicity is the subjective distress and objective burden due to cancer treatment costs and related expenses. The COST-PROM was used to measure cancer-related financial toxicity. This is a comprehensive instrument designed to consider the effects of direct and indirect costs caused by a cancer diagnosis and treatment. Examples of some of the items are: “I feel financially stressed”, “I feel I have no choice about the amount of money I spend on care”, and “I feel in control of my financial situation”. The COST-PROM is an 11-item self-reporting inventory rated on a 5-point Likert scale (0 = not at all; 5 = very much). The scale has been shown to have excellent internal consistency with Cronbach alpha = 0.9 in other studies (DeSouza et al., 2014). For this sample reliability was good (alpha = .81). A high score on this scale indicates higher level of toxicity.

Social support** – moderator or mediator variable. Social support is the *emotional*, *informational*, and *instrumental* support perceived and/or received from formal and informal support networks. The measures used to assess perceived social support are the PROMIS Instrumental, Informational and Emotional Support instruments (PROMIS, 2015). Each instrument has 4 items that are rated using a 5-point Likert scale (1= never to 5 = always). Items are summed for a raw score and then converted to t-scores. Higher scores reflect more support.

- The *NIH PROMIS Emotional Support SP4a* instrument measures the perception of being cared for and valued. Examples of items include: “I have someone who will listen”, and “I have someone to confide in”. This scale had excellent internal consistency (Cronbach alpha = 0.904).
- The *NIH PROMIS Informational Support SP4a* instrument measures the perception of available information and advice (PROMIS, 2015). Items include: “I have someone to give me good advice”, and “I have someone to turn to for suggestions”. The scale had excellent internal consistency (Cronbach alpha = 0.96).

- The *NIH PROMIS Instrumental Support SP4a* instrument measures the perception of availability assistance with tasks, and material resources (PROMIS, 2015). Questions include: “Do you have someone to run errands if you need it”, and “do you have someone to help with your daily chores”. This scale had excellent internal consistency (Cronbach alpha = 0.95).

Received social support – *moderator or mediator variable.* The short version of the Inventory of Socially Supportive Behaviors (ISSB) assesses received social support within the past month. This is a 19-item scale graded on a 5-point Likert scale ranging from “not at all”, “once or twice”, “about once a week”, “several times a week” to “about every day”. This scale assesses received Informational and Instrumental support for the past month and included responses to a prompt asking how often someone provided specific activities such as: “gave you information”, “helped you understand”, and “suggested some action”. Internal consistency for reported studies is excellent (Cronbach alpha between 90 – 94) and for this study was excellent (Cronbach alpha = 0.904) (Barrera, Sandler, & Ramsay, 1981).

Quality of life – *dependent variable (DV).* Quality of life is a multidimensional concept that encompasses a person’s perception of their overall well-being. Well-being is defined as the personal perception of how well life is going and the degree to which it is enjoyed. Quality of life was assessed using two version of the Functional Assessment of Cancer Therapy (FACT-G) scale: 1) FACT-G and 2) FACT-G Plus which adds in the socio-economic well-being subscale (Head & Faul, 2008). The quality of life domains of the FACT-G includes physical, emotional, social, and functional. The FACT-G is a 28-item scale rated on a Likert scale (0 = Not at all; 4= Very Much). Internal consistency is reported good with a total Cronbach alpha = 0.89 (Cella et al., 1993). For this sample, the FACT-G showed excellent reliability (Cronbach alpha = 0.91). The Socioeconomic Well-being scale is 17-item scale rated on a 5-point Likert scale (0 = Not at all; 4= Very Much). Respondents are asked to indicate how a statement applies to their situation and include statements such as: “I believe that being sick will hurt me financially” and “I am able to make enough money to pay for my healthcare.” In other studies, the subscale has had excellent internal consistency (Cronbach alpha = 0.92) (Head, et al., 2008). For this sample the reliability was excellent (Cronbach alpha = .94). These scales assess domains of well-being for the past 7 days. Higher scores indicate increased quality of life.

***Social Constraint** – IV.* Research has shown that social constraint may influence feelings of support (Lepore, 2002) and therefore should be considered in the analysis. The Social Constraint scale is a 15-item scale rated on a 5-point Likert scale (0 = Not at all; 4= Very Much). Examples of questions include: “How often did it seem that other people did not understand your situation” and “how often did other people avoid you”. This scale has shown good internal consistence (Cronbach alpha = 0.89). For this sample internal consistence was excellent (Cronbach alpha = .946).

Participant burden and time consideration. Scales and questions were selected to gain the most accurate information with the least respondent burden. It is generally accepted that an inventory instrument with 30 to 40 items should only take the respondent a few minutes to complete (Wills & Shinar, 2000). To complete this questionnaire, it took an estimated 20 minutes.

Data analysis

Data cleaning. Once data were uploaded to SPSS the database was prepared for analyses. See Appendix L for specific steps taken for database preparation and tests for assumptions. Data were assessed for missing responses and outliers. Each standardized instrument provided instructions for handling missing data. Scales for social support, financial toxicity and QoL were calculated as instructed by specified guidelines. A composite variable was created for perceived social support using the three PROMIS scales. The PROMIS scales met expectations for a meaningful grouping and were not highly correlation (Song, Lin, Ward, and Fine, 2013). Further justification and steps for creating the composite perceived social support variable (emotional, informational, and instrumental) can be viewed in Appendix L.

Descriptive statistics. Basic descriptive analysis provided general information about the sample (mean, median, standard deviation, frequency and percentages of ordinal measures, normal data distribution). Frequency distributions were run in SPSS for sample characteristics included basic demographics, before/after job status, before/after insurance status, and cancer-related characteristics.

Bivariate Analysis. Pearson's bivariate analysis was conducted to determine the relationships between continuous predictor variables (age, social constraint). Pearson's correlation will report if items are negatively or positively correlated. See Appendix M for specific steps and Cohen conversion values.

For IVs that are nominal or ordinal level data, One-way Analysis of Variance (ANOVA) tests were conducted with the DV being quality of life. See Appendix N for steps. An ANOVA can be used as an independent sample t test for IVs that have 2 group levels (Lawson et al., 2014). Dummy variables were created for ordinal level data See Appendix L for steps.

Specific aim 1. The first aim was to determine if received and perceived social support moderates the relationship between cancer-related financial toxicity and QoL controlling for treatment, education, employment, insurance status, marital status, and social constraint. As discussed, QoL is measured using the FACT-G and the FACT-G plus.

If social support is a moderator, it will influence the relationship between the IV and the DV. Introducing a moderating variable will change the direction or magnitude of the relationship between the IV and DV. There must be a significant interaction effect between social support and financial toxicity (Meyers et al., 2013). Refer to chapter 3 for the conceptual model of a moderator effect based off Baron et al. (1986). Holmbeck (1997) discusses two analytical methods used to determine moderator effects: multiple regression and structural equation modeling (SEM). A sample size of at least 200 is needed for SEM. Since the sample size is only 126, multiple regression methods were used.

The equation for the multiple regression analysis is as follows:

$$Y_{pred}=a+b_1X_1+b_2X_2+b_3X_1X_2 \tag{1}$$

This analysis will test if the interaction of X_1X_2 (i.e., financial toxicity, social support) is related to the remainder of Y (QoL) after X_1 (financial toxicity) and X_2 (social support) have been used to predict Y (McClelland & Judd, 1993). If the interaction variable is significant then it can account for some of the variance in the outcome variable and therefore moderates the relationship.

Data Analysis. To conduct the analysis for a moderator effect the *Introduction to Mediation, Moderation, and Conditional Process Analysis* (PROCESS) macro for SPSS was used. PROCESS is a modeling tool for SPSS and SAS that enables the analysis of moderator and mediator effects (Hayes, 2017). It is a robust tool and has been used in several peer-reviewed journal articles since 2014. The PROCESS method was selected because the Baron and Kenny (1986) method is no longer the preferred methodologically approach (Hayes, 2017). PROCESS implements simultaneous multiple regression analyses to determine if a moderation effect is present (Hayes, 2018). The PROCESS macro automatically centers the predictor variable to avoid multicollinearity, computes the interaction term, and runs simple slope analyses using ordinary least squares (Fields, 2013).

Assumptions that need to be considered for multiple regression analysis include sample size, multicollinearity of predictor variables, outliers, excluded variables and misspecification of variables. To avoid issues of multicollinearity created by the interaction term between social support and financial toxicity, the variables were centered before the interaction term was created centered (Meyers et al., 2013; McClelland & Judd, 1993; Holmbeck, 1997; Hayes, 2018). As stated, PROCESS automatically centers the variables to avoid issues with multicollinearity. Next, data should be homoscedastic meaning the variance between the residual of each predictor variable should be fairly consistent. Potential issues with heteroscedasticity (opposite of homoscedasticity) are handled automatically through the PROCESS macro using bootstrapping techniques. Bootstrapping is the process of generating a large number of replications from the data (Tabachnick & Fidell, 2013); essentially random samples from the data set multiple times. This allows for the computation of confidence intervals and determination of significance (Fields, 2013). Lastly, data for the predictor, moderator and outcome variables should be continuous, interval or ratio form. Tabulated data from the scales are in interval form. Any control variable should be in dichotomous form (entered in SPSS as 0, 1).

Hayes (2018) argues there is ultimately no difference between a hierarchical stepwise regression and a simultaneous entry. Several scholars have commented further on whether or not a stepwise or simultaneous method should be used. Holmbeck (1997), states that if the variables are considered equal in the theoretical model then it is appropriate to use a simultaneous process. Additionally, using a step-wise method relies on chance which may lead to an unstable equation (Lawson et. al., 2014). Furthermore, when there are less then 15 variables the simultaneous method will provide as good or better model fit; however, if there are more then 15 variables then the stepwise methods may be useful (NCSS & Hintze, 2007).

It is my understanding that the PROCESS macro simulates the simultaneous multiple regression. The PROCESS macro provides the ΔR^2 which is the variance in Y due to the moderation of X by the moderator variable (M) and it uses ordinary least squares (OLS) to evaluate model fit including R^2 and overall F-test. In addition, it provides bootstrap confidence levels and provides the Johnson-Neyman technique for probing interactions.

The PROCESS macro was used to conduct the moderation analysis (using simultaneous multiple regression analyses) for hypothesis 1.1 – 1.4 to determine if social supports behaved as a moderator variable in the relationship between financial toxicity and QoL. For the analyses that showed significant moderator effects, control variables (age, cancer treatment, education, employment, insurance status, and marital status) were added to the model to determine if social support continued to moderate the relationship between financial toxicity and QoL.

Final analysis was conducted to determine if social constraint had an influence in the relationship. Social constraint was added using a moderated moderator model as described by Hayes (2017). Specific steps in PROCESS for conducting these analyses and an example of the SPSS output can be viewed in Appendix O. Results are presented in chapter 7.

Specific aim 2: Aim 2 sought to determine if received and perceived social support mediates the relationship between cancer-related financial toxicity and QoL controlling for cancer treatment, education, employment, insurance status, marital status, and social constraint. QoL is determined using two variations of the FACT-G scale: 1) FACT-G and 2) FACT-G plus socio-economic well-being scale. The following equation represents the statistical analysis for a simple mediation model.

$$M = i_M + aX + e_M$$

$$Y = i_Y + c'X + b_M + e_Y \text{ (Hayes, 2017)}$$

To test for mediator effect four conditions must be met through a series of regression analyses. (See figure ___ for pathway notation.)

1) The IV must be significantly associated with the DV: financial toxicity to quality of life (path C).
2) The IV must be significantly associated with the mediator: financial toxicity to social support (path A).

3) The mediator variable must be significantly associated with DV: social support to quality of life (path B).

4) The impact of the IV on the criterion variable should be smaller when the mediator is included: financial toxicity → QoL, control for social support (Field, 2013; Hayes, 2017).

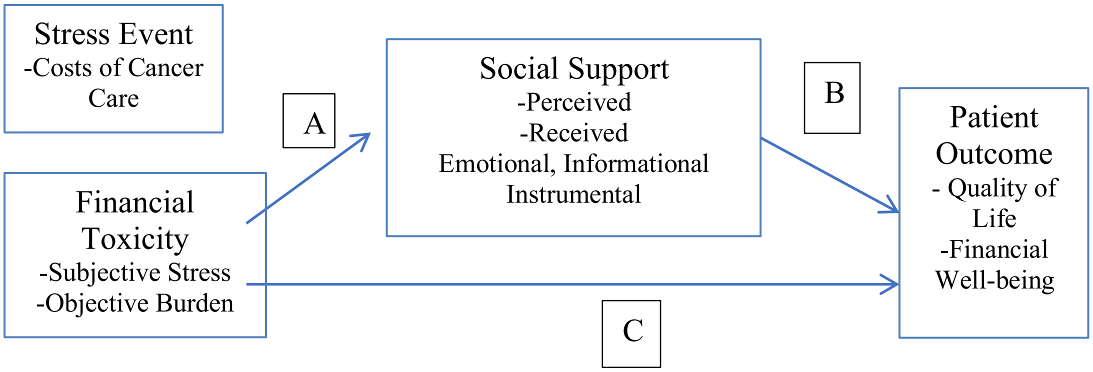

Figure 6. 1 Diagram of mediation model, adapted from Hayes (2017).

Data Analysis. In order to analyze the data for these conditions a series of correlations and linear regression analyses can be used to determine the relationships (Meyers, Gamst, & Guarino, 2013; Field, 2013); however, I again used the PROCESS macro to determine if a mediator effect exists (Hayes, 2017). The PROCESS macro can be used to conduct 92 different moderator and mediator analyses. For this analysis, models 4 and 14 were used (see Hayes, 2017 and Chapter 3 for models). PROCESS implements bootstrapping techniques to calculate standard errors and confidence intervals. Confidence levels were used to determine at a 95% confidence that the true b-value falls between the lower level and the upper level.

The data assumptions to use this analysis are: interval or ratio level of measurement, predictive relationship must be linear, and variable distribution must be normal. Issues of multicollinearity should be considered (Meyer, et al., 2013); however, social support and financial toxicity were not highly correlated. The assumption of misspecification will occur when there are irrelevant variables included in the model. Variables were added to the model when justified by theory and reason. (See steps for analysis in Appendix P). Results are presented in chapter 6.

Dissemination

Preliminary results have been disseminated through conference presentations and workshops to oncology providers including social workers, physicians, nurses, financial counselors, and administrators. I presented a poster at CSWE in 2017 on the topic of addressing financial toxicity in the educational process for oncology social workers. This poster pointed out the importance of education professionals engaging in important conversations about finances with cancer patients. Presentations were also made at the American Cancer Society Doctoral workshop, 2017 and 2018, for fulfillment of grant recipient responsibilities. Attendees for this workshop included other doctoral grant recipients and professional oncology social work researchers. In addition, I was invited to present on a cancer care access panel supported by a PCORI grant with the University of Kansas Medical Center in January 2019. This webinar was attended by medical professionals, patients and caregivers. I presented on the topic of financial toxicity pulling in preliminary results from study 2.

Future dissemination of this material will include peer-reviewed journal publications and the development of educational materials on addressing financial concerns for medical professionals. Creation of a program to highlight the importance of engaging in financial conversations to ensure all available resources to assist patients are accessed in a timely manner. I will address future research and development plans in more detail in the discussion section.

Summary

This chapter provided the research methods that were used for Study 2. Study 2 was driven by quantitative methods and analysis. Specific aims and hypotheses were presented along with sample collection procedures and detailed steps for cleaning data and statistical analysis (located in corresponding Appendices). The results from Study 2 are presented in Chapters 7. An in-depth discussion on the interpretation and finding are presented in Chapter 8.

CHAPTER 7: STUDY 2 RESULTS

“I’m told I make too much money to qualify for financial assistance. I pay $50 a month. They state it isn’t enough. I gross $770 a month. How am I to pay more? I’ve asked them why they save patients if they are going to kill them with the stress they are creating.”
- Study 2 #88 (58-year-old female, Breast Cancer)

The primary purpose of this research was to determine if social support played a role in the complex issue of cancer-related financial toxicity and if so, how does it impact the situation. In Study 1, we see that social support is present and commented on by most of the participants in that study. Many reported to benefit from received instrumental support. However, there was a clear lack of the presence of received informational and emotional support. There were also very few comments on perceived social support. These results led to more questions about patients’ experiences and how that can be improved.

This chapter will present the results from Study 2 which examined the relationships between financial toxicity, social support, and quality of life (QoL). This study used quantitative methods, described in Chapter 6, to answer the driving question: *How does social support influence cancer-related financial toxicity and patient’s QoL?* Specifically, I was interested in whether or not social support acted as a moderator or mediator variable in the relationship between financial toxicity and QoL. This chapter first presents a description of the sample characteristics followed by the results of each hypotheses for the study aims.

Sample Characteristics

There were 131 cases downloaded from the Blue survey system. One case was deleted for missing excessive amounts of data. Four cases were deleted because they did not meet study criteria for type of cancer. The remaining sample consisted of 126 participants who reported to have had breast cancer (n = 104) or blood cancer (n = 20) diagnosis and treatment in the past 5 years. The age of participants ranged from 30-83 with a mean of 54.6 (SD 10.30). For those with breast cancer the mean age was 53.8 (SD 9.56) ranging from 32-83 years; those with blood cancer had a mean age of 59.1 (SD 12.81) and ranged from 30-80 years. Most of the participants were female n=117 (94%), white n=103 (82%), and married or living with a significant other n=67 (53%). See Table 7.1 for a breakdown of each demographic characteristic.

Table 7. 1 Demographics of Participants.

Characteristic	Mean (SD)	Range
Age	54.6 (10.3)	30-83
	Frequency	Percent
Gender		
Female	117	93.6
Male	8	6.4
Missing	1	0.8
Race/Ethnicity		
White	103	81.7
Black	9	7.1
Hispanic	6	4.8
American Indian	3	2.8
Missing	4	3.2
Marital Status		
Married/Significant Other	67	53.2
Separated/Divorced	34	27
Single	13	10.3
Widowed	4	3.8
Missing	1	0.8

Education		
Graduate/Professional	39	31
Bachelor's	33	26.2
Some College/Technical School	36	28.6
High School/GED	16	15.1
Missing	2	1.9
Occupation		
Professional/Technical	62	49.2
Executive/Management	15	11.9
Clerical/Sales/Service	23	18.3
Agricultural	2	1.6
Craft/Manufacturing	5	4
Homemaker	15	11.9
Missing	4	3.2
Household Income		
Over $80,000	33	26.2
60,001-80,000	19	15.1
40,001-60,000	34	27.5
25,001-40,000	21	19.8
Less Than $25,000	13	10.3
I don't know	3	2.4
Missing	2	1.6

Participants were asked if they experienced a job change due to their cancer experience (see Table 7.2 to view reported employment status prior to diagnosis and after treatment). A third of participants n=38 (30%) reported they experienced a change in status due to their cancer experience. Over half of the participants n=66 (52%) reported to leave their job temporarily during their cancer treatment or recovery phase. A fourth n=27 (21%) reported to permanently leave their jobs due to their cancer experience.

Table 7. 2 Employment Status at Diagnosis and Current Status.

At Diagnosis	N	%	Current Job Status	N	%
Full-time	87	69	Full-time	56	44.4
Part-time	11	8.7	Part-time	15	11.9
Retired	16	12.7	Retired	24	19
Disabled	6	4.8	Disabled	17	13.5
Unemployed	1	0.8	Unemployed	9	7.1
Homemaker	5	4	Homemaker	5	4.

The majority of participants n=93 (73%) received insurance from an employer-based program prior to their cancer diagnosis. Just over a fourth of participants n=35 (28%) reported a change in their insurance due to their cancer experience. See Table 7.3 for participants' current insurance status and insurance status when diagnosed.

Table 7. 3 Insurance Status at Diagnosis and Current.

Prior Insurance Status	N	%	Current Insurance Status	N	%
Employer Paid	93	73.8	Employer Paid	67	63.3
Self-Paid	19	15.1	Self-Paid	16	15.1
Veterans	1	0.8	Veterans	2	1.9
Medicare	5	4	Medicare	12	11.3
Medicaid	6	4.8	Medicaid	4	3.8
No Insurance	2	1.6	No Insurance	4	3.8

Cancer characteristics. The majority of participants reported to have had breast cancer (n=106, 84%). Over half of participants n=78 (62%) reported to have received treatment within the past year and "No Evidence" of cancer (n=67, 53%). (See Table 7.4 for more detailed cancer specific characteristics.)

Table 7. 4 Description of Clinical Characteristics.

Characteristic	Blood Cancer (n=20)		Breast Cancer (n=106)		Total (n = 126)	
	Frequency	%	Frequency	%	Frequency	%
Cancer Type						
Blood					20	15.9
Breast					106	84.1
Treatment						
Surgery	1	5	101	95.3	102	81
Chemotherapy	16	80	79	74.5	95	75.4
Radiation	4	20	71	67	75	59.5
Stem Cell	7	35	1	0.9	8	6.3
Immunotherapy	5	25	7	6.6	12	9.5
Other	4	20	23	21.7	27	21.4
Time Since Last Treatment						
Current – 1 year	12	60	66	62.2	78	61.9
1 year – 2 years	3	15	15	14.2	18	14.3
2 year – 3 years			9	8.5	9	7.1
3 year – 4 years	1	5	8	7.5	9	7.1
4 year – 5 years	2	10	5	4.7	7	5.6
Current Status						
Active	4	20	23	21.7	27	21.4
Remission	9	45	23	21.7	32	25.4
No Evidence	7	35	60	56.6	67	53.2

Financial toxicity characteristics. Several One-way Analysis of Variance (ANOVA) were conducted to determine if certain characteristics were associated with financial burden and distress (financial toxicity). Financial toxicity and distress were assessed using the Comprehensive Score for Financial Toxicity (COST). Those who had undergone chemotherapy, had an active cancer status or were in remission, lower education, single, minority and had an income below $80,000 were significantly more likely to experience higher levels of financial toxicity. (See Table 7.5 for means, standard deviations and significance levels.) Individuals who had a bachelor's degree or higher, had a household income over $80,000, and were married reported lower financial toxicity. Insurance status was not significantly related to financial toxicity. Individuals who were unemployed had a lower mean score which tended toward significance. (See Table 7.5 for means, standard deviations and significance levels.)

Table 7. 5 Level of Financial Toxicity by Demographics.

Variable	Mean (SD)	df	*F*	Sig.	Partial Eta	Power
Treatment						
Chemotherapy	20.01 (8.54)	1, 124	4.08	.046	0.032	0.518
No Chemotherapy	16.42 (8.74)					
Cancer Status						
Active	20.41 (7.35)	2, 123	3.07	.05	0.048	0.584
Remission	21.66 (10.01)					
No Evidence	17.40 (8.24)					
Education						
Less than Bachelors	20.21 (8.33)	1, 124	5.26	.041	0.034	0.535
Bachelor or Higher	16.69 (9.08)					
Employment Status						
Unemployed	24.22 (6.22)	1, 124	3.39	.068	0.027	0.448
Other	18.73 (8.75)					
Income						
Under 80,000	20.42 (8.61)	2, 121	3.6	.03	0.056	0.657
Over 80,000	16.05 (8.33)					
Marital Status						
Single	21.09 (8.79)	1, 124	4.4	.032	0.035	0.575
Married/Other	17.74 (8.40)					
Race						
White	18.38 (8.80)	1, 123	5.18	.025	0.04	0.617
Other	22.95 (7.25)					

Univariate analysis. All scales were calculated and assessed to determine if the data met assumptions for analyses (see Appendix K for details on database preparation.)

A one-way Analysis of Variance (ANOVA) was conducted to determine if differences existed between cancer types for all scales. See Table 7.6 for descriptive statistics. There were no differences between cancer types (blood or breast) for all scales except for Received Social Support. Respondents with blood cancer reported more received social supports than those who had breast cancer.

Table 7. 6 Descriptive Statistics by Type of Cancer.

	Total		Blood Cancer		Breast Cancer			
Variable	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	*F* (1, 124)	p
COST	20.5	0-44	18.4 (11.9)	2-44	19.26 (8)	0-44	0.164	.686
Emotional Support	51.82 (8.46)	29.9-62	53.62 (7.61)	40.5-62	51.48 (8.6)	29.9-62	1.077	.301
Informational Support	52.14 (9.9)	25.6-65.6	54.69 (6.85)	39.8-65.6	51.67 (10.33)	25.6-65.6	1.576	.212
Instrumental Support	51.04 (9.74)	29.3-63.3	53.53 (11.03)	29.3-63.3	50.57 (9.46)	29.3-63.3	1.565	.213
Composite Support	51.67 (8.29)	32.6-63.6	53.95 (7.34)	41.8-63.6	51.24 (8.42)	32.6-63.6	1.808	.181
Received Support	45.74 (14.67)	19-80	52.25 (16.66)	26-80	44.52 (45.74)	19-74	4.811	**.030***
Social Constraint	21.75 (16.59)	0-60	18.55 (19.03)	0-58	22.35 (16.11)	0-60	0.882	.35
FACT-G	67.05 (19.75)	15-104	67.2 (18.66)	36-102	67.02 (20.02)	15-104	0.001	.097
FACT-G Plus	111.38 (31.09)	32-168	113.65 (30.3)	59-162	110.95 (31.35)	32-168	0.136	.723

COST Comprehensive Score for Financial Toxicity, *FACT-G* Functional Assessment of Cancer Therapy scale for QoL, *FACT-G Plus* with Socioeconomic Well-being scale.

** A one-way Analysis of Variance determined differences between groups $p < 0.05$.*

Bivariate Analysis. Several analyses were conducted to determine which variables could influence the outcome variable. A series of ANOVA analyses were conducted to determine if nominal and interval variables had a mean difference in QoL. Interval variables were transformed into dichotomous variables. See Table 7.7 for variables that showed a significant difference between groups with the Functional Assessment of Cancer Therapy scale (FACT-G), and Table 7.8 for Functional Assessment of Cancer Therapy with Socioeconomic Wellbeing (FACT-G Plus). Variables that showed a significant difference in mean QoL include: Chemotherapy, Education, Employment Status, Insurance Status, Marital Status. All analyses for homogeneity of variance (Levene's Test) were non-significant. Time since last treatment, income, and gender were assessed and were not significant.

Table 7. 7 Differences in Quality of Life (FACT-G) by Cancer Treatment and Demographics.

Variable	Mean (SD)	df	*F*	Sig.
Cancer Treatment				
Other	74.65(21.28)	1, 124	6.37	0.013
Chemotherapy	64.57(18.67)			
Education				
Less Than Bachelor	60.42(21.13)	1, 122	11.88	0.001
Bachelor or Higher	72.29(17.167)			
Employment Status				
Not Working	62.22(20.01)	1, 124	6.08	0.015
Working	70.79(19.75)			
Insurance				
No	45.5(22.52)	1, 123	5.015	0.027
Yes	67.69(19.41)			
Marital Status				
Single	62.12(20.86)	1, 123	5.772	0.018
Married/Other	70.61(18.38)			

p = .05, *FACT-G* = Functional Assessment of Cancer Therapy scale

Table 7. 8 Group Differences in Quality of Life Plus SEW (FACT-G Plus).

Variable	Mean (SD)	df	*F*	Sig.
Cancer Treatment				
Other	122.12(30.70)	1, 124	5.067	0.026
Chemotherapy	107.87(30.55)			
Education				
Less Than Bachelors	99.00(31.59)	1, 122	17.364	0.001
Bachelor or Higher	121.12(31.05)			
Employment Status				
Not Working	104.94(32.04)	1, 124	4.3	0.04
Working	116.37(29.60)			
Insurance				
No	71.00(41.18)	1, 123	7.261	0.008
Yes	112.70(30.14)			
Marital Status				
Single	102.71(31.21)	1, 123	7.072	0.009
Married/Other	117.46(29.95)			

$p = .05$

Further analyses were conducted to determine relationships between scales. In order for a mediator variable to be present the variables must show correlation. Pearson's bivariate correlations were conducted (see Table 7.9 for correlation values and significance.) Received Social Support was not significantly correlated with the FACT-G, Comprehensive Score for Financial Toxicity (COST) or social constraint variables. This violates the assumptions for the mediator analysis.

Pearson's bivariate correlations were then used to determine the relationship between age and all the scales used for the moderator and mediator analyses. Age showed a moderate negative correlation with social constraint r (124) = -.22, p < 0.013. Age was not correlated with the FACT-G, FACT-G Plus, COST or any of the social support scales.

Table 7. 9 Pearson's Bivariate Correlations (*r*) of Support, Quality of Life and Financial Toxicity Variables.

	1	2	3	4	5	6	7	8	9
1. FACT-G	1	.944***	-.591***	.528***	.510***	.477***	.570***	0.174	-.629***
2. FACT-G Plus		1	-.696***	.5548***	.556***	.506***	.606***	.195*	-.647***
3. COST			1	-.385***	-.430***	-.402***	-.460***	-0.013	.524***
4. Emotional Support				1	.777***	.622***	.893***	.377***	-.498***
5.Informational Support					1	.629***	.909***	.405***	-.534***
6. Instrumental Support						1	.854***	.337***	-.390***
7. Composite Support							1	.421***	-.535***
8. Received Support								1	-0.162
9. Social Constraint									1

*p < 0.05, **p < 0.01, ***p < 0.001; COST Comprehensive Score for Financial Toxicity, FACT-G Functional Assessment of Cancer Therapy scale for QoL, FACT-G Plus Functional Assessment of Cancer Therapy with Socioeconomic Well-being scale.

Aim 1

The first aim of this study was to determine if received and perceived social support moderates the relationship between cancer-related financial toxicity, and QoL. As presented in Chapter 6, the equation for multiple regression analysis is:

$$Y_{pred}=a+b_1X_1+b_2X_2+b_3X_1X_2 \tag{1}$$

The moderator models from Chapter 3 are presented in Figure 7.1. These models represent social support as a moderator on the relations between financial toxicity and QoL.

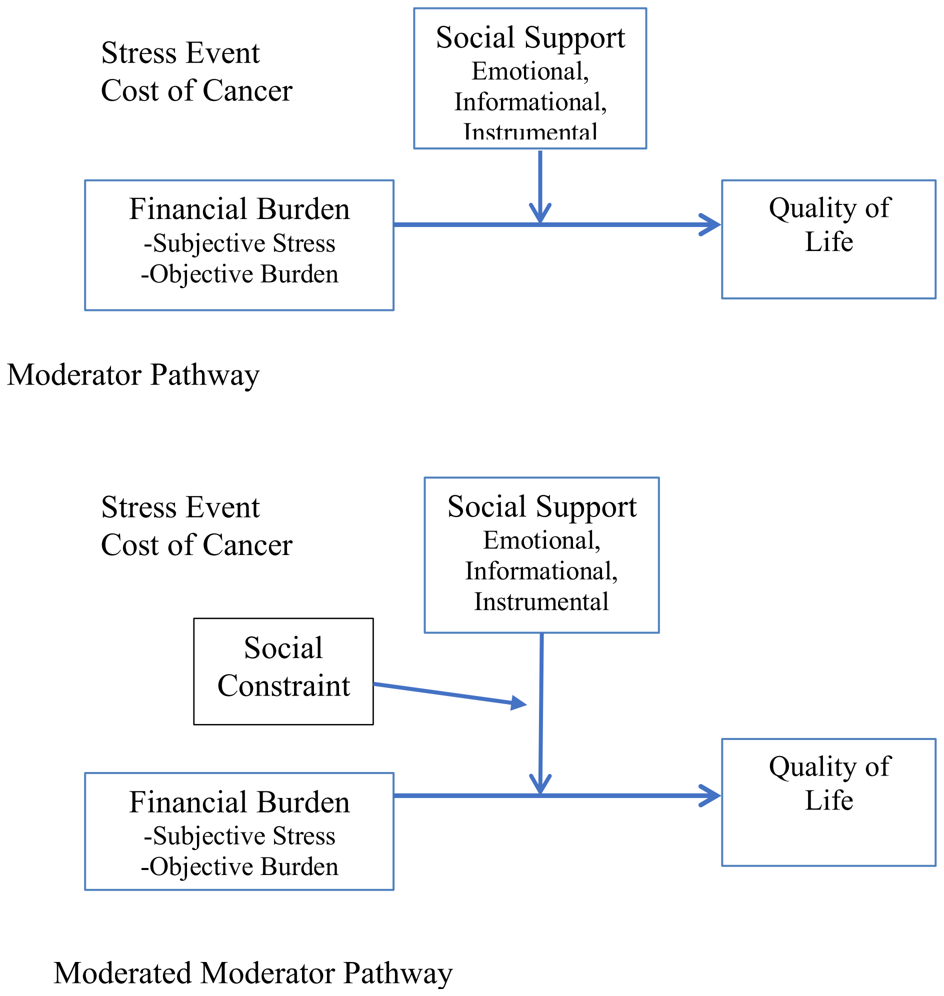

Figure 7. 1 Social Support Moderation Pathways (Hayes, 2018).

The analyses were conducted using the *Introduction to Mediation, Moderation, and Conditional Process Analysis (*PROCESS) macro for SPSS. (See Chapter 6 for details on the PROCESS macro). Continuous variables included financial toxicity, perceived social support, received social support and QoL. The variable financial toxicity was assessed using the Comprehensive Score for Financial Toxicity (COST) scale. To assess perceived social support, analyses were conducted using each perceived support separately (emotion, informational, instrumental) and then with a composite variable made from perceived emotional, informational and instrumental scales. The received social support variable was created using the Inventory of Socially Supportive Behaviors (ISSB) short form. The variable QoL was assessed in two ways: 1) four domains of quality of life using the FACT-G (physical, emotional, social, and functional); 2) the FACT-G Plus which is composed of the four domains previously stated and the socio-economic well-being scale. (Details on each scale can be reviewed in Chapter 6).

Hypothesis 1.1: *Received social support will moderate the relationship between COST and QoL (FACT-G).*

A simple moderation analysis was conducted in PROCESS using simultaneous multiple regression analysis to determine if received social support moderated the relationship between financial toxicity and QoL. Bootstrap (1,000 samples) technique was used to avoid violations of normal distribution and produce confidence intervals levels. The total model fit accounted for a significant amount of the variance in QoL, $R^2 = .38$, F (3, 122) = 25.23, $p = .001$. Variables were centered on zero prior to creating the interaction variable (interaction between financial toxicity and received social support) to avoid the risk of multicollinearity which can occur between financial toxicity, received social support and the interaction variable. Nevertheless, the interaction variable was not significant and did not account for variance in quality of life. Received social support did not moderate the relationship. This finding did not support the hypothesis. (Data tables reporting non-significant moderator analysis results can be viewed in Appendix Q Table Q.1).

Analysis by cancer type. Since there was a difference in received social support between cancer types, additional analyses were conducted on each cancer type. For individuals with blood cancer, received social support did not moderate the relationship between financial toxicity and QoL (FACT-G). However, received social support was a moderator for participants with breast cancer. (The results of that analysis are presented below.)

Breast Cancer Dataset. To test the hypothesis that received social support will moderate the relationship between financial toxicity and FACT-G, a simple moderation analysis was conducted in PROCESS (using simultaneous multiple regression analysis) using the breast cancer dataset. Received social support, financial toxicity and the interaction variable (toxicity*support) accounted for a significant amount of the variance in QoL, $R^2 = .39$, F (3, 102) = 18.18, $p = .001$. Received social support and financial toxicity were centered prior to the creation of the interaction term to avoid multicollinearity which can occur between the received social support, financial toxicity the interaction variable. The interaction variable accounted for a significant proportion of variance in quality of life, $\Delta R^2 = .03$, F (1, 102) = 5.65, p = .019. Quality of life increases as financial toxicity decreased and received social supports increased. This moderation model explains 39% of the variance in FACT-G; although, the interaction (toxicity*support) only accounts for 3% of the variance. Bootstrap technique at 1000 samples provided confidence intervals (CL). (See Table 7.10 and Figure 7.2 for moderation analysis results.)

Table 7. 10 Received Social Support and Financial Toxicity as Predictors of Quality of Life (FACT-G).

Variable	*b*	SE	95% CL	*F* (df)	R^2	ΔR^2
Predictor Variables				18.18 (3, 102)	.38	
Constant	67.08**	1.51	[64.09, 70.09]			
Financial Toxicity (centered)	-1.41**	0.22	[-1.83, -0.98]			
Received Support (centered)	0.32*	0.10	[0.11, 0.53]			
Interaction				5.65 (1, 102)		.03
Financial Toxicity x Received Support	0.03*	0.01	[0.01, 0.06]			

**p* < .05, ***p* < .01, ****p* < .001, CL= confidence intervals at 95%. FACT-G = Functional Assessment of Cancer Therapy scale .

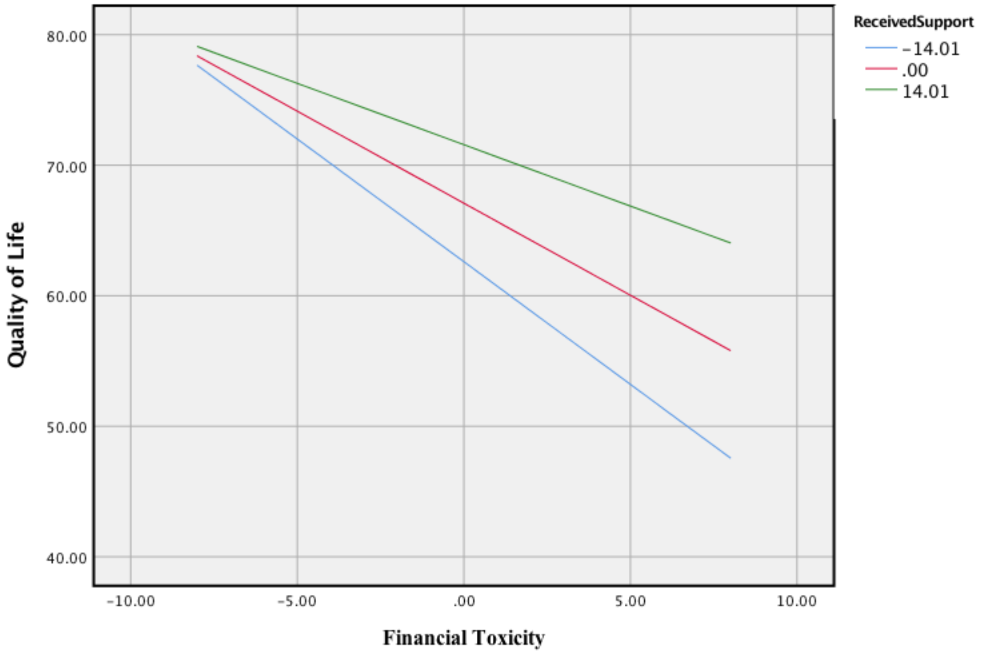

Figure 7. 2 Moderation of Financial Toxicity and QoL (FACT-G).

In this model, receive social support was significant at low, medium and high levels of social support (see Table 7.11 for conditional effects). The Johnson- Neyman technique was conducted to further probe the analysis using the parameters of one standard deviation above and below the mean of received support. When social support scores are equal to or below 69.28 units on the received support scale, financial toxicity and QoL are significantly related t (102) = -1.98, p = .05, b = -.58. As financial toxicity increases and received social support decreases, QoL also decreases.

Table 7. 11 Conditional Effects of Financial Toxicity at Levels of the Moderator.

Received Support	*b*	SE	*t*	*p*	LLCI - ULCI
Low	-1.88	0.36	-5.17	0.001	[-2.60, -1.16]
Average	-1.41	0.22	-6.55	0.001	[-1.84, -.98]
High	-0.94	0.2	-4.8	0.001	[-1.33, -.55]

CL= confidence intervals at 95%. FACT-G = Functional Assessment of Cancer Therapy scale.

Moderation analysis with control variables. A second moderation analysis was conducted adding control variables to the model. A simple moderation analysis was conducted in PROCESS (using simultaneous multiple regression analyses) to determine if received social supports moderated the relationship between financial toxicity and FACT-G controlling for cancer treatment, education, employment, and marital status. Dummy variables were created for all nominal variables. The total model fit accounted for a significant amount of the variance in FACT-G, R^2 = .49, F = (8, 96) = 17.16, p = .001. All continuous scales were centered prior to analysis to avoid multicollinearity which can occur between received social support, financial toxicity and the interaction variable. The interaction variable accounted for a significant amount of the variance in FACT-G with the addition of the control variables ΔR^2 = .03, F = (1, 96) = 8.10, p = .005. Received social support continues to moderate the relationship between financial toxicity and quality of life after taking into consideration the potential effects of the control variables. As shown in Table 7.12 the entire model was significant, accounting for 49% of the variance in FACT-G; although, the interaction (toxicity*support) only accounted for 3% of the variance. A visual glance of the interaction is provided in Figure 7.3.

Table 7. 12 Predictors of Quality of Life (FACT-G) with Control Variables.

Variable	*b*	SE	95% CL	*F* (df)	R^2	ΔR^2
Predictor Variables				17.16*** (8, 96)	.49	
Constant	37.06***	6.92	[23.32, 50.80]			
Financial Toxicity (centered)	-1.18***	0.20	[-1.58, -.78]			
Received Support (centered)	0.24**	0.09	[0.06, 0.43]			
Interaction				8.10** (1, 96)		.03
Financial Toxicity x Received Support	0.04**	0.01	[.01, 0.06]			
Control Variables						
Education	6.72*	3.14	[.4867, 12.96]			
Employment	8.43**	3.2	[2.07, 14.78]			
Insurance	14.43*	7.2	[.14, 28.71]			
Marital Status	6.23*	3.07	[.14, 12.32]			
Treatment	5.22	3.5	[-1.71, 12.15]			

*$p < .05$, **$p < .01$, ***$p < .001$, CL= confidence intervals at 95%. FACT-G = Functional Assessment of Cancer Therapy scale.

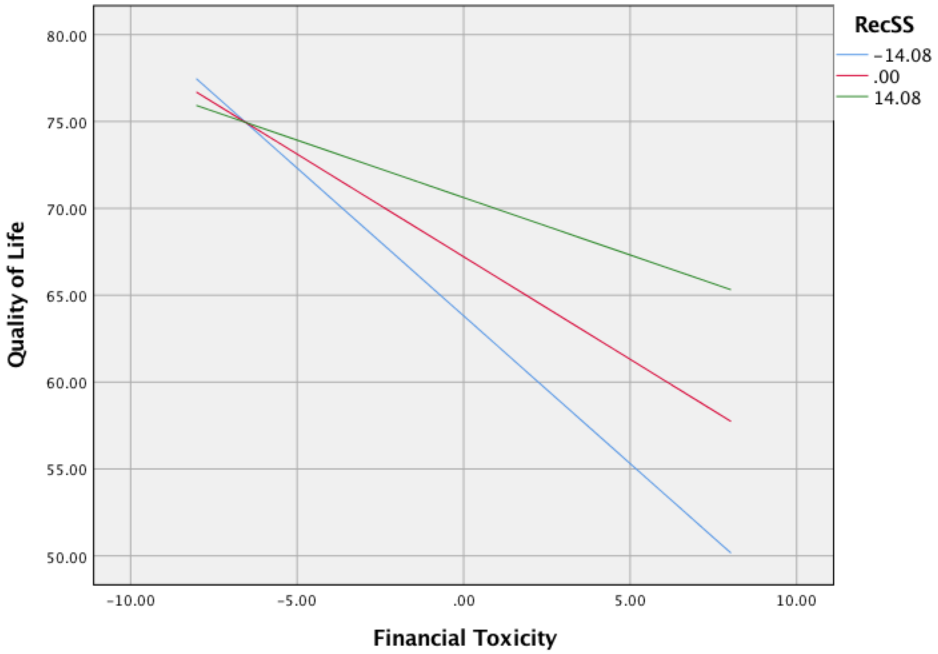

Figure 7. 3 Moderation of Financial Toxicity and Quality of Life (FACT-G) in presence of control variables.

As displayed in Table 7.13, the conditional effects of financial toxicity decrease, as received supports increases. The moderation interaction was further probed using a Johnson-Neyman technique. When social support scores are equal to or below 64.5 units on the received support scale, financial toxicity and QoL are significantly related, *t* (96) = -1.98, *p* = .05, *b* = -.44. As Financial toxicity increases and received social support decreases, QoL also decreases.

Table 7. 13 Conditional Effects of Financial Toxicity at Levels of the Moderator with Control Variables.

Received Support	*b*	SE	*t*	*p*	LLCI - ULCI
Low	-1.70	0.34	-4.98	0.001	[-2.38, -1.02]
Average	-1.18	0.20	-5.81	0.001	[-1.58, -.78]
High	-0.66	0.10	-3.64	0.001	[-1.02, -.30]

CL= confidence intervals at 95%. FACT-G = Functional Assessment of Cancer Therapy scale.

Three-way moderation analysis. A final analysis was conducted to determine if social constraint would have a moderation effect on the moderation between financial toxicity and received support. Social constraint is a continuous variable and was added to the model using a 3-way moderation or moderated moderation model (Hayes, 2018). View the model of a 3-way moderation in Figure 7. 1(b).

A 3-way moderation analysis in PROCESS (using simultaneous multiple regression analysis) was conducted to determine if received social support was associated with the relationship between financial toxicity and FACT-G taking into consideration social constraints. The total model fit accounted for a significant amount of variance in QoL, F (7, 98) = 22.01, p = .001, R^2 = .56. The interaction term between received social supports, financial toxicity, and social constraint was significant and accounted for variation in QoL, F (1, 98) = 10.03, p = 0.02, ΔR^2 = .04. This means that there is evidence of a three-way interaction between social supports, financial toxicity, and social constraint. The magnitude of the moderation of financial toxicity by social support is dependent on the effects of social constraint, though the moderation of the moderator (Received Support) explains only 4% of the variance in QoL. (See Table 7.14 and Figure 7.4 for analysis details.)

Table 7. 14 Financial Toxicity, Received Social Support, and Social Constraint as Predictors of Quality of Life (FACT-G).

Variable	b	SE	95% CL	F (df)	R^2	ΔR^2
Predictor Variables				22.01*** (7. 98)	.56	
Constant	65.38***	1.61	[62.18, 68.58]			
Financial Toxicity (centered)	-.89***	0.20	[-1.28, -0.49]			
Received Support (centered)	0.40***	0.10	[0.19, 0.60]			
Social Constraint	-0.58***	0.11	[-.79, -.37]			
Interaction				10.03 (1, 98)		.04
Financial Toxicity x Received Support x Social Constraint	-0.003*	0.00	[-0.005, -0.001]			

*$p < .05$, **$p < .01$, ***$p < .001$, CL= confidence intervals at 95%. FACT-G = Functional Assessment of Cancer Therapy scale.

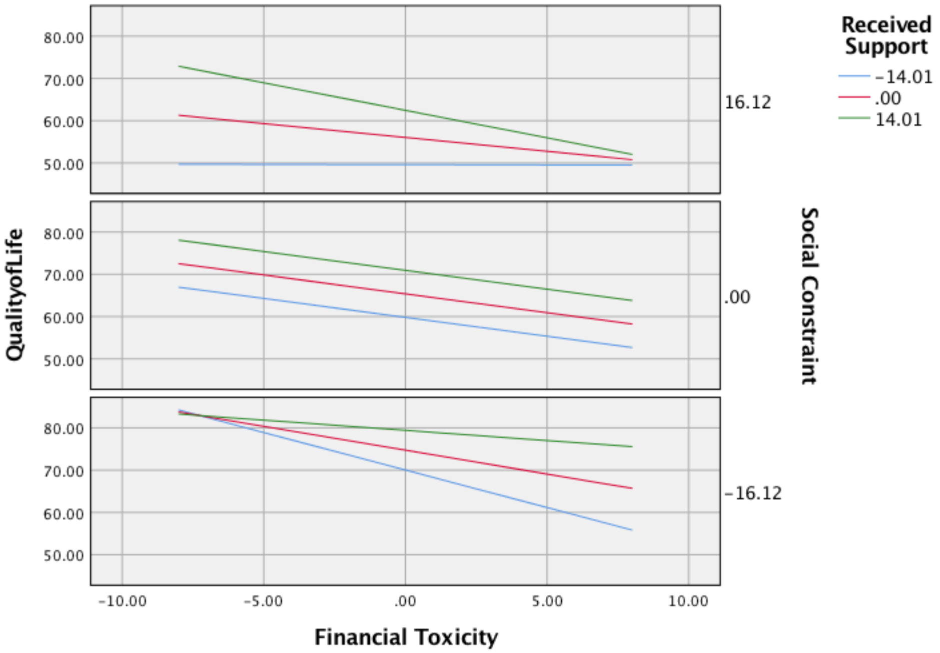

Figure 7. 4 Three-way moderation predicts Quality of Life (FACT-G).

The conditional effects of financial toxicity decrease as received supports increase; however, the effects with social constraint vary (see Table 7.15 For details). The Johnson-Neyman technique was used to further probe the conditional toxicity*support interaction according to the values of social constraint. When social constraint scores are low (equal to or below 13.63) and high (equal to or above 46) units on the social constraint scale, financial toxicity and received social support are significantly related, low *t* (99) = 1.98, *p* = .05, *b* = .025 and high *t* (99) = -1.95, *p* = .05, *b* = -.065. As financial toxicity increases and received social support decreases, social constraint increases. These analyses support the hypothesis stating that received support moderates the relationship between financial toxicity and quality of life. This moderation remained true when control variables and social constraint were added to the model.

Table 7. 15 Three-way Moderation Conditional Effects of Financial Toxicity.

Received Support	Social Constraint	b	SE	t	p	LLCI - ULCI
Low	Low	-1.77	0.35	-5.1	0.001	[-2.46, -1.08]
Low	Average	-0.89	0.35	-2.52	0.01	[-1.59, -.19]
Low	High	-0.01	0.56	-0.02	0.99	[-1.12, 1.1]
Average	Low	-1.13	0.21	-5.3	0.001	[-1.55, -.71]
Average	Average	-0.89	0.2	-4.47	0.001	[-1.29, -.50]
Average	High	-0.67	0.33	-2.02	0.05	[-1.30, -.01]
High	Low	-0.48	0.19	-2.57	0.01	[-.85, -.11]
High	Average	-0.89	0.24	-3.73	0.001	[-1.37, -.42]
High	High	-1.3	0.45	-2.89	0.005	[-2.20, -.41]

CL= confidence intervals at 95%. FACT-G = Functional Assessment of Cancer Therapy scale.

Hypothesis 1.2: *Perceived social support will moderate the relationship between financial toxicity and QoL (FACT-G).*

To determine if perceived social support moderates the relationship between financial toxicity and QoL, a simple moderation analysis was conducted in PROCESS (using simultaneous multiple regression analysis). The analysis was run individually with each variable of perceived social support (emotional, informational, instrumental, and composite perceived social support). Each variable of perceived social support and financial toxicity accounted for a significant amount of the variance in QoL. The interaction variable did not account for any variance in the perceived emotional, informational or composite (emotional, informational, and instrumental) support models. However, in the instrumental support model, the interaction variable reported significance. The confidence levels crossed zero which is in violation of accepted parameters; therefore, there is no significant interaction effect. The hypothesis that perceived support moderates the relationship between financial toxicity and QoL was not supported in this sample. (See Appendix Q Tables Q.2 -Q.5 for non-significant moderator analysis results.)

Hypothesis 1.3: *Received social support will moderate the relationship between financial burden and QoL (FACT-G Plus).*

To test this hypothesis a simple moderation analysis in PROCESS (using simultaneous multiple regression). The total model accounted for a significant amount of the variance in FACT-G Plus, F (3, 122) = 42.11, $p = .001$, $R^2 = .53$. Although, the interaction variable did not significantly account for the variance in FACT-G Plus. Received social support did not moderate the relationship. See Appendix Q Table Q.6 for non-significant moderator analysis results for hypothesis 1.3.

Analysis by cancer type. Due to the difference in received support by cancer type, these same variables were then run by each type of cancer. For participants with blood cancer, received support did not moderate the relationship between financial toxicity and quality of life. On the other hand, received support did moderate the relationship for participants with breast cancer.

Breast cancer dataset. To test the hypothesis that received social support will moderate the relationship between financial toxicity and QoL (FACT-G Plus) a simple moderation analysis in PROCESS (simultaneous multiple regression analysis) was conducted. The total model accounted for a significant amount of the variance in QoL, $R^2 = .52$, $F\ (3, 102) = 26.84$, $p = .001$. Scales were centered prior to the creation of the interaction term to avoid multicollinearity. Next, the interaction term was added to the model and accounted for a significant proportion of variance in quality of life, $\Delta R^2 = .03$, $F\ (1, 102) = 7.09$, $p = .009$. Financial toxicity decreased as received social supports and quality of life increased. This moderation model explains 52% of the variance in QoL with 3% of that amount explained by the interaction (toxicity*support). Bootstrap technique at 1000 samples provided confidence intervals (CL). (Table 7.16 and Figure 7.5 display analysis results.)

Table 7. 16 Predictors of Quality of Life (FACT-G Plus).

Variable	*b*	SE	95% CL	*F* (df)	R^2	ΔR^2
Predictor Variables				26.85** (2, 102)	.52	
Constant	111.06**	2.09	[106.02, 115.20]			
Financial Toxicity (centered)	-2.67**	0.31	[-3.29, -2.04]			
Received Support (centered)	0.46**	0.14	[0.18, 0.73]			
Interaction				7.09* (1, 102)		.03
Financial Toxicity x Received Support	0.06*	0.02	[.01, 0.10]			

*$p < .01$, **$p < .001$, CL= confidence intervals at 95%. FACT-G Plus = Functional Assessment of Cancer Therapy scale plus Socio-economic Well-being scale.

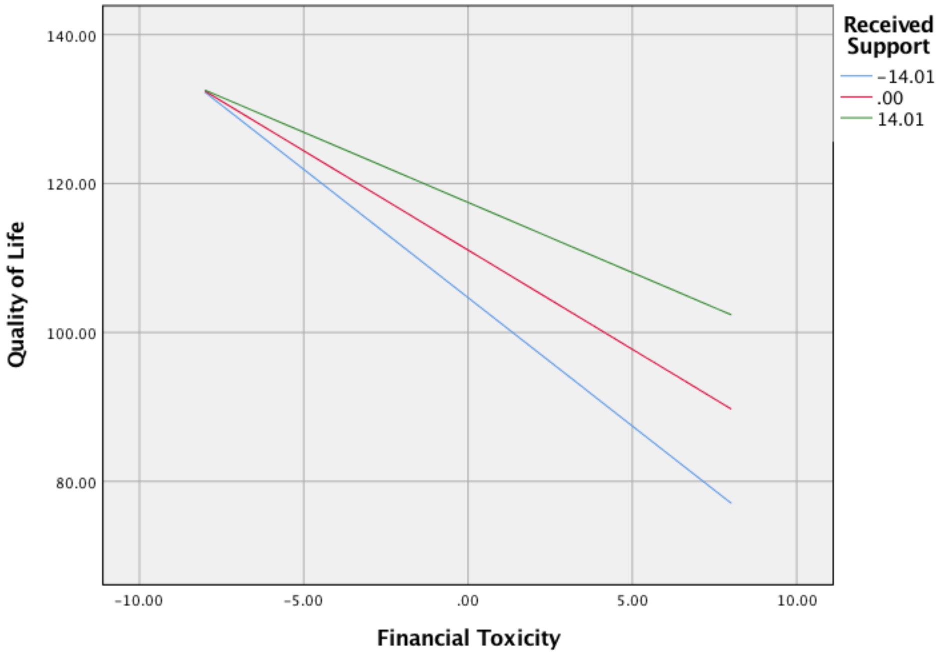

Figure 7. 5 Moderates of Financial Toxicity and QoL (FACT-G Plus).

In this model received social support was significant at low, medium and high levels of social support. (See Table 7.17.) Then the Johnson- Neyman technique was conducted to further probe the analysis using the parameters of one standard deviation above and below the mean of received support. When social support scores are equal to or below 73.09 units on the received support scale, financial toxicity and QoL are significantly related *t* (102) = -1.98, *p* = .05, *b* = -1.07. As financial toxicity increases and received social support decreases, QoL also decreases.

Table 7. 17 Conditional Effects of Financial Toxicity at Levels of the Moderator.

Received Support	*b*	SE	*t*	*p*	LLCI - ULCI
Low	-3.44	0.52	-6.69	0.001	[-4.46, -2.43]
Average	-2.66	0.31	-8.48	0.001	[-3.29, -2.04]
High	-1.88	0.32	-5.83	0.001	[-2.52, -1.24]

CL= confidence intervals at 95%. FACT-G Plus = Functional Assessment of Cancer Therapy scale plus Socio-economic Well-being scale.

Moderation analysis with control variables. A second analysis was conducted to test for moderation analysis controlling for the effects of cancer treatment, education, employment, insurance status, and marital status. A simple moderation analysis in PROCESS (using simultaneous multiple regression analysis) was conducted to determine if received social supports moderated the relationship between financial toxicity and QoL. The total model accounted for a significant amount of the variance in QoL, R^2 = .63, *F* (8, 96) = 25.04, *p* = .001. All continuous predictor variables were centered prior to analysis to avoid multicollinearity. In the analysis, the interaction term accounted for a significant amount of the variance in QoL even in the presence of the addition of the control variables, ΔR^2 = .04, *F* (1, 96) = 12.38, *p* = .0007. Received social support continues to moderate the relationship between financial toxicity and QoL. This moderation model accounts for 61% of the variance in QoL with the interaction variable (toxicity*support) accounting for 4% of the variance. (Table 7.18 and Figure 7.6 provide details of this analysis.)

Table 7. 18 Predictors of Quality of Life (FACT-G Plus) with Control Variables.

Variable	*b*	SE	95% CL	*F* (df)	R^2	Δ R^2
Predictor Variables				25.04*** (8, 96)	.63	
Constant	63.9***	12.66	[38.77, 89.03]			
Financial Toxicity (centered)	-2.4***	0.29	[-2.96, -1.83]			
Received Support (centered)	0.27*	0.12	[0.04, 0.51]			
Interaction				12.38** (1, 96)		.007
Financial Toxicity x Received Support	0.07**	0.02	[.03, 0.10]			
Control Variables						
Education	13.02**	4.16	[4.77, 21.28]			
Employment	5.41	5.24	[-4.99, 15.80]			
Insurance	30.57*	13.4	[3.96, 57.18]			
Marital Status	8.93*	41.2	[.74, 17.12]			
Treatment	3.00	4.32	[-5.58, 11.57]			

*$p < .05$, **$p < .01$, ***$p < .001$, CL= confidence intervals at 95%. FACT-G Plus = Functional Assessment of Cancer Therapy scale plus Socio-economic Well-being scale.

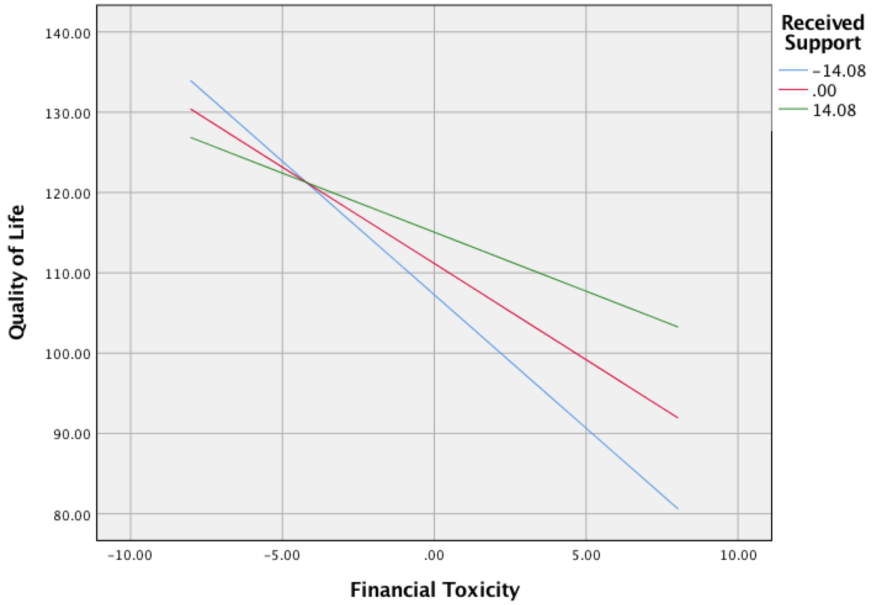

Figure 7. 6 Moderates of Financial Toxicity and QoL (FACT-G Plus) with Control Variables.

Received social support was significant at low, medium and high levels of social support. (See Table 7.19.) In order to probe the analysis for an understanding of what was going on in the analysis, the Johnson- Neyman technique was conducted (using parameters of one standard deviation above and below the mean of received support). For social support scores that are equal to or below 68.78 units on the received support scale, financial toxicity and QoL are significantly related *t* (96) = -1.99, *p* = .05, *b* = -.80. As financial toxicity increases and received social support decreases; QoL also decreases.

Table 7. 19Conditional Effects of Financial Toxicity at Levels of the Moderator with Control Variables.

Received Support	*b*	SE	*t*	*p*	LLCI - ULCI
Low	-3.32	0.52	-7.04	0.001	[-4.26, -2.39]
Average	-2.40	0.31	-8.41	0.001	[-2.96, -1.83]
High	-1.47	0.32	-5.26	0.001	[-2.03, -.92]

CL= confidence intervals at 95%. FACT-G Plus = Functional Assessment of Cancer Therapy scale plus Socio-economic Well-being scale.

Three-way moderation analysis. In the final step, social constraint was added using a three-way moderation or moderated moderation model (Hayes, 2018). A moderated moderation analysis in PROCESS (simultaneous multiple regression analysis) was conducted to determine if received social support impacted the relationship between financial toxicity and QoL taking into consideration social constraints. This model accounted for a significant amount of variance in QoL, R^2 = .80, *F* (7, 98) = 26.88, *p* = .001. The interaction term between received social supports, financial toxicity, and social constraint was significant, ΔR^2 = .02, *F* (1, 98) = 4.82, *p* = .03). This suggests that the three-way interaction between social supports, financial toxicity, and social constraint significantly explains 2% of the variance. (See Table 7.20 and Figure 7.7 for outcomes of analysis.)

Table 7. 20 Three-way Moderation of Quality of Life (FACT-G).

Variable	*b*	SE	95% CL	*F* (df)	R^2	ΔR^2
Predictor Variables				26.89*** (7. 98)	.80	
Constant	109.20***	2.28	[104.68, 113.71]			
Financial Toxicity (centered)	-1.94***	0.32	[-2.58, -1.31]			
Received Support (centered)	0.52***	0.14	[0.24, 0.81]			
Social Constraint	-0.72***	0.16	[-1.04, -.41]			
Interaction				4.82* (1, 98)		.02
Financial Toxicity x Received Support x Social Constraint	-0.003*	0.00	[-0.006, -0.003]			

**p* < .05, ***p* < .01, ****p* < .001, CL= confidence intervals at 95%. FACT-G = Functional Assessment of Cancer Therapy scale.

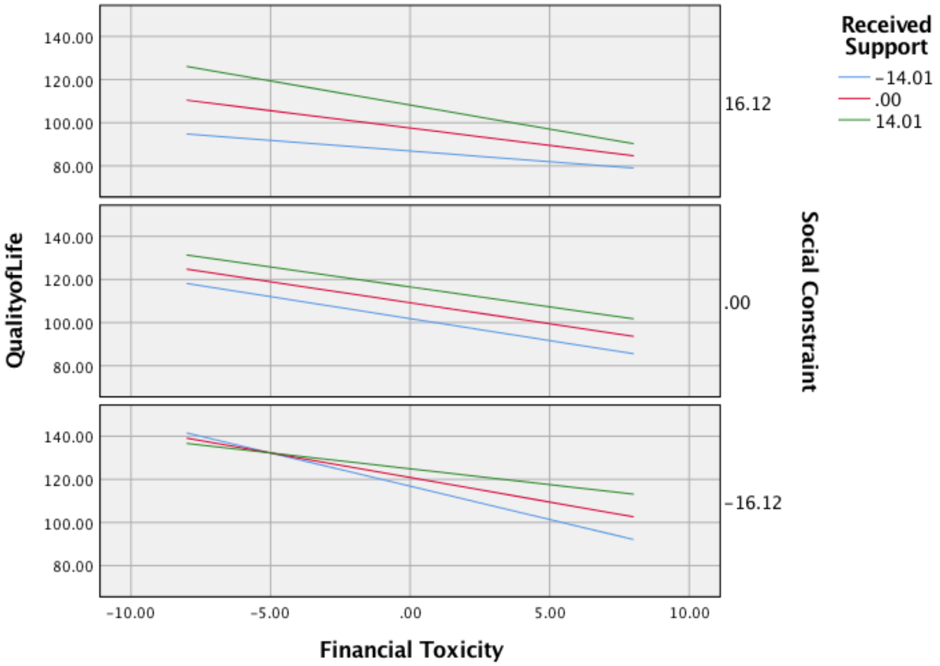

Figure 7. 7 Three-way Moderation of QoL (FACT-G Plus).

The conditional effects of financial toxicity decrease as received supports increase; however, the effects with social constraint vary (see Table 7.21 for details). The Johnson-Neyman technique was used to further probe the conditional toxicity*support interaction according to the values of social constraint. When social constraint scores are low (equal to or below 12.01) financial toxicity and received social support are significantly related, low *t* (98) = 1.98, *p* = .05, *b* = .04 and high *t* (99) = -1.95, *p* = .05, *b* = -.065. As financial toxicity increases and received social support decreases, social constraint increases.

Table 7. 21 Three-way Moderation Conditional Effects of Financial Toxicity.

Received Support	Social Constraint	b	SE	t	p	LLCI - ULCI
Low	Low	-3.09	0.52	-5.98	0.001	[-4.11, -2.06]
Low	Average	-2.04	0.55	-3.71	0.001	[-3.13, -.95]
Low	High	-0.99	0.89	-1.12	0.27	[-2.75, 0.77]
Average	Low	-2.28	0.32	-7.08	0.001	[-2.92, -1.64]
Average	Average	-1.94	0.32	-6.06	0.001	[-2.58, -1.31]
Average	High	-1.61	0.49	-3.28	0.001	[-2.58, -0.64]
High	Low	-1.85	0.44	-4.20	0.001	[-2.08, -0.85]
High	Average	-2.23	0.74	-3.01	0.003	[-2,73, -0.98]
High	High	-2.23	0.74	-3.01	0.003	[-3.70, -0.76]

CL= confidence intervals at 95%. FACT-G Plus = Functional Assessment of Cancer Therapy scale with Socio-economic Well-being Scale.

Hypothesis 1.4: *Perceived social support will moderate the relationship between financial burden and QoL (FACT-G Plus).*

Hierarchical multiple regression analyses were conducted using PROCESS macro for SPSS to determine if perceived social support moderates the relationship between financial toxicity and FACT-G Plus. Variables were added to the model in a stepwise approach. Individual analyses were conducted with each variable of perceived social support (emotional, informational, instrumental, and composite perceived support – emotional, informational and instrumental combined). A significant amount of the variance in FACT-G Plus was accounted for by perceived social support (each variation) and financial toxicity directly; however, the interaction variable for perceived emotional, informational and composite social support models did not account for any variance in FACT-G Plus. See Appendix Tables Q.7 – Q. 9 for reported moderator analysis for each variable of perceived social support and financial toxicity. The instrumental support model showed a significant interaction effect, but the confidence intervals contained zero

(CL-0.101, 0.003). This indicates non-significant interaction effect can be assumed. Perceived social support did not moderate the relationship between financial toxicity and FACT-G Plus. (See Appendix Tables Q.10 for perceived instrumental support and financial toxicity interaction results.)

Specific Aim 2

Aim 2 sought to determine if received and perceived social support mediates the relationship between financial toxicity and QoL. As previously stated, QoL is assessed using two versions of the FACT-G scale: 1) the FACT-G and 2) FACT-G Plus (with socio-economic well-being). Perceived social support was analyzed using the composite (emotion, informational, and instrumental) variable. In order to test for a mediator variable, a simple mediation model using ordinary least squares (OLS) regression-based path analysis was conducted using the PROCESS tool in SPSS. This model uses the statistical equation for a simple mediation model (Hayes, 2017):

$$M = i_M + aX + e_M \tag{2}$$

$$Y = i_Y + c'X + b_M + e_Y$$

The mediations models informing these analyses can be viewed in Figure 7.8.

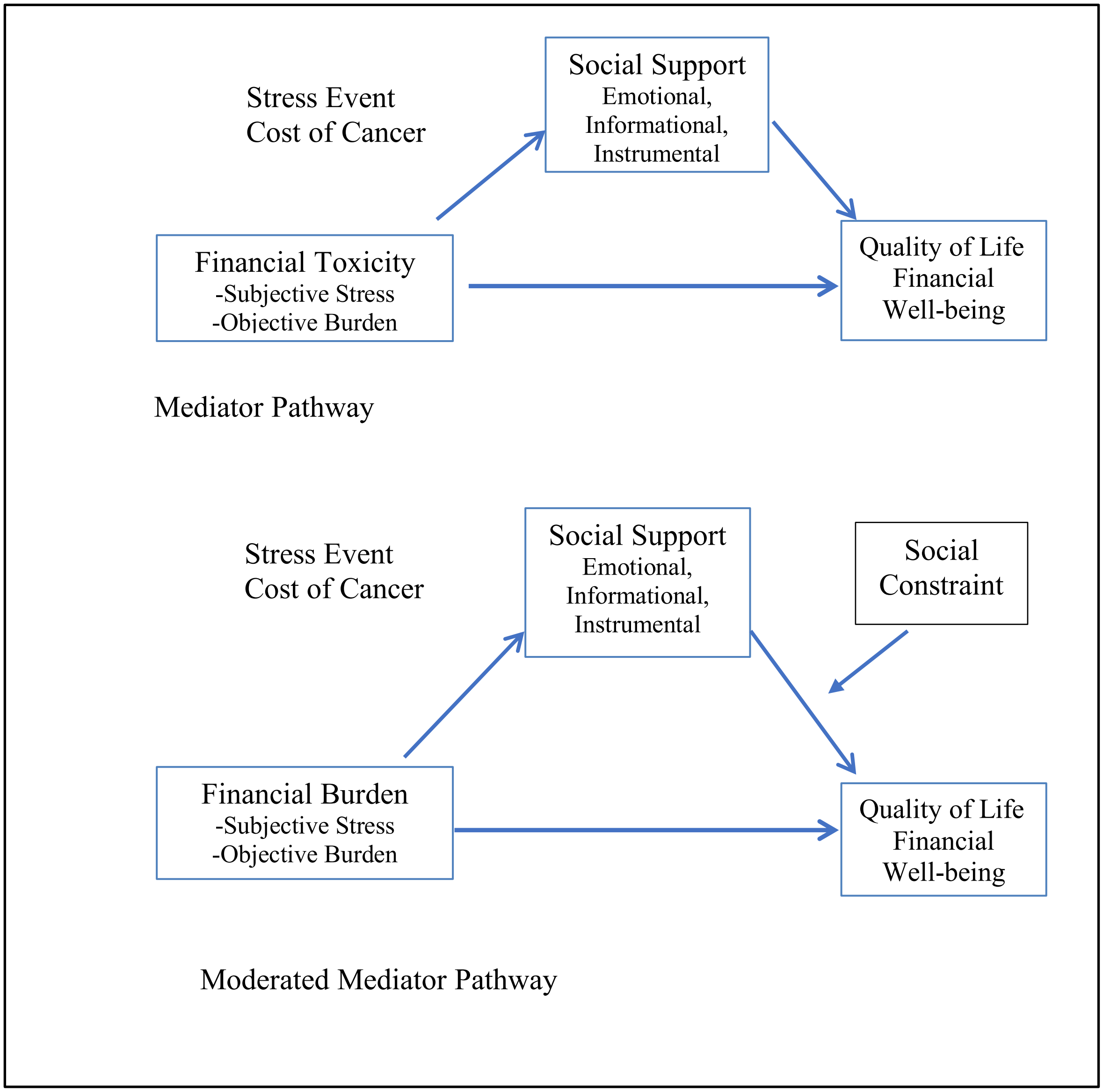

Figure 7. 8 Social Support in Mediation Pathways

Hypothesis 2.1: *Received social support mediates between financial toxicity and QoL (FACT-G).*

The data did not meet assumptions for mediation analyses. Received social support was not correlated with the FACT-G, COST, or social constraint (see Table 7.8

for correlation values.) The mediation analyses were not conducted. The hypothesis was not supported.

Hypothesis 2.2: *Perceived social support mediates between financial toxicity and QoL (FACT-G).*

To test whether perceived social support mediates between financial toxicity and QoL (FACT-G) the PROCESS macro for SPSS was used. The PROCESS macro is a path analysis-based tool using ordinary least squares linear regression analyses to determine a mediator effect. Financial toxicity significantly predicted FACT-G when the mediator variable is not in the model, $b = -1.342$, $t\,(124) = -31.20$, $F\,(1, 124) = 72.29$, $p = .001$, $R^2 = .35$. The R^2 value indicated that 35% of the variance in FACT-G can be explained by financial toxicity. Beta (b) value is negative which means that the higher financial toxicity the lower FACT-G. Next, financial toxicity significantly predicted perceived social support, $b = -0.44$, $t\,(124) = -5.85$, $F\,(1, 124) = 34.16$, $p = .001$, $R^2 = .21$ (see Figure 7.8 for Path *a*). As financial burden increases perceived social support decreases. The R^2 value for Path *a* indicates that financial burden explains 21% of the variance in the composite perceived social support variable. Then the outcome of FACT-G was predicted by financial toxicity and perceived social support. Perceived social support significantly predicts QoL in the model, $b = 0.90$, $t\,(124) = 3.5$, $p = .001$ (Path *b*); financial burden also significantly predicts QoL, $b = -0.95$, $t\,(124) = -5.69$, $p = .001$ (Path *c*). The total effect model is significant, $F\,(2, 123) = 48.33$, $p = .001$, $R^2 = .46$ (Path *c'*). The R^2 value indicates the model accounts for 46% of the variance in FACT-G. The final step indicates there is a significant indirect effect of financial toxicity on FACT-G through perceived social support, $b = -0.39$. The true b-value for the indirect effect falls between the confidence intervals [-0.64, -0.20] which does not cross zero indicating likelihood of significance indirect effect at a 95% confidence interval. (See Table 7.22 for correlations among variables and Figure 7.9 for model with analysis results).

Table 7. 22 Correlations Among Mediation Variables.

Variables	1	2	3
1. Financial Toxicity	1	-0.5*	-0.55*
2. Perceived Support		1	0.6*
3. Quality of Life (FACT-G)			1

*p < .01

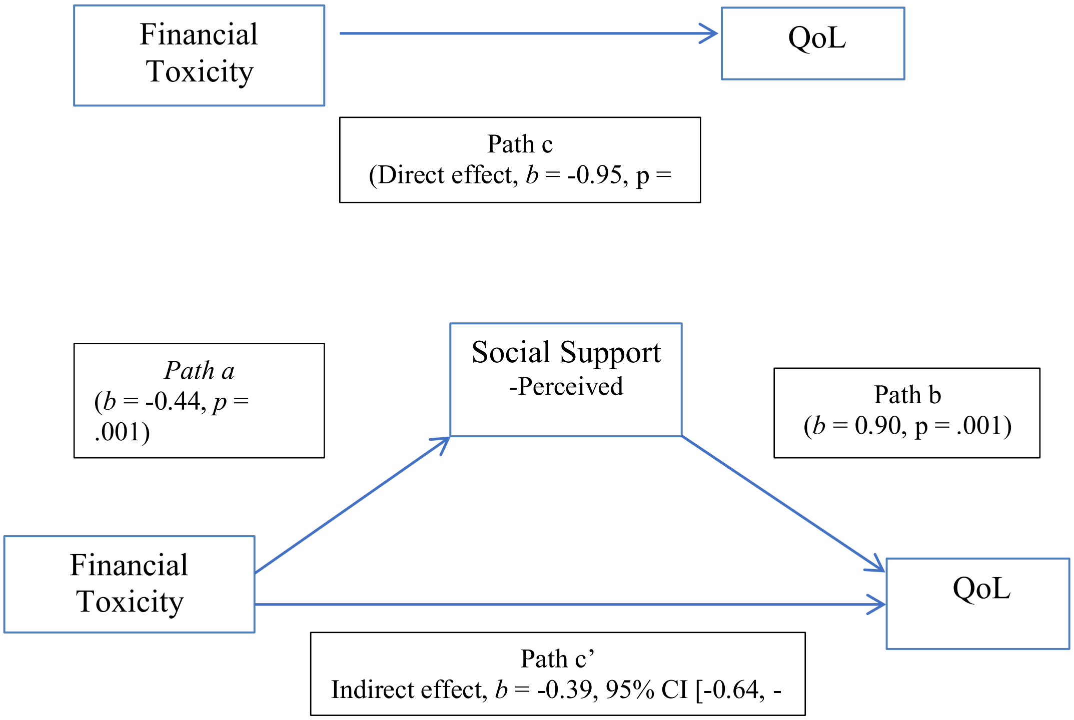

Figure 7. 9 Perceived Social Support Mediates Financial Burden as a Predictor of Quality of Life (QoL).

Further analysis was conducted to determine if perceived social support mediates between financial burden and QoL controlling for cancer treatment, education, employment, and marital status. (Insurance status was removed due to creating an error in the analysis.) There was a significant indirect effect of financial burden on QoL through perceived social support, *b* = -0.54 CI [-0.81, -0.31]. This model indicates a likely indirect effect of financial burden through perceived social support at a 95% confidence interval. (See Table 7.23 for summary of analysis results.)

Table 7. 23 Summarized Mediation Regression Analysis for Financial Toxicity, Perceived Social Support and Quality of Life.

Path	Variable	*b*	*t*	R^2	*F*	df	*p*	LLCL, ULCL
	Control Variables							
	Education	5.73	2.82				.04*	[0.14, 11.32]
	Employment	7.29	4.55				.11	[-1.72, 16.31]
	Marital Status	5.53	3.01				.068	[-0.43, 11.50]
	Treatment	6.35	1.71				.89	[-0.99, 13.69]
Path a	COST -> Support	-0.41	-4.80	.27	11.23	5, 120	.01**	[-0.57, -0.24]
Path b				.52	21.87	6, 119	.001**	
	Support -> QoL	0.92	0.17				.001*	[0.58, 1.26]
	COST -> QoL	-0.76	-4.35				.001*	[-1.11, -0.41]
Path c	COST -> QoL	-1.13	-7.06	.41	17.58	5. 120	.001*	[-1.45, -0.82]
Total Model	Direct Effect	-0.76	-4.33				.001*	[-1.26, -0.42]
	Indirect Effect	-0.54						[-0.81, -0.31]

*$p < 0.05$ *COST* Comprehensive Score for Financial Toxicity, *QOL* Quality of Life FACT-G Scale. Bootstrap sample size = 5000

Social constraint may have an impact on social support and quality of life. A final analysis was conducted to determine if social constraint impacted the relationship between financial toxicity, social support and quality of life. To determine if social constraint had an effect on the mediation model, a moderated mediator analysis (Hayes, 2018) was conducted (see Figure 7.8 b). In this model, social constraint is thought to moderate between social support and quality of life. Social constraint did not moderate the mediation [b = -0.01, CI [-.03, .01]; therefore, did not have an effect on the relationship between financial toxicity, social support and quality of life. (See Table 7.24 for analysis findings.) The hypothesis stating that perceived support mediates the relationship of financial toxicity and QoL was supported by these analyses and findings.

Table 7. 24 Perceived Support Mediation on Financial Toxicity and Quality of Life without Moderation of Social Constraint.

Path	Variable	*b*	SE	*t*	CL	*R2*	*F*	df
Path a						0.21	34.16*	1, 124
a	Financial Toxicity	-0.44*	0.08	-5.85	[-0.59, -0.29]			
	Constant	8.38*	1.38	6.06	[5.64, 11.12]			
Path b & c'						0.54	39.18*	4, 121
b	Perceived Support	0.62*	0.161	3.84	[0.30, .94]			
c'	Financial Toxicity	-0.61*	0.17	-3.6	[-.95, -0.28]			
z	Social Constraint	-0.46*	0.09	-4.88	[-.64, -.27]			
	Interaction 1	-0.01	0.01	-1.14	[-.03, .01]	0.01	1.3	1, 121
	Constant	77.92*	3.56	21.87	[70.87, 84.97]			
Path c						0.41	17.58	5. 120
c	Financial Toxicity	-0.61*	0.17	-3.6	[-9.5, -0.28]			

*p < 0.001 QOL Quality of Life FACT-G Scale. Interaction 1 = Perceived Support *Social Constraint does not Moderate the Relationship.

Hypothesis 2.3: *Received social support mediates between financial toxicity and QoL with socio-economic well-being (FACT-G Plus).*

The data did not meet the assumptions for mediator analyses. Received social support was not correlated with financial toxicity or social constraint. The mediation analysis was not conducted. Hypothesis 2.3 was not supported.

Hypothesis 2.4: *Perceived social support mediates between financial toxicity and QoL (FACT-G Plus).*

Financial toxicity significantly predicted FACT-G Plus when the mediator variable was not in the model, $b = -2.49$, $t\,(124) = -10.47$, $F\,(1, 124) = 109.64$, $p = .001$, $R^2 = .49$. The R^2 value indicated that 49% of the variance in FACT-G Plus can be explained by financial toxicity. The relationship is negative so as financial toxicity increases, quality of life decreases. Next, financial toxicity significantly predicted perceived social support, $b = -0.43$, $t\,(124) = -5.85$, $F\,(1, 124) = 34.16$, $p = .001$, $R^2 = .21$ (path a); as financial toxicity increased, perceived social support decreased. Financial toxicity accounted for 21% of the variance in social support. Then FACT-G Plus was predicted by financial toxicity and perceived social support. This was a significant effect, $F\,(2, 123) = 78.73$, $p = .001$, $R^2 = .59$. Social support significantly predicted FACT-G Plus, $b = 1.36$, $t\,(123) = 5.47$, $p = .001$ (path b); financial toxicity also significantly predicted FACT-G Plus, $b = -1.90$, $t\,(123) = -7.70$, $p = .001$ (path c). This model accounts for 59% of the variance in FACT-G Plus. Lastly, there is a significant indirect effect of financial toxicity on FACT-G Plus through perceived social support, $b = -0.60$, CL [-0.98, -0.32] (path c’). The confidence intervals do not cross zero indicating a likely significance indirect effect at a 95% confidence interval. (See Figure 7.10 for model depiction.)

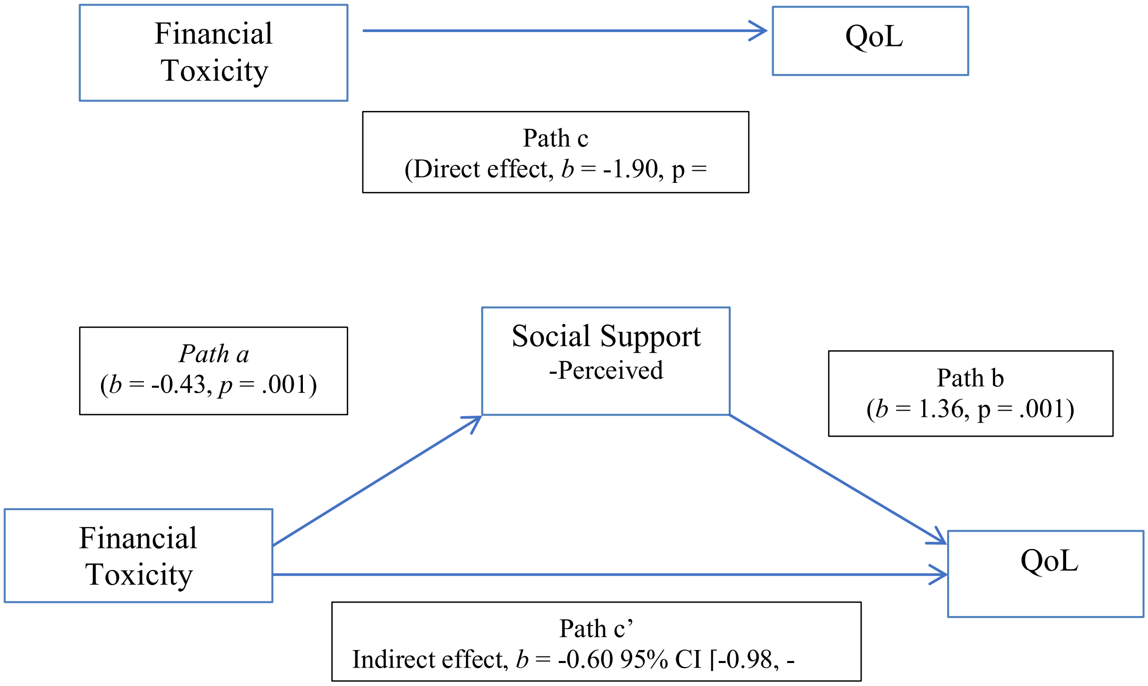

Figure 7. 10 Mediation of financial toxicity when quality of life (QoL) is assessed by Functional Assessment of Cancer Therapy plus Socioeconomic Wellbeing.

Similar to Hypothesis 2.2, further analysis was conducted controlling for cancer treatment, education, employment, and marital status. As stated before, insurance status was removed due to creating an error in the analysis. Similar to the first analysis, this model continued to show a likelihood of a significant indirect effect of financial toxicity on FACT-G Plus through perceived social support. See Table 7.25 for a summary of analysis results.

Table 7. 25 Mediation by Perceived Social Support with Control Variables.

Path	Variable	*b*	*t*	R^2	*F*	df	*p*	LLCL, ULCL
	Control Variables							
	Education	14.28	4.23				.001*	[0.7.69, 20.97]
	Employment	10.13	1.71				.09	[-1.61, 21.88]
	Marital Status	3.02	0.85				.39	[-4.05, 10.10]
	Treatment	3.88	3.7				.29	[-3.44, 11.21]
Path a	COST -> Support	-0.41	-4.80	.27	11.23	5, 120	.001*	[-0.57, -0.24]
Path b				.65	42.14	6, 119	.001*	
	Support -> QoL	1.41	6.06				.001*	[0.95, 1.87]
	COST -> QoL	-1.61	-6.5				.001*	[-2.10, -1.12]
Path c	COST -> QoL	-2.19	-9.34	.54	30.96	5, 120	.001*	[-2.65, -1.72]
Total Model	Direct Effect	-1.61	-6.5				.001*	[-2.10, -1.12]
	Indirect Effect	-0.57						[-0.94, -0.30]

*p < 0.001 COST Comprehensive Score for Financial Toxicity, QOL= Quality of Life assessed by Functional Assessment of Cancer Therapy plus Socio-Economic Well-being Scale (FACT-G Plus). Bootstrap sample size = 1000.

A third analysis was conducted to see if social constraint impacted the relationship between financial toxicity, social support and quality of life. Social constraint was added to the mediator model as a moderator on the relationship between perceived social support and quality of life. As shown in Table 7.26 social constraint did not moderate the mediation [*b* = .03, CI [-.03, .02]. Hypothesis 2.4 is supported, and perceived support mediates the relationship with financial toxicity and QoL.

Table 7. 26 Mediation without Moderation of Social Constraint

Path	Variable	*b*	SE	*t*	CL	*R2*	*F*	df
Path a						0.21	34.16*	1, 124
a	Financial Toxicity	-0.44*	0.08	-5.85	[-0.59, -0.29]			
	Constant	8.38*	1.38	6.06	[5.64, 11.12]			
Path b & c'						0.64	54.25*	4, 121
b	Perceived Support	0.97*	0.223	4.33	[0.52, 1.41]			
c'	Financial Toxicity	-1.52*	0.23	-6.50	[-1.99, -1.06]			
z	Social Constraint	-0.54*	0.13	-4.05	[-.81, -.28]			
	Interaction 1	-0.00	0.02	-.16	[-.03, .02]	0.00	.03	1, 121
	Constant	140.39*	4.87	28.85	[130.76, 150.02]			
Path c								
c	Financial Toxicity	-1.52*	0.23	-6.50	[-1.99, -1.06]			

*p < 0.001 QOL Quality of Life = Functional Assessment of Cancer Therapy plus Socioeconomic Wellbeing (FACT-G Plus) scale. Interaction 1 = Perceived Support *Social Constraint does not Moderate the Relationship between support and quality of life.

Summary of analyses. Several analyses were conducted to determine if social support moderated or mediate the relationship between financial toxicity and quality of life. Received support moderated and perceived support mediated the relationship between financial toxicity and quality of life. See Table 7.27 for the summary of analyses.

Table 7. 27 Analyses Outcome by Hypothesis.

	Hypothesis	Analysis Outcome
1.1	Received social support will moderate the relationship between financial toxicity and QoL.	Supported
1.2	Perceived social support will moderate the relationship between financial toxicity and QoL.	Not Supported
1.3	Received social support will moderate the relationship between financial toxicity and QoL including Plus SEW.	Supported
1.4	Perceived social support will moderate the relationship between financial toxicity and QoL Plus SEW.	Not Supported
2.1	Received social support mediates between financial toxicity and QoL.	Not Supported
2.2	Perceived social support mediates between financial toxicity and QoL.	Supported
2.3	Received social support mediates between financial toxicity and QoL Plus SEW	Not Supported
2.4	Perceived social support mediates between financial toxicity and QoL Plus SEW.	Supported

Summary

The purpose for the present study was to examine the experience of financial toxicity (objective burden and subjective distress) with blood cancer and breast cancer survivors. Specifically, I sought to examine the relations among financial toxicity, social support and quality of life. Social support was conceptualized as perceived (emotional, informational, and instrumental) social support and received (informational and instrumental) social support. Previous research has demonstrated that social supports can have a positive impact on the cancer experience (see Chapter 2 literature review). The current study extends this research by examining the role (moderator and mediator) of social supports in the context of financial toxicity. These analyses indicate that both received and perceived social supports play a significant role in the relationship between financial toxicity and quality of life. However, these roles were very different.

Received social support for the total sample (blood and breast cancers) only had a direct correlation with quality of life (FACT-G and FACT-G Plus). It did not have a moderator or mediator effect on the relationship between financial toxicity and quality of life. However, when the analyses were conducted on just the breast cancer respondents, received social support moderated the relationship between financial toxicity and quality of life.

In contrast, perceived social support was significantly related to quality of life and financial toxicity in the expected directions, and functioned as a mediator of the relationship between financial toxicity and quality of life. Indirectly, financial toxicity still had a negative effect through perceived social support; however, as expected, this effect was must smaller. These results show that having a perception of available support may ease the negative impact of financial toxicity.

This chapter presented the results for study 2 which examined social support as either a moderator or mediator variable. The next chapter, 8, includes a final discussion and concluding thoughts on the findings from this multiple method design project as well as present implications for practice and future ideas for research.

CHAPTER 8: DISCUSSION & CONCLUSIONS

"It hit me like a train and I'm barely recovering. I lost insurance coverage several months ago right when new lymph nodes became suspicious. They have since grown and become so painful. The same side the previous cancer was. I know I need to get help and get checked out, but the very thought of this financial burden has left me in a solitary confinement of madness in my head and just being okay with letting cancer get me (if it is) than put my family through the financial burden again. Absolute hopelessness."
-Study 2 #37 (32-year-old female, Breast Cancer)

"I was forced out of my job, after many years with good reviews, during my cancer treatment. I had no income for almost a year. Used savings up, maxed out credit cards, took loan against life insurance, withdrew money from retirement savings. Was DESPERATE and destitute. All recommended sources of help turned me down. Filed for disability retirement – finally approved. Have not recovered financially, socially, emotionally. Many "friends" dropped me after the cancer diagnosis…Need help with housework but don't know how to get this help with limited money. Still drive 1990 Toyota car, hope it holds up. Refinanced mortgage to lower interest rate. That helped. If my cancer recurs, based on my initial experience: I would likely not seek treatment; can't afford it."
- Study 2 #41 (62-year-old female, Breast Cancer)

There are no easy fixes to addressing cancer-related financial toxicity (objective burden and subjective distress), and to date there are no evidence-based practices to help patients resolve this problem. As is evident, financial toxicity is a complex issue that can leave patients financially and emotionally devastated. The purpose of this project was to gain a different perspective on cancer-related financial toxicity than what is already identified in the current literature. Specifically, I examined the role of social support within this context, determining if social support is associated with the relationships between financial toxicity and quality of life (QoL) as well as determining what types of supports were available, used or needed.

Using a multiple methods approach, two studies were conducted to answer the overarching question: *What role does social support play in the experience of cancer-related financial toxicity?* The first study used qualitative data (see Chapter 4 methods and Chapter 5 results), and the second study used quantitative data (see Chapter 6 methods and Chapter 7 results). This final chapter presents a discussion of this project bringing together the results from both studies. It discusses at length the implications for practice and further research ideas to improve patient-centered care.

Discussion

Study 1. Differing from much of the literature on financial toxicity, this study takes a unique view of this complex issue. Using qualitative methods, Study 1 answered the question: *For individuals who have had cancer, what is their experience with social support in the context of cancer-related financial toxicity?* Social support theories were used as a sensitizing lens to explore the supportive resources available and used by 26 cancer survivors who self-reported experiencing financial hardship due to their cancer. The broad categories that were identified from this analysis were the following: Helpful Support, Non-helpful Support, and Gaps in Support. First, this process allowed for the distinction of received and perceived supports to be witnessed in the data and brought to light that the data lacked the presence of perceived supports. More noticeably, it validated the presence of received social support (emotional, informational, and instrumental). In turn it gave insight into areas where support is needed (i.e., missing supports or barriers to accessing it).

It is clear that aspects of social support theories can be supported by the Helpful Support and Non-helpful Support categories. In support of Cohen and Wills (1985), participants spoke about receiving helpful supports such as emotional, informational, and instrumental support. Received emotional and informational support had a weaker presence in this data, and perceived support only had one excerpt; however, instrumental support was discussed by all of the participants. This is understandable as the overall topic was financial hardship, thus the logical solution is monetarily related. Participants reported receiving supports such as food, money, childcare, and transportation assistance from family and friends. Some received grants, medication and medical bill assistance from more formal social networks (medical professionals and organizations). Instrumental supports also included services such as advocacy efforts, managing finances, and resolving issues with complex healthcare systems. In spite of the participants' comments on receiving some form of instrumental support, the support received was not enough to offset their perception of financial burden.

It is well supported in the literature that emotional and informational supports also play important roles (Cohen & Syme, 1985; and Sarason et al., 1990 and Cohen, 2013). Emotional support is suggested to have the greatest effect on individuals who are experiencing stressful events. This is likely due to help-seeking behaviors which can lead to corresponding supportive responses from others (Cohen & Wills, 1985). Although emotional support was depicted in these interviews, not all interviewees spoke about receiving emotional support. Moreover, several stated they did not have anyone to talk to about their financial struggles. One interviewee went as far as saying she did not talk to others about her financial concerns because she was embarrassed. On a similar note, informational supports can act as a buffer (Cohen & Wills, 1985). Having information about what is expected can allow patients to prepare emotionally or find other ways to cope financially. Interviewees talked about receiving advice on finances, navigating complex systems, and receiving direction on when to seek assistance from government programs. Receiving information can allow patients to make educated decisions or emotionally prepare for an expected outcome of their medical decisions.

As a further support to this theory, the present study provides an example of social constraint in the experiences of cancer patents. Adding to the works of Lepore (2002), social constraint is observed in the context of cancer-related financial toxicity. Some participants shared experiences of receiving non-helpful supports (social constraints). Participants gave examples about behaviors from others that were likely meant to be helpful but were not interpreted as such or ended in outcomes that may have further jeopardized the support receiver's financial situation. As evidenced in the literature, stressful life events may elicit avoidant or minimizing behaviors from others (Veiel et al., 2013). This was true for some participants in this study. Here we saw instances where social network members said or did things that were interpreted by the participant as inappropriate, critical, or insensitive. Hypothetically, these aspects of social constraint could play a role in preventing patients from engaging in help-seeking behaviors.

As a result of using social support as a theoretical sensitizing lens and the iterative processes of the analysis, Gaps in Support became apparent. This category was formed by two subcategories: missing support and barriers to accessing support. Several interviewees commented on not receiving information that consequently could have directed them to take steps to overt financial catastrophes or emotionally prepare for the financial outcomes. Receiving timely information about resources through the medical system, pharmaceutical assistance, government assistance, or employer-based benefits, could potentially lead to alleviating some financial demands on patients. Unfortunately, this was not the only missing information, as most of the participants talked about lacking information on what the costs of their care would be. Some attempted to request this information but were told to not worry about it or to not talk about it. One participant was told by the hospital staff that she should know what her insurance deductible was and proceeded to not provide the participant with that information. Additionally, participants talked about receiving resources that were not helpful or did not meet their financial needs. In order for support to be interpreted as helpful, it must address a patient's need or request (Cutrona & Russell, 1990). Participants shared examples of being offered support that did not match their need for financial assistance. In these examples, participants were seeking information on financial assistance; instead, they were provided information about other services such as a free monthly massage or art therapy. "But at the end of the day it wasn't what was needed most" (#21, 36-year-old male, Lymphoma).

In addition, interviewees talked about diminishing help and missed opportunities for getting support. When patients are unable to maintain social relationships due to cutting back on entertainment, they may miss out on opportunities to connect with others and receive or request support. Having close relationship bonds may instill in others a strong desire to help and may also serve as a reminder that help is needed. These types of relationships take time to develop, however, and need to be nurtured. Creating further barriers to accessing support are feelings of embarrassment, pride and guilt - all issues that may get in the way of people reaching out to others and sharing their financial concerns. We live in a society with the ingrained idea that you should pick yourselves up by the bootstraps. Social messages falsely blame financial struggles on the person as a result of not working hard enough or not spending money wisely. On the contrary, financial struggles are a devastating consequence of the costs of cancer care. Not only are the costs of care astronomical, but patients also struggle to find helpful resources and acquire information.

In summary, we see the presence of social support in the context of financial toxicity. This in turn brings our awareness to the gaps in support that patients may experience. To an extent, these gaps may be targeted for solutions to addressing the financial devastation caused by cancer. Implications from this study will be discussed in culmination with the results from Study 2 at the end of this chapter.

Study 2. Deriving from the overarching question and aspects informed by Study 1, Study 2 sought to statistically verify the importance of social support in the context of financial toxicity due to the costs of cancer care. It attempted to answer the question: *How does social support influence cancer-related financial burden and patients' quality of life?* Specifically, Study 2 investigated the influence of social support on the relationship between financial toxicity and QoL. Conceptualizing social support through the use of theory, Study 2 investigated the moderating or mediating potential of received (informational and instrumental) and perceived (emotional, informational, and instrumental) support.

Received social support (informational and instrumental) acts as a moderator between financial burden and quality of life. Moderation implies that received social support changes the direction or magnitude of the relationship between financial burden and quality of life. Received social support acts as a buffer where increasing received social supports may decrease the effect of financial burden on quality of life. This result adds to the body of research demonstrating that received support acts as a moderator. In a study with gynecologic cancer survivors, received social support was found to moderate the relationship between physical functioning and traumatic stress (Carpenter et al., 2010). Another study conducted on the general population found that received social support buffered the relationship between financial stress and psychological well-being as well as between financial stress and psychosomatic symptoms (Aslund et al., 2014). Instrumental support was suggested to be greatest in the presence of higher financial stress and decreased the likelihood of experiencing low psychosomatic symptoms.

Consistent with buffering hypotheses, the interactions between financial toxicity and received instrumental support were significant. The interaction variable accounted for only a small amount of the variance in QoL. These findings suggest that received instrumental support does have a buffering effect on the relationship between financial toxicity and QoL.

To further examine the relationship, social constraint was added to the model. In essence, social constraint is negative support (i.e., when the support provided is interpreted by the support receiver as negative or not helpful). This study is unique in that it examines social constraint in a three-way moderation (moderated moderator) analysis. Interestingly, social constraint was observed to moderate the relationship of received social support and financial toxicity on their relationship with QoL. Prior research and theory suggest social constraint is associated with cancer-specific distress and psychological adjustment to stressful events (Adams, Winger, & Mosher, 2014). In terms of psychological outcomes, negative interactions are thought to be more salient than positive ones (Baumeister et al., 2001). Cancer patients may be more vulnerable to the effects of social constraint as they would generally be expecting to receive support and empathy from others.

In contrast, perceived social support did not interact as a moderator variable. Instead, perceived social support played the role of a mediator in the relationship between financial toxicity and QoL. This implies that the potential effect of financial toxicity on QoL can also be explained by way of perceived social support. In this interaction, financial toxicity may lead to the perception of social support which in turn changes or alters this association with QoL. While perceived social support mediates financial toxicity indirectly, it also has a direct association with QoL. As a person's awareness of perceived social support increases, the indirect influence of financial toxicity and QoL decreases. This study adds to the literature on perceived support as a mediator variable. Hodges et. al. (2012) showed that perceived social supports mediated the relationship of optimism and positive affect in cancer survivors. From a moderator perspective, Lewis et al. (2001) revealed that perceived social support moderated the impact of intrusive thoughts on QoL in long-term breast cancer survivors.

The results for Study 2 provide an interesting view of the influence of social support on the relationship between financial toxicity and QoL. They add to the literature supporting the importance of social support as a buffer to the long-term negative impact of cancer. Moreover, these findings are distinctive in that few studies on financial toxicity have examined variables that may influence (moderate or mediate) the impact financial toxicity can have on cancer patients and survivors. They provide insight into the complex variable of social support (received and perceived emotional, informational, and instrumental) and provide support to the idea that having access to support can play a valuable role in easing the financial hardship faced by many patients with cancer.

Bringing it all together. Taking a pragmatic approach to investigate this phenomenon, we are able to create an understanding of the reality faced by some cancer patients. Using an overall inductive approach, the results of these two studies are brought together to confirm the existence and significance of social support in the cancer-related financial experience. Research has shown that social support is important in the cancer experience. This research project broadens the existing literature further by exposing the importance of support in addressing the financial component of cancer.

In Study 2, received support moderates the relationship between financial toxicity and QoL. This is understandable since receiving supports such as those identified in Study 1 (food, monetary assistance, groceries, gas, childcare, advice, etc.) can provide some financial relief. Several participants in Study 1 commented on how helpful these supports were. No matter how small or large the support (emotional, informational, instrumental) was, it made a difference.

Further investigating this moderator model in Study 2, social constraint (non-helpful support) was observed to moderate the relationship between financial toxicity and received support. In this respect, as financial toxicity and social constraint increase, received support and quality of life decrease. Participants in Study 1 talked about receiving support that was not helpful or came at a cost, adding to their financial hardship. In contrast, individuals with low social constraint and high received support reported higher quality of life. These individuals were able to access the supports they needed without the constraint or non-supportive behavior of others. The presence of social constraint adds to the complexity of the situation and points to the importance of surrounding yourself with people who are supportive and understand that cancer has financial implications as well. This claim is supported by responses from participants in Study 1 who found the support and understanding they need through support groups such as Gilda's Club in Louisville, KY.

Equally important, in Study 2 perceived support mediated the relationship between financial toxicity and quality of life instead of moderating it. Perceiving something exists is a cognitive activity. The perception of support means to be conscious of its existence and to have the belief that it is realistically available if needed. In essence, this way of thinking is a means of coping with the financial experience. Believing the support exists could ease feelings of anxiousness or hopelessness. In spite of its statistical importance in Study 2, perceived support was only mentioned once in Study 1. One reason for this absence could be that participants did not believe they had someone who could help them with their financial hardship. Participants may have exhausted the resources they had access to and felt they could not ask for more help as was stated by one participant. With respect to this, it was unexpected that social constraint did not moderate the mediation model in Study 2. It may be that social constraint plays into the scenario in another capacity, which could be further explored.

If one revisits the theoretical models presented in Chapter 3, both Study 1 and Study 2 can provide further understanding. Figure 8.1 presents social support in a model adapted from the Stress-buffering Hypothesis (Cohn & Wills, 1985) and Transactional Model of Stress and Coping Theory (Lazarus & Folkman, 1984). In Figure 8.1 we see that social support is part of the appraisal process and coping responses. As stated in

Chapter 3, social support is thought to buffer the experienced burden during the appraisal process. An individual may not perceive the threat to be as much of a threat as it would be if social support was not present. Similarly, during the coping response, social support directly alters or eliminates the stress response (Cohn & Wills, 1985). Findings from Study 1 and Study 2 provided empirical support for the Stress-buffering Hypothesis in the appraisal and coping processes. As interpreted from the findings of Study 2, in perceived social support interacts as a mediator and received social support as a moderator (Figure 8.2). Both of these forms of support in turn influence the outcome (quality of life). Furthermore, social constraint (Unhelpful Supports) interacts with received social support (Helpful Support). Social Constraint regulates the buffering abilities of received support to impact the outcome. Although not presented in the model, the Gaps in Support (missing and barriers to support identified in Study 1) further detract from the coping response. When emotional, informational, and instrumental supports are unavailable or blocked due to barriers, social supports are unable to function to their capacity.

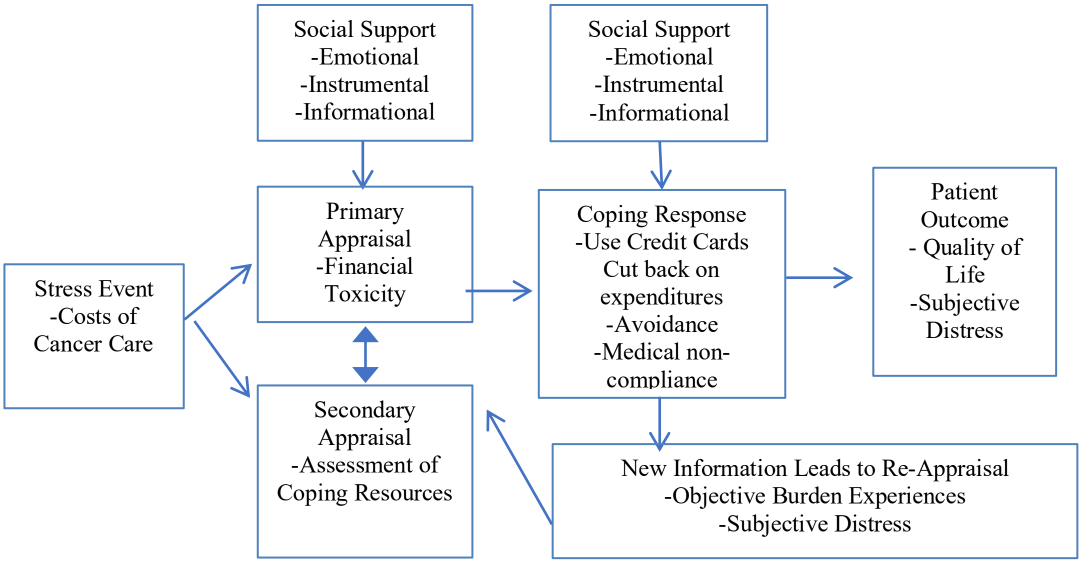

Figure 8. 1 Depiction of social support informed by the Stress and Copying Theory and the Stress-buffering Hypothesis (Cohn & Wills, 1985).

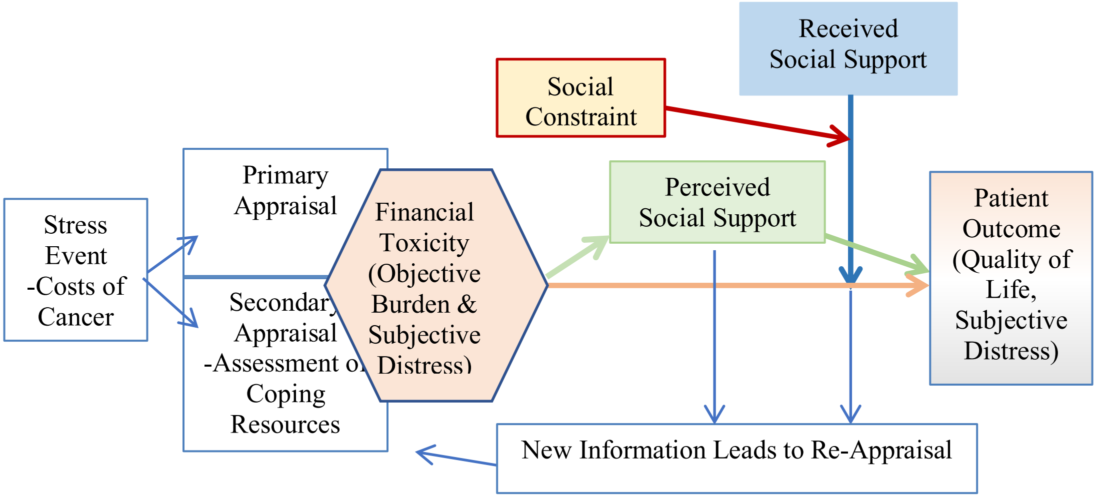

Figure 8. 2 Social support moderating and mediating the relationship between financial toxicity and quality of life.

Similarly, the Financial Toxicity Framework proposed by Carrera & Zafar (2018) allows an additional perspective in viewing the study findings. Received social support interacts along the pathway from financial toxicity to quality of life (see Figure 8.3). In considering the forms of support, we can conceivably say that received support impacts the objective burden experience. Receiving helpful information can lead to financial assistance or smarter ways to organize and pay medical bills as well as lead to food, monetary, or other tangible assistance. This, in turn, can relieve the objective financial burden, which subsequently impacts the subjective financial distress. Furthermore, perceived supports can influence the subjective distress component of financial toxicity. Having the perception that financial assistance is available and accessible if needed can alleviate the anxiety and fear of not being able to afford medical treatment or daily living expenses.

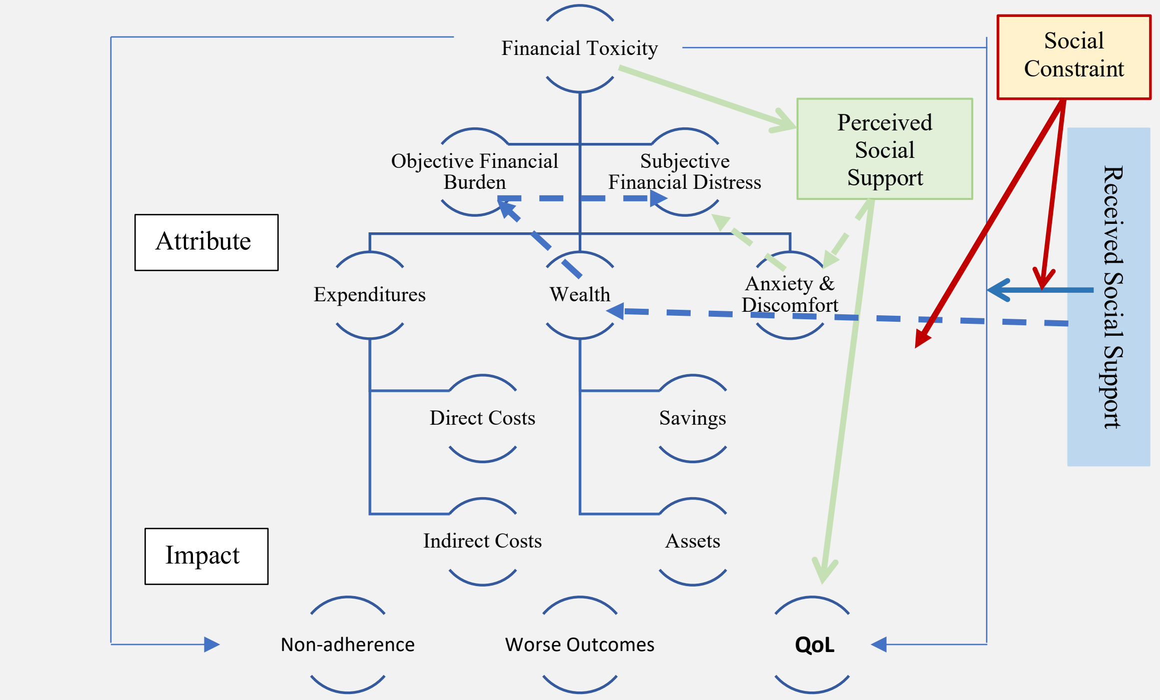

Figure 8. 3 Moderator and mediator interactions of social support using the Financial Toxicity Framework (Caerrera & Zafar, 2018).

Finally, the results from this multiple method approach aided the development of a ‘Things to Do’ checklist for oncology social workers. Largely influenced by Study 1, this checklist can guide oncology social workers or other healthcare professionals in engaging in important financial conversations and identifying supports. (See Table 8.1 to view the checklist). Oncology social workers are well trained to address these financial concerns with patients. Not all patients want to know what their costs are, but someone in the person’s support network should be aware. Furthermore, it is important to offer the information and provide it. Several participants in Study 1 commented that they were never told the costs of their care, and those who directly asked were not told. Purposely engaging in financial discussions with patients opens up that line of communication essentially giving them permission to ask for help. Furthermore, giving patients the information, they need to make informed choices about their care and related financial costs gives patients control over their situation. Moreover, it is important to recognize that these questions should be asked again at other times throughout the cancer experience as situations may change.

Table 8. 1 Checklist for Engaging Patients in Financial Toxicity Conversations

Things to do: Communicate openly with patients about financial issues. Normalize the experience of financial concerns and hardship. Address the issue in a non-judgmental or non-shaming way. Provide current and updated resources.
Questions to ask: What is the patient’s diagnosis, treatment and prognosis? Do they have insurance? • What is their deductible? • What will their costs be after insurance? • Do they qualify for Medicaid/Medicare?

Does the patient want to know what their healthcare costs will be?
- If not, do they have a support person who can assist?

Are they satisfied with their financial situation?

Do they need help understanding their medical bills and insurance forms?

Does the patient have an advocate or support person to help them organize their medical bills and insurance forms?
- Someone to assist with appeals to the insurance agency if needed or apply for other financial assistance programs?

Does the diagnosis and treatment meet Medicare and/or Social Security Benefit qualifications?

Does the patient work? Do they have a spouse/partner who works?
- What benefits do they have through their employer? (Sick leave assistance programs, part-time disability, Family Medical Leave, etc.)
- Do they feel comfortable disclosing their cancer diagnosis to their employer?

Do they have student loans that can be deferred for medical reasons?

What barriers to accessing treatment might the patient be facing?
- Does the patient need help completing paperwork?
- Do they need guidance on how to talk to others about their financial concerns?
- How to approach their employer?
- What specific support or information is it that they need?
- Does the service provided to patients match their needs?

Further considerations should be made to ensuring an environment is created that will encourage patients to discuss their financial concerns with their medical provides. As noted in Chapter 3, certain conditions of support need to meet for social support to be requested or provided. First, the request for assistance cannot be a request that will potentially harm the relationship (Cohen, 2013). This requires a certain amount of trust and comfort within the relationship for requests to be made. Second, the stress-causing issue must be socially acceptable (Cohen, 2013). Given the fact that financial discussions are generally considered taboo in our society, requesting financial assistance from others or sharing financial concerns with others can be difficult for some people. Some participants in Study 1 commented on not talking to others about their financial situation. In order to breakdown these social barriers, financial concerns should be normalized for cancer patients. There should be a level of trust, non-judgment and empathy conveyed from the healthcare professionals (financial counselor, social work, physician, etc.) to the patient. Third, overreacting to the request for assistance could lead the individual into feeling ashamed or embarrassed (Cohen, 2013), which could have further help-seeking implications. One participant in Study 1 shared her story of attempting to get information and resources. The response and lack of help she received left her feeling as though it was a racial issue, and she was angry for being treated so poorly. Fourth, the support provider needs to be capable of providing the support needed (Cohen, 2013) and needs to have access to available resources. This requires a skilled individual who is not only aware of the impact of cancer on a patient's life but is also familiar with working in social systems (healthcare, insurance, disability). Lastly, the resources must match the needs of the patient (Cutrona & Russell, 1990). Although many of the supports provided to cancer patients (resource centers, art therapy, monthly massages) provide a sense of well-being for patients, they do not directly impact the issue of financial toxicity. Several participants in Study 1 sought information and were sent to the hospital's resource center but were unable to obtain helpful advice. Others were provided resources that did not provide assistance. Consequently, there were multiple examples of those resources not meeting the needs of the participant.

In summary, the present study contributes to the knowledge and understanding of the financial experience of cancer survivors. This study highlights the importance of social support broadening its benefits within the cancer experience and highlighting its role in financial toxicity. It has also examined the different pathways by which each form of support (perceived and received) influences the situation. Cancer patients with fewer social supports are at greater risk of experiencing financial toxicity. This can be further complicated by issues of social constraint. From this investigation emerges the need for better communication with patients about their costs, the needs for adequate resources and information to help improve their circumstance, as well as the need to break down barriers that prevent patients from accessing financial assistance. It therefore follows that oncology social workers and healthcare professionals have an essential role to fulfill in assisting patients in averting financial hardship.

Implications for Practice

Findings from the present study suggest the benefits associated with social supports in the context of financial toxicity. The results from this research study should be used to inform practice of the need to ensure information and guidance is provided to patients. Social support (emotional, information, and instrumental) as it relates to financial toxicity can have a significant impact on patient outcomes. Yet, as evident by the findings of Study 1, participants lacked information that could have assisted them and potentially improved their financial outcomes. To that end, it is imperative that social workers and medical professionals address financial toxicity before it is a problem.

Proactive discussions with patients regarding the costs of cancer care should occur at the beginning of the cancer experience before treatment starts. Waiting until a patient is experiencing financial toxicity, which could be several months later, limits the availability of receiving support and assistance. Instead, all patients should be approached immediately upon their diagnosis, provided financial assistance information and encouraged to look into specific work-related benefits or other supports. As was seen in Study 1, patients were taken off-guard by the costs of their care. Many of them were unaware of the expenses until receiving an overwhelming amount of bills several months later. By not engaging in these important conversations, patients are caught off-guard and may have no idea who to approach for assistance. Oncology social workers are well positioned for engaging in these proactive conversations. They are skilled and proficient in quickly developing a trusting rapport with patients. They understand the importance of engaging in active listening and taking time to fully understanding what patients are experiencing. They are skilled in ways to put others at ease creating a comfortable safe environment for patients to share their concerns.

Justifiably, discussing finances is said to be one of the most difficult conversations for people to have. This was an issue for several participants in both studies. Financial struggles can lead to feelings of inadequacy, guilt, and embarrassment making it difficult for people to confide in others. Yet much of the information available for patients, encourages them to bring up the conversation and tells them to talk to their medical providers about their financial concerns. This could be very difficult for some patients, especially those who are embarrassed about their financial situation. Therefore, individuals who fulfill those roles should be well training and equipped to handle these difficult conversations.

Oncology social workers have the clinical skills required to engage in difficult conversation in a sensitive, empathetic and respectful manner. They seek to identify and deal with the significant stressors created by burden. They are skilled at building trusting relationships which allows them to approach difficult conversations such as finances. With respect to this, engaging in important and difficult, even taboo, conversations are a common occurrence for oncology social workers.

To the contrary, the majority of people who provide financial counseling to patients in the healthcare setting have a high school level education (Advisory Board, 2014). They lack the necessary medical understanding of diagnosis and treatment as well as how those can impact a patient’s life and ability to continue working. Furthermore, they lack the necessary training to engage in difficult, taboo conversations that require sensitivity and empathy. In spite of this, there are no policies or regulations requiring these positions receive training or certification. Consequently, many patients do not receive the information, resources or help they need.

Furthermore, there is a lack of resource availability and what is available (Medicare, financial and pharmaceutical assistance programs, charity) may not be enough to help patients once they are experiencing financial toxicity. A study by Smith, Nicolla, and Zafar (2014) and another by Spencer et. al. (2018), found that many oncology social workers and financial navigators do not have the resources needed to help patients. This can lead to avoidant behaviors or non-helpful responses from medical professionals as was seen in Study 1. Arguably, this is because issues of financial toxicity are not dealt with until it is a problem instead of addressing them from the initial diagnosis. With respect to this, a program created by Dan Sherman and the NaVectis Group (2016) addresses the needs of patients and their families early in the cancer experience. Through optimizing health insurance coverage (Medicare, Medicare, and the insurance exchange), they are able to ensure patients have the best and most affordable insurance to meet their needs. Further, they provide patients with all the available information on patient assistance, programs. Although this program has not been proven in terms of evidence-based research, it is considered to be practice informed and best practices.

To date there are no evidence-based practices to address financial toxicity, but there has been some progress. A pilot study by Shankaran et al. (2017) implemented a patient navigation program offering counseling and case management assistance. The program provided patients with access to counselors and case managers who assist with budgeting, answering medical billing questions, and applying for assistance programs. Although this study did not find a difference in financial burden, some patients did experience a decrease in anxiety over their medical costs (Shankaran et al., 2017). A second intervention, Care Payment program, provided patients with 0% APR lines of credit up to $25,000. Patients were put on repayment plans of 4% or as little as $25 per month. Patients were less likely to report barriers to care and bad credit issues as a result of the medical costs (Lessard & Solomon, 2017). Although both of these programs provided patients with assistance and some relief, patients still faced huge amounts of debt accumulation due to their treatment. This could be were the NaVectis program may be superior as it addresses financial issues through intervening by means of healthcare insurance before financial toxicity becomes a problem.

Lastly, patients can take control over their cancer-related financial experiences by seeking the support and help they need. They should be empowered to advocate for themselves or seek the assistance of someone who can advocate for them. Staying organized and on top of their medical bills and insurance forms could be a way to catch billing errors which can lead to unnecessary insurance denials. If medical expenses are denied, patients should be encouraged and assisted in finding out why. Equally important, patients should be encouraged to talk to others and openly communicate with their medical professional about their financial concerns. This could open the door to financial advice (what to pay, when to pay) or lead to other resources that may be beneficial. Support groups through organizations such as Gilda's Club offer supportive programming in a safe and encouraging environment.

Implications for Policy

In order to truly enact change and improve conditions for patients, a larger systemic change is needed. Healthcare was one of the top issues in the 2018 elections and it will continue to remain a concern as costs of care continue to rise. Policy changes at both the healthcare level and larger government level can improve conditions for patients and possibly help patients avoid financial toxicity.

From a public policy perspective, it is of utmost importance that cancer patients and survivors have "affordable, adequate, and accessible healthcare" (ACS-CAN, 2017). The Patient Protection and Affordable Care Act (ACA) ensured patients would have access to healthcare plans that covered a basic degree of cancer care, prevented denials for pre-existing conditions, and were affordable. Yet, these efforts were not enough; although, many American were able to purchase affordable insurance, patients still experienced financial toxicity. Furthermore, the current Presidential Administration and Republican-based Congress have made efforts to overturn parts and all of the ACA, which could jeopardize the financial security of many cancer patients and survivors.

Accordingly, efforts should be made to craft legislation that covers all Americans in the event of a cancer diagnosis. A universal healthcare program would provide equal health coverage to all Americans. According to Sen (2015), the United States could effectively provide a high level of universal healthcare. There is a considerable amount of evidence showing the benefits of such programing. It is well known that Canada and several countries in Europe have versions of universal healthcare, and all show better quality of health and quality of life than the United States. It is less known that poorer countries, such as Thailand, Rwanda, and some states in India (Himachal Pradesh and Tamil Nadu) are implementing universal healthcare policies and are seeing improvements in premature and infant mortality rates (Sen, 2015).

With respect to the idea of universal healthcare, Medicare-for-All appears to be promising. There are currently several proposed bills that provide versions of access to insurance options that are Medicare or Medicaid based. One bill proposed by Senator Sanders (S. 1804) and Representative Ellison (H.R. 676) is a single national health insurance program that would cover all Americans. Alternatively, three other bills provide versions of a new plan option that could be available through the ACA marketplace: Choice Act (S. 194, H.R. 194), Medicare-S Choice Act (S. 1970, H.R. 4094), and Choose Medicare Act (S. 2708, H.R. 6117). These would offer programs similar to Medicare to individuals and possibly employers. A fourth version provides a Medicare buy-in option for individuals who are nearing the eligible age for Medicare programs: Medicare at 55 Act (S. 1742), and Medicare Buy-in and Health Care Stabilization Act (H.R. 3748). These would be greatly beneficial to those nearing the age of retirement and also at a higher risk of receiving a cancer diagnosis. A final version of Medicare-for-All provides states with the authority to allow individuals a Medicaid buy-in option through the ACA marketplace: State Public Option Act (S. 2001) and (H.R.

4129) (Kaiser Family Foundation, 2019). Through legislation such as these acts a greater number of Americans will have affordable access to insurance coverage.

Unfortunately, achieving change at the governmental level can be an onerous task that could take a long time to achieve and patients need help now. Financial health literacy in the United States is considerably low (Lin, Lusardi, and Mottola, 2016). A survey in 2015 found that 63% of adults (N = 25,000) could not answer 4 out of 5 financial literacy questions correctly. Likewise, many Americans lack the financial capability to make ends meet and deal with everyday financial matters. In this same survey, 34% felt they could not come up with $2000 in a month for an unexpected emergency without borrowing and 50% did not have enough funds set aside to cover a 3 month laps in income (Lin, et. al., 2016). This is indicative of a substantial number of Americans being at risk of financial devastation in the event of a cancer diagnosis or economic downfall.

To that end, it is imperative that the health care industry assist patients. The findings from this research suggest that patients need information and guidance in understanding their medical bills and health insurance forms. This information should be understandable at a basic-educational level. Agencies (medical and insurance companies) could simplify their forms to make them easier for patients to interpret and understand. One participant in Study 1 shared her confusion over her medical bills and consequently paid bills that her insurance eventually paid as well. When she attempted to get the money back from the medical provider, she was unsuccessful about doing so in a timely manner. Had she understood her medical bills, she would not have paid them at that time and possibly could have prevented some discord as a result.

Moreover, several participants in Study 1 struggled with the overwhelming amount of medical bills and insurance forms arriving through the mail. By providing a centralized billing system where patients can access their medical bills and insurance information all in one spot could help to eliminate redundancy in the system and could relieve patients from having to manage these documents. This would make the process more patient friendly relieving the burden of receiving excessive amounts of forms and documents through the mail.

In addition, these agencies (medical and insurance) could provide trained and skilled individuals to help patients in a sensitive and empathic way. This service could assist patients in understanding what bills they need to pay and what their insurance will cover. Furthermore, just having someone to help complete paperwork could make a difference in whether or not patients complete paperwork requesting financial assistance. Likewise, assistance should be offered to caregivers as they may be responsible for managing the financial aspects of the experience.

In summary, there are several ways the American healthcare system can be improved to ease the financial burden and distress experienced by patients. The healthcare industry can take steps to improve the exchange of information and provide services from trained, skilled workers who are aware of the circumstances resulting from cancer.

Future Research

As evidence accumulates on the devastating effects of cancer-related financial toxicity, there is an urgent need to develop and implement interventions to alleviate the burden and distress experienced by patients and their families. Further research should be conducted on the NaVectis Group method of addressing financial toxicity to determine its overall effectiveness. It is imperative that research identify interventions and best practices to assure that patients can afford their cancer care and do not end up financially devastated attempting to do so.

Further research could explore patients' preferences for information and, equally important, who they would like to receive this information from. It may be important for every member of the medical team to be knowledgeable and sensitive about financial concerns. Providing patients with some guidance or at least direction as to who to get information from encourages them to continue to try to find relief. Future research could develop and assess the effectiveness of a training program for medical professionals on engaging in these difficult financial discussions in a caring and respectful way.

Another piece to the puzzle may be understanding help-seeking behaviors as they relate to financial aspects. Socially taboo issues have long constrained people from talking about such issue as politics, religion, sex, and money. This was supported in Study 2, which showed that social constraint was indeed a factor. Research could further explore ways to break down these barriers.

Limitations

The benefits of social support have long been established in the cancer experience. This study extends this knowledge into the experience of cancer-related financial toxicity. A strength of this project was the use of multiple studies. Using this pragmatic approach allowed for this topic to be explored through qualitative and quantitative measures providing different perspectives and information. Another strengths was the variety of theoretical frameworks, which informed the development of the study procedures and data analyses. Furthermore, each study provided a different perspective on the availability, use, and need for social support during the cancer experience.

Despite the use of multiple methodologies, weaknesses were identified for each study. Study 1 had an almost non-existent presence of perceived support. This lack of perceived support as well as a weak existence of received information and emotional supports could be due to the way the interview questions were designed. This was a secondary analysis and the interview questions sought to understand the overall experience of cancer-related financial hardship not specific to social support. To the contrary, there was a strong presence of received instrumental support discussed by all participants. To that end, Study 1 provided insight into the types of social support (emotional, informational, and instrumental); nevertheless, it does not indicate which is more important. The aim of this study was not to determine the level of importance but rather to identify the existence of support, its use, and need for more. What we can surmise is that received instrumental support was more talked about than any other type of support.

A strength of Study 2 was that the models accounted for a portion of the variance in QoL. However, the observed moderation variable (received social support) did not account for a large amount of the variance in QoL. According to Cohn & Willis (1985), the ability to detect a buffering effect could be dependent on the measures used. This requires having measures that directly get at the type of social support which can best respond to the stressor. In this respect, results may have shown more variance in QoL had the larger version of the scale (Inventory of Socially Supportive Behaviors short version) or a different scale been used. Another weakness was that other variables could have been included, such as are the length of treatment and number of other chronic illnesses. These variables may have explained some of the variance in QoL. Furthermore, the study design did not allow for the establishment of causality.

Study 1 and Study 2 cross-sectional designs were used, which does not allow for causal or directional inferences. In addition, a cross-sectional design prevents the evaluation of long-term financial impact. Furthermore, both studies were limited by a lack of racial diversity; most participants were white and female. Individuals from minority populations tend to have less access to financial reserves. According to the American Cancer Society (2018), Hispanics (16%) and blacks (11%) are more likely to be uninsured then Caucasians (6%). Minority populations are also more likely to be diagnosed with cancer at a later stage. It is therefore conceivable to propose these populations may experience higher toxicity and be in need of more intervention services. Future research could focus on identifying the effects of financial toxicity on minority populations and determining if racial differences exist in regard to the availability of social support.

Conclusion

It is evident that a significant number of people are impacted by the costs of cancer care and as costs continue to rise, more will experience financially toxic situations. Although financial toxicity continues to be extensively studied, answers to alleviating patients' financial distress and burden are lacking. To my knowledge these are the first studies conducted to focus on specifically how social support can impact the cancer-related financial experience. These findings confirm the existence, use, and importance of social support in this context. Furthermore, they provide empirical evidence for attending to the supportive financial needs of cancer patients.

From this investigation emerges the need for purposeful conversations surrounding financial issues at the beginning of a cancer diagnosis. Patients should be provided information about their costs of care and the amount they are responsible for instead of being surprised by the bills several months later. Exactly who is at risk is debatable; therefore, the assumption should be made that anyone with cancer is at risk of experiencing financial toxicity. All patients should be provided financial assistance and resources before they experience financial toxicity (i.e., at the beginning of their cancer experience). Furthermore, all members of the healthcare team should receive training on engaging patients in a sensitive and empathic way when handling financial discussions.

On a theoretical level, the study findings provided empirical evidence in support of the Stress-buffering Hypothesis (Cohn & Wills, 1985) and conceptually adds to the Financial Toxicity Framework proposed by Carrera & Zafar (2018). This has important implications for practice. Practitioners should understand the complexity of financial toxicity and how these supports can buffer patients' experiences.

Furthermore, the costs of care should not weigh into the decision of whether or not a person obtains cancer care. It is of the utmost importance that policies at the federal, state, and agency level address the astronomical costs of health care. Whether by cost regulation or universal health plans, systemic change needs to occur in order to effectively prevent patients from the experience of financial toxicity.

Future studies should continue to investigate evidence-based interventions for addressing financial toxicity. Equally important is examining patient preferences for information and with whom they prefer engaging in purposeful financial conversations. Other studies should explore the development of training for medical professional in engaging in sensitive financial conversations.

In considering the findings from this research, it appears that the answer to the overarching question to what role does social support play, we can unequivocally answer: an important one. Social support is a critical element in helping protect patients from cancer-related financial toxicity.

"I wish there would have been somebody, just to say, this is going to start costing you money, because all you're thinking about is, 'I want to save my life.'"
-Study 1 # (53-year-old woman, Pancreatic Cancer)

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APPENDIX A: STUDY 1 CONSENT PREAMBLE

Living with the Financial Consequences of Cancer: The Stories of Survivors Support Person Consent

You are being invited to participate in a research study by participating in a one-time interview conducted by a member of the research team. This interview can occur in your home or at our research office. The interview will ask about your experiences related to the financial and personal distress caused by a cancer diagnosis and related treatment. Completing the interview will take approximately 1 hour. Your interview will be audiotaped and then transcribed (typed out).

The purpose of the study is to learn how a cancer diagnosis impacts financial well-being, how cancer patients manage financial hardship and how financial distress affects overall quality of life. The ultimate goal is to develop sustainable and effective interventions to assist cancer patients in preventing financial hardship.

There are no foreseeable risks associated with this study besides the discomfort you might experience answering interview questions. There may be unforeseen risks. The study data collected may not benefit you directly, but it will be used to identify and address financial barriers to cancer care which could positively impact the future lives of survivors and their families.

Your completed interview will be stored in a locked file cabinet at the Kent School of Social Work. Your responses to the questions will be maintained on a password protected computer. Identifying information such as your name will not be connected to the database or your transcribed interview, nor will any of your identifying data be published in articles written about the study.

Individuals from the Department of University of Louisville Department of Medicine and the Kent School of Social Work, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPO), and other regulatory agencies may inspect these records. In all other respects, however, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed.

Taking part in this study is voluntary. By completing the interview you agree to take part in this research study. You do not have to answer any questions that make you uncomfortable. You may choose not to take part at all. If you decide to be in this study you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify.

If you have any questions, concerns, or complaints about the research study, please contact the: principal investigator at 502-852-1946.

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

UofL Institutional Review Boards
IRB NUMBER: 15.0407
IRB APPROVAL DATE: 06/04/2015 IRB EXPIRATION DATE: 05/13/2016

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

Sincerely,

Karen Kayser PhD. Barbara Head PhD.

DATE: 06/02/2015

APPENDIX B: STUDY 1 INTERVIEW GUIDE

The Experience of Financial Toxicity during the Cancer Trajectory

I would like to have a conversation with you about your experience with cancer. Specifically, I would like you to tell me in your own words the story of how your illness caused financial hardship in your life.

Point of Most Financial Distress

- When did you first start to experience financial stress related to your cancer? (Probe: Can you tell me more about that?)
- When did you reach your highest point of financial stress and what was that like for you?

Financial Situation & Health Insurance at the Time of Diagnosis

- Tell me about your financial situation during the time of your diagnosis.
- Were you employed at that time? Were you able to maintain your employment throughout your treatment? If so, tell me about the work you were doing?
- Did you have health insurance coverage? If so, what type? (Probe: private, employer, self-paid)

Understanding Assistance with Insurance, Medical Costs, and Coverage.

- What did you understand about the costs of cancer care and your insurance coverage at the time of your diagnosis?
- What assistance was given to you from the Cancer Center or any of your medical providers to guide you through the cost s and insurance coverage period during your cancer experience? (Probe: Financial counselor.)
- Did you encounter any out of pocket expenses that you did not expect? If so, what were they?

Managing the Financial Stress

- What strategies did you use to manage the financial burden during your cancer experience?
- What, if any, methods did you use to offset costs of care and expenses such as loans, credit cards, or second mortgages?

Effects of financial distress on treatment and outcomes.

- Did the worry about your financial situation affect any of your treatment decisions?
- Did you ever not receive, limit or stop treatment because of the inability to pay for it? (E.g. not filling prescriptions or taking fewer medications) Probe: Tell me more about that.

Current Quality of Life

- Looking back on your life before your cancer diagnosis, what has changed about your life overall?
- How do you think it has affected your family/loved ones?
    - How would you describe their quality of life before, during and after treatment?
- What are your current healthcare needs and are they being met or addressed? (Probe: include follow-up care, preventive screenings or other chronic conditions)

Ending interview

- If you could give another person who is diagnosed with cancer advice about finances and stress, what would it be?
- What advice would you give to the healthcare system (hospitals, cancer centers, insurance companies, government) to alleviate the financial consequences of a cancer diagnosis and treatment?
- What else do you think it would be important for me to know about financial stress and cancer that I did not ask you about today?

APPENDIX C: STUDY 1 QUESTIONNAIRE

Introduction

This questionnaire is about your experience with cancer specifically your experience with financial burden as a result of the cancer treatment, access to care, and social support during your illness. All answers are completely confidential. Please do not write your name of the questionnaire.

Section I Financial Toxicity Scale (Cost-Prom)

Below is a list of statements related to the financial impact of your illness. Please place an X in the box which describes how you feel about that statement.

	Not at all	A little bit	Some-times	Quite a bit	Very Much
I feel financially stressed.	**0**	**1**	**2**	**3**	**4**
I am satisfied with my current financial situation.	**0**	**1**	**2**	**3**	**4**
I worry about the financial problems I will have in the future as a result of my illness or treatment.	**0**	**1**	**2**	**3**	**4**
I am frustrated that I cannot work or contribute as much as I usually do.	**0**	**1**	**2**	**3**	**4**
My cancer or treatment has reduced my satisfaction with my present financial situation.	**0**	**1**	**2**	**3**	**4**
I feel in control of my financial situation.	**0**	**1**	**2**	**3**	**4**
I am able to meet my monthly expenses.	**0**	**1**	**2**	**3**	**4**
I know that I have enough money in savings, retirement or assets to cover the costs of my treatment.	**0**	**1**	**2**	**3**	**4**
I am concerned about keeping my job and income, including working at home.	**0**	**1**	**2**	**3**	**4**
I feel I have no choice about the amount of money I spend on care.	**0**	**1**	**2**	**3**	**4**

My out of pocket medical expenses are more than I thought they would be.	**0**	**1**	**2**	**3**	**4**

Section II Brief Health Literacy Screening Tool (BRIEF)

Please circle the answer that best represents your response.

	Always	Often	Some-times	Rarely	Never
How often do you have someone help you read hospital materials?	**1**	**2**	**3**	**4**	**5**
How often do you have a problem understanding the written materials about your medical condition?	**1**	**2**	**3**	**4**	**5**
How often do you have a problem understanding what is told to you about your medical condition?	**1**	**2**	**3**	**4**	**5**
	Not at all	**A little bit**	**Some-what**	**Quite a bit**	**Extre mely**
How confident are you filling out medical forms by yourself?	**1**	**2**	**3**	**4**	**5**

Introduction

This questionnaire is about your experience with cancer specifically your experience with insurance, being uninsured or receiving Medicaid coverage. It will help us to assess the impact of medical insurance on the affordability and ability to receive health care services. All answers are completely confidential.

Section III Well-Being (Fact-G Version 4)

Below is a list of statements that other people have said are important. **Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days.</u>**

Physical Well-Being

	Not at all	A little bit	Somew hat	Quite a bit	Very much
I have a lack of energy.	**0**	**1**	**2**	**3**	**4**
I have nausea.	**0**	**1**	**2**	**3**	**4**
Because of my physical condition, I have trouble meeting the needs of my family.	**0**	**1**	**2**	**3**	**4**
I have pain.	**0**	**1**	**2**	**3**	**4**
I am bothered by side effects of treatment.	**0**	**1**	**2**	**3**	**4**
I feel ill.	**0**	**1**	**2**	**3**	**4**
I am forced to spend time in bed.	**0**	**1**	**2**	**3**	**4**

Social/Family Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel close to my friends.	**0**	**1**	**2**	**3**	**4**
I get emotional support from my family.	**0**	**1**	**2**	**3**	**4**
I get support from my friends.	**0**	**1**	**2**	**3**	**4**
I am satisfied with family communication about my illness.	**0**	**1**	**2**	**3**	**4**
I feel close to my partner (or the person who is my main support).	**0**	**1**	**2**	**3**	**4**
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ and go to the next section.					
I am satisfied with my sex life.	**0**	**1**	**2**	**3**	**4**

Please circle or mark on number per line to indicate your response as it applies to the past 7 days.

Emotional Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad.	**0**	**1**	**2**	**3**	**4**
I am satisfied with how I am coping with my illness.	**0**	**1**	**2**	**3**	**4**
I am losing hope in the fight against my illness.	**0**	**1**	**2**	**3**	**4**
I feel nervous.	**0**	**1**	**2**	**3**	**4**
I worry about dying.	**0**	**1**	**2**	**3**	**4**
I worry that my condition will get worse.	**0**	**1**	**2**	**3**	**4**

Functional Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to work (include work at home).	**0**	**1**	**2**	**3**	**4**
My work (include work at home) is fulfilling.	**0**	**1**	**2**	**3**	**4**
I am able to enjoy life.	**0**	**1**	**2**	**3**	**4**
I have accepted my illness.	**0**	**1**	**2**	**3**	**4**
I am sleeping well.	**0**	**1**	**2**	**3**	**4**
I am enjoying the things I usually do for fun.	**0**	**1**	**2**	**3**	**4**
I am content with the quality of my life right now.	**0**	**1**	**2**	**3**	**4**

Section V Healthcare Access

Q1 How was your cancer found?

1- It was found during a screening test (such as a mammogram, colonoscopy)
2- It was found during a routine check-up or physical exam with my doctor.
3- It was found when I went to my doctor because I was sick and had physical symptoms.
4- It was found after I went to the emergency room because I was sick.

Q2 What type of cancer did you have? _________________

Q3 Prior to your cancer diagnosis, where did you receive most of your healthcare?

1- At my doctor's office
2- At a clinic
3- At an immediate or urgent care center
4- At the emergency room
5- I never needed healthcare

Q4 Did you get routine screening for cancer such as a mammogram or colonoscopy before your cancer diagnosis?

____ Yes ____ No

Q5 Did you go to your doctor or a clinic for regular check-ups before your cancer diagnosis?

____ Yes ____ No

Q6 At the time of your first cancer diagnosis did you have insurance?

____ Yes ____ No

If you had insurance which of the following types of insurance did you have (check all that apply)?

1- Private Insurance through my employer
2- Private insurance I purchased myself
3- Veteran's Administration coverage
4- Medicare disability insurance
5- Medicaid

Q7 Did you have medical insurance prior to your cancer diagnosis?

____ Yes ____ No

If you did not have medical insurance prior to your cancer diagnosis, what was the reason (check all that apply)?

1- My employer did not offer insurance as a benefit

2- I could not afford the cost of health insurance
3- I did not think I needed insurance
4- I was not eligible for Medicaid when I applied
5- I wasn't working and could not afford insurance
6- I didn't know how to get insurance I could afford

Q8 Which of the following insurances changes have you experienced since your cancer diagnosis?

1- None, I still have the same insurance
2- None, I still do not have any insurance
3- I lost my insurance because I can no longer work
4- I lost my insurance because I can no longer afford it
5- I became eligible for Medicaid
6- I became eligible for Medicare disability
7- I lost my insurance coverage through my employer and now pay for my own

Q9 If you have Medicaid, when did you get it?

Month ____ Year____

Q10 If you have Medicaid, did you (check all that apply)

1- Have it before you got sick with cancer
2- Apply for it when you got cancer
3- Apply for it after you got cancer because you lost your private insurance
4- Apply for it when a social worker or other person told you about it
5- Apply for it when you learned that Medicaid rules had changed making you eligible

Q11 If you have Medicaid, how did you learn about it (check all that apply)?

1- I heard on the news that I might be eligible
2- I saw a sign or was given information at the doctor's office, clinic or hospital
3- My doctor told me about it
4- A social worker or discharge planner at the doctor's office, clinic or hospital told me about it
5- A friend or family member told me about it
6- A family member has it and told me about it

Q12 Did you know that Medicaid became available to more people in Kentucky as part of the Affordable Care Act (Obama care) in January 2014?

____ Yes ___ No

Q13 Did you apply for Medicaid because you heard it was more available?

____ Yes ____ No

Section VI Demographic Questions

Gender: ___ Male ___ Female

Age:

What is your ethnicity?

1- Latina/Latino/Hispanic ancestry
2- Not Hispanic

What is your racial/ethnic group?

1- Caucasian/White
2- African-American/Black
3- Asian
4- American Indian/Alaskan Native
5- Native Hawaiian/Other Pacific Islander
6- Other __________________________

Have you ever been or are you currently married?

1- Single, never married
2- Currently married
3- Not married, but in a relationship with significant other
4- Separated or divorced
5- Widowed

How many children under the age of 18 are living in your home? _____

What is the highest level of formal education that you have completed?

1- Less than high school
2- Completed high school or GED
3- Some college (includes technical, vocational, or certificate program and Associate's degree)
4- Bachelor's degree
5- Postgraduate or professional degree (includes Master's, MD, PhD, and JD)

Do you currently work for pay? ____ Yes ____ No

What is your current job status?

1- Employed full-time
2- Employed part-time
3- Unemployed
4- Homemaker
5- Disabled
6- Retired

Before your cancer diagnosis, what was your job status?

1- Employed full-time
2- Employed part-time
3- Unemployed
4- Homemaker

5- Disabled
6- Retired

If you currently work for pay, in the last month:

How many hours per week did you work on average for pay? _3___
How many days off did you take because of physical health problems? ____
How many days off did you take because of emotional health problems? ____

What is your occupation?

1- Homemaker
2- Executive of manager
3- Professional or technical
4- Clerical, sales or service work
5- Occupation in agriculture, forestry or fisheries
6- Occupation in crafts, repair, manufacturing, transportation or operation of machinery

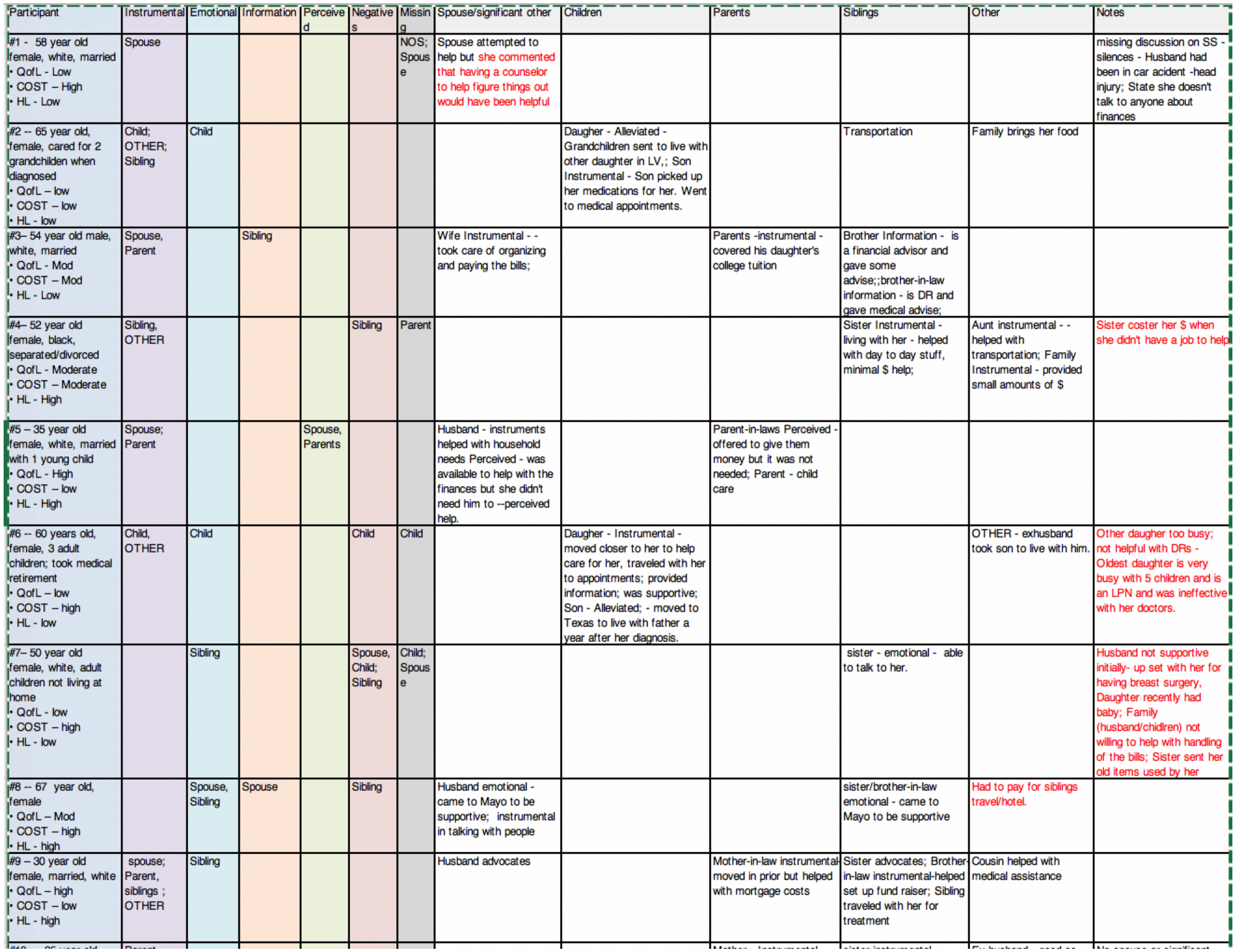
How important is your occupation or continuing to work to your well-being? If disabled or unemployed, how important was your occupation or continuing to work to your well-being?

1- Not at all important
2- Not very important
3- Somewhat important
4- Moderately important
5- Very important

What are/were your household (family) gross wages or income last year (before taxes)?

1- Less than $25,000
2- $25,001-$40,000
3- $40,001-$60,000
4- $60,001-$80,000
5- Over $80,000
6- I don't know

APPENDIX D: FAMILY PARTIALLY ORDERED META-MATRIX



Participant	Instrumental	Emotional	Information	Perceived	Negatives	Missing	Spouse/significant other	Children	Parents	Siblings	Other	Notes
#1 - 58 year old female, white, married • QofL - Low • COST – High • HL - Low	Spouse					NOS; Spouse	Spouse attempted to help but she commented that having a counselor to help figure things out would have been helpful					missing discussion on SS - silences - Husband had been in car acident -head injury; State she doesn't talk to anyone about finances
#2 -- 65 year old, female, cared for 2 grandchilden when diagnosed • QofL – low • COST – low • HL - low	Child; OTHER; Sibling	Child						Daugher - Alleviated - Grandchildren sent to live with other daughter in LV,; Son Instrumental - Son picked up her medications for her. Went to medical appointments.		Transportation	Family brings her food	
#3– 54 year old male, white, married • QofL - Mod • COST – Mod • HL - Low	Spouse, Parent		Sibling				Wife Instrumental - - took care of organizing and paying the bills;		Parents -instrumental - covered his daughter's college tuition	Brother Information - is a financial advisor and gave some advise;;brother-in-law information - is DR and gave medical advise;		
#4– 52 year old female, black, separated/divorced • QofL - Moderate • COST – Moderate • HL - High	Sibling, OTHER				Sibling	Parent				Sister Instrumental - living with her - helped with day to day stuff, minimal $ help;	Aunt instrumental - - helped with transportation; Family Instrumental - provided small amounts of $	Sister coster her $ when she didn't have a job to help
#5 – 35 year old female, white, married with 1 young child • QofL - High • COST – low • HL - High	Spouse; Parent			Spouse, Parents			Husband - instruments helped with household needs Perceived - was available to help with the finances but she didn't need him to --perceived help.		Parent-in-laws Perceived - offered to give them money but it was not needed; Parent - child care			
#6 -- 60 years old, female, 3 adult children; took medical retirement • QofL – low • COST – high • HL - low	Child, OTHER	Child			Child	Child		Daugher - Instrumental - moved closer to her to help care for her, traveled with her to appointments; provided information; was supportive; Son - Alleviated; - moved to Texas to live with father a year after her diagnosis.			OTHER - exhusband took son to live with him.	Other daughter too busy; not helpful with DRs - Oldest daughter is very busy with 5 children and is an LPN and was ineffective with her doctors.
#7– 50 year old female, white, adult children not living at home • QofL - low • COST – high • HL - low		Sibling			Spouse, Child; Sibling	Child; Spouse				sister - emotional - able to talk to her.		Husband not supportive initially- up set with her for having breast surgery, Daughter recently had baby; Family (husband/chidlren) not willing to help with handling of the bills; Sister sent her old items used by her
#8 -- 67 year old, female • QofL – Mod • COST – high • HL - high		Spouse, Sibling	Spouse		Sibling		Husband emotional - came to Mayo to be supportive; instrumental in talking with people			sister/brother-in-law emotional - came to Mayo to be supportive	Had to pay for siblings travel/hotel.	
#9 – 30 year old female, married, white • QofL – high • COST – low • HL - high	spouse; Parent, siblings ; OTHER	Sibling					Husband advocates		Mother-in-law instrumental-moved in prior but helped with mortgage costs	Sister advocates; Brother-in-law instrumental-helped set up fund raiser; Sibling traveled with her for treatment	Cousin helped with medical assistance	

Parent Information

Media Title	Excerpt Copy	Condensed Data	Financial Relat	Other types
Participant 14.d	Money problems will be here when you're dead and gone, my mother said, "You'll get medical bills, Shay, after you're dead." Guess what? We got bills right after she was dead. I mean, what are you going to do? Dig her up? I mean, really. The world will go on.		1	

Parent Emotional

Media Title	Excerpt Copy	Condensed Data	Financial Relat	Other types
Participant 25.d	My dad's helped a lot. Again, just talking with my husband. He's very helpful and understanding.			general

Parent Instrumental

Media Title	Excerpt Copy	Condensed Data	Financial Relat	Other types
Participant 10.d	My mom helped me get some paperwork filled out and I was able to get some disability income		1	
Participant 10.d	I guess the second week when I was in the hospital when my mortgage was due and I had to pay bills at home but I was in the hospital. So my family kind of came, and my mom really kind took over as a power of attorney so that she could go into my bank account and pay all my bills and get everything set up.		1	
Participant 10.d	my memory is very foggy. B: Chemo-brain P: I didn't know it lasted this long, but now that I am feeling better. It's just like I forget so much. But my mom handled, she has been a rock, just handled a lot of that.		1	
Participant 10.d	there wasn't any help. P: no, and she got it from calling around and asking, because she had to do the same thing for my father who is disabled. So she kind of knew the avenues. For me she went in there.			advocated
Participant 10.d	My mom worked a lot, she worries a lot and she had to become my primary care taker. And it's taken a toll on her			caregiver
Participant 5.do	I have a two-year-old, so there's a lot of kind of shifting him around with staying with grandparents when I'm sick or			childcare
Participant 3.do	I think that they are stabilizing now; I mean some things... there have been some things that have helped. I still have one in college but my parents started just a couple of years ago, now that they have money... you know... their logic there telling me now we never paid for you college so let us pay tuition for the last one so...		1	
Participant 9.do	She was living with us during my diagnosis and treatment and we end up.		1	

APPENDIX E: STUDY 1 TEMPLATE & EXAMPLE OF MEMOS

The below templates are informed by Corbin & Strauss (2015) chapters 6 & 10.

Memo 1: Open Data Exploration
Purpose – beginning to explore concept.

Memo 2: Develops the Properties and Dimensions Further
Purpose – is to sensitize to possible properties/dimensions.

Memo 3: Comparison and Question-Asking Memo.
Purpose – it to make more sensitive to data.

Memo 4: Summary Memo
Purpose – demonstrate the relationships between conditions, actions-interactions, and consequences.

Conceptual Heading: What defines this theme?

Questions to ask throughout the process:

1. What seems to be going on here?
2. What theme keeps emerging over and over when I read these?
3. What thoughts/ideas come through in the data even though it may not be said directly?

Example

Advocated Memo 1 Data Exploration

Provided by spouses.

- During a cancer experience patients are facing a life threatening disease. Having someone to advocate for them allows them to take a step back and let someone else have control of part of the situation. This allows the patient to focus on their health and well-being.

- 'my wife is a medical professional. She also is a person who is very conscious of what costs are and is not afraid to say, "We can't afford to have that type of service, even though you might want to have a 2nd or 3rd opinion, which is fine,

> we can deal with that. Unless, you can have that as a part of our insurance situation, I don't see ..." Your spouse can be skeptical of any 2nd or 3rd opinion just because they're out of network." #26

Spouses all for having someone to just give to all over to. They provide support, advocacy.

Excerpts in this category revolve around the concept of someone else taking control of part of the situation.

> PARENT - she got it from calling around and asking, because she had to do the same thing for my father who is disabled. So she kind of knew the avenues. For me she went in there. - #10

Knowing the avenues to take when seeking disability such as in this case or navigating the insurance world can provide a lot of assistance. In this case the patient's mother was able to advocate for her to get disability assistance when she could no longer work due to her treatment.

Provided by Child

- Adult Children were also able to provide advocacy support. --60-year-old woman with three adult children comments on how one of her children encouraged her to have a voice.
  'Yeah. She's real good at helping me advocate and encouraging me to use my voice because when you're in the middle of it's a whole different story. #6

Provided by Medical Professionals

- Med Prof provided emotional support in the form of Advocacy – this stretches the expectations of formal support providers to also include emotional supports - opposed to what is explain in theory. This may be due to the deep level at which health care can effect a patient – medical providers cross the divide between formal and information – they become personal relationships – friends.

'I felt like my healthcare system was an advocate. - #22

"Yes, she has become more of a friend and an advocate b/c she got on the phone and was talking to them and they paid attention to her. I can barely walk—but I can't use a walker or a cane—but she got on the phone and made them pay attention about it like the wheelchair back in December. So that I can get around without being stuck in the house." - #2

Advocate Memo 2 Develops

Advocate. A life threatening or severe disease, such as cancer, can cause a patient to feel vulnerable. They may feel week due to the effects of the illness itself or the physical demand treatment has on their bodies. In this emotional support theme, we see that family members (spouses, parents, adult children, siblings) and medical professionals (Nurses) served as advocates. Having someone to advocate for you allows you to take a step back and let someone else have control of part of the situation. This allows the patient to focus on their health and well-being.

Emotional supports are expected to be performed by Family and Friends. In this study several different family member roles engaged in advocating for the needs of the patient. In the below quote from #26, the participant appears to speak with confidence about his spouse's ability to handle the situation and ensure that whichever health decision the select will make the most economical sense.

Parents can have past life experiences that prove to be useful as seen in the case of a 35-year-old, single female. Knowing the avenues to take when seeking disability such as in this case or navigating the insurance world can provide a lot of assistance. In this case the patient's mother was able to advocate for her to get disability assistance when she could no longer work due to her treatment.

Adult Children were also able to provide advocacy support. In the below excerpt a 60-year-old woman with three adult children comments on how one of her offspring encouraged her to have a voice in her medical care and decision-making processes.

From the perspective of social support theory, medical professionals are in the formal support provider categories and expected to provide information and instrumental supports. In this study they are also observed providing emotional support. Med Prof provided emotional support in the form of Advocacy – this stretches the expectations of formal support providers to also include emotional supports -opposed to what is explain in theory. This may be due to the deep level at which health care can effect a patient – medical providers cross the divide between formal and information – they become personal relationships – friends.

During a cancer experience, patients are faced with a life-threatening disease. Having someone to advocate for them allows them to take a step back and let someone else have control of part of the situation. This allows the patient to focus on their health and well-being.

Advocacy Memo 3 Questioning Memo

Provider advocates for the patient's wellbeing, medical care, and health service needs. In providing this assistance, patients are comforted and may feel supported having the confidence that someone else can take care of things. Provider supports the patient by ensuring their well-being and needs are met. Acts as a voice for the patient. The patient has confidence in the provider to make sure what is needed is done.

Advocacy Memo 4 Summary Memo

A life threatening or severe disease, such as cancer, can cause a patient to feel vulnerable. They may feel weak due to the effects of the illness itself or the physical demand treatment has on their bodies. In this emotional support theme, we see that family members (spouses, parents, adult children, siblings) and medical professionals (Nurses or other providers) served as advocates. They take control of a situation and resolve the issue so that the patient does not need to worry about it. In this act they are a voice for the patient speaking up for their wellbeing, medical care, and needed health service. In providing this assistance, patients may feel supported and confident that someone else can take care of some thing for them while they focus on their treatment and survival.

According to theory, emotional support is expected to be performed by family and friends. In this study several different family members (spouse, parent, adult child, sibling) engaged in advocating for the needs of the patient. In the below quote from #26, the participant appears to speak with confidence about his spouse's ability to handle the situation and ensure that whichever health decision was made would make the most economic sense.

> "My wife is a medical professional. She also is a person who is very conscious of what costs are and is not afraid to say, 'We can't afford to have that type of service, even though you might want to have a 2nd or 3rd opinion, which is fine, we can deal with that. Unless, you can have that as a part of our insurance situation, I don't see.' Your spouse can be skeptical of any 2nd or 3rd opinion just because they're out of network." #26 (66-year-old, male, Prostate & Bladder)

This example is in accordance with the role expectations of a spouse as they are expected to be a primary support. Having a spouse available to attend appointments and assist in treatment decisions can alleviate some of the responsibility and burden from the patient.

Other family members can step into this primary supportive role as well. Parents may have past life experiences that prove to be useful as seen in the case of a 35-year-old, single female.

> "She [mother] got it from calling around and asking, because she had to do the same thing for my father who is disabled. So, she kind of knew the avenues. For me she went in there." #10 (35-year-old, female, Leukemia)

Knowing the avenues to take when seeking medical treatment or navigating the insurance world can provide valuable assistance and guidance. In this case the patient's mother was able to advocate for her to get disability assistance when she could no longer work due to her treatment.

Similarly, adult children may be in the position to provide advocacy support as well. In the below excerpt a 60-year-old woman with three adult children comments on how one of her daughters encouraged her to have a voice in her medical care and decision-making processes.

> "She's really good at helping me advocate and encouraging me to use my voice because when you're in the middle of it's a whole different story. #6 (60-year-old, female, Lung Cancer)

From the perspective of social support theory, Medical Professionals are in the formal support provider categories and expected to provide information and instrumental supports. In this study they provide emotional support as well. In the next two excerpts participants comment on their medical professionals getting them the services they needed.

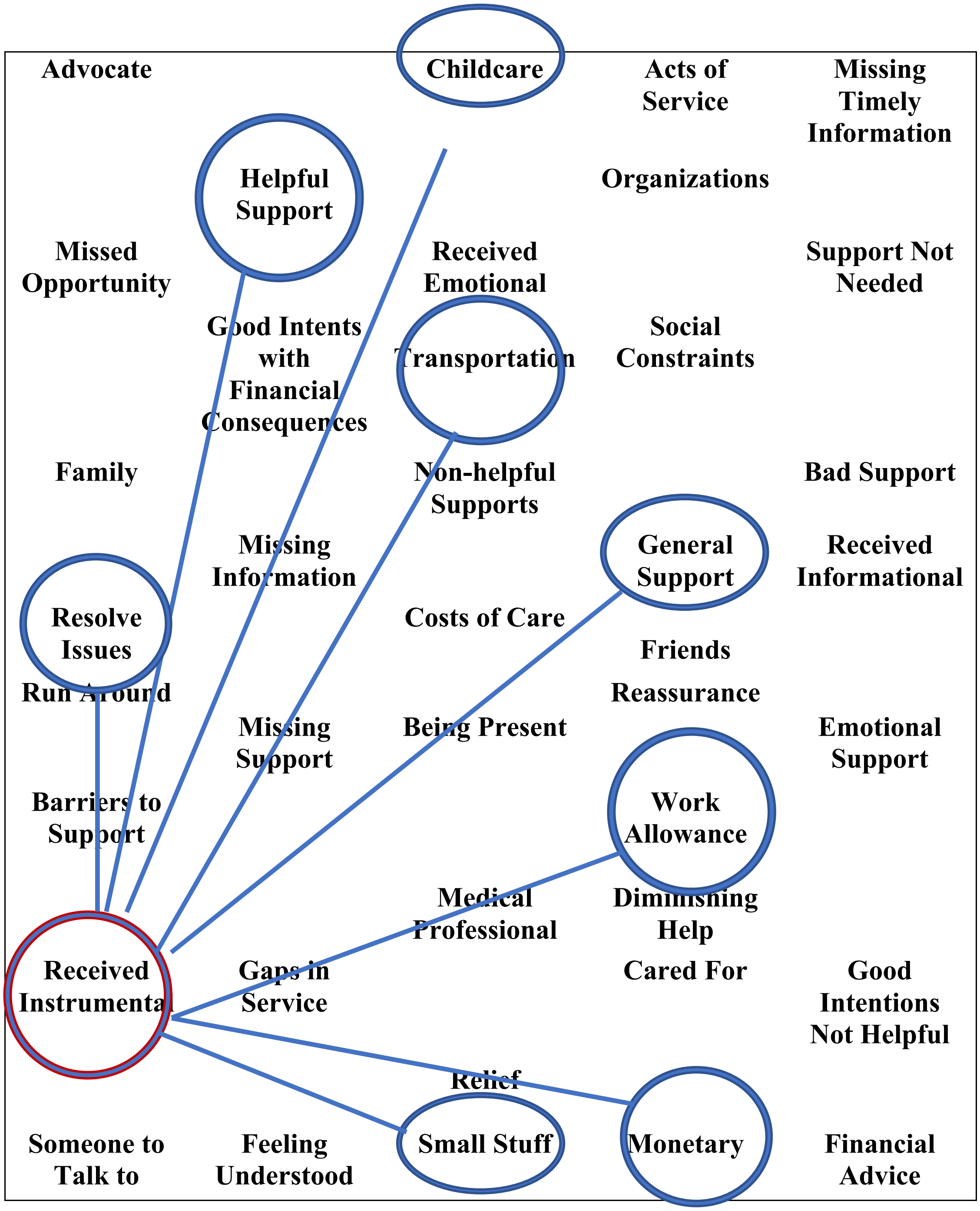
> "I felt like my healthcare system was an advocate." #22 (62-year-old, female, Breast Cancer)
>
> "Yes, she has become more of a friend and an advocate b/c she got on the phone and was talking to them and they paid attention to her. I can barely walk—but I can't use a walker or a cane—but she got on the phone and made them pay attention about it like the wheelchair back in December. So that I can get around without being stuck in the house." #2 (65-year-old, female, Breast Cancer)

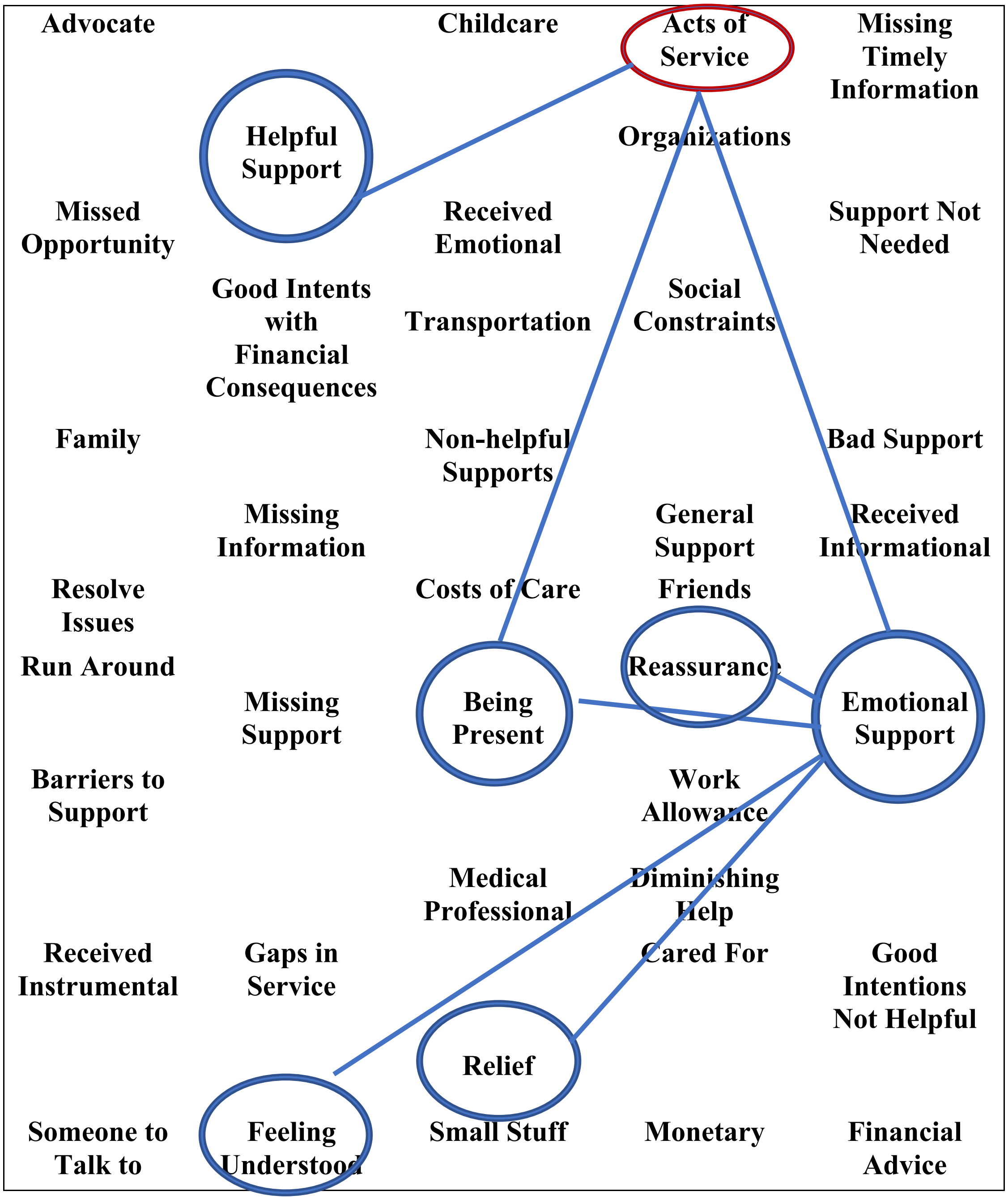
Having someone to advocate for you allows you to take a step back and let another person have control of part of the situation. This allows the patient to focus on their health and well-being.

Conceptual Heading – What defines this theme?

Provider supports the patient by ensuring their well-being and needs are met. Acts as a voice for the patient.

APPENDIX F: SITUATIONAL MAPPING




Advocate
Childcare
Acts of Service
Missing Timely Information
Helpful Support
Organizations
Missed Opportunity
Received Emotional
Support Not Needed
Good Intents with Financial Consequences
Transportation
Social Constraints
Family
Non-helpful Supports
Bad Support
Missing Information
General Support
Received Informational
Resolve Issues
Costs of Care
Friends
Run Around
Reassurance
Missing Support
Being Present
Emotional Support
Barriers to Support
Work Allowance
Medical Professional
Diminishing Help
Received Instrumental
Gaps in Service
Cared For
Good Intentions Not Helpful
Relief
Someone to Talk to
Feeling Understood
Small Stuff
Monetary
Financial Advice

APPENDIX G: STUDY 1 REFLEXIVITY

In order to further establish trustworthiness, this section will introduce me as the researcher providing background information that has prepared me for completing this research task.

This is my sixth year in the PhD program at the University of Louisville, Kent School of Social Work. I am a PhD Candidate and have successfully completed all required coursework and the comprehensive examination process. Coursework requirements included research design and analysis for both qualitative and quantitative studies. The in-depth course on qualitative analysis assisted in the development of the focus for this proposed study. Other coursework that has assisted in preparing me for this task includes theory and research ethics.

In addition to my coursework, I have had the opportunity to work on qualitative and quantitative studies with several different professors at the university. I have engaged in studies addressing the psychosocial needs of cancer patients as well as community needs analysis, teaching practices, and theory development. Working under the guidance of well-established professors has provided me with the skillset required to tackle this project.

Some skills cannot be learned through the classroom or university environment; instead, developed over life experiences. I am a non-traditional student obtaining my higher degree at an older age. Prior to returning to obtain my Master's and PhD, I worked in a variety of settings. The majority of my career was focused in mental health and child welfare. These positions helped to develop skills of empathy and understanding for the effects of oppression, life stressors, and varied life situations.

Other positions I have held over the years have prepared me as well. I spent several years working in a laboratory processing materials for cancer screening. This position provided me with insight into the breadth of those affected by cancer and the importance of cancer screening awareness. The final position that I will discuss may be most influential on my current studies. For several years I was a financial loan processor working with individuals who had poor credit ratings and excessive amounts of debt. In this position, I had the opportunity to meet with individuals who struggled financially. The experience was humbling and provided me with insight into how difficult it was for those individuals to seek financial assistance and to ask for help.

In addition to my work history experience, I have had three family members who have experienced cancer: my grandmother, uncle and step-father. These family members have all died from the effects of having lung cancer and I was unaware of their financial concerns at the time of their cancer experiences. When speaking with my mother about her and my stepfather’s experience, she elaborated on the stress of the associated costs. Although they had adequate funds to afford him care, the expense was immense and the loss that much greater after he lost his battle. Additionally, although I do not know for certain, I suspect my uncle selected to not receive cancer treatment due to cost. He was diagnosed at a late stage and the cost/benefit may not have been in his favor. As for my grandmother, she would be considered lucky back then as they removed half of her lung and with the assistance of oxygen, she survived several years after.

All of my educational, career, and life experiences have led to the development of who I am as a researcher on this project. As I engaged in the analysis process, I was challenged to recognize who I am and how that may affect the interpretation of the participant's experience. It was my goal to allow the views of the participant to not be overshadowed by any preconceptions that I had.

APPENDIX H: CONSENT PREAMBLE

Hello

You are being invited to participate in a research study by answering the following survey about understanding the financial demands cancer patients may experience during and after treatment, as well as exploring their preferences for support and information. There are no known risks for your participation in this research study. The information collected may not benefit you directly. The information learned in this study may be helpful to others. The information you provide will be used to inform medical professionals about the information patients want and need regarding the costs of cancer treatment and available resources to assist them. Your completed survey will be collected in a protected survey collection system and then stored on a password protected and secured computer. The survey will take approximately 20-30 minutes to complete.

Individuals from the University of Louisville Kent School of Social Work, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPO), and other regulatory agencies may inspect these records. In all other respects, however, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed.

Taking part in this study is voluntary. By completing this survey you agree to take part in this research study. You do not have to answer any questions that make you uncomfortable. You may choose not to take part at all. If you decide to be in this study you may stop taking part at any time.

If you have any questions, concerns, or complaints about the research study, please contact: Dr. Kayser at [telephone number]

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

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call [telephone number]. This is a 24-hour hotline answered by people who do not work at the University of Louisville.

This study is supported through a Doctoral Training Grant from the American Cancer Society and approved by the University of Louisville IRB: 17.0187.

Sincerely,
Karen Kayser, PhD and Lisa Smith, MSSW

APPENDIX I: STUDY 2 CALL FOR PARTICIPANTS

What was your experience with the financial costs of cancer treatment?

This study, conducted by researchers at the University of Louisville, is about the impact of cancer treatment on the financial well-being and quality of life of cancer survivors.

We are inviting volunteers who have been diagnosed with breast cancer or blood (Leukemia, Lymphoma, or Myeloma) cancer within the past five years to participate in this study.

This study is open to men and women 18 years and older. It involves taking a 20-30 minute online survey and it is completely anonymous.

By better understanding your experiences we may be able to help others navigate the financial terrain of cancer.

If interested in participating follow this link to the survey.
https://qmsweb.louisville.edu/blue/a.aspx?l=3325_1_AAAAAAAAaB8

Please let me know if you have any question.
Lisa Smith

APPENDIX J: STUDY 2 QUESTIONNAIRE

Financial Impact of Cancer: Patient Preferences for Information and Support

Introduction

This questionnaire is about your experience with cancer and the impact this has had on you financially. It attempts to explore your preferences to receiving information about you medical costs as well as explore helpful resources and supports you may have relied on. It will help us to assess the impact of the costs of cancer care and understand how to financially guide future cancer patients. All answers are completely confidential. This survey is expected to take about 30 minutes to complete.

Section I Contextual Questions

What type of cancer did you have?

1- Blood cancer
    a. Leukemia
    b. Lymphoma
    c. Myeloma
2- Breast cancer

What type of cancer treatment did you receive? (Mark all that apply)

1- Surgery
2- Chemotherapy
3- Radiation
4- Stem Cell Transplant
5- Immunotherapy
6- Other _________________

What is the current status of your cancer?

1- Active
2- Remission
3- Cured

When were you first diagnosed with cancer? ___yr (fill-in)

When was your last cancer treatment? ___yr ___month (fill-in)

When you were diagnosed with cancer,

	Nothing at all	A little bit	Some	Quite a bit	Very Much
How much did you understand your health insurance coverage?	**0**	**1**	**2**	**3**	**4**
How much did you understand about how much your treatment would cost?	**0**	**1**	**2**	**3**	**4**
How much did you understand how much you would have to pay out of pocket?	**0**	**1**	**2**	**3**	**4**
How much financial guidance did you received from your cancer clinic?	**0**	**1**	**2**	**3**	**4**

Which statement best describes your experience:

1. **Someone at the cancer center/hospital offered to help me understand my insurance, and medical costs.**
2. **I asked someone at the cancer center/hospital for help in understanding my insurance and medical costs.**
3. **I needed help understanding my insurance and medical costs but was not sure whom to ask.**
4. **I did not need help in understanding my insurance and medical costs.**
5. **Other_____**

During your cancer experience: (Mark all that apply)

	No One	Doctor	Financial advisor at cancer center	Social worker	Nurse	Insurance company
Who talked to you about your treatment costs?	**0**	**1**	**2**	**3**	**4**	**5**
Who talked to you about what your insurance would cover?	**0**	**1**	**2**	**3**	**4**	**5**
Who provided you with resources to get financial help?						
In your opinion, whom should talk patients about treatment costs, insurance coverage and resources? (**mark all that apply**)	**0**	**1**	**2**	**3**	**4**	**5**

Was there ever a time during your cancer experience that you felt stressed about your financial situation (any time you were concerned about the cost of treatment, managing every day expenses, what your insurance might cover, etc.)? 0-No, 1- Yes

During your cancer experience:

	Not at all	A little bit	Some-times	Quite a bit	Very Much
Were you ever concerned about how you would pay for your medical expenses?	**0**	**1**	**2**	**3**	**4**
Were you ever concerned about how much your insurance would cover?	**0**	**1**	**2**	**3**	**4**
Were you ever concerned about how you would pay for every day expenses (food, rent, utilities, etc)?	**0**	**1**	**2**	**4**	**5**

Patients have reported to experience out-of-pocket expenses related to their cancer treatment and follow-up. These include travel, over-the-counter medications, supplies, childcare, increases in co-payments and insurance premiums. Over the course of your cancer treatment, what was your estimated out-of-pocket expense?

1) **$0 - $5000**
2) **$5001 - $10,000**
3) **$10,001 - $20,000**
4) **$21,001 - $40,000**
5) **More than $40,000**

If over $40,000, how much? __________________

What is your estimated post-treatment expense per year? (I.e. medical costs for follow-up visits, screening, medication, etc.).

1) **N/A**
2) **$0 - $5000**
3) **$5001 - $10,000**
4) **Over $10,000**
   If over $10,000, how much? ______

How many times per year do you receive post-treatment services (cancer screening, medical appointment, etc.)? _______

Due to your cancer experience:

- **Did your insurance ever deny a cancer-related medical claim?**
  0 – No   1- Yes
  If yes, how many times? ________

- **Did you file an appeal with your insurance provider for not covering cancer-related medical claims?** 0 – No   1- Yes
  If yes, how many times? ________

- **Did you contact your medical providers because of an error in their billing process?** 0 – No 1- Yes
  If yes, how many times? ________

- **Did your receive collection calls due to your medical bills?** 0-No, 1- Yes

- **Did you file for bankruptcy?** 0-No, 1- Yes

Due to your cancer experience did you:

	Not at all	A little bit	Some-times	Quite a bit	Very Much	N/A
Delay receiving treatment	**0**	**1**	**2**	**3**	**4**	
Stop receiving treatment	**0**	**1**	**2**	**3**	**4**	
Alter medication choices due to costs	**0**	**1**	**2**	**3**	**4**	
Cut back on spending for food, clothing, entertainment	**0**	**1**	**2**	**3**	**4**	
Modify your mortgage or rent payment	**0**	**1**	**2**	**3**	**4**	
Negotiate bill payments	**0**	**1**	**2**	**3**	**4**	
Defer student loan payment	**0**	**1**	**2**	**3**	**4**	
Sell possessions	**0**	**1**	**2**	**3**	**4**	
Use credit cards	**0**	**1**	**2**	**3**	**4**	
Use retirement money	**0**	**1**	**2**	**3**	**4**	
Use savings	**0**	**1**	**2**	**3**	**4**	
Debt consolidation	**0**	**1**	**2**	**3**	**4**	
Use vacation time/money	**0**	**1**	**2**	**3**	**4**	
Eliminated expenses	**0**	**1**	**2**	**3**	**4**	
Gave up career/job	**0**	**1**	**2**	**3**	**4**	
Changed career/job	**0**	**1**	**2**	**3**	**4**	
Apply for patient grants	**0**	**1**	**2**	**3**	**4**	
Use employee sick-time assistance	**0**	**1**	**2**	**3**	**4**	
Open a Go Fund Me account	**0**	**1**	**2**	**3**	**4**	

What helpful information or guidance <u>did you receive</u> regarding your treatment costs, payments, insurance, etc.? (Mark all that apply)

[ ] Treatment options and costs.
[ ] Insurance coverage.
[ ] Estimate on how much I would have to pay for treatment.
[ ] Estimate on out-of-pocket expenses not covered by insurance would be.
[ ] Eligibility for disability.
[ ] Eligibility for FMLA.
[ ] Eligibility for Medicare/Medicaid.

[ ] Student loan deferment.
[ ] Resources to help pay for treatment costs.
[ ] Resources to help pay for medications.
[ ] Resources to help pay for every-day living expenses.
[ ] other ___________________

Do you feel the following information would be helpful to receive when diagnosed with cancer:

	Not at all	A little bit	Some-times	Quite a bit	Ver y Muc h
Treatment options and their costs.	**0**	**1**	**2**	**3**	**4**
What your insurance will cover.	**0**	**1**	**2**	**3**	**4**
Estimated costs you will have to pay.	**0**	**1**	**2**	**3**	**4**
How to file an appeal with your insurance company?	**0**	**1**	**2**	**3**	**4**
Estimated out-of-pocket expenses on items that are not covered by insurance.	**0**	**1**	**2**	**3**	**4**
Eligibility for disability	**0**	**1**	**2**	**3**	**4**
Eligibility for the Family and Medical leave Act (FMLA).	**0**	**1**	**2**	**3**	**4**
Eligibility for Medicare/Medicaid	**0**	**1**	**2**	**3**	**4**
Financial resources to help pay for medications?	**0**	**1**	**2**	**3**	**4**
Financial resources to help pay for treatment costs?	**0**	**1**	**2**	**3**	**4**
Financial resources to help pay for every-day living expenses (rent, food, etc.)	**0**	**1**	**2**	**3**	**4**
Who to talk to about financial questions and concerns.	**0**	**1**	**2**	**3**	**4**

What other financial information do you think would be helpful to give to patients when they are diagnosed with cancer? ____

____

How much do you agree with these statements?

	Not at all	A little bit	Some-times	Quite a bit	Very Much

Doctors should consider treatment costs and insurance coverage before making treatment recommendations.	**0**	**1**	**2**	**3**	**4**
Patients should consider treatment costs and insurance coverage before making treatment decisions.	**0**	**1**	**2**	**3**	**4**
During my cancer experience, I had all the information I needed to make a decision about treatment.	**0**	**1**	**2**	**3**	**4**
I would seek cancer treatment for no matter what the cost.	**0**	**1**	**2**	**3**	**4**

During your cancer experience, did you receive tangible financial support or assistance from:

	Not at all	A little bit	Somewhat	Quite a bit	Very much
Parents/Parents-in-law	**0**	**1**	**2**	**3**	**4**
Children	**0**	**1**	**2**	**3**	**4**
Friends	**0**	**1**	**2**	**3**	**4**
Co-workers/Employer	**0**	**1**	**2**	**3**	**4**
Faith-based Community	**0**	**1**	**2**	**3**	**4**
Non-Profit Organizations	**0**	**1**	**2**	**3**	**4**
Medical Center	**0**	**1**	**2**	**3**	**4**
Pharmaceutical Company	**0**	**1**	**2**	**3**	**4**
Other	**0**	**1**	**2**	**3**	**4**

Section II Financial Toxicity Scale (Cost-Prom)

Below is a list of statements related to the financial impact of your illness. Please place an X in the box that best describes how you feel about that statement.

	Not at all	A little bit	Some-times	Quite a bit	Very Much
I feel financially stressed.	**0**	**1**	**2**	**3**	**4**
I am satisfied with my current financial situation.	**0**	**1**	**2**	**3**	**4**
I worry about the financial problems I will have in the future as a result of my illness or treatment.	**0**	**1**	**2**	**3**	**4**
I am frustrated that I cannot work or contribute as much as I usually do.	**0**	**1**	**2**	**3**	**4**
My cancer or treatment has reduced my satisfaction with my present financial situation.	**0**	**1**	**2**	**3**	**4**

I feel in control of my financial situation.	**0**	**1**	**2**	**3**	**4**
I am able to meet my monthly expenses.	**0**	**1**	**2**	**3**	**4**
I know that I have enough money in savings, retirement or assets to cover the costs of my treatment.	**0**	**1**	**2**	**3**	**4**
I am concerned about keeping my job and income, including working at home.	**0**	**1**	**2**	**3**	**4**
I feel I have no choice about the amount of money I spend on care.	**0**	**1**	**2**	**3**	**4**
My out of pocket medical expenses are more than I thought they would be.	**0**	**1**	**2**	**3**	**4**

Section III Perceived Social Support

PROMIS -Emotional Support (Please respond to each item by marking one box per row.)

	Never	Rarely	Some-times	Usually	Always
I have someone who will listen to me when I need to talk.	**1**	**2**	**3**	**4**	**5**
I have someone to confide in or talk to about myself or my problems.	**1**	**2**	**3**	**4**	**5**
I have someone who makes me feel appreciated.	**1**	**2**	**3**	**4**	**5**
I have someone to talk with when I have a bad day.	**1**	**2**	**3**	**4**	**5**

PROMIS - Informational Support (Please respond to each item by marking one box per row.)

	Never	Rarely	Some-times	Usually	Always
I have someone to give me good advice about a crisis if I need it.	**1**	**2**	**3**	**4**	**5**
I have someone to turn to for suggestions about how to deal with a problem.	**1**	**2**	**3**	**4**	**5**
I have someone to give me information if I need it.	**1**	**2**	**3**	**4**	**5**
I get useful advice about important things in life.	**1**	**2**	**3**	**4**	**5**

PROMIS - Instrumental Support (Please respond to each item by marking one box per row.)

	Never	Rarely	Sometimes	Usually	Always
Do you have someone to help you if you are confined to bed?	**1**	**2**	**3**	**4**	**5**
Do you have someone to take you to the doctor if you need it?	**1**	**2**	**3**	**4**	**5**
Do you have someone to help with your daily chores if you are sick?	**1**	**2**	**3**	**4**	**5**
Do you have someone to run errands if you need it?	**1**	**2**	**3**	**4**	**5**

Section IV Received Social Support

We are interested in learning about some of the ways that you feel people have helped you or tried to make life more pleasant for you over the *past four weeks.* Please read each item carefully and indicate how often these activities happened to you during the ***past four weeks***.

	Not at all	Once or twice	About once a week	Several times a week	About every day
Gave you some information on how to do something.	**1**	**2**	**3**	**4**	**5**
Helped you understand why you didn't do something well.	**1**	**2**	**3**	**4**	**5**
Suggested some action you should take.	**1**	**2**	**3**	**4**	**5**
Gave you feedback on how you were doing without saying it was good or bad.	**1**	**2**	**3**	**4**	**5**
Made it clear what was expected of you.					
Told you what he/she did in a situation that was similar to yours.	**1**	**2**	**3**	**4**	**5**
Told you that he/she feels close to you.	**1**	**2**	**3**	**4**	**5**
Let you know that he/she will always be around if you need help.	**1**	**2**	**3**	**4**	**5**
Told you that you are OK just the way you are.	**1**	**2**	**3**	**4**	**5**
Expressed interest and concern in your well-being.	**1**	**2**	**3**	**4**	**5**
Comforted you by showing you some physical affection.	**1**	**2**	**3**	**4**	**5**

Told you that he/she would keep the things you talk about private.	**1**	**2**	**3**	**4**	**5**
Agreed that what you wanted to do was the right thing.	**1**	**2**	**3**	**4**	**5**
Did some activity together to help you get your mind off things.	**1**	**2**	**3**	**4**	**5**
Gave or loaned you over $25	**1**	**2**	**3**	**4**	**5**
Provided you with a place to stay.	**1**	**2**	**3**	**4**	**5**
Loaned you or gave you something (a physical object) that you needed.	**1**	**2**	**3**	**4**	**5**
Pitched in to help you do something that needed to get done.	**1**	**2**	**3**	**4**	**5**
Went with you to someone who could take action.	**1**	**2**	**3**	**4**	**5**

Section V Financial Social Support

	Never	Rarely	Some-times	Usually	Always
I have someone to talk to about my financial concerns.	**1**	**2**	**3**	**4**	**5**
I know where to get information about financial assistance to help with my cancer expenses.	**1**	**2**	**3**	**4**	**5**
I know where to get information about financial assistance to meet my everyday obligations (rent, food, utilities, etc.).	**1**	**2**	**3**	**4**	**5**
I am able to request financial help when needed.	**1**	**2**	**3**	**4**	**5**
I have friends or family who can help me financially if needed.	**1**	**2**	**3**	**4**	**5**

During your cancer experience, did you talk to a family member or friend about your financial concerns about treatment costs, lost wages, out-of-pocket expenses, etc.? 0- No; 1- Yes

- If No, what prevented you from talking about your financial concerns or stress? (open-ended) _________
- If yes, who did you talk to (spouse, child, parent, best friend, pastor, etc.) __________

Section VI Quality of Life (Fact-G Version 4)

Below is a list of statements that other people have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

Physical Well-Being

	Not at all	A little bit	Somew hat	Quite a bit	Very much
I have a lack of energy.	**0**	**1**	**2**	**3**	**4**
I have nausea.	**0**	**1**	**2**	**3**	**4**
Because of my physical condition, I have trouble meeting the needs of my family.	**0**	**1**	**2**	**3**	**4**
I have pain.	**0**	**1**	**2**	**3**	**4**
I am bothered by side effects of treatment.	**0**	**1**	**2**	**3**	**4**
I feel ill.	**0**	**1**	**2**	**3**	**4**
I am forced to spend time in bed.	**0**	**1**	**2**	**3**	**4**

Please circle or mark on number per line to indicate your response as it applies to the past 7 days.

Social/Family Well-Being

	Not at all	A little bit	Somew hat	Quite a bit	Very much
I feel close to my friends.	**0**	**1**	**2**	**3**	**4**
I get emotional support from my family.	**0**	**1**	**2**	**3**	**4**
I get support from my friends.	**0**	**1**	**2**	**3**	**4**
I am satisfied with family communication about my illness.	**0**	**1**	**2**	**3**	**4**
I feel close to my partner (or the person who is my main support).	**0**	**1**	**2**	**3**	**4**
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ and go to the next section.					
I am satisfied with my sex life.	**0**	**1**	**2**	**3**	**4**

Emotional Well-Being

	Not at all	A little bit	Somew hat	Quite a bit	Ver y muc h
I feel sad.	**0**	**1**	**2**	**3**	**4**
I am satisfied with how I am coping with my illness.	**0**	**1**	**2**	**3**	**4**
I am losing hope in the fight against my illness.	**0**	**1**	**2**	**3**	**4**
I feel nervous.	**0**	**1**	**2**	**3**	**4**
I worry about dying.	**0**	**1**	**2**	**3**	**4**

I worry that my condition will get worse.	**0**	**1**	**2**	**3**	**4**

Functional Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to work (include work at home).	**0**	**1**	**2**	**3**	**4**
My work (include work at home) is fulfilling.	**0**	**1**	**2**	**3**	**4**
I am able to enjoy life.	**0**	**1**	**2**	**3**	**4**
I have accepted my illness.	**0**	**1**	**2**	**3**	**4**
I am sleeping well.	**0**	**1**	**2**	**3**	**4**
I am enjoying the things I usually do for fun.	**0**	**1**	**2**	**3**	**4**
I am content with the quality of my life right now.	**0**	**1**	**2**	**3**	**4**

Please circle or mark on number per line to indicate your response as it applies to the past 7 days.

Economic Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I believe that being sick will hurt me financially.	**0**	**1**	**2**	**3**	**4**
People like me are able to get the healthcare they need.	**0**	**1**	**2**	**3**	**4**
I am able to make enough money to pay for my healthcare.	**0**	**1**	**2**	**3**	**4**
I have to pay more for my medical care than I can afford.	**0**	**1**	**2**	**3**	**4**
I am able to pay for my medical bills.	**0**	**1**	**2**	**3**	**4**
I can easily get information about healthcare.	**0**	**1**	**2**	**3**	**4**
I can afford medical check-ups even when I am not sick.	**0**	**1**	**2**	**3**	**4**
I have enough money to take care of my healthcare needs.	**0**	**1**	**2**	**3**	**4**
I can get the health insurance we need.	**0**	**1**	**2**	**3**	**4**
My family thinks good healthcare is important.	**0**	**1**	**2**	**3**	**4**
I know how to get the healthcare services I need.	**0**	**1**	**2**	**3**	**4**

I know people who will help me out when I am sick.	**0**	**1**	**2**	**3**	**4**
People I know best have healthy habits.	**0**	**1**	**2**	**3**	**4**
I understand the healthcare system.	**0**	**1**	**2**	**3**	**4**
The medicine I need is too expensive for me.	**0**	**1**	**2**	**3**	**4**
I am treated the same as other patients when I go for medical care.	**0**	**1**	**2**	**3**	**4**
Healthcare services are easy to get in my neighborhood.	**0**	**1**	**2**	**3**	**4**

Section VII Social Constraints

How often in the PAST MONTH has someone:

	Not at all	A little bit	Some-times	Quite a bit	Very often
Changed the subject when you tried to discuss your illness?	**0**	**1**	**2**	**3**	**4**
How often did it seem that other people did not understand your situation?	**0**	**1**	**2**	**3**	**4**
How often did other people avoid you?	**0**	**1**	**2**	**3**	**4**
How often did other people minimize your problems?	**0**	**1**	**2**	**3**	**4**
How often did other people seem to be hiding their feelings?	**0**	**1**	**2**	**3**	**4**
How often did other people act uncomfortable when you talked about your illness?	**0**	**1**	**2**	**3**	**4**
How often have other people trivialized your problems?	**0**	**1**	**2**	**3**	**4**
How often have other people complained about their own problems when you wanted to share yours?	**0**	**1**	**2**	**3**	**4**

How often did other people act cheerful around you to hide their true feelings and concerns?	**0**	**1**	**2**	**3**	**4**
How often did other people tell you not to worry so much about your health?	**0**	**1**	**2**	**3**	**4**
How often did other people tell you to try not to think about the cancer?	**0**	**1**	**2**	**3**	**4**
How often did you get the idea that other people didn't want to hear about your financial concerns?	**0**	**1**	**2**	**3**	**4**
How often did you feel as though you had to keep your feelings about your cancer to yourself because they made other people uncomfortable?	**0**	**1**	**2**	**3**	**4**
How often did other people make you feel as though you had to keep your feelings about your cancer to yourself, because it made others upset?	**0**	**1**	**2**	**3**	**4**
How often did you feel other people let you down by not showing you as much love and concern as you would have liked?	**0**	**1**	**2**	**3**	**4**
How often did you feel that you could discuss your feelings about your cancer-related financial concerns with (other people/important other) when you wanted to?	**0**	**1**	**2**	**3**	**4**

Section VIII Brief Health Literacy Screening Tool (BRIEF)

Please circle the answer that best represents your response.

	Always	Often	Some-times	Rarely	Never
How often do you have someone help you read hospital materials?	**1**	**2**	**3**	**4**	**5**
How often do you have a problem understanding the written materials about your medical condition?	**1**	**2**	**3**	**4**	**5**
How often do you have a problem understanding what is told to you about your medical condition?	**1**	**2**	**3**	**4**	**5**

	Not at all	A little bit	Some-what	Quite a bit	Extremely
How confident are you filling out medical forms by yourself?	**1**	**2**	**3**	**4**	**5**

Do you have any final thoughts or advice you would like share regarding the financial impact you have experienced due to your cancer experience? ___________

____

____

____

Section IX Demographic Questions

Home zip code:

How old are you? ____ (age in years)

Gender:

Are you male or female?

1- Male
2- Female

Race/Ethnicity

What is your racial/ethnic group?

7- African-American/Black
8- Asian
9- American Indian/Alaskan Native
10- Caucasian/White
11- Hispanic
12- Native Hawaiian/Other Pacific Islander
13- Other ___________________________

What is your current marital status?

6- Single, never married
7- Married
8- Not married, but in a relationship with significant other
9- Separated or divorced
10- Widowed

How many children under the age of 18 are living in your home? _____

What is your current job status?

7- Employed full-time
8- Employed part-time
9- Unemployed
10- Homemaker
11- Disabled
12- Retired

Before your cancer diagnosis, what was your job status?

7- Employed full-time
8- Employed part-time
9- Unemployed
10- Homemaker
11- Disabled
12- Retired

If your job status changed, did it change because of your cancer? 0 – No 1- Yes

Did you have to leave your job temporarily to receive cancer treatment or recover? 0 – No 1- Yes

Did you have to leave your job permanently due to your cancer? 0 – No 1- Yes

What was your insurance status at your <u>first cancer diagnosis</u>? (Check all that apply)

1- Employer paid private insurance
2- Self-paid private insurance
3- Veteran's Administration coverage
4- Medicare disability insurance
5- Medicaid
6- No insurance

Has your insurance status changed since your first cancer diagnosis? 0 – No 1- Yes

If yes, which of the following insurance changes did you experience?

1- I lost my because I can no longer work
2- I lost my insurance because I can no longer afford it
3- I became eligible for Medicaid
4- I became eligible for Medicare disability

What is your current insurance status? (Mark all that apply)

1- Employer paid private insurance
2- Self-paid private insurance
3- Veteran's Administration coverage
4- Medicare disability insurance
5- Medicaid
6- No insurance

What is the highest level of formal education that you have completed?

6- Less than high school
7- Completed high school or GED
8- Some college or technical school (includes technical, vocational, or certificate program and Associate's degree)
9- Bachelor's degree
10- Postgraduate or professional degree (includes Master's, MD, PhD, and JD)

What is your occupation?

7- Homemaker
8- Executive of manager
9- Professional or technical
10- Clerical, sales or service work
11- Occupation in agriculture, forestry or fisheries
12- Occupation in crafts, repair, manufacturing, transportation or operation of machinery

What were your household (family) gross wages or income last year (before taxes)?

7- Less than $25,000
8- $25,001-$40,000
9- $40,001-$60,000
10- $60,001-$80,000
11- Over $80,000
12- I don't know

Thank you for your help.

If you would be willing to participate in any follow-up questions or related studies please provide your name and email address/method to contact you.

____

APPENDIX K: QUANTITATIVE STRAND TABLE OF VARIABLES

Study 2 overview of variables, measurements, and level of measure.

Variables	**Measure**	**Level of Measure**
Independent Variable		
Financial Burden of Cancer	COST – Comprehensive Score for Financial Toxicity • 11-item, self-rated Likert scale (0 = Not at All to 5 = Very Much)	Interval
Moderator/Mediator Variable Social Support – Perceived	PROMIS – Emotional, Informational, & Instrumental short scales • Each scale has 8-items, 5-point Likert scale	Interval
Social Support - Received	Inventory of Socially Supportive Behaviors (ISSB) • 40-item, 5-point Likert scale	Interval
Criterion/Dependent Variable Quality of Life • Domains: Physical, Functional, Social & Emotional	FACT-G • 28 –item Likert scale (0 = Not at All to 4= Very Much).	Interval
• Doman: Socioeconomic	Socioeconomic Well-Being Scale • 17-item Likert scale (0 = Not at All to 4= Very Much)	Interval
Contextual Characteristics • Cancer type, • Cancer treatment, • Disease status, • Elapsed time since cancer Treatment	See questionnaire for specific questions.	Nominal/ Ordinal

Covariate • Social Constraint	Social Constraint Scale • 16 item Likert scale.	Interval
Covariate/Descriptive • Age, • Gender, • Race/Ethnicity, • Marital Status, • Employment, • Education • Insurance Status, • Income	See questionnaire for specific questions.	Interval/ Nominal/ Ordinal

APPENDIX L: PREPARING DATASET

Overview of Steps

1. Downloaded responses – n=131 – one deleted for missing data; deleted 4 for various types of cancer other than blood or breast (Colon, Kidney, Lung, Other-not specified).
2. Created SPSS database with blood and breast cancer patients.
3. Reverse coded variables and calculated scales.
4. Created Composite variable for Social Support.
5. Tested for assumptions.
6. Dummy variables were created for control variables.

Calculate Scales and Handling Missing Values

Cost scale

Missing values (4) were replaced with a simple mean substitution. This is the method the developers of the scale specified to use for missing data (de Souza). Following guidelines, items 2,6,7,8 were reverse scored and all items were totaled using SPSS (reverse codes 0-4, 1-3,2-2). In review of the data an outlier was found. Upon review of that case it was determined that a response was not entered correctly into SPSS. The correct response was determined by reviewing the original excel data file. Possible score range is 0-44. The higher the score, the worse the financial toxicity. A standard frequency distribution was conducted using SPSS. A mean score of 19.14 (SD = 8.56) range 0-44. See tests for assumptions and table for skewness and kurtosis for more information.

PROMIS Social Support scales

Guidelines for scoring the three PROMIS Social Support scales were followed. The short form for each domain was used. Two responses were missing and these where replaced with the mean score of participants responses as directed by the scale guidelines obtained from the Assessment Center (assessmentcenter.net). Raw scores were calculated and then translated to the designated T-score for each scale. The T-score allows the evaluation against the general U.S. population. A score of 50 (SD – 10) was determined by scale developers to be the average of the reference.

Composite Variable. A social support composite variable was created out of Social Support PROMIS scales following the direction of Song, Lin, Ward and Fine (2013). The variables created a meaning full grouping and were correlated but not highly correlated. A simple average approach was used as the scales are continuous. Z scores should be used when the original variables differ in variance with the outcome variable. This was not an issue but to verify such a second composite variable was created using Z scores and both composite variables were compared showing similar distribution. Creating a composite variable can control for Type 1 errors (rejecting the null hypothesis – supporting the hypothesis when it should be rejected). Power analysis were conducted to justify creating a composite variable opposed to using the Bonferroni correction. Power was high for all variables.

Steps used to create an equal weighted composite in SPSS: Transform → Compute variable → (Add each scales)/3.

Received Social Support

The short form for the Inventory of Socially Supportive Behaviors (ISSB) was used to measure the amount of social support received. Following study guidelines for scoring, 7 missing values were replaced with a simple mean substitution. Per scale tabulation instructions, mean substitution was calculated from all participant responses for that item. To obtain a total score, all items were then summed.

Social Constraint

Social Constraint required recoding of question 16. Mean substitution was used for 3 missing responses. All items were summed. The higher the score the more social constraint.

Quality of Life

Functional Assessment of Cancer Therapy scale (FACT-G) and the FACT-G plus socio-economic well-being scales were used to determine quality of life. Reversal of questions were followed: Physical Well-being subscale all 7 items; Emotional Well-being subscale item 1,3,4,5,6**;** Economic Well-being subscale items 1,4,15. Followed scale guidelines for missing data which involved adding up the individual's responses for that subscale and dividing by the number responded to.

Tests for Assumptions

Prior to conducting the analyses for the study aims, the data was reviewed to determine if it met the assumptions for analysis. Box and Whisker plots were created to identify outliers. Outliers were identified; therefore, additional analysis used histograms, skewness and kurtosis values, and the interquartile range (IQR). Outliers were all within the 1.5 IQR range so these observations stayed in the data pool.

Tests for normal distribution were conducted. Shapiro-Wilks raised concern over all scales expect the FACT-G. Upon further inspection of (histograms, skewness and kurtosis values) all scales appeared to meet expectations for normality except for social constraint. Final decision as based off the robustness of the sample size being large enough to advert issues of normality. Further, the PROCESS model used for the Mediator analysis uses bootstrap technique at 5000 samples to handle issues of non-normal distribution.

Issue of multicollinearity were examined through Pearson's Correlations. Variables were not too highly correlated. The received support variable in the blood and breast cancer dataset was not properly correlated with other variables; more information can be found in Chapter 6 and 7. To determine if the data had issues of linearity or heteroscedasticity, scatter plots and linear regressions were used. All data appeared to be linear and homoscedastic.

Outliers

Outliers can lead to Type I and Type II errors (Tabachnick, et al., 2013); therefore, careful review of the data was conducted. The presence of outliers was assessed a box and whisker plot assessment. The box and whisker plot in SPSS indicate if an observation is over 1.5 Inter-quartile Range (IQR) rule. SPSS calculates the upper and lower quartiles and then multiplies the difference by 1.5. Any observation beyond this calculation would be indicated as an outlier. According to Hoaglin and Iglewicz (1987), this IQR rule can be incorrect about 50% of the time and a more appropriate indicator is at a multiplication of 2.2. This requires that the researcher review any outliers indicated by SPSS. Box and whisker plots were reviewed and assessed for outliers.

Creating Box and Whisker Plot for Outliers.

Steps in SPSS:
1) Select Graphs
2) Legacy Dialog
3) Boxplot

4) Simple
5) Define
6) Select the variable you want to examine into the Variable box.
7) Select a categorical variable for the x-axis.
8) Select OK

Normal Distribution

Distribution was check by using the Shapiro-Wilks Analysis, Skewness and Kurtosis and if the absolute value was less than the value of the standard error multiplied by 3. The data size is large enough (n= 126) that the assumption of normality is not a concern (reference Lawson email and StatistisHowTo.com)

Shapiro-Wilks. SPSS Steps:

1) Analyze
2) Descriptive Statistics
3) Explore
4) Select data into Dependent List
5) Select Plots
    a. Select Normality plots with tests
6) Significance indicates not normal distribution.

In order to check for normality a normal distribution of data a Shapiro-Wilks analysis was conducted on all scales. The Quality of Life FACT -G scale was found to be not significant ($p < 0.118$). This indicated that the data was normally distributed. The remaining scales were found to be significant: FACT-G with Economic Well-being ($p < 0.02$), COST ($p <0.001$), Social Constraint ($p < 0.000$), Received Social Support ($p < 0.03$), Emotional, Informational and Instrumental Social Support each ($p < 0.001$), Composite Social Support ($p < 0.001$).This infers that the data for these scales is not normally distributed and required further investigation.

Skewness and Kurtosis. In order to check for normal distribution of data a descriptive analysis was conducted to identify skewness and kurtosis. When assessing for skewed data, a zero value indicates the distribution tail is equal on both sides. A positively skewed data has the tail on the right and negatively skewed has the tail on the left. The further the calculated value is from zero the more likely it indicates a non-normal distribution. A value between -1 and +1 is typically within normal range. Another method to determine normal distribution is to determine interquartile range (i.e., if the absolute value is less than the value of the standard error multiplied by 3). For this later assessment, two scales raise some concern as their values are slightly above the acceptable range (see table for values). For these two scales, bootstrapping analysis will need to be implemented. Kurtosis is the assessment of the peak of the distribution. It indicates if the peak is too sharp or too flat. Using the same assessment as above, there does not appear to be any issues with kurtosis. All scales were further viewed using scatter plots and histograms for interpretation of normative data.

Table Appendix.1: Skewness and Kurtosis Values.

Variable	Skewness	Kurtosis
COST	0.354	0.732
Emotional Support	-0.303	-0.830
Informational Support	-0.232	-0.658
Instrumental Support	-0.159	-0.90
Composite Support	-.265	-.954
Received Support	0.1.43	-0.835
Social Constraint	0.755	-0.481
FACT-G	-0.353	-0.376
FACT-G Plus	-0.351	-0.456

COST Comprehensive Score for Financial Toxicity, *FACT-G* Functional Assessment of Cancer Therapy scale for QoL, *FACT-G Plus* Socioeconomic Well-being scale.

Linearity

SPSS steps to create scatter plot using criterion variable (predicted variable).

1) Graphs → Legacy Dialog → Scatter/Dot → Select Simple → Define
2) Move dependent variable to Y Axis and independent variable to X Axis
3) Double click on chart. Select fit line.
4) Scatter plots looked acceptable. (Received social support looked concerning but had a slight linear relationship.)

Test for Homoscedasticity

Homoscedasticity results if you have a consistent relationship across the page. Heteroscedasticity exists if the relationship is erratic which is not desired. Scatter plots were conducted on all scales with no issues of heteroscedasticity.

SPSS steps to create plot to examine homoscedasticity.

1) Analyze
2) Select Regression
3) Select Linear
4) Put scale interested in Dependent and another variable in the Independent
5) Plots – put ZRESID in Y axis and ZPred in X axis
6) Continue and OK
7) Double click on the table and select “fit line” on the plot. Want line to be flat.

This provides the predictor on the x axis and error on the y axis.

Multicollinearity

Multicollinearity occurs when two IVs are highly correlated. Pearson’s Correlation was run to check for correlations (desired $r < .80$). All scales were below $r = .80$ except FACT-G and FACT-G Plus. This is expected as they are partially the same scale and will not be run in the same analysis.

Reliability

Scale reliability analysis were conducted to ensure the scale reflects the construct it is measuring.

Steps in SPSS:

1) Analysis
2) Scale
3) Reliability analysis
4) Select all items of each scale.
5) Model: Alpha
6) Select Run

Dummy Variables

Multiple regression cannot handle a nominal variable with more than 2 levels. Dummy variables were created for variables that theoretically may impact the outcome variable. Items were recoded with 0 or 1 with zero = other and 1 = category of interest.

APPENDIX M: PEARSON BIVARIATE CORRELATIONS

Pearson’s bivariate correlations were used to determine if relationships between interval/ratio level variables exist (Meyers et al., 2013; Field, 2013; Lawson et al., 2014). Pearson’s correlation report if items are negatively or positively correlated. Accepted affect values are basic Cohen conversions: -1 to -0.51 equals strong negative correlation; -0.5 to -0.20 equals moderate negative correlation; -0.19 to -0.01 equals weak negative correlation; 0.00 equals no correlation; 0.01 to 0.19 equals weak positive correlation; 0.2 to 0.50 equals moderate positive correlation; 0.51 to 1 equals a strong positive correlation. If assumptions are not met and the data contains outliers or is not normally distributed, correlations can be determined using a rank order method: Spearman’s rho or Kendall’s tau (Lawson et al. 2014; Fields, 2013).

Analysis Plan to Determine Co-variables (adapted from Lawson et al., 2014 Chapter 6)

Study Question:	What is the relationship between quality of life and interval/ratio variables listed below? • Age • Social Support • Financial Burden • Social constraint
Hypothesis:	Experimental: There is a relationship between quality of life and variables. Null: There is no significant relationship.
Expected:	There will be no relationship between quality of life and the identified variables.
Assumptions:	Interval level data, normal distributions

SPSS steps for analysis:

Analyze → Scroll down to correlate → Bivariate → Pearson

1. Select variables
2. OK to run

APPENDIX N: ANALYSIS OF VARIANCE

Analysis of Variance (ANOVA) was used to determine if there are relationships between quality of life (DV) and any nominal/ordinal variables in this study. The ANOVA will report if any significant differences occur between the groups in the analysis; therefore, indicating a variable that may affect the outcome.

Analysis Plan (adapted from Lawson, et al., 2014 – Chapter 2)

Study Question: Is there a difference in quality of life between [nominal/ordinal variable categories]?

- Disease Status
- Gender
- Race/Ethnicity
- Marital Status
- Education
- Employment
- Insurance Status
- Treatment

Hypothesis: Experimental: There is a difference in quality of life between [nominal/ordinal variable categories].
Null: There is no significant difference.
Expected: There will be no significant difference.
Type of Design: Non-Experimental Ex Post Facto
Assumptions: Nominal/Ordinal IV, Interval/ratio DV, normal distributions

SPSS Steps for Analysis:

Analyze → Select General Linear Model → Univariate

(3) Move Quality of life (DV) into Dependent box
(4) Move [nominal/ordinal level variable] (IV) into Factor box
(5) Select options: Descriptive, Estimates of Effect Size, Observed Power and Homogeneity of Variance Test
(6) Run Analysis

Partial eta-squared effect sizes (Lawson, et al., 2014):

0.010 = small effect size
0.059 = medium effect size
0.138 = large effect size

Power

As the statistical power increase the chances of making a Type II error and wrongly rejecting the null hypothesis decreases. More power to decrease risk of Type II error.

APPENDIX O: MODERATION ANALYSES IN PROCESS

Hierarchical stepwise multiple regression analysis will be simulated through the *Introduction to Mediation, Moderation, and Conditional Process Analysis* (PROCESS) macro.

Analysis Plan (adapted from Lawson, et al., 2014 – Chapter 7)

Level of Measurement: IV interval/ratio level; DV interval/ratio level
Type of Design: Non-Experimental Ex Post Facto
Number of Samples: One sample
Assumptions: Interval/ratio level data, normal distributions, linear relationship (scatter plot), homoscedasticity (error and model fit), not multicollinearity. Sample size, misspecification of variables?
Possible control variables: Interval: social constraint,
Ordinal/Nominal: cancer treatment, education, employment, insurance status, and marital status.

SPSS Steps for PROCESS Moderation Analysis

1. Select Analysis
2. Select Regression
3. Select PROCESS
4. Put Social Support in Proposed Moderator W box and Financial burden in X variable Box
5. Put Quality of life in the Y Variable box
6. Select Model #1 (or 3 for Moderated Moderator)
7. Select Options
    a. Select Mean Center, Visualizing Interactions, Regression Coefficients, Heteroscedasticity
8. Click continue
9. OK to run
10. Moderator effect is indicated by significant model fit (overall, for each variable and for interaction).
11. If significant – run again with covariates (dummy variable covariates)

12. Move: Cancer Treatment, Education, Employment, Insurance and Marital Status (items selected due to outcomes of ANOVA analysis to see if these variables played a role).
13. OK to run
14. Remove non-significant variables from the equation.
15. Add Social Constraint to Moderator Z box.
16. Select Model 3 (Model 3 used because Social Constraint is a continuous variables)

Example: SPSS Output for Moderation Analysis

Received Social Support moderates the relations between Financial Toxicity and Quality of Life (Fact-G).

```
*************** PROCESS Procedure for SPSS Version 3.3 ******************

       Written by Andrew F. Hayes, Ph.D.       www.afhayes.com
   Documentation available in Hayes (2018). www.guilford.com/p/hayes3

************************************************************************
**
Model  : 1
   Y  : QoL
   X  : COST
   W  : RecSS

Sample
Size:  106

************************************************************************
**
OUTCOME VARIABLE:
 QoL

Model Summary
       R       R-sq       MSE     F(HC0)       df1        df2          p
     .6213     .3861   253.5251    18.1830     3.0000   102.0000      .0000

Model
              coeff    se(HC0)          t              p       LLCI       ULCI
constant    67.0876     1.5141    44.3072       .0000    64.0842    70.0909
COST        -1.4101      .2153    -6.5484       .0000    -1.8372     -.9830
RecSS        .3198       .1041      3.0733       .0027      .1134      .5262
Int_1        .0335       .0141      2.3773       .0193      .0056      .0615

Product terms key:
```

```
 Int_1    :        COST     x        RecSS

Covariance matrix of regression parameter estimates:
          constant      COST      RecSS      Int_1
constant     2.2926      .0743     -.0319     -.0020
COST          .0743      .0464     -.0012     -.0017
RecSS        -.0319     -.0012      .0108      .0003
Int_1        -.0020     -.0017      .0003      .0002

Test(s) of highest order unconditional interaction(s):
      R2-chng     F(HC0)       df1        df2         p
X*W      .0287     5.6515     1.0000   102.0000      .0193
----------
   Focal predict: COST     (X)
        Mod var: RecSS    (W)

Conditional effects of the focal predictor at values of the moderator(s):

     RecSS     Effect    se(HC0)          t          p       LLCI       ULCI
  -15.5233    -1.9303      .3825    -5.0470      .0000    -2.6890    -1.1717
    1.4767    -1.3606      .2046    -6.6506      .0000    -1.7664     -.9548
   16.3567     -.8619      .2115    -4.0757      .0001    -1.2814     -.4425

Data for visualizing the conditional effect of the focal predictor:
Paste text below into a SPSS syntax window and execute to produce plot.

DATA LIST FREE/
  COST       RecSS      QoL       .
BEGIN DATA.
   -8.1406   -15.5233    77.8370
    1.7394   -15.5233    58.7652
    5.7394   -15.5233    51.0438
   -8.1406     1.4767    78.6360
    1.7394     1.4767    65.1931
    5.7394     1.4767    59.7507
   -8.1406    16.3567    79.3353
    1.7394    16.3567    70.8195
    5.7394    16.3567    67.3718
END DATA.
GRAPH/SCATTERPLOT=
 COST     WITH     QoL      BY       RecSS    .

*********************** ANALYSIS NOTES AND ERRORS *****************
******

Level of confidence for all confidence intervals in output:
```

```
  95.0000

W values in conditional tables are the 16th, 50th, and 84th percentiles.

NOTE: A heteroscedasticity consistent standard error and covariance matrix estimator wa
s used.

NOTE: The following variables were mean centered prior to analysis:
         RecSS    COST

------ END MATRIX -----
```

APPENDIX P: MEDIATION ANALYSIS IN PROCESS

The PROCRESS macro for SPSS was used to simulate the linear regression analyses to determine mediation.

Analysis Plan (adapted from Lawson, et al., 2014)

Level of Measurement:	Interval/ratio (DV), Interval/ratio (IV)
Type of Design:	Non-Experimental - Ex Post Facto
Number of Samples:	One sample
Assumptions:	Normal distributions, linear relationship

SPSS Steps for Analysis Hypotheses 2.1 – 2.4

(1) Open Data Set
(2) Analyze
(3) Regression
(4) PROCESS v3.3 by Hayes (2017)
(5) Move variables in to respective boxes
    a. DV into X Variable box
    b. IV into Y variable box
    c. Mediator Variable into Mediator(s) M box.
    d. (Moderated Mediator model 14 add to box Moderator W box – for social constraint)
(6) Select appropriate Model (4 or 14)
(7) Click on Options
    a. Select Show covariance, generate code for visualizing, show total effect (model 4 only), effect size, standardized coefficients, Heteroscedasticity (Huber-White).
(8) Continue
(9) OK to run

Example: SPSS Output for Moderation Analysis

Perceived Social Support mediates the relations with Financial Toxicity and Quality of Life (Fact-G).

```
*************** PROCESS Procedure for SPSS Version 3.3 ******************
```

```
       Written by Andrew F. Hayes, Ph.D.       www.afhayes.com
   Documentation available in Hayes (2018). www.guilford.com/p/hayes3

**********************************************************************
**
Model  : 4
   Y  : QofL
   X  : COST
   M  : CompSS

Sample
Size:  126

**********************************************************************
**
OUTCOME VARIABLE:
 CompSS

Model Summary
        R       R-sq       MSE     F(HC0)        df1        df2          p
     .4596      .2112    54.6455    34.1629     1.0000   124.0000      .0000

Model
             coeff    se(HC0)          t          p       LLCI       ULCI
constant   60.0540     1.3842    43.3844      .0000    57.3142    62.7938
COST        -.4384      .0750    -5.8449      .0000     -.5868     -.2899

Standardized coefficients
        coeff
COST     -.4596

Covariance matrix of regression parameter estimates:
          constant       COST
constant     1.9161     -.0927
COST         -.0927      .0056

**********************************************************************
**
OUTCOME VARIABLE:
 QofL

Model Summary
        R       R-sq       MSE     F(HC0)        df1        df2          p
     .6794      .4616   213.3253    48.3349     2.0000   123.0000      .0000

Model
```

```
             coeff    se(HC0)          t          p       LLCI       ULCI
constant    38.6393    11.0004     3.5125      .0006    16.8645    60.4140
COST         -.9472      .1664    -5.6930      .0000    -1.2766     -.6179
CompSS        .9004      .1783     5.0498      .0000      .5475     1.2534

Standardized coefficients
           coeff
COST      -.4169
CompSS     .3780

Covariance matrix of regression parameter estimates:
          constant       COST     CompSS
constant  121.0099    -1.1063    -1.8931
COST       -1.1063      .0277      .0119
CompSS     -1.8931      .0119      .0318

************************* TOTAL EFFECT MODEL *********************
*****
OUTCOME VARIABLE:
 QofL

Model Summary
          R       R-sq        MSE     F(HC0)        df1        df2          p
      .5907      .3489   255.9078    72.2851     1.0000   124.0000      .0000

Model
             coeff    se(HC0)          t          p       LLCI       ULCI
constant    92.7123     2.9718    31.1970      .0000    86.8302    98.5944
COST        -1.3419      .1578    -8.5021      .0000    -1.6543    -1.0295

Standardized coefficients
         coeff
COST    -.5907

Covariance matrix of regression parameter estimates:
          constant       COST
constant    8.8318     -.4169
COST        -.4169      .0249

************** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y *******
*******

Total effect of X on Y
     Effect    se(HC0)          t          p       LLCI       ULCI       c_ps       c_cs
    -1.3419      .1578    -8.5021      .0000    -1.6543    -1.0295     -.0680     -.5907
```

```
Direct effect of X on Y
    Effect   se(HC0)        t        p      LLCI      ULCI     c'_ps     c'_cs
    -.9472     .1664   -5.6930    .0000   -1.2766    -.6179    -.0480    -.4169

Indirect effect(s) of X on Y:
         Effect    BootSE   BootLLCI   BootULCI
CompSS    -.3947     .1147    -.6580    -.2112

Partially standardized indirect effect(s) of X on Y:
         Effect    BootSE   BootLLCI   BootULCI
CompSS    -.0200     .0054    -.0322    -.0109

Completely standardized indirect effect(s) of X on Y:
         Effect    BootSE   BootLLCI   BootULCI
CompSS    -.1737     .0434    -.2680    -.0972

********************** ANALYSIS NOTES AND ERRORS *****************
******

Level of confidence for all confidence intervals in output:
  95.0000

Number of bootstrap samples for percentile bootstrap confidence intervals:
  1000

NOTE: A heteroscedasticity consistent standard error and covariance matrix estimator wa
s used.

------ END MATRIX -----
```

APPENDIX Q: NON-SIGNIFICANT ANALYSIS TABLES

Hypothesis 1.1: Received social support did not moderate the relationship between COST and QoL (FACT-G) in the dataset with both Blood and Breast cancers.

Table Q.1 Hypothesis 1.1 Non-significant Interaction Variable for Hypothesis 1.1.

Variable	*b*	SE	95% CL	*p*	*F* (df)	R^2	Δ R^2
Predictor Variables				0.001	25.23 (3, 122)	0.38	
Constant	67.07	1.37	[64.35, 69.79]	0.001			
Financial Toxicity (centered)	-1.37	0.18	[-1.72, -1.02]	0.001			
Received Support (centered)	0.21	0.10	[0.02, 0.40]	0.3			
Interaction							
Financial Toxicity x Received Support	0.01	0.01	[-0.01, 0.04]	0.24	1.38 (1, 122)		0.01

Hypothesis 1.2: Perceived social support did not moderate the relationship between financial toxicity and QoL (FACT-G).

Table Q.2: Moderator Analysis of Perceived Social Support (Composite*) and FT on QofL.

$R^2 = 0.47$, $F\ (3, 122) = 40.56$, $p = 0.001$

Variable	*b*	SE	*t*	*p*	95% CL
Constant	66.33	1.4	47.33	0.001	[63.55, 69.10]
COST (centered)	-0.93	0.17	-5.55	0.001	[-1.25, -0.60]
Composite Support (centered)	0.94	0.17	5.36	0.001	[0.59, 1.28]
COST x Composite Support	-0.02	0.02	-0.99	0.32	[-0.07, 0.02]

Table Q.3: Emotional Perceived Support and Financial Burden Linear Model Predicting QoL.

$R^2 = 0.46$, F (3, 122) = 35.87, p = 0.001

Variable	b	SE	t	p	95% CL
Constant	67.17	1.36	49.25	0.001	[64.47, 69.87]
COST (centered)	-1.04	0.16	-6.68	0.001	[-1.35, -0.73]
Emotional Support (centered)	0.82	0.17	4.84	0.001	[0.48, 1.15]
COST x Emotional Support	0.004	0.02	0.22	0.82	[-0.03, 0.04]

Table Q.4: Informational Perceived Support and Financial Burden Linear Model Prediction QoL.

$R^2 = 0.43$, F (3, 122) = 32.01, p = 0.001

Variable	b	SE	t	p	95% CL
Constant	66.89	1.42	47.25	0.001	[64.09, 69.69]
COST (centered)	-1.03	0.17	-6.12	0.001	[-1.36, -0.70]
Informational Support (centered)	0.63	0.16	4.08	0.001	[0.33, 0.94]
COST x Informational Support	0.004	0.02	-0.26	0.8	[-0.38, 0.03]

Table Q.5: Instrumental Perceived Support and Financial Burden Linear Model Prediction QoL.

$R^2 = 0.44$, F (3, 122) = 41.17, p = 0.001

Variable	b	SE	t	p	95% CL
Constant	65.92	1.44	45.78	0.001	[63.07, 68.77]
COST (centered)	-1.09	0.16	-6.78	0.001	[-1.42, -0.77]
Instrumental Support (centered)	0.59	0.15	3.97	0.001	[0.30, 0.88]
COST x Instrumental Support	-0.33	0.02	-1.88	0.06	[-0.069, 0.00]

Hypothesis 1.3: *Received social support will moderate the relationship between financial burden and QoL (FACT-G Plus).*

Table Q.6 Received Social Support and Financial Burden Linear Model of QoL with economic well-being.

Variable	*b*	SE	*t*	*p*	95% CL
Constant	111.42	1.89	58.99	0.001	[107.68, 115.16]
COST (centered)	-2.54	0.25	-9.93	0.001	[-3.05, -2.04]
Received Support (centered)	0.37	0.12	3.06	0.03	[0.13, 0.62]
COST x Received Support	0.03	0.02	1.63	0.11	[-0.05, 0.06]

Hypothesis 1.4: *Perceived social support will moderate the relationship between financial burden and QoL (FACT-G Plus).*

Table Q.7: Composite Perceived Support and Financial Burden Linear Model for QoL with Socio-economic Well-being.

$R^2 = 0.59$, $F\ (3, 122) = 61.61$, $p = 0.001$

Variable	*b*	SE	*t*	*p*	95% CL
Constant	110.43	1.91	57.88	0.001	[106.66, 114.21]
COST (centered)	-1.87	0.24	-7.68	0.001	[-2.35, -1.38]
Composite Support (centered)	1.41	0.25	5.71	0.001	[0.92, 1.89]
COST x Composite Support	-0.03	0.03	-1.02	0.31	[-0.04, 0.04]

Table Q.8: Emotional Perceived Support and Financial Burden Linear Model for QoL with Socio-economic Well-being.

$R^2 = 0.58$, $F\ (3, 122) = 57.99$, $p = 0.001$

Variable	*b*	SE	*t*	*p*	95% CL
Constant	111.59	1.91	58.35	0.001	[107.81, 115.38]
COST (centered)	-2.05	0.24	-8.52	0.001	[-2.53, -1.57]
Emotional Support (centered)	1.2	0.24	4.9	0.001	[0.71, 1.68]
COST x Emotional Support	0.01	0.03	0.3	0.77	[-0.04, 0.06]

Table Q.9: Informational Perceived Support and Financial Burden Linear Model for QoL with Socio-economic Well-being.

$R^2 = 0.57$, F (3, 122) = 51.27, $p = 0.001$

Variable	b	SE	t	p	95% CL
Constant	111.46	1.96	56.92	0.001	[107.59, 115.34]
COST (centered)	-2.01	0.25	-8.06	0.001	[-2.50, -1.52]
Informational Support (centered)	0.98	0.22	4.51	0.001	[0.55, 1.42]
COST x Informational Support	0	0.02	0.11	0.91	[-0.38, 0.04]

Table 7.20: Instrumental Perceived Support and Financial Burden Linear Model for QoL with Socio-economic Well-being.

$R^2 = 0.56$, F (3, 122) = 64.07, $p = 0.001$

Variable	b	SE	t	p	95% CL
Constant	109.62	1.96	55.87	0.001	[105.73, 113.50]
COST (centered)	-2.12	0.23	-9.33	0.001	[-2.57, -1.67]
Instrumental Support (centered)	0.88	0.2	4.38	0.001	[0.48, 1.27]
COST x Instrumental Support	-0.05	0.02	-2.11	0.04	[-0.101, 0.003]

CURRICULUM VITA

Lisa C. Smith, MSSW, LMSW
PhD Candidate
University of Louisville
Raymond A. Kent School of Social Work
Phone: (502) 472-0724

EDUCATION

Ph.D. (Projected Defense March 2019)
University of Louisville
Kent School of Social Work
Dissertation Title: Role of Social Support on the Financial Impact of Cancer
Committee Chair: Karen Kayser, PhD

M.S.S.W.
University of Louisville,
Kent School of Social Work

B. S. Speech Language Pathology and Audiology
University of Nevada, Reno

B.A. Social Psychology
University of Nevada, Reno

RESEARCH INTERESTS

Oncology social work practice; health care, healthcare policy and healthcare disparities; patient-centered care; interdisciplinary healthcare teams; palliative and end-of-life care; patient-physician decision making; grief and coping.

GRANTS & SCHOLARSHIPS

American Cancer Society Doctoral Grant, $40,000, July 2016-June 2018
University of Louisville GSC & Kent School of Social Work Travel Scholarships, 2016, 2017
Strategic Plan 2020 Tuition Award 2014-2015, University of Louisville
Strategic Plan 2020 Tuition Award 2013-2014**,** University of Louisville

AWARDS & HONORS

Outstanding Field Faculty, (2018) University of Louisville Kent School of Social Work. Demonstrates genuine concern for students and initiative to resolve issues.

University of Louisville Faculty Favorite 2016-2017

Best Student Poster, (2015) International Psycho-Oncology Society/American Psychosocial Oncology Society World Congress. Washington, D.C.

Graduate Dean's Citation Award, (2013) University of Louisville, Superior Achievements in Graduate Studies

Sophia Breckenridge Leadership Award, (2013) University of Louisville Kent School of Social Work, Outstanding Potential Professional Leadership Award

PUBLICATIONS

PEER REVIEWED PUBLICATIONS

Head, B., Harris, L., Kayser, K., Martin, A., & **Smith, L. C**. (2017). As if the disease wasn't enough: Coping with the financial consequences of cancer. *Supportive Care in Cancer*, 26(3), p.975-987. doi: 10.1007/s00520-017-3918-y

Head, B., & **Smith, L. C**. (2016). Use of contemporary film as a medium for teaching an online death and grief course. *Journal of Social Work in End-of-Life & Palliative Care. 12(30), p. 1-10.* http://dx.doi.org/10.1080/15524256.2016.1201564

Smith, L. C., Kayser, K., Washington, A., & Ranja, S. (2015). A patient-centered approach to address fears of cancer recurrence during surveillance after treatment for lung cancer. Psycho-Oncology, 24 (Suppl. 2); p. 218 DOI: 10.1002/pon.3874 (**Abstract**)

PEER REVIEWED PUBLICATIONS SUBMITTED

Archuleta, A., Cotton, S., & **Smith, L. C.** (submitted). Examining an instrument for assessing organizational capacity readiness among non-profit organizations through a grant review process. Human service Organizations: Management, Leadership, & Governance.

Harris, L., Smith, L.C., & Thang, N.D. The career: Caregiving processes for grandparents raising grandchildren in the wake of the AIDS epidemic in Vietnam.

Kayser, K. Harris, L., Head, B., **Smith, L. C**., & Washington, A. (submitted). Living with the financial consequences of cancer: A life course perspective.

PUBLICATIONS IN PROGRESS

Kayser, K., Anderson, G*., Randall, J.*, Smith, L.*, Washington, A* & LaJoie, S. Investigating the effectiveness of cervical cancer interventions: A meta-analysis. (* Equal Contribution)

Smith, L.C., Kayser, K., Harris, L., Head, B., & Washington, A. A role for medical professionals in addressing costs of cancer.

Ranja, S., Kayser, K., Smith, L.C., & Kloecker, G. A patient-centered approach to address fears of cancer recurrence during surveillance after treatment for lung cancer.

PRESENTATION & POSTERS

INVITED ORAL PRESENTATIONS - Webinar

Smith, L. C. (January 16, 2019). Invitation to participate in cancer care access panel: *PCORI Metastatic Cancer Series Webinar 2: Access Disparities in Cancer and Cancer Research*. Topic: Financial Toxicity of Cancer. University of Kansas Medical Center, Kansas City, KS.

PEER REVIEWED CONFERENCE PRESENTATIONS – ORAL

Schapmire, T., Head, B., Faul, A. C., Pfeifer, M., & **Smith, L. C.** (2016). Silos to synergy: Initiating, implementing, and integrating inter-professional education in the health sciences. Counsel on Social Work Education (CSWE), Atlanta, GA. (**Oral Presentation**)

Head, B., & **Smith, L. C.** (2016). Lights, cameras, action! Use of contemporary film to stimulate higher level learning. 2016 Celebration of Teaching and Learning, *University, of Louisville*, Delphi Center for Teaching & Learning, Louisville, KY.

PEER REVIEWED CONFERENCE PRESENTATIONS – POSTER

Smith, L. C., Kayser, K., Head, B., Harris, L., & Washington, A. (2017) Financial toxicity of cancer: A role for social work educators & practitioners. *Council on Social Work Education*, Dallas, TX.

Kayser, K., **Smith, L. C**., Washington, A., Harris, L., and Head, B. (2017). The process of financial toxicity due to cancer: Why age matters. *International Psycho-Oncology Society - World Congress (IPOS)*, Berlin, Germany.

Faul, A., Cotton, S. G.*, & **Smith, L. C.*** (2016). Serving nutritional needs of older adults. *Society for Social Work and Research (SSWR)*, Washington D. C. (*Equal Contribution)

Smith, L. C., Kayser, K., Washington, A., Ranja, S., & Kloecker, G. (2015). A patient-centered approach to address fears of cancer recurrence during surveillance after treatment for lung cancer. *International Psychosocial Oncology Society/American Psychosocial Oncology Society World Congress (IPOS/APOS)*, Washington, D.C. (**Student Award**)

Smith, L. C.*, Cotton, S.*, Lawson, T. & Faul, A. C. (2014). Beyond Nutritional Needs: Low-Income, Older Adults Aging in Place. Evaluation of the Impact of Nutritional Programming for Older Adults. The Fall Graduate Research Symposium, *University of Louisville*, Louisville, KY. (*Equal Contribution)

Faul, A. C., Lawson, T. R., D'Ambrosio, J. G., Boamah, D. A., Cotton, S., Alkohaiz, M., **Smith, L. C.,** Lewis, S. N., Brown, L., & Zheng, Y. (2014). Collaborative Teaching and Learning as a Tool to Ignite the Spark in Students. 2014 Celebration of Teaching and

Learning, *University, of Louisville*, Delphi Center for Teaching & Learning, Louisville, KY.

Washington, A., Kayser, K., **Smith, L. C.,** Ranja, S., & Kloecker, G. (2014). Is There a Relationship between Patient Worry and Preferences for Follow-up Care after Curative Treatment for Lung Cancer? Research!Louisville, *University of Louisville*, Louisville, KY.

RESEARCH EXPERIENCE

Graduate Research Assistant**,** University of Louisville, Kent School of Social Work
  Financial Implications of Cancer Treatment on Patients, Multiple Methods (2013-present)
  Patient's Preferences and Quality of Life during Surveillance after Curative Treatment for Lung Cancer, Quantitative Methods (2013-2015)
  Surveillance after Curative Treatment for Lung Cancer: Physicians' Perspectives on Decision-Making, Quantitative Methods (2013–2015)

Other Research Experience*,* University of Louisville, Kent School of Social Work
  Cervical Cancer Interventions in Rural Communities: Meta-analysis, 2018-2019
  Online Teaching Methods Incorporating Film, 2015-2016
  Scale Development in Critical Thinking and Social Work, 2015
  Caregiving Processes for Grandparents raising Grandchildren in the Wake of the AIDS Epidemic in Vietnam, 2015-present
  Inter-rater Agreement among Grant Reviewers, 2014-2015
  Examining Capacity-Building Needs Across the Greater Louisville Area, 2014-2015
  Using Structural Equation Modeling to Assess Health Access in Kentucky, 2014-15
  Assessing Meal Programs in Meeting Psychosocial Needs of Older Adults, 2013-2014

TRAINING EXPERIENCES

Delphi U Online Teaching, University of Louisville Delphi Center for Teaching and Learning, June 2015
Financial Navigation for Cancer Patients, Financial Advocacy Network Regional Meeting-IL, Association of Community Cancer Centers, November 2014
Cancer Treatment: How to Make Informed Choices About Standard Care and Clinical Trials, Leukemia & Lymphoma Society, October 2014
PLAN Professional Development Program, School of Interdisciplinary and Graduate Studies, University of Louisville, 2013-2014
Mental Health First Aid, Gilda's Club, August 2014
Principles of Epidemiology in Public Health Practice, The Centers for Disease Control and Prevention (CDC), May 2014
iCOPE: Interdisciplinary Curriculum for Oncology Palliative Care Education, University of Louisville, June 2013- March 2014

TEACHING & MENTORSHIP

TEACHING

Instructor - Online Fall-Spring 2018-2019
University of Louisville, Kent School of Social Work 2017-2018

MSSW Program: *Advance Research Practice 1 & 2* 2016-2017
2015-2016

Instructor - Online Fall-Spring 2018-2019
University of Louisville, Kent School of Social Work 2017-2018
MSSW Program: *Advanced Social Work Practicum 1 & 2* 2016-2017
2015-2016

Instructor - Online Fall-Spring 2018-2019
University of Louisville, Kent School of Social Work 2017-2018
MSSW Program: *Foundation Social Work Practicum 1& 2* 2016-2017
2015-2016

Instructor - Online Fall-Spring 2018-2019
University of Louisville, Kent School of Social Work 2017-2018
MSSW Program: *Psychosocial Oncology Seminar* 2016-2017
2015-2016

Instructor - Online Spring 2018
University of Louisville, Kent School of Social Work
MSSW Program: *Psychosocial Practice in Oncology II: Community Approaches to Promote Health Equity*

Instructor - Online Summer 2018
University of Louisville, Kent School of Social Work Summer 2017
MSSW Program: *Research Methodology & Design* Summer 2016

Instructor – On Campus Fall-Spring 2014-2015
University of Louisville, Kent School of Social Work
MSSW Program: *Human Behavior in the Social Environment 1 & 2*

Substitute Instructor - Online Summer 2017
University of Louisville, Kent School of Social Work
MSSW Program: *Death and Grief*

Teaching Assistant - Online Spring 2015
University of Louisville, Kent School of Social Work
MSSW Program: *Death and Grief*

Teaching Assistant – On Campus Fall 2013
University of Louisville, Kent School of Social Work
MSSW Program: *Psychosocial Practice in Oncology II: Community Approaches to Promote Health Equity*

MENTORSHIP

Practicum Faculty Mentor Fall - Spring 2018-2019

SERVICE

COMMUNITY ENGAGEMENT

American Cancer Society - Cancer Action Network,

Legislative Team Ambassador, 2016-present
- State Lobby Day, Jefferson City, MO – 2018
- State Lobby Day, Jefferson City, MO – 2017
- National Lobby Day, Washington DC - 2016
- Advocacy activities throughout the years (2016-present).

Gilda's Club Kansas City, Volunteer, Jan 2016 – Sep 2016
Gilda's Club Louisville, Outreach Volunteer, May 2013-2015

EDITORIAL ACTIVITY

Ad-hoc Reviewer, Journal of Psychosocial Oncology, 2017-present
Grant Reviewer, Community Foundation of Louisville Fund for Louisville, 2014

PROFESSIONAL MEMBERSHIPS

Current
- AOSW, Association of Oncology Social Work, Member, 2015-present (ID 99441)
- NASW, National Association of Social Work, Member, 2016 – present (ID 886577658)
- CSWE, Council on Social Work Education, Member, 2016- present (ID 800162)
- SSWR, Society for Social Work and Research, Member, 2015- present (ID 6151)

Past
- IPOS/APOS**,** International-American Psychosocial Oncology Society, Member, 2015-2016

PROFESSIONAL LICENSURE

Current
- Licensed Master Social Worker, Missouri Board of Social Work 2017-present (ID 2017003504)

Past
- Certified Social Worker, Kentucky Board of Social Work, 2014-2017

PROFESSIONAL EXPERIENCE

Practicum Faculty Instructor August 2015- present
University of Louisville, Kent School of Social Work
Practicum Faculty Liaison
Oversee 8-16 students per semester in health-related practicum placements.

Adjunct Faculty Instructor August 2014- present
University of Louisville, Kent School of Social Work
Master's Level Social Work Core-Curriculum & Psychosocial Oncology Specialization Coursework

Social Work Intern August 2012 – April 2013
Uspiritus-Bellewood Campus
Adolescent Program
Psychosocial Intake/Assessments, Individual and Group Therapy, Grant Writing, Program Evaluation.
Social Work Intern August 2011 – April 2012
Seven Counties Services – Hope Now Hotline

Crisis Intervention Counselor
Suicide and Crisis Assessment/Intervention, Individual Therapy, Community Resource Referral.

Regional Placement Coordinator Jan. 2007-February 2012
Children's Review Program
Child & Adolescent Foster Care Placements
Case Management, Referral and Placement Coordination of Children and Adolescents in Foster Care Homes or Residential Treatment Centers.

Mental Health Technician March 2003 – August 2006
Willow Springs Mental Health Rehabilitation Treatment Center
Child & Adolescent In-patient Mental Health Treatment
Behavioral and Case Management

Assistive Technology Technician August 1997 – August 1998
Assistive Technology Center
State Disability Resource Center
Physical and Mental Assessment of Disability Needs

Mental Health Technician March 1995 -August 1997
Willow Springs Mental Health Rehabilitation Treatment Center
Child & Adolescent In-patient Mental Health Treatment
Behavioral and Case Management