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Cancer, Vulnerability, and Financial Quality of Life: A Mixed Methods Study

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By

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# Cancer, Vulnerability, and Financial Quality of Life: A Mixed Methods Study

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For people who are experiencing financial hardship, a cancer diagnosis can be devastating. For others, cancer may exacerbate financial stress, thereby influencing their livelihoods and their ability to maintain employment benefits (including health insurance), manage financial obligations, and participate meaningfully in cancer treatment. Financial quality of life is conceptualized here as the ability to manage all current obligations related to cancer care, within the context of sound health-care decision making. The purpose of this mixed methods study is to examine this concept in an availability sample of 90 cancer patients. In the quantitative portion, the variables that are hypothesized to affect financial quality of life include housing stability; one's sense of personal control within the larger context of health locus of control; demographic information; income/financial stress; health insurance adequacy; perceived barriers to care; social support; cancer diagnosis and acuity; and perceived ability to participate meaningfully in treatment. These variables fit within the adapted behavioral model for vulnerable populations by Gelberg, Andersen, and Leake (2000). The study is also underpinned philosophically by the difference and opportunity principles of John Rawls (1971, 1999). Bivariate correlations were examined, and multivariate analysis (ordinary least squares) was used to examine the impact of all the predictor variables on the criterion variable. The qualitative portion was an interview with seven participants from the quantitative portion. Content analysis was used to elicit the themes expressed. There were significant correlations between financial quality of life and age; housing stability;

income below \$10,000; health insurance adequacy; perceived barriers to care; social support; financial stress (distinct from financial quality of life); and selected aspects of treatment adherence. The multivariate regression analysis found that gender, housing stability, health insurance adequacy; fewer barriers to care; reduced financial stress; and the intentions and support/barriers aspects of treatment adherence are significant predictors of financial quality of life. Themes that emerged from the qualitative analysis (across incomes) revolved around the importance of social support; hope; creative frugality in living within one's means; dedication to treatment; and a strong sense of personal control. The research showed that this theoretical model is useful for future health-related research.

This dissertation by Christine C. Callahan fulfills the dissertation requirement for the doctoral degree in social work approved by Karlynn M. BrintzenhofeSzoc, PhD, as Director, and by Sr. Ann Patrick Conrad, PhD, Joseph Shields, PhD, and James Zabora, ScD, as readers.

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Karlynn M. BrintzenhofeSzoc, PhD, Director

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Sr. Ann Patrick Conrad, PhD, Reader

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James Zabora, ScD, Reader

## Dedication

This dissertation is dedicated to my husband, Cliff, for his unfailing and unconditional love and support throughout this process

And to the memory of Bruce M. Ross

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## Introduction

*I do know that all this care [seeking emergency medical care following a serious bicycle accident in Canada and follow-up care in the United States once she returned home] will make me poorer, for sure, to the tune of several thousand dollars. I'm grateful that I could make my decisions based on what I thought made sense medically rather than on what I could afford. Many people are not as fortunate. (Michelle Andrews in The Washington Post, November 8, 2011)*

## **Chapter 1: Introduction to the Study**

For people who are experiencing financial hardship, a cancer diagnosis can be devastating. For others, cancer may cause or exacerbate financial stress, thereby influencing their livelihood, their ability to maintain employment benefits including health insurance, their ability to manage financial obligations through available personal and social resources, and their ability to participate meaningfully in cancer treatment—in other words, their financial quality of life. Thus, the impact of cancer on financial quality of life is an area within oncology care and oncology social work that merits continued exploration and research. Understanding the economic burden of cancer in individual lives is crucial in appreciating or anticipating the array of stressors that people face when they are diagnosed and attempt to seek help and treatment. Yet the relationship of these stressors to financial quality of life is unclear. While many quality of life studies in oncology focus on medical and psychological well-being during and after cancer treatment, such studies usually have not given enough attention to other critical facets of people's lives, such as financial well-being (Ell et al., 2007; Head & Faul, 2008; Kim, 2007). Studies that do not explore the impact of cancer treatment on people's financial situations and their ability to effectively manage the myriad of costs overlook vital components of life that weave unmistakably into daily functioning. This is especially so in times of economic volatility on a societal level.

The examination of these variables on financial quality of life is the topic of the present study, and the variables to be explored here specifically include housing stability; one's sense of personal control within the larger context of health locus of control; demographic information; income and financial stress; health insurance adequacy;

perceived barriers to care; social support; cancer diagnosis and accompanying variables (stage of cancer, length of time since diagnosis, and treatments received); and perceived ability to participate meaningfully in treatment.

### **Background of the Problem**

Financial hardship in cancer and the impact of cancer on financial quality of life are growing topics of interest in the medical and psychosocial literature. Financial quality of life in this study is conceptualized as the ability to manage all current and future (including unexpected) obligations related to cancer care, within the context of sound health-care decision-making. It encompasses not only the practical aspects of meeting daily needs pertaining to food, lodging, and so forth, but also includes the implications and resources for making wise and reasonable decisions regarding the course of one's cancer treatment. Can one make the best possible health-care decisions without overwhelming worry about affording and participating in that treatment? The medical literature on cancer documents serious problems in the United States with respect to inequalities between cancer patients who have resources for cancer treatment and those who do not (Griggs et al., 2007; Reyes-Ortiz, Goodwin, Freeman, & Kuo, 2006). Cancer patients who lack health insurance, for example, are less likely to have access to medical care and to participate in cancer screening (Halpern et al., 2008). Women who are poorer are more likely to receive reduced doses of chemotherapy (Griggs et al., 2007). Level of education is also a powerful predictor for poorer long-term health outcomes and death from cancer (Kinsey, Jemal, Liff, Ward, & Thun, 2008). Health disparities in cancer are profoundly evident in minority populations, which are also more likely to be dealing simultaneously with poverty (Hughes, Gudmundsdottir, & Davies, 2007; Short,

Cornelius, & Goldstone, 2000). Inequalities exist as well in the areas of access to cancer screening (Otero-Sabogal et al., 2004); participation in prevention studies (Grann et al., 2005); and barriers to care (O'Toole, Conde-Martel, Gibbon, Hanusa, & Fine, 2003).

In terms of cancer's impact on financial outcomes, the psychosocial oncology literature continues to grow and to demonstrate that lack of resources leads to unacceptable consequences. Lauzier et al. (2008) describe in their research in Canada that patients' financial well-being suffers during the course of treatment, and this occurs even in a country that provides nationalized medicine. People who do not have health insurance (or who are under-insured and usually have difficulty absorbing ongoing co-pays and out-of-pocket expenses) face greater health complications, poorer health outcomes, and barriers to care (Traynor, 2004). Westin, Rapkin, Potts, and Smith (1999) report that health-care access is diminished in people who are uninsured, unemployed, or under-employed, and who use emergency rooms for their main source of care.

Several studies show that medical debt stemming from illness and injury—even with health insurance present—are major causes of personal bankruptcy (Himmelstein, Warren, Thorne, & Woolhandler, 2005; Seifert & Rukavina, 2006). Another study demonstrates that even among higher-income adults, lack of health insurance is correlated with decreased use of recommended cancer screenings and other health services (Ross, Bradley, & Busch, 2006). Financial distress combined with the psychological distress due to cancer diagnosis and treatment compounds the desperation that people typically experience (Francoeur, 2001; Penson et al., 2003; Williams, 2004). Thus, financial quality of life is a critical and timely component of understanding the psychosocial, economic, and medical aspects of cancer care. Considering the economic

burden of cancer also lends greater appreciation for the barriers that people face if they are not well equipped to handle cancer's costs, or if resources are deficient or non-existent to help with the care they need (Hughes et al., 2007). Measuring the financial impact of cancer, especially in vulnerable populations, is critically needed both to better understand the stressors that people face and also to present a fuller, more comprehensive picture of quality of life (Head & Faul, 2008). In doing so, moreover, cancer care for all can be improved (Institute of Medicine, 2008).

### **Interest in the Problem**

Strong interest in the topic of financial quality of life in cancer patients has been generated in this social worker from over eighteen years of experience as a clinical social worker at the Clinical Center of the National Institutes of Health (NIH) in Bethesda, Maryland. In working intensively with diverse groups of patients through the years, often for extended periods of time, this social worker has been privileged to “be allowed into” their most personal and painful experiences in dealing with cancer. Financial realities frequently are a significant source of worry and stress, and when intertwined with other personal and environmental stressors—or lack of supports that can make a difference—the outcomes have been dire indeed. Yet the study of financial variables has often been neglected. Clinicians usually relegate financial matters to an “eligibility worker” and they fail to recognize the interplay of financial and psychological variables. Clinicians, too, may feel hesitant to explore a patient's financial situation (for one reason or another) and are more than happy to avoid this reality. But neglecting one usually increases the stress of the other. Ideally they should be addressed together by clinicians.

These professional experiences have been greatly meaningful to this social worker, and they have inspired her interest in this area. Moreover, experiences shared by patients remind clinicians in the field that one can never take their health or resources for granted. The cancer experience of a patient can be similar to one experienced by his or her clinician, and vice versa. Vulnerabilities are ever-present in each of us.

### **Purpose of the Study**

This study is underpinned philosophically by a social justice perspective offered by the political philosopher John Rawls in his groundbreaking work, *A Theory of Justice* (1971, 1999). Specifically, the difference and opportunity principles intrinsic to his perspective on justice hold that attention must be given to people who are least advantaged. A recent interpretation of these principles states:

Social and economic inequalities are to satisfy two conditions: first, they are to be attached to positions and offices open to all under conditions of fair equality of opportunity; and second, they are to be to the greatest benefit of the least advantaged members of society. (Pogge, 2007, p. 106)

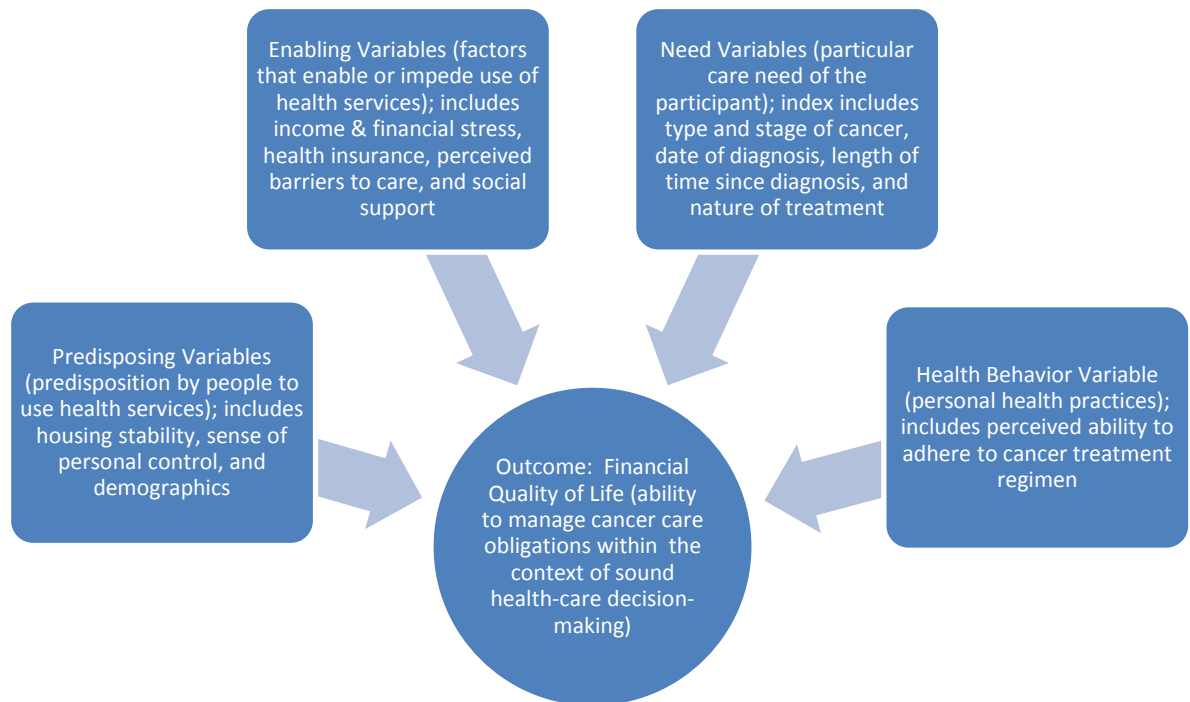
This dissertation will attempt to analyze why cancer patients are among those who are at a disadvantage within our health-care system. Moreover, it will explain why a just health-care system will not neglect such patients.

Regarding such patients who may be facing difficult consequences, this study explores selected variables, drawn from the adapted behavioral model for vulnerable populations (Gelberg, Andersen, & Leake, 2000), that can be considered to contribute to financial quality of life. These variables are chosen for their propensity towards vulnerability and their likely impact on financial quality of life. More specifically, the



twofold purpose of this study is 1) to examine quantitatively how vulnerabilities in psychological and social situations affect financial quality of life, and 2) to explore qualitatively the relationship between personal control and financial quality of life within the larger context of health locus of control. It is anticipated that if one or more of the variables is deficient or lacking, the impact on financial quality of life will be even more significant. On the other hand, the abundance of one or more positive variables might effectively reduce the negative impact of another, including the impact on financial quality of life.

The behavioral model for vulnerable populations (Gelberg et al., 2000) is adapted from Andersen's (1968, 1995) behavioral model for health-care utilization, which is a widely used model that helps predict micro and macro (i.e., psychological, social, and environmental) factors explaining people's health-care usage. Andersen (1968, 1995) structured the model to denote predisposing, enabling, and need factors or characteristics and their impact on health behaviors and outcomes. Gelberg et al. (2000) later adapted the model for use in vulnerable populations by first hypothesizing about and then testing additional variables under the predisposing, enabling, need, and health behavior domains that best predict how vulnerable groups of people will use and/or not use health-care systems. The model is also flexible in that different aspects of health-care utilization—including financial aspects of care— can be examined. The entire model contains 75 precise variables across the predisposing, enabling, need, health behavior, and outcomes domains. This study examines key variables from the model considered to be predictive of financial quality of life. See Figure 1.1 for a pictorial description of the selected variables from the adapted model:



**Figure 1.1:**

***Selection of Variables from the Adapted Behavioral Model for Vulnerable Populations with Impact on Financial Quality of Life (Gelberg et al., 2000)***

The variables outlined above are chosen for inclusion in the study because of their presumed contribution to financial quality of life. The variables are hypothesized by this researcher to be significant indicators for how financial, social, and environmental factors influence patients' ability to make sound health-care decisions regarding cancer treatment, and whether or not patients feel that resources (both psychological and social) are available to them to make the best possible decisions. This hypothesis is based on clinical and anecdotal experience, as well as from the medical and psychosocial literature.

Patients may have every possible intention to participate meaningfully in treatment, yet if they are struggling with multiple responsibilities with few, if any, resources with which to manage, all outcomes (both medical and psychosocial) will undoubtedly be compromised (Kim, 2007). For example, losses critical to daily survival—such as erosion or eventual loss of income and housing—will create huge stress rivaling responsibilities of cancer treatment. When patients begin experiencing losses that are instrumental to their ability to make wise health-care decisions and to adhere to their cancer treatment plan—losses such as housing, money, health insurance, and transportation—greater barriers to care are more likely to be created. Patients' ability to manage all financial obligations related to their cancer care and to participate in treatment also will more likely be impaired. In addition, a robust or, conversely, a poor social support system also has an undeniable impact.

Specifically, the variables are chosen for this study in order to provide a more comprehensive view of a cancer patient's typical experience. The literature presented thus far has been instructive in detailing struggles that many patients endure. From the adapted model by Gelberg et al. (2000), variables from the predisposing domain are those characteristics that a cancer patient brings to the experience, and these include factors that tend to be more stable, such as demographic information (age, gender, race/ethnicity, marital or partnership status, work, and education) and two characteristics that can vary depending on the circumstances with which one is confronted (personal control within the larger context of health locus of control and housing stability). Variables from the enabling domain are those variables that either help or impede financial aspects of usage, and these include income, health insurance, perceived barriers to care, and one's social

support system. The variable from the need domain explores the nature or the acuity of the cancer that one is facing. Finally, the variable from the health behavior domain speaks to the perceived ability to adhere to cancer treatment or to the plan proposed by one's medical staff. All of the variables are considered in an effort to see which ones—including combinations of factors—have the most significant impact on financial quality of life. The analysis presented will allow the researcher to examine the unique as well as combined effects of the selected variables on financial quality of life.

### **Research Questions and Hypotheses**

The quantitative research question in this study is: What factors (or variables) from the adapted behavioral model for vulnerable populations (Gelberg et al., 2000), which depicts critical micro and macro factors under the domains of predisposing, enabling, need, and health behavior most significantly impact financial quality of life? The qualitative research questions for this study are: Does a person's financial situation influence his or her sense of personal control with respect to treatment adherence? And how does financial quality of life influence one's sense of personal control and expectation of treatment outcomes? For the qualitative inquiry, the dependent and independent variables are interchanged in order to more fully explore the nature of personal control across all income categories (within the context of health locus of control). If patients express a strong sense of personal control and coping, do they feel more confident regarding their abilities to participate meaningfully in cancer treatment? Do they feel hopeful that they can get through treatment and achieve remission from their disease?

The major hypothesis is: The greater the vulnerabilities and deficiencies in predisposing factors and enabling factors, the greater the need factors with respect to cancer diagnosis and treatment, and the lower the perceived ability to adhere to treatment, the poorer will be the financial quality of life. The related hypotheses are: 1) Lower income and greater financial stress are correlated with a lower sense of personal control; and 2) Lower income and greater financial stress are correlated with lower financial quality of life, although a higher sense of personal control is a mediating variable.

### **Significance of the Research to Social Work**

It is important to note that a research study should have relevance not only for the knowledge base it is hopefully contributing towards, but that it also have relevance for social work theory, practice, research, ethics, and social policy. The current research has relevance for the following areas of professional concern.

**Implications for theory.** The philosophy and scientific design of this research study are largely dependent on the strength of the theories underlying it. While Andersen's behavioral model (Andersen, 1969, 1995) is widely used in health services research, the adapted model for vulnerable populations (Gelberg et al., 2000) is curiously used less so. Yet its utilization with vulnerable populations is critically needed. Its delineation of factors—including the addition of vulnerable factors such as housing stability, sense of personal control, perceived barriers to care, and financial quality of life, to name just several—more comprehensively describes the constellation of issues that people face when dealing with a life-threatening illness. Examining the interplay of these factors and issues more realistically captures the complex essence of life. Consequently, it is hoped that a meaningful contribution can be made through this research in furthering

the use of this theory and theoretical model with vulnerable populations, especially cancer patients.

**Implications for practice.** The nature of this research study is also well suited to social work practice. Social work, among the disciplines within the mental health and helping arenas, is ideal in working intensively with people struggling financially. The person-in-environment construct explicitly depicts, again, the array of factors that people face when dealing with difficult problems and crises. Yet rather than compartmentalizing financial stress, it is a substantial improvement in clinical practice to incorporate financial vulnerabilities and economic realities into the more traditional mental health inquiry and intervention (Hawkins & Kim, 2011). It is more important than ever to consider financial well-being and its impact on emotional well-being. Too often, financial wellness is not even considered when evaluating emotional wellness, but any patient will share that this stress is significant but often too embarrassing to broach with his or her social worker or medical provider. Intervening sensitively and skillfully in a truly comprehensive scope of care is critical.

**Implications for research.** More psychosocial research is needed in this area of financial vulnerability in cancer patients—people who are often struggling silently and alone, their existential and psychic pain unbeknownst to others. Corresponding to this is the need to better understand the factors and interplay of factors that contribute and/or ameliorate the stress of vulnerability. The experience of cancer patients who are dealing with various vulnerabilities across psychological, social, and environmental spectrums must be explored in-depth. The medical literature is robust in detailing medical outcomes with patients in financial need and other types of vulnerability, whether it is lack of health

insurance, health and income disparities, the impact of poverty on health, mortality, health-care access and barriers to care, competing responsibilities, and so forth. The work of Ell in social work and in medicine (Ell, Mantell, & Hamovitch, 1988; Ell, Mantell, Hamovitch, & Nishimoto, 1989; Ell & Nishimoto, 1989; Ell et al., 2002; Ell et al., 2005; Ell et al., 2007) is long-standing and ground-breaking in terms of building that social work knowledge base of financial and psychological stress in cancer patients. Yet even more social work research is needed, and the impact on social work-specific outcomes—as opposed to medical outcomes—is also critical. There has been much research in psychosocial oncology on psychological determinants and outcomes—which is laudable and necessary—yet equal attention must be paid to the financial plight also contributing to distress and need. It is hoped that this present research study can contribute to the literature in describing financial outcomes and the impact of vulnerabilities on the economic aspects of health-care decision-making, i.e., financial quality of life. Conversely, it is also hoped that those positive factors in the array of factors and variables drawn from patients' everyday life can also be better understood in the overall context of financial quality of life.

**Implications for ethics.** This research study is also underpinned by a social justice perspective—the difference principle advanced by Rawls (1971, 1999), as described previously. This principle states that any just society must give attention to its least advantaged members, and it will be more fully described in Chapter 2 of this dissertation. It is important to note that a contribution to the discourse on ethics and social justice is encouraged by the social work code of ethics (NASW, 2008), and it is hoped that this dissertation can make such a contribution. The social work code of ethics

(NASW, 2008) mandates that social workers devote themselves to the plight of vulnerable people and to do all they can to work together to improve circumstances for all, as stated in the ethical principle of social justice:

Social workers pursue social change, particularly with and on behalf of vulnerable and oppressed individuals and groups of people. Social workers' social change efforts are focused primarily on issues of poverty, unemployment, discrimination, and other forms of social injustice. These activities seek to promote sensitivity to and knowledge about oppression and cultural and ethnic diversity. Social workers strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people." The nature of this research study is to examine such plight and to explore whether or not social injustice is present in vulnerable cancer patients' circumstances. This is most notable in the issues of health insurance, housing instability, and financial stress and poverty. (NASW, 2008)

**Implications for policy.** Likewise, implications for policy are present in the proposed study. Such considerations are especially salient, given the issues and events that are occurring nationally, most notably with health-care reform in 2010 and efforts beginning in 2011 to repeal the law and to challenge components of its constitutionality. While vulnerable cancer patients and their plight are receiving increased attention, national sentiments in many segments of the population are opposed to health-care reform for a variety of political and philosophical perspectives. Yet health-care reform is not the only policy issue to be raised in this dissertation. There are implications as well for housing policy. Foreclosures in the current economy have been rampant, yet



foreclosures due to medical debt and bankruptcy must be considered as well. This study will further highlight implications for social policy against the backdrop of our nation's current economy.

### **Summary**

This introductory chapter has briefly described the study presented, along with the research questions and hypotheses, and has provided a succinct overview of the literature contributing towards its examination and why this issue is so relevant today. The next chapter will more thoroughly explore the literature and knowledge bases underlying financial quality of life within psychosocial oncology. The subsequent chapters will discuss the methodology of this dissertation, the findings from data collection and data analyses, some conclusions to be drawn from this work, and recommendations for further study.

## **Chapter 2: Literature Review**

The purpose of this chapter is to provide a review of the literature pertaining to the financial toll of a cancer diagnosis and treatment, and, consequently, to financial quality of life for cancer patients. It will provide the basis for the selection of the variables under examination here; why they were chosen as likely contributors to financial quality of life; and the presumed impact on and interplay with this vital component of quality of life. It will also explore both the philosophical and theoretical frameworks undergirding the present study and why these are such informative perspectives to use in understanding the complex phenomena known as financial quality of life in cancer patients, vulnerable and otherwise. The literature will be organized broadly by the variables under examination here, especially under the domains of the major framework of the adapted behavioral model for vulnerable populations (Gelberg et al., 2000). The variables to be explored specifically include housing stability; personal control; demographical information; income and financial stress; health insurance adequacy; perceived barriers to care; social support; cancer diagnosis and accompanying variables; and perceived ability to participate meaningfully in treatment. The social justice perspective informed by the political philosopher John Rawls' difference principle will also be thoroughly explored.

The medical and psychosocial literature is ever-growing regarding the financial plight of cancer patients, especially those who are under-served. The literature suggests that cancer patients who lack the resources that contribute to sound medical care are indeed vulnerable and exposed (Grann et al., 2005; Griggs et al., 2007; Halpern et al.,

2008; Head & Faul, 2008; Hughes et al., 2007; Kinsey et al., 2008; O'Toole et al., 2003; Otero-Sabogal et al., 2004; Penson et al., 2003; Reyes-Ortiz et al., 2006; Traynor, 2004; Westin et al., 199; Williams, 2004). Resources such as health insurance—so basic to the U.S. health-care system and how it serves patients—shelter, transportation, and social support such as concerned family members and friends make the road of cancer treatment more bearable. Deficiencies, though, make it excruciating, if not severely life-threatening or even fatal.

A cancer diagnosis is challenging enough to deal with even under the best of circumstances. Weisman and Worden (1976) in their seminal work describe the “existential plight” that confronts virtually all people when they face their cancer diagnosis for the first time. Hearing those words—“You have cancer” or “I’m afraid it’s malignant”—immediately prompts feelings of vulnerability and threats to one’s mortality and security. The prior anticipation of hearing test results confirming that diagnosis is excruciating as well. The psychological toll, thus, in people facing cancer is easily understood and appreciated.

But what of people facing simultaneous trauma of other types? What of people struggling with other responsibilities that contain as much stress? What are the areas of life impacted the most by cancer? How can clinicians of all disciplines help? How can we as social workers understand the totality of their experience and collaborate accordingly?

Though the design of this present study is a cross-sectional one, the primary focus is to explore financial quality of life in those patients who are facing multiple struggles and who are vulnerable on various fronts. Financial quality of life is an area of a cancer

patient's experience that must be explored with greater depth, and its overlap in other areas of life is unmistakable.

Financial hardship in cancer and the impact of cancer on socioeconomic well-being are growing topics of interest in the medical and psychosocial literature. Those patients who struggle financially usually have at least one or several resource deficiencies present or imminent (Griggs et al., 2007; Hughes et al., 2007; Reyes-Ortiz et al., 2006). The literature describes the impact of such a lack of resources on both medical and psychosocial outcomes.

The literature is robust in terms of the impact medically. People who lack health insurance, for instance, face greater barriers in getting needed care due to cost and have ongoing unmet health needs (Ayanian, Weissman, Schneider, Ginsburg, & Zaslavsky, 2000). Other studies show that uninsured cancer patients are more likely to die from their disease than insured patients, especially minority patients (Roetzheim et al., 2000; Sorlie, Johnson, Backlund, & Bradham, 1994; Wilper et al., 2009). One recent study also documents that even among cancer survivors, those who lack health insurance are more likely to forego further needed care related to important cancer check-ups and other medical needs (Weaver, Rowland, Bellizzi, & Aziz, 2010). Short and Mallonee (2006) studied a large sample of cancer patients drawn from the tumor registries of four hospitals in Pennsylvania and Maryland and found that those patients with higher income enjoyed greater quality of life overall, and that there are income disparities that cannot be explained solely by the effect of health on one's income. Kinsey et al. (2008) found that death from cancer is correlated with lower education. In another study, lack of health insurance is also correlated with women receiving chemotherapy doses that are reduced

from the standard of care (Griggs et al., 2007). Thus, poverty and lower socioeconomic status have been found to contribute to poorer health outcomes and poorer health-care decision-making (Institute of Medicine, 2008).

Psychosocial outcomes have also been studied extensively. Ell and her colleagues have long been involved in conducting research with diverse, under-served populations and have studied the correlations between lower socioeconomic status and coping with cancer (Ell & Nishimoto, 1989); the interplay of lower socioeconomic status, coping, attitudes towards cancer, and personal control (Ell, Mantell, Hamovitch, & Nishimoto, 1989); higher levels of depression and lower sense of control in those patients with lower socioeconomic status (Ell et al, 2005; Ell et al., 2007); and interventions targeted at those coping with such issues (Ell, Mantell, & Hamovitch, 1988; Ell, Vourlekis, Muderspach et al., 2002; Ell, Vourlekis, Nissly et al., 2002). Other studies have examined suffering and death in those with lower socioeconomic status (Hughes et al., 2007; Williams, 2004).

Recent research and policy literature have emphasized the importance of including the state of financial well-being in quality of life studies (Ashing-Giwa & Lim, 2009; Head & Faul, 2008), as well as the importance of including socioeconomic factors as we seek to understand the totality of a patient's life and experience (Institute of Medicine, 2008). There are a number of indicators commonly used to determine socioeconomic well-being, and these typically include income, housing, and on-board resources such as health insurance, education, and social support, to name a few (Danis et al., 2010). This present study examines these and other factors and their relationship to financial quality of life within an oncology context.

## **Philosophical Framework and Social Justice Implications**

The philosophical framework for this present study is drawn from the work of the political philosopher John Rawls and his difference principle. This principle provides a provocative impetus for justice in the study of social and human problems, including the right to health care. It has encouraged this social worker to more thoughtfully attempt to grasp his ideas as they apply to financial quality of life in cancer patients. Rawls was undoubtedly one of the most influential philosophers of the 20<sup>th</sup> century, and he reinvigorated the debate on philosophy's contribution to modern life and modern problems (Pogge, 2007). Throughout his prolific career, he developed a theory that he termed "justice as fairness." He developed this theory—egalitarian in nature—as an argument against utilitarian theory, a theory that has been very influential in politics and economics for several hundred years. Whereas utilitarian theory stresses that the morality or goodness of a thing or an act is determined by the greatest average or aggregate amount of happiness it can produce, Rawls' theory disputed that this is the just way to determine morality and "the good." In his groundbreaking work, *A Theory of Justice* (1971, 1999), Rawls theorized that it was ultimately not rational to embrace utilitarianism because of those individuals who would fall outside of the aggregate or the greatest number. Such individuals falling outside of the aggregate would not support others' happiness and well-being at the expense of their own. They would also likely become demoralized and discontented with their lot, which could very well lead to a host of other problems. Thus, in his view, utilitarianism is not conducive to a democracy in which all people are free and equal beings.

Rawls (1971, 1999), in his notion of justice as fairness, envisioned rather that a just society would be one that all members would believe in and be committed to. Utilitarian theory, with its emphasis on the greatest amount of pleasure and happiness produced, is not a worthy standard of judging morality and justice. Rather, he proposed a thought experiment that outlines a contractualist position guiding interactions between a just society and the individuals who live within its boundaries. (A thought experiment is a learning construct designed to explicate all facets of a concept or an idea and to see it through to its logical end.) To ensure to individuals that their society is mindful of their best interests, Rawls (1971, 1999) then posed what he termed the original position in which neutral parties develop a public criterion of justice that citizens could commit to as just, even though citizens are undoubtedly of different persuasions and ideas. This recognition of the pluralistic nature of modern society is termed by Rawls as the overlapping consensus, and it means that despite differences in political and moral philosophy, citizens could agree on a public criterion of justice or how a just society should operate. The parties in the original position develop the public criterion of justice behind what Rawls termed the veil of ignorance, which is a construct designed to keep the parties from knowing anything about the citizens or society they are representing. In this way, they can stay completely neutral about matters affecting the citizens; and they may even be representing, indirectly, their own well-being, so it behooves them especially to act justly. This leads to a discussion of Rawls' second principle of justice, comprising the opportunity principle and the difference principle.

**The difference and opportunity principles.** The most recent rendition by Rawls of his second principle of justice is written as follows: "Social and economic inequalities

are to satisfy two conditions: first, they are to be attached to positions and offices open to all under conditions of fair equality of opportunity; and second, they are to be to the greatest benefit of the least advantaged members of society” (Pogge, 2007, p. 106). The difference principle (the latter phrase) from its origins used the maximin rule by Rawls, which means that in a just social order, the lowest socioeconomic position should be maximized, and this position should be representative of the aggregate. By contrast, classic utilitarians use the maximean rule, meaning that the average in a social order should be maximized. Rawls believed that classic utilitarianism and the way it is incorporated into a social order pursuing justice would lead to intolerable consequences and worst-case scenarios. Rather, by employing the maximin rule, the lowest index position should be maximized instead of the average. It also incorporates the Pareto condition, named after the Italian economist Vilfredo Pareto, specifying that of two or more scenarios, the one should be chosen in which more are better off and none worse off than the other(s). In other words, it is acceptable to raise the highest position as long as no one is worse off under the arrangement.

Rawls accepted that in a pluralistic society and/or in a liberal democracy, differences or even inequalities between persons is inevitable and even acceptable. For instance, the division of labor within a society is perfectly acceptable, according to Rawls (1971, 1999). Even though people will differ according to natural and social backgrounds—and even with respect to luck and opportunities of chance—each person in Rawls’ egalitarian view is deserving of the same rights, liberties, and opportunities, open and available to all as free and equal beings. For example, if one looks purely at division of labor and people’s preferences for type of work in which to engage and how long to



work, one can see that there are all sorts of differences. People differ in talents and backgrounds as well, and each person must be free to pursue his or her life plan. All these things are acceptable so long as the greatest benefit in social and economic inequalities redounds to those in the lowest position, and that the conditions of the opportunity and difference principles are met. Those higher may benefit, too, but the emphasis in the difference principle stays on the lowest.

In terms of productivity, economically speaking, the difference principle alone might have the effect of untoward consequences and injustice were it not for the opportunity principle. As stated, Rawls' second principle of justice comprises both, but the opportunity principle is predominant and carries lexical priority. Regarding differences in background among people in a given social order, some may have been born into under-privileged households or may have experienced discrimination and prejudice. With the difference principle alone, their entire lot would not be improved at all if they were not able to compete for better opportunities. If overall productivity were raised, including for this group, the difference principle alone would not be violated because their position is also being raised. By introducing the opportunity principle, however, with its lexical priority, Rawls ensures that all citizens in a just social order have equal opportunity and can take advantage of these opportunities, open to all. In this way, the opportunity principle can mitigate against unintended effects of the difference principle alone.

***Application of the difference and opportunity principles.*** Rawls' voluminous work and his theory of social justice are termed grand theory. Other philosophers and scholars seek to apply any or all of his justice principles to specific political, social, and economic problems and injustices within our modern world. The philosopher Norman Daniels (1985), for instance, sought to apply Rawlsian theory to health care and how that might be considered a (qualified) need on Rawls' index of primary social goods. The social work scholar Jerome Wakefield (1988) also incorporated Rawls' justice principles as an organizing framework and distributive justice as an organizing value within the social work profession in order to theoretically ground the profession in its mission to vulnerable clients.

**Application of Rawls' theory to the problem of interest.** Because Rawls kept his theory of justice abstract, especially in his book *A Theory of Justice*, philosophers, public policy theorists, and other scholars have sought to apply his principles in order to enlighten and elucidate the debate on pressing social problems. One such issue of interest, of course, to this researcher involves the material presented here under the domain of financial quality of life in cancer patients: access to cancer care for those lacking resources and a connection between lack of health insurance and mortality (Dorn, 2008); growing, serious economic discrepancies between those Americans who have resources to participate in cancer treatment and to receive the therapy they need for better outcomes and those who lack such resources (Griggs et al., 2007; Reyes-Ortiz, Goodwin, Freeman, & Kuo, 2006); health disparities (Cooley & Jennings-Dozier, 1998); access to cancer screening (Otero-Sabogal et al., 2004; Querishi, Thacker, Litaker, & Kippes, 2004); negative perceptions of the health-care system by vulnerable populations

(Gelberg, Browner, Lejno, & Arangua, 2004); barriers to care (O'Toole et al., 2003); barriers to participation in prevention studies (Grann et al., 2005); and income disparities (Westin et al., 1999).

While some may understand and accept theoretically that people who are poor will probably not have the same opportunities and outcomes as those who possess resources, other individuals attempting to participate in and advocate for a more just, fair society indeed find these social and economic realities truly appalling.

This speaks to Rawls' focus on the elements of a just, fair society. Though he writes more in the abstract, one can argue that his principles and ideas are relevant and instructive in addressing social injustices, such as those outlined here. It is each scholar's responsibility to flesh out the abstract and apply Rawls' principles to pressing social problems that we face today.

**Rawls' index of primary social goods.** In order to provide some background on extending Rawlsian theory to cancer in financially underserved populations, it is necessary to define some concepts. Central to Rawls' work in *A Theory of Justice* (1971, 1999) are those items he characterizes as primary social goods. These are things that each individual is entitled to as free and equal individuals, and are those things necessary to what he terms pursuing each one's life plan. From Pogge (2007, p. 73), these are:

Certain basic rights and liberties...;

Freedom of movement and free choice of occupation;

Powers and prerogatives of offices;

Income and wealth;

Residual social bases of self-respect (“residual” because Rawls views the first four primary goods as bases of self-respect as well).

Norman Daniels is one philosopher who has applied Rawlsian theory to health care in our society. He argues that health care is special and is integral to the conceptualization of the primary social goods in daily life (Daniels, 1985). In his seminal work, *Just Health Care*, Daniels (1985) argues for the inclusion of health care as a part of the index of primary social goods because of its inter-connection with fair equality of opportunity and the pursuit of life plans:

Including health-care institutions among those which are to protect fair equality of opportunity is compatible with the central intuitions behind wanting to guarantee such opportunity. Rawls is primarily concerned with the *opportunity to pursue careers*—jobs and offices—that have various benefits attached to them. So equality of opportunity is *strategically* important: a person’s well-being will be measured for the most part by the primary goods that accompany placement in such jobs and offices. As noted earlier, Rawls argues it is not enough simply to eliminate formal or legal barriers to persons seeking such jobs—for example, race, class, ethnic, or sex barriers. Rather, positive steps should be taken to enhance the opportunity of those disadvantaged by such social factors as family background. The point, as noted above..., is that none of us *deserves* the advantages conferred by accidents of birth—either the genetic or social advantages. These advantages from the “natural lottery” are morally arbitrary, because they are not deserved, and to let them determine individual opportunity—and reward and success in life—is to confer arbitrariness on the outcomes. So

positive steps, for example, through the educational system, are to be taken to provide fair equality of opportunity. (pp. 45-46)

Daniels (1985) distinguishes the special nature of health care per se from health care needs and/or preferences that are more cosmetic in nature and that are not considered basic to life. He advocates for the notion of health care needs that enable functioning, as he writes:

Health care needs will be those things we need in order to maintain, restore, or provide functional equivalents (where possible) to normal species functioning. They can be divided into: 1) adequate nutrition, shelter; 2) sanitary, safe, unpolluted living and working conditions; 3) exercise, rest, and some other features of life-style; 4) preventive, curative, and rehabilitative personal medical services; 5) non-medical personal and social support services. (p. 32)

Specifically regarding the cancer experience for people who have financial vulnerabilities in the areas of housing and health insurance and for those who are indigent, application and consideration of Rawls' difference and opportunity principles to matters of injustice is deeply instructive and particularly useful. It is posited that the provisions of these principles along with the index of primary social goods are violated in three ways by the current health-care crisis: 1) the widening gap between the rich and poor in our society and, consequently, between cancer care available to those who have resources and those who do not; 2) the deepening crisis for those cancer patients who lack resources in terms of access to care and increased mortality; and 3) the greater impact on equality of opportunity—or precisely, lack of equality of opportunity—

especially as it pertains to income and wealth and the ability to pursue one's life plan.

Each one will be examined in turn.

***The widening gap.*** “Far from being an apologist for the status quo, Rawls is convinced that the society he envisions would be much better in terms of communal values than existing societies that call themselves liberal. By maintaining the fair value of the political liberties, his society would draw poorer citizens into joint public deliberations about justice and the common good. By maintaining fair equality of opportunity, it would greatly improve social mobility. By satisfying the difference principle, it would reduce existing wage-rate inequalities, thereby enhancing free time available, especially to the poorer strata of the population” (Pogge, 2007, p.188).

Presently the United States is very slowly recovering from an economic recession (and some would doubt that a recovery is occurring). Before that, however, Americans on the lower end of the socioeconomic strata were having greater and greater difficulties in making ends meet. Prices were rising faster than cost-of-living adjustments; it was becoming increasingly difficult to afford homes and to get by on wages that remain stagnant (Ehrenreich, 2008). Job growth slowed and millions were laid off of work. The housing market was decimated and countless numbers lost their homes to foreclosure. Others were priced out of the market and were unable to afford a home of their own. Employers increasingly were unable to provide health insurance benefits for employees, contributing to the alarmingly rapid rate of Americans who lack health insurance (American Cancer Society, 2008). Millions more were unable to afford health insurance plans' monthly premiums, so they did without. Medical debt can accumulate quickly and alarmingly, even when not taking into consideration protracted, serious or life-threatening

conditions. After a long political struggle, President Obama and the Congress in 2010 were able to achieve a compromise on health care reform whereby nearly all citizens will eventually have health-care coverage in the coming decade, but the political fall-out remains to be seen with an issue that inspires such divergent opinion, especially as our nation heads into the 2012 elections. Many political leaders and citizens alike remain opposed to the legislation which is now law. Several legal challenges brought by the states are ongoing.

It is posited that one huge consequence arising from this state of affairs is a growing discrepancy between those who have coverage and those do not in terms of cancer care (Griggs et al., 2007). This inequality is wholly objectionable in a Rawlsian just, fair society. It violates the reasoning and logic in the difference and opportunity principles, not only because the widening gap is unjust, but because those in the lower or lowest positions are becoming even worse off. In cancer care, those worst off are defined as those being turned away from care; those being devastated by medical debt; and those whose lives are most likely being cut short.

***The deepening crisis.***

Social and economic inequalities are to satisfy two conditions: first, they are to be attached to positions and offices open to all under conditions of fair equality of opportunity; and second, they are to be to the greatest benefit of the least advantaged members of society. (Pogge, 2007, p. 106)

Related to this, people whose situations are the worst are facing even more dire consequences. This also would be wholly objectionable in a Rawlsian just, fair society operating with the difference and opportunity principles in motion. The number of

uninsured Americans has grown year by year (Cover the Uninsured, 2011). Insurance—or lack of it—has a definite impact in terms of access to care, quality of care, and health outcomes (Griggs et al., 2007). People who lack insurance are more likely to delay work-up of a specific problem or resort to emergency department (ED) care. In the latter case, they are usually billed for services later, further compounding the problem. It takes much energy, tenacity, and resourcefulness to navigate a hospital's charity assistance program and apply for help via that route. Even if an ED diagnoses a cancer problem, a patient is still usually left without a way to pursue a treatment plan that is affordable, reasonable, and feasible.

Gradually, advocacy organizations and decision-makers are addressing this problem and bringing it to the forefront. The medical literature has been expansive over the years in describing outreach and interventions to vulnerable groups of people, such as the homeless, veterans, and those dealing simultaneously with mental health and substance abuse issues, among others. Greater and greater attention is being focused here, as people recognize that poverty and inequality in health care is a national disgrace. As more and more people are exposed to the problem—or even experiencing it themselves—badly needed attention has finally been given.

Relatedly, the issue of health disparities in cancer highlights inequality in terms of access to and use of care, as well as health outcomes and even death (Cooley & Jennings-Dozier, 1998). People belonging to racial and ethnic minorities are diagnosed later on average and often are not offered the same level of care (National Cancer Institute/Center to Reduce Cancer Health Disparities, 2004). Due to the deepening crisis, those in the lowest positions bear the brunt.



***Impact on equality of opportunity.***

For, as we have just seen, the difference principle transforms the aims of society in fundamental respects. This consequence is even more obvious once we note that we must when necessary take into account the essential primary good of self-respect and the fact that a well-ordered society is a social union of social unions. It follows that the confident sense of their own worth should be sought for the least favored and this limits the forms of hierarchy and the degrees of inequality that justice permits. Thus, for example, resources for education are not to be allotted solely or necessarily mainly according to their return as estimated in productive trained abilities, but also according to their worth in enriching the personal and social life of citizens, including here the less favored. (Rawls, 1971, 1999, pp. 91-92)

Though the parties in the original position were working on behalf of a presumed society in which there are no mental or physical disabilities, Rawls was mindful, of course, that other types of disadvantage and plight occur. Pogge (2007) reflects that Rawls was in favor of affirmative action and would seek to “level the playing field” for those who are not afforded the same opportunities as those—through no merit of their own—who are born into greater opportunity and advantage. Pogge (2007) writes specifically, for example, about racial and gender-based prejudice that Rawls would find intolerable because that interferes with equality of opportunity and relegates people to second-class citizenship. Doing so prevents people from the socioeconomic well-being they are entitled to and interferes with their ability to earn a decent living and to pursue their life plans.

With cancer in under-served populations, it is not a stretch to see from the above descriptions that people who are dealing with this diagnosis along with financial hardships are paying the price, literally and figuratively. The inequality with which they are dealing is preventing them from gaining the kind of socioeconomic security and stability they need to pursue their life plans. Indeed, their financial consequences are worsening their chances of success, and the structural inequality within our society's health-care system creates or exacerbates greater hardship. In a Rawlsian just, fair society, each individual is free to pursue life plans and to be able to generate income and independence to make life plans happen as planned and hoped for. Similar to education (as described above by Rawls, 1971, 1999), health-care services for cancer patients in need can help right the inequalities and enrich lives to the greatest extent possible—especially those lives of the least advantaged.

Rawls' views, of course, are just one set among many philosophical bents, and there is serious, ongoing debate within health-care and scholarly circles as to injustice, prioritization, need, rights, “the good,” rationing of scarce resources, and so forth. There are many—libertarians, utilitarians, communitarians, socialists, capitalists, and others—who disagree heatedly over the institutions of health-care provisions, and what defines and constitutes a just arrangement. Rawls, however, has written a beautifully elegant and persuasive grand theory that, despite disagreements, can enlighten the continuing debate. By their sheer beauty and clarity, his ideas resonate even within those who take a different position.

### **Theoretical Framework(s)—The Adapted Behavioral Model**

While the work of Rawls provides the philosophical impetus in understanding the social justice implications of health-care access, the right to health care, and health-care decision-making, the major theoretical framework for this study is drawn from an adaptation of Andersen's (1968, 1995) behavioral model for health-care utilization developed by Gelberg et al. (2000) for vulnerable populations. Andersen (1968, 1995) authored the original behavioral model to explicate micro and macro factors that predict health-care utilization, and he structured the model to denote predisposing, enabling, and need factors and their impact on health-care utilization, behavior and outcomes. Gelberg et al. (2000) later adapted the model for use in vulnerable populations by first hypothesizing about and then testing additional variables under the same predisposing, enabling, need, and health behavior domains that best predict how vulnerable groups of people will use and not use health-care systems. Studying health-care utilization in vulnerable groups is especially instructive. Such research highlights needs and problems experienced by those who are under-served and is indeed cogent and timely.

Gelberg et al. (2000) studied health-care utilization in a community-based probability sample of 363 homeless individuals in Los Angeles. In this study, these patients were interviewed and examined for four major health conditions (high blood pressure, vision impairment, skin/leg/foot problems, and tuberculosis skin test positivity). Patients with at least one health issue were followed longitudinally for eight months. The authors added vulnerable domains to the traditional domains—in other words, adding factors into the domains that more comprehensively predict patterns of health-care utilization and create a much fuller picture of why people with profound need will seek or

not seek health services. The final model contains several dozen variables across the domains. Gelberg et al. (2000) note that “conditions that contribute to the disadvantaged status of homeless persons will generally be negatively related to a good outcome” (p. 1279). The authors found that homeless persons in their sample were willing to obtain care that they believed was important and if the condition was serious and had long-term serious complications, even if it was presently asymptomatic. Seeking medical care ideally occurs simultaneously when homeless patients work with comprehensive psychosocial programs to address housing needs and mental health and substance abuse counseling issues when indicated. Gelberg et al. (2000) also found that the new factors posed under the vulnerable domains were excellent predictors of health-care utilization. They write,

Our study documents that the newly added categories to the Behavioral Model for Vulnerable Populations should be considered in studies of the health of disadvantaged populations. Residential history, mental health, substance abuse, victimization history, and competing needs do affect the use of health services and health outcomes. (p. 1290)

**Table 2.1:**

*The Adapted Behavioral Model for Vulnerable Populations (traditional and vulnerable domains) (Gelberg et al., 2000)*

<b>Predisposing</b>	<b>Enabling</b>	<b>Need</b>	<b>Health Behavior</b>	<b>Outcomes</b>
<b>Traditional Domains</b>  <b>Demographics</b> -Age -Gender -Marital status -Veteran status  <b>Health Beliefs</b> -Values concerning health and illness -Attitudes toward health services -Knowledge about disease  Social Structure -Ethnicity -Education -Social networks -Occupation -Family size -Religion	<b>Personal/family resources</b> -Regular source of care -Insurance -Income -Social support -Perceived barriers to care  <b>Community resources</b> -Residence -Region -Health services resources	<b>Perceived Health</b> -General population health conditions  <b>Evaluated Health</b> -General population health conditions	<b>Personal health practices</b> -Diet -Exercise -Self-care -Tobacco use -Adherence to care  <b>Use of health services</b> - Ambulatory care -Inpatient care -Alternative health-care Long-term care	<b>Traditional and Vulnerable Domains</b>  <b>Health Status</b> -Perceived Health -Evaluated Health  <b>Satisfaction with care</b> -General satisfaction -Technical quality -Interpersonal aspects -Coordination -Communication -Financial aspects -Time spent with clinicians -Access/availability/ Convenience -Continuity -Comprehensiveness -Administrative hassle

<b>Predisposing</b>	<b>Enabling</b>	<b>Need</b>	<b>Health Behavior</b>	<b>Outcomes</b>
<b>Vulnerable Domains</b>  <b>Social structure</b> -Country of birth -Acculturation/immigration /literacy -Sexual orientation <b>Childhood characteristics</b> -Residential history/homelessness -Living Conditions -Mobility -Length of time in the community -Criminal behavior/prison history -Victimization -Mental illness -Psychological resources -Substance abuse	<b>Personal/family resources</b> -Competing needs -Hunger -Public benefits -Self-help skills -Ability to negotiate system -Case manager/conservator -Transportation -Telephone -Information sources <b>Community resources</b> -Crime rates -Social services resources	<b>Perceived Health</b> -Vulnerable population health conditions <b>Evaluated Health</b> - Vulnerable population health conditions	<b>Personal health practices</b> -Food sources -Hygiene -Unsafe sexual behavior	

The adapted behavioral model has been used in several other research studies involving vulnerable populations, including poor Canadians' use of dental care (Muirhead, Quinonez, Figueiredo, & Locker, 2009); Hispanics/Latinos' access to care and preventive health services in Southern California (Tran, 2006); border and non-border Hispanic Texan women and their use of cancer screening services (Fernandez & Morales, 2007); and other studies involving homeless people in Los Angeles (Stein, Andersen, & Gelberg, 2007; Swanson, Andersen, & Gelberg, 2003).

Cancer patients can be another such vulnerable population when they are dealing with psychosocial and environmental stressors. Given the nature of their illness—which is often life-threatening—their needs, feelings, and perceptions must be understood and addressed as much as their medical needs, and in tandem with the medical piece. Many patients deal with a host of problems simultaneously: They cope not only with the threat to mortality and the oft-paralyzing fear that comes with diagnosis, but also with the impact on day-to-day life and its many responsibilities. It can be overwhelming. The field of psychosocial oncology has grown over the last 25-30 years as professionals from assorted disciplines seek to define people's struggles and intervene most effectively. This certainly has been true of social work, which is an established and well-regarded profession within psychosocial oncology.

In terms of cancer patients' vulnerabilities, it is important to examine less-studied phenomena. Socioeconomic well-being has not been studied as extensively as psychological well-being, depression, and anxiety in cancer patients (Head & Faul, 2008). This is especially so in under-served populations, minority populations (where there is an overlap with those who are under-served), and with those populations

grappling with a scarcity of psychosocial and environmental resources. This is why using the adapted behavioral model for vulnerable populations is so useful. A broader array of factors drawn from real life is delineated, and with measurement of selected or all variables across the domains, greater understanding and prediction are achieved. Note that Andersen was involved with the adapted behavioral model. Whereas in the original model, only health-care utilization and health status were the outcomes, in the adapted model for vulnerable populations, health-care satisfaction is the outcome. Delineated aspects of such health-care satisfaction in the adapted behavioral model include general satisfaction; technical quality; interpersonal aspects; coordination; communication; financial aspects; time spent with clinician; access/availability/convenience; continuity; comprehensiveness; and administrative hassle (Gelberg et al., 2000). Most importantly here, financial aspects of cancer care was chosen as the main outcome.

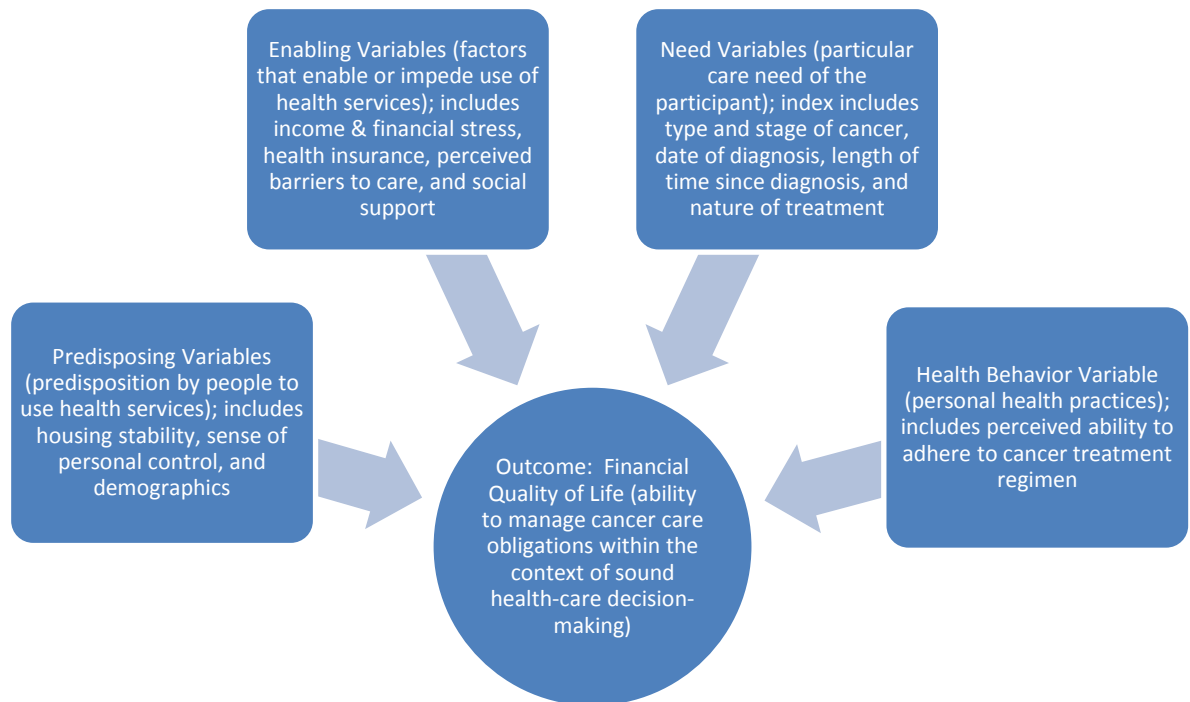
### **Conceptualization of Variables under Examination**

Now that the philosophical perspective and the theoretical model have been explicated, the next step is to apply these to the study under examination here. The quantitative research question in the present study is as follows: What factors (or variables) from the adapted behavioral model for vulnerable populations (Gelberg et al., 2000), which depicts critical macro and micro factors under the domains of predisposing, enabling, need, and health behavior, most significantly impact financial quality of life? The qualitative research questions are: Does a person's financial situation influence his or her sense of personal control with respect to treatment adherence? And how does financial quality of life influence one's sense of personal control and expectation of treatment outcomes? The major hypothesis is: The greater the vulnerabilities and



deficiencies in predisposing factors and enabling factors, the greater the need factors with respect to cancer diagnosis and treatment, and the lower the perceived ability to adhere to treatment, the poorer will be the financial quality of life. The related hypotheses are: 1) Lower income and greater financial stress are correlated with a lower sense of personal control; and 2) Lower income and greater financial stress are correlated with lower financial quality of life, although a higher sense of personal control is a mediating variable.

This research study depicts factors from the adapted behavioral model (Gelberg et al., 2000) and their presumed influence on the dependent variable, which is financial quality of life (see figure 2 below).



**Figure 2.1:** *Selected variables from the adapted behavioral model for vulnerable populations by Gelberg et al. (2000)*

### **Dependent Variable: Financial Quality of Life**

Financial quality of life is conceptualized as the ability to manage all current and future (including unexpected) financial obligations related to cancer care, within the context of sound health-care decision-making. It is not about income *per se*, but about the financial, practical, environmental, and personal resources that promote the decision-making process leading to optimal cancer care. In other words, do people feel reasonably confident that they have what they need in all respects to meet cancer's challenges and to make the best, most reasonable treatment decisions possible?

Socioeconomic indicators of health typically include factors such as income level, housing, health insurance, education, access to care, and competing responsibilities (Danis et al., 2010). Head and Faul's (2008) conceptualization of the Socioeconomic Well-Being Scale (SWBS)—which is used here to measure the dependent variable (financial quality of life)—posed that socioeconomic well-being is composed of two subscales: material capital and social capital. Material capital is defined as the “observable, tangible, owned materials that are under people’s control and that impact the ability to afford and access healthcare services, [and items include] earnings, disposable income, savings, assets, and insurance coverage” (p. 184). Social capital is defined as the “individual, family, and neighborhood resources that are available based upon people’s positions in the social system, [and items here include] norms, reputation, influence, prestige, information channels, and obligations to and from others” (p. 184). This researcher is using this SWBS to measure financial quality of life in the present study with the goal of expanding the conceptualization of quality of life in cancer studies to include financial well-being during cancer diagnosis, treatment, and survivorship.

Head and Faul (2008) report that quality of life in cancer patients is one of the three all-important measures, with the other two being survival data and cost of cancer care. They go on to elaborate that quality of life is typically regarded as a multi-dimensional construct that is subjectively reported by the patient and includes such dimensions as “physical, functional, emotional, social, family, and spiritual” (p. 183). Some quality of life instruments in oncology also include items measuring financial aspects and the economic toll of cancer, but many do not. But increasingly this is changing, and the socioeconomic impact of cancer on individual lives, especially those

who are vulnerable and dealing with health inequalities, is being considered to a much greater extent in health-related quality of life research (Ashing-Giwa & Lim, 2009).

Quality of life research shows that cancer survivors deal with ongoing challenges in the areas of physical, psychological, and spiritual well-being, functionality, and employment (Ahles et al., 2005; Ganz et al., 2002). Researchers are also looking at the impact of race/ethnicity and culture on survivorship and how quality of life can differ depending on race/ethnicity and socioeconomic status (Ashing-Giwa & Kagawa-Singer, 2006).

### **Independent Variables**

#### **Predisposing variables.**

***Housing instability.*** Housing instability is conceptualized by this researcher as participants' perception of their risk of homelessness. The literature on housing instability in cancer patients is nascent but growing, especially as the United States slowly recovers from the economic recession of 2008 and beyond, which was the worst recession this country has experienced since the Great Depression. Housing instability is distinct from homelessness, though, of course, it can lead to loss of housing if severe enough. The literature on homelessness across disciplines is profound but tends to focus on either housed/sheltered or unhoused/homeless with little literature dealing with the risk of homelessness and the slide towards homelessness that can ensue when housing is precarious and unstable. This issue is largely absent in the psychosocial literature dealing with illness, including cancer. As will be explained in the next chapter, reliable and valid instruments that measure housing instability are virtually non-existent, and researchers wishing to examine housing instability usually craft their own questions. Indeed, the National Survey of American Families (NSAF) is the only nationally representative

survey that makes inquiry into housing instability in low-income populations; this survey has been conducted by the Urban Institute three times since 1997, but in only one of those years did it inquire specifically about housing instability via one question (Reid, Vittinghoff, & Kushel, 2008).

Nevertheless, there is some literature on housing instability in patients coping with illness and other social problems and the impact on their access to health care. Housing instability is typically defined as difficulty in paying rent, spending more than fifty percent of one's income on housing, frequent moves, living in crowded situations, or "doubling up" with family or friends (Yen, Hammond, & Kushel, 2009). Reid et al. (2008) found in their meta-regression study that those who are struggling financially and who are experiencing housing instability have poorer access to health care and have more frequent hospitalizations than those who are more fortunate in these social areas. Kushel, Gupta, Gee, and Haas (2005) found that housing instability and food insecurity among low-income Americans are correlated with poorer access to outpatient health care and higher rates of acute inpatient hospital admissions. In another vulnerable population—foster care youth—Yen et al. (2009) found that a history of foster care placement engenders more problems in finding stable housing and access to medical care for these emerging young adults, among other problems. Likewise, one theoretical article on domestic violence posits that domestic violence is a leading cause of housing instability and homelessness among survivors (Baker, Billhardt, Warren, Rollins, & Glass, 2010). Jennings-Dozier, Simpson, Howard, and Marquez (2001) researched women in public housing situations and found through focus group interviewing that access to health care

among these women was compromised to a great extent. Further research on housing instability and health-care outcomes is warranted, especially in turbulent economic times.

*Sense of personal control.* Personal control is conceptualized as the degree to which one feels that health is determined by one's own behavior and actions, as opposed to a greater degree by factors outside of one's control, including doctors, other people, and chance or randomness. In other words, is a person largely in control of his or her own health and wellness, or are others more responsible to a much greater degree? Or is it all random and unexplainable? That is, no matter what I do or what others have done to me, is something bad going to happen to me anyway, beyond my control? Personal control—within the larger context of health locus of control—was selected by the researcher as a variable to study because of its contribution not only to patients' psychological and social well-being, but also to financial well-being. Several studies examine the relationship of vulnerabilities in these areas together with lower socioeconomic status (Ell, Mantell, Hamovitch, & Nishimoto, 1989; Achat, Close, & Taylor 2005). Malcerne, Drahota, & Hamilton (2005) specifically explored these relationships among children in a sample of Caucasian, African-American, and Latino American children with a range of income categories, and they found that low socioeconomic status was correlated with a lower sense of personal control, although personal control did vary by ethnicity. In another study with adults, however, there was no significant correlation between socioeconomic status and personal control (Ell & Nishimoto, 1989). An opposite notion of a strong sense of personal control is fatalism. Fatalism is subtly different from a generally low sense of personal control in that it bespeaks of the belief that when one has cancer, death is inevitable. It is akin to the

feeling that some people have that if they are diagnosed with cancer, treatment for the illness is futile and will do little, if any, good. Yet both phenomena—a low sense of personal control and fatalism—are similar and perhaps intertwined. Fatalistic beliefs are correlated with lower socioeconomic status with respect to cancer screening, especially in minority populations according to some studies (Lopez-McKee, McNeill, Bader, & Morales, 2008; Spurlock & Cullins, 2006). Yet in an earlier article that reviewed the state of the fatalism literature at that time, results of other studies are inconclusive (Powe & Finnie, 2003). It may be that low income/low socioeconomic status can fuel opposite effects: fatalism and despair on the one hand (Wilkes, Freeman, & Prout, 1994) or drive to overcome and remain optimistic about hurdles on the other, including the role of faith and belief in God (Holt, Clark, Kreuter, & Rubio, 2003).

***Demographics.*** Demographical information gathered in this study includes gender, race/ethnicity, marital/partnership status, educational level, employment, and source of income, including entitlements. The literature shows that some of these basic demographical variables are correlated with financial aspects of cancer, including race/ethnicity (Halpern et al., 2008; Otero-Sabogal et al., 2004); social support (Ell & Nishimoto, 1989; Maxwell, 1982); educational level (Kinsey et al., 2008); and employment (Lauzier et al., 2008).

**Enabling variables.**

***Income/financial stress.*** Income and degree of financial stress are conceptualized as the amount of income coming into a household and the extent of distress caused by either inadequate income and/or overwhelming obligations. These are

indicated in dollar response categories and through a subscale measuring the extent of financial strain.

***Health insurance.*** Health insurance is conceptualized as the availability and adequacy of coverage for a cancer patient's typical needs. The role of health insurance in facilitating cancer screening, treatment, and care is unmistakable. Numerous studies in the medical literature have illustrated that patients who lack health insurance and coverage for care face greater mortality (Dorn, 2008; Reyes-Ortiz et al., 2006; Roetzheim et al., 2000; Sorlie et al., 1994; Wilper et al., 2009). They also are more likely to present with advanced disease (Halpern et al., 2008) and to receive different treatment doses based on socioeconomic status and ability to pay (Griggs et al., 2007; Robbins, Pavluck, Fedewa, Chen, & Ward, 2009). Those lacking health insurance are more likely to have unmet health needs (Ayanian et al., 2000), and even among cancer survivors who must be monitored carefully to help avoid recurrence of disease, those without health insurance do not pursue appropriate follow-up care due to cost (Weaver et al., 2009). People who have higher income and yet lack health insurance are less likely to pursue appropriate cancer and other necessary health screenings (Ross, Bradley, & Busch, 2006). Medical debt, even with health insurance present, is a leading cause of bankruptcy (Himmelstein et al., 2005; Seifert & Rukavina, 2006). Those who lack health insurance also face greater barriers to care (O'Toole et al., 2003). Cancer treatment in general, even with health insurance present, poses significant financial burdens and stressors (Lauzier et al., 2008). This present study, rather than focus on medical outcomes, seeks to explore financial quality of life, and it is clear that the role of health insurance is an integral



component of that. More research is needed from patients' perspectives on how they absorb the cost of care and impact on their financial well-being (Kim, 2007).

***Perceived barriers to care.*** Perceived barriers to care—or put differently, access to care—are conceptualized as those competing responsibilities and logistical problems that may preclude meaningful participation in treatment. It is also closely connected with social support. Many of the studies including social support as a psychosocial variable also measure access to care and treatment adherence, and those are all intertwined, such that positive social support facilitates access and adherence. The inverse is also true. If barriers are reduced, access and adherence are enhanced and maximized. Barriers to care include such things as lack of reliable transportation; competing responsibilities; financial stress and inability to pay for treatment and care; fear and perceived stigmatization; fear of and feeling intimidated by the health-care system; lack of commitment from a support network; and inaccessible health-care resources. Language barriers and difficulties in navigating the health-care system are also significant factors. The literature shows that there are significant barriers to cancer screenings in under-served populations (Jernigan, Trauth, Neal-Ferguson, & Cartier-Ulrich, 2001; Otero-Sabogal et al., 2004). The barriers are compounded when actual cancer care begins; the responsibilities and expenses are significant. Addressing barriers remains a challenge.

Wilkes et al. (1994) in their seminal article on cancer and poverty write about the cycle of poverty and despair that bedevils disadvantaged populations from seeking cancer screening and care. Disparities continue to exist as well in minority groups of people. Disadvantaged groups tend to be diagnosed later when treatment options are more limited and outcomes are poorer. Barriers that encompass both psychological and social

variables must be better understood and addressed. Partnering with disadvantaged groups to research and promote interventions that challenge barriers must also be embarked upon.

***Social support.*** Social support is conceptualized as the extent to which mutually helpful and meaningful relationships that ensure such support are available, accessible, and adequate. The importance of social support in cancer patients—support that is meaningful and present—cannot be denied. Positive social support with any patient connotes the fact that there are people involved who care and want to help during the ordeal. The quality and availability of such support can vary, of course. Numerous studies have demonstrated the value of social support in lessening the distress associated with a cancer diagnosis and treatment (Friedman et al., 2005; Maxwell, 1982). Many of these studies, however, have taken place with samples of largely Caucasian, middle-class patients, and thus are not generalizable to the broader population (Friedman et al., 2005). It is necessary to assess social support in relation to other variables in more diverse samples, including those who are vulnerable and disadvantaged. Does social support serve as a protective factor with patients who are vulnerable in other areas of life?

With respect to breast cancer screening, for example, Kerans (2005) conducted a literature review of studies examining social support and other socioeconomic factors in breast cancer screening. Some studies in her review show that higher levels of social support correlate with better screening adherence, although adherence to screening is also correlated with greater affluence and education. Husaini (2001) reported that women who are married and who have strong community ties also have higher levels of breast cancer screening. An older study documented that social support, in addition to other

predisposing, enabling, and reinforcing factors (specifically, mammography beliefs and logistic issues) was significant in determining whether or not inner-city women were regular mammography users (Taylor, Thompson, Montano, Mahloch, Johnson, & Li, 1998). In a more recent study, social support was also found to be a significant correlate (in addition to mammography-related variables, how often women should have clinical breast exam or CBE, and benefits and barriers to mammography) in mammography screening in a sample of older, low-income, African-American women (Farmer, Reddick, D'Augustino, & Jackson, 2007). Lagos et al. (2008) did a study measuring social-cognitive aspects in under-served Latinas seeking genetic cancer risk assessment (GCRA) for breast and ovarian cancer and found social support to be one of the significant variables in women preparing for the GCRA process. The role of social support cannot be underestimated in how people confront and cope not only with this life-threatening illness, but also in important cancer screenings and prevention care.

#### **Need variable.**

*Cancer diagnosis and accompanying variables.* The need variable is conceptualized as the particular care need of each participant based on type and stage of cancer, date of diagnosis, length of time since diagnosis, and nature of treatment. This is done through each patient's self-report. The purpose is to measure cancer's acuity in each patient's life.

#### **Health behavior variable.**

*Perceived ability to adhere to cancer treatment regimen.* The health behavior variable refers to one's perceived ability to participate meaningfully in treatment and is conceptualized as treatment adherence in light of potential obstacles. This variable was

included to assess the relationships among all the variables, especially among barriers to care, social support, and treatment adherence. DiMatteo et al. (1993) writes that non-adherence is especially high in regimens that treat life-threatening illnesses such as cancer, and understanding the reasons for patient non-adherence are important. DiMatteo has researched non-adherence extensively, and in 2004 she conducted a quantitative review of 50 years of research in non-adherence with a meta-analysis of 569 research studies of medical treatment and 164 research studies providing correlations among non-adherence and various demographic and socioeconomic variables. DiMatteo (2004b) found in the meta-analysis that average non-adherence to medical regimens across diseases and disorders is nearly 25 percent. Of special note here, DiMatteo (2004b) found that there were 27 studies researching the correlation between income/socioeconomic status and adherence in adult and pediatric patients, and that overall adherence is positively correlated with improved income; this relationship was found to be stronger in adult patients than pediatric patients. In another set of studies in the meta-analysis measuring income specifically (rather than socioeconomic status generally) and adherence, greater income was correlated with better adherence (DiMatteo, 2004b).

DiMatteo (2004a) also conducted a meta-analysis of social support and patient adherence in the research literature between 1948 and 2001, and identified 122 articles examining correlations between these two variables. It was found that the presence of social support—practical, emotional, and unidimensional support; family cohesiveness as opposed to conflict; marital status; and living arrangements of adults—was significantly

correlated with improved adherence (DiMatteo, 2004a), with practical support demonstrating the highest correlation with adherence.

Examining patients' perceived ability to adhere to the cancer treatment plan outlined by their medical providers and how they view collaborating with them in that plan is critical. The relationship with financial quality of life is also important to study in the present research. Questions that arise revolve around whether or not financial considerations and constraints impede patients from collaborating with their providers and adhering to the treatment plan set forth. What gets in the way? Do family and friends help enough? What are the helps and hindrances? As treatment adherence is so critical in cancer care—often spelling the difference between life and death—getting the patients' perspectives is highly instructive. Moreover, examining adherence via multi-method approaches and within the context of greater patient self-advocacy is also the wave of the future (Kravitz & Melnikow, 2004).

## **Summary**

This chapter has presented a detailed review of the literature of the variables under examination in this study. It has also presented the philosophical and theoretical frameworks underpinning the study. Rawls' difference and opportunity principles from his theory of justice were explored to show how considerations of social justice are paramount in addressing inequalities in health care today. The adapted behavioral model for vulnerable populations (Gelberg et al., 2000) was also described in order to present the framework from which the selected variables were chosen to measure their impact on financial quality of life. These variables encompass both micro and macro factors so that psychosocial and environmental influences are better understood. This is salient for

those patients coming from a background of vulnerability and disadvantage. The next chapter will describe the methodology of the study.

### **Chapter 3: Methodology**

This chapter describes the methodology for the research study under examination here. It details the study design, research questions, and hypotheses, along with the sampling plan and recruitment strategies. Description of the study instrument will also be provided. Data analysis and human subjects protection are also described. Finally, strengths and limitations of the study will be discussed.

#### **Study Design**

This study is a mixed methods study. The quantitative portion is a cross-sectional study drawn from an availability sample of 90 cancer patients from two different hospitals in the Washington, DC, metropolitan area. Patients completed a structured questionnaire which took about thirty minutes to complete. The qualitative portion of the study was an in-depth inquiry in a subset of 7 patients who completed the quantitative portion of the study. This portion focused on a patient's perceptions of personal strengths and weaknesses in relationship to financial quality of life and treatment adherence. The questions were designed to solicit perceptions of personal control with respect to financial quality of life, as well as to treatment adherence. In addition, the idea behind the qualitative portion was to dovetail with and systematically determine whether or not income level and financial stress are significant factors in a patient's self-perception of strengths and weaknesses within the context of financial quality of life. Towards this end, patients were randomly selected from the sample of 90 patients from three household income categories: those who made under \$10,000; those who made between \$10,000 and \$75,000; and those who made over \$75,000.

The quantitative research question is: 1) What factors from the adapted behavioral model for vulnerable populations most significantly impact financial quality of life? The qualitative research questions are: 1) Does a person's financial situation influence his or her sense of personal control with respect to treatment adherence? 2) How does financial quality of life influence one's sense of personal control and expectation of treatment outcomes?

The hypotheses are:

Hypothesis 1: Drawn from the adapted behavioral model for vulnerable populations (Gelberg et al., 2000), the greater the vulnerabilities and deficiencies in predisposing factors and enabling factors, the greater the need factors with respect to cancer diagnosis and treatment, and the lower the perceived ability to adhere to treatment, the poorer will be the financial quality of life.

Hypothesis 2: Lower income and greater financial stress are correlated with a lower sense of personal control.

Hypothesis 3: Lower income and greater financial stress are correlated with a lower financial quality of life, although a higher sense of personal control is a mediating factor.

### **Study Population**

The sample was an availability sample of 90 patients being treated for cancer at two hospitals in the Washington, DC, metropolitan area. These two hospitals were the Washington Cancer Institute at the Washington Hospital Center and the NIH Clinical Center at the NIH campus in Bethesda, Maryland. Despite being an availability sample, a rich cross-section of cancer patients in the DC metropolitan area was desired, and this is why two different sites were chosen. A diverse sample of patients from all walks of life



was sought. For these reasons, a sample containing great diversity in income, education, types of cancer, modes of treatment, occupation, race/ethnicity, gender, and levels of financial stress, to name just several, was invited to participate. Recruitment took place via several routes: 1) collaboration with doctors, nurses, nurse practitioners, and other licensed independent providers who informed patients about the study; 2) patient self-referral in response to posted and distributed flyers; and 3) outreach to potential patients in these hospitals' day hospitals, clinics, and infusion centers.

In terms of sample size, for meaningful statistical analysis in the behavioral and social sciences, it is best to have up to 20 participants per independent variable. To illustrate, Stevens (2009) writes, "We return to the cross-validation issue in more detail later in this chapter, where we show that *for social science research, about 15 subjects per predictor are needed for a reliable equation, that is, for an equation that will cross-validate with little loss in predictive power*" (p. 71). Also, Musil, Jones, and Warner (1998) write, "...multiple regression should have 5 to 20 subjects per independent variable in the equation" (p. 277). Due to study and time constraints, however, only 90 patients were eventually recruited for this study.

### **Variables in the Quantitative Aspect of the Study**

**Dependent Variable:** The dependent variable in this study is financial quality of life, conceptualized as the ability to manage all current and future (including unexpected) financial obligations related to cancer care within the context of sound health-care decision-making. It not only refers to concrete income and resources, but also looks to the larger picture of whether or not a person feels confident that those resources are in

place to meet health-care decisions and goals and that he or she feels psychosocially ready and prepared to tackle what lies ahead.

Moreover, strong financial quality of life for cancer patients means the presence of resources and access to deal with all aspects of the crisis to the greatest extent possible. Absence of it speaks to a potential deficiency to deal with the crisis at hand. It is operationalized by the Socioeconomic Well-Being Scale (SWBS), developed and authored by Head (Head & Faul, 2008) at the University of Louisville. The scale was developed to address the fact that financial well-being has often been neglected in quality of life studies. Yet it is a critical part of daily life, as much so as psychological and social well-being. According to these authors, four major factors impact socioeconomic well-being in cancer care today: rapidly increasing costs of care, even for patients who have health insurance; financial distress due to work changes and/or ability to work; the plight of the uninsured; and the inequalities in health outcomes due to poverty (Head & Faul, 2008). These factors are significant in quality of life studies, and it is critical to include these when measuring overall quality of life and understanding the totality of a person's cancer experience. The SWBS scale is a 17-item Likert questionnaire composed of two subscales: material and social capital. Material capital refers to tangible items such as earnings and health insurance that impact people's ability to afford health care; social capital refers to personal and environmental resources that bespeak of a person's place within the social sphere and consequently his or her ability to manage obligations related to health care. The items address access to care and resources within the context of overall perceived socioeconomic well-being. (See Appendix A for the full instrument; questions 94-110 are the SWBS instrument.) The sample in the Head and Faul study was

a population of cancer patients from the tumor registry of the University of Louisville Hospital and the James Graham Brown Cancer Center. Of 1,200 cancer patients listed in the registry and approached by mail, 289 patients (24%) responded, and of these 266 (22%) responses resulted in useable data. Overall reliability for the material capital subscale was .90 and for the social capital subscale it was .85. Content validity, construct validity at the item level, and discriminant and convergent validity were used to strengthen the resulting scale. The higher the score on the scale, the better the socioeconomic well-being.

**Independent Variables:** The independent variables are organized under the domains of predisposing, enabling, need, and health behavior, as described by Gelberg et al., (2000). (In Appendix A is the entire instrument, and on page 134 is a listing of all the numbered items/questions associated with each variable below.) The first three fall under the predisposing domain:

- 1) **Housing stability:** This is conceptualized as participants' perception of their risk of homelessness. It is speculated here that potential loss of housing increasingly will be felt and experienced by cancer patients and those coping with illness especially in times of lingering economic volatility. One recent newspaper article documents this experience from one family's perspective ("No Sanctuary from Suffering," 2010). In the absence of a reliable and valid survey measuring the potential loss of housing due to illness, inquiry into housing stability is operationalized via a set of questions adapted by the researcher with permission from two housing advocacy coalitions (the Montana Council on Homelessness and the National Coalition for the Homeless) that measure whether or not

participants have a permanent place to stay and their perceived risk of homelessness (essentially losing their homes). A composite index was formulated as a continuous variable based on permanency of residence, length of time in present residence, perceived risk of losing housing due to inability to pay and/or risk of losing housing due to stress of medical condition, and reasons why participants left their last residence (if applicable).

- 2) Sense of personal control: This is conceptualized as the degree to which one feels that health is determined by one's own behavior and actions, as opposed to a greater degree by factors outside of one's control, including other people and chance or randomness. Personal control is operationalized in this study via the Multidimensional Health Locus of Control Scale-Cancer (Wallston, Wallston, & DeVellis, 1978). This is an 18-item Likert scale containing four independent subscales (internality of health locus of control, powerful others locus of control, doctors locus of control, and chance locus of control). Each subscale is scored independently, so there is not one overall, composite score. This questionnaire has been found to be reliable (alpha coefficients over .80 on its independent subscales) and valid (with excellent criterion validity) (Wallston et al., 1978). Higher scores on the powerful others locus of control, doctors locus of control, and chance locus of control subscales indicate externality whereas a higher score on the internality of health subscale indicates a greater degree of internal personal control (not externality).
- 3) Demographics: Demographics include gender, race/ethnicity, marital/partnership status, educational level, employment, and source of income, including

entitlements, and number in household, including number of minor children.

These variables are operationalized via questions denoting specific response categories for each item.

The next four variables fall under the enabling domain:

- 4) **Income and financial stress:** This is conceptualized as the amount of income coming into a household and the extent of distress caused by either inadequate income and/or overwhelming obligations. These are measured in dollar response categories, which admittedly is ordinal data. This is done, however, in such categories in order to generally capture the amounts indicated by the Federal Poverty Level (FPL), 200% of the FPL, 300% of the FPL, and so on. It is theorized as well that participants are more likely to answer this sensitive question on income via checked categories and not by writing the precise amount (which they may have declined to do, resulting in missing data). Financial stress is measured through three questions from the Profile of Adaptation to Life-Medical (PAL-M), which has an excellent overall reliability score of .80 in a sample of medically ill patients (BrintzenhofeSzoc, Aron, Jacobsen, Koziol, & Callahan, 2007). A higher score on the three items from the PAL-M indicates greater financial stress. Consequently in the study, items were then reverse-coded so that a higher score indicates greater well-being.
- 5) **Health insurance:** This is conceptualized as the availability and adequacy of coverage, and is measured by a set of questions formulated by the researcher that are designed to measure whether or not insurance coverage is present and adequate for a cancer patient's typical needs.

- 6) Perceived barriers to care: This is conceptualized not only as those competing responsibilities and logistical problems that may preclude meaningful participation in treatment, but also factors and circumstances that directly hinder participation in medical care. This variable is operationalized via several modified questions from the basic need satisfaction subscale of the Quality of Life Questionnaire (QLQ) (Bigelow, McFarland, & Olson, 1991) that makes inquiry into a participant's ability to access medical care. To give an example of how several questions were modified, in the original questionnaire, items addressing food, medicine, and clothing were grouped together, such that a participant answered one just one question regarding whether or not current income was sufficient to cover all these vital resources. It was felt that it would yield more accurate information to separate items such as these into individual questions so that participants would answer each in turn. Item scores are then reversed so that higher scores in this subscale reflect better quality of life. Consequently, in this study items were then reverse-coded so that a greater score indicated greater barriers. This subscale of the QLQ has an alpha for internal consistency of .358, which is admittedly low. Yet the subscale is making inquiry into several disparate and distinct but highly relevant areas, including housing and housing safety; income sufficiency for food and clothing; transportation for work, medical appointments, and socializing; and access to medical care. It was felt that the comprehensive nature of the subscale and the strength of the wording in each question overrode the low alpha.

- 7) Social support: This is conceptualized as the extent to which mutually helpful and meaningful relationships that ensure that social support are available, accessible, and adequate. This is operationalized via the 8-item social support subscale of the Quality of Life Questionnaire (QLQ) (Bigelow, McFarland, & Olson, 1991). This subscale has an alpha for internal consistency of .67. Higher scores on this subscale also indicate better support.

The need domain is as follows:

- 8) Cancer diagnosis and its accompanying variables: This is conceptualized as the particular care need of the participant based on type and stage of cancer, date of diagnosis, length of time since diagnosis; and nature of treatment. A composite index was formulated as a continuous variable based on the stage of disease, prognosis based on diagnosis, time since diagnosis, and treatment aggressiveness.

The health behavior domain is as follows:

- 9) Participant's perceived ability to participate meaningfully in treatment: This is conceptualized as treatment adherence in light of potential obstacles. It is operationalized via the Adherence Determinants Questionnaire (ADQ), developed by DiMatteo et al. (1993) that measures patients' adherence to treatment regimens. It is a 38-item Likert scale covering seven domains of potential patient non-compliance with cancer treatment regimens (interpersonal aspects of care, perceived utility of treatment, perceived severity of one's cancer, perceived susceptibility of the cancer to recur, subjective perceptions of one's family, close friends, and relatives regarding one's treatment plan, intentions for adherence to one's treatment plan, and support/barriers to adherence). It has a mean reliability

score of .76 with good validity (DiMatteo et al., 1993). Each of the subscales except for the subjective norms subscale is scored by summing individual item scores. For the first two subscales the range is from 8-40; for the remainder the range is 4 to 20. The subjective norms subscale score is the sum of three multiplicative items, thus producing a range from -18 to +18. The overall scale can be converted into a range from 0-100 so that all subscales are on the same metric.

The final questionnaire consisted of 126 items. It took approximately thirty minutes for each participant to complete. The final question asked if the participant was interested in being included in the sampling framework for the qualitative part of the study.

### **Data Collection Plan**

Patient recruitment for this study took place at both the Washington Cancer Institute at the Washington Hospital Center in Washington, DC, and at the NIH Clinical Center in Bethesda, Maryland. Data collection began in May 2010 and ended in October 2011. Recruitment took place via several routes: 1) collaboration with doctors, nurses, nurse practitioners, and other licensed independent providers who informed patients about the study; 2) patient self-referral in response to posted and distributed flyers; and 3) outreach to potential patients in these hospitals' day hospitals, clinics, and infusion centers. This researcher met with each patient in order to screen him or her, explain and complete the informed consent, administer the questionnaire, and provide the \$25 gift card and resource list to thank participants for their time and participation immediately after their completion of the questionnaire.



**Qualitative study sampling plan.** At the conclusion of the quantitative phase, the researcher randomly selected a subset of patients from those who agreed to be included in the qualitative part of the study. To obtain the sampling frame for this part of the study, those who agreed to participate were categorized into one of three groups based on income categories. The three income categories were: those with household incomes of \$10,000 or less; between \$10,000 and \$75,000; and above \$75,000. Using these three strata, participants from each were randomly selected. This researcher contacted the randomly selected participants to ascertain their willingness to participate, and a mutually agreeable time to meet again was determined. Once informed consent was granted, the interview was conducted and tape-recorded. All interviews were transcribed. This procedure was clearly presented in the informed consent process. The \$10 gift card was given immediately after as a thank-you for their time and participation.

### **Data Analysis Plan**

Data was entered by the researcher into the password-protected Vovici, an online survey system, and then imported into the password-protected SPSS data base for analysis. Initial data analysis examined the frequency distributions for all variables and computed descriptive statistics appropriate for each level of measurement. Estimates of reliability were conducted on all scales within the questionnaire for the current sample. Pearson's correlation coefficient (Pearson's  $r$ ) was used to determine the bivariate correlations among the independent and dependent variables. For Hypotheses 1, 2 and 3, multivariate (ordinary least squares) regression analysis was used to examine the impact of all the predictors on the criterion variable. For Hypothesis 3 specifically, it was to be determined whether or not a strong sense of personal control is a statistically significant,

mediating variable between the other independent variables in the equation (lower income and greater financial stress) and the dependent variable (financial quality of life).

Content analysis was used to elicit the themes expressed by the participants in the qualitative portion of the study.

### **Human Subjects Concerns**

Participation in this study was voluntary and each participant at both quantitative and qualitative phases signed an informed consent outlining the purposes of the study and explaining its risks and benefits. The researcher was available to answer questions and provided information on useful resources to all participants. Participants were informed that they could refuse to participate and/or answer any question they did not want to, and could withdraw from the study if they chose without any penalty or negative impact on the care they were currently receiving. Responses to the questionnaires remained confidential and secure at all times (under double-locked conditions), and each participant was assigned a number in order to ensure confidentiality and anonymity. The study was approved by the institutional review boards (IRBs) at both medical institutions as well as by the IRB at the Catholic University of America.

### **Strengths and Limitations**

This study contains both strengths and limitations. The effort and success in the design in achieving a diverse cross-section of cancer patients is one such strength. There is richness in terms of cancer type, gender, income, race/ethnicity, and education in this availability sample. Great effort was taken to ensure a rich cross-section, including outreach to patients who might not otherwise have been inclined to participate in a clinical trial. Outreach to patients from all income levels was also sought in order to

ascertain whether or not the presence or absence of one or more vulnerabilities (not necessarily financial vulnerability) was significant in financial quality of life. Another strength of the study is the mixed methods design. Triangulation of the data across both quantitative and qualitative methods provides a fuller description and understanding of the financial toll of cancer and its treatment, as well as patients' socioeconomic well-being. It also allows for participants' greater expression of their own strengths and weaknesses in their battles with cancer and how they are handling the financial aspects of treatment.

The major limitation of this study is that it is drawn from an availability sample and not from a random sample, so the results are not generalizable. Though the most diverse cross-section possible with the resources available was sought, a random sample with generalizability is the "gold standard" in social sciences research. Another limitation is the fact that only English-speaking patients were eligible to participate, again due to finite resources. It is hoped that this study can eventually be expanded in another version to include non-English-speaking patients, as it is critical to ensure that minority patients and those who speak languages other than English share their cancer experiences and the burdens they face.

## **Summary**

This chapter has described the methodology of this study, and has detailed the research questions, hypotheses, and study design of this project. The dependent and independent variables have been conceptualized and operationalized. Background of the entire study questionnaire has been provided. The data collection procedures and the data

analysis plan were also described, along with human subjects protection issues and the study's strengths and limitations. The next chapter will discuss the study's findings.

## **Chapter 4: Findings**

The purpose of this chapter is to describe the findings on financial quality of life in a cross-section of cancer patients, as well as to explore possible meanings of the findings and implications for social work and for the social problems under examination here. It will also describe characteristics of this availability sample. Information regarding reliability of the instruments used in this particular sample of patients will also be detailed.

### **Demographics**

Though this particular research study had to rely on an availability sample, great effort was taken to recruit a diverse sample of cancer patients in the Washington, DC, metropolitan region. This is why patient recruitment took place at two hospitals in the area. Indeed, a diverse group of patients in many respects was recruited. The sample consists of 90 patients with an age range of 20 to 81 and an average age of 52.7. The sample contains 60% women and 40% men. There are 34.5% African-Americans; 52.9% Caucasians; and 12.6% patients of multi-racial or other ethnicity. Three patients preferred not to answer the question on race/ethnicity. Only 4.5% patients considered themselves to be Hispanic, but this was to be expected, as the study was not available to Spanish-speaking-only patients (due to resource limitations). In terms of marital status, 50% were married; 5.6% were living with a partner; 31.1% identified themselves as single; and 13.2% were either separated, divorced, or widowed.

In terms of income and education, 15.6% of the patients earned less than \$10,000 a year; 17.8% earned between \$10,000 and \$30,000 a year; 12.2% of the patients earned

between \$30,000 and \$50,000 a year; 14.4% of the patients earned between \$50,000 and \$75,000 a year; and the remainder (34.4%) earned more than \$75,000 a year. Five percent of the patients chose not to answer the question on income categories. It is also a well-educated sample: 31.1% of the patients have a post-graduate or professional degree; 27.8% are college graduates; 20% have attended some college; 17.8% are high school graduates; and 3.3% patients have less than a high school diploma. Forty percent of the patients are currently employed, whereas 60% are not; 26.7% patients rely on income provided by a spouse or relative; 25.5% patients rely on either SSI/SSDI or public funds for income support; and 17.8% patients rely on other sources of income, such as investments and long-term disability.

In terms of statistically significant differences between the participants at the Washington Cancer Institute and at the NIH Clinical Center, there were more male participants at the NIH Clinical Center than at the Washington Cancer Institute (30 as opposed to 6) and there were more women participants at the Washington Cancer Institute than at the NIH Clinical Center (32 as opposed to 22) ( $p = .000$ ). There were no other statistically significant differences in terms of demographics (race and marital status). Nor were there statistically significant differences in income, employment status, or education between the two groups. Regarding health insurance, more participants at the NIH Clinical Center lacked health insurance, and this was statistically significant between the two groups ( $p = .013$ ). There was no statistically significant difference between the groups in terms of financial quality of life.

As this study was open to any cancer patient over the age of 18, undergoing active treatment at the two hospital sites, there is a range of cancer diagnoses, as seen in Table

4.2. Several of the diagnoses are rare, such as blastic plasmacytoid dendrite cell neoplasm and adult T-cell lymphoma/leukemia, which is indicative of the types of programs and outreach done at the NIH Clinical Center in investigating rare illnesses.

The majority of the patients (83.3 %) have health insurance. Patients received a range of therapies, including surgery, radiation, chemotherapy, hormone therapy, transplant, and various clinical trials for advanced cancers.

**Table 4.1:*****General Demographics***

<b>Characteristic</b>	<b>N</b>	<b>%</b>
Gender		
Male	36	40.0
Female	54	60.0
Race		
African American	30	34.5
Caucasian	46	52.9
Multi-racial	5	5.6
Other	6	6.9
Marital Status		
Single (single, separated, divorced, widowed)	40	44.3
Married	45	50.0
Living with Partner	5	5.6
Employment		
Full-time	23	26.4
Part-time	9	10.3
Retired	21	24.1
Disabled	1	1.1
Homemaker	5	5.6
Other	28	32.2
Education		
Less than high school	3	3.3
High school	16	17.8
Some college	18	20.0
College graduate	25	27.8
Post-graduate or professional	28	31.1
Insurance Status		
Insured	75	83.3
Not insured	15	16.7
Income		
Under \$10,000	14	16.5
\$10,000-\$75,000	40	47.1
Above \$75,000	31	36.5
Did not say	5	
Sources of income		
Current work	36	40.0
Spouse, relative, or friend	24	26.7
Public funds	2	2.0
Retirement or Social Security	28	31.1
SSI/SSDI	21	23.3
Alimony or child support	2	2.2
Other	16	17.8



**Table 4.2:***Cancer-Related Demographics*

Type	Number
Adrenal	1
AML	2
ATL	1
Bladder	1
Blastic plasmacytoid dendrite cell neoplasm	2
Bone	1
Brain	2
Breast (including other primaries)	24
Cervical	1
Collangiosarcoma	1
CML; CMML	2
Colon	4
CTCL	1
DCIS	1
Head and neck	2
Hodgkin's lymphoma	2
Lymphoma	6
Kaposi's sarcoma	1
Kidney	3
Lung	3
Mesothelioma	1
MDS	5
Melanoma	3
Multiple myeloma	2
Ovarian	3
Prostate	7
Rectal	1
Sarcoma	1
VHL	2

## Description of Instruments in this Sample by Domain from the Adapted Behavioral Model

**Table 4.3:**

*Instruments Used to Measure Variables under Each Domain*

Predisposing Variables	Enabling Variables	Cancer Need	Health Behavior	Outcome Variables
<b>Demographics</b> (race, education, marital status, source of income, education)	<b>Financial Stress:</b> Income management/Financial Stress domain from the PAL-M scale (BrintzenhofeSzoc et al., 2007)	<b>Cancer Need:</b> Cancer Composite Index (scale composed for this research)	<b>Perceived Ability to Adhere to Treatment:</b> Adherence Determinants Questionnaire (DiMatteo et al., 1993)	<b>Financial Quality of Life:</b> Socioeconomic Well-Being Scale (Head & Faul, 2008)
<b>Housing Stability:</b> Housing Composite Index (scale composed for this research)	<b>Health Insurance:</b> Health Insurance Adequacy scale (scale composed for this research)			
<b>Personal Control:</b> Multidimensional Health Locus of Control Scale (Wallston et al., 1978)	<b>Perceived Barriers to Care:</b> Quality of Life Questionnaire (basic need satisfaction domain) (Bigelow et al., 1991)  <b>Social Support:</b> Quality of Life Questionnaire (social support domain) (Bigelow et al., 1991)			

As described above, this research utilizes nine surveys and indexes (in addition to the collection of demographic and income-related information) in order to measure all variables. Three had to be constructed for the study: 1) housing composite index to measure housing instability; 2) health insurance adequacy scale; and 3) cancer need index to measure acuity of each patient's cancer diagnosis and treatment. All characteristics

and scoring of the instruments in this sample of patients will be described under the domains from Gelberg et al. (2000), following the description of the dependent variable which is financial quality of life. See Appendix A for a copy of the final questionnaire with questions on the questionnaire also delineated by variable on the last page of the survey (p. 134).

### **Dependent Variable**

The dependent variable in this research is financial quality of life, which is conceptualized as the ability to manage all current and future (including unexpected) financial obligations related to cancer care within the context of sound health-care decision-making. It is operationalized in this study by the Socioeconomic Well-Being Scale (SWBS), developed and authored by Head (Head & Faul, 2008). The SWBS contains 17 items on a Likert scale and is composed of two subscales (Material and Social Capital) that address health-care access and available resources within the overall perceived context of socioeconomic well-being. The higher the score, the better the well-being or financial quality of life. In this present study, overall reliability of the scale is .732. Scores can range from 0-68; in this sample, scores in this sample range from 14-68 with a mean of 40.5 and a standard deviation of 14.5.

### **Independent Variables**

The independent variables are organized under the domains of predisposing, enabling, need, and health behavior, as described by Gelberg et al. (2000). Here are the results under each domain, the first of which is the predisposing domain:

- 1) Housing stability: This is conceptualized as participants' perception of their risk of homelessness due to medical debt. A composite index was formulated by the

researcher as a continuous variable based on permanency of residence (Do you have a permanent place to stay: yes or no); place of residence over the past 30 days; length of time in present residence; perceived risk of losing housing due to inability to pay and/or stress of medical condition (Are you at risk for losing your home due to inability to pay your rent or mortgage, and if so, do your medical condition(s) and/or health-care costs contribute to your inability to pay for your housing: yes or no); and reasons why participants left their last place of residence (if applicable), ranging from planned move or relocation to eviction, rent troubles, condemned housing, or family conflicts. The index is composed of 6 items. During scoring, yes-and-no items were dummied in order to assist in the statistical analysis of the continuous variable. Place of residence over the past 30 days was coded as 0 for one's own rental housing or house with mortgage and 1 for other places (such as with friends or family, motel, transitional housing, shelter, hospital, etc.). Length of time in present residence was coded as 0 for more than a year in present residence and 1 for less than a year in present residence. For the last question (Why did you leave your last place of residence—check all that apply), planned move or relocation was scored as 0 whereas more problematic reasons for leaving (such as eviction, family conflicts, overcrowding, domestic violence, or condemned housing) were scored as 1. Scores over 4 indicate housing instability, and scores range from 0-7 with a mean of 1.15 and a standard deviation of 1.67.

- 2) Sense of personal control: This variable is conceptualized as the degree to which one feels that health is determined by one's own behavior and actions, as opposed

to a greater degree by factors outside of one's control, including other people and chance or randomness. It is operationalized in this study by the Multidimensional Health Locus of Control Scale-Cancer (Wallston et al., 1978). It is an 18-item Likert scale containing four independent subscales (internality locus of control, powerful others locus of control, doctors locus of control, and chance locus of control). There is not one overall score. Items on all subscales are summed. Higher scores on the powerful others, doctors, and chance subscales indicate greater externality, whereas a higher score on the internality subscale indicates less externality (and greater internality). Scores on the internality and chance subscales can range from 0-30, and scores on the doctors subscale can range from 0-20. On the powerful others subscale, scores can range from 0-15. In this present study, reliability for each of the subscales is as follows: internality ( $\alpha = .685$ ); powerful others ( $\alpha = .658$ ); doctors ( $\alpha = .526$ ); and chance ( $\alpha = .763$ ). Scores on the internality subscale range in this present study from 0-26 with a mean of 10.5 and a standard deviation of 5.96; on the powerful others subscale scores range from 0-15 with a mean of 6.7 and a standard deviation of 4.1; on the doctors subscale scores range from 0-15 with a mean of 11.65 and a standard deviation of 3.18; and on the chance subscale scores range from 0-30 with a mean of 11.37 and a standard deviation of 7.26.

- 3) Demographics: Demographics collected in this study include gender, race/ethnicity, marital/partnership status, educational level, employment, source of income including entitlements, and number in household, including the number

of minor children. For statistical analysis, gender, marital status, race, and education were dummied.

The next four variables fall under the enabling domain:

- 4) **Income and financial stress:** This is conceptualized in the present study as the amount of income coming into a household and the extent of distress caused by either inadequate income and/or overwhelming obligations. These are measured in dollar response categories and through three questions from the PAL-M (BrintzenhofeSzoc et al., 2007). Dollar response categories are collapsed into five categories (each dummied for statistical analysis): under \$10,000; \$10,000-\$30,000; \$30-\$50,000; \$50,000-\$75,000; and above \$75,000. The question was posed in this way by categories to encourage a response (as opposed to reluctance to report an exact dollar figure, thereby risking missing data) and to generally capture the categories reflected in the Federal Poverty Level (FPL), 200% of the FPL, 300% of the FPL, and so on. Income above \$75,000 is the reference number. The three items from the PAL-M are scored on a Likert scale with a range of 0-9 with a higher score indicating greater well-being. The overall reliability for the PAL-M in this study is high ( $\alpha = .875$ ). In this study, scores range from 0-9 with a mean of 4.9 and a standard deviation of 3.1.
- 5) **Health insurance:** This is conceptualized as the availability and adequacy of coverage, and is measured by a set of questions formulated by the researcher that are designed to measure whether or not insurance coverage is present and adequate for a cancer patient's typical needs. Participants were asked whether or not they had health insurance (yes or no) and then on a Likert scale participants

were asked the degree of the adequacy of that coverage for cancer treatment, for prescription medication, and for pain medication (if indicated). Overall reliability for this index is high ( $\alpha = .930$ ). For purposes of this study and to take into account missing data, questions regarding adequacy of coverage for those fifteen participants who lacked health insurance (and who did not answer the questions on adequacy of coverage) were recoded on the three remaining questions of the index to have very inadequate coverage. Scores on the index can range from 0-12 with a higher score indicating greater adequacy. Scores in this sample range from 2-12 with a mean of 8.3 and a standard deviation of 3.23.

- 6) Perceived barriers to care: This is conceptualized not only as those competing responsibilities and logistical problems that may preclude meaningful participation in treatment, but also factors and circumstances that directly hinder participation in medical care. This is operationalized via several modified questions from the basic need satisfaction subscale of the Quality of Life Questionnaire (QLQ) (Bigelow et al., 1991). The reliability of this subscale in this present study improved to .471 from the original study's Cronbach's alpha of .358. Items were reverse-coded for this study so that a higher score indicates greater perceived barriers. Scores range from 16 to 47 with a mean of 28.62 and a standard deviation of 7.5.
- 7) Social support: This is conceptualized as the extent to which mutually helpful and meaningful relationships that ensure that social support mechanisms are available, accessible, and adequate in a patient's life. It is operationalized in this study by the social support domain of the QLQ (Bigelow et al., 1991). The

reliability of this subscale in the present study also improved to .725 from the original study's Cronbach's alpha of .67. Scores can range from 5-20 with a higher score indicating more support. Scores here range from 8-20 with a mean of 15.58 and a standard deviation of 3.1.

The need domain is as follows:

- 8) Cancer diagnosis and its accompanying variables: This is conceptualized as the particular care need of the patient, and is an index based on type and stage of their cancer, date of diagnosis, length of time since diagnosis, and nature/type of treatment. Participants were asked these four questions: type of cancer, stage if known, date of diagnosis, and types of treatment they had undergone. A composite index was then formulated by the researcher as a continuous variable with a higher score indicating greater acuity. Scores range from 0-6. In order to standardize the answers and to make them more interpretable, type of cancer and stage (if known) was recoded by the researcher with input from the "blue book" (or TERI cases) of the Social Security Administration for terminal cancers, or cancers that are more fatal. If a patient indicated that he or she was dealing with a cancer largely regarded as terminal, regardless of stage, that person received a score of 1. Patients who were dealing with other cancers staged 2 or more were also coded as 1. Patients who had dealt with their cancers for more than 2 years were also coded as 1. Finally, the number of treatments patients had undergone and reported to the researcher was simply added. Scores were then summed with, again, a higher score indicating greater need or acuity. Scores in this sample range from 0-6 with a mean of 3.4 and a standard deviation of 1.4.



The health behavior domain is as follows:

- 9) Perceived ability to adhere to treatment: This is conceptualized as treatment adherence in light of potential obstacles. It is operationalized via the Adherence Determinants Questionnaire (ADQ) (DiMatteo et al., 1993), which is a 38-item Likert scale with 7 domains (interpersonal relationships with providers, perceived utility of treatment, perceived severity of the cancer, perceived susceptibility of the cancer recurring, subjective, intentions to adhere to treatment, and support/barriers with respect to treatment). Higher scores on each domain indicate greater adherence with the variable under consideration. In personal communication with the office of the instrument's author, several negatively worded items were reverse-coded for greater accuracy of the scores. Reliability scores for each domain are as follows: interpersonal ( $\alpha = .814$ ); perceived utility ( $\alpha = .762$ ); perceived severity ( $\alpha = .612$ ); perceived susceptibility ( $\alpha = .729$ ); subjective ( $\alpha = .884$ ); intentions ( $\alpha = .640$ ); and support/barriers ( $\alpha = .709$ ). The mean score for the interpersonal subscale is 25.64 with a standard deviation of 5.1 and a range of 13-32; the mean score for the perceived utility subscale is 26.74 with a standard deviation of 4.2 and a range of 16-32; the mean score for the perceived severity subscale is 6.8 with a standard deviation of 2.6 and a range of 1-12; the mean score for the perceived susceptibility subscale is 6.6 with a standard deviation of 1.69 and a range of 4-12; the mean score for the intentions subscale is 10.8 with a standard deviation of 1.6 and a range of 6-12 (one item from the intentions subscale was inadvertently omitted from the questionnaire by

the researcher); and the mean score for the support/barriers subscale is 11.17 with a standard deviation of 3.34 and a range of 5-16.

**Table 4.4:***Characteristics of Scales*

Scale	Range	Minimum	Maximum	Mean	SD	Cronbach's Alpha
Socio-economic Well-Being Scale	54	14	68	40.47	14.48	.732
Housing Composite Index	7	0	7	1.15	1.67	
Internal Control Subscale (from MHLC)	26	0	26	10.5	5.96	.685
Chance Subscale	30	0	30	11.37	7.26	.763
Powerful Others Subscale	15	0	15	6.7	4.15	.658
Doctors Subscale	15	0	15	11.65	3.18	.526
Health Insurance Adequacy	10	2	12	8.3	3.23	.930
PAL-M Subscale on income management	9	0	9	4.97	3.10	.875
Perceived Barriers (QLQ)	31	16	47	28.62	7.5	.471
Social Support Subscale (QLQ)	12	8	20	15.58	3.1	.725
Cancer Index	6	0	6	3.4	1.43	
Interpersonal Subscale (ADQ)	19	13	32	25.64	5.1	.814
Perceived Utility Subscale (ADQ)	16	16	32	26.74	4.2	.762
Perceived Severity Subscale (ADQ)	11	1	12	6.8	2.63	.612
Perceived Susceptibility Subscale (ADQ)	8	4	12	6.62	1.69	.729
Subjective Subscale (ADQ)	18	0	18	7.31	6.51	.884
Intentions Subscale (ADQ)	6	6	12	10.83	1.60	.640
Support/Barriers Subscale (ADQ)	11	5	16	11.17	3.34	.709

## Findings

**Correlations by domain.** There are a number of important correlations within each domain with financial quality of life, as outlined in the tables below. Within the predisposing domain, age is positively correlated with financial quality of life ( $r = .281, p < .01$ ), such that patients who are older have greater financial quality of life. Gender is also positively correlated ( $r = .263, p < .01$ ), so that women in the sample also have greater financial quality of life. Housing instability is negatively correlated with financial quality of life ( $r = -.393, p < .01$ ); those patients with housing instability have poorer financial quality of life. In terms of other interesting correlations, gender is negatively correlated with the chance subscale of the MHLC ( $r = -.224, p < .05$ ), such that males in the sample have a stronger sense of chance locus of control.

Within the enabling domain, those patients who earned under \$10,000 have poorer financial quality of life ( $r = -.331, p < .01$ ) (with those earning up to \$30,000 trending towards poorer financial quality of life, though it is not statistically significant). Lack of health insurance and financial quality of life are positively correlated ( $r = .398, p < .01$ ), so that those patients who lack health insurance have poorer financial quality of life. Likewise, greater health insurance adequacy is positively correlated with financial quality of life ( $r = .528, p < .01$ ). Greater perceived barriers are negatively correlated with financial quality of life ( $r = -.691, p < .01$ ), and social support is positively correlated with financial quality of life ( $r = .369, p < .01$ ). Also, not surprisingly, financial well-being (items from the income management/financial stress subscale of the PAL-M and distinct from financial quality of life) is positively correlated with financial quality of life ( $r = .678, p < .01$ ). Financial well-being is also positively correlated with

social support ( $r = .375, p < .01$ ) and health insurance adequacy ( $r = .382, p < .01$ ). It is negatively correlated with perceived barriers to care ( $r = -.681, p < .01$ ), such that those respondents who have better financial well-being have fewer barriers to care. There are other interesting significant relationships, such as the relationships among health insurance adequacy, barriers to care, and social support. Those with better health insurance adequacy have fewer barriers to care ( $r = -.453, p < .01$ ); those with more barriers have less social support ( $r = -.435, p < .01$ ).

There is not a significant correlation between financial quality of life and cancer need in this sample of patients. This suggests, then, that a more trying cancer experience with greater acuity may not mean that financial quality of life suffers.

Finally, in the health behavior (or treatment adherence) domain, financial quality of life is positively correlated with the subscales on greater perceived utility ( $r = .272, p < .01$ ), subjective ( $r = .230, p < .05$ ), and support/barriers ( $r = .545, p < .01$ ). That is, respondents who believe that their cancer treatment regimens are useful and who have greater support and fewer barriers—and whose social support members also believe strongly in their treatment plans—consequently have better financial quality of life.

There are other interesting and enlightening correlations among the health behavior (or treatment adherence) domain: the interpersonal subscale is positively correlated with the perceived utility subscale ( $r = .454, p < .01$ ), such that those respondents who have more positive relationships with their providers believe more strongly in the usefulness or value of their treatment plan (and better treatment adherence). Likewise, those respondents who have better intentions to adhere to their treatment plan also have more positive interpersonal relationships with their providers ( $r$

= .426,  $p < .01$ ), and whose social support members are also on-board with their treatment plans ( $r = .350$ ,  $p < .01$ ). Perceived severity of cancer is negatively correlated with perceived susceptibility of cancer recurrence ( $r = -.413$ ,  $p < .01$ ), such that those respondents whose cancers are more acute also believe that a recurrence is less likely. Perceived susceptibility is also negatively correlated with perceived utility ( $r = -.424$ ,  $p < .01$ ), such that those respondents who believe that their cancers are less likely to recur also believe strongly in the usefulness of their treatment plans. There is a positive correlation between the subjective subscale and the support/barriers subscale ( $r = .327$ ,  $p < .01$ ), such that those patients whose social support members agree with their treatment plans also have greater support and fewer barriers. Likewise, the support/fewer barriers subscale is also positively correlated with intent to adhere to one's treatment plan ( $r = .369$ ,  $p < .01$ ). Interestingly, perceived severity (or acuity of cancer) is not significantly correlated with intention, although perceived susceptibility is ( $r = -.283$ ,  $p < .01$ ), so that the threat of a cancer recurring may lessen intent to adhere.

**Table 4.5:*****Predisposing Domain Correlations***

Variables	Financial QoL	Age	Gender	Marital Status	Race	Education	Housing Composite Index	Internal Control	Chance	Doctors	Powerful Others
Financial QoL	1	.281**	.263**	.056	-.176	.157	-.393**	.036	-.085	.062	-.064
Age	.281**	1	.000	-.132	-.132	.128	-.344**	-.017	-.139	.042	.059
Gender	.263**	.000	1	-.091	.190	.022	-.169	-.054	-.224*	-.089	-.169
Marital Status	.056	-.132	-.091	1	-.075	.085	-.078	-.098	.177	.199	.011
Race	-.176	-.105	.190	-.075	1	-.170	.210	-.023	-.036	-.118	-.079
Education	.157	.128	.022	.085	-.170	1	-.164	-.071	-.120	-.039	-.011
Housing Composite Index	-.393	-.344**	-.169	-.078	.210	-.164	1	.096	.090	.137	.123
Internal Control	.036	-.017	-.054	.098	-.023	-.071	.096	1	.079	.181	.221*
Chance	-.085	-.139	-.224	.177	-.036	-.120	.090	.079	1	.090	.164
Doctors	.062	.042	-.089	.199	-.118	-.039	.137	.181	.090	1	.290**
Powerful Others	-.064	.059	-.169	.011	-.079	-.011	.123	.221*	.164	.290**	1

\*\* Correlation significant at the 0.01 level (2-tailed); \* correlation significant at the 0.05 level (2-tailed)

**Table 4.6:*****Enabling Domains Correlations***

Variables	Financial QOL	Under \$10,000	\$10,000-\$30,000	\$30,000-\$50,000	\$50,000-\$75,000	Income Management	Health Insurance	Health Insurance Adequacy	Barriers	Support
Financial QoL	1	-.331**	-.191	.058	.144	.678	-.398**	.528**	-.691**	.369**
Under \$10,000	-.331**	1	-.200	-.160	-.176	-.487**	.302**	-.315**	.404**	-.221*
\$10,000-\$30,000	-.191	-.200	1	-.174	-.191	-.152	-.052	.082	.129	-.061
\$30,000-\$50,000	.058	-.160	-.174	1	-.153	.058	-.076	.042	-.031	.028
\$50,000-\$75,000	.144	-.176	-.191	-.153	1	.147	-.014	-.027	-.127	.178
Income Management	.678	-.487**	-.152	.589	.147	1	-.318**	.382**	-.681**	.375**
Health Insurance	.398**	.302**	-.052	-.076	-.014	-.318**	1	-.745**	.270*	.011
Health Insurance Adequacy	.528**	-.315**	.082	.042	-.027	.382**	-.745**	1	-.453**	.102
Barriers	-.691**	.404**	.129	-.031	-.127	-.681**	.270*	-.453**	1	-.435**
Support	.369**	-.221**	-.061	.028	.178	.375**	.011	.102	-.435**	1

\*\* Correlation significant at the 0.01 level (2-tailed); \* correlation significant at the 0.05 level (2-tailed)



**Table 4.7:*****Cancer Need Domain Correlations***

Variable	Financial QoL
Cancer Need	.015

**Table 4.8:*****Health Behavior (Treatment Adherence) Domain Correlations***

Variable	Financial QoL	Interpersonal	Perceived Utility	Perceived Severity	Perceived Susceptibility	Subjective Intentions	Support/Barriers	
Financial QoL	1	.204	.272**	.046	.106	.230*	.102	.545**
Interpersonal	.204	1	.454**	-.061	-.198	.243*	.426**	.412**
Perceived Utility	.272**	.454**	1	-.079	-.424**	.383**	.585**	.463**
Perceived Severity	.046	-.061	-.079	1	-.413**	.021	.003	.029
Perceived Susceptibility	.106	-.198	-.424**	-.413**	1	-.183	-.283**	-.131
Subjective Intentions	.230*	.243*	.383**	.021	-.183	1	.350**	.350**
Support/Barriers	.545**	.412**	.463**	.029	.131	.327**	.369**	1

\*\* Correlation significant at the 0.01 level (2-tailed); \* correlation significant at the 0.05 level (2-tailed)

### **Findings from Multivariate Regression Analysis**

The quantitative research question in the present study is as follows: What factors from the adapted behavioral model for vulnerable populations (Gelberg et al., 2000), which depicts critical micro and macro factors under the domains of predisposing, enabling, need, and health behavior most significantly impact financial quality of life (outcome)? The major hypothesis from this study is as follows: The greater the vulnerabilities and deficiencies in predisposing factors and enabling factors, the greater the need factors with respect to cancer diagnosis and treatment, and the lower the perceived ability to adhere to treatment, the poorer will be the financial quality of life.

For statistical analysis, the researcher entered the variables by blocks into the regression equation, utilizing the “block” format under the predisposing, enabling, cancer need, and health behavior domains, per the adapted behavioral model. The dependent variable—financial quality of life—is scored so that higher scores indicate *better financial quality of life*.

**Table 4.9:*****Findings from Multivariate Regression Analysis***

	<b>Model 1</b>		<b>Model 2</b>		<b>Model 3</b>		<b>Model 4</b>		<b>Final Model</b>	
<b>Domain</b>	<b>B</b>	<b>Beta</b>	<b>B</b>	<b>Beta</b>	<b>B</b>	<b>Beta</b>	<b>B</b>	<b>Beta</b>	<b>B</b>	<b>Beta</b>
Constant	22.7		18.0		21.2		11.3		31.1	
Age	.186	.170	.118	.108	.117	.107	.095	.087	3.966	
Gender	7.556	.252*	3.618	.121	3.731	.125	4.343	.145		.135
Marital Status	1.210	.041	-1.215	-.042	-1.154	-.040	-.983	-.034		
Race	-4.774	-.163	.430	.014	-.151	-.005	-.174	-.006		
Education	1.057	.030	2.406	.068	2.699	.076	3.767	.106	.383	
Housing	-2.321	-.253*	.693	.076	.702	.077	.516	.056		.045
Composite Index										
Internal Control	.125	.052	.058	.024	.070	.029	-.041	-.017		
Chance	.008	.004	.066	.033	.044	.022	-.054	-.027		
Doctors	.556	.120	.137	.030	.123	.027	.049	.011		
Powerful Others	-.141	-.040	.219	.063	.204	.059	.205	.059		
Under \$10,000			.964	.024	.861	.021	4.576	.114		
\$10,000-\$30,000			-4.033	-.106	-3.468	-.091	-2.619	-.069		
\$30,000-\$50,000			.594	.014	.636	.015	1.793	.042		
\$50,000-\$75,000			2.550	.061	2.585	.062	4.454	.107		
Financial			1.618	.340*	1.601	.337*	1.506	.317	1.696	.366*
Stress/Income Management										
Health Insurance			1.347	.301*	1.311	.293*	1.005	.224*	.830	.187*
Adequacy										
Barriers			-.532	-.272*	-.545	-.279*	-.485	-.248	-.453	-.237*
Support			.224	.044	.220	.044	-.269	-.053		
Cancer Index					-.599	-.059	-.173	-.017		
Interpersonal							.261	.090		
Perceived Utility							.336	.099		
Perceived							.668	.122		
Severity							1.139	.134		
Perceived										
Susceptibility							.378	.169		
Subjective							-1.939	-.211*	-.688	
Intentions							.911	.203*	1.044	-.077
Support/Barriers								.		.244*
R Square	.279		.653		.656		.733		.651	
F-Ratio	2.826		6.803		6.421		6.009		21.53	
									9	
Df	10		18		19		26		7	

In the first model, nearly 28% of the variance in financial quality of life is explained by the variables in the predisposing domain. In the second model, 65% of the variance is explained by adding the additional variables. In the third model, 65% is also explained by adding the additional need variable (cancer composite index). In the fourth model, nearly 74% of the variance is explained by adding the final set of variables under the health behavior (or treatment adherence) domain.

In the first model, gender is significant (and is coded 0 for male and 1 for female), so that women in the sample have better financial quality of life. The housing composite index is also significant (and has a negative beta and the index is structured such that housing instability increases with a greater number), so that those who have housing instability have poorer financial quality of life. In the second model, though, both these variables drop from significance. With the addition of enabling variables, income management becomes significant, so that those with better income management have better financial quality of life. Also, health insurance adequacy is statistically significant, so that those with greater adequacy in terms of their health insurance coverage also have better financial quality of life. The barriers variable (from the basic need satisfaction subscale of the Quality of Life Questionnaire by Bigelow et al., 1991) is also significant (and carries a negative beta), so that those respondents with greater barriers had poorer financial quality of life. In model 3, income management remains significant ( $p = .011$ ), as does health insurance adequacy ( $p = .004$ ) and barriers ( $p = .040$ ). As stated, the cancer need variable (measuring respondents' self-report of cancer type, stage, length of time since treatment, and types of treatment undergone) is not significant, although the entire model is significant. (But the cancer need variable adds very little to the explained

variance, if at all.) In model 4 in which the health behavior (or treatment adherence) variable is introduced, income management remains significant, as does health insurance adequacy. Barriers drops off (in terms of statistical significance), but still trends towards significance at  $p = .059$ . The intentions subscale of the ADQ is significant at  $p = .033$  (with a negative beta), so that those respondents with less intent to adhere to treatment had poorer financial quality of life. Also, the support/barriers subscale of the ADQ is statistically significant at  $p = .047$ , so that those respondents who had greater support and fewer barriers in terms of their perceived ability to adhere to treatment also had better financial quality of life. In the final parsimonious model, in which only those variables that are significant in each block are entered in, only income management/financial stress, health insurance adequacy, barriers (from the QLQ), and support/barriers (from the ADQ) remain significant.

### **Significance of Findings**

The statistical significance of each model in this research supports the adapted behavioral model for vulnerable populations as a valid and useful theoretical model to predict financial aspects—that is, financial quality of life—of health-care utilization, and it is a promising theoretical model for further use in cancer patients and other populations facing potential vulnerabilities. Interestingly, the variables specific to income were not significant. This shows that poorer people in this sample do not have poorer financial quality of life (conceptualized as the ability to manage current and future, including unexpected, obligations related to cancer care within the context of sound health-care decision-making). This does seem counter-intuitive, as one might assume that poorer people will, of course, have poorer financial quality of life. Yet this research shows that

there are other practical, instrumental variables that impact financial quality of life in this sample to a greater degree—variables such as barriers, social support, and health insurance adequacy. On the other hand, the variable having to do with income management/financial stress (having enough money to pay for current bills and future, unexpected expenses and being free from worry about debt) remains significant. Respondents across all income groups could answer affirmatively to this set of questions, such that even if one had a high income, there might still be inadequate amounts for present expenses and great worry associated with that. (The focus in this variable is on bill-paying and worry about bills and debt as opposed to financial aspects of health-care decision-making, i.e., financial quality of life.) Health insurance adequacy and barriers/support are also extremely useful to consider. The health insurance question is especially apropos in the current political climate in which health-care reform remains controversial and under attack and constitutional challenge. The findings from this study show that respondents who have inadequate health insurance coverage (folding in those who lacked health insurance with those respondents who feel that their coverage is inadequate for their cancer needs) have poorer financial quality of life, i.e., they do not feel that they have what they need to make the best, most reasonable health-care decisions for themselves, nor do they feel that they have the resources and support necessary for better financial quality of life.

**Hypotheses 2 and 3.** The related hypotheses in this study are: 1) Lower income and greater financial stress are correlated with a lower sense of personal control; and 2) Lower income and greater financial stress are correlated with lower financial quality of life, although a higher sense of personal control is a mediating variable. Neither

hypothesis, however, was supported. The researcher conducted multivariate regression analyses on both hypotheses. The first hypothesis is not significant. For the second related hypothesis, the researcher conducted a regression analysis with financial quality of life as the dependent variable and the predictors of income (all categories) and income management/financial stress in block 1. For the second block, internal control was added. Both blocks of the second related hypothesis are significant at .000, respectively, but the crux of the hypothesis is that personal control is a mediating variable and that people with a strong sense of personal control, even if they have little money or resources at their disposal, will nevertheless have a strong financial quality of life. Yet there was no change in the R square between the models, and so the hypothesis is not supported. (Subsequently the researcher also entered the three other personal control subscales of powerful others, doctors, and chance as separate predictors, but these did not add anything either or change the non-significance of the hypothesis.) This shows in this sample of patients that personal control is not a significant factor in any regard, contrary to what the researcher hypothesized.

### **Findings from Qualitative Interviews**

The researcher chose mixed methods in order to more thoroughly explore the notion of personal control as it might impact both financial quality of life and treatment adherence. The qualitative research questions in the study are as follows: Does a person's financial situation influence his or her sense of personal control with respect to treatment adherence? And how does financial quality of life influence one's sense of personal control and expectation of treatment outcomes? For this inquiry, the variables are interchanged in order to more fully explore the nature of personal control across all

income categories (within the context of health locus of control). Content analysis was used to elicit the themes expressed. The five questions utilized by the researcher for all the interviews were these:

- 1) Tell me about your treatment experience.
- 2) Tell me about your feelings regarding treatment.
- 3) Tell me about how your financial situation impacts cancer treatment—and vice versa.
- 4) Tell me about your feelings regarding coping with cancer. In your view, where do you draw support and meaning?
- 5) What are your obstacles in being able to get the cancer treatment you need? What are the obstacles in finding positive financial quality of life? In the same way, what are your strengths in being able to get the cancer treatment you need? What are your strengths in finding positive financial quality of life?

A total of seven patients were interviewed by the researcher for this portion of the study. One patient is in the income category below \$10,000 and two patients are in the income category above \$75,000. The remainder of the patients earns income between \$10,000 and \$75,000. Diagnoses included breast cancer (1), prostate cancer (2), kidney cancer (1), leukemia (AML) (1), neurofibromatosis-1 (1), and CMML (1). Each interview lasted about 45 minutes. The following themes emerged from the content analysis:

**Importance of social support.** All of the respondents speak forcefully of the role of social support in their lives. One single respondent whose support was not as plentiful from friends said, “I wish I had a family.” Respondents credit their families with helping



them get through cancer treatment and that their families are their source of support, meaning, and comfort. They also credit their families with helping them with practical issues and with locating treatments, including clinical trials. Their families were there by their sides as they fought to survive. One younger respondent had both her mother diagnosed with breast cancer during the course of her own treatment, and then her father with colon cancer. For a while all three were battling cancer until her father died shortly after his diagnosis. She and her mother are even closer now, and the fact that both have survived breast cancer is a bond between them that will never be broken.

**Positive future expectations.** All of the respondents express great optimism about their future and with finding treatment success. Even one individual who recognizes openly that her cancer most likely will lead to her demise—but that she has beaten the odds thus far—shares that she “can’t give up. I will keep fighting until I can’t fight anymore. I’ve always been like that.” All of the respondents have either been through or are going through extensive treatments, sometimes for many years (especially for those taking part in clinical trials).

**Thriftness and frugality.** Several of the patients do not have as much money or income as the others. Nevertheless, they have learned to live frugally. One respondent who is married has learned creative, valuable skills to live as inexpensively as possible (strategies he has learned from his wife). Despite this very low income and many challenges faced, they feel optimistic about their future and have great confidence that they can master any challenges along the way. One other respondent voiced this as well: “My greatest strength is my self-discipline. I don’t live an extravagant life. I don’t take on more debt than I can afford.” On balance, not all respondents feel that they have been

adversely affected financially by their cancer treatment. Some recognize that they are fortunate and that their health insurance has provided exceptional coverage for their treatments; others express that they know they are not as fortunate as others, but they have learned strategies to help them manage effectively. One respondent is facing big challenges, however, especially with respect to housing for herself and her family. Her housing situation has been more precarious than the others, and it continues to be a source of stress. She became tearful during the interview, and said she did not know what she would do. Regardless, though, this stressor at home did not impact her plan and intent to keep pursuing her treatment regimen.

**Willing participation in treatment.** All of the respondents feel very optimistic about cancer treatment and they use phrases that essentially describe themselves as very adherent to treatment and willing to do whatever it takes to get the care they need. This did not vary across income groups. Even when they recognize obstacles and challenges, they feel determined to overcome them. The challenges do not deter them.

**Sense of personal control.** Finally, all of the respondents speak one way or another about possessing a strong sense of personal control. One respondent describes it as being an effective self-advocate, something he had always done. Another said that just as she had always been “bossy” as a child, “I’m in control, I’m in charge.” All of the respondents speak compellingly of their personal strengths and skills to see them through their present experiences.

Overall, then, the qualitative interviews support the findings from the quantitative portion of the study. In this sample, amount of income and one’s financial situation do not seem to unduly impact a patient’s sense of self-confidence and self-efficacy, or to

dissuade them from pursuing treatment actively, fully, and hopefully. All of the patients express feelings of hope and optimism. To answer the qualitative questions posed by the researcher, then, in this sample, a person's financial situation does not influence his or her sense of personal control with respect to treatment adherence. And in terms of how financial quality of life influences one's sense of personal control and expectation of treatment outcomes, it appears that, regardless of income, patients in this sample express a strong sense of hope and the strong conviction that treatment adherence is a given in their lives.

### **Summary**

This chapter outlined the findings from this research study, including a description of the scales used and their scoring and reliability in this particular sample. Findings from both the quantitative and qualitative analyses were discussed. In the next and final chapter, the entire study will be reviewed in conclusion, and implications of the findings as they relate to social work theory, practice, research, ethics, and policy will be explored.

## **Chapter 5: Summary and Conclusion**

The purpose of this chapter is to succinctly describe the study in its entirety and to discuss the implications and significance of this research for social work theory, practice, research, ethics, and policy. The study's limitations, contributions, and recommendations for future research will also be explicated.

### **Overall Summary of the Study**

**Introduction.** The purpose of this study has been to explore financial quality of life in an availability sample of cancer patients drawn from two hospitals in the Washington, DC, metropolitan area. A cancer diagnosis is a devastating experience for people and their families, and its impact ranges across one's life, from the psychological to the practical. Professionals within the field of psycho-oncology and medicine have sought to better understand cancer's toll, and much valuable work has been accomplished in terms of cancer's psychological and psychosocial impact. Numerous quality of life studies have been undertaken as well in order to examine how cancer treatment and cancer survivorship affects all facets of people's lives (psychological, functional, spiritual, and interpersonal, to name just several areas) (Ahles et al., 2005; Ganz et al., 2002). Yet financial quality of life and the socioeconomic impact of cancer have been oft-neglected areas, though it is ever so present in day-to-day life. A cancer diagnosis can cause or exacerbate existing financial stress, threatening one's livelihood, employment benefits including health insurance, ability to manage all of life's obligations, and resources that may or may not be available in order to make the best, most sound health-care decisions with respect to cancer treatment (Ell et al., 2007; Head & Faul, 2008; Kim, 2007). It is more important than ever to include this examination in

quality of life studies, especially in times of economic volatility, and to recognize that financial well-being in cancer is just as important as other measures of well-being. Moreover, all of these measures are critically important in helping clinicians, researchers, and scholars to more comprehensively understand and appreciate cancer's often devastating blow.

This study conceptualizes financial quality of life as the ability to manage all current and future (including unexpected) obligations related to cancer care, within the context of sound health-care decision-making. It includes not only available resources that a person has at his or her disposal to meet life's basic needs of food and shelter, but it also encompasses the resources and confidence that are needed to meet obligations related to one's optimal health—in this instance, cancer care. It is easy to think that this is only a matter of income. In reality, financial quality of life as conceptualized by this researcher is much broader and deeper than mere available dollars. As will be presented in the literature review, one may have dollars in terms of income yet not have another vital resource such as health insurance, and financial quality of life will be affected in one's decision-making. Or another may again have a greater income, yet be overwhelmed with debt and obligation, also adversely impacting the financial components of health-care decision-making.

The variables to be explored specifically in this study affecting financial quality of life include housing stability; one's sense of personal control within the larger context of health locus of control; demographic information; income and financial stress; health insurance adequacy; perceived barriers to care; social support; cancer diagnosis (including stage if known, length of time since diagnosis, and types of treatment

undergone); and perceived ability to participate meaningfully in treatment, i.e., treatment adherence. These variables are drawn from the adapted behavioral model for vulnerable populations (Gelberg et al., 2000), and they are chosen by the researcher for their propensity towards vulnerability and their hypothesized, likely impact on financial quality of life. The adapted model is drawn from Andersen's (1968, 1995) behavioral model, which is a widely used theoretical model in the health sciences predicting health-care utilization. The adapted behavioral model contains micro and macro variables under the domains of predisposing, enabling, need, and health behavior with their impact on outcomes, one of which is financial aspects of health-care. The adapted behavioral model is composed both of the traditional variables and consequently additional variables that encompass a more comprehensive listing of factors drawn from real life.

The study is also underpinned philosophically by the social justice perspective authored by the political philosopher John Rawls from his groundbreaking work, *A Theory of Justice* (1971, 1999). In this work he details the difference and opportunity principles, which hold that in a just society, attention must be given to people who are the least advantaged. A recent interpretation is as follows:

Social and economic inequalities are to satisfy two conditions: first they are to be attached to positions and offices open to all under conditions of fair equality of opportunity; and second, they are to be to the greatest benefit of the least advantaged members of society. (Pogge, 2007, p. 106)

One thrust of this dissertation has been to show why cancer patients—especially those facing vulnerable situations—are one such population at a disadvantage, and why a

truly just health-care system will not neglect such patients and instead will work to ensure that health care is available and accessible.

**Literature Review.** The medical and psychosocial literature is growing in terms of the impact of cancer on patients' financial well-being. It has documented inequalities in cancer care received by patients who have resources and those who do not, as well as differences in care based on income levels (Griggs et al., 2007; Reyes-Ortiz et al., 2006). Lack of health insurance is a powerful predictor for less access to care (Halpern et al., 2008) and greater mortality from cancer (Sorlie et al., 1994; Wilper et al., 2009). People who are poorer also face greater obstacles to care (O'Toole et al., 2003) and are more likely to delay needed care and to use emergency rooms as their main source of care, only when they are in desperate need (Westin et al., 1999). Inequalities are present as well with care received by racial and ethnic minorities, and these health inequalities can encompass poverty in addition (Ashing-Giwa & Kagawa-Singer, 2006; Hughes et al., 2007; Short et al., 2000). Thus, the inequalities in cancer care and the socioeconomic impact of treatment and survivorship are critical areas of study.

This study outlines support from the literature on each of the variables under consideration and their impact on financial quality of life. Financial quality of life—the dependent variable in this study—has been shown to be a key aspect of overall quality of life, but is an oft-neglected measure (Head & Faul, 2008). Quality of life studies in cancer survivorship typically include the effect of cancer treatment on one's physical, emotional, functional, and spiritual well-being (Head & Faul, 2008), and it is vital to include economic aspects as well. Studies have shown as well that financial devastation

and even bankruptcy can occur as a result of medical debt, even with health insurance present (Himmelstein et al., 2005; Seifert & Rukavina, 2006).

The independent variables in the study are chosen for their presumed, hypothesized contribution towards financial quality of life (the outcome), and these were chosen by the researcher from the adapted behavioral model for vulnerable populations (Gelberg et al., 2000). From the predisposing domain, the items include housing instability; personal control within the larger context of health locus of control; and demographic information. From the enabling domain, the items include income and financial stress; health insurance adequacy; perceived barriers to care; and social support; from the need domain, the variable includes cancer need (diagnosis, stage of disease if known, length of time since diagnosis, and types of treatment undergone); and finally from the health behavior domain, the item includes perceived ability to adhere to treatment.

Housing instability is important to study in this dissertation not only because shelter is naturally affected by income stressors, but also because of the current housing crisis that our nation has faced since 2008. It is unclear whether or not the housing climate is improving. The literature on the impact of medical illness on housing is scant, including limited instruments that measure housing instability with a slide towards homelessness as a result of illness' financial blows (as opposed to literature and research focused solely on homelessness). Yet there is some literature documenting correlations between housing instability and access to health care (Kushel et al., 2005; Reid et al., 2008). The impact of cancer treatment on housing instability in those patients facing vulnerabilities, however, must receive more focused study.



Personal control, within the larger context of health locus of control, is also chosen by this researcher as a psychological variable under the predisposing domain. It is hypothesized by the researcher that financial stress engenders a poorer sense of personal control, and that it is more likely for people under financial duress to feel tossed about by forces beyond their control. The literature, however, is varied on this issue. One study shows no correlation between socioeconomic status and personal control (Ell & Nishimoto, 1989), and another study documenting the state of the literature also posits that studies are inconclusive (Powe & Finnie, 2003). Yet one study does document a correlation between low socioeconomic status and low sense of personal control in a sample of children, although this did vary by ethnicity (Malcerne et al., 2005). So poverty may fuel opposite effects: despair and fatalism on the one hand (Wilkes et al., 1994) or resourcefulness and drive to overcome and thrive on the other (Holt et al., 2003). It is a provocative variable to examine in this study.

Demographic information includes age, gender, education, race/ethnicity, marital/partnership status, household number, employment, and source of income. The literature shows that there are correlations between some demographic information and socioeconomic well-being, such as race/ethnicity (Halpern et al., 2008; Otero-Sabogal et al., 2004) and educational level (Kinsey et al., 2008).

Income and financial stress particulars are also gathered, as is presence or lack of health insurance. Health insurance, because it is so key in our society in how cancer and other medical care is provided, is naturally relevant to this dissertation. The literature is replete in showing how a lack of health insurance leads to unacceptable outcomes, including greater mortality (Dorn, 2008), diagnosis at later stages of cancer (Halpern et

al., 2008), other unmet health needs (Ayanian et al., 2000), and non-adherence to life-saving cancer screenings, even in those with higher incomes (Ross et al., 2006). Weaver et al. (2009) also show that cancer survivors without health insurance do not follow up well with recommended periodic follow-ups for their cancers.

Perceived barriers to care is another area that is well covered in the medical and psychosocial literature, yet remains a challenge to solve. Barriers are clearly recognized as contributing to compromised medical outcomes (Jernigan et al., 2001; Otero-Sabogal, 2004), and are more prevalent in under-served populations.

Social support is another variable in the enabling domain that is chosen for inclusion because of its strong implication of helpful and meaningful relationships within one's social sphere that can perhaps ameliorate financial stress. The literature here is also replete that positive social support and support that is seen as meaningful, adequate, and accessible can lessen the distress associated with a cancer diagnosis (Friedman et al., 2005; Maxwell, 1982). Examining the role of social support in vulnerable populations is necessary in order to better address the question of support serving as a protective factor, especially when there are other areas of disadvantage identified.

The cancer need variable has been well outlined, and this study was open to patients with all different types of cancer. Through self-report, patients answered questions on their cancer type, stage of disease if known, when they were first diagnosed, and the types of treatments they had undergone. Closely related to this is the variable of perceived ability to adhere to treatment under the health behavior domain. Treatment adherence has been widely studied in the literature, showing that people facing life-threatening illnesses such as cancer can have non-adherence rates of up to 25%

(DiMatteo, 2004b). DiMatteo has researched non-adherence extensively, and she found in two meta-analyses of note in this dissertation that patients had better adherence rates if they possessed higher income (DiMatteo, 2004b) and better practical (and conflict-free) social support (DiMatteo, 2004a).

The literature shows clearly, then, that studying financial outcomes in cancer, especially in under-served populations, is vital and warranted. The medical literature shows that unequal outcomes between those who have resources and those who do not are unacceptable and tragic, and the psychosocial literature is showing the same.

### **Methodology**

This present study is a mixed methods study and utilizes a cross-sectional design. Once approval from three respective IRBs was granted, data was gathered from an availability sample of 90 patients drawn from two hospitals in the Washington, DC, metropolitan area via a structured questionnaire administered and retrieved in person for the quantitative portion of the study. For the qualitative portion, an interview took place with a subsample of patients who expressed willingness to be contacted again when the time for the interviews was indicated. Patients across all income categories were sought.

The quantitative research question for this study is: What factors from the adapted behavioral model for vulnerable populations (Gelberg et al., 2000) most significantly impact financial quality of life? The qualitative research questions are: 1) Does a person's financial situation influence his or her sense of personal control with respect to treatment adherence? 2) How does financial quality of life influence one's sense of personal control and expectation of treatment outcomes?

The quantitative hypotheses are:

Hypothesis 1: Drawn from the adapted behavioral model for vulnerable populations (Gelberg et al., 2000), the greater the vulnerabilities and deficiencies in predisposing factors and enabling factors, the greater the need factors with respect to cancer diagnosis and treatment, and the lower the perceived ability to adhere to treatment, the lower will be the financial quality of life.

Hypothesis 2: Lower income and greater financial stress are correlated with a lower sense of personal control.

Hypothesis 3: Lower income and greater financial stress are correlated with a lower financial quality of life, although a higher sense of personal control is a mediating factor.

**Dependent Variable:** The dependent variable in this study is financial quality of life, conceptualized as the ability to manage all current and future (including unexpected) financial obligations related to cancer care, within the context of sound health-care decision-making. It is operationalized in this study by the Socioeconomic Well-Being Scale (SWBS), developed and authored by Head (Head & Faul, 2008). It is a 17-item Likert questionnaire composed of two subscales (material capital and social capital). Higher scores on the overall scale indicate better socioeconomic well-being (or financial quality of life).

**Independent Variables:** The independent variables fall under the predisposing, enabling, need, and health behavior domains elucidated by Gelberg et al. (2000). Under the predisposing domain, the first three are housing instability, personal control within the larger context of health locus of control, and demographic information. Housing instability is conceptualized as participants' perception of their risk of homelessness. It is operationalized via a set of questions developed by the researcher in the absence of a

reliable and valid available instrument measuring the potential loss of housing due to illness. A composite index based on the researcher's questions was formulated as a continuous variable based on permanency of residence, length of time in present residence, perceived risk of losing housing due to cancer, and reasons why participants left their last place of residence (if applicable). Personal control is conceptualized as the degree to which one's perceived health is determined by one's own behavior and actions, as opposed to a greater degree by factors outside of one's control, including other people, doctors, and chance or randomness. It is operationalized by the Multidimensional Health Locus of Control Scale (Wallston et al., 1978) and is an 18-item Likert scale containing four independent subscales (internality, powerful others, doctors, and chance). Each subscale is scored independently so there is not one overall score. Higher scores on the internality subscale indicate greater personal internality; higher scores on the three remaining subscales indicate greater externality. Demographics gathered include gender, race/ethnicity, marital/partnership status, educational level, employment, and source of income, including entitlements, and household number.

Under the enabling domain, the next three variables are income and financial stress, presence of health insurance and health insurance adequacy, perceived barriers to care, and social support. Income and financial stress are conceptualized as the amount of income coming into a household and the extent of distress caused by either inadequate income and/or overwhelming obligations. Income is measured through response to dollar categories and financial stress is operationalized through three questions from the PAL-M (BrintzenhofeSzoc et al., 2007). For this study, the three questions are reverse-coded so that a higher score indicates less financial stress. Health insurance is conceptualized as

the availability and adequacy of coverage, and it is measured by a set of questions developed by the researcher that are designed to measure whether or not insurance coverage is present and adequate for a cancer patient's typical needs. Perceived barriers to care is conceptualized not only as those competing responsibilities and logistical problems that may preclude meaningful participation in treatment, but also factors and circumstances that directly hinder participation in medical care. It is operationalized via several modified questions from the basic need satisfaction subscale of the Quality of Life Questionnaire (Bigelow et al., 1991). Items were later reverse-coded so that higher scores indicate greater barriers. Finally, social support is conceptualized as the extent to which mutually helpful and meaningful relationships that ensure that social support are available, accessible, and adequate. It is operationalized by the social support subscale, again from the QLQ (Bigelow et al., 1991), which is an 8-item scale in which higher scores also indicate greater support.

For the need domain, a patient's experience with cancer is conceptualized as the particular care need of the participant and is based on type and stage of cancer, date of diagnosis, and the types of treatment undergone. A composite index was formulated as a continuous variable based on cancer type, stage of disease (if known), time since diagnosis, and number of treatments undergone. A higher score indicates greater cancer acuity.

Finally, under the health behavior domain, perceived ability to participate meaningfully in treatment is conceptualized as treatment adherence in light of potential obstacles. It is operationalized by the Adherence Determinants Questionnaire (ADQ),

developed by DiMatteo et al. (1994). It is a 38-item Likert scale covering seven domains of potential patient non-compliance with cancer treatment regimens.

The final questionnaire consists of 126 items and could be completed in approximately 30 minutes. Data collection took place between May 2010 and October 2011. Participants for the qualitative portion of the study were drawn from the final sample and were chosen based on their written willingness to be contacted for this interview portion. Patients were compensated for their participation in both the questionnaire and the interview portions of the study.

For data analysis, estimates of reliability are conducted on all scales within the questionnaire for the current sample. Multivariate (ordinary least squares) regression analysis is used to examine the impact of all the predictors on the criterion variable. Content analysis is used to elicit the themes expressed by participants in the qualitative portion of the study.

## **Findings**

### **Demographics**

The sample is composed of 90 patients from the Washington Cancer Institute/Washington Hospital Center and the NIH Clinical Center in Bethesda, Maryland. The average age is 52.7 with an age range of 20 to 81. It is 60% women and 40% men. There are 34.5% African-Americans; 52.9% Caucasians; and 12.6% patients of multi-racial or other ethnicity. Only 4.5% consider themselves to be Hispanic, but this low rate was expected, as the study was available only to those who spoke and understood English (due to study limitations). Fifty percent of the respondents are married; 5.6% are living with a partner; 31.1% identified themselves as single; and 13.2%

were either separated, divorced, or widowed. In terms of income, 15.6% of the patients earn less than \$10,000 a year; 47.1% earn between \$10,000 and \$75,000; and 36.5% earn more than \$75,000 a year. Regarding education, 31.1% of the patients possess a post-graduate or professional degree; 27.8% are college graduates; 20% have attended some college; 17.8% are high school graduates; and 3.3% have less than a high school diploma. In terms of work, 40% of the patients are currently working; 60% are not employed; 26.7% rely on income provided by a spouse or family member; 25.5% rely on SSI/SSDI or other types of public funds; and 17.8% rely on other sources of income, such as investments or long-term disability.

#### Bivariate Correlations

There are a number of intriguing bivariate correlations in this study. With respect to financial quality of life—the dependent variable—there are interesting correlations within each of the domains related to financial quality of life. From the predisposing domain, age is positively correlated with the dependent variable ( $r = .281, p < .01$ ), as is gender ( $r = .263, p < .05$ ), so that those who are older and who are women in the sample have better financial quality of life. Housing instability in this first domain is statistically significant ( $r = -.393, p < .01$ ), so that those patients in this study who experience housing precariousness have poorer financial quality of life. From the enabling domain, those patients who earn under \$10,000 a year have poorer financial quality of life ( $r = -.331, p < .01$ ). Health insurance ( $r = .398, p < .01$ ) and health insurance adequacy ( $r = .528, p < .01$ ) are positively correlated with financial quality of life. Perceived barriers are negatively correlated with financial quality of life ( $r = -.691, p < .01$ ) and social support is positively correlated with financial quality of life ( $r = .369, p < .01$ ), so that patients



with greater barriers and fewer supports will suffer poorer financial quality of life. Not surprisingly, financial well-being (in terms of being stress-free and with plenty of money for bills and unexpected expenses) is positively correlated with financial quality of life ( $r = .678, p < .01$ ) with interesting implications for the financial aspects of health-care decision-making within financial quality of life, as conceptualized by this researcher.

There was not a statistically significant correlation between financial quality of life and the cancer need domain in this sample of patients. Finally, from the health behavior domain, financial quality of life is positively correlated with the subscales on perceived utility ( $r = .272, p < .01$ ), subjective ( $r = .230, p < .05$ ), and support/barriers ( $r = .545, p < .01$ ), so that those patients in the sample who believe strongly in the usefulness of their cancer treatment plans, who have strong supports and few barriers, and whose supports also believe strongly in their treatment plans are experiencing better financial quality of life. In terms of the health behavior domain, then, there is a wealth of information from this sample informing providers in how they handle and underscore treatment adherence. These largely revolve around strengthening the relationships with providers and ensuring that important people in patients' lives are also in agreement with treatment adherence and with providing meaningful and useful social support and assistance.

### Multivariate Analysis

In terms of the multivariate analysis, the study finds statistical support for Hypothesis 1, indicating that the adapted behavioral model for vulnerable populations is a valid and promising model to use in further research with cancer patients, especially those who are vulnerable and underserved. For statistical analysis, the researcher entered

the independent variables into the model by blocks, utilizing the same “block” format as the adapted behavioral model. As stated, each overall block or domain is significant, although not all of the variables are. In the first block, the housing composite index is statistically significant, as is gender. In the second block, these two variables drop out. But the addition of the variables from the enabling domain make the second block significant as well. Financial level of stress is significant (and is scored in the same direction as financial quality of life, with higher scores indicating well-being), such that those patients with fewer financial stressors also have better financial quality of life. Health insurance adequacy is also significant, meaning that patients with better adequacy and coverage also have better financial quality of life. Barriers (from the basic need satisfaction subscale of the QLQ) is significant as well, so that patients with fewer barriers have better financial quality of life. In the third block, the cancer need variable is not by itself significant, but added to the variables already denoted, the block itself is significant. In the fourth block, adding the health behavior (or treatment adherence) domain, financial level of stress and health insurance adequacy remain significant. Barriers just drops off in terms of significant (with a p value of .059), and the subscales of intentions and support/barriers from the ADQ are significant. In the final parsimonious model, in which only those variables that are significant in each blocks are entered in, only financial stress/income management, health insurance adequacy, barriers, and support/barriers remain significant.

Hypotheses 2 and 3, however, are not supported statistically, indicating that low income and a low sense of personal control are not supported in this sample. Findings from the qualitative portion seem to support this as well, with patients on the lower end

of the financial spectrum nevertheless feeling optimistic and resourceful about cancer survivorship.

### **Specific Findings from the Qualitative Interviews**

The researcher chose mixed methods for this study in order to more thoroughly explore the connections between financial quality of life, personal control, and treatment adherence in patients across all income categories. The five questions posed to each participant were:

- 1) Tell me about your treatment experience.
- 2) Tell me about your feelings regarding treatment.
- 3) Tell me about how your financial situation impacts cancer treatment—and vice versa.
- 4) Tell me about your feelings regarding coping with cancer. In your view, where do you draw support and meaning?
- 5) What are your obstacles in being able to get the cancer treatment you need?

What are the obstacles in finding positive financial quality of life? In the same way, what are your strengths in being able to get the cancer treatment you need? What are your strengths in finding positive financial quality of life?

A total of seven patients were interviewed for this portion of the study. One patient earned less than \$10,000 a year; two patients earned more than \$75,000. The remainder made between \$10,000 and \$75,000. A range of cancer diagnoses was sought. Content analysis was used in order to explore emerging themes. These themes revolve around the role and importance of social support in patients' lives; future expectations

and hope; frugality and creativity in living within one's means; excitement about and dedication to treatment participation; and, finally, a strong sense of personal control and self-efficacy despite serious obstacles. The themes are common across all income groups.

**Findings pertaining to John Rawls.** All of the findings are informed by the philosophical perspective proffered by Rawls (1971, 1999) in his difference and opportunity principles. As this principle argues that a just society will give attention to the least advantaged among us, the connection is quickly made to those who are disadvantaged within the present sample of cancer patients who willingly and eagerly shared their experiences. According to the analysis, the barriers subscale from the QLQ, health insurance inadequacy, and the support/barriers subscale from the ADQ are those variables specifically pertaining to vulnerability in this sample. Barriers on its face violates the spirit of the difference and opportunity principles in that people in a just society should have access to all opportunities, including opportunities in health care. Financial barriers in health-care must not be tolerated. These imply barriers in receipt of life-saving cancer therapy (Dorn, 2008); health disparities (Griggs et al., 2007); lack of resources (Reyes-Ortiz et al., 2006); and simultaneous poverty (Hughes et al., 2007).

Daniels (1985) argues that a just health-care system will not stand for realities in which some are denied access to needed medical care. Realities that tend to perpetuate injustice include the widening gap between rich and poor in our society (Daniels, 1985; Pogge, 2007); greater mortality for those who lack medical resources (Daniels, 1985); and the violation of the principle of equal opportunity for all (Pogge, 2007).

## Significance of the Findings to Social Work

**Implications for theory.** The findings from this study support the value and usefulness of the adapted behavioral model by Gelberg et al. (2000). Its use should be as wide-spread as Andersen's (1965, 1995) original behavioral model, and because it adds multiple key variables to each domain, the adapted model presents a more comprehensive prediction of all aspects of health-care utilization. Researchers have a much wider array of variables by which to measure outcomes. This research study—and others that have used the adapted behavioral model—has found statistical significance in predicting various aspects of health-care utilization, including financial aspects of health-care utilization and decision-making or financial quality of life. Consequently, researchers and clinicians alike can target their focus and interventions and address those factor(s) that are most notably impacting outcomes in patients' lives.

While the adapted behavioral model comes out of work with homeless clients (Gelberg et al., 2000), the variables identified are easily utilized with different populations seeking care. It is critical to focus on vulnerable populations, though, not only because that is just, but also because that is where the need lies. By better understanding their experience, scholars, researchers, and clinicians alike can improve care *for all*. As Piven and Cloward (1979) point out, the most successful revolutions engender utility for all, not just the ones who are suffering the most:

The answer, perhaps, is that while some of the reforms granted during periods of turmoil are costly or repugnant to various groups in the society, and are therefore suffered only under duress, other innovations turn out to be compatible (or at least

not incompatible) with the interests of more powerful groups, most importantly with the interests of dominant economic groups. (p. 35)

Moreover, as Rawls (1971, 1999) instructs us, behind the veil of ignorance, members of a just society will promote justice for all because they will be promoting their own interests as well.

The adapted behavioral model, thus, makes a significant contribution to the medical and psychosocial literature that seeks to better understand and address the macro and micro issues faced by patients seeking health care. Gelberg et al. (2000) encourage its continued use in other populations at risk.

**Implications for practice.** The findings from this study are especially cogent for practice. And because of the broad nature of the study and of the model, the findings' applications to practice transcends social work practice as well. For social workers, the findings can help target psychosocial interventions that promote financial quality of life. For example, working together to address barriers to care is key. The significance of this particular variable in the model (specifically the support/barriers variable in the final block of the regression equation, but also the barriers variable from the second block of the equation) points out that barriers hinder the outcomes that providers are working so hard for. Medical and psychosocial outcomes are compromised when barriers are present and overwhelming. Is it transportation to care? Is it lack of social support? Is it insufficient funds or lack of health insurance for items that are vital for treatment? What are patients really telling us about the problems they face? If they tell us, do we pay attention? Are we even asking?

Addressing barriers can be challenging when resources are finite. Problems that are overwhelming to patients and families can present themselves that way to clinicians, too, often leading to job frustration and even burn-out (Simon, Pryce, Roff, & Klemmack, 2005). Some barriers are easily fixed; others far from it. Clinicians may find that searching for solutions and collaborating with patients and families is creative, energizing, and gratifying. When problems are insurmountable and/or firmly entrenched, however, it may well be that structural remedies are in order to target inequalities and injustice within the system. This is certainly so with health disparities, income inequalities, poverty, and lack of health insurance (Wilkes et al., 1994). The emerging field of financial social work considers and seeks to intervene not only with individuals in terms of their financial literacy and the impact of poverty, but also with communities in terms of greater empowerment and community organizing (Birkenmaier & Curley, 2009; Engelbrecht, 2011).

With respect to the significance of intentions to financial quality of life, it is enlightening to consider that all providers can work to strengthen a patient's intent to adhere to treatment—and also improve his or her financial quality of life. Strengthening intent can come around by fostering good working relationships between patients and staff; promoting education; encouraging social support and involvement with care; and utilizing a multi-disciplinary approach to comprehensive cancer care (to name a few). Clinical social work and case management services together can work on concerns such as financial stress, housing problems, and resource linkage.

The preponderance of significant correlations in these findings is instructive as well. Providers within a health-care setting should take extra care in promoting an

environment in which solid, trusting relationships among patients, families, and staff are valued and supported. Providers should take care as well in relating compassionately and sensitively to their patients. One-on-one interventions and group work are also vital in fostering a treatment environment that will maximize medical and psychosocial outcomes.

**Implications for research.** The significance of the findings support further research with the adapted behavioral model in other populations, diseases, and health-care initiatives. There is a need as well for further research in utilizing the Socioeconomic Well-Being Scale (Head & Faul, 2008) (the scale that measures the dependent variable, financial quality of life). This scale has been shown to be a valuable instrument within oncology care, and it makes an important contribution to the literature promoting measurement of all dimensions of quality of life. Translating the instrument into other languages is an important next step as well. Understanding socio-economic well-being in other vulnerable populations as they seek help and treatment for cancer is timely and just. It is vital as well to further develop and refine instruments that help researchers and clinicians better understand the complex array of issues that are faced within cancer by populations at risk. The Socioeconomic Well-Being Scale can also be used to measure the effectiveness of interventions, such as financial social work counseling.

**Implications for ethics.** As this dissertation has pointed out, the nature of this topic is in keeping with the social work code of ethics (NASW, 2008) in which the plight of vulnerable people is part of the job to which social workers must devote themselves. Certainly the plight of the underserved within oncology is one area badly in need of



continued focus from all disciplines. The significance of the findings from this study points out that the areas identified—notably barriers to health care, lack of health insurance, financial stress, and housing instability—are ones that a just society will continue to tackle. Rawls’ work also reminds us continually of this priority (1971, 1999).

**Implications for policy.** The findings support emphasis on policy initiatives that are just and that focus again on the underserved and those facing vulnerabilities of different kinds. Specifically, the significance of health insurance adequacy ties in with our nation’s ongoing debate about health-care reform (Himmelstein et al., 2005; Kim, 2007; Ross et al., 2006). Quite simply, the findings from this study point out that inadequacy of coverage has great impact on financial quality of life; specifically, patients who lack adequate coverage are unable to make the best, most reasonable health-care decisions possible for themselves, and they lack the resources to promote and foster the wellness and confidence that others enjoy. This study also points out the need for expanding health insurance coverage, not only for the poorest within our nation, but also for those who are still struggling to make ends meet on a meager salary. The medical literature cited throughout this dissertation shows clearly that there is greater mortality from cancer when health insurance is non-existent; this study and others focusing more on psychosocial outcomes show that economic factors influence patients’ health-care decision-making as well.

In terms of housing policy, the findings suggest that further work is needed on the impact of financial stress and bankruptcy on housing instability and the possible slide towards homelessness. Though most people in this sample are not experiencing housing instability, the fact that some are and that even this small number contributes towards the

statistical significance of this variable in the first domain is alarming. Research must be done with those cancer patients who face loss of housing due to their diagnosis and treatment—with the goal of better informing public policy. The scenario of cancer patients—or any patient facing life-threatening illness—losing their housing cannot be tolerated.

### **Limitations**

This study is limited by the small sample of patients, and by the fact that it is not a random sample of cancer patients across the United States, or even our region. Consequently, the study is prone to self-selection of participants who were most likely interested in and eager to participate in a study that delved into the financial aspects of cancer care. In addition, the fact that it was available only to English-speaking patients is a limitation as well. It is hoped that this study can be expanded with greater resources to address these limitations.

It is also hoped in a future version of this study will include a more precise enumeration of income variables—if not in a precise reported figure, then analyzed in a way that allows for more sophisticated data analysis.

### **Contributions**

This study contributes to the knowledge base in social work addressing the financial plight in cancer patients. For this researcher, it is a first step in joining other social work scholars who are also devoted to these patients. The use of the adapted behavioral model and the use of the Socioeconomic Well-Being Scale combined in this study are novel approaches in studying the plight of the underserved within oncology.

The findings show not only statistical significance but also great promise in further research.

### **Recommendations for Further Research**

Expanding the number of variables chosen from the adapted behavioral model (Gelberg et al., 2000)—or even including them all in a large-scale research study with cancer patients—is ambitious yet thought-provoking. Psychosocial interventions that also address the needs identified here—and then researching their effectiveness in various vulnerable populations—are warranted as well. The field of psychosocial oncology has contributed enormously to ameliorate the pain and suffering that cancer patients typically experience. Including those who suffer “under the radar”—be it those with no health insurance and are dying prematurely, or those patients who are undocumented, or those who lose everything because of cancer’s threat to life—is the next step for oncology social work research scholars.

## Appendix A/Study Questionnaire

1. Do you have a permanent place to stay?  
☐ Yes  
☐ No
2. Where have you stayed in the past 30 days? (Check all that apply.)

<input type="checkbox"/> Rental housing	<input type="checkbox"/> Prison/jail
<input type="checkbox"/> My own apartment or house	<input type="checkbox"/> Shelter
<input type="checkbox"/> With relative or friend	<input type="checkbox"/> Motel/hotel
<input type="checkbox"/> Transitional housing	<input type="checkbox"/> Youth shelter
<input type="checkbox"/> Treatment facility	<input type="checkbox"/> Outside
<input type="checkbox"/> Hospital	<input type="checkbox"/> Other (please describe)

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3. How long have you lived in your present place?  
☐ Less than a year  
☐ 1-5 years  
☐ 5-10 years  
☐ Over 10 years
4. Are you at risk for losing your home due to inability to pay your rent or your mortgage?  
(If yes, please continue on to question 5; if no go on to question 6.)  
☐ Yes [go to question 5]  
☐ No [skip question 5 and go to question 6]
5. If yes, do your medical condition(s) and/or health-care costs contribute to your inability to pay for your housing?  
☐ Yes  
☐ No
6. Why did you leave your last place of residence? (Check all that apply.)

<input type="checkbox"/> Planned move	<input type="checkbox"/> Lost job or no job
<input type="checkbox"/> Rent problems	<input type="checkbox"/> Went to prison or jail
<input type="checkbox"/> Relocation	<input type="checkbox"/> Went into the hospital
<input type="checkbox"/> Evicted, but for other than rent problems	<input type="checkbox"/> Aged out of foster care
<input type="checkbox"/> Conflict with family or friends	<input type="checkbox"/> Housing condemned
<input type="checkbox"/> Overcrowding	<input type="checkbox"/> Fire
<input type="checkbox"/> Domestic violence	<input type="checkbox"/> Other (Please specify)

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7. Please mark the space or circle the item that best describes your household yearly income:

- ☐ Under \$10,000
- ☐ \$10,000 to \$20,000
- ☐ \$20,001-\$30,000
- ☐ \$30,001-\$40,000
- ☐ \$40,001-\$50,000
- ☐ \$50,001-\$75,000
- ☐ Above \$75,000

	Rarely	Sometimes	Usually	Always
8. During the past month, have you had money for unexpected expenses?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. During the past month, have you had enough money to pay your bills?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. During the past month, have you been free from worry about debt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. Do you have health insurance? (This includes Medicare, Medicaid, Alliance, and other types of public assistance.) If yes, please continue on to the next three questions.

- ☐ Yes [go to question 12]
- ☐ No [go to question 15]

These questions ask about how adequate your health insurance is. Please circle the response that best reflects your experience.

12. How adequate is your health insurance in covering the cost of your cancer treatment?	Very Adequate	Adequate	Inadequate	Very Inadequate
13. How adequate is your health insurance in covering the cost of your prescription medications?	Very Adequate	Adequate	Inadequate	Very Inadequate
14. How adequate is your health insurance in covering the cost of your pain medication, if indicated?	Very Adequate	Adequate	Inadequate	Very Inadequate

These questions ask about your living situation, eating, income, transportation, and medical care. The purpose is to see if these needs are met to at least a minimum level of satisfaction or adequacy. Please circle the response that best reflects your experience.

15. How satisfied are you with your home's state of repair?	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
16. How satisfied are you with the amount of room you have in your home?	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
17. How satisfied are you with your home's furnishing?	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied

- |   |                         |                      |                        |                    |
|---|-------------------------|----------------------|------------------------|--------------------|
| 18. How satisfied are you with your home's warmth, lighting, etc.?              | Very Satisfied          | Satisfied            | Dissatisfied           | Very Dissatisfied  |
| 19. How satisfied are you with your home, considering the amount of privacy?    | Very Satisfied          | Satisfied            | Dissatisfied           | Very Dissatisfied  |
| 20. How satisfied are you with your neighbors?                                  | Very Satisfied          | Satisfied            | Dissatisfied           | Very Dissatisfied  |
| 21. How satisfied are you with your home's security, etc.?                      | Very Satisfied          | Satisfied            | Dissatisfied           | Very Dissatisfied  |
| 22. How adequate is your present income for your food?                          | Very Adequate           | Adequate             | Inadequate             | Very Inadequate    |
| 23. How adequate is your present income for medicine?                           | Very Adequate           | Adequate             | Inadequate             | Very Inadequate    |
| 24. How adequate is your present income for clothing, etc.?                     | Very Adequate           | Adequate             | Inadequate             | Very Inadequate    |
| 25. Are you worried about your future income covering the things you must have? | Terribly worried        | Quite worried        | Slightly worried       | Not at all worried |
| 26. Can you get around town as you need for work?                               | Can't get around at all | With much difficulty | With little difficulty | With no difficulty |
| 27. Can you get around town as you need for shopping?                           | Can't get around at all | With much difficulty | With little difficulty | With no difficulty |
| 28. Can you get around town as you need for medical appointments?               | Can't get around at all | With much difficulty | With little difficulty | With no difficulty |
| 29. Can you get around town as you need for visiting, etc.?                     | Can't get around at all | With much difficulty | With little difficulty | With no difficulty |
30. In the past month, have you needed medical care?
- ☐ Yes
- ☐ No
- ☐ N/A
31. If yes, did you have difficulty getting medical care?
- ☐ Yes
- ☐ No
- ☐ N/A
32. Do you have a regular or family doctor? (This includes general practitioner, family doctor, and internal medicine doctor or internist.)
- ☐ Yes
- ☐ No

33. Do you know where to get emergency medical help, if needed?

☐ Yes

☐ No

There are some things we share with family and friends; some things we can count on them for. These questions ask about your family and friends, as you see them now. Please circle the response that best represents your experience.

34. When something nice happens to you, do you want to share the experience with your family?

Always	Often	Sometimes	Never
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35. When something nice happens to you, do you want to share the experience with your friends?

Always	Often	Sometimes	Never
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36. How much would your family be of help and support if you were sick, or moving, or having any other kind of problem?

A great deal	A lot	A little	None
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37. How much would your friends be of help and support to you if you were sick, or moving, or having any other kind of problem?

A great deal	A lot	A little	None
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38. How much would anyone in the community, other than family members and friends, be of help and support to you if you were sick, or moving, or having any other kind of problem?

A great deal	A lot	A little	None
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Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree to strongly agree. For each item we would like you to mark the space or circle the item that represents the extent to which you agree or disagree with that statement. Please make sure you answer every item and that you mark only one space per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

	Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
39. If my cancer worsens, it is my own behavior which determines how soon I will feel better again.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. As to my cancer, what will be will be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
41. If I see my doctor regularly, I am less likely to have problems with my cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Most things that affect my cancer happen to me by chance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Whenever my cancer worsens, I should consult a medically trained professional.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. I am directly responsible for my cancer getting better or worse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Other people play a big role in whether my cancer improves, stays the same, or gets worse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Whatever goes wrong with my cancer is my own fault.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. Luck plays a big part in determining how my cancer improves.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. In order for my cancer to improve, it is up to other people to see that the right things happen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Whatever improvement occurs with my cancer is largely a matter of good fortune.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. The main thing which affects my cancer is what I myself do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. I deserve the credit when my cancer improves and the blame when it gets worse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
52. Following doctor's orders to the letter is the best way to keep my cancer from getting any worse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. If my cancer worsens, it's a matter of fate.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
54. If I am lucky, my cancer will get better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. If my cancer takes a turn for the worse, it is because I have not been taking proper care of myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. The type of help I receive from other people determines how soon my cancer improves.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For the following statements, please indicate how much you agree or disagree with each statement.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
57. The doctors and other health professionals sometimes ignore what I tell them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. The doctors and other health professionals listen carefully to what I have to say.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
59. The doctors and other health professionals answer all my questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. Sometimes the doctors and other health professionals use medical terms without explaining what they mean.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
61. I trust that the doctors and other health professionals have my best interest at heart.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. The doctors and other health professionals act like I'm wasting their time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. The doctors and other health professionals treat me in a very friendly and courteous manner.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
64. The doctors and other health professionals show little concern for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. The benefits of my treatment plan outweigh any difficulty I might have in following it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. My treatment plan is too much trouble for what I get out of it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
67. Because my treatment plan is too difficult, it is not worth following.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68. Following my treatment plan is better for me than not following my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
69. Following my treatment plan will help me to be healthy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
70. I'll be just as healthy if I avoid my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
71. I believe that my treatment plan will help to prevent my getting cancer again.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
72. It's hard to believe that my treatment plan will help me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
73. There are many diseases more severe than the kind of cancer I have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
74. The kind of cancer I have is not as bad as people say.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
75. The kind of cancer I have is a terrible disease.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
76. There is little hope for people with the kind of cancer that I have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
77. The chances I might develop cancer again are pretty high.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
78. I expect to be free of cancer in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
79. No matter what I do, there's a good chance of developing cancer again.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
80. My body will fight off cancer in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
81. Members of my immediate family think I should follow my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
82. I want to do what members of my immediate family think I should do about my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
83. My close friends think I should follow my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
84. I want to do what my close friends think I should do about my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
85. My relatives think I should follow my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
86. I want to do what my relatives think I should do about my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
87. I have made a commitment to my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
88. Following my treatment plan is not in my plans.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
89. I have no intention of following my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
90. Lots of things get in the way of following my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
91. I need more assistance in order to follow my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
92. I get the help I need to carry out my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
93. I am able to deal with any problems in following my treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How true has each statement been in the last seven days?

	Not at all	A little bit	Somewhat	Quite a bit	Very much
94. I believe that being sick will hurt me financially.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
95. People like me are able to get the healthcare they need.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
96. I am able to make enough money to pay for my healthcare.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
97. I have to pay more for my medical care than I can afford.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not at all	A little bit	Somewhat	Quite a bit	Very much
98. I am able to pay my medical bills.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
99. I can easily get information about healthcare.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
100. I can afford medical check-ups even when I am not sick.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
101. I have enough money to take care of my healthcare needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
102. I can get the health insurance I need.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
103. My family thinks good healthcare is important.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
104. I know how to get the healthcare services I need.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
105. I know people who will help me out when I am sick.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
106. People I know best have healthy habits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
107. I understand the healthcare system.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
108. The medicine I need is too expensive for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
109. I am treated the same as other patients when I go for medical care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
110. Healthcare services are easy to get in my neighborhood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This last section will ask information about you and your diagnosis.

111. Age\_\_\_\_\_

112. What is your gender?

☐ Male

☐ Female

113. What is your marital status?

☐ Married

☐ Living with partner

☐ Single – Divorced/separated

☐ Separated

☐ Divorced

☐ Widowed

114. Do you consider yourself to be Hispanic or Latino?  
☐ Yes  
☐ No
115. What race do you consider yourself to be?  
☐ American Indian or Alaska Native  
☐ Asian/Pacific Islander  
☐ Black or African American  
☐ Caucasian/White  
☐ Multiracial  
☐ Would rather not say  
☐ Other (Please specify)\_\_\_\_\_
116. What is the highest level of education you have completed?  
☐ Less than high school  
☐ High school graduate  
☐ Some College  
☐ College Graduate  
☐ Post-graduate or Professional
117. Which of the following are your sources of income? (Select all that apply.)  
☐ Money earned from work I do now  
☐ From spouse, relative, or friend  
☐ Public funds  
☐ Retirement or Social Security  
☐ SSI/SSDI  
☐ Alimony or child support  
☐ Other (please specify)\_\_\_\_\_  
\_\_\_\_\_
118. What is your employment status?  
☐ Full-time  
☐ Part-time  
☐ Retired  
☐ Student  
☐ Homemaker  
☐ Other (Please Specify)

119. Number of family members in household \_\_\_\_\_
120. Number of minor children \_\_\_\_\_
121. If you are employed, please describe your  
job. \_\_\_\_\_
122. What is your cancer diagnosis?  
\_\_\_\_\_
123. What was the stage of your cancer at diagnosis (if  
known)? \_\_\_\_\_
124. What was the date of your diagnosis?  
\_\_\_\_\_
125. What types of cancer treatment have you received? (check all that apply)
- ☐ Chemotherapy \_\_\_\_\_
  - ☐ Radiation therapy \_\_\_\_\_
  - ☐ Cancer surgery \_\_\_\_\_
  - ☐ Transplant
  - ☐ Other (Please specify \_\_\_\_\_)
126. Do you think that being diagnosed with cancer and undergoing treatment has  
negatively affected your financial status?
- ☐ Yes
  - ☐ No

Thank you for completing this questionnaire!

Would be you interested in taking part in a one-on-one interview with the researcher interview  
regarding these and similar issues? Sharing your experience is much appreciated.

- ☐ Yes
- ☐ No

Questions on questionnaire delineated by variable:

DV (financial quality of life)	Questions 94-110, 126
IV 1 (housing stability)	Questions 1-6
IV 2 (personal control)	Questions 39-56
IV 3 (demographics)	Questions 111-121
IV 4 (income and financial stress)	Questions 7-10
IV 5 (health insurance)	Questions 11-14
IV 6 (perceived barriers to care)	Questions 15-33
IV 7 (social support)	Questions 34-38
IV 8 (cancer need)	Questions 122-125
IV 9 (treatment adherence)	Questions 57-93

#### Questions for the Qualitative Portion of the Study with a Subset of Participants

- 1) Tell me about your treatment experience.
- 2) Tell me about your feelings regarding treatment.
- 3) Tell me about how your financial situation impacts cancer treatment—and vice versa.
- 4) Tell me about your feelings regarding coping with cancer. In your view, where do you draw support and meaning?
- 5) What are your obstacles in being able to get the cancer treatment you need? What are the obstacles in finding positive financial quality of life? In the same way, what are your strengths in being able to get the cancer treatment you need? What are your strengths in finding positive financial quality of life?

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