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EXAMINING FINANCIAL STRESS AND COPING AMONG U.S. CANCER PATIENTS AND SURVIVORS: QUANTITATIVE ANALYSES OF SURVEY DATA

by

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This manuscript has been read and accepted for the Graduate Faculty in Social Welfare in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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ABSTRACT

Examining Financial Stress and Coping among U.S. Cancer Patients and Survivors: Quantitative Analyses of Survey Data

by

Meredith Doherty

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Financial hardship, a growing problem for cancer patients and survivors, is associated with increased pain and symptom burden, reduced quality of life and psychological wellbeing, poor treatment adherence, and early mortality. Nearly one in three cancer patients reports that cancer caused some financial stress or strain. Emerging research has begun to explore the coping strategies used by cancer-affected individuals to manage the direct and indirect costs associated with cancer and its treatment. This dissertation seeks to answer three research questions: (1) what are the measurable characteristics of different cost-coping strategies? (2) what behavioral, institutional, and social factors are associated with variations in coping? and (3) to what extent do these distinct coping strategies mediate and/or moderate the relationship between material financial stress and perceived financial strain?

To address these research questions, multivariate statistical methods were used to analyze existing survey data on the financial concerns from a stratified, random, national sample of insured cancer patients and survivors (N = 511). Exploratory factor analysis was used to identify the four underlying dimensions of problem-focused cost-coping and delineate working scales for
each hypothesized coping strategy: care-altering, lifestyle-altering, self-advocacy and financial help-seeking. Stepwise logistic regression was used to model significant predictors of each cost-coping strategy. Lastly, to explore the possible effectiveness of each cost-coping strategy, linear regression-based mediation and moderation modeling using Hayes’ PROCESS analysis was used to measure the extent to which each strategy intervened in the relationship between material financial stress and the perceived financial strain.

Two strategies played meaningful intermediary roles: lifestyle-altering and self-advocacy. Lifestyle-altering, used more often by women and people of color, partially mediated the positive, linear relationship between stress and strain ($B = 0.08, p<.05$). Self-advocacy interacted with stress to buffer its impact on perceived financial strain ($B=-0.01, p<.01$).

Findings from this study contribute to the literature on financial stress and strain as social determinants of health by proposing a model of financial coping in cancer that may facilitate the development of interventions, programs and policies that improve financial wellbeing in people affected by cancer by supporting successful coping and targeting the delivery of material and psychosocial resources where they are needed most.
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CHAPTER I. STATEMENT OF THE STUDY ISSUE

Rationale and Significance

People diagnosed with cancer are materially and psychologically unprepared to deal with the costs of care. They typically encounter unexpected out-of-pocket medical expenses and may be limited in their ability to work for periods of time (CancerCare, 2016; Yabroff et al., 2015). The combined financial burden of treatment and potential for lost income is a major source of stress for people affected by cancer (Altice, Banegas, Tucker-Seeley, & Yabroff, 2017; Azzani, Roslan, & Su, 2015). Moreover, a growing number of studies have linked this experience of financial hardship to poor health outcomes and early mortality (Ramsey et al., 2016; Zafar & Abernethy, 2013).

Financial hardship in cancer is widespread and growing. Each year almost two million American men and women receive a diagnosis of cancer, and there are currently over 15.5 million cancer survivors in the United States (American Cancer Society, 2016; Siegel, Miller, & Ahmedin, 2016). At least one third will experience a degree of financial hardship due to out-of-pocket medical expenses and wages lost due to disability (Yabroff et al., 2015). For many, cancer-related financial hardship persists beyond the acute phase of their illness and throughout survivorship (Jagsi et al., 2014). Coping with these expenses affects not only the person with cancer, but their family, and the wider community as well.

The treatment advances of recent decades have improved survival and decreased overall mortality from cancer, but have also added significant cost to standard treatment protocols. Cancer patients have substantially greater out-of-pocket treatment costs and 2.5 times the risk of personal bankruptcy of people with other health conditions (Cohen, Gindi, & Kirzinger, 2012; Claxton, Panchal, Whitmore, Damico, Kenward, & Long, 2015; Ramsey et al., 2013). Even after
active treatment cancer survivors are more likely to have high personal debt and negative net worth, and are less likely to own homes than people without a cancer history (Doroudi, Coughlan, Banegas, Han, & Yabroff, 2018).

In response to rising healthcare costs, many insurance plans have employed cost-sharing mechanisms that increasingly shift the burden to patients in the form of co-insurance, co-pays, deductibles and monthly premiums (Collins, Rasmussen, Beutel, & Doty, 2015). Cost sharing related to prescription medication, outpatient care and hospital stays constitute the greatest portion of these expenses, respectively (Zafar & Abernethy, 2013). In a 2016 survey conducted by the national organization CancerCare, respondents between the ages of 25-64 reported average monthly out-of-pocket expenses of $1,112 for their cancer treatment (CancerCare, 2016). Similarly, a recent analysis of 2002-2012 Health and Retirement Study data indicated that the average annual out-of-pocket cancer treatment costs in a nationally representative sample of 1,409 traditional Medicare beneficiaries was $8,115 (Narang & Nicholas, 2016). For context, the median household income in 2015 was $38,515 for individuals 65 and older (U.S. Census Bureau, 2017), suggesting that many individuals may spend over 20% of their household income on out-of-pocket cancer costs.

Individuals and families who spend 10-20% or more of their household income on out-of-pocket medical expenses are considered underinsured (Collins et al., 2015). The number of underinsured Americans is climbing. According to the 2014 Commonwealth Fund Biennial Health Insurance Survey, the number of underinsured Americans nearly doubled from 16 million in 2004 to 31 million in 2014. For the underinsured, high out-of-pocket costs can lead to large amounts of debt, personal bankruptcy and difficulty adhering to treatment (Collins et al., 2015; Dusetzina, Winn, Abel, Huskamp, & Keating, 2014; Kaisaeng, Harpe, & Carroll, 2014). A recent
study found that the gains in coverage rates secured by the Patient Protection and Affordable Care Act of 2010 did not reduce the number of bankruptcies caused by serious illness and its treatment (Himmelstein, Lawless, Thorne, Foohey, & Woolhandler, 2019).

The excessive cost of care has well-documented health consequences. A growing body of evidence has linked cancer-related financial hardship to adverse health and treatment outcomes. Strong associations have been documented between cancer patients’ experience of financial hardship and reduced quality of life (Arastu et al., 2018; Fenn, 2014; Kale & Carroll, 2016; Lathan et al., 2016, 2016; Zafar et al., 2015), increased pain and symptom burden (Chan et al., 2018; Delgado-Guay et al., 2015; Lathan et al., 2016; Rios & Zautra, 2011), and early mortality (Ramsey et al., 2016). Furthermore, patients who experience financial hardship are more likely to report treatment delays (Casilla-Lennon et al., 2018; Wharam et al., 2019) and difficulty adhering to treatment. Many report delaying or forgoing recommended treatments and cutting back on prescribed medications to reduce their out-of-pocket costs (Bestvina et al., 2014). The term financial toxicity is now used to refer to the demonstrated impact of financial hardship on these health and treatment-related outcomes (Zafar & Abernethy, 2013). Such outcomes are distinct from health outcomes associated with low socioeconomic status alone, and have been identified across the spectrum of income and insurance status. As such, financial toxicity is increasingly cited as a common side effect cancer care, as well as a social determinant of health (Tucker-Seeley & Yabroff, 2016).

Although financial toxicity has been reported by individuals across the socioeconomic continuum (Tucker-Seeley & Yabroff, 2016) studies have shown that women, individuals identifying as racially/ethnically nonwhite, non-English speakers and those with lower educational attainment are more likely to experience cancer-related financial hardship and its
attendant health consequences (Knight et al., 2018; Ramsey et al., 2016; Shankaran, Jolly, Blough, & Ramsey, 2012). These studies build upon well-documented racial/ethnic and socioeconomic disparities in cancer incidence and mortality (Ward et al., 2004). Financial toxicity may represent a downstream social determinant of health and a potential driver of cancer health disparities for socially disadvantaged communities.

The construct of cost-coping describes the strategies used by cancer patients and survivors to manage financial stress and balance their personal and household financial needs with the costs of treatment (Zullig et al., 2013). Although the literature posits multiple cost-coping strategies (Head, Harris, Kayser, Martin, & Smith, 2018; Nipp et al., 2016) and has implicated cost-coping in the development of negative health effects (Carrera, Kantarjian, & Blinder, 2018; Zafar, 2016), in-depth knowledge of the range of strategies used by financially stressed households is sparse. There is reason to believe that cost-coping strategies can either buffer or exacerbate the impact of financial stress on health and wellbeing. Citing threats to public health, oncology providers and researchers have called for evidence-informed strategies to prevent financial stress and coping from undermining patient care and outcomes (Tucker-Seeley & Yabroff, 2016).

Social Work Role

Guided by the ethical principle of promoting social justice, the social work profession is committed to eliminating race- and class-based health disparities and building the financial capacity of underserved communities (National Association of Social Workers [NASW], 2017; Uehara et al., 2013). In many health care settings social workers are responsible for identifying and addressing patients’ financial needs and concerns. Oncology social workers have cited financial and insurance difficulties as the foremost barrier to accessing high quality cancer care.
Burg et al., 2010) and have called for improved screening and financial resource identification tools (Smith, Nicolla, & Zafar, 2014).

A deeper, more contextual understanding of financial stress and coping can inform the development of social work assessment and interventions that promote effective coping and financial wellbeing in cancer patients and survivors. A working measure of cost-coping can be useful in development of clinical tools that can be used to identify individuals at risk of financial stress, strain, and maladaptive coping strategies. Understanding the risk factors associated with different coping strategies may aid in the development of targeted community and population level interventions that direct material and psychosocial resources where they are needed. This study contributes to an emerging literature that posits cancer-related financial hardship as a health equity issue which disproportionately impacts women, the poor, and people of color.

**Specific Study Aims**

This exploratory study seeks to improve our understanding of the problem-focused cost-coping strategies used by cancer patients and survivors by (1) identifying the measurable characteristics of cost-coping and its subdimensions; (2) identifying the behavioral, social and health system factors that predict variations in coping; and (3) measuring the extent to which different coping strategies mediate or moderate the relationship between material financial stress and the subjective experience of financial strain. In order to address these aims, I conducted an analysis of secondary, cross-sectional data from an online survey of cancer patients and survivors (n=511) regarding their concerns about finances and health insurance. The overarching goals of the study are to produce a formative, working measure of cost-coping, identify modifiable factors associated with variations in coping, and measure the extent to which coping strategies succeed in buffering the impact of financial stress on wellbeing to develop a preliminary model
of financial hardship and cost-coping in cancer patients and survivors. Specifically, the study seeks to test the following hypotheses and accomplish the following aims:

**Aim 1**

Identify, through exploratory factor analysis techniques, measurable characteristics of cost-coping and its subdimensions in the survey data. H1: Cost-coping is a measurable latent construct that can be measured across multiple subdimensions.

**Aim 2**

Identify behavioral, social, and health system factors that most strongly predict variations in cost-coping. Specifically, stepwise logistic regression is employed to predict cost-coping outcomes from behavioral (e.g. patient activation score), health system (e.g. health insurance type and associated out-of-pocket medical costs), and social (e.g. gender, race/ethnicity, and income). H2: Coping style will vary by behavioral, health system, and social factors such that, upon examination of multiple indicators, distinct typologies and modifiable factors will emerge.

**Aim 3**

Measure, using Hayes’ PROCESS method of regression-based mediation and moderation analysis, the extent to which different cost-coping strategies mediate or moderate the relationship between material financial stress (i.e. difficulty paying bills due to cancer treatment) and financial strain (i.e. psychological distress attributed to finances). H3: Each cost-coping strategy will have a distinct and measurable impact on the relationship between financial stress and financial strain.
CHAPTER II. REVIEW OF THE LITERATURE

Financial Stress and Strain

One of the challenges of conducting research on financial hardship in cancer is the lack of consistency in naming and defining the phenomenon. Financial hardship encompasses both the subjective and objective experiences of cancer patients and survivors when they encounter difficulties balancing their household financial responsibilities with the direct and indirect costs associated with their cancer diagnosis. One way of understanding the construct divides it into two dimensions: financial stress and financial strain. Financial stress represents objective, measurable financial demands, and financial strain represents one’s subjective perception of difficulty or distress related to managing those demands (Francoeur, 2005; Sharp, Carsin, & Timmons, 2013). Both financial stress and strain have been associated with adverse psychological outcomes including increased distress, depression, and anxiety in cancer patients and survivors (Ell, et al., 2008; Sharp, et al., 2013). Individuals and groups vary in the degree to which financial stress leads to subjective strain. Although financial stress and strain tend to be significantly correlated on average, the pattern and strength of the relationship depends on mediating and moderating factors, including a patient’s ability to rally personal and social resources in order to cope with stress (Francoeur, 2005).

Cost-Coping Strategies

In their conceptual framework of financial hardship in cancer, Altice and colleagues (2017) added a third feature to the stress and strain model: coping behaviors. Their model proposed three distinct but overlapping dimensions: (1) material conditions, (2) psychological responses, and (3) coping behaviors. Their review of the empirical literature identified patterns in measuring these three dimensions. The material conditions typically measured in research on
financial hardship include out-of-pocket expenses, missed work, lost income, medical debt and bankruptcy. Psychological responses are often measured in terms of subjective distress about managing household finances after or during cancer treatment. Coping behaviors they identified in the literature related to care- and lifestyle-altering behaviors like delaying or forgoing medical care, reducing medications to save money, and cutting back on essential and non-essential household spending.

Despite the abundant and growing body of literature on financial hardship, coping strategies have been relatively understudied (Carrera et al., 2018). Coping falls broadly into two types: (1) person-oriented/emotion focused and (2) task/problem focused (Head, et al., 2018; Lazarus & Folkman, 1984). In qualitative interviews with financially-burdened cancer patients, Head and colleagues (2018) identified a number of emotion and problem focused coping strategies. In their study they found people were engaged in emotion focused cost-coping strategies like using personal strengths, accessing social support, expressing emotion and engaging in self-care. They also described problem focused strategies like going into debt, accessing financial assistance, making lifestyle changes, changing treatment protocol, being proactive and negotiating with insurance.

Care-altering and lifestyle-altering are two cost-coping strategies that have received the most scholarly attention to date (Bestvina et al., 2014; Huntington et al., 2015; Irwin et al., 2014; Jagsi et al., 2014; Kent et al., 2013; Lee & Khan, 2016; Lee & Salloum, 2016; Nipp et al., 2016; Zafar, Chino, Ubel, Rushing, & Samsa, 2015; Zullig et al., 2013). As stated previously, care-altering describes how some cancer patients and survivors cope with the cost of their care by delaying or forgoing aspects of medical treatment. Lifestyle-altering refers to coping with the costs of care by altering spending and borrowing habits (Nipp et al., 2016).
Care-altering, also referred to as cost-related nonadherence (CRN), has been associated with adverse health consequences in cancer and other illnesses (Hershman et al., 2011; Osterberg & Blaschke, 2005). Although the exact estimates are unknown, two large population-based studies using data from the National Health Interview Survey from 2003-2006 (Weaver, Rowland, Bellizzi, & Aziz, 2010) and 2010 (Kent et al., 2013) concurred that 10-20 percent of cancer patients and survivors had delayed or declined necessary medical care in the last 12 months due to cost.

The only reliability-tested measure of care-altering is a measure of cost-related medication nonadherence. Respondents are asked if in the last six months they have ever skipped a dose of medication, took a smaller dose, or delayed refilling, and how many times in the last 12 months they did not fill a prescription (Pierre-Jacques et al., 2008). Many care-altering and CRN studies adapted this instrument to measure other kinds of treatment nonadherence, like delaying or forgoing medical appointments and testing.

The two primary drivers of care-altering that have been identified in the empirical literature are financial hardship and high out-of-pocket medical costs. The risk of engaging in cost-related medication nonadherence has been positively correlated with rising prescription co-payments (Dusetzina et al., 2014; Kaisaeng et al., 2014; Neugut et al., 2011; Streeter, Schwartzberg, Husain, & Johnsrud, 2011) and self-reported financial stress and strain (Kent et al., 2013; Markman & Luce, 2010; Zafar et al., 2013; Zullig et al., 2013). Other factors that have been empirically linked to care-altering behavior in past studies are age, race/ethnicity and gender. Analyzing a nationally representative sample of cancer patients and survivors, Lee and colleagues found that younger patients, women, African American and Hispanic individuals were more likely to cite treatment costs as a barrier to adherence (Lee & Khan, 2016; Lee &
These demographic disparities by age, gender and race are persistent and have also been found in smaller, less heterogeneous study samples (de Souza, Kung, O’Connor, & Yap, 2017; Martin, Shreffler, Schoster, & Callahan, 2012; Zafar et al., 2013).

People respond to financial hardship and out-of-pocket costs differently. Under the same financial circumstances, only some patients respond by altering care and reducing adherence to treatment and medication (Briesacher, Gurwitz, & Soumerai, 2007). Piette et al. (2006) proposed a conceptual model of factors influencing care-altering behavior in people with chronic illness. The model proposes that there are, in addition to primary financial pressures, interactional factors related to clinician, patient, health system and medication characteristics that increase one’s risk of care-altering (Piette, Heisler, Horne, & Alexander, 2006). Patient-physician trust (Piette, Heisler, Krein, & Kerr, 2005) and patient health beliefs (Piette, Beard, Rosland, & McHorney, 2011) have been identified as possible mediators of the relationship between financial hardship and care-altering. Efforts to identify other modifiable factors associated with care-altering behavior is ongoing.

Like care-altering behaviors, lifestyle-altering strategies range in severity. Some cope proactively by simply cutting back on leisure spending, while other people are driven to cut back on basics like food and clothing or to depleting assets, borrowing money and filing for bankruptcy (Altice et al., 2017). As a singular concept, lifestyle-altering has been relatively understudied and efforts to operationalize and measure it are incomplete. However, aspects of lifestyle-altering such as changing spending habits, borrowing money, and filing for bankruptcy have been well-documented (Altice et al., 2017; Head et al., 2018; Nipp et al., 2016). Nipp and colleagues (2016) delineated lifestyle-altering cost-coping with the following survey items
(adapted from Schrag et al., 2009): reduced spending on basics and on leisure activities, borrowed money, used savings, family worked more, and/or sold possessions.

Many studies of lifestyle-altering have used small, convenience samples which make it difficult to estimate its prevalence. However, the accumulated evidence suggests that many cancer patients and survivors alter their lifestyle, spending and borrowing habits to accommodate the costs of treatment (Jagsi et al., 2014; Markman & Luce, 2010; Meneses, Azuero, Hassey, McNees, & Pisu, 2012; Shankaran et al., 2012; Zafar et al., 2013; Zafar et al., 2015). For example, in studies of cancer patients who had contacted a financial assistance program, 68-78 percent cut back on leisure activities, 46-57 percent reduced spending on basics like food and clothing, and 46 – 50 percent used savings to pay for treatment (Nipp et al., 2016; Zafar et al., 2013). Patients commonly borrow from friends, family and banks to cover expenses, such that nearly 3 percent of American cancer survivors file for bankruptcy within two years of diagnosis (Meneses et al., 2012; Nipp et al., 2016; Zafar et al., 2013).

In addition to the potential for lifestyle-altering to affect quality of life (Meneses et al., 2012), some of these coping strategies have been shown to impact physical health outcomes. A 2016 study conducted by Ramsey and colleagues (2016) revealed that cancer survivors who filed for bankruptcy died earlier than propensity score matched counterparts who had not filed for bankruptcy. These findings suggest that some forms of care- and lifestyle-altering coping are potentially dangerous, and may carry higher risks for health and wellbeing than other cost-coping strategies.

**Predictors of Financial Stress and Variations in Coping**

Financial hardship has been reported across demographic populations but is known to disproportionately impact younger patients, women, and African American and Hispanic
individuals (Ramsey et al., 2016; Shankaran et al., 2012). These associations persist across studies despite some differences in the definition and measurement of financial hardship (Altice et al., 2017).

Nipp and colleagues (2016) conducted a small study (n=174) using a cross-sectional survey to disentangle care-altering and lifestyle-altering strategies and identify predictors of each coping style among adult cancer patients receiving financial assistance program. To predict each cost-coping outcome, they examined the following patient characteristics: age, marital status, race, income, education, chemotherapy duration, cancer site, and presence of metastatic disease. They found that both care- and lifestyle-altering were associated with younger age (< 65), lower income, higher education, non-breast cancer diagnosis and non-metastatic disease. Among these respondents, those at risk for care-altering, rather than lifestyle-altering, were more likely to be younger (<65) and have lower incomes (< $20,000/year). Unlike other studies, race/ethnicity was not significantly associated with financial hardship and cost-coping.

The study by Nipp et al. (2016) surveyed a small sample that overrepresented individuals with breast cancer, and had a low response rate, so findings may not accurately reflect the general population of cancer patients and survivors. When designing the measure and developing statistical models, the researchers did not include behavioral factors that might have provided psychological insight into what motivates people to cope with financial stress in different ways. Similarly, positive coping like self-advocacy and help-seeking were not examined. Further research is needed to develop distinct, comprehensive typologies of cost-coping which can be used to identify patients who may be at risk of engaging in riskier coping strategies like care-altering.
The extent to which past studies of financial hardship and cost-coping were explicitly informed by social or behavioral theory is unknown. There is a clear conceptual connection to the theories, models and frameworks that form the social determinants of health research paradigm. For example Pearlin’s Stress Process Model (Pearlin, 1989; Pearlin, Menaghan, Lieberman, & Mullan, 1981), described in the next section, provides a rationale and framework for examining the mediating effects of coping on the relationship between financial stress and strain. However, Pearlin’s model has not been applied to an empirical examination of cost-coping in cancer patients and survivors. The following section presents how this theoretical framework will guide each of the research aims.
CHAPTER III. CONCEPTUAL FRAMEWORK

This study is conceptually organized by Pearlin’s Stress Process Model, a sociological adaptation of stress and coping theory. The Stress Process Model invokes social structural relationships to illustrate the processes of toxic stress development that are thought to underlie the disparities in health attributed to differences in race, gender, and socioeconomic status.

Expanding upon Selye’s original conceptualization of stress (Selye, 1956), the Stress Process has three elements: (1) stressors, (2) stress mediators, and (3) stress outcomes (Pearlin et al., 1981). Stressors can be thought of as threatening or burdensome experiences that an individual must respond to, stress mediators are internal and external resources that individuals leverage to manage stressful experiences (e.g. coping). Stress outcomes are the effects of stressful experiences, such as distress and other health effects (Pearlin, 1989). In this model, both stressors and stress mediators are determined by psychosocial and environmental factors like socioeconomic status and social role.

Early stress and coping theory emphasized internal, psychological processes (Lazarus, 1993). But has since grown to include social and relational factors. Link and Phelan (1995) proposed a link between social stress and illness, proposing that socioeconomic status functions as a fundamental cause of health disparities that cannot be fully accounted for by individual behavior or lifestyle factors. Like earlier theories of stress, the sociological perspectives acknowledge that stress has a direct impact on physical and mental health, but adds that social roles and socioeconomic status determine the type and magnitude of stress that one is exposed to. This differential exposure to stress is thought to be responsible for health outcomes that vary by race, gender, marital status and income (Thoits, 2010). Stressors can be acute, life events or they can be chronic conditions that allow stress to proliferate across the life course and across
generations (Aneshensel, 1992; Thoits, 2010). In a persistently inequitable society, race, class and gender can be considered primary sources of stress (Dohrenwend & Dohrenwend, 1970).

People vary in their vulnerability and response to stress. This may be attributed to their ability to cope with stressful experiences, since coping has been shown to reduce the impact of stressors (Thoits, 2010). Coping, when personal and social resources are rallied to manage a stressful experience, is thought to mediate the impact of stress on physical and mental health outcomes. Coping strategies are characterized as emotion- or problem-focused, and have differing degrees of success in proactively managing stress (Lazarus, 1993). Emotion-focused strategies focus on managing thoughts, perceptions and feelings to reduce stress, while problem-focused coping attempts to reduce stress by changing the external circumstances. Not all coping strategies produce positive outcomes. Some strategies exacerbate primary stressors, causing further problems and producing secondary and tertiary compounding stressors (Pearlin, 1989; Pearlin & Bierman, 2013). Coping is, as well, a socially-situated phenomenon that varies by one’s access to psychosocial and material resources (Thoits, 2006).

Conceptually and methodologically, coping can function as either a mediator or moderator of the impact of stressors on stress outcomes (Frese, 1986). Coping acts as a mediator when it links stressors to stress outcomes in a causal pathway. It should therefore be significantly correlated with both the antecedent stressor and the stress outcome. When coping acts as a moderator, it interacts with the antecedent stressor to either increase or decrease the stressor’s effect on the outcome. This study applies the Stress Process Model to develop a model of financial hardship and cost-coping in cancer patients and survivors (see Figure 1), and tests coping as a mediator (see Figure 2) and moderator (see Figure 3) of the stress process. Financial stress acts as the stressor and financial strain acts as the stress outcome.

Figure 2. Cost-coping as a mediator in the stress process
Figure 3. Cost-coping as a moderator in the stress process
CHAPTER IV. METHODOLOGY

Overview

This exploratory study examined the cost-coping strategies of adults living with cancer by conducting secondary analysis of cross-sectional survey data on the financial concerns of 511 cancer patients and survivors, described further below (CancerCare, 2016). The study was designed to achieve three specific aims:

Aim 1: Apply factor analysis techniques to survey data to develop a preliminary measure of cost-coping and its subdimensions.

Aim 2: Use step-wise logistic regression to model the significant social, behavioral and health system factors that most strongly predict variation in cost-coping.

Aim 3: Measure the extent to which each cost-coping strategy mediates and/or moderates the relationship between financial stress and strain.

3a) Regression-based simple mediation model to measure extent to which each coping strategy explains the impact of financial stress on the experience of financial strain.

3b) Regression-based moderation models to measure the extent to which each strategy either buffers or amplifies the impact of financial stress on the experience of financial strain.

Design and Sample

Cross-sectional survey data for this dissertation have been provided by CancerCare, a non-profit psychosocial support organization for people affected by cancer (see Appendix 2 for data use agreement). Between July and December 2015 CancerCare conducted the “Cancer Patient Access and Engagement Study”, a series of six online cross-sectional surveys on the experiences of cancer patients and survivors across the continuum of care. The surveys were developed by CancerCare staff in collaboration with leaders in oncology research to capture and
describe the unmet needs of U.S. cancer patients and survivors across six areas of care: (1) understanding the diagnosis of cancer; (2) treatment planning; (3) communication with the care team; (4) financial and insurance issues; (5) symptoms, side effects and quality of life; (6) survivorship. The surveys were pilot-tested with a sample of CancerCare participants for feasibility and then administered online to a sample drawn from national market research panels. To participate, respondents had to: (1) be 25 years of age or older, (2) have ever been diagnosed with cancer by a medical professional, and (3) have health insurance. Respondents were drawn from national consumer panels used in market research and contacted by email to participate in an online survey about their experiences accessing and engaging in health care. Approximately 3,000 email invitations were sent out per survey. Online filters were used to select a purposive, stratified sample of cancer patients and survivors to represent population distributions by U.S. geographic region and cancer type. To match U.S. national demographic data, approximately 25% of respondents were selected to represent each geographic region (Northeast, Southeast, Western US, and Midwest). Fifty percent of participants were drawn to represent the major cancer-types (breast, colorectal, lung, and prostate cancer) and the remaining half represented all other cancers excluding non-melanoma skin cancer (CancerCare, 2016).

This dissertation analyzed data from one of the six surveys from the original study, the survey of patients’ financial and insurance concerns which was completed 511 cancer patients and survivors. If 3,000 invitations were sent then 17% of those contacted were both eligible to participate and completed the survey (see Table 2 for sample characteristics). As a secondary data analysis, this dissertation posed unique research questions that were not asked in the original descriptive study and tested hypotheses for financial hardship and coping that were not part of the original study. Sample characteristics can be found in Table 2.
Measures

The survey includes 51 items related to the financial impact of cancer and coping with the cost of care. Some of the items are unique to this study and others were drawn from federal health service research surveys like the National Health Interview Survey and the Medical Expenditures Panel Survey (Yabroff et al., 2012). Only one measure in the survey has been psychometrically evaluated in past studies, the patient activation measure (PAM-10), a validated and reliable measure designed to assess individuals’ ‘self-concept as manager of their own health needs’ where higher scores indicate higher activation (α=0.82) (Hibbard & Gilburt, 2014, p. 8).

Cost-coping

To estimate cost-coping, 32 survey items were selected from the 51 items that constitute the original survey. The principal investigator selected these items following a comprehensive review of the scholarly literature on financial stress and coping in cancer. The items selected are similar to the unvalidated measures used in past studies Jagsi et al., 2014; Nipp et al., 2016; Zullig et al., 2013).

“How often (never, rarely, sometimes, often or always) did/do you do each of the following in order to reduce your expenses related to your cancer treatment… (1) postpone or skip medical appointments; (2) postpone or skip follow up testing; (3) postpone or skip bloodwork; (4) delay or skip complementary treatment; (5) postpone or skip psychological support; (6) skip dosage of prescribed drugs; (7) cut pills in half; (8) apply for copay assistance for medication; (9) discuss changing treatments to one that costs less; (10) choose a lower cost medication than what the doctor recommended; (11) apply for financial assistance for non-medical expenses; (12) order medication from outside US online; (13) apply for financial assistance from my doctor; (14) estimate cost before agreeing to treatment; (15) appeal a denial of benefit from you insurance
company; (16) find out cost before filling a prescription for side effects/symptoms; (17) estimate cost before going to emergency room; (18) review the explanation of benefits from insurance company; (19) ask insurance company for help understanding coverage; (20) find out cost of lab test or scans before agreeing to treatment; (21) considered changing to a different doctor because of cost; (22) considered a non-traditional treatment that costs less.”

“Which of the following have you experienced as a result of bills related to your cancer treatment (yes or no)…(23) I declared bankruptcy; (24) I borrowed money from a bank or credit union; (25) I cut back on non-essential items; (26) I borrowed money from family/friends; (27) I moved to a less expensive home; (28) I missed rent/mortgage payments; (29) I cut back on groceries, transportation, clothing, tuition; (30) I missed paying bills like heat, electricity, phone; (31) I asked for financial help from a church or community organization; (32) I applied for financial assistance from a patient support organization.”

**Domain 1: Demographics**

**Current age.** Age was measured as a categorical variable with six categories, which were collapsed prior to analysis into the following two categories: (1) 25-64; (2) 65 or older. The cutoff threshold was selected because studies have shown significant differences in exposure to financial hardship by age, in which individuals under 65 have greater risk of financial hardship (Knight et al., 2018).

**Race/Ethnicity.** Race and ethnicity were measured as a mutually exclusive categorical variable with the following seven categories: (1) African American; (2) Asian; (3) Hispanic; (4) Pacific Islander; (5) White (not Hispanic); (6) Multi-racial; (7) other.

**Gender.** Gender was measured as a categorical variable with two categories: (1) female; (2) male.
**Education.** Education was measured as a categorical variable with seven categories. In order to simplify data and improve interpretability of findings, these categories were collapsed into two categories: (1) high school diploma or less; (2) some college or more.

**Income.** Income was measured as a categorical response to the following prompt, “What was your total 2014 household income before taxes?” Response options are: (1) less than $25,000; (2) $25,000 – $34,999; (3) $35,000 – $49,999; (4) $50,000 - $74,999; (5) $75,000 - $99,999; (6) $100,000 - $149,999; (7) $150,000 or more; (8) Prefer not to answer. Only the first seven responses were used in analyses. To improve the interpretability of analyses the income variable was transformed to reflect 2015 Federal Poverty Guidelines for a family of four (U.S. Department of Health and Human Services, 2015) so that the final variable contained four categorical responses: (1) ≤150%FPL; (2) 150%–300% FPL; (3) 300%FPL – 600% FPL; (4) ≥600% FPL.

**Domain 2: Behavioral**

Patient activation was measured using the 10-item Patient Activation Measure (PAM), a validated measure designed to assess individuals’ ‘self-concept as manager of their own health needs’ (Hibbard & Gilburt, 2014, p. 8). The scale contains items related to health beliefs, knowledge, skills and confidence. Higher scores indicate greater activation and can be coded and analyzed as either continuous (scale of 0-100) or ordinal variables (1-4). See Table 2 for frequency distribution of demographic variables.

**Domain 3: Health Status**

**Cancer type.** Cancer type was measured with a categorical response to the following prompt, “what type of cancer were you most recently diagnosed with?” Response options included: (1) bladder; (2) brain; (3) breast (early stage); (4) breast (metastatic); (5) colon or
rectal; (6) endometrial/cervical/ovarian; (7) head/neck; (8) kidney; (9) leukemia; (10) liver; (11) lung; (12) lymphoma; (13) melanoma; (14) myeloma; (15) pancreatic; (16) prostate; (17) stomach; (18) thyroid; or (19) other.

**Time since diagnosis.** Time since diagnosis was measured with a categorical response to the following prompt, “how long ago were you first diagnosed with cancer?” Response options include: (1) within the last 12 months; (2) between 13 months and 2 years ago; (3) between 2 years and years ago; (4) more than 4 years ago.

**Treatment status.** Treatment status was measured with a categorical response to the following prompt, “What is your current cancer status?” Response options include: (1) in active treatment; (2) completed treatment and on maintenance; (3) completed treatment and not on maintenance.

**Work reduction.** Employment changes related to cancer and its treatment were measured with a categorical response to the following prompt, “What was your employment status while you were being treated for cancer?” Response options included: (1) I continued working full time; (2) I continued working part-time; (3) I switched from working full time to part time; (4) I stopped working; (5) Does not apply, I was not working before receiving treatment. For analyses, this item was transformed into a binary variable where categories 3 and 4 were collapsed to represent work hour reduction during treatment (yes/no). See Table 2 for frequency distribution of health status variables.

**Domain 4: Health System Factors**

**Insurance type.** Insurance type was measured as a categorical, but not mutually exclusive, response to the following prompt, “what type of health insurance do you have? Please select all that apply.” Response options included: 1) commercial/private insurance through and
employer, 2) private insurance via Healthcare.gov (the insurance exchange), 3) Medicare/Medicaid, 4) private Medigap, 5) Tricare/Champus.

**Estimated monthly out-of-pocket costs.** Monthly out-of-pocket treatment costs were measured using ordinal responses to the following prompt, “Thinking about the time when you were getting cancer treatment, on average, how much did you spend (less than $100, $101-$250, $251-$500, more than $500, don’t know) out of pocket each month on the following? Your best estimate will do:” (1) co-payments and deductibles for drugs, doctor visits and tests; (2) non-prescription/OTC medications; (3) services to help with symptoms and side effects like acupuncture or massage; (4) transportation to and from clinic visits, babysitting; (5) special clothing, wigs, etc. Responses to the five items were averaged and scored as a single variable ranging from 0-20, where higher scores represent higher estimated monthly out-of-pocket costs.

**Difficulty anticipating out-of-pocket treatment costs.** Difficulty anticipating treatment costs, a measure of price transparency, was measured using responses to the following prompt, “How difficulty or easy was it for you to determine the out-of-pocket cost of treatments before you incurred the expense?” Ordinal response options were: (1) very difficult; (2) somewhat difficult; (3) neither difficulty nor easy; (4) somewhat easy; (5) very easy. For analyses, this item was transformed. Categories 1 and 2 were collapsed and a binary variable was created to represent those who found out-of-pocket treatment costs to be somewhat to very difficulty to anticipate (yes/no).

**Ease of understanding insurance coverage.** Understandability of insurance was measured using responses to the prompt, “how difficulty or easy is it for you to understand what your insurance covers for your care” and treated as a continuous variable ranging from 1(very difficult) to 5 (very easy). See Table 2 for frequency distribution of health system factors.
Domain 5: Financial Hardship

Financial stress. Financial stress was measured using a single item, “To what degree has your cancer treatment caused you financial hardship (i.e. difficulty paying your bills)?” Response options included: (1) none; (2) a little; (3) some; (4) a lot; or (5) an extreme amount. For analyses this ordinal variable was treated as a continuous variable where higher scores indicated greater financial stress.

Financial strain. Financial strain, a measure of psychological distress attributed to financial hardship, was measured using a single item, an ordinal measure of the degree of psychological distress attributed to financial hardship. Respondents were asked, “Thinking about a time when you were getting cancer treatment, how distressed (e.g. anxious, extremely upset) were you from thinking about your finances? Response options included: (1) not at all distressed; (2) a little distressed; (3) somewhat distressed; (4) very distressed or (5) extremely distressed. For analyses this ordinal variable was treated as a continuous variable where higher scores indicated greater strain.

Analytic Strategy

The following analyses were conducted by the Principal Investigator using StataIC (version 15.1):

Aim 1

Exploratory factor analysis was conducted to identify the underlying dimensions of cost-coping among the 32 cost-coping items. The items were first tested for factorability using Bartlett’s test of sphericity and Kaiser Meyer-Olkin test (Tabachnick, Fidell, & Ullman, 2007). Then, item distributions were tested for normality, which determined the appropriate extraction method to use with the data. Because distributions were non-normal and some items were binary,
Principle Axis Factor analysis (PAF) was used (Costello & Osborne, 2005). PAF is a common method of exploratory factor analysis that measures correlations across multiple items to identify underlying “factors.” Factors are highly correlated clusters of survey items which represent underlying theoretical concepts or dimensions of a larger theoretical construct. Varimax rotation was then used to minimize cross-loading of variables onto multiple factors, a rotation technique that can be used to produce more distinct factors or dimensions (Tabachnick, Fidell & Ullman, 2007).

**Aim 2**

Analyses conducted in Aim 1 produced working measures of four distinct cost-coping strategies. These measures were used as outcome variables in Aim 2 to predict variation in cost-coping from social, behavioral and health system factors using logistic regression. Predictors for each cost-coping strategy were grouped into five domains for the initial phase of model building: (1) demographics (i.e. age, education, income, race/ethnicity, gender); (2) behavioral characteristics (i.e. patient activation score); (3) health status (i.e. cancer type, time since cancer diagnosis, treatment status, and work reduction due to illness); (4) health system features (i.e. insurance type, difficulty anticipating out-of-pocket treatment cost, ease of understanding insurance coverage, average monthly out-of-pocket costs); and (5) financial stress (i.e. cancer-related difficulty paying bills). Logistic regression was determined to be most readily interpretable statistical method for these data, so each outcome variable (i.e. care-altering, lifestyle-altering, self-advocacy and financial help-seeking) was transformed into a binary variable. Table 1 below presents a frequency table of the transformed binary outcome variables used in Aim 2.
A model predicting each coping strategy (care-altering, lifestyle-altering and self-advocacy) was created for each of the five variable domains listed above. First, each independent variable in the domain was tested in unadjusted models predicting each cost-coping outcome using logistic regression (See Table 4 for independent predictor models). Those found to be marginally significant ($p < .05$) were included in the domain model. Significant predictors in each domain were retained and tested in adjusted models predicting care-altering, lifestyle-altering and self-advocacy coping styles. Predictors that maintained significance in adjusted models ($p < .05$) were included in the final predictive models of each cost-coping strategy.

For the purpose of conducting regression analyses, independent categorical variables with multiple response options were either collapsed into two theoretically meaningful categories (e.g., age was collapsed into two groups: 64 and under; 65 and over; education was collapsed into two groups: high school education or less and some college or more) or transformed into dummy variables where each categorical response was analyzed in the model as a binary variable (e.g. cancer type, time since diagnosis and treatment status). Other ordinal variables were treated as continuous because they could more easily be understood in terms of magnitude and behaved as normally distributed variables. The two variables treated this way were financial stress ($M = 2.43; SD = 1.28$) and monthly out-of-pocket treatment costs ($M = 7.31; SD = 4.84$).

The following analyses were conducted by the Principal Investigator using SPSS Statistics (version 25):

**Aim 3**

In accordance with the Stress Process Model which suggests that coping can mediate or moderate the relationship between stressors and stress outcomes, each coping variable was tested in both possible roles. First, financial stress, strain and the cost-coping strategies were first tested
for normality and transformed to meet assumptions of regression-based mediation and moderation modeling. Then, in three separate analyses, Hayes’ PROCESS method of simple mediation modeling (Hayes, 2012) was used to measure the mediated (direct and indirect) effect of care-altering, lifestyle-altering and self-advocacy on the relationship between financial stress and strain. To identify possible interaction effects between coping and financial stress in predicting financial strain, the PROCESS method of simple moderation modeling was then used on all three coping strategies to test for the significance and magnitude of each as conditional variables (Hayes, 2012).

**Permission and Human Subjects Review**

I acquired written permission from CancerCare to use data from their Cancer Patient Access and Engagement Study for my dissertation, as well as any presentations or publications emanating from it (See Appendix 2).

**Ethical Considerations**

Because survey data were de-identified prior to analysis, CUNY Hunter College’s Human Research Protection Program determined this study to be exempt from Institutional Review Board review. The use of de-identified, existing data for the current study constitutes minimal risk to participants. Procedures for informed consent were conducted by the researchers responsible for data collection and respondents permitted CancerCare to use their de-identified responses for the purposes of ongoing research as part of the informed consent process in the original study. The de-identified data were stored in the Principal Investigator’s password protected computer and all statistical analyses conducted on that computer at Silberman School of Social Work, CUNY Graduate Center, or the PI’s home. Potential benefit to society was
assumed to be much greater than the minimal risk associated with the use of this data for the proposed study.

Table 1

*Cost-coping Binary Outcome Variables*

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>Yes-1</th>
<th>No-0</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often (never, did/do you do each of the following in order to reduce your expenses related to your cancer treatment:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care-altering: (1) postpone or skip medical appointments; (2) postpone or skip follow up testing; (3) postpone or skip bloodwork; (4) postpone or skip filling a prescription; (5) delay or skip complementary treatment; (6) postpone or skip psychological support; (7) skip dosage of prescribed drugs; (8) cut pills in half; (9) choose a lower cost medication; (10) order medication from outside US</td>
<td>409</td>
<td>101</td>
</tr>
<tr>
<td>Self-advocacy: (1) estimate cost before going to ER; (2) estimate cost before agreeing to treatment; (3) appeal a denial of benefit from your insurance company; (4) estimate cost before filling a prescription; (5) find out cost before filling a prescription for side effects/symptoms; (6) review the explanation of benefits from insurance company; (7) ask insurance company for help understanding coverage; (8) find out cost of lab test or scans before agreeing to testing</td>
<td>428</td>
<td>82</td>
</tr>
<tr>
<td>Financial help-seeking: (1) applied for co-payment assistance; (2) applied for financial assistance for non-medical expenses; and (3) applied for financial assistance through provider.</td>
<td>292</td>
<td>218</td>
</tr>
<tr>
<td>Which of the following have you experienced as a result of bills related to your cancer treatment:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifestyle-altering: (1) I borrowed money from family/friends; (2) I missed rent/mortgage payments; (3) I cut back on groceries, transportation, clothing, tuition; (4) I missed paying bills like heat, electricity, phone.</td>
<td>197</td>
<td>313</td>
</tr>
</tbody>
</table>
CHAPTER V. FINDINGS

Sample Characteristics

The sample included 510 respondents ranging in age from 25 to 75 years old and over half the respondents identified as female (64.7%). Most respondents identified their race/ethnicity as White (70.8%), followed by African American (18.6%) and Hispanic (5.9%). The majority of respondents had at least some college education (81.3%) and just over half (59.5%) reported annual incomes under 300% FPL. Most respondents had health insurance through their provider (64.5%) followed by Medicare/Medicaid (54.1%); health insurance percentages total over 100 because categories were not mutually exclusive and some (17.5%) respondents had multiple forms of insurance. The most common form of cancer reported was early breast cancer (22.4%) followed by prostate (10.2%) and colorectal (8.0%). Most respondents had been diagnosed over 4 years ago (44.3%) and had completed treatment (46.5%). See Table 2 for complete sample characteristics.

Table 2

Sample Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>% (N= 510)</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (Years)</td>
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<td></td>
</tr>
<tr>
<td>25-34</td>
<td>13.9</td>
<td>71</td>
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<tr>
<td>35-44</td>
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<td>45-54</td>
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<td>55-64</td>
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<td>65-74</td>
<td>29.6</td>
<td>151</td>
</tr>
<tr>
<td>&gt;75</td>
<td>3.5</td>
<td>18</td>
</tr>
<tr>
<td>Gender</td>
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<td></td>
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<td>Female</td>
<td>64.7</td>
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<td>Male</td>
<td>35.3</td>
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<td>18.6</td>
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<td>Hispanic</td>
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<td>White</td>
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<td>361</td>
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<tr>
<td>Characteristic</td>
<td>% (N= 510)</td>
<td>N</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>------------</td>
<td>----</td>
</tr>
<tr>
<td>Multiracial</td>
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<td>Other</td>
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<td><strong>Education</strong></td>
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<td>Less Than High School</td>
<td>1.4</td>
<td>7</td>
</tr>
<tr>
<td>High School Graduate (Or GED)</td>
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<td>89</td>
</tr>
<tr>
<td>Some College</td>
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<td>Associate’s Degree</td>
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<td>Bachelor’s Degree</td>
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<td>Doctorate/Professional Degree</td>
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<td><strong>Annual Income</strong></td>
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<td>≤150% FPL</td>
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<td>150% - 300% FPL</td>
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<td>300% - 600% FPL</td>
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<td>167</td>
</tr>
<tr>
<td>&gt;600% FPL</td>
<td>6.0</td>
<td>29</td>
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<tr>
<td><strong>Insurance Type</strong>*</td>
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<td></td>
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<td>Private Through Employer</td>
<td>64.5</td>
<td>181</td>
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<td>Private Through Healthcare.Gov</td>
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<td>Medicare/Medicaid</td>
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<td>Private Medigap</td>
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<td>Tricare/Champus</td>
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</tr>
<tr>
<td>Other</td>
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<td>29</td>
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<tr>
<td>Multiple</td>
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<td>89</td>
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<tr>
<td><strong>Cancer Type</strong></td>
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</tr>
<tr>
<td>Bladder</td>
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<td>18</td>
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<tr>
<td>Brain</td>
<td>2.2</td>
<td>11</td>
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<tr>
<td>Breast (Early)</td>
<td>22.4</td>
<td>114</td>
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<tr>
<td>Breast (Metastatic)</td>
<td>6.5</td>
<td>33</td>
</tr>
<tr>
<td>Colon Or Rectal</td>
<td>8.0</td>
<td>41</td>
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<tr>
<td>Endometrial, Cervical, Ovarian</td>
<td>6.7</td>
<td>34</td>
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<tr>
<td>Head / Neck</td>
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<td>Kidney</td>
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<tr>
<td>Pancreatic</td>
<td>2.4</td>
<td>12</td>
</tr>
<tr>
<td>Prostate</td>
<td>10.2</td>
<td>52</td>
</tr>
<tr>
<td>Stomach</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Thyroid</td>
<td>4.9</td>
<td>25</td>
</tr>
<tr>
<td>Other (E.G. Esophageal, Intestinal,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sarcoma/Bone, Sebaceous, Testicular</td>
<td>8.8</td>
<td>45</td>
</tr>
<tr>
<td><strong>Time Since Dx</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Characteristic</td>
<td>% (N= 510)</td>
<td>N</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>------------</td>
<td>----</td>
</tr>
<tr>
<td>&lt;12 Months</td>
<td>14.3</td>
<td>73</td>
</tr>
<tr>
<td>13 Months – 2 Years</td>
<td>20.0</td>
<td>102</td>
</tr>
<tr>
<td>2 – 4 Years</td>
<td>21.4</td>
<td>109</td>
</tr>
<tr>
<td>&gt;4 Years</td>
<td>44.3</td>
<td>226</td>
</tr>
<tr>
<td>Treatment Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In Active Treatment</td>
<td>20.2</td>
<td>103</td>
</tr>
<tr>
<td>Completed Treatment - On Maintenance</td>
<td>31.8</td>
<td>162</td>
</tr>
<tr>
<td>Completed Treatment</td>
<td>46.5</td>
<td>237</td>
</tr>
<tr>
<td>Work Change</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continued Working Fulltime</td>
<td>8.6</td>
<td>44</td>
</tr>
<tr>
<td>Reduced Work Hours</td>
<td>91.4</td>
<td>466</td>
</tr>
</tbody>
</table>

* Totals more than 100% because groups are not mutually exclusive

**Aim 1: Identify measurable characteristics of cost-coping, and delineate working measures of care-altering, lifestyle-altering and self-advocacy coping strategies.**

The 32 items selected for analysis were determined to be highly factorable (Bartlett $p$ <.001, KMO=0.929). The principle axis factor analysis (PAF) with orthogonal varimax rotation resulted in four factors with Eigenvalues over 1.0, accounting for 45%, 29%, 11% and 8% of variance respectively. Examination of scree plot confirmed that a three- or four-factor structure was most appropriate (See Figure 4). For the final cost-coping model, items with the highest factor loadings from each factor were retained to produce an initial 25-item measure of cost-coping (see Table 3 for a summary of the initial 25-item cost-coping measure).

The first three factors were well-aligned with the hypothesized conceptual dimensions of care-altering, lifestyle-altering and self-advocacy cost-coping styles. The fourth factor that emerged was unexpected, but is theoretically viable as it contained three items related to financial help-seeking behavior, including: (1) applied for co-payment assistance; (2) applied for financial assistance for non-medical expenses; and (3) applied for financial assistance through provider. This factor was then tested as a coping strategy labeled Factor 4 “financial help-seeking” in Aims 2 and 3, findings are outlined below.
Factor 1 was well-aligned with the concept of care-altering, the 10 items with factor loadings over 0.65 retained for this dimension include “how often (never, rarely, sometimes, often or always) did/do you do each of the following in order to reduce your expenses related to your cancer treatment: (1) postpone or skip medical appointments; (2) postpone or skip follow up testing; (3) postpone or skip bloodwork; (4) postpone or skip filling a prescription; (5) delay or skip complementary treatment; (6) postpone or skip psychological support; (7) skip dosage of prescribed drugs; (8) cut pills in half; (9) choose a lower cost medication; (10) order medication from outside US?”

In Factor 2, items with factor loadings over 0.59 were retained. These 8 items were fairly well-aligned with the hypothesized cost-coping dimension of self-advocacy. The items retained for the self-advocacy domain include, “how often (never, rarely, sometimes, often, or always) did/do you do each of the following…(1) estimate cost before going to ER; (2) estimate cost before agreeing to treatment; (3) appeal a denial of benefit from your insurance company; (4) estimate cost before filling a prescription; (5) find out cost before filling a prescription for side effects/symptoms; (6) review the explanation of benefits from insurance company; (7) ask insurance company for help understanding coverage; (8) find out cost of lab test or scans before agreeing to testing.”

In Factor 3, items with factor loadings over 0.5 were retained. These 4 items were conceptually well-aligned with the hypothesized cost-coping dimension of lifestyle-altering. The 4 items retained for the lifestyle-altering domain include “which of the following have you experienced as a result of bills related to your cancer treatment (yes or no)… (1) I borrowed money from family/friends; (2) I missed rent/mortgage payments; (3) I cut back on groceries, transportation, clothing, tuition; (4) I missed paying bills like heat, electricity, phone.”
Aim 2: Identify behavioral, social and health system factors that predict variations in coping.

The purpose of this analysis was to identify significant predictors of variations in cost-coping identified in Aim 1: care-altering, lifestyle-altering, self-advocacy, and financial help-seeking. Special emphasis was placed on behavioral characteristics, social factors, and features of the healthcare system. Independent predictors were similar across coping styles and variables from every domain were significantly associated with each outcome. A full summary of the independent predictors of each outcome are presented in Table 4.
Table 3

*Cost-coping Survey Items by Dimension*

<table>
<thead>
<tr>
<th>Cost-Coping Survey Items by Dimension</th>
<th>Factor</th>
<th>Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often (never, rarely, sometimes, often or always) did/do you do each of the following in order to reduce your expenses related to your cancer treatment:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(1) postpone or skip medical appointments</td>
<td>1</td>
<td>0.84</td>
</tr>
<tr>
<td>(2) postpone or skip follow up testing</td>
<td>1</td>
<td>0.85</td>
</tr>
<tr>
<td>(3) postpone or skip bloodwork</td>
<td>1</td>
<td>0.83</td>
</tr>
<tr>
<td>(4) postpone or skip filling a prescription</td>
<td>1</td>
<td>0.85</td>
</tr>
<tr>
<td>(5) delay or skip complementary treatment</td>
<td>1</td>
<td>0.70</td>
</tr>
<tr>
<td>(6) postpone or skip psychological support</td>
<td>1</td>
<td>0.75</td>
</tr>
<tr>
<td>(7) skip dosage of prescribed drugs</td>
<td>1</td>
<td>0.87</td>
</tr>
<tr>
<td>(8) cut pills in half</td>
<td>1</td>
<td>0.75</td>
</tr>
<tr>
<td>(9) choose a lower cost medication</td>
<td>1</td>
<td>0.82</td>
</tr>
<tr>
<td>(10) order medication from outside US</td>
<td>1</td>
<td>0.68</td>
</tr>
<tr>
<td>(11) estimate cost before going to ER</td>
<td>2</td>
<td>0.75</td>
</tr>
<tr>
<td>(12) estimate cost before agreeing to treatment</td>
<td>2</td>
<td>0.79</td>
</tr>
<tr>
<td>(13) appeal a denial of benefit from you insurance company</td>
<td>2</td>
<td>0.54</td>
</tr>
<tr>
<td>(14) estimate cost before filling a prescription</td>
<td>2</td>
<td>0.84</td>
</tr>
<tr>
<td>(15) find out cost before filling a prescription for side effects/symptoms</td>
<td>2</td>
<td>0.81</td>
</tr>
<tr>
<td>(16) review the explanation of benefits from insurance company</td>
<td>2</td>
<td>0.58</td>
</tr>
<tr>
<td>(17) ask insurance company for help understanding coverage</td>
<td>2</td>
<td>0.64</td>
</tr>
<tr>
<td>(18) find out cost of lab test or scans before agreeing to testing</td>
<td>2</td>
<td>0.81</td>
</tr>
<tr>
<td>(19) applied for co-payment assistance;</td>
<td>4</td>
<td>0.51</td>
</tr>
<tr>
<td>(20) applied for financial assistance for non-medical expenses</td>
<td>4</td>
<td>0.56</td>
</tr>
<tr>
<td>(21) applied for financial assistance through provider</td>
<td>4</td>
<td>0.56</td>
</tr>
<tr>
<td>Cost-Coping Survey Items by Dimension</td>
<td>Factor</td>
<td>Factor Loading</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>--------</td>
<td>---------------</td>
</tr>
<tr>
<td>Which of the following have you experienced as a result of bills related to your cancer treatment (yes/no):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(22) I borrowed money from family/friends</td>
<td>3</td>
<td>0.55</td>
</tr>
<tr>
<td>(23) I missed rent/mortgage payments</td>
<td>3</td>
<td>0.60</td>
</tr>
<tr>
<td>(24) I cut back on groceries, transportation, clothing, tuition</td>
<td>3</td>
<td>0.51</td>
</tr>
<tr>
<td>(25) I missed paying bills like heat, electricity, phone</td>
<td>3</td>
<td>0.70</td>
</tr>
</tbody>
</table>

Predictors of Care-Altering

Of 510 respondents, 123 (24%) reported that they had *never* engaged in any of the 10 care-altering behaviors identified for this study, and another 218 (43%) reported that this question was *not applicable* to their situation. The remaining 169 respondents (33%) reported engaging in some form of this behavior at least once.

**Demographics.** When all independently significant demographic factors were accounted for in a single model only age and income emerged as significant predictors of care-altering. Specifically, individuals under 65 years old had twice the odds of those over to 65 to report care-altering behavior, and individuals in the >150% FPL and 150%-300% FPL income brackets had 3.2 and 2.7 times the odds of those in the >600% FPL bracket respectively.

**Behavioral.** In unadjusted models, patient activation emerged as a significant predictor, where lower activation scores were associated with care-altering behavior. Such that every unit decrease in activation produced a 5% increase in the odds of care-altering.

**Health status.** Treatment status emerged as a significant predictor in the adjusted model of the health status domain. Individuals in active and maintenance treatment for cancer had twice the odds of those post-treatment to report care-altering.
Health system factors. In the adjusted model of health system factors, high monthly out of pocket medical costs, difficulty anticipating out-of-pocket costs and ease of understanding insurance coverage emerged as a significant predictor of care-altering. Specifically, for every unit increase in out-of-pocket costs there was a 13% increase in the odds of care-altering, those who found it difficult to anticipate the out-of-pocket costs of treatments had twice the odds of those who found it easy to anticipate, and for every unit increase in ease of understanding insurance coverage there was a 30% reduction in odds of care-altering.

Financial stress. Higher levels of financial stress were associated with care-altering such that every unit increase in perception of financial stress produced a twofold increase in the odds of care-altering.

Predictors of care-altering: final model. When all of the significant predictors from each domain were accounted for in the final model, monthly out-of-pocket costs ($OR = 1.09, p < .05$), ease of understanding insurance coverage ($OR = 0.73, p < .05$) and financial stress ($OR = 1.76, p < .001$) significantly predicted care-altering behavior. The final model is presented in Table 5. When accounting for other relevant variables, every unit increase in perception that insurance coverage is easy to understand produced a 27% reduction in odds of care-altering, while every unit increase in financial stress almost doubled the likelihood of care-altering. Final model of care-altering outlined in Table 6.

Predictors of Self-advocacy

Of 510 respondents, 82 (16%) reported that they never engaged in any form of self-advocacy identified in this study. The remaining 428 (84%) engaged in self-advocacy at least once. On a scale of 8-40, where 40 represents maximum engagement in self-advocacy, the
average score was 17.8, indicating that although most of the respondents self-advocated on occasion, most did not rely on self-advocacy intensively.

**Demographics.** Of the demographic variables, only age was significantly associated with self-advocacy behavior such that individuals under 65 years old had 2.6 times the odds of engaging in self-advocacy.

**Behavioral.** Patient activation was not significantly associated with self-advocacy.

**Health status.** After accounting for all the significant health status variables, in the adjusted domain model only cancer type was a significant predictor of self-advocacy. Specifically, individuals with thyroid cancer had 61% lower odds of engaging in self-advocacy compared to individuals with other cancer types.

**Health system factors.** After accounting for all significant health system factors, high monthly out-of-pocket medical costs and difficulty anticipating out-of-pocket treatment costs were significantly associated with self-advocacy. For every unit increase in monthly out-of-pocket costs there was a 30% increase in the odds of self-advocacy. Individuals who reported difficulty anticipating out-of-pocket costs of treatment had 12 times the odds of engaging in self-advocacy than those who did not perceive such difficulty.

**Financial stress.** Higher financial stress significantly predicted self-advocacy behavior such that every unit increase in financial stress increased the odds of self-advocacy 2.5 times.

**Predictors of self-advocacy: final model.** In the fully adjusted model, cancer type, monthly out-of-pocket costs, difficulty anticipating out-of-pocket treatment costs, and financial stress predicted self-advocacy behavior. Specifically people with thyroid cancer had 89% lower odds than individuals with other cancer types to engage in self-advocacy ($OR = 0.21, p < .01$).
### Table 4

**Independent Predictors of Coping Strategy**

<table>
<thead>
<tr>
<th></th>
<th>Care-altering (n=292)</th>
<th>Self-advocacy (n=510)</th>
<th>Lifestyle-altering (n=510)</th>
<th>Financial help-seeking (n=510)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%/M (SD)</td>
<td>OR</td>
<td>SE</td>
<td>CI</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under age 65</td>
<td>33%</td>
<td>2.32</td>
<td>0.49</td>
<td>1.53 - 3.52</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥BA/BS</td>
<td>48%</td>
<td>0.85</td>
<td>0.18</td>
<td>0.57 - 1.28</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>64%</td>
<td>1.07</td>
<td>0.23</td>
<td>0.71 - 1.64</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤150%</td>
<td>25%</td>
<td>2.77</td>
<td>1.21</td>
<td>1.17 - 6.54</td>
</tr>
<tr>
<td>150-300</td>
<td>34%</td>
<td>2.60</td>
<td>1.10</td>
<td>1.14 - 5.95</td>
</tr>
<tr>
<td>300-600</td>
<td>35%</td>
<td>1.80</td>
<td>0.75</td>
<td>0.80 - 4.06</td>
</tr>
<tr>
<td>(≥600)</td>
<td>6%</td>
<td>1.00</td>
<td>0.23</td>
<td>0.63 - 1.61</td>
</tr>
<tr>
<td><strong>Race / Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>18%</td>
<td>2.06</td>
<td>0.64</td>
<td>1.12 - 3.79</td>
</tr>
<tr>
<td>Asian</td>
<td>2%</td>
<td>1.74</td>
<td>1.87</td>
<td>0.19 - 4.78</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>6%</td>
<td>3.00</td>
<td>1.85</td>
<td>0.89 -</td>
</tr>
<tr>
<td>White</td>
<td>71%</td>
<td>0.45</td>
<td>0.12</td>
<td>0.27 - 0.74</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Health Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>First diagnosed</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 12 months</td>
<td>14%</td>
<td>1.23</td>
<td>0.39</td>
<td>0.69 - 2.33</td>
</tr>
<tr>
<td>13m – 2 years</td>
<td>20%</td>
<td>1.19</td>
<td>0.32</td>
<td>0.71 - 2.02</td>
</tr>
<tr>
<td>2-4 years</td>
<td>21%</td>
<td>1.79</td>
<td>0.51</td>
<td>1.03 - 3.12</td>
</tr>
<tr>
<td>≥4 years</td>
<td>44%</td>
<td>0.55</td>
<td>0.11</td>
<td>0.37 - 0.84</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Reduced work hours</strong></td>
<td>9%</td>
<td>9.05</td>
<td>9.22</td>
<td>1.23 - 66.65</td>
</tr>
<tr>
<td><strong>Treatment status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td>20%</td>
<td>1.64</td>
<td>0.46</td>
<td>0.94 - 2.86</td>
</tr>
<tr>
<td>Maintenance</td>
<td>32%</td>
<td>1.55</td>
<td>0.35</td>
<td>0.96 - 2.40</td>
</tr>
<tr>
<td>Post</td>
<td>47%</td>
<td>0.52</td>
<td>0.11</td>
<td>0.35 - 0.79</td>
</tr>
<tr>
<td><strong>Cancer type</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bladder</td>
<td>4%</td>
<td>1.24</td>
<td>0.80</td>
<td>0.18 - 1.28</td>
</tr>
<tr>
<td>Brain</td>
<td>2%</td>
<td>1.44</td>
<td>1.13</td>
<td>0.31 - 6.76</td>
</tr>
<tr>
<td>Breast (early)</td>
<td>22%</td>
<td>0.65</td>
<td>0.15</td>
<td>0.41 - 1.02</td>
</tr>
<tr>
<td>Health System Factors</td>
<td>Care-altering (n=292)</td>
<td>Self-advocacy (n=510)</td>
<td>Lifestyle-altering (n=510)</td>
<td>Financial help-seeking (n=510)</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------------</td>
<td>-----------------------</td>
<td>------------------------</td>
<td>----------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Insurance Type</td>
<td>OR</td>
<td>SE</td>
<td>CI</td>
<td>OR</td>
</tr>
<tr>
<td>Breast (meta)</td>
<td>7%</td>
<td>1.85</td>
<td>1.00</td>
<td>0.59 - 3.63</td>
</tr>
<tr>
<td>Colorectal</td>
<td>8%</td>
<td>1.34</td>
<td>0.55</td>
<td>0.62 - 2.98</td>
</tr>
<tr>
<td>Female repro</td>
<td>7%</td>
<td>1.46</td>
<td>0.73</td>
<td>0.31 - 1.04</td>
</tr>
<tr>
<td>Leukemia</td>
<td>5%</td>
<td>3.65</td>
<td>2.72</td>
<td>0.85 -</td>
</tr>
<tr>
<td>Prostate</td>
<td>10%</td>
<td>0.56</td>
<td>0.17</td>
<td>0.30 - 1.04</td>
</tr>
<tr>
<td>Thyroid</td>
<td>5%</td>
<td>2.95</td>
<td>2.20</td>
<td>0.57 - 5.07</td>
</tr>
<tr>
<td>Monthly out-of-pocket health costs (0-20)</td>
<td>7.3 (4.8)</td>
<td>1.15</td>
<td>0.03</td>
<td>1.09 - 1.21</td>
</tr>
<tr>
<td>Easy to understand insurance coverage (1-5)</td>
<td>3.5 (1.1)</td>
<td>0.61</td>
<td>0.07</td>
<td>0.50 - 0.76</td>
</tr>
<tr>
<td>Difficult to anticipate OOP cost of treatment</td>
<td>26.3</td>
<td>2.93</td>
<td>0.85</td>
<td>1.66 - 5.18</td>
</tr>
</tbody>
</table>

Financial Stress

| Financial stress [1-5]  | 2.4 (1.3) | 2.10 | 0.22 | 1.71 - 2.58 | 2.49 | 0.35 | 1.89 - 3.27 | 3.26 | 0.35 | 2.65 - 4.02 | 2.10 | 0.18 | 1.78 - 2.49 |

Behavioral

| PAM [0-40] | 32.4 | 0.95 | 0.02 | 0.91 - 0.99 | 0.96 | 0.02 | 0.90 - 1.00 | 0.96 | 0.02 | 0.93 - 0.99 | 0.93 | 0.02 | 0.91 - 0.97 |
Every unit increase in monthly out-of-pocket costs \((OR = 1.27, p < .001)\), and financial stress \((OR = 1.89, p < .001)\) increased the odds of self-advocacy by 27% and 89% respectively. People who found in difficult to anticipate the out-of-pocket costs of their treatment had 12 times the odds of engaging in self-advocacy \((OR = 12.10, p < .001)\). The final model is presented in Table 5.

**Predictors of Lifestyle-Altering**

Of 510 respondents, the majority (61.4%, \(n=313\)) did not report having engaged in lifestyle-altering activities in response to cancer treatment costs. Another 25% (\(n=125\)) reported at least one lifestyle-altering event, while 19 individuals endured all four major lifestyle-altering events.

**Demographics.** Among demographic variables, age, gender, race/ethnicity, and household income emerged as significant predictors of lifestyle-altering in independent and adjusted domain models. Individuals under 65 years old had 3.7 times the odds of lifestyle-altering than older adults, women had 1.9 times the odds of men, people in the <150% FPL income bracket had twice the odds of those in the highest income bracket to engage in care-altering. People identifying as White had 60% lower odds than non-White respondents of experiencing lifestyle-altering.

**Behavioral.** Lower patient activation level was marginally associated with lifestyle altering in independent models such that every unit increase in activation reduced the odds of lifestyle-altering by 5%.

**Health status.** After accounting for all significant predictors of lifestyle-altering in the health status domain, employment changes and cancer type remained significant. Individuals who reported reduced work hours during treatment had 3.3 times the odds of experiencing
lifestyle-altering. People with cancers of the female reproductive system had 2.4 times the odds and individuals with prostate cancer had 60% lower odds of experiencing lifestyle-altering.

**Health system factors.** Among factors related to the health system, insurance coverage, monthly out-of-pocket costs, and difficulty anticipating treatment costs were significantly associated with lifestyle-altering in the domain adjusted model. Having multiple forms of insurance reduced the odds of lifestyle-altering by 53%, while every unit increase in monthly out-of-pocket costs increased lifestyle-altering by 10%. Individuals who found it difficulty to anticipate treatment costs had 2.6 times the odds of lifestyle-altering.

**Financial stress.** For every unit increase in reported financial stress the odds of lifestyle-altering increased 3.3 times.

**Predictors of lifestyle-altering: final model.** In the final adjusted model, gender, race/ethnicity, financial stress and difficulty anticipating treatment costs were significant predictors of lifestyle-altering. Women had twice the odds of men ($OR = 2.00, p < .01$), and White people had half the odds of those identifying as another race/ethnicity ($OR = 0.50, p < .05$) of lifestyle-altering in response to treatment costs. Those who found it difficult to anticipate treatment costs had almost twice the odds of lifestyle altering than those who did not ($OR = 1.85, p < .05$), and every unit increase in financial stress increased the odds of lifestyle-altering threefold ($OR = 2.90, p < .001$). The final model is presented in Table 5.

**Predictors of Financial Help-Seeking Behavior**

Of 510 respondents, 218 had *never* engaged in financial help-seeking, while another 87 felt that this question was *not applicable* to their experience. The remaining 203 individuals (39.8%) engaged in some form of financial help-seeking activity at least once.
**Demographics.** In the domain adjusted demographics model only age and ethnicity were significantly associated with financial help-seeking. Individuals under 65 had almost three times the odds of engaging in financial help-seeking than those over 65 and individuals identifying as white had 58% lower odds of financial help-seeking.

**Health status.** Among variables related to health status, employment changes and cancer type were significantly associated with financial help-seeking. Individuals who experienced reduced work hours had nearly six times the odds of seeking out financial assistance and individuals with prostate cancer had nearly half the odds of those with other cancers.

**Behavioral.** Higher patient activation scores increased the odds of financial help-seeking such that unit increase in patient activation score odds of financial help seeking decreased the odds of financial help-seeking by 6%.

**Health system factors.** Among health system factors understandability of insurance coverage and monthly out-of-pocket treatment costs were associated with financial help-seeking. For every unit increase in understandability of insurance coverage odds of financial help-seeking decreased by 19%. Similarly for every unit increase in monthly out-of-pocket costs the odds of financial help-seeking increased by 20%.

**Financial stress.** Financial stress was significantly associated with financial help-seeking behavior such that every unit increase in difficulty paying bills due to cancer doubled the odds of financial help seeking.

**Predictors of financial help-seeking: final model.** In the fully adjusted model of all five domains, financial help-seeking was significantly predicted by age, patient activation score, financial stress and high monthly out-of-pocket treatment costs. Individuals under 65 years old were almost twice as likely to engage in financial help-seeking ($OR = 1.63, p < .001$), and for
every unit increase in patient activation the odds of financial help-seeking decreased by 5% (OR = 0.95, p <.05). For every unit increase in financial stress the odds of financial help-seeking nearly doubled (OR = 1.57, p <.001) and for every unit increase in monthly out-of-pocket medical costs the odds of financial help-seeking increased 10% (OR = 1.10, p <.001). The final model of financial help-seeking is presented in Table 5.

Table 5

Final Models Predicting Each Cost-coping Strategy

<table>
<thead>
<tr>
<th>Predictors of Care-Altering: Final Model</th>
<th>OR</th>
<th>SE</th>
<th>95% Confidence Interval</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monthly OOP [0-20]</td>
<td>1.09</td>
<td>0.04</td>
<td>1.06 - 1.22</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Financial stress [1-5]</td>
<td>1.73</td>
<td>0.22</td>
<td>1.40 - 2.22</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Ease of understanding insurance [1-5]</td>
<td>0.73</td>
<td>0.09</td>
<td>0.57 - 0.92</td>
<td>&lt;.01</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Predictors of Self-Advocacy: Final Model</th>
<th>OR</th>
<th>SE</th>
<th>95% Confidence Interval</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monthly OOP [0-20]</td>
<td>1.27</td>
<td>0.06</td>
<td>1.16 - 1.34</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Difficult to anticipate tx cost</td>
<td>12.09</td>
<td>8.51</td>
<td>2.83 – 51.60</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Financial stress [1-5]</td>
<td>1.89</td>
<td>0.31</td>
<td>1.37 - 2.47</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Thyroid cancer</td>
<td>0.21</td>
<td>0.12</td>
<td>0.07 - 0.67</td>
<td>&lt;.01</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Predictors of Lifestyle-Altering: Final Model</th>
<th>OR</th>
<th>SE</th>
<th>95% Confidence Interval</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (female)</td>
<td>2.00</td>
<td>0.53</td>
<td>1.32 - 3.48</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Race/Ethnicity (White)</td>
<td>0.50</td>
<td>0.14</td>
<td>0.29 - 0.86</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Difficult to anticipate tx cost</td>
<td>1.85</td>
<td>0.51</td>
<td>1.07 – 3.15</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Financial stress [1-5]</td>
<td>2.90</td>
<td>0.37</td>
<td>2.49 - 3.85</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Predictors of Financial Help-Seeking: Final Model</th>
<th>OR</th>
<th>SE</th>
<th>95% Confidence Interval</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (under 65)</td>
<td>1.63</td>
<td>0.37</td>
<td>1.17-2.99</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Patient Activation Score</td>
<td>0.95</td>
<td>0.02</td>
<td>0.91-0.99</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Financial stress [1-5]</td>
<td>1.67</td>
<td>0.16</td>
<td>1.38-2.03</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Monthly OOP [0-20]</td>
<td>1.10</td>
<td>0.03</td>
<td>1.07-1.20</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

*Categorical dummy variable compared to members of all other categories;
▲Binary variable compared to null option;
OOP refers to out-of-pocket costs
Aim 3: Analyze quantitative survey data to measure the extent to which each cost coping strategy mediates and/or moderates the relationship between financial stress and strain.

**Correlations.** Highly significant, positive correlations were found between financial stress and strain ($r = 0.63$, $p < .001$), financial stress and care-altering ($r = 0.56$, $p < .001$), financial stress and lifestyle-altering ($r = 0.59$, $p < .001$), and financial stress and self-advocacy ($r = 0.49$, $p < .001$). Similarly significant correlations were found between financial strain and care-altering ($r = 0.43$, $p < .001$), financial strain and lifestyle-altering ($r = 0.47$, $p < .001$), and financial strain and self-advocacy ($r = 0.39$, $p < .001$).

In order to test the overall fit of the hypothesized mediation and moderation models Hayes’ PROCESS method (specifically Models 1 and 4) was employed. First, variables were tested for normality and transformed to meet assumptions of linear regression. The distributions of each of the three coping variables were found to be zero-inflated. As such, the null responses in care-altering, lifestyle-altering and self-advocacy were dropped from analyses in order to comply with the assumption of normality required for regression-based analyses. Removing the null responses did not significantly reduce statistical power, and it also made more sense conceptually to measure the extent of mediation and moderation using responses that affirmed some cost-coping behavior. Descriptions of each variable are presented in Table 6.

**Mediation.** Simple mediation models using the PROCESS method (Model 4) were implemented testing care-altering, lifestyle-altering, self-advocacy and financial help-seeking coping strategies as independent mediators of financial stress’ impact on financial strain. Model results indicated the presence of a significant mediating effect for lifestyle-altering only ($p < .05$). The $a$ path was significant, such that financial stress was positively associated with lifestyle-altering ($B = 0.43$, $p < .001$). As were the $c$ ($B = 0.54$, $p < .01$) and $c’$ ($B = 0.46$, $p < .01$)
paths which show the total and direct effect of stress on strain. Lifestyle-altering accounted for a small but significant indirect effect of stress on strain ($B = 0.08, p < .05$). This finding suggests that financial stress may increase strain via lifestyle-altering. See Figure 5.

Table 6

*Descriptive Summary of Variables Tested for Mediation/Moderation*

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Range</th>
<th>M</th>
<th>(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial Stress</td>
<td>510</td>
<td>[1-5]</td>
<td>2.43</td>
<td>1.28</td>
</tr>
<tr>
<td>Financial Strain</td>
<td>510</td>
<td>[1-5]</td>
<td>2.53</td>
<td>1.26</td>
</tr>
<tr>
<td>Lifestyle-altering#</td>
<td>197</td>
<td>[1-4]</td>
<td>1.69</td>
<td>1.02</td>
</tr>
<tr>
<td>Financial help-seeking#</td>
<td>205</td>
<td>[4-15]</td>
<td>8.54</td>
<td>3.11</td>
</tr>
</tbody>
</table>

#Null responses removed

**Moderation.** Moderation models using the PROCESS method (Model 1) to identify the presence of significant and independent interaction effects between financial stress and each of the constructs of interest, care-altering, lifestyle-altering and self-advocacy coping styles respectively. Results indicated that only self-advocacy yielded a significant interaction effect with financial stress in predicting financial strain. The main effect of self-advocacy on financial strain was significant and positive ($B = .05, p < .05$), while the interaction effect of self-advocacy and financial stress was significant and negative ($B = -.01, p < .01$). Suggesting that self-advocacy may dampen the effect of financial stress on strain. See Figure 6.
Figure 5. Simple mediation model with lifestyle-altering as mediator

Figure 6. Relationship between stress and strain moderated by self-advocacy
Post-Hoc Analyses

While completing the analyses, an issue emerged that called for post-hoc analyses. In Aim 2, financial stress was a significant independent predictor of all coping outcomes. When financial stress was added to the final models, relationships between variables from other domains and the outcome variables were either diminished or rendered inert across all four coping outcomes. Financial stress is a powerful downstream indicator of all four coping strategies and it could be a clinically useful measure. In order to hone in on more upstream determinants of financial toxicity post-hoc analyses were conducted to model significant predictors of financial stress.

Post-hoc Analysis Methods

The same methods of modeling the cost-coping outcomes in outlined Aim 2 were used to model significant predictors of financial stress. I determined that logistic regression would yield the most readily interpretable results for this research question. As such, the outcome variable, financial stress, was modified from an ordinal (1-5) to a binary variable (0-1). The ordinal financial stress measure was recoded in such a way that responses to the question “To what degree has your cancer treatment caused you financial hardship (i.e. difficulty paying your bills)?” were coded as “1” if the response was “a little,” “some,” “a lot,” or “an extreme amount” and coded as “0” if the response was “none.” Step-wise logistic regression was then performed using the variables from four predictor domains – (1) demographics; (2) behavioral; (3) health status; and (4) health system factors. Each predictor domain was modeled with the binary financial stress outcome to identify significant predictors from each domain. The significant predictors from each domain were reserved and tested in a final, multi-domain model of financial stress.
**Post-hoc Analysis Findings: Predictors of Financial Stress**

**Demographics.** Age, income, and race/ethnicity were significant predictors of financial stress in the adjusted domain model. Individuals under 65 years old were nearly six times more likely than those over 65 to experience financial stress, individuals in the <150% FPL and 150%-300% FPL income brackets were 2.9 and 2.2 times more likely to report financial stress than those in the >600%FPL bracket. White respondents were half as likely as non-White respondents to report financial stress.

**Behavioral.** Activation scores were independently associated with financial stress, for every unit increase in activation score the odds of financial stress decreased by 5%.

**Health status.** Among health status variables, employment change, cancer type and time since diagnosis emerged as significant predictors of financial stress both independently and in adjusted domain models. Individuals with reduced work hours were seven times more likely to report financial stress than those who did not work less, those diagnosed in the last 12 months were two times more likely to experience financial stress than those diagnosed more than 12 months ago, and those with early breast cancer and prostate cancer had approximately half the the odds of those with other cancer types.

**Health system factors.** Among health system factors, monthly out of pocket costs, insurance type, ease of understanding insurance and difficulty anticipating out-of-pocket costs were significantly associated with financial stress in the adjusted domain model. Specifically, every unit increase in monthly OOP costs increased the odds of financial stress by 25%; having a plan purchased on the Affordable Care Act marketplace increased the odds of financial stress 2.3 times; difficulty anticipating treatment costs increased the odds of financial stress 2.5 times; and ease of understanding insurance coverage decreased the odds of stress by 23%.
Table 7

**Predictors of Financial Stress**

<table>
<thead>
<tr>
<th>Predictors</th>
<th>OR</th>
<th>SE</th>
<th>95% Confidence</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>▲ Age (under 65)</td>
<td>3.15</td>
<td>0.86</td>
<td>2.05 - 5.57</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>* Race/Ethnicity</td>
<td>0.44</td>
<td>0.12</td>
<td>0.26 - 0.77</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Income (&gt;(600% FPL)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;150% FPL</td>
<td>5.18</td>
<td>1.90</td>
<td>2.52 - 10.65</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>150% - 300% FPL</td>
<td>2.69</td>
<td>0.87</td>
<td>1.42 - 5.06</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>▲ Reduced work hours</td>
<td>4.21</td>
<td>2.57</td>
<td>1.28 - 13.90</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>* Diagnosed in last 12 months</td>
<td>2.09</td>
<td>0.71</td>
<td>1.07 - 4.07</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Monthly OOP [0-20]</td>
<td>1.21</td>
<td>0.04</td>
<td>1.10 - 1.24</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Ease of understanding insurance coverage</td>
<td>0.76</td>
<td>0.08</td>
<td>0.57 - 0.89</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>▲ Difficult to anticipate OOP cost of</td>
<td>1.90</td>
<td>0.48</td>
<td>1.01 - 3.01</td>
<td>&lt;.05</td>
</tr>
</tbody>
</table>

* Categorical dummy variable compared to members of all other categories
▲ Binary variable compared to null option

**Predictors of financial stress: final model.** In the final adjusted model, age, income, race/ethnicity, reduced work hours, monthly out-of-pocket medical costs, time since diagnosis, difficulty anticipating out-of-pocket treatment costs and ability to understand insurance coverage predicted financial stress. Specifically, those under 65 years old were three times more likely to report financial stress than those over 65 (OR = 3.15, p < .001). White respondents were half as likely as non-Whites (OR = 0.44, p < .001) to report stress, and those with annual household incomes <150% FPL (OR = 5.18, p < .001) and 150%-300% FPL (OR = 2.69, p < .001) were five and three times more likely to report financial stress than those in the >600% FPL bracket.

People who reduced work hours were four times more likely to report financial stress than those who had not reduced work hours (OR = 4.21, p < .05). Individuals diagnosed in the last 12 months had twice the odds of those diagnosed more than 12 months ago (OR = 2.09, p < .05). For every unit increase in monthly out-of-pocket costs, the odds of financial stress increased by 20% (OR = 1.20, p < .001). Those who found it difficult to anticipate out-of-pocket treatment costs
were almost twice as likely to report financial stress \((OR = 1.89, p < .05)\). For every unit increase in ease of understanding insurance coverage the odds of financial stress decreased by 23\% \((OR = 0.77, p < .05)\). The final model predicting financial stress is presented in Table 7.
CHAPTER VI. DISCUSSION

The overall goal of this dissertation is to advance knowledge of the coping strategies that insured cancer patients and survivors use to balance the financial needs of their household with the direct and indirect costs of having cancer. This exploratory study aimed to develop a model of financial hardship and coping that can be used to identify modifiable behavioral and social factors associated with successful coping (i.e. coping that reduces psychological distress). In doing so, we hoped to generate testable hypotheses on social and psychological aspects of cost-coping, and contributes to the theoretical knowledge of financial hardship as a social determinant of health. This section offers interpretations of the study findings and possible future directions in light of the current literature on financial toxicity and the methodological limitations of the study. suggest that the goals and aims were effectively achieved.

Exploratory factor analysis revealed a four factor solution for items related to cost-coping in a survey of cancer patients and survivors. Each factor aligned to a hypothesized problem-focused coping strategy and were given the following concept labels: care-altering, lifestyle-altering, self-advocacy and financial help-seeking. Two of these factors identified were well-aligned with measures of lifestyle-altering and care-altering used in past studies (Nipp et al., 2016; Zullig et al., 2013). The first dimension identified in the factor analysis comprised ten items that are highly consistent with the unvalidated survey items used to measure care-altering in a study conducted by Nipp and colleagues (2016). The second cost-coping strategy identified, lifestyle altering, was narrowed down to four items – (1) borrowing money from friends and family, (2) missing rent/mortgage payments, (3) missing essential utility payments, and (4) cutting back spending on groceries, transportation, clothing and/or tuition. Despite minor differences, this categorization is well-aligned with the unvalidated measures of lifestyle-altering
used in external studies (Nipp et al., 2016; Zullig et al., 2013). Additionally, two factors emerged that have not yet been explicitly measured in the context of cancer financial toxicity: self-advocacy and financial help-seeking.

The third cost-coping strategy consisted of eight survey items that are best described using the term *financial self-advocacy*, but specifically measure the actions people took to prepare for medical costs before agreeing to a treatment. These items reflect a certain level of knowledge about how the fee-for-service health care system operates. Although self-advocacy has been promoted as a necessary skill for cancer patients and survivors (Hagan & Donovan, 2013; Walsh-Burke & Marcusen, 1999), it has not been well-studied in relation to cancer-related financial behaviors and responses to financial hardship.

The fourth dimension of cost-coping emerged unexpectedly. It contained three items related to asking for financial and copayment assistance from treatment providers and non-profit organizations which seemed to describe *financial help-seeking*. There is very little empirical research on financial help-seeking and the role of financial assistance programs in reducing financial stress and toxicity. The proportion of cancer patients in the general population seeking financial assistance is uncertain, however nearly 40% of the respondents in this relatively study reported reaching out to various patient financial assistance programs for help with their medical bills. The limited number of studies in this area suggest a lack of transparency and consistency in patient financial assistance programs (Zafar, Peppercorn, Asabere, & Bastian, 2017), and the possibility that they increase overall drug costs and reinforce existing cancer health disparities (Zafar & Peppercorn, 2017; Zullig, Wolf, Vlastelica, Shankaran, & Zafar, 2017). More research should be conducted on this important, heavily relied upon aspect of the cancer support network.
Together, these findings suggest that there are at least four distinct behavioral responses to financial stress in cancer, however further research is needed to validate this measure and the underlying concepts. Past studies on financial toxicity have largely emphasized two cost-coping strategies: care-altering and lifestyle-altering (Nipp et al., 2016; Zullig et al., 2013). Findings from this study lend empirical support to the unvalidated measures of care-altering and lifestyle-altering used in those studies. Findings from this study go on to suggest two additional cost-coping behaviors: self-advocacy and financial help-seeking. There is little research on these two coping strategies in the literature on financial toxicity in cancer and more should be conducted to understand their role in containing or proliferating financial toxicity.

These four coping strategies were found to vary somewhat by social, behavioral and health system factors, but seemed to have more commonalities than differences. Findings shed light on a number of common predictors of cost-coping. Financial stress, measured here as “difficulty paying one’s bills due to cancer,” was a strong predictor of all four strategies. High monthly out-of-pocket costs, difficulty anticipating out-of-pocket treatment costs or understanding what was covered by one’s health insurance were also important predictors. Financial stress was such a strong common predictor that post hoc analyses were conducted to identify factors associated with financial stress. These were found to be age (being younger than 65), race/ethnicity (identifying as non-White), income (annual household income ≤ 300% FPL), reducing work hours due to cancer, high monthly out-of-pocket costs and difficulty understanding insurance or anticipating out-of-pocket costs. Differences in the measurement of financial stress make it difficult to link this finding perfectly to those of past studies, however a 2017 systematic review conducted by Gordon et al. identified the following determinants of financial stress among 25 studies: identifying as female, African American or Hispanic, younger age, low income or
reduced work hours, and having high out-of-pocket costs or no health insurance. Results from the current study lend support to those of past studies and go on to suggest that the understandability and interpretability of insurance coverage may also play a role in financial stress and cost-coping.

Findings shed light on the cost-coping processes of cancer patients and survivors and contribute to the literature on the structural basis of exposure to cancer-related financial stress. It was determined that only two cost-coping strategies played meaningful roles in the relationship between financial stress (i.e. difficulty paying one’s bills due to cancer) and financial strain (i.e. psychological distress attributed to cancer-related financial hardship), and could therefore be implicated in the stress process. Lifestyle-altering was found to significantly mediate \( B = 0.08, p < .05 \) the positive, linear relationship between stress and strain, explaining its effect. One the other hand, self-advocacy was found to interact significantly \( B = -0.01, p < .01 \) with financial stress to buffer its effect on financial strain.

The individuals most likely to report lifestyle-altering experiences in this sample were women, individuals identifying as non-White, and those who experience reduced employment during cancer treatment. Lifestyle-altering was the only strategy explored in this study that was significantly associated with gender, race/ethnicity in fully-adjusted models. These findings contribute to the growing evidence on race- and gender-based disparities in cost-coping. For example, in a large sample of women with a history of breast cancer Jagsi and colleagues (2015) found that racial and ethnic minorities were more likely to endure both care- and lifestyle-altering experiences, which they called privations. In light of these findings, the term privation may be preferable to lifestyle-altering because it more accurately captures the distress that these experiences can cause. Furthermore, its role in proliferating financial stress via mediation may be
sufficient reason to rethink labeling it as a “coping strategy.” There is limited research on the experiences of people who experience privations and life alterations related to cancer treatment cost. Future studies should explore the situational contexts and decision making processes involved in lifestyle-altering to better understand how these outcomes can be averted.

These findings point to a meaningful inequity in the health system in which women, people of color and individuals without adequate employment protections are more likely to seriously alter their lifestyles to accommodate the cost of their treatment in ways that pose a threat to their mental health and wellbeing. These results are consistent with the literature on cancer health disparities in suggesting that these populations may be unduly burdened, materially and psychologically, by inefficiencies in the current American health care system. (Glanz, Croyle, Chollette, & Pinn, 2003).

**Study Limitations**

As a secondary analysis of survey data this study has certain limitations that should guide interpretation of these findings. Because 3000 invitation emails were sent, the final sample of 511 represents a 17% response and inclusion rate. This accounts for individuals who were ruled out because they did not have a history of cancer, were under 25 years old, or did not have health insurance. The remaining were self-selected to participate in an online survey which limited the sample to individuals who engage in market research with access to the internet. The result was a sample distribution that should be considered marginally representative of the U.S. population of cancer patients and survivors, where only 78% of the population has access to a home computer with broadband internet access (U.S. Census Bureau, 2017). Further, since the survey was only provided in English, findings should not be generalized to individuals who do not read English.
Similarly, some individuals may have been too fatigued or seriously ill to participate, these findings cannot be thought to represent that subpopulation of cancer patients.

In addition to being reliant on self-report, another limitation of this study is that measures of cost-coping, stress, and strain were not validated instruments. This is because the survey was originally designed to collect in-depth descriptive data on American cancer patients and survivors and was not aimed at testing correlational or causal relationships. Many variables were categorical or ordinal where continuous measures would have allowed for more granular analyses. For example, a more precise measure of objective financial stress could have been generated using a ratio of annual household income to monthly out-of-pocket expenses if these data points had been collected using continuous rather than ordinal/categorical response options. Further, if data on household size and marital status had been collected, analyses using annual household income would have been interpreted more effectively. In light of these limitations, findings should be considered exploratory rather than conclusive, suggesting areas for further exploration and serving to generate hypotheses and research questions for future studies.

**Implications for Policy**

Findings suggest that cancer-related financial stress represents a significant psychosocial burden that affects several vulnerable populations that social workers serve. Women, people of color, the poor and underinsured are unduly burdened by the material and psychological costs of cancer treatments. Cancer patients, especially those from traditionally marginalized backgrounds, would benefit from guaranteed access to high-quality insurance plans with minimal or zero cost-sharing requirements.

The importance of health insurance type and quality in predicting financial stress was seen in findings throughout this study. Bivariate analyses in this study showed that having
Medicare or Medicaid insurance coverage reduced the risk of engaging in lifestyle-altering and financial help-seeking strategies. Younger patients and survivors, specifically those under 65 years old and therefore not qualifying for Medicare, were more likely to report financial stress. This has been found repeatedly in past studies (Banegas et al., 2016; Shankaran & Ramsey, 2015; Yabroff et al., 2015; Zafar et al., 2013) and has been attributed, at least in part, to the protective effect of Medicare for older adults (Yabroff et al., 2015). Further, individuals reporting household annual incomes 300% above the federal poverty line were more likely to report financial stress. Despite living just above the poverty line, people who earn above 138% FPL are not eligible for Medicaid in many states and must rely on either employer-sponsored or Marketplace insurance plans, which vary greatly in cost-sharing requirements (Buttorff, Andersen, Riggs, & Alexander, 2015; Graves & Mishra, 2016; Thorpe, Allen, & Joski, 2015). As a possibly remedy to underinsurance and financial stress, policy makers have been exploring the expansion of public insurance options through Medicare (Friedman, 2013) or Medicaid (Wikelius & O’Toole, n.d.).

Factors related to the understandability of insurance and ability to anticipate out-of-pocket costs were also important in predicting financial stress and cost-coping. Health service researchers are exploring the utility of price transparency tools and cost of care discussions for reducing health care spending, but at this time there is limited evidence that cancer patients and survivors will benefit from these interventions (Henrikson & Shankaran, 2016; Shih, Nasso, & Zafar, 2018; Sinaiko & Rosenthal, 2016). Furthermore, although it’s generally a good idea to understand the details of one’s health insurance coverage, there is limited evidence to suggest that health insurance literacy reduces financial stress in cancer. In fact there is some evidence
that the effort needed to access and understand health insurance and cost information is highly burdensome for cancer patients and survivors (George, Grant, James, Mir, & Politi, 2018).

**Implications for Practice**

In the absence of a robust policy response, clinical interventions are needed to bolster effective coping and to target material resources and psychological support where they are most beneficial. Clinical programs aimed at reducing financial hardship should be adapted to reflect emerging distinctions in coping style. Social workers and other psychosocial oncology providers need the tools to (1) identify individuals at risk for financial stress and (2) identify individuals using risky or distressing coping strategies like care-altering and some life-altering behaviors. Providers will then be prepared to deliver targeted psychosocial support that can include material or specialized behavioral interventions.

This study outlined important predictors of financial stress and coping that might be useful as clinical indicators of patients at risk of financial toxicity. As stated previously, certain patient populations may be at greater risk. These include women, people of color, those with annual household incomes below 300% FPL (< $75,000 / year ) and individuals with high deductible insurance plans who are likely to incur high out-of-pocket costs related to treatment. Financial stress can be measured by the question “have you had difficulty paying your bills due to cancer treatment?” These indicators can be used to inform the development of screening tools for the early identification of financial toxicity in clinical practice.

This study highlighted the benefits of financial self-advocacy, a coping strategy shown to decrease financial strain/distress. Oncology social workers and financial navigators can teach self-advocacy skills, help people make sense of their coverage and plan appropriately for the out-of-pocket costs of treatment. As such, these findings may inform the development of evidence-
based patient-education, screening and decisional support tools that support optimal problem and emotion focused coping.

**Implications for Research**

To date, few studies have examined the ways that people cope with treatment-related financial stress. Future research would benefit from the development of a valid and reliable scale of cost-coping. The preliminary measure developed in this dissertation offers a beginning for developing such a scale. In this study, however, only problem-focused coping strategies were identified. Recent studies have begun to identify other coping strategies that should be explored in greater depth and adequately measured (Head et al., 2018). In particular, emotion-focused coping and social support may have positive impacts on health and mental health outcomes in financially burdened cancer patients that deserve greater attention.

Financial help-seeking emerged as a distinct strategy for a large subset of respondents in this study. In general, financial assistance programs have not been well-examined in the scholarly literature despite the reliance of them in clinical practice. Support for the effectiveness of financial assistance programs has been largely anecdotal, suggesting a need for more extensive evaluation studies. The universe of cancer financial assistance programs should be mapped out to better understand how these programs can be optimized to meet the growing financial needs of cancer patients and to target subpopulations more precisely.

**Conclusion**

This dissertation sought to (1) identify distinct problem-focused coping strategies by testing the underlying factor structure of commonly used measures of cost-coping; (2) model the social, behavioral and health system factors that predict coping strategy variations; and (3) identify the role that cost-coping plays in the relationship between financial stress and strain. In
summary, the findings of this dissertation suggest that individuals affected by cancer cope with the out-of-pocket costs of their care differently, often according to the cultural and social positions. Cost-coping strategies vary and can either buffer or proliferate stress, and as a result, can have serious impacts on health and mental health. The findings should be interpreted in light of the its limitations as a cross-sectional study with a relatively small sample. Future studies are needed to develop, evaluate and implement screening tools for the identification of cancer patients and survivors at risk of encountering financial stress, and to develop interventions that support self-advocacy and prevent the need to rely on care-altering and lifestyle-altering cost-coping strategies.
Appendix 1. CancerCare Survey 4 - Financial and Insurance Issues

(Note: Programming instructions in blue)

Thank you for participating in our survey.

The purpose of this study is to learn about the impact of healthcare insurance and financial issues on people with cancer. The information you provide will be used to create support programs and influence policy to assist people with cancer.

As you answer the questions in this survey please base your answers on your personal experiences and knowledge about healthcare insurance and finances related to your cancer treatment.

The survey should take approximately 20 minutes to complete. All of your responses will remain confidential and will not be tied to any information that could identify you.

First, please tell us a little bit about yourself:

(PN: Force a single response.)

1. What is your age?
   - Under 25 years (Thank and terminate respondent)
   - 25 to 34 years
   - 35 to 44 years
   - 45 to 54 years
   - 55 to 64 years
   - 65 to 74 years
   - 75 or older

(PN: Allow entry of 5-digit ZIP code)

2. What ZIP code do you live in?

(PN: Force a single response.)

3. What is your current cancer status?
   - Diagnosed but do not have a plan for treatment (Thank and terminate respondent)
   - Diagnosed and have a plan for treatment but not yet begun treatment
   - In active treatment
   - Completed treatment and on maintenance therapy
   - Completed treatment and not on maintenance therapy
   - I do not have cancer / have never had cancer (Thank and terminate respondent)
Other Please specify _______
4. What type of health insurance do you have? Please select all that apply.

- Commercial/Private insurance through an employer
- Private insurance via Healthcare.gov (the insurance exchange)
- Medicare/Medicaid
- Private Medigap
- Tricare/Champus
- I don’t have health insurance (Thank and terminate respondent)
- Other (please specify) __________________________

5. How long ago were you first diagnosed with cancer?

- Within the last 12 months
- Between 13 months and 2 years ago
- Between 2 years and 4 years ago
- More than 4 years ago

6. What type of cancer were you most recently diagnosed with?

- Bladder
- Brain
- Breast (Early Stage)
- Breast (Metastatic)
- Colon or rectal
- Endometrial, cervical, or ovarian
- Head/neck
- Kidney
- Leukemia
- Liver
- Lung
- Lymphoma
- Melanoma
- Myeloma
- Pancreatic
- Prostate
- Skin (Thank and terminate respondent)
- Stomach
- Thyroid
- Other (please specify) __________________________
7. Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally. If the statement does not apply to you, please select N/A (not applicable).

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree Strongly</th>
<th>Disagree</th>
<th>Agree</th>
<th>Agree Strongly</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. When all is said and done, I am the person who is responsible for taking care of my health</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>b. Taking an active role in my own health care is the most important thing that affects my health</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>c. I know what each of my prescribed medications do</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>d. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.</td>
<td>[ ]</td>
<td>[ ]</td>
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</tr>
<tr>
<td>e. I am confident that I can tell a doctor concerns I have even when he or she does not ask.</td>
<td>[ ]</td>
<td>[ ]</td>
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</tr>
<tr>
<td>f. I am confident that I can tell a nurse practitioner, and/or physician assistant concerns I have even when he or she does not ask.</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
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<tr>
<td>g. I am confident that I can follow through on medical treatments I may need to do at home</td>
<td>[ ]</td>
<td>[ ]</td>
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</tr>
<tr>
<td>h. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>i. I know how to prevent problems with my health</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
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</tr>
<tr>
<td>j. I am confident I can figure out solutions when new problems arise with my health.</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>k. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

8. At what kind of medical facility (are you receiving / did you last receive) your cancer treatment?

- [ ] Academic Medical Center/ Comprehensive Cancer Center
- [ ] Community Cancer Center
- [ ] Community hospital
- [ ] Private physician practice
- [ ] VA Medical Center
- [ ] Don’t know/ I’m not sure
9. What type of cancer treatment have you received? Please select all that apply.

- [ ] Surgery
- [ ] Radiation
- [ ] Interventional Radiology
- [ ] Intravenous (I.V.) Chemotherapy
- [ ] Oral (pill) Chemotherapy
- [ ] Oral (pill) Hormonal Therapy
- [ ] Treatment targeted specifically for (PN: Pipe in Q6 answer.) cancer
- [ ] Immunotherapy
- [ ] Complementary or alternative therapies
- [ ] Don’t know/ I’m not sure (PN: Exclusive answer.)

10. What was your employment status while you were being treated for cancer?

- [ ] I continued working full time
- [ ] I continued working part time
- [ ] I switched from working full time to working part time
- [ ] I stopped working
- [ ] Does not apply, I was not working before receiving treatment

The next set of questions is about your insurance coverage for your cancer care.

11. Overall, **how well do you think you understand** what your insurance covers for your cancer care?

   - [ ] Do Not Understand At All
   - [ ] Understand Slightly
   - [ ] Understand Somewhat
   - [ ] Understand Very Well
   - [ ] Understand Completely

12. Overall, **how difficult or easy is it for you to understand** what your insurance covers for your cancer care?

   - [ ] Very Difficult
   - [ ] Somewhat Difficult
   - [ ] Neither Difficult nor Easy
   - [ ] Somewhat Easy
   - [ ] Very Easy
13. Overall, how satisfied are you with your insurance coverage for your cancer treatment?

```
<table>
<thead>
<tr>
<th>Very Dissatisfied</th>
<th>Moderately Dissatisfied</th>
<th>Neither Satisfied nor Dissatisfied</th>
<th>Moderately Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
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</tr>
</tbody>
</table>
```

14. How satisfied are you with the following aspects of your insurance coverage for your cancer treatment?

```
<table>
<thead>
<tr>
<th>a. The choice of doctors</th>
<th>Very Dissatisfied</th>
<th>Somewhat Dissatisfied</th>
<th>Neither Satisfied nor Dissatisfied</th>
<th>Somewhat Satisfied</th>
<th>Very Satisfied</th>
<th>No Opinion</th>
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</thead>
<tbody>
<tr>
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<tr>
<td>b. The choice of hospitals and/or treatment centers</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<td>☑</td>
<td>☑</td>
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<tr>
<td>c. Affordability of co-payments</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>d. Affordability of deductibles</td>
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<tr>
<td>e. My ability to pay for medications recommended by my doctor</td>
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<tr>
<td>f. Amount I have to pay for the tests recommended by my doctor</td>
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<td>g. In-network access to psychological counseling/support</td>
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<tr>
<td>h. Access to an insurance case manager who explains/assists with coverage issues</td>
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<tr>
<td>i. Access to Clinical trials</td>
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<tr>
<td>j. Access to newly approved treatments or drugs</td>
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<td>k. Access to advanced imaging technology</td>
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<tr>
<td>l. Access to complementary therapies such as acupuncture or massage</td>
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<tr>
<td>m. Getting timely approvals for tests or procedures</td>
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<td>☐</td>
<td>☐</td>
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<tr>
<td>n. Access to genetic testing</td>
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</tbody>
</table>
```

15. Are you concerned you may lose your insurance if you are unable to work?

☐ Yes
☐ No
16. Do you have access to alternative health insurance coverage if you are unable to work and lose your employer sponsored coverage?

- Yes
- No
- Don’t know

17. Overall, how difficult or easy was it to find a doctor to treat you for cancer who takes your insurance?

- Very Difficult
- Somewhat Difficult
- Neither Difficult nor Easy
- Somewhat Easy
- Very Easy

18. If your insurance had no limits, would you have chosen a different doctor?

- Yes
- No
- I’m not sure

19. Overall, how difficult or easy was it to find a really good hospital or cancer treatment center that takes your insurance?

- Very Difficult
- Somewhat Difficult
- Neither Difficult nor Easy
- Somewhat Easy
- Very Easy

20. If your insurance had no limits, would you have chosen a different hospital or treatment center?

- Yes
- No
- I’m not sure

21. If your insurance had no limits, would you have chosen to get different cancer treatment than you are receiving/received?

- Yes
- No
- I’m not sure
22. Have you heard of cancer treatment plans that are limited or required by an insurance company?

- Yes
- No
- I'm not sure

The next set of questions is about the financial issues related to your overall experience being treated for cancer.

23. Thinking about the time when you were getting cancer treatment, how distressed (e.g. anxious, extremely upset, or in emotional pain) were you from worrying thinking about your finances?

- Not at all distressed
- A little distressed
- Somewhat distressed
- Very distressed
- Extremely distressed

24. To what degree has your cancer treatment caused you financial hardship (i.e. you are/were unable to meet your financial obligations because of your cancer treatment trouble paying your bills)?

- None
- A little
- Some
- A lot
- An extreme amount

25. How often do you do each of the following in order to REDUCE your expenses related to your cancer treatment?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Postpone or skip doctor's appointments</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>b. Postpone or skip follow-up testing</td>
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<tr>
<td>c. Postpone or skip blood work</td>
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<tr>
<td>d. Postpone or not fill prescriptions</td>
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<tr>
<td>e. Delay or skip complementary treatment</td>
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<tr>
<td>(such as acupuncture, massage therapy,</td>
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<tr>
<td>nutrition counseling)</td>
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<td></td>
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<tr>
<td>f. Postpone or skip psychological</td>
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<td></td>
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<tr>
<td>counseling or support</td>
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<td></td>
</tr>
<tr>
<td>g. Skip dosages of prescribed drugs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
h. Cut pills in half

i. Apply for co-pay assistance to cover medication costs

j. Discuss changing my treatment to one that costs less

k. Choose to use a lower cost medication than what the doctor recommended

l. Apply for financial assistance for non-medical expenses such as transportation

m. Order medications on-line from non-US sources

n. Apply for financial assistance from my doctor/hospital

(PN: Force a single response but allow multiple responses.)

26. Who have you spoken to in your doctor’s office about treatment costs? Please select all that apply.

- Primary Care Physician
- Doctor treating me for cancer
- Physician Assistant or Nurse Practitioner
- Nurse
- Physician office staff member (e.g. receptionist, office manager)
- Patient Financial Services staff member
- Social Worker
- No one
- Other ________________

(PN: Repeat Q27 for each person selected in Q26.)

27. When did you first discuss treatment costs of [PN: With each repeat of Q27 pipe in the respective name of person selected in Q26.]?

- While scheduling my first appointment
- When first discussing treatment options with the doctor
- After learning what my insurance would cover but before starting treatment
- After starting treatment
- When I realized that paying the bills was becoming a problem
- Other ________________

(PN: Force a single response but allow multiple responses.)

28. Who in your doctor’s office offered you help or advice about paying your medical bills? Please select all that apply:

- Primary Care Physician
- Doctor treating me for cancer
- Patient Financial Services staff member
- Physician Assistant or Nurse Practitioner
- Nurse
- Physician office staff member (e.g. receptionist, office manager)
- Social Worker
- No one
- Other ________________
29. How helpful was the advice about paying your medical bills that you received from each of the following?

<table>
<thead>
<tr>
<th></th>
<th>Very Unhelpful</th>
<th>Somewhat Unhelpful</th>
<th>Neither Helpful nor Unhelpful</th>
<th>Somewhat Helpful</th>
<th>Very Helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care Physician</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>Doctor treating me for cancer</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>Physician Assistant or Nurse Practitioner</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>Nurse</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>Physician office staff member (e.g. receptionist, office manager)</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>Patient Financial advisor</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>Other</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>Social Worker</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
</tbody>
</table>

30. Overall, have you gotten the help you need to manage your medical bills?

❑ Yes
❑ No
❑ Not sure yet

31. How often do you feel your healthcare team takes your financial situation into consideration when recommending treatment options?

Never ❑ Rarely ❑ Sometimes ❑ Often ❑ Always ❑

32. Which of the following BEST describes how often you discuss your financial concerns with someone in your doctor's office?

❑ Every appointment
❑ Whenever I get a bill
❑ Monthly
❑ Every few months
❑ Rarely
❑ Never
33. Which of the following have you experienced as a result of bills related to your cancer treatment? Please select all that apply:

- I asked for financial help from a church or community organization
- I applied for financial assistance from a patient support organization
- I considered declaring bankruptcy
- I declared bankruptcy
- I borrowed money from a bank or credit union
- I cut back on non-essential expenses, such as vacations, movies, dining out
- I borrowed money from family/friends
- I moved to a less expensive home
- I missed rent/mortgage payments
- I cut back on groceries, transportation, clothing, tuition
- I missed paying bills such as heat, electricity, phone
- I applied for financial assistance from my doctor’s office or hospital
- Other (please specify) __________________________

34. Have you considered cashing in your life insurance to pay for your cancer treatment?

- Yes
- No
- Not applicable, I don’t have life insurance

35. Have you taken money from your pension plan or retirement account to pay for your cancer treatment?

- Yes
- No
- Not applicable, I don’t have a pension plan or retirement account
36. Thinking about your experience being treated for cancer, how often do you (or did you) do the following?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Determine the expense to you before going to the emergency room</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>b. Estimate the cost to you before agreeing to a treatment your doctor recommended</td>
<td></td>
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</tr>
<tr>
<td>c. Appeal the denial of benefits from your insurance company</td>
<td></td>
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<tr>
<td>d. Find out the cost to you before filling a prescription for a treatment drug</td>
<td></td>
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<tr>
<td>e. Find out the cost to you before filling a prescription for a drug that helps with side effects or symptoms</td>
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<tr>
<td>f. Review the explanation of benefits from your insurance company</td>
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<td></td>
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<tr>
<td>g. Ask the insurance company for help in understanding your coverage</td>
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<td></td>
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<tr>
<td>h. Consider changing to a different doctor because of cost</td>
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<td></td>
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</tr>
<tr>
<td>i. Find out the cost to you before getting lab tests or scans</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j. Agree to a test or procedure that your insurance didn’t cover</td>
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<td></td>
</tr>
<tr>
<td>k. Consider non-traditional treatment that costs less</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

37. Are you familiar with term “formulary” as described above?
- Yes
- No

38. Are you aware that insurance plans often have several levels of coverage for cancer drugs and that the amount you pay out of pocket may change depending on the drugs your doctor prescribes?
- Yes
- No
- I’m not sure
39. Are you aware that your co-pay amount may be different depending on if you are receiving treatment in the hospital or in your doctor’s office?

☐ Yes
☐ No
☐ I’m not sure

(PN: Only ask Q40 if answer to Q4 was “Medicare/Medicaid” or “Private Medigap” AND answer to Q9 was “Intravenous Chemotherapy (I.V.)”.)

40. Was your infusion (ie. intravenous or I.V.) therapy covered under Medicare Part B (your medical benefits)?

☐ Yes
☐ No
☐ I’m not sure

(PN: Only ask Q41 if answer to Q40 was “Yes”.)

41. On average, what was the co-pay per infusion?

☐ Less than $50
☐ $51 - $150
☐ $151 - $300
☐ $301 - $500
☐ More than $500

(PN: Only ask Q42 if answer to Q4 was “Medicare/Medicaid” or “Private Medigap” AND answer to Q9 was “Oral Chemotherapy (Pill)” or “Oral Hormonal Therapy (Pill)”.)

42. Was your oral therapy covered under Medicare Part D (your drug benefits)?

☐ Yes
☐ No
☐ I’m not sure

(PN: Only ask Q43 if answer to Q42 was “Yes”.)

43. On average, what was the co-pay per prescription?

☐ Less than $50
☐ $51 - $150
☐ $151 - $300
☐ $301 - $500
☐ More than $500
44. How difficult or easy was it for you to determine the out-of-pocket cost of each of the following BEFORE you incurred the expense?

<table>
<thead>
<tr>
<th></th>
<th>Very Difficult</th>
<th>Somewhat Difficult</th>
<th>Neither Difficult nor Easy</th>
<th>Somewhat Easy</th>
<th>Very Easy</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Scans and X-rays</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>b. Procedures</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>c. Treatments</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>d. Physician fees</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>e. Hospital fees</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
</tbody>
</table>

45. Thinking about the time you were getting cancer treatment, on average, how much did you spend out of pocket each month on the following? Your best estimate will do.

<table>
<thead>
<tr>
<th></th>
<th>Less than $100</th>
<th>$101-250</th>
<th>$251-500</th>
<th>More than $500</th>
<th>Don’t know/ I’m not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Co-payments and deductibles for drugs, doctor visits and tests</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>b. Non-prescription medications (that is, over-the-counter drugs)</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>c. Services to help with symptoms and side effects such as acupuncture or massage therapy</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>d. Transportation to and from clinic visits, baby-sitting,</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
<tr>
<td>e. Special clothing, wigs, etc.</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
<td>❑</td>
</tr>
</tbody>
</table>

46. What percent of your total cancer treatment costs do you think have been covered by your insurance? Your best estimate will do.

☐ I’m not sure

% of total treatment costs covered by insurance

The remaining few questions are asked to provide us with some demographic information so we can better understand the study findings.

47. What is your gender?

☐ Male
☐ Female
48. What Is Your Ethnicity?
- African American
- Asian
- Hispanic
- Pacific Islander
- White (not Hispanic)
- Multi-racial
- Other

49. What was your total 2014 household income before taxes?
- Less than $25,000
- $25,000 to $34,999
- $35,000 to $49,999
- $50,000 to $74,999
- $75,000 to $99,999
- $100,000 to $149,999
- $150,000 or more
- Prefer not to answer

50. What is the highest level of education or degree you have completed?
- Less than high school
- High school graduate (includes equivalency)
- Some college, no degree
- Associate's degree
- Bachelor's degree
- Master's degree
- Doctorate / professional degree

51. If you have Commercial/Private insurance, who is your provider? Please select all that apply.
- Private insurance through an employer
- United Healthcare
- Aetna
- Cigna
- Humana
- Kaiser Permanente
- Blue Cross Blue Shield
- Other (please specify)

This completes the survey. Thank you very much for your feedback.
Appendix 2. Signed Data Use Agreement

Data Use Agreement: CancerCare Data Set
All individuals with access to the data are to sign and submit along with a CancerCare Manuscript Proposal

Investigator Name: Meredith Doherty
Investigator Institution: 
Project Title: 
Lead Data Manager: 

CancerCare Data Set will be released to the above referenced investigator, as indicated here. Methodology and survey demographics are attached:

(a) Patient Survey 1: Understanding the Diagnosis of Cancer
(b) Patient Survey 2: Participation in Treatment Planning and Decisions
(c) Patient Survey 3: Communication with the Care Team
(d) Patient Survey 4: Financial and Insurance Issues
(e) Patient Survey 5: Symptoms, Side Effects and Quality of Life
(f) Patient Survey 6: Survivorship

In accepting this data from CancerCare, the Investigator agrees to use the data only for the CancerCare approved research project. (Attach Manuscript Proposal)

Investigator agrees to submit a new proposal to CancerCare for any new project in which the data is to be used and will not proceed to use the data for an additional project without approval and a signed agreement from CancerCare.

The data may only be shared within the team working on the analysis project. Requests from other individuals for access to the data should be referred to the CancerCare Data Set Manager (Ellen Sonet).

The investigator agrees to follow the CancerCare Data Set Policies on Data Management and Security as follows:

1. Use or disclose the data set only as permitted by this Agreement or as required by law;
2. Use appropriate safeguards to prevent use or disclosure of the DATA SET other than as permitted by this Agreement or required by law;
3. Report to CancerCare any use or disclosure of the data set of which it becomes aware that is not permitted by this Agreement or required by law, including the presence of prohibited identifiers in the data set;
4. Require any of Investigators’ subcontractors or, agents that receive or have access to the data set to agree to the same restrictions and conditions on the use and/or disclosure of the data set that apply to Investigator under this Agreement; and
5. Not use the information in the data set, alone or in combination, to identify or contact the individuals who are data subjects.

The term of this Agreement begins as of the effective date and terminates 5 years from effective date. If the Investigator desires to keep the data set for a longer period, a justification in writing should be made to CancerCare.

Investigator may terminate this agreement at any time by notifying CancerCare and returning or destroying the data set.
CancerCare will provide written notice to Investigator within ten (10) days of any determination that he/she has breached a material term of this Agreement. CancerCare shall afford Investigator an opportunity to cure said alleged material breach upon mutually agreeable terms. Failure to agree on mutually agreeable terms for cure within thirty (30) days shall be grounds for the immediate termination of this Agreement by CancerCare.

Ellen Sonet will serve as the lead data manager for this analytic project and will serve as the liaison with the CancerCare.

All CancerCare Data Set publications must be prepared in collaboration with CancerCare and co-authored by a CancerCare staff member. Any exceptions to this requirement must be noted and agreed to as part of this agreement.

Exception: Meredith Doherty may access this data for her dissertation and derivative publications, which are exempt from CancerCare co-author requirements.

Copies of all manuscripts arising from the project must be sent to the CancerCare prior to publication, for reference.

Any publication using CancerCare Data Set data must acknowledge the contributions of the CancerCare Data Set to the project with the following citation: "This publication was supported by CancerCare and is based on data from its 2016 Patient Access and Engagement Study."

Agreed to:

CancerCare Data Set Investigator

Meredith Doherty

Effective Date: 2/1/17

CancerCare Data Set Manager

Ellen W. Sonet

Ellen Sonet

2/21/2017
Effective Date: 2/11/1

2/21/2017
Appendix 3. IRB Determination Notice

Determination Notice
Activity Does Not Require CUNY HRPP/IRB Review

06/28/2017

Meredith Doherty,
Hunter College

RE: IRB File #2017-0067
   Exploring Themes of Patient Access and Engagement in Cancer Care: Financial Wellbeing, Quality of Life and Value.

Dear Meredith Doherty,

The above-referenced research proposal was reviewed on 06/28/2017. Based on the information you have provided, the proposed research does not require CUNY HRPP or IRB review because:

[ ] It does not meet the CUNY HRPP definition of research: A systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.

[X] It does not involve human subjects as defined by CUNY HRPP: A living individual about whom an investigator (whether professional or student) conducting research obtains (1) data through intervention or interaction with the individual, or (2) identifiable private information.

[ ] CUNY is not engaged in the proposed research: CUNY employees or agents\(^1\) obtain, for the purposes of the research project, (1) data about the subjects of the research through intervention or interaction with them; (2) identifiable private information about the subjects of the research; or (3) the informed consent of human subjects for the research.

Comments:

Please refer to CUNY HRPP Guidance: When is CUNY HRPP or IRB Review Required for further clarification regarding these criteria. Should your proposed activity change, please re-submit to the CUNY HRPP for re-evaluation of this determination.

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\(^1\) Employees or agents refers to individuals who: (1) act on behalf of CUNY; (2) exercise institutional authority or responsibility; or (3) perform institutionally designated activities. Employees or agents can include staff, students, contractors, and volunteers, among others, regardless of whether the individual is receiving compensation.

If you have any questions, please contact:
References


Hayes, A. F. (2012). *PROCESS: A versatile computational tool for observed variable mediation, moderation, and conditional process modeling.* University of Kansas, KS.

Head, B., Harris, L., Kayser, K., Martin, A., & Smith, L. (2018). As if the disease was not enough: Coping with the financial consequences of cancer. *Supportive Care in Cancer, 26*(3), 975–987. https://doi.org/10.1007/s00520-017-3918-y


https://doi.org/10.1037/a0022025


https://doi.org/10.1200/JCO.2011.37.9511


