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STRESS AND CANCER TREATMENT: HOW A FAMILY'S ADAPTABILITY AND COHESION AFFECTS FINANCIAL STRESS

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THESIS

A thesis submitted in partial fulfillment of the
requirements for the degree of Master of Science in Family Sciences in the
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By

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ABSTRACT OF THESIS

STRESS AND CANCER TREATMENT: HOW A FAMILY'S ADAPTABILITY AND COHESION AFFECTS FINANCIAL STRESS

According to the American Cancer Society (2019), it is estimated that 1,762,450 new cancer diagnoses occurred in 2019 in the United States. Currently, cancer remains one of the leading causes of death worldwide (American Cancer Society, 2019). As cancer affects the family, roles within the family will shift (e.g., transitioning to a caregiving relationship), causing each family member to adapt. With the costs of cancer steadily increasing, this potentially leaves a devastating impact on the family. When considering family function in terms of Family Systems, John Rolland created the Family Systems Illness Model to explain how families adapt to an illness, which is the lens families are viewed from in this study. In the present study, cancer stress and financial stress are examined with family adaptability and cohesion as a mediator. While the present study showed few relationships between cancer stress, financial stress, and family adaptability and cohesion, this could be attributed to the limitations of the study.

KEYWORDS: STRESS, CANCER, FAMILY SYSTEMS, FINANCE.

Emily Marie Johnson

April 24, 2020

STRESS AND CANCER TREATMENT: HOW A FAMILY'S ADAPTABILITY AND COHESION AFFECTS FINANCIAL STRESS

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Chapter 1: Introduction

According to the American Cancer Society (2019), it is estimated that 1,762,450 new cancer diagnoses occured in 2019 in the United States. With the number of new yearly cancer diagnoses being alarmingly high, it is unsurprising to find out that there are over 16 million Americans living with cancer as of 2015 (American Cancer Society, 2019). Consequently, cancer remains one of the leading causes of death worldwide (American Cancer Society, 2019). With its worldwide prominence, cancer affects individuals and families alike. Not only can cancer create stress for an individual, but it can also create similar effects within families (Goswami & Gupta, 2018; Laizner, 2018). Stress is defined as a physical, mental, and emotional response to life events that place threats on one's physical, emotional, or overall well-being, (Cohen, 2016). Rates of depression, anxiety, and post-traumatic stress remain significantly high within family members who are affected by cancer, especially due to the increased stress caused by the caregiving role (Goswami & Gupta, 2018). As cancer affects the family, roles within the family will shift (e.g., transitioning to a caregiving relationship), causing each family member to adapt to the process (Laizner, 2018).

A cancer diagnosis not only creates stress within the family, but the sheer costs of treatment can also have a devastating impact on a family (Balfe et al., 2016; Amir et al., 2012; Cagle et al., 2016). In 2017, the direct medical costs of cancer amounted to 147.3 billion US dollars, with the average patient paying roughly $150,000- $300,000 per year (American Cancer Society, 2019). Out of this 147.3 billion, 52% accounts for outpatient treatment, while the remaining 48% accounts for hospital visits and extended stays (American Cancer Society, 2019). Considering the outrageous costs associated with cancer care, it is clear to see how financial stress can add to cancer stress on the family, especially if the family is in a lower socioeconomic class or a part of a minority population. The American Cancer Society (2019) states that roughly 28.5 million Americans are uninsured, limiting a family or individual's ability to afford cancer care. This financial stress can, like cancer stress such as coping skills, worry, grief, shame, etc., cause family members to adopt new roles in order to keep the family system functioning (Goswami et al., 2018). For example, one partner may go from the primary breadwinner to becoming the patient, forcing the other partner to take on the role as the primary financial provider.

The present cancer stress impacts everyone within the family system, and each individual's response to those stressors, in turn, affects the family system's roles and cohesion (Laizner, 2018; Areia, 2019; Bouchal et al., 2015). When viewing the family as a systemic unit, it must be considered how each individuals' role in the family contributes to its cohesion and function (Walsh, 2012). Notably, in the context of terminal illness, the roles of each family member can change dramatically, creating a different outlook on the current relationship. Uncertainty concerning the illness timeline and new onset of disabilities as the illness progresses can compound the stress a family system is under while coping with illness (Rolland, 1994; 1999; 2005). There is a period during which family members will mourn the loss of family life as they knew it, and a time at which the system begins adapting to the changes brought about by the illness (Walsh, 2012). Each family member will adapt to change differently and at a different rate, thereby leaving the family system in a state of flux until adaptation gives way to a new equilibrium within the system (Walsh 2012; Laizner, 2018).

Considering the changes that families coping with cancer go through, it is not surprising that family cohesion, as well as the ability to communicate, dissolves under extreme stress (Bouchal et al, 2015; Kulkarni et at., 2014; Laizner et al., 2018). In addition to the stressor of having a loved one with cancer, families are left overwhelmed with the financial burden associated with cancer treatment (Balfe, 2016; Hamel et al., 2016). Due to family communication taking a toll during the period of illness due to various role changes, stress of both the patient and the remaining family is consistently increasing. (Rolland 1999, 2005). Families coping with a cancer diagnosis could benefit greatly from having access to family therapy to aid with their individual and systematic coping process following the diagnosis.

Laizner et al. (2018) found within his study of family patterns and therapeutic interventions when coping with cancer that family function was affected, especially when depression was present within the parents or caregivers. Areia et al. (2019) and Golblatt et al. (2019) conducted studies on families coping with a cancer diagnosis, finding declining family function, especially due to role changes within the family. Rolland (1999) created the Family systems illness model (FSI) to explain changes families coping with illness face. The family systems illness model (FSI) (Rolland, 1999, 1994, 2005) provides a framework for understanding how family systems adapt to change over time in the context of illness (Walsh, 2012). The theory accounts for stress accumulation, family role changes, and other adaptations common to major system transitions. Understanding these processes can provide insight into how family relationships change due to stressors associated with serious illness within the system. The FSI divides illness into three variables: psychosocial types of illness, time phases of illness evolution, and components of family system variables and functioning (Walsh, 2012). Each variable is considered in terms of the family life cycle, the time phase of the illness, and beliefs held by the family regarding the condition (Walsh, 2012). Considering Rolland's research and more recent studies adapting the FSI model, it is apparent that families coping with an illness face various stressors that families without illness do not. Conversely, the effects of financial stress on families coping with cancer has been neglected within the current research literature. Some literature has acknowledged the financial burden of paying for cancer treatments out of pocket, as well as the loss of financial security due to a loss of income, which in turn, has been associated with lifestyle changes (Amir, Hennings, Wilson, & Young, 2011). However, research is needed to understand how financial stress affects family cohesion as a whole. The purpose of the current study is to extend the FSI framework through examining the relationship between perceived cancer stress and financial stress present within families coping with a cancer diagnosis, as well as the mediating role of family cohesion and adaptability.

Chapter 2: Literature Review

Stress Associated with Cancer

When coping with a cancer diagnosis, there are various new and old stressors that create increasing pressure on families (Walsh, 2012). With each family member responding to stressors individually, this can create conflict within the family, affecting family cohesion as a whole (Areia et al., 2019). Each family member often takes on a new role after a cancer diagnosis, the roles range from caregiver to new primary breadwinner, a second caregiver to siblings, etc. These new roles likely send families into a mode of crisis, making the likelihood of family cohesion decrease due to the family's struggle with adaptability (Golblatt et al., 2019). Various forms of cancer stress are associated with adapting to a cancer diagnosis, such as depression, anxiety, guilt, shame, and anger. This emotion associated with cancer stress greatly affects each individual's and family's ability to adapt to the diagnosis and create functioning support for one another (Walsh, 2012). Adding the overwhelming cost of cancer treatment to cancer stress to the present cancer stress, this creates various barriers for families to adapt to. (Balfe et al., 2016)

Financial Stress Affecting Families Coping with Cancer

When a family is coping with a cancer diagnosis, the potential financial stress may not be immediately realized (Amir et al., 2011; Balfe et al., 2016). The initial diagnosis tends to overwhelm families and patients alike, especially as cancer is often perceived as a death sentence (Hamel et al, 2016). When considering financial stress within families coping with cancer, it is important to acknowledge that the costs of treatment are not only a burden to the patient, but to the family as well (Amir et al., 2011). Cancer treatment is costly, and with varying amounts of insurance coverage, it is common for families to pay out-of-pocket for cancer treatments, potentially depleting their savings (Cagle et al., 2016). Cagle et al. (2016) found that one-third of the participants in his study reported spending most or all of their life savings to pay for cancer treatments. This finding exemplifies the devastating financial burden cancer treatment can have on a family. It has been noted in the literature that many of the financial issues reported by families coping with cancer are substantial (Rotter et al., 2019).

Although out-of-pocket costs are considered a consequential financial burden (Balfe et al., 2016), other aspects of day-to-day life can also contribute to financial stress. Specifically, the loss of employment by the patients and caregivers, as well as the reduced number of hours worked by family members to spend time with their loved one all contribute to a significant loss of income during the times of illness (Balfe et al., 2016; Amir et al., 2011). Because of issues with employment, patients and their family members have fewer opportunities to maintain a steady flow of income, furthering the financial burden on the family. In a similar vein, some cancer patients will return to work prematurely in order to reinstate their income, while other patients will be out of the workforce indefinitely (Balfe et al., 2016). Many cancer patients will struggle to return to work, and at times the absence itself can lead to job loss, lowering the family's financial stability significantly (Hamel et al., 2016).

After reviewing the various causes for income loss and financial stress, it is important to note the effects that this stress will have on the family lifestyle, considering around one-third of these families deplete their life savings (Cagle et al., 2016). Although treatment costs clearly have a profound impact on families, it is crucial to note that financial stress is not necessarily as devastating for the majority of families. Most families found that they struggled with simply losing daily luxuries, such as letting go of a premium subscription to a cable company, in order to save money (Amir et al., 2011). This financial stress can also lead to families struggling to pay for their children's extracurricular activities and educational opportunities. (Knight et al., 2018). Following a cancer diagnosis, the financial stress generally causes lifestyle and role changes within the family, however, there is little research regarding the effect that financial stress has on family cohesion and functioning.

Hidden costs of cancer. After the initial cancer diagnosis, families focus heavily on getting their ill loved one into a promising and effective treatment method. Families are often not aware of exactly how cancer can be a heavy financial burden. Beginning simply with considering the cost of cancer treatment alone and limitations to insurance coverage; this leads many families to pay out-of-pocket for the treatment (Hamel et al., 2016). As mentioned before, some families have reported depleting their life savings in order to pay for cancer treatments. The costs of cancer that are hardly recognized are the costs of transportation, travel costs (i.e., hotel rooms, plane tickets, etc.), reduced income due to reduced hours, the potential need for in-home care, and the potential loss of income due to unemployment (Hamel et al., 2016). Unsurprisingly, the financial burden of cancer treatment is rarely discussed between the patient and the doctor. If finances are mentioned when discussing a treatment plan, 63% of the time, the conversation is initiated by the patient or a family member (Hamel et al., 2016; Knight et al., 2018). The number one concern that patients have in regard to cost is insurance coverage and loss of income due to time off of work. Because the financial burden is rarely discussed between doctor and patient, many families are unaware of how the costs of cancer add up, leading to financial stress later in the treatment process (Knight et al., 2018).

Financial toxicity in cancer treatment. Financial toxicity refers to the financial strain, struggles, and stress experienced by cancer patients and their families (Knight et al., 2018). Often, the financial burden experienced is shifted onto the patient, creating complex levels of stress. One-fourth of cancer patients, insured or not, reported depleting their life savings to pay for treatment (Cagle et al., 2016). Because of the elevated stress, it has been suggested that higher rates of financial toxicity are tied to higher mortality rates within cancer patients (Knight et al., 2018) Part of the increase in mortality rate is due to stress, but also due to the direct result financial toxicity has on a cancer patient's care. Patients suffering from financial toxicity are the least likely to follow their treatment plan due to the fear that the expenses associated will lead the individual to bankruptcy (Rotter et al., 2019). In an attempt to deviate from the treatment plan, patients will delay refilling prescriptions, space out the time in between treatments, or forgo treatment altogether. The stage and malignancy of cancer affect financial toxicity as well, meaning the more advanced a cancer is, the less likely an insurance company is to cover the cost, deepening the burden on the family (Cagle et al., 2016). Acknowledging the financial struggle cancer patients face during treatment, it can be clearly seen how this stress can add up to high amounts of overall stress.

Role of Caregiver

Associated stress with caregiving. Caregivers for cancer patients take on various roles, such as managing medication and medical appointments, providing transportation, maintaining housework, and providing emotional support (Fumis et al., 2015). It is clear to see that with each of these roles, caregivers are extremely likely to experience financial, personal, and mental stress (Kulkarni et al., 2014). In fact, it has been discovered that the psychological impact of the caregiver is almost as extreme as that of the patient (Goswami et al., 2018). Not only must caregivers care for the patient, but they also manage the emotional needs of the remaining family members. Often, the caregiver is essentially the spokesperson for the patient, announcing the initial diagnosis to the family, along with status updates regarding the patient's health (Goswami et al., 2018). Because of this, caregivers experience extreme pressure, leading them to report poorer health levels, anxiety, and depression (Goswami et al., 2018; Kulkarni et al., 2014; Areia et al., 2019). In fact, 22.7% of caregivers in Gupta et al., (2018) study reported suffering from severe levels of depression. Other milder, yet significant, psychological effects are consistently taxing caregivers as well. Due to this, there is a fear that the caregiver will become the hidden patient, making various support outlets necessary for patients, caregivers, and their families (Fumis et al., 2015). However, one of the key factors for resilience within caregiving is the family function and support (Hwang et al., 2018). Because of this, including mental health support is not only necessary for the patient and caregiver, but coping strategies for the family in its entirety are crucial to building resilience.

Caregiving and PTSD. With the significant psychological effects already affecting caregivers and their families, Post Traumatic Stress Disorder (PTSD) or Post Traumatic Stress Symptoms (PTSS) are increasingly common within this population. In fact, the amount of hospital, specifically the ICU, visits can affect the severity of PTSD and PTSS (Fumis et al., 2015). Patients who have malignant cancer and are in and out of the hospital display the strongest symptoms of PTSD/PTSS, along with their caregivers (Fumis et al., 2015). This is due to the fact that when the patient is in the ICU, there is uncertainty surrounding the patient outcome, forcing families to begin to consider end-of-life care (Fumis et al., 2015). If this happens continuously, caregivers and families experience symptoms of repeated stress. Given caregivers are already at a heightened risk of anxiety and depression, it is easy to see how repeated, illness-related events can lead to PTSD/PTSS (Ariea et al., 2019).

Family Cohesion as a Coping Mechanism

Effects on family function. Each family experiences illness uniquely as they navigate the symptoms and suffering associated with a family member's illness (Walsh, 2016). When looking at cancer through the lens of the FSI, it is important to acknowledge three distinguishing facets to family functioning: the phase of the family life cycle and cohesion required, the alteration of structure in life phases of the family, and periods of higher or lower psychosocial demands caused by the illness (Rolland, 1994; 2005). Specific to the effects of parental death on a family, the family's life cycle stage can be a particularly important factor in shaping the family's coping process. For example, if the family is in the early stages of the family life cycle, there will be a period of grieving the life goals that may never be achieved, particularly those surrounding parenting and childrearing (Rolland, 1999; 2005). The experience of parental illness is different for those in the latter stages of the family life cycle who have already achieved many of the life goals that they wished to accomplish. Considering both ends of the life cycle, there are a variety of challenges that come with illness in each section of the lifespan. Regardless of the life cycle stage, a cancer diagnosis introduces new stressors to the family system, which can lead to lower levels of cohesion within the family system (Rolland, 1999; 2005).

Rolland (1999; 2005) notes that in the FSI, it is important to gain an understanding of the family's response to past crises to gauge how the family will cope with the current illness. Because a terminal illness is considered a moderate to severe crisis for families, it is extremely important for the family to adapt and restructure itself quickly, accommodating new life changes with this illness and its anticipatory outcome (Rolland, 1994; 2005) When viewing a past record of how families reorganize in crises related to illness, it becomes much easier to track and predict common coping strategies and skills that have been ingrained within the family.

When a family is coping with cancer, commonly, one or multiple family members will often take on the role of caregiver, which can be accompanied by great distress (Haley et al., 2002). However, the role of caregiver is not limited to one family member, it is often a split effort between the spouses/partners, children, and extended family members. Evidence has shown that the stress of the family member's role as a caregiver can depend on race, culture, ethnicity, and social support (Haley et al., 2002). Due to different expectations within cultures, some are more apt to take care of their terminally ill loved ones than others. For example, African American families are more likely to take care of their family members when they fall ill, rather than white families (Haley et al., 2002). This also ties into relationships, such as who will head the house after a parent passes. In some cultures, after the passing of the father, his son, no matter the age, may feel responsible to take on a fatherly role within the family. Various different members of the family will begin to feel as if they need to reorganize functioning, preparing for the impending loss of a loved one, which is often the most difficult part of the process.

When considering the FSI, one must notice the formation of new roles in the family, and how the potential of death can impact each family member through the span of the illness (Haley et al., 2002). Research conducted at Sloan Kettering Memorial Hospital (Pessin et al., 2002), found that psychological aspects, such as depression, can have the strongest effect on families and patients during the terminal stage of illness. Depression is commonly found in both family members and the patient as they reach the end of their road with a terminal illness (Pessin, Rosenfeld, & Breitbart, 2002; Areia et al., 2019). At the end of life, much of the depression experienced by both the patient and the family is due to loss of autonomy, loss of health, and the loss of a loved one from the family system (Edwards and Banks, 2004; Areia et al., 2019). In addition, the level of uncertainty accompanying the illness can greatly impact anxiety levels within family members, adding on to the burden of likely depression (Rolland, 1999). Pessin et al. (2002) found that levels of anxiety greatly depend on the level of control and mastery that the family feels as if they have when coping with the illness and its effects. This anxiety is greatly affected by the family's belief system about the illness, and how prepared they feel to cope (Rolland, 1994; 1999; 2005). If a family is struggling to come to terms with an illness and is unsure of the amount of life their loved one has left, the level of anxiety within the family is much likely to be higher. Tying this idea of anxiety into the FSI, the lack of certainty of the trajectory of the illness greatly increases anxiety within the family and decreases family functioning.

Effects on the couple relationship. When considering terminal illness on the family, especially at the ending stages of the illness, the couple relationship is often greatly affected. Notably, the most affected area of the couple relationship is the change in intimacy (Rolland, 1994; 1999; 2005). Intimacy is threatened in multiple ways, especially in the couple's sexual routine (i.e. frequency) and daily routine (Lynch, 2016). Intimacy must be maintained in other ways, especially when deciding what aspects of the couple's life the illness is allowed into. If the couple allows the struggle of the illness to flood into their relationship, intimacy will be lost, and the partners may withdraw from one another (Rolland, 1994; 1999; 2005).

With the onset of a terminal illness, boundaries are threatened within the couple, often leading the couple to enter a state of crisis. Boundaries must be redefined as the relationship changes from what the couple considers normal, especially if one member of the couple is taking on the role of the caregiver (Lynch, 2016). As the couple adjusts to the illness, it is extremely important to not allow discussing and caring for the illness to completely take over their lives; the couple should not cut out activities they once enjoyed (Rolland, 1999; 2005). Boundaries must be set with what the illness can be included in, and activities that the couple must keep separate from the illness, in order to maintain intimacy. It is extremely common for the couple to recognize the mortality of the situation and either pull away from their partner or fuse to one another as a way to cope with the stress of the impending loss (Rolland, 1999; 2005). This boundary definition depends on the levels of depression and uncertainty that the illness presents. Rolland, (1994; 2005) found that some of the caretakers may engage in other things, such as an affair, to avoid feeling the pain of the illness, whereas others refuse to leave their loved one's side.

Defining boundaries regarding the needs of the patient is of utmost importance, especially when deciding the roles of the spouse as the caregiver (Rolland, 1994; 2005). It is important to decide which tasks of care can be handled by the individual, by their spouse as a caretaker, and/or by a professional caretaker. Setting new boundaries as the illness progresses into the terminal phase is extremely important, especially when attempting to balance intimacy and caretaking. In order to create effective boundaries and maintain intimacy when dealing with the impending death of a terminally ill partner, communication is the most important aspect of this adjustment process (Rolland, 1994; 1999). The couple must form effective communication skills surrounding the illness, creating a safe and open space to communicate about difficulties regarding the new demands of the terminal illness. Rolland (1999; 2005) found that couples often find it intimidating to explore new territory together and are afraid to communicate about the illness, fearing they will burden their partner. While a couple coping with an illness must communicate frequently, it is still important to set a boundary, even with communication. This boundary applies especially if there are differing ideas about the prognosis of the patient. For example, if one partner has a more negative outlook than the other partner, this does not necessarily need to be shared, (Rolland, 2005). Specifically, this is true for when couples are discussing the potential outcomes of death from the ill partner. While not everything must be shared, maintaining open communication regarding death prepares both partners for what is to come in the near future of their relationship (Rolland, 1999; 2005).

Open communication between couples is crucial, especially when experiencing the overflow of emotions that occurs with the end stages of a terminal illness (McLean and Hales, 2010). Frequently, a level of shame or guilt associated with the illness causes the couple to minimize communication, as an effort to avoid associated feelings (Rolland, 1999; 2005; Lynch, 2016). In order to keep on track for positive adjustment, the couple must be open and validate one another's feelings of anger, hopelessness, ambivalence, death wishes, or escape fantasies (Rolland, 2005). Such feelings are exceptionally common when dealing with a terminal illness, and the couple must acknowledge them in order to properly care and support one another. Because emotional reactivity is inevitable within couples coping with a terminal illness, these couples must be able to tolerate strong emotions and maintain a level of forgiveness if something irrational is said (Rolland, 2005).

When a couple is dealing with a chronic illness, it is common for the disease to be seen from a skewed idea of it being "my" problem or just the patient's problem. Couples are able to determine their level of functioning with dealing with illness by encouraging one another to view this as a joint problem, not the patient's problem (Rolland, 1999; 2005). While the ill partner has many emotions to organize regarding the illness, the well partner is commonly experiencing similar feelings, such as preparing for death, or mourning of their past lifestyle. If the illness is just viewed as the patient's problem, it is especially likely that an issue of power and control will be established between the ill and well spouse. By creating this power struggle, Rolland (2004) notes that the couple is not working cohesively, adding to the burden of the illness and potential feelings of resentment between partners. Lewis, Hammond, and Woods (1993) found that if the illness demanded more than the couple communicated about, depressed moods are increasingly likely, negatively affecting the marriage and decreasing marital satisfaction during the time of illness; this finding is supported through a study completed by Lynch, 2016.

Effects on children. When a terminal illness occurs in a family, especially to a parent, the children are often affected in a multitude of ways. Depending on the age of the children, the relationship with the ill parent can cause great amounts of grief and stress, based on the level of understanding and attachment (Saldinger et al., 2004; Lynch, 2016).

When a parent becomes terminally ill, they have a more difficult time providing for and connecting with their child. Saldinger et al. (2004) found that the relationship with the parent is often limited by the physical and emotional inability to reach out to the child, and the child's reactivity to the parents deteriorating condition. This study found that throughout the process of the illness, the children often feel a strong desire to maintain a connection with their ill parent, even if the parent is unable to maintain connection due to the severity of his or her health changes (Saldinger et al., 2004). The desire for the child to maintain a relationship with the dying parent can extend into such a deep desire for attachment that the child will create fantasies about their parents responding to their attachment bids. Saldinger et al. (2004) found that it is common for the parent and child to desire stronger attachment during the final phases of life, and efforts made to maintain this attachment after death can have a strong impact on the healing process. Although this connection is strongly desired, it may not always be maintained properly, due to the lack of control and unpredictability of the impending death and terminal illness (Saldinger et al., 2004).

The effects of terminal illness on children is not solely determined by the child's relationship with their ill parent. Child functioning can also be defined by the rest of the family's adjustment to the illness, and the support that they receive (Lewis et al., 1993). Keeping this in mind, Lewis et al. (1993) find it very important to note that how the well parent is adjusting to the illness greatly affects child outcomes. For the children, especially younger, the well parent acts as a resource for the child, providing information about the parent's illness, and providing emotional support to the child's reactivity to the stress (Lewis et al., 1993). If the well parent was coping well and emotionally available for the child, then according to the study by Lewis et al. (1993), the children generally showed higher rates of self-esteem and more productive coping. However, Lewis et al. (1993) found within their study that if parental communication was low between the parents regarding expectations of care, that depression rates were often higher, decreasing the quality of the marriage. If the marriage is not proving to be well, the child will often display negative signs of adjustment and responses to the parent with the terminal illness.

These problems only begin to amplify as the children get older, creating a new number of stressors during adolescence. Similar to the results found by Saldinger (2004) and Lewis (1993), Sieh, Dikkers, Visser-Meily, and Meijer (2012), discovered that the adjustment of an adolescent is also heavily influenced by the quality of relationship and attachment with the ill parent. If the parent and child have a poor attachment relationship, they are much more likely to experience high levels of stress (Sieh et al. 2012). Similar to the findings by Lewis et al. (1993), Sieh et al. (2012) also found that if the parents displayed a poor marital relationship, then the child is much more likely to experience heightened stress in relation to the illness. After Sieh (2012) confirmed information that has been previously proven, they then went on to study gender differences in relation to adolescent stress. The study conducted found that female adolescents are much more likely to display levels of stress rather than adolescent males (Sieh et al. 2012). All in all, the effects that illness, in this case, cancer, has on children depends heavily on family relationships, as the family works as a systems model.

Chapter 3: Theoretical Framework

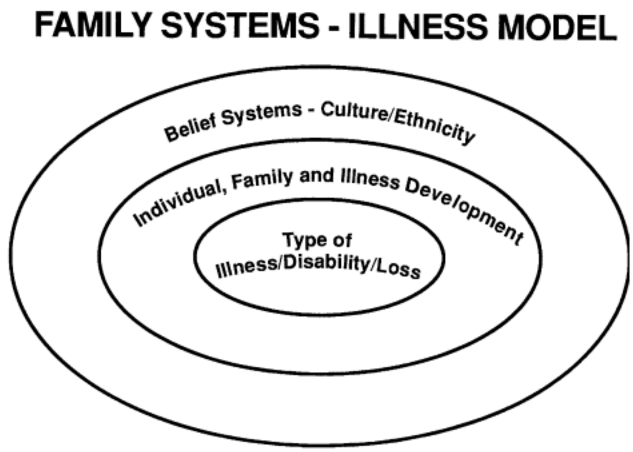
Examining theoretical frameworks used in the present study, it is important to understand the basics of the theoretical study of families. Murray Bowen noted the importance of the effects that family members have on one another, due to the fact that they share a history and a future (Walsh, 2012). This gave Bowen the idea that families work together as a system, and not simply as individual moving parts (Walsh, 2012). After other researchers, such as Minuchin and Kerr began to apply this theory in research, and in practice, family systems theory became the dominant theory to analyze families. Furthering this idea, John Rolland adapted Family Systems theory to an illness in the family, studying how the family system adapts and changes when a member of the system falls ill (Rolland, 1999). In the present study, each theory is discussed in the context of cancer diagnoses in families, and the associated cancer and financial stress.

Family Systems Theory

When examining parental cancer's effect on a nuclear family, it is crucial to gain an understanding of the overall idea of Family Systems Theory. Family units have a shared history and have a shared future (Walsh, 2012). Minuchin, a researcher studying family systems in depth, noted that families did, in fact, work as a system, and each familial interaction has power and affect over family member behaviors (Minuchin, 2012). For example, the couple relationship between two parents can have a great effect on the child's current and future behavior. If the couple relationship between the parents is historically negative, it would not be surprising for the children to act out, or to struggle in future romantic relationships. Because of this, Minuchin encouraged researchers to view the family as a holistic system, paying attention to the relationships that the elements have on one another (Johnson, 2004). The idea is the causal relation of behaviors, meaning that each response to communication is related, affect the way family members communicate and function as a unit. When the system is going through a change in the elements, such as an illness, job loss, etc., the hierarchy of the family system can be altered, causing the family cohesion to decline and chaos to ensue (Walsh, 2012). Because families consistently face changes as such throughout the lifecycle, researcher John Rolland adapted family systems theory to illness, encouraging professionals to consider the family when distributing care (clinical guidelines).

Family Systems Illness Model

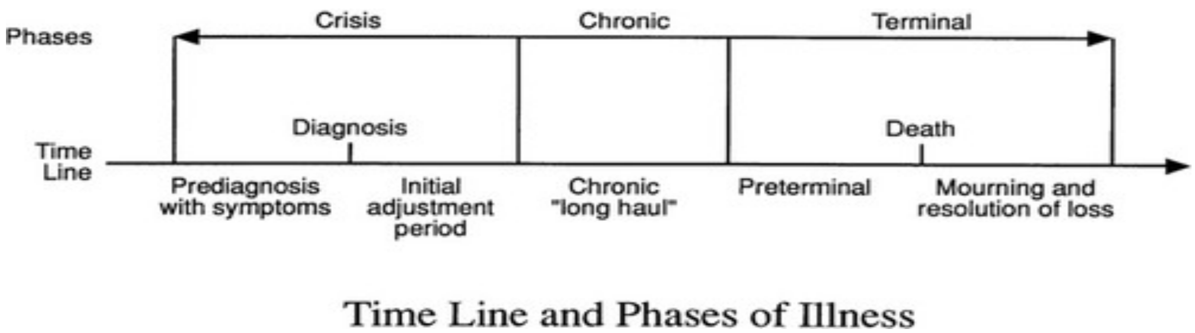
Figure 1.1: Family Systems Illness Model Diagram.



Cancer can have a devastating impact on the family system and the Family Systems Illness Model (FSI) is integral to understanding the effects illness has on a family (Rolland, 1999; 2004). The FSI, operating from a family systems perspective, measures family reactions to stressors caused by illness over time, consistently using family as the interactive focal point of the processes (Rolland, 1994). The FSI also keeps track of how the family interacts with its environment (e.g., the healthcare system; Rolland, 1994) in response to the stressor. Rolland (1999) examines the goodness of fit between the psychosocial demands brought on by the terminal illness, and how the family functions within the limits of the illness. The main focus of the FSI is to track the systematic interaction between the family and the illness-induced stress.

According to the FSI, the illness progresses in three stages: crisis, chronic, and terminal; with each stage demanding a different role from each family member (Rolland, 1994).

Figure 1.2: Phases of Family Systems Illness Model



During the crisis stage, the family is left to deal with the panic of not knowing the outcome of the diagnosis, as well as the readjustment period that occurs after the diagnosis is finalized. In the crisis stage, the family must learn to cope with the changes brought about by the illness, such as adapting to daily symptoms, adapting to the healthcare environment, and creating relationships with the care team at the clinic. (Walsh, 2012). The crisis stage demands the most initial adjustment and the functioning of the family system are tested. Rolland (1994) notes that during the crisis stage, healthcare providers have the most influence on the family's outlook on their loved one's prognosis. The chronic stage of illness essentially refers to the time where the family has adjusted to life with the diagnosis and have fallen into what is considered to be their new normal (Walsh, 2012, p. 315). Lastly, during the terminal stage, death is inevitable, and the family must begin coping with emotions and grief associated with the death of the family member (Walsh, 2012, p. 315). During this time, families will struggle to adapt and reorganize the family system due to the loss of their loved one. Depression is often present in family members and the patient as they reach the end of their life with a terminal illness (Pessin, Rosenfeld, & Breitbart, 2002; Edwards & Clarke, 2004; Teixeira & Pereira, 2016; Areia et al., 2019). This proves to be one of the most difficult aspects of the terminal phase, which often affects families long term. The family systems illness model provides an extensive framework for the reorganization of families during the time of illness, paving the way to allow researchers to understand the challenges that families face when coping with illness.

The Current Study

When considering the varying effects that cancer can have on the family system and family functioning, it is crucial to note the effects that role changes within the family have in regard to each family member's coping skills. This level of coping is connected to functionality and family cohesion. The purpose of the current study is to examine the connection between cancer stress and financial stress through a family's adaptation and cohesion abilities. The present study tests four hypotheses:

1. Participants' perceived stress about cancer will be significantly and positively related to their perceptions of the financial stress associated with a cancer diagnosis.
2. Higher levels of participant cancer stress will be related to lower levels of reported family adaptability and cohesion.
3. In turn, higher levels of family adaptability and cohesion will be associated with lower levels of cancer and financial stress.

4. Cancer Stress will be related to Financial stress through the mediation role of family adaptability and cohesion.

Chapter 4: Methodology

Participants

To qualify for the present study, an individual must have a cancer diagnosis or have a member of the family with a cancer diagnosis. Participants were recruited from hospitals, the Cancer Support Community network, as well as social media platforms, such as Facebook. Participants were gathered with the snowball effect as well, as current participants and organizations were encouraged to inform others about this study. The participants completing the survey were required to be over the age of 18 within the participating families. In order to recruit participants, flyers (see Appendix A) to sign up for the study were distributed to various cancer support groups, displayed in hospitals, and emailed in newsletters via the Cancer Support Community. The flyer provided information about the study, a QR code to provide easy access to the Qualtrics survey, as well as the researcher's contact information to answer further questions. Participation in this study was completely voluntary, giving participants the ability to stop at any time point in the study.

Measures

The participants were given a three-part questionnaire to complete. The first two sections of the questionnaire are the Response to Stress Questionnaire (RSQ), specifically the RSQ for financial problems and for cancer stress (Compas et. al, 2006). After completing both sections of the RSQ, the participants then completed the Family

Adaptability and Cohesion Scale IV (FACES IV) to measure family cohesion and well-being (Franklin, Streeter, Springer, 2001).

Demographic Variables. Each participant completed a series of questions to define the demographics of this study. Specifically, these items will focus on the participant's age, race, sex, marital status, financial status, and education status (Hamel et al., 2016). The financial status items will be used to capture information about their ability to meet their expenses both before and since the diagnosis. The participants were asked questions regarding their cancer diagnosis, such as the stage of cancer, when they were diagnosed, where they are in treatment, and their medical insurance provider. Although 84 participants contributed, only 53 of the participant data were utilized due to missing data and attrition. Out of all participants in the current sample, (n=53) 93.4% identified as Caucasian, 1.9% Hispanic, and 3.8% Asian, no other race or ethnicity was present in the sample. 46.3% of the sample was between 84 to 75, 52.6% was between 70 and 41, and 1.1% was between 40-28, with the youngest participant being 28. The sample was primarily female at 64% of the participants identified as female, 34% as male, and 1.9% as other. Out of the sample 77.4% were married, over 60% of the participants had a Bachelor degree or higher, and 77.4% of the participants identified as the patient, and 22.6 identified as a family member. 20.8% of participants experienced job loss or reduction of hours following a cancer diagnosis in themselves or a family member. Roughly 50% of the sample reported that they had another family member who had also been diagnosed with cancer. Nearly 50% of the participants made over $75,000, and the 77.3% of the participants had less than $25,000 of debt. 9.4% of the sample reported having $100,000+ in debt. The demographic data is displayed in Table 1 below:

Table 1
*Demographic Characteristics of Participants (*N *= 53)*

Characteristic	*n*	%
Gender		
Woman	34	64.2
Man	18	34.0
Other	1	1.9
Race or ethnicity		
White	50	94.3
Black	0	0
Hispanic	1	1.9
American Indian or Alaskan Native	0	0
Native American	0	0
Asian	2	3.8
Other	0	0
Age (years)		
28-40	7	46.3
41-70	26	52.6
75-84	19	1.1
Marital Status		
Single	4	7.5
Dating/Courting	3	5.7
Married	41	77.4
Divorced/Separated	4	7.9
Other	1	1.9
Education		
Less than high school degree	1	1.9
High school degree/equivalent	2	5.7
Some college, no degree	12	22.6
Associate degree	2	3.8
Bachelor degree	15	28.3
Professional degree	6	11.3
Graduate degree	15	28.3

Response to Stress Questionnaire- Cancer Stress. Within the RSQ, participants completed the questionnaire measuring the stress levels associated with witnessing a family member struggle with cancer. Each participant will be given the RSQ measuring stress of cancer and family financial troubles. The RSQ for cancer and financial stress each contain 57 items. The RSQ uses a Likert-type scale ranging from *not* *at all* (scored as 1) to *a lot* (scored as 4). RSQ-Cancer Stress (CS), uses questions to scale perceived stress and coping behaviors. For example, on the RSQ-CS asks, "I do something to try to fix the stressful parts of having (a family member with) cancer." Not only does this questionnaire measure the levels of stress, but it also asks the participants to write their coping mechanisms as well. These survey questions from the RSQ-CS will allow the researcher to measure stress and evaluate coping skills in order to compare them to other families struggling with cancer. The RSQ has been adapted to various stressors to analyze stress levels. In previous use, the RSQ has alpha= 0.71 for the majority of the variations of the questionnaire (Conner-Smith, 2000).

Response to Stress Questionnaire- Finance Version: Questions measuring coping within the RSQ-Finance Version (FV) are presented as "When I am trying to sleep, I can't stop thinking about the stressful aspects of money problems or I have bad dreams about money problems," or "My mind just goes blank when something stressful happens related to money problems, I can't think at all." These questions determine the behaviors surrounding financial stress. Both the RSQ-FV and RSQ-PC show high validity in previous studies completed in related topics, generally showing alpha= 0.71 (Wadsworth & Compas, 2002; Jaser et al., 2005).

Family Adaptability and Cohesion. FACES IV is a 62-item questionnaire that measures family cohesion and well-being. Similar to the RSQ, FACES IV is measured using response options ranging from *very dissatisfied* (reported as 1) to *extremely satisfied* (measured as 5). This survey uses questions to report family cohesion within specific family interactions. For example, FACES IV will ask questions such as: "Family members seem to avoid contact with each other when at home," and "Our family becomes frustrated when there is a change in plans or routines." Each question scales the family's ability to adapt to change, measure how tasks are completed, and note boundaries within the family system. FACES IV is a commonly used assessment, providing high levels of validity and reliability. (Franklin, Streeter, Springer, 2001).

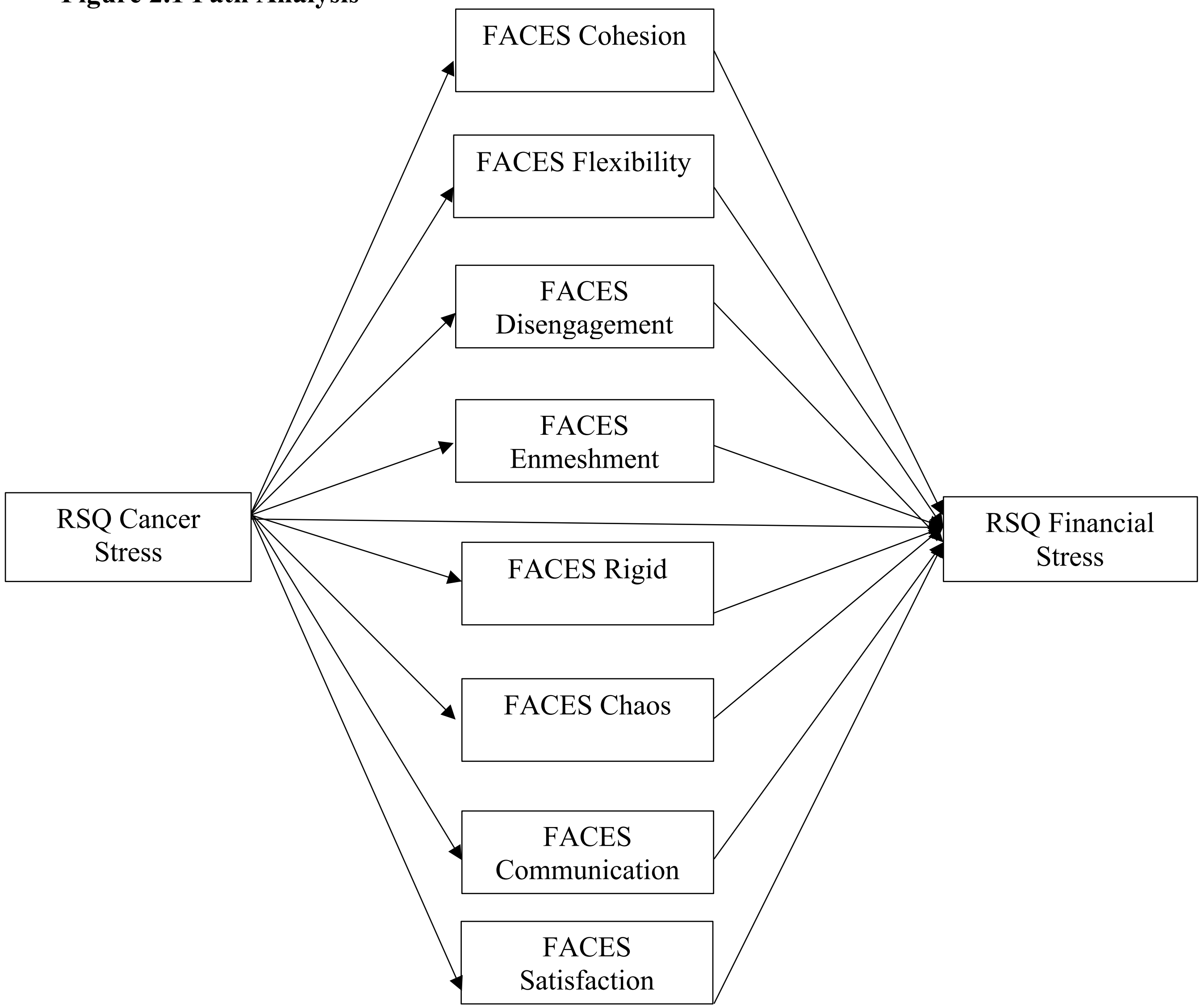
Procedure

Before beginning the study, each participant was given an informed consent which highlights the risks and issues of confidentiality. After signing the informed consent, the participants were given a three-part survey to complete, measuring their cancer and financial stress as a family. The survey was not distributed to children, as this study measured the participants' view of their own coping, and family coping. Next, each participant filled out the survey. The survey was delivered online via Qualtrics administered via email or via the QR code presented on the recruitment flyer in order to allow the participants to access the survey anywhere. Each participant was thanked for their participation in the survey and be given an option to enter a drawing to win $150, per 50 participants.

Analytical Strategy

The current study utilized a path analysis (displayed in figure 2) examining the relationship between perceived cancer stress and perceived financial stress in families coping with late-stage cancer, as well as the mediating role of family adaptability and cohesion. Preliminary analyses examine a bi-variate correlational matrix across all study variables. Data was collected with SPSS 25 (IBM Corporation, 2016) and analyses were run through AMOS 24.0 (Arbuckle, 2014) to obtain estimates. Full information maximum likelihood (FIML) was used to account for missing data. FIML is preferable to other methods because it allows all available data to be utilized when estimating model parameters and standard errors (Enders, 2001). Standardized coefficients were reported in analyzes. A range of fit indices was used to assess the goodness-of-fit, including the Chi-square statistic/degrees of freedom ratio, comparative fit index (CFI), and the Root Mean Square Error Approximation (RMSEA). Measures of income, debt, and overall health were accounted for in analyses as control variables. These controls were chosen due the affect the amount of income and debt could have on general financial stress levels, potentially skewing the outcome results. Additionally, the present study controls for overall health as well, assuming that if one's health is lower quality in general, this could also skew the outcome data.

Figure 2.1 Path Analysis



Chapter 5: Results

Preliminary Analysis

A zero-order, bivariate, correlational matrix, as well as means, standard deviations, and skewness of the study are shown below. Associations to note, FACES flexibility and FACES cohesion displayed a statistically significant relationship (*p* <

0.001), meaning that if a family has strong flexibility, it is more likely to be cohesive in nature. FACES disengagement was negatively associated with FACES flexibility (p < 0.001), meaning that if family members are disengaged, the family will display less flexibility. FACES rigid was positively correlated with FACES enmeshment (p < 0.002), meaning that if the family had very rigid tendencies, the likelihood of the family being enmeshed was much higher. FACES communication was negatively correlated with FACES chaos, (p < 0.001), meaning the more communication present within the family, the less likely that the family system will be chaotic. FACES family satisfaction was positively correlated with FACES family communication (p < 0.001), meaning that the more communication displayed in the family system, the higher the reported levels of satisfaction were. The RSQ Finance version was positively correlated with RSQ cancer stress (p < 0.001), meaning that cancer stress and financial stress are associated with one another.

Because of the elevated stress levels that are often experienced with a cancer diagnosis (Goldblatt, et al., 2019; Lewis et al., 1993, Rolland, 1999), it was surprising to find that there was only one connection between adaptability and cohesion, cancer stress and financial stress. This finding is unexpected, especially with there being a lack of a significant relationship between cancer stress, financial stress, and family communication. During uncertain times and changing roles due to illness, in this case a cancer diagnosis, the family's ability to communicate theoretically affects the experiences of stress (Rolland, 1999; 2004). Considering this information from previous research, it was expected that there would be a significant relationship between at least one of the forms of stress, cancer and financial, and communication, however, this was not the case. Additionally, when examining the FACES subscales in comparison to both RSQs, it was hypothesized that if families displayed higher levels of cohesiveness and adaptability, that they would express less stress. However, the present study found that the majority of the FACES subscales did not have any connection to stress, making this hypothesis impossible to prove. FACES rigid did have a significant connection to cancer stress, meaning that cancer stress caused rigidity to increase in families. Thinking of circumstances that families experience after a cancer diagnosis, the stress, according to Rolland (1999) will cause families to reorganize and take on new roles, which could cause the family to become more rigid, as this result suggests.

The controls also appeared significant in the bivariate correlation as income was related to FACES cohesion ($p < 0.013$), FACES chaos ($p < 0.041$), RSQ- Cancer Stress ($p < 0.005$), and RSQ- Financial Stress ($p < 0.002$). This indicates that income is related directly to cancer and financial stress, as well as family cohesion and chaos. While debt did not show any correlation, overall health showed significant relationships. Overall health was related to cohesion ($p < 0.033$), family satisfaction ($p < 0.029$), RSQ- Cancer Stress ($p < 0.015$), and RSQ- Financial Stress ($p < 0.001$). Essentially, the control shows overall health has significant relationships with cohesion, satisfaction, cancer stress, and financial stress. The data is displayed in **Table 2** on the following page.

Table 2: Bivariate Correlations of Study Variables

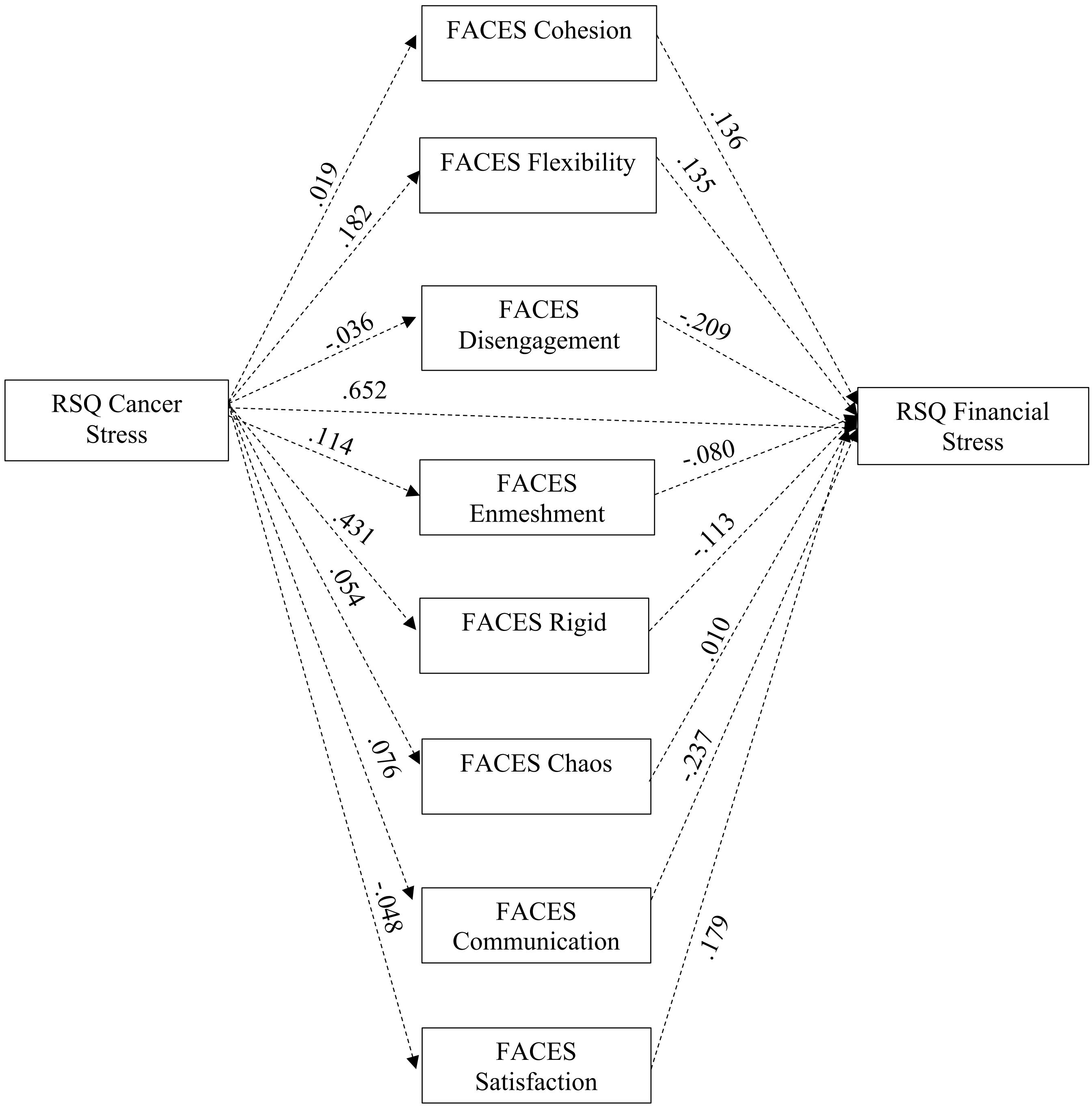
	1	2	3	4	5	6	7	8	9	10	11	12	13
1. FACES Cohesion													
2. FACES Flexibility	.815***												
3. FACES Disengagement	-.878**	-.836***											
4. FACES Enmeshment	-.167	-.184	.210										
5. FACES Rigid	-.273*	-.070	.171	.409**									
6. FACES Chaos	-.742***	-.675***	.732***	.211	.234								
7. FACES Communication	.848***	.874***	-.852***	-.233	-.250	-.740***							
8. FACES Satisfaction	.833***	.874***	-.853***	-.221	-.363**	-.735***	.927***						
9. Cancer Stress	.019	.182	.036	.114	.431***	.054	.076	-.048					
10. Financial Stress	-.042	.103	.003	-.103	.249	.121	-.044	-.132	.766***				
11. Income	.344*	.255	-.236	-.119	-.252	-.288*	.188	.241	-.388**	.466**			
12. Debt	.092	.231	-.147	-.065	-.065	-.045	.154	.116	.079	.216	.133		
13. Overall Health	.293*	.164	-.171	.102	-.154	-.196	.166	.189	-.301*	-.369*	.473***	-.021	
Mean	4.21	3.69	2.06	1.73	2.32	1.98	3.92	3.59	2.13	1.85	4019.61	1.98	3.53
Std Deviation	.908	.794	.823	.537	.679	.736	.930	.961	.406	.438	1760.50	1.54	.911
Skewness	-2.29	-1.21	1.71	.471	.221	.625	-1.32	-.915	.090	.057	.333	.333	.327
Range	4.00	3.86	3.57	2.14	2.86	2.71	4.00	4.00	1.66	1.81	5000.00	5.00	3.00
Range Min	1.00	1.00	1.14	1.00	1.00	1.00	1.00	1.00	1.40	1.00	1000.00	1.00	2.00
Range Max	5.00	4.86	4.71	3.14	3.86	3.71	5.00	5.00	3.06	2.81	6000.00	6.00	5.00

Note: Three stars (***) indicates $p < .001$, two stars (**) indicates $p < .01$, and one star (*) indicates $p < .05$.

Structural Equation Modeling

Original model. Structural Equation Modeling (SEM) was used to assess the relationships among cancer related stress, family adaptability and cohesion, and financial stress. Figure shows the standardized path coefficients for the SEM for participants. The initial model tested did not fit the data and did not show any significant paths. The initial model fit indices were as follows: $\chi 2(104\text{-}49) = 55$, $p < .001$; RMSEA = 0.380; 95% CI [0.249, 0.412]; CFI = 0.092.; TLI -0.502. $\chi 2/df = 8.518$. As shown, the initial hypotheses did not show any significant pathways. None of the controls proved to be significant. This figure (Figure 1) is displayed again below.

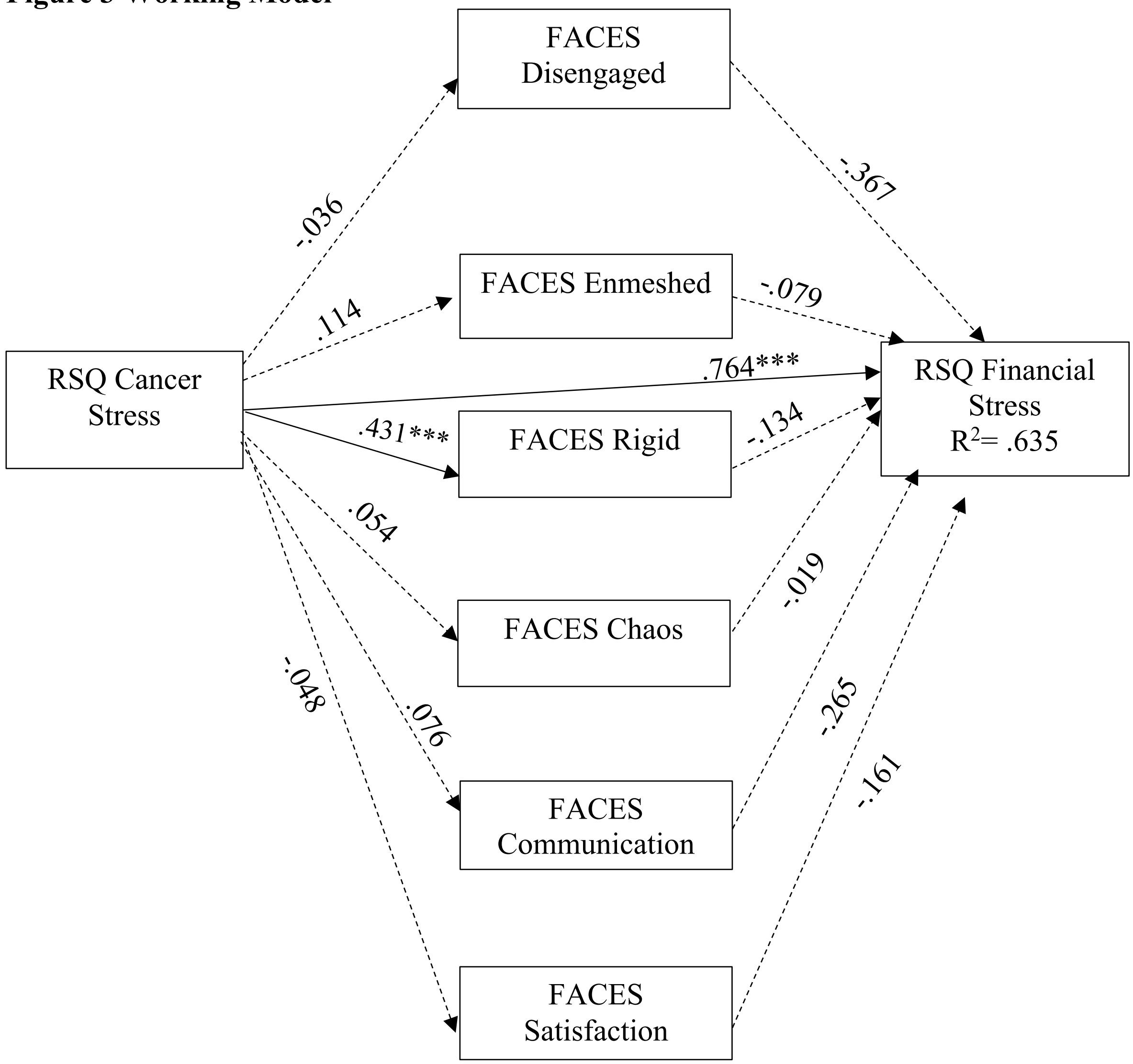
Figure 2.2 Path Analysis of Initial Model



Note: Three stars (***) indicates p< .001, two stars (**) indicates p< .01, and one star (*) indicates p<.05.
Model fit: : $\chi2(104\text{-}49) = 55$, $p < .001$; RMSEA = 0.380; 95% CI [0.249, 0.412]; CFI = 0.092.; TLI -0.502. $\chi2/df = 8.518$.

Working model. By removing FACES cohesion and flexibility, a stronger model fit was discovered, creating significant pathways. This model is referred to in the present study as the working model. Model fit indices suggested the model fit the data reasonably well $\chi 2(77\text{-}56) = 21.504$, $p < .001$; RMSEA = 0.29; 95% CI [5.192, 5.192]; CFI = 0.; TLI 0. $\chi 2/df = 5.639$. Standardized coefficients are shown. Significant paths are shown. RSQ Cancer Stress was associated with FACES Rigidity (ß = 0.431. , $p < 0.001$), respectively. Additionally, RSQ Cancer Stress was associated with RSQ Financial Stress (ß = 0.764. , $p < 0.001$), respectively. It is important to note that FACES disengagement has an almost significant relationship with financial stress (ß = -0.367. , $p < 0.067$), The new model is displayed below:

Figure 3 Working Model



Note: Three stars (***) indicates p< .001, two stars (**) indicates p< .01, and one star (*) indicates p<.05.
Model fit: $\chi 2(77\text{-}56) = 21.504$, $p < .001$; RMSEA = 0.29; 95% CI [5.192, 5.192]; CFI = 0.; TLI 0. $\chi 2/df = 5.639$.

Chapter 6: Discussion

The present study extends the literature by investigating how the stressors associated with a cancer diagnosis affect financial stress, mediated by the family adaptability and cohesion. By studying family adaptability and cohesion via FACES IV, the present study measured the varying family types (i.e. Balanced, Rigid Cohesive, Midrange, Flexibly Unbalanced, Chaotic Disengaged, and Unbalanced), and how the characteristics of these families may mitigate the relationship between the stress of a cancer diagnosis and the associated financial stress of said diagnosis.

Preliminary Analyses

The present study did find strong, significant bivariate correlations between poorer communication and flexibility and families reporting chaotic, rigid, and lower family satisfaction. These correlations indicate that the FACES variables have relationships to one another. This is important to note because this indicates that certain family behaviors are previously related, within the FACES Scale. When looking at the correlations between the varying family behaviors, the correlation table shows that specific family behaviors can lead to other behaviors. For example, in correlations, it was found that if a family is reporting higher levels of rigidity, meaning there is a relationship to enmeshment. Families that reported higher levels of communication showed higher levels of cohesion and satisfaction. Although FACES communication did not portray a significant line related to stress, it is possible that with more participants, higher levels of communication could be related to stronger family coping mechanisms.

An interesting finding to note in the present study is that there were not many correlations found between cancer stress and financial stress with the FACES subscales of cohesion: flexibility, disengagement, enmeshment, chaos, communication, and satisfaction. The preliminary findings did indicate a significant correlational relationship between cancer stress and rigidity, showing strong significance as indicated in table 2. This lack of significant relationships is a surprising find, as family adaptability and cohesion were expected to show some type of relationship to cancer stress and financial stress. Typically, the experienced level of chaos that occurs during a cancer diagnosis, especially during the crisis phase would involve a greater need for family adaptability and cohesion (Rolland, 1999). With families being forced to reorganize unexpectedly, the present study hypothesized that this would lead to poorer family adaptability and cohesion, increasing cancer stress and financial stress. Potentially, if the sample size were larger and more diverse, there could have been more significant connections between each of the variables in the model.

Structural Equation Modeling

In the present study, there are two models that were tested, the initial model and the working model. Originally, the initial model did not indicate that there were any relationships between cancer stress, family adaptability and cohesion, and financial stress. These findings were surprising, as there was only one significant path between cancer stress and rigidity, the rest showed no significance. The connection between cancer stress and financial stress was nearly significant. This near significant relationship could be explained by the smaller sample size; if the sample size were larger, there would be a chance at having more significant results. This was surprising, especially when looking at behavioral patterns after a cancer diagnosis explained by Rolland (2004). Essentially, in the FSI, there is the idea that families will go through a crisis phase after the initial diagnoses, which, theoretically could change the family's adaptability and cohesion, increasing cancer stress and financial stress. These predictions were not confirmed in the results of the first model. A potential cause for the lack of issues with adaptability and cohesion could be linked to the stage of the FSI that each participant was experiencing. For example, if a participant was in the chronic phase of the FSI, there is a chance that their family has efficient adaptability and cohesion. However, this does not account for the lack of connection between adaptability and cohesion in regard to cancer stress and financial stress, be it a positive or negative association. The working model displayed similar results, however, there were significant relationships between cancer stress and financial stress, as well as cancer stress and rigidity. The link between cancer stress and rigidity could be due to the chaos of reorganization potentially experienced by the family in the crisis phase of the FSI. A larger sample size would be needed to test this hypothesis.

Each model was controlled for income, debt, and overall health, with income and overall health showing significant results, especially in cancer and financial stress. Considering these results, the significance of the controls could imply that income has a direct relationship with cancer and financial stress, similar results are shown in overall health. Reviewing the structural equation model, while the original model did not fit, the new model showed the family characteristic that significantly linked to stress was family rigidity. When looking at the skewness of each of the variables, it is shown that FACES cohesion, flexibility, disengagement, and communication were all highly skewed, all outside of -1 to 1 range. FACES cohesion and communication were negatively skewed, indicating the distribution of responses was skewed to the right, meaning there were a higher number of participants indicating more cohesion and communication. FACES flexibility and disengagement were positively skewed, meaning that there was a lower number of participants indicating levels of flexibility and disengagement. The high level of skewness is likely due to the lack of diversity in the small sample causing the distributions to be skewed, rather than evenly distributed. This meaning a larger sample size could, potentially, create more significant pathways linking family adaptability and cohesion with cancer related cancer and financial stress.

Hypothesis 1 stated participants' perceived stress about cancer will be significantly and positively related to their perceptions of the financial stress associated with a cancer diagnosis. The findings of the final SEM model indicate a significant and positive relationship between the perceived stress of cancer and financial stress associated with a cancer diagnosis, thus confirming the hypothesis. This finding provides evidence that financial stress associated with cancer diagnoses may be impacted by the stress of a cancer diagnosis itself. This finding was unsurprising given the findings by Knight et al., (2018) which stated the costs and financial toxicity associated with cancer treatment adds significant stress on patients and caregivers.

Hypothesis 2 stated that higher levels of participant cancer stress will be related to lower levels of reported family adaptability and cohesion. Although the present study did find a relationship between cancer related stress and financial stress, there were no significant relationships between each stressor and low adaptability and cohesion. There was one significant result between cancer stress and rigidity. This could potentially be due to the fact that, as stated by Rolland (1999, 2004) in the FSI, roles change within the family when an illness occurs. It is not uncommon for family members to have to become full time caregivers, become financial providers, or take on any other new role within the family (Rolland, 2004). Due to the many new stressors provided in a cancer diagnosis, it appears that families will become more rigid in their family roles, potentially due to the lack of control and chaos experienced in time of diagnosis. Essentially, this finding provides evidence that cancer stress can lead to increased levels of rigidity in the family system. When looking at the data, FACES cohesion, flexibility, disengagement, and communication were all highly skewed; which could act as an explanation of the lack of significant pathways. This skewness could lead to less significant pathways due to the fact that there is not a standard distribution of data, meaning the participants were indicating similar higher or lower numbers in these variables. This high positive skewness indicates a higher level of cohesion, communication, and flexibility, meaning that most participants reported higher levels of cohesion, communication and flexibility in their families. Additionally, disengagement was negatively skewed, meaning that participants reported lower levels of disengagement with their families. Potentially, the phase of the illness and length of illness time could have an effect on the skewness of this data, meaning that the longer a family has coped with an illness, in this case, cancer, the more likely they are to be well adjusted, (Rolland, 2004; Hwang et al., 2018) Additionally, the lack of significant results is likely related to the lower sample size that did not contain much diversity.

Hypothesis 3 stated that higher levels of family adaptability and cohesion will be associated with lower levels of cancer and financial stress. Similar to Hypothesis 2, unfortunately, no significant relationships were found between reported levels of family adaptability and cohesion and reported financial stress associated with a cancer diagnosis.

It is also important to note that FACES disengagement was nearly significantly related to financial stress. This could potentially show a more significant result if there were more participants in the sample. Because FACES cohesion was negatively skewed, this indicated that participants were reporting higher levels of cohesion than what would be seen in a normal distribution. This could be attributed to the stage of the FSI that the participant was in, meaning if there were more participants in the chronic phase, the family is much more likely to report higher amounts of cohesion. In the chronic phase of the FSI, the family has adjusted to life with the illness and it is considered to be the "new normal," meaning that the family is settled into their new roles, and no longer in crisis; this inferring that in the chronic phase, higher levels of cohesion are likely (Rolland, 2004)

Hypothesis 4 stated that Cancer Stress will be related to Financial stress through the mediation role of family adaptability and cohesion. Unfortunately, no significant pathways were found to mediate the relationship between cancer stress and financial stress through family adaptability and cohesion. This finding was surprising, especially considering that one of the biggest stressors of a cancer diagnosis is the financial implications (Lewis et al., 1993; Goldblatt et al., 2019). The lack of significant results would likely differ if the sample size were larger and more diverse, this would provide the opportunity for the sample results to follow a more standard distribution.

Additionally, financial stress had an R^2= .635, indicating that over 63% of the observed variation can be explained by the working model's inputs, indicating that based on the current findings, the majority of financial stress associated with a cancer diagnosis may be impacted by the emotional toll of cancer stress itself. This indicates that the family adaptability and cohesion scales did not mediate stress levels in a positive or negative manner. When looking at the sample, over half of the participants were women, and a small amount of men were in the sample. Due to this finding, there was a comparison attempt in differences in responses between men and women. Although neither all men nor all women models had a large enough sample for proper model fit, differences between genders were tested for independent and dependent variables of cancer stress and financial stress, respectively. Subsequent t-tests indicate significant variance between males and females in financial stress (p=.011). None of the participants identifying as "other" were used in the dataset, therefore they were not used in the t-test. Although this cannot be confirmed with the present analyses, this could possibly indicate that men are experiencing higher levels of financial stress than women. While this is not in the present study, future research could benefit from a larger and more diverse sample size to test the significance between genders.

Chapter 7: Implications

Theoretical Implications

When examining the results from this study, at the very least, there are indications of stress levels, both emotionally and financially, when given a cancer diagnosis. The present study hypothesized that after a cancer diagnosis, the way families adapted to stress based on their family style in the FACES IV scale, would affect the levels of reported financial stress. This hypothesis means that families with a cancer diagnosis already display elevated stress levels due to the illness, and if they are displaying lower levels of adaptability and cohesion, they may be more likely to struggle when coping with the associated financial stress of cancer treatment. This study found a significant and positive pathway for FACES rigidity with cancer stress. As stated previously, FACES cohesion (skewness= -2.29), flexibility (skewness= -1.21), disengagement (skewness= 1.71), and communication (skewness= -1.32), were highly skewed, affecting the results as the outcomes were not equally distributed, likely due to the lower number of participants. However, due to the fact that the results indicated elevated stress levels in families coping with a cancer diagnosis and finances, in addition to the connection to some of the FACES measures, this provides evidence that families are experiencing some level of cancer-related and financial stress. The implications of the data found in the present study show that there are statistically significant stress levels in this population, and that future research must be conducted in order to gain more breadth when understanding these stress levels. With more research in this area, clinicians would have a better indication of what therapeutic focus would benefit cancer patients and their families the most.

Psychotherapy as Part of Cancer Treatment

As seen in the review of the literature, we can see that there are many stressors put upon families and patients struggling with cancer. As mentioned before, although FACES communication did not indicate a significant link to cancer associated stress levels in the present study, it is still likely that increasing communication within the family system would potentially reduce stress levels. With this in mind, if this suggests success in further studies, family therapy would be a beneficial and integral part of cancer care; benefitting both the patient and their family. Considering this, there is some literature stating that psychotherapy is a great benefit to cancer patients, the caregivers, and their families. In fact, a randomized clinical study (Borji et al., 2017) evaluating the efficiency of Cognitive Behavioral Therapy (CBT), within depression and anxiety management within caregivers (Borji et al., 2017). While this did prove to be helpful, due to CBT's idea that anxiety and depression management behaviors can be learned (Borji et al., 2017), this does not acknowledge the conflicts in regard to family functioning. When considering appropriate therapy techniques for families struggling with cancer stress, ideally, a family would benefit from a more systems-based type of therapy. While there has shown to be success with CBT, this lacks the integration of family systems model, and how to treat the system, rather than the individual.

Continuing this idea, a therapeutic model called Emotionally Focused Therapy, that is often used with couples, has been tested on couples facing illness, such as cancer. Emotionally Focused Therapy (EFT) puts a heavy emphasis on creating a safe space to express underlying emotions, and address attachment insecurities (Tie & Poulsen, 2013). Because the process of coping with illness and grief is generally a traumatic experience for the family, and attachment bonds within the family come to the forefront, EFT is thought to be a successful therapeutic intervention option for families, especially if they are anticipating death due to illness. The literature discusses that illness can often activate the attachment system, causing one to return to their internal working model (Tie & Poulson, 2013; Giese-Davis et al., 2002; Greenburg, 2012). In a study conducted with 16 couples, one suffering from terminal cancer, were to attend 8 sessions of EFT, and were tested both before and after for hopelessness, depression, and marital adjustment (Tie & Poulson 2013). The outcome of this study displayed that levels of depression significantly decreased within the patient, and moderately decreased within the spouse as well (Tie et al., 2013). Because EFT creates a safe space for couples to express emotions, the idea noted is that the improvement in communication brought the couples to a more secure attachment, comforting one another through the anticipated grief of the loss (Greenburg, 2012). This same space created by EFT to express emotions, ideally, would be very effective when working with families struggling with cancer as well.

Limitations

Limitations in the present study will provide guidelines for future research directions. The current study employs a cross-sectional research design, meaning that the findings should not be interpreted from a causal perspective. Examining how the study's constructs change over time in relation to the variables would be a valuable addition to future research. Additionally, the present study had high attrition rates, meaning many participants began the survey but did not complete it; out of 84 total participants, only 53 were used in data analyses. The study may have been limited in the representatives of the sample, due to the fact that the sample was majority white, married, and educated. In addition to demographics, the present study was limited in participants. Consequently, the findings are more difficult to generalize to a larger population of families managing a cancer diagnosis. This is strongly due to the spread of COVID-19, causing the study to be closed earlier than expected in order to avoid collecting skewed results

Future Research

When considering future research to add onto what has been conducted in the present study, there is a need to further investigate the link between cancer related stress and family adaptability and cohesion. First, future research would be needed to conduct a study with a larger sample size in order to make the results more generalizable. With a larger sample size, researchers should focus on gaining a more diverse sample, rather than having a study restricted to a majority race. Future research also could address the ethnic and racial differences in access to healthcare. Additionally, future research would benefit from conducting a similar, but longitudinal, study, examining how the variables change over time. When considering the context of demographics, this raises the issue of access to healthcare, especially with the sample being primarily Caucasian. This begs the question of there being a more diverse sample, yet other racial identities do not have as much access to healthcare, making them ineligible for the study, as they would not be in active treatment (Esnaola & Ford, 2012).

Conclusion

With cancer being one of the leading causes of death in the modern world, it is unsurprising to find out that there are over 16 million Americans living with cancer as of 2015 (American Cancer Society, 2019). With its worldwide prominence, cancer affects individuals and families alike, creating stress for all (Goswami & Gupta, 2018; Laizner, 2018). Because families work as a system, a cancer diagnosis can deeply disrupt the function. Considering this, John Rolland created the Family Systems Illness Model to explain the experiences within the family system at the time of a diagnosis, which is the lens in which families are viewed within the present study. In addition to cancer stress on the family system, the financial implications of cancer create stress as well (Amir et al., 2012; Balfe et al., 2016). The current study examines cancer stress and financial stress with family adaptability and cohesion. While the present study showed few relationships between cancer stress, financial stress, and family adaptability and cohesion, this could be attributed to the limitations of the study. Future research should be conducted with a larger, and more diverse sample size, increasing the likelihood of significant results.

Appendices

Appendix A

Struggling with malignant cancer?

If you are 18 or older and suffer from late stage cancer, you may be eligible to participate in a research study.

Assessing stress associated with malignant cancer, and its effect on family coping and cohesion.

This study will include a one-time survey assessing the effects of financial and emotional stress on participants and their families, as well as the effect this stress has on family functioning. The goal of this study is to assess family coping skills, and how the family functions under the extreme stress of coping with cancer. Ideally, the results of this study will advocate for cancer patients and their family's need to include family counseling in comprehensive care.

Participants will:

Complete a one-time online survey while completing paperwork.
Be given resources for local agencies providing family counseling.
Provide data creating an interdisciplinary approach to cancer treatment.

Location

The survey will be distributed at Markey Cancer Center and Baptist Health Oncology. This is a one-time 20-minute survey which will be distributed while waiting for an appointment or during a hospital stay. After completing the survey, contact with participants will be complete.

Are you eligible?

Over the age of 18, with either you or a partner suffering from a late stage cancer diagnosis.
Currently in active treatment at a local cancer center.
Have at least one child under the age of 18 living in your home.

If you're unsure if you meet the requirements, call or email a member of the study team:

Emily Johnson, Couple and Family Therapy Master's Candidate
Study coordinator
em.johnson@uky.edu
678-451-5901

Appendix B

Consent to Participate in a Research Study

KEY INFORMATION FOR FAMILY STRESS IN CANCER PATIENT STUDY

As a patient or family member of an individual treated at the University of Kentucky Markey Cancer Center, you are being invited to take part in a research study about your financial and cancer stress, in relation to your family functioning. We hope to learn how cancer and financial stress in cancer patients and their families affect family cohesion, and its ability to function as a unit. To be eligible for this study, you must be over the age of 18, you or your partner must have a malignant cancer diagnosis in active treatment and have children under 18 living in your home.

Your participation in this study will include a one-time survey during the 2019 Fall Semester. Benefits of this study include the opportunity to self-reflect on your accumulated stress and coping behaviors. On a societal level, we will gain a better understanding of cancer and financial stress in cancer patients and their families, and how counseling can be a benefit to families in treatment.

This study does not have more risk of harm than you would experience on a daily basis. However, some questions may make you feel uncomfortable, and you may choose to skip and not to answer them. Should you feel great discomfort, the researcher will provide you with resources, or you can make an appointment at UK Counseling Center (106 Frazee Hall, 859-257-8701) or UK Family Center (205 Scovell Hall, 859- 257-7755).

Participation is voluntary, and you may quit the survey at any time. You will not lose any services, benefits, or rights if you choose not to volunteer.   The survey will take about 15-20 minutes to complete

Your response to the survey is confidential and identifiable information such as your name, will be removed from the information collected in this study. You will be assigned an ID number and your personal information will be removed. Data will be stored on a password protected computer that only the researchers will have access to. Due to the nature of Qualtrics, an online data collector, please be aware, while we make every effort to safeguard your data once received from the online survey/data gathering company, given the nature of online surveys, as with anything involving the internet, we can never guarantee confidentiality of the data while still on the survey gathering company's servers, or while en route to us. It is also possible the raw data collected for research purposes may be used for marketing or reporting purposes for Qualtrics after the research is concluded, depending on the company's Terms of Service and Privacy Policies.

The person in charge of this study is Emily Johnson, a Couple and Family Therapy Master's Student at the University of Kentucky, Department of Family Science. If you have questions, suggestions, or concerns regarding this study or if you want to withdraw from the study her contact information is: em.johnson@uky.edu. If you would like to contact the supervisor of this study, contact D. Bruce Ross, PhD., Bruce.Ross@uky.edu. Furthermore, if you have any concerns about your rights as a volunteer in this research, contact staff in the University of Kentucky (UK) Office of Research Integrity (ORI) between the business hours of 8am and 5pm EST, Monday-Friday at 859-257-9428 or toll free at 1-866-400-9428.

PARTICIPANT'S AGREEMENT: By clicking "I AGREE" below, you agree that you have read the information provided above and are voluntarily agreeing to participate in this research study. If you do not agree, please close this web browser.

() I AGREE

Appendix C

Demographic Questions

1. What race/ethnicity do you identify with?
   a. White
   b. Black or African American
   c. Hispanic
   d. American Indian or Alaskan Native
   e. Native American
   f. Asian
   g. Native Hawaiian

   Other (Please specify): _______________ .

2. Do you identify as _____________.
   a. Male
   b. Female
   c. Other (Please Specify): _____________.

3. What is your date of birth?
   a. ____________________

4. What is your current marital status _______?
   a. Single
   b. Dating/Committed relationship
   c. Engaged
   d. Married
   e. Separated/Divorced
   f. Other (Please Specify): ____________.

5. How satisfied are you in your current relationship?
   a. Very dissatisfied
   b. Dissatisfied
   c. Neutral
   d. Somewhat satisfied
   e. Satisfied
   f. Very satisfied

6. What is the highest level of education you have achieved?
   a. Less than high school degree
   b. High school degree or equivalent

c. Some college, but no degree
d. Associate degree
e. Bachelor degree
f. Professional degree
g. Graduate degree

7. What is your current income?
    a. Less than $25,000
    b. 25,000 to $34,999.
    c. $35,000 to $49,999.
    d. $50,000 to $74,999.
    e. $75,000 to $99,999.
    f. $100,000+

8. What is your current level of debt?
    a. $0 to $5,000
    b. $5,000 to $24,999.
    c. 25,000 to $49,999
    d. $50,000 to $74,999.
    e. $75,000 to $99,999.
    f. $100,000+

9. Have you or your partner recently experienced job loss or decreased work hours?
    a. Yes
    b. No

10. Are you or your partner in active cancer treatment?
    a. Yes
    b. No

11. Where are you (or partner) currently receiving treatment?
    a. __________

12. What stage of cancer have you been diagnosed with?
    a. Stage I
    b. Stage II
    c. Stage III
    d. Stage IV

13. Who is your current insurance provider?

a. _______________

14. Have any other family members been diagnosed with cancer?
    a. Yes
    b. No

15. How is your overall health today?
    a. Very poor
    b. Poor
    c. Average
    d. Good
    e. Excellent

Appendix D

FACES IV: Questionnaire

Directions to Family Members

Family members should complete the instrument independently, not consulting or discussing their responses until they have been completed.
Fill in the corresponding number in the space provided answer sheet.

Using the 5-point Likert scale provided below, please indicate the degree to which you agree or disagree with each statement about yourself.

1	2	3	4	5
Strongly Disagree	**Generally Disagree**	**Undecided**	**Generally Disagree**	**Strongly Agree**

1. Family members are involved in each other's lives. 1 2 3 4 5
2. Our family tries new ways of dealing with problems. 1 2 3 4 5
3. We get along better with people outside our family than inside. 1 2 3 4 5
4. We spend too much time together. 1 2 3 4 5
5. There are strict consequences for breaking the rules in our family. 1 2 3 4 5
6. We never seem to get organized in our family. 1 2 3 4 5
7. Family members feel very close to each other. 1 2 3 4 5
8. Parents equally share leadership in our family. 1 2 3 4 5
9. Family members seem to avoid contact with each other when at home. 1 2 3 4 5
10. Family members feel pressured to spend most free time together. 1 2 3 4 5
11. There are clear consequences when a family member does something wrong. 1 2 3 4 5
12. It is hard to know who the leader is in our family. 1 2 3 4 5
13. Family members are supportive of each other during difficult times. 1 2 3 4 5
14. Discipline is fair in our family. 1 2 3 4 5
15. Family members know very little about the friends of other family members. 1 2 3 4 5
16. Family members are too dependent on each other. 1 2 3 4 5
17. Our family has a rule for almost every possible situation. 1 2 3 4 5
18. Things do not get done in our family. 1 2 3 4 5
19. Family members consult other family members on important decisions. 1 2 3 4 5
20. My family is able to adjust to change when necessary. 1 2 3 4 5
21. Family members are on their own when there is a problem to be solved. 1 2 3 4 5
22. Family members have little need for friends outside the family. 1 2 3 4 5
23. Our family is highly organized. 1 2 3 4 5
24. It is unclear who is responsible for things (chores, activities) in our family. 1 2 3 4 5
25. Family members like to spend some of their free time with each other. 1 2 3 4 5
26. We shift household responsibilities from person to person. 1 2 3 4 5

27. Our family seldom does things together. 1 2 3 4 5
28. We feel too connected to each other. 1 2 3 4 5
29. Our family becomes frustrated when there is a change in plans or routines. 1 2 3 4 5
30. There is no leadership in our family. 1 2 3 4 5
31. Although family members have individual interests, they still participate in family activities. 1 2 3 4 5
32. We have clear rules and roles in our family. 1 2 3 4 5
33. Family members seldom depend on each other. 1 2 3 4 5
34. We resent family members doing things outside the family. 1 2 3 4 5
35. It is important to follow the rules in our family. 1 2 3 4 5
36. Our family has a hard time keeping track of who does various household tasks. 1 2 3 4 5
37. Our family has a good balance of separateness and closeness. 1 2 3 4 5
38. When family problems arise, we compromise. 1 2 3 4 5
39. Family members mainly operate independently. 1 2 3 4 5
40. Family members feel guilty if they want to spend time away from the family. 1 2 3 4 5
41. Once a decision is made, it is very difficult to modify that decision. 1 2 3 4 5
42. Our family feels hectic and disorganized. 1 2 3 4 5
43. Family members are satisfied with how they communicate with each other. 1 2 3 4 5
44. Family members are very good listeners. 1 2 3 4 5
45. Family members express affection to each other. 1 2 3 4 5
46. Family members are able to ask each other for what they want. 1 2 3 4 5
47. Family members can calmly discuss problems with each other. 1 2 3 4 5
48. Family members discuss their ideas and beliefs with each other. 1 2 3 4 5
49. When family members ask questions of each other, they get honest answers. 1 2 3 4 5
50. Family members try to understand each other's feelings. 1 2 3 4 5
51. When angry, family members seldom say negative things about each other. 1 2 3 4 5
52. Family members express their true feelings to each other. 1 2 3 4 5

1	2	3	4	5
Very Dissatisfied	**Somewhat Dissatisfied**	**Generally Satisfied**	**Very Satisfied**	**Extremely Satisfied**

53. The degree of closeness between family members. 1 2 3 4 5
54. Your family's ability to cope with stress. 1 2 3 4 5
55. Your family's ability to be flexible. 1 2 3 4 5
56. Your family's ability to share positive experiences. 1 2 3 4 5
57. The quality of communication between family members. 1 2 3 4 5
58. Your family's ability to solve conflicts 1 2 3 4 5
59. The amount of time you spend together as a family. 1 2 3 4 5
60. The way problems are discussed. 1 2 3 4 5
61. The fairness of criticism in your family. 1 2 3 4 5
62. Family member's concern for each other. 1 2 3 4 5

Thank you for your cooperation!

Appendix E

RSQ-Cancer Stress
This is a list of things about having cancer or a family member sick with cancer that individuals sometimes find stressful or a problem to deal with. Please circle the number indicating how stressful the following things have been for your child in the past 6 months.

1	2	3	4
Not at All	**A Little**	**Somewhat**	**Very**

a. Concerns about how sick you/the family member looks and feels 1 2 3 4
b. Concerns about how worried other people in the family are about you/the family member 1 2 3 4
c. You/the family member being gone from home a lot 1 2 3 4
d. Concerns about getting cancer yourself (family member only) 1 2 3 4
e. Concerns about another family member becoming sick 1 2 3 4
g. Not knowing what to say to your friends and other people about the cancer 1 2 3 4
h. You (or family member) not having as much time to spend with the family 1 2 3 4
i. Having to take care of other people in your family 1 2 3 4
k. Doing things that you (or the family member) usually takes care of when s/he is not sick 1 2 3 4
l. Other: ____ 1 2 3 4

Circle the number that shows how much control I generally think I have over these problems.

1	2	3	4
None	**A little**	**Some**	**A lot**

Think of all the stressful parts of having cancer or a family member who is sick with cancer that have been stressful for you. For each item below, circle one number from 1 (not at all) to 4 (a lot).

WHEN DEALING WITH HAVING (Or A FAMILY MEMBER SICK) WITH CANCER
1. I try not to feel anything. 1 2 3 4
2. When dealing with the stress of having (a family member with) cancer, I feel sick to my stomach or get headaches. 1 2 3 4
3. I try to think of different ways to change or fix the situation. 1 2 3 4
4. When faced with having (a family member with) cancer, I don't feel anything at all, it's like I have no feelings. 1 2 3 4
5. I wish that I were stronger and less sensitive so that things would be different. 1 2 3 4
6. I keep remembering what happened has happened cancer or can't stop thinking about what might happen. 1 2 3 4
7. I let someone, or something know how I feel. 1 2 3 4
8. I have decided I am okay with the way I am, even though I'm not perfect. 1 2 3 4
9. When around other people, I act like I (or my family member) never got cancer. 1 2 3 4
10. I just have to get away from everything when I am dealing with the stress of having (a family member with) cancer. 1 2 3 4

11. I deal with having (a family member with) cancer by wishing it would just go away, that everything would work itself out. 1 2 3 4
12. I get really jumpy when I am dealing with having (a family member with) cancer. 1 2 3 4
13. I realize that I just have to live with things the way they are. 1 2 3 4
14. When I am dealing with the stress of having (a family member with) cancer, I just can't be near anything that reminds me of what is happening. 1 2 3 4
15. I try not to think about it, to forget all about it. 1 2 3 4
16. When I am dealing with having (a family member with) cancer, I really don't know what I feel. 1 2 3 4
17. I ask other people or things for help or for ideas about how to make things better. 1 2 3 4
18. When I am trying to sleep, I can't stop thinking about the stressful aspects of having (a family member with) cancer or I have bad dreams about it. 1 2 3 4
19. I tell myself that I can get through this, or that I will be okay. 1 2 3 4
20. I let my feelings out. 1 2 3 4

    I do this by: (Check all.) Writing in journal/diary, Drawing/painting, complaining to let off steam, Being sarcastic/making fun, Listening to music, Punching a pillow, Exercising, Yelling, Crying, None of these

21. I get help from other people or things when she is trying to figure out how to deal with my feelings. 1 2 3 4

You're half done. Before you keep working, look back at the first page so you remember the aspects of having a cancer diagnosis or a family member with a cancer diagnosis that have been stressful for you lately. Remember to answer the questions below thinking about these things.

22. I just can't get myself to face having (a family member with) cancer. 1 2 3 4
23. I wish that someone would just come and take away the stressful parts of having (a family member with) cancer. 1 2 3 4
24. I do something to try to fix the stressful parts of having (a family member with) cancer. 1 2 3 4 Write one thing you did:____

____

25. Thoughts about having (a family member with) cancer just pop into her/his head. 1 2 3 4
26. When I am dealing with having (a family member with) cancer, I feels it in my body. 1 2 3 4

    Check all that happen: my heart races, my breathing speeds up, I feel hot or sweaty, my muscles get tight, None of these

27. I try to stay away from people and things that make me feel upset or remind me of having (a family member with) cancer. 1 2 3 4
28. I don't feel like myself when I am dealing with the stress of having (a family member with) with cancer, it's like I am far away from everything. 1 2 3 4
29. I just take things as they are; I go with the flow. 1 2 3 4
30. I think about happy things to take my mind off the stressful parts of having (a family member with) cancer or how I am feeling. 1 2 3 4
31. When something stressful happens related to having a parent with cancer, I can't stop thinking about how I am feeling. 1 2 3 4
32. I get sympathy, understanding, or support from someone. 1 2 3 4

33. When something stressful happens related to having (a family member with) cancer, I can't always control what I do. 1 2 3 4
34. I tell myself that things could be worse. 1 2 3 4
35. My mind just goes blank when something stressful happens related to having (a family member with) cancer, I can't think at all. 1 2 3 4
36. I tell myself that it doesn't matter, that it isn't a big deal. 1 2 3 4
37. When I am faced with the stressful parts of having a (a family member with) cancer, right away I feel really: 1 2 3 4

Check all that she feels: Angry, Sad, Worried/anxious, Scared, None of these.

38. It's really hard for me to concentrate or pay attention when something stressful happens related to having (a family member with) cancer. 1 2 3 4
39. I think about the things I am learning from having (a family member with) cancer, or something good that will come from it. 1 2 3 4
40. After something stressful happens related to having (a family member with) cancer, I can't stop thinking about what I did or said. 1 2 3 4
41. When stressful parts of having (a family member with) cancer happen, I say to myself, "This isn't real." 1 2 3 4
42. When I am dealing with the stressful parts of having (a family member with) cancer, I end up just lying around or sleeping a lot. 1 2 3 4
43. I keep my mind off stressful parts of having (a family member with) cancer by: 1 2 3 4 5

Check all that she does: Exercising 5 Seeing friends 5 Watching TV 5 Playing video games 5 Doing a hobby 5 Listening to music 5 None of these

44. When something stressful happens related to having a (a family member with), I get upset by things that don't usually bother me. 1 2 3 4
45. I do something to calm myself down when I am dealing with the stress of having (a family member with) cancer. 1 2 3 4

Check all that I do: 5 Take deep breaths 5 Pray 5 Walk 5 Listen to music 5 Take a break 5 Meditate 5 None of these

46. I just freeze when I am dealing with stressful parts of having (a family member with) cancer, I can't do anything. 1 2 3 4
47. When stressful things happen related to having (a family member with) I sometimes act without thinking 1 2 3 4
48. I keep my feelings under control when I have to, then lets them out when they won't things worse. 1 2 3 4
49. When something stressful happens related to having (a family member with) cancer, I can't seem to get around to doing things I am supposed to do. 1 2 3 4
50. I tells myself that everything will be all right. 1 2 3 4
51. When something stressful happens related to having (a family member with) cancer, I can't stop thinking about why this is happening. 1 2 3 4
52. I think of ways to laugh about it so that it won't seem so bad. 1 2 3 4
53. My thoughts start racing when I am faced with the stressful parts of having (a family member with) cancer. 1 2 3 4
54. I imagine something really fun or exciting happening in my life. 1 2 3 4
55. When something stressful happens related to having (a family member with) cancer, I can get so upset that I can't remember what happened or what I did. 1 2 3 4
56. I try to believe that it never happened. 1 2 3 4

57. When I am dealing with having (a family member with) cancer, sometimes I can't control what I do or say. 1 2 3 4

Thank you for your participation!

Appendix F

RSQ Financial Stress—Parent Self Evaluation

Even when things are going well, almost every family has financial worries or money troubles now and then. This is a list of things about money problems that people sometimes find stressful or a problem to deal with. Please circle the number indicating how stressful the following things have been for you in the past 6 months.

1	2	3	4
Not at All	**A Little**	**Somewhat**	**Very**

a. I (or my spouse/partner) lost a job 1 2 3 4
b. I (or my spouse/partner) couldn't find work 1 2 3 4
c. We had to postpone medical care to save money 1 2 3 4
d. We could not pay all of our bills 1 2 3 4
e. Things in our home did not work the way they should (no electricity, no water) 1 2 3 4
f. I couldn't buy something important because we didn't have enough money 1 2 3 4
g. We had to stay in a homeless shelter or public place 1 2 3 4
h. We had to apply for federal assistance to make ends meet 1 2 3 4
i. Other ____ 1 2 3 4

Circle the number that shows how much control you generally think you have over these problems.

1	2	3	4
None	**A little**	**Some**	**A lot**

Below is a list of things that people sometimes do, think, or feel when something stressful happens. Everyone deals with problems in their own way – some people do a lot of the things on this list or have a bunch of feelings, other people just do or think a few of these things.

Think of all the stressful parts of money problems that you indicated above. For each item below, circle one number from 1 (not at all) to 4 (a lot) that shows how much you do or feel these things when you have the problems with money like the ones you indicated above. Please let us know about everything you do, think, and feel, even if you don't think it helps make things better.

WHEN DEALING WITH THE STRESS OF MONEY PROBLEMS:
How much do you do this?
1. I try not to feel anything. 1 2 3 4
2. When dealing with the stress of money problems, I feel sick to my stomach or get headaches. 1 2 3 4
3. I try to think of different ways to change or fix the situation. 1 2 3 4
Write one plan you thought of:____
____

4. When problems with money happen, I don’t feel anything at all, it's like I have no feelings.
1 2 3 4
5. I wish that I were stronger and less sensitive so that things would be different. 1 2 3 4
6. I keep remembering what happened with money problems or can’t stop thinking about what might happen.1 2 3 4
7. I let someone, or something know how I feel. 1 2 3 4
    Check all you talked to: Spouse/Partner, Friend, Physician, Brother/Sister, Clergy Member, My children, Parent, Nurse, Therapist/Counselor, None of these
8. I decide I’m okay the way I am, even though I’m not perfect. 1 2 3 4
9. When I’m around other people I act like money problems never happened. 1 2 3 4
10. I just have to get away from everything when I am dealing with the stress of money problems. 1 2 3 4
11. I deal with the stress of money problems by wishing it would just go away, that everything would work itself out. 1 2 3 4
12. I get really jumpy when I am dealing with the stress of money problems. 1 2 3 4
13. I realize that I just have to live with things the way they are. 1 2 3 4
14. When I am dealing with the stress of money problems, I just can’t be near anything that reminds me of what is happening. 1 2 3 4
15. I try not to think about it, to forget all about it. 1 2 3 4
16. When I am dealing with the stress of money problems, I really don’t know what I feel.
1 2 3 4
17. I ask other people or things for help or for ideas about how to make things better 1 2 3 4
    Check all you talked to: Spouse/Partner, Friend, Physician, Brother/Sister, Clergy Member, My children, Parent, Nurse, Therapist/Counselor, None of these
18. When I am trying to sleep, I can’t stop thinking about the stressful aspects of money problems or I have bad dreams about money problems. 1 2 3 4
19. I tell myself that I can get through this, or that I will be okay. 1 2 3 4
20. I let my feelings out. 1 2 3 4
    I do this by: (Check all that you did.) Writing in my journal/diary, Drawing/painting, Complaining to let off steam, Being sarcastic/making fun, Listening to music, Punching a pillow, Exercising, Yelling, Crying, None of these
21. I get help from other people or things when I’m trying to figure out how to deal with my feelings. 1 2 3 4
    Check all that you went to: Spouse/Partner, Friend, Physician, Brother/Sister, Clergy Member, My children, Parent, Nurse, Therapist/Counselor, None of these
22. I just can’t get myself to face the stress of money problems. 1 2 3 4
23. I wish that someone would just come and take away the stressful aspects of money problems.
1 2 3 4

You’re half done. Before you keep working, look back at the first page so you remember the aspects of having money problems that have been stressful for you lately. Remember to answer the questions below thinking about these things.

24. I do something to try to fix the stressful aspects of money problems. 1 2 3 4
Write one thing you did:____
____

25. Thoughts about the stressful aspects of money problems just pop into my head. 1 2 3 4
26. When I am dealing with the stress of money problems, I feel it in my body. 1 2 3 4
    Check all that happen: My heart races, My breathing speeds up, None of these, I feel hot or sweaty, My muscles get tight
27. I try to stay away from people and things that make me feel upset or remind me of the stressful aspects of money problems. 1 2 3 4
28. I don't feel like myself when I am dealing with the stress of money problems, it's like I am far away from everything. 1 2 3 4
29. I just take things as they are; I go with the flow. 1 2 3 4
30. I think about happy things to take my mind off the stressful aspects of money problems or how I'm feeling. 1 2 3 4
31. When something stressful happens related to money problems, I can't stop thinking about how I am feeling. 1 2 3 4
32. I get sympathy, understanding, or support from someone. 1 2 3 4
    Check all you went to: Spouse/Partner, Friend, Physician, Brother/Sister, Clergy Member, My children, Parent, Nurse, Therapist/Counselor, None of these
33. When something stressful happens related to money problems, I can't always control what I do.1 2 3 4
    Check all that happen: I can't stop eating, I can't stop talking, I do dangerous things, I have to keep fixing/checking things, None of these
34. I tell myself that things could be worse. 1 2 3 4
35. My mind just goes blank when something stressful happens related to money problems, I can't think at all. 1 2 3 4
36. I tell myself that it doesn't matter, that it isn't a big deal. 1 2 3 4
37. When I am faced with the stressful parts of money problems, right away I feel really: 1 2 3 4
    Check all that you feel: Angry, Sad, Worried/anxious, Scared, None of these
38. It's really hard for me to concentrate or pay attention when something stressful happens related to money problems. 1 2 3 4
39. I think about the things I'm learning from the situation, or something good that will come from it.1 2 3 4
40. After something stressful happens related to money problems I can't stop thinking about what I did or said. 1 2 3 4
41. When stressful parts of money problems happen, I say to myself, "This isn't real." 1 2 3 4
42. When I'm dealing with the stressful parts of money problems, I end up just lying around or sleeping a lot. 1 2 3 4
43. I keep my mind off stressful parts of money problems by: 1 2 3 4 5
    Check all that you do: Exercising, Shopping, Watching TV, Reading, Doing a hobby, Listening to music, None of these
44. When something stressful happens related to money problems, I get upset by things that don't usually bother me. 1 2 3 4
45. I do something to calm myself down when I'm dealing with the stress of money problems. 1 2 3 4
    Check all that you do: Take deep breaths, Pray, Walk, listen to music, Take a break, Meditate, None of these
46. I just freeze when I am dealing with stressful parts of money problems, I can't do anything. 1 2 3 4

47. When stressful things happen related to money problems, I sometimes act without thinking. 1 2 3 4
48. I keep my feelings under control when I have to, then let them out when they won't make things worse. 1 2 3 4
49. When something stressful happens related to money problems, I can't seem to get around to doing things I'm supposed to do.1 2 3 4
50. I tell myself that everything will be all right. 1 2 3 4
51. When something stressful happens related to money problems, I can't stop thinking about why this is happening. 1 2 3 4
52. I think of ways to laugh about it so that it won't seem so bad. 1 2 3 4
53. My thoughts start racing when I am faced with the stressful parts of money problems. 1 2 3 4
54. I imagine something really fun or exciting happening in my life. 1 2 3 4
55. When something stressful happens related to money problems, I can get so upset that I can't remember what happened or what I did. 1 2 3 4
56. I try to believe that it never happened. 1 2 3 4
57. When I am dealing with the stress of money problems, sometimes I can't 1 2 3 4

Thank you for participating!

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