WELL-BEING, SELF-TRANSCEENDENCE, AND RESILIENCE OF PARENTS OF CHILDREN WITH CANCER

by

Jouhayna Bajjani

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DEDICATION

To all the families of children who have and continue to go through the journey of cancer, with admiration and gratitude for their trust and willingness to share their perspective to help advance science and healthcare.
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ABSTRACT

The specific aims for this study were to: (a) describe positive and negative well-being in parental caregivers of children with cancer, (b) examine if parental caregivers’ personal factors (i.e., resilience and/or demographic characteristics) and child-related contextual factors (i.e., ill child’s cancer characteristics and/or demographic characteristics) predict parental caregivers’ positive and negative well-being, and (c) test if self-transcendence mediates the relationship between resilience and well-being (positive and negative) in parental caregivers of children with cancer.

Eighty parental caregivers whose children were diagnosed with any type of childhood cancer since at least two months prior to study start participated and completed a demographic instrument, the General Well-Being Schedule, the Center for Epidemiologic Studies Depression Scale, the State scale of the State-Trait Anxiety Inventory, the Self-Transcendence Scale, and the Brief Resilience Scale. Descriptive statistics were used to describe sample demographics, levels of positive and negative well-being, self-transcendence levels, and resilience levels. Standard multiple regression was used to examine predictors of well-being. Baron and Kenny’s three-step mediation analysis was used to test if self-transcendence mediated the relationship between resilience and well-being (positive and negative).

Both positive and negative well-being exist in parental caregivers of children with cancer as 47% of parental caregivers were in the ‘positive well-being’ category with total General Well-Being Schedule scores above the positive well-being cutoff of 73, 36.3% were in the ‘depressed’ category with total scores above the depression cutoff of 16 on the Center for Epidemiologic Studies-Depression Scale, and 45% had scores that exceeded the mean anxiety score of 39.64 on
the State Scale of the State-Trait Anxiety Instrument. None of the child-related contextual factors were found to predict positive and negative well-being in parental caregivers of children with cancer. Resilience positively predicted general well-being and negatively predicted depression and anxiety in parental caregivers of children with cancer. Satisfaction with current financial status negatively predicted depression. Employment status negatively predicted anxiety such that those who were not employed had significantly lower anxiety than those who were employed part-time and full-time. Self-transcendence mediated the relationship between resilience and positive and negative well-being respectively.
CHAPTER 1: STATEMENT OF THE PROBLEM

Introduction

Childhood cancer profoundly impacts the well-being of significant numbers of parental caregivers in the U.S. each year. Childhood cancer continues to be the leading cause of death from disease in children under fifteen years of age despite advances in treatment (National Cancer Institute, 2008). The consequences of childhood cancer severely impact parental caregivers’ well-being, defined as one’s subjective sense of wholeness and health (Chin-A-Loy & Fernsler, 1998; Reed, 1991b, 1992, 1996a, 2008b). The empirical evidence for negative well-being, defined by the presence of/or increased negative health outcomes, in this population is extensive and includes: depression, anxiety, posttraumatic stress, increased illness, decreased quality of life, strained marital relationships, and early death (da Silva, Jacob, & Nascimento, 2011; Dockerty, Williams, McGee, & Skegg, 2000; Fotiadou, Barlow, Powell, & Langton, 2008; Jones, 2007; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Kerr, Harrison, Medves, Tranmer, & Fitch, 2007; Klassen et al., 2008; Patterson, Holm, & Gurney, 2004; Rivera, 2008; Witt et al., 2010).

Contrastingly, the empirical evidence for positive well-being, defined by the presence of/or increased positive health outcomes, in parental caregivers is scarce and mostly focused on parental caregivers whose children are at the survivorship stage and not in active cancer treatment (Barakat, Alderfer, & Kazak, 2006; Michel, Taylor, Absolom, & Eiser, 2009). Each year, 160,000 parents learn their children have cancer and 90,000 parents lose their children to cancer (World Health Organization & International Union Against Cancer, 2005). According to a 2007 report by the Agency for Healthcare Research and Quality, parents of children with cancer
face significantly greater financial strains than parents of children with other diseases as the average pediatric cancer stay is more than twice as expensive as that for children with other diseases ($17,500 versus $8,500 per stay) and is about two days longer than the typical stay (6.4 versus 4.5 days) (Merrill, Nagamine, & Hambrick, 2007). Between 2000 and 2005 alone, costs for childhood cancer hospital stays more than doubled as they increased from $785 million in 2000 to $1.7 billion in 2005 (Merrill et al., 2007).

Parents of children with cancer are particularly at a disadvantage concerning their well-being when compared to parents of children with other health conditions (Barrera et al., 2004; Goldbeck, 2006; Johnston, Steele, Herrera, & Phipps, 2003). Parents of children with cancer deal with the daily threat to their children’s life as well as the significantly difficult, painful, and expensive treatments of their ill children. Treatments for childhood cancer usually extend over a number of years and include aggressive therapies (e.g., chemotherapy, radiation, surgery, transfusions, and/or bone marrow transplant) that require frequent clinic visits and hospitalizations (Jones, 2007; Moore & Beckwitt, 2004; Patterson et al., 2004). Not only do parental caregivers witness and frequently assist in painful and traumatic medical procedures for their ill children; they also have to manage their own feelings as well as those of the rest of the family (e.g., siblings).

Parents have significant changes in their own lives from living with their children’s cancer, such as feelings of loneliness, financial burdens, employment challenges to secure income, and the need to care for other children (Jones, 2007; Moore & Beckwitt, 2004; Patterson et al., 2004). Such negative consequences on the well-being of parental caregivers strain their participation and compliance with their ill children’s complex health care needs (Melnyk et al.,
and even affect the children’s own well-being given the strong empirical link between parental well-being and that of their children (Best, Streisand, Catania, & Kazak, 2001; Blotcky, Raczynski, Gurwitch, & Smith, 1985; Davis, Parra, & Phipps, 2010; Frank, Blount, & Brown, 1997; Lieb, Isensee, Hofler, Pfister, & Wittchen, 2002; Mereuta & Craciun, 2009; Robinson, Gerhardt, Vannatta, & Noll, 2007; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006). Thus, investigating the well-being of parental caregivers of children with cancer is of paramount importance and constitutes the focus of the current study.

In order to enhance well-being of parents, a thorough understanding is crucial for: 1) what factors predict well-being? and, 2) what generative mechanisms do these predictors use to do their work? This is because developing and testing interventions without these two steps provides a distorted understanding of the effects of the intervention delivered and falls short of explaining why an intervention did or did not work. This, delays the development of clinical knowledge needed for providing high-quality care. Therefore, a thorough understanding of parental well-being, what factors predict well-being, and what generative mechanisms these predictors use to do their work should precede any expenditure of resources on testing interventions aimed at enhancing parental well-being. This is because advance knowledge of what works and why it works reduces the research-to-practice gap (Sidani & Braden, 1998) and constitutes the judicious use of resources especially in the current health care economy.

There are three major areas relating to parental well-being that have not yet adequately been addressed in the current literature and will be addressed in the current study (Table 1): 1) empirical evidence for parental positive well-being, 2) which parental personal factors and/or child-related contextual factors predict parental positive and negative well-being, and 3) what is
the underlying generative mechanism through which parental personal factors—such as resilience—facilitate positive well-being.

**TABLE 1: Alignment of Current Knowledge Gaps with Research Aims and Hypotheses.**

<table>
<thead>
<tr>
<th>Current Knowledge Gaps</th>
<th>Research Aims</th>
<th>Research Hypotheses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Empirical evidence for positive well-being in parents of children with cancer is scarce in contrast to the extensive evidence for negative well-being.</td>
<td>Aim 1: Describe positive and negative well-being in parents of children with cancer.</td>
<td>Hypothesis 1. Both positive and negative well-being exist in parental caregivers of children with cancer.</td>
</tr>
<tr>
<td>2. Empirical evidence is limited and inconclusive regarding which parental personal factors (i.e., parental resilience and/or parental demographic characteristics) and which child-related contextual factors (i.e., ill child’s cancer characteristics and/or child’s demographics) predict positive and negative well-being in parents of children with cancer.</td>
<td>Aim 2: Examine if parental personal factors (i.e., parental resilience and/or parental demographic characteristics) and child-related contextual factors (i.e., ill child’s cancer characteristics and/or demographic characteristics) predict parental positive and negative well-being in parents of children with cancer.</td>
<td>Hypothesis 2. Parental personal factors (i.e., parental resilience and/or parental demographic characteristics) and child-related contextual factors (i.e., ill child’s cancer and/or demographic characteristics) predict positive and negative well-being in parents of children with cancer.</td>
</tr>
<tr>
<td>3. Empirical evidence for an underlying generative mechanism (i.e., a mediator) through which parental personal factors (such as resilience) facilitate positive and negative well-being is lacking.</td>
<td>Aim 3: Test if the underlying generative mechanism of self-transcendence mediates the relationship between resilience and well-being (positive and negative) in parents of children with cancer.</td>
<td>Hypothesis 3. Self-transcendence mediates the relationship between resilience and well-being (positive and negative) in parents of children with cancer.</td>
</tr>
</tbody>
</table>

Little is known about parental positive well-being as the majority of studies focused on negative well-being such as: depression, anxiety, posttraumatic stress, increased illness, decreased quality of life, strained marital relationships, and early death (da Silva et al., 2011; Dockerty et al., 2000; Fotiadou et al., 2008; Jones, 2007; Kazak, Boeving et al., 2005; Kerr et al., 2007; Klassen et al., 2008; Patterson et al., 2004; Rivera, 2008; Witt et al., 2010). The few studies that investigated positive well-being focused on psychological growth in parents of
childhood cancer survivors (Barakat et al., 2006; Michel et al., 2009), who differ from parents of children currently in cancer treatment.

Parental personal factors that have been investigated for their role in predicting parental well-being include: resilience and demographic characteristics (i.e., age, marital status, educational level, number of work hours, financial status, gender, ethnicity, and employment status). In the current study, resilience is defined as a positive characteristic that lessens the negative effects of stress and enables one to function psychologically at an exceedingly high level despite life’s adversities (Richardson, 2002; Wagnild & Collins, 2009; Wagnild & Young, 1993; White, Bichter, Koeckeritz, Lee, & Munch, 2002). Resilience is positively linked to positive well-being both theoretically (McCubbin & McCubbin, 1993, 1996) and empirically (Brody & Simmons, 2007; McCubbin, Balling, Possin, Frierdich, & Bryne, 2002; Nicholas et al., 2009). However, in the population of parental caregivers, neither the quantitative relationship between resilience and positive well-being nor the mechanism through which resilience facilitates positive well-being has been studied. Parental demographic characteristics that have been investigated for their role in predicting parental well-being have mixed or inconclusive findings (Dolgin et al., 2007; Fotiadou et al., 2008; Greening & Stoppelbein, 2007) and thus were further investigated in this study (Aim 2).

Child-related contextual factors that have been investigated for their role in predicting parental well-being include: child’s demographic characteristics (i.e., age and gender) and child’s cancer characteristics (i.e., cancer type and time since diagnosis). However, findings from these studies were also mixed or inconclusive (Dolgin et al., 2007; Goldbeck, 2006; Lou, 2006) and hence were further investigated in this study (Aim 2).
Despite the growing literature on the effectiveness of interventions that promote parental positive well-being (Kazak, Simms et al., 2005; Sahler et al., 2005; Sahler et al., 2002), studies that specifically examine the underlying generative mechanisms through which parental personal factors actually facilitate positive well-being are scarce and do not tackle the role of spirituality in facilitating well-being (Sahler et al., 2005), a highly relevant area in the context of childhood cancer (Crom, 1995; Schneider & Mannel, 2006).

Thus, for an underlying generative mechanism to be relevant for the population of parental caregivers of children with cancer, who deal with highly abstract and existential problems; this mechanism needs to extend beyond concrete problem solving approaches and it needs to have a spiritual component (Crom, 1995; Schneider & Mannel, 2006). Self-transcendence theoretically answers the quest for such an underlying generative mechanism. This is because self-transcendence is a type of reasoning that is ‘post-formal’ in nature as it is more encompassing than formal logic’s hypothetic-deductive approach for the solution of abstract problems (Reed, 1991b). According to Reed’s Theory of Self-Transcendence, self-transcendence is a mechanism that facilitates well-being in the face of adversity (Reed, 2008b, 2013).

Furthermore, self-transcendence is empirically linked to well-being in other adult and caregiver populations (Acton & Wright, 2000; Chen & Walsh, 2009; Chin- A-Loy & Fernsler, 1998; Coward, 1990, 1991, 1995, 1996; Coward & Kahn, 2004, 2005; Coward & Lewis, 1993; Ellermann & Reed, 2001; Enyert & Burman, 1999; Josefsson, Larsson, Sydsjo, & Nylander, 2007; Kausch & Amer, 2007; Kinney, 1996; Mellors, Erlen, Coontz, & Lucke, 2001; Mellors, Riley, & Erlen, 1997; Nygren et al., 2005; Pelusi, 1997; Ramer, Johnson, Chan, & Barrett, 2006; Runquist, 2007; Runquist & Reed, 2007). This suggests that self-transcendence will function
similarly in parental caregivers and is thus hypothesized to ‘mediate’ the relationship between resilience and well-being (positive and negative aspects) in parents of children with cancer. The purpose of the current study is to explore parental well-being (i.e., both positive and negative aspects), which factors (i.e., parental personal factors or child-related contextual factors) predict well-being, and through which mechanisms do these predictors work

**Study Aims and Hypotheses**

The specific aims for this study are:

Aim 1. Describe positive and negative well-being in parents of children with cancer.

Aim 2. Examine if parental personal factors (i.e., parental resilience and/or parental demographic characteristics) and child-related contextual factors (i.e., ill child’s cancer characteristics and/or demographic characteristics) predict parental positive and negative well-being.

Aim 3. Test if self-transcendence mediates the relationship between resilience and well-being (positive and negative) in parental caregivers of children with cancer.

This study’s hypotheses are:

Hypothesis 1. Both positive and negative well-being exist in parental caregivers of children with cancer.

Hypothesis 2. Personal factors (i.e., parental resilience and parental demographics) and contextual factors (i.e., ill child’s cancer characteristics and demographics) predict positive and negative well-being.

Hypothesis 3. Self-transcendence mediates the relationship between resilience and well-being (both positive and negative) in parental caregivers of children with cancer.
Significance

The current study offers a thorough understanding of parental well-being (i.e., both its positive and negative aspects), which factors predict it, and through which mechanism these predictors work. Such knowledge has clinical and economic implications for it facilitates early identification of parents at greatest risk for negative well-being and consequently contributes to the reduction in healthcare disparities among parents. Knowledge acquired from the current study guides interventions that reduce parental suffering and decrease economic burdens caused by negative well-being (e.g., psychological distress) (Sloper, 2000; Steele, Long, Reddy, Luhr, & Phipps, 2003), depression (Barrera et al., 2004; Bayat, Erdem, & Gul Kuzucu, 2008; Dolgin et al., 2007; Elkin et al., 2007; Fotiadou et al., 2008), anxiety and posttraumatic stress (Dolgin et al., 2007; Kazak, Boeving et al., 2005). Early identification of what predicts positive well-being in parents ultimately contributes to the improvement of their children’s well-being as parents’ well-being is strongly linked to that of their children (Best et al., 2001; Blotcky et al., 1985; Davis et al., 2010; Frank et al., 1997; Lieb et al., 2002; Mereuta & Craciun, 2009; Robinson et al., 2007; Wijnberg-Williams et al., 2006).

The link between psychological distress and increased mortality is strong. Findings from a 2012 meta-analysis of 10 large prospective cohort studies from the Health Survey for England involving 68,222 adults from general population samples over 35 years revealed a dose-response association between psychological distress and increased mortality (Russ et al., 2012). Hence, given the extensive evidence for psychological distress in parents of children with cancer, it is anticipated that these parents will consequently have an increased mortality risk. Furthermore, mental disorders are ranked among the top five medical conditions concerning direct medical
spending and the expenditures for all mental disorders was estimated at 57.5 billion in 2006 (Soni, 2009). In 2009, depression costs reached 22.8 billion dollars with mean annual prescription drug expenditures for depression at $742 per person for that year (Soni, 2012). The economic burden exerted by depression in the U.S. in 2000 was 83.1 billion dollars; out of which 26.1 billion dollars (31%) were direct medical costs, 5.4 billion dollars (7%) were suicide-related mortality costs, and the remaining 51.5 billion dollars (62%) were costs relating to workplace losses(Greenberg et al., 2003). Thus, focusing on reducing negative well-being (e.g., depression) in this population has substantive economic gains.

The current study has research implications in that it provides a foundation for a program of research that focuses on well-being promotion in parents of children with cancer by mobilizing parents’ inherent capabilities—such as self-transcendence. Findings from this study provide empirical evidence for the role of self-transcendence in parents of children with cancer. Self-transcendence is not only an inherent developmental capability that sustains well-being (Reed, 2008b); but it also has a pragmatic advantage in that it is amenable to translation into interventions (Acton & Wright, 2000; Chen & Walsh, 2009; Coward, 1995; Coward & Kahn, 2004, 2005; Kausch & Amer, 2007) and self-transcendence interventions have been empirically found to promote well-being in other adult (Coward & Kahn, 2004, 2005) and caregiver (Chen & Walsh, 2009; Kausch & Amer, 2007) populations.

This study expands current knowledge on self-transcendence for it extends the use of the Theory of Self-Transcendence to the population of parents of children with cancer, where it has never been studied before. Given this study’s theory-driven approach to the identification of predictors and underlying mechanisms that facilitate well-being, this study can reduce the
research-to-practice gap for it illuminates what and how self-transcendence interventions are supposed to work before expending resources on testing them in parents of children with cancer.

**Worldview and Philosophical Perspective**

One’s worldview depicts the lens through which one sees the world. As such, the approach to knowledge production and research is also bound to be influenced by this ‘lens’. The lens through which I see the world is one that views humans as being indivisible wholes that are inherently capable of self-healing and that the role of healthcare providers is to provide a context that is conducive for healing. Thus, I ascribe to the Simultaneous Action (SA) worldview, which sees humans as wholes that are more than the sum of their parts and who are in rhythmical and mutual changes with their environments in self-organizing ways (Fawcett, 1993). The changes that humans go through are unidirectional, unpredictable, and involve stages of organization, disorganization, and more complex organization (Buck, 2006; Fawcett, 1993; Reed, 1992, 1997; Richardson, 2002). Consistent with the SA worldview, I view parental caregivers as inherently capable of self-organizing in order to meaningfully integrate challenges in a manner that sustains their well-being despite the adversity of their children’s cancer. I view nursing as having an important role in facilitating humans’ self-organization and well-being promotion (Fawcett, 1993). Hence, my current study investigates ‘both’ positive and negative aspects of well-being, well-being predictors, and mediators that promote well-being in parents as opposed to solely focusing on how their well-being deteriorates given their children’s cancer.

Also linked to one’s worldview is one’s chosen philosophical perspective, which shapes one’s theorizing, research, and practice. I align with Reed’s intermodernism, which values empirical evidence that varies in its observability; champions the search for meaning and
intuition in nursing; and embraces multiple pragmatic paths in the quest for understanding of phenomena (Reed, 2011). Intermodernism stems from the intersection of modernism and postmodernism and furthermore offers an extension of knowledge development by clinicians educated to use various patterns of knowing in practice (Reed, 1995, 2006a). My ascribing to the SA worldview and my aligning with the philosophical perspective of intermodernism have shaped my choice of a guiding theory for my study, my hypothesized theoretical model, and my entire research approach.

**Theory**

Theories offer tentative advanced understandings of phenomena (Chinn & Kramer, 2008; Reed, 2010). As Albert Einstein stated: “You can never solve a problem on the level on which it was created” (Einstein, n.d.). Hence, understanding phenomena requires a ‘cognitive leap’ in proposing solutions. Such a cognitive leap entails courage, creativity, and skill; courage to let go of certainties, creativity to look for relationships that ‘appear’ non-existent, and skill to make a leap when proposing solutions. In the general realm of knowledge building, ‘problems’ usually involve phenomena that are not well-understood; thus, ‘problem solving’ entails theorizing to build hypothesized theoretical models that are subjected to testing in order to advance one’s understanding of such phenomena. As such, theorizing is the process, while theories are the outcome of that process (Reed, 2010). The below section describes: first, the theory that I chose to guide my study as well as the rationales behind its choice; and second, my hypothesized theoretical model (Figure 1). My hypothesized theoretical model represents my proposed ‘cognitive leap’ and is tested in this study.
**Current Study’s Guiding Theory: The Theory of Self-Transcendence**

In my search for a guiding theory that aligns with my worldview while still offering an advanced understanding of my phenomenon of interest (the well-being of parental caregivers of children with cancer), I was particularly influenced by Reed’s Theory of Self-Transcendence (Reed, 1991b, 1992, 1996a, 2008b, 2013). Another theory that influenced my theorizing is, The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993, 1996), for it theoretically links resilience to positive well-being. The Resiliency Model of Family Stress, Adjustment, and Adaptation purports that families with high resilience factors, such as hardiness, have an easier time adjusting if they view changes as growth producing, develop a sense of control over their outcomes in life, and use an active rather than passive orientation in adapting to the cancer situation. Although this theory is applicable to the study of well-being in parents of children with cancer, it does not explicate the underlying mediator through which resilience facilitates well-being and also underestimates the role of spirituality as a driving force in the process of familial reintegration from life’s adversity. This theory mentions spirituality in the context of it being a desired outcome within the concepts of ‘balance and harmony’ (McCubbin et al., 2002; McCubbin & McCubbin, 1993, 1996), which does not fit with my view of humans as wholes whose spirituality is indivisible from their inherent processes of self-organization.

In contrast, the Theory of Self-Transcendence is especially suited to guide my current study because it is consistent with the SA worldview, to which I ascribe, and is particularly relevant in the context of parents of children with cancer. Similar to the SA worldview’s depiction of humans as indivisible wholes (Fawcett, 1993), the theory of self-transcendence
describes self-transcendence as including the following indivisible human dimensions: cognitive, emotional, behavioral, and spiritual (Reed, 2009a). This theory is particularly relevant in the context of childhood cancer because self-transcendence specifically becomes evident in situations that confront the individual with personal mortality or that of a loved one (Reed, 2009a), as in the context of being the parent of a child with cancer.

The Theory of Self-Transcendence has three main concepts: self-transcendence, well-being, and vulnerability. Self-transcendence is an inherently self-organizing type of mental reasoning that leads to self-boundaries expansion. In using self-transcendence, one must choose to de-center oneself and go beyond the limitations posed by the self, time, and space (Reed, 1996a); hence, leading to self-boundaries expansion (Reed, 1991b, 1992, 1996a, 2008b). Self-transcendence enables individuals to sustain well-being through expanding their self-boundaries in four directions: a) intrapersonally (inwards); b) interpersonally (horizontally); c) transpersonally (upwards); and, d) temporally (by linking one’s past and future to make meaning of the present) (Buck, 2006; Reed, 1991a, 1991b, 1992, 1996b, 2008b, 2013). Well-being is one’s subjective sense of wholeness and health (Chin- A-Loy & Fernsler, 1998; Reed, 1991b, 1992, 1996a, 2008b) and consists of both positive and negative aspects. Vulnerability is defined as one’s mortality awareness that emerges in situations involving one’s own impending death or the threat or actual death of a loved one. This theory purports that there are two central relationships: 1) A non-linear relationship between vulnerability and self-transcendence, and 2) A direct and positive relationship between self-transcendence and positive well-being in contrast with a direct and negative relationship between self-transcendence and negative well-being. According to this theory, well-being is an outcome of self-transcendence (Reed, 2008b). The
Theory of Self-Transcendence also depicts the presence of personal and contextual factors that influence the process of self-transcendence as it relates to well-being.

**Hypothesized Theoretical Model**

The current study extends The Theory of Self-Transcendence in three ways. First, by adding the concept of ‘parental resilience’ - as an example of a personal factor- and testing the hypothesis that self-transcendence mediates the relationship between ‘resilience’ and well-being (i.e., Aim 3). Second, by investigating which parental personal factors (i.e., parental resilience and/or parental demographic characteristics) and which child-related contextual factors (i.e., ill child’s cancer characteristics and/or demographic characteristics) predict positive and negative well-being in parents of children with cancer (i.e., Aim 2). Third, this study extends the use of The Theory of Self-Transcendence to the population of parental caregivers of children with cancer, where it has never been studied before. Table 2 provides an overview of which concepts from The Theory of Self-Transcendence are addressed in this study’s hypothetical theoretical model along with their respective definitions. The current study assumes that the concept of vulnerability is the context in which parental caregivers of children with cancer live and thus, does not measure it. Figure 1 provides a visual illustration of the interrelationships among the selected concepts that are investigated in this study.
**TABLE 2. Constructs, Concepts, and Definitions.**

<table>
<thead>
<tr>
<th>Construct</th>
<th>Concept</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Transcendence</td>
<td>Parental Self-Transcendence</td>
<td>Self-transcendence is a post-formal type of reasoning that facilitates the individual’s well-being through expanding self-boundaries in four directions: (a) intrapersonally (i.e., inwards), (b) interpersonally (i.e., horizontally), (c) transpersonally (i.e., upwards), and (d) temporally (Buck, 2006; Reed, 1991a, 1991b, 1992, 1996b, 2008b).</td>
</tr>
<tr>
<td>Well-Being</td>
<td>Parental Well-Being</td>
<td>Well-being is one’s subjective sense of wholeness and health (Chin-ALoy &amp; Fernsler, 1998; Reed, 1991b, 1992, 1996a, 2008b) that is derived from one’s continuous seeking and making choices towards a more satisfied whole existence. Well-being consists of both positive and negative aspects.</td>
</tr>
<tr>
<td></td>
<td>Positive Well-Being</td>
<td>Positive well-being is defined by the presence of/or increased positive health outcomes.</td>
</tr>
<tr>
<td></td>
<td>Negative Well-Being</td>
<td>Negative well-being is defined by the presence of/or increased negative health outcomes.</td>
</tr>
<tr>
<td>Vulnerability</td>
<td>Parental Vulnerability</td>
<td>Vulnerability is one’s mortality awareness that emerges in situations involving one’s own impending death or the threat or actual death of a loved one (Reed, 2008b). (The current study assumes that the concept of vulnerability is the context in which parental caregivers of children with cancer live and thus, does not measure it).</td>
</tr>
<tr>
<td>Personal Factors</td>
<td>Parental Personal Factors</td>
<td>Personal Factors are those factors, relating to the person’s own attributes, that influence the process of self-transcendence as it relates to well-being (Reed, 2008b). Parental personal factors include parental resilience and parental demographic characteristics.</td>
</tr>
<tr>
<td></td>
<td>Parental Resilience*</td>
<td>Resilience is a positive personal characteristic that lessens the negative effects of stress and enables one to function psychologically at an exceedingly high level despite life’s adversities (Richardson, 2002; Wagnild &amp; Collins, 2009; Wagnild &amp; Young, 1993; White et al., 2002).</td>
</tr>
<tr>
<td></td>
<td>Parental Demographic</td>
<td>In the current study, these include: parental age, spiritual affiliation/use of faith in daily life, marital status, educational level, number of work hours, satisfaction with financial status, gender, ethnicity, and employment status.</td>
</tr>
<tr>
<td></td>
<td>Characteristics</td>
<td></td>
</tr>
<tr>
<td>Contextual Factors</td>
<td>Child-Related Contextual</td>
<td>Contextual Factors are those factors, pertaining to the person’s context or living environment, that influence the process of self-transcendence as it relates to well-being (Reed, 2008b).</td>
</tr>
<tr>
<td></td>
<td>Characteristics</td>
<td>In the current study, these include: cancer diagnosis, time since cancer diagnosis, and number of relapses.</td>
</tr>
<tr>
<td></td>
<td>Child’s Demographic</td>
<td>In the current study, these include: ill child’s current age and gender.</td>
</tr>
<tr>
<td></td>
<td>Characteristics</td>
<td></td>
</tr>
</tbody>
</table>

* refers to the added concept (of parental resilience) to the rest of the concepts described by Reed in her Theory of Self-Transcendence.
FIGURE 1. Hypothesized Theoretical Meditation Model.

The current study’s hypothesized theoretical model describes ‘parental well-being’ as the main concept of interest that consists of both positive and negative aspects (Aim 1). Both ‘parental personal factors’ as well as ‘child-related contextual factors’ link directly to ‘parental well-being’ and are hypothesized to predict parental well-being (Aim 2). ‘Child-related contextual factors’ include: ‘child’s demographic characteristics’ and ‘child’s cancer characteristics.’ ‘Parental personal factors’ include: ‘parental demographic characteristics’ and ‘parental resilience.’ Furthermore, ‘parental resilience’ is hypothesized to link to ‘parental well-being’ through the underlying generative mechanism of ‘parental self-transcendence,’ which is the hypothesized mediator for the relationship between ‘parental resilience’ and ‘parental well-being’ (Aim 3).
A variety of theorizing steps and patterns of knowledge contributed to the proposition of my hypothesized theoretical model. I used Peplau’s cycle of inquiry as my selected theory development strategy for it guided the development of my hypothesized theoretical model while simultaneously anchoring it in my interpersonal therapeutic relationships with clients and their families. I also used abduction as my selected type of reasoning for it allows for the triangulation of three different patterns of knowing – personal, empirical, and conceptual – that fuel my abductive ‘jump in thinking’ to ‘land on’ the current study’s hypotheses (Reed, 1995, 1996b, 2010, 2011) as proposed explanations for parental well-being, its predictors, and mediators.

The personal pattern of knowing consists of making ‘abductive leaps’ towards explaining a phenomenon of interest based on practical knowledge from one’s interactions with patients in the clinical field and from personal values and biases. Throughout my work as a consultation-liaison psychiatric nurse dealing with parents of children with cancer, I learned that parents who seemed to do better were those who were able to generally put things into perspective beyond the concrete aspect of the here and now. They were able to shift their focus to things that connect them with pleasant entities, such as spiritual practices, family and friend gatherings, and self-connectedness by trying to be as healthy as they can despite the constraints of having to spend extended amounts of time with their hospitalized child. Also during my experience, I found that my role as a nurse was not to teach them what to do, but rather to shed light on their own capabilities of doing the above things as these are inherently present within them. Thus, based on the personal pattern of knowing, I am ‘abductively’ hypothesizing that there is evidence for positive well-being as well as negative well-being in parents of children with cancer (Hypothesis 1).
The empirical pattern of knowing involves making ‘abductive leaps’ towards possible explanations for a phenomenon of interest stemming from empirical studies. Based on current literature, parental resilience is empirically positively linked –though only qualitatively- to positive well-being in the population of parental caregivers of children with cancer (Brody & Simmons, 2007; McCubbin et al., 2002; Nicholas et al., 2009). In other adult populations, resilience is quantitatively positively linked to positive well-being (Haley & Harrigan, 2004; Ross, Holliman, & Dixon, 2003; Tang, 2007; White et al., 2002). Other parental personal factors, such as parental demographic characteristics, have been investigated as predictors of well-being with mixed and inconclusive findings Also, contextual factors, such as the ill child’s demographic and cancer-related characteristics, have been investigated as predictors of parental well-being with mixed and inconclusive results (Dolgin et al., 2007; Goldbeck, 2006; Lou, 2006). Although self-transcendence has not yet been studied in parental caregivers, however extant literature has found that self-transcendence is empirically positively linked to well-being in other adults and caregiver types (Acton & Wright, 2000; Chen & Walsh, 2009; Chin- A-Loy & Fernsler, 1998; Coward, 1990, 1991, 1995, 1996; Coward & Kahn, 2004, 2005; Coward & Lewis, 1993; Ellermann & Reed, 2001; Enyert & Burman, 1999; Josefsson et al., 2007; Kausch & Amer, 2007; Kinney, 1996; Mellors et al., 2001; Mellors et al., 1997; Nygren et al., 2005; Pelusi, 1997; Ramer et al., 2006; Runquist, 2007; Runquist & Reed, 2007). The literature suggests that both resilience and self-transcendence will be positively linked to well-being in parents of children with cancer. Thus, based on the empirical pattern of knowing, I am ‘abductively’ hypothesizing that personal factors (i.e., parental resilience and parental
demographic characteristics) and contextual factors (i.e., ill child’s cancer and demographic characteristics) predict positive and negative well-being (Hypothesis 2).

The conceptual pattern of knowing entails cognitively linking concepts. Both resilience and self-transcendence are theoretically linked to positive well-being. This is because the Resiliency Model of Family Stress, Adjustment, and Adaptation links parental resilience to parental positive well-being (McCubbin et al., 2002; McCubbin & McCubbin, 1993, 1996) and the Theory of Self-Transcendence theoretically links self-transcendence to positive well-being (Reed, 2008b) as well. Furthermore, based on the conceptual definitions, resilience and self-transcendence are conceptually linked to each other. This is because both concepts have a role in helping individuals’ integrate challenges and existential problems in the face of adversities (Reed, 2008b; Richardson, 2002). Integration involves a meaningful synthesis of paradoxical and conflicting elements, a process that occurs within self-transcendence (Reed, 1991b, 1992). Self-transcendence works by fostering four types of self-boundaries expansion (Reed, 1991b, 1992, 1996a, 2008b): 1) intrapersonal (inward), 2) interpersonal (horizontal), 3) transpersonal (upward), and 4) temporal. The first three types of self-boundaries expansion conceptually correspond to the three resilience factor types described in qualitative studies on resilience in parents of children with cancer (Brody & Simmons, 2007; McCubbin et al., 2002; Nicholas et al., 2009). Thus, based on the conceptual pattern of knowing, I am ‘abductively’ hypothesizing that self-transcendence mediates the relationship between resilience and well-being in parents of children with cancer (Hypothesis 3).
Conclusion

In summary, the conceptual and theoretical bases for the current study were described in Chapter 1. Well-being consists of both positive and negative aspects. The importance of investigating which factors predict well-being and the mechanism through which these predictors work to facilitate well-being in parents of children with cancer was discussed. The reasoning behind the current study’s hypothesis that one’s self-transcendence acts as a mediator that naturally unfolds in adverse life situations to provide an underlying mechanism that facilitates the impact of resilience on well-being was described. Finally, the significance of this study and how nursing has an important role in facilitating one’s engagement in self-transcendence were discussed in Chapter 1. Chapter 2 includes a synthesis of the literature on the concepts selected for investigation in my hypothesized theoretical model.
CHAPTER 2: REVIEW OF LITERATURE

Chapter 2 consists of a synthesis of the literature on: positive and negative well-being in parents of children with cancer, predictors of well-being, and the mediators through which these predictors work. The literature review is organized according to the main concepts that were selected for the current study (Table 2) and compares between research in parents of children with cancer (whenever available) and research in other caregiver and/or adult populations.

Parental Self-Transcendence

Self-transcendence is a self-organizing type of mental reasoning that allows self-boundaries expansion to achieve broadened perspectives and behaviors helpful in deriving meaning from adverse experiences (Reed, 2008b). As such, self-transcendence not only entails cognitive and emotional perspectives, but also consists of actual behaviors that help in the individual’s meaning derivation. Self-transcendence is inherently present in individuals and unfolds naturally in situations that involve one’s mortality or that of a loved one. Self-transcendence is not only an inherent developmental capability that sustains well-being (Reed, 2008b); but it also has a pragmatic advantage in that it is amenable to translation into interventions (Acton & Wright, 2000; Chen & Walsh, 2009; Coward, 1995; Coward & Kahn, 2004, 2005; Kausch & Amer, 2007). Furthermore, self-transcendence interventions have been empirically found to promote well-being in other adult (Coward & Kahn, 2004, 2005) and caregiver (Chen & Walsh, 2009; Kausch & Amer, 2007) populations.
**Self-Transcendence and Problem-Solving**

In using self-transcendence, one must choose to de-center oneself and go beyond the limitations posed by the self, time, and space; hence, leading to self-boundaries expansion (Reed, 1991b, 1992, 1996a, 2008b). Self-transcendence enables individuals to sustain well-being in the face of adversity through expanding self-boundaries in four directions: a) intrapersonally (downwards), b) interpersonally (horizontally), c) transpersonally (upwards), and d) temporally (by linking one’s past and future to make meaning of the present) (Buck, 2006; Reed, 1991a, 1991b, 1992, 1996b, 2008b). In contrast to ‘formal’ hypothetic-deductive types of reasoning, such as problem solving, that seek self-focused strivings for identity and intimacy as well as absolute answers to questions in life; self-transcendence extends beyond these approaches and is thus considered a ‘postformal’ type of mental reasoning. This is because self-transcendence is more contextual, more pragmatic, more spiritual, and more tolerant of life’s ambiguity and paradoxes than formal hypothetic-deductive types of reasoning (Reed, 2008b).

**Self-Transcendence and Spirituality**

Spirituality is defined as the connectedness with corporeal and incorporeal entities that enables individuals to derive meaning out of events (Buck, 2006; Reed, 1992). As such, both self-transcendence and spirituality converge on their allowing individuals to connect with and extend beyond the self and immediate situations in deriving meaning out of adversities (Reed, 2008b). However, self-transcendence is more encompassing than spirituality because self-transcendence combines the individual’s cognitive/emotional perspectives and behavioral dimensions, to their spirituality. Thus, the current study will not measure spirituality separately.
as it views spirituality as existing within self-transcendence, which directly and positively links to well-being.

The view of spirituality as a component within self-transcendence that facilitates well-being is congruent with the Theory of Self-Transcendence (Reed, 2008b) and is empirically supported by a number of studies. Schneider and Manner (2006) using a qualitative phenomenological method, investigated the role of spirituality in parents of children with cancer and found that parents’ experiencing of spirituality positively influenced their coping through both religious and secularized manners. Crom (1995), using a similar method, examined the experience of South American mothers who brought their children to the United States for cancer treatment and found that the mothers’ use of faith was helpful for their adaptation to their children’s cancer. Kausch and Amer (2007) also supported the view of spirituality being a component of self-transcendence in their study of family caregivers of terminally ill AIDS/HIV patients; for they found a significant relationship between self-transcendence and spirituality in this population. Therefore, given that self-transcendence incorporates a spiritual component makes it particularly relevant to the context of parents of children with cancer, where spirituality is known to be vital (Crom, 1995; Schneider & Mannel, 2006).

**Self-Transcendence and Well-Being**

The Theory of Self-Transcendence purports that self-transcendence predicts well-being (Reed, 2008b). In the population of parents of children with cancer, self-transcendence has not yet been investigated. However, self-transcendence has extensively been studied in other adults (Chin- A-Loy & Fernsler, 1998; Coward, 1990, 1991, 1995, 1996; Coward & Kahn, 2004, 2005; Coward & Lewis, 1993; Ellermann & Reed, 2001; Kinney, 1996; Mellors et al., 2001; Mellors et
al., 1997; Nygren et al., 2005; Pelusi, 1997; Ramer et al., 2006; Runquist & Reed, 2007) and
caregiver types (Acton & Wright, 2000; Chen & Walsh, 2009; Enyert & Burman, 1999;
Josefsson et al., 2007; Kausch & Amer, 2007; Runquist, 2007) with a majority of findings
supporting the Theory of Self-Transcendence. This suggests that self-transcendence will function
similarly in parents of children with cancer and thus will directly and positively link to their
positive well-being and will directly and negatively link to their negative well-being. Hence, the
current study extends the Theory of Self-Transcendence to the population of parents of children
with cancer, where it has never been studied before.

**Self-transcendence in caregivers.** The literature on self-transcendence in caregivers,
other than parents of children with cancer, is focused on three caregiver types: family caregivers
of terminally ill adults (Enyert & Burman, 1999; Kausch & Amer, 2007); family caregivers of
newborns (Josefsson et al., 2007; Runquist, 2007); and caregivers of elders (Acton & Wright,
2000; Chen & Walsh, 2009; Kim, 2008).

**Family caregivers of terminally ill adults.** Findings from two studies (Enyert & Burman,
1999; Kausch & Amer, 2007) of self-transcendence in family caregivers of terminally ill adults
supported the Theory of Self-Transcendence. Enyert and Burman (1999) used a qualitative
method combining ethnographic techniques and grounded theory to study family caregivers
whose adult loved ones died within the past six months to one year of the start of the study. This
study found that family caregivers were able to find meaning as a result of their caregiving
experience and thus qualitatively linked self-transcendence to well-being in the caregiving
context.
Kausch and Amer (2007) studied family caregivers whose loved one died of HIV/AIDS by conducting a thematic analysis of 31 participants’ responses to open-ended questions about AIDS Memorial Quilt panel making, coping with loss, spirituality, acceptance and how these connected to self-transcendence. This study found that quilt panel making provides: validation, creation of a living memory of the deceased, help in accepting one’s loss, connections with the community of survivors, and connection to a higher power. Although this study’s findings were limited by the small sample size, panel makers had higher self-transcendence scores and lower depression scores when compared to non-panel makers. Furthermore, after removing outlier scores, depression scores of panel makers became significantly lower than those of non-panel makers and it also found that both groups’ self-transcendence levels were negatively correlated with depression. As such, these findings support the Theory of Self-Transcendence that directly links self-transcendence to well-being.

**Family caregivers of newborns.** Josefsson et al. (2007) compared levels of self-transcendence across four groups: a) Women with postpartum depression, b) Healthy postpartum women, c) Age matched healthy non-postpartum women, and d) Non-postpartum women with major depression. Contrary to the hypothesized relationships normally seen in the Theory of Self-Transcendence, women with postpartum depression had higher levels of self-transcendence than healthy postpartum women. However, the difference was a weak one. Moreover, the study reported that in non-depressed women, the postpartum group had significantly lower self-transcendence than controls and the difference was moderate. These findings are contrary to what is expected according to the Theory of Self-Transcendence and the authors report no natural explanation for these differences (Josefsson et al., 2007). In contrast, a qualitative study
investigating women at two to five weeks postpartum and found that self-transcendence and coping techniques were what enabled these women to persevere in the provision of care for their children despite their postpartum fatigue (Runquist, 2007); thus supporting the Theory of Self-Transcendence.

**Family caregivers of elders.** Among caregivers of family members with dementia, self-transcendence was linked to the caregiving experience and the Theory of Self-Transcendence was described as a way to help caregivers find meaning and reconciliation in difficult life situations (Acton & Wright, 2000). However, the authors point to the need for further research to investigate how self-transcendence actually links to caregiving and the need to test the efficacy of strategies that promote self-transcendence in caregivers (Acton & Wright, 2000).

Chen and Walsh (2009) also focused on self-transcendence in caregivers of elders by investigating whether a creative bonding intervention would increase self-transcendence in Taiwanese nursing students caring for elders. Despite the fact that creative activities have been used to strengthen self-transcendence (Reed, 1991b), Chen and Walsh (2009) found that the intervention group that received the creative bonding intervention did not have significantly higher self-transcendence scores as compared to the control group arguing that the low mean age for the sample of nursing students (mean age = 18.3 years) may have accounted for the lower self-transcendence scores when compared to other studies involving older samples.

A dissertation study that investigated the relationships between self-transcendence and mental health outcomes in South Korean elders and their caregivers found that caregivers’ self-transcendence positively and significantly predicted their own depression and negative affect, which is contrary to the expected negative correlations between self-transcendence and
depression and negative affect respectively (Kim, 2008). The author argued that this could be due to data transformations that were done for the depression and affect scores to normalize the dataset.

**Self-transcendence in adults.**

*Adults with illnesses.* Studies that explored self-transcendence in adults with illnesses involved individuals with either AIDS or advanced cancer. Findings from these studies provide qualitative and quantitative empirical evidence for the reliance of adults on self-transcendence to maintain their well-being in the context of their illnesses. Only two studies investigated the link between self-transcendence and well-being in samples that included both men and women (Mellors et al., 2001; Mellors et al., 1997); while the rest of the studies were gender-specific. Mellors et al. (1997) investigated both men and women with HIV and found a moderate positive relationship between self-transcendence and quality of life. In a later study, Mellors et al. (2001) investigated both men and women with AIDS and found that participants transcend the emotional and physical suffering of their illness through their use of self-transcendence by creating a meaningful life, achieving a sense of connectedness, and engaging in self-care. The section that follows describes the studies that were gender-specific in their approaches to examining self-transcendence in adults with illnesses.

*Studies with men.* All three studies that specifically focused on men with illnesses, found that self-transcendence was useful in maintaining men’s well-being and thus these studies support the Theory of Self-Transcendence. One study investigated 420 adults with HIV/AIDS that are predominantly Hispanic males and found that self-transcendence had significant positive relationships with levels of energy and acculturation (Ramer et al., 2006). An earlier
phenomenological study investigated eight gay men with AIDS and found that participants alleviated their sense of aloneness and isolation through their use of self-transcendence by:
accepting the closeness of death, creating a legacy, reaching out for help and helping others, and participating only in activities that had meaning for them (Coward & Lewis, 1993). Another study investigated 24 men between the ages of 61 and 84 years who attended a prostate cancer support group and found that participants had high self-transcendence scores, averaging 50 out of a possible range of 15 to 60. These high levels of self-transcendence in this sample indicate that individuals use self-transcendence to help them in facing their illness (Chin-A-Loy & Fernsler, 1998).

Studies with women. A number of studies specifically focused on women with illnesses across different stages of their illness trajectories: diagnosis, treatment, and survivorship. These studies consistently found that self-transcendence is a resource for well-being in the context of serious illnesses such as: AIDS and cancer. Two longitudinal qualitative studies that investigated the experience of women newly diagnosed with breast cancer over 14 and 8 months respectively, found that participants use self-transcendence to resolve their spiritual disequilibrium by: reconnecting with themselves, others, and/or a higher power (Coward & Kahn, 2004, 2005). Similarly, Kinney (1996) describes her experiencing of self-transcendence through her own dealing with breast cancer by reconstructing and integrating herself.

Also, a phenomenological study investigating the lived experience of self-transcendence in women with AIDS reported that participants found meaning in their lives through self-transcendence by: giving to and receiving from others and maintaining hope (Coward, 1995). An earlier phenomenological study investigating the lived experience of self-transcendence in
women with advanced breast cancer reported that participants derived meaning in their lives through their use of self-transcendence by: accepting unchangeable situations, reaching out beyond themselves to help other women, and permitting others to help them (Coward, 1990). A quantitative study investigating the same population found that self-transcendence decreased illness distress through the mediating effect of emotional well-being (Coward, 1991).

Pelusi (1997) focused on cancer survivors in a phenomenological study that investigated the lived experience of self-transcendence in women who survived breast cancer. Similar to findings from studies that investigated women who were not at the survivorship stages yet, Pelusi (1997) found self-transcendence as a resource for well-being. Self-transcendence helped participants survive their cancer journey by: setting life priorities, looking within oneself, and finding meaning in life.

**Healthy adults.** Similar to the literature on adults with illnesses, a number of studies provide evidence for the use of self-transcendence as a resource for well-being in healthy young, middle, and older adults. A study investigating healthy adults with ages ranging from 19 to 85 years found that self-transcendence had strong positive relationships with and coherence, self-esteem, and hope (Coward, 1996). Similar results were found by a study that investigated oldest-old adults in Sweden and reported moderate positive relationships that linked self-transcendence to resilience, sense of coherence, and purpose in life. However, this study found that self-transcendence was significantly positively related to mental health only in women (Nygren et al., 2005).

A study that investigated middle-aged adults found significant inverse relations between self-transcendence and depression. This study also found that self-transcendence was more
predominant among women than men and that it was higher among groups of older adults (Ellermann & Reed, 2001). Another study that focused on adults included 61 sheltered homeless adults and found a strong positive relationship between self-transcendence and well-being (Runquist & Reed, 2007).

In conclusion, the majority of literature on self-transcendence in healthy or ill adults and caregivers supports the Theory of Self-Transcendence in its view of self-transcendence as a resource that facilitates well-being suggesting that self-transcendence will function similarly in parents of children with cancer. Consequently, the current study hypothesizes that self-transcendence not only will directly and positively link to positive well-being and will directly and negatively link to negative well-being; but that self-transcendence also mediates the relationship between resilience and positive well-being in parents of children with cancer (Aim 3, see Table 1). Hence, the current study extends the Theory of Self-Transcendence to the population of parents of children with cancer, where it has never been studied before.

**Parental Well-Being**

Well-being is one’s subjective sense of wholeness and health (Chin- A-Loy & Fernsler, 1998; Reed, 1991b, 1992, 1996a, 2008b). Another definition for well-being is that it is a satisfactory condition of existence characterized by health, happiness, and prosperity (Merriam-Webster Online Dictionary, 2011). Despite diverse definitions for well-being, there is convergence on the view that well-being is a ‘broad construct,’ which is represented by ‘less abstract concepts’ that are more amenable to measurement.

In the literature on well-being in parents of children with cancer (excluding childhood cancer survivors), some researchers focus solely on the negative aspect of well-being and thus
represent well-being by negative measurable concepts such as: mood disturbances, psychological distress, adjustment difficulties, depression, anxiety, and posttraumatic stress. Contrastingly, other researchers focus solely on the positive aspect of well-being and hence represent well-being by positive measurable concepts such as: mental health, quality of life, growth through uncertainty, and life satisfaction. While other researchers focus on both negative and positive aspects of well-being and therefore represent well-being by a combination of negative and positive measurable concepts. Moreover, some researchers represent well-being by a single concept and thus use a single instrument to measure it; while others represent well-being using multiple concepts and use multiple instruments for its measurement. This variation in defining, representing, and measuring well-being is influenced by the researcher’s selected philosophical worldview and epistemology.

Consistent with the Simultaneous Action (SA) worldview that views humans as wholes entailing more than the sum of their parts and who are in rhythmical and mutual interchanges with their environments in self-organizing ways (Fawcett, 1993), the current study views well-being as one’s subjective sense of wholeness and health that is derived from one’s continuous seeking and making choices towards a more satisfied whole existence. Thus, the current study views well-being as a subjective, relative, and active process that includes both: negative as well as positive aspects. Negative well-being is defined by the presence of/or increased negative health outcomes and positive well-being is defined by the presence of/or increased positive health outcomes (Table 2). Well-being is subjective in that it entails one’s own awareness and satisfaction with one’s own existence. Well-being is relative because it is personally determined by each individual at a particular point in time and is subject to change based on that individual’s
collection of life experiences. Well-being is an active process because it entails a continuous seeking of betterment and making choices on the part of the individual towards a more satisfied state of existence.

Finally, the inclusion of both positive and negative aspects in the current study’s definition of well-being is in-line with the two-factor model of affective health. This model purports that studying what is ‘right’ with people is as important as studying what is ‘wrong’ with them because each plays a unique role in maintaining overall health (Smith & Zautra, 2008). Consequently, the current study’s definition of well-being accounts for the differential roles of both positive and negative aspects of well-being. The section that follows describes the literature on well-being in parents of children with cancer, who are undergoing cancer treatment and are not at the survivorship stage. It includes: a) studies that focus on negative well-being, b) studies that focus on positive well-being, and c) studies that focus on both aspects of well-being (negative and positive).

**Studies Focusing on Negative Well-Being**

The literature on the well-being of parents of children with cancer provides extensive evidence for negative well-being that includes: depression, anxiety, posttraumatic stress, increased illness, decreased quality of life, strained marital relationships, and early death (da Silva et al., 2011; Fotiadou et al., 2008; Jones, 2007; Kazak, Boeving et al., 2005; Kerr et al., 2007; Patterson et al., 2004; Rivera, 2008; Witt et al., 2010).

A total of ten empirical studies specifically focused on negative well-being in the population of parents of children with cancer. Six out of the ten studies measured well-being using a single instrument (Elkin et al., 2007; Jurbergs, Long, Ticona, & Phipps, 2009; Lou, 2006;
Murphy, Flowers, McNamara, & Young-Saleme, 2008; Sloper, 2000; Wijnberg-Williams et al., 2006); while the remaining four studies used multiple instruments to measure well-being (Bayat et al., 2008; Dolgin et al., 2007; Greening & Stoppelbein, 2007; Norberg, Lindblad, & Boman, 2005; Sahler et al., 2005).

**Studies denoting negative well-being using a single concept.** Murphy, Flowers, McNamara, and Young-Saleme (2008), Elkin et al. (2007), and Jurbergs, Long, Ticona, and Phipps (2009) each denoted negative well-being by the following different concepts respectively: adjustment difficulties, depression, and posttraumatic stress. Whereas Wijnberg-Williams (2006), Lou (2006), and Sloper (2000) each denoted negative well-being by the same concept of psychological distress.

Murphy et al. (2008) used a descriptive cross-sectional design to compare the well-being of parents of children with cancer to that of parents of healthy children using the Brief Symptom Inventory (BSI) to measure parental adjustment difficulties. Contrary to what was expected from the literature, Murphy et al. (2008) found no significant group differences in parental adjustment among mothers of children with cancer, fathers of children with cancer, and fathers of healthy controls and reported BSI scores in the normal range of psychological functioning in the three study groups.

Elkin et al. (2007) used a descriptive cross-sectional design to investigate the well-being of mothers of children with cancer using the Beck Depression Inventory, Version II (BDI-II) to measure parental depression. Depression levels were found to be elevated in 30% of mothers of children with cancer, which is consistent with the current literature on parents of children with cancer.
Jurbergs et al. (2009) used a descriptive cross-sectional design to compare the well-being of parents of children with cancer to that of parents of cancer survivors and parents of healthy children. Jurbergs et al. used the Impact of Events Scale-Revised (IES-R) to measure parental posttraumatic stress symptoms (PTSS). Contrary to current literature, Jurbergs et al. (2009) found that parents of children on active cancer treatment had similar PTSS levels as parents of healthy children and that parents of children who were more than five years past their diagnosis reported the lowest PTSS scores when compared with other parents including parents of healthy children.

Wijnberg-Williams et al. (2006), Sloper (2000), and Lou (2006) represented the construct of well-being using the single negative concept of psychological distress. Although each of the two studies by Wijnberg-Williams et al. (2006) and Sloper (2000) used different instruments to measure psychological distress over time using a longitudinal design; both studies had similar findings in that they found little change over time regarding parental psychological distress during the first 18 months after their children’s cancer diagnosis. Wijnberg-Williams et al. (2006) used the 12-item version of the General Health Questionnaire (GHQ-12) to measure psychological distress in mothers and fathers of children with cancer at time of diagnosis (T1), after six months (T2), after one year (T3), and after five years (T4). A significant decrease was found in psychological distress of mothers and fathers only when comparing their scores five years after diagnosis (at T4) with their scores one year after diagnosis (at T3). There were no significant differences in psychological distress of mothers or fathers when comparing their scores at time of diagnosis (at T1), after six months (at T2), or after twelve months (at T3).
Sloper (2000) used the Malaise Inventory to measure psychological distress in mothers and fathers of children with cancer at two time points: six months after diagnosis (T1) and eighteen months after diagnosis (T2). Similar to the study findings by Wijnberg-Williams et al. (2006), Sloper (2000) reported no significant changes in parental psychological distress from six months after diagnosis to eighteen months after diagnosis of their children. However, Sloper (2000) reported high levels of distress in 51% of mothers and around 40% of fathers at both T1 and T2.

Lou (2006) used the 30-item version of the General Health Questionnaire (GHQ-30) to measure psychological distress in parents of children with cancer using a descriptive cross-sectional design. Although this study did not specifically look into the relationship between time since diagnosis and psychological distress, Lou (2006) reported that 67.7% of parents had their children diagnosed with cancer since less than six months and that 68% of respondents had significant psychological distress (using a cutoff of six or more symptoms on the GHQ-30).

**Studies denoting negative well-being using multiple concepts.** In contrast to the studies that used single concepts to denote negative well-being, the four studies described next used multiple concepts in their representation of negative well-being. For example, two studies denoted well-being by two negative concepts: ‘depression’ and ‘anxiety’ (Bayat et al., 2008; Norberg et al., 2005). Another study denoted well-being using three negative concepts: ‘depression,’ ‘anxiety,’ and ‘posttraumatic stress’ (Greening & Stoppelbein, 2007). Similarly, a large multi-site study also used three negative concepts to represent well-being: ‘mood disturbance,’ ‘depression,’ and ‘posttraumatic stress’ (Dolgin et al., 2007; Sahler et al., 2005). As such, depression and anxiety were the two concepts most commonly used to denote negative
well-being in studies of parents of children with cancer and were thus selected in the current study to denote negative well-being.

The majority of studies denoting negative well-being using multiple concepts used Beck Depression Inventory-version II (BDI-II) to measure depression (Greening & Stoppelbein, 2007; Sahler et al., 2005); while only one study used the original version of Beck Depression Inventory (BDI) (Bayat et al., 2008) and one study used Zung Self Rating Depression (Norberg et al., 2005). Also, the majority of these studies used the entire State-Trait Anxiety Inventory (STAI) to measure anxiety (Bayat et al., 2008; Norberg et al., 2005); while one study exclusively used the State Scale of the STAI (Greening & Stoppelbein, 2007). A description of the instruments selected for use in the current study to measure depression and anxiety will follow in later sections of this chapter.

Although both Greening and Stoppelbein (2007) and Sahler et al. (2005) investigated the relationship between problem-solving and negative well-being in parents of children with cancer; the designs and findings of these two studies were different. Greening and Stoppelbein (2007) used a descriptive cross-sectional design and found that parents’ depression, anxiety, and posttraumatic stress symptoms increased as their use of problem-solving, negative self-blame, and negative affect increased. Greening and Stoppelbein concluded that problem-solving strategies can be anxiety-provoking because they typically entail confronting the stressor.

Sahler et al. (2005) conducted a two-arm randomized clinical trial comparing mothers of children with cancer who received a problem solving skills training (PSST-intervention group) to those receiving usual psychosocial care (UPC-control group). In contrast to the findings by Greening and Stoppelbein (2007), Sahler et al. (2005) found that depression, posttraumatic
stress, and mood disturbance scores significantly improved in the PSST-intervention group as compared to the UPC-control group from T1 (2-16 weeks post-diagnosis) to T2 (4-10 months post-diagnosis). Also, improvements in depression and posttraumatic stress were maintained at T3 (10 months or more post-diagnosis). Sahler et al. (2005) argued that these findings support the efficacy of the PSST intervention in decreasing depression and posttraumatic stress in mothers of children with cancer.

Dolgin et al. (2007) reported on the data obtained from the larger study by Sahler et al. (2005) by including all mothers in the UPC group (all measurements at T1, T2, and T3) as well as the preintervention assessments of the PSST-intervention group (measurements at T1 only). Dolgin et al. (2007) reported that mothers of children with cancer had elevated depression levels that significantly declined from T1 to T2 and from T2 to T3. Dolgin et al. (2007) also described three adjustment trajectories within the sample that included subgroups of mothers with: high-declining, moderate-stable, and low-stable distress levels.

Norberg et al. (2005) used a descriptive cross-sectional design to compare the well-being of parents of children with cancer to that of parents of healthy children and found that parents of children with cancer consistently reported higher levels of depression and anxiety. Bayat et al. (2008) also used a descriptive cross-sectional design to study relationships among depression and anxiety among other concepts in parents of children with cancer and found no significant relation between depression and state anxiety scores for neither mothers nor fathers.

**Studies Focusing on Positive Well-Being**

Six studies denoted well-being using solely positive concepts (Eiser, Eiser, & Stride, 2005; Goldbeck, 2006; Lin, Yeh, & Mishel, 2010; Robinson et al., 2007; Svavarsdottir, 2005;
Svavarsdottir & Sigurdardottir, 2006). Additionally, each of these studies relied on a single concept to represent positive well-being. Despite the fact that these studies used positive measurable concepts to represent well-being, findings were not predominantly positive across studies as some studies found lower levels of positive well-being in parents of children with cancer when compared to parents of healthy children or parents of children with other chronic illnesses.

Eiser, Eiser, and Stride (2005) and Goldbeck (2006) both used the positive concept of quality of life to represent positive well-being; however each study used a different instrument to measure it: the Short-Form 36 Health Survey, version 2 (SF-36 v2) (Eiser et al., 2005) versus the Ulm Quality of Life Inventory for Parents (ULQIE) (Goldbeck, 2006). Eiser et al. (2005) used a descriptive cross-sectional design and found that in comparison to population norms, mothers of children with cancer reported lower quality of life across most subscales except in the subscales relating to physical function and pain, where mothers reported functioning within the normal range.

Goldbeck (2006) used a longitudinal design to compare well-being across three parent groups: parents of children with cancer, parents of children with diabetes or epilepsy, and parents of healthy children at one to two weeks after their child’s diagnosis (T1) and at two to three months after diagnosis (T2). Similar to the findings by Eiser et al. (2005), Goldbeck (2006) found that in comparison to parents of healthy children at T1, parents of children with cancer reported significantly lower quality of life across most dimensions, except regarding their satisfaction with their family situation that was ‘higher’ than that of parents of healthy children. Parents of children with cancer consistently reported poorer quality of life than parents of
children with diabetes or epilepsy. A similar pattern was found when comparing parents of children with diabetes or epilepsy to parents of healthy children. Goldbeck related these findings to the fact that childhood illness brings family members closer.

Robinson et al. (2007) used the concept of global mental health to represent positive well-being and measured it using the Symptoms Checklist 30-Revised (SCL-30-R). In this study, Robinson et al. used a case control design to compare the positive well-being of parents of children with cancer to that of parents of healthy children. In contrast to the findings of Eiser et al. (2005) and Goldbeck (2006), Robinson et al. (2007) found no significant differences between parents of children with cancer and parents of healthy children regarding their well-being, specifically their global mental health. The well-being of fathers and mothers of children with cancer played a significant role in the well-being of their children and that the association between father and child distress was dependent upon a number of family and child factors. However, the association between mother and child distress was consistent across child’s gender, age, cancer diagnosis, treatment severity, and family environment (Robinson et al., 2007).

Lin et al. (2010) used the concept of growth through uncertainty to denote positive well-being and measured it using the Growth Through Uncertainty Scale (GTUS). Lin et al. found that parental positive well-being, namely their growth through uncertainty, was only affected by parental uncertainty when mediated by coping. As such, parental coping strategies—such as searching for spiritual meaning and increasing religious activities—were the mediators for the relationship between uncertainty and growth through uncertainty in parents in Taiwan (Lin et al., 2010).
Svavarsdottir (2005) and Svavarsdottir and Sigurdardottir (2006) denoted well-being by the positive concept of general well-being and measured it using the General Well-Being Schedule (GWB). Svavarsdottir (2005) examined the general well-being of parents of children with cancer in Iceland over time and found no statistically significant differences in parental general well-being at baseline, at 12 months, and at 18 months. Svavarsdottir and Sigurdardottir (2006) used a one-group pre-test and post-test quasi-experimental design to test whether a family-level educational and support intervention for parents of children newly diagnosed with cancer would improve parental general well-being at six months and at one year follow-up. Both mothers’ and fathers’ general well-being significantly increased one month after the intervention; however there were no significant changes in parental general well-being at one year follow-up.

**Studies Focusing on Both Positive and Negative Well-Being**

Some studies focused on both positive and negative well-being (Barrera et al., 2004; Fotiadou et al., 2008). Barrera et al. (2004) denoted positive well-being by the concept of global mental health and denoted negative well-being by the concepts of depression and anxiety. Consistent with the findings of Robinson et al. (2007), Barrera et al. (2004) also reported no significant differences in global mental health of mothers of children with cancer and mothers of children with acute illnesses. Mothers of children with cancer did not significantly differ from mothers of children with acute illnesses regarding their anxiety levels. However, significantly higher depression levels in mothers of children with cancer were found when compared to mothers of children with acute illnesses, which is consistent with the literature (Dolgin et al., 2007; Norberg et al., 2005).
Fotadiou et al. (2008) also focused on both positive and negative well-being and used the concepts of life satisfaction and psychological distress to represent positive and negative well-being respectively. Fotadiou et al. (2008) compared the well-being of parents of children with cancer to that of parents of healthy children and found that when compared to parents of healthy children, parents of children with cancer had significantly lower satisfaction with life and significantly higher levels of depression, anxiety, and psychological distress. These findings were consistent with the previous literature (Lou, 2006; Norberg et al., 2005; Sloper, 2000; Wijnberg-Williams et al., 2006).

In summary, the literature on positive well-being in parents of children with cancer is scarce as compared to the extensive evidence for negative well-being. Still, the investigation of both aspects of well-being, positive and negative, is crucial because studying what is ‘right’ with people is as important as studying what is ‘wrong’ with them. This is because the positive and negative aspects of well-being are not mutually exclusive and each aspect plays a unique role in maintaining overall health (Smith & Zautra, 2008). Thus, the current study aims at describing both positive and negative well-being in parents of children with cancer (Aim 1, see Table 1).

**Parental Personal Factors**

In the current study, parental personal factors include: parental resilience and parental demographic characteristics, both of which will be described in the following section.

**Parental Resilience**

The current study selectively focused on parental resilience as an example of a personal factor; hypothesizing that resilience significantly predicts well-being in parents of children with cancer (Hypothesis 2) and that resilience influences well-being through self-transcendence
(Hypothesis 3). The rationales behind this selection and hypotheses stem from definitional, theoretical, and empirical bases as will be described in the following section.

By definition, resilience is a positive personality characteristic that lessens the negative effects of stress and enables one to function psychologically at an exceedingly high level despite life’s adversities (Richardson, 2002; Wagnild & Collins, 2009; Wagnild & Young, 1993; White et al., 2002). As such, resilience is especially relevant in the study of well-being in parents of children with cancer, who not only deal with the adversity of their children’s cancer, but also are confronted with a variety of other challenges in their own lives such as feelings of loneliness, financial burdens, employment challenges to secure income, and the need to care for other children (Jones, 2007; Moore & Beckwitt, 2004; Patterson et al., 2004). Thus, the definition of resilience conceptually links it to well-being in parents of children with cancer.

Theoretically, The Resiliency Model of Family Stress, Adjustment, and Adaptation links resilience to positive well-being for it purports that families with high resilience factors, such as hardiness, have an easier time adjusting if they view changes as growth producing, develop a sense of control over their outcomes in life, and use an active rather than passive orientation in adapting to the cancer situation (McCubbin & McCubbin, 1993, 1996). Hence, resilience is theoretically linked to well-being in parents of children with cancer.

Empirical evidence for the link between resilience and well-being in parents of children with cancer is from qualitative studies (Brody & Simmons, 2007; McCubbin et al., 2002; Nicholas et al., 2009). Brody and Simmons (2007) interviewed eight fathers to investigate resources that helped them deal with their children’s cancer and found that support from others
(family and friends) in addition to having a positive outlook on the child’s illness were helpful strategies for fathers of children with cancer.

McCubbin et al. (2002) examined resiliency factors that helped parents in dealing with their children’s cancer. However, this study included both mothers and fathers (25 mothers and 17 fathers) and was specific to parents of children who were at the survivorship stage. Resiliency factors were found to be helpful to parents in dealing with their children’s cancer included: internal family mobilization and reorganization, social support from the health care team, extended family, the community, and the workplace, and changes in appraisal to make the situation more comprehensible, manageable, and meaningful. Nicholas et al. (2009) conducted a grounded theory study that interviewed 16 fathers of children in cancer treatment and found that the strategies for resistance that helped fathers deal with their children’s cancer included: integration, healthy personal lifestyle and attitudes, support seeking, hope and spirituality, and reframing priorities.

In other adult populations, resilience is quantitatively linked to well-being (Haley & Harrigan, 2004; Ross et al., 2003; Smith, Tooley, Christopher, & Kay, 2010; Tang, 2007; White et al., 2002). This suggests that resilience will operate similarly in parents. Hence, Hypothesis 2 in the current study tests whether resilience actually predicts well-being in parents of children with cancer.

Findings from studies that examined the qualitative link between resilience and well-being in parents of children with cancer converge on the view that resilience is a personal characteristic that helps parents deal with the adversity of their children’s cancer. Resilience does that by propelling parents in three different directions when seeking solutions: (a) inwards (i.e.,
seeking solutions from within such as reframing experiences and priorities and changing one’s appraisal of the situation); (b) horizontally (i.e., seeking solutions through interactions with others such as eliciting support from friends, family, church, coworkers, and health care team); and (c) vertically (i.e., eliciting support from spiritual sources). Interestingly and based on the theory of self-transcendence, the concept of self-transcendence captures the three directions for seeking solutions: inwards, horizontal, and upwards. This is so because self-transcendence is as a type of mental reasoning that enables individuals to sustain well-being through expanding self-boundaries in four directions: (a) intrapersonally (inwards), (b) interpersonally (horizontally), (c) transpersonally (upwards), and (d) temporally (by linking one’s past and future to make meaning of the present) (Buck, 2006; Reed, 1991a, 1991b, 1992, 1996b, 2008b). Thus, Hypothesis 3 in the current study tests whether self-transcendence is the mechanism through which resilience influences well-being. Specifically, self-transcendence is the hypothesized mediator for the relationship between resilience and well-being in parents of children with cancer (Hypothesis 3, Table 1).

**Parental Demographic Characteristics**

In the population of parents of children with cancer, the majority of studies examined the ‘predictive role’ of parental demographic characteristics in influencing parental well-being. Only Sahler et al. (2005) investigated the ‘moderator role’ for parental demographic characteristics. Sahler et al. (2005) found that mothers’ marital status and age functioned as moderators-influencing the relationship between mothers’ acquisition of problem solving skills and their well-being. As such, single mothers and younger mothers who received a problem solving skills
training intervention reported significantly lower negative well-being as compared to married or partnered mothers and older mothers respectively (Sahler et al., 2005).

Studies that investigated the predictive role of parental demographic characteristics in influencing parental well-being could fit into one of the three categories: (a) studies that found no significant relationships between demographic characteristics and well-being; (b) studies that found significant relationships between demographic characteristics and well-being; and (c) studies whose findings were mixed regarding the presence of significant relationships between demographic characteristics and well-being.

**Studies that found no significant relationships between demographic characteristics and well-being.** Studies that investigated the predictive role of the following parental demographic characteristics: parental age, marital status, and educational level, found no significant relationships between each of these parental demographic characteristics and parental well-being. As such, parental age did not significantly relate to parental mood disturbance, depression, or posttraumatic stress (Dolgin et al., 2007), or to parental adjustment or coping (Greening & Stoppelbein, 2007). Also, parental marital status had no significant relationships with parents’ mood disturbance, depression, or posttraumatic stress (Dolgin et al., 2007), parental adjustment or coping (Greening & Stoppelbein, 2007), or with parental anxiety or depression (Norberg et al., 2005). The relationship between parental educational level and well-being became nonsignificant once parental coping variables were controlled for (Lou, 2006).

**Studies that found significant relationships between demographic characteristics and well-being.** Studies that investigated the predictive role of the following parental demographic characteristics: parental reduced number of work hours due to caregiving and
perceived unsatisfactory financial status, reported significant relationships between each of these characteristics and well-being. As such, parents who had to cut down working hours to take care of their ill child had significantly lower levels of optimism than those who did not (Fotiadou et al., 2008). Parents who perceived less satisfactory financial status had significantly greater levels of psychological distress than parents who were satisfied with their financial status (Lou, 2006).

**Studies whose findings were mixed regarding the presence of significant relationships between demographic characteristics and well-being.** Findings were mixed regarding whether parental gender, ethnicity, and employment status significantly predicted parental well-being (Fotiadou et al., 2008; Greening & Stoppelbein, 2007). Compared to fathers, mothers had significantly lower levels of optimism and higher levels of anxiety (Fotiadou et al., 2008); significantly lower quality of life (Goldbeck, 2006); and significantly higher levels of anxiety and depression (Norberg et al., 2005). In contrast, other studies found no significant differences among mothers and fathers regarding their depression, life satisfaction, and coping (Fotiadou et al., 2008); psychological distress (Lou, 2006); and adjustment (Greening & Stoppelbein, 2007). Parental ethnicity did not have a significant relationship with parental adjustment or coping (Greening & Stoppelbein, 2007). Similarly, maternal ethnicity did not have a significant relationship with maternal mood disturbance, depression, or posttraumatic stress when child’s age, gender, diagnosis of a brain tumor or leukemia, mothers’ age, marital status, and education were controlled for (Dolgin et al., 2007). However, when the same sample was recoded such that the reference mother was 35 years with some college education, married, English-speaking, non-Hispanic, non-Israeli, Caucasian, with an 8-year-old female child; ethnicity became significantly related to posttraumatic stress. As such, Hispanic mothers whose
primary language was Spanish had significantly higher levels of posttraumatic stress compared to mothers of other ethnicities. Also, Israeli mothers’ posttraumatic stress, unlike mothers of other ethnicities, experienced an increase in posttraumatic stress during the fifth to seventh months post cancer diagnosis in their children (Dolgin et al., 2007). One study found that employed parents had significantly higher levels of optimism than unemployed parents (Fotiadou et al., 2008). In contrast, another study found that parental occupation did not have a significant relationship with parental adjustment or coping (Greening & Stoppelbein, 2007).

**Child-Related Contextual Factors**

The section that follows describes child-related contextual factors and includes: child’s cancer characteristics and child’s demographic characteristics. The literature on the role of child-related contextual factors as predictors for parental caregivers’ well-being is limited and contradictory.

**Child-Related Cancer Characteristics**

In the current study, child-related cancer characteristics include: the ill child’s cancer diagnosis, time since cancer diagnosis, and number of relapses. Findings are mixed regarding whether having a child diagnosed with cancer significantly predicts parental well-being. Some studies found that having a child with cancer, regardless of cancer type, was significantly related to parental negative well-being (Fotiadou et al., 2008; Goldbeck, 2006; Norberg et al., 2005). Goldbeck (2006) found that parents of children with cancer reported significantly lower parental quality of life when compared with parents of children with diabetes/epilepsy and when compared to healthy controls. Similarly, Fotadiou et al. (2008) found that when compared with parents of healthy children, parents of children with cancer reported lower levels of optimism
and decreased subjective health perception. Also, Fotadiou et al. (2008) and Norberg (2005) found that parents of children with cancer reported higher levels of anxiety and depression in comparison to parents of healthy children. Interestingly, the child’s cancer type did not significantly relate to mothers’ negative affectivity and posttraumatic stress symptoms (Dolgin et al., 2007).

Study findings were also mixed regarding whether time since cancer diagnosis significantly predicts parental well-being. Norberg et al. (2005) found that time since diagnosis had significant effects on parental well-being; whereby emotional distress was highest in parents whose children were diagnosed with cancer since less than two months. Similarly, Dolgin et al. (2007) found that time since diagnosis had a significant effect on mothers negative affectivity and posttraumatic symptoms as those significantly decreased at 3- and 6- month follow-up visits. Goldbeck (2006) also reported that fathers’ well-being increased significantly within the first three months after the child was diagnosed with a chronic disease. In contrast, time since diagnosis had no significant relationship with parental psychological distress (Lou, 2006), parental optimism (Fotiadou et al., 2008), or parental adjustment (Greening & Stoppelbein, 2007).

Norberg et al. (2005) reported that whether the child had a relapse or not was surprisingly found to have no significant effects on parental anxiety and depression. Contrastingly, Jursbergs et al. (2009) reported that parents of children that experienced relapse had the highest posttraumatic stress scores, almost double that of parents whose children had no history of relapse and were off treatment. Jurbergs et al. (2009) relate their findings to the idea that simply having a child with cancer does not necessarily lead to increased posttraumatic stress scores in
parents; but that having a child with cancer makes parents ‘vulnerable to a second hit’ (such as a relapse) whose occurrence is what then leads to a significant increase in posttraumatic stress.

**Child’s Demographic Characteristics**

The majority of studies reported that the ill child’s gender was not significantly related to parental well-being. Child’s gender had no significant relationships with parental adjustment (Greening & Stoppelbein, 2007), parental psychological distress (Lou, 2006), or mothers’ negative affectivity and posttraumatic stress symptoms (Dolgin et al., 2007). Contrarily, Goldbeck (2006) reported that parents of girls report lower parent quality of life as compared to parents of boys.

Similarly, the majority of studies reported that the ill child’s age did not significantly relate to parental psychological distress (Lou, 2006), parental adjustment (Greening & Stoppelbein, 2007), or mothers’ negative affectivity and posttraumatic stress symptoms (Dolgin et al., 2007). However, Goldbeck (2006) found a significant relationship between the ill child’s age and parental well-being reporting that parents of younger children had lower parental quality of life scores than parents of older children.

In summary, the empirical evidence is limited and inconclusive regarding which parental personal factors (i.e., parental resilience and/or parental demographic characteristics) and which child-related contextual factors (i.e., ill child’s cancer characteristics and/or child’s demographics) predict positive and negative well-being in parents of children with cancer. Hence, this constitutes one of the current study aims (Aim 2, Table 1).
Conclusion

In conclusion, Chapter 2 included a synthesis of the extant literature on the concepts selected for investigation in the current study: parental self-transcendence, parental well-being, parental personal factors (including parental resilience and demographic characteristics), and child-related contextual factors (child-related cancer and demographic characteristics). Study methods are described in Chapter 3.
CHAPTER 3: METHOD

This chapter includes a description of the current study’s research design, sample, setting, human subjects’ protection, recruitment, data collection, measures, and data analyses procedures.

Research Design

The current study used a descriptive cross-sectional design to explore parental positive and negative well-being, whether parental personal factors and/or child-related contextual factors predict parental positive and negative well-being, and whether parental self-transcendence is the underlying mechanism that mediates the relationship between resilience and positive well-being in parents of children with cancer.

Sample and Setting

A convenience sample of 93 parents of children with cancer was recruited from a large acute care children’s hospital in the DC metropolitan area: Children’s National Medical Center (CNMC) anticipating about a 10% missing data rate. Field (2009) suggests that the typical sample size used to achieve the standard power of .80 considering up to three predictors and expecting a medium effect is 80. Thus, this study oversampled by 13 additional participants to ensure a large-enough sample and reduce bias due to missing data.

The target population in this study included parents whose children had cancer and were receiving cancer treatment during the data collection phase of this study. The study’s inclusion criteria for parents were parents or guardians of children: (1) with any type of childhood cancer diagnosed since at least two months prior to the study start date; (2) whose child was receiving cancer treatment; (3) who are able to read or speak English; and, (4) who are of any age and ethnicity and are willing to participate in the study. Exclusion criteria were parents or guardians
of children with cancer: (1) who are in end-of-life stages, and (2) whose children are cancer survivors.

**Human Subjects’ Protection**

The Institutional Review Board (IRB) Human Subjects Committees at the University of Arizona and at Children’s National Medical Center (CNMC) (Appendix A) reviewed the current study to assess confidentiality, safety, and potential risks before granting approval for this study. Once approval was granted, the primary investigator (PI) provided potential participants with written and oral explanations of the study purpose, procedures for completing the questionnaires, potential risks and benefits, and the voluntary and anonymous nature of their participation. Participants were informed of their right to withdraw from the study at any time and assured that their participation (or lack of) would not affect the care their children received. The PI also informed participants of the various strategies in place to protect participants’ confidentiality: (1) de-identifying data by assigning a code number for each study participant and using the code number for data entry and analysis while separately and securely storing any identifying information from informed consents and participant coding procedures under lock that was accessible only to this study’s PI and her advisor; (2) ensuring electronic data integrity by password protecting and storing two copies of the original data set in SPSS files; and, (3) locking all filled-out study instruments immediately following data entry into the SPSS data set and shredding the instrument hard copies seven years after study completion. Potential risks involved in asking participants to fill out this study’s instruments were minimal; however the PI was prepared to provide participants with referral information to local mental health services in the DC metropolitan area should they request it during data collection.
Procedures

Recruitment

Continuous snowballing recruitment was done at CNMC. The PI coordinated all recruitment strategies with a contact person as specified by CNMC. The PI recruited study participants using person-to-person recruitment. The PI was available daily for person-to-person recruitment on the pediatric oncology outpatient and inpatient units. Other snowballing recruitment strategies included asking participants to refer other parents whom they thought might be interested in joining the study.

Data Collection

Potential participants were screened based on the study’s inclusion criteria and exclusion criteria. If they were excluded based on the criteria, they received an explanation and were thanked for their time. After the PI administered the informed consent to participating parents, study packets were given to the participants along with instructions to return them to the PI after giving them sufficient time to complete (negotiated with the parents). Participants who agreed to be in the study carefully read and signed the consent form and read the instructions for answering each of the study instruments. Each study packet included a cover letter, a consent form, along with the study instruments (Table 3). Participants who were unable to complete and return their study packets directly to the PI, received a postage-paid return envelope for that purpose (Figure 2).

Two weeks following participant enrollment in the study, the PI mailed a reminder postcard to participants who still had not returned their study packets to encourage participants to return them. Data was collected through self-administration by one of the parental caregivers of
each child-based on availability. Each participant took approximately 32 minutes to fill out the study instruments.

FIGURE 2. Data Collection Procedure.

**Measures**

Each study packet consisted of: (1) a cover letter, (2) a consent form, and (3) six study instruments: (a) a self-transcendence instrument, (b) a positive well-being instrument, (c) two negative well-being instruments, (d) a resilience instrument, and (e) a demographic instrument (Table 3).

<table>
<thead>
<tr>
<th>Construct</th>
<th>Concept</th>
<th>Measure &amp; References for Reliability &amp; Validity</th>
<th># of Items</th>
<th>Time (Min)</th>
<th>Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-Transcendence</strong></td>
<td>Parental Self-Transcendence</td>
<td>Self-Transcendence Scale (STS) (Reed, 1991a, 2009a)</td>
<td>15</td>
<td>4</td>
<td>Range: 15-60; higher score indicates greater self-transcendence level.</td>
</tr>
<tr>
<td><strong>Well-Being</strong></td>
<td>Parental Well-Being</td>
<td>General Well-Being Schedule (GWB)</td>
<td>18</td>
<td>10</td>
<td>Range: 0-110; higher score indicates positive well-being.</td>
</tr>
<tr>
<td></td>
<td>Positive Well-Being</td>
<td>(Svavarsdottir, 2005; Svavarsdottir &amp; Sigurdardottir, 2006)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>General Well-Being</td>
<td>Center for Epidemiologic Studies Depression Scale (CES-D) (McDowell, 2006)</td>
<td>20</td>
<td>7</td>
<td>Range: 0-60; higher score indicates greater depression level.</td>
</tr>
<tr>
<td></td>
<td>Negative Well-Being</td>
<td>State-Trait Anxiety Inventory-State Scale (STAI-S) (Barrera et al., 2004; Greening &amp; Stoppelbein, 2007; Norberg et al., 2005)</td>
<td>20</td>
<td>5</td>
<td>Range: 20-80; higher score indicates greater anxiety level.</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Personal Factors</strong></td>
<td>Parental Resilience</td>
<td>Brief Resilience Scale (BRS) (Smith et al., 2008)</td>
<td>6</td>
<td>2</td>
<td>Range: 1-5; higher score indicates greater resilience level.</td>
</tr>
<tr>
<td></td>
<td>Parental Demographic Characteristics</td>
<td>Demographic Instrument</td>
<td>9</td>
<td>2</td>
<td>Checklist</td>
</tr>
<tr>
<td><strong>Contextual Factors</strong></td>
<td>Child’s Demographic Characteristics</td>
<td>Demographic Instrument</td>
<td>2</td>
<td>1</td>
<td>Checklist</td>
</tr>
<tr>
<td></td>
<td>Child’s Cancer Characteristics</td>
<td>Demographic Instrument</td>
<td>3</td>
<td>1</td>
<td>Checklist</td>
</tr>
</tbody>
</table>

Total Time Requirement (in minutes): 32
Self-Transcendence Instrument

Parental self-transcendence was measured by the Self-Transcendence Scale (STS) developed by Reed (1991a, 2009a). The STS is a 15-item instrument that measures self-transcendence as a single dimension. Each item uses a 4-point Likert-type scale ranging from 1 (not at all) to 4 (very much). The total STS score, which can range from 15 to 60, is then divided by the total number of items to generate a final STS score ranging from 1 to 4 with greater scores indicating higher levels of self-transcendence. Although the STS has not yet been used in the population of parents of children with cancer, it was selected to measure self-transcendence in this study because it has been extensively used in various caregiver populations both nationally and internationally, in which it has demonstrated high reliability scores. Kausch and Amer (2007) used the STS to measure self-transcendence in caregivers who lost loved ones to HIV/AIDS and reported that the STS had a Cronbach’s alpha coefficient of .90. Kim (2008) used the STS to measure self-transcendence in caregivers of elders and reported a Cronbach’s alpha of .77. In the current sample, the STS demonstrated good internal consistency with a Cronbach’s alpha of .86 (Table 4).

Well-Being Instruments

Positive well-being instrument. Parental positive well-being was measured using the General Well-Being schedule (GWB). The GWB is a self-administered questionnaire that assesses how the individual feels about his or her inner personal state (McDowell, 2006). The GWB was developed by Dupuy in 1977 and consists of 18 items that measure the following six dimensions: positive well-being, general health, self-control, vitality, anxiety, and depression. Fourteen items of the GWB use a 6-point Likert-type scale representing intensity or frequency.
The remaining four items use 0 to 10 rating scales defined by adjectives at each end. The total score for the GWB ranges from 0 to 110 with greater scores indicating positive well-being. The proposed cut off points for the GWB total score represent three levels of well-being: (1) a score of 0 to 60 reflects ‘severe distress;’ (2) a score of 61 to 72 reflects ‘moderate distress;’ and, (3) a score of 73 to 110 indicates ‘positive well-being.’ The GWB has been used in the population of parents of children with cancer with high internal consistency reliability scores: Cronbach’s alpha value was .86 for mothers and .91 for fathers (Svavarsdottir, 2005; Svavarsdottir & Sigurdardottir, 2006). In the current study sample, the GWB demonstrated good internal consistency as the Cronbach’s alpha was .91 (Table 4).

**Negative well-being instruments.** Parental negative well-being was measured using the Center for Epidemiologic Studies Depression Scale (CES-D) to measure parental depression and the State Scale of the State-Trait Anxiety Inventory (STAI-S) to measure parental anxiety.

The CES-D is a self-administered questionnaire that measures depression. The CES-D was developed by Radloff and the National Institute of Mental Health in 1972 and is one of the best-known depression measurement tools for it has been extensively used in multiple large studies across age, culture and different sociodemographic groups and has published population norms (McDowell, 2006; Radloff, 1977). The CES-D consists of a total of 20 items using a 0 to 3 response scale. Sixteen items are negatively worded and the remaining four items are positively worded. The total score for the CES-D can range from 0 to 60. The proposed cut off point for the CES-D is 16 or more, which is considered indicative of depression. Although no studies to-date have used the CES-D in the population of parents of children with cancer, the current study selected the CES-D to measure depression because empirical evidence suggests
that the positive items on the CES-D form a separate dimension and are not merely the inverse of the negative items (McDowell, 2006). Thus, the CES-D conceptually aligns well with this study’s hypothesized theoretical model, which views well-being as consisting of both positive and negative aspects that are separate entities and not merely each other’s opposites (Smith & Zautra, 2008). Also, the CES-D outperforms other instruments such as the Beck Depression Inventory (BDI) in populations with high depression prevalence as in the population of parents of children with cancer (McDowell, 2006). The CES-D has been used in caregivers of children with cystic fibrosis with high internal consistency reliability scores ranging from .85 to .94 (Driscoll, Montag-Leifling, Acton, & Modi, 2009). In the current study sample, the CES-D also demonstrated good internal consistency as the Cronbach’s alpha was .86 (Table 4).

The STAI is a self-administered questionnaire that distinguishes between state and trait anxiety. The STAI was developed by Spielberger (1983) and is one of the best-established anxiety measures as it has been used in thousands of studies and is one of the most widely used anxiety instrument (Speilberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). This study specifically used the State Scale of the STAI (STAI-S) because it measures anxiety as a temporary condition that is experienced in specific situations – as that of having a child with cancer – as opposed to the Trait Scale of the STAI (STAI-T) that measures one’s general tendency to perceive situations as threatening. The STAI-S consists of 20 items using a 1 to 4 scale with the total STAI-S score ranging from 20 to 80 with greater scores indicating higher anxiety. Greening and Stoppelbein (2007) and Barrera et al. (2004) used the STAI-S in their studies of anxiety in parents of children with cancer; however, neither study reported on the internal consistency reliability of the STAI-S in this population. Bayat et al. (2008) and Norberg
et al. (2005) used the complete STAI including both its state and trait scales in their studies of anxiety in parents of children with cancer. Norberg et al. (2005) described good internal consistency reliability scores for both: parents of children with cancer and their controls reporting Cronbach’s alpha values of .96 and .91 respectively. In the current study sample, the STAI-S also demonstrated good internal consistency as the Cronbach alpha was .96 (Table 4).

**Resilience Instrument**

Parental resilience was measured by the Brief Resilience Scale (BRS). The BRS was developed by Smith, Dalen, Wiggins, Tooley, Christopher, and Bernard (2008). The BRS is a six-item instrument that measures resilience as unitary construct. It consists of three positively-worded items and three negatively-worded items. Each item uses a 5-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). The BRS is scored by reverse coding the three negatively-worded items and then calculating the mean of all the six items. The total BRS score could range from 1 to 5 with higher scores indicating higher resilience. Although the BRS has not yet been used in the population of parents of children with cancer; it was selected for use in this study. This is because unlike other resilience instruments, which assess resources that promote resilience, the BRS specifically measures resilience as the person’s actual ability to rebound from life’s adversities (Smith et al., 2008; Smith et al., 2010). Thus, the BRS conceptually aligns with the current study’s hypothesized theoretical model that views resilience as a positive personality characteristic that lessens the negative effects of stress and enables one to function psychologically at an exceedingly high level despite life’s adversities (Table 2). Also, the BRS is brief, easy to use, and has acceptable internal consistency reliability scores ranging
from .80 to .91 (Smith et al., 2008). In the current study, The BRS scale demonstrated good internal reliability consistency as the Cronbach’s alpha in this sample was .77 (Table 4).

Demographic Instrument

The demographic instrument was developed specifically for this study and consisted of a total of fourteen questions that addressed: parental demographic characteristics, sick child’s demographic characteristics, and the child’s cancer characteristics. Parental demographic characteristics collected in this study’s demographic instrument included: parental age, parental religious affiliation, marital status, educational level, number of work hours, satisfaction with financial status, gender, ethnicity, and employment status. Child’s demographic characteristics collected were: the sick child’s current age and gender. Child’s cancer characteristics collected included: type of cancer, time since cancer diagnosis, and number of relapses.

Data Analysis

The PI analyzed the data using SPSS version 22. Descriptive statistics were used to describe sample demographics, levels of self-transcendence, positive and negative well-being, and resilience (Aim 1) as well as interrelationships among them. Total parental scores, standard deviation, reliability coefficients, and bivariate correlations were calculated for the, the self-transcendence instrument (STS), the three well-being instruments (GWB, CES-D, and STAI-S), and the resilience instrument (BRS). Standard multiple regression analyses were used to examine if parental personal factors (i.e., parental resilience and/or parental demographic characteristics) and child-related contextual factors (i.e., ill child’s cancer characteristics and/or demographic characteristics) predicted parental positive and negative well-being in parents of children with cancer (Aim 2). Baron and Kenny’s three-step mediation analysis (Baron & Kenny, 1986;
Bennett, 2000) was used to test if the hypothesized mediator (self-transcendence) mediates the relationship between the independent variable (resilience) and the outcome variable (positive and negative well-being) in parents of children with cancer (Aim 3).

**Before Mediation**

![Diagram of Before Mediation Model]

**After Mediation**

![Diagram of After Mediation Model]

FIGURE 3. Testing of Hypothesized Mediation Model.

As depicted in Figure 3, mediation testing involved examining two scenarios for the effect of resilience on well-being (positive and negative respectively): before and after the introduction of the hypothesized mediator of self-transcendence. The upper section of Figure 3
represented the effect of resilience on well-being, before introducing self-transcendence; whereby \( c \) denoted the total effect of resilience on well-being before controlling for self-transcendence. The lower section of Figure 3 also represented the effect of resilience on well-being, but this time after introducing self-transcendence; whereby \( c' \) denoted the direct effect of resilience on well-being after controlling for self-transcendence. Also, the effect of resilience on self-transcendence was represented by \( a \) and the effect of self-transcendence on well-being was represented by \( b \). The product term of the path coefficients \( ab \) represented the indirect effect of resilience on well-being through the intervening mediator of self-transcendence and was referred to as the ‘index of mediation’ (Preacher & Kelley, 2011). As such, the total effect of resilience on well-being was the sum of both: the direct effect of resilience on well-being (\( c' \)) and the indirect effect of resilience on well-being (\( ab \)). Thus, \( c = c' + ab \) and \( ab = c - c' \) (Preacher & Kelley, 2011; Rucker, Preacher, Tormala, & Petty, 2011).

Following the tradition of Baron and Kenny, mediation testing was done by running three regression equations (twice, considering positive well-being and negative well-being respectively). In the first equation, the mediator (self-transcendence) was regressed on the independent variable (resilience). For a mediator effect to be present, resilience should significantly predict self-transcendence (i.e., \( a \) should be significant).

In the second equation, the outcome variable (positive and negative well-being respectively) was regressed on the independent variable (resilience). For a mediator effect to be present, resilience should significantly predict well-being (positive and negative respectively). That is, the total effect of resilience on well-being, before controlling for self-transcendence, should be significant (i.e., \( c \) should be significant). At this point, it would be reasonable to
consider that having a significant total effect is a prerequisite step to consider further testing for mediation; as otherwise, if there was no significant total effect to start with, and then an indirect effect would not exist. However, starting with a significant total effect is not always the determining factor for whether one should proceed to test for mediation or not. Baron and Kenny (1986, p. 1177) caution that in the case where \( c \) is underpowered, “then it is critical that the investigator further examines not only the significance of the coefficients but also their absolute size.” Placing an unnecessary focus on the significance of the total effect as the deciding factor to determine whether one should test for mediation or not can be misleading. This is because a significant indirect effect can exist even when the total effect is not significant (Rucker et al., 2011). Moreover, current literature recommends that the focus in mediation testing needs to be on quantifying and reporting the effect size of indirect effects rather than on the significance of total and direct effects (Preacher & Kelley, 2011; Rucker et al., 2011). Therefore, as described in chapter 4, the data in the current study was analyzed taking into account these considerations.

In the third equation, the outcome variable (positive and negative well-being respectively) was regressed on both the independent variable (resilience) and the mediator (self-transcendence) simultaneously. For a mediator effect to be present, two conditions should be met. First, the mediator (self-transcendence) should significantly predict the outcome variable (positive and negative well-being respectively) (i.e., \( b \) should be significant). Second, the direct effect of the independent variable (resilience) on the outcome variable (positive and negative well-being respectively)-after controlling for the mediator (self-transcendence)-must be either less significant in the third equation than it was in the second (i.e., \( c' < c \)), indicating ‘partial mediation;’ or the direct effect becomes no longer significant (i.e., \( c' = 0 \)), indicating ‘full
mediation.’ Another consideration that was taken into account during data analysis as described in chapter 4 was that claiming full mediation once the direct effect of the independent variable on the outcome variable becomes nonsignificant (after controlling for the mediator) might erroneously deter the investigator from examining additional mediators that may have a role in mediating the effects of the independent variable on the outcome variable. This is because a significant additional indirect effect can exist even when the direct effect is not significant (Rucker et al., 2011).

Therefore, despite that fact that Baron and Kenny’s three-step mediation testing requirements are to have: in Step 1) – the independent variable (resilience) significantly predict the mediator (self-transcendence); in Step 2) – the independent variable (resilience) significantly predict the outcome variable (well-being, which includes both positive and negative well-being); and in Step 3) – the mediator (self-transcendence) significantly predict the outcome variable (well-being) in a manner where the previously significant relation between the independent variable (resilience) and dependent variable (well-being) is either less significant or no longer significant. It is important to not place unnecessary focus solely on the significance of the total and direct effects of the independent variable on the outcome variable because this can lead to erroneous conclusions regarding mediation. Chapter 4 will describe in detail the analysis for the data obtained in this study along with the various considerations that were taken into account during data analysis to ensure statistical conclusion validity of the results.
Conclusion

The current study’s research design, sample, setting, human subjects’ protection, recruitment, data collection, measures, and data analyses procedures were discussed in Chapter 3. Chapter 4 will include the current study’s data analysis and results.
CHAPTER 4: RESULTS

This study investigated: (1) both aspects of well-being (positive and negative) in parental caregivers of children with cancer; (2) whether parental caregivers’ personal factors (i.e., caregivers’ resilience and/or demographic characteristics) and child-related contextual factors (i.e., ill child’s cancer characteristics and/or demographic characteristics) predicted positive and negative well-being in parental caregivers; and, (3) whether self-transcendence mediated the relationship between resilience and well-being (positive and negative) in parental caregivers of children with cancer. This chapter details the results of the statistical analyses and the findings are organized following each of the current study’s aims 1, 2, and 3 respectively.

Sample Description

A convenience sample of 93 parental caregivers of children with cancer were invited to participate in the current study with an 88.9% participation rate. Thus, 80 caregivers returned their filled surveys and constituted this study’s sample while 13 caregivers were excluded from this sample. Out of the thirteen excluded cases, nine had declined participation and the remaining four had consented to participate but did not return their filled out surveys. Reasons for declining participation included: lack of time to fill out study surveys (four caregivers), recently having participated in another study (one participant), or no reported reason (four participants). Four caregivers consented to participate in the current study, but did not return their filled surveys despite mailing out reminder post cards two weeks after having consented to participate. Given that the typical sample size used to achieve the standard power of .80 considering up to three predictors and expecting a medium effect is 80 (Field, 2009), this study oversampled by 16%
(i.e., by 13 additional participants) to ensure a large enough sample and reduce bias due to missing data.

Table 4 describes the concepts that were selected for the current study along with their respective measures, mean scores, standard deviations, and score ranges.

**TABLE 4. Constructs, Concepts and Scores on Measures of the Hypothesized Theoretical Mediation Model.**

<table>
<thead>
<tr>
<th>Construct</th>
<th>Concept</th>
<th>Measure</th>
<th>N</th>
<th>M (SD)</th>
<th>Potential Range</th>
<th>Actual Range</th>
<th>Cronbach’s Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parental Caregivers’ Personal Factors</strong></td>
<td>Parental Demographic Characteristics</td>
<td>Demographic Instrument</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Parental Resilience</strong></td>
<td></td>
<td>Brief Resilience Scale (BRS) (Smith et al., 2008)</td>
<td>80</td>
<td>3.51 (0.63)</td>
<td>1-5</td>
<td>1.83-5</td>
<td>.77</td>
</tr>
<tr>
<td><strong>Child-Related Contextual Factors</strong></td>
<td>Child’s Demographic Characteristics</td>
<td>Demographic Instrument</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Child’s Cancer Characteristics</strong></td>
<td></td>
<td>Demographic Instrument</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Self-Transcendence</strong></td>
<td>Parental Self-Transcendence</td>
<td>Self-Transcendence Scale (STS) (Reed, 1991b, 2008b)</td>
<td>80</td>
<td>47.56 (7.65)</td>
<td>15-60</td>
<td>26-60</td>
<td>.86</td>
</tr>
<tr>
<td><strong>Well-Being</strong></td>
<td>Parental General Well-Being</td>
<td>General Well-Being Schedule (GWB) (McDowell, 2006)</td>
<td>80</td>
<td>69.34 (17.38)</td>
<td>1-110</td>
<td>30-103</td>
<td>.91</td>
</tr>
<tr>
<td><strong>Parental Depression</strong></td>
<td></td>
<td>Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977)</td>
<td>80</td>
<td>13.28 (9.57)</td>
<td>0-60</td>
<td>0-44</td>
<td>.86</td>
</tr>
<tr>
<td><strong>Parental Anxiety</strong></td>
<td></td>
<td>State-Trait Anxiety Inventory-State Scale (STAI-S) (Speilberger et al., 1983)</td>
<td>80</td>
<td>39.64 (14.42)</td>
<td>20-80</td>
<td>20-76</td>
<td>.96</td>
</tr>
</tbody>
</table>
Parental Caregivers’ Personal Factors

Parental Caregivers’ Demographic Characteristics

Parental caregivers were recruited from both inpatient and outpatient oncology units at Children’s National Medical Center (CNMC) in Washington, D.C. As depicted in Table 5, of all participants, 82% were mothers, 14% were fathers, and 4% were other relative such as aunt/uncle or grandparents. The majority of parental caregivers were females (86%) and 72% of them were partnered (i.e., married or remarried). Ages of parental caregivers ranged between 20 and 62 years and their mean age was 40.41 years (SD = 8.35). A little over half of parental caregivers were White/Caucasian (52%), and the remaining caregivers were divided as follows: 31% African American, 8% Asian, 3% Hispanic, and 6% unspecified.

The majority of parental caregivers had completed graduate education (54%), 34% completed undergraduate education, and 12% completed high school diploma or below. The majority of parental caregivers (42%) worked full-time (i.e., 40 or more hours/week), followed by 35% who were not currently employed, and 23% who worked part-time (i.e., worked from 3 to 39 hours/week). The majority of parental caregivers (58%) reported being satisfied (satisfied, very satisfied) with their current financial status, 20% reported being neutral, and 22% reported being dissatisfied (dissatisfied, very dissatisfied). Lastly, the majority of parental caregivers (41%) reported using faith daily in their life, followed by 40% reporting using faith some to most days, in contrast to 19% who reported never using faith in their daily life.
TABLE 5. Parental Caregivers’ Demographic Characteristics (N=80).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship to the child with cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>66</td>
<td>82</td>
</tr>
<tr>
<td>Father</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>Other relative</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>69</td>
<td>86</td>
</tr>
<tr>
<td>Male</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partnered (married/remarried)</td>
<td>58</td>
<td>72</td>
</tr>
<tr>
<td>Non-partnered (single, divorced, widowed)</td>
<td>22</td>
<td>28</td>
</tr>
<tr>
<td>Age (M=40.41, SD=8.35)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-32 years</td>
<td>11</td>
<td>15</td>
</tr>
<tr>
<td>33-42 years</td>
<td>35</td>
<td>47</td>
</tr>
<tr>
<td>43-52 years</td>
<td>23</td>
<td>31</td>
</tr>
<tr>
<td>53-62 years</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Ethnic background</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>42</td>
<td>52</td>
</tr>
<tr>
<td>African American</td>
<td>25</td>
<td>31</td>
</tr>
<tr>
<td>Asian</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Unspecified</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Educational level completed</td>
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<td></td>
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<tr>
<td>Graduate education</td>
<td>43</td>
<td>54</td>
</tr>
<tr>
<td>Undergraduate education</td>
<td>27</td>
<td>34</td>
</tr>
<tr>
<td>High school or below</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time employment (40 or more hours/week)</td>
<td>34</td>
<td>42</td>
</tr>
<tr>
<td>Part-time employment (3 to 39 hours/week)</td>
<td>18</td>
<td>23</td>
</tr>
<tr>
<td>Not currently employed (2 or less hours/week)</td>
<td>28</td>
<td>35</td>
</tr>
<tr>
<td>Satisfaction with current financial status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfied/very satisfied</td>
<td>46</td>
<td>58</td>
</tr>
<tr>
<td>Neutral</td>
<td>16</td>
<td>20</td>
</tr>
<tr>
<td>Dissatisfied/very dissatisfied</td>
<td>17</td>
<td>22</td>
</tr>
<tr>
<td>Use of Faith in daily life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily</td>
<td>33</td>
<td>41</td>
</tr>
<tr>
<td>Some to most days</td>
<td>32</td>
<td>40</td>
</tr>
<tr>
<td>Never</td>
<td>15</td>
<td>19</td>
</tr>
</tbody>
</table>

**Parental Caregiver Resilience**

The current study used the Brief Resilience Scale (BRS) to measure resilience in parental caregivers. The possible total score on the BRS could range between 1 and 5 with higher scores indicating higher resilience. In the current study, the total BRS (T-BRS) score ranged from 1.83
to 5 and the mean was 3.51 (SD=0.63). T-BRS had a normal distribution with 75.2% of the scores clustered between the scores of 3 and 4, and the majority of scores (46.5%) were above the mean, indicating high resilience in this sample (Table 4).

**Child-Related Contextual Factors**

**Child’s Demographic Characteristics**

Parental caregivers who participated in this study were asked to report the following demographic characteristics of their ill children: child’s age and gender. In the current sample, the age of the children ranged between 1 year or less to 25 years. The mean age of the children was 8.77 years (SD=5.51). Nearly half of the children (49%) were under the age of 8 years. The children were almost equally divided by gender with 48% females and 52% males (Table 6).

**Child’s Cancer Characteristics**

Parental caregivers also reported on the following cancer characteristics of their children: type of cancer, time since cancer diagnosis, and number of relapses. The majority of children (48%) had a diagnosis of Leukemia or lymphoma, and the rest of the sample was nearly equally divided between children with solid tumors (27%) and brain or spinal tumors (25%). The time since cancer diagnosis ranged between 2 months and 19 years with a mean of 2.50 years (SD=3.12). Almost half of the children (51%) had received a cancer diagnosis during the past year and a half. The majority of the children did not have any relapses (82%), followed by 13% had 1 relapse, and the remaining 5% had anywhere between 2 and 5 relapses (Table 6).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s age (M= 8.77 years, SD=5.51 years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 to 7 years</td>
<td>39</td>
<td>49</td>
</tr>
<tr>
<td>8 to 15 years</td>
<td>30</td>
<td>37</td>
</tr>
<tr>
<td>16 to 25 years</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>Child’s gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>38</td>
<td>48</td>
</tr>
<tr>
<td>Male</td>
<td>42</td>
<td>52</td>
</tr>
<tr>
<td>Type of cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Solid tumor</td>
<td>22</td>
<td>27</td>
</tr>
<tr>
<td>Leukemia/Lymphoma</td>
<td>38</td>
<td>48</td>
</tr>
<tr>
<td>Brain/Spinal tumor</td>
<td>20</td>
<td>25</td>
</tr>
<tr>
<td>Time since cancer diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 months to &lt; 1.5 years</td>
<td>41</td>
<td>51</td>
</tr>
<tr>
<td>1.5 years to &lt; 2.5 years</td>
<td>15</td>
<td>19</td>
</tr>
<tr>
<td>2.5 years to 19 years</td>
<td>24</td>
<td>30</td>
</tr>
<tr>
<td>Number of relapses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No relapse</td>
<td>66</td>
<td>82</td>
</tr>
<tr>
<td>1 relapse</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>2 to 5 relapses</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Parental Caregivers’ Self-Transcendence

The current study used the Self-Transcendence Scale (STS) to measure self-transcendence in parental caregivers. The possible total score on the STS could range between 15 and 60 with higher scores indicating higher levels of self-transcendence. In the current study, the total STS (T-STS) score ranged from 26 to 60 and the mean was 47.56 (SD=7.65). T-STS had a negatively skewed distribution with scores clustered to the right at the high values indicating high self-transcendence in this sample such that 75.4% of scores clustered between 40 and 55, leaving only 12.5% of scores under 40 and 12.1% of scores above 55 (Table 4).

Results for Study Aim 1

Study Aim 1 was to describe both aspects of well-being (positive and negative) in parental caregivers of children with cancer.
Parental Caregivers’ Well-Being

Positive well-being. Parental caregivers’ positive well-being was measured by the General Well-Being Schedule (GWB). The possible total GWB score could range between 0 and 110 with greater scores indicating positive well-being. In the current study, the total GWB (T-GWB) scores ranged from 30 to 103 and the mean was 69.34 (SD=17.38) (Table 4). The proposed cut off points for the T-GWB score represent three levels of well-being: a score of 0 to 60 reflects ‘severe distress,’ a score of 61 to 72 reflects ‘moderate distress,’ and a score of 73 to 110 indicates ‘positive well-being.’ In the current study, 35% were in the severe distress category, 18% were in the moderate distress category, and 47% were in the positive well-being category.

Negative well-being. Parental caregivers’ negative well-being was measured using the Center for Epidemiologic Studies Depression Scale (CES-D) to measure parental depression and the State Scale of the State-Trait Anxiety Inventory (STAI-S) to measure parental anxiety.

The possible total CES-D score could range between 0 and 60, with a cutoff point of 16 or more being indicative of significant depressive symptoms. In the current study, the total CES-D (T-CES-D) ranged from 0 to 44 and the mean was 13.28 (SD=9.57) (Table 4). 63.7% of T-CES-D scores were below the depression cutoff of 16, leaving 36.3% of caregivers with scores indicative of significant depressive symptoms.

The possible total STAI-S score could range between 20 and 80 with greater scores indicating higher anxiety. In the current study, the total STAI-S (T-STAI-S) scores ranged from 20 to 76 and the mean was 39.64 (SD=14.42) (Table 4). T-STAI-S had a positively skewed
distribution with scores clustered to the left at the low values indicating low anxiety in this sample. In this sample, 55% of scores clustered below the mean.

In summary, the current study’s findings supported Hypothesis 1, which was that: both positive and negative well-being exist in parental caregivers of children with cancer. This is because although 47% of parental caregivers were in the ‘positive well-being’ category with total General Well-Being Schedule scores above the positive well-being cutoff of 73; the current study found that 36.3% of parental caregivers were in the ‘depressed’ category with total scores above the depression cutoff of 16 on the Center for Epidemiologic Studies-Depression Scale. Also, 45% of parental caregivers had scores that exceeded the mean anxiety score of 39.64 on the State Scale of the State-Trait Anxiety Instrument.

Results for Study Aim 2

Study Aim 2 was to examine if parental caregivers’ personal factors (i.e., caregivers’ resilience and/or demographic characteristics) and child-related contextual factors (i.e., ill child’s cancer characteristics and/or demographic characteristics) predicted positive and negative well-being in parents of children with cancer. Bivariate correlation analyses were conducted to examine zero-order relationships between parental caregivers’ personal factors and each of the well-being measures (positive and negative) (Table 7). Bivariate correlation analyses investigating zero-order relationships between child-related contextual factors and each of the well-being measures were also conducted (Table 7). For the bivariate correlation analyses, preliminary analyses that checked for any violations in the assumptions of normality, linearity, and homoscedasticity were done and whenever the assumption of normality was violated, Spearman’s r was used instead of Pearson’s ‘r.’ Standard multiple regression analyses were used
to assess the additive and relative contributions of predictors to the variance in each of the well-being measures (positive and negative). Only the variables that had significant zero-order correlations with any of the well-being measures were entered into the multiple regression analyses. Preliminary analyses were carried out to ensure that there were no violations of the assumptions of normality, linearity, multicollinearity, and homoscedasticity.

**Parental Demographic Characteristics That Were Not Significantly Related to Well-Being**

In the current study, there were no significant relationships between the following parental demographic characteristics (age, marital status, educational level, gender, ethnicity, or use of faith in daily life) and well-being (positive or negative) (Table 7).

**Parental Demographic Characteristics That Were Significantly Related to Well-Being**

A small significant negative relationship was found between the parental caregivers’ satisfaction with current financial status and depression levels such that parental caregivers with lower levels of satisfaction with their financial status had significantly higher levels of depression, $r = -0.242$, $n=79$, $p = .032$. As such, the level of satisfaction with one's financial status accounted for 5.85% of the variation in depression levels in parental caregivers (Table 7).

A small significant negative relationship was also found between the parental caregivers’ employment status and anxiety levels such that parental caregivers who were not employed had significantly lower anxiety scores than those who were employed (half-time and full-time respectively, $r = -0.240$, $n=80$, $p = .032$ (Table 7).
Parental Caregiver Resilience Was Significantly Related to Well-Being

The current study found a significant positive medium relationship between the parental caregivers’ resilience and their general well-being, \((r = .32, n=80, p = .002)\). This study also found a significant negative medium relationship between resilience and depression \((r = -.37, n=80, p = .000)\) and between resilience and anxiety \((r = -.36, n=80, p = .001)\) (Table 7).

**TABLE 7. Correlations Between Parental Caregivers’ Personal Factors and Well-Being (N=80).**

<table>
<thead>
<tr>
<th>Parental Caregivers’ Personal Factors</th>
<th>Positive Well-Being</th>
<th>Negative Well-Being</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T-GWB</td>
<td>T-CES-D</td>
</tr>
<tr>
<td>Parental Caregivers’ Resilience</td>
<td>.32**</td>
<td>-.37**</td>
</tr>
<tr>
<td>Parental Caregivers’ Demographic Characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>.08</td>
<td>-.23</td>
</tr>
<tr>
<td>Marital status</td>
<td>-.10</td>
<td>.18</td>
</tr>
<tr>
<td>Educational Level</td>
<td>-.04</td>
<td>-.05</td>
</tr>
<tr>
<td>Gender</td>
<td>-.11</td>
<td>.14</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>.11</td>
<td>.00</td>
</tr>
<tr>
<td>Use of Faith in daily life</td>
<td>.08</td>
<td>-.06</td>
</tr>
<tr>
<td>Satisfaction with current financial status</td>
<td>.15</td>
<td>-.24*</td>
</tr>
<tr>
<td>Employment status</td>
<td>.01</td>
<td>-.10</td>
</tr>
</tbody>
</table>

*Note. T-GWB= Total General Well-Being score; T-CES-D= Total Depression score; T-STAI-S= Total Anxiety score. *Correlation is significant at the 0.05 level (2-tailed). **Correlation is significant at the 0.01 level (2-tailed).*

Child-Related Contextual Factors That Were Not Significantly Related to Well-Being

Child-related contextual factors consisted of child demographic characteristics (i.e., child’s gender and age) and the child’s cancer characteristics (type of cancer, time since cancer diagnosis, and number of relapses). In the current study, none of the child-related contextual factors was found to have a significant relationship with well-being of parental caregivers (Table 8).
TABLE 8. Correlations Between Child-Related Contextual Factors and Well-Being (N=80).

<table>
<thead>
<tr>
<th>Child-Related Contextual Factors</th>
<th>Positive Well-Being (T-GWB)</th>
<th>Negative Well-Being (T-CES-D)</th>
<th>Negative Well-Being (T-STAI-S)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s Demographic Characteristics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>.06</td>
<td>.02</td>
<td>-.04</td>
</tr>
<tr>
<td>Age</td>
<td>-.06</td>
<td>-.03</td>
<td>.00</td>
</tr>
<tr>
<td>Child’s Cancer Characteristics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of cancer</td>
<td>.14</td>
<td>-.19</td>
<td>-.02</td>
</tr>
<tr>
<td>Time since cancer diagnosis</td>
<td>.04</td>
<td>-.10</td>
<td>-.11</td>
</tr>
<tr>
<td>Number of relapses</td>
<td>.00</td>
<td>-.01</td>
<td>.05</td>
</tr>
</tbody>
</table>

Note. T-GWB= Total General Well-Being score; T-CES-D= Total Depression score; T-STAI-S= Total Anxiety score.

Multiple Regression Analysis to Examine Predictors of Well-Being (Positive and Negative)

Only variables that had significant zero-order correlation with any of the well-being measures were entered into the multiple regression analyses that examined the additive and relative contributions of predictors to the variance in well-being. Thus, only the following three variables: employment status, satisfaction with current financial status, and resilience were entered into the multiple regression analyses conducted to determine predictors of positive and negative well-being in caregivers of children with cancer.

Multiple Regression Analysis to Examine Predictors of Positive Well-Being

Multiple regression analysis whereby the three variables: resilience, employment status, and satisfaction with current financial status were entered as potential predictors of positive well-being -specifically general well-being- found that the total variance in general well-being explained by this model was 13%; $F (3, 75) = 3.73, p = .015$. However, out of the above three variables entered into the model, only resilience made a significant and unique contribution to explain the variance in general well-being ($Beta = .31, p = .006$). Resilience alone predicted
9.8% of the variance in general well-being. Neither employment status nor satisfaction with current financial status were found to significantly predict general well-being (Table 9).

TABLE 9. Predictors of Positive Well-Being (General Well-Being).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standardized Coefficients</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with current financial status</td>
<td>.167</td>
<td>1.543</td>
<td>.127</td>
</tr>
<tr>
<td>Employment status</td>
<td>.024</td>
<td>.218</td>
<td>.218</td>
</tr>
<tr>
<td>Resilience</td>
<td>.308</td>
<td>2.857</td>
<td>.006</td>
</tr>
</tbody>
</table>

*Note. Dependent Variable: Total GWB Score*

Multiple Regression Analysis to Examine Predictors of Negative Well-Being (Depression and Anxiety)

Multiple regression analysis whereby the three variables: resilience, employment status, and satisfaction with current financial status were entered as potential predictors of negative well-being -specifically depression- found that the total variance in depression explained by this model was 21.3%, $F(3, 75) = 6.77, p = .000$. Out of the above three variables entered into the model, resilience made the greatest significant unique contribution to explain the variance in depression ($Beta = - .351, p = .001$) thus uniquely explaining 12.25% of the variance in depression. Satisfaction with current financial status also made a significant unique contribution to explain the variance in depression ($Beta = - .247, p = .02$) and was able to uniquely explain an additional 6% of the variance in depression. Employment status was not found to significantly predict depression (Table 10).
Multiple regression analysis whereby the three variables: resilience, employment status, and satisfaction with current financial status were entered as potential predictors of negative well-being - specifically anxiety- found that the total variance in anxiety explained by this model was 17.8%, $F(3, 75) = 5.408, p = .002$. Out of the above three variables entered into the model, resilience again made the greatest significant unique contribution to explain the variance in anxiety ($\text{Beta} = -.325, p = .003$) thus uniquely explaining 10.50% of the variance in anxiety. Employment status also made a significant unique contribution to explain the variance in anxiety ($\text{Beta} = -.245, p = .022$) and was able to uniquely explain an additional 5.95% of the variance in anxiety. Satisfaction with current financial status was not found to significantly predict anxiety (Table 11).

The current study’s Hypothesis 2 was that: parental caregivers’ personal factors (i.e., caregivers’ resilience and demographic characteristics) and child-related contextual factors (i.e.,...
ill child’s cancer characteristics and demographic characteristics) predicted positive and negative well-being in parental caregivers of children with cancer. In summary, the current study findings only partially supported Hypothesis 2, as only a few parental personal factors—namely resilience, employment status, and satisfaction with current financial status—none of the child-related contextual factors were found to predict positive and negative well-being in parental caregivers of children with cancer. Specifically, the three main predictors for well-being in parental caregivers were: resilience, employment status, and satisfaction with current financial status with resilience being the strongest unique contributor to the variance in both positive and negative well-being. Resilience positively predicted general well-being and negatively predicted depression and anxiety in parental caregivers of children with cancer.

**Results for Study Aim 3**

Study Aim 3 was to test if self-transcendence mediates the relationship between resilience and well-being (positive and negative well-being respectively) in parental caregivers of children with cancer. This was done using Baron and Kenny’s three-step mediation analysis by running three regression equations (Baron & Kenny, 1986; Bennett, 2000) for each of the positive and negative well-being measures (general well-being, depression, and anxiety as shown in Figures 4, 5, and 6 respectively).
Self-Transcendence mediates the relationship between Resilience & General Well-being in Parental Caregivers of Children with Cancer

Before Mediation

$$c = .32^{**}$$

After Mediation

$$a = .24^*$$  $$b = .53^{**}$$  $$c' = .19^*$$

* $p < .05$.  **$p < .01$.

FIGURE 4. Self-Transcendence Mediates the Relationship Between Resilience and General Well-Being.

In the first equation, the proposed mediator (self-transcendence) was regressed on the independent variable (resilience). For a mediator effect to be present, resilience should significantly predict self-transcendence (i.e., the regression coefficient, $a$, representing the effect of self-transcendence on positive well-being should be significant). In the current study, resilience was found to significantly predict self-transcendence ($a = .24$, $p = .03$), thus satisfying the first condition for mediation (Figure 4).
In the second equation, the outcome variable (positive well-being) was regressed on the independent variable (resilience). For a mediator effect to be present, resilience should significantly predict positive well-being. That is, the total effect of resilience on positive well-being, before controlling for self-transcendence, should be significant (i.e., the regression coefficient, $c$, representing the total effect of resilience on positive well-being before introducing self-transcendence should be significant). In the current study, resilience was found to significantly predict positive well-being before controlling for self-transcendence ($c = .32, p = .004$), thus satisfying the second condition for mediation (Figure 4).

In the third equation, the outcome variable (positive well-being) was regressed on both the independent variable (resilience) and the mediator (self-transcendence) simultaneously. For a mediator effect to be present, two conditions should be met. First, the mediator (self-transcendence) should significantly predict the outcome variable (positive well-being). That is, the regression coefficient, $b$, representing the effect of self-transcendence on positive well-being should be significant. Second, $c'$, the direct effect of the independent variable (resilience) on the outcome variable (positive well-being) after controlling for the mediator (self-transcendence) should be either less significant in the third equation than it was in the second (i.e., $c' < c$) indicating ‘partial mediation’; or the direct effect becomes no longer significant (i.e., $c' = 0$) indicating ‘full mediation.’ In the current study, both above-described conditions were satisfied, thus indicating that self-transcendence was a partial mediator for the relationship between resilience and positive well-being in parental caregivers. First, self-transcendence was found to significantly predict positive well-being ($b = .53, p = .00$). Second, the direct effect of resilience
on positive well-being, after controlling for self-transcendence, became less significant in the third equation than it was in the second with $c' = .19, p = .04$ (i.e., $c' < c$) (Figure 4).

Baron and Kenny’s three-step mediation analyses was conducted to test whether self-transcendence mediated the relationship between resilience and negative well-being (depression and anxiety) in parental caregivers of children with cancer. As shown in Figure 5, self-transcendence was found to partially mediate the relationship between resilience and depression in parental caregivers.

Self-Transcendence mediates the relationship between Resilience & Depression in Parental Caregivers of Children with Cancer

Before Mediation

![Diagram showing before mediation with $c = -.37^{**}$]

After Mediation

![Diagram showing after mediation with $c' = -.24^{*}$ and $c' < c$ indicating partial mediation]

* $p < .05$. **$p < .01$.

FIGURE 5. Self-Transcendence Mediates the Relationship Between Resilience and Depression.
Also, self-transcendence was found to partially mediate the relationship between resilience and anxiety in parental caregivers (Figure 6).

Self-Transcendence mediates the relationship between Resilience & Anxiety in Parental Caregivers of Children with Cancer

Before Mediation

\[ c = -0.33^{**} \]

After Mediation

\[ a = 0.24^* \]
\[ b = -0.48^{**} \]
\[ c' = -0.22^* \]

\[ c' < c \]
thus indicating partial mediation

* \( p < 0.05 \). ** \( p < 0.01 \).

FIGURE 6. Self-Transcendence Mediates the Relationship Between Resilience and Anxiety.

In conclusion, the current study’s Hypothesis 3 was that self-transcendence mediated the relationship between resilience and positive and negative well-being in parental caregivers of children with cancer. The current study findings supported Hypothesis 3 as self-transcendence was found to partially mediate the relationship between resilience and positive and negative well-being respectively in parental caregivers.
CHAPTER 5: DISCUSSION

The current study highlighted the need to investigate well-being in parental caregivers of children with cancer. There is extensive evidence for how having a child with cancer negatively affects well-being in their caregivers due to the diverse stressors it imposes on them. Not only do negative consequences on parental caregivers’ well-being strain their participation and compliance with their ill children’s complex health care needs, these also affect the children’s own well-being as there is a strong empirical link between parental well-being and that of their children (Best et al., 2001; Blotcky et al., 1985; Davis et al., 2010; Frank et al., 1997; Lieb et al., 2002; Mereuta & Craciun, 2009; Robinson et al., 2007; Wijnberg-Williams et al., 2006).

The current study defined well-being as consisting of both positive and negative aspects that are not mutually exclusive. Furthermore, to understand well-being in parental caregivers, the current study argued that this should be first preceded by measuring both aspects of well-being (Study Aim 1), then exploring what factors predict positive and negative well-being (Study Aim 2), and thirdly studying how or what mechanisms do these predictors use to do to their work. These steps are necessary to develop interventions that promote well-being in this population. This is because developing and testing interventions without these steps could provide a distorted understanding of the effects of the intervention delivered and could not explain why an intervention did or did not work. Subsequently, this would delay the development of clinical knowledge needed for providing high-quality care and would not constitute judicious use of resources especially in the current health care economy. Hence, knowledge acquired from the current study provides the foundation for a program of research that focuses on well-being.
promotion in parents of children with cancer by mobilizing parental caregivers’ inherent capabilities - such as self-transcendence.

A thorough review of the literature revealed that: (1) the empirical evidence for positive well-being in the population of parental caregivers is scarce contrary to the extensive evidence for negative well-being; (2) the current empirical evidence available is limited and inconclusive regarding which personal factors (i.e., parental caregiver resilience and/or demographic characteristics) and which contextual factors (i.e., ill child’s cancer characteristics and/or demographic characteristics) predict positive and negative well-being in parents of children with cancer; and, (3) although there is theoretical (based on the Theory of Self-Transcendence) and empirical support for self-transcendence acting as a mechanism that facilitates well-being in the face of adversity in several populations other than the population of parental caregivers of children with cancer, the actual testing of whether self-transcendence mediates the relationship between resilience and positive well-being in parental caregivers of children with cancer is still lacking.

The section that follows discusses the research findings of the current study in the context of the theoretical framework and current literature. This section is organized according to the research hypotheses 1, 2, and 3 respectively.

**Discussion of Current Study Findings for Research Hypothesis 1**

Research Hypothesis 1 in the current study was that both positive and negative well-being exist in parental caregivers of children with cancer. The current study’s findings supported the study Hypothesis 1. This is because the current study found that although 47% of parental caregivers were in the ‘positive well-being’ category with total General Well-Being Schedule
scores above the positive well-being cutoff of 73; 36.3% of parental caregivers were in the ‘depressed’ category with total scores above the depression cutoff of 16 on the Center for Epidemiologic Studies-Depression Scale and 45% of parental caregivers had scores that exceeded the mean anxiety score of 39.64 on the State Scale of the State-Trait Anxiety Instrument. As such, the presence of positive well-being is not merely the absence of negative well-being as both aspects co-exist and each aspect of well-being plays a unique role in maintaining overall health (Smith & Zautra, 2008). These findings also support the current study’s definition of well-being that accounts for the differential roles of both positive and negative aspects of well-being. Hence, the empirical evidence for both positive and negative aspects of well-being in parental caregivers of children with cancer highlights the importance of focusing on both positive and negative well-being as opposed to solely focusing on how well-being deteriorates given their children’s cancer.

**Discussion of Current Study Findings for Research Hypothesis 2**

Research Hypothesis 2 in the current study was that personal factors (i.e., parental caregivers’ demographic characteristics and resilience) and contextual factors (i.e., ill child’s demographic and cancer characteristics) would predict positive and negative well-being in parental caregivers of children with cancer. Current study findings only partially supported Research Hypothesis 2 because none of the contextual factors and only three personal factors (namely, parental caregivers’ resilience, their employment status, and their satisfaction with current financial status) predicted their positive and negative well-being.
Parental Caregivers’ Demographic Characteristics That Were Not Significantly Related to Well-Being in the Current Study

**Relationship of well-being to: age, marital status, and educational level.** The current study found no significant relationships between the following parental demographic characteristics (age, marital status, educational level) and well-being (positive or negative). This finding was consistent with the literature (Dolgin et al., 2007; Greening & Stoppelbein, 2007; Norberg et al., 2005) suggesting the need to focus on other personal factors that have significant roles in predicting well-being in this population.

**Relationship of well-being to: gender, ethnicity, and use of faith in daily life.**
Although the current study found no significant relationships between the following parental demographic characteristics (gender, ethnicity, or use of faith in daily life) and well-being (positive or negative), these findings were consistent with some studies while contrasted with others, thus necessitating further investigation.

The current study findings were similar to other studies that found no significant differences among mothers and fathers regarding their well-being such that gender was not significantly related to depression, life satisfaction, or coping (Fotiadou et al., 2008); psychological distress (Lou, 2006); or adjustment (Greening & Stoppelbein, 2007). However, this study’s findings contrasted with previous studies that reported gender as having a significant relationship with well-being in parental caregivers. Specifically, mothers were reported to have significantly lower quality of life than fathers (Goldbeck, 2006), higher levels of anxiety and depression than fathers (Norberg et al., 2005), and lower levels of optimism and higher levels of anxiety than fathers (Fotiadou et al., 2008).
Current study findings were consistent with other studies that found no significant relationships between ethnicity and well-being in parental caregivers. Parental caregiver ethnicity did not have a significant relationship with their adjustment or coping (Greening & Stoppelbein, 2007); mood disturbance, depression, or posttraumatic stress when other factors were controlled for (Dolgin et al., 2007). One possible explanation to this seeming non-significant relationship between ethnicity and well-being could be because the current study sample was rather homogenous with the majority of participants being either White/Caucasian (52%), or African American (31%).

The current study finding contrasted with previous studies that found links between the use of faith in daily life and well-being in parental caregivers as was reported by Schneider and Mannel (2006) who found that parents’ experiencing of spirituality in their daily life positively influenced their coping through both religious and secularized manners. Similarly, another study had found links between mothers’ daily use of faith and their adaptation to their children’s cancer (Crom, 1995).

In conclusion, there is a need to further investigate whether gender, ethnicity, and use of faith in daily life significantly relate to well-being in parental caregivers of children with cancer.

Parental Caregivers’ Demographic Characteristics That Were Significantly Related to Well-Being in the Current Study

The current study found that parents with lower levels of satisfaction with their financial status had significantly higher levels of depression. This finding was similar to the results in previous studies whereby parents with lower levels of satisfaction with their financial status had significantly greater levels of psychological distress than those who were satisfied with their
financial status (Lou, 2006). However, given that the majority of this study’s sample were highly
educated and employed, which could be considered as resources, this finding cannot be
generalized to those that have lower educational levels and unemployed.

In the current study, parental caregivers who were not employed had significantly lower
anxiety scores than those who were employed (half-time and full-time respectively). One
possible explanation for this was that lower number of work hours translated into having more
time to spend with their children and possibly reducing anxiety in parental caregivers. Although
optimism was not measured in the current study, the finding that unemployed caregivers had
significantly lower anxiety scores (i.e., negative well-being) than their employed counterparts
would seem contradictory to the findings from previous studies that reported that employed
parents had significantly higher levels of optimism (i.e., positive well-being) than unemployed
parents (Fotiadou et al., 2008). Further, the current study results contrast with the results from a
study that found that parental occupation did not have a significant relationship with parental
adjustment or coping (Greening & Stoppelbein, 2007). One possible explanation for this seeming
contradiction across findings from these three studies is that positive well-being is not merely the
opposite or the absence of negative well-being (which is how well-being is conceptualized in this
study). Thus, despite the seeming contradictory findings, one could posit that employed parents
can significantly be more anxious (as per the results of the current study) and still have higher
levels of optimism than their unemployed counterparts as having a high level of optimism does
not necessarily mean they would not be anxious. That is, having high levels of positive well-
being does not negate the possibility of having high levels of negative well-being and vice versa.
Parental Caregivers’ Resilience Was Significantly Related to Well-Being in the Current Study

Parental caregivers with higher levels of resilience had higher levels of general well-being and lower levels of depression and anxiety. These findings adds to the current body of knowledge for, to-date, no studies known to this writer had empirically tested the quantitative relationship between resilience and well-being in parental caregivers of children with cancer. However, these findings were expected given the empirical evidence for the link between resilience and well-being in this population from qualitative studies (Brody & Simmons, 2007; McCubbin et al., 2002; Nicholas et al., 2009). Also this study’s findings that resilience significantly related to well-being is consistent with The Resiliency Model of Family Stress, Adjustment, and Adaptation that purports that families with high resilience factors have an easier time adjusting if they view changes as growth producing, develop a sense of control over their outcomes in life, and use an active rather than passive orientation in adapting to the cancer situation (McCubbin & McCubbin, 1993, 1996). The current study findings on resilience are also consistent with this study’s conceptual definition of resilience as a positive personality characteristic that lessens the negative effects of stress and enables one to function psychologically at an exceedingly high level despite life’s adversities (Richardson, 2002; Wagnild & Collins, 2009; Wagnild & Young, 1993; White et al., 2002).

Child-Related Contextual Factors That Were Not Significantly Related to Well-Being in the Current Study

Child-related contextual factors consisted of: child demographic characteristics (i.e., child’s gender and age) and the child’s cancer characteristics (i.e., type of cancer, time since
cancer diagnosis, and number of relapses). In the current study, none of the child-related contextual characteristics was found to have a significant relationship with well-being of parental caregivers. As described in the following section, these findings were consistent with findings of some studies and contrasted with others, thus highlighting the need to further investigate the relationship between child-related contextual factors and parental caregivers’ well-being as described in the following section.

**Relationship of well-being to: child’s age and gender.** The lack of any significant relationships between the child’s demographic characteristics (i.e., child’s age and gender) and well-being in parental caregivers in this study was consistent with the literature that also did not report any significant relationships between child’s gender or age and parental adjustment (Greening & Stoppelbein, 2007), parental psychological distress (Lou, 2006), and mothers’ negative affectivity and posttraumatic stress symptoms (Dolgin et al., 2007). However the current study findings contrast with a previous study’s finding that parents of girls and parents of younger children had lower quality of life as compared to parents of boys or parents of older children (Goldbeck, 2006). This highlights the need to further investigate this area.

**Relationship of well-being to: child’s type of cancer diagnosis, time since cancer diagnosis, and number of relapses.** This study found no significant relationships between the child’s cancer characteristics (i.e., type of cancer diagnosis, time since cancer diagnosis, and number of relapses) and well-being in parental caregivers. These findings only add to the mixed findings in the literature.

Dolgin et al. (2007) found no significant relationships between child’s cancer type and mother’s negative affectivity or posttraumatic stress symptoms. (Dolgin et al., 2007) Lou (2006)
found similar results related to time since cancer diagnosis and parental psychological distress (Lou, 2006). Cancer type has not been found to be related to parental optimism (Fotiadou et al., 2008), or parental adjustment (Greening & Stoppelbein, 2007). Similar to Norberg et al. (2005) findings are also consistent related to the number of cancer relapses and parental caregivers’ anxiety or depression.

In contrast, Goldbeck (2006) and Dolgin et al. (2007) both found positive relationships between time since cancer diagnosis and father’s wellbeing (Goldbeck, 2006) and a significant negative relationship between time since cancer diagnosis and mothers negative affectivity and posttraumatic symptoms (Dolgin et al., 2007). The current study findings also contrast with the literature that found a significant positive relationship between number of relapses and posttraumatic stress scores in parental caregivers (Jurbergs et al., 2009).

**Discussion of the Results of Multiple Regression Analysis That Investigated Predictors of Well-Being in Parental Caregivers of Children with Cancer**

The three variables entered into the regression analyses were: employment status, satisfaction with current financial status, and resilience. The current study found that combined, these predictors explained: 13% of the variance in general well-being, 21.3% of the variance in depression, and 17.8% of the variance in anxiety of parental caregivers. Also, out of these three well-being predictors, resilience was the strongest unique contributor to the variance in both positive and negative well-being in parental caregivers as resilience alone: positively predicted 9.8% of the variance in general well-being, negatively predicted 12.2% of the variance in depression, and negatively predicted 10.5% of the variance in anxiety in parental caregivers of children with cancer. Additionally, satisfaction with current financial status uniquely and
negatively predicted 6% of the variance in depression such that higher levels of satisfaction with current financial status, predicted lower depression scores. Also, employment status uniquely and negatively predicted 5.95% of the variance in anxiety in parental caregivers such that lower number of work hours predicted lower anxiety levels.

In summary, no other studies to-date that have specifically investigated the empirical relationship between resilience and well-being in parental caregivers of children with cancer. Thus, these findings help build current knowledge as well as guide interventions that strengthen resilience, which in turn would enhance well-being in this population. Also, these findings point to the importance of focusing on parental demographic characteristics such as employment status and satisfaction with current financial status that were found to significantly predict well-being in this population. Consequently, these findings highlight the need to consider health policy changes that would modify these demographic characteristics to enhance well-being in this population by for example allowing parental caregivers medical leaves that would not jeopardize their financial income to help them care for their children with cancer and help maintain their well-being.

**Discussion of Current Study Findings for Research Hypothesis 3**

Research Hypothesis 3 in the current study was that self-transcendence mediated the relationship between resilience and positive and negative well-being in parental caregivers of children with cancer. Current study findings supported Hypothesis 3 as self-transcendence was found to partially mediate the relationship between parental caregivers’ resilience and their positive well-being. Also, self-transcendence was found to partially mediate the relationship between resilience and depression and anxiety respectively. That is, as depicted in the current
study’s hypothesized theoretical mediation model, self-transcendence significantly positively predicted positive well-being and the direct effect of resilience on positive well-being, after controlling for self-transcendence, became less significant than what it was before controlling for self-transcendence indicating partial-mediation. Also, self-transcendence significantly negatively predicted negative well-being (depression and anxiety respectively) and the direct effect of resilience on negative well-being, after controlling for self-transcendence, became less significant than what it was before controlling for self-transcendence indicating partial-mediation.

Although self-transcendence has not yet been investigated in the population of parental caregivers, the current study findings are consistent with The Theory of Self-Transcendence that purports that self-transcendence predicts well-being (Reed, 2008b). This theory is particularly relevant in the context of childhood cancer because self-transcendence specifically becomes evident in situations that confront the individual with personal mortality or that of a loved one (Reed, 2009a), as in the context of being the parent of a child with cancer. The current study findings are consistent with other studies that also supported the Theory of Self-Transcendence in other adults (Chin- A-Loy & Fernsler, 1998; Coward, 1990, 1991, 1995, 1996; Coward & Kahn, 2004, 2005; Coward & Lewis, 1993; Ellermann & Reed, 2001; Kinney, 1996; Mellors et al., 2001; Mellors et al., 1997; Nygren et al., 2005; Pelusi, 1997; Ramer et al., 2006; Runquist & Reed, 2007) and in other caregiver types (Acton & Wright, 2000; Chen & Walsh, 2009; Enyert & Burman, 1999; Josefsson et al., 2007; Kausch & Amer, 2007; Runquist, 2007).
Implications for Theory

This study expanded current knowledge on self-transcendence for it extended the use of the Theory of Self-Transcendence to the population of parental caregivers of children with cancer, where it has never been studied before. The current study also extended the boundaries of the Theory of Self-Transcendence by adding the concept of ‘resilience’ as an example of a personal factor and by testing the hypothesis that self-transcendence mediated the relationship between resilience and well-being in parental caregivers of children with cancer. Given this study’s theory-driven approach to the identification of predictors and underlying mechanisms that facilitate well-being, the findings from this study illuminate how self-transcendence interventions are expected to work before expending resources on testing such interventions.

Implications for Clinical Practice

Study findings provided a more thorough understanding of parental caregivers’ well-being (i.e., both its positive and negative aspects), what factors predict it, and through which mechanism these predictors work. This knowledge has clinical and economic implications in that it facilitates early identification of parents at greatest risks for negative well-being. This in turn contributes to the reduction in healthcare disparities among parental caregivers and reduces their suffering as well as the economic burdens caused by negative well-being such as depression and anxiety. The current study found that caregivers’ lower number of work hours predicted lower anxiety levels while lower satisfaction with current financial status predicted higher depression levels. These points to the importance of further examining policies that would allow parental caregivers medical leaves from work without jeopardizing their financial income to help them care for their children with cancer and help maintain their well-being. Moreover, early
identification of what predicts positive and negative well-being in parental caregivers can ultimately contribute to the improvement of their children’s well-being given the strong empirical link between well-being of parental caregivers and that of their children (Best et al., 2001; Blotcky et al., 1985; Davis et al., 2010; Frank et al., 1997; Lieb et al., 2002; Mereuta & Craciun, 2009; Robinson et al., 2007; Wijnberg-Williams et al., 2006).

Current study findings revealed that parental caregivers’ resilience was the strongest unique predictor for their well-being. This has significant clinical implications because contrary to personal factors that are not amenable to change (e.g., age or ethnicity), finding a predictor that is amenable to change can be a focus for intervention development. Moreover, the current study finding that the relationship between resilience and positive well-being was mediated by self-transcendence also has significant clinical implications. This is so because self-transcendence is an inherent developmental capability of mental reasoning that is readily present in all humans and it not only sustains well-being, but also is amenable to translation into interventions (Acton & Wright, 2000; Chen & Walsh, 2009; Coward, 1995; Coward & Kahn, 2004, 2005; Kausch & Amer, 2007). Furthermore, self-transcendence interventions have been empirically found to promote well-being in other adult (Coward & Kahn, 2004, 2005) and caregiver (Chen & Walsh, 2009; Kausch & Amer, 2007) populations. Therefore, given that self-transcendence: (1) is inherently present in humans, (2) mediates the relationship between resilience and positive well-being in parental caregivers of children with cancer, (3) is amenable to translation into interventions that have been empirically found to promote well-being in other adult populations; thus the next logical step in the knowledge-building process is to design self-transcendence interventions and test them in the population of parental caregivers with cancer.
As such, findings from this study would provide the empirical basis for designing and testing such self-transcendence interventions.

**Implications for Research**

In the current study, none of the contextual factors and only three personal factors (i.e., parental caregivers’ resilience, their employment status, and their satisfaction with current financial status) predicted positive and negative well-being in parental caregivers of children with cancer.

The lack of any significant relationships between the following parental demographic characteristics (e.g., age, marital status, educational level) and well-being (e.g., positive or negative) was consistent with the literature (Dolgin et al., 2007; Greening & Stoppelbein, 2007; Norberg et al., 2005). However, the lack of significant relationships between the following parental demographic characteristics (i.e., gender, ethnicity, or use of faith in daily life) and well-being (i.e., positive or negative), although consistent with some studies it contrasted with others, thus necessitating further investigation.

Child-related contextual factors investigated in this study consisted of: child demographic characteristics (i.e., child’s gender and age) and the child’s cancer characteristics (i.e., type of cancer, time since cancer diagnosis, and number of relapses). In the current study, none of the child-related contextual characteristics was found to have a significant relationship with well-being of parental caregivers. These findings were consistent with some studies and contrasted with others, thus highlighting the need to further investigate the relationship between child-related contextual factors and parental caregivers’ well-being.
Qualitative research is needed to further understand self-transcendence from the perspective of caregivers of children with cancer. What are the ways that parental caregivers express self-transcendence in the context of having a child with cancer? What strategies can be used to foster self-transcendence in parental caregivers? Findings from qualitative research questions would guide building interventions aimed at enhancing parental caregivers’ well-being through fostering their self-transcendence.

**Study Limitations**

The current study has two main limitations: generalization and causal inference. Given that a convenience sample was used to recruit parental caregivers of children with cancer in the DC area who are English-speaking, then the results are mostly applicable to DC metropolitan parental caregivers who are English-speaking. The convenience sample in the current study underrepresented the Hispanic ethnicity as only those who were English-speaking were enrolled in the current study despite the large number of Hispanic potential participants that could have been included had they been English-speaking. Thus, future studies that are geared to include non-English speaking parental caregivers are needed. Also, given that the majority of the samples were college-educated may also limit generalizability.

The second limitation in the current study is the use of cross-sectional data which limits the ability to draw causal inferences as those would require longitudinal study designs and intervention studies. However, in this exploratory study, Baron and Kenny’s three-step mediation analyses allowed for testing relationships and proposing potential predictors and mediators in the relationships between parental personal factors and well-being in parental caregivers of children with cancer. Although longitudinal studies are needed to test causal relationships, the analysis of
mediators in descriptive studies helps identify information about why or how a direct association between an independent variable and a dependent variable occurs. Hence, findings from this exploratory are the basis for future intervention studies and longitudinal studies that could test causal relationships.

**Conclusion**

Caregiving a child with cancer can have significant impacts on well-being of parental caregivers. To better understand these impacts, it is important to focus on both aspects of well-being: positive and negative as the presence of one does not exclude the presence of the other. Some parental caregivers’ demographic characteristics were found to predict their well-being such that not being currently employed predicted lower levels of anxiety and being satisfied with one’s current financial status predicted lower depression levels in parental caregivers of children with cancer. However, the most significant personal factor that could predict well-being in parental caregivers was their resilience; such that higher resilience predicted higher levels of general well-being and lower levels of depression and anxiety respectively. Furthermore, a type of mental reasoning that is inherently developmentally present in all humans and that is amenable to be translated into interventions called self-transcendence has been found to mediate the relationship between resilience and well-being in parental caregivers. Such that, after controlling for self-transcendence, the strength of the relationship between resilience and positive well-being is significantly reduced indicating that self-transcendence is the generative mechanism that facilitates the predictive relationship that resilience has over well-being.

The current study had various strengths: it was the first to test the empirical relationships between resilience and well-being as well as the relationships between self-transcendence and
well-being in parental caregivers. It uncovered predictors of well-being as well as how they work by testing the mediating role of self-transcendence. Also, this study was the first to test the Theory of Self-Transcendence in the population of caregivers of children with cancer. Findings from the current study have significant implications for theory development, clinical practice, and research.
APPENDIX A:

HUMAN SUBJECTS INSTITUTIONAL REVIEW BOARD (IRB) FORMS -

THE UNIVERSITY OF ARIZONA

CHILDREN’S NATIONAL MEDICAL CENTER (CNMC)

Name of Institution or Organization Providing IRB Review (Institution/Organization A): Children's National Medical Center

IRB Registration #: IRB00000414

Federalwide Assurance (FWA) #, if any: FWA00004487

Name of Institution Relying on the Designated IRB (Institution B): The University of Arizona

FWA #: 00004218

The Officials signing below agree that The University of Arizona may rely on the designated IRB for review and continuing oversight of its human subjects research described below: (check one)

( ) This agreement applies to all human subjects research covered by Institution B's FWA.

(✓) This agreement is limited to the following specific protocol(s):

Name of Research Project: Well-Being, Self-Transcendence, and Resilience in Parental Caregivers of Children with Cancer

Name of Principal Investigator: Pamela Hinds, PhD, Children's National, Jonayna Bajjani-Gebura, MSN, BSN, PhD Candidate, University of Arizona

Sponsor or Funding Agency: Children's National Department of Nursing Research and Quality Outcomes Award Number, if any: Department Funds

( ) Other (describe):

The review performed by the designated IRB will meet the human subject protection requirements of Institution B's OHRP-approved FWA. The IRB at Institution/Organization A will follow written procedures for reporting its findings and actions to appropriate officials at Institution B. Relevant minutes of IRB meetings will be made available to Institution B upon request. Institution B remains responsible for ensuring compliance with the IRB's determinations and with the Terms of its OHRP-approved FWA. This document must be kept on file by both parties and provided to OHRP upon request.

Signature of Signatory Official (Institution/Organization A):

Print Full Name: Mark Butshaw, MD Institutional Title: Chief Academic Officer

Date: 10/08/2014

NOTE: The IRB of Institution B must be designated on the OHRP-approved FWA for Institution B.

Signature of Signatory Official (Institution B):

Print Full Name: Jennifer Barton, Ph.D. Institutional Title: Interim Senior Vice President for Research

Date: 11/23/14
# Institutional Review Board (IRB) Committee Review

**Date:** November 26, 2014  
**Principal Investigator:** Jouhanya Elie Bajjani  

<table>
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<th>Protocol Number:</th>
<th>1411560251</th>
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<tr>
<td>Protocol Title:</td>
<td>Well-being, self-transcendence, and resilience in Parental Caregivers of Children with Cancer</td>
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</table>

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<tr>
<th>Level of Review:</th>
<th>Deferral of IRB Oversight</th>
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<tbody>
<tr>
<td>Determination:</td>
<td>Approved</td>
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</table>

**Documents Reviewed Concurrently:**
- **HSPP Forms/Correspondence:** Bajjani, College of Nursing, New Project, F204, Application for Deferral of IRB Oversight, updated.docx  
- **HSPP Forms/Correspondence:** signature page.pdf  
- **Other:** Bajjani, College of Nursing, New Project, IRB application + protocol + amendments submitted and approved by CNMC-the IRB of record-June 1 2014.pdf  
- **Other:** Bajjani, College of Nursing, New Project, Scientific Review Committee Letter from CNMC-the institution overseeing the research-Jan 13 2014.pdf  
- **Other Approvals and Authorizations:** Bajjani, College of Nursing, New Project, IRB approval letter from CNMC-the IRB of record-March 31 2014.pdf  
- **Other Approvals and Authorizations:** Nursing_Bajjani.pdf

**Institution Designated the IRB of Record:** When an institution is the designated IRB of record, the UA IRB will not review the project. The University of Arizona agrees that it will rely on the review, approval, and continuing oversight by the institution IRB of those protocols approved by the institution pursuant to the terms of the Institutional Review Board Authorization Agreement (if applicable) and as outlined in the HSPP files.

- The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).
- All documents referenced in this submission have been reviewed and approved. Documents are filed with the HSPP Office. If subjects will be consented the approved consent(s) are attached to the approval notification from the HSPP Office.

This project has been reviewed and approved by an IRB Chair or designee.
INSTITUTIONAL REVIEW BOARD (FWA00004487)
REPORT OF PROTOCOL ACTION
NOTIFICATION OF EXPEDITED NEW STUDY APPROVAL

From: Children's National Medical Center Institutional Review Board (CNMC IRB)
To: Pamela Hinds, PhD
Re: Study#: Pro00004661
Well-Being, Self-Transcendence, and Resilience in Parental Caregivers of Children with Cancer
Well-Being, Self-Transcendence, and Resilience in Parental Caregivers of Children with Cancer
Risk: Minimal Risk

The IRB has reviewed and approved the protocol referenced above on 3/31/2014 for a period of 12 months. The IRB determined that the study meets the criteria for expedited review under category(ies):
- This research will be performed on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or will employ a survey, interview, oral history, focus group, program evaluation, human factors, etc., evaluation, or quality assurance methodologies.

This IRB approval will expire on 3/30/2015.

As appropriate, approval of the study and the consent form(s) is for the period of 3/31/2014 to 3/30/2015. Please note that it is the Investigator's responsibility to ensure that the Continuing Review Report is submitted to the IRB in a timely fashion.

The Principal Investigator is responsible for the following:
1. Submission in writing of any and all changes to this study (e.g., protocol, recruitment materials, consent forms, assent forms, etc.) to the IRB for review and approval prior to initiation of the changes, as applicable.
2. Submission in writing of any and all adverse event(s) that occur during the course of the study.
3. Submission in writing of any and all unanticipated problems involving risks to subjects or others.
4. Use of IRB approved copies of the consent forms, assent forms, surveys, questionnaires, letters, advertisements, etc., in the research, as applicable. Do not use expired consent documents.

For additional information, forms, and templates go to IRBNet Home > General Information.

Warning: This is a private message for Children’s National Medical Center parties only. If the reader of this message is not the intended recipient you are hereby notified that any dissemination, distribution or copying of this information is STRICTLY PROHIBITED.

Children's National Medical Center
111 Michigan Avenue, NW
Washington, DC 20010
(301) 895-0420

https://www.irbnet.org/eResearch/Doc/0/S839VTS4AMHKH36f1N56C9TTCB0/fromStrin... 10/7/2014
APPENDIX B:

INSTRUMENTS
Self-Transcendence Scale (STS) ©Reed, 1987

DIRECTIONS: Please indicate the extent to which each item below describes you. There are no right or wrong answers. I am interested in your frank opinion. As you respond to each item, think of how you see yourself at this time of your life. Circle the number that is the best response for you.

<table>
<thead>
<tr>
<th>At this time of my life, I see myself as</th>
<th>Not at all</th>
<th>Very little</th>
<th>Somewhat</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Having hobbies or interests I can enjoy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Accepting myself as I grow older.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Being involved with other people or my community when possible.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Adjusting well to my present life situation.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Adjusting to the changes in my physical ability.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Sharing my wisdom or experience with others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Finding meaning in my past experiences.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Helping younger people or others in some way.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Having an interest in continuing to learn about things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Putting aside some things that I once thought were so important.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. Accepting death as a part of life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. Finding meaning in my spiritual beliefs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. Letting others help me when I may need it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. Enjoying my pace of life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. Letting go of past regrets.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Thank you very much for completing these questions. Do you have any comments?
This section of the examination contains questions about how you feel and how things have been going with you. For each question, fill in the circle next to the answer which best applies to you.

1. How have you been feeling in general? (DURING THE PAST MONTH)
   o In excellent spirits
   o In very good spirits
   o In good spirits mostly
   o I have been up and down in spirits a lot
   o In low spirits mostly
   o In very low spirits

2. Have you been bothered by nervousness or your "nerves"? (DURING THE PAST MONTH)
   o Extremely so—to the point where I could not work or take care of things
   o Very much so
   o Quite a bit
   o Some—enough to bother me
   o A little
   o Not at all

3. Have you been in firm control of your behavior, thoughts, emotions OR feelings? (DURING THE PAST MONTH)
   o Yes, definitely so
   o Yes, for the most part
   o Generally so
   o Not too well
   o No, and I am somewhat disturbed
   o No, and I am very disturbed

4. Have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if everything was worthwhile? (DURING THE PAST MONTH)
   o Extremely so—to the point that I have just about given up
   o Very much so
   o Quite a bit
   o Some—enough to bother me
   o A little bit
   o Not at all
5. Have you been under or felt you were under any strain, stress, or pressure? (DURING THE PAST MONTH)
   - Yes—almost more than I could bear or stand
   - Yes—quite a bit of pressure
   - Yes—some, more than usual
   - Yes—some, but about usual
   - Yes—a little
   - Not at all

6. How happy, satisfied, or pleased have you been with your personal life? (DURING THE PAST MONTH)
   - Extremely happy—could not have been more satisfied or pleased
   - Very happy
   - Fairly happy
   - Satisfied—pleased
   - Somewhat dissatisfied
   - Very dissatisfied

7. Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or of your memory? (DURING THE PAST MONTH)
   - Not at all
   - Only a little
   - Some—but not enough to be concerned or worried about
   - Some and I have been a little concerned
   - Some and I am quite concerned
   - Yes, very much so and I am very concerned

8. Have you been anxious, worried, or upset?
   - Extremely so—to the point of being sick or almost sick
   - Very much so
   - Quite a bit
   - Some—enough to bother me
   - A little bit
   - Not at all

9. Have you been waking up fresh and rested? (DURING THE PAST MONTH)
   - Every day
   - Most every day
   - Fairly often
   - Less than half the time
   - Rarely
   - None of the time
10. Have you been bothered by any illness, bodily disorder, pains, or fears about your health?
   o All the time
   o Most of the time
   o A good bit of the time
   o Some of the time
   o A little of the time
   o None of the time

11. Has your daily life been full of things that were interesting to you? (DURING THE PAST MONTH)
   o All the time
   o Most of the time
   o A good bit of the time
   o Some of the time
   o A little of the time
   o None of the time

12. Have you felt down-hearted and blue? (DURING THE PAST MONTH)
   o All the time
   o Most of the time
   o A good bit of the time
   o Some of the time
   o A little of the time
   o None of the time

13. Have you been feeling emotionally stable and sure of yourself? (DURING THE PAST MONTH)
   o All the time
   o Most of the time
   o A good bit of the time
   o Some of the time
   o A little of the time
   o None of the time

14. Have you felt tired, worn out, used up, or exhausted? (DURING THE PAST MONTH)
   o All the time
   o Most of the time
   o A good bit of the time
   o Some of the time
   o A little of the time
   o None of the time
For each of the four scales below, note that the words at each end of the 0 to 10 scale describe opposite feelings. Fill in the circle along the bar which seems closest to how you have generally felt DURING THE PAST MONTH.

15. How concerned or worried about your HEALTH have you been? (DURING THE PAST MONTH).

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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Not concerned at all  
Very concerned

16. How RELAXED or TENSE have you been? (DURING THE PAST MONTH).

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<th>1</th>
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</table>

Very relaxed  
Very tense

17. How much ENERGY, PEP, and VITALITY have you felt? (DURING THE PAST MONTH).

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<th>0</th>
<th>1</th>
<th>2</th>
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</tbody>
</table>

No energy at all, listless  
Very energetic, dynamic

18. How DEPRESSED or CHEERFUL have you been? (DURING THE PAST MONTH).

<table>
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<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
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</tbody>
</table>

Very depressed  
Very cheerful

**Scoring**
For questions 1, 3, 6, 7, 9, 11, and 13, score 1=5, 2=4, 3=3, 4=2, 5=1, and 6=0.
For questions 2, 4, 5, 8, 10, 12, and 14, score 1=0, 2=1, 3=2, 4=3, 5=4, and 6=5.
For questions 15 and 16, score 0=10, 1=9, 2=8, 3=7, 4=6, 5=5, 6=4, 7=3, 8=2, 9=1, and 10=0.
For questions 17 and 18, score 1=1, 2=2, 3=3, 4=4, 5=5, 6=6, 7=7, 8=8, 9=9, and 10=10.

**Interpretation of Scores**
0 to 60 equals "Severe distress."
61 to 72 equals "Moderate distress."
73 to 110 equals "Positive Well-Being."
Center for Epidemiologic Studies-Depression Scale (CES-D) ©Radloff & NIMH, 1972

**DIRECTIONS:** Below is a list of the ways you may have felt or behaved. Please tell me how often you have felt this way during the past week.

<table>
<thead>
<tr>
<th>0= rarely or none of the time (less than 1 day)</th>
<th>1= some or a little of the time (1-2 days)</th>
<th>2= occasionally or a moderate amount of the time (3-4 days)</th>
<th>3= most or all of the time (5-7 days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>During the past week</td>
<td>Less than 1 day</td>
<td>1-2 days</td>
<td>3-4 days</td>
</tr>
<tr>
<td>1. I was bothered by things that usually don’t bother me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. I did not feel like eating; my appetite was poor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. I felt that I could not shake off the blues even with help from my family or friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. I felt I was just as good as other people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. I had trouble keeping my mind on what I was doing.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. I felt depressed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. I felt that everything I did was an effort.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. I felt hopeful about the future.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. I thought my life had been a failure.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. I felt fearful.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. My sleep was restless.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12. I was happy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13. I talked less than usual.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14. I felt lonely.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15. People were unfriendly.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16. I enjoyed life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17. I had crying spells.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18. I felt sad.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19. I felt that people dislike me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20. I could not get “going.”</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
### Brief Resilience Scale (BRS) © Smith et al. (2008)

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I tend to bounce back quickly after hard times.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2.</td>
<td>I had a hard time making it through stressful events.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>3.</td>
<td>It does not take me long to recover from a stressful event.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>It is hard for me to snap back when something bad happens.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>5.</td>
<td>I usually come through difficult times with little trouble.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I tend to take a long time to get over set-backs in my life.</td>
<td></td>
<td></td>
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</tbody>
</table>
Demographic Instrument

1. Parent’s age (in years): ……

2. Parent’s marital status:
   o Married
   o Single
   o Divorced
   o Widowed

3. Parent’s religious affiliation/use of faith in daily life:
   o Every day
   o Most days
   o Some days
   o Never

4. Parent’s educational level
   o High school or below
   o Undergraduate Education
   o Graduate Education

5. Parent’s number of work hours per week (in hours): ……………

6. Parent’s satisfaction with current financial status
   o Very satisfied
   o Satisfied
   o Neutral
   o Dissatisfied
   o Very dissatisfied

7. Parent’s gender: Male Female

8. Parent’s ethnic background
   o White/Caucasian
   o Hispanic
   o African-American
   o Pacific Islander
   o Asian
9. Parent’s employment status
   - Full-time employment
   - Part-time employment
   - Not currently working

10. Child’s cancer diagnosis: ...........................................

11. Child’s current age: .................years and ...........months

12. Child’s gender: Male............ Female..............

13. Child’s time since cancer diagnosis: ............years and ...........months

14. Child’s number of relapses: .............................................
REFERENCES


