

Parent Caregivers of a Child with a Chronic Illness:

Effects on Psychological Outcomes

by

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ABSTRACT

Over 25% of children in the United States suffer from a chronic illness, and close to 70% of all childhood deaths are due to chronic illness. Prevalence of childhood chronic illness continues to increase, and as a result, the pervasiveness of parents faced with stress associated with caregiving for their child with a chronic illness is also rising. The Stress Process Model (SPM) conceptualizes the caregiving experience as a multidimensional process influenced by the caregiving context, primary and secondary stressors, resources, and caregiver outcomes. Utilizing the SPM, the goals of this study were to examine the relations between caregiving stress (role overload and role strain) and resources (instrumental support, social support, and positive attitudes) and psychological outcomes (depression and anxiety) to determine whether resources moderated the associations between caregiving stress and psychological outcomes.

Participants included 200 parent caregivers of a child with a chronic illness. Participants responded to an online survey that measured demographics, role overload (Role Overload scale), role strain (The Revised Caregiver Burden Measure), instrumental support and social support (Medical Outcomes Survey), positive attitudes about caregiving (Brief Assessment Scale for Caregivers), depression (Patient Health Questionnaire-9), and anxiety (Generalized Anxiety Disorder scale-7). Pearson correlations and six hierarchical regression models were tested to examine caregiving stress, resources, and psychological outcomes.

Consistent with the study hypotheses, positive correlations between caregiving stress (role overload and role strain) and depression and anxiety were found. Negative correlations were found between resources (instrumental support, social support, positive

attitudes) and depression and anxiety. Both instrumental support and social support had negative moderating effects on the relations between role overload and psychological outcomes (depression and anxiety). Positive attitudes also negatively moderated the relations between role strain and psychological outcomes. Thus, when participants reported high instrumental and social support, they also reported low depression and anxiety, even when role overload was high. Participants also reported low anxiety and depression when they reported high positive attitudes, even when role strain was high. Implications of these findings are discussed.

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CHAPTER 1

THE PROBLEM IN PERSPECTIVE

According to the United States (U.S.) Centers for Disease Control (CDC, 2017), chronic illness is not only the leading cause of disability among children aged 6 to 18, it is also the leading cause of death, accounting for nearly 70% of all childhood deaths in the U.S. A chronic illness is a long-lasting, incurable but treatable condition that gradually worsens overtime, affecting the everyday life of the afflicted (CDC, 2017). According to the Center for Managing Chronic Disease (CMCD, 2018), chronic illnesses may vary in severity, but they are typically degenerative and require ongoing maintenance, often presenting continual challenges as the disease progresses. Causing compromised quality of life and lifelong disability and often leading to death, many chronic illnesses progress despite efforts to treat and contain the disease activity (CDC, 2017; CMCD, 2018). As stated by the Mayo Clinic's (2018) list of diseases, chronic illnesses in children can take many forms, including: metastatic and non-metastatic forms of cancer; blood cancer (e.g., leukemia); auto-immune disorders (e.g., juvenile rheumatoid arthritis, lupus); HIV/AIDS; cystic fibrosis; cerebral palsy, neurological disease (e.g., multiple sclerosis, juvenile fibromyalgia, Spina Bifida); and severe digestive disorders (e.g., gastroparesis, Hepatitis-C).

The prevalence of chronic illness among children in the U.S. is significant and on the rise (CDC, 2017). Given the above definition of chronic illness, nearly 18% of children suffered from a chronic illness in 2011, over 25% in 2014, and over 27% one year later. Based on annual reports, this is a substantial increase (CDC, 2017). Chronic illness is the second leading cause of death in children aged 1 to 14 years old, with cancer

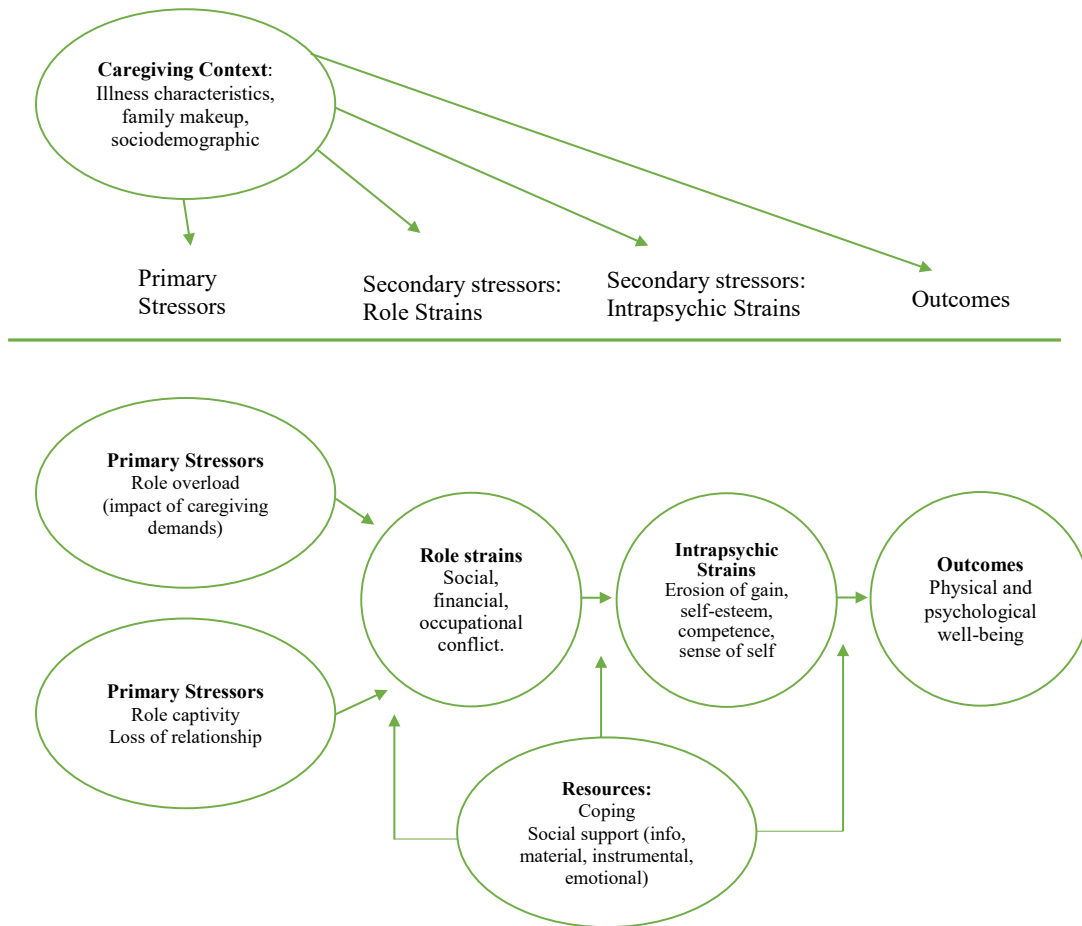
being the second leading cause of death in children aged 5 to 14 years old. There were significant increases in over half of the top ten most prevalent childhood chronic illnesses from 2012 to 2015 (CDC, 2017), indicating a corresponding increase in the number of parents who face the challenges of their child's chronic illness. For example, cancer is one of the many chronic illnesses that affect the lives of children and their parents, with an estimated 10,400 children aged 14 and under and 15,300 children aged 15 to 19 formally diagnosed with some form of cancer in 2016 (CDC, 2017). In 2016, with 1,790 fatalities from childhood cancer, approximately three to four thousand parents experienced the death of their child (aged 19 years or younger) due to cancer alone (US Cancer Statistics Working Group, 2017). This is only one example of the many chronic illnesses that affect the lives of children and their parents. Given the variation in inclusion and exclusion of certain chronic illnesses across data-collection agencies, statistical outcomes of chronic illnesses are complicated to report accurately. For example, the classifications of chronic illness reported by the CDC, by the Mayo Clinic, and by CMCD differ. This makes it difficult to report statistics on specific chronic illnesses. However, the data consistently reflect the staggering number of parents who are tasked with coping with their child's chronic illness each year. Given the caretaker role often assumed by parents of children with a chronic illness and the potential impact of this role on parents, this study examined the psychological outcomes of parent caregivers of children with a chronic illness using the Stress Process Model (Pearlin, 1990) as the theoretical framework.

Theoretical Framework: Stress Process Model

Based on a synthesis of four quantitative and two qualitative studies, the National

Center on Caregiving at Family Caregiver Alliance (FCA, 2006) reported that many useful models explaining caregiving stress exist in the literature. Researchers have noted that Pearlin's (1990) Stress Process Model (SPM), which views caregiving within the context of the caregiving experience, is particularly helpful for understanding the ways in which multiple caregiving stressors can affect caregivers' outcomes (i.e., physical and psychological well-being). Because caregiving stress is a multidimensional process (Pearlin, Mullan, Semple, & Skaff, 1990), the demands of caregiving can give rise to various types of stress. A focus on only one dimension of caregiving stress may cause omission of other critical dimensions for an individual's experience and situation; therefore, a multidimensional model may better encompass the many ways caregivers are affected by their caregiving role (FCA, 2006). Furthermore, a multidimensional model such as the SPM can identify important dimensions and domains that may contribute to caregiving outcomes, differentiate among distinct features of the stress process, and identify the influence of certain supports. There are five main components of the SPM: (1) caregiving context; (2) primary stressors; (3) secondary stressors; (4) outcomes; and (5) resources (Pearlin et al., 1990). Figure 1 depicts Pearlin's Stress Process Model. Each component of the model is introduced below. Research related to each component within the context of parent caregiving is then discussed.

Figure 1
Pearlin's Stress Process Model



(Perlin et al., 1990)

Caregiving Context

In the first component of the SPM, caregiving context, Pearlin et al. (1990) included sociodemographic characteristics of the caregiver and care recipient such as age, education, and gender and socioeconomic characteristics such as income and expenses, single or two-income family, and caregiver's occupation (FCA, 2006). Caregiving context includes work schedule and hours worked, demands of the job, and work location (ability to work remotely, in the home, or outside the home). Context is also specific to the illness, when symptoms began, when illness was diagnosed, the demands of care

required by the illness, and the length of time the caregiver has provided care. Another crucial component of contextual features includes caregiving arrangements – whether the caregiver is primary (tending to a majority of caregiving responsibilities) or secondary (providing backup support for the primary caregiver and care recipient). Some primary caregivers receive help from others while others do not. Understanding family makeup and which family members are involved in caregiving is important as this can affect the caregiving demands on the caregiver. The degree of commitment from others may be varied, as some of these people are very involved while others may have limited time and resources or lack interest in helping with caregiving responsibilities. Additionally, secondary caregivers may be helpful (e.g., provide respite and emotional support), or they may add to the primary caregiver’s stress. Caregiving context can be a substantial source of stress. In the SPM, these stressors are referred to as primary and secondary stressors.

Primary and Secondary Stressors

Primary stressors, the second component of the SPM, refers to “events and experiences that derive directly from the person’s illness” (FCA, 2006, p. 21). The SPM postulates that three processes are affected by primary stressors: role overload; role captivity; and loss of the relationship (Pearlin et al., 1990). Role overload refers to the impact of caregiving on the caregiver (e.g., time and energy). It can be understood as the ‘juggling’ of multiple roles and responsibilities. This is commonly associated with difficulty developing or maintaining valued relationships outside the caregiving relationship and an inability to participate in valued leisure activities (Bastawrous, Gignac, Kapral, & Cameron, 2014). Role overload is a salient issue among caregivers of parents as well as for children across various caregiving contexts. The second process

affected by primary stressors is role captivity with the caregiver feeling trapped or unable to have a life outside of caregiving. In adult children caring for parents, this is associated with fulfilling an unexpected or unwanted role (Bastawrous et al., 2014). Loss of the relationship, the third process, encompasses caregivers' perceptions of the extent to which they have lost intimacy and social exchanges with the ill person. This focus on the relationship is an important yet typically overlooked aspect of caregiving (FCA, 2006). Although role captivity and loss of the relationship are pertinent stressors for some caregivers (particularly adult children who are caregivers of parents), these two processes are not commonly reported among parent caregivers of children (Brown, 2008; Coffey, 2006). Therefore, they were not examined in the current study.

Secondary stressors, the third component of the SPM, are considered secondary as they do not arise directly from the care recipient's illness (Pearlin et al., 1990). Two types of secondary stressors include role strains and intrapsychic strains (FCA, 2006). Role strains are the tensions and conflicts that arise from maintaining other roles in addition to caregiving, such as employment and family relationships, and from socio-economic and financial strain. Role strain varies considerably, as many outside roles (e.g., employment) can serve as a buffer, such as providing respite from caregiving. It should be noted that, according to the FCA's (2006) report, less than half of working caregivers reported experiencing conflict at work, suggesting that some caregivers view work as stressful while others view it as non-stressful or as a social outlet that differs from the stressful home environment. With this, it is important to understand that changes in employment affect caregivers differently. Some experience work as an additional stress versus a respite from caregiving demands, and some must work for an income to pay for basic

necessities while for others career is integrated into their identity, thus resulting in varying levels of loss (Stephens, Franks, Martire, Norton, & Atienza, 2009). Said differently, for many individuals, their career holds significant meaning in their life's journey and their identity (i.e., career identity), and loss of career identity can impact their sense of identity (Inkson, 2007).

Intrapsychic strains, the second type of secondary strain, occur when primary stressors start eroding a person's self-concept, identity, or sense of self (FCA, 2006). There are five domains in which erosion can occur – mastery, self-esteem, competence in the caregiving role, feelings of gain in caregiving, and one's sense of self (Pearlin et al., 1990). Although role strain can affect a caregiver's well-being, the erosion of self-concept has a more direct and deleterious impact on well-being, and erosion of one's sense of self can produce cascading detriments in other psychological domains, such as anxiety and depression (Skaff & Pearlin, 1992). Stressors, whether primary and-or secondary, affect outcomes of caregiving (i.e., caregiver's physical and psychological well-being).

Outcomes of Caregiving

Outcomes of caregiving is the fourth component of the SPM (Pearlin et al., 1990). Caregiving can affect outcomes related to a caregiver's physical health and emotional well-being. Health refers to subjective health, whether caregivers perceive their health to be changing, whether they currently have any health problems, including diagnosed illnesses and symptoms, and whether they are getting treatment currently for these problems. With heavy caregiving demands, some people delay going to the doctor or take care of their own health needs in other ways. Some caregivers may also engage in

behaviors, such as overuse of alcohol and drugs, lack of exercise, and poor nutrition, that worsen their health (FCA, 2006).

In addition to physical health, caregiver's psychological well-being is also impacted by caregiving. The two most frequently assessed dimensions of psychological well-being among caregivers are depression and anxiety (FCA, 2006). In fact, the FCA (2006) report indicates that family caregivers suffer from higher rates of depression and anxiety than do non-caregivers of the same age and gender and estimated that 50 and 80 percent of caregivers of older adults experience symptoms of depression and/or anxiety. Anthony-Bergstone, Zarit, and Gatz (1988) examined symptoms of psychological distress among caregivers of dementia patients and found that caregivers react to and experience emotional distress in various ways (e.g., sadness, depression), with some experiencing anger, worry, and anxiety. In a more recent study, also comparing caregivers to a non-caregiver control group of similar age and gender, Hansen, Slagsvold, and Reidun-Ingebretsen (2013) found that caregivers of parents suffer from significantly higher rates of depression, anxiety, and anger.

Studies examining the aforementioned caregiving stress (role overload and intrapsychic strains) have demonstrated positive associations between caregiving stress and depression. In their meta-analysis of 84 studies differentiating caregiver and noncaregiver stress, Pinqart and Sorensen's (2003) found that caregivers reported more depressive symptoms than did non-caregivers, and higher depression was associated with lower self-efficacy (confidence in oneself to adapt to situational demands). Specifically examining 300 spousal caregivers, Bookwala and Schulz (1998) found that decreased self-efficacy was associated with higher depression. Further, Mausbach et al. (2012)

found that higher role overload was related to more depressive symptoms among 126 male and female caregivers of a spouse with dementia. Depression was also associated with intrapsychic strains, including self-efficacy and sense of mastery (belief that general life circumstances are under one's control). In other words, increased strain and corresponding reductions in self-efficacy and mastery were correlated with higher depression scores. Akin to these results, a similar study that examined caregivers of a parent with Alzheimer's revealed a positive association between caregiver role overload and anxiety and a negative association between caregiving self-efficacy and anxiety (Mahoney, Regan, Katona, & Livingston, 2005). Additionally, among 65 primary caregivers of a family member with dementia, Rapp and Chao (2000) found a positive correlation between role strain and anxiety, specifically anxiety symptoms of nervousness, anxiousness, worrying, and irritability. Based on these studies, it is evident that stressors related to caregiving have a negative impact on the well-being of caregivers.

It should be noted, however, that caregiving may also have a positive impact on caregiver well-being. For example, Rapp and Chao (2000) examined protective factors, including potentially positive impacts of caregiving (increased bond with care recipient, increased sense of purpose, and sense of satisfaction in helping a loved one) and found these positive impacts of caregiving mediated the effects of role strain on psychological well-being. Another protective factor that may buffer detrimental influences of caregiving stress includes resources available to the caregiver.

Resources

Caregivers' resources, the last component of the SPM (Pearlin et al., 1990), can

lessen the negative impact of stress on well-being (FCA, 2006). Two types of resources, coping and social support, have been investigated extensively (e.g., MaloneBeach & Zarit, 1995; Mittelman et al., 1995; Mittelman, Roth, Coon & Haley, 2004; Schulz et al., 2003; Whitlatch, Zarit, & von Eye, 1991; Zarit & Leitsch, 2001). Coping includes the ways in which caregivers manage both primary stressors and the multiple roles in their lives. According to Lazarus and Folkman's (1984) transactional theory of stress and coping, individuals evaluate how a stressful event may harm their well-being, determine personal resources available to handle such stress, and respond in a way that mediates the stress (i.e., coping). With this, coping can be problem- or emotion-focused. Viewed as more adaptive, problem-focused coping involves creating strategies to approach and solve problems. Emotion-focused coping, often an appropriate approach when a problem cannot be solved, emphasizes modulating emotional responses to stressors (Lazarus & Folkman, 1984).

The second resource, social support, is multidimensional with two broad dimensions including the sources of and types of support. Sources of support include both informal (from family members, friends, or volunteers) and formal (from paid helpers). To understand these sources of support, it is important to understand the social environment of the parents within a social ecological context (Bronfenbrenner, 1979), as some parent caregivers experience social isolation while others experience support and assistance with caregiving demands from friends and family (Kazak & Wilcox, 1984). Informal support may include these social supports or attachments with individuals or groups that promote a greater ability to deal with transitions and short- and long-term stress regarding caregiving (Brown, Brown, & Preston, 2012). Formal services include a

wide range of community programs. It is important to consider the type of help provided, by whom, and how often.

Four types of support include informational, material, instrumental, and emotional support (FCA,2001). Informational support is the provision of advice or informational guidance that assists in problem-solving (Wills, 1991). This may include information provided by healthcare professionals that aids in important decision-making (e.g., treatment options) or the exchange of information with other caregivers or peers that may influence decisions regarding caregiving (e.g., financial planning, coordination of caregiving duties; Waters et al., 2017). Material support is defined as tangible support, such as material goods (meals, medical supplies, clothing) and financial assistance (Langford, Browsher, Maloney, & Lillis, 1997). While some families qualify for financial relief services that help with house payments, car payments, or groceries, other families receive material support from peers and family (Waters et al., 2017). Instrumental support includes concrete methods of assistance from others (Langford et al., 1997) and may include help with caregiving tasks and duties (e.g., respite, errands) or with other household chores (Helgeson, 1993). Emotional support relates to providing empathy, concern, affection, encouragement, or caring and can include displays of warmth and compassion, extending a ‘listening ear,’ or making someone feel loved and valued (Langford et al., 1997; Sarason & Sarason, 2009). These supports are comprised of who helps, the type of help provided and the value of the assistance, the ways the help is provided (willingly or reluctantly), and whether the help addresses the caregiver’s needs directly, as well as how the family gets along and solves problems (FCA, 2006).

Taken together, the SPM is a multidimensional approach to understanding the ways in which a caregiver's context, primary stressors related to caregiving demands, secondary stressors related to role strain or intrapsychic strain, and utilization of support-related resources influence caregiving outcomes (i.e., well-being). Although primarily examined with caregivers of older adults, such as parents and spouses, these components of the SPM (caregiving context, stressors, outcomes, and resources) can also be applied to parent caregivers of children with a chronic illness. The focus of this study related to how components of the SPM apply to parent caregiver's well-being.

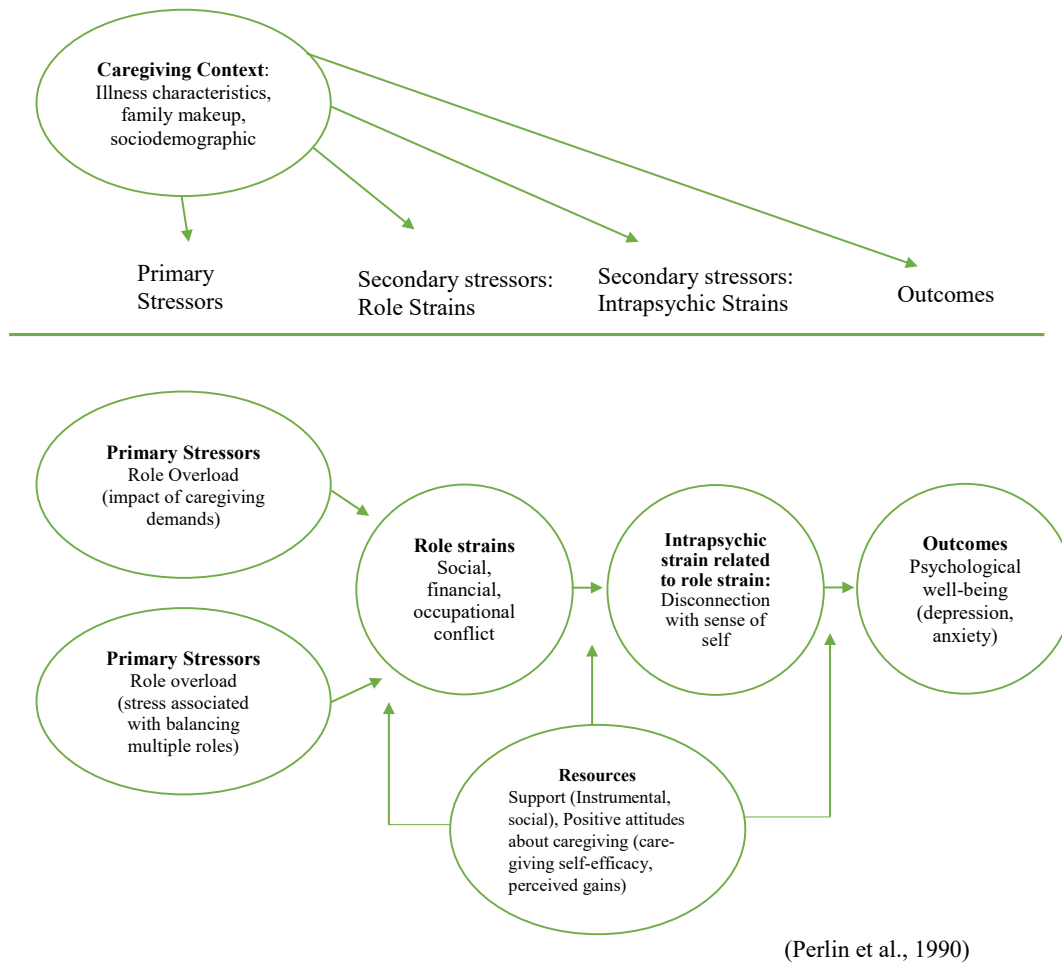
Parent Caregivers of a Child with a Chronic Illness and Related Research

As just discussed, researchers have examined caregiving stress in the context of adult caregivers providing care for parents and spouses (e.g., Bookwala & Schulz, 1998; Mausbac et al. 2012; Mahoney et al., 2005; Schulz et al., 2003; Zarit & Leitsch, 2001). There is more limited research, however, on caregiving for a child. Although being a caregiver for a child brings some of the same stressors as when caring for a parent or spouse, there are also unique stressors when the caregiver is also the parent. In their review of the literature on the impact of stress on parent caregivers, Brown et al. (2008) noted that financial stress, role strains, separations, adjusting to the medical system, departures from normal routines and future plans, and general uncertainty regarding the child's prognosis can lead directly and indirectly to anxiety and depression for parent caregivers. Parent caregivers' access to emotional support (social supports, processing stress with others) and instrumental support (help with caregiving duties, providing respite) is influential in maintaining their own well-being (Brown et al., 2008). In support of the findings from Brown et al.'s (2008) review, in a recent qualitative study examining

stress and coping strategies among 30 ethnic minority parent caregivers of a child with a chronic illness, Waters and colleagues (2017) found that a lack of these supports was associated with higher levels of stress, depression, and anxiety. Whether the supports are formal (paid or community resources) or informal (help from friends or family), the effects on parent caregivers' outcomes (well-being) were consistent with a negative association (Waters, 2017).

Components of the SPM are applicable to explaining the various impacts childhood chronic illness can have on parents and families. To understand each of the five components of the SPM in application to parent caregivers, it is important first to understand the initial component, the caregiving context for parent caregivers (Pearlin et al., 1990). (See Figure 2 for Pearlin's Stress Process Model in the Context of Parent Caregiving.)

Figure 2
Pearlin's Stress Process Model in the Context of Parent Caregiving



Caregiving Context Associated with Child's Chronic Illness

Specific contexts of caregiving include illness characteristics (e.g., diagnosis, symptom maintenance, prognosis) and family makeup (e.g., single parents, co-parenting, multiple children; FCA, 2006). Family makeup may also impact socioeconomic (SES) stability, as single parents and families with multiple children endure more financial hardship due to medical bills, changes in employment, or limited income in comparison to two-parent families (Brown et al, 2006). The caregiving context can differ markedly when caring for a child with an illness that requires around the clock assistance versus

caring for a child with some degree of independence, when the disease has periods of remittance versus no remission, when living in a one- versus two-parent family, and when there is one child versus multiple children in the family (Brown et al., 2008). According to Shudy et al.'s (2006) systematic literature review including 115 reports examining the impact of critical pediatric chronic illness on caregivers and their families, family structures are increasingly reorganized to meet the needs of the child's illness. This reorganization impacts the couple, siblings, and the family system. Depending on the illness, its severity, and treatment complexity, families may be required to become intensely involved in the care and maintenance of the ill child. As families must initiate a number of changes in family structure and functioning at the onset of the child's illness (redistributing family members' roles and responsibilities), the child's chronic illness often affects the family unit and how it adopts to health management strategies (Brown et al., 2008).

Illness characteristics. The child's diagnosis, the severity of symptoms, care management and maintenance required by the child's symptoms, the child's level of limitation, and prognosis can affect the parent caregiver individually as well as the family. Due their chronic nature, many illnesses necessitate daily, consistent intervention to manage the child's symptoms. For example, examining children with chronic respiratory disease, Waters and colleagues (2017) found that parent caregivers experienced elevated stress related to the child's illness and ongoing disease maintenance. Among parent caregivers of children with leukemia, higher symptom severity for the child was associated with negative outcomes, including stress and anxiety for the parent (Best, Steisand, Catania, & Kazak, 2001). In one study with 54 mothers and

42 fathers of children with neurofibromatosis, greater symptom severity in children was associated with the parents experiencing greater depression, more family conflict, and less social support (Noll et al., 2008). Studying 71 mothers caring for their child with cancer, Steele et al. (2003) found that as mothers adjusted to the demands of the child's illness, reports of depression decreased over a 6-month period while caregiving stress remained high and relatively stable. In addition to the severity of the illness, Brown et al.'s (2008) literature review indicated a number of significant predictors of parental reports of greater stress and symptoms of depression and anxiety. These included the number of stress-management resources and psychoeducational (information) resources requested regarding the child's health, the child's prognosis, and the amount of time the parents had to adjust to the illness and to the caregiving role. These factors may also be related to the stress parents may experience concerning their child's unclear future (e.g., the child's diagnosis and prognosis), to sadness associated with unrealized ideas about the child's future, or to difficulties navigating uncertainties that they cannot control (Chentsova-Dutton et al., 2002).

In addition to affecting the parent, the child's illness can impact the family system in a variety of ways including changes in roles, responsibilities, and family structure, as well as challenges in balancing care management as a family unit with multiple stressors. According to Shudy and colleagues' (2006) literature review, in response to the child's illness, the whole family experiences stress. When a parent caregiver has other children, the illness demands of the ill child may alter the time the parent has available for the healthy children and the extent to which healthy children may feel obliged to help with caregiving or household tasks (Shudy et al., 2006). With this, as the reciprocal

relationship between the illness and the family's adaptation influences changes in family routines, structure, and functioning, a redistribution of roles and responsibilities may result. As a family establishes practices to manage the child's illness, it is also tasked with balancing these practices with other functions and roles that family members fulfill, such as allowing children to still be children (Waters et al., 2017). Also complicating this balance, other factors that shape the ways in which families manage the child's chronic illness include the parent caregiver's work schedule, support from others (friends, co-parents, family), multiple roles (partner, parent to other children, other family roles), children's activities, and quality time with children (Bernheimer et al., 2003; Yinusa-Nyahkoon et al., 2010).

According to Coffey's (2006) metasynthesis (a meta-analysis across 30 qualitative studies), critical times (e.g., time of diagnosis, time following diagnosis, and major milestones) also have an impact on a parent caregiver's well-being. For example, many parent caregivers expressed experiencing shock at the diagnosis and associated this time with deep depression, isolation, and fear (Coffey, 2006). Parent caregivers also identified the initial impact of the diagnosis and the first year following diagnosis as the hardest in terms of accepting the diagnosis and its implication for necessary care and for impact on the future. Hatton, Canam, Thorne, and Hughes (1995) found that many parent caregivers described their adjustment to the consequences of the diagnosis as a time of "intangible losses" and a loss of "joy" (p. 57). Additionally, other critical times that parents identified included changes in the child's condition, exacerbation of physical symptoms, increased caregiving demands on the parents, and major milestones for the child and the child's peers (Coffey, 2006). For example, some major milestones not met

by the child due to his or her illness include advancing to the next grade, increasing in physical strength to gain a higher level of independence, or failing to progress similar (physically or academically) to peers (Coffey. 2006).

Family makeup and sociodemographics. In addition to illness characteristics, family makeup and socioeconomic status also impact the caregiving context in unique ways. According to the U.S. Census Bureau (2017), in 2016, the percent of children under the age of 18 living only with their mother was 23% and those living with a sole-father was four percent, indicating a significant increase in single-parent homes. The Brown et al. (2008) literature review indicated that for single versus two-parent families, outcomes are poorer among single-parent families. For example, the incomes of single-parents were an estimated 47% of that of married couple household incomes, and single parents reported higher overall negative economic impact (financial stress, employment loss, financial deterioration) as well as higher estimated out-of-pocket costs, including time off work (Brown et al., 2008). Thomas and Sawhill's (2005) review of the impact of family structure on family income revealed that, across all racial-ethnic categories, children in single-parent families were more than four times as likely as children with married-parent families to live in poverty. These findings are particularly salient in the case of pediatric chronic illness, which habitually taxes the economic resources of families even under the best of conditions (Brown et al., 2008). Additionally, single-parent caregiving is associated with having fewer social supports. This may be particularly true for single fathers who have reported that lack of financial and social resources was associated with lack of tending to their own physical health, which resulted in higher reports of chronic illness among the fathers who were caregivers as compared to

non-caregiver fathers (Janzen, Green, & Muhajarine, 2006). For single mothers, experiencing financial hardship and having less social support were associated poorer mental health outcomes, including more symptoms of depression and anxiety (Crosier, Butterworth & Rodgers, 2007).

Having multiple children in the family can also affect the stress caregiver's experience. In Coffey's (2006) metasynthesis, parent caregivers identified spending substantial time and energy worrying about their other children who are the siblings of the ill child. For example, in addition to worry regarding the potential impact on their own relationship with their well children, they were also concerned about the relationship between the well children and ill child and were uncertain regarding how to maintain a normal family life and to manage the appropriateness of utilizing help from their well children in caring for the ill child (Hirose & Ueda, 1990). A child's chronic illness can affect the whole family (Coffey, 2006). Siblings are often tasked with assuming some caregiving responsibilities, and parent caregivers often struggle to find time for the well children. These factors can have a negative impact on the well children and on the family unit (Ray & Ritchie, 1993). In a two-year longitudinal study that included parents of 26 children with cancer, results indicated the most difficult caregiving activities were providing emotional support to the child with the chronic illness and to other children in the family and managing the family (Svavarsdottir, 2005). Given caregiver experiences of distress regarding caregiving and family-related stressors, it is important to understand the family context of parent caregivers. This study examined the length of time the child has been ill, the child's diagnosis and prognosis, whether the child was receiving treatment and possibility for remission, the level of caregiving required given the child's

condition (e.g., full-time care, the child is capable of completing his or her own activities of daily living), and presence of critical times. This study also examined the parent's relationship status, parenting status (single- two-parent, or co-parenting), number of children in the home, and income.

The second and third components of the SPM include primary and secondary stressors (Pearlin et al., 1990). These components provide further support for the importance of caregiving context and delineate the demands of caregiving and the occupational, financial, and social strains associated with caregiving.

Primary and Secondary Stressors Associated with Child's Chronic Illness

Having a child with a chronic illness can be a substantial stressor for parents (Kazak, 2001, Kazak & Meadows, 1998). Parent caregivers are tasked with managing medical expenses, determining caregiving roles and performing duties, and coordinating schedules to accommodate the child's medical needs and doctor's appointments, as well as other caregiving tasks. Also experiencing anxiety about unpredictable outcomes and pressures to become educated about the child's illness and treatment options, the demands on physical, emotional, and financial resources can lead to increased stress (Mayo Clinic, 2018) and can be detrimental to a parent's social and occupational functioning (Chentsova-Dutton et al., 2002). As these primary stressors refer to the impact of caregiving demands on the caregiver, they can be understood as role overload (Pearlin, 1990). The consequences of these detriments (e.g., losing sources of intrapersonal security and social, financial, and occupational stability) can become another compounding source of stress (Chentsova-Dutton et al., 2002). These tensions that ensue from efforts to sustain multiple roles in addition to caregiving are a secondary

stress called role strain (Pearlin, 1990). As chronic illnesses require ongoing disease management and maintenance, parent caregivers are tasked with a multitude of stressors (Waters, 2017). Therefore, it is important to understand the demands of the caregiving role regarding treatment, disease management, and balancing various roles simultaneously, as well as changes to occupational, financial, and social aspects of life.

Role Overload: Demands of the caregiving role. Caring for a child with a chronic illness can present parent caregivers with a number of stressors that can cause role overload (e.g., treating and tending to the illness, discussing the illness with the child and others, and managing the effects of illness on the child's well-being and school functioning), as many chronic illnesses have the potential to alter significantly the child's and the parents' quality of life (Mayo Clinic, 2018). Parents are also confronted with decisions regarding their child's treatment and informing friends and family of the child's condition, treatment needs, and prognosis (Mayo Clinic, 2018). Waters et al. (2017) identified challenges parent caregivers face at the intersections of parenting, managing the child's illness, and negotiating their own relationships (friends, family, partners). Parents reported struggling with exacerbations of the child's symptoms, the child's emotional response to the symptoms, and attempts to manage situations that can compromise the child's health (e.g., avoiding interactions with friends or family members who have cold or flu symptoms to accommodate immunosuppression). The ongoing, intermittent, and unpredictable nature of chronic illness exacerbations can certainly contribute to parent caregivers' stress (Waters et al., 2017). Additionally, parents may experience stress regarding the need to discuss the child's condition and the issues

surrounding it with teachers and administrators at the child's school when the child's illness necessitates such conversations (Mayo Clinic, 2018).

Many stressors (e.g., limited access to financial resources, maintaining other significant relationships, managing daily routines, and work-family balance) are dynamic in nature and converge to create more caregiving challenges (Waters et al., 2017). As noted by McClellan and Cohen (2007), parent caregivers are tasked with balancing the management of their child's illness with the other roles that they possess simultaneously (i.e., co-parents, parents to multiple children, partners, workers). Consequently, parents often experience the stress of these additional demands commensurate with caregiving for their chronically ill child. This aspect of role overload refers to balancing multiple roles and overexertion (Pearlin, 1999). The stress of caregiving can also be compounded among parent caregivers who struggle socioeconomically and assume the multitude of responsibilities of caring for a chronically ill child while having limited financial resources necessary to care for the child (Mullins et al., 2011).

The magnitude of the stressors parent caregivers face also varies by illness severity, prognosis, duration of the illness, treatment for the illness, and demands of the treatment (Streisand & Tercyak, 2004). For example, similar to parents of children with other illnesses, parents of children with cancer encounter tasks that can be stressful, such as assisting children with medical procedures, coping with hospitalizations, and adjusting to school absences. Additionally, often cancer treatment can last for over two years at a time, and the physical side-effects (e.g., hair loss, malaise, and nausea from chemotherapy) of many cancer treatments require additional adjustments (Kazak & Meadows, 1998, Streisand & Tercyak, 2004). Although chronic illnesses can leave parent

caregivers with unanswered questions and concerns about their child's future, parents whose children face terminal outcomes (e.g., cystic fibrosis, some cancers) experience stress that is compounded by emotional distress. For example, given the terminal nature of cystic fibrosis, where the child's life is relatively normal for years and then the child becomes increasingly ill, it is understandable that parents' stress and adjustment vary as a function of the child's health (Streisand & Tercyak, 2004). Because the demands of the caregiving role can consume much of parent caregivers' time, physical and emotional energy, and financial resources, this role may impact parent caregivers' employment and financial stability as well as their ability to engage in social and leisure activities (Crespo, Carona, Silva, Canavarro, & Dattilio, 2011).

Role Strain: Occupational, financial, and social changes. The spillover effect of role overload on social, financial, and occupational areas of life can result in the secondary stress role strain for parent caregivers (Carona, Pereira, Moreira, Silva, & Canavarro, 2013). According to the National Alliance for Caregiving (NAC) 2009 report, 78% of parents of children with chronic illnesses reported making significant changes to their employment situation due to caregiving responsibilities. This national survey included a random sample of 1,280 parent caregivers including 858 White, 200 African-American, 201 Hispanic, 200 Asian-American, and 21 other parent caregivers who identified as another racial-ethnic identity (NAC, 2009). The changes in employment included cutting hours, taking a leave of absence, switching to a less demanding job, giving up work entirely, and losing benefits. Among parents who were employed before the child's diagnosis, a little more than half were still employed at some time while they were caring for their child (NAC, 2009).

Approximately 30% of families with a chronically ill child identified experiencing a profoundly detrimental impact on the family's dynamics (e.g., decreased family adjustment) in addition to deterioration in finances, social relationships, and loss of employment (Montgomery, Oliver, Reisner & Fallat, 2002). Coffey's (2006) metasynthesis concluded that most mother caregivers had to give up their jobs in order to care for the child with chronic illness, which placed financial strain on the family. Most mothers also identified the loss of their job as socially isolating. In addition to having their finances impacted, an overwhelming majority of parents noted that caregiving affected their social well-being, such as limiting the amount of time they spend with friends and family and restricting their ability to participate in other recreational activities (NAC, 2009).

Caregivers' lives can also be affected in various other ways as care demands can lead to marital and family conflict and the abandonment of social and religious activities (Semple, 1992). In the absorption of the caregiving role, other identities of the caregiver may get lost, causing intrapsychic strains. Historically, this consequence has been well-documented in the literature and suggests a need to understand the experience of caregivers (Thompson & Doll, 1982; Zarit, Orr, & Zarit, 1985). From their early research, Zarit and colleagues (1985) began characterizing caregivers as the "hidden patients" who need their own care and attention to address the ways in which the caregiving role impacts them. In other words, because caregivers' well-being and identities (social, interpersonal, occupational) can be affected by the demands of caregiving, it is important to learn more about the unique ways in which the caregivers are affected. More recently, the literature on parents' caregiving stress has noted an

association between the caregiving experience and one form of intrapsychic strains related to intrapsychic attunement – difficulties maintaining sense of self (Demirtepe-Saygili et al., 2012). In comparison to the caregiving for older adult literature that may address more than one of the five aspects of intrapsychic strains (loss of self-concept, mastery, competence, gain, and self-esteem), a comprehensive analysis of these five intrapsychic strains is less common in the parent caregiving literature (Pinquart et al., 2003_b). For this reason, although intrapsychic strains are important to the caregiving experience, this study examined the disconnection with the sense of self that has been shown to be related to role strains among parent caregivers (Brown et al., 2008).

In Brown's (2008) systematic literature review examining parents' caregiving stress (e.g., impact of illness on finances, family roles, and social roles, and parents' well-being related to caregiving responsibilities), the social impact on parent caregivers was emphasized. Across 20 studies, issues related to loneliness, social isolation, and limited social supports were reported by fathers and mothers, including single, married, and co-parenting parents (Brown et al., 2008). Crosier, Butterworth, and Rodgers' (2007) research with parent caregivers also revealed that sociodemographics, household income, financial hardship, and social support accounted for 94% of the variance in mental health, with financial hardship and limited social support being the strongest predictors. Reviewing the literature on dyad parents of chronically ill children, Hauenstein (1990) noted that a lack of social support and social resources was associated with significant emotional distress. Given these findings, it is important to understand the ways in which caregiving stress and subsequent changes in occupational, financial, and social roles and status may affect parent caregiver psychological and physical well-being.

The impact of caregiving stress on psychological and physical well-being comprises the fourth component of the SPM, outcomes of caregiving (Pearlin et al., 1990). This study examined role overload as primary stress and role strain as secondary stress. Specifically, role overload included parents' experience of feeling exhausted, overloaded with roles and responsibilities, and lack of time for oneself. Role strain included changes to finances, to work and social (recreational and relational) activities, and to intrapsychic attunement (losing one's sense of self).

Outcomes of Caregiving Associated with Child's Chronic Illness

Caregivers face an assortment of challenges that frequently erode their physical, financial, and psychological resources. According to Chentsova-Dutton et al. (2002), due to focusing on their child's health, many parent caregivers with chronically ill children experience depression, anxiety, and personal health problems such as poorer general physical health and more physical ailments than does the general public. Parent caregivers may experience impairments in psychosocial functioning (e.g., lack of time and resources to socialize, loss of employment), with reduced social engagement placing parent caregivers at risk for reduced psychological and physical well-being. According to the NAC's (2009) report described above, over 50% of parent caregivers endorsed high ratings of emotional stress (i.e., four or five on a 5-point scale). Additionally, nearly half of the parents reported sacrificing time with family and friends, and financial burden was reported to increase social sacrifice three-fold. With this, parent caregivers were 26% more likely to report "fair" or "poor" health than were the non-caregivers in the comparison group, and 30% reported worsened health since caregiving began (NAC, 2009, p. 48). The negative associations between stress and both psychological and

physical well-being of parent caregivers are well-documented in the literature (e.g., Brown et al., 2008; Coffey, 2006; Eccleston, Fisher, Law, Bartlett, & Palermo, 2015; Khanna, Prabhakaran, Patel, Ganjiwale, & Nimbalkar, 2015; Miodrag, Burke, Tanner-Smith, & Hodapp, 2015; Streisand & Tercyak, 2004). Therefore, research needs to consider parent caregivers' experience of stress and their psychological and physical well-being.

Physical well-being. Although not directly examined in the present study, research has revealed an association between diminished physical well-being among parent caregivers (NAC, 2009). Undoubtedly, caregiving-related stressors can have a negative effect on parent's psychological well-being, and, if not managed, these stressors can lead to increased negative outcomes for caregiver's physical health. For example, parents of children with chronic illnesses are twice as likely as the general adult population to report they are in poorer health (NAC, 2009). The chronic stress of caregiving for a child can lead not only to physiological changes such as hypertension, general malaise, and decreased physical energy levels but also to increased medical illness and decreased physical well-being that are often associated with stress, depression, and anxiety (Schulz & Beach, 1999). In their study with 63 mothers and 49 fathers caregiving for their child with cancer, Speechley and Noh (1992) found that these parents experienced psychological symptoms of depression and anxiety as well as significant physical symptoms such as fatigue, physical ailments including backaches, headaches, and muscle pain, and more frequent occurrences of common illnesses (e.g., flu, common cold) in comparison to a non-caregiver parent group. Additionally, among cultures such as Eastern cultures in which physical as compared to emotional symptoms are considered

more acceptable, a greater number of parent caregivers of children with cancer reported physical symptoms as compared to parents from Western cultures (Martinson, Liu-Chiang, & Yi-Hua, 1997). In their meta-analysis, Miodrag et al. (2015) examined 19 studies assessing parent caregivers' physical health using the health sub-domain of the parenting stress index. Compared to non-caregiver groups, parent caregivers experienced more muscle soreness, headaches, back and shoulder pain, chronic fatigue, sleep deprivation, and poorer perceptions of the overall quality of their physical health. Additionally, parent caregivers reported getting sick more often, having higher blood pressure, acquiring their own chronic illness (e.g., diabetics, cardiovascular conditions), and premature aging. Given the scope of the current study, however, the aspect of well-being examined was psychological well-being.

Psychological well-being. Although psychological well-being is defined in various ways, the construct commonly includes positive affect (feelings of happiness, satisfaction) and negative affect (feelings of sadness, anger, anxiety; Bryant & Veroff, 1982). With this, psychological well-being relates to the excess of positive over negative feelings or affect, and diminished well-being relates to experiencing negative affect in excess of positive affect (Bradburn & Noll, 1969). Bryant and Veroff (1982) pointed out that positive and negative affect may also include self-perceptions (efficacy, adequacy, acceptance, and adjustment to strain). Common experiences of caregiving relate to many challenging adjustments, including sustaining caregiving demands, functioning under greater levels of stress, and adapting to varying levels of caregiving self-efficacy. With this, as parent caregivers are tasked with learning to accept the ways the child's illness affects the child's quality of life, the child's future, the parent's future, and the family's

functioning, these experiences may influence a caregiver's self-perception of well-being (Waters et al., 2017).

In their chapter on the impact of the stress related to parenting a child with a chronic illness, Streisand and Tercyak (2004) suggested that the complex nature of caregiving for a chronically ill child is associated with reduced quality of life and psychological well-being for parent caregivers. For example, the stress of caregiving is associated with frequent worry, role strain, symptoms of anxiety, and symptoms of depression (Streisand & Tercyak, 2004). According to the Diagnostic and Statistical Manual-5 (DSM-5; American Psychiatric Association, 2013), anxiety symptoms include excessive anxiety and worry, fatigue, difficulty concentrating, irritability, feeling tense or on edge, and sleep disturbance. Depression symptoms include depressed mood (feeling sad, empty, hopeless), lack of pleasure in most activities, changes in sleep and appetite, restlessness, loss of energy, feelings of worthlessness or guilt, diminished concentration, and thoughts of suicide. A high prevalence of clinically significant depression and anxiety among parent caregivers has been demonstrated in many studies. For example, Waxmonsky et al. (2006) examined depression symptoms among 129 parent caregivers of children with severe autoimmune disorders that required frequent hospitalizations and found that nearly half of the parents reported clinically significant depression. In their study including 193 parent caregivers of chronically ill children, Everhart, Fiese, and Smyth (2008) assessed associations between parents' caregiving stress, symptoms of anxiety, and risk factors for worsening anxiety, such as socio-economic demographics, the child's well-being, and the family's adjustment. Overall, they found high reports of

anxiety among parents before and after controlling for risk factors suggesting that anxiety was a prominent and common experience across parent caregivers.

Examining both anxiety and depression symptoms among 204 parent caregivers, Khanna and colleagues (2015) found that 75% of parent caregivers reported clinically significant depressive symptoms (37% mild and 38% moderate to severe) and 67% reported clinically significant anxiety symptoms (50% mild and 17% moderate to severe), with an overwhelming majority experiencing both anxiety and depression. Consistent with this finding, Rao, Pradhan, and Shah (2004) found that over 80% of the 30 parent caregivers in their study experienced both symptoms of depression and anxiety. In their review of psychological interventions for parent caregivers of chronically ill children, Eccleston et al. (2015) examined 47 randomized controlled trials to assess parental mental health outcomes. Their summary also highlighted this overlap, as parent caregivers reported higher levels of clinically significant anxiety and depression (pre-psychological intervention) than did non-caregivers.

In addition to depression and anxiety examined in quantitative studies, in Coffey's (2006) meta-synthesis involving qualitative studies on parents of a child with a chronic illness, several themes emerged that depicted common deficits to psychological well-being for parent caregivers. Across the 11 studies reviewed, themes related to experiences of depression and anxiety emerged. Depressive symptoms included difficulty dealing with the emotional consequences of stressors and experiences of loss (e.g., loss of ideal family roles and relationships, loss of career, loss of normal childhood experiences for ill child). These emotional experiences included feeling overwhelmed by responsibilities and feelings of helplessness, sadness, and anger. Anxiety symptoms were identified as

“living in worry,” excessive fear and anxiety, and feeling tense with unsolvable problems. In addition, many parent caregivers described experiencing dissonance between the desire to tend to the child’s needs and the desire to detach emotionally or to withdraw physically due to the overwhelming nature of caregiving (Coffey, 2006).

Although there is some variation across different types of child chronic illness and subsequent levels of demand on parent caregivers, overall, similar and significant effects on psychological well-being have been illuminated. For example, clinically significant depression and anxiety have been reported by parents of children whose illness causes physical limitations (e.g., spina bifida, cerebral palsy; Miller, Gordon, Daniele, & Diller, 1992), requires daily maintenance practices (e.g., autoimmune disorders; Rodrigue, Geffken, Clark, Hunt, Fishel, 1994), and fluctuates between remitting and active disease levels (e.g., cancer; Hoekstra-Weebers, Jaspers, Klip, & Kamps, 2000). Parent caregivers whose child’s autoimmune disorder is unpredictable by nature also experience higher levels of stress and depression in comparison to parents of healthy children (Hookham, 1985). Unsurprisingly, parents caring for a child with life-limiting and terminal illness manifest increased symptoms of depression and anxiety (Quittner et al., 1998). As noted above, parenting a child with cancer has a profound impact on the parents' own psychological functioning, as parent caregivers among this group display higher levels of anxiety and depression akin to their elevated stress levels. Anxiety and depressive symptoms are seen in parent caregivers both while their children are being treated for cancer and when their children are considered to be in remission or off treatment (Kazak & Meadows, 1998; Speechley & Noh, 1992; Streisand et al., 2001). Longitudinal studies have also indicated that these negative impacts on mental health outcomes for parents

(depression and anxiety) may vary over the course of the child's illness as parents adapt or do not adapt to the disease management demands (Kovacs et al., 1990). For example, during times of high stress, depression and anxiety are higher, and severity of anxious and depressive symptoms can vary based on the child's illness and the illness trajectory. Caregiving for a child with a chronic illness can certainly have a profound impact on parents' psychological well-being through experiences of living with uncertainties and fear about the child's well-being, of struggling to find hope and to manage anger and sadness, and of trying to adapt to the new role and new bond with the ill child (Coffey, 2006). This study examined psychological outcomes related to psychological well-being, specifically symptoms of anxiety and symptoms of depression.

Resources Associated with Child's Chronic Illness

As outcomes of caregiving may be moderated by the utilization of resources, it is important to examine resources (instrumental and social supports) and attitudes that may influence outcomes of caregiving. The fifth component of the SPM (Pearlin et al., 1990), resources, describes the influence of such factors on caregivers' well-being.

Resources associated with parent caregivers include supports (NAC, 2009) and personal attitudes about caregiving (Kovacs, 1990). Two types of supports are particularly important to parent caregivers – instrumental and social (emotional) support. Although previously discussed when introducing the SPM in the context of caregiving in general, conceptualizations of instrumental support (Langford et al., 1997) and social support (Sarason & Sarason, 2009) also apply to the context of caregiving for a child. Instrumental support includes others providing concrete assistance such as financial help or help with specific duties (Langford et al., 1997). In the context of parent caregiving,

instrumental support may include help with caregiving demands, providing respite, and doing errands. Social or emotional support provides interpersonal connections and an outlet for the caregiver to process emotional stress (Langford et al., 1997) and may consist of having a social support network (friends, family, support groups) with whom to share thoughts and feelings regarding the caregiving role. Access to social and instrumental resources are particularly important for parent caregivers, as having fewer supports has been associated with increasing levels of anxiety and depression (Hauenstein, 1990).

In addition to supports, a second resource is the attitude a caregiver has about caregiving. Positive attitudes about the caregiving role include caregiving self-efficacy and perceived personal gains from caregiving. Caregiving self-efficacy includes the caregiver's perceived competence and satisfaction in the caregiving role (Mausbach et al., 2012). Personal gains from caregiving includes beliefs regarding the rewards of caregiving, such as growing as a person and deepening the relationship with the child (Rapp & Chao, 2000). Resources have been identified as protective factors for psychological well-being in the context of caregiving for adults. Specifically, instrumental and social support (Del-Pino-Casado et al., 2018), perceived caregiving competence (Cheng, Lam, Kwok, Ng, & Fung, 2012), caregiving satisfaction (Del-Pino-Casado, Palomino-Moral, & Frías-Osuna, 2015), and personal gains (Hansen et al., 2013) have been identified as protective factors. Therefore, it is important to consider how these resources may also be protective for parent caregivers caring for chronically ill children.

Support: instrumental and social. Instrumental and social (emotional) support have been extensively examined in the caregiving literature (Del-Pino-Casado, Frías-Osuna, Palomino-Moral, Ruzafa-Martínez, & Ramos-Morcillo, 2018) and the stress and coping literature (Waters et al., 2017). Both instrumental and social supports are relevant to the experiences of parent caregivers for various reasons. Instrumental support is defined in the caregiving literature as supportive actions performed for a care provider, including tangible chores, favors, errands, and tasks, such as help preparing meals, watching other children during medical visits, and pharmacy runs to help the parent caregiver (Morelli, Lee, Arnn, & Zaki, 2015). Instrumental support may be provided formally (hired help with childcare) or informally (help from loved ones; NAC, 2009). It can also be in the form of sharing information (regarding the child's illness, coping, or other resources), assisting the caregiver in attending to his/her own needs (going to own doctor's visits), or providing monetary assistance (NAC, 2009).

Indeed, managing their own well-being can be challenging for caregivers. According to Wiener, Vasquez, and Battles (2001), over 85% of 31 parent caregivers reported needing more help or information related to their own well-being, how to communicate and manage stress effectively, how to find support groups, and how to manage their child's illness. Additionally, according to national data (NAC, 2009), 85% of parent caregivers reported feeling that they needed more assistance or information on one or more topics regarding caregiving, including information related to their own well-being (stress management, family-work balance), communicating with doctors, and managing the child's disease. Nearly 50% reported needing more information regarding managing their own stress and managing multiple roles. Not only do parents request or

report needing the information, they also report benefits to their wellbeing after receiving information. For example, Hoekstra-Weebers et al. (2000) found that parents of children with cancer experienced decreased anxiety when they were provided information by healthcare providers that aided in decisions regarding their child's treatment. Examining 30 primary parent caregivers, Clements et al. (1990) found that almost a third of the caregivers reported having responsibility for the care of the household as well as responsibility for the chronically ill child. Lacking time to tend to their own needs, these caregivers reported higher stress, anxiety, and depression than did those who had help with household responsibilities.

Finances is also a resource for families with a chronically ill child. As cited in the caregiver literature, financial resources tend to include more formal than informal services (NAC, 2009; Shudya et al., 2006). Of six national programs identified by the NAC (2009) as available to assist caregivers financially, 62% of parent caregivers preferred a \$3,000 tax credit, 35% preferred receiving minimum wage for some of their time spent caregiving, and 23% preferred respite services. The NAC indicated that 19% of parent caregivers reported having hired help with childcare; however, many families cannot afford to hire outside help (Bromer & Henly, 2004). Although families and communities of lower income families may offer help with respite or childcare services, Waters et al. (2007) noted that many caregivers struggle with leaving their child with someone who lacks formal training in managing the child's disease. When parent caregivers do receive formal respite daycare services, however, they experience less depression than do parent caregivers who do not receive these services (Clark, 2002).

Social (emotional) support occurs through interpersonal interactions that can provide a sense of belongingness and personal meaning, and the feelings of connectedness, acceptance, and feeling valued can have a long-term effect on one's well-being including self-concept, attitudes, and affective states (Sarason & Sarason, 2009). Social support includes perceived social support and is defined as sources of support (e.g., partner, family, friends, healthcare staff, support group members) who provide an emotional connection that serves to alleviate, in some way, the negative effects of stress on psychological well-being (McGrath, 2001). The provision of social support can include the emotional expression of affection, compassion, empathy, and willingness to help the caregiver by an individual in whom the caregiver confides for emotional processing (Demirtepe-Saygili & Bozo, 2011).

In the parent caregiving literature, many sources of support have been identified as helping parent caregivers manage the stress associated with caring for their chronically ill child. The literature highlights the importance of support from family members (e.g., Kazak & Meadows, 1998; Kazak & Wilcox, 1984; Walsh, 2003), from close friends (Kazak & Meadows, 1998), from community members (Greeff & Wentworth, 2009), from support groups with other parent caregivers (Coffey, 2006), and support from health professionals (Coffey, 2006; Kepreotes et al., 2010). The importance of these sources of support was further highlighted by a mixed-method study that included 95 caregivers of a child with a chronic illness. The most common sources of support reported by parent caregivers included supports from family, friends, support groups, hospital staff, and faith-based groups (Nabors et al., 2013).

In order for support to have a positive effect on parent caregivers, parents must use this support. Indeed, utilization of social supports is one of the most important determinants of caregiver outcomes (e.g., depression and anxiety), as those who utilize social supports perceive less caregiving stress (Streisand & Tercyak, 2004) and experience less anxiety (Nabors et al., 2013). It should be noted, however, that Nabors et al. (2013) found mixed effects of support from hospital staff on anxiety, as some parents identified difficult interactions that were associated with higher anxiety while others identified supportive (mediating) effects that were associated with lower anxiety. Among parent caregivers of children with pediatric cancer, the level of social support parents received during their child's illness was associated with parent caregivers' experience of anxiety and depression symptoms, in that social support was perceived to mitigate such symptoms (Speechley & Noh, 1992). According to a national study including 354 single mothers and 1,689 partnered parent caregivers, social support was the strongest predictor for poor mental health outcomes (depression and anxiety) in single and partnered parent caregivers (Crosier et al., 2007). Additionally, Demirtepe-Saygili and Bozo (2011) found that perceived social support predicted fewer depressive symptoms and moderated the associations between caregiving stress and depressive symptoms for 90 parent caregivers of children with leukemia. More social support had an alleviating effect on depression symptoms.

Additionally, instrumental and social support may mutually influence one another. For example, finding childcare may be challenging for some parents, particularly those who do not have established social support networks. Parent caregivers lacking social supports may be in an even greater need of instrumental support, such as help with

childcare (Waters et al., 2017). Although parents have noted the potential for developing social supports with other parents, barriers to developing social supports can sometimes be embedded in the demands of the caregiving role. Many parent caregivers express a desire to engage in face-to-face meetings to connect with such supports, learn about other parents' experiences, learn they are not alone, and learn stress management strategies to cope with the child's illness and balance the demands they face. They also report that without instrumental support, however, logistic barriers (e.g., scheduling, transportation) often complicate their efforts to attend these meetings (Waters et al., 2017).

Unsurprisingly, in Coffey's (2005) metasynthesis, parents who reported lacking both social and instrumental support reported higher stress, anxiety, and depression. Having instrumental and social support has been identified as a protective factor to negative outcomes of caregiving, such as anxiety and depression. Another variable, personal attitudes toward caregiving, is a second resource that may have protective qualities.

Positive attitudes regarding the caregiving role. The way in which a caregiver views the caregiving role can influence psychological well-being outcomes. There are two major components of attitudes regarding caregiving including caregiving self-efficacy, which includes perceived competence and self-satisfaction with caregiving (Mausbach et al., 2011), and perceptions of gains from caregiving, which includes personal growth from caregiving (Hansen et al., 2013). Unlike global self-efficacy, caregiving self-efficacy has been conceptualized as a caregiver's belief in her or his ability to manage the demands of caregiving and perform caregiving tasks competently (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002). As caregivers' value-judgements regarding their competency tend to be highly correlated with their

reported satisfaction within the caregiving role, the construct of caregiving self-efficacy also includes caregivers' satisfaction with the caregiving role (Steffen et al., 2002). These dimensions of caregiving self-efficacy, including caregiving competence (Del-Pino-Casado, Palomino-Moral, & Frías-Osuna, 2015) and caregiving satisfaction (Hansen, Slagsvold, & Ingebretsen, 2013), have been found to moderate negative effects of caregiving stress on psychological outcomes in caregivers of adult care recipients.

Although caregiving self-efficacy was first examined in the context of adult children caring for elderly parents, it has also been examined in the context of parent caregivers caring for chronically ill children (e.g., Brown et al., 2008; Coffee, 2006). For example, Ray and Ritchie (1993) examined the perceptions of 29 parent caregivers and noted that parents who viewed themselves as competent in managing the demands of caregiving and the multiple roles associated with parent caregiving perceived caregiving as less stressful and reported less anxiety. In their longitudinal study with 113 parent caregivers of children with leukemia, Best et al. (2001) examined caregiver self-efficacy at two timepoints (before treatment and after the child's final treatment). Parents who reported higher self-efficacy (belief in caregiving competency) also reported lower anxiety at both time-points. Additionally, parents who experienced increased self-efficacy at the end of treatment reported lower anxiety at the end of treatment. To assess caregiver self-efficacy among 53 parent caregivers of chronically ill children, Rodrigue et al. (1994) utilized a composite score of perceived competence and satisfaction. Perceived competency and satisfaction with caregiving scores were higher for parent caregivers who had been in the role longer and lower for those whose child's disease was more challenging to maintain. In addition, higher self-efficacy and satisfaction were associated

with lower anxiety. Self-efficacy in the caregiving role was also associated with additional gains. For example, in their longitudinal study using national survey data that included over 8,000 caregivers, with approximately one-fourth of these parent caregivers, Marks, Lambert, and Choi (2002) found that parent caregivers who reported higher caregiving self-efficacy (competence) expressed fewer depressive symptoms and increased self-esteem, meaning, engagement, fulfillment, and pride over a three-year period. Not only did self-efficacy mediate the association between stress and well-being, Rapp and Chao (2000) found that both self-efficacy and beliefs about the positive impact of caregiving, including gaining personal intrapsychic strengths and fulfillment from caregiving role, also mediated the effect of caregiving stress on psychological well-being.

Another aspect of positive attitudes about caregiving that may affect parent caregivers' view of the caregiving role relates to caregivers' perceptions of "personal gains" (p. 591) from the caregiving experience (Pearlin et al., 1990). Potential gains of caregiving refer to the rewards of caregiving that may include deepening the parent-child bond and feeling fulfilled by engaging in something meaningful (Hansen et al., 2013), as well as developing new skills, intrapsychic strengths, and growing as a person (Pearlin et al., 1990). Although caregiving is linked to stress, anxiety, and depressed mood (e.g., Coffey, 2006), because of the perceived rewards of caregiving, the experience may also be associated with increased well-being (Hansen, 2013). As noted by Hatton et al. (1995), some caregivers experienced the loss of an "ideal relationship" (p. 571) with their child due to the complex nature of caregiving needs; however, others experienced a closer bond with their child. Crespo et al. (2011) found that among 97 parent caregivers a positive perception of a strengthened parent-child relationship and fulfillment within the

caregiving role predicted a perception of the family's functioning. This perception of gains was also associated with less caregiving stress, a greater sense of control in the caregiving context, and reports of better quality of life. The experience of a closer bond emerging between the parent and the child has also been cited in qualitative research with parent caregivers who identified the deepening of the parent-child bond as a strength that promoted hardiness in the parent's own and the family's ability to adapt to the child's illness (Coffey, 2006). This deeply personal bond is experienced by many caregivers as unique and resilience-inducing and as a meaningful experience that stimulates a feeling of fulfillment (Hansen et al., 2013).

Relatedly, in their six-year longitudinal study that included 30 parent caregivers of a child with a severe autoimmune disorder, Kovacs et al. (1990) found that caregivers who endorsed new and meaningful personal growth, including intrapsychic strengths reported less stress, depression, and anxiety overtime. Additionally, this perception of personal growth moderated the effect of stress on symptoms of depression and anxiety over the six years. More recently, Silva, Carona, Crespo, and Canavarro (2015) examined "emotional uplifts" (p. 179), the positive attitudes regarding caregiving that operate as protective factors by buffering stress and thus contributing to better psychological well-being. Specifically, these attitudes included the acquisition of personal strengths, an improved relationship with the child, and finding meaning and personal growth from caregiving. For the 180 parent caregivers in their study, Silva et al. found that these positive meanings attributed to the caregiving role moderated the positive association between stress and anxiety and ultimately served as a protective factor against negative effects of stress on well-being. Using the same measure of positive attitudes as used by

Silva et al., Carona, and colleagues (2013) compared 117 parent caregivers to a non-caregiver comparison group. They found a moderation effect for parent caregivers' (but not non-caregivers) positive attitudes about caregiving related to personal growth, meaning, and fulfillment. This perception moderated the effect of stress on psychological well-being. Therefore, in addition to caregiver self-efficacy, this positive attitude regarding personal gains from the caregiving experience may be a protective factor with the potential to buffer the detrimental effects of caregiving stress on psychological well-being.

Taken together, research has shown that instrumental support can play an important role in helping parent caregivers balance caregiving and other multiple roles (NAC, 2009), that social support can aid parent caregivers in gaining stress management strategies (McGrath, 2001), and that both social support and instrumental support can have positive effects on psychological well-being (Nabors et al., 2013). Given that positive attitudes about caregiving may serve as a protective factor to the negative impact of caregiving stress on well-being, it is important to understand the ways in which instrumental and social supports as well as positive attitudes about caregiving (self-efficacy and perceived gains) may impact the well-being of parent caregivers.

Furthermore, although caregiving competency, satisfaction, and perceived gains have been examined more widely in the literature on caregiving for older adults (e.g., Pinquart & Sörensen, 2003_b) than in the parent caregiving literature (e.g., Silva et al., 2015) the current literature on parent caregivers suggests these concepts apply to the context of parents caring for chronically ill children (Marks et al., 2002). Given this gap in the literature as well as the well-established associations between the experiences of parent

caregiving and stress (Streisand & Tercyak, 2004), anxiety (Khanna et al., 2015), and depression (Khanna et al., 2015), this is an important area for research. This study examined instrumental and social support, including help with caregiving and daily responsibilities and perceived social support. This study also examined positive attitudes, including beliefs regarding gains from caregiving, such as increasing closeness in the parent-child relationship, finding meaning in caregiving, promoting personal growth, and feelings of satisfaction and feeling good about oneself.

Summary of Parent Caregiver Literature

The demands of parental caregiving can be associated with considerable stress, including role overload and strains on the physical, emotional, and financial resources of the caregiver (Crespo et al., 2011). Within the context of the caregiving experience, Pearlin's (1990) Stress Process Model views caregiving stress as a multidimensional process that provides a basis for understanding the multiple ways in which caregiving stressors can affect caregivers' psychological well-being, specifically symptoms of depression and anxiety. Although the five main components of the SPM (caregiving context, primary stressors, secondary stressors, outcomes, and resources) have been applied more widely to research examining the effects of caregiving stress on caregivers of older adults, such as parents or spouses, the SPM also provides a framework for understanding parent caregivers caring for children with a chronic illness (Demirtepe-Saygili et al., 2012).

Within the context of caring for a chronically ill child, Brown et al. (2008) noted that parent caregivers may be affected by specific characteristics of the child's illness (e.g., diagnosis, symptom maintenance, illness trajectory, prognosis) and family makeup

(e.g., single parents, co-parenting, multiple children, sociodemographics). The caregiving context can influence the experience of primary stressors (role overload) and secondary stressors (role strain). The role of caregiving can directly impact the caregiver's experience of stress, including role overload related to many of the demands of the caregiving role (Waters et al., 2017). Undoubtedly, these demands can cause caregivers to feel overwhelmed, exhausted, and challenged to complete all necessary tasks, leaving them with little time for themselves. Caregiving can also have a secondary stress effect of role strain, such as strain on other roles causing changes to occupational, financial, and social functioning (Carona et al., 2013). Secondary strain can lead to reduced engagement in activities the caregiver once found enjoyable, such as social, recreational, and career-related activities. Role strain can also cause difficulties in maintaining intrapsychic attunement and a sense of self (Demirtepe-Saygili et al., 2012). It is well-documented in the literature that these stressors have an impact on caregivers' psychological well-being (Pinquart et al., 2003_b). Specifically, caregiving stress (both role overload and role strain) are positively associated with symptoms of depression and anxiety for parent caregivers (Khanna et al., 2015). However, certain resources may be a protective factor against the effect of caregiving stress on caregiving outcomes. These resources include instrumental support, social support, and positive attitudes regarding the caregiving role (Waters et al., 2017). These positive attitudes include caregiving self-efficacy (feeling competent and satisfied in the caregiving role) and perceived gains from caregiving, such as growing as a person, strengthening the parent-child bond, and feeling that the caregiving role is meaningful (Silva et al., 2015). Although there is a wealth of literature examining the moderating effects of such resources on the relation between stress and well-being among

caregivers of older adults, there is a paucity of research examining these interactions in the context of parent caregiving.

To bridge this gap, based on the SMP and the literature suggesting that resources can moderate the associations between caregiving stress and caregiver outcomes, the present study examined the effects of caregiving stress and resources on psychological outcomes of depression and anxiety. Specifically, this study investigated the moderating role of instrumental support, social support, and positive attitudes regarding caregiving on the relation between stress (role overload and strain) and psychological outcomes of caregiving (i.e., symptoms of depression and anxiety).

The Present Study

The goal of the present study was to utilize a multidimensional approach to examine resources (protective factors) influencing the psychological outcomes of parent caregivers caring for their child with a chronic illness. The first goal was to examine the correlations between 1) caregiving stress (role overload and role strain) and psychological outcomes (anxiety and depression) and 2) resources (instrumental and social support, and positive attitudes regarding caregiving) and psychological outcomes (anxiety and depression). The second aim was to examine moderation effects of resources (instrumental support, social support, and positive attitudes) on the relations between caregiving stress (role overload and role strain) and psychological outcomes (symptoms of depression and anxiety). Figure 3 depicts the SPM Moderation Model.

Specifically, this study investigated the following research questions (RQ) and hypotheses (H):

RQ 1: What are the associations between stress (role overload and role strain) and psychological outcomes (depression, anxiety)?

H1a: Role Overload and Role Strain on Depression: Based on the literature suggesting that role overload and role strain are positively associated with depression (Khanna et al., 2015), it was expected that more role overload and role strain would be related to more depression.

H1b: Role Overload and Role Strain on Anxiety: Based on the literature suggesting that role overload and role strain are positively associated with anxiety (Khanna et al., 2015), it was expected that more role overload and role strain would be related to more anxiety.

RQ 2: What are the associations between resources (instrumental support, social support, and positive attitudes) and psychological outcomes (depression, anxiety)?

H2a: Instrumental and Social Support on Depression: Based on the literature suggesting that instrumental and social support are negatively associated with depression (Hoekstra-Weebers et al., 2011; Crosier et al., 2007), it was expected that more support (instrumental and social) would be related to less depression.

H2b: Instrumental and Social Support on Anxiety: Based on the literature suggesting that instrumental and social support are negatively associated with anxiety (Waters et al., 2017; Crosier et al., 2007), it was expected that more support (instrumental and social) would be related to less anxiety.

H2c: Positive Attitudes on Depression: Based on the literature suggesting that positive attitudes regarding caregiving are negatively associated with depression (Marks et al., 2002), it was expected that more positive attitudes would be related to less depression.

H2d: Positive Attitudes on Anxiety: Based on the literature suggesting that positive attitudes regarding caregiving are negatively associated with anxiety (Silva et al., 2015), it was expected that more positive attitudes would be related to less anxiety.

RQ3: Does instrumental support moderate the associations between stress (role overload and role strain) and psychological outcomes (depression, anxiety)?

H3a: Instrumental Support and Role Overload on Depression: Based on the literature suggesting that instrumental support moderates the positive association between role overload and depression (Hoekstra-Weebers et al., 2011), it was expected that instrumental support would moderate the effect of role overload on depression, such that there would be no relation for high instrumental support and a there would be a positive relation for low instrumental support.

H3b: Instrumental Support and Role Overload on Anxiety: Based on the literature suggesting that instrumental support moderates the positive association between role overload and anxiety (Hoekstra-Weebers et al., 2011), it was expected that instrumental support would moderate the effect of role overload on anxiety, such that there would be no relation for high instrumental support and a there would be a positive relation for low

instrumental support.**H3c: Instrumental Support and Role Strain on Depression:** Based on the literature suggesting that instrumental support moderates the positive association between role strain and depression (Demirtepe-Saygili & Bozo, 2011), it was expected that instrumental support would moderate the effect of role strain on depression, such that there would be no relation for high instrumental support and a there would be a positive relation for low instrumental support.

H3d: Instrumental Support and Role Strain on Anxiety: Based on the literature suggesting that instrumental support moderates the positive association between role strain and anxiety (Waters et al., 2017), it was expected that instrumental support would moderate the effect of role strain on anxiety, such that there would be no relation for high instrumental support and a there would be a positive relation for low instrumental support.

RQ4: Does social support moderate the associations between stress (role overload and role strain) and psychological outcomes (depression, anxiety)?

H4a: Social Support and Role Overload on Depression: Based on the literature suggesting that social support moderates the positive association between role overload and depression (Speechley & Noh, 1992), it was expected that social support would moderate the effect of role overload on depression, such that there would be no relation for high social support and a there would be a positive relation for low social support.

H4b: Social Support and Role Overload on Anxiety: Based on the literature suggesting that social support moderates the positive association between role overload and anxiety (Speechley & Noh, 1992), it was expected that social support would moderate the effect of role overload on anxiety, such that there would be no relation for high social support and a there would be a positive relation for low social support.

H4c: Social Support and Role Strain on Depression: Based on the literature suggesting that social support moderates the positive association between role strain and depression (Demirtepe-Saygili & Bozo, 2011), it was expected that social support would moderate the effect of role strain on depression, such that there would be no relation for high social support and a there would be a positive relation for low social support.

H4d: Social Support and Role Strain on Anxiety: Based on the literature suggesting that social support moderates the positive association between role strain and anxiety (Nabors et al., 2013), it was expected that social support would moderate the effect of role strain on anxiety, such that there would be no relation for high social support and a there would be a positive relation for low social support.

RQ5: Does positive attitudes regarding caregiving moderate the associations between stress (role overload and role strain) and psychological outcomes (depression, anxiety)?

H5a: Positive Attitudes and Role Overload on Depression: Based on the literature suggesting that positive attitudes moderate the positive

association between role overload and depression (Marks et al., 2002), it was expected that positive attitudes would moderate the effect of role overload on depression, such that there would be no relation for high positive attitudes and a there would be a positive relation for low social positive attitudes.

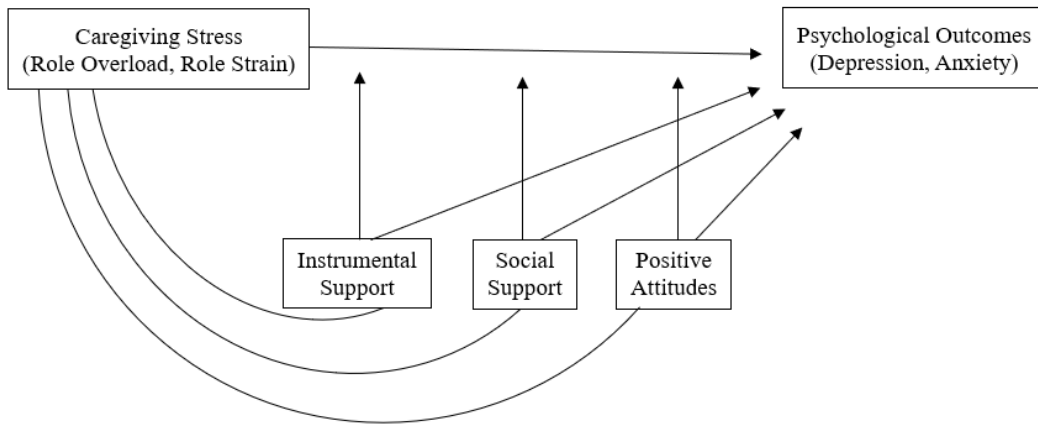
H5b: Positive Attitudes and Role Overload on Anxiety: Based on the literature suggesting that positive attitudes moderate the positive association between role overload and anxiety (Rapp & Chao, 2000), it was expected that positive attitudes would moderate the effect of role overload on anxiety, such that there would be no relation for high positive attitudes and a there would be a positive relation for low social positive attitudes.

H5c: Positive Attitudes and Role Strain on Depression: Based on the literature suggesting that positive attitudes moderate the positive association between role strain and depression (Silva et al., 2015), it was expected that positive attitudes would moderate the effect of role strain on depression, such that there would be no relation for high positive attitudes and a there would be a positive relation for low social positive attitudes.

H5d: Positive Attitudes and Role Strain on Anxiety: Based on the literature suggesting that positive attitudes moderate the positive association between role strain and anxiety (Silva et al., 2015), it was expected that positive attitudes would moderate the effect of role strain on

anxiety, such that there would be no relation for high positive attitudes and a there would be a positive relation for low social positive attitudes.

Figure 3
SPM Moderation Model



CHAPTER 2

METHODOLOGY

Recruitment and Procedures

After Institutional Review Board (IRB) approval for this study was obtained (see Appendix A), participants were recruited via flyers posted on: (1) community organizations' Listservs for parents on national health-related websites; (2) Listservs of charity organizations that fund a wish for children with life-threatening illnesses; (3) University affiliated Facebook pages; and (4) local children's hospitals (e.g., Phoenix Children's Hospital Palliative Care Unit, Banner Cardon Pediatric Oncology Unit, and Hospice of the Valley Ryan's House for children). Recruitment flyers were also sent to individuals who participated in the author's master's thesis project who had consented to receiving contact for future research. (See Appendix B for Recruitment Flyer).

Participants were provided online informed consent before completing the screening questionnaire (see Appendix C). After consenting to participate in the study, participants first completed the screening questionnaire (see Appendix D), and participants who meet eligibility requirements were redirected to the research questionnaire (see Appendix E). Both questionnaires were hosted by Qualtrics. Participation time was approximately 12 minutes (1-2 minutes for screening and 10-11 minutes for the research questionnaire). Upon completion, participants were assigned a unique ID number, and those who expressed interest were entered into a raffle to win a \$50 Amazon gift card. The odds of winning were one in ten.

Participants

Given that the context of caregiving may influence parent caregivers' outcomes,

participants had to meet inclusion criteria in order to participate. Specifically, children under the age of five are developmentally less capable of communicating their symptoms, and children over the age of 15 begin driving and gain independence in caring for their needs (Brown et al., 2012). Additionally, parents' perceptions may differ during the first three months following the child's diagnosis (Coffey, 2006). Thus, these criteria included: (1) Parent caregiver of a child, between ages of 5 and 15, diagnosed with a chronic illness, (2) at least 3 months had passed since the child's diagnosis, (3) parent identifies as primary or co-caregiver, and (4) parent speaks English fluently.

Initially, 228 parent caregivers expressed interest in participating. Twelve of the parents did not meet the screening requirements, and 16 did not complete the all of the necessary questionnaire measures. Those 16 participants with data missing were removed from the sample. Therefore, the final sample included 200 parents. This sample size was consistent with previous cross-sectional studies conducted with parent caregivers (e.g., Waters, 2017, Silva et al., 2015). According to G*Power a priori power analysis, a sample size of 198 was needed (33 in each of the six models) to have 80% power for detecting a small sized effect when employing the traditional .05 criterion of statistical significance (Faul, Erdfelder, Lang, & Buchner, 2009). Therefore, the sample size ($n = 200$) was consistent with a prior power analysis.

The final sample ($n = 200$) included 162 females (81.0%) and 28 males (19.0%) ranging in age from 28 to 57 years old ($M = 37.73$, $SD = 5.53$). The length of time since the child's diagnosis ranged from three months to 13.5 years ($M = 5.65$ years, $SD = 3.25$). The child's age ranged from five to 15 years old ($M = 8.29$ years, $SD = 2.98$).

Of the 200 participants, approximately 146 (73.0%) identified as White/European American, 20 (10.0%) as Asian/Asian-American, 19 (9.5%) as Hispanic/Latino(a), 12 (6.0%) as Black/African-American, 1 (0.5%) as Native American or Pacific Islander, and 2 (1.0%) as other. A majority of the participants (137, 68.5%) reported being married, 22 (11.0%) reported being partnered and living together, 19 (9.5%) reported being partnered and living separately, and 22 (11.0%) reported being single. Partnered couples (married, living together, living separately) reported being married or in a committed relationship for an average of 13.83 years ($SD = 5.77$ years, range = < 1 to 31 years).

Approximately one-third of the participants reported having a graduate or professional degree ($n = 72$, 36.0%), and nearly one-fourth reported having a bachelor's degree ($n = 44$, 22.0%). The most frequently reported yearly income ranges were \$25,000-\$49,999 ($n = 50$, 25.0%) and \$50,000-\$74,999 ($n = 48$, 24.0%), with the primary source of this income being their partner's income ($n = 82$, 41.0%).

When asked the number of children in the home, the most prevalent responses were one child ($n = 68$, 34.0%) and two children ($n = 61$, 30.5%). Most participants identified their parenting status as partnered and raising the child(ren) together ($n = 150$, 75.0%). Although more participants identified their parenting status as single ($n = 39$, 19.5%) than participants who identified their relationship status as single ($n = 22$, 11.0%), this is because some single-parent participants identified being in a relationship in which their partner does not live in the home or does not help raise the child. See Table 1 for demographic characteristics of caregivers and Table 2 for sample demographic characteristics by caregiver gender.

Table 1
Demographic Characteristics of Caregivers

	<i>n</i>	Percentage
Gender		
Male	38	19.0%
Female	162	81.0%
Racial/Ethnic Identification		
Asian/Asian-American	20	10.0%
Black/African-American	12	6.0%
Hispanic/Latino(a)	19	9.5%
Native American or Pacific Islander	1	0.5%
White/European American	146	73.0%
Other	2	1.0%
Education Level		
High School Diploma/Equivalent	32	16.0%
Vocational/Technical School	3	1.5%
Associate's degree	13	6.5%
Some College	36	18.0%
Bachelor's Degree	44	22.0%
Graduate or professional degree	72	36.0%
Yearly Household Income		
\$0-\$24,999	14	7.0%
\$25,000-\$49,999	50	25.0%
\$50,000-\$74,999	48	24.0%
\$75,000-\$99,999	33	16.5%
\$100,000-\$149,999	42	21.0%
\$150,000-\$199,999	8	4.0%
Greater than \$200,000	5	2.5%
Source(s) of Income		
Solely Participant	28	14.0%
Solely Participant's Partner	82	41.0%
Participant's and Partner	76	38.0%
Multiple (partner and other support)	14	7.0%
Number of Children		
One	68	34.0%
Two	61	30.5%
Three	39	19.5%
Four	23	11.5%
Five or Greater	9	4.5%
Relationship Status		
Married	137	68.5%
Partnered – Living Together	22	11.0%
Partnered – Living Separately	19	9.5%
Single	22	11.0%
Parenting Status		
Partnered – Raising Child Together	150	75.0%
Co-Parenting - Living Separately	11	5.5%
Single Parent	39	19.5%

Table 2
Sample Demographic Characteristics by Caregiver Gender

	Male <i>n</i>	Percentage	Female <i>n</i>	Percentage
Gender				
Male	38	---	---	---
Female	---	---	162	---
Racial/Ethnic Identification				
Asian/Asian-American	0	0.0%	20	12.3%
Black/African-American	8	21.1%	4	2.5%
Hispanic/Latino(a)	2	5.3%	17	10.5%
Native American or Pacific Islander	0	0.0%	1	0.6%
White/European American	28	73.7%	118	72.8%
Other	0	0.0%	2	1.2%
Education Level				
High School Diploma/Equivalent	4	10.5%	28	17.3%
Vocational/Technical School	0	5.3%	1	0.6%
Associate's degree	2	5.3%	11	6.8%
Some College	14	36.8%	22	13.6%
Bachelor's Degree	10	26.3%	34	21.0%
Graduate or professional degree	8	21.1%	64	39.5%
Yearly Household Income				
\$0-\$24,999	0	0.0%	14	8.6%
\$25,000-\$49,999	12	31.6%	38	23.5%
\$50,000-\$74,999	6	15.8%	42	25.9%
\$75,000-\$99,999	4	10.5%	29	17.9%
\$100,000-\$149,999	12	31.6%	30	18.5%
\$150,000-\$199,999	2	5.3%	6	3.7%
Greater than \$200,000	2	5.3%	3	1.9%
Source(s) of Income				
Solely Participant	20	52.6%	8	4.9%
Solely Participant's Partner	2	5.3%	80	49.4%
Participant's and Partner	14	36.8%	62	38.3%
Multiple (partner and other support)	2	5.3%	12	7.4%
Number of Children				
One	14	36.8%	54	33.3%
Two	16	42.1%	45	27.8%
Three	4	10.5%	35	21.6%
Four	4	10.5%	19	11.7%
Five or Greater	0	0.0%	9	5.6%
Relationship Status				
Married	30	78.9%	107	66.0%
Partnered – Living Together	8	21.1%	14	8.6%
Partnered – Living Separately	0	0.0%	19	11.7%
Single	0	0.0%	22	13.6%
Parenting Status				
Partnered – Raising Child Together	36	94.7%	114	70.4%
Co-Parenting - Living Separately	2	5.3%	9	5.6%
Single Parent	0	0.0%	39	24.1%

Illness characteristic of child. The most frequently reported illnesses were cancer ($n = 121$, 60.5%), neurological disease ($n = 20$, 10.0%), and autoimmune disorder or primary immunodeficiency disorder (e.g., lupus, hypogammaglobulinemia; $n = 15$, 7.5%). Four participants (2.0%) indicated “other” and specified their child’s condition (i.e., omphalocele, type 1 neurofibromatosis, postural orthostatic tachycardia syndrome, chronic lung disease). Exact illnesses are reported in Table 3.

Over half of the sample indicated that their child’s condition limits the child’s lifespan (i.e., life-limiting) or is terminal ($n = 147$, 73.5%), that remission is not possible ($n = 114$, 57.0%), and that their child is actively undergoing medical treatment ($n = 179$, 85.0%). Over 80 percent reported that caregiving need was high ($n = 116$, 58%); however, half ($n = 103$, 51.5%) reported that their child’s quality of life was Good to Very Good. Complete descriptive for the chronically ill child are presented in Table 3.

Participants dropped from final sample. Of the 16 participants who did not complete the research survey and were dropped from the final sample, 12 discontinued the survey after or during the demographic questionnaire, and 4 stopped after or during the first measure of the main study variables (role overload). Therefore, due to the order in which measures were presented in the survey, these participants may not have been missing at random. Among these 16 participants, a majority were male ($n = 14$, 87.5%), single ($n = 12$, 75.0%), had a high school diploma or equivalent ($n = 11$, 68.8%), and reported annual incomes of \$25,000-\$49,999 ($n = 13$, 81.3%).

Table 3
Descriptives of the Child's Chronic Illness

Types of Illness	<i>n</i>	Percentage
Cancer	121	60.5%
Leukemia	49	24.5%
Metastatic Cancer	45	22.5%
Non-Metastatic Cancer	27	13.5%
Neurological	20	10.0%
Autoimmune Disorder/Primary Immunodeficiency	15	7.5%
Congenital Heart Disease	13	6.5%
Renal Disease	7	3.5%
Multiple Co-Morbid Chronic Illnesses	7	3.5%
Severe Digestive Disorder	5	3.0%
Other (Specified)	4	2.0%
Mitochondrial Disease/DNA Deletion	4	2.0%
Cystic Fibrosis	3	1.5%
Child's Prognosis		
Life-Limiting/Terminal	147	73.5%
Non-Terminal; Non-Life-Limiting	53	26.5%
Medical Treatment		
In Treatment	170	85.0%
Not in Treatment	24	12.0%
Not sure of Options	6	3.0%
Caregiving Required		
Very High (e.g., constant care)	116	58.0%
High	48	24.0%
Moderate	13	6.5%
Low	12	6.0%
Very Low (e.g., less than 25% of the time)	11	5.5%
Child's Quality of Life		
Very Good	52	26.0%
Good	51	25.5%
Fair	37	21.5%
Poor	48	24.0%
Very Poor	6	3.0%
TOTAL		200
		100%

Measurement of Study Constructs

In addition to a demographic questionnaire, participants completed measures that assessed the study constructs. These constructs included primary caregiver stress (role overload), secondary caregiver stress (role strain), outcomes of caregiving (symptoms of depression and anxiety), resources (instrumental support, social support, and positive attitudes regarding caregiving).

Demographic Questionnaire. Participants were asked to provide standard demographic information (e.g., age, gender, ethnicity, education status, and household income). Context data including family makeup and child illness characteristics were also collected in the demographic questionnaire. Family makeup included multiple-choice and open-ended questions regarding the parent's relationship status (single, coupled, co-parenting – living separately, and co-parenting – living together) and number of children in the family. The child's illness characteristics included the amount of time since diagnosis (open-ended), and multiple-choice items regarding whether the parent was engaging in active care for the child, and whether the child was currently receiving medical treatment, the disease activity (active versus remitted), the prognosis (terminal, life-limiting, neither), and presence of critical times (e.g., the first year, exacerbations of child's symptoms; see Appendix E). Visual analogue scales ranging from 1 to 100 with specific anchors were used to assess level of care the child required, the child's quality of life, and the extent to which the caregiving affected the parent's financial stability, job stability, and household income. For example, these anchors included, 0 – 20 = Very Low; 21 – 40 = Low; 41 – 60 = Moderate; 61 – 80 = High; 81 – 100 = Very High.

Primary caregiver stress. Primary stress – role overload – was measured using Pearlin et al.'s (1990) Role Overload scale. This four-item scale was designed to measure role overload among caregivers such as feeling exhausted and overwhelmed and lack of time for oneself. A sample item included, “you are exhausted when you go to bed at night.” Participants rated the extent to which each statement described them on 4-point Likert-type scale (ranging from 1 = “not at all” to 4 = “completely”). Responses were summed and averaged to create a “role overload” score, with higher scores reflecting more role overload. Responses to items have shown good internal consistency reliability (Cronbach's $\alpha = .80$). Pearlin et al., (1990) provided evidence for construct validity by examining associations between this measure and other established measures of role overload and discriminant validity through factor analysis indicating that role overload is a distinct, conceptually independent construct reflecting caregiver stress. Responses to items showed good internal consistency reliability for the study sample (Cronbach's $\alpha = .83$).

Secondary caregiver stress. Secondary stress – role strain – was measured using the Objective Burden subscale of The Revised Caregiver Burden Measure (Montgomery, Borgatta, & Borgatta, 2000). The subscale included five items measuring intrapsychic, social, occupational, and financial strains that result secondary to the demand of caregiving. For the purpose of this study, instructions were modified to replace the original “care recipient” terminology to fit the context of the parent caregiver. For example, the wording was changed to ask participants to rate items “As a result of assisting your child with a chronic illness, have your caregiving responsibilities”. Sample items include, “How have your caregiving responsibilities kept you from recreational

activities” and “Caused your work or social life to suffer”. Items are rated on a 5-point scale ranging from 1 = “Not at all;” to 5 = “A great deal”. Responses were summed and averaged with higher scores indicating higher role strain. Although this measure was designed for caregivers of older adults, it has been applied in the context of parent caregivers (e.g., Crespo et al., 2011, Carona et al., 2013). Responses to this measure indicated strong internal consistency among caregivers of older adults (Cronbach's $\alpha = .93$; Montgomery et al., 2000) and for parent caregivers (Cronbach's $\alpha = .84$; Carona et al., 2013). Evidence of construct validity was provided by correlating this measure with other established measures of role strain, and factor analysis indicated discriminant validity by suggesting that role strain is a conceptually independent dimension of caregiver stress (Montgomery et al., 2000). Responses to this measure indicated strong internal consistency for the study sample (Cronbach's $\alpha = .90$).

Outcomes of caregiving. Two outcomes of caregiving relating to psychological well-being were assessed. These included depression (depressive symptomatology) and anxiety (symptoms of anxiety).

Depression was measured with the 9-item Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer, & Williams, 2001). Each of the items on this measure corresponds to specific DSM-5 symptoms of depression, making this a favorable and efficient measure to use with parent caregivers (e.g., Del-Pino-Casado et al., 2015, Khanna et al., 2015). Eight of the nine items were administered. Because this instrument was self-administered online, the item regarding suicidal ideation was omitted, in accordance with ASU’s IRB policies. Participants were instructed to rate how often they have been bothered by eight symptoms (e.g., “feeling tired or having little energy”) using a scale from “0” (not at all)

to “3” (nearly every day). Responses to items were summed with higher scores indicating more symptoms of depression. Responses to items of the PHQ-9 indicated strong internal reliability (Cronbach's $\alpha = .89$) and test-retest reliability ($\alpha = .86$; Kroenke et al., 2001). Evidence of diagnostic criterion validity was provided through two studies including 6,000 patients who underwent an independent re-interview by mental health professionals (Kroenke et al., 2001). Construct validity was supported by strong associations between the PHQ-9 and other established instruments assessing depression and measures of functional status and symptom-related disability days (Kroenke et al., 2001). Responses to items of the PHQ-9 indicated strong internal reliability for the study sample (Cronbach's $\alpha = .86$).

Anxiety was measured with the 7-item Generalized Anxiety Disorder scale (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006). Although symptoms of anxiety and depression frequently co-occur, this measure has been shown to assess distinct dimensions of anxiety. Additionally, the GAD-7 has been used to examine anxiety among parent caregivers (e.g., Waters et al., 2017). The GAD-7 instructed participants to rate symptoms (e.g., “worrying too much about different things”) from the previous two weeks using a 0 (“not at all”) to 3 (“nearly every day”) scale. Items were summed and averaged with higher scores indicating greater symptoms of anxiety. Responses to items have shown good internal consistency reliability (Cronbach's $\alpha = .92$) and test-retest reliability ($\alpha = .83$). and criterion, construct, and discriminant validity (Spitzer et al., 2016). Evidence for procedural validity, diagnostic criterion validity, and construct validity was supported by comparing GAD-7 results with independent diagnoses made by mental health professionals, functional status measures, and symptom-related disability

days. Construct validity was supported through analysis of covariance examining associations between the GAD-7 and other diagnostic measures (e.g., Beck Inventory). Evidence for criterion validity was provided through sensitivity, specificity, predictive values, and likelihood ratios for cutoff scores with formal diagnoses from mental health providers. Confirmatory factor analyses revealed that anxiety as measured by the GAD-7 and depression as measured by the PHQ-9 reflect distinct dimensions, and procedural validity was assessed by means of intraclass correlation (Spitzer et al., 2016). Responses to GAD-7 items showed good internal consistency reliability for the study sample (Cronbach's $\alpha = .88$).

Resources. Three types of resources were assessed in this study. These included instrumental support, social support, and positive attitudes.

Instrumental support and social support were measured using the Tangible Support and Emotional/informational Support subscales of the Medical Outcomes Study-Social Support Survey (MOS-SS; Sherbourne & Stewart, 1991). The MOS-SS is a brief, multidimensional, self-administered, social support survey developed to examine perceived support in four domains (emotional/informational, tangible/instrumental, affectionate, and social interaction) for individuals in medical contexts. The four item Tangible Support subscale assesses perceived access to instrumental support. Sample items included, “someone to help with chores or errands,” and “someone to prepare you meals.” To fit the context of caregiving, items were modified slightly, (i.e., help with “miscellaneous tasks” was reworded to “caregiving responsibilities” and “take you to the doctor” was reworded to “take your child to the doctor”). The eight item Emotional/informational subscale was used to measure social support. This subscale

examines perceived availability of a confidante, someone to turn to for advice, and someone with whom to share feelings and feel understood. A sample item included, “someone to share your most private worries and fears with.” Instructions were modified, asking participants to “consider the caregiving role” when providing answers. Ratings were made on a five-point Likert-type scale (“0” = none of the time to “4” = all of the time). For each subscale, an average score was derived by summing and averaging responses. Higher scores indicate greater instrumental and greater social support. Responses to items on each subscale have shown internal consistency as single measures (Tangible Cronbach's $\alpha = .84$; Emotional Cronbach's $\alpha = .80$) and as a composite measure (Cronbach's $\alpha = .82$; Sherbourne & Stewart, 1998). Evidence for discriminant validity of the subscales was provided through a multi-trait correlation matrix and factor analysis. Construct validity was supported through comparisons of other health and well-being measures assessing support (Sherbourne & Stewart, 1998). For participants in this study, responses to items on each subscale showed good internal consistency (instrumental support Cronbach's $\alpha = .86$; social support Cronbach's $\alpha = .97$).

Positive attitudes regarding the caregiving role were assessed with the five-item Positive Personal Impact subscale of the Brief Assessment Scale for Caregivers (BASC) of the Medically Ill (Glajchen et al., 2005). The BASC is a 14-item instrument designed to measure the overall impact of caregiving on caregivers. Items from the positive impact subscale assessed the extent to which taking care of the child with a chronic illness has “drawn the two of us closer together,” and “brought meaning to my life.” Items were rated on a 4-point Likert-type scale (1 = “agree a lot” to 4 = “disagree a lot”). Ratings were summed and averaged with higher scores indicating more positive attitudes.

Responses to items have shown good internal consistency reliability (Cronbach's $\alpha = .76$), and evidence of construct validity is based on correlations with other established instruments measuring various aspects of caregiver burden and experience, such as the Burden Assessment Scale and Objective Caregiver Burden Scale (Glajchen et al., 2005). The Positive Personal Impact subscale has been used in the context of caregiving for chronically ill children (Glajchen et al., 2005) and has been used with the Revised Caregiver Burden Measure (Montgomery et al., 2000). Responses to items indicated strong internal consistency reliability for this study sample (Cronbach's $\alpha = .84$).

Data Analytic Plan

Data were analyzed in IBM SPSS Statistics Version 24 (IBM Corp, 2017). One-tailed Pearson Product Moment correlation analyses were run to investigate the two hypotheses related to RQ1 (H1a, H1b) and the four hypotheses related to RQ2 (H2a, H2b, H2c, H2b). The error rate for each correlation was set at .01.

Six hierarchical regression analyses were run to test the models investigating RQ3, RQ4, and RQ5. Prior to running hierarchical regressions, to reduce multicollinearity with the interaction terms and to render the regression coefficients more meaningful and interpretable, role overload and role strain (independent variables), support and attitudes (moderators), and depression and anxiety (outcome variables) were grand mean centered (Aiken & West, 1991). According to the guidelines for testing multiple moderating effects (Frazier, Tix, & Barron, 2004), interaction terms were introduced in separate steps of the regression analysis. When significant interactions were found, simple slope tests were conducted to decompose the interaction (Aiken & West,

1991). Significant interactions were decomposed using Preacher's (2016) online calculator to compute specific values needed to plot two-way interactions.

Model 1 examined the interactions between role overload and instrumental support on depression (H3a) and the interactions between role strain and instrumental support on depression (H3c). Model 2 examined the interactions between role overload and instrumental support on anxiety (H3b) and the interactions between role strain and instrumental support on anxiety (H3d). For both models, role overload, role strain, and instrumental support were entered in Step 1. The interaction between role overload and instrumental support was added to the model in Step 2. The interaction between role strain and instrumental support was added in Step 3.

Model 3 examined the interactions between role overload and social support on depression (H4a) and the interactions between role strain and social support on depression (H4c). Model 4 examined the interactions between role overload and social support on anxiety (H4b) and the interactions between role strain and social support on anxiety (H4d). For these models, role overload, role strain, and social support were entered in Step 1. The interaction between role overload and social support was added in Step 2, and the interaction between role strain and instrumental support was added in Step 3.

Model 5 examined the interactions between role overload and positive attitudes on depression (H5a) and the interactions between role strain and positive attitudes on depression (H5c). Model 6 examined the interactions between role overload and positive attitudes on anxiety (H5b) and the interactions between role strain and positive attitudes on anxiety (H5d). For both models, role overload, role strain, and positive attitudes were

entered in Step 1. In Step 2, the interaction between role strain and positive attitudes was added to the model, as research indicates that positive attitudes about the caregiving role has a greater influence on role strain than on role overload (Marks et al., 2002; Silva et al., 2015). In Step 3, the interaction between role overload and positive attitudes was added.

CHAPTER 3

RESULTS

Preliminary Analyses

Means, standard deviations, and ranges of averaged scores on role overload, role strain, instrumental support, social support, positive attitudes, depression, and anxiety can be found in Table 4. The study variables were tested for normality, skewness, and kurtosis; all were normally distributed ($SE = +/- 1$). The data met the following assumptions required for regression: variables were continuous; linear relationships existed between study variables; there were no significant outliers; independence of observation was satisfied (Durbin-Watson: $d = 2.12$); data showed homoscedasticity; and the residuals were approximately normally distributed (Shapiro Wilk: $p = .32$).

Table 4
Descriptive Statistics for All Study Variables

	<i>M</i>	<i>SD</i>	<i>Range</i>
Role Overload	2.82	0.60	1.25-4.00
Role Strain	3.69	0.99	1.20-5.00
Instrumental Support	2.41	0.86	1.00-4.50
Social Support	2.99	1.13	1.00-5.00
Positive Attitudes	3.98	0.79	1.40-5.00
Depression	2.21	0.70	1.00-4.00
Anxiety	2.37	0.72	1.00-4.00

One-tailed Pearson Product Moment correlations among the study variables were calculated. These are presented in Table 5 along with the Cronbach alphas for the assessment of each variable.

Table 5
Correlations among Study Variables

	α	1	2	3	4	5	6	7
1. Role Overload	.83	1.00	.59**	-.27*	-.38**	-.37**	.50**	.56**
2. Role Strain	.90		1.00	-.24**	-.44**	-.20*	.68**	.54**
3. Instrumental Support	.86			1.00	.37**	-.12	-.52**	-.47**
4. Social Support	.97				1.00	.27*	-.43**	-.50**
5. Positive Attitudes	.84					1.00	-.51**	-.57**
6. Depression	.86						1.00	.71**
7. Anxiety	.88							1.00

Note: ** $p \leq .000$ level; * $p \leq .01$ level

Tests of Hypotheses

H1: Relations of caregiving stress on psychological outcomes. Consistent with predictions that greater role overload and role strain would be associated with greater depression (H1a), significant positive correlations between role overload and depression ($r = .50, p = .000$) and between role strain and depression ($r = .68, p = .000$) were found. It was also hypothesized that greater role overload and role strain would be positively related to anxiety (H1b). Significant positive correlations between role overload and anxiety ($r = .56, p = .000$) and between role strain and anxiety ($r = .54, p = .000$) were found. Based on the Pearson correlation analysis, H1a and H1b were supported. More caregiving stress was associated with more depression and anxiety (see Table 5 for correlation results).

H2: Relations of resources on psychological outcomes. The resources examined were instrumental and social support and positive attitudes. Consistent with the prediction that greater support (instrumental and social) would be associated with less depression (H2a), correlational analyses revealed a significant negative association between instrumental support and depression ($r = -.52, p = .000$) and between social support and

depression ($r = -.43, p = .000$). It was also predicted that greater support (instrumental and social) would be associated with less anxiety (H2b). The correlation analyses revealed significant negative correlations between instrumental support and anxiety ($r = -.47, p = .000$) and between social support and anxiety ($r = -.50, p = .000$). Instrumental support and social support were negatively related to anxiety.

H2c predicted that more positive attitudes would be related to less depression. A significant negative correlation between positive attitudes and depression ($r = -.51, p = .000$) was found. The data analysis also revealed that more positive attitudes were associated with less anxiety (H3d). There was a significant negative correlation between positive attitudes and anxiety ($r = -.57, p = .000$), indicating that more positive attitudes was related to less anxiety (see Table 5 for correlation results). Based on these findings, H2a, H2b, H2c, and H2d were supported.

H3: Instrumental support and caregiving stress on psychological outcomes.

To address RQ3, four hypotheses were tested. The hierarchical regression results of Model 1, which focused on depression as the dependent variable, indicated that, at Step 1, caregiving stress and instrumental support significantly predicted depression, $\Delta R^2 = .467, \Delta F(1,196) = 38.62, p < .001$. The effects of role overload, role strain, and instrumental support accounted for 46.7% of the variance in depression. As can be seen in Table 6, all three beta weights were significant. Consistent with the prediction that instrumental support would moderate the effect of role overload on depression (H3a), adding the interaction variable of role overload by instrumental support to the regression model (Step 2) explained an additional 6.2% of the variance in depression. This change in R^2 was significant, $\Delta F(1,196) = 38.62, p < .05$. As can be seen in Table 6, the beta weights

for the three predictors as well as for the interaction variable were significant. To test H3c, the interaction variable between role strain and instrumental support was added to the regression model in Step 3. The interaction variable did not explain additional variance in depression, $\Delta R^2 = .001$, $\Delta F(1,195) = 30.85$, $p > .05$; therefore, instrumental support did not moderate the relation between role strain and depression. Table 6 presents the hierarchical regression results for depression.

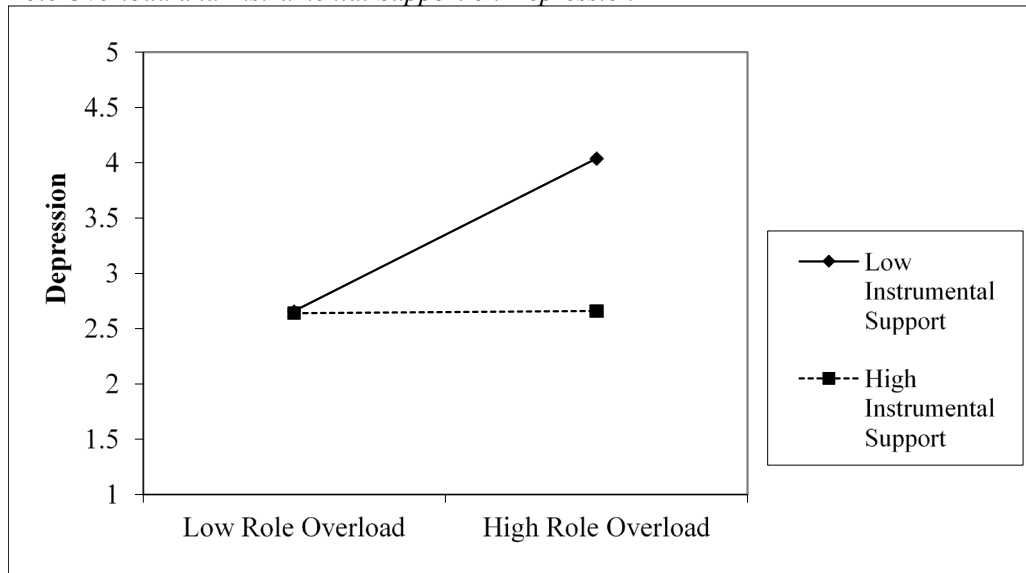
To explore the significant interaction variable at Step 2, the significant interaction between role overload and instrumental support was probed following the recommendations of Aiken and West (1991). Simple slope analysis revealed that, as predicted, the relation between role overload and instrumental support negatively moderated depression. Figure 4 depicts the simple slope analysis. Instrumental support moderated the association between role overload and depression, such that, when instrumental support was high, there was no relation between role overload and depression, and when instrumental support was low, there was a positive relation.

Table 6
Caregiving Stress and Instrumental Support on Depression Model Results

	Depression				
	β	t	ΔR^2	df	ΔF
Step 1			.467	3, 197	50.89***
Role Overload	.15*	2.21*			
Role Strain	.57*	8.19**			
Instrumental Support	-.16*	-1.07*			
Step 2			.062	1, 196	38.62*
Role Overload	.35*	2.00*			
Role Strain	.57*	8.08**			
Instrumental Support	-.35*	-1.93*			
RO*Instrumental Support	-.34*	-1.19*			
Step 3			.001	1, 195	30.85
Role Overload	.27*	1.26*			
Role Strain	.67*	3.70*			
Instrumental Support	-.25*	-1.03*			
RO*Instrumental Support	-.40*	-1.05*			
RS*Instrumental Support	-.16*	-0.61			

Notes: RO = Role Overload; RS = Role Strain; *** $p \leq .001$ level; ** $p \leq .01$ level; * $p \leq .05$ level

Figure 4
Role Overload and Instrumental Support on Depression



For Model 2, for which anxiety was the dependent variable, hierarchical regression results indicated that, at Step 1, caregiving stress and instrumental support

predicted anxiety, $\Delta R^2 = .322$, $\Delta F(1,197) = 26.58$, $p < .001$. Again, examination of the beta weights presented in Table 7 reveals that all three variables (role overload, role strain, and instrumental support) were significant predictors of anxiety. Consistent with the prediction that instrumental support would moderate the effect of role overload on anxiety (H3b), adding the interaction between role overload and instrumental support to the regression model (Step 2) explained an additional 5.3% of the variance in anxiety. This change in R^2 was significant, $\Delta F(1,196) = 20.99$, $p < .01$. The addition of the interaction between role strain and instrumental support to the regression model in Step 3 (H3d) did not explain additional variance in anxiety, $\Delta R^2 = .001$, $\Delta F(1,195) = 16.71$, $p > .05$. Instrumental support did not moderate the association between role strain and anxiety. Table 7 presents the hierarchical regression results for anxiety.

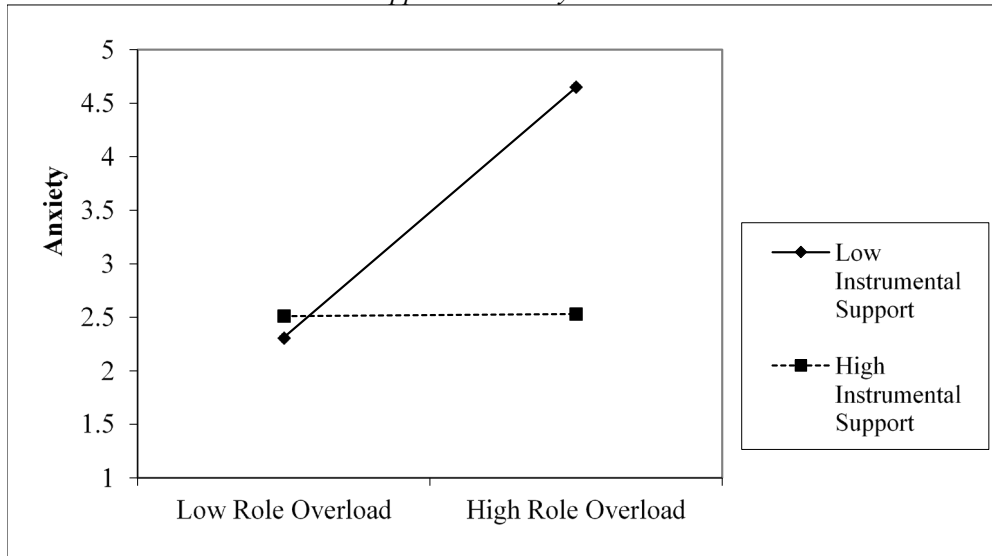
The significant interaction effect of role overload by instrumental support on anxiety found in Step 2 was probed using Aiken and West's (1991) suggestions. Simple slope analysis revealed that, as predicted, the relation between role overload and instrumental support negatively moderated anxiety. As can be seen in Figure 5, when participants reported high instrumental support, there was no relation between role overload and anxiety. When participants reported low instrumental support, there was a positive relation.

Table 7
Caregiving Stress and Instrumental Support on Anxiety Model Results

	Anxiety				
	β	t	ΔR^2	df	ΔF
<u>Step 1</u>			.322	3, 197	26.58***
Role Overload	.22*	2.86**			
Role Strain	.40*	4.97**			
Instrumental Support	-.38*	-1.58*			
<u>Step 2</u>			.053	1, 196	20.99**
Role Overload	.59*	2.75*			
Role Strain	.39*	4.85**			
Instrumental Support	-.48*	-1.16*			
RO*Instrumental Support	-.58*	-1.79*			
<u>Step 3</u>			.001	1, 195	16.71
Role Overload	.53*	2.13*			
Role Strain	.43*	2.10*			
Instrumental Support	.49*	1.65*			
RO*Instrumental Support	-.52*	-1.24*			
RS*Instrumental Support	-.07	-0.23			

Notes: RO = Role Overload; RS = Role Strain; *** $p \leq .001$ level; ** $p \leq .01$ level; * $p \leq .05$ level

Figure 5
Role Overload and Instrumental Support on Anxiety



Based on these analyses, instrumental support had a negative moderation effect on the association between role overload and depression (H3a) and between role overload and anxiety (H3b). However, instrumental support did not moderate the effect of role

strain on depression (H3c) or anxiety (H3d). Therefore, H3a and H3b were supported and H3c and H3d were not supported.

H4: Social support and caregiving stress on psychological outcomes. To examine the hypotheses regarding the moderating effects of social support and caregiving stress on psychological outcomes, two models were tested. Model 3 focused on depression as the dependent variable, and the results of the hierarchical regression at Step 1 indicated that role overload, role strain, and social support significantly predicted depression, accounting for 49.0% of the variance in depression, $\Delta F(1, 197) = 53.76, p < .001$. As shown in Table 8, the beta weights were significant for these three variables. H4a predicted that social support would moderate the effect of role overload on depression. Adding the interaction variable, (role overload by social support) to the model in Step 2 explained an additional 5.3% of the variance in depression, $\Delta F(1, 196) = 40.87, p < .05$. As shown in Table 8, the beta weights for the three predictors as well as for the interaction variable were significant. The addition of the interaction variable (role strain by social support) to the regression model (H4c) did not explain additional variance in depression, $\Delta R^2 = .002, \Delta F(1, 195) = 32.51, p > .05$. Social support moderated the relation between role overload and depression (H4a), but social support did not moderate the association between role strain and depression (H4c). Table 8 presents the hierarchical regression results for depression.

To explore the significant interaction effect between role overload and social support (Step 2), the significant interaction was probed per Aiken and West's (1991) recommendations. Simple slope analysis revealed that, as predicted, the relation between role overload and social support negatively moderated depression. As can be seen in

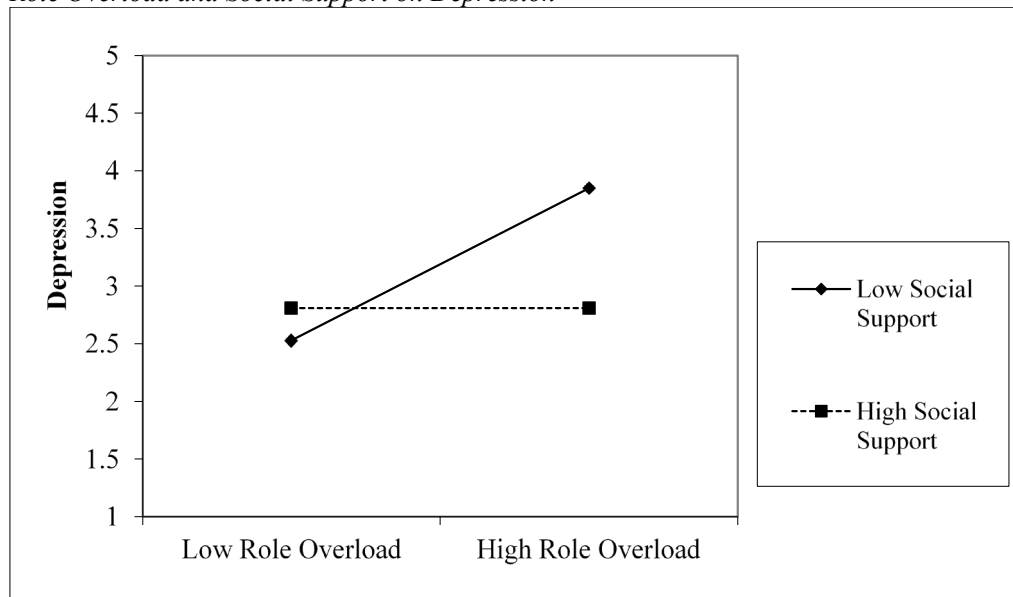
Figure 6, when social support was high, there was no relation between role overload and depression, and when instrumental support was low, there was a positive relation.

Table 8
Caregiving Stress and Social Support on Depression Model Results

	Depression				
	β	t	ΔR^2	df	ΔF
<u>Step 1</u>			.490	3, 197	53.76***
Role Overload	.13*	1.84*			
Role Strain	.54*	7.58***			
Social Support	-.15*	-2.38*			
<u>Step 2</u>			.053	1, 196	40.87*
Role Overload	.33*	1.90*			
Role Strain	.52*	7.21***			
Social Support	-.19*	-2.40*			
RO* Social Support	-.33*	-1.27*			
<u>Step 3</u>			.002	1, 195	32.51
Role Overload	.31*	1.52*			
Role Strain	.56*	2.67*			
Social Support	.21*	1.71**			
RO* Social Support	-.30*	-1.20*			
RS* Social Support	-.05	-1.19			

Notes: RO = Role Overload; RS = Role Strain; *** $p \leq .001$ level; ** $p \leq .01$ level; * $p \leq .05$ level

Figure 6
Role Overload and Social Support on Depression



H4b and H4d were examined Model 4, for which anxiety was the dependent variable. The hierarchical regression results indicated that, at Step 1, role strain, role overload, and social support significantly predicted anxiety, $\Delta R^2 = .321$, $\Delta F(1,197) = 26.53$, $p < .001$. Again, examination of the beta weights indicates that all three variables were significant predictors of anxiety. Consistent with the prediction that instrumental support would moderate the effect of role overload on anxiety (H4b), adding the interaction between role overload and social support in Step 2 explained an additional 6.2% of the variance in anxiety which was a significant change in R^2 , $\Delta F(1,196) = 20.31$, $p < .05$. In contrast with H4d, the addition of the interaction between role strain and instrumental support to the regression model (Step 3) did not explain additional variance in anxiety, $\Delta R^2 = .005$, $\Delta F(1,195) = 17.07$, $p > .05$ (see Table 9 for hierarchical regression results).

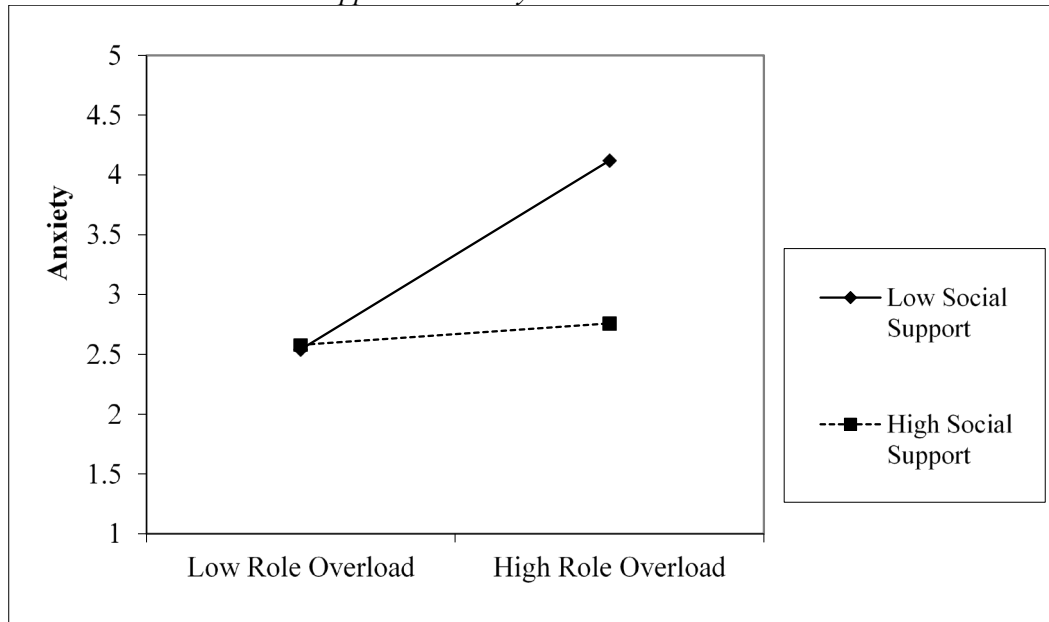
Again, as per Aiken and West's (1991) recommendations, the significant interaction at Step 2 was explored. Consistent with the prediction that role overload would moderate the effect of role overload on anxiety, simple slope analysis revealed that, the relation between role overload and social support negatively moderated anxiety. When participants reported high social support, there was no relation between role overload and anxiety. When social support was low, the relation between role overload and anxiety was positive. See Figure 7 for simple slope analysis.

Table 9
Caregiving Stress and Social Support on Anxiety Model Results

	Anxiety				
	β	t	ΔR^2	df	ΔF
<u>Step 1</u>			.321	3, 197	26.53***
Role Overload	.22*	2.76*			
Role Strain	.39*	4.80***			
Social Support	-.34*	-1.48*			
<u>Step 2</u>			.062	1, 196	20.31*
Role Overload	.44*	2.21*			
Role Strain	.37*	4.49***			
Social Support	-.33*	-1.06*			
RO* Social Support	-.35*	-1.20*			
<u>Step 3</u>			.005	1, 195	17.07
Role Overload	.22*	1.98*			
Role Strain	.77*	3.22**			
Social Support	-.55*	-1.64*			
RO* Social Support	-.43*	-1.13*			
RS* Social Support	-.52*	-1.76			

Notes: RO = Role Overload; RS = Role Strain; *** $p \leq .001$ level; ** $p \leq .01$ level; * $p \leq .05$ level

Figure 7
Role Overload and Social Support on Anxiety



Based on these analyses, social support negatively moderated the association between role overload and depression (H4a) and between role overload and anxiety

(H4b). However, social support did not moderate the effect of role strain on depression (H4c) or anxiety (H4d). Therefore, H4a and H4b were supported and H4c and H4d were not supported.

H5: Positive attitudes and caregiving stress on psychological outcomes. The last four hypotheses predicted that positive attitudes would have moderating effects on the relations between caregiving stress and psychological outcomes. The hierarchical regression results of Model 5 focused on depression as the dependent variable and indicated that, at Step 1, caregiving stress and positive attitudes significantly predicted depression, $\Delta R^2 = .472$, $\Delta F(1,197) = 50.54$, $p < .001$. The beta weights for role overload, role strain, and positive attitudes were significant (see Table 10). When the interaction between role strain and positive attitudes was added to the regression model (Step 2), this explained an additional 5.4% of the variance in depression which was a significant change in R^2 , $\Delta F(1,196) = 38.47$, $p < .05$. As can be seen in Table 10, the beta weights for the three predictors as well as for the interaction variable were significant. This finding was consistent with H5c predicting that positive attitudes would moderate the effect of role strain on depression. To examine H5a, the interaction between role overload and positive attitudes was added to the regression model (Step 3). This addition did not explain additional variance in depression, $\Delta R^2 = .01$, $\Delta F(1,195) = 30.84$, $p > .05$ (see Table 10 for hierarchical regression results).

To explore the significant interaction at Step 2, the interaction between role strain and positive attitudes was probed (Aiken & West, 1991). Simple slope analysis revealed that, the relation between role strain and positive attitudes negatively moderated

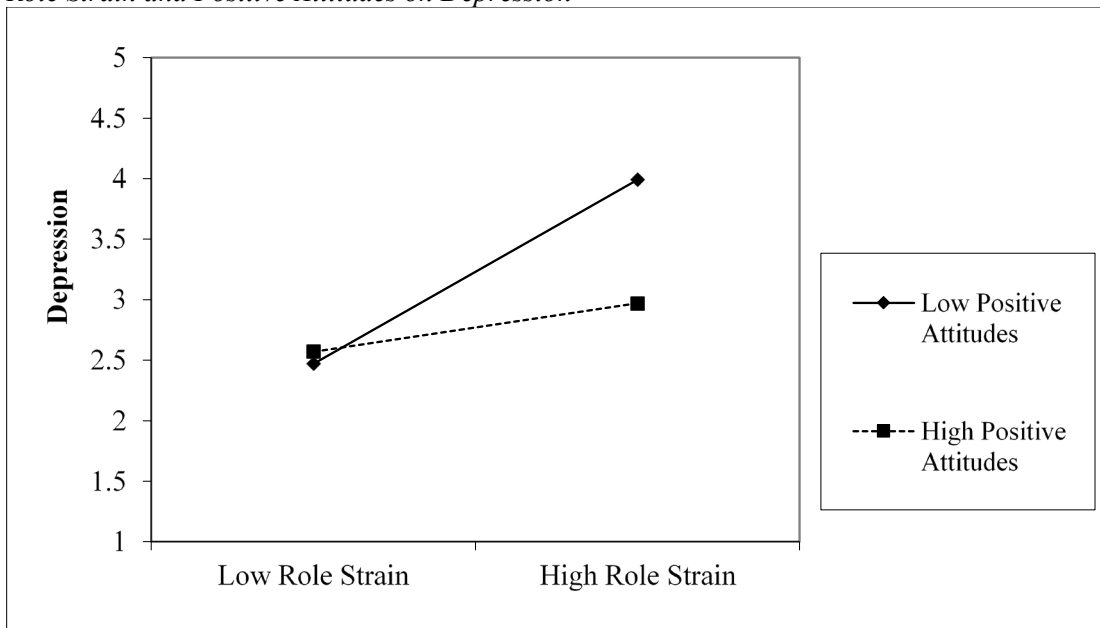
depression. As depicted in Figure 8, when participants reported high positive attitudes, there was no relation between role strain and depression.

Table 10
Caregiving Stress and Positive Attitudes on Depression Model Results

	Depression				
	β	t	ΔR^2	df	ΔF
<u>Step 1</u>			.472	3, 197	50.54 ^{***}
Role Overload	.14*	1.89*			
Role Strain	.59*	8.50 ^{***}			
Positive Attitudes	-.46*	-1.72*			
<u>Step 2</u>			.054	1, 196	38.47*
Role Overload	.10*	1.36*			
Role Strain	.63*	2.93 ^{**}			
Positive Attitudes	-.25*	-1.06*			
RS*Positive Attitudes	-.48*	-1.29*			
<u>Step 3</u>			.020	1, 195	30.84
Role Overload	.45*	1.04*			
Role Strain	.80*	1.75*			
Positive Attitudes	-.42*	-1.33*			
RS* Social Support	-.52*	-1.46*			
RO* Social Support	-.37*	-0.81			

Notes: RO = Role Overload; RS = Role Strain; ^{***} $p \leq .001$ level; ^{**} $p \leq .01$ level; ^{*} $p \leq .05$ level

Figure 8
Role Strain and Positive Attitudes on Depression



For Model 6, for which anxiety was the dependent variable, hierarchical regression analysis results indicated that, at Step 1, role overload, role strain, and positive attitudes were significant predictors of anxiety, $\Delta R^2 = .324$, $\Delta F(1,197) = 26.84$, $p < .001$. Examination of beta weights indicates that role overload, role strain, and positive attitudes significantly predicted anxiety. Supporting the prediction that positive attitudes would moderate the effect of role strain on anxiety (H5d), the interaction between role strain and positive attitudes (entered in Step 2) explained an additional 5.2% of the variance in anxiety. This change in R^2 was significant, $\Delta F(1,196) = 20.07$, $p < .05$. The addition of the interaction between role overload and positive attitudes to the regression model in Step 3 (H3b) was not significant, $\Delta R^2 = .01$, $\Delta F(1,195) = 15.98$, $p > .05$ (see Table 11 for hierarchical regression results).

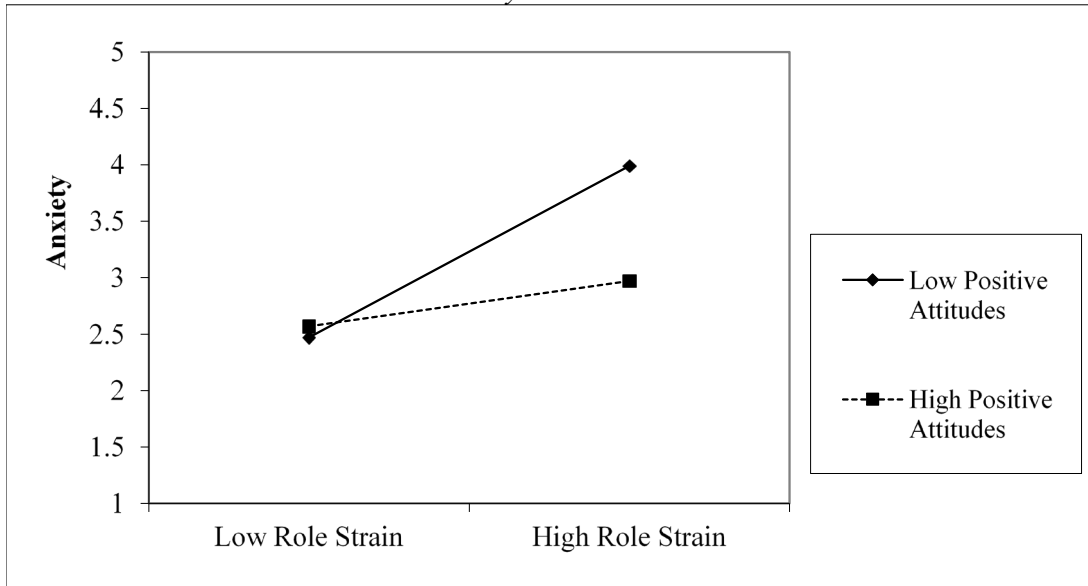
The significant interaction in the prediction of anxiety found in Step 2 was probed (Aiken & West, 1991). Simple slope analysis revealed that positive attitudes negatively moderated the relation between role strain and anxiety. Figure 9 depicts the simple slope analysis. As participants reported high positive attitudes, there was no relation between role strain and anxiety. When positive attitudes were low, there was a positive relation between role strain and anxiety.

Table 11
Caregiving Stress and Positive Attitudes on Anxiety Model Results

	Anxiety				
	β	t	ΔR^2	df	ΔF
<u>Step 1</u>			.324	3, 197	26.84***
Role Overload	.25*	3.04*			
Role Strain	.40*	5.14***			
Positive Attitudes	-.63*	-1.93*			
<u>Step 2</u>			.052	1, 196	20.07*
Role Overload	.24*	2.72**			
Role Strain	.56*	1.41*			
Positive Attitudes	-.17*	-1.63*			
RS*Positive Attitudes	-.27*	-1.41*			
<u>Step 3</u>			.001	1, 195	15.98
Role Overload	.36*	1.73*			
Role Strain	.48*	1.92*			
Positive Attitudes	-.23*	-0.64*			
RS* Social Support	-.28*	-1.15*			
RO* Social Support	-.13*	-0.25			

Notes: RO = Role Overload; RS = Role Strain; *** $p \leq .001$ level; ** $p \leq .01$ level; * $p \leq .05$ level

Figure 9
Role Strain and Positive Attitudes on Anxiety



Based on these analyses, positive attitudes had a negative moderation effect on the association between role strain and depression (H3c) and between role strain and anxiety (H3d). However, positive attitudes did not moderate the effect of role overload on

depression (H3a) or anxiety (H3b). Therefore, H3c and H3d were supported, and H3a and H3b were not supported.

CHAPTER 4

DISCUSSION

This study was based on Pearlin's (1990) Stress Process Model (SPM) which provides a theoretical, multidimensional model for conceptualizing the caregiving experience. As such, the SPM aids in distinguishing different types of caregiving stress, identifying influences of distinct supports, and delineating important components that may contribute to caregiving outcomes. Given the prevalence of chronic illness among children (CDC, 2017) and the corresponding pervasiveness of parents facing the stress associated with their child's chronic illness (Mayo Clinic, 2018), this study explored the predictors and moderators of two psychological outcomes, depression and anxiety, among parent caregivers of children with a chronic illness. The first goal of this study was to investigate the relations between caregiving stress, resources, and their psychological outcomes. A second goal was to explore whether resources (instrumental support, social support, and positive attitudes) moderated the associations between caregiving stress (role overload and role strain) and psychological outcomes (depression and anxiety).

When components of the SPM theory (Pearlin et al., 1990) were examined (i.e., primary stressors, secondary stressors, resources, and outcomes), the data supported this theory. Results indicated that more caregiving stress was related to more depression and anxiety and that more resources were related to less depression and anxiety. The data also revealed that both instrumental and social support moderated the associations between role overload and caregiving outcomes and that positive attitudes moderated the associations between role strain and caregiving outcomes.

Relations Between Caregiving Stress and Psychological Outcomes

As stress is a multidimensional process, the demanding caregiving role can bring about various types of stress (Pearlin et al., 1990). Specifically, the SPM (Pearlin et al., 1990) identifies two types of caregiving stress: role overload and role strain. Role overload, a primary stressor, refers to the impact of caregiving demands on the caregiver. Role strain is a secondary stressor and refers to tensions associated with sustaining multiple roles. The literature indicates that parent caregivers generally report higher levels of stress, anxiety, and depression than do non-caregivers (Pinquart & Sorensen, 2003). Correspondingly, participant responses on the caregiving stress measures indicated that, on average, they experienced a high level of role overload (Pearlin et al., 1990) and a moderate-to-high level of role strain (Montgomery et al., 2000). Additionally, the average total scores for the study sample on the PHQ-9 and GAD-7 represented clinically significant depression in the moderately severe-to-severe cutoff ranges (Kroenke et al., 2001) and clinically significant anxiety in the severe cutoff range (Spitzer et al., 2016), respectively.

As predicted, both types of caregiving stress (role overload and role strain) were positively associated with depression and anxiety among the parent caregivers in this study. When role overload increases, so too do depression and anxiety, and when role strain increases, depression and anxiety also increase. The positive relations between caregiving stress with depression and anxiety may be explained by the stress process theory of caregiving that posits that caregiving stress is related to physical, financial, and psychological hardship (Pearlin et al., 1990). Although not termed “hardships” in the

current study, depression and anxiety were conceptualized as psychological outcomes of caregiving.

As noted above, role overload is a primary stressor that results from the demands of caregiving. Role overload has been linked with restrictions on caregivers' ability to tend to personal relationships and to engage in activities outside of the caregiving context (Bastawrous et al., 2014) and with caregivers feeling overexerted (Mullins et al., 2011). As noted by Waters et al. (2017), when caregivers experience role overload, they are more likely to neglect their own physical and emotional needs, experience worrying about their child's well-being, and feel fearful about their own ability to care for their child. Such experiences are also reflected in more symptoms of depression and anxiety (Eccleston et al., 2015). The findings for the parent caregivers in this study add further evidence related to the relations between role overload and the psychological well-being of the caregivers. As these caregivers experienced more demands related to caring for their chronically ill child, the more anxiety and depression they also experienced.

In addition to role overload, role strain had direct positive relations with both psychological outcomes. Role strain, a secondary stressor, has been linked to an erosion of one's sense of self (Stephens et al., 2009), to unwanted changes in areas of occupational, financial, and social functioning (Carona et al., 2013), and to struggles with accepting uncertainties and learning to adapt to and balance multiple roles (Waters et al., 2017). Again, these experiences are also related to more depression and anxiety (Streisand & Tercyak, 2004). Accordingly, for parent caregivers in this study, those who experienced more role strain also experienced more depression and anxiety.

Because experiences that provoke depression and anxiety may be embedded in the caregiving role, caregiving stress (role overload and role strain) can be positively related to symptoms of depression and anxiety. Similar to the finding that parent caregivers reported more depression and anxiety when role overload was high, parent caregivers in this study also reported more depression and anxiety when they reported higher role strain. Thus, these findings are consistent with previous research demonstrating that the experience of more caregiving stress is associated with experiencing more symptoms of depression and anxiety among parent caregivers (Streisand & Tercyak, 2004).

Relations Between Resources and Psychological Outcomes

The SPM (Pearlin et al., 1990) includes various types of resources including external resources (support) and internal resources (attitudes). In the current study, two types of support were examined, instrumental and social support. Instrumental support refers to the provision of concrete assistance or help with tangible tasks and can be formal or informal support (Clark, 2002). Social support refers to interpersonal interactions that provide various forms of positive affectivity, such as emotional connectedness (Sarason & Sarason, 2009). A third resource studied was positive attitudes, which within the caregiving role refers to perceptions of satisfaction with and gains from caregiving such as personal growth. Prior literature suggests that instrumental support, social support, and positive attitudes about caregiving are negatively associated with depression (Crosier et al., 2007; Hoekstra-Weebers et al., 2011; Marks et al., 2002) and with anxiety (Waters et al., 2017; Crosier et al., 2007; Silva et al., 2015). This study's findings support the previous research findings.

Instrumental support, social support, and positive attitudes were each negatively associated with both depression and anxiety. As these parent caregivers experienced more of each resource, they reported fewer symptoms of depression and less anxiety. These findings are consistent with the stress process theory indicating that resources are related to psychological outcomes of caregivers (Pearlin et al., 1990).

Given the physical demands of caregiving, instrumental support can provide practical, tangible, and specific assistance with various tasks and caregiving duties (NAC, 2009). For example, providing respite, helping with errands, and assisting with doctors' visits and treatment can increase parent caregivers' ability to tend to and balance caregiving demands (Morelli et al., 2015). Indeed, the importance of instrumental support as a resource for the psychological well-being of parents caring for a chronically ill child is highlighted by study findings that instrumental support was negatively related to depression and anxiety. This finding adds to the related literature on caregiving and to the SPM (Pearlin et al., 1990).

Social support, a second type of external support, provides opportunities for parent caregivers to process with others their emotions and experiences regarding the caregiving role and to engage in interactions dedicated to focusing on the caregiver's own well-being (Brown et al., 2008). According to Brown et al. (2012), social support can also foster the acquisition of effective coping skills and promote a greater ability to adapt to stressful circumstances. Social networks and interpersonal connections are an important resource of social support for parent caregivers, as they provide an outlet for processing affective responses to stress and for receiving affection, empathy, and encouragement (Crespo et al., 2011). Consistent with Sarason and Sarason's (2009)

conceptualization of social support and the value of having a support network who foster positive affectivity, it is not surprising that more social support was associated with less depression and less anxiety among the current study sample.

The third type of resource assessed was caregiver attitudes. The personal belief that one's caregiving role is rewarding can increase the positivity of a caregiver's experience (Pearlin et al., 1990). Feeling effective and fulfilled in the role, believing that the role is meaningful and promotes personal growth, and feeling as though the caregiving experience strengthens the parent-child bond can increase caregivers' sense of worthiness, satisfaction, and meaningfulness (Hansen et al., 2013). As such, this study's finding that the more parent caregivers reported positive attitudes about caregiving, the less they experienced depression and anxiety, is consistent with the literature.

Taken together, instrumental support, social support, and positive attitudes can promote adaptability, coping fluency, and positive affectivity (Crosier et al., 2007; Marks et al., 2002; Silva et al., 2015). Although these findings are correlational and no causal relationships can be made, understanding caregiving stress (specifically role overload and role strain) and caregiving resources (instrumental support, social support, and positive attitudes about caregiving) is essential for understanding parent caregivers' experience of depression and anxiety.

Moderating Effects of Resources

This study also examined whether the three resources would moderate the effects of stress on depression and anxiety. The resources were instrumental support, social support, and positive attitudes.

Moderating effects of instrumental support. The literature indicates that instrumental support has been negatively associated with depression and anxiety; however, it has also been shown to moderate the associations between role overload and outcomes of depression (Hoekstra-Weebers et al., 2011) and anxiety (Waters et al., 2017). In the current study, reports of more instrumental support negatively moderated the relation between role overload and depression, such that it weakened the relation. Parents who reported a high perception of instrumental support reported low depression, even when reported role overload was high. Similarly, instrumental support also negatively moderated the relation between role overload and anxiety, such that parent caregivers who reported high instrumental support and high role overload also reported low anxiety.

The moderating effect of instrumental support was not found for role strain; however, previous studies have reported a moderating effect of instrumental support on the relation between role strain and depression (Demirtepe-Saygili & Bozo, 2011) and role strain and anxiety (Waters et al., 2017). The nonsignificant finding in the current study may be explained by the distinct properties of role overload and role strain related to caregiving for a child with a chronic illness. Given the function of instrumental support, such as receiving help with errands and other daily tasks, this type of support may allow caregivers more opportunities to tend to their own needs, which may be related then to lower depression and anxiety (Del-Pino-Casado et al., 2018). Increasing opportunities to focus on one's own well-being may mitigate the impact of the caregiving role on the caregiver (i.e., role overload). However, greater instrumental support alone may not be sufficient in relieving the impact of tensions associated with sustaining

multiple roles (i.e., role strain) on psychological outcomes. Said differently, the experiences of depression and anxiety associated with balancing roles and ongoing challenges to deal simultaneously with caregiving demands, the responsibilities of parenting, and learning about the child's needs may not be assuaged by obtaining help with caregiving tasks (Crespo et al., 2011). Rather, this type of support may be more effective at tempering the effects of role overload on psychological outcomes (Nabors et al., 2013).

Additionally, tangible resources (i.e., instrumental support) available to the parents whose incomes are around the poverty line could differ from those on the high end of annual income (Federal Register, 2016). With this, similar supports received by different parent caregivers could have a differential impact on the parents (Brown et al., 2008). For example, two parents may receive the same amount of tangible assistance, but for a parent who is lacking in available instrumental supports, any support (big or small) may be more impactful than for a parent who has existing access to instrumental supports, whether formal or informal. Compared to caregivers with greater financial means, parent caregivers with less financial resources must often assume more roles and responsibilities; therefore, their role strain remains high, even if receiving instrumental support (Brown et al., 2008). Furthermore, the severity of the child's illness may place unique demands on the parent caregiver. Although not examined in this study, the severity of the child's illness, the level of caregivers' needs, and the degree to which the caregiver's needs were being met are important factors to consider in relation to how instrumental support impacts parent caregivers' stress.

In summary, the finding that instrumental support moderated the effect of role overload on depression and anxiety supports the previous research that also examined these moderating effects (Hoekstra-Weebers et al., 2011). The current study finding related to role strain is not consistent the Waters et al. (2017) finding. Waters et al. examined parents of children with one homogeneous illness (asthma), which may differ from the current study sample in terms of the child's needs and the degree of caregiving stress experienced, as children in this study had various life-limiting and potentially terminal illnesses requiring distinct degrees of caregiving need. For example, caring for a child with cancer may require uniquely challenging demands. Thus, the non-significant finding of the moderating effect of instrumental support on the relation between role overload and psychological outcomes may be explained by the severity of the child's illness (Best et al., 2001) or the distinct characteristics of role overload and role strain (Hoekstra-Weebers et al., 2011).

Moderating effects of social support. Social support has also been shown to moderate the associations between caregiving stress and the outcomes of depression (Demirtepe-Saygili & Bozo, 2011; Speechley & Noh, 1992) and anxiety (Nabors et al., 2013; Speechley & Noh, 1992). In the current study, social support negatively moderated the associations between role overload and depression. Parents who reported a high perception of social support reported less depression and less anxiety, even when reported role overload was high. Social support, however, did not moderate the association between role strain and depression or between role strain and anxiety.

The distinct dimensions of caregiving stress may explain the discrepant findings. Social support may help alleviate the negative impact of caregiving demands (role

overload) but may not aid in relieving the challenge of balancing multiple roles (role strain). Parents who experience socioeconomic difficulties may have reduced time and energy to access their social supports. For example, if experiencing strain in multiple areas (occupational, social, and financial), a parent caregiver may not have the necessary flexibility (time or energy) to connect with social supports (Brown et al., 2012).

Additionally, due to the difficulty of balancing multiple roles, some parent caregivers may have fewer opportunities to connect to community and social activities, and this may lead to the experience of social isolation and subsequently diminished social support (Kazak & Wilcox, 1984).

Taken together, the findings related to support and role overload are consistent with the literature which supports the moderating effect of social support by role overload on depression and on anxiety for parent caregivers of a child with a chronic illness (Speechley & Noh, 1992). However, the findings related to role strain are not consistent with the literature demonstrating interaction effects of role strain by social support on depression (Demirtepe-Saygili & Bozo, 2011) and on anxiety (Nabors et al., 2013). The study findings suggest that social support may aid in managing the way in which the demands of caregiving impact caregivers. For example, support in interpersonal relationships may aid a parent caregiver in making a challenging decision regarding the child's care. Receiving social support may help the caregiver come to a decision, feel at peace with the decision, or feel confident in the decision (Demirtepe-Saygili et al., 2012). In addition, having social support may also reflect emotional support and having someone as a confidante to share emotions of being exhausted and overwhelmed by caregiving. Expressing one's feelings to someone who cares and understands can be

therapeutic and help reduce negative emotional outcomes such as depression and anxiety. Thus, social support may be more beneficial in alleviating role overload than role strain.

Moderating Effects of Positive Attitudes. The literature also suggests that positive attitudes about caregiving can moderate the associations between role strain the experience of depression and of anxiety (Silva et al., 2015). Supporting this literature, a significant moderating effect of positive attitudes on the association between role strain and depression was found. Positive attitudes weakened the association, such that parents who endorsed positive attitudes about caregiving reported low depression, even when reported role strain was high. Positive attitudes also negatively moderated the association between role strain and anxiety. Parents who reported high positive attitudes and high role strain also reported low anxiety.

Researchers have also noted that positive attitudes moderates the associations between role overload and depression for caregivers of older adults (Marks et al., 2002) and anxiety for caregivers of other family members (Rapp & Chao, 2000). In contrast to what has been previously reported, significant moderation effects between role overload and positive attitudes were not found on depression or anxiety for this sample of parent caregivers. This finding may relate to differences in caregiving context and experiences between previous samples which focused on caregivers of mature adults, and the current study sample was specifically focused on caregivers of children. Although caregivers of mature adults and caregivers of children have some shared experiences, particularly related to the care-recipient's illness, caregiving for a child also involves unique requirements that impact parents' perception of the caregiving role. For example, parent caregivers are responsible for the roles of both caregiving and parenting. Caregivers of

mature older adults do not have a responsibility for fostering the multiple dimensions of maturation that parents have (Demirtepe-Saygili et al., 2012). Although parent caregivers are certainly overloaded with tasks, this overload may also be conceptualized differently than it is for caregivers of older adults. Specifically, in Rapp and Chao's (2000) study and Marks et al.'s (2002) study, role overload assessed perceived burden, whereas the current study assessed role overload as responsibilities of caregiving. Additionally, when parent caregivers are overwhelmed by the challenges related to caregiving, they often lack internal and external resources (e.g., time and energy) to care for themselves and tend to their own basic needs (Streisand & Tercyak, 2004). Conceptualizing the caregiving role as satisfying or meaningful may not influence the impact of the caregiving demands on the parent caregiver; however, it may relieve tension or strains associated with sustaining multiple roles (Cheng et al., 2012; Hansen et al., 2013).

The findings of this study lend support to the existing literature. There were moderating effects of positive attitudes on the relation between role strain and the two psychological outcomes. There was no moderating effect for role overload, which may be related to parent caregiving factors as well as distinct aspects of role overload and role strain (Pearlin et al., 1990).

Caregiving stress and resources can affect parent caregivers' psychological outcomes (Brown et al., 2003; Silva et al., 2015; Waters et al., 2017), and as 200 parent caregivers in this study also reported, social and instrumental support can mitigate the deleterious effect of role overload on psychological outcomes. Additionally, positive attitudes regarding the caregiving role can mitigate the effect of role strain on depression and anxiety. As such, these results point to the importance of connecting parent

caregivers to instrumental and social supports and modeling strategies to develop positive attitudes about caregiving.

Limitations

Limitations of the current study must be noted when interpreting these findings. It is important to recognize the ethnic and cultural diversity in the U.S., as this diversity could have differential effects on parent caregivers' experience of stress and their coping resources (Brown et al., 2008). Although the current study sample consisted of male and female parent caregivers, a majority of parents in this study identified as female (81.0%) and White/European American (73.0%), which limits the generalizability of the findings. Other demographic characteristics also need to be noted. The sample was generally well educated; however, approximately one third of participants reported yearly incomes of less than \$50,000. Socioeconomic status, a potentially important factor, was not taken into consideration in this study. Importantly, results were based on a sample of participants who were partially recruited for a previous study through various support networks. This could have differentially affected the amount of caregiving stress parents reported compared to parents who are not affiliated with such networks and communities. As such, the parents in this sample may have had greater access to support-based resources for parents (e.g., support groups), the child (e.g., day camps with opportunities to build coping skills and a sense of illness-associated community), and the family (e.g., hospital programs with mental health professionals), which could have affected the findings. Given the demographic of the sample and these recruitment strategies, the current study sample was attenuated on variables of income, education, and gender. Generalizability of the results may be limited and may generalize best to parents with

access to support network(s) that consist of mostly Caucasians and either married or partnered parent caregivers (Keese & Neimeyer, 2008).

Although the sample size for this study is consistent with a priori power analysis, the moderate sample-size may limit the generalizability of these results for parent caregivers who have children with varying types of chronic illnesses and different levels of life-limitations. Without examining potential child and illness related differences, as well as their differential impact on caregiving, conclusions cannot be made regarding potential differences in caregiving stress and the psychological outcomes. Additionally, as 16 parent caregivers were dropped from the final sample due to incomplete responses to survey measures, an order effect of the measures on the survey may have limited some parent caregivers from completing the survey. Whether or not these data were missing at random was not analyzed. Given the demographics of the participants who did not complete the survey, caregiving context as well as the order of survey items (assessing caregiving stress before positive attitudes) may have influenced those who did not complete the survey.

Relationship context of the sample must also be noted. The partnered or married parents in the current study were in their romantic relationship for a relatively long time ($M = 13.83$ years). Coupled parent caregivers may have support with caregiving tasks from a partner that single parent caregivers may not have (Carona et al., 2013). Because of this, parent caregivers in this sample may have had more assistance with caregiving tasks and more practice with balancing caregiving responsibilities with a partner who may serve as a secondary caregiver. This partner-related support has been associated with greater psychological adjustment to the demands of child's illness within the family

system (Carona et al., 2013; Clark et al., 2002). Finally, because this study was unable to access symptoms of depression and anxiety before the child's diagnosis, whether participants' reports were specific to their caregiving outcomes exclusively or if they reflect premorbid depression and anxiety could not be determined.

Future Directions

A longitudinal study would be useful in examining whether instrumental support, social support, and positive attitudes mitigate the effect of caregiving stress on psychological outcomes at different stages of the child's illness, thus providing more context and meaning to such associations. Results may differ if analyses compared prognosis (i.e., terminal versus non-terminal) and "critical times" (e.g., time following diagnosis, major milestones; Coffey, 2006). These are areas of exploration for future analysis. Future research may also benefit from comparisons between parent caregivers of a child with a terminal illness and those with a child with a non-terminal illness to examine which resources may be most (and least) beneficial under distinct circumstances (Kazak et al., 2003). Future research should also examine a more diverse sample, including more parents of minority status, single parents, and parents who may have limited access to support-based resources. Comparing the caregiving stress experiences across diverse groups may provide further knowledge regarding the benefit of resources to various parent caregiver populations with unique experiences, including cultural stressors, gender (e.g. masculinity), and socioeconomic status.

Clinical Implications and Conclusions

There are several important clinical implications of these findings. First, understanding the psychological risks for parent caregivers with low access to and

utilization of resources may help healthcare professionals to identify caregivers at risk for suffering psychological challenges. Given that caregivers with high caregiving stress and low resources are at risk for developing clinically significant depression and anxiety, it is valuable for care providers to have tools to help them recognize caregivers who may benefit from the provision of resources (Demirtepe-Saygili et al., 2012). These findings may aid in assessing caregivers' risk for depression and heightened anxiety. With this, it is important that mental health professionals working in hospital settings are aware of resources available for at-risk caregivers. Knowledge about support groups that promote social support and about government-funded and non-profit agencies that provide respite and financial services to caregivers may benefit caregivers with high role overload.

Cognitive behavioral therapy (CBT) has been empirically supported as an intervention for depression and anxiety (Beck, Rush, Shaw, & Emery, 1987; Clark & Beck, 2010), and counseling psychologists are uniquely trained in utilizing cognitive-behavioral interventions. As the parent caregivers in this study reported clinically significant depression and anxiety, it is incumbent upon counseling psychologists and other mental health professions to utilize their knowledge and skills in these interventions when working with parent caregivers of children with a chronic illness. Caregivers struggling with role strain may benefit from individual or group-based interventions that focus on CBT-based cognitive reframing or cognitive restructuring to place emphasis on the positive aspects of the caregiving role (e.g., personal growth, deepening of the parent-child bond). The findings from this study can, therefore, help counseling psychologists and other healthcare providers to assess risk and respond with appropriate resources and interventions that are most suited to assuage caregiving stress.

Second, in addition to the potential for aiding in the assessment of psychological risk among parent caregivers, the study findings also support the development of a group intervention designed specifically for parent caregivers. As targeting distinct dimensions of caregiving stress may differentially improve psychological outcomes, such an intervention ought to consider parents' caregiving context, caregiving stress experiences, and utilization of resources when screening and assigning parents into intervention groups (Carona et al., 2013). The child's illness characteristics should also be considered, as hearing about parents' struggles in preterminal and terminal stages of the child's illness may be discouraging and challenging for parents whose child is not terminal. Alternatively, hearing about relevantly more marginal struggles may cause parents of terminal children to feel disconnected with other caregivers' experiences. A suitable group match can support the development of meaningful social interactions and mutually beneficial interpersonal relationships. It would be important for the group-based intervention to provide childcare during the group, as childcare is a practical barrier for many parent caregivers engagement in therapeutic activities (Eccleston et al., 2015). Given that caregivers' social networks are an important resource for coping with the demands of caregiving, the group would benefit from learning social skills to support positive social interactions between caregivers. Utilizing of the concept of caregiving gains may help to foster positive affectivity and positive thinking patterns (Crespo et al., 2011). Additionally, interventions that facilitate personal growth amidst adversity and develop mindfully positive meanings of the caregiving experience may support the development of positive attitudes. For example, parents may be encouraged to process the value of the ramified meaning of the caregiving role in addition to the ways in which the

role may be personally meaningful, as this may broaden attention placed on challenging aspects of caregiving also to include positive aspects (Carona et al., 2013).

Third, in addition to providing social support, fostering a sense of community among parent caregivers may also increase opportunities to learn about and access instrumental supports. With this, community support is an important form of instrumental support. Parent caregivers who are isolated or newer to the caregiving role may especially benefit from connecting with the parent caregiving community to learn about resources that provide assistance with financial, occupational, and childcare-related demands. In such cases, parent caregivers often call on physicians to provide information regarding resources (McCubbin et al., 2002). Thus, it is important for counseling psychologists and other mental health professionals to engage in outreach, providing physicians with information regarding community-based resources that provide supports (instrumental and social) and cognitive-behavioral interventions.

Finally, although some existing literature examined parent caregiving stress through the SPM (Pearlin, et al., 1990), this study was the first, or one of the first, to examine the moderating effects of three different resources on the relation between two types of caregiving stress and two psychological outcomes. Focusing on primary stress (role overload) and secondary stress (role strain) as well as external supports (instrumental and social) and the role of one's own attitudes about the caregiving experience was a strength of the study, as it provided insight into several dimensions of parent caregivers' experiences. Overall, the results from this study add to the understanding of the associations between caregiving stress, resources, and symptoms of depression and anxiety among parent caregivers of a chronically ill child. It also provides

empirical support for the application of the SPM in the context of parent caregivers' caregiving experiences. These findings have important implications for researchers interested in constructs related to caregiving stress and caregiver resources, and for counseling psychologists and other mental health providers working with parent caregivers and their families. Mental health and healthcare professionals working with parent caregivers are encouraged to explore further the beneficial effects that support and positive attitudes can have on parent's psychological outcomes.

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APPENDIX A
IRB APPROVAL

EXEMPTION GRANTED

Sharon Kurpius
CISA: Counseling and Counseling Psychology
480/965-6104
sharon.kurpius@asu.edu

Dear Sharon Kurpius:

On 9/28/2018 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Parent Caregivers of a Child with a Chronic Illness: Effects on Well-Being
Investigator:	Sharon Kurpius
IRB ID:	STUDY00008885
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> • IRB Consent- Parent Caregiver Stress.2.pdf, Category: Consent Form; • CITI-C_Johnson_9-1-14.pdf, Category: Non-ASU human subjects training (if taken within last 3 years to grandfather in); • CITI-S_Kurpius-11-30-17.pdf, Category: Non-ASU human subjects training (if taken within last 3 years to grandfather in); • CITI_Johnson, C_refresher-1-29-18.pdf, Category: Non-ASU human subjects training (if taken within last 3 years to grandfather in); • IRB_Appendices.pdf, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • Recruitment Flyer - Parent Caregiver Stress.pdf, Category: Recruitment Materials; • IRB Protocol - Parent Caregiver Stress.docx, Category: IRB Protocol; • Exempt Wizard Completion Receipt.pdf, Category: Other (to reflect anything not captured above);

The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 9/28/2018.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc:
Courtney Johnson

APPROVAL: MODIFICATION

Sharon Kurpius
CISA: Counseling and Counseling Psychology
480/965-6104
sharon.kurpius@asu.edu

Dear Sharon Kurpius:

On 2/8/2019 the ASU IRB reviewed the following protocol:

Type of Review:	Modification
Title:	Parent Caregivers of a Child with a Chronic Illness: Effects on Well-Being
Investigator:	Sharon Kurpius
IRB ID:	STUDY00008885
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> • IRB_Appendices.pdf, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • IRB Protocol - Parent Caregiver Stress.docx, Category: IRB Protocol; • CITI-C_Johnson_9-1-14.pdf, Category: Non-ASU human subjects training (if taken within last 3 years to grandfather in); • CITI_Johnson_C_refresher-1-29-18.pdf, Category: Non-ASU human subjects training (if taken within last 3 years to grandfather in); • Exempt Wizard Completion Receipt.pdf, Category: Other (to reflect anything not captured above); • IRB Consent- Parent Caregiver Stress.2.pdf, Category: Consent Form; • Recruitment Flyer - Parent Caregiver Stress.pdf, Category: Recruitment Materials; • CITI-S_Kurpius-11-30-17.pdf, Category: Non-ASU human subjects training (if taken within last 3 years to grandfather in);

The IRB approved the modification.

When consent is appropriate, you must use final, watermarked versions available under the "Documents" tab in ERA-IRB.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc: Courtney Johnson

APPENDIX B
RECRUITMENT FLYER

Parent Caregiver Stress Project

- *Interested in participating in research about parents of children with a chronic illness?*
- *Are you a caregiver of a child, between the ages of 5 and 15, diagnosed with a chronic illness?*
- *Have at least 3 months passed since the child was diagnosed?*



If you answered “yes” then you are eligible to participate in a research study on understanding parent caregiver stress and protective factors regarding the effects of caregiving stress on parents’ well-being.

During this study you will complete:

- An online survey regarding your stress associated with caring for your child’s health, the support you receive, and your well-being (~10-12 minutes to complete).

Upon completion of the study, participants will be entered into a raffle to win a \$50 Amazon gift card. One in every ten participants will win!

To participate, please follow this link:

https://asu.co1.qualtrics.com/jfe/form/SV_9Zwmu2upric5HXT

Questions? Contact parentsDCresearch@gmail.com

APPENDIX C
INFORMED CONSENT

Title of research study: Parent Caregivers of a Child with a Chronic Illness: Effects on Well-Being

Investigator: Courtney Johnson (Arizona State University) and Sharon Robinson-Kurpius, Ph.D. (Arizona State University)

Why am I being invited to take part in a research study?

We invite you to take part in a research study because you are the parent caregiver of a child, between the ages of 5 and 15, who has been diagnosed (at least 3 months ago) with a chronic illness. You must be 18 or older to participate.

Why is this research being done?

Given the complex challenges parents face when caring for a child with a chronic illness, parents are challenged with substantial stress. Support (social and instrumental support) and beliefs about the benefits of caregiving have been shown to have beneficial effects on mitigating experiences of stress for parent caregivers while increasing individual well-being. However, limited research exists on these resources can benefit parents experiencing stress regarding caring for their child's chronic illness specifically. Thus, the purpose of this research is to gain a better understanding of how parent caregivers experience caregiving stress and how support and caregiving stress may influence such stress.

How long will the research last?

This study will take place in 2 parts: (1) screening survey and (2) research survey. We expect that individuals will spend 1-2 minutes completing the screening survey, and 8-10 minutes completing the research survey (10-12 minutes total).

How many people will be studied?

We expect about 120 individuals will participate in this research study.

What happens if I say yes, I want to be in this research?

You will be presented with several electronic questionnaires to complete independently. You will first complete a screening survey to ensure that you meet the requirements for this study. You will then be asked to complete a research survey, which should take no more than 20 minutes to complete and asks you to answer demographic questions and complete several questionnaires. Upon completion of the research survey, you will be entered into a raffle in which one in every ten participants will win a \$50 Amazon gift card. The research team will email this payment once you have completed the survey and the raffle has been drawn for every ten participants.

What happens if I say yes, but I change my mind later?

You can leave the research at any time, and it will not be held against you.

Is there any way being in this study could be bad for me?

Because some of the questions ask you to reflect on stress associated with caring for your child with a chronic illness, there is a minimal probability that you may feel slight psychological discomfort such as, mild feelings of anxiety or distress. However, if you experience any emotional discomfort during the study, it will probably feel similar or the same as the way you felt before starting the survey. It is unlikely that the questions in the study would increase your experience of stress, anxiety, or sadness.

Will being in this study help me in any way?

We cannot promise any direct benefits to you or others from your taking part in this research. However, some participants may find it helpful to answer questions about the supports and gains they feel result from caregiving. A potential benefit may come from thinking about positive feelings regarding parent caregiving.

Results from this study may also help psychology researchers better understand the experiences of parent caregivers which informs clinical training and intervention.

What happens to the information collected for the research?

All information from this study will be held confidential. Only the Primary Investigators will have access to your online responses to survey items. You will not be asked to provide any personal information, except for the information that is required for sending compensation (your name and email address). To protect your anonymity, you will be assigned a unique ID number which will be used in place of your name so that no one will be able to know who provided which responses to items on the survey. Names will not be linked to the study data. In reports or publications that may result from this study, your answers will be pooled with approximately 100 other participants, and there will be no way to identify your answers. We will not use any identifying information in these reports.

Who can I talk to?

If you have questions, concerns, or complaints, talk to the research team (from Arizona State University) at ParentCaregivingResearch@gmail.com. You may also contact Courtney Johnson at Courtney.K.Johnson@asu.edu or Dr. Sharon Robinson-Kurpius at Sharon.Kurpius@asu.edu.

This research has been reviewed and approved by the Social Behavioral IRB. You may talk to them at (480) 965-6788 or by email at research.integrity@asu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone aside from the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

This form explains the nature, demands, benefits and any risk of the project. By checking the box below you agree knowingly to assume any risks involved. Remember, your participation is voluntary. You may choose not to participate or to withdraw your consent and discontinue participation at any time without penalty or loss of benefit. In checking the box below, you are not waiving any legal claims, rights, or remedies. A copy of this consent form can be sent to you upon request.

I have read the CONSENT FORM above and agree with all the terms and conditions. I acknowledge that by completing the survey, I am giving permission for the investigator to use my information for research purposes. Additionally, you are also allowing other researchers access to your de-identified data (upon approval by the PIs, Courtney Johnson and Sharon Kurpius, Ph.D., Faculty Supervisor).

APPENDIX D
SCREENING QUESTIONNAIRE

1. Are you and the parent of a child between the ages of 5 and 15, diagnosed with a chronic illness?
 - a. Yes, legal parent
 - b. Yes, step-parent
 - c. No
2. Has at least 3 months passed since your child's diagnosis?
 - a. Yes
 - b. No
3. How long ago was your child diagnosed with a chronic illness?
 - a. ____ years
 - b. ____ months (if necessary)
4. Are you your child's primary caregiver?
 - a. Yes, I am primary caregiver more than 50% of the time
 - b. My partner and I share co-caregiving responsibilities (~50-50)
 - c. No, I am not primary caregiver
 - d. Other, please specify: _____
5. What languages do you speak fluently?
 - a. Please specify: _____
6. Please indicate your child's chronic illness.
 - a. Metastatic cancer
 - b. Non-metastatic cancer
 - c. Blood cancer (e.g., leukemia)
 - d. Autoimmune disorder/ primary immunodeficiency disorder (e.g., lupus, hypogammaglobulinemia)
 - e. Heart Disease
 - f. Renal Disease
 - g. Cystic Fibrosis
 - h. Neurological Disease (e.g., spina bifida, myelomeningocele, cerebral palsy, muscular dystrophy, epilepsy)
 - i. Severe Digestive (e.g., Crohn's disease, gastroparesis, Hepatitis-C)
 - j. Mitochondrial Disease/Mitochondrial DNA deletion
 - k. Diagnostician uncertain
 - l. Multiple from above
 - m. Other (please specify) _____

APPENDIX E
RESEARCH SURVEY

1. How old are you?
 - a. Please specify: ____ years

2. What is your gender identity?
 - a. Male
 - b. Female
 - c. Trans male/Trans man
 - d. Trans female/Trans woman
 - e. Genderqueer/Gender non-conforming
 - f. Different identity (please state)

3. Which best describes your racial/ethnic background? (mark one or more):
 - a. Asian/Asian-American
 - b. Black/African-American
 - c. Hispanic/Latino(a)
 - d. Native American or Pacific Islander
 - e. White/European-American
 - f. Other (please specify)_____

4. What is your relationship status?
 - a. Married, in a heterosexual relationship
 - b. Married, in a same-sex relationship
 - c. In a committed heterosexual relationship
 - d. In a committed same-sex relationship
 - e. Engaged, in a heterosexual relationship
 - f. Engaged, in a same-sex relationship
 - g. Divorced
 - h. Single

5. What best describes your household?
 - a. I am a single parent
 - b. I am one of two parents raising our child(ren) in our home
 - c. I am co-parenting (living separately)
 - d. I am co-parenting (living together)

6. What is the highest level of education you have completed?
 - a. Less than high school

- b. High school diploma or equivalent (e.g. GED)
 - c. Vocational/technical school
 - d. Associate's degree
 - e. Some college
 - f. Bachelor's degree
 - g. Graduate or professional degree (e.g. MA, Ph.D., MD, JD)
7. What is your typical yearly household income before taxes?
- a. \$0-\$25,000
 - b. \$25,000-\$49,999
 - c. \$50,000-\$74,999
 - d. \$75,000-\$99,999
 - e. \$100,000-\$149,999
 - f. \$150,000- 199,999
 - g. Greater than \$200,000
8. How many people contribute to your household income?
- a. One – solely my own
 - b. One – solely my partners'
 - c. Two – mine and my partners
 - d. Multiple (e.g., two incomes and financial support from other family members)
9. How long have you and your partner been in a romantic relationship together?
- a. ____ years
 - b. ____ months
10. If you are married to your partner, how long have you been married?
- a. ____ years
 - b. ____ months
11. How many children do you have?
- a. Please specify number of children: _____
 - b. Please specify ages of children: _____
12. If custody is shared, how many children live with you 50% of the time or more?

- a. Please specify: _____
13. How old is your child with a chronic illness?
- a. ____ years
 - b. ____ months
14. Has this caregiving role impacted your employment, relationships, or social activities?
- a. Yes
 - b. No
15. How long has your child been affected by a chronic illness?
- a. ____ years
 - b. ____ months (if applicable)
16. When was your child diagnosed with his/her chronic illness?
- a. ____ years
 - b. ____ months (if applicable)
17. Is your child's disease active (versus in remission?)
- a. Yes
 - b. No
 - c. I am not sure
18. Is remission possible for your child's chronic illness?
- a. Yes
 - b. No
 - c. I am not sure
19. Is your child currently receiving treatment for the chronic illness?
- a. Yes
 - b. No
 - c. We are unaware of treatment options
20. Do you engage in active care for your child's chronic illness (e.g., regular doctors' appointments)?
- a. Yes
 - b. No

21. What is the level of your child's caregiving needs?

0-20 = Very Low	21-40 = Low	41-60 = Moderate	61-80 = High	81-100 = Very High
-----------------	-------------	------------------	--------------	--------------------

0 |-----| 100

22. **Very Low** (My child can complete his/her) > your child's quality of life? **Very High** (My child requires

0-20 = Very Poor	21-40 = Poor	41-60 = Fair	61-80 = Good	81-100 = Very Good
------------------	--------------	--------------	--------------	--------------------

0 |-----| 100

23. Please indicate the extent to which caring for your child has affected your financial stability:

0-20 = Very Low	21-40 = Low	41-60 = Moderate	61-80 = High	81-100 = Very High
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0 |-----| 100

24. Please indicate the extent to which caring for your child has affected your job/career stability:

0-20 = Very Low	21-40 = Low	41-60 = Moderate	61-80 = High	81-100 = Very High
-----------------	-------------	------------------	--------------	--------------------

0 |-----| 100

25. Please indicate the extent to which caring for your child has affected your household income:

0-20 = Very Low	21-40 = Low	41-60 = Moderate	61-80 = High	81-100 = Very High
-----------------	-------------	------------------	--------------	--------------------

0 |-----| 100

26. Please indicate your child's prognosis:

- a. Non-terminal, non-life-limiting (no reduced life expectancy)
- b. Life-limiting
- c. Terminal

27. Are you currently experiencing any of the following critical times?

- a. currently in the first year of the child's diagnosis (i.e., less than one year has passed since the child's diagnosis)
- b. exacerbation of the child's physical symptoms (requiring more caregiving demands)
- c. major milestones for the child and their peers

d. other, please specify _____

28. Anything else you would like to include regarding your child's condition, please provide here:

a. _____

Primary Stress: Role Overload (Role Overload scale; Pearlin et al., 1990)

Here are some statements about your energy level and the time it takes to do the things you have to do. How does each statement describe you?

1 = Not at all 2 = Somewhat 3 = Quite a bit 4 = Completely

- 1) You are exhausted when you go to bed at night.
- 2) You have more roles and responsibilities than you can handle.
- 3) You don't have time just for yourself.
- 4) You work hard as a caregiver but don't seem to make any progress.

Secondary Stress: Role Strain (Revised Caregiver Scale; Montgomery et al., 2000)

As a result of assisting your child with a chronic illness, have your caregiving responsibilities:

1 = Not at all 2 = A little 3 = Moderately 4 = A lot 5 = A great deal

- 1) Kept you from recreational activities?
- 2) Caused your work or social life to suffer?
- 3) Given you little time for friends and relatives?
- 4) Caused financial conflicts?
- 5) Caused you to lose touch with yourself?

Psychological Well-Being: Depression (PHQ-9 ; Kroenke et al., 2001)

Over the last 2 weeks, how often have you been bothered by any of the following problems?

0 = Not at all 1 = Several days 2 = More than half the days 3 = Nearly every day

1. Little interest or pleasure in doing things
2. Feeling down, depressed, or hopeless
3. Trouble falling or staying asleep, or sleeping too much
4. Feeling tired or having little energy
5. Poor appetite or overeating

6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down
7. Trouble concentrating on things, such as reading the newspaper or watching television
8. Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual

Psychological Well-Being: Anxiety (GAD-7; Spitzer et al., 2006)

Over the last 2 weeks, how often have you been bothered by the following problems?

0 = Not at all 1 = Several days 2 = More than half the days 3 = Nearly every day

1. Feeling nervous, anxious or on edge
2. Not being able to stop or control worrying
3. Worrying too much about different things
4. Trouble relaxing
5. Being so restless that it is hard to sit still
6. Becoming easily annoyed or irritable
7. Feeling afraid as if something awful might happen

Instrumental and Social Support (MOS-SS; Sherbourne & Stewart, 1991)

Tangible support

Considering your role as a caregiver, if you need it, how often if someone available to help with the following:

0= None of the time
1 = A little of the time
2 = Some of the time
3 = Most of the time
4 = All of the time

1. Someone to help you with caregiving responsibilities
2. Someone to take you (or your child) to the doctor if you needed it
3. Someone to prepare you meals
4. Someone to help with daily chores or errands when you need it

Emotional/informational support

Considering your role as a caregiver, if you need it, how often if someone available to help with the following:

- 0= None of the time
- 1 = A little of the time
- 2 = Some of the time
- 3 = Most of the time
- 4 = All of the time

1. Someone you can count on to listen to you when you need to talk
2. Someone to give you information to help you understand a situation
3. Someone to give you good advice about a crisis
4. Someone to confide in or talk to about yourself or your problems
5. Someone whose advice you really want
6. Someone to share your most private worries and fears with
7. Someone to turn to for suggestions about how to deal with a personal problem
8. Someone who understands your problems

Positive Attitudes Regarding Caregiving (BASC; Glajchen et al., 2005)

Please rate whether you agree or disagree with each of these statements as it applies to you in your care of your child this month:

0= does not apply 1= disagree a lot 2 = disagree a little 3 = agree a little 4 = agree a lot

1. Taking care of my child has drawn the two of us closer together.
2. Taking care of my child has brought meaning to my life.
3. Taking care of my child has made me feel satisfied.
4. Taking care of my child has made me grow as a person.
5. Taking care of my child has made me feel good about myself as a caregiver.